

## Death and dying process and palliative care: a necessary claim for nursing undergraduation

*Processo de morte e morrer e cuidados paliativos: um pleito necessário para graduação em enfermagem*

*Proceso de muerte y el morir y cuidados paliativos: un reclamo necesario para la carrera de enfermería*

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### ABSTRACT

**Objective:** to analyze the perception of undergraduate nursing students about the theme, “the process of death and dying” and its approach during their training. **Method:** descriptive, exploratory study, with a qualitative approach developed with students of the last year of undergraduate nursing in a public university in Rio de Janeiro. **Results:** 57 students participated in the study and, after organizing the data, the following classes emerged: “Feelings about death”; “The need to approach the content of death in training education”; “The patient's death experience” and “Care attitude towards the process of death. **Final considerations:** nursing undergraduation education must have included the study of thanatology and the philosophy of palliative care, due to the importance given that death is an inexorable consequence of life. The study reaffirms the importance of this discussion happening during the nursing education training and over nursing work.

**Descriptors:** Universities; Education, Public Health Professional; Education, Nursing; Thanatology; Palliative Care.

### RESUMO

**Objetivo:** analisar a percepção dos estudantes de graduação em enfermagem sobre a temática “o processo de morte e morrer” e sua abordagem durante sua formação. **Método:** estudo descritivo, exploratório, com abordagem qualitativa, desenvolvido com alunos do último ano de graduação em Enfermagem de uma universidade pública do Rio de Janeiro. **Resultados:** Participaram do estudo 57 estudantes e, após a organização dos dados emergiram as classes: “Sentimentos frente à morte”; “A necessidade da abordagem do conteúdo de morte na graduação”; “A vivência da morte do paciente” e “Atitude de cuidado diante do processo de morte”. **Considerações finais:** uma formação que contemple o estudo da tanatologia e a filosofia dos cuidados paliativos é de suma importância, dado ao fato de que a morte é consequência inexorável da vida. O estudo reafirma a necessidade constante desta discussão durante a formação e o exercício da enfermagem.

**Descritores:** Universidades; Educação Profissional em Saúde Pública; Educação em Enfermagem; Tanatologia; Cuidados Paliativos.

### RESUMEN

**Objetivo:** analizar la percepción de los estudiantes de enfermería sobre el tema “El proceso de la muerte y el morir” y su enfoque durante los estudios de formación. **Método:** Investigación descriptiva, exploratoria, con enfoque cualitativo desarrollado junto a estudiantes del último año de pregrado en enfermería en una universidad pública de Rio de Janeiro. **Resultados:** En el estudio participaron 57 alumnos y, tras organizar los datos, surgieron las siguientes clases: “Sentimientos ante la muerte”; “La necesidad de abordar el contenido de muerte en el pregrado”; “La experiencia de la muerte del paciente” y “Actitud de cuidado ante el proceso de muerte”. **Consideraciones finales:** una formación que incluya el estudio de la tanatología y la filosofía de los cuidados paliativos es de suma importancia dado que la muerte es una consecuencia inexorable de la vida. El estudio reafirma la necesidad de que esta discusión sea constante durante la formación y el ejercicio de la enfermería.

**Descriptores:** Universidades; Educación en Salud Pública Profesional; Educación en Enfermería; Tanatología; Cuidados Paliativos.

## INTRODUCTION

Despite death and end-of-life care being an essential aspect of nursing and other healthcare professions, the evaluation of the effectiveness of teaching on these topics reveals that it is necessary to improve their understanding in nursing training<sup>1</sup>. Some authors argue that the effective delivery of care in this context requires an individual effort that depends on facing one's own fear of death and dying, as these topics are often avoided in academic and professional environments<sup>2,3</sup>. These situations can also elicit negative reactions and emotions that may impact the quality of care provided to patients and their families during the end-of-life process, when they are dealing with the possibility of death<sup>4</sup>.

Paper extracted from the monograph “The perspective of the nursing student towards the death and dying process” (2019), from the Nursing Graduate Course at the Escola de Enfermagem Anna Nery, Universidade Federal do Rio de Janeiro.

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In the contemporary world, death is often denied, and individuals are not made aware of their own mortality<sup>5</sup>. This affects nursing training, which leaves professionals unprepared to provide care in this context, as they do not reflect about it. As a result, their acts might be mechanical and focused on technique, leading to dehumanization of the process and of those involved, even if the intention is to avoid suffering<sup>6</sup>.

The ability to offer the best care, regardless of whether the caregiver is a nurse or not, requires a humanized approach. This means respecting the individuality of each patient and, for that, it is necessary to recognize them not simply as beings with biological needs, but as biopsychosocial and spiritual agents with inherent rights that must be respected to ensure their ethical dignity<sup>4</sup>.

This context calls for an examination of nursing students' professional practice, which includes curricular internships and personal preparation to face the end-of-life process. One's perception of death will undoubtedly affect their behavior and actions. As for future health professionals, their perception and approach will affect not only their personal relationship with death, but also their professional performance when caring for patients in this situation.

Considering the complexity and subjectivity of the theme, the following question was elaborated: how do nursing students perceive the process of death and dying when exposed to the topic during their academic training?

Therefore, the present study aims to analyze the perception of undergraduate nursing students regarding the theme of "palliative care and death and dying process" in their training.

## THEORETICAL FRAMEWORK

Throughout human history, death has been one of the phenomena that has most captivated the imagination of individuals. In the Middle Ages, death was generally considered to be a natural family event, preceded by specific rituals according to the family's liturgical orientation<sup>5</sup>. It was a collective and communal experience, involving public rituals that engaged the entire community, including children, who were exposed to and dealt with the reality of death from an early age<sup>6</sup>.

The progress of science and technology has led to increased survival rates for people with chronic diseases, stabilizing health conditions even in cases of advanced stages, through the use of artificial life-sustaining treatments<sup>7</sup>. However, despite the investment in healthcare technology, death is no longer considered a collective event, but rather an individual one, shifting from a public to a private matter and from a natural part of the life cycle to a phenomenon that must be avoided, often at all costs.

It is believed that the silence around death and dying is related to the societal taboo surrounding these topics, but also to the healthcare model propagated in Brazilian undergraduate health courses, which emphasizes prevention, diagnosis and effective treatment and cure of diseases<sup>3,7</sup>. During their education, healthcare professionals become committed to preserving life, with a focus on its biological and biomedical aspects. They prepare to maintain this life, as their training is centered on healing, which is seen as their greatest reward. However, when they encounter patients in critical conditions, they usually feel insecure in the face of uncertainty<sup>3</sup>.

This happens because, during their education, healthcare professionals are not as adequately prepared to deal with death as they are to maintain life. The uncertainties surrounding death are gaps left by the lack of discussion and reflection on this complex phenomenon in a comprehensive and contextualized manner. However, teaching about death is an even greater challenge, as many professors often feel unqualified to discuss this topic or are apprehensive due to their own unpreparedness<sup>4,7</sup>.

Undergraduate courses, especially in nursing, are based on extremely technical procedures, with less focus on encouraging students to reflect on issues related to the finitude of life. Consequently, there is a clear need for a process of change in the education of future healthcare professionals, so that they are technically competent and capable of dealing with their own emotions, preparing them to provide humanized care<sup>1</sup>.

## METHOD

This is a descriptive, exploratory study using a qualitative approach, following the recommended steps for the reporting qualitative research - COREQ<sup>8</sup>. Qualitative research was chosen to provide a comprehensive and in-depth understanding of the students' perception on the topic. As a descriptive study, it presents characteristics that allow portraying the in-depth essence of the phenomenon, enabling the researcher to investigate the knowledge, opinions, and attitudes of the participants through analysis, recording, and interpretation<sup>9</sup>.

The study included 57 out of 102 final-year undergraduate nursing students of a public university in the city of Rio de Janeiro, Brazil. Participants were included if they were over 18 years old and enrolled in the last year of the nursing program. Those who had suspended or dropped out of compulsory subjects in the last year were excluded. The sample was selected using non-random probability sampling and data were collected from August to November 2018. Among those eligible, 21 students refused to participate due to discomfort discussing the topic of the study.

After obtaining approval from the Research Ethics Committee of the institution, the students were contacted via email or smartphone text message and provided with a clear explanation of the research purpose. Those who agreed to participate scheduled an interview according to their availability and preference. Once they signed the informed consent form, an in-depth, semi-structured individual interview was conducted in a private room or outdoor environment within the nursing school premises. Each participant was assigned an identifier consisting of the letter A and a number from 1 to 57.

The assistant researcher conducted the interviews after receiving training from her advisor and support from the Study Group *Gestão, Educação e Cuidados em Saúde e Enfermagem* (GECSE) (Management, Education, and Care in Health and Nursing), both with expertise in this type of research.

The interview script included a questionnaire for gathering sociodemographic information, which assessed the following variables: age, gender, civil status, religion, and previous technical nursing course. In addition, it had open-ended questions addressing experiences related to the process of death and dying and the approach to the subject during the participants' education. The script underwent a pilot test with 05 students. To maintain the anonymity of participants, the interviews were identified according to the order they were conducted.

A reflective diary was created to take notes and add information as participants narrated their personal experiences and behavior during the interview. This allowed the researcher to observe their reflections on the methodological aspects of data collection<sup>10</sup>. The interviews lasted an average of 10 minutes and were audio-recorded. Later, they were fully transcribed, along with the field notes. Subsequently, the participants validated the content of the transcription through email communication.

The size of the intentional sampling was determined by theoretical saturation. Therefore, data collection was ceased when the main researcher and interviewer deemed that any new information gathered would not significantly contribute to achieving the research objectives.

For the qualitative analysis of the data, the IRAMUTEQ software (*Interface de R pour they Analyzes Multidimensionnelles de Textes et de Questionnaires*) was used. This software allows for five types of analysis: classic text statistics, specificities of research groups, descending hierarchical classification, similitude analysis, and word cloud<sup>11</sup>.

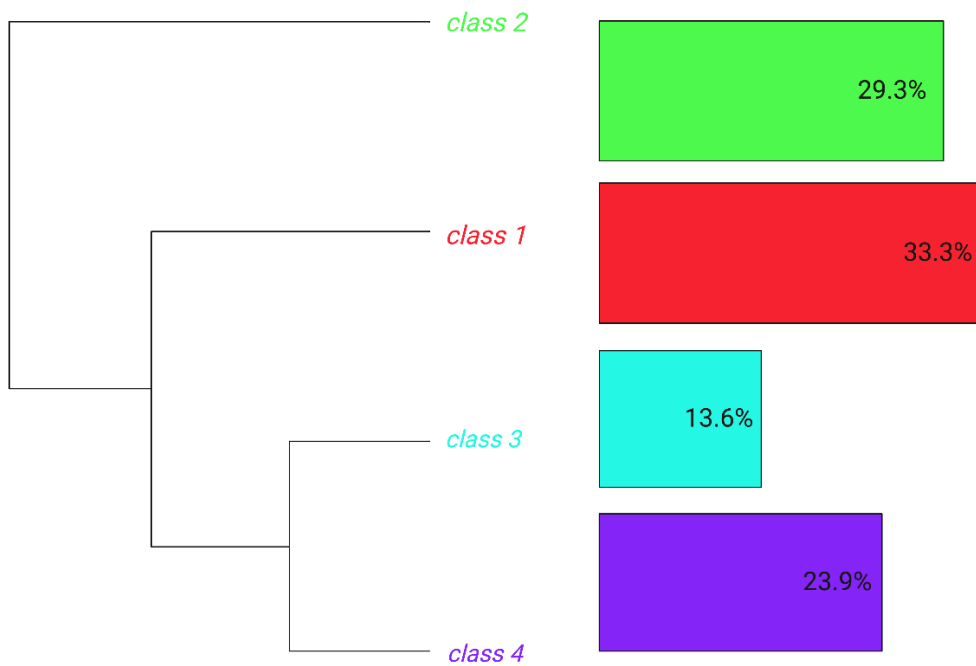
Six steps were followed to carry out the data analysis, based on the precepts of a qualitative research approach, namely: 1. organizing and preparing data for analysis; 2. reading and rereading all data for evaluating the transcribed content; 3. detailed analysis with the coding process; 4. describing people and categories for analysis and evaluating all classes using the presented CHD analysis; 5. extracting the meaning of the data and 6. after data analysis, presenting the results with personal interpretation based on the literature<sup>11</sup>.

The interpretation process was conducted using elements of thematic content analysis<sup>12</sup> to identify and analyze, through inferences, the nuclei of meaning produced by the text segments generated by IRAMUTEQ.

## RESULTS

The participants were predominantly female (91.2%), had a mean age of 24.3 years (standard deviation 4.4), were single (87.7%), identified as belonging to Christian religions (58%) and reported not having a technical nursing course before the undergraduate course (75.4%).

The analysis of the interviews resulted in 464 Initial Context Units (UCI) and 547 analyzed segments, which represents 84.83% of the corpus. The Descending Hierarchical Classification (DHC) was generated by crossing the texts, resulting in four semantic classes as illustrated in Figure 1, which depicts the context of meaning of the words, facilitating the understanding and interpretation of the presented results<sup>11</sup>.



**FIGURE 1:** Dendrogram of Descending Hierarchical Classification (CHD). Rio de Janeiro, RJ, Brazil, 2018.

It should be noted that class 1 represents the highest proportion of the corpus (33.2%), followed by class 2 (29.3%), class 4 (23.8%), and finally class 3 (13.6%). To enhance these findings, the main words of each class are presented in Figure 2, which shows the observed results for frequency (%) and chi-square (chi2).

Class 1 (word)	(%)	(chi2)	Class 2 (word)	(%)	(chi2)	Class 3 (word)	(%)	(chi2)	Class 4 (word)	(%)	(chi2)
<b>Think</b>	75.89	124.41	<b>Duty</b>	81.48	80.28	<b>Stay</b>	44.12	63.33	<b>Worry</b>	82.46	122.33
<b>Death</b>	60.59	90.83	<b>Discipline</b>	96.67	70.23	<b>Bed</b>	100	58.42	<b>Final</b>	82.14	55.5
<b>Come</b>	86.96	66.57	<b>Education</b>	61.39	64.11	<b>Cry</b>	90	50.87	<b>Provide</b>	75.86	45.85
<b>Die</b>	62.5	57.2	<b>Topic</b>	80.95	59.44	<b>Day</b>	48.57	39.51	<b>Comfort</b>	69.7	40.9
<b>Fear</b>	87.5	45.72	<b>Palliative</b>	67.14	56.95	<b>Child</b>	77.78	32.24	<b>Person</b>	43.38	40.48

**FIGURE 2:** Main words of each class according to frequency and chi-square. Rio de Janeiro, RJ, Brazil, 2018.

The factorial analysis by correspondence allowed visualizing the words with the highest percentages in terms of mean frequency and difference between them. The most prominent words were those with a  $p\text{-value} < 0.0001$ , which includes more words than those shown in Figure 2. Additionally, the analysis revealed that classes 3 and 4 are in the same quadrant, indicating a strong correlation between the words. The other classes are on opposite quadrants with specific semantic contexts.

Regarding the analysis of the factorial axes and word proximity by correlation, it is observed that classes 3 and 4 are positioned along the same factorial axis and are clustered together on the horizontal axis, indicating a strong relationship between the patient's death experience and the care attitude towards the death process. Class 1, which denotes feelings about death, is arranged in the upper right plane and is closer to classes 3 and 4. Finally, Figure 3 illustrates class 2, which is located farther away from the other classes, and highlights the importance of addressing death-related topics in undergraduate education.

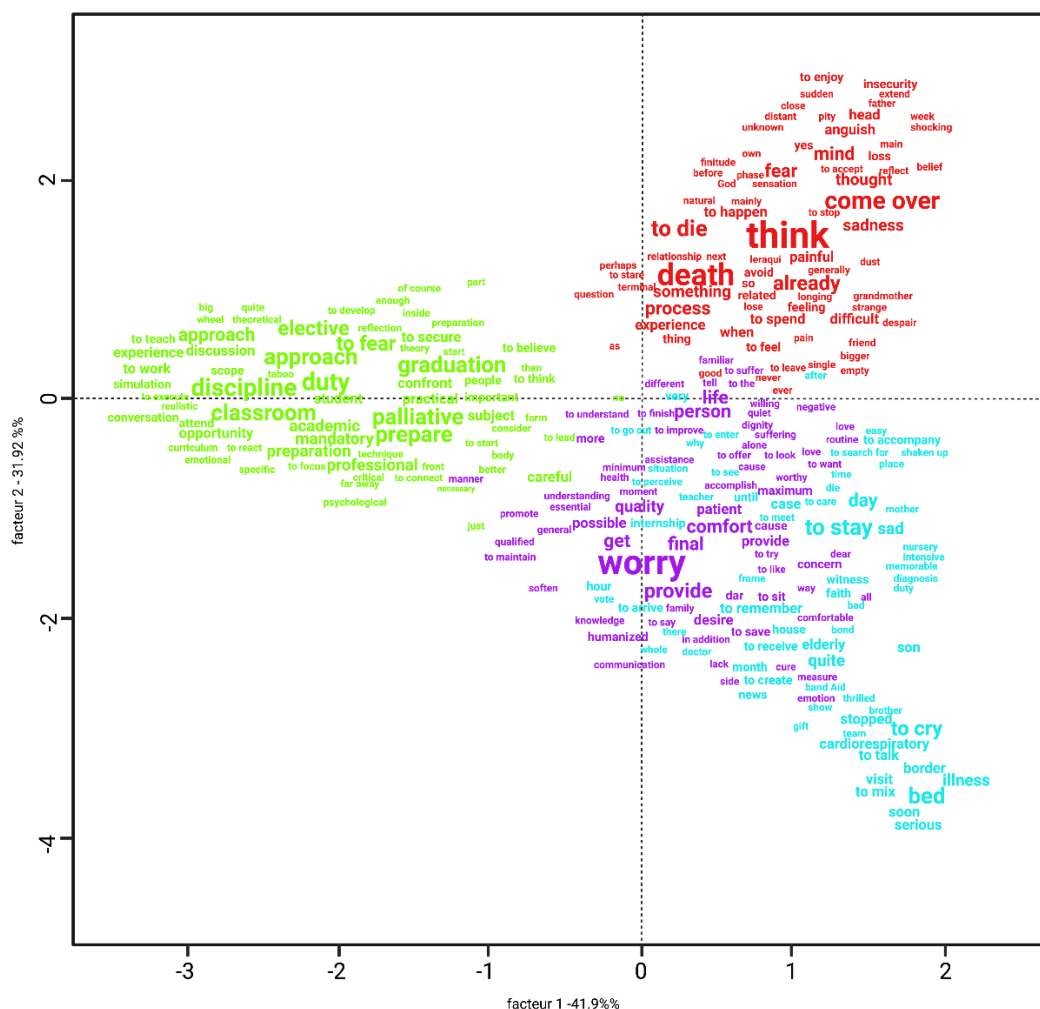


FIGURE 3: Factorial Correspondence Analysis of the four classes in the dendrogram. Rio de Janeiro, RJ, Brazil, 2018.

To provide a more comprehensive understanding of the expressed emotions, we present below some excerpts that exemplify each of the identified classes.

#### Class 1: Feelings about death

This class revealed that when confronted with death and dying, whether their own or others', the students experienced sadness, anxiety, fear, and a painful process.

*I've thought about the process of death before, both my own and other people's. It makes me feel very distressed. I don't feel good when I think about the dying process. And this feeling is much more evident when it is related to the death of other people, such as family members and friends. (A3)*

*I consider death a natural part of life, but the way it happens can be really traumatic and negative [...] (A5)*

#### Class 2: The need to address death in undergraduate education

This class highlights the need for a direct approach to the subject in undergraduate education, with a mandatory course on the subject, coupled with practical experiences that allow for discussion, confrontation, and deeper exploration of the subject.

*[...] the approach to the topic in undergraduate education should focus not only on the technical preparation of the body, but also on how to deal with the situation and with the person and their family in the process of death. (A24)*

*[...] I don't feel like the undergraduate education prepares us to face the death process. When it happened, I wasn't prepared and even now that I'm finishing the course, I still don't feel prepared. (A6)*

### Class 3: Experience with a patient's death

This class relates to the students' experiences with the process of death and dying in mandatory internships during the undergraduate course.

*I was really shaken. I reached out to talk to some friends and that made dealing with it a little easier. It is definitely a situation I won't forget. (A3)*

*I witnessed a cardiorespiratory arrest for the first time in a 6-month-old baby [...] the most difficult moment for me was seeing the mother come into the ICU in tears, because her only child, who was only six months old, did not make it. When she walked in, I couldn't stay. I had to leave and go cry. (A26)*

### Class 4: Care attitude towards the dying process

This class highlights the reflection and concern of students regarding their performance in situations related to the process of death and dying.

*I worry about how I would have to deal with the person's and their family members' emotions, as well as my own. The patient may be gone, but the family member has lost someone they love, and nurses witness the whole situation. (A5)*

*Every time we see a patient suffering [...] we carry that suffering home. Sometimes we don't know how to deal with it, and it can make us sick too[...] (A20)*

## DISCUSSION

The participants of the research are mainly women, a result that is consistent with the profile found in other studies. Nursing has traditionally been a profession dominated by women, and it still is, even though men have been increasingly entering the field in recent years<sup>13</sup>.

Most participants in the study profess Christian religiosity, which is consistent with the results of the latest demographic census from 2010<sup>14</sup>. Religiosity is believed to significantly influence individuals' views on the process of death and dying. Given the subjective nature of the meaning given to death, religiosity is regarded as an important ally in accepting and coping with death. Specific cultural and religious contexts can influence nurses' attitudes towards death. In the Christian tradition, for instance, death is commonly viewed as a gateway to afterlife or as a natural part of life, which can facilitate appropriate care. Moreover, religion can offer explanations in the quest for meaning that characterizes human existence in the face of death<sup>15</sup>.

A study conducted in Palestine showed that nursing students had a positive attitude towards caring for terminally ill patients, which may be influenced by Islamic religious beliefs that recognize death as an inevitable and normal process, but also by the cultural practice of caring for relatives in their last days of life. However, the authors suggest that the attitudes of Palestinian students could be further improved by enhancing their knowledge about palliative care<sup>16</sup>.

An American survey evaluated the perception of death and dying among beginning, intermediate and final year undergraduate nursing students and found that most students consider death as a natural part of life. However, there was a difference between the levels of study, as students with less practical experience had the greatest fear of death<sup>17</sup>.

The thought of death, whether one's own or someone else's, can bring about feelings of powerlessness and guilt, leading to existential anguish. That is why it is so common to see people adopt a defensive posture or avoid the topic altogether, since distancing oneself from the idea can create a sense of protection within one's own imagination. Providing nursing care during the death and dying process is particularly challenging, requires specialized nursing skills and is influenced by personal beliefs. It is believed that nurses who have a positive perception of death are more likely to develop better end-of-life care skills for their patients<sup>15</sup>.

Nursing students recognize the physical and emotional challenges faced when discussing death and communicating bad news to individuals. While most people understand that death is an inevitable part of the biological process of human life and a constant occurrence, discussing it reminds them of the mortality of close people and family members<sup>3</sup>. It should be noted that nursing students frequently have personal feelings and previous experiences with loss. Therefore, it is crucial to approach these experiences appropriately and, if possible, facilitate the meaningful integration of lived experience with learning<sup>1</sup>.

A recent survey conducted in three European countries found that students' attitudes towards caring for terminally ill patients did not change significantly as they progressed through their undergraduate studies, regardless

of the country. This reinforces the need to improve student's training for emotionally exhausting end-of-life care, confronting their feelings of sadness, anguish, and fear when faced with death<sup>18</sup>.

Another study carried out in Switzerland found that nursing students have positive attitudes towards end-of-life patient care, and that these attitudes tend to improve as students progress through their years of education. In addition, the opportunities for professional encounters with terminally ill patients and the self-perception of developing a nursing competence in palliative care contributed to the development of positive attitudes<sup>19</sup>.

For years, the World Health Organization (WHO) and other globally recognized health institutions have highlighted the importance of knowledge of Palliative Care and Thanatology in the training of professionals and as part of health systems<sup>20</sup>. It is suggested that if this demand for greater knowledge on the subject of finitude were being met, healthcare workers could have been better prepared to face the pandemic<sup>21</sup>.

Previous studies have strongly demonstrated deficiencies in academic nursing training related to palliative care and thanatology<sup>1-5,21,22</sup>. The scarcity or lack of disciplines on these contents in universities results in professionals with a limited ability to face situations related to the process of death and dying<sup>23</sup>. A recent meta-analysis review found a gap in knowledge about end-of-life care among nursing students, including philosophy and principles, psychosocial and spiritual care, and pain and symptom management<sup>24</sup>. However, the results revealed positive attitudes towards end-of-life care among nursing students, which is encouraging. This shows a clear incompatibility between knowledge and attitudes about end-of-life care, with nursing students demonstrating favorable attitudes, even without the necessary knowledge.

In a Polish study, medical and nursing students reported that they believed they would face difficulties in caring for patients at the end of life. When asked about their greatest concerns related to the topic, they cited the management of psychosocial care, communication with the patient, cooperation and interaction with the patient's family, and coping with the emotional impact of death, which were also indicated as the areas that required more attention in their training. The students expressed they would rather avoid working with terminally ill patients in their future careers, due to the negative emotions they could have and their difficulties in developing coping strategies<sup>25</sup>.

It is important to recognize that the concepts of the soul's transcendence and spirituality/religiosity and the use of psychological defense mechanisms inherent to human beings are not always sufficient and effective for a satisfactory care for individuals in the process of death and dying. Educational initiatives for the study of death and dying, such as discussion groups, training courses as continuous education and specialization courses have been proposed at the national and international level to address this gap in academic training in health<sup>26</sup>.

The education processes during nursing undergraduate studies indicate that students who learn about the subject generally want to contribute to positive end-of-life care life during their professional work. The teaching-learning process in this context has good results when using active teaching methodologies, such as realistic simulation and problem-based learning, as these are good alternatives to deal with demanding situations and are practiced in safe environments, with the support and guidance of experienced teachers and fellow students<sup>27,28</sup>.

Theoretical approaches confront the values and experiences of students, providing reflection on issues involving finitude. It is essential that the training process encourages the discussion of these subjects, enabling reflection and including the theme in a cross-disciplinary way throughout all periods and courses of the nursing program<sup>29</sup>.

Regarding the emotions experienced during practical encounters with a patient's death, a study addressing bioethical issues related to end-of-life care decisions with 45 healthcare professionals revealed that most of them had not received training in palliative care and that those who worked exclusively in the ICU were more willing to discuss the topic of death with their family members and respect previously shared decisions. However, decisions not to resuscitate critically ill or healthy elderly patients who do not wish to be resuscitated still created conflict regarding respect for the patient's autonomy, even when the patient had previously expressed their wishes<sup>4</sup>.

Experiences with end-of-life care can help nursing students learn specific skills<sup>30</sup>. Therefore, nursing schools should provide students with opportunities for clinical practice in palliative care and training in simulated end-of-life care.

The findings of an Italian study indicate that nursing students in Italy may have a better understanding of the needs of terminally ill patients than students from other countries. Exposure to both theoretical and practical learning processes capable of shaping and modifying their attitudes towards death and care for terminally ill patients are the most significant predictive factors for the promotion of positive attitudes<sup>31</sup>.

The results of the present study indicate that knowledge and comprehension of the topic are directly associated with weakness in the nursing curriculum, especially regarding the inclusion of mandatory courses on the subject. The superficial theoretical approach to death restricts opportunities for training nurses, hindering their understanding of the practice of care.

The development of practical skills must be based on the knowledge and experiences gained during training. However, the limited attention and reflection on this topic have a significant impact on the understanding of the care process, as it is insufficient for the development of a compassionate and sensitive praxis when addressing the human needs that arise in this stage of life. Combined with constant stress and difficulties dealing with their own feelings, this lack of training is a risk factor for the development of compassion fatigue, which is considered a threat to the mental health and well-being of future nurses<sup>32</sup>.

### Study limitations

A limitation of this study was the collection of data in a single university, which may limit the generalizability of the results. Additionally, the interviews with students were conducted individually and there were no extended discussions, which could have provided more diverse perspectives about the process of death and dying. Most researches around the world have used a quantitative instrument to assess the same object, while the authors of this study have relied solely on qualitative data, which has reduced the opportunity to compare these findings with other realities.

### FINAL CONSIDERATIONS

The present study has identified four distinct dimensions that constitute students' perceptions of death and dying process: their feelings about death, experiences with this situation, attitudes towards it, and cognitive processes related to it. Especially in academic training, death is characterized as a multifaceted phenomenon, as expected of a human experience with a complex interplay of social, cultural, biological and symbolic factors.

It is believed that discussions and learning opportunities about death and dying process promote an individual-centered practice. However, it is essential to acknowledge the influence of feelings on our actions, perceptions, and understanding of the world when offering support and training to future professionals.

Therefore, the present study reveals the challenge and the necessity of an education on death, using strategies and mechanisms to help developing skills in this area. Consequently, it is possible to envision the preparation of future nurses to deliver quality and humane care, close to the patient and their family, ensuring their dignity and citizen rights until the end of their lives.

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#### Authors' Contributions

Conceptualization, L.A.C.T., C.C.T.C. and G.O.P.; methodology, L.A.C.T., C.C.T.C. and G.O.P.; validation, L.A.C.T., C.C.T.C. and G.O.P.; formal analysis, L.A.C.T., C.C.T.C. and G.O.P.; investigation L.A.C.T. and C.C.T.C.; resources, L.A.C.T., C.C.T.C. and G.O.P.; data curation, L.A.C.T. and C.C.T.C.; manuscript writing, L.A.C.T., P.C.S.T.A., M.G.R.M., G.O.P. and A.M.T.G.; writing—review and editing, L.A.C.T., P.C.S.T.A., M.G.R.M., G.O.P. and A.M.T.G.; supervision G.O.P.; project administration, G.O.P. All authors have read and agreed to the published version of the manuscript.