

Palliative Care Symptom Assessment for Patients with Cancer in the Emergency Department: Validation of the Screen for Palliative and End-of-Life Care Needs in the Emergency Department Instrument

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Abstract

Objective: We sought to develop and validate a novel palliative medicine needs assessment tool for patients with cancer in the emergency department.

Methods: An expert panel trained in palliative medicine and emergency medicine reviewed and adapted a general palliative medicine symptom assessment tool, the Needs at the End-of-Life Screening Tool. From this adaptation a new 13-question instrument was derived, collectively referred to as the Screen for Palliative and End-of-life care needs in the Emergency Department (SPEED). A database of 86 validated symptom assessment tools available from the palliative medicine literature, totaling 3011 questions, were then reviewed to identify validated test items most similar to the 13 items of SPEED; a total of 107 related questions from the database were identified. Minor adaptations of questions were made for standardization to a uniform 10-point Likert scale. The 107 items, along with the 13 SPEED items were randomly ordered to create a single survey of 120 items. The 120-item survey was administered by trained staff to all patients with cancer who met inclusion criteria (age over 21 years, English-speaking, capacity to provide informed consent) who presented to a large urban academic emergency department between 8:00 AM and 11:00 PM over a 10-week period. Data were analyzed to determine the degree of correlation between SPEED items and the related 107 selected items from previously validated tools.

Results: A total of 53 subjects were enrolled, of which 49 (92%) completed the survey in its entirety. Fifty-three percent of subjects were male, age range was 24–88 years, and the most common cancer diagnoses were breast, colon, and lung. Cronbach coefficient α for the SPEED items ranged from 0.716 to 0.991, indicating their high scale reliability. Correlations between the SPEED scales and related assessment tools previously validated in other settings were high and statistically significant.

Conclusion: The SPEED instrument demonstrates reliability and validity for screening for palliative care needs of patients with cancer presenting to the emergency department.

Introduction

THE EMERGENCY DEPARTMENT is increasingly recognized as an important venue for the identification of palliative care needs, as well as the initiation of related therapeutic interventions.^{1–7} Emergency department visits at the end of life, in particular, have been identified as indicators of poor quality of care.^{1,4} The National Priorities Partnership convened by the National Quality Forum has identified as a quality measure that terminally ill patients should not need

to seek more than one emergency department visit during the last 30 days of life, as a means of obtaining routine palliative care at the end of life. Using tools developed in the palliative medicine clinic setting, recent investigation has shown that emergency department patients have unmet palliative care needs.⁸ Early identification of palliative care needs in the emergency department may lead to better management and reduced need for subsequent emergency department care for physical, spiritual, psychological, or social suffering.

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Accepted February 10, 2011.

Many symptom assessment tools are commonly used in palliative medicine to assess the physical, social, therapeutic, spiritual, and psychological needs of patients. One comprehensive palliative care needs assessment tool is the Needs at the End-of-Life Screening Tool (NEST), a 13-question instrument developed from the experience of terminally ill patients across the United States that screens for palliative care needs in four domains: (1) social needs, (2) existential matters, (3) symptoms (physical and psychological), and (4) therapeutic matters.⁹ The NEST instrument, as well as other palliative care needs assessment tools, have been developed and validated in palliative care and oncology clinic settings. A similarly brief, comprehensive palliative medicine screening tool has not yet been adapted for use in the emergency department setting.

In the emergency department, an ideal symptom assessment instrument should be easily understood by the patient and providers, rapid to administer, simple to analyze and interpret, and valid. An ideal tool should be brief, yet comprehensive, and multidimensional. Such a tool could be used to identify needs and initiate treatment plans that can be continued across care settings—from the emergency department to inpatient or outpatient management.

The objective of this study was to assess the reliability and validity of a novel, comprehensive, palliative care symptom assessment tool designed for use in the emergency department by examining its individual scale reliability and comparing its performance to established palliative care needs assessment tools used in palliative medicine and oncology settings. This tool, the Screening for Palliative Care Needs in the Emergency Department (SPEED) instrument, extends the concept of screening for unrecognized palliative needs in a new but very important setting—the emergency department. Unlike other tools, such as NEST, SPEED was developed by emergency medicine and palliative medicine experts, making SPEED uniquely suited to the emergency department setting.

Methods

Study design

A prospective observational cohort study was used to compare the performance of a palliative care symptom assessment tool to domains of the previously validated NEST tool.

Setting

This study was conducted at an urban, university-based academic medical center with an annual emergency department census of approximately 82,000 patients. A comprehensive cancer center is on site, with a 72-bed inpatient oncology ward and a 16-bed inpatient palliative medicine service.

Formulation of the SPEED instrument

An expert panel of 12 emergency clinicians, including 3 physicians board-certified in both Emergency Medicine and in Hospice and Palliative Medicine, was convened to develop items for the SPEED instrument. All emergency clinicians had a minimum of 10 years of professional, attending-level emergency medicine practice. Each participant had completed the Become an EPEC Trainer or the Become an EPEC-EM Trainer conference offered by The EPEC Project

(Education in Palliative and End-of-life Care)TM and all actively teach palliative and end-of-life care content in their clinical setting. Experts were asked to examine the original NEST instrument (Table 1)⁹ to identify if question domains translated to the most commonly encountered palliative care needs identified in emergency department patients. Participants were then asked to adapt NEST into items that would potentially identify commonly encountered palliative needs in the emergency department setting, as well as have potential to longitudinally evaluate related interventions initiated from the emergency department, while recognizing the unique challenges of the emergency department, such as time constraint in administering a symptom assessment tool. After the expert group data was considered, the SPEED instrument was developed (Table 1) by consensus. In conference, the expert panel reviewed the instrument and concluded that the SPEED screening tool possessed face validity with respect to commonly encountered needs.

Development of validation survey

Item matching. To validate the SPEED questionnaire, each item of SPEED was matched to similar questions from surveys that have been previously validated in clinical settings outside the emergency department. A database of 86 validated symptom assessment tools from the palliative medicine literature, totaling 3011 questions, were reviewed to identify screening questions similar to the 13 items of SPEED.^{9–105}

Item reduction. The 3011-item database was organized by the study team to reflect the core domains of physical, spiritual, psychological, spiritual, and therapeutic. For each item of the SPEED survey instrument, 5 to 13 questions that were most similar to the SPEED items were identified. Included items were similar in intent and wording to the SPEED item and all members of the core study group had to agree on the inclusion of each question. Question stem and answer choices for all selected items were adapted to a Likert 0–10 scale, with 0 meaning “not at all” and 10 meaning “a great deal.” For consistency across all questions, wording was adjusted so that a lower number referred to a more positive patient experience, and a high number meant a negative patient experience. Once items were finalized, all items were randomly ordered, using random number generation, into a single instrument with the 13 SPEED questions to form a 120-item survey.

Selection of participants

Emergency department patients with active cancer were recruited to participate in the study between February and April 2009. All patients over 21 years old who presented between the hours of 8:00 AM and 11:00 PM with a diagnosis of active cancer were surveyed regardless of their chief complaint. For purposes of this study, a patient with active cancer was defined as a patient that (1) was undergoing or in the last 12 months had undergone cancer-directed therapy (radiation/chemotherapy), (2) was known to or found by care providers in the emergency department to have metastatic disease, or (3) reported directly that he or she had symptoms related to known cancer. Patients were excluded if they were non-English speaking, intoxicated, too ill, or otherwise unable

TABLE 1. COMPARISON OF NEST AND SPEED BY ITEM DOMAIN AND QUESTION

| <i>NEST</i> | <i>SPEED</i> |
|---|--|
| | <i>Social</i> |
| <ol style="list-style-type: none"> 1. How much of a financial hardship is your illness for you or your family? 2. How much trouble do you have accessing the medical care you need? 3. How often is there someone to confide in? 4. How much help do you need with things like getting meals or getting to the doctor? | <ol style="list-style-type: none"> 1. How much difficulty are you having with your medication (for example, obtaining medications, knowing how or when to take them, managing side effects)? 2. How much difficulty are you having getting outpatient follow-up (for example, transportation, arranging, making or forgetting appointments)? 3. How much difficulty are you having getting your care needs met at home (for example, bathing, dressing, and meals)? |
| | <i>Therapeutic</i> |
| <ol style="list-style-type: none"> 1. How much do you feel your doctors and nurses respect you as an individual? 2. How clear is the information from the medical team about what to expect regarding your illness? 3. How much do you feel that the medical care you are getting fits with your goals? | <ol style="list-style-type: none"> 1. How much difficulty are you having communicating with your doctors about your care preferences? 2. How much difficulty are you having with the care your clinical team is providing? 3. How much difficulty are you having getting medical care that fits with your goals? |
| <i>Symptom Matters</i> | <i>Physical</i> |
| <ol style="list-style-type: none"> 1. How much do you suffer from physical symptoms such as pain, shortness of breath, fatigue, bowel, or urination problems? 2. How often do you feel confused or anxious or depressed? | <ol style="list-style-type: none"> 1. How much are you suffering from pain? 2. How much are you suffering from shortness of breath? 3. How much are you suffering from other physical symptoms? |
| | <i>Psychological</i> |
| | <ol style="list-style-type: none"> 1. How much are you suffering from anxiety? 2. How much are you suffering from depression? 3. How much are you suffering from feeling overwhelmed? |
| <i>Existential</i> | <i>Spiritual</i> |
| <ol style="list-style-type: none"> 1. How much does this illness seem senseless and meaningless? 2. How much does religious belief or your spiritual life contribute to your sense of purpose? 3. How much have you settled your relationship with the people close to you? 4. Since your illness, how much do you live life with a special sense of purpose? | <ol style="list-style-type: none"> 1. How much does this illness seem senseless or meaningless? |

to complete the instruments, or were unable to provide informed consent.

Methods of measurement

The 120-item tool was administered during daytime hours by trained research assistants. Three research assistants were trained in survey administration and introduced to the aims of the study prior to subject recruitment. During subject recruitment, a research assistant first obtained written informed consent to participate in the study. The research assistant then verbally administered each question in series to the subject. Data was entered into an Excel database (Microsoft, Seattle, WA), using a unique anonymous identifier for each subject. The unit of analysis was the SPEED question, and this was compared to answers for those survey items from matched questions from previously validated surveys.

Primary data analysis

SPSS (IBM, Chicago, IL) was used to obtain the Cronbach coefficient α for each SPEED scale. A value of 0.7 or higher was

considered to indicate good internal consistency of the items in the same scale.

Institutional review board

This protocol was approved through Northwestern University Feinberg School of Medicine Institutional Review Board.

Results

Characteristics of study subjects

A total of 53 subjects were enrolled, and 49 (92%) completed the 120-item survey in its entirety. Fifty-three percent of subjects were male with an age range of 24–88 years and a mean age of 59 years. The most common cancer diagnoses were breast (16%), colon (14%), and lung (14%; Table 2).

Face and content validity

Face and content validity were achieved through expert group consensus of emergency providers with expertise in

TABLE 2. RESPONDENT CHARACTERISTICS

| | |
|----------------------------|-----------|
| Respondents | 53 |
| Female | 47% |
| Age (years), mean (SD) | 59 (16.1) |
| Ethnicity | |
| White | 68% |
| African American | 23% |
| Hispanic | 6% |
| Cancer diagnosis | |
| Breast | 16% |
| Colon | 14% |
| Lung | 14% |
| Lymphoma | 11% |
| Admitted to inpatient ward | 55% |

SD, standard deviation.

emergency medicine and emergency department aspects of palliative care. A national, interdisciplinary group of emergency medicine providers including attending physicians, nurses, nurse practitioners, a chaplain, and a social worker all with more than one decade of professional emergency medicine and principle discipline practice were convened by a series of conference calls to review all of the SPEED items. Each item was discussed in its ability to not only assess a domain, but to have potential impact on the action of the emergency department provider to change management with respect to consultation, disposition, or referral.

Concurrent validity

Cronbach coefficient α for survey scales ranged from 0.716 to 0.991, indicating strong correlation (Table 3). Questions that

dealt with the physical domain of palliative care—namely, pain and shortness of breath—performed particularly well. Questions that dealt with social concerns also met the 0.7 Cronbach α correlation threshold. As is consistent with other validation studies that show a trend toward lower α scores among social domains, the social domains in SPEED exhibit lower overall internal consistency.^{106,107} Additionally, we also performed corrected item correlation, with α ranging from 0.326 to 0.970, suggesting that no one item alone is a predictor for overall burden of palliative care needs.

Limitations

There are several limitations to this study. First, items against which SPEED was validated were modified for scale uniformity. While the investigators kept this modification to a minimum, it could represent a change in the parent question. Scale uniformity could introduce the risk of subjects answering similarly on contiguous questions, however, the benefit of continuity among SPEED items and validating items was thought to outweigh this risk. Additionally, this trend was not observed, and moderated survey administration likely reduced this risk. Items on SPEED in the social domain performed less well than other domains. Items on previously validated surveys that deal with social concerns have also performed less well. SPEED items follow this pattern, which may reflect the nature of the subject matter, but still maintain correlation to answers found on previously validated items. Additionally, because SPEED was not studied independently from the pool of 120 questions used to validate the tool, the time to complete SPEED was not measured. Finally, the patient population in our tertiary medical center emergency department study may not generalize to some emergency department settings. Specifically, our population was mostly

TABLE 3. SPEED SCALE PERFORMANCE

| Domain/SPEED item | Number of items | Cronbach coefficient alpha |
|---|-----------------|----------------------------|
| Physical | | |
| 1. How much are you suffering from pain? | 11 | 0.921 |
| 2. How much are you suffering from shortness of breath? | 11 | 0.991 |
| 3. How much are you suffering from other physical symptoms? | 11 | 0.893 |
| Spiritual | | |
| 4. How much does this illness seem senseless or meaningless? | 11 | 0.890 |
| Social | | |
| 5. How much difficulty are you having getting your care needs met at home (for example, bathing, dressing, and meals)? | 6 | 0.773 |
| 6. How much difficulty are you having with your medication (for example, obtaining medications, knowing how or when to take them, managing side effects)? | 6 | 0.795 |
| 7. How much difficulty are you having getting outpatient follow-up (for example, transportation, arranging, making or forgetting appointments)? | 8 | 0.716 |
| Therapeutic | | |
| 8. How much difficulty are you having getting medical care that fits with your goals? | 11 | 0.910 |
| 9. How much difficulty are you having communicating with your doctors about your care preferences? | 11 | 0.940 |
| 10. How much difficulty are you having with the care your clinical team is providing? | 11 | 0.914 |
| Psychological | | |
| 11. How much are you suffering from anxiety? | 7 | 0.933 |
| 12. How much are you suffering from depression? | 11 | 0.920 |
| 13. How much are you suffering from feeling overwhelmed? | 5 | 0.889 |

Caucasian English-speaking oncology patients in a tertiary care medical center.

Discussion

The SPEED instrument is the first comprehensive symptom assessment tool validated for use with emergency department patients that have palliative or end-of-life care needs.

In the emergency department, patients with complex medical problems may have difficulty communicating their care needs effectively due to their acute distress and provider time constraints. In one emergency department study on communication in a large academic, urban medical center, the time spent on medical introduction and physical examination was 7 minutes and 31 seconds with an average time to first interruption at 12 seconds; only 16% of patients in the study were asked if they had any questions at discharge.¹⁰⁸ In addition to time constraints, other limitations exist as barriers to emergency medicine providers discussing palliative care issues with patients. These include but are not limited to the lack of pre-existing relationship with a patient, perception of death as failure, and a focus on aggressive resuscitation.^{6,109} However, even if the emergency clinician or patient is thinking about complex issues that need to be discussed, patients may not be able to communicate these needs and emergency clinicians may be reluctant to or unskilled at exploring these needs, namely pain management, *de novo*.⁷ The SPEED instrument is a brief, multidimensional symptom assessment tool designed to be comprehensive, yet rapid in the assessment of domains of palliative care in an emergency department.¹¹⁰ The SPEED instrument is intended to assist emergency department providers with a brief comprehensive “first-pass” assessment that allows the identification of palliative needs that likely require intervention either in the emergency department, as an inpatient, or in follow-up. In particular, the social domain of SPEED is meant to assess deeper causal relationships between symptoms and care needs that challenge emergency department patients with serious illness. For example, the patient with a chief complaint of pain may have an underlying issue with medication management—obtaining them, managing them, or experiencing unwanted side effects—that prompted the emergency department visit.

Developed by Emergency Medicine and Palliative Medicine experts, SPEED has unique features that distinguish it from other brief assessment tools and makes this instrument applicable to the emergency department setting. Many brief assessment tools used in palliative medicine or oncology settings are domain focused and can be limited in their applicability in the multidisciplinary emergency department setting. Typically, broader exploration would require two or more screening instruments, which becomes even less practical in an emergency setting. This study shows that respondents’ answers to SPEED scale items correlate well with those items on previously validated symptom assessment tools, across several domains. This indicates that the SPEED instrument is a valid tool to comprehensively, but efficiently assess the palliative care needs of oncology patients presenting to the emergency department.

The present study indicates that the SPEED instrument is a valid survey at identifying palliative care needs in the emergency department. Further studies are required to elucidate the therapeutic and operational implications of

screening for palliative care needs of such patients. Specifically, the operational implications of administering the SPEED tool needs to be further clarified. The SPEED tool is designed to be administered in a quick and efficient manner by all levels of emergency department provider, including physician, nurse, chaplains, and social work. This present study was not designed to study the feasibility of administration of the SPEED tool, but rather to independently validate the individual questions. The accessibility of the survey also lends itself to potential application in a triage kiosk setting as well. Further studies will also have to elucidate if the SPEED tool is effective at identifying the palliative care needs of non-cancer patients as well, such as chronic pain and non-oncologic chronic illness. However, this study demonstrates that the SPEED screening tool is valid to screen for palliative care needs of the oncology patient presenting to the emergency department.

Author Disclosure Statement

No competing financial interests exist.

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