# Peer Review File

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**Reviewer A**

The development of CODE-EM, an assessment of the quality of care delivered in an emergency department setting for Asian patients, may help to better inform future initiatives directed as improving the care delivered for this vulnerable population.

*Abstract*

Comment 1: Line 33: May be beneficial to elaborate on what is included in the phrase "significant palliative care needs".

Reply 1: "Significant palliative care needs" include symptom control for moderate to severe pain, dyspnoea or fatigue.

Changes in text: We have elaborated more on this in both the Abstract and Introduction. The text has been updated in page 3, lines 67 to 68 for Abstract and page 5, lines 115 to 116 for Introduction.

Comment 2: Line 38: Participants comprised of the next of kin…

Reply 2: We respectfully disagree with the reviewer on the use of "comprised of". Several reputable dictionaries (e.g., Merriam-Webster [https://www.merriam-webster.com/words-at-play/can-you-use-comprised-of-grammar]) have discouraged its use. Nevertheless, to avoid ambiguity, we shall change the phrasing to "composed of".

Changes in text: We have changed the text to "Participants composed of the next-of-kin to thirty dying patients…" in page 3, line 74.

*Introduction*

Comment 3: Line 64: Change to a three-fold increase from 2017

Reply 3: This has been changed.

Changes in text: We have modified our text as advised (page 5, line 108).

Comment 4: Line 67: Would recommend rewording this sentence as patients may not only present for symptom management but also for distress around EOL, caregiver burden, reservations around death occurring at home, etc.

Reply 4: We thank the reviewer for the insightful suggestion. We have modified this statement to include the recommendation.

Changes in text: The new statement now reads: "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)." This is updated in page 5, lines 111 to 114 of Introduction.

Comment 5: Line 81: Change to self-administered questionnaire

Reply 5: This has been changed.

Changes in text: We have modified our text as advised (page 5, line 127).

Comment 6: Line 83: it would be helpful to know in what context this questionnaire has been previously validated to give the readers a point of comparison.

Reply 6: The CODE questionnaire was previously validated in a population that consisted of predominantly White British (95.8%) and Christians (76.4%) in a community setting *(reference: Mayland CR, Lees C, Germain A, et al. Caring for those who die at home: The use and validation of "Care Of the Dying Evaluation" (CODE) with bereaved relatives. BMJ Support Palliat Care 2014;4:167–174).*

Changes in text: We have modified the text to "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 setting (9)" in page 5, lines 123 to 126.

Comment 7: Line 90: would elaborate on "palliative or hospice care" here. It seems you're referencing the interaction of patients previously seen by palliative or hospice care providers but it is unclear.

Reply 7: We thank the reviewer for this suggestion. Yes, we are referring to the

patients' regular palliative and hospice care providers.

Changes in text: We have amended the text to "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…" in page 6, line 136.

*Methods*

Comment 8: Line 138: what is the difference between terminal discharge from the ED or death?

Reply 8: "Terminal discharge from EDs" refers to situations where patients are alive upon discharge from EDs and subsequently passed away at home while "death" refers to patients who died in the ED.

Changes to text: We have changed the text in page 8, lines 191 to 193 to clarify this. The new statement reads, "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."

Comment 9: A comment re the goal of achieving a good death (line 250) within the Asian community. It strikes me that the definition of a good death may be strikingly different for Asian patients. I would recommend that the author include any research or data that has sought to define this in your particular patient population.

Reply 9: The concept of a "good death" consists of similar core components across ethnic groups but are greatly shaped by individual personal experiences, underlying diseases and cultural beliefs.

Changes to text: We have added in this statement "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" in page 13, lines 305 to 308 to reflect this. *(Reference: Krikorian A, Maldonado C, Pastrana T. Patient's Perspectives on the Notion of a Good Death: A Systematic Review of the Literature. J Pain Symptom Manage 2020;59:152–164.)*

Comment 10: Line 254: please define long term palliative care.

Reply 10: In our study, "long term palliative care" refers to patients who are on regular outpatient follow-up and review with the palliative care teams.

Changes to text: We have changed the phrase "long term palliative care" to "regular palliative care follow-up" for clarity in page 13, line 315.

Comment 11: Line 280: replace "shortfall" with "shortcomings"

Reply 11: This has been changed as suggested.

Changes to text: We have amended the text in page 14, line 340.

**Reviewer B**

I would like to congratulate the authors with successfully validating the CODE-EM within an Asian setting. Although the authors are already quite transparent and clear about their method, I do have a few questions and recommendations.

*Major comments*

Comment 1: In the introduction section the authors state to validate the CODE™ in a multi-ethnic Asian population. The results show a predominance of Chinese ethnicity followed by Malay and rarely Indian or others. I understand the conclusion that the study includes generalisability to their local population and can be seen as a strength. However, I fail to understand the conclusion that the results of the pilot are unlikely to be affected given that different ethnic groups have been found to have equal ease in discussing death. I believe that this conclusion should be taken more cautiously as the number of people with Malay and Indian ethnicity are small, and, information regarding religion (which might also influence the ease of discussing death) is lacking.

Reply 1: We have amended this comment and changed it to a limitation.

Changes to text: This statement has been amended under Limitation: "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" in pages 15 to 16, lines 364 to 367.

Comment 2: In the conclusion section the authors conclude that the pilot study shows CODE-EM to be valid and reliable for assessing quality of end-of-life care among ED patients, which is true for the Asian ED setting. I would recommend the authors to

explicitly include the setting in the conclusion. Moreover, I would recommend the authors to also include this setting in the title.

Reply 2: We thank the reviewer for the suggestion. We have made this clearer in our Conclusion.

Changes to text: The phrase "among ED patients" has been changed to "among Asian ED patients" in page 16, line 384.

Comment 3: Although the authors provide the CODE-EM Questionnaire in the supplementary material, I believe the paper would benefit from being more transparent about which question are removed from the original CODE questionnaire, and if relevant, why. I am aware that the authors state in the caption of table 2 that 23 out of 40 CODE™ questions were used due to its relevance to the ED setting. However, it would help me as a reader, when the removed questions are mentioned (in the supplementary material).

Reply 3: In order to explain the modifications of the original CODE™ to derive a ED-relevant CODE-EM questionnaire, we have added in a Supplementary Table 2 comparing the original and new questionnaires, including rationale behind the changes and omission of certain questions.

Changes to text: We have changed the footnote under Table 2 to "Supplementary Tables 1 and 2 illustrate the questions in CODE-EM and the modifications from original CODE™, respectively."

*Minor comments*

Comment 4: I believe the readability of table 1 could benefit from: 1) making a clearer distinction between EOL patients and participants, and 2) providing the total number of patients/participants.

Reply 4: We have amended Table 1 to make the distinction clear, "participants" are renamed as "next-of-kin participants" and the total numbers of EOL patients and next-of-kin participants have also been added into the subheadings of the table. Additionally, we added a footnote to define these 2 populations.

Changes to text: Changes have been made to Table 1.
The following footnote is added:
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.

**Reviewer C**

Emergency presentation for end-of-life patients is unavoidable, and studies such as this one contribute to improving the quality of dying and quality of death of end-of-life patients, and are of great significance. The burden on the respondents is also taken into consideration, and the feasibility is also evaluated. Let me ask you some questions.

Comment 1: I didn't understand how CODE-EM was created. How did you develop it from CODE?

Reply 1: We used relevant questions out of the original 40-item CODE™ for our CODE-EM questionnaire and rephrased some wordings to suit the ED context. The questions were selected due to their relevance to the emergency department settings and the other items were removed as they were not applicable in our area of practice. This was done in discussion with Dr Catriona Mayland, the principal investigator for the original CODE™ questionnaire. Details of which questions were omitted or amended and the rationale for doing so are now illustrated in Supplementary Table 2.

Changes to text: We have elaborated on this in page 8, lines 184 to 191: "… the newly developed questionnaire renamed "Care Of the Dying Evaluation - Emergency Medicine" (CODE-EM) (Supplementary Table 1), derived using the original 40-item CODE™. 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 Supplementary Table 2."

Comment 2: Is it necessary to verify the correlation with other measuring means?

Reply 2: Due to the small number of questions, we decided to use Comparative Fit Index (CFI) and factor analysis for assessing the construct validity without measuring the correlation matrix. Based on the current results, the 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).

Changes to text: No change was made to the text.

Comment 3: For COMMUNICATION, the internal validity and item-total score are not high enough. The number of questions is small and it is difficult to evaluate, but are there any plans to improve it in the future?

Reply 3: We do agree with the reviewer that the small number of questions is a limitation. However, even though the measures are lower than the other sections, we still observe an item-total correlation of 0.43 which is considered to be "very good discrimination" (https://www.questionmark.com/item-total-correlation/). Due to the emotional distress from the acute or imminent loss of their family member, the questionnaire would need to be of an appropriate length. Hence, there was the consideration to keep the length of the questionnaire short; despite so, the COMMUNICATION section still performed an acceptable level.

Changes to text: We have elaborated more under Limitations in page 16, lines 375 to 379. 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).

Comment 4: Due to the small number of samples, I think it is too early to draw conclusions about reliability and validity. It is a pilot study, and it is well worth the study, but I think that the expression of the conclusion needs to be changed.

Reply 4: We thank the reviewer for the comment. We will revise it in a more conservative way.

Changes to text: We have changed the Conclusion in page 16 lines 383 to 385 to: "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…"

**Reviewer D**

The authors conducted the mixed methods study to examine the CODE questionnaire, which is a tool to evaluate the EOL care in EDs.
Overall, this is a well-written manuscript, but there are several things that need to be clarified for further improvement.

*Major concerns*

Comment 1: It is mentioned that each of the 3 study cites has an annual ED census of more than 100,000 (line 113). In line 181, the screened patients are only 39 with 3

institutions combined. This seems very small for that census. Do you have the number of how many ED visits during the study period?

Reply 1: The annual census of more than 100,000 refers to all patients who attend the Eds. These include walk-in patients and ambulance cases with any condition such as trauma, cardiac arrest and myocardial infarction. During the period of this pilot study (between January and April 2019), there were 18,502 patient visits in Patient Acuity Category (PAC) 1 and PAC 2; and these patients were screened for eligibility. These were patients who required either immediate (PAC 1) or urgent (PAC 2) medical attention and had attended ED for any reason. PAC 1 patients are those with imminent cardiorespiratory compromise while PAC2 are those who requires early attention, failing which deterioration is likely. PAC 3 (ambulatory and non-urgent) patients were not included as EOL patients are sick and not triaged to PAC 3 based on our EDs' routine practice. Of these 18,502 patient visits, 132 patients fulfilled our inclusion criteria and 102 patients were excluded due to various reasons. We have included a new Figure 1 to explain these numbers with better clarity. The original number of 39 referred to only the 30 recruited patients and 9 patients who refused participation.

Changes to text: We have expanded in the Results section on number of patients screened in page 10 lines 236 to 237 and included Figure 1 for clarity.

Comment 2: The main objective of this study is the validity and reliability of the tool, CODE. Is a sample size of 30 good enough for that purpose? It might be good enough for feasibility, but it is not clear for validity/reliability. If it is enough, please describe the rationale somewhere (either methods or discussion section).

Reply 2: As it is an exploratory analysis without statistical testing, we were unable to derive a sample size for the justification. The small number of sample size might cause imprecision for the analysis in the pilot study, and we will further assess it in a larger scale. To account for the limitation, we will revise the conclusion in a more conservative way.

Changes to text: We have changed the Conclusion in page 16, lines 383 to 385 to: "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…"

Comment 3: Based on the post-survey interview, the authors interpreted that 7 surrogates (23.3%) said it was emotionally distressing and stated that wording has to be adjusted. The author also said that the timing of the survey was appropriate because 20 (66.7%) said yes. However, this means 33.3% didn't think it is appropriate. The interpretation of the interview results seems somewhat subjective. Is

a 23.3% (who felt distressing) a good enough number so that wording has to be changed? The interpretation of the interview results needs to be more clarified.

Reply 3: We recognise that the interpretation of the interview results could be subjective. Due to the sensitive nature of the research topic, the emotive component of the survey question contributed heavily to the decision to alter the wording despite not having a specific cut-off proportion. The primary concern was to minimise any emotional distress to any of the participants through a minor change in wording (the word "die" was changed to "pass away"). We agree with the reviewer that the inappropriateness of the timing of the survey is also worthy of consideration, though less easily addressed. The participants were also unable to provide consensus on alternative timing of the survey and we have reflected this in the Discussion: "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."

Changes to text: No change has been made to the text.

*Minor concerns*

Comment 4: Line 121, "patient is not a candidate for cardiopulmonary resuscitation…" What do you mean by "not a candidate"? Does that mean the patient was already DNR/I?

Reply 4: We refer to patients who were not likely to benefit from cardiopulmonary resuscitation, endotracheal intubation, or transfer to the intensive care unit due to medical futility from acute or underlying medical conditions. These patients may already have do-not-resuscitate orders established before coming to ED or after thorough assessment upon arrival to ED.

Changes to text: We have elaborated on this under "Patient selection" in page 7, lines 170 to 172.

Comment 5: Line 169. What is the definition of "catastrophic death"?

Reply 5: Catastrophic death refers to sudden death by an acute calamitous event such as massive intracranial haemorrhage in an otherwise healthy individual. We had classified our death trajectories based on this reference: *Lunney JR. Patterns of Functional Decline at the End of Life. JAMA; 2003;289(18):2387.* To align with the original words used for classification and to make it clearer for readers, we have changed the phrase "catastrophic death" to "sudden death".

Changes to text: We have updated the text in page 10, line 245.