Original Article

Validation of "Care of the Dying Evaluation" in Emergency Medicine (CODE-EM): pilot phase of end-of-life management protocol offered within emergency room (EMPOWER) study

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Background: An increasing number of patients who present to emergency departments are at their end-of-life phase and have significant palliative care needs such as in symptom control for pain and dyspnoea. Evaluating quality of care provided is imperative, yet there is no suitable tool validated in the emergency and Asian settings. We aim to examine the face and construct validity, and reliability of a newly developed questionnaire, Care of the Dying Evaluation - Emergency Medicine, for measuring the quality of end-of-life care in an Asian emergency context.

Methods: A mixed methods pilot study was conducted. Participants composed of the next-of-kin to thirty dying patients who presented to the emergency departments of three public hospitals in Singapore. Qualitative evaluation, using cognitive "think-aloud" interviews, and quantitative analysis were employed. Percentage agreement and κ statistic were measured to evaluate temporal stability of the questionnaire. Cronbach's α and item-total correlations were used to assess internal consistency within the constructs. Confirmatory factor analysis was performed for construct validity.

Results: All participants reported clear understanding of the questionnaire with no ambiguity; a minority felt the questions caused emotional distress (7/30, 23.3%). The questions showed moderate to good test-retest reliability. Internal consistencies within the constructs were good for "ENVIRONMENT" and "CARE", and moderate for "COMMUNICATION". Factor loadings range from 0.40 to 0.99.

Conclusions: The Care of the Dying Evaluation - Emergency Medicine questionnaire may be valid and reliable for use in an Asian emergency setting. Our prospective multicentre study using this evaluation tool may provide more insight on the quality of care rendered to dying patients and identify areas for improvement.

Trial registration: ClinicalTrials.gov (NCT03906747).

Keywords: Palliative care; terminal care; hospital emergency services; quality of care

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Introduction

Globally, the population is ageing, with the number of persons aged 80 years and above projected to rise to 425 million by 2050, a three-fold increase from 2017 (1). Consequently, an increase in chronic illnesses and comorbidities is prevalent among patients presenting to the emergency departments (EDs), rendering the care of such patients to be more complex. More patients will be attending EDs for symptom control, mental distress, ease of access to healthcare and caregiver stress at their end-of-life phase (2,3), which is defined by the European Society for Emergency Medicine as patients facing a rapid deterioration in health with imminent death in an emergency medicine setting (4). Such critically ill and dying patients have significant palliative care needs that include management of moderate to severe symptoms of pain, fatigue and dyspnoea (3). Apart from infrastructural constraints due to its inherent chaotic and overcrowded environment (5,6), emergency physicians are also inadequately trained in pain and symptom management for such patients (7).

While some efforts have been undertaken to establish protocolised management pathways for ED end-of-life patients, quality of care is still not optimised and more can be done (8). To cope with changing demands in healthcare needs in the EDs, the assessment of quality of care rendered to end-of-life patients is particularly important to identify areas for improvement to ensure a good death. One such available instrument is the "Care of the Dying Evaluation" (CODE^{TM}), a shortened and validated version of "Evaluating Care and Health Outcomes – for the Dying" which measures components relating to best practice for care of the dying, previously validated in a Caucasian population within the community settings (9).

CODE^{TM} is a 40-item self-administered questionnaire that evaluates the quality of care in the last days of life and immediate post-bereavement period. Within CODE^{TM}, three constructs, 'CARE', 'ENVIRONMENT' and 'COMMUNICATION', are examined in detail. However, it has not been validated in a predominantly Asian population and was not administered in an ED setting. Differences in perspectives and attitudes towards end-of-life care are known to exist among various ethnic groups (10,11), and these differences may be more apparent among Asians who are generally thought to be more conservative and reserved in exploring end-of-life issues due to cultural and religious beliefs (12,13). Furthermore, the experience and interaction of patients and family members with the clinical team in ED may contrast with their regular palliative or hospice care providers as there is no pre-existing patient-physician relationship, and ED physicians are less adept at dealing with death-related issues (14). We aim to validate the use of the CODE^{TM} questionnaire in the EDs of a multi-ethnic Asian population in Singapore.

This study constitutes the pilot phase of our multi-centre study, "End-of-life Management Protocol Offered Within Emergency Room" (EMPOWER); the final and complete study protocol has been published separately (15). The objectives of this pilot were to examine the face and construct validity, and reliability of a newly developed questionnaire for measuring the quality of end-of-life care in EDs in the Asian context, taking reference from the CODE^{TM} questionnaire (9).

We present the following article in accordance with the STROBE reporting checklist (available at http://dx.doi.org/10.21037/apm-21-380).

Methods

Study design

We conducted a mixed methods study between January and April 2019 at the EDs of three public hospitals [National University Hospital (NUH), Changi General Hospital (CGH) and Khoo Teck Puat Hospital (KTPH)] in Singapore. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). Ethics approval was obtained from the National Healthcare Group Domain Specific Review Board (DSRB reference no: 2018/00838) and the study protocol was registered with ClinicalTrials.gov (NCT03906747). All enrolled participants provided written informed consent.

Study setting

The public hospitals included in this study, namely NUH,

CGH and KTPH, belong to the three main healthcare clusters in Singapore – the National University Health System, Singapore Health Services and National Healthcare Group, which serve the country's western, eastern and northern populations, respectively (16). Each of these three hospitals are tertiary centres with annual ED census of more than 100,000 attendances.

Patient selection

Next-of-kin of patients who fulfilled all the following inclusion criteria were invited to participate:

- ❖ Actively dying patient or high likelihood of mortality within the current admission (based on attending physician's clinical judgement using available clinical data);
- ❖ Family accepts that the goals of care are provision of comfort, symptom relief and respect of dignity;
- ❖ Patient is not a candidate for cardiopulmonary resuscitation, endotracheal intubation or transfer to the intensive care unit due to medical futility from acute or underlying medical conditions (these include patients who may already have do-not-resuscitate orders established before coming to ED or after thorough assessment upon arrival to ED);
- ❖ Any of the life-limiting conditions: chronic frailty with poor functional state and limited reversibility [Karnofsky Performance Scale (KPS) <40%] (17); chronic severe illness with poor prognosis [terminal cancer, end-stage renal failure (refusal or withdrawal of dialysis), end-stage respiratory, heart or liver disease, advanced neurological disease]; or, acute severe catastrophic conditions and at risk of dying with complications that are not reversible, as subject to the treating clinician's judgement.

We excluded the following subjects: vulnerable population (for example prisoners and pregnant women); refusal to participate; patients who have been recruited, or had declined participation during the previous ED attendance(s); patients in peri-arrest state; and/or family members who are not present at the patient's bedside.

Study procedure

Participants, i.e., next-of-kin of end-of-life patients, were requested to complete the newly developed questionnaire renamed "Care of the Dying Evaluation - Emergency Medicine" (CODE-EM) (Appendix 1), derived using the original 40-item CODE^{TM}. The questions were selected due to their relevance to the ED settings and the other items were removed as they were not applicable in our area of practice. Wordings of the original questions were also rephrased as required to fit the ED context. Details of which questions were omitted or amended and the rationale for doing so are illustrated in Table S1. This first questionnaire completion was done at bedside in the EDs after the patients had received treatment, before or shortly after transfer to wards, terminal discharge from the EDs (where patients passed away at home) or death occurring in EDs.

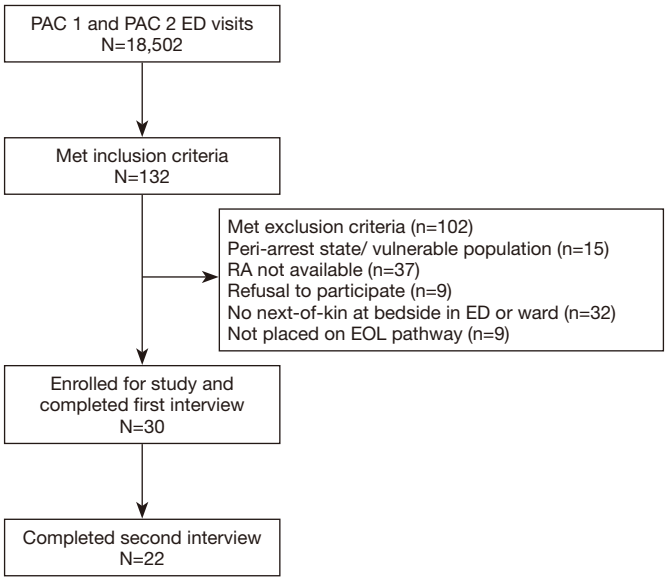
After completion of the questionnaire, an interview about their experience was conducted by trained research assistants to prompt participants to articulate their thoughts (the "think-aloud" method for cognitive interviews) as they read and answered the questions (18). This helped to improve our knowledge about whether the questions had been understood and how answers had been formulated, in terms of language, length, timing and relevance. Additionally, a standard set of interview questions was asked as a combined approach to elicit its clarity and appropriateness. The key questions included in the interview are as follows:

(I) Were the questions easy to understand and was the wording clear?
(II) Did the questions make you feel emotionally distressed?
(III) Were any of the questions irrelevant?
(IV) What were your thoughts on the length of this survey?
(V) Was the survey conducted at an appropriate timing?
(VI) Any other feedback you would like to share?

For those who were willing to complete the questionnaire for a second time, the second interview was conducted by phone or by mail with a return envelope one month later.

Data collection

The questionnaires and interviews were conducted by trained research assistants at each study site and responses recorded real-time on standardized paper-based case report forms. Data collected is then entered anonymously into an electronic database in the Research Electronic Data Capture (REDCap) system and maintained at the Singapore Clinical Research Institute's secured server.



ED - emergency department; EOL - end-of-life; PAC - patient acuity category; RA - research assistant; PAC 1 were patients with imminent cardiorespiratory compromise, requiring immediate attention while PAC 2 were those who require urgent attention, failing which deterioration is likely.

Figure 1 Flowchart illustrating patient screening and enrolment.

Statistical analysis

The interviews about the experience of completing the questionnaire was recorded. To ensure data integrity, a random selection of completed questionnaires and written interview transcripts (n=15) were independently reviewed to check for data entry errors by a study investigator (MTC) not directly involved in data collection; any discrepancy was verified and discussed with a third independent investigator (WSK).

Quantitative analysis was carried out using R, version 4.0.0 (R Foundation for Statistical Computing, Vienna, Austria). The temporal stability of the developed questionnaire, CODE-EM, was assessed using the following measures: percentage agreement and κ statistic (Cohen's for nominal response options and weighted for ordinal response options). As the kappa might not be reliable for rare observations, the criteria for good stability over time are defined as percentage agreement >70% or κ >0.60 and moderate stability over time as percentage agreement >30% or κ >0.40 (19,20). Cronbach's α and item-total correlations were measured to assess internal consistency within the three constructs of "CARE", "ENVIRONMENT" and "COMMUNICATION". Confirmatory factor analysis was used to assess construct validity. The suitability of questions was examined by inspection of the Comparative Fit Index (CFI).

Results

Participants' and patients' characteristics

During the enrolment period, there were 18,502 eligible patient visits and 132 patients fulfilled our inclusion criteria; 102 patients were excluded due to various reasons (*Figure 1*). A total of 30 bereaved next-of-kin (participants) agreed to participate (76.9%). All of them completed the CODE-EM questionnaire and were interviewed in the first assessment; 22 of them (73.3%) completed the CODE-EM questionnaire a second time one month later (*Table 1*). Just over half of the end-of-life patients (17/30, 56.7%) were male while the participants comprised more females (16/30, 53.3%). There was a predominance of Chinese ethnicity among both patients and participants (*Table 1*). A summary of their baseline demographics is illustrated in *Table 1*. Most of the deceased patients had chronic frailty as the predominant death trajectory (19/30, 63.3%), followed by sudden death (5/30, 16.7%), cancer (4/30, 13.3%) and organ failure (2/30, 16.7%). Patients experienced multiple symptoms, with dyspnoea affecting two-thirds (20/30, 66.7%), while others experienced drowsiness (16/30, 53.3%), weakness or fatigue (11/30, 36.7%), excessive secretions (7/30, 23.3%), terminal

Table 1 Summary of end-of-life patients and participants' characteristics and interview results

Variables	Categories	Results, N (%)
EOL patients (n=30)		
Median age, in years (IQR)		82.5 (78 to 89)
Gender	Male	17 (56.7)
	Female	13 (43.3)
Race	Chinese	23 (76.7)
	Malay	5 (16.7)
	Indian	1 (3.3)
	Others	1 (3.3)
Next-of-kin participants (n=30)		
Gender	Male	14 (46.7)
	Female	16 (53.3)
Race	Chinese	22 (73.3)
	Malay	5 (16.7)
	Indian	1 (3.3)
	Others	2 (6.7)
Relationship to EOL patients	Spouse	3 (10.0)
	Child	21 (70.0)
	Grandchild	4 (13.3)
	Niece/nephew	1 (3.3)
	Employed caregiver	1 (3.3)
Completed 2nd assessment	Yes	22 (73.3)
Were the questions easy to understand/wording was clear?	Yes	30 (100.0)
Did the questions make you feel emotionally distressed?	Yes	7 (23.3)
Were any of the questions irrelevant?	Yes	7 (23.3)
What are your thoughts on the length of this survey?	Just nice	27 (90.0)
	Too long	3 (10.0)
Was the survey conducted at an appropriate timing?	Yes	20 (66.7)

EOL, end-of-life; IQR, interquartile range. Results presented in n (%) unless otherwise stated. EOL patients are actively dying patients or patients who have high likelihood of mortality within the current admission. Next-of-kin participants refer to the next-of-kin of these EOL patients; next-of-kin participants completed the Care of the Dying Evaluation - Emergency Medicine (CODE-EM) questionnaire.

restlessness (5/30, 16.7%), delirium (5/30, 16.7%), cough (4/30, 13.3%) and vomiting (2/30, 6.7%).

Interview results

All the participants reported a clear and easy understanding of the questionnaire with unambiguous wording. Only a minority felt that the questions made them emotionally distressed (7/30, 23.3%) (*Table 1*); among them, some generally felt disturbed as the questionnaire involves discussion of death and particularly in Q19 (which asks if the next-of-kin was informed that the patient would die soon) where a strongly emotive word, "die," was used.

Seven participants (23.3%) perceived that some of the

Table 2 Results of rest-retest reliability

Questions	Raw agreement	Kappa statistics	Rate
Q1	0.55	0.34	Moderate
Q2	0.55	0.6	Moderate
Q3	0.45	0.55	Moderate
Q4	0.55	0.44	Moderate
Q5	0.77	–0.08	Good
Q6	0.86	0.33	Good
Q7	0.41	0.22	Moderate
Q8	0.36	–0.01	Moderate
Q9	0.55	0.36	Moderate
Q10	0.41	0.27	Moderate
Q11	0.68	0.57	Moderate
Q12	0.68	0.55	Moderate
Q13	0.73	0.41	Good
Q14	0.5	0.29	Moderate
Q15	0.5	0.33	Moderate
Q16	0.41	0.39	Moderate
Q17	0.36	0.56	Moderate
Q18	0.36	0.08	Moderate
Q19	0.91	0.61	Good
Q20	0.45	–0.1	Moderate
Q21	0.68	0.47	Moderate
Q22	0.68	0.4	Moderate
Q23	0.91	0.46	Good

Tables S1 and S2 illustrate the questions in CODE-EM and the modifications from original CODE™, respectively.

questions were irrelevant. One example was a participant who considered Q7 (which enquires if the patient appears to be in pain) extraneous as he was unable to tell if the unconscious patient was in pain and suggested that the study team tailor the questions to cater for such circumstances.

Many of the participants (27/30, 90.0%) thought the length of the survey was "just nice", while 3 of them felt it was "too long". Two-thirds of the participants (20/30, 66.7%) reported that the survey was conducted at an appropriate timing. For those who responded that the survey should be conducted later, there was no consensus on the best possible timing. More details on the interview answers with open questions are summarised in Table S2.

Test-retest reliability

Two statistics measuring test-retest reliability, i.e., raw agreement and kappa statistics, are reported in *Table 2*. Negative kappa values were obtained for Questions 5, 8 and 20, which indicate that kappa did not function well in these questions and we had to rely solely on raw agreement. Questions that explored the participants' trust and confidence in ED nurses and doctors (Q5 and Q6), whether patients appeared to have breathing difficulty (Q13), communication regarding imminent death (Q19) and overall support given in ED (Q23) showed "good" test-retest reliability. All other questions achieved "moderate" reliability.

Table 3 Result of internal consistency and construct validity

Composite scale	Mean score [range]	Internal consistency		Construct validity
		Cronbach's α	Item-total correlation	Factor loadings
Environment (ranges from 3–15)	6.79 [3–13]	0.84		
Q2: The bed area in the ED and surrounding environment was comfortable for the patient			0.93	0.99
Q3: The bed area in the ED and surrounding environment was comfortable for the family			0.71	0.42
Q4: The bed area in the ED and surrounding environment had adequate privacy for the patient			0.75	0.33
Care (ranges from 4–16)	6.00 [4–11]	0.73		
Q1: There was enough help with nursing care in the ED, such as giving medicines, changing diapers and helping the patient find a comfortable position in bed			0.39	0.59
Q5: Did you have confidence and trust in the ED nurses who were caring for the patient?			0.68	0.47
Q6: Did you have confidence and trust in the ED doctors who were caring for the patient?			0.68	0.40
Q17: How would you assess the overall level of emotional support given to you by the ED healthcare team?			0.8	0.94
Communication	3.40 [2–6]	0.66		
Q15: During the time in the ED, the patient's care and treatment was discussed with you and/or the family			0.43	0.87
Q16: The healthcare team at the ED explained the patient's condition and treatment in a way you found easy or difficult to understand			0.43	0.28

ED, emergency department.

Internal consistency

The internal consistency was good for "ENVIRONMENT" (Cronbach's α=0.84) and "CARE" (Cronbach's α=0.73) suggesting that the inter-item correlations were high, and the items were reliable as individual scales (*Table 3*). However, the internal consistency of "COMMUNICATION" was moderate with a Cronbach's α of 0.66.

Construct validity

The Comparative Fit Index (CFI) was 0.87 confirming suitability of the data for factor analysis. The factor loadings for most of the questions were relatively high, ranging from 0.40 to 0.99, except Question 16 (factor loading =0.28) and Question 4 (factor loading =0.33) (*Table 3*).

Discussion

The results from this pilot study support the feasibility of the use of CODE™ in a culture (multi-racial Asian population) and environment (ED setting) that is vastly different from its original validation cohort (9). In our sample, CODE-EM demonstrated good face and content validity, and moderate to good test-retest reliability over time. From the results of the post-questionnaire interviews, only one question (Q19) required minor change in the wordings used, where participants expressed that the word "die" was too 'strong' and alternative wording was suggested. This finding is consistent with a previous local study (21). Otherwise, the CODE-EM was largely well-received by our pilot cohort and did not cause emotional distress in the vast majority despite death being considered generally taboo in the local population who have disparate

cultural and religious beliefs (22,23).

We observed good internal consistency for items under "ENVIRONMENT" (Cronbach's α=0.84) and "CARE" (Cronbach's α=0.73). This is especially important in ED where overcrowding with packed trolleys and lack of privacy for grieving are frequent issues (6,24,25). Assessing quality of care under these 2 components will be paramount for improvement.

Asians are known to have different perspectives about death and are generally phobic of discussing death openly (22,23). While the main core constituents of a "good death" such as alleviation of pain and the need for closure remains the same among different ethnicities, there are variations in degree of importance of these elements due to underlying cultural and religious diversity that shape an individual's experience (26). Additionally, the cultural diversity also means that death and grief experiences are handled differently among family members of various ethnicities (23). To ensure a "good death", fulfilment of palliative care needs of imminent dying patients in the ED is becoming more pressing due to the growing number of acutely ill ageing population (27). Moreover, barriers to implementation of end-of-life care in the ED have been well recognised (5,6,28). Such challenges include a fast-paced environment with limited information at-hand, lack of rapport and relationship with patients on regular palliative care follow-up, the default "save-all" mentality among ED physicians and perceived difficulty in dealing with bereaved family members (28). In this pilot, we have shown that the CODE-EM questionnaire is a valid and reliable instrument to assess quality of end-of-life care both in the Asian context and emergency setting. Knowledge on deficiencies will facilitate future infrastructure planning and enhanced care pathways. This information can be used to improve emergency end-of-life care in various EDs across the globe.

In our pilot study, 6 out of the 7 participants who felt distressed actually commented the timing was appropriate. It is possible that bereaved next-of-kin may find it consoling and therapeutic to participate in such surveys to talk about their experience, which may aid in emotional healing and closure (29,30). Given the sensitive nature of the topic, there is no good and appropriate time, as evident by the lack of consensus among our study cohort on when is the best time. Yet, it is also important to minimise recall bias and the assessment should be conducted as early as possible.

The default focus of ED physicians is to provide aggressive care to "reverse" death, which may inadvertently lead to futile care and may not alleviate suffering of the dying (31). Understanding the perspectives of the next-of-kin using CODE-EM on how their loved ones were cared for may encourage change in practice mentality among ED physicians. Components in CODE-EM can also allow us to identify if emergency physicians are deficient in specific domains such as pain management or communications. These results can effect targeted changes in training syllabus in the emergency residency programme, with added focus and specialised courses on areas of inadequacies.

Apart from medical management, communications including addressing emotions and spiritual needs is an important component in end-of-life care. While previous qualitative studies have shown ED personnel to be lacking in such communications (32,33), our assessment tool will quantify the extent of inadequacy from the perspectives of bereaved family members. The CODE-EM questionnaire will allow us to pinpoint shortcomings in various aspects of ED palliative care, especially in terms of care, communications and infrastructure. Following this pilot, we have proceeded with a multicentre study using CODE-EM to evaluate the quality of end-of-life care provided in the ED (15). Our study findings in a multicultural Singapore will advise potential barriers and areas for improvement in palliative care among ED patients internationally.

Strengths and limitations

One of the strengths of our study include generalisability in our local population, as the ethnic distribution in our pilot mirrors the proportions of each race in Singapore (34). Also, our cohort comprised an almost equivalent proportion of male (46.7%) and female (53.3%) participants, which would give a good representation of acceptability and emotional effects from both genders.

In addition, as opposed to the original CODE™ validation study in which the relatives were enrolled 2 to 3 months after bereavement (9), our participants were approached at the bedside in ED while their loved ones were acutely ill. This may add to their emotional burden but would have reduced recall bias with real-time evaluation.

Our study has its limitations. First, our sample size is relatively small with 30 participants. As this was a pilot phase of a larger prospective multi-centre study (15), our main aim was to assess feasibility and validity of using this questionnaire in our population with maximum achievable sample size within our specified timeframe. The study results showed our participants were quite representative of our local population in terms of the gender and

ethnicity distribution (34). Further, we achieved a response rate of 76.9% among eligible participants based on our selection criteria and a fairly high retest participation rate of 73.3% to assess test-retest reliability. Second, although different ethnic groups have been found to have similar ease in discussing death (21), the predominance of Chinese ethnicity in our study may have resulted in under-representation of other ethnic groups. Hence, the results may not be applicable in countries with dissimilar ethnic proportions.

Third, while we tried to provide more robust data by adopting two methods of statistical testing (percentage agreement and kappa) for test-retest reliability, kappa measures showed extreme or negative values in some questions and we could only rely on raw percentage agreement. Although kappa is commonly used to measure agreement and has the advantage of not being based on probabilistic model (20), it performs poorly when marginal distributions are very asymmetric and may be difficult to interpret (35). When kappa is inadequate in certain questions, we used percentage agreement to supplement such limitation.

Fourth, we only observe moderate consistency in "COMMUNICATION". This could be related to a slightly different angle of the questions and fewer items within this construct, as we had to ensure that the questionnaire was of an acceptable length in light of the emotional distress the participants could be facing. However, item-total scores for both Q15 and Q16 were more than 0.4, which indicated very good discrimination (36). This suggests that the items had high inter-item correlations and worked well together as individual scales.

Conclusions

This pilot study shows CODE-EM may be a valid and reliable evaluation tool for assessing quality of end-of-life care among Asian ED patients. It may help us understand the perspectives of the bereaved next-of-kin on the quality of end-of-life care rendered in the EDs and in a real-time fashion at patients' bedside, minimising recall bias. Our prospective multicentre study will further advise current barriers so that improvements can be made to better end-of-life care for ED patients internationally.

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Footnote

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Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study was approved by the National Healthcare Group Domain Specific Review Board (DSRB reference no: 2018/00838) and informed consent was taken from all individual participants.

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Appendix 1 CODE-EM Family Survey Tool

CODE-EM Questionnaire						
1	There was enough help with nursing care in the ED, such as giving medicines, changing diapers and helping the patient find a comfortable position in bed.	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
2	The bed area in the ED and surrounding environment was comfortable for the patient.	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
3	The bed area in the ED and surrounding environment was comfortable for the family.	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
4	The bed area in the ED and surrounding environment had adequate privacy for the patient	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
5	Did you have confidence and trust in the ED nurses who were caring for the patient?	Yes, in all of them	Yes, in some of them	No, not in any of the nurses		
6	Did you have confidence and trust in the ED doctors who were caring for the patient?	Yes, in all of them	Yes, in some of them	No, not in any of the doctors		
7	In your opinion, during the patient's stay in the ED, did the patient appear to be in pain?	Yes, all of the time	Yes, some of the time	No, s/he did not appear to be in pain		
8	In your view, did the doctors and nurses in the ED do enough to help relieve the pain?	Yes, all of the time	Yes, some of the time	No, not at all	Not applicable, s/he was not in pain	
9	In your opinion, during the stay in the ED, did the patient appear to be restless?	Yes, all of the time	Yes, some of the time	No, s/he did not appear to be restless		
10	In your view, did the doctors and nurses in the emergency department do enough to help relieve the restlessness?	Yes, all of the time	Yes, some of the time	No, not at all	Not applicable, s/he was not restless	
11	In your opinion, during the stay in the ED, did the patient appear to have a "noisy rattle when breathing?	Yes, all of the time	Yes, some of the time	No, s/he did not have a noisy rattle to the breathing		
12	In your view, did the doctors and nurses in the ED do enough to help relieve the "noisy rattle" when breathing?	Yes, all of the time	Yes, some of the time	No, not at all	Not applicable, s/he did not have a noisy rattle to the breathing	
13	In your opinion, during the stay in the emergency department, did the patient appear to have difficulty breathing?	Yes, all of the time	Yes, some of the time	No, s/he did not have difficulty breathing		
14	In your view, did the doctors and nurses in the emergency department do enough to help relieve the breathing difficulty?	Yes, all of the time	Yes, some of the time	No, not at all	Not applicable, s/he did not have difficulty breathing	
15	During the time in the ED, the patient's care and treatment was discussed with you and/or the family.	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
16	The healthcare team at the ED explained the patient's condition and treatment in a way you found easy or difficult to understand.	Very easy	Easy	Neutral	Difficult	Very Difficult
17	How would you assess the overall level of emotional support given to you by the ED healthcare team?	Very poor	Poor	Fair	Good	Excellent
18	The ED healthcare team discussed the patient's religious or spiritual needs.	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
19	Were you told that the patient would be likely to die soon?	Yes	No			
19a)	If yes, who told you s/he was likely to pass away soon?					
20	Did a member of the ED healthcare team talk to you about what to expect during the dying process (e.g. what symptoms may arise)?	Yes	No			
20a)	If yes → Was the discussion about what to expect during the dying process helpful?	Yes	No			
20b)	If no → Would a discussion about what to expect during the dying process have been helpful?	Yes	No			
21	In your view, the patient was treated with respect and dignity by the ED doctors.	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
22	In your view, the patient treated with respect and dignity by the ED nurses.	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
23	Overall, in your opinion, were you adequately supported during the patient's stay in ED?	Yes	No			

CODE-EM, Care of the Dying Evaluation - Emergency Medicine; ED, emergency department.

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Table S1 Derivation of CODE-EM from original CODE questionnaire

	Original CODE[TM]	CODE-EM	Rationale for change
1	There was enough help available to meet his/her personal care needs, such as washing, personal hygiene and toileting needs. Scale: • Strongly agree • Agree • Neither agree nor disagree • Disagree • Strongly disagree	Omit	Not always required during ED stay, shorten survey, point regarding nursing care included in question 2 instead.
2	There was enough help with nursing care, such as giving medicines and helping him/her find a comfortable position in bed. Scale: • Strongly agree • Agree • Neither agree nor disagree • Disagree • Strongly disagree	There was enough help with nursing care **in the ED**, such as giving medicines, **changing diapers** and helping the patient find a comfortable position in bed. -Use same scale	Specific to ED stay
3	The bed area and surrounding environment was comfortable for him/her. Scale: • Not applicable, s/he died at home • Strongly agree • Agree • Neither agree nor disagree • Disagree • Strongly disagree	- The bed area in the ED and surrounding environment was comfortable for the patient. - **The bed area in the emergency department and surrounding environment was comfortable for the family.**	- Specific to ED stay - Modification in scale: remove 1st option - Additional question to assess family's comfort in the ED environment.
4	The bed area and surrounding environment had adequate privacy for him/her. Scale: • Not applicable, s/he died at home • Strongly agree • Agree • Neither agree nor disagree • Disagree • Strongly disagree	The bed area **in the ED** and surrounding environment had adequate privacy for the patient.	- Specific to ED stay - Modification in scale: remove "NA, s/he died at home" option
5	In your opinion, how clean was the ward area that s/he was in? Scale: • Not applicable, s/he died at home • Very clean • Fairly clean • Not at all clean	Omit	Not a major issue in ED
6	Did you have confidence and trust in the nurses who were caring for him/her? Scale: • Yes, in all of them • Yes, in some of them • No, not in any of the nurses	Did you have confidence and trust in the **ED nurses** who were caring for the patient? -Use same scale	Specific to ED stay
7	Did you have confidence and trust in the doctors who were caring for him/her? Scale: • Yes, in all of them • Yes, in some of them • No, not in any of the doctors	Did you have confidence and trust in the **ED doctors** who were caring for the patient? -Use same scale	Specific to ED stay
8	The nurses had time to listen and discuss his/her condition with me. Scale: • Strongly agree • Agree • Neither agree nor disagree • Disagree • Strongly disagree	Omit	As time is often limited due to the fast pace in ED, effective communication by ED staff may be better measured by how much the family was involved and understood i.e., questions 16 and 19 below.
9	The doctors had time to listen and discuss his/her condition with me. Scale: • Strongly agree • Agree • Neither agree nor disagree • Disagree • Strongly disagree	Omit	As above
10	In your opinion, during the last two days, did s/he appear to be in pain? Scale: • Yes, all of the time • Yes, some of the time • No, s/he did not appear to be in pain	In your opinion, during the **patient's stay in the ED**, did the patient appear to be in pain? -Use same scale	Specific to ED stay
11	In your view, did the doctors and nurses do enough to help relieve the pain? Scale: • Yes, all of the time • Yes, some of the time • No, not at all • Not applicable, s/he was not in pain	In your view, did the doctors and nurses **in the ED** do enough to help relieve the pain? -Use same scale	Specific to ED stay
12	In your opinion, during the last two days, did s/he appear to be restless? Scale: • Yes, all of the time • Yes, some of the time • No, s/he did not appear to be restless	In your opinion, during the stay **in the ED**, did the patient appear to be restless? -Use same scale	Specific to ED stay
13	In your view, did the doctors and nurses do enough to help relieve the restlessness? Scale: • Yes, all of the time • Yes, some of the time • No, not at all • Not applicable, s/he was not restless	In your view, did the doctors and nurses in the emergency department do enough to help relieve the restlessness? -Use same scale	Specific to ED stay
14	In your opinion, during the last two days, did s/he appear to have a 'noisy rattle' to his/her breathing? Scale: • Yes, all of the time • Yes, some of the time • No, s/he did not have a noisy rattle to the breathing	In your opinion, during the stay **in the ED**, did the patient appear to have a "noisy rattle" when breathing? -Use same scale	Specific to ED stay
15	In your view, did the doctors and nurses do enough to help relieve the 'noisy rattle' to his/her breathing? Scale: • Yes, all of the time • Yes, some of the time • No, not at all • Not applicable, s/he did not have a noisy rattle to the breathing	In your view, did the doctors and nurses **in the ED** do enough to help relieve the "noisy rattle" when breathing? -Use same scale	Specific to ED stay
		In your opinion, during the stay in the emergency department, did the patient appear to have difficulty breathing? -Use same scale as above	Additional question, to review the 4 main symptoms (pain/SOB/rattle/agitation) included in our clinical charts.
		In your view, did the doctors and nurses in the emergency department do enough to help relieve the breathing difficulty? -Use same scale as above	As above
16	During the last two days, how involved were you with the decisions about his/her care and treatment? Scale: • Very involved • Fairly involved • Not involved	During the time **in the ED, the patient's care and treatment was discussed with you and/or the family.** Scale: • Strongly agree • Agree • Neither agree nor disagree • Disagree • Strongly disagree	Specific to ED stay and a more objective measure of communication by ED staff. Rephrased as a statement using a 5-point scale.
17	Did any of the healthcare team discuss with you whether giving fluids through a 'drip' would be appropriate in the last two days of life? Scale: • Yes • No • Don't know	Omit	Not routinely discussed in the ED
18	Would a discussion about the appropriateness of giving fluids through a 'drip' in the last two days of life have been helpful? Scale: • Yes • No • Not applicable, we had these types of discussions	Omit	As above
19	Did the healthcare team explain his/her condition and/or treatment in a way you found easy or difficult to understand? Scale: • Very easy • Fairly easy • Fairly difficult • Very difficult • They did not explain his/her condition or treatment to me	**The healthcare team at the ED explained the patient's condition and treatment in a way you found easy or difficult to understand.** Scale: • Strongly agree • Agree • Neither agree nor disagree • Disagree • Strongly disagree	Rephrased as a statement using 5-point scale
20	How would you assess the overall level of emotional support given to you by the healthcare team? Scale: • Poor • Fair • Good • Excellent	How would you assess the overall level of emotional support given to you by the **ED** healthcare team? -Use same scale	Specific to ED stay
21	Overall, his/her religious or spiritual needs were met by the healthcare team. Scale: • Strongly agree • Agree • Neither agree nor disagree • Disagree • Strongly disagree	**The patient's religious or spiritual needs were discussed with the ED healthcare team.** -Use same scale	We do not have chaplain services in ED, but we can review patient's religious background and offer to allow the family to bring in their own religious support or conduct rituals.
22	Overall, my religious or spiritual needs were met by the healthcare team. Scale: • Strongly agree • Agree • Neither agree nor disagree • Disagree • Strongly disagree	Omit	No routine assessment of family's spiritual needs.
23	Before s/he died, were you told s/he was likely to die soon? Scale: • Yes • No → If 'Yes', who told you s/he was likely to die soon?	**Were you told that the patient would be likely to die soon?** -Use same scale → If 'Yes', who told you s/he was likely to die soon?	Similar but rephrased as patient may not have died yet in the ED
24	Did a member of the healthcare team talk to you about what to expect when s/he was dying (e.g., symptoms that may arise)? Scale: • Yes • No	Did a member of the **ED** healthcare team talk to you about what to expect when the patient was dying (e.g., what symptoms may arise)? -Use same scale	Specific to ED stay
25	Would a discussion about what to expect when s/he was dying have been helpful? Scale: • Yes • No • Not applicable, we had these types of discussions	Would a discussion about what to expect when the patient was dying have been helpful? -Use same scale	Same
26	In your opinion did s/he die in the right place? Scale: • Yes, it was the right place • No, it was not the right place • Not sure • Don't know	Omit	Patient may not have died in the ED
27	I was given enough help and support by the healthcare team at the actual time of his/her death. Scale: • Strongly agree • Agree • Neither agree nor disagree • Disagree • Strongly disagree	Omit	Patient may not have died in the ED
28	After s/he had died, did individuals from the healthcare team deal with you in a sensitive manner? Scale: Yes No Not applicable, I didn't have any contact with the healthcare team	Omit	Patient may not have died in the ED
29	How much of the time was s/he treated with respect and dignity in the last two days of life? Please answer for both doctors and nurses Scale: • Always • Most of the time • Some of the time • Never • Don't know	**In your view, the patient treated with respect and dignity by the ED doctors.** **In your view, the patient treated with respect and dignity by the ED nurses.** Scale: • Strongly agree • Agree • Neither agree nor disagree • Disagree • Strongly disagree	Same but we have formatted as 2 separate questions. -Using the standard 5-point scale
30	Overall, in your opinion, were you adequately supported during his/her last two days of life? Scale: • Yes • No	Overall, in your opinion, were you adequately supported during the patient's stay **in ED?** -Use same scale	Specific to ED

Omit = question not to be included in our study; In bold = changes in wording of the question; The patient is referred to as the "patient" rather than s/he or him/her to suit our local language use. CODE[TM], Care of the Dying Evaluation; ED, emergency department.

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Table S2 Summary of pilot study responses on the questionnaire

Questions	Yes	No	Open question results	Actions on the questionnaire revision
1. Were the questions easy to understand/wording was clear?	30 (100%)	0 (0%)		No actions
1a. If no, which questions?				
1b. How can this be improved?				
2. Did the questions make you feel emotionally distressed?	7 (23.3%)	23 (76.7%)		Revise the wording in Q19
2a. If yes, which questions?			Q13, Q19	
2b. How can this be improved?			Q13: One participant noticed that his mother was struggling to breathe when he arrived at the ED. He also noticed that the space in ED was constrained, but felt it was understandable. Hence, he thought that these could be improved. *(Subject ID NPP002, male)* Q19: One participant felt that the word 'die' carries a strong meaning. He suggested to change to something more neutral (i.e., worsen). *(Subject ID NPP007, male)* General comments: Two participants commented that the questionnaire was generally difficult to answer as the topic was on death at a point in time when their loved ones were actively dying. Overall, the questions made them feel emotionally distressed. *"No particular question, emotionally distressed in general in view of current situation" (Subject ID KPP013, male)* *"(Emotionally distressed) in general, as this concerns life and death" (Subject ID NPP011, male)*	
3. Were any of the questions irrelevant?	7 (23.3%)	23 (76.7%)		No actions
3a. If yes, which questions?			Q5, Q6, Q7, Q18, Q19, Q20	
3b. How can this be improved?			Q5 & Q6: One participant commented that she came to the hospital with confidence in staff/professionals and thus, should not be asked these questions. *(Subject ID CPP001, female)* Q7: One respondent felt that he was unable to tell if his grandfather was in pain as he (patient) was unconscious. He thinks that if there were no symptoms, the family would not have sent the patient to the ED, thus he felt that we could tailor the questions accordingly. *(Subject ID NPP004, male)* Q18 (Subject KPP004 chose "Neutral"): "Doctor did not raise this question at all" *(Subject ID KPP004, male)* Q18 (Subject KPP006 did not choose any answers): One participant felt that this question was irrelevant and may also be insensitive. *(Subject ID KPP006, female)* Q19 & Q20: One respondent mentioned that these two questions seemed to be overlapping. *(Subject ID KPP001, male)* Q20: Participant felt that this question was irrelevant as he was already aware of dying process beforehand. *(Subject ID KPP003, male)*	
4. What are your thoughts on the length of this survey?	Just nice: 27 (90.0%)	Too long: 3 (10.0%)		No actions
4a. If too long, which questions should be taken out?			• *"Not sure, slightly too long." (Subject ID KPP007, female)*	
5. Was the survey conducted at an appropriate timing?	20 (66.7%)	10 (33.3%)		No actions
5a. If you feel the timing was inappropriate, what would be a better timing? (Other options e.g. should be done later in the ED/after the patient's demise/a week later, etc)			• *"Probably best later" (Subject ID CPP002, male)* • *"At least 1 day after demise" (Subject ID KPP003, male)* • *"1-2 days after admission to ward" (Subject ID KPP006, female*) • *"Unsure" (Subject ID KPP008, female)* • "(*The timing*) would depend on the condition of the patient." *(Subject ID NPP003, female)* • One respondent felt that the stay in ED was not long enough and a more appropriate time would be after the patient had "completed" the stay (i.e. admitted to inpatient ward). *(Subject ID NPP004, male)* • *"There is no 'good' time. It all depends on individuals' coping." (Subject ID NPP011, male)* • *"A week later would be more appropriate." (Subject ID NPP012, male)*	
6. Any other feedback you would like to share with us?			• One participant suggested that there should have been a place for the body other than the mortuary while waiting for undertaker. *(Subject ID CPP001, female)* • "Range of choices should be shortened." *(Subject ID KPP001, male)* • For Question 19, one respondent commented that "Yes or No" does not answer the question as the attending doctor did not explicitly state imminent demise but merely explained in terms of higher probability of death. *(Subject ID KPP004, male)* • *"Might be too long for others in this situation" (Subject ID KPP008, female)* • *"The timing of conducting the survey can be quire subjective. But for family, it was appropriate. Waiting time for bed is too long." (Subject ID NPP001, female)* • *"Length of survey might be subjective; depends on the state of mind of the interviewee. Waiting time for bed is unbearable." (Subject ID NPP003, female)* • One participant felt that the survey should be conducted at a time when it's "not too early or too late". *(Subject ID NPP005, female)*	No actions

ED, emergency department.

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