



## Effectiveness of a perinatal and pediatric End-of-Life Nursing Education Consortium (ELNEC) curricula integration



Eileen R. O'Shea <sup>a,\*</sup>, Suzanne Hetzel Campbell <sup>b,1</sup>, Arthur J. Engler <sup>c,2</sup>, Rachel Beauregard <sup>a,3</sup>, Elizabeth C. Chamberlin <sup>b,4</sup>, Leanne M. Currie <sup>b,5</sup>

<sup>a</sup> Fairfield University, School of Nursing, 1073 North Benson RD, Fairfield, CT 06824, USA

<sup>b</sup> University of British Columbia, School of Nursing, T201-2211 Wesbrook Mall, Vancouver, BC V6T 2B5, Canada

<sup>c</sup> University of Connecticut School of Nursing, 231 Glenbrook Rd., Unit 2026, Storrs, CT 06269-2026 USA

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### SUMMARY

**Background:** Educational practices and national guidelines for best practices of providing palliative care to children and their families have been developed and are gaining support; however, the dissemination of those practices lags behind expectations. Incorporating education for pediatric palliative care into nursing pre-licensure programs will provide guidelines for best practices with opportunities to enact them prior to graduation.

**Objective:** To evaluate the effect of an integrated curriculum for palliative care on nursing students' knowledge.

**Design:** Matched pretest–posttest.

**Setting:** One private and one public university in the northeastern United States.

**Participants:** Two groups of baccalaureate nursing students, one exposed to an integrated curriculum for palliative care and one without the same exposure.

**Methods:** Pre-testing of the students with a 50-item multiple choice instrument prior to curriculum integration and post-testing with the same instrument at the end of the term.

**Results:** This analysis demonstrated changes in knowledge scores among the experimental ( $n = 40$ ) and control ( $n = 19$ ) groups that were statistically significant by time (Wilks' Lambda = .90,  $F(1, 57) = 6.70$ ,  $p = .012$ ) and study group (Wilks' Lambda = .83,  $F(1, 57) = 11.79$ ,  $p = .001$ ).

**Conclusions:** An integrated curriculum for pediatric and perinatal palliative and end-of-life care can demonstrate an increased knowledge in a small convenience sample of pre-licensure baccalaureate nursing students when compared to a control group not exposed to the same curriculum. Future research can examine the effect on graduates' satisfaction with program preparation for this specialty area; the role of the use of the curriculum with practice-partners to strengthen transfer of knowledge to the clinical environment; and the use of this curriculum interprofessionally.

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### Introduction

More than a decade has passed since the US Institute of Medicine (IOM) issued the report "When children die: Improving palliative and end-of-life care for children and their families" (Committee on Palliative and End-of-Life Care for Children and Their Families, 2003). The authors of the report identified that, children with life-threatening

conditions and their families often fail to receive effective, consistent, timely, and competent care that meets their physical, emotional, and spiritual needs. Furthermore, the authors recommended that medical and nursing schools need to prepare health care professionals in basic and advanced skills in pediatric palliative care (holistic comfort care possibly including curative treatments) and end-of-life care (holistic comfort care focused on palliation of symptoms), so that providers do not learn this type of care by trial and error. Enhancing health care provider education for this specialty area has become an international concern in which several nations are working collaboratively to establish competent and compassionate pediatric palliative providers (Downing et al., 2013; Palliative Care Curriculum for Undergraduates (PCC4U) Project Team, 2012).

Pediatric palliative care is formally recognized and supported by several specialty professional organizations worldwide (e.g., American Academy of Pediatrics, World Health Organization; and National Hospice and Palliative Care Organization) and in 2003 the American Association

\* Corresponding author. Tel.: + 1 203 254 4150; fax: + 1 203 254 4126.

E-mail addresses: [eoshea@fairfield.edu](mailto:eoshea@fairfield.edu) (E.R. O'Shea), [Suzanne.Campbell@nursing.ubc.ca](mailto:Suzanne.Campbell@nursing.ubc.ca) (S.H. Campbell), [arthur.engler@uconn.edu](mailto:arthur.engler@uconn.edu) (A.J. Engler), [rachel.beauregard@ynhh.org](mailto:rachel.beauregard@ynhh.org) (R. Beauregard), [Elizabeth.Chamberlin@ubc.ca](mailto:Elizabeth.Chamberlin@ubc.ca) (E.C. Chamberlin), [leanne.currie@nursing.ubc.ca](mailto:leanne.currie@nursing.ubc.ca) (L.M. Currie).

<sup>1</sup> Tel.: + 1 604 822 7748; fax: + 1 604 822 7423.

<sup>2</sup> Tel.: + 1 860 486 0573; fax: + 1 860 486 0001.

<sup>3</sup> Tel.: + 1 203 254 4150; fax: + 1 203 254 4126.

<sup>4</sup> Tel.: + 1 604 822 8070.

<sup>5</sup> Tel.: + 1 604 822 7466.

of Colleges of Nursing (AACN) developed an End-of-Life Nursing Education Consortium (ELNEC) with train-the-trainer core curricula (End-of-Life Nursing Education Consortium (ELNEC), 2014; Jacobs et al., 2009; Malloy et al., 2007). Although significant strides have been made in developing education and national practice guidelines, there is a lack of formal education for healthcare professionals (Crozier and Hancock, 2012; Moody et al., 2011; O'Shea and Bennett Kanarek, 2013) resulting in dissemination, implementation, and evaluation of this important care lagging behind (Moody et al., 2011; O'Shea and Bennett Kanarek, 2013). Infusing this education into health professional education programs will help enhance future practices of health care providers.

## Background

Several studies from nursing and medicine describe the lack of adequate preparation and understanding of pediatric palliative care among pediatric health care professionals resulting in lack of effective and timely delivery of specialized care for high need pediatric patients living with potentially fatal conditions (Davies et al., 2008; Docherty et al., 2007; Engler et al., 2004; Moody et al., 2011; O'Shea and Bennett Kanarek, 2013). Several reasons for lack of education include the following: confusion in defining palliative care versus hospice care; inexperience in discussing end-of-life choices and symptom management such as non-pharmacologic pain management; and inexperience in initiation of conversations about what palliative care means (Contro et al., 2004; Kolarik et al., 2006; Thompson et al., 2009; Wolfe et al., 2011).

For example, Thompson et al. (2009) found that 42% of the pediatricians surveyed defined palliative care as the same as hospice care and consequently only made referrals when curative treatment was no longer feasible. Additionally, approximately 50% of respondents had never referred patients to palliative care and 30% did not know if local services existed (Thompson et al., 2009).

Studies by Contro et al. (2004) and Kolarik et al. (2006) found that community physicians and medical residents in a pediatric specialization felt inexperienced in communicating end-of-life issues such as discussion about transitioning into palliative care and do not resuscitate status. Further, family members described feelings of distress caused by uncaring staff, and 54% of the staff reported that emotional, psychological, and social support was lacking within the work environment (Contro et al., 2004). Finally, Knapp et al. (2011) identified that although nurses felt comfortable discussing hospice care with families, 40% of the sample did not know when to refer a patient to palliative care.

Results of these studies provided an impetus to enhance the baccalaureate nursing curricula at one private university located in the northeast of the United States. Additional motivation was derived from school of nursing alumni surveys in which graduates felt “unprepared to manage conversations and care related to death and dying,” especially for perinatal and pediatric patients and their families. This led to the development of an integrated curriculum including palliative and end-of-life care for pediatric and perinatal patients. Thus, the purpose of the study was to evaluate baccalaureate nursing students' knowledge of perinatal and pediatric palliative and end-of-life care curricula integration in comparison to a control group for whom this content had not yet been integrated.

## Methods

The study used a matched pretest posttest study design with two groups of baccalaureate nursing students: one group received an education intervention; the other group did not. The investigators received IRB approval from the two universities prior to the initiation of the study.

## Sample and Setting

Full-time baccalaureate nursing students from two nonaffiliated universities in the northeastern United States participated in the study. Intervention group participants attended a mid-sized liberal arts university, whereas participants in the control group attended a large state-run university. Both nursing programs were 4-year, 8 semester programs. For both cohorts, their programs started in September 2008 and the students graduated in May 2012. At the time of the pretest evaluation, participants in the intervention group were selected from a full cohort of students (approximately 70) that were enrolled in one of two courses in their 6th semester (January–May 2011): either 1) pediatric nursing or 2) maternal child health. The posttest evaluation for this group was taken after completing the alternating course (maternal child health or pediatrics) in the 7th semester (September–December, 2011). The maternal child and pediatric courses at the intervention university met for a total of 35 didactic hours over 14 weeks with 42 clinical hours, per course. Participants in the control group were in their 7th semester (September–December 2011) and were enrolled in a pediatric nursing course. These students were also taking a separate maternal child health course concurrently. There was no explicit palliative/end-of-life content in the course the control group took other than a brief mention when a condition was potentially fatal. The control group sample was drawn from approximately 120 students (60 per semester). The course for the control group lasted 14 weeks with 4 h of class/week and 126 clinical hours.

## Intervention Design

Faculty members in both the intervention and control groups are experts in the maternal child and pediatric fields, and have been practicing in these specialty areas for more than 25 years. Faculty members who provided the education for the intervention group had participated in the ELNEC Core Curriculum training for Pediatric and Perinatal Palliative and End-of-Life Care and were considered “trainers.” They had also been active members of the integration of palliative care curriculum throughout the baccalaureate program. The intervention group received an enhanced pediatric and perinatal curricula adapted from ELNEC Project (American Association of Colleges of Nursing, 2008; End-of-Life Nursing Education Consortium (ELNEC), 2014; Owen and Grealish, 2006) the control group received standard education, not specific to ELNEC content. Examples of how the ELNEC curriculum were taught in the maternal–child course included a class on the high risk newborn that incorporated Module 2 from the ELNEC curriculum: “Perinatal and neonatal palliative care.” This lecture was accompanied by several simulations in the course: 1st trimester bleeding – (a) spontaneous abortion and (b) gestational trophoblastic disease; three emergency deliveries: shoulder dystocia (Connelly and Campbell, 2013), prolapsed cord, and abruptio placenta – any of which can end in maternal and/or infant death. There was also a postpartum hemorrhage scenario (Campbell, 2013) where the mother can die, and finally a high-risk newborn simulation where the 4300gms/4.3 kg infant of a diabetic mother is experiencing hypoglycemia and respiratory distress, that can result in harm/death. Inherent in maternal/infant health is much potential for infant and maternal mortality and the risks are high globally. These simulations incorporated with the ELNEC curriculum were designed to raise students' awareness of these outcomes and how to react. In the pediatric nursing course, three ELNEC modules (pediatric specific) were integrated over the semester. Power point, lecture, and case studies were the methods utilized to deliver the content. The three ELNEC modules were as follows: communication, pain, and symptom management. Additionally, a culminating simulation scenario, which utilized a student improvisational actor, seemed to make a significant impression on the student nurses. The scenario featured an adolescent (student improvisational actor) who role-played an adolescent that was admitted with the diagnosis of

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