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Palliative Care Needs of Seriously Ill, Older Adults Presenting to the Emergency Department

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Abstract

Objectives—To identify the palliative care needs of seriously ill, older adults in the emergency department (ED)

Methods—The authors conducted a cross-sectional structured survey. A convenience sample of 50 functionally impaired adults 65 years or older with coexisting cancer, congestive heart failure, end-stage liver or renal disease, stroke, oxygen-dependent pulmonary disease, or dementia was recruited from an urban academic tertiary care ED. Face-to-face interviews were conducted using the Needs Near the End-of-Life Screening Tool (NEST), McGill Quality of Life Index (MQOL), and Edmonton Symptom Assessment Survey (ESAS) to assess 1) range and severity of symptoms, 2) goals of care, 3) psychological well-being, 4) health care utilization, 5) spirituality, 6) social connectedness, 7) financial burden, 8) the patient-clinician relationship, and 9) overall quality of life.

Results—Mean age was 74.3 (SD $\pm$ 6.5) years and cancer was the most common diagnosis. Mean quality of life on the MQOL was 3.6 (SD $\pm$ 2.9). Over half of the patients exceeded intra-test severity-of-needs cutoffs in four categories of the NEST: physical symptoms (47/50, 94%), finances (36/50, 72%), mental health (31/50, 62%), and access to care (29/50, 58%). The majority of patients reported moderate to severe fatigue, pain, dyspnea, and depression on the ESAS.

Conclusions—Seriously ill, older adults in an urban ED have substantial palliative care needs. Future work should focus on the role of emergency medicine and the new specialty of palliative care in addressing these needs.

Keywords

Palliative Care; Geriatrics; Quality of life

INTRODUCTION

The U.S. Institute of Medicine defines serious and complex medical conditions as persistent, substantially disabling or life-threatening, and requiring treatments and interventions across

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a broad scope of medical, social, and mental health services to achieve the best outcome.¹ As the population ages and emergency department (ED) visits continue to increase,^{2,3} the number of older adults with serious and complex illness who present to the ED will also continue to rise.⁴ In 2006, adults 75 years or older visited the ED at the second highest rate for any age group, with 60.2 visits per 100 persons, or about 10.2 million visits.² Older adults were also more likely to present to the ED with conditions requiring immediate life-sustaining and/or palliative treatments.^{2,5}

In response to the growing numbers of older adults with advanced illness cared for in the ED, several medical centers have recently initiated pilot programs to deliver ED-based palliative care consultation.^{6–8} Palliative care involves symptom assessment and treatment, aid with decision making and establishing goals of care, practical support for patients and caregivers, and mobilization of community support and resources to assure a secure and safe living environment. In addition to focusing on relief of burdensome symptoms, palliative care teams can aid in complex medical decision-making regarding life-sustaining treatments and facilitate alternative discharge plans.

To enable the delivery of ED-based palliative care services, however, we must first identify which older adults in the ED could benefit from emergent palliative care services and what their palliative care needs are. To this end, this study was designed to identify the palliative care needs of older adults in the ED. We hypothesized that the palliative care needs of seriously ill, older adults in the ED would be substantial, especially with regard to burdensome physical and mental symptoms.

METHODS

Study Design and Population

A cross-sectional, structured survey about palliative care needs was administered to a convenience sample of 50 seriously ill, older adults and their primary caregivers face-to-face at the bedside in an urban ED by a single trained interviewer. The 41-bed ED has over 100,000 visits per year and is part of a large, urban academic tertiary care medical center. The institutional review board at Mount Sinai School of Medicine approved all study procedures.

Patients had to meet the following inclusion criteria: 1) age 65 years or over; 2) a history of at least one of seven serious and complex medical conditions (cancer requiring chemotherapy, radiation, and/or surgery other than local excision; congestive heart failure; end-stage liver disease; chronic renal failure on hemodialysis; stroke; oxygen-dependent pulmonary disease; or dementia of any type); and 3) a functional deficit, defined as an Eastern Cooperative Oncology Group (ECOG) Performance Status grade of two or greater (unable to carry out any work activities, even light house or office work; may or may not be able to provide self-care).⁹ Functional status was selected rather than disease severity, as impairment in functional status is typically the best indicator of survival and palliative care need in the setting of advanced illness.^{10,11} Patients also had to pass a cognitive screen using the six-item screener.¹² Those who scored 4 or less were excluded, as this has been shown in ED patients to be sensitive and specific for the detection of cognitive impairment as compared to the longer Mini-Mental State Examination.¹³

A caregiver was defined as a spouse, partner, or first-degree relative who was also the primary care provider for a patient included in the study. The caregiver had to be present at the bedside to participate.

Survey Content and Administration

The patient survey was based on the Needs Near the End of Life Care Screening Tool (NEST),¹⁴ a sensitive and reliable set of bedside questions to assess and screen individual patients' overall care requirements in the setting of serious and life-limiting illness. The instrument consists of thirteen categories of need: financial, access to care, caregiving, illness distress, physical health, mental health, closeness, spirituality, settledness, purpose, patient/provider communication, information, and goals of care. Intra-test cutoffs exist for each of the 13 domains, above which more detailed testing is done using the Edmonton Symptom Assessment Scale (ESAS) and/or the NEST-48, to determine in what sub-categories there is need for intervention. The ESAS, a validated nine-item screening tool developed for assessing symptom distress in palliative care patients, contains detailed questions on the severity of physical and mental symptoms.^{15,16} Quality of life was assessed with a single question from the McGill Quality of Life Questionnaire (MQOL), with patients self-rating QOL on a scale of zero to ten representing very bad to excellent QOL.^{17,18}

A validated 13-item screening instrument for measuring caregiver burden was administered - the Caregiver Strain Index.¹⁹ This index assesses physical, emotional, and financial aspects of stress in caring for a loved one. Any "yes" response indicates a need to intervene in that particular area, and a score of seven or higher indicates severe stress.

Between 13:00 and 21:00 hrs, Monday through Friday, a research assistant electronically monitored the tracking board and flagged patients who were over 65 years or older and had one of the seven medical conditions as recorded by the triage nurse. Patients were assessed for English language fluency and cognition. If the patient spoke English, the cognitive screen was administered. If the patient was not cognitively impaired and spoke English, the medical history was verified to be sure the patient had one of the seven clinical conditions above. The interviewer then administered the ECOG Performance Scale and if the patient scored two or greater, he or she were invited to participate. If a caregiver was present at the bedside, he or she was also invited to participate at that time. All study subjects provided informed consent to participate. Patients were compensated \$20 for participation.

Data Analysis

Means, standard deviations (SD), 95% confidence intervals (CI), and medians were determined for all continuous data and proportions, and 95% CI were determined for all categorical data. The 13 categories of palliative care need were first ranked according to the proportion of patients who scored above the intra-test cutoff. Because our objective was to use the results in the design of an ED-based palliative care intervention, a threshold of one-half (or 25 patients) was used to determine significance. For each category in which the majority of patients scored above the cutoff on the NEST-13, all results of further testing with ESAS and/or NEST-48 are described whether or not the majority of patients met criteria for intervention.

RESULTS

Enrollment

Of the 92 patients approached for participation, 53 were eligible for inclusion and 50 enrolled (enrollment rate of 94%). Thirty-three were excluded based upon cognitive deficits and six did not meet inclusion criteria based on their functional status. Fourteen primary caregivers were available and all fourteen chose to participate (enrollment rate of 100%). All interviews were completed in their entirety in the ED.

Patient Characteristics

Fifty patients were interviewed, their mean age was 74.3 years ($SD \pm 6.5$), and 29 were female (58%). Race and ethnicity was almost equally divided among white (16 of 50, or 32%), black or African American (18 of 50, 36%), and Hispanic (16 of 50, 32%). Median income was \$25,000/year, and half of the participants had not completed high school. Cancer (21 of 50 patients, 42%) and congestive heart failure (12 of 50, 24%) were the two most commonly reported conditions of the seven inclusion criteria. Table 1 describes patient characteristics in more detail.

Palliative Care Needs

As demonstrated in Figure 1, palliative care needs were reported in all 13 categories of the NEST-13, while a majority of patients exceeded cutoffs for financial need (36/50, 72%), access to care (29/50, 58%), caregiving needs (36/50, 72%), physical health (47/50, 94%), and mental health (31/50, 62%). Results of more detailed testing (ESAS and NEST-48) and need for intervention in these four categories is described below.

Financial Needs ($n = 36$): Patients needed intervention for help with insurance coverage (15, 42%), missing work due to illness (1, 3%), caregivers working to pay medical costs (2, 6%), caregivers missing work to provide care (13, 36%), or using savings or incurring debt to pay medical expenses (9, 25%).

Access to Care ($n = 29$): Six patients (21%) needed help finding providers and/or clinics that could provide care for their particular illness.

Caregiving Needs ($n = 36$): Thirty-two (89%) patients needed help with homemaking tasks, 20 (55.6%) needed help with nursing or personal care, and all 36 had significant limitations in activities of daily living.

Physical ($n = 47$) and *Mental Health* ($n = 31$): Over half of patients met criteria for intervention for pain, fatigue, depression, anxiety, and/or shortness of breath.

Quality of Life (QOL) ($n = 50$): Mean QOL was 3.62 ($SD \pm 2.92$) on the McGill index.

Caregiver Burden: Fourteen caregivers completed the caregiver portion of the survey, with half exceeding the defined cutoff for severe stress. More than half of caregivers reported problems with sleep, confinement, physical strain, and emotional or family problems that were related to caring for a loved one.

DISCUSSION

A cohort of urban, functionally impaired, older adults presenting to the ED with serious illness have substantial palliative care needs, and suffer from many burdensome symptoms. While patients reported needs in all categories, more than half of older adults in our cohort suffered not just from physical symptoms, but also from mental distress, financial hardship, unmet care-giving needs, and difficulty accessing care. They reported problems obtaining specialty care for their conditions, getting insurance to cover treatments, and paying medical bills. They needed assistance with nursing, housekeeping, and personal care, and had limited ability to carry out activities of daily living. Not surprisingly, they rated their overall quality of life poorly.

The mission of emergency medicine has traditionally been to provide life-sustaining and disease-directed treatments for patients with acute illness. For some emergency patients, particularly older adults with advanced and end-stage disease, traditional life-prolonging

treatments offered by emergency providers may not be concordant with patients' goals, or even address the needs for which they sought emergency care. Chronic diseases are now the leading causes of death, and there is a high prevalence of physical, psychosocial, spiritual, and financial suffering associated with serious and complex illness across many systems of care, including EDs.²⁰ The NEST has been shown to be a useful tool in identifying palliative care needs in the inpatient setting,²¹ and our data show that it is also feasible to use in the emergency setting through a research protocol. Clinical feasibility is currently limited by the lack the resources and skill set of emergency providers.

This study is the first step in the design of a palliative care intervention that will be tailored to seriously ill, functionally impaired older adults in the ED. Such patients require assessment and treatment of burdensome symptoms, as well as access to a range of social services that address caregiver, psychosocial, spiritual, and financial needs. Palliative care can be delivered at the same time as curative or life-prolonging therapies, and tailoring the inpatient consultative model to ED patients may relieve some of the burden on emergency providers. Palliative medicine can help match treatments to patients' goals, and is designed to provide the type of interdisciplinary care older adults with serious and complex illness require to achieve the best possible outcomes.

LIMITATIONS

Despite the importance of our findings, our study does have limitations. While it was feasible to conduct a palliative care needs assessment using a research protocol and a trained research assistant, this does not translate into clinical feasibility, especially in a crowded ED where providers have limited time with each patient. Patient sampling was not representative of all seriously ill, older adults, was conducted at only one ED, and does not provide information on the proportion of patients who present to our ED with palliative care needs. Our small sample size makes it impossible to test differences by patient type or draw other conclusions, although we believe it is the first important step in the design of a palliative care intervention that is tailored to patients needs. While we were able to enroll a few caregivers of patients who were unable to participate due to cognitive impairment, over 30 patients who were approached did not pass the cognitive screen, and had no surrogate decision maker present who could provide consent.

CONCLUSIONS

Seriously ill, older adults in an urban emergency department have substantial palliative care needs that are not limited to relief of physical and mental symptoms, but also include financial needs and problems accessing care. Future work should focus on the role of emergency medicine and the new specialty of palliative care in addressing these needs.

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Figure 1.
Percentage of patients exceeding intra-test severity of needs cutoffs for each category on the *NEST-13*.

Table 1

Patient Characteristics (N=50)

Variable	n	% (N = 50)
Age, mean, SD	74.3 y	6.52 y
Male gender, No, %	21	42
Race/Ethnicity		
White	16	32
Black/African American	18	36
Hispanic	16	32
Diagnosis *		
Cancer	21	42
CHF	12	24
ESLD	3	6
ESRD	8	16
CVA	9	18
Pulmonary	7	14
Dementia	2	4
Income		
\$0–24,999	30	60
\$25,000–49,000	11	22
\$50,000–99,999	3	6
\$100,000+	1	2
Education		
Less than high school	18	36
High school/GED	15	30
Some college or higher	17	34

* Some patients suffered from more than one condition; CHF = congestive heart failure; ESLD = end stage liver disease; ESRD = end stage renal disease; CVA = cerebrovascular accident; GED = general equivalency diploma.