Content analysis of the effects of palliative care learning on the perception by nursing students of dying and dignified death

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Nurse
Education
Today
International Journal for Health Comp Foundables

PII: S0260-6917(19)31545-X

DOI: https://doi.org/10.1016/j.nedt.2020.104388

Reference: YNEDT 104388

To appear in: Nurse Education Today

Received date: 11 October 2019

Revised date: 23 January 2020

Accepted date: 2 March 2020

Please cite this article as: C. Martí-García, L. Ruiz-Martín, M. Fernández-Alcántara, et al., Content analysis of the effects of palliative care learning on the perception by nursing students of dying and dignified death, *Nurse Education Today*(2020), https://doi.org/10.1016/j.nedt.2020.104388

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Title: CONTENT ANALYSIS OF THE EFFECTS OF PALLIATIVE CARE LEARNING ON THE PERCEPTION BY NURSING STUDENTS OF DYING AND DIGNIFIED DEATH

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Funding Source: The present research did not receive any funding

Declarations of interest: none declared

Ethical Approval: The research project and conditions of their participation were described before obtaining their verbal consent, confirming that their responses would be anonymous. It was also explained that they could withdraw from the study at any stage without prejudice and that the support of the teacher was available at any time (no request for this support was made). All personal data obtained in this study were treated in accordance with national data protection legislation (Law 3/2018, 5 December). The research was approved by the Research Ethics Committee of the University.

Abstract

Background. Providing care for dying people and the death of patients are stressing

situations faced by nursing students during their clinical practice. Learning about palliative

care improves the management of emotions and the ability to cope when caring for patients

in end-of-life processes. However, there is little knowledge on the effect of this learning on

the students' perceptions of their own death.

Objectives. To determine the effect of a palliative care course on the thoughts of nursing

students about their own death.

Design. A qualitative, descriptive, and comparative study was conducted based on content

analysis, administering an open-ended questionnaire on dying and death at the start and end

of a palliative care course.

Participants. The study included 85 volunteers studying Palliative Care in the second year

of their Nursing Degree at the University of Granada (Spain).

Results. Students described their perceptions in more detail after the course, with more

numerous code citations, and their post-course responses evidenced a reduction in anxiety

about their own death and an increased recognition of the need to respect the decisions of

patients for a dignified death.

Conclusions. Palliative care learning modifies the perception by nursing students of their

own death and their understanding of a dignified death, which may enhance the care they

deliver to patients at the end of life.

Keywords: Palliative Care, Nursing, Training, Death, End of Life Care, TMT

Introduction

Dealing with the death of patients poses a major challenge to nurses-in-training (Smith-Han, Martyn, Barrett & Nicholson, 2016), and end-of-life care (EOLC) is known to cause stress and anxiety, especially in young people with little or no personal experience of death (Loerzel & Conner, 2016).

EOLC learning is essential to meet the needs of patients and health care professionals, providing training in the management of emotions and effective coping strategies (Sand, Olsson & Strang, 2017). However, little is known about the effect of this type of learning on the perceptions by nursing students of their own dying process or their attitudes towards death.

Background

Providing care for dying people is an essential nursing duty (Loerzel & Cooner, 2016) that must often be faced by nursing students during clinical practice. This care is influenced by various factors, including the previous training of professionals and their attitudes towards death and the dying process, shaped by their previous experience (Bermejo, Villacieros & Hassoun, 2018).

Previous studies have related the lack of experience of nursing students with dying patients to the increasingly rare contacts of young people with death, which has almost become a taboo subject in Western society (Santos & Hormanez, 2013). It has been demonstrated that specific training in palliative care (PC) increases the frequency of conversations of nursing students with patients and caregivers at the end of life (Harden, Price, Duffy, Galunas & Rodgers, 2017) and improves their attitudes towards death (Schmidt-RioValle, et al., 2012). However, despite the major importance given to EOLC by

the World Health Organization (Davies & Higginson, 2004), university curricula in countries such as the USA or Spain assign fewer than 15 hours (Loerzel & Conner, 2016) or no time at all (Cabañero-Martínez, 2019) to this subject.

Little evidence is available on the personal experience of students with death.

Authors have investigated the experiences of nursing students with death during their clinical training (Edo-Gual, Tomás-Sábado, Bardallo-Porras & Monforte-Royo, 2014), after the death of a patient (Heise, Wing & Hullinger, 2018), or while caring for dying patients and their relatives (Ranse, Ranse & Pelkowitz, 2018). Another study evaluated the attitudes of medical students facing the death of the patient in order to prepare an appropriate training course (Smith-Han et al., 2016).

However, there has been no in-depth analysis of nursing students' own thoughts on death or whether these are modified by previous experience or by specific training. Loerzel and Conner (2016) reported that students continue to feel uncomfortable after training about their "personal inner knowledge of the end of life", i.e., their opinions, beliefs, and personal values related to death and dying.

The representation by nursing students of their own death and dying process may have a major impact on the end-of-life care they can deliver to patients. Professionals frequently avoid dying patients in order to maintain a distance from their own thoughts on death (Loerzel & Conner, 2016), with the death of another being a reminder of their own mortality (Santos & Hormanez, 2013). One study found that the main emotions of nursing students in this respect were a fear of dying, painful thoughts about their own death, anguish, sadness, and suffering related to what is lost or left behind (Martí-García et al., 2017). It has been proposed that healthcare professionals should analyze and become aware

of their own ideas about death and dying as part of their training to enhance their support of dying patients and their relatives, reduce their own anxiety, and improve their ability to cope (Schillerstrom, Sanchez-Reilly, & O'Donnell, 2012).

With this background, the objective of this study was to examine the changes produced by a PC course in the thoughts, beliefs, and emotions of nursing students on their own death and on dying, physical death, and a dignified death.

Methods

A qualitative, descriptive, and comparative study was conducted based on content analysis, administering an open-ended questionnaire both before and after the PC course. Cases were compared among each other with respect to the unit of meaning and the timing (pre- vs. post-intervention) (Flick, 2015).

Participants

An intentional sampling approach was adopted. Participants were nursing students assigned to the PC course in the 2nd year of their Nursing Degree at the University of Granada (Spain). Students on national or international exchange programs and/or whose first-year studies were at another center were excluded to ensure that no similar learning had previously been received. All enrolled students provided consent to participation in the study

Among the 147 students assigned to the PC course, eligibility criteria were not met by 14, participation was refused by 19, data were missing for 26, and incomplete responses were received from 3, leaving a final study sample of 85 students (76% females) with mean

age of 23 (SD=7.74) years. No professional or personal experience in caring for the dying was reported by 96.47% and 74.12% of participants, respectively (Table 1).

Characteristics of the PC course

The PC course is mandatory and is worth six European Credits Transfer System (ECTS) credits, requiring 60 presential hours and 90 autonomous study hours. It is taught in the second semester of the 2nd year before clinical practice sessions in health care centers. The program is taught by three nursing teachers and comprises four parts (General concepts, Clinical nursing care, Psychosocial care, and Ethical and legal aspects) with 30 hours of lectures, 25 hours of practical sessions (clinical cases, demonstrations, and simulations) and 5 hours of assessments and tutorials. The training program was described in more detail in a previous study (Schmidt-RioValle et al 2012).

Data gathering

Participants completed a self-administered anonymous questionnaire on the first and final days of the PC course. It contained three open questions:

- 1) Briefly describe the emotions evoked by the idea of your own death. What emotions does thinking about your own death evoke?
- 2) Write as specifically as possible what you consider will happen to you as you physically die?.
 - 3) What do you consider to be "a dignified death"?

The first two questions were obtained from the "Mortality Attitudes Personality Survey" (Rosenblatt, Greenberg, Solomon, Pyszczynski & Lyon, 1989), used in previous studies of the Terror Management Theory (TMT) to elicit emotions and thoughts about the

responders' own death, while the third is used to gather information on their beliefs and cultural values (Burgin, Sanders, Vandellen & Martin, 2012). Each student used the same code for both questionnaires to enable comparison of their responses.

Data analysis

Content analysis is a systematic and objective method to make valid inferences based on verbal, visual, or written data and to quantify specific phenomena (Downe-Wamboldt, 1992), analyzing manifest and latent content with an emphasis on variation and comparison (Graneheim and Lundman, 2004; Graneheim, Lindgren & Lundman, 2017). Inductive content analyses were performed on the discourses of participants before and after the PC course, obtaining condensed categories and significant materials.

The completed questionnaire was the unit of analysis and the words, sentences, and/or paragraphs were the units of meaning. Table 2 exhibits the procedure followed for the analysis, which established three main categories (to be physically dying, to be physically dead, and dignified death) and eleven subcategories.

Comparisons between before and after the PC course were conducted by calculating the absolute and relative frequencies of the different categories with respect to the total and the absolute and relative frequencies of each subcategory with respect to the total category. Given the wide diversity of codes, those with a relative frequency < 5 % at either time point were excluded (Mayring, 2014, pp. 86-87). This type of analysis is possible when the results of qualitative analysis can be quantified through the frequency of category citations, as in content analysis, and when qualitative analysis software offers simple quantitative procedures (Mayring, 2014, pp.116-117). Software Atlas.ti version 7.0 was used for this purpose in the present study.

Various approaches were adopted to improve the trustworthiness of the study (Graneheim and Lundman, 2004): 1) Teaching and research experience of the teachers on the study subject and on the use of qualitative methodology; 2) Participant selection strategy to maximize the degree of diversity and variations in the group under study; 3) Utilization of a self-administered questionnaire that did not involve interaction with participants; 4) Differentiation of the initial and condensed units of meaning before assigning codes, subcategories, and categories (Table 2), with confirmation of this analysis by two external researchers following a triangulation strategy; 5) Longitudinal Pre post evaluation study design, asking the same participants the same questions at two different time points (Flick, 2014); and 6) application of qualitative analysis software with simple quantitative procedures to compare between time points with no mediation by researchers. *Ethical considerations*

Students were invited to volunteer for participation in the study on the first day of their PC course, immediately after the initial description of the course contents (anthropological perspective on death and dying in their cultural setting). The research project and conditions of their participation were described before obtaining their verbal consent, confirming that their responses would be anonymous. It was also explained that they could withdraw from the study at any stage without prejudice and that the support of the teacher was available at any time (no request for this support was made). All personal data obtained in this study were treated in accordance with national data protection legislation (Law 3/2018, 5 December). The research was approved by the Research Ethics Committee of the University.

Results

Three main categories were identified. Overall, participants described their perceptions in greater detail at the end of the course, when they provided a greater number of quotes in the three categories (Table 3).

Category 1: Beliefs on being physically dead

These beliefs were organized into two subcategories (see Table 3). In the case of the organic process, clinical signs related to death and its process (e.g., organ failure, brain death or cardiac arrest) were described as analogous to switching off a machine, with the body draining its battery before disconnection.

"When I am dying I will physically wear away little by little" [P79 pre]
"I suppose my body will gradually deteriorate and my systems will stop working" [P9

post]

The most frequent change after the course was in the students' perception of a progressive deterioration, with a larger number of quotes describing the process in terms of wear or a worsening.

"Before dying I will feel physically deteriorated and with a poor appearance"
[P31post]

Responses on emotions mainly reflected the distress and anxiety produced by thoughts of dying.

"Thinking about it makes me feel sort of anxious" [P62 pre]

The percentage of quotes related to these emotions was 51.72 % before the course and 26.09 % at its end. References to death-related sadness and pain emerged after but not before the PC course.

"...I will be sad to leave, to not be with my loved ones anymore" [P56 post]

Category 2: To be physically dead

This category attracted the largest number of codes after the course, being described as a biological process involving decomposition with clinical signs such as rigidity, cyanosis, or loss of pupil reflex.

"Shortly after dying, the process of putrefaction will begin, which will decompose the body until nothing is left, only the bones. It will gradually decompose from the inside outwards". [P15 pre]

"Once I am dead I will be cold and pale, and my muscles will be stiff." [P10 post]

After the course, there were more quotes on the fact of feeling nothing after death, although there were fewer quotes on the end of existence or to the fact that nothing happens after death.

"After dying I do not think I will feel anything physically or mentally". [P 76 pre]

"After I am physically dead I will feel nothing at all because I am already dead". [P8 post]

Before the course, there were more quotes on the denial of death, understood as the difficulty of imagining it and the avoidance of death-related thoughts.

"I don't like to think about death much, but it does worry me". [P3 pre].

"Respect, some fear. Anyway, I try to think as little as possible about my own death" [P13 pre].

There were fewer quotes on death-related anxiety and fears and on avoidance at the end of the course, but expressions of sadness and feelings of uncertainty were more frequent.

"I get very anxious and avoid thinking about it, because when I do I have problems sleeping and concentrating on anything else" [P34 pre]

"The emotions that I feel when thinking of my own death have changed. I feared being alone, feeling pain and not having enjoyed my life, as if I had lost it. But I don't worry about this much anymore. I'm living my everyday life, enjoying it and not thinking about when my time comes. What I'm most worried about now is how my relatives and friends will be, how they would suffer with my death, and I also fear not having said goodbye to them before, not seeing them again" [P62 post]

With respect to preferences, some students indicated a wish to be cremated after death, at both the start and end of the course.

"Once I die my body will decompose and, as it is often said, "the worms will eat me", although it is probable that this won't happen if I choose cremation, which I am more drawn to" [P17 pre].

"... when I'm dead I want to donate my organs and be cremated" [P59 post]

Category 3: Dignified death

Perceptions of a "dignified death" differed in relation to general, physical, emotional, and social conditions.

Under general conditions, twice the number of participants considered a dignified death to be a progressive death in which the person dies gradually after than before the start of the course.

"... the body will progressively shut down until it loses all of its functions". [P30 pre]

Physical conditions were considered important at both time points, although a dignified death was more frequently defined as free of pain or suffering with the best possible quality of life and comfort after the course.

"Dignified death is that in which the person doesn't suffer, no unnecessary therapeutic tests are made (therapeutic obstinacy)..." [P17 post]

The "emotional conditions" subcategory was mainly identified with dying in peace at both time points, although there was a slight decrease in the number of related quotes after the course. For the "social conditions" subcategory, dying surrounded by loved ones was considered to define a dignified death both before and after the course.

Finally, in relation to decision making, there were twice as many references to the importance of patients' ability to decide their own end-of-life process after than before the course. Respecting the wishes of parents was considered important at both time points.

"I consider that having a dignified death is when they let you be happy during the final moments, among your loved ones, allowing you to share this moment with those who want to be there until the end and respecting rights and duties" [P16 pre].

"...in which people can decide how the process should be and are able to choose, to say goodbye, to organize their affairs". [P35 post].

Discussion

In this study, a course on palliative care produced changes in the perception by nursing students of their own death. Participants described death as an organic process, inherent to the process of life, in line with previous studies (Dias et al., 2014), but as more difficult to accept when unexpected (Junior & Eltink, 2011). Ranse et al. (2018) also found that unexpected death was of particular concern to students after providing care for a dying patient, both in terms of the manner of death and the physical changes undergone by the dying patient. After the course, the students more frequently referred to death as a progressive deterioration than as a disruptive event (Dias et al., 2014) and demonstrated an increased acquisition of competences and abilities on clinical signs and symptoms related to dying and death.

Death can be perceived as a transition in which emotions of pain, uncertainty, and relief prevail or as a natural process of human development (Santos & Hormanez, 2013). Before the course, the responses reflected anxiety-related emotions caused by delivering EOLC, and these emotions have been described as distancing health care professionals from dying patients and their relatives (Lewis, Reid, McLernon, Ingham, & Traynor, 2016). There were fewer expressions related to these emotions after the course, when there was an increase in quotes related to sadness or loss. Passing from (fear-related) anxiety to (lossrelated) sadness can be understood as an emotional development that improves or facilitates the acceptance of death. In this regard, previous studies in nursing students have indicated that death-related anxiety and fear are modulated by social and emotional competencies associated with positive coping (Edo-Gual, Monforte-Royo, Aradilla-Herrero & Tomás-Sábado, 2015), while sadness is considered a normal reaction in the process of adapting to and coping with the end of life (Arranz, Barbero, Barreto & Bayés, 2003). The emotional training of students can reduce the traumatic impact of death (Smith-Han et al., 2016), even when conducted online (Tan, Ross & Duerksen, 2013). It has been observed that the fear of death is greater in students with lesser clinical training and experience (Espinoza, & Sanhueza, 2012). Before the course, students were more likely to be in a state of denial about death as a protection mechanism against negative emotions (Santos & Hormanez, 2013).

There was also a greater trend after the course towards considering a dignified death as a progressive process, considering death to be "bad" when unexpected. There was also an increase in quotes relating a dignified death to the participation of patients in decision-making and to a respect for their wishes. It has been observed that medical students who received specific training change their view on the death of others, progressing from a self-

perception of "superheroes" or "saviors" to one of professionals tasked with preserving the quality of life of patients and helping them to achieve a dignified death with minimal anxiety (Smith-Han et al., 2016). It has been reported that contact with end-of-life processes by young people increases their awareness of the importance of decision making by patients and respect for their wishes (Kavalieratos, Ernecoff, Keim-Malpass, & Degenholtz, 2015).

Well-designed PC courses can help students to manage death-related emotions (Mondragón-Sánchez, Cordero, Espinoza & Landeros-Olvera, 2015) and should offer time and space for their expression (Santos & Hormanez, 2013). Training centered on self-awareness about death was found to have a positive effect on the attitudes of students towards EOLC (Bailey & Hewison, 2014), supporting the need to include modules on the death of self and others in the curriculum of nursing degrees.

Fear about one's own death can hinder the reporting of bad news, adding to the conspiracy of silence (Ciałkowska-Rysz & Dzierżanowski, 2013; Mondragón-Sánchez et al., 2015) and having a negative impact on the relationship between healthcare professionals and their patients (Loerzel & Conner, 2016).

The present study analyzed data gathered from second-year students in a single nursing school, limiting the generalization of its findings. In addition, no analysis was conducted of the possible influence of the personal/professional experience of participants in caring for the dying, although the vast majority had no such experience. A further limitation was that no account was taken of potential gender differences in the expression of emotions and in death-related attitudes and behaviors (Sándor, Birkás, & Győrffy, 2015).

Conclusions

In this study, perceptions of nursing students about their own death and being dead were modified by a palliative care course. It produced a decrease in dying-related anxiety and denial and an increase in sadness and loss, which can be interpreted as a greater acceptance of death. The course also increased the inclusion of decision-making by patients and respect for their wishes in the students' understanding of a dignified death.

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Table 1. Sociodemographic data and previous experience of participants

Variables	n	%
Sex		
Female	65	76.47
Male	20	23.53
Professional experience care of dying patients		
Yes	3	3.53
No	82	96.47
Personal experience care of dying relatives		
Yes	22	25.88
No	63	74.12

Table 2. Creation of categories and subcategories

Category	Sub-categories		
Beliefs about physically dying	Organic dying process		
	Feelings about dying		
To be physically dead	Biological attributes		
	Spiritual attributes		
	Emotions and feelings		
	Preferences		
Dignified death	General conditions		
	Physical conditions		
	Emotional conditions		
	Social conditions		
	Decision-making		

Table 3: Categories and subcategories extracted from the content analysis before and after the intervention, expressed in absolute (categories) and relative (subcategories) frequencies

	Pre		I	Post	
	c/TC	%	c/TC	%	
Category: Beliefs about physically dying	130/579	22.45%	149/668	22.31%	
Subcategory: Organic dying process	101/130	77.69%	126/149	84.56%	
Vital organ failure	20/101	19.80%	17/126	13.49%	
Weakness and tiredness	15/101	14.85%	16/126	12.70%	
Asphyxia or shortness of breath	7/101	6.93%	9/126	7.14%	
Loss of consciousness	12/101	11.88%	7/126	5.56%	
CA	6/101	5.94%	9/126	7.14%	
Progressive deterioration	1/101	0.99%	14/126	11.11%	
Shutting down	7/101	6.93%	3/126	2.38%	
Subcategory: Feelings about dying	29/130	22.31%	23/149	15.44%	
Anguish and anxiety	15/29	51.72%	6/23	26.09%	
Sorrow/Pain	0/29	0.00%	6/23	26.09%	
Category: Being physically dead	260/579	44.91%	271/668	40.57%	
Subcategory: Biological attributes	39/260	15.00%	35/271	12.95%	
Physical attributes of the corpse	12/39	30.77%	8/35	22.86%	
Decomposition	23/39	58.97%	22/35	62.86%	
Subcategory: Spiritual attributes	45/260	17.31%	55/271	20.30%	
Stopping existing	14/45	31.11%	12/55	21.82%	
Feeling nothing	10/45	22.22%	17/55	30.91%	
Doubts or no beliefs about death	8/45	17.78%	6/55	10.91%	
Subcategory: Emotions and feelings	144/260	55.38%	143/271	52.77%	
Denial	13/144	9.03%	4/143	2.80%	
Anxiety about death	68/144	47.22%	48/143	33.57%	
Sadness	12/144	8.33%	23/143	16.08%	
Uncertainty	10/144	6.94%	18/143	12.59%	
Subcategory: Preferences	32/260	12.31%	38/271	14.02%	
Choice of cremation	12/32	37.50%	13/38	34.21%	
Category: Dignified death	189/579	32.64%	248/668	37.13%	
Subcategory: General Conditions	31/189	16.40%	19/248	7.66%	
Progressive	11/31	35.48%	12/19	63.16%	
Depends on type of death	10/31	32.26%	3/19	15.79%	
Subcategory: Physical conditions	62/189	24.34%	94/248	37.90%	
Death without pain or suffering	43/62	69.35%	69/94	73.40%	
Death with highest possible quality of life	3/62	4.84%	16/94	6.38%	
Subcategory: Emotional conditions	26/189	13.76%	30/248	12.10%	
Dying in peace	12/26	46.15%	12/30	40.00%	
Subcategory: Social conditions	37/189	19.58%	46/248	18.55%	

Dying surrounded by loved ones, being				
accompanied	26/37	70.27%	31/46	67.39%
Subcategory: Decision-making	33/189	17.46%	59/248	23.79%
Autonomy to decide about your own				
death process	8/33	24.24%	24/59	40.68%
Respecting the wishes of patients. Wishes				
fulfilled	13/33	39.39%	20/59	33.90%

Table shows the number of times that each code (c= code) was cited resulting from the analysis of each category concerning the total number of codes in each category or subcategory as appropriate (TC= Total codes). Each column represents the point of data collection: pre and post-course.

CRediT author statement

Celia Martí-García: Conceptualization, Data Curation, Formal Analysis, Writing-original draft. Laura Ruiz-Martín: Data Curation, Writing – review & editing. Manuel Fernández-Alcántara: Data Curation, Methodology, Writing – review & editing. Rafael Montoya-Juárez: Conceptualization, Methodology, Data Curation, Software, Writing – review & editing. César Hueso-Montoro: Methodology, Software, Writing – review & editing. María Paz García-Caro: Conceptualization, Methodology, Data Curation, Software, Writing – review & editing.

Highlights

- After the learning, participants described their perceptions in more detail.
- Palliative care learning reduces the expression of dying-related distress and anxiety
 and increases the expression of sadness about loss, improving acceptance and
 coping ability.
- This learning improves knowledge of the clinical signs of death and supports the definition of dignified death as free of pain and suffering and respectful of the patient's wishes.