

PALLIATIVE CARE: CHALLENGES FOR TEACHING IN THE PERCEPTION OF NURSING AND MEDICAL STUDENTS

CUIDADOS PALIATIVOS: DESAFIOS PARA O ENSINO NA PERCEPÇÃO DE ACADÊMICOS DE ENFERMAGEM E MEDICINA

CUIDADOS PALIATIVOS: DESAFÍOS PARA LA ENSEÑANZA EN LA PERCEPCIÓN DE LOS ESTUDIANTES DE ENFERMERÍA Y MEDICINA

Ramona Garcia Souza Dominguez¹
Amanda Santos Veiga Freire²
Claudia Feio da Maia Lima³
Natádina Alves Souza Campos⁴

How to cite this article: Dominguez RGS, Freire ASV, Lima CFM, Campos NAS. Palliative care: challenges for teaching in the perception of Nursing and Medical students. Rev baiana enferm. 2021;35:e38750.

Objective: to identify the difficulties in addressing palliative care and terminality in the perception of Nursing and Medical students from a public university. **Method:** this is an exploratory, descriptive study with a qualitative approach, whose data collection was carried out between September 2019 and January 2020, through semi-structured interviews. **Results:** two main thematic categories emerged: Challenges of communication in palliative care and Unpreparedness to deal with dying and death. **Final Considerations:** Nursing and Medical students present difficulties related to communication in palliative care and end-of-life situations. This unpreparedness was also present in dealing with death, human suffering and moral conflicts arising from religious beliefs.

Descriptors: Palliative Care. Comfort Care. Medical Graduate Education. Nursing Education. Health Professional Training.

Objetivo: identificar as dificuldades na abordagem dos cuidados paliativos e da terminalidade na percepção de acadêmicos de Enfermagem e Medicina de uma universidade pública. *Método:* trata-se de estudo exploratório, descritivo, com abordagem qualitativa, cuja coleta de dados foi realizada entre setembro de 2019 e janeiro de 2020, por meio de entrevista semiestruturada. *Resultados:* emergiram duas categorias temáticas principais: Desafios da comunicação em cuidados paliativos e Despreparo para lidar com o morrer e a morte. *Considerações finais:* identificou-se que os acadêmicos de Enfermagem e Medicina apresentam dificuldades relacionadas à comunicação na assistência em cuidados paliativos e em situações de fim de vida. Demonstrou-se ainda o seu despreparo em lidar com a morte, o sofrimento humano e os conflitos morais decorrentes de crenças religiosas.

Descritores: Cuidado Paliativo. Cuidados de Conforto. Educação de Graduação em Medicina. Educação em Enfermagem. Formação Profissional em Saúde.

¹ Oncologist Nurse. PhD in Health Sciences, Cancer Epidemiology and Critical Units Management. Adjunct Professor at the Universidade Federal do Recôncavo da Bahia. Santo Antônio de Jesus, Bahia, Brazil. ramonagarcia@ufrb.edu.br. <http://orcid.org/0000-0002-3131-3953>.

² Bachelor in Health. Universidade Federal do Recôncavo da Bahia. Santo Antônio de Jesus, Bahia, Brazil. <http://orcid.org/0000-0003-4525-2490>.

³ Nurse. PhD in Nursing. Adjunct Professor at the Universidade Federal do Recôncavo da Bahia. Santo Antônio de Jesus, Bahia, Brazil. <http://orcid.org/0000-0002-4718-8683>.

⁴ Bachelor in Health. Universidade Federal do Recôncavo da Bahia. Santo Antônio de Jesus, Bahia, Brazil. <http://orcid.org/0000-0001-9970-2405>.

Objetivo: identificar las dificultades para abordar los cuidados paliativos y la terminalidad en la percepción de los estudiantes de Enfermería y Medicina de una universidad pública. Método: se trata de un estudio exploratorio y descriptivo con un enfoque cualitativo, cuya recogida de datos se llevó a cabo entre septiembre de 2019 y enero de 2020, a través de entrevistas semiestructuradas. Resultados: surgieron dos categorías temáticas principales: Desafíos de la comunicación en los cuidados paliativos y Falta de preparación para lidiar con el morir y la muerte. Consideraciones finales: se identificó que los estudiantes de Enfermería y Medicina presentan dificultades relacionadas con la comunicación en cuidados paliativos y situaciones al final de la vida. También se demostró su falta de preparación al tratar la muerte, el sufrimiento humano y los conflictos morales derivados de las creencias religiosas.

Descriptor: Cuidados Paliativos. Cuidados de Confort. Educación de Grado en Medicina. Educación de Enfermería. Formación Profesional en Salud.

Introduction

The World Health Organization (WHO) defines Palliative Care (PC) as an approach that aims to improve the quality of life of patients and their families before problems related to diseases that threaten life continuity, prevention and relief of suffering, with early identification, evaluation and treatment of pain and other demands of psychological, psychosocial and spiritual orders⁽¹⁾.

Given the set of epidemiological and demographic transformations that culminated in population aging and the increase in the incidence of cases of chronic noncommunicable diseases (CNCDS), responsible for approximately 80% of deaths in the Americas⁽²⁾, PC represents a necessary strategy for health care. Despite the progressive expansion of this line of care in developed countries, its access is still difficult in developing countries, such as Brazil⁽¹⁾.

Among the main obstacles pointed out by the WHO for the advancement of PC is deficient or non-existent knowledge of principles and practices by health professionals⁽¹⁾, revealing the gaps in the approach of this theme in the curriculum of graduate courses.

Moreover, the finitude of life is also seen as synonymous with failure by health professionals, a feeling that comes from a formative process of valuing technical foundations, to the detriment of the holistic conception of the human being and centered, almost exclusively, in the fight against the disease, while there are censorship to talk about death. Factors that result in the devaluation of actions that propose dignity in

terminality⁽³⁻⁴⁾ and bring emotional challenges and a feeling of unpreparedness for PC.

In Brazil, Nursing curricula present some specific advances, such as the existence of elective, mandatory disciplines and extension projects focused on the theme⁽⁵⁾. However, the approach of the contents related to PC often occurs insufficiently in the training process of nurses and physicians, which may culminate in emotional difficulties and feeling of unpreparedness in care⁽⁵⁻⁶⁾.

This research is justified by the relevance of understanding the challenges for teaching PC in Nursing and Medical graduation from the students' eyes, in order to raise the demands for the approach of the theme. It seeks to offer subsidies for reflection on the competencies of the graduate, understanding that the training of those professionals must be adequate to the epidemiological reality of the country.

Based on this panorama and in view of the current relevance of this theme, the study aims to identify the difficulties in addressing PC and terminality in the perception of Nursing and Medical students from a public university.

Method

This is an exploratory, descriptive study with a qualitative approach, based on the Consolidated criteria for reporting qualitative research (COREQ). The choice of this approach resulted from the possibility of understanding the infinite human productions that are inserted

in the midst of relationships, representations and intentionality, object of qualitative research that, most likely, cannot be translated into quantitative numbers and indicators⁽⁷⁾.

The participants were 44 students from a Federal Higher Education Institution (HEI), 23 Nursing students and 21 Medical students. The inclusion criteria were being a Nursing or Medical student, aged 18 years or older, regularly matriculated from the sixth semester, since they start to have contact with the contents of health courses in a more specific way. It is noteworthy that the study site adopts the training modality in two cycles. Nursing and Medical courses are structured in 11 and 14 semesters, respectively, and the first 6 semesters are attended in the Interdisciplinary Bachelor of Health (BIS). BIS students without defined terminality were excluded. Random sampling was used to choose the participants, and data collection was terminated by theoretical saturation⁽⁸⁾, that is, at the time when there was no new information about the phenomenon studied.

Data were collected between September 2019 and January 2020, through semi-structured interviews, scheduled through an electronic form sent by e-mail, performed in person in a reserved room at the University itself and recorded with electronic device. A script composed of open and closed questions was used to enable the interviewee to discuss the subject in question without being restricted to the question posed⁽⁷⁾. The variables of interest were: age, gender, graduate course, semester, year of admission and religion. The script of the interview presented the guiding question: "What are the difficulties that you identify in the approach of PC and terminality during your academic training?"

The audios of the interviews were transcribed, confirmed and analyzed, following the path of content analysis⁽⁹⁾, composed of the following steps: pre-analysis (organization and transcription of the collected material); exploitation of the material (successive readings and extraction of the central ideas expressed, to systematize the data); and construction of categories and grouping of

elements, according to their similarities. From the treatment of the results, two main thematic categories emerged: "Challenges of communication in palliative care" and "Unpreparedness to deal with dying and death."

The study was approved by the human Research Ethics Committee (REC) under Opinion n. 2.857.547 and the Certificate of Presentation for Ethical Appreciation (CAAE) n. 95097218.0.0000.0056, and was conducted in accordance with the required ethical standards and respecting Resolution n. 510/16 of the National Health Council (NHC). The anonymity of the participants was maintained with the substitution of the names by NS (Nursing student) or MS (Medical student), followed by numbers that corresponded to the sequence of interviews.

Results

Among the 21 Medical students, 15 were female and 6 were male, with ages ranging from 21 to 39 years. As for religion, the participants self-reported as Protestant (11), Catholic (4), without religion (4), messianic (1) and pagan (1). Among the religious, 9 self-reported as practitioners, 1 non-practitioner, and 7 did not answer the question. Regarding the academic semester, the participants attended the sixth semester (4), the seventh (2), the tenth (3), the eleventh (2), the twelfth (1), the last year, residency, (8) and did not provide this information (1).

Among the 23 Nursing students, 20 were female and 3 male, aged between 19 and 51 years. As for religion, 7 were Protestants, 11 Catholics, 3 Spiritists and 2 without religion. Of the religious, 11 were practitioners, 6 were non-practitioners and 4 did not answer the question. Regarding the academic semester, 9 participants attended the sixth semester; 12, the seventh; 1, the eighth; and 3, the ninth.

After analyzing the results, two categories emerged, which are described below: Challenges of communication in palliative care and Unpreparedness to deal with dying and death:

Challenges of communication in palliative care

This category translates the idea that participants have about the obstacles in communication of the team with patients and family members, when the therapeutic plan is based on PC. The interviewees' statements evidenced challenges in the communication process in PC, especially in the relationships of professionals with patients in palliation and their families. The unpreparedness and insecurity for dialogue with those individuals were evidenced, such as the difficulty in dealing with their subjectivities:

The main difficulties I found, I think are related more to how to deal with the patient and the family, to talk about those issues, because it is still very little discussed at the university. (NS19).

There is still a lot to learn, consolidate this knowledge and be able to deal with the process of terminality, with both the patient and family members, how to approach, to make this approach in this situation of terminality. In addition to knowledge in some things, such as talking, how to transmit this information, to tell the family or to the patient that this is already a terminal state, the knowledge to communicate. (NS22).

So, I think this is the hardest part of everything, it is hard for me to talk to a family that there would be the possibility of a palliative care and making this family understand what palliative care is. For me that is the big difficulty. (MS15).

Some participants revealed that they felt humanly connected to deal with each other, from a relational perspective involving communication and interpersonal relationships, because they believed it to be relevant; however, they identify the need to be associated with consistent technical-scientific training on PC:

What I have to offer at the moment are humanistic care skills, sensitivity, which I already consider quite relevant for palliative care. But I need, in addition to the skills I have, technical and scientific knowledge, to offer strategies for promoting the care as comprehensive as possible to those patients. (NS23).

It is noteworthy that the inefficiency of interprofessional communication was extracted from the statements of the interviewees of the Medical course, revealing difficulties regarding the understanding and fulfillment of the patient

care plan by the team, an issue not mentioned by the Nursing students:

[...] there has to be a huge communication from the team for us to determine whether that patient is a palliative patient. And in the handover, sometimes, it is not reported that the patient is palliative. So, they go and put certain medications, antibiotic, in patients who are under palliative care, who are no longer [...] who no longer need this care. (MS3).

[...] the greatest difficulty is precisely the other professionals, because from the moment we have an understanding as a doctor that there is a finiteness of treatment, it is also complicated for the team to understand this. During the residency, we had such a case in surgery, already had a probable negative outcome and decided to end the efforts, give more comfort to him until he reached death, but the team was quite in doubt about this, because they interpreted that there was more to do. Why don't you do that? [...] It is not going to change the outcome of the patient at all [...] it does not make sense. It is little discussed and the team does not have as much depth in discussions about palliation and finitude. (MS20).

Unpreparedness to deal with dying and death

This category highlights the ineptitude that the participants express before the reality of dying and death, due to the feeling of great vulnerability, the difficulty of accepting finitude and the greater perspective of health to heal and not care. The meaning units revealed the existence of gaps before terminality and the process of death and dying. Their statements highlighted the unpreparedness and insecurity to report and deal with the outcome of death:

I think that [the difficulty is] the unpreparedness that we have about palliative care, which ends up preventing us from reacting to the situation. I think the hardest thing is to give the news of death. (NS5).

I think a difficulty for me would be to deal with the moment of death, with the family, I do not know how my reaction would be in the service, I do not feel prepared in practice, to experience it. (NS17).

I think for me [the difficulty] would be much more the issue of dealing with the process of death, with accepting this process of death, with the suffering of the family member, accompanying this family, this patient and understand how this process of death took place, accepting [...]. (NS18).

The challenges faced by the students of the two courses for the deconstruction of the negative idea of death were also demonstrated, such as emotional unpreparedness to face the issues related to terminality:

Death is still treated as a taboo, yet one tries in every way to avoid it, even if it brings more suffering to the individual. Talking about palliative care refers to death and it is difficult to argue about it. (MS6).

Deconstruct every idea of death as something that brings only pain, from professional failure to the idea of ending a cycle. (NS9).

[...] the difficulties found lie more in the issue of how I should deal with this situation, by the fact that I am very sensitive and end up getting involved very emotionally with the other's pain. (NS12).

In addition to the points already highlighted, the Medical students mentioned important issues regarding the moral conflicts of behaviors in the process of identifying and defining the moment of terminality, in addition to the obstacles found to disassociate religious beliefs from aspects of care:

I have already participated in a palliative extubation which warned that everything was not as well resolved as I imagined [...]. For me, it was going to be very calm, but then my moral judgments were able to recollect this, if what we had done was to anticipate the patient's death or if what we had done was comfort, allowing a comfortable death. (MS4).

My difficulty is to understand, is to separate the faith from the real, because as I have faith, as I am Christian, I believe that God can do the impossible, for example. I think that is my biggest difficulty. In some moments I question myself: couldn't I have had a little more faith in this patient? If it took a little longer maybe he could come back just like the other patient did? (MS5).

Discussion

The findings of this investigation indicate that knowledge about death and dying, a reality close to many patients in PC, is still small in the perspective of the approach and deepening in the professional training of nurses and physicians, with emphasis on interpersonal and team communication skills to give bad news, and the naturalization of the process of death and dying. The graduate students from both courses presented difficulties for the consolidation of communication as an instrument of care in health practices, especially in the condition of PC and/or terminality.

Communication is part of human relations and is an essential skill of health care. The students bring to light the difficulties to dialogue with patients and family members in critical and

fragile situations. This result was found in a study developed in the laboratory of nursing practices of a graduate course in southern Brazil, using realistic simulation through actors focused on the communication of cancer diagnosis and onset of PC. Participants were observed regarding the behavior before communication of critical situation in PC⁽¹⁰⁾.

The data resulted in the identification of the fear of talking to the family, the insecurity of going through this reality, the little experience in those situations and the feelings of denial, anger and guilt. The use of realistic simulation allowed developing active listening, empathy and nonverbal communication, while skills and competencies to be improved in graduation. This process can also help the students, as a learning method, as a facilitator of the dialogue about the process of death and dying, to qualify the communication of difficult news that require subtlety and delicacy in their approach and understanding of their own feelings, regarding health care⁽¹⁰⁾.

Those difficulties are more evident upon recovering the historical predominance of the vertical-oriented care and medical hegemony that permeate the team-patient relationship and the construction of fragmented health care focused on the disease⁽¹¹⁾.

However, since PC has a multidisciplinary character and care aimed at maintaining the quality of life of patients outside of therapeutic possibility and their families, it enables the rescue and revaluation of interpersonal relationships in the care process, even after the patient's death. Therefore, communication is an essential tool for health care, because it allows identifying and embracing the needs of patients in palliation⁽¹²⁻¹³⁾ and the preparation of family members for the experience of the mourning process⁽¹⁴⁾, reinforcing the human character of care.

Moreover, the communication about end-of-life care with individuals in the process of death and dying often enables a relationship of greater agreement regarding the care plan between the professional and the patient, impacting the decision-making regarding the interventions to

be performed⁽¹⁵⁾. The results of an American study revealed that discussing end-of-life care issues, at least 30 days before the deaths of assisted patients, allowed them to be more receptive to PC and less prone to aggressive interventions, resulting in better quality at the time of death⁽¹⁶⁾.

The findings of this research demonstrated the importance of training professionals capable of dealing with biopsychosocial and spiritual demands, by the development of individual human abilities, at the time when they highlighted gaps in theoretical contents. By itself, teaching what cannot become technical is already a great challenge that demands the cross-sectionality of the theme in the syllabus of graduate courses, to provide practical experiences in dealing with the subjectivity of being. Although those experiences bring plural results, due to the natural process of professional maturation, they offer the opportunity to work on individual aspects, in order to support greater confidence in the professional future⁽¹⁷⁾.

Another study showed that Nursing and Medical students recognized internships and practices as an opportunity to develop the skills needed to provide this type of care. This teaching strategy allowed exercising the search for emotional balance in the midst of the process of self-identification or family identification with the situations experienced by patients, initiating a cycle of empathy and distancing from the emotional maturity necessary for palliative care⁽¹⁷⁾.

Furthermore, the lack of mandatory curricular components addressing PC and terminality in a cross-sectional way generates learning difficulties in practices and internships, because the student was not presented to the theoretical content. The offer of elective disciplines can supplement this gap, but it should not be the main strategy to prepare students to deal with those situations, guaranteeing the right to dignity and end-of-life comfort for assisted patients⁽¹⁷⁾.

A study conducted in several hospitals with resident physicians of different specialties and Medical students from a private educational institution showed that only 23% of participants rated their communication skills as good or very good, and talking about the end of attempts at

curative treatment was pointed out as the most difficult news to communicate. Over 50% of those subjects felt impacted by the communication of bad news, relating it to emotional issues and low professional self-esteem⁽¹⁸⁾.

In PC, the way a message is transmitted influences the way the patient and family members will deal with the diagnosis, treatment and end-of-life moment⁽¹⁹⁾. This reinforces the understanding that the development of those communication skills should occur during graduation, to broaden the students' view of the care complexity of those individuals, respecting autonomy with their care plan and strengthening the bond with the team, providing confidence, tranquility and comfort⁽¹²⁻¹³⁾.

Multidisciplinary work and communication in the team comprise other major challenges for the teaching of PC, by understanding the importance of overcoming existing obstacles in communication and interprofessional relationship, as well as by the relevance in achieving successful care in PC. This work model requires professionals the ability to dialogue with other areas of knowledge, flexibility, respect, appreciation of other knowledge and shared leadership⁽²⁰⁾.

The association of those factors is fundamental for the definition of the appropriate care plan for patients in palliation and family care, with respect to the principles of beneficence and non-maleficence. Other important demands for teaching were revealed in the findings related to the challenges faced with the outcome of death that permeate its acceptance, dealing with human suffering, conflicts arising from religious beliefs and interventions for quality at the end of life.

In the contemporary Western sociocultural scenario, death is one of the main taboos, described as something undesirable, unpleasant and misunderstood⁽²¹⁾. Those factors can be reinforced by a technical training, focused on healing rather than caring, generating for the students a feeling of rejection of the theme, which considers the teaching practice still very resistant to death, capable of contributing to the unpreparedness in the behavior of end-of-life care.

Those aspects demonstrate that academic education based on valuing the preservation and maintenance of life at any cost⁽²²⁾, to the detriment of care focused on quality and issues that permeate death, dying and mourning as natural events, can contribute to the association of death with professional failure, unsuccessful work and emotional dilemmas.

A study conducted with Medical, Nursing and Occupational Therapy professionals and students showed that those categories did not feel prepared by the university to cope with death, due to the superficial approach of the theme⁽²¹⁾. This fact can be partially explained by the professor's own unpreparedness to deal with terminal issues, due to his/her personal beliefs and values; it also reflects a training that needs to be continuously reviewed, updated and improved.

Moreover, this theme has been commonly addressed in isolation in non-mandatory disciplines specific to the curriculum and with excessively theoretical content, and the real experiences during graduation with the death of patients are treated with distancing and silence. It is understood that death is one of the possible outcomes of health care in all life cycles, which requires investing in professors' training to teach end-of-life care with broader and transdisciplinary approaches at different times and opportunities of medical and nursing education, including practices and internships⁽²³⁾.

The approach of those themes still in the graduate course allows identifying conflicting feelings and attitudes in the students, which can be discussed and worked through a sensitive and human view. Regarding the Nursing team in a hospital environment, regarding the challenges and conflicts experienced with the patient in the process of dying/death, the most recurrent feelings were sadness, pain, empathy and dismay⁽²⁴⁾, corroborating the results of this study regarding the emotional demands encountered in coping with terminality and death.

Moreover, during the care of finite patients, professionals face a series of divergences related to therapeutic approaches, and palliative

extubation is mentioned by one of the study participants. Thus, moral and ethical questions concern the team before the PC, since interventions that delay the departure are no longer a priority⁽²⁴⁾, because they seek to offer comfort to the patient, avoiding unnecessary interventions that do not present therapeutic results. Such questions reflect the appreciation of the maintenance of life at any cost, even with suffering, rather than focusing on good death. Those factors show the lack of preparation and insufficient knowledge for the joint implementation of a palliative therapeutic plan.

Religious beliefs are part of the strategies used by health students to cope with difficulties with death and dying, as demonstrated in a study conducted in a university hospital with Nursing students⁽²²⁾. However, when making use of this strategy, the professional needs to find balance in decision-making, since those situations can generate secondary internal conflicts due to limitations of care interventions before patient autonomy and death inexorability. In this sense, it is of paramount importance to insert those themes in an expanded and permanent way in the training process of those professionals.

This study contributed to the visibility of gaps in the professional training of physicians and nurses in the approach of PC, terminality and death, providing reflections for the understanding of the inclusion and/or improvement necessary in the syllabus of those graduate courses, for the broader, qualified and safer professional health training. Data collection in only one Higher Education Institution can be pointed out as a limitation of this study.

Final Considerations

The participants of this research present convergent difficulties, related to the communication of common themes in PC, especially in end-of-life situations. There was also the unpreparedness to deal with death and dying, human suffering, therapeutic limitation and moral conflicts arising from religious beliefs. Those findings point to teaching demands

directed to approaches in PC in Nursing and Medical graduate courses.

Looking at graduates from different courses in health training confirmed how much this care weakens if communication is not effective and aggregating. The difficulties pointed out in the research were very close, because, in addition to uniting weaknesses in the training, they reveal the great challenge of the efficient interpersonal relationship, generating safety and support, especially situations that address PC and the process of death and dying.

Collaborations:

1 – conception, design, analysis and interpretation of data: Ramona Garcia Souza Dominguez, Amanda Santos Veiga Freire, Claudia Feio da Maia Lima and Natádina Alves Souza Campos;

2 – writing of the article and relevant critical review of the intellectual content: Ramona Garcia Souza Dominguez, Amanda Santos Veiga Freire, Claudia Feio da Maia Lima and Natádina Alves Souza Campos;

3 – final approval of the version to be published: Ramona Garcia Souza Dominguez, Amanda Santos Veiga Freire, Claudia Feio da Maia Lima and Natádina Alves Souza Campos.

Funding:

Fundação de Amparo à Pesquisa do Estado da Bahia (FAPESB).

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Received: September 12, 2020

Approved: November 8, 2020

Published: January 20, 2021



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