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COVID-19 Pandemic Response: Development of Outpatient Palliative Care Toolkit Based on Narrative Communication

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Abstract

Context: The coronavirus disease 2019 (COVID-19) pandemic laid bare the immediate need for primary palliative care education for many clinicians. Primary care clinicians in our health system reported an urgent need for support in advance care planning and end-of-life symptom management for their vulnerable patients. This article describes the design and dissemination of palliative care education for primary care clinicians using an established curriculum development method. **Objectives:** To develop a succinct and practical palliative care toolkit for use by primary care clinicians during the COVID-19 pandemic, focused on 2 key elements: (i) advance care planning communication skills based on the narrative 3-Act Model and (ii) comfort care symptom management at the end of life. **Results:** The toolkit was finalized through an iterative process involving a team of end-users and experts in palliative care and primary care, including social work, pharmacy, nursing, and medicine. The modules were formatted into an easily navigable, smartphone-friendly document to be used at point of care. The toolkit was disseminated to our institution's primary care network with practices spanning our state. Early feedback has been positive. **Conclusion:** While we had been focused primarily on the inpatient setting, our palliative care team at Johns Hopkins Bayview Medical Center pivoted existing infrastructure and curriculum development expertise to meet the expressed needs of our primary care colleagues during the COVID-19 pandemic. Through collaboration with an interprofessional team including end-users, we designed and disseminated a concise palliative care toolkit within 6 weeks.

Keywords

communication skills curriculum, comfort care at the end of life, narrative communication, COVID-19, primary palliative care

Introduction

Outpatient providers often lack confidence in providing high-quality primary palliative care for seriously ill and dying patients due in part to limited training.[1] During the early stages of the COVID-19 pandemic, the potential consequences of this education gap on the well-being of patients and their families came sharply into focus.

Informed by health systems impacted early by the virus, palliative care organizations (eg, Center to Advance Palliative Care, VitalTalk, and Respecting Choices) swiftly made resources widely available online.[2-4] One strength of these COVID-19 palliative care materials was their breadth, including many scripts, mnemonic devices, and recommendations. However, multiple colleagues at our institution shared their perceptions that these abundant resources were challenging to navigate and put into practice in the primary care setting. Some also shared their view that the scripts and mnemonics might be insufficiently flexible to adapt to complex goals of care discussions, as has been reported in the literature.[5-6] We saw an opportunity to design a concise toolkit built upon the narrative approach to goals of care conversations already integrated in multiple programs at our institution (the 3-Act Model[7]).

This article describes the development of a practical and high-yield palliative care toolkit for use by clinicians caring

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for nonhospitalized patients during the COVID-19 pandemic, with support related to advance care planning (ACP) communication skills and symptom management at the end of life.

Innovation

At the time of this project, our palliative care clinical team at Johns Hopkins Bayview Medical Center (JHBMC) was composed of 2 physicians, a registered nurse, a chaplain, and a pharmacist; we provided clinical care solely in our 450-bed hospital. In 2019, to help drive our growing educational and program development efforts, we formed the Palliative Creative Operations Team (PCOT), consisting of a physician and nurse from the clinical team, plus a business analyst and administrative coordinator. Our weekly meetings included personal check-ins, creative brainstorming, candid peer-to-peer communication, and outcomes-oriented organization and accountability.

The PCOT used a rapid cycle of Kern's Six-Step Approach to Curriculum Development to pivot preexisting inpatient education efforts to support the specific needs of outpatient providers in our community during the pandemic.[8] Our interprofessional team of contributors included social work, nursing, pharmacy, and medicine—and spanned palliative care and primary care, the latter including general internal medicine (GIM) and geriatrics. Per needs assessment, we identified our aim to be the rapid dissemination of a concise, user-friendly toolkit that would enable primary care clinicians to conduct ACP discussions using the 3-Act Model and identify potential management strategies for patients with COVID-19 who elect to remain at home for end-of-life comfort care.

Accordingly, we organized our curricular content into 2 modules: (i) ACP and (ii) Comfort Care at End of Life for Patients at Home (see Online Appendix). We grounded the content with references to key related literature[9-11] and online resources.[3] The core of Module 1 is the 3-Act Model, the JHBMC palliative care team's home-grown narrative approach to communication, adapted to the context of outpatient ACP during COVID-19. Usually taught through a 2-day multimodal training, we honed the 3-Act Model to the most concise iteration possible while still conveying its key principles. Module 2 prepares outpatient providers for the possible limitations of home hospice during the pandemic by providing evidence-based end-of-life symptom management tips for dyspnea, pain, anxiety, agitation, and respiratory secretions. The module also suggests proactive planning with clinic staff regarding home medication delivery, provision of medical equipment, and bereavement support.

Outcomes

After many focused iterations in a short time span, the completed toolkit, created in Microsoft Word, was formatted in Adobe Acrobat as a PDF file, with hyperlinks connecting elements in the Table of Contents to every section. Central to the aim of this project, the toolkit could be easily viewed and navigated on a clinician's smartphone at point of care.

We sent the completed toolkit via email to all 38 faculty members of the GIM division at JHBMC, as well as clinicians within the Johns Hopkins Geriatrics division. We also shared the modules with leaders of Johns Hopkins Community Physicians (JHCP), who decided to disseminate to all of their 300+ providers at >30 practices across Maryland. With each phase of the sharing, we explicitly welcomed feedback with the aim of ongoing iterative improvement, and encouraged recipients to share the toolkit with interested colleagues. The initial feedback was positive. Numerous colleagues across disciplines expressed gratitude for the modules. One general internist (and medical education expert) wrote: "Great work . . . happy to help circulate. Love that . . . you all are thinking about how we manage this in areas besides the inpatient units." Another ambulatory clinician commented: "The palliative care guide is amazing! So well done."

We made complementary efforts to address the education gap in primary palliative care for outpatient clinicians during the COVID-19 pandemic via other media. The palliative care team members helped lead webinars in both ACP and comfort care symptom management for JHCP clinicians, as well as end-of-life symptom management education for the GIM clinic pharmacist. Further, the toolkit (and its associated collaborative process) helped open lines of communication, resulting in the palliative care team providing phone support for outpatient colleagues during the pandemic.

Discussion

Our interprofessional team of collaborators designed a toolkit with 2 modules tailored to meet our ambulatory colleagues' expressed needs in the setting of the COVID-19 pandemic. Amid the shifting and growing clinical demands of the pandemic, our small palliative care team pivoted existing organizational and educational infrastructure to this project, enabling the design and wide dissemination of the toolkit within 6 weeks.

Organizations with national scale made primary palliative care educational resources readily available in the setting of COVID-19,[3-5] and many palliative care providers (ourselves included) found them valuable. In a recent study, the palliative care program at 2 institutions developed a toolkit to support nonpalliative care colleagues in the hospital setting.[12] Our project has important differences from these other resources: (i) our toolkit is tailored for primary care clinicians; (ii) our communication module does not use mnemonics or detailed scripts, but rather is grounded in a narrative approach; (iii) our contributors included end-users, as well as interprofessional colleagues; (iv) we report using a well-established approach to curriculum development to anchor design and implementation.

Given the small size of our palliative care program and the many competing priorities we faced, the preexisting PCOT—with its focus on strong organizational methods and creative nonhierarchical collaboration—was crucial to this project's success. Another critical component was the strong partnership that blossomed between the inpatient palliative care team and key ambulatory programs (GIM and geriatrics). We expect this

collaboration to become increasingly robust and valuable as the pandemic evolves. Already, the expansion of telemedicine has created many opportunities for our team to provide support for our outpatient colleagues in caring for home-bound patients with advanced illness.

Multiple limitations of this project should be considered. First, the toolkit was designed and initially distributed at one health care system. However, our diverse team of collaborators stretched across specialties, disciplines, and institutions within the system; and through partnerships and sharing, the toolkit has found its way into the hands of providers far removed from our system. Second, due to time constraints, outcome measures thus far are limited to spontaneous written feedback from colleagues. We hope to assess feasible behavioral outcomes, such as end-user surveys or web-tracking, in the future.

A variety of approaches to teaching primary palliative care communication exist. For all their value, one might view mnemonics and scripts as roadmaps as useful as their fidelity to, and our ability to see, the roads we travel with our patients. But serious illness does not take a prescribed path, and with the onset of the COVID-19 pandemic, we all traveled largely in the dark. Our hope in teaching a narrative approach is to provide not a map but an adaptive GPS (global positioning system) to help guide the way through an increasingly complex, dynamic terrain.

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Supplemental Material

Supplemental material for this article is available online.

References

1. Lakin JR, Block SD, Billings JA, et al. Improving communication about serious illness in primary care: a review. *JAMA Intern Med*. 2016;176(9):1380-1387.
2. CAPC COVID-19 Response Resources. 2020. Accessed March 2020. https://www.capc.org/toolkits/covid-19-response-resources
3. Back A, Tulsky JA, Arnold RM. Communication skills in the age of COVID-19. *Ann Intern Med*. 2020;172(11): 759-760.
4. Respecting Choices COVID-19 Resources. 2020. Accessed March 2020. https://respectingchoices.org/covid-19-resources/#planning-conversations
5. Eggly S, Penner L, Albrecht TL, et al. Discussing bad news in the outpatient oncology clinic: rethinking current communication guidelines. *J Clin Oncol*. 2006;24(4):716-719.
6. Wittenberg-Lyles EM, Goldsmith J, Sanchez-Reilly S, Ragan SL. Communicating a terminal prognosis in a palliative care setting: deficiencies in current communication training protocols. *Soc Sci Med*. 2008;66(11):2356-2365.
7. Wu DS, Kern DE, Dy SM, Wright SM. Narrative approach to goals of care discussions: a novel curriculum. *J Pain Symptom Manage*. 2019;58(6):1033-1039.
8. Thomas PA, Kern DE, Hughes MT, Chen BY. *Curriculum Development for Medical Education: A Six-Step Approach*. Johns Hopkins University Press; 2016.
9. McPherson ML. *Demystifying Opioid Conversion Calculations: A Guide for Effective Dosing*. 2nd ed. American Society of Health-System Pharmacists; 2018, pp. 86-95.
10. Walsh D, Rivera NL, Davis MP, Lagman R, Legrand SB. Strategies for pain management: Cleveland Clinic Foundation Guidelines for opioid dosing for cancer pain. *Support Cancer Ther*. 2004;1(3):157-164.
11. National Comprehensive Cancer Network. NCCN Clinical Practice Guidelines in Oncology. Adult Cancer Pain, v.1.2020. Accessed May 8, 2020. https://www.nccn.org/professionals/physician_gls/pdf/pain.pdf
12. Thomas JD, Leiter RE, Abrahm JL, et al. Development of a palliative care toolkit for the COVID-19 pandemic. *J Pain Symptom Manage*. 2020;S0885-3924(20):30425-30455.