ORIGINAL RESEARCH

End of life care pedagogy, death attitudes, and knowing participation in change

Vidette Todaro-Franceschi, Mark Spellmann

School of Nursing, Hunter College, City University of New York and Graduate Center, New York, USA.

Correspondence: Vidette Todaro-Franceschi. Address: 425 East 25th St New York, 10010. Telephone: 212-481-4449. Email: vtodaro@hunter.cuny.edu

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Abstract

Background: End of life care continues to be an area of glaring concern in health care. In addition, literature points to continued inconsistencies in end of life care education for those in the health professions, despite accumulating studies which suggest that preparation is needed to care for those who are dying and their loved ones. Some research findings suggest that there is a relationship between perceptions of preparedness and ability to provide care at the end of life and the nurse's professional and perhaps personal quality of life. Thus, the purpose of this internally funded research project was to explore whether or not there would be changes in students' death attitudes and power as knowing participation in change after they received coursework on end of life care (EOLC).

Methods: A pre-test post-test design was used with participants as their own controls. Barrett's nursing theory of power as knowing participation in change formed the theoretic backdrop for this study in which sixty undergraduate (N = 12 RN to BSN students; N = 48 generic students) and 6 graduate students participated. The pedagogic intervention consisted of either a full term elective on EOLC or four discontinuously placed classes during the junior year. Twenty eight of the students took a full term class on EOLC and the rest had four discontinuously placed lectures.

Results: The findings were statistically significant for both death attitudes and power (as knowing participation in change).

Conclusions: Teaching EOLC may enhance not only the quality of living-dying experiences for those entrusted to our care but also the carer's personal and professional quality of life through their knowing participation in change. Since professional quality of life is known to be related to quality of care rendered, productivity, retention and recruitment of nurses, we would do well to explore this area further.

Key words

End of life care, Death attitudes, Power, Knowing participation in change, Professional quality of life

1 Introduction

One hundred percent of us will die and at some point will need EOLC. Despite this, there continue to be glaring inadequacies in how people are cared for at the end of life [1]. One in four patients nearing the end of life continue to

describe insufficient pain and symptom management and one in three families report inadequate emotional support while their loved ones are dying [1].

Early studies in EOLC nursing education focused in large part on how the teaching and study of death-related topics could change attitudes, diminish anxiety, and enhance comfort level with ideas of death and dying [2-4]. More recent studies of EOLC education in nursing continue to reflect these and similar findings [5-8].

In a recent study in which alumni were surveyed at a school of nursing (Total N=154), it was found that those student participants (N =68) who had taken a full term elective course offering on death, dying and bereavement perceived themselves to be more prepared to care for the dying and their loved ones than those who had not (N=86) [9]. One way ANOVA revealed statistically significant changes in perceptions of preparedness (F (1,152) = 51.85, P < .0001, M (elective) = 3.43 and M (no elective) = 2.60, where 4 = strongly agree and 1 = strongly disagree) which was not surprising. More tantalizing was that many of the participants perceived that their 'way of being in the world' had been changed by their having received EOLC education. In the aforementioned study, changes in one's way of 'being in the world' was defined as appreciating things in life more, for example, taking time to smell the flowers, see the butterflies, and be with loved ones (F (1,152) = 19.50, P = <.01, M = 3.09 (elective) and M = 2.74 (no elective), where 4 = strongly agree and 1 = strongly disagree) [9]. Thus, it was surmised that EOLC pedagogy may help to enhance the quality of life for the carers—the nurses—in addition to the likelihood of improving the quality of care rendered to those who are dying and their loved ones [9].

We were interested in expanding upon the previous study findings which suggested that a nurse's professional and personal quality of life can be enhanced through receiving EOLC education. To do this we decided to explore whether there would be differences in two things: death attitudes and power as knowing participation in change [10, 11] for nursing students who took either a term elective course on the subject or who alternatively received EOLC content placed in four seminars spread out over the course of a year. It was intuited that receiving didactic content on EOLC would contribute to not only changes in their death attitudes but would also contribute to changes in their power (as knowing participation in change).

Theoretical underpinnings

Psychiatric mental health nurse, scholar and theorist Elizabeth Barrett's [10-12] theory of power as knowing participation in change, predicated on Martha Rogers' [13] science of unitary human beings (SUHB), formed the theoretical framework for this study. In the SUHB both human beings and their environments are perceived as energy fields that are inseparable in nature and continuously changing. Change is noted to occur in a mutual, rather than causal process between human beings and their environment; it emerges from the whole and is participatory—it is a unitary view wherein all is essentially one [14]. Change is also noted to be nonlinear and any description of directional outcomes is not consistent with a unitary view. Hence, the researchers chose not to couch their expectation of any outcomes (hypotheses) in a positive or negative direction.

Barrett defined power as "the capacity to participate knowingly in the nature of change…as manifest by awareness, choices, freedom to act intentionally, and involvement in creating changes" [10] (p. 207). It is difficult to describe in an acausal manner how power as knowing participation is manifested, however, one could say that when one is more aware, is in tune with their choices, feels free to act and is actively involved in creating change, one's power as knowing participation is more readily visible, whereas when one is less aware, less knowledgeable about choices that can be made, feels unable to act freely, and is less involved in creating change, one's power is less apparent. Power is, however, always present, and is manifested wholly by our awareness, choices, freedom and involvement [10, 11].

It was conjectured that having received EOLC education student's power scores would be higher than they were before they had learned about death, dying and bereavement. Power is not limited to professional or personal confines, and as such changes in power are indicative of changes in one's way of being in the world (as a knowing participant in change).

Educators engaged in teaching EOLC know that you simply cannot teach about death and dying without also teaching and reflecting upon life and living [15]. They are inseparable; there is no life without death and no death without life. This is in keeping with a unitary view upon which Barrett's power theory is predicated.

2 Method

2.1 Design and procedures

For this study we used a pre-test/post-test design with participants as their own controls. After Institutional Review Board approval volunteers were recruited via circulated flyers and a verbal invitation by a research assistant (RA) the first evening of classes. Using a script, the RA provided an oral explanation of the project and obtained consent. Volunteers who agreed to participate completed the Death Attitude Indicator (DAI) survey [3], the Power as Knowing Participation in Change tool (PKPCT) [10, 11], and a short demographic questionnaire prior to the start of the first class on EOLC. All data was numerically coded for confidentiality. The participants again completed the DAI and PKPCT after the last class.

2.2 Tool description

Hopping's DAI [3] consists of two parts; the first is composed of twenty four 5-point (0-4) rating scale items which address beliefs, emotions, opinions, and behaviors related to death, dying and bereavement. The second part consists of multiple choice, fill-in and short text answers. The second part is used for information only purposes and is not reflected in the scoring.

The only record found of the DAI instrument was in Hopping's master's work [3] in which she administered the DAI to 79 first semester senior nursing students enrolled in a large university medical center school of nursing in the Midwest. Pretest comparisons revealed no difference between groups while post-test scores showed significant differences (p <.05) in a number of items. Hopping reported test-retest reliability at .64, significant at the p < .05 level and noted its potential to measure death attitudes. Notably it was in the early stages of psychometric development and a literature review revealed no further work had been done with this tool. Permission to use the tool was obtained from the American Journal of Nursing who own the copyright from the original publication.

An exploratory factor analysis of the items in the DAI was conducted to determine whether it was a uni-dimensional scale, and a two factor solution was obtained. An inspection of the scree plot, along with identification that fewer than half of the twenty four analyzed items loaded above r = .4 on the first factor indicated that the DAI was measuring two distinct constructs (eigenvalues = 3.4 and 2.4.). Review of item content revealed that factor one was measuring beliefs concerning death, and the second factor was measuring death avoidance. Items loading on these two factors were tested for internal consistency, and Chronbach's alpha for the death beliefs subscale was .65, and for the death avoidance subscale .70. Item total minus item correlation values obtained indicated that items for both subscales were contributing to each subscale's internal consistency. The correlation between the two subscales was r = .25, p = .03, indicating divergent validity of the two subscales.

The PKPCT [10, 11] is a firmly established semantic differential scale with four concepts-awareness, choices, freedom to act intentionally and involvement in creating change, each representing a distinct field behavior, which combined provide a description of one's power (as knowing participation in change). There are twelve scorable scales for each behavior, the scores ranging from one to seven. The higher the score, the higher the manifestation of one's power. One scale item appears twice for each concept that isn't scorable and is used for retest reliability. Reliability/validity has been well-established by Barrett and others [10, 11]. For this study Chronbach's alpha coefficients ranged from > .84 to .91 for all concept scales, both pre and post-test.

2.3 Participants

A voluntary convenience sample was sought; only nursing students who were taking either an EOLC elective course (graduate or undergraduate) or were receiving EOLC education in the undergraduate generic curriculum were invited to participate. There were no other inclusion or exclusion criteria. Our university has a culturally diverse student body; nursing students are predominantly female. Classes are representative of the student population at our school and also the regional population at large.

Sixty six students completed the study (56 females; ages 19-50; mean 24 years old); six were graduate students who took a three credit full term elective course on EOLC, ten were generic students who took a full term three credit undergraduate EOLC elective, twelve were RN to BSN pathway students who took the same full term undergraduate elective (total N= 28 took a full term elective course on the subject), and the remaining thirty eight participants were generic undergraduate students who attended four discontinuously placed classes on EOLC over the course of a year.

The participants were culturally diverse (24 Asian, 7 Black, 9 Latino, 1 Native American, 23 White; 2 Other [Middle Eastern, Polish]). Their religion also varied (5 Agnostic, 4 Atheist, 6 Buddhist, 6 Jewish, 4 Baptist, 16 Protestant, 20 RC, 5 Other [Mormon, Syrian, Eclectic, unidentified]).

2.4 Pedagogic intervention

Those participants who took a full term course on death and dying received the full End of Life Nursing Education Consortium (ELNEC) [16] program content in addition to time for focused group discussions of personal attitudes and beliefs regarding dying, death, and bereavement. Some class time was also spent discussing professional quality of life (compassion contentment, compassion fatigue, and burnout). ELNEC modules as developed by the American Association of Colleges of Nursing and City of Hope National Medical Center include the following: 1) Introduction to palliative and end of life care, 2) Pain management, 3) Symptom management, 4) Ethical issues, 5) Cultural aspects, 6) Communication, 7) Loss and bereavement and, 8) Final hours [16]. The difference between the undergraduate and graduate level course was primarily in the depth of information taught regarding pain and symptom management.

More than half of the participants (N = 38 generic junior undergraduates) did not take a full term course on the subject, and instead attended four curriculum required discontinuously placed classes on EOLC over the course of a year, the topics of which were all introductory in nature and explored cultural, ethical and legal aspects of dying and death, and pain and symptom management at the EOL.

3 Results

3.1 Tests of the study hypotheses

There were significant differences between pre-test and post-test scores of power and death attitudes overall. Paired t-tests were conducted on the entire sample to test whether nursing students changed on the three primary measures—power, death beliefs and death avoidance. Mean scores rather than total sum scores were obtained for all scales and subscales. The advantage of mean totals rather than sum totals is that all scale means are represented on the scale that items were answered. Descriptive statistics were obtained for all measurements in the tests of the hypotheses.

The mean power (PKPCT) score increased significantly from pre-test to post-test (t = 3.7, df = 65, p <.001). The mean difference increased 1.2 scale points, and with a standard deviation of 2.6, thus the effect size for gain in the power score represented an increase of almost half a standard deviation (.46 sd), which is a moderately large effect size.

The death attitude scores on both subscales of the DAI also changed. The paired t-test for death beliefs demonstrated significant gains from pre- to post-test (t = 5.9, df = 65, p < .001). The mean score increase of .4, and the standard deviation

was .05, thus the gain represented an increase of about .8 standard deviation which represents a large effect size. The paired t-test for death avoidance showed a trend toward significance (t = 1.9, df = 65, p = .07). The effect size for the increase was approximately one quarter of a standard deviation. As part of a larger pattern of gains, this trend toward significance may take on greater weight than would an isolated finding.

3.2 Further exploration of the data

To test whether power and death attitudes changed differentially over time for nursing students who received four discontinuously placed lectures versus a full term course, Repeated Measures ANOVA's were conducted, using the Barrett PKPCT total score, and the two DAI subscale measures. The group x time interaction was significant for the Barrett PKPCT measure (F=13.0, df= 1, 65, p = .001). The mean scores rose from 5.2 to 5.3 for the group that received four lectures, while the full course group mean scores rose from 5.1 to 5.7 at post-test. The Repeated Measures ANOVAs for the DAI subscale measures did not yield significant group x time interactions.

Comparisons and differences were also sought among demographic variables such as age, gender, religion, and ethnicity, as well as tests for interaction effects between the latter variables. There were no appreciable differences related to any of the other variables.

4 Discussion and implications

While the sample size was relatively small, the findings of this study add to the data that EOLC educators continue to accrue which supports the importance of EOLC education for nurses. The literature of prior research indicates that education about death, dying and bereavement can change attitudes about death which clearly plays a part in how practitioners go about caring for the dying and their loved ones. Our results are in line with previous findings. What is new about this study that bears further reflection is its focus as to how EOLC education might enhance the nurse's power as knowing participation in change, which in turn may augment positive changes in nurses' personal as well as professional lives.

Although the power scores changed even more significantly in the group that took a full term elective course offering and the death attitude sub-scale scores did not, because the sample size was small and numbers in each group asymmetric, the difference may not count for much. What is clear from this and other studies is that further research on EOLC pedagogy is warranted given the current state of EOLC in health care. Any attempt to improve EOLC needs to include the exploration of the ways in which education for nurses and other health care professionals may impact the quality of care being rendered.

In a similar fashion one could make a case for pursuing this line of inquiry further to establish how perceptions of preparedness to care for the dying might in fact impact on the carer's professional quality of life. If a perceived lack of preparedness and ability contribute to the manifestation of compassion fatigue and/or burnout (Todaro-Franceschi, unpublished data), then it is clearly an area that nurses, educators and administrators need to explore further because we know that compassion fatigue and burnout impact both the cared for and the carers [15]. Enhancing power as knowing participation in change is advantageous indeed, for nurses facing death (and otherwise) in practice are often called upon to act with assertion and moral courage. Further exploration of how EOLC pedagogy can lead to the enhancement of the nurses' knowing participation and consequently changes in the nurse's ways of being in the world (both personally and professionally), may help illuminate ways in which educators and nurse leaders can contribute to enriched professional quality of life for nurses.

The majority of nurses face death on a regular basis, and all will face it personally and with loved ones. In health care there is much focus on the cared for, and perhaps not enough focus on the carers. If nurses are not adequately prepared to care for the dying and their loved ones, we are doing a disservice to both the cared for and the carers [15]. In conclusion, it would

seem that nurse educators can make a significant difference by enhancing death attitudes and knowing participation in change through EOLC pedagogy.

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