Arts-Based Reflection on End-of-Life Care: Student Narrative Analysis

Maryann O. Forbes, PhD, RN, CNE Adelphi University, Garden City, NY Virginia C. Oates, DNP, RN Adelphi University, Garden City, NY

November 2018



Introduction

- Multiple factors can negatively influence student ability to provide patient-centered care for dying patients:
 - Students may have been caregivers for dying patients or experienced death and dying in their own families.
 - Limited experience with environments of care for dying patients
 - Difficulty understanding the complex role of the nurse in end-of-life care.

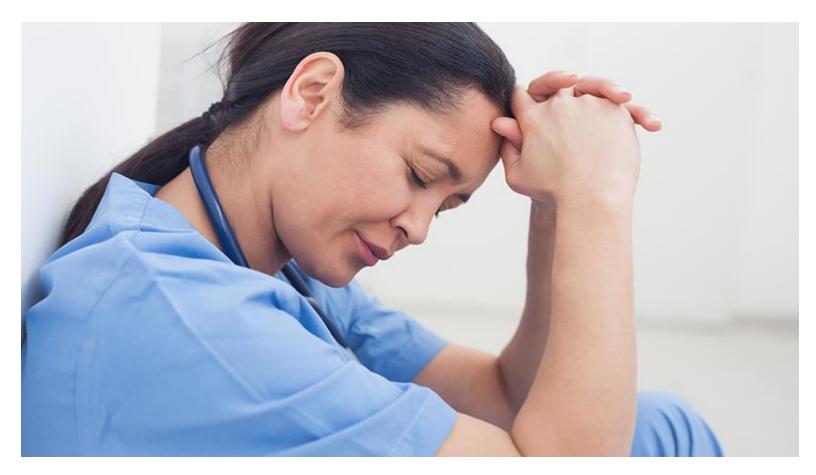


"Hand-off"

- New grad nurse is assigned to a 62-year-old female with breast cancer, metastasis to lung, bone, and brain.
- Patient is alert but disoriented, experiencing pain from bone metastasis, experiencing severe dizziness on ambulation.
- The oncologist just left the room; patient and family were told there are no more treatment options. The oncologist recommends hospice.
- The patient is crying uncontrollably and her spouse and 4 children are in the room.



New Graduate Nurse's Reaction "Am I Prepared to Deal With This?"





Background

- Undergraduate students are not being well prepared to deliver palliative care (Ferrell, Malloy, Mazanec, & Virani, 2016).
- New teaching/ learning strategies are needed to teach end-of-life care that focus on affective learning.



Arts-based Pedagogy in Nursing Education

- Humanities in nursing education
- Arts can encourage reflection, create meaning and engage nursing students
- Focuses on the *affective* domain of learning
- Interpersonal and caring aspects of nursepatient relationship

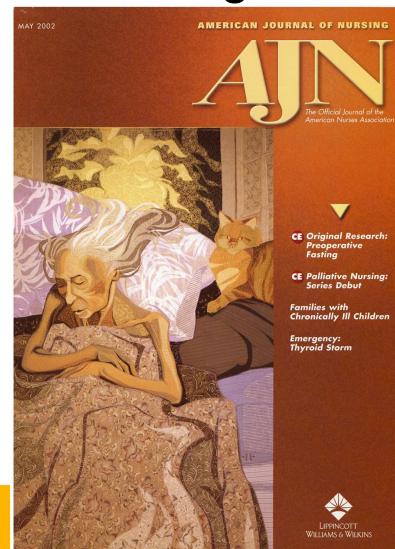


Literature Review

- Significant gaps exist in both the qualitative and quantitative research knowledge about art-based pedagogy (Rieger et al, 2016).
- Recommendations:
 - Arts-based initiatives should be used to develop student's relational skills, such as empathy, awareness of multiple perspectives, and understanding of a person's unique context.



Meet the Artist: Thread on Fabric Images





Purpose

 The purpose of this qualitative narrative analysis study was to explore the impact of an arts-based student reflection assignment on student affective learning regarding end-of life nursing care in an online older adult course.



Narrative Analysis

 Focuses on storytelling or personal accounts

• Different approaches utilized

• May involve the use of an art form



Student Assignment Guidelines

- (N=21) undergraduate nursing students selected one of six thread-onfabric images related to end-of-life care and were asked to sit quietly and reflect on the image for at least five minutes before writing.
- The images were of a dying patient alone, with a caregiver, or a family.





Student Assignment Guidelines

1. Imagine that you are the nurse assigned to care for this patient experiencing end- of- life symptoms, describe what you might see, hear, smell and feel when you enter the room -and what is going on? Give as much detail as possible in your narrative.

2. If you are the patient's nurse, make a nursing diagnosis and identify the details and reasons that lead you to that conclusion.

3. Take a minute to imagine that you are the patient's primary caregiver and you are visiting the room. What are you thinking and feeling, what are you saying, and what are you doing?

4. Think about being the dying person depicted in this image. If you are the dying person, what are you thinking and feeling? What do you want, and what do you need?



Sample

- Twenty-one undergraduate students
- Students enrolled in a junior level Nursing Care of the Older Adult online course in an undergraduate baccalaureate program.
- Participation was voluntary and confidential without impact on course grade.
- Research was conducted during two semesters



Data Analysis

- Content analysis was utilized to analyze student narratives.
- Two researchers independently completed lineby-line coding to identify key phrases or meaning

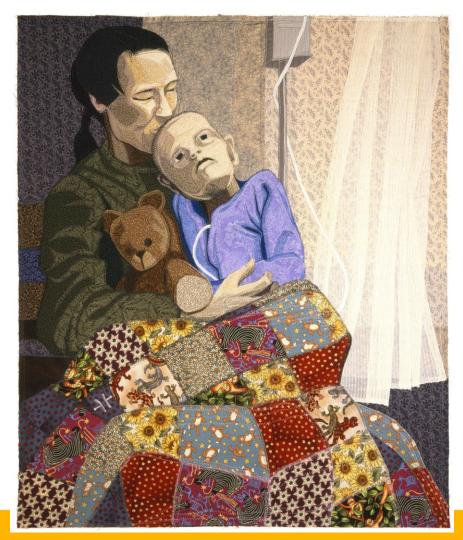


Themes/ Categories

- Environment at end of life
- Empathy for the patient experience
- Nursing role at end of life
- Student reflections and self-awareness.



Artistic Images: Child





Theme: Environment at End-of-Life

- Student's descriptions of the environment were rich with description and included the perception of a "heavy, tense atmosphere" with strong emotions of despair and love existing together in the room.
- The room was described by one student as *"uncomfortably silent*" and another noted the room was quiet and still *"the sense of rush may be absent" and "things moved at a slower pace."*
- Students noted the importance of measures to ensure comfort and dignity.



Artistic Images: At Night





Theme: Empathy for the Patient Experience

- Students were acutely aware of the atmosphere of tension in the room in *At Night.*
- They reflected on the presence of sadness and family members' conflicted feelings.
- Narrative responses included a "heavy, tense, atmosphere with saddened family members in the room, no eye contact, no engagement in conversation between family members as they may have had a big argument, uncomfortably silent."
- Another student commented that it was "reassuring to see family in attendance, tenseness overrides the positive effects of having a close support system."



Theme: Nurse's Role at End-of-Life

- Students reflected on the importance of the nurse's role in end-of-life care and felt frustrated that they could not do more in the situation.
- They frequently commented on the need to provide basic care to ensure that the patient's physiologic needs were met.



Student Quote: Nurse's Role at End-of-Life

"What can I say to make this situation any better? Another part of me wants to heal all her worries and illness at the press of a button; a part of me doesn't want to say anything because there's nothing to be said. Instead, I do what nurses do best and nurse her to the best condition she can possible be in at the moment. I make sure she's not hungry, I make sure she's not thirsty, and I make sure she's all cleaned up."



Theme: Student Reflection and Self-awareness

- Students were experiencing a sense of helplessness and anger at the disease.
- They recognized the power of their own emotions when caring for patients at end of life and wanted to be able to compartmentalize their feelings.
- They also were fearful that they would not know how to speak to the family.



Student Quote: Student Reflection and Self-Awareness

 "I see something that makes me want to cry. I feel something that makes me want to cry. I can feel their (patient and family member) body heat radiating off one another. I can feel my hatred for disease and illness."



Discussion

Environment of End-of-Life:

 Further emphasis may be needed in nursing education to address the possible emotional conflicts that students/ nurses may anticipate from family members, sometimes expressed in front of the patient.

Empathy for the Patient Experience:

 Students commented frequently about their own desire to have loved ones present at the end of life, and then projected that sentiment to the dying patient in the images.



Discussion

Nurse's Role at End-of-Life

- Students expressed the realization of the importance of the nurse's time and presence in palliative care and the qualities needed on the part of the nurse in order to provide compassionate care.
- Although students believed that helping families navigate difficult moments was an important nursing role, there was little mention of the spiritual needs of the patients and families.



Discussion

Student Reflections and Self Awareness

- They were able to express negative emotions, such as anger and despair that they may experience when confronted with the complexities of the dying process.
- They reflected on the importance of the nurses' communication with the patient and family.



Implications/Recommendations

- This need for companionship to the patient during the dying process warrants further discussion with nursing students, as they will undoubtedly care for patients that are alone and without caregivers or loved ones.
- Future replication of this research should be structured to include spirituality needs assessment as part of the guiding questions.



Conclusion

 Arts-based pedagogy is an affective teaching strategy that can be used to enhance student understanding of the complexities of end-of-life care and promote empathy.



Thank you

- Sincere appreciation to Deidre Scherer for providing dignity and respect to patients at the end of their lives while illustrating this life experience and converting these images into a beautiful art form.
- We are truly grateful for her collaboration in using thread on fabric images in nursing education.

http://dscherer.com/portfolios/traveling-exhibitions/



-Questions?



References

- American Nurses Association. (2017). Call for Action : Nurses Lead and Transform Palliative Care Call for Action : Nurses Lead and Transform Palliative Care.
- Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K., & Kyngäs, H. (2014). Qualitative Content Analysis. SAGE Open, 4(1), 215824401452263. https://doi.org/10.1177/2158244014522633
- Ferrell, B., Malloy, P. A. M., Mazanec, P., & Virani, R. (2016). CARES: AACN's new competencies and recomemendations for educating undergraduate nursing students to improve palliative care. *Journal of Professional Nursing*, *32*(5), 327–333. https://doi.org/10.1016/j.profnurs.2016.07.002
- Fitzpatrick, J. J. (2017). Narrative Nursing: Applications in Practice, Education, and Research. *Applied Nursing Research*, *37*, 67. https://doi.org/10.1016/j.apnr.2017.08.005
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, *24*(2), 105–112. https://doi.org/10.1016/j.nedt.2003.10.001
- Horton-Deutsch, S., & Sherwood, G. (2017). *Reflective Practice: Transforming Education and Improving Outcomes* (2nd ed.). Indianapolis: Sigma Theta Tau International.
- Rieger, K. L., Chernomas, W. M., McMillan, D. E., Morin, F. L., & Demczuk, L. (2016). Effectiveness and experience of arts-based pedagogy among undergraduate nursing students: a mixed methods systematic review. *JBI Database of Systematic Reviews and Implementation Reports*, *14*(11), 139–239. https://doi.org/10.11124/JBISRIR-2016-003188
- Smith, M. B., Macieira, T. G. R., Bumbach, M. D., Garbutt, S. J., Citty, S. W., Stephen, A., ... Keenan, G. (2018). The Use of Simulation to Teach Nursing Students and Clinicians Palliative Care and End-of-Life Communication : A Systematic Review, 35(8), 1140–1154. https://doi.org/10.1177/1049909118761386

