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Family reliance on physicians' decisions in life-sustaining treatments in acute-on-chronic respiratory diseases in a respiratory intensive care unit: A single center study

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### **Abstract**

Introduction: In intensive care units, many patients are unable to participate in decision making regarding life-sustaining treatments. This study aimed to evaluate the opinion of family members about family and physician participation in life-sustaining treatment decisions and to examine which factors can influence the decision.

Methods: This is a prospective exploratory observational study using convenience sampling. Inquiry interviews were conducted over a 3-year period with 126 family members (out of 303 potential participants) of patients with acute-on-chronic respiratory failure, who had been admitted to the respiratory intensive care unit (RICU) and were dependent on invasive or noninvasive ventilation (without airways intubation). Patients of ≤18 years, those with a stay length of less than 3 days, and oncologic patients were excluded.

Results: A majority of the participant family members, 123/126 (97.6%) had an opinion about their involvement in decision making about life-sustaining treatments. Physician choice preferred by 54/123 (43.90%), 55/123 (44.72%) wished to share the decision with the physician, and 14/123 (11.38%) decided for a family option. All the patients were incompetent at the time of inquiry. Autonomy prior to admission to the RICU influenced the decision.

Conclusions: A majority of families rely on physicians to help in the decision-making process of life-sustaining treatments in acute-on-chronic respiratory diseases. From the family point of view, the principle of autonomy can be exercised by surrogating the decision making process to the physician. The sociological and cultural characteristics of each country deserve special attention in these kinds of studies.

Key-words: End-of-life; surrogate decision making; cultural and geographical influences in end-of-life decision making.

### Introduction

Intensive care units (ICUs) were originally conceived for acute conditions—illness or injuries. Subsequently, their scope was extended to acute-on-chronic diseases, and today ICUs are often repositories for patients with end-stage diseases who have a high mortality risk<sup>1</sup>. This trend is expected to have important implications regarding patient involvement in end-of-life treatment options, mainly through advance directives (ADs).

In southern European countries like Portugal, where this practice is uncommon, the first steps regarding ADs are being taken by way of discussion and legislative enforcement. However, despite the manifest utility of ADs, only 20–30% of patients have such a document, even in Anglo-Saxon countries where ADs are encouraged<sup>2</sup>.

Thus, if the patient is incompetent to decide<sup>3</sup>—because of an acute condition or heavy sedation—and has no valid ADs regarding life-sustaining treatments, the decision making shifts from the patient to the family. The legitimacy of family as decision makers derives from the close relationship that normally exists among family members or, as Dan Brock expresses it, "patient-regarding grounds for family authority"<sup>4</sup>.

Serious concerns exist, however, about the philosophical justification for substituted judgment<sup>5</sup>. In addition, the practice of the principle of autonomy is not understood and exerted uniformly in all countries, as is shown in the differences between Anglo-Saxon and southern European countries<sup>6</sup>, which maintain differing attitudes about end-of-life matters<sup>7-9</sup>. As one example, decision making is predominantly physician centered in Europe, whereas in the USA, the patients and families are much more involved in that process<sup>10</sup>. It should be remembered also that because most of the patients in the ICU are elderly, the responsibility for decision making falls on the younger generations. It is well known that in Europe, people in different countries hold widely varying views about their intergenerational responsibilities to their elders. For example, in Spain, Italy, Greece, and Portugal, people feel strongly bound by obligations towards their parents, while in Finland, Ireland, and Netherlands, children's obligations to parents are thought to be minimal<sup>11</sup>. Hence, it is important to know the family member variables that can influence the decision.

This study was conducted in a single respiratory ICU (RICU) in a university hospital in Lisbon, Portugal, where patients' families are seldom requested to participate directly in the decision-making process<sup>12</sup>. The aim was to understand family participation in decisions about end-of-life issues in the hospital RICU: Do family members wish to help decide about life-sustaining treatments for patients who are incompetent to decide? Would they rather delegate such matters to the physician? What variables, if any, influence that choice?

The factors that can influence the decision-making process are, on the one hand, related to the patient (age, co-morbidities, dependency on daily-life activities before admission and competency at the time of inquiry) and on the other, to the family members, both demographically (age, gender, occupation, household [co-habitation]) and non-demographically (relationship with patient, depression, prognosis)<sup>6</sup>.

Another important factor to consider is that such decisions not solely rational; they include cultural and emotional components<sup>13</sup>. In our study, we considered the relevance of depression<sup>14</sup>, communication (because it is well known that patients and families who trust their physicians feel comfortable relying on the physician for help in making decisions<sup>15</sup>), and prognostic implications<sup>16</sup>, since, in spite of prognostic uncertainty, they allow families to make a decision based on the likely outcomes of treatments.

## **Objective**

To evaluate the perception of family members and factors that influence the decision-making process concerning lifesustaining treatments.

#### Methods

This study was conducted, via inquiry interviews, over 3 years (October 2007 to March 2011) in the RICU of the Pulmonology Department of Santa Maria University Hospital, a 14-bed unit (8 high-risk and 6 intermediate non-invasive ventilation beds). The unit has 3 consultant physicians and 2 assistant physicians. This is a prospective exploratory observational study based on family members' availability, willingness to volunteer, and easy access (convenient sample). We interviewed the family members of patients in the RICU with acute-on-chronic respiratory failure and dependent on invasive or noninvasive ventilation. Excluded were patients of ≤ 18 years, those with a stay length of less than 3 days, and oncologic pathology.

For each patient enrolled the following data was recorded:

- Patient data: days of stay in the ICU, diagnosis, type of ventilation, age, gender, religion, household, occupation, severity index (APS/APACHE II), previous health state, previous episodes of mechanical ventilation, patients' advance directives (if any).
- Family member data: age, gender, relationship, cohabitation, residency, education, occupation, religion, communication with the staff doctor, depression according to the Hamilton Depression (HAM-D) Rating Scale, rating of care in the unit (very good/good/reasonable/bad), and patient prognosis (very good/good/reasonable/bad) from the family's perspective.

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Before they answered the questions, each family member was informed about the severity of the disease on a scale of 1–10

(considering the APACHE II severity index) and assured that answers would not be considered in any decisions regarding

life-sustaining treatments.

A physician administered the questionnaire, first taking some time in conversation to put the family at ease and to establish

an informal atmosphere. The administering physician recorded the answers after making sure of their content and meaning.

Each family member was asked the following question: Considering that your next of kin is incompetent, in case of life-

sustaining treatments, who should be the responsible for that decision?

The following options were given to the family members:

I. Family

II. Physician

III. Family + Physician

IV. Doesn't know/Doesn't answer

The competency of the patient depended on their mental abilities and cognitive capabilities required to execute a legally

recognized act rationally<sup>17</sup>.

The study was approved by the Ethics Committee of Santa Maria Hospital and authorized by the National Committee of Data

Protection. The study design, procedure, and results were monitored by an independent statistical consultancy agency.

Statistical Analysis

The results were analyzed with descriptive univariable and bivariable statistics, using average, standard deviation, median,

and quartile for the quantitative variables, and counts and percentages for the qualitative variables. The significance of the

association between two qualitative variables was assessed using the chi-square independence test or the Fisher's exact test

where appropriate. All tests were two-sided, using a type I error of 5% (unless otherwise stated). IBM SPSS Statistics 19

software (SPSS; Chicago, IL) was used for all statistical analyses.

Results

One visiting family member per patient participated in the inquiry. There were 126 (41.58%) interviewees out of 303 potential

participants.

#### **Patient statistics**

The majority of patients were elderly, with an average age of approximately 71 years and a higher median of 74 years. About 41% were more than 75 years old (middle-old and very elderly)<sup>18</sup>; only 29% were  $\leq$  65. Males accounted for 65% (n = 82) of the patients, and 94 (75%) lived with family members. The education level was very low, as 59% had very low or low literacy (according to the analphabets/IV standard of education). There were 119 (94%) Caucasians, and 113 (90%) were retired.

Acute-on-chronic respiratory failure from chronic respiratory disease, with or without congestive heart failure, was responsible for 102 (81%) of ICU admissions. The median severity indices, APS and APACHE II, were 17 and 26 respectively (superior limit 35 and 45), indicating the severity of the diseases. Invasive mechanical ventilation was required by 71 patients (56%), pointing to a serious respiratory failure.

In terms of previous health, 99 (79%) had required no previous mechanical ventilation. Most of the patients, 114 (91%), had no ADs regarding mechanical ventilation and 112 (89%) had none regarding hemodialysis. All expressed directives were verbal, not written. A large number of patients (113, 90%) had been lucid prior to their hospitalization (i.e., had the ability to think clearly and rationally); the exacerbation probably being responsible for their incompetency. Further, before RICU admission, 77 (61%) were physically autonomous (independent in activities of daily living [ADL]).

## Family member statistics:

The average age was 53 years with a slightly higher median (55 years). The family visitors were mostly sons, daughters, and in-laws. Because females are more typically frequent visitors in Portugal, 97 (77%) were female. A close relationship between patient and visitor (spouse, adult son/daughter, parent or sibling) existed in 105 (83%) of the participants; thus, in most cases, the relationship was close enough for the participant to know the patient's values and expectations.

Despite close family ties, a great majority, 113 (90%), lived in urban areas and did not live with the patient. Secondary or university education accounted for 47%. The difference in literacy compared to the patients can be explained by the age of family members and by the economic and social evolution of the country in the last decades. In terms of employment, 71 (56%) were employed, and 111 (88%) considered themselves religious. The low rate of employment was likely owing to retirement or unemployment. The majority of family members (66%) had some degree of depression (slight, moderate, or serious) as measured by the HAM-D Rating Scale. No anti-depression treatment was prescribed to those who had any degree of depression.

All who participated were asked about the medical information provided to them. The majority 88 (70%) were interested in it, but many desired different information, with 56 (44%) wishing for a general explanation and 58 (46%) a more specific elucidation. Even so, 68 (54%) considered themselves enlightened, and 58 (46%) felt more comfortable after receiving information from the physician. A majority, 99 (79%), classified the care provided in the ICU as very good. For 58 (46%) of the family members, the prognostic expectation of the patient was bad. The global mortality was 59.5%

## Bivariable exploratory analysis

We established three categories of family members for each patient/participant:

- a. Family members who favor a physician decision (PD)
- b. Family members who prefer a shared decision (SD)
- c. Family members who opt solely for a family decision (FD)

The results showed that 54 family members opted for physician decision (PD), 55 for shared decision (SD) and 14 for family decision (FD). The option for physician involvement (PD + SD = 109) against no physician involvement (FD) clearly favors physician involvement (alone or shared) p < 0.0001. However, the small number in FD group may introduce some bias in the analysis.

We also analyzed if the number of days with ventilation at the time of inquiry had any relation to family members' options. In general, from a clinical point of view, ventilation is considered prolonged if a patient needs ≥ 21 days<sup>19</sup>. However, since in this study the evaluation of prolonged ventilation is not from a clinical perspective, but from the family's emotional condition, we used a subjective ≥ 14-day as a cut-off, a period of time that can have some influence in the options of decision-making. Thus, considering the two groups (Fig. 1), it was verified that for a prolonged stay, the options shifted toward a shared decision. Again, the small number of patients in the prolonged group may introduce some bias in the analysis.

The results of the influence of some of the variables on the families' options are shown in Tables 1 to 3.

When the previous health state (lucidity and autonomy in ADL before ICU admission) was considered (Table 1), because a great majority of patients from all 3 groups (PD, SD and FD) had been lucid, there was no difference between physician and family participation. In the case of autonomous patients prior to admission, family members leaned strongly toward a physician decision, whereas a family decision was favored for patients that were completely dependent before admission in the ICU.

Invasive mechanical ventilation (IMV) can be a traumatic experience for both patient and family. In acute-on-chronic respiratory diseases, patients are likely to be subjected to repeated IMV<sup>20</sup>. Thus, this variable should be considered in analyzing the family's options. In this study, although the number of patients with a previous episode of mechanical ventilation was small (27), a majority of participants with previous experience did not want physician involvement. Had they any fear of medical futility? In an opposite option, family members having no previous experience with IMV favored physician involvement, choosing either a sole (75.9%) or shared decision (83.6%).

ADs regarding mechanical ventilation 12/126 (9.5%), hemodialysis (14/126 [11.2%]), or cardiopulmonary resuscitation 13/126 (10.3%), were all verbal. In Portugal, there is no data regarding ADs because any relevant legal implementation is very recent. In terms of the main diagnosis, the family of patients with congestive heart failure without any chronic respiratory disease chose physician decision, (16/17, alone or shared). Regarding the mode of ventilation, in IMV, 63/71 families chose to entrust the physician with the decision (alone or shared). The severity of the situation (intubation/ventilator/sedation) from the family perspective shifted the decision toward the physician.

In the patient demographics analysis, it was verified that family members of older patients prefer a physician decision (a 75-year median compared to 72 for shared and 70 without the physician). However, the p-value is not significant (p = 0.83). In terms of household, 88.8% who opted for total physician responsibility, 60% of those who chose shared decision, and 85.7% of those choosing no physician partnership live with the patient (p = 0.18). Thus, it seems that when family members live with the patient, they are more likely to take the responsibility for decision making. The proximity resulting from the cohabitation leads to a better knowledge of patients values and, as such, the family member is more liable to assume involvement in the decision making process.

Although the education level of the patients was generally quite low in all the groups, the family members of those patients with a higher education chose an SD (29.1 %) when compared with a PD (11.1 %) and an FD (14.3 %). A higher literacy level of the patient, demonstrates an intrinsic desire of his family member to know and dialogue with the physician about the disease (p = 0.56). A different behavior was seen with regard to the education level of the family member (Table 2). Those with a secondary or university level education chose an FD (57.2%), while those with low or very low literacy opted for a PD (37.0%). The previous reasoning in the situation of literacy level favors the option for family autonomy in the decision-making process (p = ns).

Although the majority of family members in the 3 groups considered themselves religious, the proportion with religion was higher (94.4%) for the PD group than for the FD or SD, both of which had values below 86% (p = 0.12). When depression is

considered, a shift occurs toward a PD (alone or shared) according to the severity of the depression but without statistical significance (p = 0.52) (see Table 3).

The family's satisfaction with the care provided seems to have no influence on their choice. Regarding the prognosis from the family perspective, two groups were considered: very good/satisfactory and bad. There is an option for physician involvement (alone or shared) in either group, although it is not statistically significant (p = 0.83).

## **Inferential Analysis**

For the inferential data analysis, the end-points (PD, SD, and FD) were crossed with the following:

- 1) Demographics (gender, age, education, cohabitation, employment status, and religion)
- 2) Previous health state and mechanical ventilation, autonomy, and advanced directives
- 3) Information (type, understanding, and feeling after communication)
- 4) Depression (depressed and non-depressed) and prognosis

We verified that independence between the family members and the patient autonomy is rejected. A significant majority of respondents that opted for a totally physician responsibility are family members of an autonomous patient (70% as against 55% for shared decision and 43% for family decision, p = 0.090). In our opinion, the families do not want to assume the burden of responsibility of decision in a patient, who prior to the admission in the ICU was completely independent in his activities of daily living. Somehow it is a defensive posture.

#### **Discussion**

An analysis of the univariables (age median and severity index) identifies a trend in patients and diseases admitted into our RICU: they are elderly, acute-on-chronic patients with a severe exacerbation and, in this study, without any written ADs.

The family members surveyed in this study had close links with the patient; a reasonable educational level; good knowledge, in most of the cases, of their family situations; and some degree of depression, as expected in this situation. Thus, they were in good position to represent the patient's expectations and values (e.g., moral and religious)<sup>21</sup>.

The bivariable analysis points out clearly, with statistical significance, that family members desire physician involvement in the decision-making process, either alone or shared with family members, independent of patient competency. When the situation is more serious (i.e., an incompetent patient), this option is clearer. This result is to be expected, given that the decision-making process at the end of life with an incompetent patient is a burden with which few people feel able to deal

alone. Thus, given the chance, they will delegate such a difficult decision to someone (a physician) who, because of knowledge and experience, is in a better position to make the best decision.

The PD option showed no relationship with the number of days of hospitalization in the ICU. In our experience, with an increasing length of stay, the family's expectations and hopes in the clinical improvement become more somber, and they become more reliant on the physician's words and decisions. However, the small number of cases with the cut-off limit of ≥ 14 days may have biased the results.

In this study, prior to admission autonomy favoring the option for a physician decision seems to be the only variable influencing the decision-making process.

Since ancient Greek times, the exercise of medicine in terms of physician decision making has been based on principles of beneficence and non-maleficence. In modern medicine, however, the conduct underlying that process is structured, at least in some countries (USA and northern Europe), around the principle of autonomy (or patient/family compromise)<sup>22</sup> as against southern European countries, where the principle of beneficence is still ascendant. In the daily exercise of medicine, a confrontation exists between the perception and practice of these two principles—beneficence and autonomy. Of late, in the southern European medical community, the principle of autonomy is slowly making inroads in the behavior of the physicians. In our opinion, this ascendancy of the principle of autonomy may stem more from a defensive attitude on the part of the physician, rather than from a belief in the intrinsic competency of patients and families in free and rational reasoning. Whatever the reason, it is pertinent for physicians in southern European countries to know and understand what families think about the surrogate decision-making process in end-of-life situations, namely in life-sustaining treatments.

In looking at delegated responsibility, a consideration of values is also paramount. It is well known that it is the surrogate's responsibility to represent the personal values of the patient and no else's. However, as Ortega y Gasset, Spanish humanist and philosopher observed, "I am I plus my circumstances." Thus, it seems utopian to believe that in such a situation, the surrogate can make a decision completely independent of his own existence and the elements surrounding him, which are decisive influences over his judgment. This idea is demonstrated by the fact that in this study, patient autonomy prior to admission seems to have statistically influenced the decision. The likely emotional state of family members also raises a question: Can frail and anguished family members make a free and rational judgment?

Finally, the sociological and cultural components of the families must also be considered. According to Edward T Hall, an American anthropologist, culture influences the way people think, feel, and act: "Culture is communication and communication

is culture"<sup>23</sup>. Therefore, it is foreseeable that different cultures would communicate in different ways. In the case of doctor-patient/family, this communication will probably not be identical.

To the best of our knowledge, this is the first and only study of its kind in Portugal. In this study, our goal was, first, to find out which option the surrogate would prefer regarding the responsibility of decision (physician, shared, or family decision) and second, if that choice would depend on the degree of competency of the patient and the influence of certain variables—the patient, the surrogate family member, and the circumstances of the situation. From the data analysis, it seems that for family members of incompetent patients, the principle of autonomy can be exercised by surrogating to the physician, alone or together with the family member, the responsibility of decision. Further, the only variable, autonomy prior to admission, had some statistically significant influence in that choice. Other variables need further study. A greater knowledge, considering each country's cultural and social reality, is fundamental to understanding the process of decision making in order to avoid or at least minimize potential ethical conflicts in ICUs.

This study had some shortcomings: first, the small number of answers in some groups could be a source of bias in the analysis. Second, as in any study wherein the variables may be highly subjective, the answers must be interpreted carefully. We tried to avoid the individual error of misinterpretation by limiting to two the number of physicians who administered the questionnaire, the author being responsible for more than 90% of the interviews. The interviews also took place in a serene atmosphere, as we attempted to put the families at ease. We explained the goals of the study to the families, along with our expectations from their answers, to avoid any ambiguity; we also clarified that, whatever their options, their choices would not influence the ICU staff decisions. The family members seemed comfortable during the interviews, and many of them praised the study. Although all the efforts were made to put the family members at ease, it is not always possible for them to exchange their views in an open and sincere manner. Third, a variable that was not considered but that might influence the decision-making process is the economic impact of disease in the family. Considering the diminished health status and physical autonomy of these patients—and, in most cases, their poor economic status—their care may have been an economic burden for the families, which could have implications for their decision-making. Fourth, the extent and limits of family involvement in the decision-making process were not completely clear. These limitations and factors indicate the need for further studies of this kind in Portugal because some of these matters have not been treated.

## Conclusion

In Portugal, families are not asked to participate in decisions pertaining to life-sustaining treatments of their relatives when the patients themselves are not in the position of making that decision. This study suggests that the majority of families rely on

physicians, while others want to share the decision-making process. In a shared decision, it is important to know if they want to have a say or simply to be informed. This study also points out that factors, such as autonomy can influence the decision of the families and others that these matters need further study.

Finally, this study has greatly clarified one aspect: the social and cultural setting of each country—including the literacy level of family members, the way the family and the physician interact, the kind of information the physicians provide, and the extent of family involvement physicians are prepared to accept—are major factors to be considered and reflected upon in any analysis of surrogate decision making.

### References

- Gavrin JR. Ethical considerations at the end of life in the intensive care unit. Crit Care Med 2007;35(2 Suppl):S85-94.
- Sprung CL, Eidelman LA. Worldwide similarities and differences in the foregoing of life-sustaining treatments.
   Intensive Care Med 1996;22(10):1003–1005.
- 3. Ferrand E, Bachoud-Levi AC, Rodrigues M, Maggiore S, Brun-Buisson C, Lemaire F. Decision-making capacity and surrogate designation in French ICU patients. Intensive Care Med 2001;27(8):1360–1364.
- 4. Brock D. What is the moral authority of family members to act as surrogate for incompetent patients? Milbank Q 1996;74(4):599–618.
- 5. Emanuel E, Emanuel L. Proxy decision making for incompetent patients: An ethical and empirical analysis. JAMA 1992;267(15):2067–2071.
- Azoulay E, Pochard F, Chevret S, Adrie C, Annane D, Bleichner G, et al. Half the family members of intensive care
  unit patients do not want to share in the decision-making process: a study in 78 French intensive care units. Crit Care
  Med 2004; 32(9):1832–1838.
- 7. Heyland DK, Cook DK, Rocker GM, Dodek PM, Kutsogiannis DJ, Peters S, et al. Decision-making in the ICU: perspectives of the substitute decision-maker. Intensive Care Med 2003;29(1):75–82.
- 8. Yaguchi A, Truog RD, Curtis JR, Luce JM, Levy MM, Mélot C, Vincent JL. International differences in end-of-life attitudes in the intensive care unit: results of a survey. Arch Intern Med 2005;165(17):1970–1975.
- Vincent JL. Ethical principles in end-of-life decisions in different European countries. Swiss Med Wkly 2004;134(5-6):65–68.
- 10. Levy MM. Evaluating our end-of-life practice. Crit Care 2001;5(4):182–3.
- 11. European Judicial Network in Civil and Commercial Matters. http://ec.europa.eu/civil justice/index en.htm.

  Accessed on October 17, 2012.
- 12. Cardoso T, Fonseca T, Pereira S, Lencastre L. Life-sustaining treatment decisions in Portuguese intensive care units: a national survey of intensive care physicians. <a href="http://ccforum.com/content/7/6/R167">http://ccforum.com/content/7/6/R167</a>. Accessed on July 15, 2012.
- 13. Damasio A. Descartes' Error: Emotion, Reasoning, and the Human Brain. New York: Harper; 1995.
- 14. Pochard F, Azoulay E, Chevret S, Lemaire F, Hubert P, Canoui P, et al. Symptoms of anxiety and depression in family members of intensive care unit patients: ethical hypothesis regarding decision-making capacity. Crit Care Med 2001;29(10):1893–1897.

- 15. Mechanic D, Meyer S. Concept of trust among patients with serious illness. Soc Sci Med 2000;51(5):657–668.
- 16. Evans LR, Boyd EA, Malvar G, Apatira L, Luce JM, Lo B, White DB. Surrogate decision-makers' perspectives on discussing prognosis in the face of uncertainty. Am J Respir Crit Care Med 2009;179(1):48–53.
- 17. Bisbing SB. Competency and capacity: a primer. In: Sarban SS, Gibofsky A, Firestone MH, et al. editors. Legal Medicine. 4<sup>th</sup> ed. American College of Legal Medicine. St Louis: Mobsy; 1988;32-43.
- 18. Silver Innings Foundation. http://www.silverinnings.com. Accessed on April 12, 2013.
- Nazir IL, Timothy SW. Prolonged mechanical ventilation in critically ill patients: epidemiology, outcomes and modeling the potential cost consequences of establishing a regional weaning unit. Crit Care 2011;15(2):R102 doi: 10. 1186/cc 10117.
- 20. Wakatsuki M, Sadler P. Invasive mechanical ventilation in acute exacerbation of COPD: prognostic indicators to support clinical decisions. JICS 2012;13(3):238-243.
- 21. Arnold RM, Kellum J. Moral justifications for surrogate decision making in the intensive care unit: Implications and limitations. Crit Care Med 2003;31(5 Suppl):S347–353.
- 22. White DB, Braddock CH 3rd, Bereknyei S, Curtis JR. Towards shared decision making at the end of life in intensive care units: opportunities for improvement. Arch Intern Med 2007;167(5):461–467.
- 23. Rogers ME, Hart WB, Mike Y. Edward T. Hall and the history of intercultural Communication: the United States and Japan. Keio Communications Review 2002;24:3–26.

# Figure legends:

Figure 1. Questionnaire day and decision option.

Table 1. Patient health state and advance directives before admission

## **Family Option**

	_		PD	SD	FD	DA/DK	p Value
	N = 126		54	55	14	3	
	=-	Lucid	92.60%	85.40%	92.90%	100%	
	Lucidity	Partially Lucid	5.50%	7.30%	7.10%	0.00%	
		Confused	1.90%	7.30%	0.00%	0.00%	P= 0.43
	-	Total Autonomy	70.3%	54.50%	42.90%	100%	
	Autonomy	Partial	18.50%	36.40%	21.40%	0.00%	
	,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	Totally Dependent	5.60%	9.10%	35.70%	0.00%	
		Bedridden	5.60%	0.00%	0.00%	0.00%	P= 0.09
	MV	Yes	24.10%	16.40%	35.70%	0.00%	
		No	75.90%	83.60%	64.30%	100%	P=0.26
		Yes	3.70%	3.60%	0.00%	0.00%	
	MV	No	9.30%	3.60%	7.10%	0.00%	
		Unknown	87.00%	92.80%	92.90%	100%	P= 0.76
ctive		Yes	9.30%	1.80%	7.10%	0,0%	
se Dire	HD	No	7.40%	3.60%	7.10%	0.00%	
Advance Directive		Unknown	83.30%	94.60%	85.80%	100%	P=0.29
•		Yes	9.30%	0.00%	4.20%	0.00%	
	CPR	No	7.40%	5.50%	4.20%	0.00%	
		Unknown	83.30%	94.50%	91.60%	100%	P=0.15

PD = Physician decision; SD = Shared decision; FD = Family decision; MV = Mechanical ventilation; HD = Hemodialysis; CPR = Cardiopulmonary resuscitation; DK/ DA = Don't know / Didn't answer.

Table 2. Family member and patient demographics

			Family option				
			PD	SD	FD	DK/DA	p Value
	N = 126		54	55	14	3	
	Condon	Male	18.5%	29.1%	14.3%	33.3%	
	Gender 	Female	81.5%	70.9%	85.7%	66.7%	P= 0.30
	Relationship to patient	1st degree (spouse, son, brother)	79.6%	85.5%	85.7%	100%	
		Other	20.4%	14.5%	14.3%	0.0%	
Family Member	Cohabitation with the patient	Yes	50.0%	32.7%	42.9%	33.3%	
از ا		No	50.0.%	67.3%	57.1%	66.7%	
Fan	D	Urban	90.7%	89.1%	85.7%	100%	
	Residence	Rural	9.3%	10.9%	14.3%	0.0%	P= 0.19
	Education Level	Preschool / Primary	37.0%	23.6%	21.4%	33.3%	
		Basic	20.4%	27.3%	21.4%	33.3%	
		College / University	42.6%	49.1%	57.1%	33.3%	P=0.56
	Religion	Without	5.6%	18.2%	14.3%	0.0%	
	Keligion	With	94.4%	81.8%	85.7%	100%	P= 0.13
				Family	option		
		<u>-</u>	PD	SD	FD	DK/DA	
	N = 126		54	55	14	3	
()	Gender	Male	18,50%	29.10%	14.3%	33.3%	
phic		Female	81.5%	70.9%	85.7%	66.7%	
mogra	Patient Age	Median	75.0	72.0	69.5	79.0	P= 0. 83
Patient Demographic		Analfabet / Primary	61.1%	50.9%	78.6%	66.7%	
Pat	Education level	Basic	27.8%	20.0%	7.1%	0.0%	
	Education level	2º Degree / University	11.1%	29.1%	14.3%	33.3%	P= 0.56

PD = Physician decision; SD = Shared decision; FD = Family decision; DK/DA = Don't know / Didn't answer;

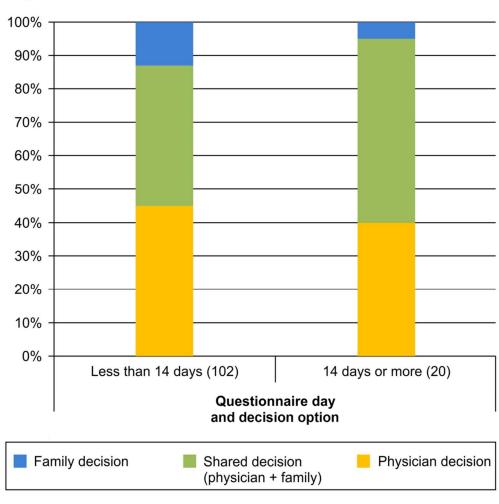
<sup>%</sup> of each group; Basic = 6 years of schooling

Table 3. Family member depression, satisfaction with care provided, and family prognostic expectation

			Family Option					
			PD	SD	FD	DK/DA	<i>p</i> Value	
	N= 126		54	55	14	3		
		Without	29.5%	32.7%	50.0%	66.7%		
	Depression	Slightly	25.9%	29.1%	21.4%	33.3%		
	Depression .	Moderate	18.5%	18.2%	14.3%	0%		
	-	Serious	25.9%	20.0%	14.3%	0.0%	p= 0.52	
	Care	Very Good	83.3%	72.7%	78.6%	100%		
per		Good	16.7%	27.3%	14.3%	0.0%		
Family Member	(in ICU)	Satisfactory	0.0%	0.0%	0.0%	0%		
Famil	(	Bad	0.0%	0.0%	7.1%	0.0%		
		Very Good	3.7%	5.5%	0.0%	0.0%		
	-	Good	24.1%	25.5%	35.7%	0.0%		
	Prognosis	Satisfactory	20.4%	20.0%	14.3%	0.0%		
	-	Bad	46.3%	45.5%	35.7%	100%		
		Unknown	5.5%	3.5%	14.3%	0.0%	p= 0.83	

PD = Physician decision; SD = Shared decision; FD = Family decision; DK/DA = Don't know / Didn't answer.





93x96mm (300 x 300 DPI)