

Perception of Nursing Students about Palliative Care and Death in Patients with Advanced Cancer

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Abstract

Objective: To know the perception of nursing students about palliative care and death in relation to patients with advanced cancer.

Methodology: Descriptive research with qualitative approach, carried out in a private Higher Education Institution in Curitiba, with 35 nursing students, from June to August 2018. The collection was performed through a semi-structured questionnaire to evaluate the sociodemographic and academic profile of the participants and by an interview composed of six questions to answer the objective.

Results: Four categories were extracted from the interviews, including palliative cancer patients: signs and symptoms; feelings and experience of the academic; death and palliative care.

Conclusion: For nursing students palliative care is seen as comfort measures that should be provided to the patient outside of therapeutic possibility of cure. And death is seen as an end to human life, and that causes impotence.

Keywords: Palliative Care; Death; Advanced Cancer; Perception of the Academic; Quality of Life

Introduction

Cancer is a disease that presents the disordered growth of malignant cells that propagate to adjacent organs and tissues, and when disseminated, cause metastasis. This disease can be acquired in various ways, including heredity when there are cases in the family; exposure to environmental risks such as alcohol and cigarette consumption; and infection such as Papilloma Human Virus (HPV) [1,2].

Due to the increasing number of cancer cases, a public health problem is considered. Second, the National Cancer Institute José de Alencar Gomes da Silva - INCA (2018) the cancers with the highest incidence in the world in 2013 were lung (1.8 million), breast (1.7 million), intestine (1.4 million) and prostate (1.1 million). In Brazil, more than 600,000 new cases occur annually, in which most cases are in the South and Southeast region [3]. According to GLOBOCAN 2018, an estimated 18.1 new cases of cancer worldwide and 9.6 million cancer deaths worldwide [4].

One of the reasons for the high cancer mortality rate is the diagnosis that occurs due to difficulties with diagnostic examinations of the disease (computed tomography, magnetic resonance imaging, mammography) that are high-cost tests that are often not offered by the public system, or suffer from the waiting line in covenants, similar symptomatology with other diseases can also hinder this diagnosis [5].

Late diagnosis and disease progression decreases the chances of cure altogether, gradually increasing difficulty in treatment followed by death [5]. Thus, these patients require care for symptom relief and to provide their well-being, this practice known as palliative care (CP). CP aims to provide the quality of life (QOL) of patients and family members facing a disease outside of therapeutic possibility of cure, through prevention and relief of suffering, as well as ensuring a dignified death. Therefore, early identification, evaluation and treatment of physical, psychosocial and spiritual symptoms [6] is necessary.

CP and death are little topics addressed in hospitals, because professionals are not trained and prepared to deal with the end of the patient’s life, since the focus of nursing graduation is on cure and not death. In the health courses there is no discipline that addresses CP, to stimulate the critical thinking of the academic, in order to verify the importance, function and objectives of these cares [7].

When considering the difficulty of health professionals in working with CP and death; the absence of discussions in the academic environment on this theme is justified the performance of this research, which has as a guiding question: What is the knowledge of nursing students about palliative care and death in oncology with patients with advanced cancer?

Objective of the Study

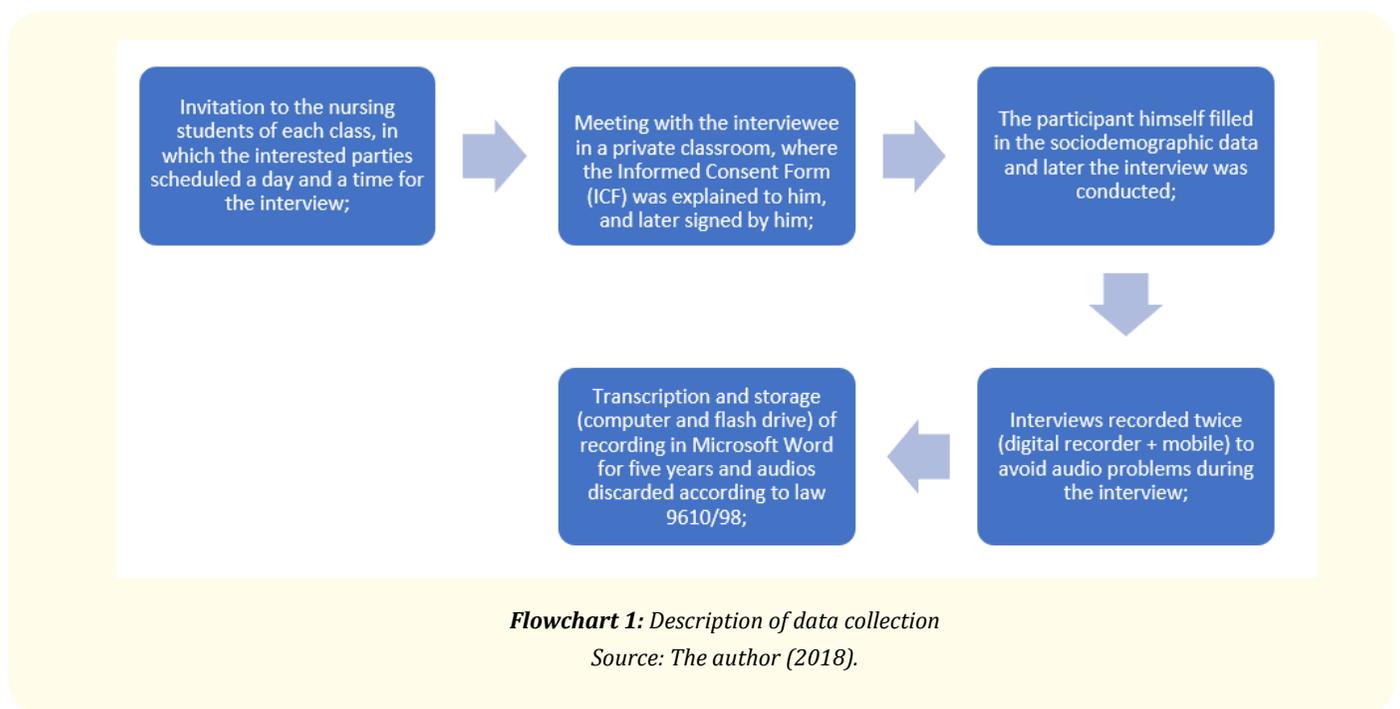
The objective of this work is to know the perception of nursing students about palliative care and death in front of patients with advanced cancer.

Materials and Methods

This is descriptive research with a qualitative approach. The research was conducted in a Curitiba college, in which in 2018 all had enrolled in the nursing course. Each course period has approximately 40 students per class. The sample consisted of 35 nursing students. Because it is qualitative pesquisa, there was no number of predefined participants. The interviews were conducted until the data responded to the objective of the study. Nursing academics were included in the research regardless of the period they are attending. As an exclusion criterion, nursing students under 18 years of age were considered.

Data collection occurred from June to August 2018 on the college campus. The collection was performed through a semi-structured questionnaire to evaluate the sociodemographic and academic profile of the participants, and by an interview composed of six questions to answer the objective.

The interviews lasted a maximum of 10 minutes and could extend according to the responses of each participant. The steps of data collection are described in flowchart 1, the following.



Statistical analysis was performed descriptively for the items of the participant’s characterization instrument. Subsequently, this information was tabulated and presented in the form of a frame, graph and/or table. The qualitative data were analyzed by content analysis proposed by Creswell [8], through the steps described in the transcription steps, stage of data reading, coding step, description step, discussion step, interpretation step.

Data collection began after approval by the Research Ethics Committee (CEP) of the Instituto Paranaense de Otorhinolaryngology (IPO), under opinion no. 2,666,463 of 05/21/2018. The participants of the research were identified through an codification to ensure the anonymity and confidentiality of the information, thus identified with the letter “A”, referring to academic and with X (number in Arabic numerals in increasing order of the participants surveyed).

All digital and printed collected material will be in possession of the graduate, and will be stored in folders, CD and thumb drive, for a period of five years. The information will be confidential and confidential.

Results and Discussion

To compose this study, 35 nursing students were interviewed, two from the 1st period, three of the 2nd period, three of the 3rd period, two of the 4th period, one of the 5th period, five of the 6th period and nineteen of the 8th period. It is noteworthy that the 7th period there was no participation, because the faculty did not have a class of this period, due to the change of curriculum. Table 1 shows sociodemographic data.

Sociodemographic Data N° Academics (=35)	
Age Group	
10 - 20	8
21 - 30	11
31 - 40	13
41 - 50	3
Civil Status	
Single	21
Married	14
Widower	0
Divorced	0
Profession/Occupation	
Intern	4
Student	6
Nursing Technician	9
Nursing Assistant	1
Other	15
Family Monthly Income - SM*	
1 a 3	11
4 a 6	12
7 a 9	4
10 a 12	2
Not Reported	6
Religious Belief	
Catholic	10
Evangelical	9
Spiritist	1
Umbanda	1
Christian	2
It has no	12

Table 1: Sociodemographic data of the interviewed academics

*SM - minimum wage.

Fonte: The author (2018).

Four categories were extracted from the interviews, including palliative cancer patients: signs and symptoms; feelings and experience of the academic; death and palliative care.

Category 1: Palliative cancer patient: signs and symptoms

Cancer patients are debilitated due to the disease's own evolution and treatment, manifesting themselves through symptoms. It is a disease considered serious due to its rapid evolution and aggressiveness, which brings several changes in the life of the affected individual, including in the plans of personal life [2].

For nursing students, the patient diagnosed with advanced cancer has a serious disease and becomes a weakened patient, dependent on devices or devices and consequently, require special family care and/or health professionals, as observed in the statements below:

- "(...) a well-debilitated person sometimes sustained by machines and going through a very serious health situation" (A2).
- "All health professionals should provide a rest and differentiated care, because they are already so very sensitive and bedridden" (A7).
- "(...) he is very aggressive, leaves the patient very weak and greatly affects his life and generates various conflicts, the person has a totally different perception of life" (A16).

The above statements corroborate Freire., *et al.* [9] who mentions that patients with advanced cancer are more debilitated, especially if they are in the final phase of life that comprises the last weeks or 48 hours of life. At this stage the symptoms are more frequent and severe, which directly affects their quality of life and causes you to need support and follow-up of everyone around you [9].

It is perceived the need to emphasize that it is not all patients with advanced cancer who are weakened, but this occurs, because these patients are seen as people who tend to evolve to death, having many symptoms.

During the interviews and when reading them after transcripts, the statements sound as if the interviewees felt sorry for patients with advanced cancer. For Salik [10] the cancer patient is afraid and afraid of being seen with pity, especially by family members, since it is a feeling that causes impotence and disillusionment, worsening their state of health.

Another issue well mentioned by the interviewees is pain as one of the most significant symptoms that becomes one of the main care, according to the following statements:

- "(...) comfort, especially against pain, I find this very important" (A17).
- "(...) soften pain is to try a condition so a little more dignified for him before death" (A28).

The data collected corroborate the literature, in which it is described that pain affects about two-thirds of the population with advanced cancer, so their control becomes the most important goal of this phase, so that the patient feels comfortable (PCA, 2012).

It is evident that pain control in cancer patients is directly related to the improvement of the individual's quality of life as well as a longer survival, but the control of this symptom is not only the use of medications, but in the performance of a multidisciplinary team that provides non-pharmacological therapies, which also has positive results in pain relief [11]. In the area of CP, the definition Total Pain (total pain) is adopted, which consists of the relief of physical, psychological, social pain, and spiritual pain, which respectively, to alleviate the malaise felt by the body, the question of emotional phenomena, the loss of autonomy in not being able to perform activities only, and finally the postmortem questions [12].

However, there are still patients who suffer from poor pain control in their final phase, and with this end up progressing to a palliative sedation, thus demonstrating that inadequate control of this symptom negatively affects the quality of life of this individual and reduces contact with your family members at an important time [13].

In the units in CP is common, health professionals, use sedation for the patient who is affected by pain, bringing great suffering, but for family members and even for the cancer patient the word sedation fits to the end of life, by rushing death, but this is not what occurs, since this technique is used to relieve suffering, and elimination of resistant symptoms [13]. Pain is one of the symptoms most cited by patients with advanced cancer, and causes discomfort, impossibility and dependence in some situations, but it is important to point out that this symptom is not the only one found at this stage [14].

Symptoms that can also be found in these patients are dyspnea, excessive tiredness, nausea and vomiting, consequently negatively compromising quality of life if not evaluated and treated correctly [14].

In addition to pain, the interviewees cited the comfort measures, as important to cancer patients in palliative care, and that should be extended to their family, with the objective of providing a better quality of life and a dignified death:

- “(...) doctors choose to improve their quality of life, not let them suffer anymore and have a measure of comfort” (A16).
- “(...) comfort is essential for human dignity so that people feel good when they are suffering, I think it is essential” (A25).

Comfort consists in alleviating the patient’s suffering, that is, relieving the discomforts that the individual may be suffering, giving him the chance of a quiet death without pain, without emotional problems, bringing support to him and his family members. It is essential for a good evolution of the picture, brings tranquility to both, more clearly and objectively, conducting attitudes that calm both parties [15].

Comfort can be used in several cases, and not only in cancer patients, but in all those suffering from some serious or chronic disease that require measures to feel comfortable and more peaceful, but few people know identify what this concept really is and when it can be used [15].

Comfort for the family must remain even if the patient’s death occurs, so that they learn from the support how to live grief, since the patient who left would like and reassure themselves to know that their loved ones are receiving emotional and spiritual support [13].

In the interviewees’ statements, the comfort provided the family appeared while the patient was alive. This shows the fragility of concept in relation to CP, its objectives and at what times should be used.

Category 2: Feelings and experience of the academic

The feeling most cited by the academics was the feeling of sadness, in knowing that patients with advanced cancer will evolve to death and because they no longer have possibilities for curative intervention.

For future nursing professionals, the feeling towards the patient in CP is one of sadness and impotence, in seeing that he will not be able to perform any action to prevent this patient from dying, only providing comfort [16]:

- “(...) sad, very sad, to see the person dying and not be able to do anything” (A12).
- “(...) it is very sad because we always have to be there telling the truth to the family” (A18).
- “(...) it was very sad because I saw him die in front of me because of lung cancer” (A1).

The interviewee’s speech, A12, which mentions that there is nothing else to do with the patient with advanced cancer, demonstrates that CP is little discussed in graduation. Opposing this idea, Silva., *et al.* [17] states that comfort measures can be offered to patients and their families, and consequently this will provide a better quality of life.

Regarding the testimony of the A18, telling the patient and family that the disease no longer has a cure is difficult, because often the health professional is not prepared for this and feels powerless. This occurs, because during undergraduate courses in the area of health, academics are taught that they must save lives and when faced with situations of non-cure, they cannot correctly break the news and/or feel powerless [18].

Keeping the truth between the team, the patient and the family members brings unimaginable benefits; the patient aware of what is happening can “plan” how his death process will occur and die, and that he can accomplish his last wills and desires; for the family to know the truth, possibly, it will avoid pathological mourning; all these factors will contribute to the improvement of quality of life and a dignified death [18].

Category 3: Death

Death has several concepts, but for health it is a natural process of life, in which the individual may die from some disease early, or by natural death due to his advanced age. Therefore, death is when life is definitively ceased, where the disease becomes irreversible and the patient ceases to respond to the stimuli of treatment, inevitably progressing to death. Cancer is one of the diseases most associated with death, due to its rapid and inevitable progression [19].

For some of the interviewee's death is accepted as a natural aspect of life. The discourses report that after a few years, experience teaches to accept more quietly, but at first it is difficult to face it. People tend to become colder with the experience of death, so that this is an easier way to deal with this moment, in an attempt at less suffering and sadness, so that the pain of loss is less, for many the death of a young person is much more dolorid than an elderly person. Therefore, most create a shield so that anguish will decrease and become something, more natural and peaceful to face [20]:

- “(...) many people do not accept death as a natural process. My reaction to death, now I think I understand as a natural process of life that happens to everyone” (A18).
- “(...) I've had several cases, as I've been working in this area for 14 years, I'm already more used to it, it's already a normal situation, but at first it was difficult” (A19).

Being “cold” in relation to death is not a very relevant action, since patient care is directly linked in how you see the patient, if it is tenderly you will be able to provide the best care for him, but if it is in a restrictive and insensitive way, this care will not be adequate enough to bring the necessary comfort. However, this does not mean that the health professional cannot absorb all the feelings of the patient and take this to his home, because it affects the emotional and can interfere in the relationship with the family and work.

Professionals do not yet certainly know how to deal with death, since it is not treated as it should, as a natural evolution of life, when talking about death bad feelings arise, such as suffering and anguish, which leads to sadness for the loss of a patient, stirring often with the psychological of these professionals, which is not good, because this will result in experience taken to the family environment, being able to interfere in the coexistence of the individual with his personal and also professional life, so it must be due to the undergraduate awareness of academics in how to deal with death, not making them “cold” and insensitive and also not too involved in situations cited in such situations [21].

One of the interviewees said that when the person dies, it is no use suffering because of it, that you should do something for the individual while you are alive, as demonstrated in the following report:

- “(...) died buries I don't have much crying, you have to take the opportunity to talk while the person is alive because after he dies it is no use sending flower” (A3).

The speech of the interviewee A3 causes the health professional to reflect his care practice. Where it is shown that for him there is nothing more to do after the death of the patient. It is noteworthy that this work involves CP, so when the patient goes to death, needs to welcome family members, to make mourning healthy. For Reigada., *et al.* [22] the family feels powerless and presents much sadness, thus, she deserves care after the death of her loved one.

The individual is afraid to face death, which comes along with various doubts, such as: is there life after death? Or the desperation to die and leave loved ones, and yet the dread of losing someone very close to you, who will cause you great suffering and distress, but it must rather be faced as something natural in life, which will one day come to all who live and can be at any time [20]. Below, the participants' reports follow:

- “(...) I don't have much acceptance of death despite agreeing to palliative care, I don't accept very well and suffer a lot, suffer with the patient, so for me death is not a cool thing” (A20).
- “(...) we do not know how to deal with it, we are not ready to deal with this part of life, we always see a lot the side as nursing that always greatly stresses the side of life, the part of health, and death I don't think it's such a worked thing” (A29).
- “(...) ah I still suffer a lot from death because it's a huge sense of loss it's a horrible sense of loss” (A34).

For the nursing academic death is an enigma to be studied, since he graduates to practice healing, always seeking the possibility of saving the patient, and almost never thinking about the possibility of death. Death represents a major failure for health professionals, interfering with their emotional, so this concept should be worked since graduation, to avoid this feeling of impotence, and consequently better care provided to patients and family members in the final phase of life [23].

Death is a very particular feeling, which depends heavily on how the person feels about it; it's individual as you face and overcome that moment. For nursing students it is also very complicated, because nursing is a health course and that for the most part it is reinforced that the course is as synonymous with life, care is health, and when death is debated, the academic does not know how to react to this, and feels helpless, as discussed in the previous categories.

Category 4: Palliative care

When asked for the interviewees what cp is, what their concept, the vast majority, had in mind that they are measures for comfort at the end of life, special care, which are acts for the patient to feel good, it was cited that it is used for critical patients who no longer respond to treatments, and for patients that the family no longer want invasive measures. The WHO in 2002 updated the concept of CP, defined in 1990, to: Palliative care consists of the assistance promoted by a multidisciplinary team, which aims to improve the quality of life of the patient and his/her in the face of a disease that threatens life, through the prevention and relief of suffering, early identification, impeccable evaluation and pain treatment and other physical, social, psychological and spiritual symptoms [6].

CP are measures offered to patients in advanced cancer who no longer have possibilities of cure, where therapeutic interventions are only used to reduce the suffering and symptoms of cancer, improving the patient's QOL, but not prolonging their lifetime. Also bringing support to family members who are suffering from the possibility of losing their loved one. Therefore, CP are considered comprehensive care bringing benefits to terminally ill patients [24].

Next, some reports of the interviewees that corroborate the previous idea:

- “(...) it is the care that a terminally ill person needs, is a special care of a certain health professional” (A3).
- “What I know about palliative care is that they come into critically ill patients with little life perspective where treatments no longer have so much effect” (A8).
- “(...) palliative care is when the family or patient does not want to undergo invasive measures, such as intubation” (A12).
- “Palliative care is precisely the comfort measures for the patient, it is from a simple care with pain that the patient with cancer” (A17).
- “Palliative care I know that’s when the patient is terminally ill and that he only needs care to have a more comfortable life” (A22).

According to the above reports, it is perceived that the idea of CP is for patients who have a few days of life, this shows that the concept of these cares is little widespread in graduation; however, but another point that can interfere with the perception of academics, is that the patient with advanced cancer (CA) is referred late to CP.

CP are not performed only when the patient is at the end of life, but when the individual is diagnosed with some chronic and aggravating disease that can lead to several serious health complications; initially, these care stems from curative treatment, but when it is observed that this treatment does not bring the expected benefits, cp [25].

A patient diagnosed with advanced cancer can live for years, but needs necessary care, with an interdisciplinary team to ensure symptom control and consequently improve quality of life [2].

A study by Temel., *et al.* [26] shows that patients with non-small cell lung cancer who obtained early CP had considerable improvements in QOL and longer survival. While a study by Wright., *et al.* [27] demonstrates that palliative chemotherapy brings negative questions to terminal cancer patients, significantly affecting the individual’s well-being.

Subcategory 1: Who should perform the CP?

This subcategory emerged, due to several reports that CP should be performed by the nursing team and the patient’s family, according to the following interviews:

- “(...) nurses and also by the family, the family can help” (A7).
- “(...) is a health professional, a nurse, a technician or an auxiliary” (A3).

However, there were academics who cited the multidisciplinary team as necessary to perform the quality CP actions, as mentioned in the following reports:

- “(...) a multidisciplinary team that has a psychologist, social worker, nutritionist and physician” (A19).
- “(...) overall I believe that the multidisciplinary team” (A12).

For cp, a multidisciplinary team is required, composed of the nursing team, physician, psychologist, physiotherapist, pharmaceutical, nutritionist, among others, with the objective of ensuring care in their integrality to the patient and his/her [13].

According to the a7 report, the family should perform the CP, however, according to Reigada., *et al.* [22] the family should not provide CP but receive this care since the diagnosis extending to after death.

Respondents A3 and A7 cite nurses as one of the professionals of the CP team. For Gomes and Othero [28] cp are not performed only by nurses, since they cannot perform these measures alone involving various factors, so it is essential that the entire interdisciplinary team participates, from the pharmacist, to the nursing technician, so that the CP is unique for each type of individual [28].

Although not the only professional on the team, the nurse has a special role, since it is he who will evaluate all the needs that the patient and his family present, so that the support offered is adequate and determined by the whole team. It is the nurse who will particularly identify the needs, since he is the one who knows the care that can help in this discovery in order to improve [29]. Therefore, it is essential in CP, that the team has a significant participation, because all working together will bring more benefits to the patient and his/her family.

Subcategory 2: Palliative care at graduation

The answers were very heterogeneous regarding the theme of CP being addressed during graduation, this is because students from the initial periods were attending basic subjects. As mentioned in the following reports:

- “No, and I think nowadays should be taboo even for institution to talk about it” (A3).
- “Not yet, I had training only in the hospital environment” (A6).

And the last periods answered that they had something about CP, including in the discipline of oncology, but it was only one or two classes, passed on in a more superficial way, which disappointed these academics:

- “Yes, in oncology”(A22).
- “We had in the discipline of palliative care and discipline of oncology” (A25).
- “Palliative care only, one class” (A32).
- “I had in oncology class, but very superficial” (A34).
- “I had in very superficial oncology, i expected more and i didn’t” (A31).

Regarding nursing students, some know exactly that CP means relieving the symptoms of patients with advanced cancer seeking improvement of QOL, not decreasing or prolonging their lifetime, only bringing both emotional and physical comfort. However, there is also the part of students who do not understand the meaning of paliar a patient, who believe that this care will treat the disease prolonging the lifespan and even healing this patient. And this doubt is generated precisely because it does not have a specific discipline in graduation [30].

It is perceived that nursing students do not have a direct contact with patients who are in CP, and this can generate an emotional conflict at a time when they come across this situation and death. This occurs, therefore, students are not prepared theoretically and emotionally in graduation, on advanced diseases, palliative care and the final phase of life; the focus is mostly healing [31].

However, nursing students should be prepared to deal with these patients within graduation, so that when they are in a hospital environment they are not surprised by these situations, causing emotional and psychological discomfort.

The graduation follows the curricular strategies of the Ministry of Education (MEC), where a specific matter of palliative care and death is not really found. However, there may be strategies to improve the approach of these topics during graduation. Another important issue is that this research speaks of the association of CP with oncology, but I reiterate that it can be used with all chronic diseases, so it does not need to be worked exclusively on oncology [32].

Conclusion

It is concluded that the perception of nursing students about CP and death is very similar, where CP is described as measures of comfort at the end of life, special care provided to the patient, used when there is no more chances of treatment, since death was defined as the end of human life, where it is a moment of loss that some individuals accept and others not so much, so the objective of the research has been achieved.

This research has points for reflection, mainly related to teaching practice, because it is visible that the subject proposed in the present research demonstrated that students feel dissatisfied with the approach performed to the theme, because the class aimed at the subject has a small workload and cannot thus be exposed and debated the theme as it should. On the other hand, this does not prevent academics from seeking knowledge through their own means, through books and articles of the proposed content.

For academics who obtained information on the subject during graduation, the approach was superficial in a way that frustrated them, so it is important to implement something deeper on the subject, so that academics are formed with knowledge on this subject that is so debated today, being an essential way for improving palliative care to end-of-life patients due to advanced cancer.

Conflict of Interest

There is no conflict of interest.

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