

Nurse-Led, Telephone-Based Primary Palliative Care Intervention for Patients With Lung Cancer

Domains of Quality Care

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Palliative care is traditionally delivered by specialty-trained palliative care teams. Because of a national workforce shortage of palliative care specialists, there is an urgent need to explore alternative models of palliative care delivery to meet the needs of patients living with serious illness. As part of a multisite randomized controlled trial, 2 registered nurses without previous palliative care experience were trained to deliver a primary palliative care intervention to patients with newly diagnosed lung cancer. The intervention focused on assessing and managing symptoms, psychosocial needs, education, and initiating goals-of-care discussions. The primary outcome, improved symptom burden and quality of life, was not statistically significant. Despite this finding, nurses addressed 5 of the 8 National Consensus Project Guidelines domains of quality palliative care: structure and processes of care; physical, psychological, and social aspects of care; and ethical and legal aspects. Patients'

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The views expressed in this article are those of the authors and do not necessarily reflect the position or policy of the Department of Veterans Affairs. The authors have no conflicts of interest to disclose.

This study was supported by the Department of Veterans Affairs, Health Services Research and Development, NRI# 15-456.

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DOI: 10.1097/NJH.0000000000001005

engagement in goals-of-care discussions, a measure of high-quality palliative care, increased. Clinical recommendations offered by the nurses to the patients' clinicians were addressed and accepted on a timely basis. Most patients rated satisfaction with the intervention as "very or extremely" satisfied. These findings may inform future nurse-led palliative care interventions on the specific quality domains of palliative care.

KEY WORDS

domains of quality care, lung cancer, nurse-led, primary palliative care intervention, telephone-based

alliative care is patient- and family-centered care that optimizes quality of life (QOL) by anticipating, preventing, and reducing suffering.¹ The benefits of specialty palliative care on patients' QOL and care quality within health care systems have been demonstrated by multiple studies over the last 2 decades.²⁻⁴ However, partly because of a national shortage of palliative care specialists, many patients who may benefit do not receive timely palliative care, and the National Consensus Project Guidelines¹ recommend that palliative care is the responsibility of all clinicians and disciplines.⁵ Training and using nurses to deliver primary palliative care offers the benefits of an expanded, cost-efficient workforce.⁶ Therefore, the effects of nurses providing palliative care to patients with newly diagnosed lung cancer were studied given the established benefits of specialist palliative care among these patients. The intervention focused on 5 of the 8 quality palliative care domains: structure and processes; physical, psychological, and social aspects; and ethical and legal aspects (National Consensus Project). Three domains were not core components of the intervention: cultural aspects, spiritual aspects, and care of the imminently dying. The study protocol, intervention, and primary results have been previously reported.^{8,9}

Most palliative care studies focus on patient-reported or available administrative data outcomes including QOL,

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symptom burden, and health care utilization (eg, emergency department [ED] visits). ^{10–12} These outcomes are important; however, there are benefits to examining the components of the intervention to determine on which specific palliative care domains nurses can make the greatest impact. ¹³ For example, several studies have used nurses to improve the uptake of advance care planning (ACP) for patients and their caregivers. ^{14,15}

Advance care planning interventions are part of the *ethical and legal* domain of palliative care. ¹ The results of these studies highlight important outcomes including improvement in quality of patient-clinician communication, increased occurrence of goals-of-care discussions, decreased caregiver anxiety, ¹⁴ improved patient self-efficacy, ¹⁶ and completion of ACP documentation. ¹⁷ An underpinning of ACP interventions is the nurses' ability to develop trusting relationships with patients and families, which is a fundamental tenet of palliative nursing care. ¹⁸

In this secondary analysis, the effects of a telephone-based primary palliative care nursing education and training among patients with lung cancer are described. The National Consensus Project quality domains¹ addressed in the intervention, the clinical recommendations offered to clinicians by the study nurses, the impact of the nurses initiating goals-of-care discussions, patient satisfaction with the intervention, and health care utilization are reviewed. Insights from semistructured survey questions from the nurses on the positive aspects of the study and lessons learned that may inform future primary palliative care studies are reported.

METHODS

The parent study was a multisite, randomized controlled trial of a telephone-based nurse-led palliative care intervention for outpatients with newly diagnosed lung cancer within 2 months of diagnosis, of any stage or type. 8 Three geographically diverse Veterans Affairs (VA) medical centers were the study sites. A telephone delivery method was used to reach patients in broader geographical areas, including rural communities, and to decrease the burden of in-person visits. 19-21 A total of 151 patients were recruited with 73 randomized to the intervention group and 78 randomized to the control group. The study was conducted over 30 months. For this secondary analysis, descriptive statistics and a 2-sample test of proportions were used to assess changes in advance directives documents pre and post intervention. A semistructured survey was developed to elicit the study nurses' perspectives on the primary palliative care educational preparation, aspects of the intervention that were positive, areas that could be improved for future studies, and the nurses' role. Furthermore, patient satisfaction was assessed by inviting patients in the intervention group to complete an 8-item exit survey within 2 weeks of study completion. This survey was constructed and used in the pilot study. Patients were asked to rate their overall satisfaction with the intervention, satisfaction with symptom management, timely follow-up on issues, and assistance with care coordination.

Description of the Primary Palliative Care Education and Clinical Training

Nurses were baccalaureate-prepared registered nurses with extensive experience in clinical and research roles; thus, they possessed strong assessment and clinical judgment skills. Neither nurse had experience delivering palliative care. They were supervised by the principal investigator (PI), a board-certified advanced practice nurse with extensive pulmonary and palliative care experience. Palliative care education consisted of participating in a 1-day End-of-Life Nursing Education Consortium course for veterans¹⁸ and an 8-hour online VitalTalk²² communication course, and acquiring knowledge on common lung cancer symptoms and management by selected readings and weekly discussions with the PI. Symptom assessment and management protocols from the End-of-Life Nursing Education Consortium were adapted and tailored for patients with lung cancer. The nurses received training from the PI on how to use the Conversation Starter Kit²³ as a guide for initiating goals-of-care conversations with patients. Practice sessions were conducted with the nurses and study staff team members.

The nurses were hired as study nurses and were not embedded in a clinical team. Each nurse shadowed physicians, nurse practitioners, and nurses from the specialty palliative care consult team, oncology, pulmonary, and cardiothoracic surgery for 2 weeks. These clinical rotations fostered relationships between the study nurses and clinical experts to facilitate future communication. The nurses met with the PI and study team members weekly to address participant or study nurse concerns. The nurses had access to palliative care specialists to review difficult cases and receive clinical advice.

The intervention focused on 5 of the 8 domains of quality palliative care: *structure and processes of care*; *physical, psychological, and social aspects of care*; and *ethical and legal* aspects. These domains were selected based on results from the pilot study⁸ to best meet the needs of veterans recently given a diagnosis of lung cancer (Table 1.) Three domains, namely, *cultural aspects, spiritual aspects,* and *care of the imminently dying,* were not included in the intervention because the inclusion criteria enrolled patients with any stage of lung cancer in an effort to integrate palliative care more upstream⁹; thus, patients were not imminently dying. Intervention activities that fell under the provision of *structure and processes* of care domain included documenting the details and outcomes of each study call. A research template was developed in the electronic



TABLE 1 Five Domains of Quality Palliative Care Applied by Study Nurses	
National Consensus Guidelines: Palliative Care Quality Domains	Intervention: Specific Nursing Activity
Structure and process of care	 Primary palliative care education Patient education regarding lung cancer and treatments Care coordination among medical teams Clinical recommendations to providers via EHR Phone calls to patients and clinics
Physical aspect of care	Assessment and management of main lung cancer symptoms
Psychological aspect of care	Assessment and management of psychological symptoms such as depression and history PTSD.
Social aspects of care	 Assessment and management of social needs Coordination of care with social services, transportation, and finances
Ethical/legal aspects of care	Initiation of goals-of-care discussions
Abbreviations: EHR, electronic health record; PTSD, posttraumatic stress disorder.	

health record for the nurses to report patient assessments and offer clinical recommendations to the patients' lung cancer team. This process ensured the patients' main lung cancer clinician read and signed the notes, and followed up with recommendations offered by the study nurse. Given that patients could receive their lung cancer care in the community from non-VA providers, the study nurses were responsible for calling patients' clinicians to report adverse symptoms and ensure patients' needs were addressed in a timely manner. In addition, the study nurses engaged with the oncology nurse navigators at each study site on a weekly basis to coordinate care. The main role of nurse navigators is to coordinate care services for patients and families.²⁴ Because of a high volume of cancer patients, VA nurse navigators typically offer services to patients residing long distances, for example, >300 miles, from the medical center. As such, delineation of roles and responsibilities among the oncology and study team was needed to maximize efficiency and prevent duplication of services.

Intervention activities that fell under the provision of *physical, psychological, and social domains* included nurses routinely assessing physical and psychological symptoms commonly associated with lung cancer, including dyspnea, pain, cough, fatigue, gastrointestinal disturbances, anxiety, and depression, using validated questionnaires. Nurses play a major role in addressing patients' social aspects of care provision, ²⁵ which in a large integrated health care system, is often complex for patients to navigate. For example, the nurses assessed basic needs such as transportation for medical appointments and adequate food supply. Finally, nursing activities that fall under the *ethical and legal* domain included using a structured communication guide, The Conversation Starter Kit, ²³ to facilitate patients and families engaging in

goals-of-care conversations. Patient activation to discuss their goals of care with their clinicians and family members was assessed by measuring changes in scores from baseline to study completion for 2 questions from the Health Care Communication Questionnaire. The 2 dichotomous questions were as follows: (1) "Have you discussed with your doctor the treatments you want if you are unable to speak for yourself?" and (2) "Have you discussed with the person most involved in your care the treatments you want if you are unable to speak for yourself?" In addition, we collected data from the patient's electronic health record on documented advance directives before and after enrolling in the study.

RESULTS

Of the 151 patients recruited, most were male (98%), White (85%), and single (57%). Most were given a diagnosis of Non-Small Cell Lung Cancer (NSCLC) (65%) and were in American Joint Committee on Cancer – tumor, node, metastasis stage 3 or 4 (63%). The results of patients assigned to the intervention arm are reported.

Structure and Processes of Care

Among the 73 patients in the intervention arm, the nurses made 56 recommendations based on patient assessments, and 47 of these (84%) were accepted and acted upon by clinicians. The recommendations included (1) topics around care coordination (n = 23, 49%) (eg, communication among primary care clinicians and subspecialists), (2) new symptom management (n = 13, 28%) (eg, dyspnea, pain, and cough) and medication changes for existing symptoms (n = 5, 11%), and (3) referrals to services (n = 6, 13%) (eg, social workers or dietitians).



Among the 6 referrals for support services, 4 recommendations were accepted by clinicians, and patients received those services. Of the 9 recommendations (16%) that clinicians did not act upon, 4 were for care coordination, 2 were referrals for supportive services, 2 were for symptom management, and 1 was a medication change. Most of the recommendations not acted upon were from non-VA clinicians.

Physical, Psychological, and Social Aspects of Care

The nurses conducted regular symptom assessment and management according to the study protocol and as needed, if patients contacted the study nurses between study calls. Despite regularly addressing physical and psychological symptoms as well as social needs, we found no statistically significant improvements in symptom burden measured by the total Functional Assessment of Cancer Therapy-Lung (P = .45) and subscales, ²⁷ namely, physical wellbeing (p = .32), lung cancer symptoms (p = .30), functional well-being (p = .75), social well-being (p = .55), and emotional well-being (p = .35). The nurses adhered to End-of-Life Nursing Education Consortium symptom protocols and applied nonpharmacologic and pharmacologic management guidelines. 18 They reported uncontrolled symptoms to the patients' lung cancer clinician and implemented the recommended changes offered by clinicians, as described previously. If patients reported acute or severe symptoms, the nurses recommended reporting to the nearest ED. Importantly, the nurses coordinated care with clinical team members and helped ensure patients had access to basic needs, such as their medications, food, and transportation.

Ethical and Legal Aspects of Care

Fifty-two of patients (93%) in the intervention arm (n = 73) reported that reviewing the Conversation Starter Kit²³ with the nurse helped them think about their goals of care. Of these patients, 44 (85%) reported they initiated goals-of-care conversations and ACP with their clinician or family members. Despite patients reporting they initiated ACP conversations, no significant change in scores from baseline to follow-up between the study groups were found on 2 Health Care Communication Questions: (1) "Have you discussed with your doctor the treatments you want if you are unable to speak for yourself?" and (2) "Have you discussed with the person most involved in your care the treatments you want if you are unable to speak for yourself?"

Advance directives, not including Physician Orders for Life-Sustaining Treatment forms, were completed before the study by 26 patients (36%) in the intervention arm and 35 (45%) in the control arm. Among the patients without an advance directive at baseline, 10 of 47 (21.3%) in the

intervention group completed advance directives during the study period compared with only 4 of 43 patients (9.3%) in the control group (2-sample test of proportions, P = .12; 95% confidence interval, -2.6% to 26.5%), a 129% relative increase in completion rate.

Satisfaction With the Intervention

Patients enrolled in the intervention group completed an 8-item exit survey within 2 weeks of study completion assessing their satisfaction with the intervention; completion rate was 75%. Overall, 56 of the patients (77%) rated being highly or extremely satisfied (8.9 [SD, 1.8]) with the intervention (Likert scale, 0 [not at all satisfied] to 10 [extremely satisfied]). In addition, 48 of 51 (94%) stated they received timely follow-up and treatment recommendations from the study nurse. Forty-three of 50 (86%) stated the nurse helped them access resources and services, and 38 of 54 (70%) stated being enrolled in the study helped them better manage their symptoms. Importantly, 52 of 56 (93%) reported the nurses helped them think about their goals of care, and 44 of 55 (80%) initiated goals-of-care conversations and/or ACP with their clinicians and family members.

Nurses' Perspectives on the Intervention: Lessons Learned

The nurses offered insights on study strengths and areas for improvement (Table 2.) They reported the palliative care educational curriculum helped them prepare to deliver the intervention. One of the nurses had previous training in motivational interviewing and behavioral activation and suggested those techniques be incorporated into future trainings. Specifically, the nurse applied motivational interviewing skills when initiating goals-of-care conversations. Both nurses expressed using the Conversation Starter Kit²³ was useful to guide goals-of-care discussions.

Both nurses relayed variation in clinician and team communication among the 3 study sites. Sites that had active nurse navigator teams were easier to coordinate care; however, there was overlap in roles and clarification of responsibilities.²⁴ This overlap was confusing resulting in inefficient communication among staff and patients. Often, the study nurses made repeated phone calls to oncology clinics to ensure patients' needs were addressed in a timely manner. The nurses spent much of the time on care coordination and addressing patients' psychosocial needs. Examples of these activities include communicating with non-VA medical teams to arranging patient transportation to medical appointments. Given the intervention prioritized the patients' needs, the nurses felt obligated to meet the patients' immediate concerns. Finally, both study nurses stated they were able to build relationships over the phone with patients and the patients appreciated the



TABLE 2 Nurses' Perspectives on the Intervention	
Study Strengths	Areas Needing Improvement
Primary palliative care education curriculum	More time shadowing palliative care teams
Prioritizing patients' concerns, coordinating care, accessing social services, and resolving physical concerns	Routine interdisciplinary team palliative care meetings to address patients' needs
Routine telephone calls built patient trust	 Challenging to fully appreciate and examine patients' physical symptoms via phone Training on telephonic communication skills
Care coordination with oncology nurse navigators	 Overlap between the study nurses' and nurse navigators' roles and responsibilities led to inefficient communication/variation among 3 study sites Include nurse navigators at study onset
Conversation Starter Kit	Incorporate motivational interviewing skills

prompt follow-up calls and treatments as a result of the nursing calls. 30

Health Care Use

A total of 35 patients reported to the ED; 22 (63%) were in the intervention group and 13 (37%) were in the control group. The study nurses recommended patients (n = 3) in the intervention arm report to the ED for severe symptoms. The main symptoms patients experienced were cough, dyspnea, and gastrointestinal disturbances (eg, acute pain or gastrointestinal bleed). Among patients who were hospitalized (n = 30), 19 (63%) were in the intervention group, and 11 (37%) were in the control group. The main reasons for hospitalization were acute symptoms (n = 2), infections (n = 1), pneumonia (n = 2), or cardiac symptoms such as atrial fibrillation (n = 1).

DISCUSSION

In this article, nursing activities and effects on domains of care of a telephone-based, primary palliative care intervention delivered to patients with lung cancer are described. Study nurses focused on 5 of the 8 National Consensus Project Guidelines domains of quality palliative care: structure and processes; physical, psychological, and social; and ethical and legal aspects of care. An important finding under the quality domain of physical, psychological, and social was nurses recommending patients report to the ED for acute or severe symptoms. These recommendations resulted in a higher number of ED visits and hospitalizations for patients in the intervention arm; however, immediate care was received, which may have prevented complications. Main findings under the quality domain of structure and processes of care include clinical recommendations offered by the nurses to the patients' clinicians. Most of the recommendations were addressed and accepted on a timely basis. These transactions resulted in patients reporting they received timely care that was responsive to their needs. The *ethical and legal aspects of care* focused on the study nurses initiating goals-of-care conversations with patients using a structured tool. Patients' engagement in goals-of-care discussions increased considerably demonstrating that nurses can be trained to initiate these important conversations. The discrepancy between patients reporting initiating goals-of-care conversations and a statistically nonsignificant change in outcomes may be due to patient interpretation of the outcome questions, such as "if you are unable to speak for yourself." Finally, patients rated satisfaction with the intervention and the study nurse as "very or extremely" satisfied.

The nurses spent most of their time on care coordination and facilitating communication among the patients' clinician they identified as most responsible for their lung cancer care. This finding is not surprising given that nurses are trained and skilled at care coordination³¹; however, these activities may be delegated to nurse navigators or other members of the lung cancer team. Nurses prioritized patients' needs, which mainly involved addressing and solving social issues. Although the nurses had access to social workers, they felt compelled to help patients in the moment. These activities, albeit important, could be delegated to other team members freeing the study nurses to focus on issues that require skilled nursing, such as nonpharmacologic symptom or stress management.³²

The study findings align with several other studies supporting nurses' impact on delivering specific domains of primary palliative care. Houben and colleagues¹⁵ tested the effect of a 1.5-hour nurse-led ACP intervention among patients with chronic obstructive pulmonary disease on quality of patient-clinician communication, prevalence of ACP discussions 6 months post intervention, and anxiety and depression in patients and their loved ones. The results demonstrated the intervention improved the quality of communication, increased the occurrence of ACP discussions within

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6 months, and decreased anxiety in loved ones. Walczak et al¹⁶ evaluated the efficacy of a nurse-facilitated communication support program for patients with advanced uncurable cancer and their caregivers to assist them in discussing prognosis and end-of-life care. They found patients receiving the support program gave significantly more cues that they wished to discuss prognosis, end-of-life care, and future care options; however, they failed to ask specific questions. This finding implies that applying motivational interviewing techniques may motivate patients to ask direct questions about prognosis and end-of-life care from trusted clinicians.^{28,29}

Sinclair et al³³ evaluated the impact of a nurse-led ACP intervention among patients with a diagnosis of severe respiratory disease on satisfaction, QOL, and health care utilization. The intervention did not improve the primary outcomes; however, among the patients who died during the follow-up period, there were significantly fewer outpatient consultations, reduced length of stay in acute hospital settings, and increased length of stay in palliative care beds in the last 90 days of life. Finally, a recent trial trained oncology infusion nurses to deliver primary palliative care to patients with advanced cancers including lung. 14 Consistent with our results, there was no improvement in QOL, anxiety, or depression; however, there was a significant improvement in ACP rates.³⁴ An interdisciplinary palliative care team may be required to improve QOL; however, these findings imply nurses can impact important primary palliative care domains including effective goals-of-care conversations and ACP.

Limitations

The study has several limitations because we only trained 2 registered nurses to deliver the intervention among 3 study sites. The nurses did not have previous palliative care training; thus, our educational curriculum may not have been sufficiently robust to meet the needs of our patient population. Despite the nurses being able to build relationships with patients over the telephone, it was challenging to fully appreciate patients' physical needs and observe nonverbal communication. It is possible that delivery of the intervention via telephone negatively impacted the primary outcomes; therefore, telehealth or in-person options should be explored in future research. The roles and responsibilities of the study nurses frequently overlapped with existing oncology nurse navigators, leading to inefficient communication and workloads. Future pragmatic trials should examine outcomes of an integrative model of care using nurses embedded in clinical settings to deliver specific palliative care domains. The study was not adequately powered to determine the difference between study groups for ACP and documentation, although there was a large relative increase among patients in the intervention arm. Finally, routine clinical meetings with a palliative care multidisciplinary team may have more fully addressed patients' needs and offered comprehensive services.

CONCLUSION

The primary results of this nurse-led, primary palliative care intervention did not improve QOL or symptom burden among patients with newly diagnosed lung cancer. However, the nurses successfully applied 5 of the 8 domains of quality palliative care to deliver comprehensive lung cancer care. The nurses rightly prioritized patients' needs by focusing on care coordination and assisting patients with social aspects of care. Goals-of-care conversations were initiated with patients using a standard guide, prompting patients to discuss their treatment wishes with family members and their clinicians. The nurses offered recommendations to clinicians based on patient assessments, and most were accepted and acted upon enhancing timeliness of care delivery. These findings call for further research to identify which specific palliative care quality domains can be effectively delivered by nurses to impact patient- and family-reported outcomes in cancer care.

Acknowledgments

The authors thank the dedication of Hong T.K. Nguyen, BS, who supported this study by creating databases as well as assisting with study coordination and manuscript preparation.

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Nurse-Led, Telephone-Based Primary Palliative Care Intervention for Patients With Lung Cancer: Domains of Quality Care

TEST INSTRUCTIONS

- Read the article. The test for this nursing continuing professional development (NCPD) activity is to be taken online at www.nursingcenter. com/ce/JHPN. Tests can no longer be mailed or faxed.
- You'll need to create an account (it's free!) and log in to access My Planner before taking online tests. Your planner will keep track of all your Lippincott Professional Development online NCPD activities for you.
- There's only one correct answer for each question. A passing score for this test is 8 correct answers. If you pass, you can print your certificate of earned contact hours and access the answer key. If you fail, you have the option of taking the test again at no additional cost.
- For questions, contact Lippincott Professional Development: 1-800-787-8985.
- Registration deadline is June 5, 2026.

PROVIDER ACCREDITATION

Lippincott Professional Development will award 2.0 contact hours for this nursing continuing professional development activity.

Lippincott Professional Development is accredited as a provider of nursing continuing professional development by the American Nurses Credentialing Center's Commission on Accreditation.

This activity is also provider approved by the California Board of Registered Nursing, Provider Number CEP 11749 for 2.0 contact hours. Lippincott Professional Development is also an approved provider of continuing nursing education by the District of Columbia, Georgia, West Virginia, New Mexico, South Carolina, and Florida, CE Broker #50-1223. Your certificate is valid in all states.

Payment: The registration fee for this test is \$21.95.

DISCLOSURE STATEMENT

The authors and planners have disclosed that they have no financial relationships related to this article.