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Promoting Death Literacy in Palliative Care Nursing Education Using Narrative Pedagogy

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Abstract

Undergraduate nursing students develop their training in a real context, where they are frequently confronted with clinical cases of clients in the end-of-life process but feel uncomfortable with palliative and end-of-life care. This pre–post study with a pre-experimental design evaluated the impact of an educational intervention on nursing students and their compassion levels, spiritual preparedness, and attitudes toward death. A total of 62 students participated in a training program consisting of 25 contact hours based on narrative pedagogy (theoretical and practical classes). The results showed that educational intervention positively impacted different dimensions, particularly self-compassion and spirituality, as well as reduced fear of death and increased neutral acceptance. Nursing education should prioritize the inclusion of death, dying, and end-of-life care across the nursing curriculum's fundamental courses.

Keywords: *Palliative care; education; nursing; death literacy; compassion; narrative pedagogy.*

1. Introduction

Palliative care has gained relevance in health services, becoming an integral part of the holistic approach to people with chronic, incurable, and progressive illnesses. The World Health Organization (2014) highlighted this goal and approved a commitment to strengthen palliative care as a component of integrated treatment throughout life. Providing compassionate care for dying patients is a crucial aspect of nursing. It enhances nurses' ability to promptly attend to their patients' physical, spiritual, and emotional requirements. However, nurses often hesitate to discuss death with both their patients and colleagues (Tamaki et al., 2019). Nurses can gain information and cultivate adequate attitudes toward end-of-life (EoL) care through death

education (Mastroianni et al., 2015). Undergraduate education should offer nursing students a chance to cultivate the competencies needed for EoL encounters. According to Shaw and Abbott (2017), students who are provided with such education are more inclined to develop into proficient healthcare providers.

Based on Human Caring Science Theory (Watson & Woodward, 2020), spiritual care should be a paramount cornerstone in nursing practice and education. In this sense, promoting spirituality and spiritual care is relevant, along with compassion (the intentional sensitivity to suffering and the commitment and motivation to alleviate it). Considering the specificity of caring for a person and family in palliative and EoL conditions, as well as the positive attitudes toward death when nursing students perform clinical placements (Novais et al., 2021), improving these attitudes in training programs in palliative care nursing is important. Several studies have demonstrated that training and courses in active learning strategies (such as simulation, drama, narrative pedagogy, and roleplaying) can enhance the confidence of nursing students and foster more positive attitudes toward death and EoL care (Ozpulat et al., 2023; Tamaki et al., 2019; Zhu et al., 2023).

To the best of our knowledge, no Portuguese studies have described these experiences for undergraduate nursing students. To effectively provide outstanding EoL care in a real-world setting, nursing students must receive sufficient preparation during their undergraduate studies. The gold standard of nursing practice is contingent upon the value of the nursing education imparted, as well as students meeting the necessary qualifications. Therefore, this study aimed to evaluate the impact of an educational intervention based on narrative pedagogy on senior nursing students' compassion levels, spiritual preparedness, and attitudes toward death.

2. Methodology

2.1. Study design

This pre–post interventional study with a pre-experimental design was conducted between October 2023 and November 2023. The STROBE cross-sectional reporting guidelines were used to report this paper. Research permission was granted from the Ethics Committee of Polytechnic University of Leiria (CE/IPLEIRIA/54/2023). Likewise, necessary permissions were obtained from the scale owners and students who agreed to participate in the research (via the button to accept to participate in the e-survey).

2.2. Participants and Recruitment

The population included 120 students in the 4th year of the nursing degree. The sample was obtained using a convenience sampling method. Eligible participants were students aged over 18 years; enrolled in the palliative care nursing course; and fluent in Portuguese. International

incoming mobility students were excluded. A total of 62 students participated (response rate = 51.67%) with an average of 22.61±2.84 years of age (range: 20–32). The vast majority were female (90.3%), single (95.2%), lived in a rural context (51.6%), and stated having a spiritual belief (74.2%).

2.3. Educational Intervention

The contents and approaches were developed by two faculty members associated with the palliative care nursing course and two nurses with clinical experience in the same area. The sessions were tailored to the needs identified during the initial assessment (pretest). The curriculum included the main themes affiliated with the four pillars of palliative care, namely symptom control associated with "total pain"; therapeutic and effective communication; family care; and interdisciplinary teamwork (Wantonoro et al., 2022). Conventional pedagogy has its limitations when dealing with sensitive topics such as death, namely a lack of flexibility, experience, and interactivity. Alternatively, narrative pedagogy can be used to investigate difficult topics using narration, explanation, and reconstruction of stories and experiences (Zhu et al., 2023).

The narrative training program lasted five weeks, with each participant receiving a total of twenty-five hours of training. The theoretical component lasted fifteen hours (eight sessions: seven 2-hour sessions and one 1-hour session) and the practical component lasted ten hours (five 2-hour sessions). Each week, using expository and interrogative methodology, there were lectures on the following contents: a) values and attitudes towards death and the EoL; b) compassionate communication and person-centered approach, and management of bad news/family conference; c) “total pain” and symptom management in evitable suffering; d) comfort measures in EoL – education of patients, families, and caregivers; e) spirituality and spiritual care competence; f) bereavement support; g) interprofessional teamwork in palliative care; and h) self-care of professionals. Concomitantly, practical lessons were presented in 8-12-person classes and used active learning strategies centered on self and relational skills, especially using autoscopy, roleplaying, case-based learning, team-based learning, and autobiographical narratives. In addition, real clinical cases were used to bring the simulated context closer to that of clinical practice in areas such as the communication of bad news, the development of the family conference, symptom control, and care at the EoL. All practical sessions maintained the same structure throughout the program, including a first phase of negotiation and task assignment (prebriefing); a second phase implementing the training activities using ready-made narrative materials and self-made materials based on students’ own experiences of life and death; and a final debriefing phase to foster critical reflection.

2.4. Data Collection

The e-survey took approximately 12 minutes to complete and was submitted only after all the survey contents had been completed to ensure non-missing values. Data were collected before and after the intervention and included four parts:

1) Socio-demographic data (age, gender, marital status, place of residence and spiritual beliefs);

2) Death Attitude Profile-Revised (DAP-R) Scale (developed by Wong et al., 1994; Portuguese version by Loureiro & Jesus, 2010) to assess students' attitudes toward death. The DAP-R consists of 32 items grouped into five distinct dimensions corresponding to different attitudes: fear of death (7 items), death avoidance (5 items), neutral acceptance (5 items), approach acceptance (10 items) and escape acceptance (5 items). All use a 7-point Likert scale (ranging from 1 = strongly disagree to 7 = strongly agree). Fear of death and death avoidance are attributed to negative death attitudes. Neutral acceptance, escape acceptance, and approach acceptance are attributed to positive death attitudes. The total DAP-R alpha coefficient had good reliability.

3) Compassionate Engagement and Action Scale (CEAS) (developed by Gilbert et al., 2017; Portuguese version by Cunha et al., 2023). This 30-item scale with a 10-point response score (ranging from 1 = never to 10 = always) is divided into three domains: compassion for others (10 items); compassion from others (10 items); and (3) self-compassion (10 items). Each scale separately assesses the individual's compassionate attributes and actions when facing a situation of difficulty or suffering. Higher scores indicate higher compassion levels. The scale has good internal consistency.

4) Spirituality and Spiritual Care Rating Scale (SSCRS) (developed by McSherry et al., 2002; Portuguese version by Martins et al., 2015) consists of 17 items and identifies nurses' perceptions of spirituality and spiritual care. Participants are asked to rate four factor-based subscales: Spirituality, Spiritual Care, Religiosity, and Personalised Care, using a 5-point scale (ranging from 0 = strongly disagree to 4 = strongly agree). The scale's alpha value was 0.76.

2.5. Data Analysis

The data were analyzed using the Statistical Package for Social Sciences (SPSS, v.24.0). Central tendency (mean) and dispersion measures (standard deviation, range) were used for descriptive statistics. The dependent group t-test was used to analyze the pretest and post-test scores. The level of significance was set at $p < 0.05$.

3. Results and Discussion

In the DAP-R's initial assessment, neutral acceptance was the dimension with the highest mean score, while death avoidance had the lowest mean score. Individuals often avoid confronting mortality due to their fear and uncertainty regarding death. This behaviour underscores the importance of promoting death literacy. With the development of the program, the average response tended to decrease in death avoidance and fear, the latter showing statistical significance ($t = 1.98$; $p = 0.026$). These data are consistent with the evidence highlighted in other studies (Novais et al., 2021; Williams et al., 2022; Zahran et al., 2022). Only neutral acceptance was statistically significant after intervention ($t = -1.99$; $p = 0.026$), meaning that participants viewed death as an integral part of life (Table 1). Notwithstanding, there was a slight increase in post-intervention response scores in two subscales: approach acceptance (death viewed as a passageway to a happy afterlife) and escape acceptance (death viewed as an escape from a painful existence).

Regarding the CEAS, there was also an improvement in the mean score of all the instrument's dimensions, with a statistically significant positive effect in the self-compassion dimension ($t = -1.87$; $p = 0.034$). Self-compassion has been demonstrated to be an important mediator of professional self-care (Mesquita Garcia et al., 2021; Mills et al., 2017). Therefore, it is a relevant dimension for palliative care nurses, which is why the results achieved in this domain are considered positive. Compassion in healthcare has been gaining greater attention, particularly concerning perceptions and implications for ill people and healthcare professionals, as well as the systematization of interventions that promote compassionate care (Malenfant et al., 2022). Compassion, as an empathetic construct, is crucial in care settings as it promotes information and dialogue and creates a space for dying and accepting death by family caregivers (Skorpen Tarberg et al., 2020). Therefore, compassion was a prominent area in lesson development related to communicating bad news and managing family conferences.

Education and self-reflection are paramount for the development of spiritual care competency among healthcare professionals (Gijsberts et al., 2019). Spiritual care includes creative, narrative, and ritual work. In this sense, the students were asked to write an individual critical narrative to holistically evaluate their experience of suffering or the process of death and dying, thus mobilizing their feelings and meaning of purpose associated with humanized care. Connecting, or reconnecting, with a unique sense of spirituality can serve as a powerful resource for resilience (Miller et al., 2023). After the intervention, there was an overall change in the score of four SSCRS domains. However, only the "spirituality" domain stood out with a statistically positive change ($t = -2.25$; $p = .014$). Educational interventions based on narrative pedagogy seem to help nursing students develop compassion and promote positive attitudes toward death and spiritual care preparedness.

Table 1. Pretest and Posttest Scale Scores.

Instruments	Pretest		Posttest		Paired samples test			
	Mean	SD	Mean	SD	Mean	SD	*t*	*p*
Death Attitude Profile-Revised (DAP-R) Scale								
DAP-R – death fear	3.62	1.29	3.09	1.30	0.49	1.85	**1.98**	**.026***
DAP-R – death avoidance	3.06	1.37	2.75	1.39	0.33	1.97	1.24	0.11
DAP-R – neutral acceptance	5.47	0.89	5.81	0.76	-0.35	1.29	**-1.99**	**.026***
DAP-R – approach acceptance	3.47	1.29	3.87	1.49	-0.39	1.99	-1.44	0.08
DAP-R – escape acceptance	3.11	1.23	3.26	1.46	-0.20	1.87	-0.81	0.21
Compassionate Engagement and Action Scale (CEAS)								
CEAS – self-compassion	6.41	1.04	6.78	1.14	-0.38	1.51	**-1.87**	**.034***
CEAS – compassion for others	7.38	0.98	7.58	1.10	-0.11	1.53	-0.53	0.30
CEAS – compassion from others	6.49	1.15	6.58	1.17	-0.04	1.45	-0.22	0.42
Spirituality and Spiritual Care Rating Scale (SSCRS)								
SSCRS – spirituality	4.08	0.61	4.35	0.55	-0.28	0.91	**-2.25**	**.014***
SSCRS – spiritual care	4.08	0.39	4.17	0.49	-0.06	0.56	-0.82	0.21
SSCRS – religiosity	1.67	0.70	1.64	0.78	0.04	1.09	0.29	0.39
SSCRS – personalized care	4.52	0.51	4.61	0.52	-0.08	0.75	-0.83	0.20

Standard deviation (SD); * $p<0.05$

3.1. Study limitations

The present study has some limitations such as the sample size and the duration of the educational intervention program, which prevented the deepening of some contents. Some of the items had high initial scores and did not increase, a result which could be due to a ceiling effect. Furthermore, we only employed a quantitative approach to assess the effects of death education. Qualitative research methodologies are advisable for a more comprehensive evaluation of students' emotional experiences. Another drawback of this study was the use of a cross-sectional design rather than a longitudinal method, which could further examine the impact of training across various levels of nursing courses and types of training. Another constraint arises from the utilization of self-report questionnaires, which may tend to provide the socially desired results.

4. Conclusion

Nursing education has been updated by developing knowledge and practice, in a continuous flow of exchange between the academic and clinical components of nursing. Holistic palliative care encompasses a multiplicity of care where nurses are particularly important in facilitating the different transitions faced by the ill person and their family. Narrative pedagogy involves acquiring knowledge that goes beyond formal knowledge (cognitive dimension) and encompasses an affective disposition where the use of self in the relationship involves areas such as compassionate and spiritual care, allowing for the development of a positive attitude towards death. This educational intervention showed a positive impact on different dimensions,

particularly in the areas of self-compassion and spirituality, and reducing fear of death and increasing neutral acceptance. Our findings may assist educators in gaining a deeper comprehension of the significance and immediacy of death education, while also offering a novel approach to the subject.

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