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Medical Futility and End-of-Life Decisions in Critically ill Patients: Perception of Physicians and Nurses on Central Region of Portugal

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Abstract

Introduction: The Intensive Care Unit (ICU) is the setting where patients are given the most advanced life sustaining treatments. However, it is also the setting where death is common and end-of-life care is frequently provided. The aim of this study was to understand the reality of the decision making process on end-of-life in ICUs of several hospitals in the central region of Portugal.

Methods: A questionnaire to assess end-of-life decision making and attitudes towards medical futility in the ICU was developed. It comprises socio-demographic-professional variables and questions on end of life decision making process and medical futility, attitudes and believes. Between May and October 2010, 183 questionnaires were returned from a total of 235 delivered - 78% response rate.

Results: The 183 returned questionnaires included 147 nurses (80%) and 36 physicians (20%); 60% were female; median age was 39 years-old; 86% were catholic. Reasons pointed out for excessive/unjustified treatments, by more than half of nurses and physicians, included non-acceptance of treatment failure, insufficient training on ethical issues, difficulty on accepting death, incorrect evaluation on clinical condition; difficulties in communication were pointed out by a third of nurses and physicians.

Fifty four percent of nurses and 74% of physicians have never had any training or education concerning medical futility and end-of-life issues. Seventy-seven percent of nurses and 69% of physicians considered that they felt the need of training/education on medical futility and end-of-life issues: 64% of physicians because of control of symptoms and 43% of nurses because of the need of a better communication among nurses, physicians and patients' family (i.e. physicians *vs* nurses- physicians *vs* families-nurses *vs* families). There were statistically significant differences between nurses and physicians on answers concerning whom should be and who is, in fact, involved on end-of-life decisions.

To reduce the occurrence of medical futility, strategies that were pointed out included mainly education and training and enhancing communication inside the ICU team and with the families.

Conclusion: This study has shown problems of communication, namely discrepancies of opinion between nurses and physicians and discrepancies between on whom should be and whom is in fact involved on end-of-life decisions. These discrepancies, together with the lack of education/training were the main findings that might explain difficulties found in the decision making process. Strategies to find an improvement in communication and to narrow the span between what is thought to be the correct choice and what is actually done are thus warranted.

Keywords: Medical futility; End-of-life decisions; Perception; Living wills; Knowledge and behavior; Health professionals; Intensive care unit; Terminally ill patients; Critically ill patients

Abbreviations: ICU: Intensive Care Unit; DNR: Do-Not-Resuscitate

Introduction

Critical care is an integral part of hospital care, and the intensive care unit (ICU) is the setting where patients are given the most technologically advanced life sustaining treatments. The ICU is, however, also a setting where death is common and end-of-life care is frequently provided [1].

Collaboration could be defined as: "ICU nurses and physicians cooperatively working together, sharing responsibility for problem solving and decision-making, to formulate and carry out plans for patient care" [2]. End-of-life care in most settings is delivered by an interdisciplinary team that includes nurses and physicians. Therefore, ideally, end-of-life decisions should be made after discussions between all members of the interdisciplinary team. However, interdisciplinary collaboration about end of- life care is often poor and the physician is the major decision maker in the end-of-life process. In an integrated review of current research it was found that physicians often make these decisions alone or with minimal input from others [3].

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In Europe, patient-physician relationships are still somewhat paternalistic [4]. Despite a decade of autonomy having "paradigmatic status", little is known about how physicians apply the principle in clinical settings. Physicians believe patient wishes and values are important, but other considerations are often equally or more important. This suggests that patient autonomy does not guide physicians' decisions as much as is often recommended in the ethics literature [5]. Traditionally, families have been much more involved in end-of-life decision making in the United States of America than in Europe. In the ETHICUS study, done in 37 ICUs in 17 European countries, end-of-life decisions were discussed with the family more commonly in northern (84%) and central (66%) than in southern (47%) Europe [4].

End-of-life decision making is the process that healthcare providers, patients, and patients' families go through when considering what treatments will or will not be used to treat a life-threatening illness. Living wills and considerations to withhold or withdraw therapy could be considered as possible forms within the decision making process.

Living wills provide an opportunity for patients to express their preferences in writing before a critical illness occurs [3]. However, it has been shown that there is very little evidence regarding the effect that type of instruments on the treatment of acutely ill patients in the ICU [6].

Other form of end-of-life decision making is withholding or withdrawing life-sustaining therapies. Considerations to withhold or withdraw therapy are common issues in intensive care units (ICUs), as 35-90% of deaths in an ICU happen after therapy has either been withheld or withdrawn [2]. Withholding and withdrawal of life sustaining treatment were introduced to avoid the futile suffering of dying patients. These practices are based on the principles of bioethics; they are common worldwide, have been approved by the international scientific community, and must not be confused with euthanasia [7].

Several multicenter studies involving European countries, where Portugal was included, have been done [4], but we have a lack of knowledge concerning how the decision making process is made in our country.

Therefore, the aim of our study is to understand the reality of the decision making process on the end of life in several ICUs of hospitals in the central region of Portugal.

Material and Methods

The authors developed a questionnaire to assess end-of-life decision making and attitudes towards medical futility in the ICU, which has been called the medical futility questionnaire (see Supplementary file-1) and was based on previous personal experience with medical futility and on a literature review. Completion of the final version of the questionnaire was achieved after a pilot study.

The medical futility questionnaire was delivered to physicians and nurses working on the ICUs of 8 Portuguese hospitals (see Supplementary file-2) located in the central region of Portugal. All ICUs were mixed (surgical-medical).

Questionnaires were personally delivered to the chief nurses of the enrolled ICUs who then delivered them to physicians and nurses and were returned by mail.

The medical futility questionnaire comprises 2 main sections: section 1 concerning socio-demographic-professional variables of the participants with 6 questions; section 2 concerning questions on end-of- life decision making process and medical futility attitudes and believes with a total of 16 questions.

Between May and October 2010, 183 questionnaires were returned from a total of 235 delivered-78% response rate.

The study has been approved by the Ethics Committees of the different hospitals involved in the study (see Supplementary file-2 for the name of the hospitals). Informed consent was obtained from all the participants.

Categorical variables were described as absolute frequencies (n) and relative frequencies (%); median and percentiles were used for continuous variables. Pearson Chi-square test and Mann-Whitney test were used for comparisons. Statistical significance was considered at $p<0.05$. SPSS19.0 was used for statistical analysis.

Results

Results obtained from the 183 returned questionnaires included 147 nurses (80%) and 36 physicians (20%); socio-demographic variables of the participants are presented in Table 1.

Answers to questions concerning attitudes and believes towards end of life issues in the ICU and medical futility are shown on Table 2. We would like to highlight the following:

Reasons pointed out for excessive/unjustified treatments, by more than half of nurses and physicians, included non-acceptance of treatment failure, insufficient training on ethical issues, difficulty on accepting death, incorrect evaluation on clinical condition; difficulties in communication were pointed out by a third of nurses and physicians (Table 2).

Fifty four percent of nurses and 74% of physicians have never had any training or education concerning medical futility and end-of-life issues. Seventy-seven percent of nurses and 69% of physicians considered that they felt the need of training/education on medical futility and end-of-life issues: 64% of physicians because of control of symptoms and 43% of nurses because of the need of a better communication among nurses, physicians and patients' family (i.e. physicians *vs* nurses- physicians *vs* families-nurses *vs* families) (data not shown).

	Nurse	Physician	p[1]
Gender, n(%)			
Female	94(64)	15(42)	0.015[1]
Male	53(36)	21(58)	
Religion n(%)			
Catholic	130(88)	27(75)	-
Protestant	1(0)	0(0)	
Agnostic	15(10)	7(19)	
Other	0(0)	2(6)	
Age (years)			
Median (P25-P75)	38,00 (32-43)	45,00 (37-51)	0.001[2]
Professional experience (years)			
Median (P25-P75)	15,00 (10-19)	20,00 (11-26)	0.058[2]
Professional experience ICU			
Median (P25-P75)	9,00(6-12)	8,00(2-11,50)	0.181[2]
Rate response n(%)	147(77)	36(82)	0.484[1]

[1]Qui-Square Test; [2]Mann-Whitney test; P25- Percentile 25; P75-Percentile 75

Table 1: Socio-demographic variables, professional experience and response rate.

To reduce the occurrence of medical futility, strategies that were pointed out included mainly education and training and enhancing communication inside the ICU team and with the families.

Sixty-seven percent of nurses and 72 % of physicians were never faced with living wills from patients. Seventy-seven percent of nurses and 69% of physicians considered that the existence of a National Registry of living wills will facilitate end-of-life decisions (data not shown).

There were no statistical significant differences in the answers to the questionnaire concerning age, gender or religion (data not shown).

There were statistical significant differences between nurses and physician concerning decisions assumed in terminally ill patients (Question 10) - Table 2; in addition, comparing question 11 ".In your opinion, who should be involved in decisions concerning terminally ill patients?" with question 12 "During your professional experience, who is involved in decisions concerning terminally ill patients?" there were statistically significant differences in all items, except for the item related with ICU physician, i.e., it was consensual that the ICU physician should always be involved in decisions concerning terminally ill patients (Table 3).

Discussion

The main findings from this study are as follows: First, more than half of physicians and nurses considered that occasionally there were excessive/unjustified treatments in the ICU, while about forty percent of nurses and about a quarter of physicians considered that frequently there were excessive/unjustified treatments. These findings support earlier empiric observations that futility does occur in the ICU setting [8]. Difficulties in the control of symptoms for the physicians, and difficulties of communication between the team (physicians *vs* nurses-physicians *vs* families-nurses *vs* families) for the nurses, has been among those problems reported as being more important for these ICU professionals. Communication problems have been reported in several other studies as one area that needs intervention in order to find strategies to improve the decision making process concerning end-of life-decisions [9,10]. Heland et al. have highlighted the need to

	Nurse (n=147)		Physician (n=36)		p[1]
	n	(%)	n	(%)	
8. Do you consider that in your workplace are situations where the treatments are excessive / unjustified?					0.130
Occasionally/Never	86	(59)	26	(72)	
Always/Frequently	61	(41)	10	(28)	
13- If you think there have been excessive / unjustified procedures, which would you consider being the principle reasons?					
Difficulty accepting death					0.802
Yes	80	(55)	20	(57)	
Inability to accept failure					0.093
Yes	112	(77)	22	(63)	
Incorrect evaluation on clinical condition					0.261
Yes	68	(47)	20	(57)	
Religious convictions					0.447
Yes	8	(5)	3	(9)	
Insufficient training on ethical issues					0.806
Yes	95	(65)	22	(63)	
Family conflicts					0.544
Yes	23	(16)	7	(20)	
Insufficient communication					0.679
Yes	47	(32)	10	(29)	
Others					0.585
Yes	5	(3)	0	(0)	
9. What degree of importance do you rate on the existence of medical futility in the practice of health professionals?					1.000
Important/Very Important	138	(94)	34	(94)	
Not important/Little important	9	(6)	2	(6)	
10. When indicate, are the following decisions assumed in terminally ill patients?					
10.1 Not start artificial support of vital functions					**0.001**
Occasionally/Never	**113**	**(77)**	**18**	**(50)**	
Always/Frequently	**33**	**(23)**	**18**	**(50)**	
10.2 Stop artificial support of vital functions					**0.008**
Occasionally/Never	**104**	**(71)**	**17**	**(47)**	
Always/Frequently	**43**	**(29)**	**19**	**(53)**	
10.3 Deciding not to resuscitate (DNR)					**<0.001**
Occasionally/Never	**89**	**(61)**	**10**	**(28)**	
Always/Frequently	**58**	**(39)**	**26**	**(72)**	
10.4 Certificate brainstem death					**0.027**
Occasionally/Never	**68**	**(46)**	**9**	**(26)**	
Always/Frequently	**79**	**(54)**	**26**	**(74)**	

[1]Qui-Square Test

Table 2 - Questions on end-of-life decision making process and medical futility.

	Nurse				Physician				Comparisons between nurses and physicians	
	In your opinion, who should be involved in decisions concerning terminally ill patients?		During your professional experience, who is, in fact, involved in decisions concerning terminally ill patients?		In your opinion, who should be involved in decisions concerning terminally ill patients?		During your professional experience, who is, in fact, involved in decisions concerning terminally ill patients?		Should be involved*	Is, in fact, involved*
									p[1]	p[1]
The patient's physician										
Always	93	(63)	37	(26)	24	(67)	13	(36)		
Frequently	22	(15)	10	(7)	5	(14)	6	(17)	0.760	**0.025**
Occasionally	26	(18)	34	(24)	7	(19)	13	(36)		
Never	6	(4)	63	(44)	0	(0)	4	(11)		
p[1]	<0,001				-					
The legal surrogate of the patient										
Always	77	(52)	15	(10)	10	(28)	3	(8)		
Frequently	39	(27)	17	(12)	11	(31)	6	(17)	**0.011**	0.738
Occasionally	20	(14)	67	(47)	11	(31)	19	(53)		
Never	11	(7)	44	(31)	4	(11)	8	(22)		
p[1]	<0,001				0,039					
The ICU physician										
Always	135	(92)	131	(90)	27	(75)	29	(81)		
Frequently	11	(7)	10	(7)	6	(17)	5	(14)	**0.025**	0.626
Occasionally	1	(1)	5	(3)	3	(8)	2	(6)		
Never	0	(0)	0	(0)	0	(0)	0	(0)		
p[1]	-				0,834					
The ICU nurses										
Always	119	(81)	17	(12)	19	(53)	10	(28)		
Frequently	15	(10)	26	(18)	7	(19)	9	(25)	**0.005**	**0.010**
Occasionally	9	(6)	63	(44)	9	(25)	10	(28)		
Never	4	(3)	38	(26)	1	(3)	7	(19)		
p[1]	<0,001				-					
The patient's family										
Always	80	(55)	16	(11)	13	(36)	6	(17)		
Frequently	35	(24)	33	(23)	9	(25)	8	(22)	**0.033**	0.547
Occasionally	26	(18)	66	(45)	12	(33)	15	(42)		
Never	5	(3)	31	(21)	2	(6)	7	(19)		
p[1]	<0,001				-					
The ethics committee										
Always	60	(41)	1	(1)	2	(6)	0	(0)		
Frequently	38	(26)	9	(6)	3	(9)	0	(0)	**<0.001**	0.216
Occasionally	44	(30)	49	(34)	26	(74)	11	(31)		
Never	3	(2)	84	(59)	4	(11)	25	(69)		
p[1]	<0,001				-					

[1]Qui-Square Test;* This comparisons were made with categories colapsed:Always/Frequently; Occasionally/Never

Table 3: Comparisons between who should be and who is, in fact, involved on end-of-life decisions.

put an emphasis on collaborative decision making between all health professionals, the patient and family. Second, concerning opinions about who should be involved in the end-of life decisions, nurses had different opinions from physicians, and only opinions concerning ICU physician and ICU nurse involvement were able to gather more than fifty-percent of the opinions of both professional categories. This finding is in agreement with other studies, where nurses and other professionals must be involved in these decisions [11]. Third, concerning opinions on whom is, in fact, involved in end-of-life decisions, only opinions on the involvement of the ICU physician were consensual. Moreover, percentages on whom is, in fact, involved in end-of-life decisions are not only statistically significant less than those concerning whom should be involved, but also they differ significantly between nurses and physicians. These findings are in agreement with the aforementioned study [11] where the discrepancy on whom should be, and whom is in fact, is found. This discrepancy, together with the difficulties in communication, are probably the most important findings from this study and point out for the areas that needs improvement. Strategies in order to find a better communication and to narrow the span between what is thought to be the correct choice and what is actually done are

thus needed. Fourth, lack of training/education concerning end-of-life decision making may explain the results concerning medical futility that has been indicated by more than half of the nurses and about three quarters of the physicians; this finding is in accordance with other studies [5,11] where lack of specific education on end-of-life issues, namely futility has been felt by a large percentage of physicians and nurses on the ICU setting, with some studies reaching percentages as high as 90% [8]. Our findings are also in agreement with the findings from Aslakson et al. [12], where, despite the growing emphasis on end-of-life care, neither physicians nor nurses think that their educational preparation or clinical experiences have prepared them well to help patients and patients' families at the end-of-life. Although previous studies have shown that Religion is an important determinant of attitudes towards dying, death and end-of-life care, and that significant differences can be found among different religions [4], we could not find any difference as 86% of the respondents were catholic.

This study presents some limitations: first, the questionnaire was not submitted to a process of validation; second, concepts like the one of "communication" were not clearly defined as it was assumed as a "common-sense" definition.

Strengths from the study include the inclusion of all ICUs from a region, a relatively high response rate and the raising of hypothesis to understand difficulties in the decision making process towards end-of-life decisions in critically ill patients.

Conclusion

In conclusion, the present study has shown problems of communication, namely discrepancies of opinion between nurses and physicians and discrepancies between on whom should be and who is in fact involved on end-of-life decisions. These discrepancies, together with the difficulties in lack of education/training were the main findings from our study that might explain difficulties found in the decision making process. Strategies to find an improvement in communication and to narrow the span between what is thought to be the correct choice and what is actually done are thus warranted.

Our study has add to our knowledge by showing some of the difficulties in finding the ways to compassionately guide the patient and family through end-of-life decisions, which may be one of the biggest challenges for all the physicians and nurses working in ICUs.

Key Messages

Concerning end-of-life decisions, we found problems of communication, namely discrepancies of opinion between nurses and physicians, and discrepancies between on whom should be and whom is, in fact, involved;

These discrepancies, together with the difficulties in lack of education/training were the main findings from our study that might explain difficulties found in the decision making process;

Strategies to find an improvement in communication and to narrow the span between what is thought to be the correct choice and what is actually done are thus warranted.

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