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Outcomes of a National Training Curriculum to Advance Generalist Level Palliative Care

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Abstract

Background: The adoption of palliative care as an integral component of health care has led to the need for generalist level providers, especially important in serious illnesses such as cancer.
Objectives: The goals of this National Cancer Institute-funded training program were to (1) identify the eight domains of quality palliative care applied to oncology practice, (2) demonstrate skills for oncology advanced practice registered nurses (APRNs) in the domains of palliative care, and (3) develop goals for implementing the skills training in practice through process improvement, staff education, and clinical care.
Design: The training program led by the End of Life Nursing Education Consortium (ELNEC) project included oncology APRNs in a three-day training course with one-year follow-up for ongoing support and to assess impact.
Settings: Five training courses included 430 APRNs from 46 U.S states including both pediatric and adult oncology settings. The project included 25% minority participants.
Measurement: Measures included participant goal implementation, course evaluations, and surveys to assess implementation and palliative care practices (precourse, 6 and 12 months postcourse).
Results: The ELNEC oncology APRN training course resulted in changes in practice across domains, improved perceived effectiveness in clinical practice, and valuable insight regarding the challenges in generalist level palliative care implementation.
Conclusion: The ELNEC oncology APRN course serves as a model for the palliative care field to advance generalist level practice. Future training efforts can build on this project to reach more oncology professionals and those in other areas of serious illness care.

Keywords: advanced practice nursing; cancer; generalist palliative care; nursing education; palliative care in oncology

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Background

The recognition of palliative care as an essential component of serious illness care has led to the critical demand for generalist level palliative care delivery.[1–3] The palliative care field has developed strong consensus that demands for such care far exceed present or future capacity of specialist level care.[4,5] This need for generalist palliative care is especially significant in oncology wherein there has been strong evidence regarding deficiencies in areas of care such as pain and symptom management, psychosocial support, advanced care planning, and end-of-life care.[6,7]

National guidelines, consensus panels, and professional organizations have articulated the need for palliative care education to prepare clinicians in serious illness care to achieve competence in palliative care domains and integrate it into their practice.[4,8] In oncology, there has also been strong recognition of the need for palliative care from the time of a cancer diagnosis and across settings of care. Several clinical trials of palliative care in oncology have demonstrated positive outcomes both at an individual patient level, such as in symptom management and earlier access to hospice, and in system level metrics such as decreased costs and avoidance of hospital admissions.[3,9–11]

Advanced practice registered nurses (APRNs) are primary providers of cancer care from time of diagnosis, during cancer treatment, in both inpatient and outpatient settings, and in both pediatric and adult care. APRNs have significant potential to integrate palliative care within their role and thus address this need for generalist level care.[12–15]

The project was approved by the institutional review board. The five-year project spanned August 2017–August 2022 with one national course held in each project year.

The purpose of this training project was to prepare APRNs in oncology settings to integrate palliative care within their current role to improve the quality of care for patients. The End of Life Nursing Education Consortium (ELNEC) began in 2000 as a national and international education program to train nurses in palliative care.[16] In recognition of the need to train oncology APRNs as generalist providers of care, the ELNEC project developed a curriculum for these clinicians. This article reports on outcomes of a five-year (2017–2022) National Cancer Institute (NCI)-funded training grant (R25CA217270-04), the ELNEC oncology APRN training program.

Project Methods

The learning objectives of the training courses were as follows:

- Objective 1: Identify the eight domains of quality palliative care applied to oncology practice.
- Objective 2: Demonstrate skills for oncology APRNs in the domains of palliative care.
- Objective 3: Develop goals for implementing the skills training in practice through process improvement, staff education, and clinical care.

Course Design

Agenda

The agenda for this course is depicted in Supplementary Table S1 and includes the schedule for the three-day training course. The course was organized by the palliative care domains, as defined by the National Consensus Project for Quality Palliative Care. Days 1 and 2 were organized by each domain. Each session included diverse teaching strategies such as lecture, discussion, video clips, case studies, and other adult learning strategies. Day 3 was devoted to skills enhancement, building on the content of the two prior days. The course included small group work with skills application such as applying symptom management knowledge to patient cases, role play of communication skills such as providing support to a grieving patient or family member, or conducting a spiritual assessment.

This agenda and skills training were intended to improve the participant's ability to incorporate the generalist palliative care knowledge and skills into their roles as APRNs in practice. For example, these APRNs' roles included nurse practitioners in outpatient clinics, professional practice leaders on inpatient units, case managers, and other APRN roles. The training was intended to prepare APRNs to serve as a clinical resource to address common patient concerns such as pain or symptom management and to be generalist providers to offer psychosocial care, facilitate interdisciplinary family meetings, and to offer support to their nursing colleagues.

These generalist palliative care APRNs were also intended to serve as a link to the specialty palliative care team, directing patients who need specialist care to them. The three-day course provided opportunities for networking with others to facilitate learning and generate ideas for postcourse goals. A course website was developed to house educational materials and foster networking among participants. The course marketing was done using e-mail announcements through ELNEC and the Oncology Nursing Society and through the ELNEC newsletters, website, and flyers distributed at meetings.

Webinars

Monthly webinars were also held for course participants to attend for one year after course participation. Ten webinars were held for 12 months for each cohort with no webinars in 2 months to avoid holiday and vacation schedules. These were designed to reinforce course content, provide new content as requested, share goal achievement by participants, and facilitate networking. Each webinar devoted half of each one-hour session to continued education (e.g., updates in pain management, additional content based on course evaluations) and half the time was devoted to open discussion as participants shared their goal progress and experiences with each other. Each webinar was offered twice to accommodate the range in time zones of participants. The monthly webinars averaged 60–70% participation rates.

Setting/subjects

The course was limited to U.S. participants. The course was designed for in-person training but two of the five courses were converted to virtual format due to COVID-19 travel restrictions. The complete curriculum was presented for the virtual courses on zoom with the laboratory sessions conducted in breakout sessions. Criteria for participation in the training included the following:

- APRNs with at least five years of oncology nursing experience
- Nurses in adult and pediatric care settings
- Master's or Doctor of Nursing Practice degree
- Commitment to spend time with the palliative care team within their institution (40 hours over 12 months recommended). This was intended to foster collaboration by the APRNs with the specialty palliative care service.
- Agreement to attend webinars monthly over the next 12 months to provide ongoing education and support
- Mandatory follow-up evaluations completed at 6 and 12 months postcourse
- Letters of support from the oncology program and from the palliative care service

Applications were reviewed by the project investigators using a structured evaluation tool. Participants who were selected received free course registration and a travel stipend that covered hotel costs, and minority applicants could also apply for additional support to pay for airline costs. These costs are paid through the NCI funding.

Outcome Measurement

Course evaluation

Participants completed a course evaluation each course day to evaluate the curriculum content and teaching methods and rate the clarity of presentations, quality, and value of content to the participant as a clinician. All evaluation data (precourse, course, and postcourse) were completed online by course participants on Red Cap. Data were analyzed using descriptive statistics.

Goal evaluation

Three individual goals were required as part of the course application. Applicants described their goals for integrating palliative care in their APRN practice. Throughout the three-day course, participants refined their goals. The 6- and 12-month follow-up of the participants, cancer program leaders, and palliative care team leaders were analyzed to evaluate the application of the course training and the ability of the nurse participants to serve as generalists in palliative care and support palliative care integration in oncology. Surveys were sent to the individuals in oncology and in palliative care who provided the participant's letters of support only at 12 months postcourse.

Palliative care practice

Participants completed a survey precourse, and at 6 and 12 months postcourse to describe their involvement in palliative care practices such as symptom management, making referrals to the palliative care service, supporting clinical staff in end-of-life care, or participation in family meetings.

Results

Demographic data

Table 1 presents demographic data ($N = 430$) from these courses. The courses included 25% under-represented minority participants, from primarily adult settings (88%), and most participants were nurse practitioners (85%). The APRNs had a mean of 19 years practice as a nurse, 14 years in oncology, and were a mean of 9 years since completion of their highest degree. The participants came from 46 states.

Table 1. Demographics

N = *430*	*Total*	*%*
Participant—gender		
Male	9	2.09
Female	420	97.67
Declined to answer	1	0.23
Participant—ethnicity		
Hispanic	20	4.7
Non-Hispanic	403	93.7
Declined to answer	7	1.6
Participant—race		
American Indian/Alaskan Native	2	0.47
Asian	29	6.74
Black or African American	34	7.91
More than one race	11	2.56
Native Hawaiian or Pacific Islander	2	0.47
White	343	79.77
Declined to answer	9	2.09
Patient population		
Adult only	382	88.84
Pediatric only	31	7.21
Both	17	3.95
Participant title/position		
Clinical nurse specialist	35	8.14
Nurse practitioner	364	84.65
Other (PAs, Educator, RN, etc.)	31	7.21
No. of years of experience	*Mean*	
As a nurse	19 years	
Since completion of highest degree	9 years	
In oncology	14 years	
No. of states represented	46	

Course evaluation data

Course evaluations rated the speakers' mastery of the topic, clarity and quality of content, and usefulness of the session. Lectures and laboratory sessions were evaluated. All sessions were rated >4.7 on a scale 0 = not effective to 5 = very effective (Table 2).

Participant integration of palliative care skills training

Course participants were asked to rate the frequencies in which they participated in some common areas of APRN palliative care practices. This included participation in a family meeting, informing patients that their cancer treatment was not working, recommending a palliative care consult to a patient or to an oncologist, speaking with a family member about bereavement services, or preparing staff for the death of a patient. Table 3 describes the participants' perceived effectiveness of their own clinical practice according to each of the NCP domains for quality palliative care.

These data demonstrate the opportunities for APRNs to influence all eight aspects of quality patient care, including

TABLE 2. COURSE EVALUATIONS

	Speaker's knowledge/ mastery of topic	*Clarity and content quality*	*Usefulness to you*	*Appropriateness of techniques or teaching method used*
Domain 1: Structure and processes of care	4.90	4.86	4.77	
Domain 2.1: Physical aspects-pain management (adults)	4.93	4.88	4.85	
Domain 2.1: Physical aspects-pain management (pediatrics)	4.96	4.98	4.93	
Domain 2.2: Physical aspects-symptom management (adults)	4.84	4.73	4.8	
Domain 2.2: Physical aspects-symptom management (pediatrics)	4.98	4.98	4.98	
Domain 3: Psychological and psychiatric aspects of care (adults)	4.86	4.79	4.81	
Domain 3: Psychological and psychiatric aspects of care (pediatrics)	4.85	4.85	4.83	
Domain 4: Social aspects of care	4.83	4.88	4.86	
Domain 5: Spiritual, religious, and existential aspects of care	4.89	4.88	4.86	
Domain 6: Physical aspects of care	4.85	4.79	4.72	
Domain 7: Care of the patient at the end of life (adults)	4.95	4.91	4.87	
Domain 7: Care of the patient at the end of life (pediatrics)	4.96	4.94	4.96	
Domain 8: Ethical and legal aspects of care	4.89	4.85	4.82	
Pain case studies: Adults				4.71
Pain case studies: Pediatrics				4.76
Communication laboratory: Focus on assessment and coordinating-adults				4.70
Communication laboratory: Focus on assessment and coordinating-pediatrics				4.71
Communication laboratory: Goals of care/advance care planning-adults				4.77
Communication laboratory: Goals of care/advance care planning-pediatrics				4.82
Communication laboratory: Critical skills				4.77
Responsible conduct of research	4.85	4.79	4.62	
Small groups Q & A: Review of symptoms-assessment-adults				4.71
Small groups Q & A: Review of symptoms-assessment-pediatrics				4.92
Small groups Q & A: Psychological/psychiatric-adults				4.79
Small groups Q & A: Psychological/psychiatric–pediatrics				4.85
Breakout: Further time on pain assessment/ management				4.72
Breakout: How to communicate with colleagues about palliative care				4.71
Breakout: Self care				4.79
Breakout: Nuts/bolts of primary oncology PC: Discussions about billing, documentation, QI, staffing				4.57
Breakout: Assisting the children of sick or dying oncology patients				4.67
Breakout: Spiritual care communication				5.00
Let us hear from you; opportunities for APRNs in staff education and development	4.89	4.83	4.80	
Where do you go from here?				
Scale 0 = not effective 5 = very effective				

APRNs, advanced practice registered nurses.

Table 3. Self-Rating of Efficacy by National Consensus Project Domain

	1		2		3		4		5	
NCP domains	n	%	n	%	n	%	n	%	n	%
The structure and process of care										
Precourse ($n=430$)	8	1.86	42	9.77	121	28.14	175	40.70	83	19.30
6 Months postcourse ($n=372$)	4	1.08	15	4.03	76	20.43	164	44.09	113	30.38
12 Months postcourse ($n=350$)	0	0.00	4	1.14	56	16.00	164	46.86	126	36.00
Physical aspects of care										
Precourse ($n=430$)	1	0.23	18	4.19	94	21.86	189	43.95	128	29.77
6 Months postcourse ($n=372$)	4	1.08	5	1.34	48	12.90	192	51.61	123	33.06
12 Months postcourse ($n=350$)	0	0.00	2	0.57	31	8.86	182	52.00	135	38.57
Psychosocial and psychiatric aspects of care										
Precourse ($n=430$)	8	1.86	68	15.81	168	39.07	125	29.07	61	14.19
6 Months postcourse ($n=372$)	4	1.08	17	4.57	106	28.49	160	43.01	85	22.85
12 Months postcourse ($n=350$)	0	0.00	2	0.57	69	19.71	164	46.86	115	32.86
Social aspects of care										
Precourse ($n=430$)	4	0.93	73	16.98	192	44.65	115	26.74	51	11.86
6 Months postcourse ($n=372$)	3	0.81	18	4.84	97	26.08	180	48.39	65	17.47
12 Months postcourse ($n=350$)	0	0.00	4	1.14	69	19.71	175	47.04	102	29.14
Spiritual, religious, and existential aspects of care										
Precourse ($n=430$)	34	7.91	127	29.53	153	35.58	72	16.74	43	10.24
6 Months postcourse ($n=372$)	9	2.42	39	10.48	132	35.48	125	33.60	67	18.01
12 Months postcourse ($n=350$)	3	0.86	19	5.43	83	23.71	159	45.43	86	24.57
Cultural aspects of care										
Precourse ($n=430$)	26	6.05	125	29.07	160	37.21	75	17.44	44	10.23
6 Months postcourse ($n=372$)	8	2.15	22	5.91	141	37.90	149	40.05	52	13.98
12 Months postcourse ($n=350$)	2	0.57	9	2.57	98	28.00	155	44.29	86	24.57
Care of the imminently dying patient										
Precourse ($n=430$)	17	3.95	81	18.83	124	28.83	123	28.60	85	19.77
6 Months postcourse ($n=372$)	8	2.15	22	5.91	80	21.51	175	47.04	88	23.66
12 Months postcourse ($n=350$)	2	0.57	8	2.29	56	16.00	152	43.43	132	37.71
Ethical and legal aspects of care										
Precourse ($n=430$)	22	5.12	101	23.49	162	37.67	94	21.86	51	11.86
6 Months postcourse ($n=372$)	10	2.69	27	7.26	129	34.68	145	38.98	61	16.40
12 Months postcourse ($n=350$)	1	0.29	14	4.00	90	25.71	151	43.14	94	26.86

Scale 1 = not at all effective to 5 = very effective.

processes of care as well as physical, psychological, social, and spiritual dimensions. Participant's scores revealed increased perception of effectiveness at 6 months postcourse and increasing further at 12 months post-training.

Table 4 describes the participants' reports of their palliative care practices measured precourse, 6 months postcourse, and 12 months postcourse. The APRNs reported increased frequency of these palliative care practices since attending the course in each area post-training. This included participation in family meetings, aspects of communication, recommending palliative care consultation, discussing bereavement services, and supporting clinical staff in end-of-life care.

Oncology program and palliative care team evaluation

The oncology program and palliative care team leaders who provided letters of support were surveyed by e-mail using Red Cap at 12 months postcourse to gain their perspectives on the benefits of the APRNs attending the course. These leaders were asked to identify the benefits of the APRNs' participation and to rate their level of satisfaction with participation by the nurse. They could also provide comments. Responses were received from 128 oncology leaders and 130 palliative care leaders. The most commonly cited benefit of the training project by both oncology and palliative care leaders was that the APRNs felt empowered to promote palliative care.

Other feedback was that patients in these settings are receiving better pain and symptom management, better support is provided to family caregivers, and more advance directives are completed. On a scale of 1 = extremely dissatisfied to 10 = extremely satisfied, the mean ratings of overall satisfaction with the training course to prepare the APRNs were a mean of 8.36 by palliative care leaders and 8.41 by oncology leaders.

Limitations

The project was successful as described in the mentioned outcomes despite the challenges of implementation during the peak period of the COVID-19 pandemic. The project included 430 participants representing 86% of the original goal of 500. The greatest challenge of the project was related to the need to convert the format due to COVID-19 travel restrictions.

Table 4. Palliative Care Practices by Advanced Practice Registered Nurses

	0/Never		*1–3/Rarely*		*4–6/Sometimes*		*7–9/Very often*		*10/Always*	
	n	%	n	%	n	%	n	%	n	%
Participated in a family meeting discussing/identifying a patient's goals of care?										
Baseline ($n=430$)	73	16.98	176	40.93	102	23.72	52	12.09	27	6.28
6 Months postcourse ($n=416$)	40	9.62	83	19.95	155	37.26	120	28.85	18	4.33
12 Months postcourse ($n=350$)	17	4.86	47	13.43	113	32.29	147	42.00	26	7.43
Told patients that the current cancer treatment they are on is no longer working?										
Baseline ($n=430$)	50	11.63	154	35.81	128	29.77	77	17.91	21	4.88
6 Months postcourse ($n=416$)	14	3.37	36	8.65	140	33.65	287	68.99	38	9.13
12 Months postcourse ($n=350$)	24	6.86	79	22.57	90	25.71	186	53.14	41	11.71
Recommended a patient consider a palliative care consult?										
Baseline ($n=430$)	41	9.53	166	38.60	128	29.77	74	17.21	21	4.88
6 Months postcourse ($n=416$)	29	6.97	54	12.98	155	37.26	154	37.02	24	5.77
12 Months postcourse ($n=350$)	12	3.43	28	8.00	114	32.57	168	48.00	28	8.00
Recommended to an oncologist that the patient has a palliative care consult?										
Baseline ($n=430$)	55	12.79	173	40.23	127	29.53	60	13.95	29	6.74
6 Months postcourse ($n=416$)	33	7.93	78	18.75	148	35.57	136	32.69	21	5.05
12 Months postcourse ($n=350$)	13	3.71	41	11.71	124	35.43	142	40.57	30	8.57
Spoken with a family member regarding bereavement services?										
Baseline ($n=430$)	176	40.93	156	36.28	66	15.35	23	5.35	9	2.09
6 Months postcourse ($n=416$)	105	25.24	133	31.97	136	32.69	42	10.10	9	2.16
12 Months postcourse ($n=350$)	44	12.57	127	36.29	102	29.14	63	18.00	14	4.00
Prepared clinical staff for impending death of a patient?										
Baseline ($n=430$)	61	14.19	230	53.49	91	21.16	37	8.60	11	2.56
6 Months postcourse ($n=416$)	125	30.05	106	25.48	142	34.13	76	18.27	19	4.57
12 Months postcourse ($n=350$)	36	10.29	79	22.57	110	31.43	101	28.86	24	6.86
Score of 0 = not effective to 5 = very effective										

The project included planned collaboration between the oncology APRNs and the palliative care teams, although this was sometimes challenging as these teams were overwhelmed by the demands of the pandemic and had limited time for mentoring. Feedback was received from ~30% of the oncology and palliative care leaders, also likely due to the many other demands on their time. Future trainings should consider how to support time for the APRNs to observe and collaborate with the palliative care teams as this experience was identified by the participants as valuable.

Discussion

The oncology APRN training was a valuable project to prepare these clinicians to integrate palliative care within their oncology practice roles. The course evaluation demonstrated that the content and teaching methods were very effective.

The ELNEC project offers many of their curriculum as online courses (www.aacnnursing.org/ELNEC), however, the consistent feedback has been that APRNs prefer in-person training. They identify the need for in-person networking with peers in similar positions and for mentorship by the expert faculty. Two courses were held virtually and were highly rated, but these participants also voiced the preference for in-person opportunities.

There is a need for similar courses to train APRNs in areas beyond oncology such as pulmonary, cardiac, and geriatric nursing. ELNEC does have a general APRN training program to meet these needs, but there has not been funding available to replicate the support provided by NCI for the oncology APRN course to allow for registration and travel costs or follow-up evaluation. The investigators are seeking funding to continue the oncology APRN course for an additional five years.

Conclusion

This NCI-supported training project addressed an important workforce issue of preparing oncology clinicians to integrate palliative care within their advanced practice nursing roles. Evaluation data demonstrated the feasibility of such training and participant application of the knowledge into patient care. The investigators recognize the many challenges of providing education and supporting practice change in very busy clinical oncology settings, particularly given the impact of the pandemic on staff demands and priorities.[17–19]

This training project can serve as a model for other clinical areas beyond oncology as they also develop ways to best support generalist level clinicians to integrate palliative care within their clinical specialties. The project elements of evidence-based curricula, clinical experts serving as faculty, reinforcement postcourse, and individualized goals were seen as strengths of the training with potential for application to further expansion in oncology and in other areas.

Nurses remain as the primary clinicians and as clinical leaders in implementing patient-centered care. Training programs such as this will be essential to prepare the workforce for the ever-growing demands for palliative care.

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Author Disclosure Statement

No competing financial interests exist.

Supplementary Material

Supplementary Table S1

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