



Published in final edited form as:

*Acad Emerg Med.* 2016 December ; 23(12): 1394–1402. doi:10.1111/acem.13083.

## Shared Decision Making to Support the Provision of Palliative and End-of-Life Care in the Emergency Department: A Consensus Statement and Research Agenda

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### Abstract

**Background:** Little is known about the optimal use of shared decision making (SDM) to guide palliative and end-of-life decisions in the emergency department (ED).

**Objective:** The objective was to convene a working group to develop a set of research questions that, when answered, will substantially advance the ability of clinicians to use SDM to guide palliative and end-of-life care decisions in the ED.

**Methods:** Participants were identified based on expertise in emergency, palliative, or geriatrics care; policy or patient-advocacy; and spanned physician, nursing, social work, legal, and patient perspectives. Input from the group was elicited using a time-staggered Delphi process including three teleconferences, an open platform for asynchronous input, and an in-person meeting to obtain a final round of input from all members and to identify and resolve or describe areas of disagreement.

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The authors have no relevant financial information or potential conflicts to disclose.

**Conclusion:** Key research questions identified by the group related to which ED patients are likely to benefit from palliative care (PC), what interventions can most effectively promote PC in the ED, what outcomes are most appropriate to assess the impact of these interventions, what is the potential for initiating advance care planning in the ED to help patients define long-term goals of care, and what policies influence palliative and end-of-life care decision making in the ED. Answers to these questions have the potential to substantially improve the quality of care for ED patients with advanced illness.

There is a crisis in end-of-life care for older adults in the United States. Too often, patients receive care that is unwanted and that causes suffering without providing meaningful improvements in the duration or quality of life.<sup>1</sup> This crisis is the product of many forces including a fragmented healthcare system, perverse financial incentives, and a lack of physician training and resources to support end-of-life care. Palliative care (PC) is specialized care for people with a serious illness, often but not always at the end of life, which focuses on relief of symptoms.<sup>2,3</sup> PC has been shown to improve patient quality of life,<sup>4,5</sup> relieve pain and dyspnea,<sup>6,7</sup> reduce inpatient length of stay,<sup>6</sup> and reduce healthcare costs.<sup>6,8-10</sup> Because of these benefits, expanding access to and promoting the use of PC services are major public health priorities.<sup>11</sup> Recognition of these benefits has led to a substantial increase in the number of hospitalized patients in the United States seen by a PC service.<sup>12</sup> These advances have largely been accomplished through coordination between PC specialists and clinical leaders in internal medicine,<sup>13-16</sup> surgery,<sup>17,18</sup> and critical care medicine.<sup>19</sup>

Over the past decade, the emergency department (ED) has been recognized as an essential environment for initiating PC. In the United States, EDs are a common site of care for those with advanced illness, particularly older adults. Many of these patients present with poorly controlled symptoms from a chronic illness. Decisions made while in the ED often have a profound impact on the trajectory of subsequent treatments.<sup>20</sup> Thus, the ED is a critical setting for reviewing care goals and determining the need for PC.<sup>21,22</sup>

Initial research on palliative and end-of-life care in the ED has been promising. The initiation of PC in the ED has been shown to decrease inpatient length-of-stay,<sup>6,23</sup> increase quality of life,<sup>4,5</sup> and increase patient and family satisfaction.<sup>4</sup> ED initiation of PC is helpful in part because patients who receive PC consultation in the ED have a higher rate of PC consultation during hospital admission and a shorter time to PC consult compared to traditional ED care.<sup>24</sup> Use of PC services in the first 48 hours of admission is associated with shorter hospital length of stay, reduction in the total cost of hospitalization, and decreased in-hospital mortality.<sup>7,8</sup> Despite the advantages of initiating PC in the ED and ongoing educational and clinical efforts to improve integration of PC services,<sup>25-28</sup> emergency physicians are responsible for only 3% of PC referrals and only 5% of EDs have a plan for providing PC.<sup>12</sup>

Several barriers to dissemination of PC in the ED have been identified. Emergency providers report discomfort in discussing palliative and end-of-life treatment because of insufficient training in end-of-life communication skills, absence of prior provider-patient relationships, and uncertain knowledge about prognosis.<sup>29,30</sup> Another common barrier is the lack of

availability of PC specialists and services.<sup>31</sup> Finally, incomplete or inaccessible medical records can present a significant barrier to ED providers' understanding of patient treatment preferences. A recent study found that although about half of patients aged 65 years and older reported having a health care proxy and 40% reported having a living will, subsequent review of their electronic medical record confirmed documentation of this only 4% of the time.<sup>32</sup>

Shared decision making (SDM) provides a means of making decisions that supports the patient's right to be involved in his or her healthcare. PC in a healthcare system that respects patient autonomy requires patient choice; SDM allows that choice to be informed by relevant information about prognosis and the likely clinical course of various treatment options. While multiple specialties have embraced the use of SDM to support PC, uptake in EDs has not been as swift. Of 38 studies examining SDM tools in advanced illness, none focused on emergency providers or ED patients.<sup>35</sup> Incorporating SDM in the ED for other types of decisions has been shown to improve patient pain outcomes,<sup>36</sup> improve patient satisfaction,<sup>36,37</sup> decrease decisional conflict,<sup>38</sup> and increase satisfaction with the decision-making process.<sup>39</sup> Surveys of practicing emergency physicians indicate that SDM is widely accepted and already used across a broad range of other clinical decisions.<sup>40,41</sup>

When considering which patients are most likely to benefit from palliative and end-of-life approaches in the ED, two distinct types of encounters predominate. One scenario is the patient who presents with a near-terminal or terminal event such as acute stroke, massive coronary event, or major trauma. In these cases, the utility of SDM about PC engagement will depend largely on the prognosis, the ability of the patient to communicate goals of care or access to a surrogate decision-maker, and the rapidity with which PC services can be provided. For these patients, research should focus on how to guide emergency providers in appropriate and effective conversations about the provision of end-of-life care. A second, more common scenario is a patient who has been living with advanced illness for many months or years, while suffering from a fluctuating symptom burden and unmet PC needs. For this patient, SDM about PC engagement may serve to address both acute symptoms as well as long-term goals of care. There may also be a role for discussing or at least initiating advance care planning (ACP) in the ED with these patients to help the patient define their long-term goals, plan for death, and avoid unwanted medical care.

Recognizing these two different scenarios and the tremendous need for and potential to use emergency care to improve the quality of end-of-life care, the 2016 Society for Academic Emergency Medicine Consensus Conference working group on SDM for PC was convened to identify the priority research questions regarding SDM for PC in the ED. Research that answers these critical questions will improve the effectiveness of and broaden the availability of PC among the large, growing, and vulnerable population of patients with end-of-life care needs receiving ED care.

## METHODS

A group of experts was convened to prioritize a research agenda for SDM related to palliative and end-of-life care in the ED. The group coauthors sought membership from a

diverse group of people familiar with ED and/or PC services or who had expertise in SDM research or in public policy and legislation regarding end-of-life issues. Contributions from group members were elicited using a time-staggered Delphi process that combined input obtained from three teleconferences, an open platform for asynchronous input, and an in-person meeting to identify and resolve or describe areas of disagreement. Ideas described during the three teleconferences were recorded by the coleaders and used to generate an outline. Asynchronous contributions to the project were facilitated through access to the outline via a Google doc. Once the group had defined five overarching research questions to guide the work, subgroups were formed to identify and summarize the available literature and define important, unanswered questions. A manuscript draft and a summary of the main findings were presented at the SAEM Consensus Conference on SDM and a final round of feedback was obtained. This article reports the final evidence summary and prioritized research agenda.

## RESULTS

Key research questions are listed in Table 1. Below we provide background information and an expanded research agenda for each of these key questions.

### **Research Question 1: Which ED patients are likely to benefit from SDM conversations regarding the provision of PC and how can these patients be rapidly identified?**

The first step in initiating conversations regarding palliative and end-of-life care is to identify which ED patients are likely to benefit.<sup>42,43</sup> Indiscriminate application of SDM conversations about end-of-life care would cause undue burden on both physicians and patients in an already time-constrained environment. Certainly, all patients deserve pain and symptom management as part of their ED care; however, in select patients, symptom relief itself, rather than life-prolonging measures, should be the primary focus of the ED encounter. Published descriptions of efforts to identify ED patients likely to benefit from PC have focused on provider-administered screening tools for PC needs.<sup>44</sup> However, barriers remain to large-scale implementation of screening for and early initiation of PC in the ED. Patients or providers may prefer a more private or less hectic space than is readily available, and they may wish for the presence of key family members or caregivers that are not present. Emergency providers also need to avoid pressuring patients to make decision under the duress of acute symptoms. Screening tools for PC are only useful if resources required to provide PC are available. An expanded research agenda for issues related to the identification of ED patients likely to benefit from PC is presented in Table 2.

### **Research Question 2: What are the most effective interventions to promote SDM regarding palliative and end-of-life care in the ED?**

To date, interventions to increase the initiation and utilization of PC in the ED have primarily focused on linking ED patients to PC services and increasing training and education about PC services among ED providers. In several small projects, education of emergency physicians and healthcare providers about PC has been associated with increased use of PC/hospice referrals, decreased inpatient length of stay, and increased physician-reported comfort managing end-of-life symptoms and discussing end-of-life issues.<sup>23,40,45</sup>

Educational programs have also been used to shift the major source of PC unit referrals from inpatient consults to ED and outpatient providers.<sup>31</sup> Additionally, a PC pathway<sup>23</sup> and a PC trigger tool<sup>45</sup> have been used to increase PC engagement in the ED. These projects each demonstrate impressive gains in ED-specific PC integration; however, the explicit use of SDM to promote PC in the ED has not yet been examined closely and integration of PC into ED care has not been widespread.

SDM in palliative and end-of-life care conversations has been implemented successfully with improved outcomes in non-ED settings.<sup>35</sup> Written educational material and educational videos have both shown benefit to patients needing PC.<sup>46–51</sup> Many other specialties have successfully integrated PC into their practice and education models, often utilizing the expertise of interdisciplinary teams,<sup>46</sup> and these experiences can help guide PC integration in the ED.<sup>17–19,52</sup> Barriers to using SDM to promote PC in the ED include differences in expectations between the ED and PC providers,<sup>31</sup> lack of emergency physician training,<sup>53–55</sup> systems-based logistic challenges,<sup>52,56</sup> policy barriers,<sup>53</sup> lack of 24-hour PC availability, limitations in patient decision-making capacity and health literacy,<sup>57</sup> and lack of access to comprehensive clinical information.<sup>55</sup> In general, large-volume EDs and those based in academic hospitals have more PC resources than small EDs and those not affiliated with an academic center. These smaller EDs may have to adopt significantly different approaches to use SDM to promote PC. Essential research questions related to the development and testing of SDM methods to promote PC in the ED are listed in Table 3.

### **Research Question 3: What are the optimal outcome measures to use in studies examining the provision of palliative and end-of-life care in the ED?**

At present, the inconsistent use of outcomes limits the ability to compare efficacy between interventions to promote PC. Because no single outcome can determine whether conversations about and the provision of resources to support end-of-life care are helpful, it will always be necessary to measure a spectrum of outcomes. Domains to assess the impact of SDM to support PC include patient-, family-, provider-, and system-level outcomes and will include both objective and subjective measures.

Objective measures of SDM and PC include (but are not limited to) penetration of ACP documents among ED patients; availability of ACP documents among ED patients; adherence of treatment with previously recorded wishes in ACP documents; and healthcare utilization metrics, such as frequency of PC consultation, rate of ED recidivism, cost of encounters, and mortality. Provision of palliative therapies (e.g., morphine for dyspnea, spiritual care, and family meetings) versus life-sustaining or disease management treatment for patients with advanced illness in the ED may also be important to measure. Objective measures cannot fully capture the value of PC interventions. Subjective measures used to assess the value of PC in previous studies include assessments of patient satisfaction with care, patient-reported anxiety, depression, psychological and spiritual well-being, quality of life, and concordance between desired and received care.<sup>5,6,36–38,56,58,59</sup> Barriers to the use of patient-reported outcomes in PC research include poor patient prognostic awareness<sup>60</sup> and questionnaire burden for patients and families.<sup>61</sup>

Patients' families and caregivers are essential members of the healthcare team at the end of life. Furthermore, many ED visits are initiated by patient's caregivers, who may be overwhelmed or lack the support needed to care for advanced illness at home. Accordingly, family and caregivers are frequently included in both PC and SDM studies.<sup>47,49</sup> Previous studies have utilized family satisfaction with care and family-patient agreement regarding decisions as outcomes. The successful provision of PC in the ED requires "buy-in" from ED providers. Therefore, characterizing the extent of providers' knowledge and support of the use of SDM for PC may be informative.<sup>62</sup> Knowledge, attitude, and practices surveys as well as provider satisfaction measures<sup>63</sup> have been used to assess provider response to both SDM<sup>64</sup> and PC interventions.<sup>65</sup> Finally, system-level outcomes to evaluate the effect of palliative and end-of-life care interventions include measurements of healthcare utilization and cost. Research in both the inpatient<sup>6,8-10</sup> and the ED<sup>4,6,8,23</sup> settings has demonstrated benefits for these outcomes. Future studies should continue to examine system-level outcomes to determine the effect of interventions on total costs and types of treatment provided. Essential research questions related to the identification of optimal outcomes for ED-based PC studies are listed in Table 4.

#### **Research Question 4: Which ED patients are likely to benefit from ACP and what tools are available to promote an SDM approach to ACP in the ED?**

During the last few months of life, many older adults receive care that is discordant with their preferences, increases suffering, and disrupts normal closure and grieving.<sup>1,67</sup> ACP addresses these problems by

1. Supporting patients in reaching an informed decision about end-of-life care preferences,<sup>68</sup>
2. Giving patients control over their end-of-life care,
3. Increasing patient and family satisfaction with the dying process, and
4. Reducing healthcare costs.

Yet, most older patients have not discussed end-of-life care preferences with their healthcare providers, and many individuals receive ED care during their last few months of life. These ED visits provide an important opportunity to promote ACP by impressing upon the patient that unexpected medical events are likely to occur again and that patients have the right to control their medical care. ED-based or ED-initiated discussions about end-of-life care plans do not occur in a vacuum. Many ED patients with advanced illness have at least considered their goals and some have discussed these goals with a physician, but availability of ACP documents among older adults receiving ED care is generally very low.<sup>69</sup> The most common form of ACP that ED patients report completing is a Health Care Power of Attorney, but the extent to which a patient representative understands and is able to represent the patient's interests varies. The Physician Orders for Life-Sustaining Treatment (POLST) Paradigm provides a more structured approach to ACP; helps convey patient preferences;<sup>70-73</sup> directs treatment that it is concordant with patient's wishes;<sup>72,74,75</sup> and can be easily interpreted by physicians, paramedics, and long-term care nurses.<sup>76</sup> Nonetheless, questions remain regarding how to extend the implementation of POLST. Completion of POLST typically takes at least an hour, so is probably not appropriate for an ED visit, but it may be possible

to use an ED visit to initiate patient interest in POLST. For older patients in good health or whose prognosis is uncertain, other ACP modalities such as a living wills or a Health Care Power of Attorney are more appropriate. Critical questions for use in the ED include which ED patients are likely to benefit from ACP conversations, which interventions are likely to be most effective to encourage these conversations, and how best to document or pass forward these conversations so that they impact care is unknown. Essential research questions related to how SDM can help patients and providers initiate or reassess ACP goals during the ED visit and document these goals are listed in Table 5.

**Research Question 5: What are the current and future financial and policy forces influencing the use of SDM to support the provision of palliative and end-of-life care in the ED?**

Integrating SDM for PC and end-of-life care into ED practice is a challenging task affected by many external forces.<sup>77</sup> Healthcare finance reform is arguably one of the most powerful of these forces. Recent payment reform policies may improve the quality of end-of-life care by connecting care delivery to reimbursement,<sup>1,53,77-79</sup> but the enactment of the Affordable Care Act and value-based purchasing policy from the Center for Medicare and Medicaid Services (CMS) remain unknown.<sup>80,81</sup> Furthermore, CMS recently expanded reimbursement to include ACP discussions,<sup>53</sup> but did not include emergency physicians in this expansion,<sup>82</sup> which has been advocated for by The American College of Emergency Physicians.<sup>83</sup>

Other policies limit the patients' ability to engage with SDM in end-of-life care. The current CMS regulations that form the payment framework around end-of-life care exert substantial financial pressure on patients and providers to keep older adults out of hospitals and skilled nursing facilities.<sup>84,85</sup> These costs influence the choices older adults have when they think about what kind of care they would like to have at the end of life and the setting in which they would like to receive that care. Also complicating the situation is the complex structure and eligibility requirements of the Medicare Hospice Benefit.<sup>78,84</sup> At present, enrollment requires certification from two physicians and a signed statement from the patient that they choose to forgo life-sustaining treatment for their disease.<sup>53,86</sup> These factors combine to create an all-or-none hospice paradigm that frequently conflicts with guidelines for the clinical practice of PC.<sup>87</sup> The SDM process is weakened when patients are forced to choose between "all-or-none" care. As a result, many patients miss out on the benefits of reasonable care.<sup>1,77,79,86,88</sup>

While costs constrain some patient choices, opaque cost information also presents challenges to SDM as it pertains to patient's personal financial health at the end of life. When patient asks the deceptively simple question of "How much will this therapy cost me?" there is often no way to provide an accurate answer.<sup>78,89</sup> Patients and their caregivers struggle to incorporate cost information into treatment decisions at the end of life because of unknown or unknowable charges, concealed pricing, and difficulty anticipating the cascade of consequences that might result from even a single diagnostic test.<sup>89</sup>

A final external force impacting SDM for end-of-life care is the funding streams for end-of-life research.<sup>77</sup> Historically, federal financial support of these types of investigations has been tenuous<sup>53,77,78</sup> but the National Institutes of Health,<sup>78</sup> National Institute on Aging,<sup>90</sup>

the U.S. Department of Health and Human Services,<sup>91</sup> and the Patient-Centered Outcomes Research Institute<sup>77</sup> recently increased the availability of funds for innovative research on end of life and PC. However, because of the sensitive nature of end-of-life care, it is possible that some federal sources may not be well positioned to support some of the most innovative research in this field.<sup>77,92</sup> Private foundations with special interest in the aging population like the West Health Institute and the Hartford Foundation<sup>92</sup> or healthcare systems themselves may be more flexible in this regard.<sup>53,79,80</sup> Essential research questions related to the influence of financial and policy forces influencing the provision of palliative and end-of-life care in the ED are listed in Table 6.

## CONCLUSION

The decision to initiate PC or to engage in conversations about end-of-life care preferences can be challenging for both provider and patient in any setting, even more so when the provider has limited knowledge about the patient's clinical condition, goals, and values. Nonetheless, there is a critical need for improvements in end-of-life care, and the ED is an essential setting for using shared decision making to align care with patient preferences. Unfortunately, little is known about how to best incorporate shared decision making regarding palliative and end-of-life care into the clinical practice of emergency medicine. The critical research questions defined here provide direction for efforts to improve care for ED patients with advanced illness, frailty, or end-of-life needs.

## Acknowledgments

The 2016 SAEM Consensus Conference was sponsored by the Academy of Geriatric Emergency Medicine, the American College of Emergency Physicians, the Mayo Clinic, and Washington University in St. Louis-Department of Emergency Medicine.

None of the sponsors had a role in the design and conduct of the study; the collection, management, analysis, and interpretation of the data; or the preparation, review, or approval of the manuscript.

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**Table 1**

## Key Research Questions to Guide Efforts to Advance the Use of SDM for PC in the ED

Question 1	Which ED patients are likely to benefit from SDM conversations regarding the provision of PC and how can these patients be rapidly identified?
Question 2	What are the most effective interventions to promote SDM regarding palliative and end-of-life care in the ED?
Question 3	What are the optimal outcome measures to use in studies examining the provision of palliative and end-of-life care in the ED?
Question 4	Which ED patients are likely to benefit from ACP and what tools are available to promote an SDM approach to ACP in the ED?
Question 5	What are the current and future financial and policy forces influencing the use of SDM to support the provision of palliative and/or end-of-life care in the ED?

ACP = advance care planning; PC = palliative SDM = shared decision making.

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**Table 2**  
Expanded Agenda for Research Question 1: Which ED Patients Are Likely to Benefit From SDM Conversations Regarding the Provision of PC and How Can These Patients Be Rapidly Identified?

Topics	Questions
1. Patient and system factors associated with unmet PC needs	<ul style="list-style-type: none"> <li>a. Which characteristics of ED patients are associated with having unmet palliative or end-of-life care needs (e.g., sociodemographic characteristics, disease-specific factors)?</li> <li>b. How can these patients be rapidly identified?</li> <li>c. Which types of EDs have the highest burden of patients with unmet palliative or end-of-life care needs (e.g., academic vs. nonacademic, urban vs. rural, availability of local PC and hospice service infrastructure, ED-based PC availability)?</li> </ul>
2. Emergency provider use of and access to PC	<ul style="list-style-type: none"> <li>a. What emergency provider characteristics and behaviors are associated with PC referrals?</li> <li>b. Does ED provider training in PC improve PC referrals?</li> <li>c. How can we improve identification of patients who are ready and eligible to transition to hospice?</li> <li>d. How can we identify processes to support the rapid access to PC for ED patients with advanced illness?</li> <li>e. How can we identify processes to support the rapid access to PC for critically ill ED patients?</li> </ul>

PC = palliative care; SDM = shared decision making.

**Table 3**

Expanded Agenda for Research Question 2: What Are the Most Effective Interventions to Promote SDM Regarding Palliative and End-of-life Care in the ED?

Topics	Questions
1. Patient education	a. How can patient educational materials aid ED providers in employing SDM for PC?
2. Provider training	a. How can provider educational materials promote use of SDM for PC in the ED? b. How can the use of decision aids help patients and providers better assess a patient's PC needs?
3. Systems design	a. What models of care can allow providers to rapidly access PC resources for critically ill ED patients? b. What models of care can be developed that allow for access to outpatient PC resources for ED patients being discharged? c. How might models of rapid access to PC resources be adapted to settings without PC services?
4. Experience	a. Which qualitative and semiquantitative assessments of the patient experience can promote SDM and palliative treatments in the ED?

PC = palliative care; SDM = shared decision making.



**Table 4**  
Expanded Agenda for Research Question 3: What Are the Optimal Outcome Measures to Use in Studies Examining the Provision of Palliative and End-of-life Care in the ED?

Topics	Questions
1. Patient experience	What are the optimal measures to assess the patient experience resulting from the receipt of PC in the ED?
2. Family and caregiver experience	What are the optimal measures to assess the effect of ED PC services on the experience of family and caregivers?
3. Provider knowledge, attitudes, and behaviors	What are the optimal measures to assess provider knowledge of, attitudes toward, and willingness to use shared decision making for the provision of palliative and end-of-life care in the ED?
4. Resource utilization	What are the most effective methods for measuring the impact of ED-based interventions in palliative and end-of-life care on healthcare costs and utilization?

PC = palliative care.

**Table 5**  
 Expanded Agenda for Research Question 4: Which ED Patients Are Likely to Benefit From ACP, and What Tools Are Available to Promote a SDM Approach to ACP in the ED?

Topics	Questions
1. Documentation of patient priorities and goals of care	a. What is the best method of documenting ACP preferences so that they are accessible when patients come to the ED? b. How can technology be leveraged to facilitate access to these critical documents in a timely fashion including use of electronic medical records and access to Web-based orders and documentation? c. What is the feasibility and effect of creating or improving access to registries or health information exchanges that contain advanced directives?
2. Using the ED to initiate ACP conversations	a. Which ED patients are most likely to benefit from and be most receptive to ACP conversations? b. What are the barriers to conducting advance care planning in the ED and how can these barriers be overcome? c. What tools can be used to support ACP conversations and link these conversations to further discussions with primary and admitting providers?
3. Clarifying patient priorities and values to inform ED decisions	a. How can SDM be effectively used in patients with advanced illness to define or clarify priorities in the ED, including i. Which diagnostic tests are congruent with patient priorities and goals of care? ii. Which medical interventions are congruent with patient priorities and goals of care? iii. Which disposition (i.e., admission, discharge, alternative care settings such as home, or hospice) is most congruent with patient priorities and goals of care? iv. With family or outpatient providers to explore if and how patient's wishes can best be met? b. Which patients and under what conditions do patients who have previously stated ACP goals change their goals in the face of a medical emergency?

ACP = advance care planning; SDM = shared decision making.

**Table 6**

Expanded Agenda for Research Question 5: What Are the Influence of Financial and Policy Forces on the Provision of Palliative and End-of-life Care in the ED?

Topics	Questions
1. Current policies	a. How do current healthcare policies affect patient access to PC in the ED?
2. Future policies	a. How can healthcare policies be structured to increase access to PC in the ED? b. What policy changes should be advocated for as a result of research findings?
3. Research funding	a. What sources of funding are currently available to researchers in these areas and what additional sources may be available in the future?

PC = palliative care.

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