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## Emergency Department Experiences of Acutely Symptomatic Patients with Terminal Illness and Their Family Caregivers

Alexander K. Smith, MD, MS, MPH, Mara A. Schonberg, MD, MPH, Jonathan Fisher, MD, Daniel J. Pallin, MD, MPH, Susan D. Block, MD, Lachlan Forrow, MD, and Ellen P. McCarthy, PhD, MPH

Division of Geriatrics (A.K.S.), Department of Medicine, University of California, San Francisco, and Veterans Affairs Medical Center (A.K.S.), San Francisco, California; and Harvard Medical School (M.A.S., J.F., D.J.P., S.D.B., L.F., E.P.M.); Division of General Medicine and Primary Care (M.A.S., L.F., E.P.M.), Department of Medicine, and Department of Emergency Medicine (J.F.), Beth Israel Deaconess Medical Center; Department of Emergency Medicine (D.J.P.), Brigham and Women's Hospital; Division of Emergency Medicine (D.J.P.), Children's Hospital; and Department of Psychosocial Oncology and Palliative Care (S.D.B.), Dana-Farber Cancer Institute and Brigham and Women's Hospital, Boston, Massachusetts, USA

### Abstract

**Context**—Despite increased focus on improving palliative care in the emergency department (ED), there is little research on how to best address the specific needs of this patient population. We know little about the experiences of acutely symptomatic patients seen in the ED.

**Objectives**—To better understand the specific needs of this population to improve care of terminally ill patients.

**Methods**—Using in-person semi-structured interviews, we explored the attitudes, experiences, and beliefs of 14 patients and seven family caregivers on the inpatient palliative care consult service who had been admitted through the ED at two academic medical centers. We used a grounded theory approach to code responses. Transcripts were coded by a palliative medicine physician, an emergency medicine physician, and a general internist. Discrepancies were resolved by consensus. Coded sections were iteratively reviewed for interpretation, and concepts were collapsed into themes.

**Results**—Five distinct themes emerged: 1) unprepared for managing symptoms at home; 2) uncertainty and anxiety; 3) communication is essential; 4) mixed experiences with symptom management; and 5) conflicting perspectives about the purpose of palliative care clinicians in the ED.

**Conclusion**—Patients and caregivers identified systems, communication, and clinical issues in ED care that should be a focus for future research.

### Keywords

Emergency department; pain; patient; caregiver; palliative care; qualitative research

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Address correspondence to: Alexander K. Smith, MD, MS, MPH Division of Geriatrics, UCSF 4150 Clement St. (181G) San Francisco, CA 94121, USA aksmith@ucsf.edu..

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## Introduction

Because many patients are hospitalized during the last months of life, the inpatient hospital setting is a major focus of efforts to improve end-of-life care. Until recently, much less attention has been focused on the emergency department (ED), even though most of these patients are evaluated and treated in the ED before they are admitted to the hospital.<sup>1</sup> In recognition of this opportunity to improve care, the Education on Palliative and End-of-Life Care (EPEC) Project developed a new curriculum for emergency medicine professionals (EPEC-EM).<sup>2</sup> The American Board of Emergency Medicine cosponsored palliative medicine as a recognized subspecialty.<sup>3-5</sup>

Despite mounting interest in improving palliative care in the ED, there is little research in this area.<sup>6</sup> In particular, we have very little information from the perspective of patients and their family caregivers. We know little about the decision making process that brings acutely symptomatic patients with terminal illness to the ED, their care experiences in the ED, and their perspectives about seeing palliative care clinicians in the ED. Eliciting the perspectives of patients and caregivers is critically important at this early formative stage, as we seek to improve palliative care in the ED with the goal of providing high quality care centered on the needs of patients and caregivers. To this end, we conducted a qualitative study to explore the perceptions, experiences, and beliefs of acutely symptomatic patients with terminal illness seen in the ED and their family caregivers. We included patients who were previously identified as palliative care or hospice patients, as well as patients who were newly seen by the palliative care service over the course of admission.

We previously reported findings from focus groups with ED care providers (nurses, physicians, social workers, and ED technicians).<sup>7</sup> ED care providers identified the multiple domains as critical to improving the ED care for patients with palliative care needs, including six “themes” and seven attitudinal and structural “obstacles” to palliative care in the emergency department. Domains that cut across these themes and obstacles, and were rated as high priorities for improvement by providers, included: 1) communication issues between outpatient and ED providers, patients, and family caregivers; 2) inadequacies in pain management training; and 3) attitudinal and structural barriers to incorporating palliative care into the ED. We used these domains as a starting point for our semi-structured interviews with patients and family caregivers. We believe that through a better understanding of the specific needs of this population, a coordinated and collaborative effort among emergency physicians, outpatient care providers, and palliative care specialists may lead to improved care of terminally ill patients.

## Methods

### Study Design and Sample

We conducted a qualitative study using semi-structured, in-person interviews with patients on the inpatient palliative care consult service who were admitted through the ED at two academic medical centers, and their family caregivers. These two medical centers are located within a large metropolitan area and have active inpatient palliative care services. At the time of the study, these palliative care services rarely saw patients in the ED. Clinicians on the palliative care service identified patients who had been admitted through the ED within the previous seven days. We approached all identified patients to be interviewed, and where available, their family caregivers. If patients were too ill to be interviewed, then we approached only their family caregiver. All interviews were conducted by a single study investigator with graduate level training in qualitative research and previous experience conducting semi-structured interviews with patients and caregivers (A.K.S.). Subjects completed a brief demographic questionnaire. The charts of participating patients were abstracted for clinical information

pertaining to their ED visit and palliative care consult. All interviews were conducted within a week of the ED visit and lasted approximately 30 minutes. All interviews were conducted over a five-month period in 2008. Participants were given an honorarium for their time.

### Data Collection

The multidisciplinary team of investigators from emergency, palliative, and general internal medicine developed a focus group guide (see Appendix) based on our previous research with ED providers, clinical experience in this topic area, expertise in qualitative research, and a review of the literature.<sup>6, 7-9</sup> Questions were open-ended and the interviewer used probes to clarify and further explore responses. The interviews began by asking participants about the circumstances surrounding their decision to visit the ED. Participants were then asked to describe their ED experience, with a particular focus on the domains of communication with ED providers, attention to pain and symptom management, the physical environment of the ED, and unmet needs. Participants were asked to describe what “palliative care” meant to them. We explored further whether they felt they would have benefited from seeing a palliative care clinician earlier in the course of their hospitalization or in the ED. Investigators reviewed transcripts from the first four interviews and added questions to the study guide to further clarify ideas and explore specific areas in greater detail.

### Data Analysis

Sessions were recorded, and transcribed verbatim by a professional transcription service. Qualitative analyses were conducted using an iterative process that followed standard grounded theory techniques.<sup>10, 11</sup> Transcripts were coded by three physicians (A.K.S., J.F., M.A.S.) experienced in palliative, emergency, and general internal medicine, respectively. These investigators coded a portion of the transcripts together to develop a common coding structure. A single investigator (A.K.S) then coded the remainder of the transcripts, selecting excerpts from the transcripts deemed particularly illustrative for independent coding by the coders from the other specialties. Coded sections were reviewed for further interpretation, and concepts were collapsed into themes. Discrepancies (<5) were resolved by consensus. New codes were added as new themes emerged and prior transcripts were recoded iteratively until no new insights emerged. In qualitative research, sampling until the point of redundancy or thematic saturation provides evidence of the credibility of developed theory and is an accepted sampling end-point.<sup>10, 11</sup> Illustrative quotes provided herein have been edited for grammar. Identifying information of patients has been altered to protect patient confidentiality. Frequencies of reported themes are provided as a point of reference. This study was approved by the institutional review board of the Dana-Farber/Harvard Cancer Center, which covers all participating institutions.

## Results

### Characteristics of Study Participants

Fourteen patients and seven caregivers participated (Table 1). Participants varied in age (range 20-89) and were split evenly in terms of gender. Most patients had cancer and two patients were enrolled in hospice prior to admission. The most common reason for the ED visit was pain. Themes are described briefly in Table 2 and at greater length below.

### Detailed Discussion by Theme

**Unprepared for Managing Symptoms at Home**—At the index visit, all participants were seen in the ED for symptoms that patients and family caregivers felt unable or unprepared to manage at home. In nearly all cases, patients or their caregiver contacted the outpatient provider and were advised to go to the ED. The following quote from the wife of a 56-year-

old man with metastatic cancer who developed back pain (eventually diagnosed as spinal cord compression) is representative:

I was trying to get him to sleep one night and he was in a lot of pain. I was giving him more Dilaudid on top of more Dilaudid, and I gave him so much medication and it wasn't even touching [the pain]...I thought I was going to overdose him because he had so much...

This caregiver contacted her husband's oncologist, who advised calling an ambulance (“[the doctor] said ‘I think you better come in [to the hospital]’”). The patient and caregiver reported that the oncologist contacted the emergency department to advise them to obtain an MRI to rule out spinal cord compression, but the need for aggressive pain management was not communicated effectively.

Another patient, a frail 88-year-old woman with advanced chronic conditions cared for by home hospice, became nauseated and experienced repeated episodes of vomiting. Her husband called 911 rather than contacting hospice providers. The patient, who lacked decision making capacity at the time the ambulance was called, later expressed anger that her husband had brought her to the hospital (“I was going to kill him for shipping me [to the hospital]. What do I want to hang around like this for...just to suffer is all I am doing.”). The patient's husband responded:

I say I don't believe it, I believe that you would like to be alive; you want to watch your children mature to older men and women, and you have a grandson. There are others around you that depend on you and whatever you have to offer, and you have to take them into consideration too. You can't just turn your back on the world.

In each of these examples, family caregivers felt unprepared to manage acute symptoms at home. One family member demonstrated an inappropriate fear of opioid analgesia, and the other disagreement about goals of care. It is possible that the ED visit in the second case could have been avoided with better outpatient symptom management, or if there was less ambiguity in the end-of-life planning process in the setting of a terminal illness. Educating patients (and primary care givers) and optimizing outpatient strategies may improve overall quality of care.

**Uncertainty and Anxiety**—The emergency department is often a hectic setting, and the noise and activity can be overwhelming and anxiety-provoking to any patient, let alone those with terminal illness. Patients and caregivers described increased anxiety, often associated with the long wait times in the waiting room and long wait times to be admitted to the hospital. These patients were often symptomatic while waiting, and uncertain and worried as to what the exacerbation in symptoms might imply. One 52-year-old man with cancer stated: “It is just the uncertainty of when you go to the Emergency Room, you don't know what is happening to you, you don't know what is wrong with you.” Or, as another patient explained:

The stretchers are not comfortable. They put you in that room, they close the curtains, and they just leave you in there...you don't know what is going on. So they say, “Okay, we are going to admit you, you got a room,” but you are still waiting, and you are just wondering, “What is going on, what is taking so long?”

**Communication Is Essential**—Communication of expectations and reassurance was identified as a paramount area influencing a patients' perception of the ED encounter. Many subjects described profoundly positive interactions with care providers in the ED who were able to provide a positive experience in a time of distress. For example, one 74-year-old man with cancer and no formal caregiver, who described the emergency department environment as “overwhelming,” related the following experience: “I seemed distressed. A social worker came by and said, ‘You know, you are not alone.’ She said ‘I don't want you worrying all

alone.” A 44-year-old woman with sarcoma had high praise for the ED nurses: “[The nurses] tried to meet all my needs right away, they tried to advocate for me to make sure that the doctors came in and gave me results quickly and explain what the plan was.”

Other subjects, however, expressed frustration at being asked the same questions by multiple providers, although many of them recognized that this was inevitable in a teaching hospital setting where physicians work in shifts. Some described a feeling of distance and impersonal interactions. For example, one patient who had visited the ED on multiple occasions stated:

I have had the pain for over a year, so I have a long history, so something should be written [about me], not like some person who just comes in and has the flu...my condition should be taken a lot more seriously and looked at [more closely], not, “We will get to you.”...I am the patient, I am a customer, I am the one sitting there in pain and having problems. I know that they have too many people coming in and they are looking at too many people at the same time, but it is like you are taking a number at the deli.

Waiting and triage to acuity are two unfortunate, but necessary, parts of managing a busy ED, where the focus of the staff must be to address acutely life-threatening conditions as they arise. While no patient likes to wait, the message that this is distressing to those with pain or enhanced anxiety due to terminal illness was clear. Solutions may include both communication and structural changes, such as improved outpatient symptom management, improved communication between outpatient and ED providers, predetermined care plans, greater transparency about the reasons for long wait times, ways to mitigate wait times in palliative care patients such as direct admissions or curtailed work-ups, or special pathways that assure pain needs are addressed quickly.

**Mixed Experiences with Symptom Management**—Although pain was the primary complaint for half of the patients, several patients experienced pain in addition to another symptom that brought them to the ED. The theme “pain management is essential” was pervasive where 14/21 patients described incomplete pain management. “Effective treatment of pain” was noted in six interviews. Several participants described prolonged experiences of pain in the waiting room. In another instance, a 74-year-old man with gastric cancer, who presented with urinary retention from a metastatic obstructing lesion, described his pain in the ED: “I could not lay on my left side, right side, stomach even, or back. The pain was excruciating.”

**Conflicting Perspectives About Palliative Care Clinicians in the ED**—In the single case in which a palliative care provider saw a patient in the ED – the 56-year-old man with cancer and spinal cord compression discussed above – the caregiver described a lack of coordination of care and effective communication between ED and palliative care providers.

[The nurses and the palliative care provider] were butting heads. I saw a couple of the nurses and they were just like pissed at her ... the nurse said [to us], “You can have [the pain medication] every 2 hours,” but [the palliative care provider] had the order written for every ½ hour to 1 hour... the nurse just didn’t want to deal with giving him the pain medications that frequently.

The patient later stated, “Certainly, it was helpful for [the palliative care provider] to be there to be an advocate for your care, somebody who really knew you, so you had some continuity in terms of management of your pain.”

However, this example also highlights the need for education and a coordinated approach, set in advance, between ED teams and palliative care teams. Clearly, working together will provide the best outcome for a patient, as, from the ED perspective, those who suddenly appear and

start giving orders without an appreciation for the special challenges of the ED environment can be both disruptive and dangerous. There needs to be a collaborative approach to assure that acute issues are addressed, pain management is addressed, and the patient receives compassionate care as part of the routine delivery of care in the ED.

Patients and caregivers who had been seen previously by the palliative care team would have welcomed the involvement of palliative care in the ED. Among participants who met a palliative care provider for the first time after their ED visit, the opinions were mixed. When asked what palliative care meant to these patients and caregivers, those who viewed palliative care as a symptom management service (“the pain team”) were more inclined to view involvement of palliative care in the ED positively. In contrast, those who equated palliative care with end-of-life care expressed serious reservations. For example, a 44-year-old woman with sarcoma had undergone multiple interventional endobronchial procedures to relieve bronchial obstruction due to tumor. When she developed shortness of breath and went to the ED, she expected to have the same procedure again. She was surprised when her surgeon informed her that the tumor was too advanced to risk repeating the procedure. Over the course of her hospitalization, she transitioned to intensive comfort measures and was cared for by the palliative care team. When asked if it would have been helpful to see a palliative care provider in the ED, she stated:

No, I think that I saw [the palliative care providers] at about the right time, because it takes a certain amount of time for a person to realize that the time for focusing on a cure has ended, and that there will be no active treatment of disease itself to try to cure it. It takes a person a certain amount of time to take all of that in.

The caregiver of the 76-year-old woman with breast cancer described above explained:

I think that it was a bit of a shock to discover that this pain meant we were transitioning to palliative care, so I can't conceive of having met [the palliative care providers in the ED], because I don't think that they had decided [that she should transition to palliative care] yet, or if they had decided, it would have been a bit of a shock to learn it [in the ED]...the word “palliative” would have implied a different stage in her cancer.

## Discussion

We report on a qualitative analysis of perceptions, experiences, and beliefs of patients with palliative care needs seen in the ED, and their family caregivers. Participants identified systems, communication, and clinical issues that should be targeted for improvement in future research and quality improvement initiatives.

We previously described qualitative findings of focus groups with ED providers.<sup>7</sup> Similarities and differences between the perspectives of ED providers and the patient and caregiver perspectives presented here are notable. First, ED providers' highest priority for improvement was improved communication between inpatient and outpatient providers. In the present study, nearly all patients were referred to the ED by outpatient providers, highlighting the need for good communication between inpatient and outpatient providers about reasons for the ED visit, previous treatment modalities, and established preferences for high intensity care. Our finding that patients and caregivers were unprepared to manage symptoms at home suggests the need for improved education about end-of-life symptoms, and system changes to rapidly respond to the needs of patients in the outpatient setting. The often busy, loud, and overcrowded ED is not the optimal treatment location for many patients with terminal illness, and these findings suggest a gap in our system's ability to care adequately for these patients at home. Like other issues in emergency medicine, the concerns raised by patients in our study may represent a failure of the larger health care system. It is these very same system issues that set the ED up



for failure with this group of patients, and communication, education, and coordination initiatives are needed to interdict and improve care for future patients

Second, the enhanced anxiety associated with waiting described by these participants was striking, not only in the “waiting” room, but also in the ED if there was a delay in explaining the cause of the exacerbation in symptoms, or waiting for a bed in the hospital. This anxiety is potentially addressable through better communication about care plans and reasons for waiting. Many patients and caregivers also expressed anxiety over the implications of their symptoms in relation to their overall prognosis, and were looking for more information about their disease. While communication may not have been optimal, many of the questions they sought answers to were not easily answered by ED providers. Providers and patients alike described the ED as a tremendously busy place with competing demands for providers’ attention. In a busy ED, there is an inherent tension between maximum efficiency of the medical work-up of a patient and the ability to move a patient to the inpatient setting. The intensity of care and access to a wide range of resources often mean that patients spend more time in the ED rather than less. Because of these and other factors, overcrowding and long wait times are likely to increase, not decrease with time.<sup>12-17</sup> Thus, strategies to ameliorate anxiety and discomfort are welcome, including improvement in pain and symptom management skills of ED providers, and for particularly complex or challenging symptoms, earlier palliative care involvement and consultation in the ED.

Furthermore, the magnitude of these patients’ illnesses may have created unique barriers to effective communication. When complex, terminally ill patients with acute symptom care needs enter the ED, the focus on patient-centered care may be sorely tested. Inadequate communication has been associated with poor patient satisfaction among all ED patients.<sup>18</sup> Future research and quality improvement initiatives might focus on methods of efficiently improving the quality of communication between ED staff, providers, patients, and caregivers. For those patients who must be seen in the ED, there may be a role for managing expectations about the ED process, the reasons for long wait times, and the methods of triaging patients to be seen from the waiting room.

Another, and perhaps the most important theme identified, was pain management. Inadequately treated pain was a major reason for dissatisfaction with the ED encounter. Patients came to the ED with symptoms, yet in some instances either waited in the waiting room in discomfort or were treated ineffectively in the ED. In our previous study, ED providers, particularly emergency medicine residents, noted serious shortcomings in their training in pain and symptom management. Furthermore, oligoanalgesia is a well-known problem for all ED patients.<sup>19</sup> In the case of terminally ill patients, this problem is different in two ways: (1) terminally ill patients may have developed tolerance, and require doses of opioids that are unsafe for opioid-naïve patients; and (2) the risk of aggressive analgesia in terminally ill patients is different from the risk in patients with reversible underlying disease processes. Ethically, if the patient, family, and clinician agree that the primary treatment goal is to provide comfort, the potential risk of an earlier death as a side effect of medications is acceptable (the “double effect” principle).<sup>20</sup> A primary focus of ED care is diagnosis and stabilization. Our findings suggest that symptom management needs to be a higher priority and incorporated into the stabilization process.

Patients and caregivers in our study who were familiar with palliative care from a previous hospitalization, outpatient visit, or hospice, were open and welcoming of the concept of palliative care clinicians in the ED. However, if this is not a coordinated approach, there can be a perception of an adversarial relationship between providers, which has the potential to be more damaging to patient care than helpful. Notable, however, are the serious reservations expressed by participants who “transitioned” to palliative care over the course of their

hospitalization. Patients and caregivers who at the time of the ED visit were still focused on life-prolonging treatment expressed their unpreparedness to transition to exclusively palliative care in the ED. Their comments revealed a deep concern about being seen by the team that cares for dying patients before they were ready to conceptualize themselves as dying. Our findings highlight the need for a broader educational initiative for patients and providers about the role of palliative care in enhancing quality of life, relieving symptoms throughout the illness trajectory, as well as its contributions to improving care at the end of life. Palliative care should optimally be introduced to patients as a standard component of high quality multidisciplinary care early in the course of their illness trajectory, prior to a crisis in symptoms that precipitates an ED visit. Our findings also underscore the potential for greater involvement of palliative care teams in the ED, education of ED providers in symptom management and communication skills, and collaboration between palliative care and ED providers.

Limitations to our study design are worth considering. Although we sampled to the point of thematic saturation, our sample size was small, and selection bias may have influenced our findings. This study was conducted at two academic medical centers in a major metropolitan area and may not represent the experiences of patients in other health care systems (e.g., rural or suburban health centers, community hospitals, non-academic centers). To minimize recall bias, we limited our sample to patients seen by a palliative care team who were admitted via the ED within the previous seven days. Consequently, however, we did not collect data about patients admitted for longer time periods prior to palliative care consult, who may have benefited from earlier identification as patients with palliative care needs in the ED. Finally, patients without palliative care needs may have similar concerns as the patients in this study; the extent to which concerns with communication and symptom management are shared by other patient populations was not explored in this study. In many cases, the inconveniences of ED experiences may be similar for terminally ill patients and patients with reversible threats to life. What differs is the relative value of the inconvenience for this distinct patient group. Terminally ill patients might, conceivably, be better served by a system that placed more emphasis on comfort and less emphasis on access to emergency care at all costs.

In summary, we present the experiences of acutely symptomatic and seriously ill patients seen in the ED, and their family caregivers. Two very important areas identified to improve the delivery of care in the ED were communication and pain management. Many of the issues raised about ED care may be symptoms of a larger breakdown in the health care system as whole. Ultimately, ED providers, outpatient care providers, and palliative care providers need work together to move toward interventions and system changes that improve the quality of care experiences for seriously ill patients and families who are seen at a vulnerable time: acutely symptomatic, anxious, waiting, and wondering what is happening to them, in the busy and crowded confines of the ED.

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## Appendix

### Interview Guide

#### I. Warm up and Introduction

- Consent
- Explain taping session
- [For interviews with caregivers, substitute “your loved one” for “you” below]

#### II. Reasons for ED visit 5 min

- What brought you to the emergency department?
  - What were the events that immediately led up to your ED visit?
  - What was your family's role in the decision to go to the ED? Your physician's role?
  - What sort of care did you seek to treat this issue before going to the ED?

#### III. ED Care Experiences 20 min

- What was your experience like in the ED?
  - Let's focus on doctors: How was communication with the ED doctors?
    - In what ways was communication with doctors good? In what ways could it have been better?
  - Now let's focus on nurses: How was communication with your the ED nurses?
    - In what ways was communication with nurses good? In what ways could it have been better?
  - How was the physical environment in the ED?
  - If you had pain in the ED, how long did it take to be recognized? How long to be treated? How long to be relieved?
  - How about other symptoms?
- Where any of the goals that brought you to the ED unmet? How?
- Now that you have met the palliative care team, can you tell me what palliative care means to you?
- Do you think seeing a palliative care clinician in the ED might have helped you? How about earlier in your hospitalization?
- Please tell me about other ED care experiences you've had in the past few months.
- How might your ED care have been improved?
- Is there anything more that you wish could have been done in the ED? I wish...

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**Table 1**Characteristics of Participants (*n*=21)

| Characteristic                                                                   | Value         |
|----------------------------------------------------------------------------------|---------------|
| Age, average $\pm$ SD                                                            | 59 $\pm$ 22   |
| Female, <i>n</i> (%)                                                             | 10 (47)       |
| Race/ethnicity, <i>n</i> (%)                                                     |               |
| Non-Hispanic White                                                               | 18 (86)       |
| Non-Hispanic Black                                                               | 2 (10)        |
| Hispanic                                                                         | 1 (5)         |
| Academic medical center 1 (versus 2) <i>n</i> (%)                                | 8 (38)        |
| Days between ED admission and interview, average $\pm$ SD                        | 3.1 $\pm$ 2.0 |
| Participant type, <i>n</i> (%)                                                   |               |
| Patient                                                                          | 14 (67)       |
| Caregiver                                                                        | 7 (33)        |
| Characteristics of patients ( <i>n</i> =14)                                      |               |
| Married, <i>n</i> (%)                                                            | 9 (64)        |
| Primary symptom need, <i>n</i> (%)                                               |               |
| Pain                                                                             | 7 (50)        |
| Shortness of breath                                                              | 2 (14)        |
| Other symptom                                                                    | 5 (36)        |
| Primary disease, <i>n</i> (%)                                                    |               |
| Cancer                                                                           | 12 (86)       |
| Other                                                                            | 2 (14)        |
| Pain assessed in ED, <i>n</i> (%)                                                | 14 (100)      |
| Opioid administered in ED, <i>n</i> (%)                                          | 7 (50)        |
| Admitted from hospice, <i>n</i> (%)                                              | 2 (14)        |
| Seen by inpatient palliative care service on prior hospitalization, <i>n</i> (%) | 5 (36)        |
| Days between ED admission and palliative care consult, average $\pm$ SD          | 1.9 $\pm$ 1.5 |
| Primary reason for palliative care consult                                       |               |
| Pain                                                                             | 5 (36)        |
| Other symptom                                                                    | 3 (21)        |
| Goals of care                                                                    | 6 (43)        |
| Documented DNR at time of interview, <i>n</i> (%)                                | 7 (50)        |
| Documented advance care planning conversation at time of interview, <i>n</i> (%) | 7 (50)        |

**Table 2**Themes Emerging from Semi-Structured Interviews with Patients and Caregivers ( $n=21$ )

| Theme                                                                  | Brief Explanation                                                                                                                                                                                                                                                                                                                                                                                                                                    | Proportion of Participants Endorsing Theme $n$ (%)          |
|------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------|
| 1. Unprepared for managing symptoms at home                            | Patients and caregivers attempted to manage symptoms at home, but were unprepared for managing the severity of symptoms experienced.                                                                                                                                                                                                                                                                                                                 | 16 (76)                                                     |
| 2. Uncertainty and anxiety                                             | Patients and caregivers wanted more information about the reasons for long wait times, the triage process in the waiting room, and the next steps in the workup and treatment of their symptoms. Lack of this information led participants to uncertainty and feelings of anxiety.                                                                                                                                                                   | 9 (43)                                                      |
| 3. Communication is essential                                          | Although some participants described profoundly positive interactions with providers, others described feeling like they were being treated like a number. Many participants felt that they should have a higher priority because of their frequent visits to the hospital, the complexity of their illness, and their short life expectancy. Many Participants were frustrated about being asked the same questions multiple times by ED providers. | Successes – 7 (33%) Challenges – 14 (67)                    |
| 4. Mixed experiences with symptom management                           | Some patients were very satisfied with pain and symptom management. Others described instances of significant pain that either went unnoticed, untreated, or were treated ineffectively.                                                                                                                                                                                                                                                             | Effective treatment – 6 (29) Inadequate treatment – 14 (67) |
| 5. Conflicting perspectives about palliative care clinicians in the ED | Patients who were established palliative or hospice patients prior to the ED visit would have welcomed the involvement of palliative care clinicians in the ED. Participants who equated palliative care with end-of-life care expressed serious concerns.                                                                                                                                                                                           | In favor – 14 (67) Opposed – 7 (33)                         |