Published in final edited form as:

Ann Intern Med. 2018 January 02; 168(1): 71–72. doi:10.7326/M17-2164.

A Research Agenda for High-Value Palliative Care

Katherine R. Courtright, MD, MS, J. Brian Cassel, PhD, and Scott D. Halpern, MD, PhD

Perelman School of Medicine at the University of Pennsylvania, Philadelphia, Pennsylvania; and Virginia Commonwealth University, Richmond, Virginia.

Palliative care has catapulted from being misunderstood and viewed cautiously by many clinicians to being among the most sought-after services by health care systems nationwide. This is the greatest possible testimony to the field's potential value. However, because demand has quickly outstripped the supply of palliative care specialists (1), the field's ability to sustainably provide high-value care is paradoxically threatened by its own success. We propose a research agenda organized around 5 key questions on the optimal organization and allocation of limited resources in specialty palliative care to close the gap between the workforce and patient need. The Table provides important considerations and proposed approaches for addressing each research challenge. Amid a growing body of evidence on the potential value of specialty palliative care (2), we posit that answering these questions is essential to maximize value and inform much-needed policies to support such care (3).

WHO IS MOST LIKELY TO BENEFIT?

Although evidence suggests that palliative care improves outcomes for some seriously ill populations (2), specialists cannot see all of these patients. Yet clinicians' failure to reliably identify patients who need specialty palliative care results in inefficient and inequitable care, particularly for those with serious illnesses other than cancer. This has prompted many health care systems to implement triggers to facilitate patient identification. However, the criteria underlying these triggers are often based on diagnosis and prognosis, which may be poor surrogates for actual needs, and no high-quality evidence yet suggests that triggers improve outcomes.

To optimize efficiency, specialty palliative care must be delivered to patients with the greatest need for specialized services rather than those with the poorest prognoses. Identifying such patients automatically using electronic health records could both enrich

Current Author Addresses: Dr. Courtright: 5048 Gates Building, Hospital of the University of Pennsylvania, 3400 Spruce Street, Philadelphia, PA 19104., Dr. Cassel: 1101 East Marshall Street, Sanger Hall Suite 6030, Box 980230, Richmond, VA 23298., Dr. Halpern: 726 Blockley Hall, 423 Guardian Drive, Philadelphia, PA 19104. **Requests for Single Reprints:** Katherine R. Courtright, MD, MS, 5048 Gates Building, Hospital of the University of Pennsylvania, 3400 Spruce Street, Philadelphia, PA 19104; katherine.courtright@uphs.upenn.edu.

Author Contributions: Conception and design: K.R. Courtright, J.B. Cassel, S.D. Halpern. Analysis and interpretation of the data: S.D. Halpern.

Drafting of the article: K.R. Courtright, J.B. Cassel.

Critical revision of the article for important intellectual content: K.R. Courtright, J.B. Cassel, S.D. Halpern.

Final approval of the article: K.R. Courtright, J.B. Cassel, S.D. Halpern.

Collection and assembly of data: S.D. Halpern.

Disclosures: Authors have disclosed no conflicts of interest. Forms can be viewed at www.acponline.org/authors/icmje/ConflictOfInterestForms.do?msNum=M17-2164.

enrollment in palliative care trials and promote patient-centered allocation of the limited resources in specialty palliative care (4). Need-based patient identification would benefit from better clinician documentation of uncontrolled symptoms, psychosocial distress, and care preferences and goals. However, even without perfect documentation, technology-driven solutions may improve detection of all types of palliative care needs by revealing patterns in what is documented (5).

WHAT SERVICES ARE MOST BENEFICIAL?

Specialty palliative care teams offer various services that may have different effects on patient, caregiver, and financial outcomes. Research is needed to understand how different types of palliative care clinicians contribute to these outcomes and how such relationships are modified by institutional culture around providing primary palliative care—that is, palliative care delivered by patients' primary clinicians. Because estimates suggest an insurmountable deficit of palliative care physicians relative to patients with serious illness in the United States (1), understanding which services nonphysicians or primary care clinicians can deliver as well or better is essential to maximizing value.

WHERE SHOULD PATIENTS RECEIVE CARE?

Hospital-based consultation is the predominant model for delivering specialty palliative care in the United States. However, experimental evidence for outpatient and home-based palliative care is more plentiful and of higher quality than for inpatient services (2). Given a finite supply of palliative care clinicians, comparative effectiveness studies should be done to determine where their efforts have the greatest clinical and economic effect.

Analogously, considerable attention has been given to improving palliative care in the intensive care unit despite limited evidence of its effectiveness there (6). Although critically ill patients have great needs, allocating palliative care resources to seriously ill patients on the ward, in the emergency department, or even further “upstream” may offer longer-term clinical benefits and greater cost savings.

WHEN SHOULD PATIENTS RECEIVE CARE?

Several studies have supported the concept that “early” palliative care improves outcomes for patients with cancer. However, timing of care delivery varies widely among similar patients (7). Research is needed to determine what constitutes “early” and how such definitions differ by illness and care setting.

Evidence is also needed to guide the optimal duration of palliative care services. In most circumstances, single visits by specialists are unlikely to be sufficient. But when it comes to sustainable, equitable, and courteous consultation, knowing when to sign off is as important as knowing when to sign on.

HOW CAN EFFICIENT, EQUITABLE CARE BE IMPLEMENTED?

Even when we have learned which patients are most likely to benefit from which services in what settings and when along their disease trajectories, the challenge of how best to promote effective service delivery will remain. For such questions of how to change clinician behavior around specialty palliative care consultation, the field of behavioral economics offers much insight (8). For example, a recent trial showed that several clinician-targeted nudges significantly reduced an undesirable and costly behavior (9). If successful in improving patient- or family-centered outcomes or restraining costs, these types of simple interventions could go a long way toward optimizing the implementation of specialty palliative care. Finally, to be most effective, targeted delivery models for specialty palliative care need to incorporate complementary efforts to improve primary palliative care.

WHAT ARE THE COSTS AND CHALLENGES?

As in other areas of medicine, value in palliative care remains challenging to define and therefore measure. No single outcome measure for palliative care satisfies the interests of all stakeholders. Furthermore, efforts to measure the cost-effectiveness of palliative care interventions have used various methods and insufficiently captured all relevant components of cost (10), particularly the unintended additional costs and burdens to patients and families. Despite these and other challenges, rigorous investigation to answer the 5 questions above should be a priority for clinicians, investigators, funders, policymakers, and health care system leaders who share the goal of sustainable delivery of high-quality palliative care, at the lowest cost, to those most likely to benefit (3).

References

1. Lupa D; American Academy of Hospice and Palliative Medicine Workforce Task Force. Estimate of current hospice and palliative medicine physician workforce shortage. *J Pain Symptom Manage* 2010;40:899–911. [PMID: 21145468] doi:10.1016/j.jpainsymman.2010.07.004 [PubMed: 21145468]
2. Kavalieratos D, Corbelli J, Zhang D, Dionne-Odom JN, Ernecoff NC, Hanmer J, et al. Association between palliative care and patient and caregiver outcomes: a systematic review and meta-analysis. *JAMA* 2016;316:2104–2114. [PMID: 27893131] doi:10.1001/jama.2016.16840 [PubMed: 27893131]
3. Meier DE, Back AL, Berman A, Block SD, Corrigan JM, Morrison RS. A national strategy for palliative care. *Health Aff (Millwood)* 2017; 36:1265–1273. [PMID: 28679814] doi:10.1377/hlthaff.2017.0164 [PubMed: 28679814]
4. Hayward RA, Kent DM, Vijan S, Hofer TP. Multivariable risk prediction can greatly enhance the statistical power of clinical trial sub-group analysis. *BMC Med Res Methodol* 2006;6:18 [PMID: 16613605] [PubMed: 16613605]
5. Kreimeyer K, Foster M, Pandey A, Arya N, Halford G, Jones SF, et al. Natural language processing systems for capturing and standardizing unstructured clinical information: a systematic review. *J Biomed Inform* 2017;73:14–29. [PMID: 28729030] doi:10.1016/j.jbi.2017.07.012 [PubMed: 28729030]
6. Carson SS, Cox CE, Wallenstein S, Hanson LC, Danis M, Tulsky JA, et al. Effect of palliative care-led meetings for families of patients with chronic critical illness: a randomized clinical trial. *JAMA* 2016;316: 51–62. [PMID: 27380343] doi:10.1001/jama.2016.8474 [PubMed: 27380343]

7. Kozlov E, Carpenter BD, Thorsten M, Heiland M, Agarwal A. Timing of palliative care consultations and recommendations: understanding the variability. *Am J Hosp Palliat Care* 2015;32:772–5. [PMID: 25024458] doi:10.1177/1049909114543322 [PubMed: 25024458]
8. Emanuel EJ, Ubel PA, Kessler JB, Meyer G, Muller RW, Navathe AS, et al. Using behavioral economics to design physician incentives that deliver high-value care. *Ann Intern Med* 2016;164:114–9. [PMID: 26595370] doi:10.7326/M15-1330 [PubMed: 26595370]
9. Meeker D, Linder JA, Fox CR, Friedberg MW, Persell SD, Goldstein NJ, et al. Effect of behavioral interventions on inappropriate antibiotic prescribing among primary care practices: a randomized clinical trial. *JAMA* 2016;315:562–70. [PMID: 26864410] doi:10.1001/jama.2016.0275 [PubMed: 26864410]
10. Gardiner C, Ingleton C, Ryan T, Ward S, Gott M. What cost components are relevant for economic evaluations of palliative care, and what approaches are used to measure these costs? A systematic review. *Palliat Med* 2017;31:323–337. [PMID: 27670418] doi:10.1177/0269216316670287 [PubMed: 27670418]

Research Challenges and Proposed Approaches Toward High-Value Specialty Palliative Care

Table.

Research Challenges	Proposed Approaches
Who: Identify patients and families most likely to benefit	Target on the basis of patient- or family-reported needs
What: Distinguish the most effective component(s) of palliative care	Leverage electronic health records and applied bioinformatics for scalable solutions
Where: Determine where patients and families receive the greatest benefits	Identify patient- and family-centered outcome measures appropriate for different palliative care processes
When: Define the optimal times to initiate palliative care	Strategically deploy multidisciplinary personnel on the basis of needs and economic effect
How: Implement novel and effective palliative care delivery models	More rigorously evaluate the effect of inpatient consultation
	Do comparative effectiveness studies of specialist care provided across different sites
	Consider costs and burdens to patients and families associated with additional inpatient or outpatient visits
	Find evidence-based definition of “early” in the context of diagnosis, prognosis, and needs
	Optimize duration of specialist involvement to maximize effectiveness and minimize opportunity costs
	Increase need-based penetration of services through behavioral economic and other strategies
	Improve and disseminate primary palliative care education and training