

RESEARCH ARTICLE (ORIGINAL) 

Palliative care in undergraduate nursing education: A mixed-methods study

Cuidados paliativos na formação inicial em enfermagem: Um estudo de métodos mistos

Cuidados paliativos en la formación inicial de enfermería: Un estudio de métodos mixtos


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Abstract

Background: With the progression of the epidemiological transition, palliative care skills should be acquired already in undergraduate nursing education. However, most nursing schools have been slow to adapt to the needs emerging from this new context.

Objectives: To identify the perceptions and knowledge of final-year undergraduate nursing students in Brazil and Portugal about palliative care and compare them with their experiences in clinical practice.

Methodology: Multicenter, exploratory, and descriptive study with a qualitative approach. Fifteen students were interviewed in 2018: 10 Brazilian students and five Portuguese students. Data were analyzed using Bardin's content analysis technique. Patricia Benner's model was used as theoretical framework.

Results: The narratives revealed dissatisfaction with the palliative care content in the curricula, frustration with the experiences in clinical practice, and conceptual misconceptions about the theme.

Conclusion: The curricula should be adapted and palliative care content integrated into mandatory subjects.

Keywords: palliative care; chronic disease; health transition; education, nursing, diploma programs; nursing; knowledge

Resumo

Enquadramento: Com o avançar da transição epidemiológica, faz-se necessária a aquisição de competências em cuidados paliativos já na formação inicial de enfermagem. No entanto, a maioria das instituições formadoras têm demorado a adaptar-se às necessidades emergentes deste novo contexto.

Objetivos: Identificar as percepções e os conhecimentos de finalistas do curso de enfermagem no Brasil e em Portugal sobre cuidados paliativos e relacioná-los às suas experiências na prática clínica.

Metodologia: Estudo multicêntrico, exploratório e descritivo, de natureza qualitativa. Foram entrevistados 15 estudantes, 10 brasileiros e cinco portugueses, no decorrer de 2018. Os dados foram submetidos a análise de conteúdo de Bardin. Utilizou-se o modelo de Patricia Benner para o suporte teórico.

Resultados: As narrativas trouxeram à tona sentimentos de insatisfação com o conteúdo em cuidados paliativos disponibilizado pelas escolas e de frustração em relação às experiências vividas na prática clínica. Revelaram-se equívocos conceptuais sobre a temática.

Conclusão: Os currículos precisam de ser adaptados e de incorporar conteúdos de cuidados paliativos em disciplinas obrigatórias.

Palavras-chave: cuidados paliativos; doença crónica; transição epidemiológica; programas de graduação em enfermagem; enfermagem; conhecimento

Resumen

Marco contextual: Con el avance de la transición epidemiológica, la adquisición de competencias en cuidados paliativos es ya necesaria en la formación inicial de enfermería. Sin embargo, la mayoría de las instituciones de formación ha tardado en adaptarse a las nuevas necesidades de este nuevo contexto.

Objetivos: Identificar las percepciones y los conocimientos de los estudiantes de último curso de enfermería de Brasil y Portugal sobre los cuidados paliativos y relacionarlos con sus experiencias en la práctica clínica.

Metodología: Estudio multicéntrico, exploratorio y descriptivo, de carácter cualitativo. Se entrevistó a 15 estudiantes, 10 brasileños y cinco portugueses, durante 2018. Los datos se sometieron al análisis de contenido de Bardin. Se utilizó el modelo de Patricia Benner como base teórica.

Resultados: Los relatos pusieron de manifiesto sentimientos de insatisfacción con los contenidos sobre cuidados paliativos puestos a disposición por las escuelas y de frustración respecto a las experiencias vividas en la práctica clínica. Se pusieron de manifiesto malentendidos conceptuales sobre el tema.

Conclusión: Es necesario adaptar los planes de estudio e incorporar contenidos de cuidados paliativos en las asignaturas obligatorias.

Palabras clave: cuidados paliativos; enfermedad crónica; transición de la salud; programas de graduación en enfermería; enfermería; conocimiento

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Introduction

Palliative care has emerged globally as one of the main responses to the suffering caused by advanced chronic diseases. This modality of care improves the quality of life of thousands of patients and their caregivers and families. Nurses play a key role in achieving this goal, but they can only perform it properly if they have the necessary knowledge to provide high-quality care and feel capable of providing it.

Several healthcare entities have recognized the importance of including palliative care in the undergraduate curricula of healthcare professionals, promoting the inclusion of correlated and mandatory subjects into higher education curricula (Arias-Casais et al., 2019). Still, most education institutions have been slow to adapt to the needs emerging from this new context.

Considering the global need for palliative care and the increasing interaction and mobility between Portuguese-speaking countries, a multicenter study was conducted involving the European and South American contexts, more specifically Portugal and Brazil.

According to the 2018 Portuguese Palliative Care Observatory report, there has been a favorable development in the inclusion of palliative care content into undergraduate education, although the situation of palliative care in Portugal is “scarce and in need of greater investment” (Pereira et al., 2018, p. 11).

In Brazil, undergraduate nursing education usually offers few subjects with themes such as death, dying, and grief. The opportunities for clinical practice in palliative care are even rarer. This reality is also common to other health programs (Costa et al., 2016; Caldas et al., 2018).

Students’ perceptions can be very useful to design and assess curriculum content because they reflect social and job market representations, as well as expectations and possible obstacles in the teaching and learning process. This article aims to identify the perceptions and knowledge of final-year undergraduate nursing students about palliative care and compare them with their experiences in the area of palliative care during their undergraduate education.

Background

Healthcare quality is one of the leading governmental priorities worldwide and an ethical obligation of health ministries and health resource management bodies. It is linked to different aspects, including the skills of the nursing team, which holds great potential for its improvement (Ribeiro et al., 2017).

Patricia Benner, a nursing theorist, developed several proposals for nursing education, with a high potential to adapt to the needs arising from the most prevalent morbidity and mortality conditions and the emerging technological changes. Inspired by Heidegger and Gadamer, she proposed a theoretical framework of interpretation for the skill acquisition process based on the

Dreyfus Model (Escobar-Castellanos & Jara-Concha, 2019).

Benner’s theory places great emphasis on hands-on learning and proper student mentoring. For the author, the real experience that helps the acquisition of skills does not come only from the passage of time but also from “the refinement of preconceived notions and theory through encounters with many actual practical situations that add nuances or shades of differences to theory” (Benner, 1982, p. 407). This model can be applied to nursing education, with the different levels reflecting the changes students go through during clinical practice, as they assimilate knowledge and use it in each specific context (Escobar-Castellanos & Jara-Concha, 2019).

Clinical practice is very relevant to the teaching and learning process in palliative care, although its incorporation is not a priority in most curricula (Costa et al., 2016). These activities allow identifying the difficulties in delivering this type of care.

Incorporating ethics and humanized care in clinical practice is also a vital aspect of the model and a critical parameter for palliative care. The nurse’s identity integrates scientific knowledge, skills, and ethics to act in different situations, especially when faced with instability. Changes in the teaching and learning process are essential for students to acquire these characteristics. The theoretical model proposed by Benner challenges nursing schools to analyze their curricula to ensure that they are training future nurses capable of facing the daily challenges of care delivery (Handwerker, 2012).

In this study, the results were analyzed in the light of Benner’s framework to examine the teaching of palliative care and undergraduate nursing students’ perceptions of the theme and their experiences.

Research questions

What are the perceptions of final-year undergraduate nursing students about palliative care? What palliative care experiences did these students have in academic settings?

Methodology

This study is a multicenter, exploratory, and descriptive research, with a qualitative approach, based on Patricia Benner’s model (Benner, 1982). The Consolidated criteria for REporting Qualitative research (COREQ) checklist was used for its presentation.

Final-year students of the Nursing School of Porto (*Escola Superior de Enfermagem do Porto*, ESEP) and the Nursing School of the University of São Paulo (*Escola de Enfermagem da Universidade de São Paulo*, EEUSP) were invited to participate in the study through a convenience sampling process until theoretical saturation was reached. Data saturation was reached when new elements that could change the understanding of the

studied phenomenon were no longer found (Nascimento et al., 2018). Students from other years of study were excluded because they might not yet have attended the relevant course units. Data were collected in Portugal during the first semester of 2018 and in Brazil during the second semester.

ESEP is a polytechnic higher education institution (HEI) dedicated to undergraduate and postgraduate (postgraduate and master's degree) nursing education. End-of-life patient care is taught at the undergraduate level in the subject of Bioethics.

EEUSP aims to prepare nurses, teachers, researchers, and specialists in all areas of nursing, offering undergraduate, postgraduate (master's, doctoral, and specialization degrees), and university extension programs. End-of-life patient care is taught in optional subjects.

All the requirements of the Portuguese National Council of Ethics for the Life Sciences were met. The ESEP Ethics Committee authorized students' participation in this study by means of an order from its President. Participants received the relevant information and signed the informed consent form. All relevant ethical considerations regarding the Brazilian participants and institution were also observed (Opinion no. 1.122.824).

Face-to-face semi-structured interviews were conducted with the volunteer students on the premises of the HEIs. The interviews were conducted at a private venue without the presence of third parties. Participants were

ensured the anonymity of their answers and data confidentiality. The interview script included the following questions: "In your opinion, what does it mean to provide palliative care? How do you assess your experience of providing palliative care? What were the difficulties encountered in providing palliative care? What facilitated the provision of palliative care?"

Data were analyzed using the content analysis technique recommended by Bardin (2016). After interview transcription, the following steps were taken: pre-analysis (systematization of the initial ideas, reading of the interviews, formulation of hypotheses, and development of indicators), exploration of the material (coding), and interpretation (inferences based on the treatment of the results; Silva & Fossá, 2015). The material was explored using the Dedoose® online software that has several tools to support qualitative analysis.

Results

The participants were 15 female students aged 21 to 31 years, single, enrolled in the last year of their undergraduate nursing studies, in a total of five Portuguese students and 10 Brazilian students.

Data were organized into categories and subcategories resulting from the analytical procedures used, as shown in Table 1.

Table 1

Categories and subcategories found in the qualitative analysis

CATEGORIES	SUBCATEGORIES
1. Conceptions about palliative care	<ul style="list-style-type: none"> • Care recipients • Objectives • Main characteristics
2. Teaching palliative care in undergraduate education	<ul style="list-style-type: none"> • Curricula content • Biomedical model
3. Experiences of palliative care in clinical practice	<ul style="list-style-type: none"> • Facilitators • Difficulties

The category Conceptions about palliative care gathers students' perceptions of palliative care recipients, their objectives, and main characteristics.

Most interviewees in Portugal reported that palliative care is restricted to people who are in the last stage of their life: "it's when a person is already in the last stage of life, it's basically to maintain . . . provide care to . . . so that the person suffers as little as possible" (B.C., 23 years old). Terms like *terminal phase* stood out:

So for me palliative care . . . I think it's an area that addresses patients who are in the terminal phase, who need care that ultimately will reduce their pain or discomfort in that final stage. (A.M., 23 years old)

In the majority of Brazilian participants' answers, no association was found between palliative care and end

of life: "I think that palliative care is everything that involves diseases that have no cure, chronic diseases, even the simplest ones like diabetes and hypertension, but it is still very much associated with more severe diseases or more serious situations." (M.V.S., 27 years old). The term was linked to advanced diseases:

So, in my opinion, palliative care is to promote patient comfort, unlike what many people think, that it's at the end of life, I think palliative care is that which no longer has a cure, does not have a prognosis. (C.M.V., 27 years old)

In Portugal, the respondents often mentioned the promotion of dignity and the relief of suffering as objectives of palliative care, mainly by reducing the level of pain and discomfort.

To provide [palliative] care to . . . so that the

person suffers as little as possible, for example in terms of pain, basically it's really the care needed . . . so that the person is . . . as good as possible. (B.C., 23 years old)

Promotion of comfort and quality of life were the most frequently mentioned objectives by Brazilian students:

[Providing palliative care] means promoting the comfort of the person who is going through a disease that no longer has a cure, the disease no longer has a cure right, so, the proposal is to provide palliative care to the person, which means promoting comfort until the end of their life. (M.B.O., 23 years old)

Humanized care was considered one of the most relevant characteristics of palliative care in Portugal: "And, during my studies, I feel that this part was left out in many of the subjects, and even in some internships. And in palliative care, this human side is extremely important" (A.M., 23 years old).

The Brazilian students mentioned patient-centered care and the assistance provided by an interdisciplinary team more frequently.

Nurses often focus on what is best for them, not on the patient, you see? It's like: 'Oh, let's do it this way, it's faster' or 'let's do that, it's what we can do for today'. I don't think it has to be like that, you have to think about the patient's care and comfort so that he or she can return home as soon as possible and in the best possible way. (A.C.S., 23 years old)

The category Teaching palliative care in undergraduate nursing education includes the interviewees' perceptions of the curricula content at HEIs, the opportunities for practical experience, and the influence of the biomedical model in palliative care.

According to the Portuguese students, palliative care content is lacking and is taught in an inadequate manner.

I think that right now I wouldn't know what I was supposed to do or the care that I was supposed to provide. I don't think we have... I don't have the proper training for this, which is an area where I still need a lot of experience, a lot... not experience, but a lot of knowledge and some experience to be able to provide the best care. (A.F., 23 years old)

Similar to the students in Portugal, the Brazilian participants mentioned the lack of palliative care content during their undergraduate studies.

In the undergraduate degree? No, nothing. What I had in the undergraduate degree ... gee, I only learned in the League, because if I had to rely on what I learned in the undergraduate degree ... Palliative care is lacking in undergraduate degrees. If USP doesn't have it, imagine the others [schools]. That's it. (A.C.S., 23 years old)

Some Portuguese students mentioned the biomedical model to explain the difficulties of incorporating the principles of palliative care in education.

Maybe sometimes they even focus on things that are not so common or are more medical and

more biochemical. And the things that relate more to Nursing, which they should really focus on, like palliative care or really caring for the person... And in palliative care, this human side is extremely important. (A.M., 23 years old)

Not just the technical terms. We all leave there knowing the technical terms, at least in the Nursing School, otherwise we don't leave. But what's missing is a bit of the human being, of being affectionate, giving a friendly word... That's it. I think that's it. We place great value on the technical aspects and we don't value as much the kindness, the affection, the friendly word that many people like. (J.A., 26 years old)

Students from both countries reported feeling a lack of learning opportunities in clinical practice. Next are some facilitators and difficulties identified in the category Experiences of palliative care in clinical practice.

The main difficulties reported by Portuguese students were communication with the family, emotional management, and the dying process.

So, one of the difficulties that I felt when I had . . . not a palliative care situation but a situation of several patients who were very ill and . . . [the relatives] seemed as if they didn't want to admit that the situation was serious, and sometimes it's very difficult to deal with that situation. I think it's more that difficulty, of dealing ourselves with that situation, caring for a person who is not going to evolve, not going to get better, and . . . the family members. I think that these two situations are the most complicated ones. (A.S., 30 years old)

Brazilian students gave similar answers, indicating that communication with the family, the dying process, and emotional management were their main difficulties.

I think that the main difficulties, concerning the newborn, are to deal with the family ... the team that had to communicate that the child would not leave the hospital, I think that it must have been the most difficult thing for them ... I think that nursing as a whole doesn't know very well how to deal with palliative care . . . We keep expecting it to be the role of a psychologist or social worker, and it's really everyone's job. (M.V.S., 27 years old)

Portuguese students reported the following facilitators: the support provided by faculty and colleagues and the contents on non-pharmacological strategies and communication that were part of the curricula.

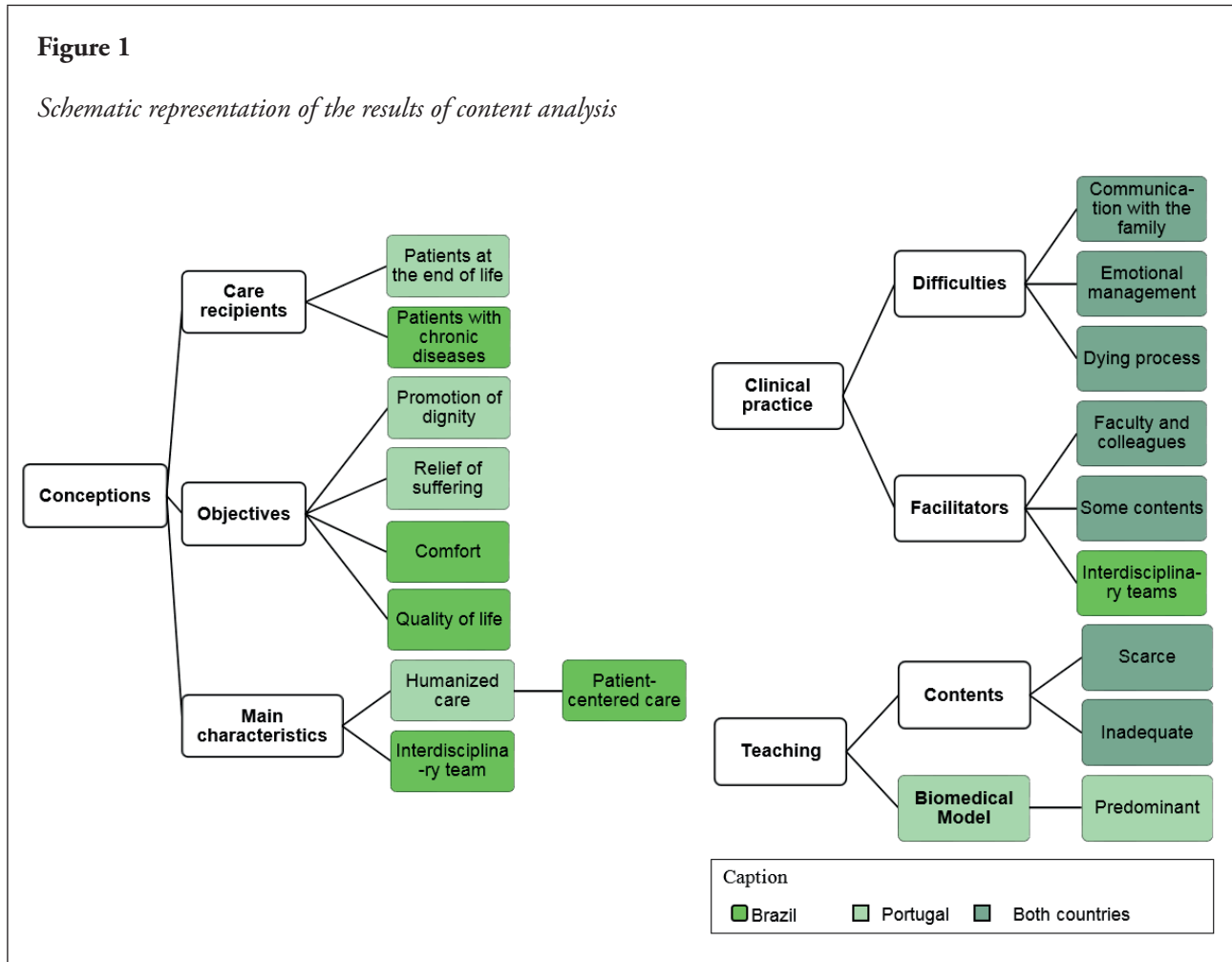
At the time, what helped me was the support from the other professionals, speaking as a student . . . I think that feeling their support, sometimes one simple word from them, that support from others, from colleagues, is very important . . . Yes, [the teachers] they were very supportive, they are very careful about that. Whenever they notice that there is a patient in that situation, they are really, really careful. . . . And yes, I got a lot of support from them as well. (A.S., 30 years old)

Brazilian students reported the following facilitators on a more frequent basis: the support from other professionals, their previous knowledge about palliative care, and interprofessional help.

I didn't receive, like, help ... I sought knowledge in the literature and talked to some people who

were more involved in palliative care, they were able to help me broaden my vision and I was able to provide more dignified care to the person. (A.L., 23 years old)

Figure 1 shows the main results of the content analysis of the interviews.



Discussion

This study proposed to assess the perceptions and knowledge of Brazilian and Portuguese nursing students about palliative care and compare them to their experiences during their undergraduate studies.

The participants expressed their dissatisfaction with the palliative care content taught by the schools and frustration with the experiences lived with patients under their care. On the other hand, it was evident that they placed great value on the support provided by the teachers and the healthcare team during clinical practice. These aspects were identified using Benner's approach, in which the researchers are not limited to their previous knowledge, using it for research design and changing their assumptions according to the results (Santos et al., 2016). The interviews revealed some misconceptions about the concept of palliative care. One of the inaccuracies found was related to care recipients. In some cases, an exclusive association was found between palliative care and patients

at the end of life. This misconception is common across several health professions (Horowitz et al., 2014).

In the interviews with both groups, few participants included the patient's family members or caregivers as palliative care recipients, according to the definitions of the World Health Organization (WHO, 2020).

Among the objectives of palliative care, relief of suffering, promotion of comfort, and preservation of dignity were considered key aspects amongst the guiding principles of palliative care. However, the promotion of quality of life was rarely mentioned, despite being a fundamental concept of the philosophy of palliative care (WHO, 2020).

In Portugal, humanized care was highlighted as one of the main characteristics of palliative care, while Brazilian students mentioned patient-centered care and the help provided by multi-professional teams. These characteristics are essential for this modality of care (Wu & Volker, 2012).

One of the obstacles mentioned by the Portuguese stu-

dents was the overvaluation of the biomedical model. This finding was also found in a study conducted with Portuguese nurses, who mentioned that the major influence of the biomedical model in their practice was harmful to the care provided to people with chronic diseases (Sousa et al., 2015).

Portuguese and Brazilian students mentioned the same main difficulties in palliative care: communication with the family, emotional management, and the dying process. Identifying these themes allows for more comprehensive research on the teaching and learning process in palliative care and its enhancement.

Communication is a crucial issue in palliative care and the humanization of care. Several studies highlight the importance assigned to it by patients, which contrasts with the professionals' major difficulties in communicating effectively, especially in the moments prior to the patient's death (Brighton & Bristowe, 2016).

Students from both HEIs found that emotion management was another challenging aspect. Professionals who provide palliative care are exposed to several risks related to existential issues, psychological challenges, and emotional distress. However, there is evidence that these professionals derive great satisfaction from their work (Sansó et al., 2015), suggesting that nurses can successfully overcome these risks if provided with the right tools.

The dying process, which the students also mentioned, was explored in another study on nursing students' perceptions that revealed the need for reflection and discussion in the academic environment about the dying process and death (Oliveira et al., 2016).

Portuguese students mentioned some facilitators of the provision of palliative care, namely the support from faculty and colleagues and the content on non-pharmacological and communication strategies acquired during their studies. For Brazilian students, the facilitators were the multi-professional teamwork, the knowledge about palliative care, and the support from other professionals. Students perceived the importance of these aspects during practical learning moments.

Benner's model of skill acquisition values the incorporation of critical analysis in the teaching and learning process while enhancing training in care settings through careful monitoring by teachers and tutors (Escobar-Castellanos & Jara-Concha, 2019). This scenario is not only the one desired by students but also the most favorable one to the incorporation of palliative skills.

A limitation of this study was the difference in the number of interviewees in each country; nevertheless, the researchers conducted the interviews until theoretical saturation was reached, as advocated in qualitative studies.

Conclusion

The approach used in this study provided a unique perspective on Brazilian and Portuguese students' perceptions and learning experiences about palliative care. Its results can be used to develop more comprehensive

studies on the topic and provide HEIs with information to improve their curricula, thus contributing to the education of more competent nurses in one of the most important areas of nursing sciences: caring.

HEIs need to adapt their curricula to the demands arising from the epidemiological transition and the growth of advanced chronic diseases that require more and more resources from health services. Increasing the quality of life of patients with advanced chronic diseases has become one of the main objectives of health-promoting entities, placing palliative care in a prominent position in today's society.

Thus, this study recommends incorporating compulsory subjects of introduction to palliative care in undergraduate curricula to explore the history of palliative care, its philosophy and guiding principles. At a later stage, it is recommended that specific subjects on palliative nursing care, with practical components, be offered to ensure the students' access to information and experiences, non-pharmacological therapies, communication, interdisciplinary assistance, and promotion of the quality of life. Content about the dying process should also be addressed in a dedicated, mandatory subject.

There is a need to promote learning in clinical palliative care settings, combined with a comprehensive perspective of care, keeping in mind the bioethical foundations. It is believed that this strategy can help students become professionals with skills to autonomously and effectively intervene in situations of life-threatening diseases and the dying and bereavement processes while making clinical and reflective decisions.

Benner's theory may be an important ally in the process of incorporating these suggestions into nursing curricula. Its model of combining theoretical, practical, and ethical aspects in the teaching and learning process has a major potential for training future nurses prepared to relieve the suffering, promote the quality of life, and meet the multiple needs of patients with advanced chronic diseases.

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