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▶ **To cite this version:**

Claire Roger, Jérôme Morel, Nicolas Molinari, Jean Christophe Orban, Boris Jung, et al.. Practices of end-of-life decisions in 66 southern French ICUs 4years after an official legal framework: A 1-day audit. Anaesthesia Critical Care & Pain Medicine, 2015, 34 (2), pp.73 - 77. 10.1016/j.accpm.2014.10.001 . hal-01759479

HAL Id: hal-01759479

https://hal.umontpellier.fr/hal-01759479

Submitted on 19 Nov 2018

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Practices of end-of-life decisions in 66 southern French ICUs 4 years afteranofficiallegalframework:A1-dayaudit

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Keywords:
End-of-life
Withholding
Withdrawing
Family communication

A B S T R A C T

Objective: Since the implementation of two French laws in 2002 and 2005 and the implementation of guidelines about End-of-Life (EoL) decisions, few studies concerning EoL practices in French intensive care units (ICUs) have been reported. This study was aimed at assessing compliance with recommendations and current legislation concerning EoL decisions.
Method: Prospective observational study based on 1-day audit conducted from January to May 2009 in 66 southern French ICUs.
Results: Six hundred and twenty-five patients were included (median age: 63 [52–76] years, median SAPS II: 46 [34–58]). The written designation of a surrogate decision-maker was reported for 87 (15%) patients. Advance directives were completed for only 4% of patients. The EoL decision-making process consisted in a multidisciplinary approach for 99 (47%) patients and was recorded in the medical chart for 63 (64%) cases. Families were informed about medical decisions in 58% of cases. This proportion was higher (87%) if a decision to forego life-sustaining therapy was made. EoL decisions consisted of withholding treatments for 72 (94%) patients and withdrawal of treatments for 5 (6%) patients. In the multivariate stepwise logistic regression, four variables were independently associated with a decision to forego life support: preexisting dependence on others ($P < 0.0001$), advance directives ($P = 0.01$), age ($P = 0.008$) and the SAPS 2 score ($P = 0.009$).
Conclusion: The major finding of the present study is the existence of a gap between the widely approved EoL recommendations made by scientific societies and the daily practice of southern French ICUs. Even if EoL decisions are mostly shared with relatives, their written documentation in medical charts remains insufficient. Concerning EoL practices, the withdrawal of treatment remains an uncommon decision.

Abbreviations: EoL, end-of-life; ICU, intensive care unit; SAPS, simplified acute physiology score; SD, standard deviation; OR, odds ratios.

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1. Introduction

The overall mortality rate in intensive care units (ICUs) is around 20% with a large part of deaths occurring after decisions to withhold or withdraw life-sustaining therapy [1–4]. The quality of dying patient care has been a focus of increasing research over the last decade. It is considered an indicator of ICU quality [5–7]. Nevertheless, a great deal of variation exists in EoL practices between and within countries [8–13]. In France, recommendations by scientific societies and two laws have clarified the ethical and legal aspects of EoL decisions [14]. In 2002, laws required that patients were informed about their diagnosis, the associated potential outcomes and the option to designate a surrogate (on an official written form), especially for decision-making in case of incompetence [15]. In 2005, a law concerning patient EoL promoted the patient's right to make her/his own decisions, including the right to refuse unwanted therapies [16]. This strengthens the possibility for establishing advance directives and designating a surrogate decision-maker [17]. For incompetent patients, decisions to forego life-sustaining therapy should be made after a multidisciplinary staff meeting and the procedure should be reported in the medical chart [18]. However, recommendations are difficult to implement. Moreover, a great variability has been reported concerning practices relating to patient information and decisions concerning EoL care [2,8,9,13]. In 2009, an audit focusing on the implementation of 13 recommendations was performed in 66 French ICUs [19]. Two of these recommendations detailed patient information and ethical decision procedures. Therefore, the aim of the present study was to evaluate compliance with these two recommendations and with current legislation concerning EoL decisions 4 years after their implementation.

2. Methods

A 1-day audit was performed in order to verify the implementation of 13 recommendations in 66 French ICUs [19]. Because this study was observational, the need for informed consent was waived in accordance with French law. All patients or their relatives were informed about the study by the ICU physicians and could refuse participation. The study was approved by the Institutional Review Board of the Nîmes University Hospital (IRB09/04/03).

2.1. Study design

As described in a previous study, the AzuRea group is a network including 66 ICUs (33 in academic hospitals and 33 in non-academic hospitals), representing 710 beds [20]. From January to May 2009, a 1-day audit was conducted after obtaining informed consent from each ICU department head. Sixty-four residents were in charge of the study. They were required to be in the last 2 years of their educative process and should have spent 6-months as residents in the ICU in order to have knowledge of its organization. In each university system, a senior investigator trained a group of residents before the audit day.

2.2. Data collection

As described previously, the residents had to fill a case-report form (20 sheets) including [19]:

- patient characteristics at admission;
- past medical history;
- information concerning closest patient relatives and surrogate decision-makers;
- the identification of the general practitioner;
- the patient goals of care comprising treatment and EoL care planning;
- information concerning ethical discussions and EoL decisions were collected:
  - multiprofessional approach,
  - documentation of the decisions,
  - information shared with families,
  - withholding or withdrawing life-sustaining therapies (mechanical ventilation, vasopressors, renal replacement therapy, artificial nutrition);
- the existence of advance written directives.

The type of hospital (academic or non-academic), the number of ICU beds, the ratio of nurses to patients and the number of doctors present on the audit day were collected. The mortality rate was measured 28 days after the audit day by contacting each ICU.

2.3. Statistical analysis

Because this observational study was part of an audit concerning 13 recommendations, the specific number of subjects needed was not calculated for the present part of the study. The quantitative variables are expressed as means [standard deviation (SD)] or medians [first quartile (Q1), third quartile (Q3)] according to variable distributions. Qualitative variables are expressed as percentages.

A univariate analysis was first performed using Chi^2 tests or Fisher exact tests when necessary for qualitative factors and using analysis of variance or Mann-Whitney tests when necessary for quantitative factors. Then, we used unconditional multivariate logistic regression to estimate the adjusted odds ratios (ORs) and 95% confidence intervals (CIs) for the association between selected factors and foregoing life-sustaining treatments. For model building, we applied forward stepwise introduction of selected variables from univariate analysis ($P = 0.20$). Model fit was assessed by the Hosmer-Lemeshow test. All analyses were performed using SAS version 9.2 (SAS Institute Inc, Cary, North Carolina) using a two-sided type 1 error rate of 0.05 as the threshold for statistical significance.

3. Results

3.1. Study population

The characteristics of the study population are described in Table 1.

3.1.1. Relationship with relatives

Upon ICU admission, contact with relatives was reported for 582 (93%) patients (Table 2). In the 43 (7%) remaining patients, no relatives were clearly reported. An official surrogate decision-maker designated in a written sheet was reported for 87 (15%) patients, with no differences observed between patients admitted from the emergency department or from home ($n = 36.41\%$), the other hospital wards ($n = 47$, 54%), and long-term facilities ($n = 3$, 3%), ($P = 0.25$, missing data = 1). The identification of the patient's general practitioner was reported for 392 (63%) patients. The rate of general practitioner identification was similar in patients with an ICU stay < 2 days (16/28, 57%) and those with an ICU stay ≥ 2 days (375/596, 63%) ($P = 0.55$).

3.1.2. Ethical discussions and end-of-life decisions

Ethical discussions occurred in 411 (66%) patients. These ethical considerations were either recorded on the medical chart for 166 (40%) patients or orally discussed by physicians and/or nursing staff for 245 (60%) patients.

Table 1
Characteristics of the study population ($n = 625$).

Characteristics	Measure
Age, median [IQ1–IQ3], year	63 [52–76]
Sex, *n* (%)	
Men	391 (63)
Women	234 (37)
Physiologic assessment, *n* (%)	
MacCabe 0	383 (61)
MacCabe 1	181 (29)
MacCabe 2	61 (10)
Admission SAPS II, median [IQ1–IQ3]	46 [34–58]
Cause of admission, *n* (%)	
Medical	393 (63)
Surgery	
Urgent	169 (27)
Non-urgent	63 (10)
Audit day assessment	
SOFA, median [Q1–Q3]	3 [1–6]

SAPS: simplified acute physiology score; Q1: first quartile; Q3: third quartile; SOFA: sequential organ failure assessment.

Table 2
Identity of the closest relatives ($n = 625$).

Identification of relatives	*n*	%
No relatives identified	43	7
Spouse/partner	261	42
Children	168	27
Parent	65	10
Other family member	53	9
Other relative	27	4
Missing data	8	1

Eighteen patients (4%) formulated advance directives. These patients had directly communicated these directives to the medical staff. These directives were written for 2 patients and orally given for 16 patients. For 2 patients, the general practitioner was involved in the transmission of their advance directives to the ICU staff. An EoL decision-making process had been implemented for 210 (34%) patients on the audit day. In 41 (20%) patients, this decision-making was made upon ICU admission. The discussion was conducted using a multiprofessional approach (physicians and nurses) for 99 (47%) patients. It was written in the medical chart for 63 (64%) cases (Table 3). Among 210 patients with EoL decision-making processes, 122 relatives (58%) were informed of the medical decisions involved. For 77 patients (12% of the overall study population), a decision to forego life-sustaining therapies was made. The median number of EoL decisions (withholding or withdrawing) was 1 EoL decision per unit and 19 units did not report EoL decisions on the audit day. Decisions to forego life support consisted in withholding therapies for 72/77 (94%) patients (including the withholding of cardiopulmonary resuscitation (CPR) in the case of cardiac arrest for 23 (30%) patients) and in withdrawal therapies for 5/77 (6%) patients (Table 4). Of the 77 patients with a decision to forego life-sustaining therapy, 35 (45%) patients died. When this decision was restricted to limit CPR in case of cardiac arrest, the mortality rate was lower than after a more extensive withholding or withdrawal decision (7/23 (30%) versus 28/54 (52%) patients, $P = 0.03$). Among patients for whom deliberations about a decision to forego life-sustaining therapy occurred, relatives were informed in 67/77 (87%) of cases, as compared to 55/133 (41%) of the relatives in the group of patients for whom no decision to forego life-sustaining therapy was made ($P < 0.0001$). Four parameters were independently associated with a decision to forego life support, namely:

- reported previous poor quality of life;
- age;
- patient severity assessed via the simplified acute physiology score (SAPS 2);
- available advance directives (Table 5).

Table 3
EoL decision-making practices.

EoL decision-making process	*n*	%
EoL discussion		
Yes	210	34
No	415	66
Timing of the discussion ($n = 210$)		
ICU admission	41	20
During ICU stay	91	43
Undocumented	78	37
Multidisciplinary discussion ($n = 210$)		
Yes	99	47
No	111	53
Documentation of the discussion ($n = 99$)		
Written in the medical chart	63	64
Undocumented	31	31
Missing data	5	5

EoL: End-of-Life; ICU: intensive care unit.

Table 4
Characteristics of decisions to forego life-sustaining therapies (DFLST) ($n = 77$).

DFLST	*n*	%
No CPR in case of cardiac arrest	23	30
Withholding treatment	49	64
Withdrawal of treatment	5	6
Withholding and/or withdrawal ($n = 54$)		
Renal replacement therapy	36	67
Vasopressors	31	57
Mechanical ventilation	23	43
Transfusions	19	35
Nutrition	9	16

CPR: cardiopulmonary resuscitation; DFLST: decisions to forego life-sustaining therapies.

Table 5
Results of multivariate stepwise logistic regression on DFLST.

Variable	Odds ratios	95% confidence interval	*P*
Previous poor quality of life			
Yes	1		
No	8.11	3.16–20.81	< 0.0001
Advance directives			
Yes	1		
No	5.12	1.48–17.73	0.01
Age increase (per year)	1.03	1.008–1.053	0.008
SAPS 2 increase (per point)	1.02	1.006–1.043	0.009

SAPS: simplified acute physiology score. The following variables were entered in the multivariate stepwise logistic regression: cause of admission, type of hospital (academic, non-academic), age, SAPS 2 score, MacCabe score, advance directives and previous poor quality of life. *P* (Hosmer-Lemeshow) = 0.5312.

4. Discussion

The present 1-day audit carried out in 66 southern French ICUs evaluated compliance with recommendations and legal

obligations concerning EoL practices as determined by French law and scientific societies [15,16]. The major finding is the observed gap between the widely published and approved EoL recommendations based on legislation and daily practice in French ICUs [14,16]. Documentation of EoL practices remains insufficient.

The present study identifies the aspects of EoL decisions that are still problematic. First, though the ICU staff had identified relatives for 93% of patients, only 15% of patients officially designated a surrogate decision-maker. The MAHO and LATAREA 2 studies also reported less than 20% of surrogate decision-maker designation [21,22]. Second, only 4% of the present cohort formulated advance directives before ICU admission. These advance directives were mostly reported by the patient her- or himself. This recommendation, as specified by the 2005 French law, was established to protect patient autonomy and to ensure a shared decision [16]. However, the present findings as previously reported in other studies, highlight that this practice remains exceptional in Europe (except in the Netherlands) [9].

In the literature, contradictory results were reported: in a recent study, elderly Americans were more likely to complete advance directives (67%) and this was associated with better respect of patients' wishes [23]. However, some studies also reported few effects of advance directives on EoL decision-making [24,25]. Official surrogate decision-maker designation and advance directives formulation were two key points of 2005 legislation, but are difficult to apply in daily practice.

Ethical discussion had occurred in one-third of the study population. The deliberations of this discussion were disclosed to 58% of families. This finding suggests that French intensivists remain reluctant to share decision-making with patients and their relatives. However, in patients with a decision to forego life support, 87% of their relatives were informed of EoL decisions, which is a higher rate as compared to the LATAREA 1 study (44%) [4]. Explicit, clear and early information to ICU patient relatives is an important goal in order to improve the satisfaction of relatives with EoL care and to prepare them for the loss of their loved ones [28–30]. Another important finding is the incomplete documentation of EoL decisions in the present study (63%), despite its statutory requirement [31]. This finding is consistent with data from the Ethicus study, (involving 37 ICUs in 17 European countries) reporting that the decision documentation followed a prevalence gradient from North (88%) and Central (77%) to Southern (34%) Europe [32]. A recent Dutch study reported poor and incomplete documentation on withholding and withdrawing life support: in 32% of the cases, ICU team members involved in the EoL decisions were not mentioned [33]. Moreover, 36% of EoL decisions were not shared with patient relatives. Nevertheless, the documentation of medical decisions is crucial to preserve the continuity of inpatient care and to ensure transparency in such decisions. Discussions occurred after multidisciplinary collaboration for 47% of patients. Few changes have taken place concerning shared EoL decisions since the LATAREA 1 study, which reported that only 54% of decision-making processes involved the nursing staff [4]. Previous studies demonstrated a wide variability across countries. In a single ICU study in Lebanon, nurses were not involved in 26% of EoL decisions [34]. An Italian study involving 84 ICUs reported that decisions were shared by physicians and nurses in 24.5% of cases and by a single physician in 18.6% [35]. However, in half of the cases, these decisions involved a physician from another unit. This proportion is higher than in 2001 (2%) [4]. Multidisciplinary collaboration concerning EoL care is strongly encouraged in the 2005 French law [16]. This collaboration is associated with increased family satisfaction and can prevent ICU staff burnout [36–38]. Among the 625 patients enrolled in the present study, decisions to forego life-sustaining therapy occurred in 77 (12%) patients, but this rate was certainly underestimated by the associated transversal design (ICU stays were not considered across their entire durations). Our data suggest that the EoL practices in the south of France have not changed since the implementation of the official recommendations. In 2001, the LATAREA study reported that withholding or withdrawal decisions represented 11% of ICU admissions [4]. The Ethicus study showed a similar rate (10%) in Europe [8]. More recently, Azoulay et al. [2] reported that the decisions to forego life support represented 8.6% of admissions, whereas the LATAREA 2 study found a similar rate (12%) as in 2001 [2,22]. Previous studies in North America reported much higher rates [13,39]. Although many ethicists and critical care societies consider that there is no ethical and legal distinction between withholding and withdrawing life-sustaining treatments, our findings indicate that withholding is the most common decision made by French intensivists [40,41]. These results are consistent with data reported from Greece, Lebanon and southern Europe [32,34,42]. Heterogeneity also exists in the practical aspects of withholding or withdrawal of treatments [43,45]. Vasopressors and dialysis were the most frequently limited therapies in the present study. Physicians' reluctance to withdraw mechanical ventilation still persists. Withdrawal of mechanical ventilation, in particular tracheal extubation, seems to be a more difficult act for French intensivists [46]. The present study cannot detail this practice.

Certain limitations concerning the present study should be acknowledged. All the studied ICUs were concentrated in the south of France. Since previous works have demonstrated a North-to-South gradient in EoL practices in Europe, our results may have been affected by regional cultures. Given that all ICUs were located in southern France, the present findings cannot be extrapolated to the whole country or to another country. However, the number of participating ICUs was large and EoL recommendations were not reviewed before performing the present 1-day audit/study. Therefore, our findings probably reflect current daily practice in French ICUs. We did not investigate the necessary actions that require implementation in order to improve intensivists' compliance with these recommendations.

5. Conclusion

In conclusion, efforts to improve EoL care are still needed in French ICUs, despite the existence of guidelines. Even if EoL decisions are mostly shared with relatives, their written documentation in medical charts remains insufficient. Concerning EoL practices, the withdrawal of treatment remains an uncommon decision. Our findings demonstrate that progress is required at each step of the patient pathway, from the general practitioner to the intensivist. Currently, we intend to plan a prospective study involving several ICUs from throughout France to report updated data about EoL practices in France 10 years after the implementation of the legal recommendations.

Authors' contributions

CR, JM, JCO, EF, OD, TR, BR conceived and designed the study. NM performed statistical analysis. CR, JM, JCO, EF, OD, TR, AF, SS, PB, TR, BR analyzed the data. CR, TR wrote the manuscript. All other authors made critical revisions of the manuscript for intellectual content.

Disclosure of interest

The authors declare that they have no conflicts of interest concerning this article.

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