Variations in nurse involvement in end-of-life practices in intensive care units worldwide (ETHICUS-2): a prospective observational study.

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Abstract

Purpose

explore global ICU nurse involvement in end of life decisions, ETHICUS-2 prospective multinational, observational study was performed.

Methods

This is a secondary analysis of data obtained from the ETHICUS-2 study. Patients were followed until ICU discharge, death, or 2 months from the first decision to limit life-prolonging therapies. Data were collected by an ICU clinician recording end of life decisions typically at the time of first limitation. Nursing related questions included: were withholding or withdrawing treatment discussed with nurses? Who initiated the end of life discussion? Was a nurse involved in making the end of life decision? Was there agreement between physicians and nurses. Global regions were compared related to these four questions.

Results

A significant difference was found between regions, (p< .001) with Northern Europe and Australia/New Zealand having the most discussion with nurses and Latin America, Africa, Asia and North America the least. The percentages of nurses who were involved end of life decision ranging between 3-44%, the differences were statistically significant. Agreement between physicians and nurses related to decisions resulted in wide range of responses (27-86%) (p < .001). The percentages of EOL decisions in which agreement between physicians and nurses was not applicable included a wide range of responses from 0-41%

Conclusion

A large variability in nurse involvement in end of life care in the ICU was found. Perhaps due to perception of physicians and nurses view of themselves. Varying levels of expertise and experience of clinicians.

Take-home message

This study highlights the pressing need to establish a shared decision-making process between nurses and physicians in many regions globally to enhance end-of-life care for patients.

Introduction

Intensive Care Units (ICUs) were initially designed to provide treatment and save the lives of acutely ill patients. Unfortunately, despite all attempts, some patients die in the ICU. A 2014 global epidemiological audit described ICU mortality rates ranging from 9.3 to 26.2% [1]. Furthermore, most deaths in the ICU are not unexpected, and goals and choices transition from extending life to preserving a reasonable quality of life and providing end-of-life (EOL) palliative care [2].
ICU doctors and nurses agree that the senior physician is the most appropriate and legal person to decide whether life-saving measures should continue or not [3]. The process of end of life decision making should take all key shareholders' perspectives into consideration [4;5]. Nurses most frequently are present at the bedside, devoting time providing care for both patients and family members. They play a crucial role as coordinators between all parties involved in decision making [6]. Despite this, research suggests that nurses have a limited role in the EOL decision-making process, and are occasionally excluded [7;8].

Van den Bulcke, et al. explored the ethical decision-making climate in the ICU, they found that a good ethical climate is one in which team members respect each other and where nurses are involved in decision making. The team validated an ethical climate tool using a Delphi iterative consultation process among clinicians from 68 adult ICUs in 13 European countries and the USA. The investigators found active involvement of nurses in EOL care, a culture of not avoiding EOL decisions and ethical awareness as crucial elements in a good ethical climate [9].

Global differences in nurse involvement in EOL decisions exist [10;11;12;13]. A multi-center European study exploring 4,248 ICU EOL decision showed a wide range of physician-reported nurse involvement, from 2 to 100% of all EOL decisions [14]. A USA survey including 598 ICU nurse perspectives of palliative care communication, found that 60% of the sample agreed that physicians do not ask for nurses’ perspectives on prognosis, goals of care, and palliative care and that only 41% of the nurses believed that physicians support nurses’ involvement in these discussions [12]. Several studies from South African, Bahrain and Turkey found that 70–75% of nurses were not involved in the decision-making process [15;13;16]. Other qualitative investigations found similar results. Furthermore, nurses do not consider that they had a voice when presenting their professional viewpoints when a do not resuscitate (DNR) directive was being considered [13]. O’Neill et al performed a study in Bahraini describing the nurses’ role within the clinical team as being order- oriented, in that the nurses carried out the orders of the doctor [13]. A Norwegian study exploring perceptions of nurse involvement of 27 relatives of 21 deceased patients found that while the nurses provided excellent compassionate bedside care, they were vague and evasive in their communication, and only a few relatives commented that nurses participated in meetings with doctors and relatives [7].

These studies describe a wide range of nurse involvement in EOL practices.

The aim of this paper is to explore global nurse involvement in EOL decisions based on a secondary analysis of a prospective multinational, observational study, of consecutive adult ICU patients included in the ETHICUS-2 study.

**Method**

This study is a secondary analysis of data obtained from the ETHICUS-2 study. It investigated EOL in 199 ICUs in 36 countries worldwide, including 8 prospectively defined regions- Africa, Asia, Central, Northern and Southern Europe, Latin and North America and Australia/New Zealand [2]
Participants

A total of 12,850 consecutive adult patients admitted to participating ICUs who died or had any limitation of life-saving interventions over a 6-month period were selected for inclusion. Patients were followed until ICU discharge, death, or 2 months from the first decision to limit life-prolonging therapies. End-of-life outcomes were classified into 5 mutually exclusive categories: withholding or withdrawing of life-prolonging therapy, active shortening of the dying process, failed CPR, and brain death [2].

The study instrument included several items addressing nurse involvement in EOL issues. These questions were: (1) Was withholding or withdrawing treatment or shortening of the dying process discussed with nurses? (2) Who initiated the discussion of the issue of withholding, withdrawing and/or shortening the dying process? (3) Was a nurse involved in making the end of life decision? (4) Was there agreement between physicians and nurses related to this decision? Global regions were compared for responses to these four issues.

Data were collected by an appointed ICU clinician, either physician or nurse, who then recorded end of life decisions or their unit representative, typically at the time of first limitation, and some data were collected following this time point. Data from each patient were entered into the Ethicus-2-dedicated and secure website.

Data Analysis. Data were analyzed with the software SPSS (Version 25 for Windows; IBM SPSS, Armonk, NY, USA). The descriptive analysis included proportions, means, and standard deviation. The inferential analysis was performed using the chi-squared test and Camer’s V level of association for categorical variables. The level of significance was set at 0.05.

Ethical declaration of a waiver of informed consent and investigational review board approval was obtained for each participating center based on the fact that this was an observational study acquiring only data available in the medical record, which were predefined study variables such as co-morbidities, date and time of ICU and hospital admission and religion of physician and patient. No study interventions were performed and all patients remained anonymous.

Results

This secondary analysis included 12,850 patients or 14.6% of the total 87,951 admissions for the 199 centers during the 6-month study period. Treatment limitations occurred in 10,401 (80.9%) of the study patients. The most common limitation was withholding life-sustaining therapy (5661 [44.1%]), followed by withdrawing life-sustaining therapy (4680 [36.4%]), then active shortening of the dying process (60 [0.5%]) [2].

There was great variation between regions as to whether withholding or withdrawing therapy or shortening of the dying process was discussed with nurses (range: 11–62%). In addition, the range of responses that were missing for this item ranged from 9–68%. A statistically significant difference was
found between regions, \(p < .001\) with Northern Europe and Australia/New Zealand having the highest discussion with nurses and Latin America, Africa, Asia and North America the lowest (see Table 1).

<table>
<thead>
<tr>
<th>Region</th>
<th>Discussed with nurses- (n (%))</th>
<th>Not discussed with nurses- (n (%))</th>
<th>Missing data- (n (%))</th>
<th>Total ((n))</th>
</tr>
</thead>
<tbody>
<tr>
<td>Africa</td>
<td>39 (24)</td>
<td>15 (9)</td>
<td>108 (67)</td>
<td>162</td>
</tr>
<tr>
<td>Latin America</td>
<td>60 (11)</td>
<td>330 (58)</td>
<td>181 (32)</td>
<td>571</td>
</tr>
<tr>
<td>North America</td>
<td>243 (27)</td>
<td>590 (64)</td>
<td>85 (9)</td>
<td>918</td>
</tr>
<tr>
<td>Asia</td>
<td>530 (29)</td>
<td>961 (52)</td>
<td>347 (19)</td>
<td>1838</td>
</tr>
<tr>
<td>Australia/New Zealand</td>
<td>328 (61)</td>
<td>162 (30)</td>
<td>51 (9)</td>
<td>541</td>
</tr>
<tr>
<td>Central Europe</td>
<td>2162 (56)</td>
<td>1131 (29)</td>
<td>600 (15)</td>
<td>3893</td>
</tr>
<tr>
<td>Northern Europe</td>
<td>1430 (62)</td>
<td>668 (29)</td>
<td>207 (9)</td>
<td>2305</td>
</tr>
<tr>
<td>Southern Europe</td>
<td>1159 (44)</td>
<td>624 (24)</td>
<td>839 (32)</td>
<td>2622</td>
</tr>
<tr>
<td>Total</td>
<td>5951</td>
<td>4481</td>
<td>2418</td>
<td></td>
</tr>
</tbody>
</table>

Chi Square: \(p < .001\), level of association Cramer's \(V = .276\).

Few respondents reported that nurses first brought up the topic of withholding or withdrawing therapy or shortening the dying process (range:0–1%). The vast majority of responses described the ICU physician as the person who first brought up this issue. Despite these very low percentages, statistically significant differences were detected between the 8 regions \(p < .001\) (Table 2).
Table 2
(Q11): Number and percentage* of health care professionals who first initiated the topic of withholding or withdrawing therapy or shortening the dying process by region.

<table>
<thead>
<tr>
<th>Region</th>
<th>ICU MD</th>
<th>Primary MD</th>
<th>Consulting MD</th>
<th>Nurses</th>
<th>Patient</th>
<th>Family</th>
<th>missing</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Africa N (%)</td>
<td>52 (32)</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>108</td>
<td>162</td>
</tr>
<tr>
<td>Africa N (%)</td>
<td>(0.6)</td>
<td></td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>(0.6)</td>
<td>(67)</td>
<td></td>
</tr>
<tr>
<td>Asia n (%)</td>
<td>680 (37)</td>
<td>163</td>
<td>24</td>
<td>1</td>
<td>44</td>
<td>579</td>
<td>347</td>
<td>1839</td>
</tr>
<tr>
<td>Asia n (%)</td>
<td>(9)</td>
<td>(1)</td>
<td>(1)</td>
<td>(0.1)</td>
<td>(2)</td>
<td>(32)</td>
<td>(19)</td>
<td></td>
</tr>
<tr>
<td>Central n Europe (%)</td>
<td>2714 (70)</td>
<td>154</td>
<td>134</td>
<td>10</td>
<td>131</td>
<td>150</td>
<td>600</td>
<td>3893</td>
</tr>
<tr>
<td>Central n Europe (%)</td>
<td>(4)</td>
<td>(3)</td>
<td>(1)</td>
<td>(3)</td>
<td>(4)</td>
<td>(15)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Latin n America (%)</td>
<td>352 (62)</td>
<td>12</td>
<td>6</td>
<td>0</td>
<td>2</td>
<td>18</td>
<td>181</td>
<td>571</td>
</tr>
<tr>
<td>Latin n America (%)</td>
<td>(2)</td>
<td>(1)</td>
<td>(0.4)</td>
<td>(3)</td>
<td>(32)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>North n America (%)</td>
<td>543 (59)</td>
<td>128</td>
<td>62</td>
<td>3</td>
<td>29</td>
<td>68</td>
<td>85</td>
<td>918</td>
</tr>
<tr>
<td>North n America (%)</td>
<td>(14)</td>
<td>(7)</td>
<td>(0.3)</td>
<td>(3)</td>
<td>(7)</td>
<td>(9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>North Europe %</td>
<td>1590 (69)</td>
<td>268</td>
<td>75</td>
<td>23</td>
<td>84</td>
<td>59</td>
<td>206</td>
<td>2305</td>
</tr>
<tr>
<td>North Europe %</td>
<td>(12)</td>
<td>(3)</td>
<td>(1)</td>
<td>(4)</td>
<td>(3)</td>
<td>(9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Australia/ New Zealand</td>
<td>388 (72)</td>
<td>50</td>
<td>13</td>
<td>0</td>
<td>22</td>
<td>17</td>
<td>51</td>
<td>541</td>
</tr>
<tr>
<td>Australia/ New Zealand</td>
<td>(9)</td>
<td>(2)</td>
<td>(4)</td>
<td>(3)</td>
<td>(9)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>South n Europe %</td>
<td>1628 (62)</td>
<td>7</td>
<td>28</td>
<td>10</td>
<td>12</td>
<td>93</td>
<td>844</td>
<td>2622</td>
</tr>
<tr>
<td>South n Europe %</td>
<td>(0.3)</td>
<td>(1)</td>
<td>(0.4)</td>
<td>(0.5)</td>
<td>(4)</td>
<td>(32)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*number of providers who first brought up topic/total number of providers in that region

Chi Square: p < .001, level of association Cramer's V = .206, p < .001

Few reports described nurses as being involved in making the EOL decision, with percentages of nurses who were involved ranging between 3–44%. The highest percentages were in Australia/New Zealand and Central Europe with the lowest in Latin America, Africa and Asia. These differences were statistically significant (p < .001) (Table 3)
The last question exploring whether there was agreement between physicians and nurses related to EOL decisions also, collected a wide range of responses (27–86%) (p < .001). The percentages of EOL decisions in which participants concluded that agreement between physicians and nurses was not applicable also garnered a wide range of responses from 0–41% (Table 4).
Table 4
Number and percentage* of agreement between doctors and nurses on EOL decisions by region

<table>
<thead>
<tr>
<th>Region</th>
<th>Yes n (%)</th>
<th>Yes n (%)</th>
<th>Missing n (%)</th>
<th>NA n (%)</th>
<th>Total n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Africa</td>
<td>53 (33)</td>
<td>1 (0.6)</td>
<td>108 (67)</td>
<td>0 (0)</td>
<td>162</td>
</tr>
<tr>
<td>Asia</td>
<td>1172 (64)</td>
<td>5 (0.3)</td>
<td>347 (19)</td>
<td>314 (17)</td>
<td>1838</td>
</tr>
<tr>
<td>Central Europe</td>
<td>2878 (74)</td>
<td>70 (0.2)</td>
<td>600 (15)</td>
<td>408 (11)</td>
<td>3893</td>
</tr>
<tr>
<td>Latin America</td>
<td>155 (27)</td>
<td>10 (0.2)</td>
<td>181 (32)</td>
<td>234 (41)</td>
<td>571</td>
</tr>
<tr>
<td>North America</td>
<td>630 (69)</td>
<td>0 (0)</td>
<td>85 (9)</td>
<td>203 (22)</td>
<td>918</td>
</tr>
<tr>
<td>Northern Europe</td>
<td>1989 (86)</td>
<td>1 (0)</td>
<td>206 (9)</td>
<td>109 (5)</td>
<td>2305</td>
</tr>
<tr>
<td>Australia/New Zealand</td>
<td>436 (81)</td>
<td>0 (0)</td>
<td>51 (9)</td>
<td>54 (10)</td>
<td>541</td>
</tr>
<tr>
<td>Southern Europe</td>
<td>1436 (55)</td>
<td>90 (0.3)</td>
<td>841 (32)</td>
<td>336 (13)</td>
<td>2622</td>
</tr>
<tr>
<td>Total</td>
<td>8749</td>
<td>177</td>
<td>2419</td>
<td>1658</td>
<td></td>
</tr>
</tbody>
</table>

Chi Square < .001, level of association Cramer’s V = .210, p < .001

Discussion

This study compared the global differences in nurse involvement in critical care EOL decisions. The most surprising findings are the low percentages of nurse involvement and team agreement in EOL decisions. The findings show a significant variability in nurse involvement. Ten times as many Australia/New Zealand nurses are involved in end-of-life decisions compared to nurses in Africa and Latin America.

Initiating end of life decisions, A 2015 New Zealand study reported that nurses often initiated the EOL discussions with their medical colleagues, were the majority 77%, n = 157 participation in end-of-life decision-making positively influenced in their job satisfaction [17]. These results are contrary to findings in the current study which reflected very small incidence of nurse initiation of EOL discussion, specifically in New Zealand/Australia where no initiation was reported. This discrepancy may be explained by the differences in data entry in the two studies. In the current study most of the data entry was performed by physicians, compared to the Coombs study where nurses were the principal investigators exploring nurses’ perceptions [17]. In Asia, we found that a third of the end-of-life decisions were initiated by family, which is three-fold compared to other regions of the world. In Asian countries dying and death is perceived not as a personal issue but as a family issue, and this view is particularly true in Korea and China [18;19]. ICU doctors in low- and middle-income nations are less likely to restrict life-sustaining care than those in high-income nations, but they are more likely to do so in response to requests from families that are under financial strain [20]. An Indian study found a significant difference between religious and secular nurses demonstrating that religious nurses reported a higher desire to initiate EOL care.
discussions with family members considering themselves religious [21]. Most physician respondents in the current study concluded that the ICU physician initiates the end-of-life care discussions.

Nurse involvement EOL Discussions- Our study found that on a global level few nurses were involved in EOL decisions. Similarly, a 2016 global review investigating EOL decision-making process among nurses and doctors in the ICU found that nurses were not viewed as integral to the part [3]. However, an African ICU nurse's study noted 29% of the 100 respondents reported being involved in decision-making. Thirteen percent reported being asked to participate in the decision-making process by medical colleagues. Around a quarter (22%) reported that they often initiated end-of-life discussions with their medical colleagues [16]. In a multi-center study Latour, et al explored 162 European ICU nurses. Their findings demonstrated that although 64% of nurses evaluated futile care delivered to patients, only 48% were included in the decision-making process by physicians [11], they also found that the more experienced physicians appreciated greater nurse involvement in the decision-making process, which created a more harmonized approach to the end-of-life care [3]. Contrary to the results of the current study, a New Zealand ICU nurses study found 70% actively participated in decision-making and a significant association between active involvement by the more experienced nurses with more ICU years of experience [22]. Coombs and colleagues [22] concluded that although nurses were actively involved in decision making considerably fewer (30%, n = 60) reported always being asked to participate in the decision-making process by medical colleagues. Results from various qualitative research studies showed that nurses, despite their desire to be more involved, felt that they were not actively involved enough during the decision-making process and were disappointed about not being invited for end of life care discussions [10]. These results substantiate the wide range of findings in the present study.

We also found a large percentage of missing data and "not applicable". There are a few different explanations for this occurrence: first, in some situations the patient's condition might quickly deteriorate, possibly to CPR, without allowing adequate time for discussion, explaining why clinicians leave this question blank. Secondly, another interpretation might be that the most applicable decision seemed obvious to all and there was no need for a discussion. Last but not least, a potentially concerning explanation may be that some of the physicians who completed the data entry form hold the belief that nurses should not be involved in such decision-making processes. These missing data are similar to the findings from the ETHICUS-I study in which many physicians answered that discussion with nurses was not applicable [14].

Physician- nurse agreement on EOL decision- Our study found large variability in EOL agreement between professionals. The range was from 20% to almost 90% agreement between ICU professionals. This might reflect cases where the patient died very suddenly and there was no time for discussion and therefore "no agreement", however the range is from 5–41% reflecting a great variability. A 2020 Australian qualitative study found that inconsistencies in doctors' decision-making process caused moral distress and nurses felt that there was no recourse to take if any disagreement issues arose. Frequent physician rotations also impacted on inconsistencies in decision making. The changes in decisions also influenced families and nurses thus needed to assist families during this period as well as overcome their own distress [23].
A multi-center study from 2014 discovered that nurses with more ICU clinical experience are more likely to take the lead in convincing physicians to reach a decision. In units where there is a high level of mutual respect or when there is disagreement among physicians, it is more probable that the opinions of nurses will be taken into consideration [24].

Limitations Data collection for this study was conducted using an observational questionnaire which limits interpretation of the data. Investigations collected data in this study based on physicians’ perceptions. The amount of missing data leaves a great deal of uncertainty as to why so many clinicians did not answer some of the questions while answering others. Many countries were involved and the variability of English comprehension of the questionnaire may account for variabilities. We did not monitor the quality of data and left this to the discretion of the principle investigator.

**Conclusion**

In this world wide EOL study we reveal that there is a large variability in nurse involvement in end of life care in the ICU. This could be due to the way physicians and nurses view themselves and each other. The level of expertise and experience of the physician, as well as the level of clinical experience of the nurses, also significantly impact the involvement of nurses in end-of-life decision making. When aiming for best possible ethically justified individualized end-of-life decisions and good ethical climates, ICUs nurses’ engagement and involvement are important elements. Modern guidelines also generally promote interdisciplinary approaches.

**Declarations**

Authorship statement authorship change form

Julie Benbenishty contribution to conception and design; analysis, and interpretation of data; Drafting the work; Final approval of the version to be published

Freda DeKeyser Ganz analysis, and interpretation of data; Drafting the work; Final approval of the version to be published

Alexandre Lautrette conception and design; analysis, and interpretation of data; Drafting the work; Final approval of the version to be published

Ulrich Jaschinski contribution to conception and design; analysis, and interpretation of data; Drafting the work; Final approval of the version to be published

Avneep Aggarwal, contribution to conception and design; analysis, and interpretation of data; Drafting the work; Final approval of the version to be published

Eldar Søreide contribution to conception and design; analysis, and interpretation of data; Drafting the work; Final approval of the version to be published
Manfred Weiss contribution to conception and design; analysis, and interpretation of data; Drafting the work; Final approval of the version to be published

Knut Dybwik contribution to conception and design; analysis, and interpretation of data; Drafting the work; Final approval of the version to be published

Elif Ayşe Çizmeci contribution to conception and design; analysis, and interpretation of data; Drafting the work; Final approval of the version to be published

Roberto carlos miranda Ackerman contribution to conception and design; analysis, and interpretation of data; Drafting the work; Final approval of the version to be published

Belén Estebanez-Montiel contribution to conception and design; analysis, and interpretation of data; Drafting the work; Final approval of the version to be published

Bara Ricou contribution to conception and design; analysis, and interpretation of data; Drafting the work; Final approval of the version to be published

Annette Robertsen contribution to conception and design; analysis, and interpretation of data; Drafting the work; Final approval of the version to be published

Charles L. Sprung contribution to conception and design; analysis, and interpretation of data; Drafting the work; Final approval of the version to be published

Alexander Avidan contribution to conception and design; analysis, and interpretation of data; Drafting the work; Final approval of the version to be published

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