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# Mapping the future for research in emergency medicine palliative care: A research roadmap

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## Abstract

**Background:** The intersection of emergency medicine (EM) and palliative care (PC) has been recognized as an essential area of focus, with evidence suggesting that increased integration improves outcomes. This has resulted in increased research in EM PC. No current framework exists to help guide investigation and innovation.

**Objective:** The objective was to convene a working group to develop a roadmap that would help provide focus and prioritization for future research.

**Methods:** Participants were identified based on clinical, operation, policy, and research expertise in both EM and PC and spanned physician, nursing, social work, and patient perspectives. The research roadmap setting process consisted of three distinct phases that were time staggered over 12 months and facilitated through three live video convenings, asynchronous input via an online document, and a series of smaller video convenings of work groups focused on specific topics.

**Results:** Gaps in the literature were identified and informed the four key areas for future research. Consensus was reached on these domains and the associated research questions in each domain to help guide future study. The key domains included work focused on the value imperative for PC in the emergency setting, models of care delivery, disparities, and measurement of impact and efficacy. Additionally, the group identified key methodological considerations for doing work at the intersection of EM and PC.

**Conclusions:** There are several key domains and associated questions that can help guide future research in ED PC. Focus on these areas, and answering these questions, offers the potential to improve the emergency care of patients with PC needs.

## INTRODUCTION

Palliative care (PC) provides physical, spiritual, psychological, and social support to patients with a serious illness; is appropriate at any point in the disease course; and is appropriate at any age. Those most in need are often at end of life and patients approaching the end of life face increased illness burden, complexity of care, utilization of the health care system, and associated costs.[1,2] This has a direct impact on emergency care. In this last year of life it is estimated that 75% of older adults will present to the to the emergency department (ED).[3,4]

As such, the intersection of PC and emergency medicine (EM) has been recognized as an essential area of focus, with early evidence suggesting that increased integration improves both patient-centered care and hospital operational outcomes.[5–7] This has resulted in calls for increased access to PC for ED patients in national guidelines and awareness campaigns.[8,9] To leverage and sustain gains, patients, hospital administrators, and health care leaders must see evolving and sustained rigorous evidence that demonstrates the value of this increased integration and creates a clear roadmap for efficient and effective implementation.

Early work etched the exploratory roadmap for a PC research agenda in 2009, which offered several areas for prioritization.[10] These included the foundational work that was needed to describe the population in need, the attitudes of clinicians, and the external support services needed to deliver care in the ED as well as work to develop optimal screening tools, and assess the impact of interventions on outcomes and of the education of clinicians.

Following this, has been a rapid increase in ED PC evidence in the past several years (Figure 1). With this has come increased federal funding for work focused on the intersection of EM and PC.[11] COVID further accelerated the speed of innovation in this domain, with several new models of care delivery, such as telemedicine for EM PC delivery, emerging in the peer-reviewed literature in the past 12 months.[12–15]

To build on prior robust efforts to identify areas of research in this domain, additional subspecialized foci within EM PC have emerged, such as shared decision making for PC in the ED, geriatric care, and oncology care.[16–18] With this rapid pace of growth, it is critical that the EM PC community create a framework to help provide focus and prioritization for future research.

With that objective in mind, a group was assembled through the Society for Academic Emergency Medicine's (SAEM) Palliative Medicine Interest Group and in collaboration with members of the American Academy of Hospice and Palliative Medicine (AAHPM). The group's purpose was to identify the gaps in the research to date, determine the key themes in EM PC research moving forward, and help provide focus and priority for investigation in the future.

## METHODS

The methods for developing the research roadmap (Table 1) were informed by stakeholder interviews and through the input of leaders outside of the EM PC community who had led similar work in other fields of study and served as key advisors in the design phase. Participants were assembled with the aim of convening a group of experts with clinical, operational, policy, and research expertise in both EM and PC. This was done through solicitation of interest through society interest group meetings as well as through posts on the society listservs. The "core group" was designed to be interdisciplinary and composed of physicians, nurses, and advanced practice providers. As such, once the initial group had been assembled we identified missing representation and purposefully solicited interest from recommendations made by group members to ensure diversity of experience and background. The result was a 20-person core group of thought leaders in both PC and EM, which represented primary clinicians, clinical researchers, hospital administrators, and a primary PhD investigator.

The research roadmap setting process consisted of three distinct phases that were time-staggered over 12 months (August 2020–August 2021) and facilitated through three live video convenings of the core group, asynchronous input via an online document, and a series of smaller video convenings of work groups focused on specific topics. Work group members were also members of the larger core group.

In the first phase, a work group was assembled to review the current available literature. Given several recent systematic reviews,[19–23] it was determined that a de novo comprehensive scoping review was not necessary and instead this group focused on synthesizing the themes in the literature based on the current systematic reviews and their knowledge of the literature as experts and through an additional database of 5248 citations collected by one of the work group members (RW) for a thematic ontology of EM PC that was under way. This work group met three times to discuss their findings in the literature and through facilitated discussion identified themes. This work group then presented their environmental scan and analysis of the current themes to the core group at a video convening. The environmental scan served to frame the gaps in the research and identify future themes to guide the next phase of the work.

In the second phase, four work groups were established to review each of the four focus areas identified in Phase 1. These work groups met over the course of 2 months and drafted key questions and considerations in their thematic domains. A second convening of the core group was then held to deliberate these considerations and questions, which were then amended and presented to external stakeholders, including patient representatives and clinicians in PC and EM who had not been a part of the work to date, for further input and refinement.

In the third and final phase, a work group was convened to match the questions and considerations to methods and identify key considerations in study design for the roadmap. The resulting document, which is presented here in the results, summarizes the key research roadmap and methodological considerations. This was circulated both within the group

and outside of it for additional input and refinement, after which the research roadmap as presented here was endorsed by the core group and presented at the SAEM Annual Meeting and a subsequent SAEM Palliative Medicine Interest Group meeting. After final review, it was endorsed by the board of SAEM. The research committee of the AAHPM has reviewed this document and affirms its value. This statement indicates the committee's highest level of support.

## RESULTS

### Gaps in the literature to date

In the first phase of this work we undertook a review of the current literature, as synthesized in several systematic reviews, as well as a review of additional citations collected as a part of an ongoing effort to create an ontology of the EM PC literature which was already under way and is being published separately. The goal of this was to identify gaps in the current evidence base. This effort uncovered several thematic domains of published work.

The first domain related to *establishing the need for PC in EDs*, with a significant focus on characterizing the patients that present to EDs with unmet PC needs[3,24–39] and qualitative studies examining the barriers and facilitators of doing this work in an ED setting.[40–46] The perspectives of ED clinicians and administrators has been systematically explored with a focus on barriers to care delivery,[41,42,47–52] along with a body of work focused on editorials and calls to action.[53–59]

The second theme related to *models of care delivery*. This work primarily focused on conceptual models[60–64] and small pilot studies that often explored disease-specific models.[6,65–70] Among the frequently studied models of care delivery was primary PC or the training and education of ED clinicians in targeted PC skills.[71–75] The literature on model development also focused heavily on specific tools for communication, screening, and consults.[7,19,76–81]

In facilitated discussion related to gaps, several clear gaps were identified and consensus reached related to the most pressing areas for future research focus. The first related to *understanding the value imperative for PC in EM*, with a focus on expanding on the limited literature currently available on the perspectives of patients,[37,46,82–84] communities, and clinicians not previously identified through research (including PC providers, subspecialists, social workers, and case managers). The second gap that emerged related to *models of care delivery* with a need to build and test new interventions and to further investigate the limited literature on issues surrounding care delivery in the context of workforce development.[85,86] The third gap related to *disparities*, specifically understanding the prevalence, contributing factors and best strategies to mitigate them. The fourth and final gap was related to *measurement and efficacy*, recognizing that little work has been done to establish the best measures and outcomes suited to PM in the ED.

The key considerations and questions to help provide focus and priority for researchers follow:

### Key research area: The value imperative for PC in the emergency setting

**Considerations—**With the growing interest in integrating PC into EM it is essential that there is a demonstrated understanding of what the value proposition is of this increased integration. This value will be different for different stakeholders and it is critical to understand the nuances of each. Related to the system, it will be important to understand what the value proposition is for health care system administrators and be able to articulate the value delivered in the context of quality, cost, and appropriateness. Related to patients and communities, it is particularly important that future studies begin to capture and address the perspectives of patients and community members in this focus of research, creating a clear understanding of what their needs are and what value they derive from the programs and services that are being designed and tested. It will be essential that these patient voices are diverse and reflect the diversity of the patient population seen and treated in EDs. Along with this, comes a more nuanced body of work that should begin to take shape, not only focused on "why PC in EM" more generally but also starting to address the question of "what" and "how much" PC is required in the EM setting to meet these needs (also see "Models of care delivery" section below). This will, in many ways, stem from the exploration of what the health care systems, patients, families and the communities being served value most.

As researchers focus on understanding the most pressing needs and values in this domain, it is particularly important that there is engagement of communities that have not been robustly represented to date. This includes patients, caregivers, and family members. Specific attention should also be paid to cross-cultural differences and barriers to uptake. It will also be important to understand and augment the limited literature related specifically to death in the ED. As researchers consider the value drivers for different stakeholders, it will be important to parse out how these drivers differ in different contexts. In particular, there is an opportunity to create a more clear understanding of what the unique value imperatives were that drove the rapid increase in ED–PC integration during COVID[12,13,48,85,87,88] and how many of these programs remain relevant after the pandemic recedes.

### Research questions

**Question 1: What is the patient, caregiver, and bereaved family member perspective on PC delivered in the ED setting?:** What is the value identified by patients and families of having this care delivered in the ED? What is the acceptability and value of different forms of PC as perceived by these communities? What is the impact of missed opportunities for PC in the ED? What is the impact on families and caregivers of ED death? How do these perspectives and impacts differ in different communities? How does engaging families and caregivers in the ED around death change their experience?

**Question 2: What is the perceived system value of PC delivered in the ED setting?:** What is the value imperative identified by system and departmental leaders? What is the value of different forms of PC as perceived by these stakeholders? What is the impact of missed opportunities for PC in the ED? What is the societal impact of delivering this care in the ED?

**Question 3: What are the perceptions and experience of non–emergency physicians related to PC provided in the emergency setting?:** What is the impact perceived by non-ED clinicians related to this care? What are the perspectives of other clinical staff within the ED environment as well as in the prehospital and postacute setting? What are the perceptions of PC clinicians and specialty physicians related to delivering this care in the ED or the opportunity cost of it not being delivered?

**Question 4: How does PC in the ED modify and improve the illness experience of patients and families with serious illness?:** Specifically what are the impacts for patients and families of addressing symptom control, advance care planning, serious illness conversations, psychological and social distress, spiritual care, and bereavement in the ED? What is the value imperative of addressing the PC needs of specific populations such as those in cardiology, renal disease, pediatrics, and oncology in the ED?

**Question 5: How has the COVID pandemic changed these perspectives?:** Specifically, how has COVID changed clinicians' perception of the importance and acceptability of EM–PC integration? What was the value delivered through these models of care, and which ones continue to exist? How has the role of technology and training changed?

## Key research area: What we are doing (models of care delivery)

**Considerations—**After more than a decade of research that provided examples of educational interventions and clinical pilot programs, there is no predominant, generalizable, or reproducible model of care that has emerged and undergone fidelity testing, evaluation of effectiveness, or a measure of sustainability. Research that shifts from descriptive studies to implementation and dissemination science can develop that model. This body of research will build on the limited work that has tried to quantify impact[20,23] and can focus not only on what the models are but also on increasing knowledge around the process for the prioritization of different models, which will help create a way for leaders to match the right models to the right environments and populations. Important domain-specific models should also receive more attention, for example, in observation medicine, prehospital (EMS), and telemedicine.

### Research questions

**Question 1: What are the most effective models of PC in the ED and how does this vary across EDs?:** What elements do tested and refined models include, and how reliably are they being delivered? What are effective domain-specific and disease-specific models? What are the considerations that should be used to evaluate which models to implement at a given site? How is high-value care delivered in urban, rural, academic, community, and freestanding EDs? How can informatics be used to support model design and care delivery?

**Question 2: How should the different models of care delivery be prioritized?:** What specific forms of PC are perceived as *most* beneficial by patients, families, communities, and care organizations? What are the frameworks to help support prioritization and to evaluate the different impact of the different models? How can current models of care in EM (such as trauma-informed care) inform the development of care delivery models of ED PC? Who

should be providing PC in the ED setting? How should the interdisciplinary team be used to leverage impact? How should this be considered in the context of other ED care delivery?

**Question 3: What has the sustained impact been of efforts related to primary PC for EM teams and how do we scope and spread?:** What are the effects of these programs on important outcomes (see "Outcomes" section below)? Within these multipronged approaches, which aspects of them are the most effective to ensure sustained adoption?

**Question 4: How should the workforce be designed and what roles should different team members play?:** Specifically, what are the optimal roles for subspecialty trained EM PC clinicians, emergency physicians, PC physicians, EM advanced practice providers, nurses, social workers, case managers, spiritual caregivers, prehospital teams, and other interdisciplinary team members?

### Key research area: Disparities

**Considerations**—Disparities in PC access, delivery, and outcomes has not been widely explored and presents the greatest opportunity for foundational investigation through both qualitative and quantitative methods. This is the area that has had by far the least substantive work accomplished to date. Disparities to be explored include those that might exist based on race, ethnicity, religion, payer type, age, socio-economic status, gender identity, culture, language, physical and cognitive abilities, housing type, or ED location or resources. This body of work should focus not only on understanding the presence of disparities but also on how they differ between groups and what the regulatory landscape is that either protects or jeopardizes access, quality, and outcomes.

#### Research questions

**Question 1: Do disparities in ED PC delivery exist and, if so, what is the magnitude of the disparities with respect to access, care delivery, and patient experience?:** How are different groups affected differently? Do patients that seek care in Eds with different characteristics and resources have different outcomes? What is the role of the local environment, demographics, and community need in determining the disparities that are present once patients are in the ED?

**Question 2: Who is at highest risk of unrecognized PC needs in the emergency setting?:** Are there populations or clinical conditions that are overlooked, both currently in the ED and in the context of the new models of care delivery being proposed? What is the impact of having different types of access to subspecialty and/or primary PC available to underserved and at-risk populations? What is the impact of differential access to subspecialty trained ED providers and how does this differ across different communities?

**Question 3: What policies and protocols might be developed to improve ED PC for underserved communities?:** What local, regional, or national policies already exist, and how do they function to protect or jeopardize access, quality, and outcomes? What new policies and protocols could be used to increase access, increase quality, and improve

outcomes? What are effective programs for combating bias and increasing empathy related to unique patient needs?

### Key research area: Measurement of impact and efficacy

Throughout all of these focus areas, it is essential researchers carefully consider the outcomes and measures that they are using to appropriately evaluate impact and efficacy. In addition to the considerations outlined below, existing quality indicators need to be validated in the ED setting, and new indicators with specific relevance to EM PC can be developed and tested. When researchers are selecting outcomes, it will also be important that they are not only measured in the context of the ED encounter but aim to detect impact anywhere in the course of serious illness care. It will be important when developing these measures that that they are evaluated with an explicit goal of understanding how they may differ in different communities and based on different populations' preferences.

**Consideration 1: Selection of outcomes—**Understanding that an important focus for the next phase of research will be on evaluating the efficacy of intervention models on outcomes of interest to both EM and PC, it will be important for researchers to develop conceptual frameworks to support the clear association between intervention components and outcomes. This will help support future researchers in their ability to explicitly define outcomes that are clearly impacted by their interventions. Preliminary work will assist in understanding the performance of different measures from the EM or PC evidence base, and new outcomes may need to be developed. In addition to efficacy, process measures like balancing measures (impact on ED processes and costs) will also need to be studied. It will be necessary to develop outcomes that reflect both the longitudinal nature of serious illness and the reality of often brief ED encounters.

**Consideration 2: Measurement—**With defined outcomes, identifying how to measure these outcomes will be critical. It is likely that investigators will need to rely on a hybrid of adapted existing measures and new measures that they develop to assess the outcomes of relevance to this environment.

**Consideration 3: Accessibility of measures/outcomes in the ED—**Work focused on measurement of impact and efficacy will have to be cognizant of the challenge of collecting certain measures in the ED, especially patient-centered ones, and the need to assess use and usability.

**Potential outcomes and measures for use in EM PC research—**In Figure 2 we offer potential outcomes and measures that that may be used in future EM PC research. These are organized according to an ecological model (patient oriented, provider oriented, health system oriented, and community health oriented) and are meant to generate ideas and not be an exhaustive list. These should be applied in the content of the preceding considerations.

### Methodological considerations

As with all fields of research, methodological considerations represent unique challenges and call for special considerations related to the design and execution of the work. While little has been done to understand the issues specific to doing research at the intersection of EM and PC, there have been efforts made to elucidate the barriers related to conducting research in PC.

Further work is needed to understand the unique challenges in EM PC research and to ultimately create EQUATOR Network reporting guidelines that address these considerations. Until this is done, researchers working at this intersection should leverage the preexisting guidelines adapted for PC research. Among these, are guidelines that help guide the design and reporting of Delphi studies in PC,[89] direct the reporting of patient populations and service characteristics,[90,91] provide a taxonomy to help guide clinical trial recruitment,[92] and direct researchers to a list of best practices for evaluating services and treatments in end-of-life care.[93] Given the unique considerations raised by doing research related to EM PC, additional extensions to existing guidelines are also likely warranted. It will be important that researchers engage in thoughtful, transparent planning and systematic delivery of their interventions and ensure consistent reporting of results and that the longitudinal nature of serious illness is accounted for in their design.[94]

Additionally, there is also a need for leveraging innovative approaches to research that acknowledge the unique interdisciplinary and patient-centered nature of this work, such as experience based co-design.[95] These methods, which have been used infrequently in EM PC research,[63] will allow researchers access to methods that meaningfully engage patients, families, and frontline staff throughout the design and evaluation process.

## DISCUSSION

We present a research roadmap intended to help provide focus and priority for the EM PC research community. The result of this research will hopefully produce evidence that will demonstrate the value proposition of PM integration into EM practice. This value, if appropriately evaluated, will be articulated in the context of patient outcomes and experience, quality, and cost with an appropriateness amplifier accounting for the care being delivered at the right place, at the right time, and for the right patient population and context.

This work builds on the prior work of Quest et al.[10] over a decade ago. What our study demonstrates is that while some of the foundational work outlined in that original paper has been done, such as describing the population of patients with serious illness in the ED, much of it remains. This is especially true for work previously identified related to outcomes and effectiveness.

The output of this working group also demonstrates that new areas of focus, both in this content domain and in research more broadly, have emerged. Our research agenda highlights critical areas of focus related to intervention sustainability and disparities in care that were not previously identified.

This work on demonstrating impact will need to be paired with a clear understanding of exactly what PC in EM entails, which will allow health care systems to focus on the highest yield components and forgo those that are less effective. To do this, research will have to demonstrate the reproducibility and sustainably of models to deliver this care.

In addition to the areas of focus presented here, this work made clear the gaps in our evidence base connected to equity, and this in particular warrants close focus and inclusive research strategies. Some of these strategies[96,97] can be borrowed from other specialties who have partnered closely with communities to make inroads in understanding and addressing equity and structural racism.

Related to methods, this work highlights the need for future work focused on the unique aspects of PC research and the importance of how specific guidelines such as the EQUATOR reporting standards capture these elements. Currently there are 31 CONSORT extensions ranging from randomized controlled trials of artificial intelligence to cupping, herbal therapies, and acupuncture. The growing focus on the integration of PM and EM warrants a focus on the unique challenges of doing this work and the creation of guidelines that address these considerations. This exercise should be performed not only for randomized controlled trials but also for observational studies, diagnostic studies, prognostic studies, and systematic reviews. This will require funding and cooperation. Finally, these discussions demonstrated the collaborative care environment both of the ED and of PC practice and the need to leverage this multidisciplinary and community-focused work environment to build models that engage all clinicians and patients.

## LIMITATIONS

This work is limited in several ways. Most members of the core group are from academic and urban settings, and almost all have exclusively practiced in the United States. As the integration of PM and EM expands, research will need to focus on the needs of community hospitals and will need to take place in different geographic regions. Although many role groups were engaged in this process, including physicians, nurses, social workers, and community members, they were not all a part of the core working group and some groups that are critical to the delivery of PC (chaplains, case managers) were not included. Future work will need to ensure that these role groups are central to the design and execution of research efforts.

## CONCLUSIONS

With the rapid growth of interest and academic work focused on improving access for ED patients to palliative care concepts during their emergency encounter, it will be important that researchers are able to focus and prioritize their efforts. This research agenda outlines several areas of focus, and research questions, that when answered will aid in understanding the value imperative for increased integration of palliative medicine into the ED, ways to design these systems of care delivery, our understanding of where inequity exists and strategies for reducing disparities, and considerations related to measurement and study design.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## REFERENCES

1. Medicare spending at the end of life: a snapshot of beneficiaries who died in 2014 and the cost of their care. Kaiser Family Foundation. 2016. Accessed February 20, 2021. https://www.kff.org/medicare/issue-brief/medicare-spending-at-the-end-of-life/

2. Duncan I, Ahmed T, Dove H, Maxwell TL. Medicare cost at end of life. Am J Hosp Palliat Care. 2019;36(8):705–710. [PubMed: 30884954]

3. Smith AK, McCarthy E, Weber E, et al. Half of older Americans seen in emergency department in last month of life; most admitted to hospital, and many die there. Health Aff (Millwood). 2012;31(6):1277–1285. [PubMed: 22665840]

4. Teno JM, Gozalo PL, Bynum JP, et al. Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions in 2000, 2005, and 2009. JAMA. 2013;309(5):470–477. [PubMed: 23385273]

5. Wu FM, Newman JM, Lasher A, Brody AA. Effects of initiating palliative care consultation in the emergency department on inpatient length of stay. J Palliat Med. 2013;16(11):1362–1367. [PubMed: 23971709]

6. Grudzen CR, Richardson LD, Johnson PN, et al. Emergency department-initiated palliative care in advanced cancer: a randomized clinical trial. JAMA Oncol. 2016;2(5):591–598. [PubMed: 26768772]

7. Wang DH, Heidt R. Emergency department admission triggers for palliative consultation may decrease length of stay and costs. J Palliat Med. 2021;24(4):554–560. [PubMed: 32897797]

8. Carpenter CR, Bromley M, Caterino JM, et al. Optimal older adult emergency care: introducing multidisciplinary geriatric emergency department guidelines from the American College of Emergency Physicians, American Geriatrics Society, Emergency Nurses Association, and Society for Academic Emergency Medicine. J Am Geriatr Soc. 2014;62(7):1360–1363. [PubMed: 24890806]

9. ACEP - Delaying Palliative Care and Hospice Care Services in the Emergency Department. 2013. Accessed July 28, 2020. https://www.choosingwisely.org/clinician-lists/american-college-emergency-physicians-delaying-palliative-and-hospice-care-services-in-emergency-department/

10. Quest TE, Asplin BR, Cairns CB, Hwang U, Pines JM. Research priorities for palliative and end-of-life care in the emergency setting. Acad Emerg Med. 2011;18(6):e70–e76. [PubMed: 21676052]

11. Estimates of funding for various research, condition, and disease categories (RCDC). NIH RePORT: Research Portfolio Online Reporting Tools. NIH (National Institute of Health); 2021. Accessed August 9, 2021. https://report.nih.gov/funding/categorical-spending#/

12. Lee J, Abrukin L, Flores S, et al. Early intervention of palliative care in the emergency department during the COVID-19 pandemic. JAMA Intern Med. 2020;180(9):1252–1254. [PubMed: 32501486]

13. Stoltenberg M, Jacobsen J, Wilson E, et al. Emergency department-based palliative care during COVID. J Palliat Med. 2020;23(9):1151–1152. [PubMed: 32579868]

14. Lai L, Sato R, He S, et al. Usage patterns of a web-based palliative care content platform (PalliCOVID) during the COVID-19 pandemic. J Pain Symptom Manage. 2020;60(4):e20–e27. [PubMed: 32730951]

15. Aaronson EL, Daubman BR, Petrillo L, et al. Emerging palliative care innovations in the ED: a qualitative analysis of programmatic elements during the COVID-19 pandemic. J Pain Symptom Manage. 2021;62(1):117–124. [PubMed: 33161031]

16. George NR, Kryworuchko J, Hunold KM, et al. Shared decision making to support the provision of palliative and end-of-life care in the emergency department: a consensus statement and research agenda. Acad Emerg Med. 2016;23(12):1394–1402. [PubMed: 27611892]

17. Carpenter CR, Heard K, Wilber S, et al. Research priorities for high-quality geriatric emergency care: medication management, screening, and prevention and functional assessment. Acad Emerg Med. 2011;18(6):644–654. [PubMed: 21676064]

18. Brown J, Grudzen C, Kyriacou DN, et al. . The emergency care of patients with cancer: setting the research agenda. Ann Emerg Med. 2016;68(6):706–711. [PubMed: 26921969]

19. Wilson JG, English DP, Owyang CG, et al. End-of-life care, palliative care consultation, and palliative care referral in the emergency department: a systematic review. J Pain Symptom Manage. 2020;59(2):372–383.e1. [PubMed: 31586580]

20. da Silva SD, Nunes CM, Gomes B. Effectiveness of emergency department based palliative care for adults with advanced disease: a systematic review. J Palliat Med. 2016;19(6):601–609. [PubMed: 27115914]

21. Cooper E, Hutchinson A, Sheikh Z, Taylor P, Townend W, Johnson MJ. Palliative care in the emergency department: a systematic literature qualitative review and thematic synthesis. Palliat Med 2018;32(9):1443–1454. [PubMed: 30028242]

22. George N, Phillips E, Zaurova M, Song C, Lamba S, Grudzen C. Palliative care screening and assessment in the emergency department: a systematic review. J Pain Symptom Manage. 2016;51(1):108–119.e2. [PubMed: 26335763]

23. Kirkland SW, Ghalab A, Kruhlak M, et al. An assessment of emergency department-based interventions for patients with advanced or end-stage illness: a systematic review. J Palliat Med. 2021;24(4):605–618. [PubMed: 33555970]

24. Wong J, Gott M, Frey R, Jull A. What is the incidence of patients with palliative care needs presenting to the emergency department? a critical review. Palliat Med. 2014;28(10):1197–1205. [PubMed: 25118197]

25. Lawrenson R, Waetford J, Gibbons V, Kirk P, Haggar S, Reddy R. Palliative care patients' use of emergency departments. N Z Med J. 2013;126(1372):80–88.

26. Wallace EM, Cooney MC, Walsh J, Conroy M, Twomey F. Why do palliative care patients present to the emergency department? Avoidable or unavoidable? Am J Hosp Palliat Care. 2013;30(3):253–256. [PubMed: 22628898]

27. Oulton J, Rhodes SM, Howe C, Fain MJ, Mohler MJ. Advance directives for older adults in the emergency department: a systematic review. J Palliat Med. 2015;18(6):500–505. [PubMed: 25763860]

28. Rosenwax LK, McNamara BA, Murray K, McCabe RJ, Aoun SM, Currow DC. Hospital and emergency department use in the last year of life: a baseline for future modifications to end-of-life care. Med J Aust. 2011;194(11):570–573. [PubMed: 21644868]

29. Lee YH, Chu D, Yang NP, et al. Emergency visits among end-of-life cancer patients in Taiwan: a nationwide population-based study. BMC Palliat Care. 2015;14:25. [PubMed: 25956135]

30. Ouchi K, Wu M, Medairos R, et al. Initiating palliative care consults for advanced dementia patients in the emergency department. J Palliat Med. 2014;17(3):346–350. [PubMed: 24387752]

31. Grudzen CR, Richardson LD, Morrison M, Cho E, Morrison RS. Palliative care needs of seriously ill, older adults presenting to the emergency department. Acad Emerg Med. 2010;17(11):1253–1257. [PubMed: 21175525]

32. Beynon T, Gomes B, Murtagh FE, et al. How common are palliative care needs among older people who die in the emergency department? Emerg Med J. 2011;28(6):491–495. [PubMed: 20943837]

33. Mayer DK, Travers D, Wyss A, Leak A, Waller A. Why do patients with cancer visit emergency departments? Results of a 2008 population study in North Carolina. J Clin Oncol. 2011;29(19):2683–2688. [PubMed: 21606431]

34. Leak A, Mayer DK, Wyss A, Travers D, Waller A. Why do cancer patients die in the emergency department?: an analysis of 283 deaths in NC EDs. Am J Hosp Palliat Care. 2013;30(2):178–182. [PubMed: 22556288]

35. Grudzen CR, Hwang U, Cohen JA, Fischman M, Morrison RS. Characteristics of emergency department patients who receive a palliative care consultation. J Palliat Med. 2012;15(4):396–399. [PubMed: 22468771]

36. Green E, Ward S, Brierley W, Riley B, Sattar H, Harris T. "They shouldn't be coming to the ED, should they?": a descriptive service evaluation of why patients with palliative care needs present to the emergency department. Am J Hosp Palliat Care. 2017;34(10):984–990. [PubMed: 27903774]

37. Green E, Shaw SE, Harris T. "They shouldn't be coming to the ED, should they?" A qualitative study of why patients with palliative care needs present to the emergency department. BMJ Support Palliat Care. 2019;9(4):e29.

38. Köstenberger M, Neuwersch S, Weixler D, Pipam W, Zink M, Likar R. Prevalence of palliative care patients in emergency departments. Wien Klin Wochenschr. 2019;131(17–18):404–409. [PubMed: 31375918]

39. Verhoef MJ, de Nijs E, Horeweg N, et al. Palliative care needs of advanced cancer patients in the emergency department at the end of life: an observational cohort study. Support Care Cancer. 2020;28(3):1097–1107. [PubMed: 31197539]

40. Argintaru N, Quinn KL, Chartier LB, et al. Perceived barriers and facilitators to goals of care discussions in the emergency department: a descriptive analysis of the views of emergency medicine physicians and residents. CJEM. 2019;21(2):211–218. [PubMed: 29737962]

41. Goepp JG, Meykler S, Mooney NE, Lyon C, Raso R, Julliard K. Provider insights about palliative care barriers and facilitators: results of a rapid ethnographic assessment. Am J Hosp Palliat Care. 2008;25(4):309–3 14. [PubMed: 18550780]

42. Lamba S, Nagurka R, Zielinski A, Scott SR. Palliative care provision in the emergency department: barriers reported by emergency physicians. J Palliat Med. 2013;16(2):143–147. [PubMed: 23305188]

43. Grudzen CR, Richardson LD, Major-Monfried H, Kandarian B, Ortiz JM, Morrison RS. Hospital administrators' views on barriers and opportunities to delivering palliative care in the emergency department. Ann Emerg Med. 2013;61(6):654–660. [PubMed: 22771203]

44. Stone SC, Mohanty S, Grudzen CR, et al. Emergency medicine physicians' perspectives of providing palliative care in an emergency department. J Palliat Med. 2011;14(12):1333–1338. [PubMed: 22136262]

45. McCallum KJ, Jackson D, Walthall H, Aveyard H. Exploring the quality of the dying and death experience in the emergency department: an integrative literature review. Int J Nurs Stud. 2018;85:106–117. [PubMed: 29885547]

46. Kongsuwan W, Matchim Y, Nilmanat K, Locsin RC, Tanioka T, Yasuhara Y. Lived experience of caring for dying patients in emergency room. Int Nurs Rev. 2016;63(1):132–138. [PubMed: 26748741]

47. Smith AK, Fisher J, Schonberg MA, et al. Am I doing the right thing? Provider perspectives on improving palliative care in the emergency department. Ann Emerg Med. 2009;54(1):86–93.e1. [PubMed: 18930337]

48. Aaronson EL, Petrillo L, Stoltenberg M, et al. The experience of emergency department providers with embedded palliative care during COVID. J Pain Symptom Manage. 2020;60(5):e35–e43. [PubMed: 32882358]

49. Haydar SA, Almeder L, Michalakes L, Han PK, Strout TD. Using the surprise question to identify those with unmet palliative care needs in emergency and inpatient settings: what do clinicians think? J Palliat Med. 2017;20(7):729–735. [PubMed: 28437203]

50. Wright RJ, Lowton K, Robert G, Grudzen CR, Grocott P. Emergency department staff priorities for improving palliative care provision for older people: a qualitative study. Palliat Med. 2018;32(2):417–425. [PubMed: 28429643]

51. Di Leo S, Alquati S, Autelitano C, et al. Palliative care in the emergency department as seen by providers and users: a qualitative study. Scand J Trauma Resusc Emerg Med. 2019;27(1):88. [PubMed: 31533807]

52. Marck CH, Weil J, Lane H, et al. Care of the dying cancer patient in the emergency department: findings from a national survey of Australian emergency department clinicians. Intern Med J. 2014;44(4):362–368. [PubMed: 24528993]

53. Rosenberg M, Lamba S, Misra S. Palliative medicine and geriatric emergency care: challenges, opportunities, and basic principles. Clin Geriatr Med. 2013;29(1):1–29. [PubMed: 23177598]

54. Kompanje EJ. The worst is yet to come. Many elderly patients with chronic terminal illnesses will eventually die in the emergency department. Intensive Care Med. 2010;36(5):732–734. [PubMed: 20229043]

55. Ouchi K, George N, Schuur JD, et al. Goals-of-care conversations for older adults with serious illness in the emergency department: challenges and opportunities. Ann Emerg Med. 2019;74(2):276–284. [PubMed: 30770207]

56. George N, Bowman J, Aaronson E, Ouchi K. Past, present, and future of palliative care in emergency medicine in the USA. Acute Med Surg. 2020;7(1):e497. [PubMed: 32395248]

57. McNamara R. Emergency palliative care. Emerg Med J. 2020;37(5):260–261. [PubMed: 32201377]

58. Wang DH. Beyond code status: palliative care begins in the emergency department. Ann Emerg Med. 2017;69(4):437–443. [PubMed: 28131488]

59. Hughes J. Palliative care in emergency medicine: a perennial skill with a new emphasis. CJEM. 2019;21(2):163–164. [PubMed: 30892176]

60. Lamba S, Quest TE. Hospice care and the emergency department: rules, regulations, and referrals. Ann Emerg Med. 2011;57(3):282–290. [PubMed: 21035900]

61. Grudzen CR, Stone SC, Morrison RS. The palliative care model for emergency department patients with advanced illness. J Palliat Med. 2011;14(8):945–950. [PubMed: 21767164]

62. Lamba S, Mosenthal AC. Hospice and palliative medicine: a novel subspecialty of emergency medicine. J Emerg Med. 2012;43(5):849–853. [PubMed: 20580876]

63. Shoenberger J, Lamba S, Goett R, et al. Development of hospice and palliative medicine knowledge and skills for emergency medicine residents: using the Accreditation Council for Graduate Medical Education Milestone Framework. AEM Educ Train. 2018;2(2):130–145. [PubMed: 30051080]

64. Blackwell RW, Lowton K, Robert G, Grudzen C, Grocott P. Using experience-based co-design with older patients, their families and staff to improve palliative care experiences in the emergency department: a reflective critique on the process and outcomes. Int J Nurs Stud. 2017;68:83–94. [PubMed: 28095347]

65. Kistler EA, Sean Morrison R, Richardson LD, Ortiz JM, Grudzen CR. Emergency department-triggered palliative care in advanced cancer: proof of concept. Acad Emerg Med. 2015;22(2):237–239. [PubMed: 25639187]

66. Mahony SO, Blank A, Simpson J, et al. Preliminary report of a palliative care and case management project in an emergency department for chronically ill elderly patients. J Urban Health. 2008;85(3):443–451. [PubMed: 18363108]

67. Ting SM, Li P, Lau FL, et al. Acute bereavement care in the emergency department: does the professional-supported volunteers model work? Eur J Emerg Med. 1999;6(3):237–243. [PubMed: 10622390]

68. Rosenberg M, Rosenberg L. Integrated model of palliative care in the emergency department. West J Emerg Med. 2013;14(6):633–636. [PubMed: 24381685]

69. Carron PN, Dami F, Diawara F, Hurst S, Hugli O. Palliative care and prehospital emergency medicine: analysis of a case series. Medicine (Baltimore). 2014;93(25):e128. [PubMed: 25437023]

70. Weng TC, Yang YC, Chen PJ, et al. Implementing a novel model for hospice and palliative care in the emergency department: an experience from a tertiary medical center in Taiwan. Medicine (Baltimore). 2017;96(19):e6943. [PubMed: 28489813]

71. Gisondi MA, Lu DW, Yen M, et al. Adaptation of EPEC-EM curriculum in a residency with asynchronous learning. West J Emerg Med. 2010;11(5):491–499. [PubMed: 21293772]

72. Lamba S, DeSandre PL, Todd KH, et al. Integration of palliative care into emergency medicine: the Improving Palliative Care in Emergency Medicine (IPAL-EM) collaboration. J Emerg Med. 2014;46(2):264–270. [PubMed: 24286714]

73. Shoenberger JM, Yeghiazarian S, Rios C, Henderson SO. Death notification in the emergency department: survivors and physicians. West J Emerg Med. 2013;14(2):181–185. [PubMed: 23599867]

74. Lamba S, Pound A, Rella JG, Compton S. Emergency medicine resident education in palliative care: a needs assessment. J Palliat Med. 2012;15(5):516–520. [PubMed: 22577784]

75. Goldonowicz JM, Runyon MS, Bullard MJ. Palliative care in the emergency department: an educational investigation and intervention. BMC Palliat Care. 2018;17(1):43. [PubMed: 29514625]

76. Glajchen M, Lawson R, Homel P, Desandre P, Todd KH. A rapid two-stage screening protocol for palliative care in the emergency department: a quality improvement initiative. J Pain Symptom Manage. 2011;42(5):657–662. [PubMed: 22045368]

77. Leiter RE, Yusufov M, Hasdianda MA, et al. Fidelity and feasibility of a brief emergency department intervention to empower adults with serious illness to initiate advance care planning conversations. J Pain Symptom Manage. 2018;56(6):878–885. [PubMed: 30223014]

78. Ouchi K, Knabben V, Rivera-Reyes L, et al. Preparing older adults with serious illness to formulate their goals for medical care in the emergency department. J Palliat Med. 2017;20(4):404–408. [PubMed: 27797638]

79. Ouchi K, Block SD, Schonberg MA, et al. Feasibility testing of an emergency department screening tool to identify older adults appropriate for palliative care consultation. J Palliat Med. 2017;20(1):69–73. [PubMed: 27632230]

80. George N, Barrett N, McPeake L, Goett R, Anderson K, Baird J. Content validation of a novel screening tool to identify emergency department patients with significant palliative care needs. Acad Emerg Med. 2015;22(7):823–837. [PubMed: 26171710]

81. Kistler EA, Stevens E, Scott E, Philpotts LL, Greer JA, Greenwald JL. Triggered palliative care consults: a systematic review of interventions for hospitalized and emergency department patients. J Pain Symptom Manage. 2020;60(2):460–475. [PubMed: 32061721]

82. Smith AK, Schonberg MA, Fisher J, et al. Emergency department experiences of acutely symptomatic patients with terminal illness and their family caregivers. J Pain Symptom Manage. 2010;39(6):972–981. [PubMed: 20434873]

83. Parris RJ, Schlosenberg J, Stanley C, Maurice S, Clarke SF. Emergency department follow-up of bereaved relatives: an audit of one particular service. Emerg Med J. 2007;24(5):339–342. [PubMed: 17452701]

84. Wright R, Lowton K, Hansen BR, Grocott P. Older adult and family caregiver preferences for emergency department based-palliative care: an experience-based co-design study. Int J Nurs Sties Advances. 2021;3:100016.

85. Wright R, Hayward B, Kistler E, Vaughan Dickson V, Grudzen C. That was a game changer: clinical impact of an emergency department-based palliative care communication skills training workshop. Emerg Med J. 2020;37(5):262–264. [PubMed: 31350282]

86. Lamba S, DeSandre PL, Quest TE. Opportunities and challenges facing the integrated physician workforce of emergency medicine and hospice and palliative medicine. J Emerg Med. 2016;51(6):658–667. [PubMed: 27613448]

87. Fusi-Schmidhauser T, Preston NJ, Keller N, Gamondi C. Conservative management of COVID-19 patients--emergency palliative care in action. J Pain Symptom Manage. 2020;60(1):e27–e30.

88. Chidiac C, Feuer D, Naismith J, Flatley M, Preston N. Emergency palliative care planning and support in a COVID-19 pandemic. J Palliat Med. 2020;23(6):752–753. [PubMed: 32311287]

89. Jünger S, Payne SA, Brine J, Radbruch L, Brearley SG. Guidance on Conducting and REporting DElphi Studies (CREDES) in palliative care: recommendations based on a methodological systematic review. Palliat Med. 2017;31(8):684–706. [PubMed: 28190381]

90. Currow DC, Wheeler JL, Glare PA, Kaasa S, Abernethy AP. A framework for generalizability in palliative care. J Pain Symptom Manage. 2009;37(3):373–386. [PubMed: 18809276]

91. Currow DC, Tieman JJ, Greene A, Zafar SY, Wheeler JL, Abernethy AP. Refining a checklist for reporting patient populations and service characteristics in hospice and palliative care research. J Pain Symptom Manage. 2012;43(5):902–910. [PubMed: 22445274]

92. Hagen NA, Wu JS, Stiles CR. A proposed taxonomy of terms to guide the clinical trial recruitment process. J Pain Symptom Manage. 2010;40(1):102–110. [PubMed: 20488653]

93. Higginson IJ, Evans CJ, Grande G, et al. Evaluating complex interventions in end of life care: the MORECare statement on good practice generated by a synthesis of transparent expert consultations and systematic reviews. BMC Med. 2013;11:111. [PubMed: 23618406]

94. Neta G, Glasgow RE, Carpenter CR, et al. A framework for enhancing the value of research for dissemination and implementation. Am J Public Health. 2015;105(1):49–57. [PubMed: 25393182]

95. Borgstrom E, Barclay S. Experience-based design, co-design and experience-based co-design in palliative and end-of-life care. BMJ Support Palliat Care. 2019;9(1):60–66.

96. Brown Speights JS, Nowakowski AC, De Leon J, Mitchell MM, Simpson I. Engaging African American women in research: an approach to eliminate health disparities in the African American community. Fam Pract. 2017;34(3):322–329. [PubMed: 28387794]

97. Brockie T, Azar K, Wallen G, O'Hanlon Solis M, Adams K, Kub J. A conceptual model for establishing collaborative partnerships between universities and Native American communities. Nurse Res. 2019;27(1):27–32.
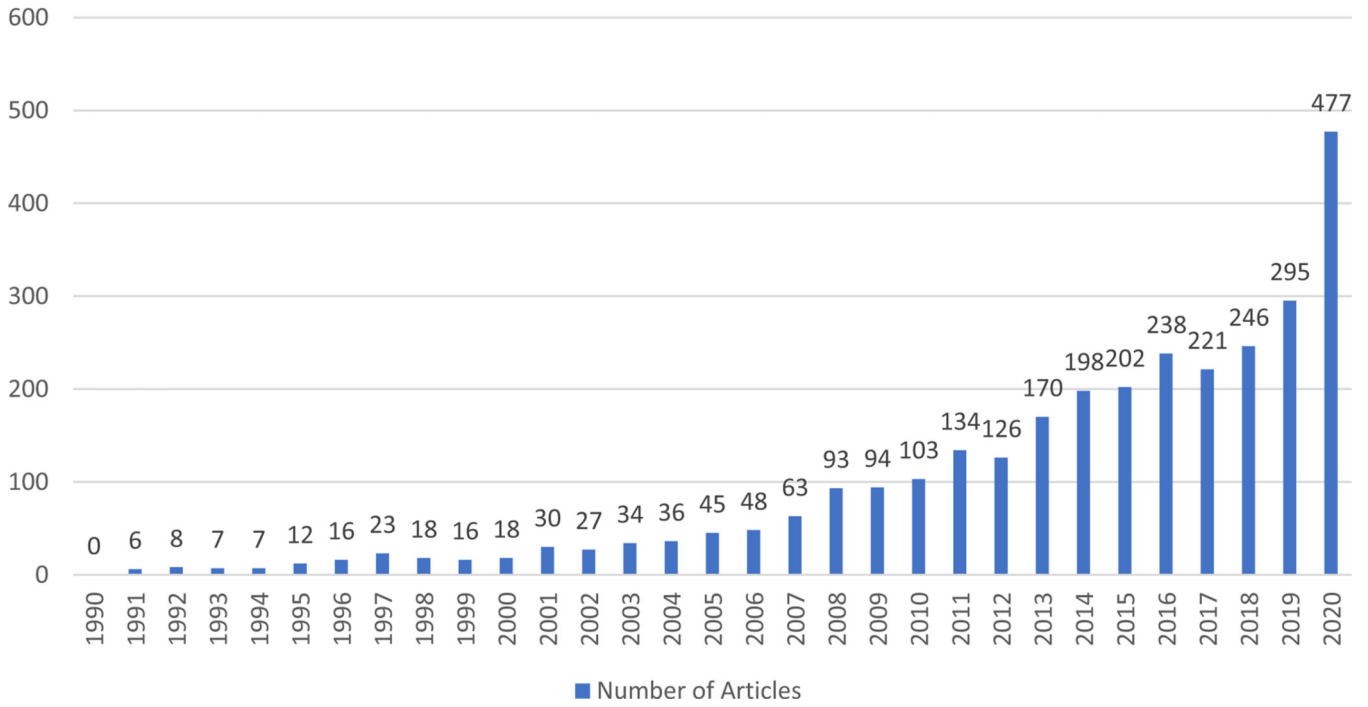
## Publications in Emergency Medicine Palliative Care



**FIGURE 1.**

Results of a search run by a medical librarian in Ovid Medline, Embase.com, and CINAHL in July 2021 to find the quantity of publications per year on the topic of palliative or hospice care in the ED. Conference abstracts were excluded. Search terms were restricted to the title and subject heading fields. The full search is provided in the supplement.
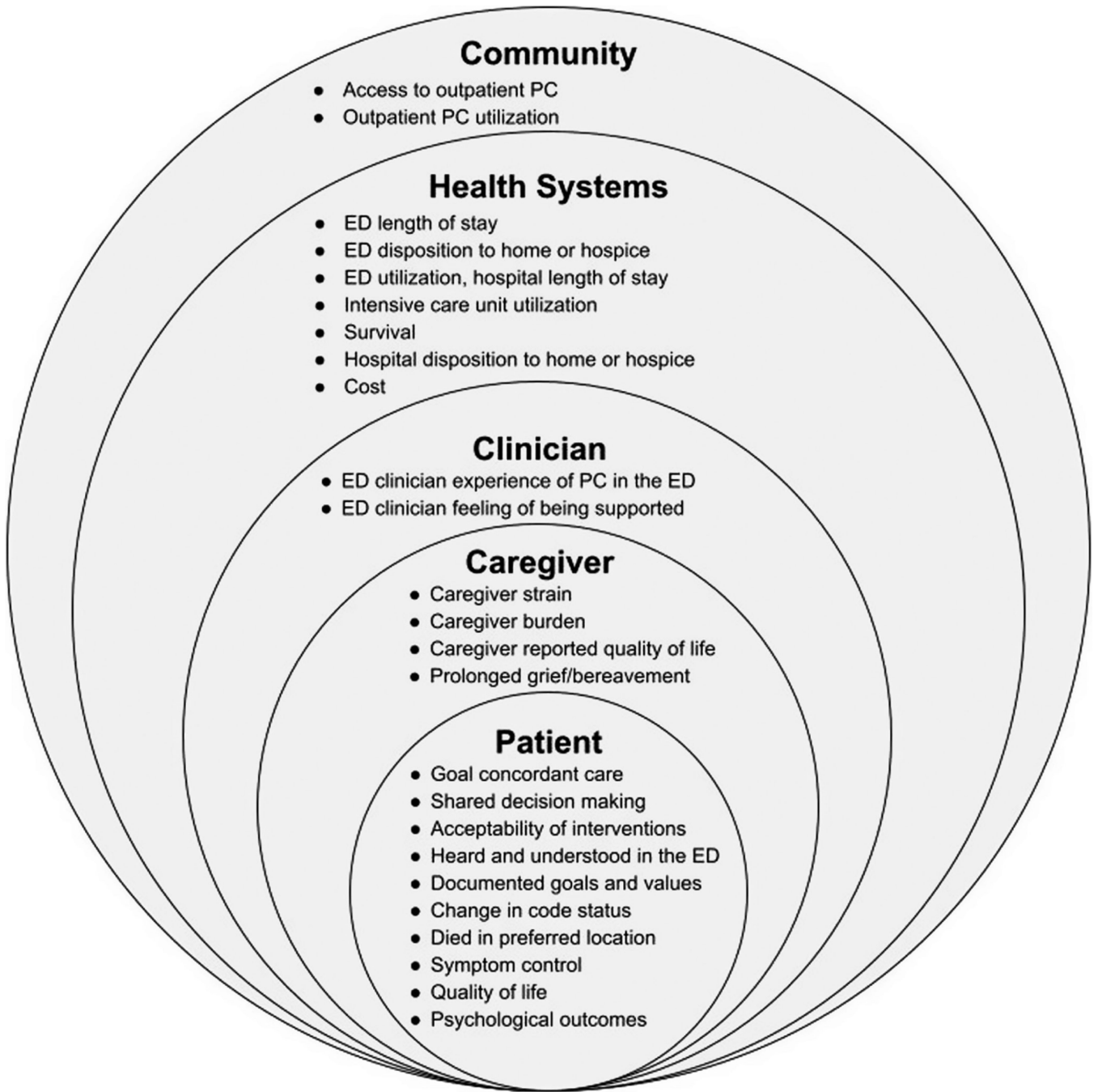
**FIGURE 2.**

Outcomes and measures are organized using the social ecological model and idea-generating, not an exhaustive list. PC, palliative care.

**TABLE 1**

Methods for developing the research roadmap

| Process step | Mechanism |
|---|---|
| Identify core group and missing representation; workshop and finalize methods | Core group Meeting 1 |
| Review and synthesize the research to date | Work group 1 |
| Identify current gaps in the literature | Work group 1 |
| Present research to date and current gaps; brainstorm future themes | Core Group Meeting 2 |
| Brainstorm key questions for future research in each thematic domain | Work group 2–5 |
| Present key questions for future research in each thematic domain; Identify key questions for future research in each thematic domain | Core Group Meeting 3 |
| Present draft questions to participants outside of core group for input | Video calls with external stakeholders |
| Identify methodological considerations for future research based on thematic domains | Work group 6 |
| Present draft research agenda to participants outside of core group for input | Video calls with external stakeholders |
| Present findings and final ratification | SAEM Annual Meeting and subsequent SAEM Palliative Medicine Interest Group meeting |