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Initiating End-of-Life Care at the Emergency Department: An Observational Study

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Abstract

Objective: Terminally ill patients at their end-of-life (EOL) phase attending the emergency department (ED) may have complex and specialized care needs frequently overlooked by ED physicians. To tailor to the needs of this unique group, the ED in a tertiary hospital implemented an EOL pathway since 2014. The objective of our study is to describe the epidemiological characteristics, symptom burden and management of patients using a protocolized management care bundle. **Methods:** We conducted an observational study on the database of EOL patients over a 28-month period. Patients aged 21 years and above, who attended the ED and were managed according to these guidelines, were included. Clinical data were extracted from the hospital's electronic medical records system. **Results:** Two hundred five patients were managed under the EOL pathway, with a slight male predominance (106/205, 51.7%) and a median age of 78 (interquartile range 69-87) years. The majority were chronically frail (42.0%) or diagnosed with cancer or other terminal illnesses (32.7%). The 3 most commonly experienced symptoms were drowsiness (66.3%), dyspnea (61.5%), and fever (29.7%). Through the protocolized management care bundle, 74.1% of patients with dyspnea and/or pain received opiates while 59.5% with copious secretions received hyoscine butylbromide for symptomatic relief. **Conclusion:** The institution of a protocolized care bundle is feasible and provides ED physicians with a guide in managing EOL patients. Though still suboptimal, considerable advances in EOL care at the ED have been achieved and may be further improved through continual education and enhancements in the care bundle.

Keywords

emergency department, protocol, care bundle, pathway, initiation, end-of-life care

Introduction

The emergency department (ED) has traditionally focused on the provision of aggressive resuscitation and stabilization of the acutely ill or injured patients.[1-3] However, this approach may not be appropriate for patients having irreversible and terminal, or catastrophic untreatable acute illnesses, who are at the end of their lives.[4-6] As the population of Singapore rapidly ages, the proportion of citizens aged 65 years and above is expected to double to 900 000 by 2030.[7] Consequently, more patients will continue to present to the ED with progressive decline from chronic illnesses. Over half of these deaths will likely be attributable to chronic illnesses.[8] The needs of such patients are often complex and multifaceted, which may be inadequately addressed or overlooked amid the chaos in the ED.[1]

Prior to the introduction of a specific care pathway, the management of patients at the end-of-life (EOL) phase was dependent on the primary ED physicians, with significant variability in care. To deal with the deficits in palliative care in the ED, our hospital, the National University Hospital instituted the EOL pathway in 2014. As the first line of care provision in the health-care system, the ED visit can be critical in shaping the trajectory of the imminently dying patient. The institution of a palliative care protocol may help reduce barriers to starting optimal ED EOL care and facilitate the rapid identification of patients who would benefit from a noncurative, palliative approach, thereby reducing unnecessary patient discomfort, procedures, and costs.[2,9,10] To the best of our knowledge, the impact of quality improvement for EOL care in the ED has not been evaluated in the local setting.

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This study aims to describe the epidemiological characteristics, symptom burden, and management of patients using a protocolized EOL care bundle.

Methods

This observational study utilized the database of EOL patients from our hospital's ED between November 1, 2014 and February 28, 2017. Our hospital is a tertiary university-affiliated academic medical center with about 1100 beds and a yearly ED census of approximately 130 000 patients. During this period of 28 months, patients who attended our ED and were managed according to the EOL pathway were prospectively followed up. Relevant data were collected and entered into this database. Waiver of informed consent for this study was obtained from the local institutional ethics board.

All patients aged 21 years and above, who had attended our ED and managed according to these guidelines, were included in this study. Inclusion criteria were patients assessed by the attending ED physician to be actively dying or having severe illness with very high risk of mortality, necessitating a palliative approach with EOL care (Appendix 1). Patients who were still alive during the database review were excluded for the purpose of this study.

Additional clinical data from these patients were extracted from the electronic medical records. Information on patient demographics, symptoms, comorbidities, baseline function, clinical management (including measures for comfort), disposition, length of hospitalization, cause of death, communications with the family, and prior do-not-resuscitate decisions were reviewed. The EOL pathway was developed by the ED palliative care workgroup in collaboration with the hospital's inpatient palliative care team, which consists of palliative medicine specialists, nurses, and medical social workers. The pathway comprises a care bundle (Appendix 1) with clearly stated clinical management guidelines for ED doctors and nurses, a private room (designated as quiet room) for the patients and their family, and initiatives for EOL care education for ED staff to facilitate the delivery of EOL care at the ED. Members of the palliative care workgroup also provided on-call advice during the initial implementation of the EOL pathway. We delineated the trajectories of dying into 4 categories (Table 1).[11]

Two trained study investigators (M.F.M.I. and S.Y.P.W.) independently reviewed the patient data obtained from the electronic medical records, and a trajectory was assigned based on comorbidities, functional status, clinical presentation, and cause of death. A third investigator (R.Y.P.) adjudicated the final trajectory assigned when there was disagreement between the trajectories designated.

Statistical Analysis

Data were recorded and populated in Microsoft Excel (Microsoft Corp, Redmond, Washington). The data were then exported into Stata version 14 (StataCorp LP, College Station, Texas) for statistical analyses. Categorical variables are reported as proportions while medians with interquartile ranges (IQRs) are reported for continuous variables. The inter-rater reliability for determination of death trajectories was calculated using κ score.

Table 1. Trajectories of Dying.

Advanced cancer	Patients with known cancer that is locally advanced or with distant metastasis
Frailty	Patients who were bed-bound, restricted in their activities of daily living or had severe cognitive impairment
Organ failure	Patients who have conditions, such as cirrhotic liver disease, end-stage renal failure, advanced heart failure, advanced chronic obstructive pulmonary disease, among others
Sudden death	Patients who were healthy or who had stable or early chronic illness prior to the ED visit

Abbreviation: ED, emergency department.

Results

A total of 208 patients were identified as being at their EOL phase and managed according to the EOL care bundle in the ED between November 1, 2014 and February 28, 2017 (Table 2). Three patients were excluded as they were still alive at the time of review. Over half of these patients were males (106/205, 51.7%) with a median age of 78 (IQR: 69-87) years. The majority (166/205, 81.0%) of these patients were self-referred to the ED.

There was very good inter-rater reliability for determination of death trajectories ($\kappa = 0.88$). The trajectories of these patients were predominantly chronic frailty (86/205, 42.0%) and cancer or terminal illness (67/205, 32.7%) (Table 3). A large proportion of these patients had poor premorbid functional status due to multiple medical conditions (35.1%) or oncological conditions with solid tumor cancers (32.7%) (Table 2). Only 30.2% of patients had prior discussion on extent of resuscitation (Table 3).

Regarding clinical presentation, more than half of the patients experienced drowsiness, followed by dyspnea and fever (Table 4). Subjective symptoms such as pain could not be assessed in patients who presented in cardiac arrest. Three-quarters (103/139) of patients with dyspnea and/or pain received opiates for symptomatic relief while 59.5% (25/42) with copious secretions received hyoscine butylbromide. Although the ED has a policy of restricting visitor access into the clinical area, the EOL protocol allowed for the presence of family members at the bedside for 96.6% of these patients. However, only 48.3% experienced privacy with their loved ones at the EOL phase through the use of the quiet room.

A large proportion of patients (155/205, 75.6%) were admitted to the ward while 21.0% (43/205) died in the ED (Table 5). Only 3.4% (7/205) were terminally discharged from the ED to spend their last days at home with their loved ones. The majority (170/205, 82.9%) of the patients died during the same

Table 2. Baseline Demographics and Comorbidities.

Characteristic	Patients (n = 205)
Age (years), median (IQR)	78 (69-87)
Male gender, n (%)	106 (51.7)
Mode of arrival, n (%)	
Public ambulance	188 (91.7)
Walk-in	13 (6.3)
Private ambulance	4 (2.0)
Referral source	
Self	166 (81.0)
Nursing home	24 (11.7)
General practitioner or family physician	5 (2.4)
Home hospice	4 (2.0)
Palliative services	1 (0.5)
Others	5 (2.4)
Baseline function, n (%)	
Bedbound or ADL dependent	105 (51.2)
ADL independent	59 (28.8)
ADL assisted	40 (19.5)
Unknown	1 (0.5)
Underlying primary pathology, n (%)	
Poor premorbid or functional status	72 (35.1)
Solid tumor malignancy	67 (32.7)
Dementia	17 (8.3)
Chronic organ dysfunction	15 (7.3)
Hematological malignancy	4 (2.0)
Nil identified	30 (14.6)
Other comorbidities, n (%)	
Hypertension	134 (65.4)
Diabetes mellitus	65 (31.7)
Cardiovascular disorders	
Ischemic heart disease	52 (25.4)
Arrhythmias	37 (18.1)
Congestive cardiac failure	21 (10.2)
Valvular diseases	10 (4.9)
Neurological disorders	
Cerebrovascular disease	60 (29.3)
Other neurological disease	71 (34.6)
Respiratory disorders	
Asthma	10 (4.9)
Chronic obstructive pulmonary disease	9 (4.4)
Other respiratory diseases	54 (26.3)
Gastrointestinal disorders	75 (36.6)
Renal disorders	54 (26.3)
Endocrine disorders	35 (17.1)
Psychiatric disorders	36 (17.6)
Rheumatological disorders	19 (9.3)

Abbreviations: ADL, activities of daily living; IQR, interquartile range.

admission and more than half of these patients (92/170, 54.1%) died within 24 hours.

Discussion

The global phenomenon of silver tsunami will increase the burden on health-care resources as the prevalence of chronic frailty increases. Advances in technology and management of acute illnesses have helped an increasing number of patients to live long enough to eventually develop cancer, frailty, and end-stage organ disease.[12] These patients will present to the ED with complex medical and psychological needs, seeking help for refractory symptoms and for alleviation of caregiver stress. In our study, 70% of patients already required some or full assistance with activities of daily living prior to presentation at the ED, while more than 90% of the patients at their EOL phase experienced at least 1 symptom that required medical management. This reflects the high acute care needs of patients at the end of their lives, as well as the necessity for a specially tailored care path in the management of such patients.

Table 3. Palliative Care Status and Trajectories of Dying.

Patient Status	Patients, n (%) (n = 205)
Palliative care status[a]	
Previous discussion on limitations of resuscitation	62 (30.2)
On follow-up with home hospice care	47 (22.9)
Previously seen by palliative care	37 (18.0)
No previous discussion on extent of care and not known to a hospice or palliative team	109 (53.2)
Trajectory of dying	
Chronic frailty	86 (41.9)
Cancer or terminal illness	67 (32.7)
Sudden death	42 (20.5)
End-stage organ failure	10 (4.9)

[a]Some patients have more than one palliative care status.

Conventionally, the overcrowded and chaotic ED has been a suboptimal place for EOL care. The lack of a peaceful and tranquil infrastructure in ED does not allow for family members to spend meaningful time with their loved ones during their last moments.[13,14] The ED physicians are also perceived to lack knowledge and confidence in managing such patients as palliative care contradicts their typical training on aggressive resuscitation measures. The initiation of palliative care from ED by emergency physicians was found to be at a dismal rate of 18% in one recent study.[15] Emergency physicians, being at the forefront of hospital health-care delivery, encounter death regularly and should be able to differentiate the need for active resuscitation from futility in aggressive care. Various Colleges for emergency physicians[16,17] recommend for the early recognition of patients at the EOL phase as well as communication and establishments of goals of care in order to initiate palliative treatments in the ED. The provision of comprehensive EOL care bundles are a good step toward this, especially for emergency physicians who may not be proficient in rendering EOL care.

The majority (74.6%) of patients in our study was of the advanced cancer and chronic frailty trajectories. However, close to half of these patients (67/153, 43.8%) did not have any previous discussions on the extent of care and were also not known to any hospice care or palliative services. This may reflect cultural influences on decision-making regarding extent of care. As an Asian society with a strong Confucian ethic, the principle of filial piety is one that is deeply entrenched.[18] As such, seeking the services of palliative care may be unthinkable as it may be

Table 4. Symptoms, Investigations, and Management.

Symptoms, Investigations, and Management	Patients, n (%) (n = 205)
Symptoms[a]	
Drowsiness	136 (66.3)
Shortness of breath[b]	126 (61.5)
Fever	61 (29.7)
Pain[b]	42 (20.5)
Secretions	42 (20.5)
Nausea and/or vomiting	28 (13.7)
Agitation	13 (6.3)
Unable to assess subjective symptoms	26 (12.7)
Symptom burden	
0 symptoms / unable to assess	13 (6.3)
1 to 2 symptoms	117 (57.1)
3 or more symptoms	75 (36.6)
Investigations done in ED	
Blood investigations (excluding arterial blood gas and blood cultures)	174 (84.9)
Arterial blood gas	94 (45.9)
Blood cultures	70 (34.2)
Chest X-ray	174 (84.9)
CT scan	55 (26.8)
Medical management in ED	
IV fluids	155 (75.6)
Opiates	113 (55.1)
Antibiotics	112 (54.6)
Hyoscine butylbromide	38 (18.5)
Antipsychotics	16 (7.8)
Benzodiazepines	6 (2.9)
Supportive management in ED	
Use of the quiet room (for privacy)	99 (48.3)
Family present	198 (96.6)
Primary ED diagnosis	
Infection (respiratory, urinary, skin, or unknown source)	94 (45.9)
Deterioration of underlying pathology	41 (20.0)
Neurological pathology (CVA or ICH)	35 (17.1)
Cardiovascular pathology (IHD, CCF, or aortic pathology)	18 (8.8)
Out-of-hospital cardiac arrest with unclear cause	6 (2.9)
Organ dysfunction (endocrine or renal disorders)	5 (2.4)
Bleeding gastrointestinal tract	5 (2.4)
Others	1 (0.5)

Abbreviations: CCF, congestive cardiac failure; CT, computed tomography; CVA, cerebrovascular accident; ED, emergency department; ICH, intracranial hemorrhage; IHD, ischemic heart disease; IV, intravenous.
[a]Some patients experienced more than 1 symptom.
[b]Of all, 126 patients experienced shortness of breath; 42 patients experienced pain. 139 patients experienced either both or 1 of the 2 symptoms.

Table 5. Clinical Outcomes.

Clinical Outcomes	Patients, n (%) (n = 205)
Disposition from ED	
Admitted to inpatient services	155 (75.6)
Death in ED	43 (21.0)
Terminal discharge from ED	7 (3.4)
Death within the same admission (in-hospital)	170 (82.9)
Length of stay in ED (hours), median (IQR)	4.70 (3.18-6.88)
Length of stay in hospital (days), median (IQR)	0.64 (0-3.6)

Abbreviations: ED, emergency department; IQR, interquartile range.

perceived as "giving up" on therapy for one's loved ones.[19] This may be coupled with inadequate or incorrect perceptions on what palliative care encompasses.[20] Another barrier may also be the physician's lack of familiarity with palliative care or approaches as well as EOL communications.[21-24] To overcome these barriers, more resources need to be channeled toward public education pertaining to palliative care, increase palliative care education for physicians, as well as the development of systems facilitating a seamless transition to palliative care.

One in 5 (20.5%) patients in our study cohort experienced a sudden, unexpected death. This trajectory of death will be most familiar to ED physicians who handle this scenario more often than any other specialty in the hospital. In this unique group of patients, the abruptness of decline presents additional considerations and challenges. The lack of a uniform definition of medical futility leads to ambiguity in its implementation among physicians.[25,26] In the local context, in the absence of an advanced medical directive, the final authority in medical decision-making lies with the treating physician. Involving and collaborating with family members early in this decision-making process is crucial. However, the difficulty of explaining medical futility, coupled with a short time frame from health to imminent death, psychosocial turmoil, and spiritual needs of family members, often presents a herculean task to the health-care professionals in the emergency setting. A lack of acceptance by family members during this dark time often becomes a key barrier despite enunciation of the prolonged suffering experienced by the patient through futile resuscitation measures.

Various initial interventions were instituted for the EOL patients when they presented to the ED. Most patients (84.9%) had some form of blood investigations performed. The initial blood tests may aid in the prognostication of patients in the sudden death group by serving as objective measures of the severity of the acute illness and in determining its reversibility, especially in patients whose premorbid statuses are not well understood or information not readily available. This helps to streamline decision-making, shifting toward EOL care rather than continuing aggressive resuscitation. However, the utility of these blood investigations may be minimal or even redundant in those who are chronically sick and imminently dying, causing unnecessary distress and discomfort to the patient.

More than half (54%) of the patients studied had received antibiotics. Yet, the benefit of antibiotics in patients in the EOL phase is not well elucidated.[27] Different studies have yielded conflicting results in this aspect. A prospective cohort study reported prolonged survival but did not improve comfort in nursing home residents with advanced dementia following antibiotic treatment of suspected pneumonia.[27] In contrast, another study similarly looking at patients with dementia found that giving antibiotics resulted in alleviation of discomfort.[28] Other

studies exploring the effect of antibiotics in terminally ill patients have produced similarly divergent results.[28,29] With the evidence available, it is difficult to draw conclusions on whether giving antibiotics to the terminally ill is beneficial.

Despite most people in the local population citing their own home as the preferred place of death,[30] there was an extremely low rate of terminal discharges from the ED (3.4%). This low proportion of terminal discharges may be due to physician as well as patient and family factors. On the part of the physician, it may be more time-consuming and disruptive to the usual workflow in the ED to arrange for a terminal discharge. In particular, there is limited access to community palliative services that are needed to facilitate home care support upon terminal discharge.[23] From the family's perspective, refractory symptoms and caregiver fatigue may be the main reasons these patients present to the ED for review and admission.[12] Even in patients with advanced medical directives, family members may feel fearful and helpless when there is an acute worsening of symptoms such as pain and breathlessness. Lee and Pang found that while relatives of patients with cancer had an almost equal preference for the patient to be at home or in the hospital for terminal care, 37.5% of those who initially wanted their loved ones to be in the hospital would prefer them to spend their final hours or days at home if there was adequate support.[30] This suggests the need for greater accessibility, coordination, and better development of home hospice services.

Bailey and colleagues grouped ED deaths as "spectacular—a sudden, often traumatic event leading to death," and "subtacular—the gradual process of dying in the terminally ill, presenting for symptom management."[1] Our study demonstrated that most of the patients were of the latter group, and management of dying patients undeniably constitutes a significant portion of emergency work. Our study further shows that the institution of an EOL care bundle may help improve the quality of care rendered through the early identification of patients and subsequent provision of care to palliate distressing symptoms such as pain and dyspnea. It also highlights gaps that can be improved upon in the delivery of palliative care, such as allowing more EOL patients to experience privacy with their loved ones in a quiet room and the facilitation of terminal discharges.

Limitations

Our study has several limitations. Firstly, although the database of patients was prospectively populated, electronic medical records were retrospectively reviewed for some clinical variables, with its inherent misclassification and information biases. Secondly, we were unable to determine the circumstances of death in patients who were terminally discharged. Finally, the assignment of a single dying trajectory may perhaps be an oversimplification of the dying process in some of the cases. This may be especially so in patients with cancer or organ failure resulting in frailty, where assigning a single trajectory may indeed be difficult. We tried to circumvent possible biases by having 2 independent study investigators, along with a third adjudicator as required, in the assignment of trajectories to ensure that each patient in the study was assigned as appropriate a trajectory as possible. This assignment of trajectories may act as a useful tool in prognostication and deciding on goals of care.

Conclusions

Our study demonstrates the feasibility of introducing an EOL care bundle to improve the consistency of care of EOL patients in the ED. Emergency department physicians need to be well versed with EOL goals of care given the increasing attendances of such patients. Though still suboptimal, considerable improvements in EOL care in the ED have been achieved and can be improved further through continual education and quality improvement projects involving health-care professionals and the public.

Authors' Note

The authors have made various contributions to this study including (i) the conception and design of this study (ii) data acquisition, analysis and interpretation (iii) drafting, revision and final submission of this manuscript.

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Supplemental Material

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