

Received: 2014.05.13
Accepted: 2014.05.20
Published: 2014.10.21

Experiences of Slovene ICU Physicians with End-of-Life Decision Making: A Nation-Wide Survey

Authors' Contribution:
Study Design A
Data Collection B
Statistical Analysis C
Data Interpretation D
Manuscript Preparation E
Literature Search F
Funds Collection G

ABCDEF 1 **Urh Groselj**
ABCDEF 2 **Miha Orazem**
ABCEF 2 **Maja Kanic**
ABCDE 2,3 **Gaj Vidmar**
ABCDEF 4,5 **Stefan Grosek**

1 Department of Pediatric Endocrinology, Diabetes and Metabolic Diseases, University Children's Hospital, UMC Ljubljana, Ljubljana, Slovenia
2 Faculty of Medicine, University of Ljubljana, Ljubljana, Slovenia
3 University Rehabilitation Institute of the Republic of Slovenia, Ljubljana, Slovenia
4 Department of Pediatrics, Faculty of Medicine, University of Ljubljana, Ljubljana, Slovenia
5 Department of Pediatric Surgery and Intensive Therapy, UMC Ljubljana, Ljubljana, Slovenia

Corresponding Author: Stefan Grosek, e-mail: stefan.grosek@kclj.si

Source of support: The publication of the study was supported by the Slovenian National Research Agency grant J3-4252

Background: Advances in intensive care medicine have enormously improved ability to successfully treat seriously ill patients. However, intensive treatment and prolongation of life is not always in the patient's best interest, and many ethical dilemmas arise in end-of-life (EOL) situations. We aimed to assess intensive care unit (ICU) physicians' experiences with EOL decision making and to compare the responses according to ICU type.

Material/Methods: A cross-sectional survey was performed in all 35 Slovene ICUs, using a questionnaire designed to assess ICU physician experiences with EOL decision making, focusing on limitations of life-sustaining treatments (LST).

Results: We distributed 370 questionnaires (approximating the number of Slovene ICU physicians) and 267 were returned (72% response rate). The great majority of ICU physicians reported using do-not-resuscitate (DNR) orders (97%), withholding LST (94%), and withdrawing antibiotics (86%) or inotropes (95%). Fewer ICU physicians reported withdrawing mechanical ventilation (52%) or extubating patients (27%). Hydration was reported to be only rarely terminated (76% of participants reported never terminating it). In addition, 63% of participants had never encountered advance directives, and 39% reported to "never" or "rarely" participating in decision making with relatives of patients. Nurses were reported to be "never" or "rarely" involved in the EOL decision making process by 84% of participants.

Conclusions: Limitation of LST was regularly used by Slovene ICU physicians. DNR orders and withholding of LST were the most commonly used measures. Hydration was only rarely terminated. In addition, use of advance directives was almost non-existent in practice, and the patients' relatives and nurses only infrequently participated in the decision making.

MeSH Keywords: **Intensive Care Units • Resuscitation Orders • Withholding Treatment**

Full-text PDF: <http://www.medscimonit.com/abstract/index/idArt/891029>



Background

Advances in intensive care medicine have enormously improved treatment of seriously ill patients. However, intensive treatment and prolongation of life is not always in the patient's best interest [1]. Thus, difficult decisions frequently need to be made about limitation of life-sustaining treatments (LST) [2,3]. Approximately 20% of patients die during or shortly after a stay in intensive care units (ICUs) [4]. According to most previous studies, over 50% of all ICU deaths are associated with withholding or withdrawing LST [3,5–7].

Previous surveys demonstrated that the limitation of LST (e.g., do-not-resuscitate (DNR) order, withholding and withdrawing therapy) is a common practice when therapeutic measures are considered to be futile; however, substantial international differences in end-of-life (EOL) practices are reported [8–20].

Beside other contributions, a highly important insight into EOL decision making is provided by the Ethicus Study Group, presenting important international comparisons on the issue and empirical assessments of the most important aspects of EOL decision making [5,21–23]. The limitation of LST is reported as being more common in northern European countries as compared to southern Europe. Unresponsiveness to therapy is reported as the most common primary reason for EOL decision making. In addition, a more paternalistic pattern of EOL decision making is characteristic for southern Europe, with less communication with patients and their families, and the best interests of the patient are less commonly considered [5,21–25].

National and international recommendations and guidelines were developed regarding limitation of LST in ICUs [26–28]. Currently, the national guidelines on EOL decision making are being finalized in Slovenia, because the issue is being increasingly recognized as important among physicians. However, no previous studies exist on EOL decision making in Slovenia. Thus, the main aim of the present study was to assess ICU physician experiences with EOL decision making.

Material and Methods

Study design

A cross-sectional study was conducted involving physicians from all 35 ICUs in Slovenia; we included all physicians who work regularly and/or perform overnight shifts in the ICUs. A questionnaire to assess their experiences with EOL decision making was designed. The study was approved by the Slovene National Medical Ethics Committee (Decision No.163/10/11).

Questionnaire

The questionnaire was designed to assess the experiences of the participating ICU physicians with EOL decision making, focusing on limiting LST in the ICUs (the term “limiting LST” included both withholding and withdrawing LST. “Withholding” was defined as not introducing additional treatment or not intensifying existing treatment, while “withdrawing” was defined as discontinuing a treatment that a patient was already undergoing.

The questionnaire was anonymous and took on average 15 minutes to complete. It consisted of 25 questions, 2 of them which open-ended. The first part of the questionnaire included questions on demographic characteristics of the participants, along with 3 questions assessing participant experiences with ethical committees. Other questions were designed to assess participant experiences with discontinuation of treatment when it was deemed futile in ICU patients. The questionnaire is available upon request.

The questionnaires were personally distributed to all ICUs in Slovenia. All ICU heads and/or other available ICU physicians were personally invited to voluntarily and anonymously participate. The questionnaires were collected in sealed boxes placed in a room to which only ICU staff had access. Subsequently, 3 weeks after distribution, we personally collected all the submitted questionnaires. The distribution and collection of the questionnaires took place from November 2011 to February 2012.

Statistical analysis

Results of the study are reported based on their frequency distributions. Where appropriate, the averages and standard deviations (SD) were calculated. Fisher's exact test and Fisher-Freeman-Halton test were used for analyzing contingency tables; the significance level was set at $p \leq 0.001$ due to the large number of tested hypotheses. The analyses were performed using IBM® SPSS® Statistics 20 (IBM Corp., Somers, NY, USA).

Results

Characteristics of study participants

The responses from ICU physicians from all 35 Slovene ICUs are included in the study. Altogether, 370 questionnaires were distributed (the number approximately represented the total number of Slovene ICU physicians), and 267 questionnaires were returned (the response rate was 72%). Of the 260 total study participants, 134 (52%) were males. Participant age ranged from 27 to 68 years, with a median of 43.5 years (SD 9.6 years). Participants' years of work as a physician ranged

from 2 to 41 years, with a median of 17.8 years (SD 9.6 years), and their years of work in the ICU ranged from 0 to 38 years, with a median of 12.1 years (SD 8.8 years). The other characteristics of study participants are listed in Table 1.

Only 60% of study participants indicated they knew how to proceed when facing an ethical dilemma and only 23% of all participants had consulted the ethics committee. Furthermore, 42% of the responders knew name of the ethics committee head in their institution, and 17% of them reported there was no ethics committee in their institution.

Experiences with EOL decision making

Most participants (90%) had been involved in the decision making process regarding limitation of LST. In 2011, 47% of them were involved 2–5 times, 20% 5–10 times, 20% more than 10 times, and 13% never. In the period 2006–2011, 32% of them were involved more than 15 times, 25% 2–5 times, and 22% 5–10 times.

The most common reasons for limitation of LST were terminal illness (62%), brain death (28%), and persistent vegetative state (7%). The decision making process regarding limitation of LST was in almost all cases (97%) initiated by the physician; in the remaining 3% the process was initiated by relatives of the patient. Furthermore, the relatives were reported to “never” or “rarely” participate in decision making in 39% of cases, and nurses were reported to be “never” or “rarely” involved in the EOL decision making process in 84%. Table 2 shows the main characteristics of the LST limitation decision making process.

Most (63%) participants had never encountered advanced directives in practice. Not using any instructions regarding the limitation of LST was reported by 37% of participants, 32% used written instructions, and 31% used oral instructions. A special form to be used for limitation LST was used very rarely (less than 0.5% of participants). In most cases (51%) the decision to limit LST was implemented immediately after adopting it and communicating it to the relatives. Within 6 hours from making the decision, it was implemented in 25% cases; only rarely (4%) did implementation take more than 24 hours.

The study participants reported deciding more frequently to use a DNR order as compared to withholding of treatment (67% used a DNR order “frequently”, whereas 48% used withholding of treatment “frequently”; $p < 0.001$). Detailed data on how frequently responders made decisions about different types of limitation of LST are presented in Table 3. With regard to the type of ICU, the responders from medical ICUs used DNR orders more frequently as compared to the responders from surgical and/or pediatric ICUs ($p < 0.001$). Furthermore, board-certified ICU physicians were more likely to use DNR orders

Table 1. The characteristics of ICU physicians.

	N* (%)
ICU type (N=260)	
Surgical	126 (49)
Medical	110 (42)
Pediatric	24 (9)
Field of specialization (N=261)	
Anesthesiology	110 (43)
Internal medicine	102 (40)
Pediatrics	24 (10)
Surgery	11 (4)
Other	8 (3)
Status (N=262)	
Specialist	214 (82)
Senior resident	35 (13)
Junior resident	13 (5)

* N – total number of answers; each answer is presented as the number of answers and the percentage of all answers.

“frequently” as compared to residents (71% vs. 52%; $p < 0.001$). No other statistically significant differences among the compared groups were found when compared with their gender, working status, years of work, or knowledge about how to proceed when facing an ethical dilemma ($p = N_s$ for all comparisons).

The study participants reported deciding less frequently to withdraw mechanical ventilation or extubating patients as compared to withdrawal of inotropes or antibiotics (12% reported using withdrawal of mechanical ventilation or extubation “frequently”, and 66.7% used withdrawal of inotropes or antibiotics “frequently”; $p < 0.001$). Interestingly, only 3% of participants from surgical ICUs reported using withdrawal of mechanical ventilation or extubation “frequently” as compared to approximately 20% in medical and pediatric ICUs ($p < 0.001$). No other statistically significant differences in the frequency of use of withdrawal of antibiotics or inotropes among the compared groups were found when compared with regard to their gender, working status, years of work, or knowledge about how to proceed when facing an ethical dilemma ($p = N_s$ for all comparisons).

Termination of hydration was reported to be only rarely used in Slovene ICUs, and 76% of participants reported never terminating it (Table 3). Termination of hydration was most used by physicians from medical ICUs (9.9%) as compared to 3.1% at the surgical ICUs and to 0% at the pediatric ICUs; however,

Table 2. Characteristics of the decision-making process regarding limitation of life-sustaining treatments.

	Never	Rarely	Mostly	Always
Who is involved in DMP*				
I decide alone (N=230)	128 (56%)	90 (39%)	10 (4%)	2 (1%)
Decision is taken at meeting of involved physicians (N=256)	2 (1%)	12 (5%)	136 (53%)	106 (41%)
Decision is taken at meeting of involved physicians and nurses (N=222)	131 (59%)	56 (25%)	25 (11%)	10 (5%)
Ethical committee is involved (N=189)	135 (71%)	43 (23%)	8 (4%)	3 (2%)
Inclusion of patient and/or relatives in DMP* (N=223)	15 (7%)	72 (32%)	99 (44%)	37 (17%)
Disagreement among physicians in DMP* (N=223)	25 (11%)	160 (72%)	35 (16%)	3 (1%)
Disagreement between surrogate/relatives and physicians in DMP* (N=215)	28 (13%)	159 (74%)	23 (11%)	5 (2%)
I have disagreed with termination of futile treatment (N=223)	68 (31%)	148 (66%)	5 (2%)	2 (1%)
I have declined to be involved in DMP* (N=222)	176 (79%)	42 (19%)	4 (2%)	0 (0%)

* DMP – decision-making process; N – total number of answers; each answer is presented as the number of answers and the percentage of all answers.

Table 3. The reported frequencies of decisions about different types of termination of life-sustaining treatments.

	Frequently	Rarely	Never
DNR (N=225)	151 (67%)	68 (30%)	6 (3%)
Withholding treatment (N=218)	104 (48%)	101 (46%)	13 (6%)
Withdrawal of inotropes (N=223)	136 (61%)	75 (34%)	12 (5%)
Withdrawal of antibiotics (N=220)	100 (45%)	90 (41%)	30 (14%)
Withdrawal of mechanical ventilation (N=218)	24 (11%)	87 (40%)	107 (49%)
Extubation (N=215)	6 (3%)	51 (24%)	158 (73%)
Withdrawal of hydration (N=214)	13 (6%)	39 (18%)	162 (76%)

*N – total number of answers; each answer is presented as the number of answers and the percentage of all answers.

**The term “withholding” treatment was understood as not to introduce additional treatment or to intensify existing treatment, while the term “withdrawing” treatment was understood as to discontinue a treatment that a patient is already undergoing.

the differences were slightly above the threshold of statistical significance; $p=0.018$).

Discussion

This is the first study to assess the experiences of Slovene ICU physicians with EOL decision making. Prior to this study, Slovenia had not taken part in any of the international studies on EOL decision making. Completed questionnaires were obtained from all 35 Slovene ICUs, which included pediatric, medical, and surgical ICUs. Altogether, responses from approximately three-quarters of all the Slovene ICU physicians were included, making the study fairly representative of the population. In most previous survey studies the response rates were

50–70% [11,14,17–19,29]. However, few previous studies include all the national ICUs or compared different types of ICUs.

We are aware of different approaches towards defining the term “futility” as reported by Schneiderman, Pellegrino, and others [30–33]. Since, according to the literature, no general agreement exists on the definition of the term “futility”, we left the definition of the term to the ICU physicians’ own understanding of the term. Thus, in our study, we were interested about EOL decision making from the point at which any further treatment was assessed as futile by involved clinicians.

Our results show that limitation of LST is widely practiced in Slovene ICUs. The proportions of physicians who reported using withholding (94%) or withdrawing (86% for antibiotics

and 95% for inotropes) LST were comparable to or even higher than in most of the previous national and international surveys [10,18]. However, we observed substantial differences in reported frequencies of using different measures of limitation of LST. The DNR order was reported to be even slightly more frequently used (by 97% ICU physicians) than withholding of treatment. Furthermore, it was shown to be more frequently used in the medical ICUs as compared to surgical and pediatric ICUs. Similarly, a recent German survey shows the DNR order is the most common measure of limitation of LST, followed by withdrawal of inotropes, hemodialysis, and antibiotics [29].

Not surprisingly, withdrawal of inotropes (95%) or of antibiotics (86%) was reported to be much more frequently used than withdrawal of mechanical ventilation (51%) or of extubation (27%). This is in line with some previous studies showing that extubation especially is quite rarely performed [12]. We could thus discriminate between the “soft” (e.g., withdrawal of inotropes or antibiotics) and the “hard” (e.g., extubation or withdrawal of mechanical ventilation) measures of withdrawal of LST, in line with the fact that the first were reported to be much more commonly used than the later. The “soft” measures might thus be preferable for the ICU physicians from a practical point of view, despite no difference or even some opposite claims with regard to the ethical point of view found in the literature [34]. Nevertheless, also most previous surveys indicated that withdrawal of therapy is more difficult for ICU physicians than withholding therapy [11,12,18]. Interestingly, extubation or withdrawal of mechanical ventilation were reported to be more regularly used in pediatric and medical ICUs, but only very rarely in surgical ICUs, but the reason is not clear. Furthermore, when compared to the Ethicus Study – despite its geographic positioning and its cultural roots in Central Europe – Slovenia seems to be more similar to southern European countries regarding extubation or the withdrawal of mechanical ventilation [5].

The decision making process regarding limitation of LST was reported to be almost always initiated by the ICU physician. The decision was reported to be usually taken at a meeting of the involved physicians. Furthermore, merely 17% of ICU physicians reported always including patients and/or relatives in EOL decision making (“never” or “rarely” was selected by 39%). Furthermore, nurses were reported to be “never” or “rarely” involved in the EOL decision making process by 84% of physician respondents, which is quite concerning. This all indicates a rather paternalistic pattern of EOL decision making, which is more characteristic of southern European countries [5,11,21,35].

Our study confirmed the previous impressions from ICU clinical practice that advance directives were only very rarely used, and most of our participants had not encountered a single one, despite their potential clinical significance in decision making. This is in concordance with some previous studies, which showed

that advance directives were available for fewer than 5% of patients in all countries apart from the Netherlands [3,12,18]. This could be due to the restrictiveness of current Slovenian law on advance directives, which has several procedural pre-conditions for their use to be valid and are binding for physicians only in situations in which treatment is clearly futile.

Termination of hydration was reported to be only rarely used in Slovene ICUs, with 76% of participants never terminating it. However, differences were found among ICUs: hydration was most frequently terminated by participants from medical ICUs (9.9%), and more rarely by those from surgical ICUs (3.1%) and never by those from pediatric ICUs. Similarly, in a German study, termination of hydration was reported by 3–5% of physicians [29]. The EURELD study in 6 European countries showed that hydration is most frequently terminated in the Netherlands (11%) and least frequently in Italy (2.6%) [3].

Finally, merely 60% of the ICU physicians reported knowing how to proceed when facing an ethical dilemma, which indicates a need to strengthen medical ethics education and infrastructure, which would be especially important for ICUs, in which ethical dilemmas appear on a daily basis.

This main limitation of this study is that the questionnaire only indirectly measured the real situation in the ICUs regarding EOL decision making. On the other hand, it presents the first national data on this very important issue in Slovenia and could serve as a solid basis for preparation of national guidelines, as well as being the basis for developing further observational studies of EOL decision making in ICUs.

Conclusions

This was the first nation-wide study on experiences with EOL decision making in Slovene ICU physicians. Firstly, we found the limitation of LST to be ethically acceptable to ICU physicians. Most widely practiced was DNR order, followed by the withholding of treatment. In addition, we found differences in reported frequencies of using “soft” (e.g., withdrawal of inotropes or antibiotics) and “hard” (e.g., extubation or withdrawal of mechanical ventilation,) measures of withdrawal of LST. Furthermore, termination of hydration was reported to be only rarely used, mostly in the medical ICUs. In addition, advance directives were almost non-existent in practice, and the patients’ relatives and nurses only infrequently participated in EOL decision making. Finally, better medical ethics education and infrastructure should be developed for ICUs and hospitals.

Conflict of interest

The authors declare no conflicts of interest.

Acknowledgements

We thank all the ICU physicians for their very kind participation in the study and the Slovene Society of Intensive Care

Medicine for cooperation and support. We also thank the late Akad. Prof. Joze Trontelj, MD, PhD, the chair of the National Medical Ethics Committee, for his most valuable suggestions and support. This article is dedicated to his esteemed memory.

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