Available online at www.sciencedirect.com

ScienceDirect

Nurs Outlook 69 (2021) 626–631

Nursing Outlook

www.nursingoutlook.org

Development and protocol for a nurse-led telephonic palliative care program

Audrey J. Tan, DO[a,b*], *Rebecca Yamarik, MD, MPH*[c],
Abraham A. Brody, PhD, RN, FAAN[b,d], *Frank R. Chung, MD*[a],
Corita Grudzen, MD, MSHS, FACEP[a,e], *The EMPallA Telephonic Working Group* [1]

[a]*Ronald O. Perelman Department of Emergency Medicine, NYU Grossman School of Medicine, New York, NY*
[b]*Division of Geriatric Medicine and Palliative Care, NYU Grossman School of Medicine, New York, NY*
[c]*Department of Medicine, Tibor Rubin Long Beach Veteran Affairs, Long Beach, CA*
[d]*Hartford Institute for Geriatric Nursing, NYU Rory Meyers College of Nursing, New York, NY*
[e]*Department of Population Health, NYU Grossman School of Medicine, New York, NY*

ARTICLE INFO

Article history:
Received 10 September 2020
Received in revised form 30 November 2020
Accepted 17 December 2020
Available online January 21, 2021.

Keywords:
Palliative care
Program development
Telehealth
End of life care
Hospice care

ABSTRACT

Background: The COVID-19 pandemic has resulted in a profound transformation of health care delivery toward telemedicine models.

Purpose: We present the structure of a nurse-led telephonic palliative program and operational metrics to influence further development of tele-palliative programs.

Methods: The nurses engage with seriously ill patients for 6 months with the goal of discussing advance care planning (ACP) and addressing self-identified issues related to their illness.

Findings: Of the first 100 program graduates, 78% were actively engaged and 51% named a health care agent and/or engaged in ACP. Of the 18 patients who died during the study, 13 (72%) were enrolled in hospice services.

Discussion: Our preliminary results indicate that seriously ill patients are willing to engage with nurses and to participate with discussions on ACP.

Conclusion: Given the gaps in health care exposed by the COVID-19 pandemic, this innovative program serves as an important model for bringing palliative care directly to patients.

Cite this article: Tan, A.J., Yamarik, R., Brody, A.A., Chung, F.R., & Grudzen, C. (2021, July/August). Development and protocol for a nurse-led telephonic palliative care program. Nurs Outlook, 69(4), 626–631. https://doi.org/10.1016/j.outlook.2020.12.011.

---

*Corresponding author: Audrey Tan, NYU Langone Health, Ronald O. Perelman Department of Emergency Medicine, 227 E. 30th Street, First Floor, New York, NY 10016.

E-mail address: audrey.tan@nyulangone.org (A.J. Tan).

[1] The EMPallA Telephonic Working Group: Anne Kim, MS, NP; Stephen Ryan, RN, MSW, CHPN; Laraine Ann Chiu, MSN, RN; Mara Flannery; Julia Brickey.

https://doi.org/10.1016/j.outlook.2020.12.011

Introduction

The arrival of the COVID-19 pandemic has prompted a rapid transformation of health care from a traditional outpatient clinic model to a telemedicine model. The transformation was performed out of necessity and with the support of flexibilities provided by Centers for Medicaid and Medicare Services and private insurers around reimbursement, allowing many clinicians across hospice and palliative care settings to move rapidly toward telephonic palliative care. However, programs had, and continue to have, limited guidance on best practices (CMS.gov, 2020).

Telephonic care has not traditionally been used in palliative care and specifically, nurse-led models are a relatively new area for the field. Payers have taken the lead in developing telephonic programs to address the diverse needs of patients with serious illness. Aetna's Compassionate Care Program supports members with advanced illnesses via nurse case managers, which demonstrated a reduction in acute care days by 82%, a reduction in ICU care days by 86% and a decrease in emergency department (ED) use by 78% (Krakauer et al., 2014). SCAN Health Plan's Program for Advanced Illness, a telephonic case management program carried out by nurses, has demonstrated reductions in Medicare costs while increasing hospice utilization for their members (Spettell et al., 2009; Yamarik & Mattews, 2015). It remains unclear, however, how nurse-led telephonic care may affect quality of life, symptom burden, and caregiver distress. Additionally, patient identification, structure, and operational aspects of these programs have not been well described, making program replication challenging.

An ED visit is a sentinel event for older adults with serious illness, often signifying a breakdown in care coordination and worsening clinical and functional status, thus making it an ideal setting from which to identify patients and caregivers who may benefit from palliative care services (Ferrell et al., 2018; Grudzen et al., 2016; Smith et al., 2010). Delivering palliative care to these patients via a nurse-led telephonic model may assist these patients with controlling their symptoms, establishing goals of care, and improving quality of life for patients with advanced illnesses in a novel, accessible, and cost-effective model of care. Our manuscript aims to (1) describe the development and implementation of a nurse-led telephonic palliative care program for patients with serious illness who are discharged after an ED visit or an observation stay and (2) provide preliminary operational and clinical outcomes for the first 100 program graduates.

Methods

Design and Sample

The nurse-led telephonic palliative care program is part of the Emergency Medicine Palliative Care Access research study, a large Patient-Centered Outcomes Research Institute-funded randomized control trial comparing facilitated, outpatient specialty palliative care to nurse-led telephonic palliative care delivery after an ED visit (Grudzen et al., 2019). While the telephonic program is part of the larger trial, it operates as a pragmatic clinical initiative and not a strictly protocolized research intervention. Patients and their caregivers are recruited at 18 separate hospital EDs across nine states. Thirteen hundred and fifty patients and 675 of their informal caregivers will be enrolled over a 5-year period.

Eligibility Criteria

English- or Spanish-speaking patients 50 years or older who are scheduled for ED discharge or ED observation status are eligible for the study. Disease criteria include advanced cancer or end-stage organ failure, which is defined as New York Heart Association Class III or IV heart failure, End-Stage Renal Disease with glomerular filtration rate <15 ml/min/m^2, or Global Initiative for Chronic Obstructive Lung Disease Stage III, IV, or oxygen-dependent Chronic Obstructive Pulmonary Disease (National Kidney, 2002; New York Heart Association & Harvey, 1973). English- or Spanish-speaking adult primary caregivers are also eligible to participate if they are an: (1) immediate or extended family member; or (2) close friend who lives with the eligible patient full time. Caregivers must possess a working telephone and cannot be compensated for providing care to a patient.

Program Description

The nurse-led telephonic palliative care program is a national program based at New York University Langone Health. A team of three registered nurses (RNs) certified in hospice and palliative nursing is supervised by two physician board-certified in hospice and palliative medicine (A.T., R.Y.), with additional clinical support and supervision provided by a board-certified geriatric and palliative nurse practitioner (A.B.). The supervisors provide clinical support via regular weekly team meetings, as well as, ad hoc support to the nurses as needed on specific cases.

Training for Nurses
Initial training sessions for the three RNs is comprised of web-based modules and in-person didactic sessions. Online modules include topics on pain and symptom management (Pain Management, 2019; Symptom Management, 2015), palliative considerations for specific disease processes (Relief of Suffering Across the Disease Trajectory, 2017), and refining communication skills (Communication Skills, 2020). Additionally, the RNs complete an online web-based training on motivational interviewing (Gardia & Barnett), a 3-hr web- and telephone-based training in Problem Solving Theory (Bakitas et al., 2009), and an in-person training on advance care planning (ACP) through the Respecting Choices Last Steps program

(Respecting Choices Last Steps). Training is also ongoing, and a portion of every monthly team meeting is dedicated to content-specific training based on needs identified by both the nurses and supervising providers in a collaborative process. Although no formal testing is incorporated into the training, any knowledge gaps are identified by program supervisors and ad hoc education is provided to the nurses (Figure 1).

Data Collection and Measures

Patients enrolled in the nurse-led telephonic palliative care program are followed over a 6-month period. Within 48 to 72 hr of enrollment, the telephonic RN places an introductory call to the patient. During this call, the nurse uses standardized scripting to introduce the concepts of palliative care and discusses the purpose and structure of the program. The nurse subsequently completes a standardized palliative care assessment with the patient within two weeks of enrollment. The assessment includes the Edmonton Symptom Assessment System Revised (Chang et al., 2000), Palliative Performance Scale (Anderson et al., 1996) and disease-specific questions. Additional questions assess for unmet palliative care needs and are based on the eight established palliative care domains (Ferrell et al., 2018; Kroenke et al., 2003; Puchalski & Romer, 2000; Relief of Suffering Across the Disease Trajectory, 2017): (1) structure and processes of care; (2) physical aspects of care; (3) psychological and psychiatric aspects; (4) social aspects of care; (5) spiritual, religious, and existential aspects of care; (6) cultural aspects of care; (7) care of the patient at the end of life; and (8) ethical and legal aspects of care. Caregiver burden is assessed using the Caregiver Strain Index (Robinson, 1983).

	Description	Reliability	Internal consistency (Cronbach's alpha)
Edmonton Symptom Assessment System Revised (Chang et al., 2000)	Self-reported assessment tool of symptoms	0.8	0.79
Palliative Performance Scale (Ho et al., 2008)	Assessment of a patient's functional performance	0.67–0.71	0.91
Caregiver Strain Index (Robinson, 1983; Thornton & Travis, 2003)	Assessment tool to measure strain related to care provision	0.88	0.86

Figure 1 – Measures of symptoms, functioning and care provision strain.

For each patient, three goals are prioritized: (1) to identify a surrogate decision maker; (2) to conduct and document an ACP conversation; (3) to address caregiver burden if the CSI > 7 (Robinson, 1983). ACP is emphasized due to its relevance for every patient with serious illnesses, whereas the other domains do not necessarily apply to all patients. Goals can be modified depending on patient engagement and preference, and additional needs are identified through subsequent calls with the patient.

Communication With Providers

Communication with the patient's health care team is a key component of the program. Upon patient enrollment, the patient's primary provider and/or specialist receives a standard welcome letter describing the program and the role of the telephonic nurse. After 1 month, providers are contacted via email or phone, and updated on goals of care conversations, symptoms issues, and questions regarding prognosis or assistance with completion of advance directive documentation. Nurses subsequently contact providers on an ad hoc basis until the 6-month graduation from the program. In addition, for hospitalized patients, nurses reach out to inpatient providers to deliver critical information about patients' goals of care.

Evaluation

To ensure quality assurance, a nurse self-assessment checklist is completed at 3 and 6 months to ensure adherence to programmatic guidelines. Operational metrics include patient engagement, which is defined as active communication between the telephonic nurse and patient throughout the intervention period . Additional metrics include the completion of an ACP note, identification of a health care agent (HCA), and the sharing of wishes with the patient's HCA. Call characteristics, including the amount of time spent in chart review, calls, and documentation are also tracked.

Findings

An analysis of the first 100 patients enrolled in the program between April 2018 and August 2019 was

Table 1 – Patient Characteristics of First 100 Patients

	N	Percentage
Age (years), mean (SD)	68 (10)	
Range	50–95	
Gender (female), N (%)	54	54%
Ethnicity (Hispanic), N (%)	14	14%
Race, N (%)		
White	53	53%
Black/African American	32	32%
Asian	2	2%
Other	13	13%
Born in United States, N (%)	85	85%
Illness, N (%)*		
Advanced cancer	42	42%
Heart failure	26	26%
End stage renal disease	17	17%
Chronic obstructive pulmonary disease	29	29%

* Patients may have multiple illnesses.

Table 2 – Rate of Advance Care Planning (n = 100) (No. %)

	N	Percentage
ACP note completed*	42	42%
HCA designated**	51	51%
ACP wishes shared with HCA***	28	28%

* Completion of a distinct ACP note type in the electronic medical record.

** Nurse documentation of a patient's allocation of a HCA.

*** Nurse documentation that patient wishes were shared with the HCA.

performed. Table 1 demonstrates the baseline demographics and illnesses represented by this group.

Seventy-eight (78%) were actively engaged with a telephonic nurse until program graduation, transfer to hospice, or death. Nine patients (9%) were lost-to-follow-up and 13 patients (13%) withdrew from the program before 6 months. Eighteen patients died during the intervention period, and 13 of the 18 (72%) enrolled in hospice services prior to death.

The average patient caseload per nurse per week was 18 (range: 5–26), excluding those who died or withdrew from the intervention. An average of 10 calls (range: 0–41) were made per patient with a median cumulative call duration of 223 min (range: 5–1,005) over 6 months. The nurses placed a total of 206 outgoing calls or emails to the patients' care teams and received a total of 222 responses during the intervention period. Of the 31 enrolled caregivers, nurses were able to reach 20 of them (65%) via phone or email.

Table 2 describes early outcomes of the program, including advance directive completion (42%), HCA appointments (51%), and sharing of wishes with the patient's HCA (28%).

Discussion and Recommendations

We describe here the design and implementation of a novel nurse-led palliative care program. Additionally, initial analyses of our results demonstrated an overall patient engagement rate of 78% and 42% engagement with ACP. Patient engagement in our program is high, likely due to the ability to overcome those challenges encountered by palliative care delivered via the traditional outpatient model such as the logistics of scheduling, the scarcity of services, and difficulties associated with travel, particularly in more rural locations (Finlay et al., 2018). Additionally, the COVID-19 pandemic brought forth new barriers, including infection control and concerns around the exposure to a vulnerable population. Palliative care delivered telephonically may overcome these challenges through ease of delivery and the ability to bring palliative care directly to the patient. In a study on advanced heart failure patients undergoing a mixed in-person and telephonic palliative care model, Bakitas et al. (2017) demonstrated that 69% of participants attended all intervention sessions (Bakitas et al., 2017). A similar study describing a nurse-led, telephone-based palliative care intervention for newly diagnosed lung cancer patients showed an 85% retention rate through their 3-month program. Our data also demonstratesthat seriously ill patients are willing to engage in nurse-led telephonic palliative care programs and that engagement rates in our program do not differ from other telephonic interventions.

The early analysis also demonstrated that nearly two-thirds of patients who died in our program were enrolled in hospice services, which suggests that nurses are able to facilitate goals of care discussions between patients and caregivers and to assist with referrals to hospice services telephonically. A study analyzing a Medicare fee-for-service sample population demonstrated that, in 2015, about half of the patients who died were on hospice (Teno et al., 2018). Similarly, the National Hospice and Palliative Care Organization reported that in 2016, 48% of all Medicare decedents received 1 day or more of hospice care and were enrolled in hospice at the time of death (NHPCO Facts and Figures: 2018 Edition, 2018).

Limitations of the telephonic program can be categorized into challenges with patients, providers, and HCAs. Establishing regular contact with patients by telephone, both initially and on a weekly or biweekly basis for 6 months, is often difficult. Patients are often resistant to answering calls from numbers that are not from a trusted source, while scheduling calls for patients who are feeling ill or have numerous medical commitments is challenging. Additionally, some patients transition to skilled nursing facilities or long-term care, which can make contact more difficult. Engaging with providers is another challenge for the telephonic nurses as routes of communication vary based on institutional culture and norms. During ACP conversations, the nurses attempt to schedule a three-way telephone call with the patient and HCAs, however, this can often be challenging. When this is not possible, nurses have first engaged in an ACP conversation with the patient, followed by a separate call with the HCA to discuss and share the patient's goals and priorities of care.

Conclusion

Our manuscript is one of the first papers to clearly describe the components of a nurse-led telephonic palliative care program for patients with serious illness. Our preliminary results indicate that seriously ill patients and their caregivers are willing to engage with nurses within the program and to participate with discussions about ACP and transitions to hospice. Given the gaps in health care exposed by the COVID-19 pandemic, this innovative program can serve as an important model for bringing palliative care directly to patients through nurse-led teams.

Credit Statement

A.T.: Oversight of clinical program; authoring, drafting and critically revising the manuscript; R.Y.: Oversight of clinical program; drafting and critically revising the manuscript; A.B.: Oversight of clinical program; drafting and critically revising the manuscript; F.C.: Critically revising the manuscript; C.G.: Conception and design of study; drafting and critically revising the manuscript; The EMPallA Telephonic Working Group: Critically revising the manuscript. All authors approved of the final version of the manuscript.

Acknowledgments

Funding: This work was supported by the Fan Fox & Leslie R. Samuels Foundation and partially supported through a Patient-Centered Outcomes Research Institute (PCORI) Award (PLC-1609-36306).

REFERENCES

Anderson, F., Downing, G. M., Hill, J., Casorso, L., & Lerch, N. (1996). Palliative performance scale (PPS): A new tool. *Journal of Palliative Care, 12*(1), 5–11. https://www.ncbi.nlm.nih.gov/pubmed/8857241.

Bakitas, M., Dionne-Odom, J. N., Pamboukian, S. V., Tallaj, J., Kvale, E., Swetz, K. M., Frost, J., Wells, R., Azuero, A., Keebler, K., Akyar, I., Ejem, D., Steinhauser, K., Smith, T., Durant, R., & Kono, A. T. (2017). Engaging patients and families to create a feasible clinical trial integrating palliative and heart failure care: Results of the ENABLE CHF-PC pilot clinical trial. *BMC Palliative Care, 16*(1), 45, doi:10.1186/s12904-017-0226-8.

Bakitas, M., Lyons, K. D., Hegel, M. T., Balan, S., Brokaw, F. C., Seville, J., Hull, J. G., Li, Z., Tosteson, T. D., Byock, I. R., & Ahles, T. A. (2009). Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: The Project ENABLE II randomized controlled trial. *Journal of American Medical Association, 302*(7), 741–749, doi:10.1001/jama.2009.1198.

Chang, V. T., Hwang, S. S., & Feuerman, M. (2000). Validation of the edmonton symptom assessment scale. *Cancer, 88*(9), 2164–2171, doi:10.1002/(sici)1097-0142(20000501)88:9<2164::aid-cncr24>3.0.co;2-5.

CMS.gov. (2020). *President Trump expands telehealth benefits for medicare beneficiaries during COVID-19 outbreak*. Retrieved from https://www.cms.gov/newsroom/press-releases/president-trump-expands-telehealth-benefits-medicare-beneficiaries-during-covid-19-outbreak.

Communication Skills. (2020). https://www.capc.org/training/communication-skills/.

Ferrell, B. R., Twaddle, M. L., Melnick, A., & Meier, D. E. (2018). National consensus project clinical practice guidelines for quality palliative care guidelines. *Journal of Palliative Medicine, 21*(12), 1684–1689, doi:10.1089/jpm.2018.0431.

Finlay, E., Rabow, M. W., & Buss, M. K. (2018). Filling the gap: Creating an outpatient palliative care program in your institution. *American Society of Clinical Oncology Education Book, 38*, 111–121, doi:10.1200/EDBK_200775.

Gardia, G., & Barnett, E.*Applying motivational interviewing techniques and interventions in palliative care*. California State University: Shiley Institute for Palliative Care. https://csupalliativecare.org/programs/motivational-interviewing/.

Grudzen, C. R., Richardson, L. D., Johnson, P. N., Hu, M., Wang, B., Ortiz, J. M., Kistler, E. A., Chen, A., & Morrison, R. S. (2016). Emergency department-initiated palliative care in advanced cancer: a randomized clinical trial. *JAMA Oncology, 2*(5), 591–598, doi:10.1001/jamaoncol.2015.5252.

Grudzen, C. R., Shim, D. J., Schmucker, A. M., Cho, J., Goldfeld, K. S., & Investigators, E. M. (2019). Emergency medicine palliative care access (EMPallA): protocol for a multicentre randomised controlled trial comparing the effectiveness of specialty outpatient versus nurse-led telephonic palliative care of older adults with advanced illness. *BMJ Open, 9*(1) e025692, doi:10.1136/bmjopen-2018-025692.

Ho, F., Lau, F., Downing, M. G., & Lesperance, M. (2008). A reliability and validity study of the Palliative Performance Scale. *BMC Palliative Care, 7*(10), doi:10.1186/1472-684X-7-10.

Krakauer, B., Agostini, J., & Krakauer, R. (2014). Aetna's compassionate care program and end-of-life decisions. *Journal of Clinical Ethics, 25*(2), 131–134. https://www.ncbi.nlm.nih.gov/pubmed/24972063.

Kroenke, K., Spitzer, R. L., & Williams, J. B. (2003). The patient health questionnaire-2: validity of a two-item depression screener. *Medical Care, 41*(11), 1284–1292, doi:10.1097/01.MLR.0000093487.78664.3C.

National Kidney, F. (2002). K/DOQI clinical practice guidelines for chronic kidney disease: evaluation, classification, and stratification. *American Journal of Kidney Disease, 39*(2 Suppl 1), S1–266. https://www.ncbi.nlm.nih.gov/pubmed/11904577.

New York Heart Association, & Harvey, R.j. M. (1973). *Nomenclature and criteria for diagnosis of diseases of the heart and great vessels* (7th ed.). Little.

NHPCO Facts and Figures: 2018 Edition. (2018). National hospice and palliative care organization. https://39k5cm1a9u1968hg74aj3 ×51-wpengine.netdna-ssl.com/wp-content/uploads/2019/07/2018_NHPCO_-Facts_Figures.pdf.

Pain Management. (2019). https://www.capc.org/training/pain-management/.

Puchalski, C., & Romer, A. L. (2000). Taking a spiritual history allows clinicians to understand patients more fully. *Journal of Palliative Medicine, 3*(1), 129–137, doi:10.1089/jpm.2000.3.129.

Relief of Suffering Across the Disease Trajectory. (2017). https://www.capc.org/training/relief-of-suffering-across-the-disease-trajectory/.

Respecting Choices Last Steps. https://respectingchoices.org/overview-of-programs-and-services/.

Robinson, B. C. (1983). Validation of a caregiver strain index. *Journal of Gerontology, 38*(3), 344–348, doi:10.1093/geronj/38.3.344.

Smith, A. K., Schonberg, M. A., Fisher, J., Pallin, D. J., Block, S. D., Forrow, L., & McCarthy, E. P. (2010).

Emergency department experiences of acutely symptomatic patients with terminal illness and their family caregivers. *Journal of Pain Symptom Management, 39*(6), 972–981, doi:10.1016/j.jpainsymman.2009.10.004.

Spettell, C. M., Rawlins, W. S., Krakauer, R., Fernandes, J., Breton, M. E., Gowdy, W., Brodeur, S., MacCoy, M., & Brennan, T. A. (2009). A comprehensive case management program to improve palliative care. *Journal of Palliative Medicine, 12*(9), 827–832, doi:10.1089/jpm.2009.0089.

SymptomManagement. (2015). https://www.capc.org/training/symptom-management/.

Teno, J. M., Gozalo, P., Trivedi, A. N., Bunker, J., Lima, J., Ogarek, J., & Mor, V. (2018). Site of death, place of care, and health care transitions among US medicare beneficiaries, 2000-2015. *Journal of American Medical Association, 320*(3), 264–271, doi:10.1001/jama.2018.8981.

Thornton, M., & Travis, S. S. (2003). Analysis of the reliability of the modified caregiver strain index. *Journal of Gerontology B Psychological Science Social Science,* 58(2), S127–S132, doi:10.1093/geronb/58.2.s127.

Yamarik, R. B. R., & Mattews, L (2015). *A health plan's innovative telephonic case management model to provide palliative care* (TH303) Philadelphia, PA.