

Nursing Students' Death Attitudes Change After Palliative Care Immersion Experience

Janelle Fauni

University of Florida

Abstract

Nurses will provide care to a dying patient at some point in their career – an event that many nurses remember for the remainder of their careers. Attitudes toward death can impact the care they provide. Using an experiential learning framework, the College of Nursing initiated the Comfort Shawl Project to enable nursing students to interact with dying patients through a psychosocial immersion in palliative care. This study tracked nine female senior nursing students' death attitudes as they engaged in the project by completing the Death Attitudes Profile (DAP), a 12-item survey with two subscales: fear of death and death acceptance, at the beginning, middle, and end of their year-long experience. Paired t-tests were conducted to examine change in death attitudes over the one-year period. Results showed a significant reduction in fear of death from baseline and a significant increase in acceptance of death from baseline. There were no significant changes in fear of death and acceptance of death from midpoint to end of program. Positive attitudes toward death can contribute to increased confidence and competency in caring for patients at the end of life. Future research will focus on an increased sample size and inclusion of a control group.

Keywords: death attitudes, palliative care, nursing education, experiential learning

(199 words)

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Introduction

Palliative and end-of-life (PEOL) education in undergraduate nursing curricula can impact nursing students' attitudes toward death, ultimately affecting the quality of care they will provide to their future patients. Since it is known that nursing students' personal attitudes toward death and end-of-life are shaped during their initial education programs (Kurz & Hayes, 2006), it is important for nursing schools to provide adequate PEOL education. A study evaluating PEOL education in medical and nursing schools across the United States found that a majority of these schools utilize lectures, seminars/small group discussions, and case discussions to teach PEOL issues and the average time devoted to PEOL education is less than 15 hours (Dickinson, 2007). Although there are the Competencies and Recommendations for Educating Undergraduate Nursing Students (CARES), a set of proficiencies to guide undergraduate curriculums in providing quality palliative care education, there is still an immense variability in the quality and time invested in teaching the topic across nursing schools (American Association of Colleges of Nursing (AACN), 2017). Thus, a year-long PEOL immersion experience, called the Comfort Shawl Project, was initiated at the University of Florida College of Nursing to accompany didactic learning and give nursing students a fulfilling PEOL education.

Within the Comfort Shawl Project, a study was conducted that focused on the death attitudes of senior nursing students who participated in the project. Specifically, this study tracked the participants' death attitudes as they completed the immersion experience. There are numerous studies on the effects of PEOL education in nursing students' attitudes toward death, however, a majority provided PEOL education through didactic learning like online readings, lectures, etc., while very little incorporated learning through experience. Therefore, the purpose

of this study was to examine whether a PEOL immersion experience had an effect on nursing students' attitudes toward death. The study particularly evaluated if participation in the Comfort Shawl Project led to a decrease in fear of death and an increase in acceptance of death.

Background

Death Attitudes

Nursing students will eventually be exposed to dying patients in their career – with their earliest experiences making lasting impacts on their professional and personal lives (Kent, Anderson, & Owens, 2012). Inadequate preparation to care for PEOL patients may lead to negative attitudes toward death and further cause fear of death and death anxiety. Death anxiety is as an unpleasant emotion that originates from existential concerns caused by the contemplation of death of the self or others (Nyatanga & Vocht, 2006) and it can negatively affect a nurse's ability to provide quality care. Those who have higher levels of anxiety and fear of death have been found to be more reluctant in caring for PEOL patients (Peters et al., 2013). The unwillingness to care for PEOL patients can adversely influence quality of care and patient satisfaction as there may be a lack of patient advocacy, communication, care coordination, and empathy by the nurse. Fear of death is also strongly correlated with emotional exhaustion and nurse burnout (Malliarou, Zyga, Fradelos, Evangelos, & Sarafis, 2015). Burnout is deemed as “a syndrome of physical exhaustion including negative self-concept, negative job attitude, and loss of concern and feeling for patients” (Keidel, 2002). It is evident that a nurse's death attitudes not only affect the ability to provide adequate care to their patients, but it also affects their own mental and physical health. Hence, undergraduate nursing education should implement PEOL education to its students who are still in their beginning stages of developing attitudes toward death.

Palliative and End-of-Life Education

The implementation of PEOL education in undergraduate nursing curricula is vital so that nursing students who are starting to develop attitudes toward death can acquire the necessary skills to provide care to PEOL patients and eventually foster positive death attitudes. An educational framework that satisfies the 17 palliative care competencies presented by the AACN, will ensure the delivery of quality PEOL care across illness trajectories and settings (AACN, 2017). Some key competencies noted in the CARES document include recognizing one's own values and beliefs about serious illness and death, performing a comprehensive assessment of pain and symptoms in those with serious illness, and implementing self-care strategies to support moral distress and compassion fatigue (AACN, 2017). A nurse who has sound knowledge on PEOL care will allow them to be more comfortable in caring for PEOL patients. They will be able to better advocate for their patients' wishes as well as establish therapeutic relationships by practicing empathy and providing support. These vital skills will allow a nurse to help their patient go through a "good death" and avoid development of death anxiety or fear of death.

Experiential Learning

Experiential learning is defined as the process where knowledge is generated through the transformation of experience (Kolb, 1984). It allows for a person to have contact with the specific environment as well as exposure to processes that are highly variable and uncertain (Gentry, 1990). Since didactic learning alone is not sufficient for the development of clinical expertise (McHugh & Lake, 2010), experiential learning serves as a useful method for nursing students who are expected to be capable of adjusting in extremely variable clinical settings. Fortunately, interest in experiential learning in nursing education has increased in recent years (Green & Holloway, 1996), with nursing schools incorporating more hours in the clinical setting,

problem-based learning exercises, simulations, and role-playing. These experiential methods have been used to teach nursing students how to perform proper wound care, cardiopulmonary resuscitation, and assessments. Students may find it rewarding if these experiential learning methods can be implemented for PEOL education as well. Nursing students will be able to have a fulfilling PEOL education if they had hands-on opportunities to reinforce their knowledge learned didactically, or in the classroom. Examples of hands-on learning experiences include clinical rotations at a hospice center or simulations that involve caring for a PEOL patient and family. It is vital for nursing curricula to provide their students adequate environments that will allow them to utilize their PEOL knowledge and skills. Opportunities for students to reflect or debrief on their experiences is also necessary for proper growth and learning (Kolb, 1984).

The Comfort Shawl Project

The Comfort Shawl Project began in 2014 at the University of Florida College of Nursing with the goals of providing handmade shawls to PEOL patients, providing senior nursing students with a PEOL immersion experience, and fostering community participation and intergenerational education between nursing students and older adult volunteers (Glover, Horgas, Castleman, Turpening, & Kittelson, 2017). As the project receives donations from the community, the members of the project prepare each donated shawl by sewing on a label and making a custom descriptive sheet that includes a picture of the shawl, the name of the shawl, the crafter's name, and instructions on how to clean and care for the shawl. Prepared shawls are then donated to PEOL patients at UF Health Shands Hospital. The Comfort Shawl Project students attend the interdisciplinary palliative care team meetings before gifting shawls to decide which patients on the palliative care service would enjoy a shawl. The palliative care team is composed of a nurse practitioner, a physician assistant, a social worker, physicians, psychologists,

chaplains, and hospice consultants. After gifting to patients, the students write a reflection about each gifting experience. Other activities within the project include reading *Being Mortal* by Atul Gawande, a novel about a physician's experiences and thoughts about PEOL care; visiting the Prairie Creek Conservation Cemetery, a green burial site; gifting shawls to patients at Haven Hospice, a local hospice care center; organizing knitting circles with project volunteers and recruits; and participation in Death over Dinner to discuss advance care planning over a meal.

The Comfort Shawl Project is continuing to grow in many different aspects. To date, over 700 shawls have been gifted to patients facing a serious illness, about 20 volunteers have committed to donating on a regular basis, and the project received Institutional Review Board approval to evaluate the project participants' development of palliative care competencies, measures of empathy, and attitudes toward death as they partook in the immersion experience (Glover et al., 2017). As the Comfort Shawl Project continues to flourish, more patients are receiving comfort and more nursing students are developing communication and PEOL care skills.

Methods

This study utilized a quantitative approach with the use of a survey called the Death Attitudes Profile (DAP) to examine changes in death attitudes over time. The research was conducted at a large academic medical center in the southeastern United States and all study procedures were approved by the University of Florida Institutional Review Board.

Participants

The subjects were nine female white senior nursing students between 20-23 years of age who voluntarily participated in the Comfort Shawl Project and this study between June 2016 and April 2017.

Procedures

The nine nursing students were asked to complete the DAP survey (see Appendix A for complete survey) at the beginning, middle, and end of their involvement with the Comfort Shawl Project.

Measures

Since fear and acceptance of death tend to coexist together in one's personal death attitudes (Feifel, 1990), the Comfort Shawl Project utilized two subscales from the Death Attitudes Profile-Revised (DAP-R), a tool developed to measure the multiple dimensions of attitudes toward death (Wong, Reker, & Gesser, 1994). One of the subscales included in the Comfort Shawl Project's 12-item DAP was Fear of Death. Fear of death is defined as a specific and conscious feeling that can ultimately lead to death anxiety or death avoidance (Wong, Reker, & Gesser, 1994). The other subscale chosen to represent Acceptance of Death for the project's version of the DAP was Neutral Acceptance, one of the three components of death acceptance subscales from Wong's DAP-R. Neutral acceptance is when one accepts death as an inevitable part of life and when one does not fear nor welcome it (Wong, Reker, & Gesser, 1994). The items on the Comfort Shawl Project's DAP are rated on a Likert scale where 1 = "strongly agree" and 5 = "strongly disagree." Seven questions from the survey pertained to the Fear of Death subscale and five questions pertained to the Death Acceptance subscale. A mean score was calculated for each subscale per completed survey (see Appendix B for scoring guidelines). For the Fear of Death subscale, a higher score indicated less fear of death and possible scores can range from 1-35. For the Death Acceptance subscale, a higher score indicated less acceptance of death and possible scores can range from 1-25. For purposes of presenting the data in a way that

made intuitive sense, the data was reverse-scored so that lower scores indicated less fear of death and higher scores indicated greater acceptance of death.

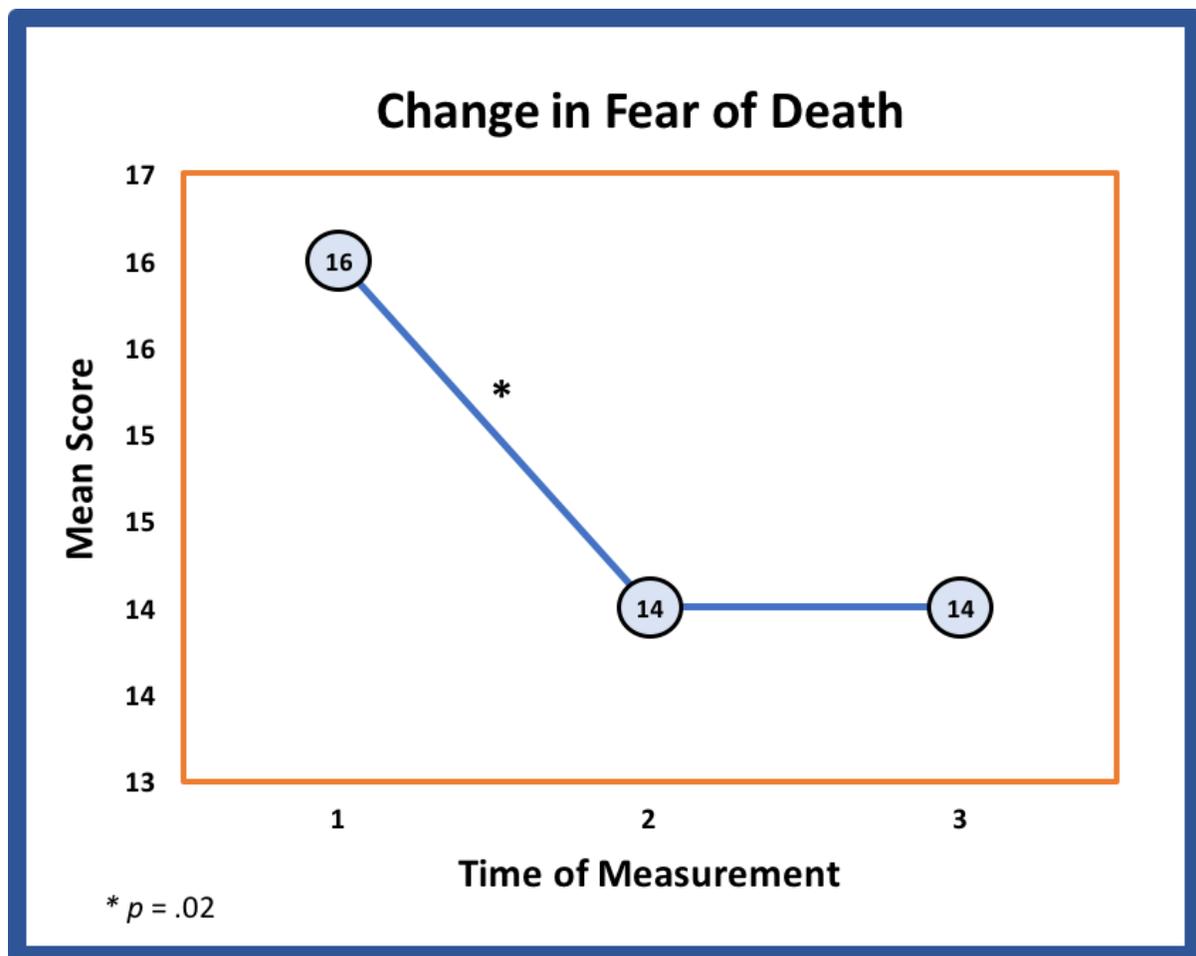
Data Analysis

The data from the completed DAPs was entered using SPSS software (IBM, version 25) and content was verified by a second member of the research team.

Results

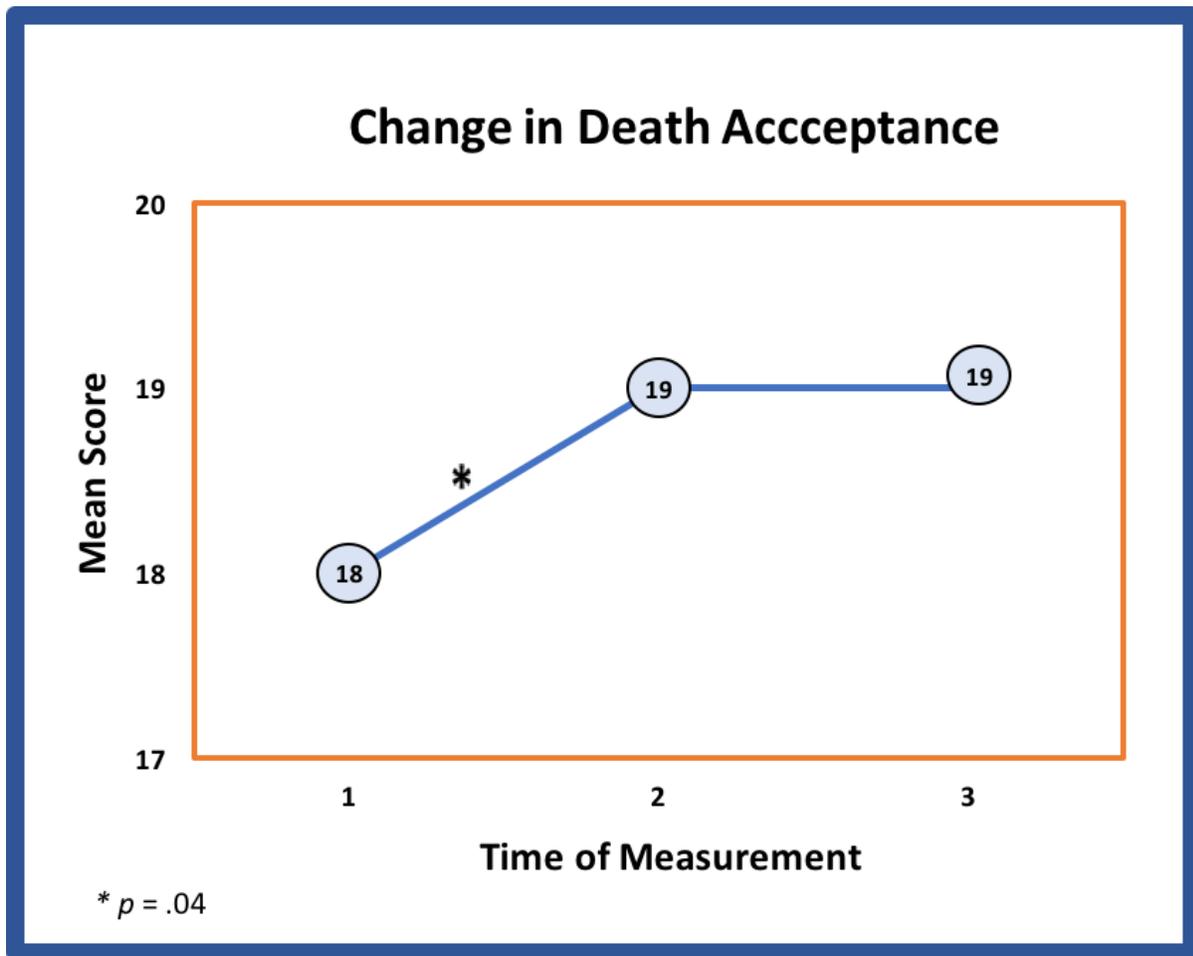
Fear of Death

The participants' mean fear of death significantly reduced from baseline ($M = 16$, $SD = 3.6$) to the midpoint ($M = 14$, $SD = 4.1$) ($t = 2.9$, $df = 8$, $p = .02$). There were no significant changes in fear of death from midpoint to end of program.



Death Acceptance

The participants' mean acceptance of death significantly increased from baseline ($M = 18, SD = 1.2$) to the midpoint ($M = 19, SD = 1.2$) ($t = -2.4, df = 8, p = .04$). There were no significant changes in fear of death from midpoint to the end of the program.



Discussion

Nursing students often feel anxious when interacting with PEOL patients and many believe that incorporating PEOL education into their curricula will greatly benefit them (Mutto, Cantoni, Rabhansl, & Villar, 2012). Although many nursing schools do include death and dying education in their curriculums, teachings are often limited to a brief lecture, case study, or assigned readings (Hebert, Moore, & Rooney, 2011). The aim of this study was to examine

whether a PEOL immersion experience had an effect on nursing students' death attitudes. The findings of this study exhibited a significant decrease in fear of death and a significant increase in acceptance of death after only a few months of involvement in the experiential immersion project, while the subscales remained stagnant in the second half of the project. These findings indicate the value of the Comfort Shawl Project in the development of positive attitudes toward death amongst nursing students, with the initial exposures having the most impact. A prior study that examined the association between nurses' personal death attitudes and their attitudes toward the care of dying patients actually found that attitudes towards caring for dying patients were significantly negatively correlated with fear of death and positively correlated with death acceptance (Wang, C. Li, Zhang, & Y. Li, 2018). Therefore, the participants of the Comfort Shawl Project who developed less fear of death and greater acceptance of death are more likely to provide more compassionate and patient-centered care to PEOL patients.

Fear and acceptance of death levels did not increase nor decrease in the second half of the project. The scores may have stopped increasing in the second half due to the variance of activities at different time points. The Comfort Shawl Project activities in the first half of the project included weekly gifting of shawls to PEOL patients at UF Health Shands Hospital, touring Haven Hospice and gifting to their patients, visiting Prairie Creek Conservation Cemetery, reading *Being Mortal*, and attending knitting circles with older adult volunteers. Activities in the second half of the project included weekly gifting of shawls to PEOL patients at UF Health Shands Hospital, attendance at knitting circles, and participation in Death over Dinner. The greater amount of interaction with older adults and PEOL patients in the first half of the project might have had the most impact in shaping the nursing students' death attitudes compared to the second half activities. Another possible reason for the stagnant levels of death

attitudes in the latter portion of the project might be a ceiling effect. For example, if a student achieves death acceptance, is there a way for them to accept death even more? Or perhaps a student reaches a point where they do not fear death, is it possible for a person to further increase their lack of fear towards death? Death acceptance and fear of death resemble “yes or no” questions in which it may be hard to exactly measure even with a tool like the DAP. Attitudes toward death is undoubtedly a complex and intricate topic in which achieving perfect scores in the DAP may not even be realistic.

Meaningful connections between students, course content, clinical experience, and the PEOL patient is apparently the key for teaching PEOL care (Hold, Blake, & Ward, 2015), which the Comfort Shawl Project ultimately provides its members. The findings of this study exemplifies the benefits of learning by experience and volunteering. A similar study found that a group of students who participated in a Palliative Care Companion Program, a volunteer program where students spend time with PEOL patients, exhibited increased knowledge of palliative care, improved attitudes about PEOL care, and fewer concerns about providing care to PEOL patients, when compared to their classmates who did not participate in the program (Kwekkeboom, Vahl, & Eland, 2005). Another study that evaluated the effects of a nursing elective course about caring for dying patients on fourth-year nursing students concluded that the course along with the requirement of volunteering in a hospice setting resulted in the students gaining a deeper understanding of the needs of PEOL patients and families (Jeffers & Ferry, 2014). Hospice volunteers are known to change as they spent time in the hospice setting. Their outlooks on life changed, they became more accepting of death, they learned strategies to prevent compassion fatigue or burnout, and most described their involvement as a rewarding experience and highly recommended it to others (Claxton-Oldfield S. & Claxton-Oldfield J., 2007). It goes to show that

a successful way of increasing the knowledge and skills of nursing students is by giving them opportunities to practice and implement what they have been taught in the classroom to actual PEOL patients in PEOL clinical settings.

An aspect of the Comfort Shawl Project that may have positively influenced the participants' attitudes toward death is the opportunity to reflect on their experiences. According to Kolb's experiential learning theory, learning is not effective without reflection (Kolb, 1994). A study that explored the benefits of reflective practice in nurses who took a care of the dying course found that reflective practice resulted in increased critical thinking, listening, observing, and knowledge amongst its subjects (Durgahee, 1996). Reflection allows for one to look back on a certain experience and think about what they did, what they learned, and what they will do in the future. As the Comfort Shawl Project students gifted each shawl to a PEOL patient, they wrote a reflection of the experience. Meeting and interacting with PEOL patients, especially with minimal prior experience, can be challenging and distressing. Being able to reflect on these occurrences allows the students to identify and analyze their feelings and emotions as well as learn how to properly cope with them, preventing death anxiety, compassion fatigue, and burnout. As students increase their time reflecting on their interactions with PEOL patients, not only do they eventually gain the proper tools in caring for the patients and themselves, but they also decrease their fears of dying and increase their acceptance of death.

Limitations

Although all of the Comfort Shawl Project participants completed the surveys for the study, the group of nine senior nursing students is still considered a small sample size. Due to this limitation, the use of non-parametric statistical procedures is recommended for further study. All of the participants were also white women in their early twenties. The lack of diversity in

race and age is not representative of all nursing students. Another limitation is that the participants had varying amounts of involvement in the immersion experience. For example, due to schedule conflicts, only five of nine students went to the Prairie Creek Conservation Cemetery. Also, gifting shawls at UF Health Shands Hospital is volunteer-based, meaning the members voluntarily sign up for the dates they were able to gift to patients. This resulted in some members having more gifting experiences than others. The study was also conducted at one university, so the findings may not apply to other settings. The lack of a control group is another limitation. Comparison to a group of senior nursing students who only received didactic teachings or did not participate in the palliative care immersion experience may make the findings of this study more valid. Due to the limitations of this study, the findings of this study cannot be generalized.

Conclusion

Nursing students' attitudes toward death tend to influence the care they provide to their patients. It is crucial for undergraduate nursing curricula to incorporate PEOL education so that nursing students will foster positive attitudes toward death and be able to provide adequate care for PEOL patients or patients in general. Through the numerous activities of the Comfort Shawl Project, a palliative care immersion experience, nursing students acquire the chance to interact with PEOL patients and cultivate adequate PEOL competencies. Based on the results of this study, participation in the Comfort Shawl Project effectively decreases fear of death and increases acceptance of death in nursing students. These positive changes in death attitudes highlight the impact of an experiential learning experience can make in senior nursing students. The findings of this study are useful for the improvement of PEOL education in nursing curricula. Nursing curricula can incorporate experiential learning in addition to the typical

didactic methods. Further research is recommended comparing the efficacy of didactic and experiential learning in PEOL education. To address this particular study's limitations, further research involving a larger and more diverse sample size, a control group, and more structure in the project activities are needed.

The Comfort Shawl Project is currently continuing to study its members' attitudes toward death. The newest cohort of the Comfort Shawl Project is also completing the DAP at the beginning, middle, and end of their involvement in the project. This newest set of data is planned to be compared with a control group made up of students who are not involved in the Comfort Shawl Project and are in the current senior nursing class. Those in the control group have already completed the DAP in January 2018 and this data will be incorporated in the next death attitudes study.

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Appendix A

The Death Attitudes Profile

Death Attitudes

Directions: Please indicate how strongly you agree or disagree with each of the following statements. Please answer every question and feel free to use any point on the scale. There are no right or wrong answers.

1. Death is no doubt a grim experience.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

2. The prospect of my own death arouses anxiety in me.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

3. Death should be viewed as a natural, undeniable, and unavoidable event.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

4. Death is a natural aspect of life.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

5. I am disturbed by the finality of death.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

6. I have an intense fear of death.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

7. I would neither fear death nor welcome it.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

8. The subject of life after death troubles me greatly.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

9. The fact that death will mean the end of everything as I know it frightens me.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

10. Death is simply a part of the process of life.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

11. The uncertainty of not knowing what happens after death worries me.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

12. Death is neither good nor bad.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

Appendix B

The Death Attitudes Profile Scoring Guidelines

Two subscales for use in Comfort Shawl Project, 2016, from the Death Attitudes Profile (Wong, Reker, & Gesser, 1994). Add the items and divide by number of items, none are reversed, to create a mean for each subscale.

Death Attitude Profile - Scoring

Directions: Please indicate how strongly you agree or disagree with each of the following statements. Please answer every question and feel free to use any point on the scale. There are no right or wrong answers.

Fear of Death Subscale**1. Death is no doubt a grim experience.**

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

2. The prospect of my own death arouses anxiety in me.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

5. I am disturbed by the finality of death.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

6. I have an intense fear of death.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

8. The subject of life after death troubles me greatly.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

9. The fact that death will mean the end of everything as I know it frightens me.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

11. The uncertainty of not knowing what happens after death worries me.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

Neutral Acceptance Subscale**3. Death should be viewed as a natural, undeniable, and unavoidable event.**

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

4. Death is a natural aspect of life.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

7. I would neither fear death nor welcome it.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

10. Death is simply a part of the process of life.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

12. Death is neither good nor bad.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree