

Family Reliance on Physicians' Decisions in Life-Sustaining Treatments in Acute-on-Chronic Respiratory Diseases in a Respiratory ICU: A Single-Center Study

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BACKGROUND: In ICUs, many patients are unable to participate in decision-making regarding life-sustaining treatments. This study evaluated the opinions of family members about family and physician participation in life-sustaining treatment decisions and examined factors that influence those decisions. **METHODS:** This was a prospective exploratory observational study that used 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 ICU and were dependent on invasive or noninvasive mechanical ventilation. Patients of ≤ 18 years old, with a stay of < 3 days, and oncologic patients were excluded. **RESULTS:** Ninety-eight percent (123/126) of the participant family members had an opinion about their involvement in decision-making about life-sustaining treatments. Physician choice was preferred by 54/123 (44%), 55/123 (45%) wished to share the decision with the physician, and 14/123 (11%) wished the family to decide. All the patients were incompetent at the time of inquiry. Autonomy prior to admission to the respiratory ICU influenced the decision. **CONCLUSIONS:** A majority of the families relied on physicians to help in the decision-making process about life-sustaining treatments in patients with acute-on-chronic respiratory diseases. From the family's point of view, the principle of autonomy can be exercised by delegating the decision-making process to the physician. To assume a uniform ethical conduct is to antagonize the definition of ethics. *Key words:* end of life; surrogate; decision-making; death. [Respir Care 2014;59(3):411–419. © 2014 Daedalus Enterprises]

Introduction

ICUs were originally conceived for acute conditions—illness or injuries. Subsequently their scope was extended to acute-on-chronic diseases, and today ICUs often admit patients with end-stage diseases and high mortality risk.¹ This trend is expected to have important implications regarding patient involvement in end-of-life treatment deci-

sions, mainly through advance directives. In southern European countries, such as Portugal, where advance directives are uncommon, the first steps are being taken through discussion and legislation. However, despite their utility, only 20–30% of patients have an advance directive, even in Anglo-Saxon countries, where advance directives are encouraged.²

Thus, if the patient is incompetent to decide,³ because of an acute condition or heavy sedation, and has no valid advance directives regarding life-sustaining treatments, the decision-making shifts from the patient to the family. The legitimacy of family members 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.”⁴

Serious concerns exist, however, about the philosophical justification for substituted judgment.⁵ In addition, the practice of the principle of autonomy is not uniformly understood and exerted in all countries, as is shown in the

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differences between Anglo-Saxon and southern European countries,⁶ which have different attitudes about end-of-life matters.⁷⁻⁹ As one example, decision-making is predominantly physician-centered in Europe, whereas in the United States the patients and families are much more involved in the process.¹⁰ Most ICU patients are elderly, so the responsibility for decision-making most frequently falls on younger people. 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 toward their parents, whereas in Finland, Ireland, and the Netherlands, children's obligations to parents are thought to be minimal.¹¹ Hence, it is important to know the family member variables that can influence the decision.

The present study was conducted in a single respiratory ICU in a university hospital in Lisbon, Portugal, where patients' families are seldom requested to participate directly in the decision-making process.¹² The aim was to understand family participation in decisions about end-of-life issues in the respiratory ICU. 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 influence that choice?

The factors that can influence the decision-making process are, on the one hand, related to the patient (age, comorbidities, independence in daily-life activities before admission, and competency at the time of inquiry), and, on the other hand, to the family members, both demographically (age, sex, occupation, co-habitation) and non-demographically (relationship with patient, depression, prognosis).⁶

Another important factor is that end-of-life decisions are not solely rational; they include cultural and emotional components.¹³ In our study we considered the relevance of depression,¹⁴ communication (because it is well known that patients and families who trust their physicians feel comfortable relying on the physician for help in making decisions¹⁵), and prognostic implications,¹⁶ since, despite prognostic uncertainty, they allow families to make a decision based on the likely outcomes of treatments. We therefore studied the perceptions of family members and factors that influence the decision-making process concerning life-sustaining treatments.

Methods

This prospective exploratory observational study was approved by the ethics committee of Santa Maria Hospital and authorized by the Portuguese National Committee for Data Protection. The study design, procedure, and results

QUICK LOOK

Current knowledge

When patients with acute-on-chronic respiratory failure requiring mechanical ventilation are unable to participate in end-of-life decisions, family members are asked to make these difficult decisions.

What this paper contributes to our knowledge

In Portugal a majority of surveyed family members relied on physicians to help in the decision-making process. From the family members' point of view, the principle of autonomy can be exercised by surrogating the decision-making to the physician. The sociological and cultural characteristics of individual countries should be considered in these decisions.

were monitored by an independent statistical consultancy agency.

This study was conducted over 3 years (October 2007 to March 2011) in the respiratory ICU of the Pulmonology Department of Santa Maria University Hospital, a 14-bed unit (8 high-risk and 6 intermediate noninvasive ventilation beds), in Lisbon, Portugal. The unit has 3 consultant physicians and 2 assistant physicians. We interviewed a convenience sample (ie, available and willing to participate) of family members of patients in the respiratory ICU who had acute-on-chronic respiratory failure and were dependent on invasive or noninvasive mechanical ventilation. We excluded patients ≤ 18 years old, whose ICU stay was < 3 days, and whose pathology was oncologic.

For each patient we recorded ICU stay, diagnosis, type of ventilation, age, sex, religion, household, occupation, acute physiology score and Acute Physiology and Chronic Health Evaluation (APACHE II) score, previous health state, previous episodes of mechanical ventilation, and advance directives (if any). For each family member we recorded age, sex, relationship to the patient, cohabitation, residency, education, occupation, religion, communication with the staff doctor, depression according to the Hamilton Depression Rating Scale, the family member's rating of the ICU care (very good, good, reasonable, or bad), and the family member's understanding of the patient's prognosis (very good, good, reasonable, or bad).

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 phy-

sician 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 responsible for that decision? The following options were given to the family members.

- Family
- Physician
- Family plus physician
- Don't know or no answer

The competency of the patient depended on their mental abilities and cognitive capabilities required to rationally execute a legally recognized decision.¹⁷

Statistical Analysis

The results were analyzed with descriptive univariable and bivariable statistics, using average, standard deviation, median, and quartiles for the quantitative variables, and counts and percentages for the qualitative variables. The significance of the association between 2 qualitative variables was assessed using the chi-square independence test or the Fisher exact test where appropriate. All tests were 2-sided, using a type-1 error of 5% (unless otherwise stated). All statistical analyses were made with statistics software (SPSS 19, SPSS, Chicago, Illinois).

Results

One visiting family member per patient participated in the inquiry. There were 126 (42%) interviewees out of 303 potential participants.

Univariable Exploratory Analysis

Patient Statistics. The majority of patients were elderly, with an average age of approximately 71 years and a median of 74 years. About 41% were > 75 years old,¹⁸ and 29% were ≤ 65 years old. Males accounted for 65% ($n = 82$) of the patients, and 94 (75%) lived with family members. Their educational level was very low: 59% had very low or low literacy (according to the alphabets/IV standard of education). There were 119 (94%) whites, 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 Acute Physiology Score and APACHE II scores were 17 and 26, respectively (upper limits 35 and 45). Invasive mechanical ventilation was required by 71 patients (56%).

In terms of previous health, 99 (79%) had not previously required mechanical ventilation. Most of the patients, 114 (91%), had no advance directives regarding mechanical ventilation, and 112 (89%) had none regarding hemodialysis. All the expressed directives were verbal, not written. A large number of patients, 113 (90%), had been lucid prior to their hospitalization (ie, could think clearly and rationally), and the exacerbation was probably responsible for the incompetency. Further, before respiratory ICU admission, 77 (61%) were physically autonomous (independent in activities of daily living).

Family Member Statistics. The average age was 53 years, and the median was 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 the patient and visitor (spouse, adult son/daughter, parent or sibling) existed in 105 (83%) of the participants, so in most cases the relationship was close enough for the participant to know the patient's values and expectations.

Despite close family ties, 90% (113) 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 the family members and the economic and social evolution of the country in recent decades. In terms of employment, 71 (56%) were employed, and 111 (88%) considered themselves religious. The majority of family members (66%) had some degree of depression (slight, moderate, or serious), as measured by the Hamilton Depression Rating Scale. No anti-depression treatment was prescribed to those who had 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: 56 (44%) wanted a general explanation, and 58 (46%) wanted 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. Fifty-eight (46%) family members believed that the prognosis of their patient was "bad." The global mortality was 60%.

Bivariable Exploratory Analysis

We established 3 categories of family members: those who favored a physician decision on life-saving treatment; those who preferred a shared decision-making; and those who preferred the decision be solely from the family.

Fifty-four family members opted for physician decision, 55 for shared decision, and 14 for family decision. One-

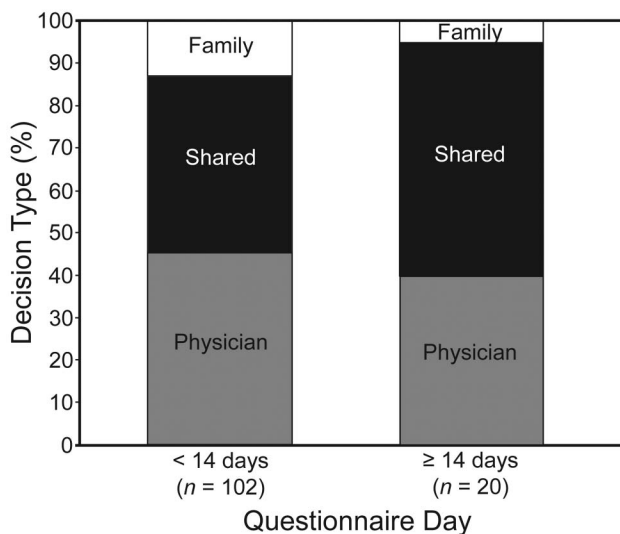


Fig. 1. Effect of duration of mechanical ventilation on family members' preferences about decision-making about life-saving treatments. We chose 14 days as representing prolonged ventilation.

hundred nine family members preferred physician involvement (ie, preferred either physician decision or shared decision-making), whereas 17 preferred no physician involvement (family decision) ($P < .001$). However, the small number that preferred family decision-making may introduce bias in the analysis.

We also analyzed if the number of mechanical-ventilation days at the time of inquiry had any relation to the family members' preference. In general, from a clinical point of view, ventilation is considered prolonged at ≥ 21 days.¹⁹ However, since in this study the evaluation of prolonged ventilation was not from a clinical perspective but from the family's emotional perspective, we subjectively chose ≥ 14 days as the cutoff, which is a period of time that can have some influence in the options of decision-making. Thus, considering the 2 groups (Fig. 1), it was verified that with a stay ≥ 14 days the family members' preference tended to shift toward shared decision-making. But, again, the small number of patients in the prolonged-ventilation group may introduce bias in the analysis.

Tables 1, 2, and 3 show the results of the influence of some of the variables on the families' preferences.

When the patient's previous health state (lucidity and autonomy in activities of daily living before ICU admission) was considered (see Table 1), because a great majority of patients in all 3 groups (physician decision, shared decision, and family decision) 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

who were completely dependent before admission in the ICU.

Invasive mechanical ventilation can be a traumatic experience for both patient and family. In acute-on-chronic respiratory diseases, patients are likely to undergo repeated invasive mechanical ventilation.²⁰ Thus, this variable should be considered in analyzing the family's preferences. In the present study, although the number of patients who had previously undergone mechanical ventilation was small (27), a majority of family members 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 invasive mechanical ventilation favored physician involvement, choosing either physician-only decision-making (76%) or shared decision-making (84%).

Advance directives regarding mechanical ventilation (12/126, 10%), hemodialysis (14/126, 11%), or cardiopulmonary resuscitation (13/126, 10%) were all verbal. In Portugal there is no data regarding advance directives, because the relevant legal implementation is very recent. In terms of the main diagnosis, the families of patients with congestive heart failure without any chronic respiratory disease chose physician decision (16/17, alone or shared). Regarding the mode of ventilation, for invasive mechanical ventilation, 63/71 families chose to entrust the physician with the decision (alone or shared). The severity of the situation (intubation, ventilation, or 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 was not significant ($P = .83$). In terms of cohabitation, 89% who opted for total physician responsibility, 60% of those who chose shared decision, and 86% of those choosing no physician partnership live with the patient ($P = .18$). 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 cohabitation leads to a better knowledge of the patient's values, so 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 patients with more education chose shared decision-making (29%) more than physician decision-making (11%) or family decision-making (14%). A higher literacy level of the patient could demonstrate an intrinsic desire of his family member to know and dialogue with the physician about the disease ($P = .56$). A different behavior was seen with regard to the education level of the family member (see Table 2). Those with a second-

Table 1. Patient Health State and Advance Directives Before Admission

	Family Member's Preference About Life-Saving Treatment Decisions, %				<i>P</i>
	Physician Decision (<i>n</i> = 54)	Shared Decision (<i>n</i> = 55)	Family Decision (<i>n</i> = 14)	Don't Know/ Didn't Answer (<i>n</i> = 3)	
Lucidity					
Lucid	92	86	93	100	
Partially lucid	6	7	7	0	
Confused	2	7	0	0	.43
Autonomy					
Total autonomy	70	55	43	100	
Partial autonomy	18	36	21	0	
Totally dependent	6	9	36	0	
Bed-ridden	6	0	0	0	.09
Mechanical ventilation					
Yes	24	16	36	0	
No	76	84	64	100	.26
Advance directive instructions					
Mechanical ventilation					
Yes	4	4	0	0	
No	9	4	7	0	
Unknown	87	92	93	100	.76
Hemodialysis					
Yes	9	2	7	0	
No	7	4	7	0	
Unknown	84	94	86	100	.29
Cardiopulmonary resuscitation					
Yes	9	0	4	0	
No	7	6	4	0	
Unknown	84	94	92	100	.15

ary or university level education chose family decision-making (57%), while those with low or very low literacy opted for physician decision-making (37%). The previous reasoning in the situation of literacy level favors the preference for family autonomy in the decision-making process ($P = .56$).

Although the majority of family members in the 3 groups considered themselves religious, the proportion with religion was higher (94%) in the physician-decision group than in the family-decision or shared-decision group, both of which had values at or below 86% ($P = .12$). When depression was considered, there was a trend toward physician decision-making (alone or shared) according to the severity of the depression, but the association was not statistically significant ($P = .52$) (see Table 3).

The family's satisfaction with the care provided seemed to have no influence on their preferences. Regarding the family's understanding of the prognosis, 2 groups were considered: very good/satisfactory and bad. There was a preference for physician involvement (alone or shared) in both groups, although the relationship was not statistically significant ($P = .83$).

Inferential Analysis

For the inferential data analysis, the end points (physician decision, shared decision, and family decision) were crossed with:

- Demographics (sex, age, education, cohabitation, employment status, and religion)
- Previous health state and mechanical ventilation, autonomy, and advance directive
- Information (type, understanding, and feeling after communication)
- Depression (depressed and non-depressed) and prognosis

We verified that independence between the family members and patient autonomy is rejected. A significant majority of respondents who opted for total physician responsibility were family members of an autonomous patient (70% were against and 55% for shared decision, and 43% were for family decision, $P = .09$). In our opinion, the families do not want to assume the burden of responsibility.

Table 2. Family Member and Patient Demographics

	Family Member's Preference About Life-Saving Treatment Decisions, %				
	Physician Decision (<i>n</i> = 54)	Shared Decision (<i>n</i> = 55)	Family Decision (<i>n</i> = 14)	Don't Know/ Didn't Answer (<i>n</i> = 3)	<i>P</i>
Family members					
Sex					
Male	19	29	14	33	
Female	81	71	86	67	.30
Relationship to patient					
1st degree (spouse, son, brother)	80	85	86	100	
Other	20	15	14	0	
Cohabitation with the patient					
Yes	50	33	43	33	
No	50	67	57	67	.18
Residence					
Urban	91	89	86	100	
Rural	9	11	14	0	.19
Education					
Preschool/primary	37	24	22	33	
6 years of school	20	27	21	33	
College/university	43	49	57	33	.56
Religion					
Without	6	18	14	0	
With	94	82	86	100	.13
Patients					
Sex					
Male	19	29	14	33	
Female	81	71	86	67	
Age, median y	75	72	70	79	.83
Education					
Analfabet/primary	61	51	79	67	
6 years of school	28	20	7	0	
Secondary degree/university	11	29	14	33	.56

ity of decision for a patient who, prior to ICU admission, was completely independent in his activities of daily living. Somehow it is a defensive posture.

Discussion

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

The family members we surveyed had close links with the patient; a reasonable educational level; good knowledge, in most 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 (eg, moral and religious).²¹

The bivariable analysis points out clearly, with statistical significance, that the family members desired

physician involvement in the decision-making process, either alone or shared with family member. When the situation was more serious (ie, an incompetent patient) this preference was 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 physician-decision preference showed no relationship with the number of days of hospitalization in the ICU. In our experience, with longer stay the family's expectations and hope for 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 cutoff limit of ≥ 14 days may have biased the results.

Table 3. Family Member Depression Scores, Satisfaction With Care Provided, and Expectation About the Patient's Prognosis

	Family Member's Preference About Life-Saving Treatment Decisions, %				<i>P</i>
	Physician Decision (<i>n</i> = 54)	Shared Decision (<i>n</i> = 55)	Family Decision (<i>n</i> = 14)	Don't Know/ Didn't Answer (<i>n</i> = 3)	
Depression					
Without	29	33	50	67	
Slightly	26	29	22	33	
Moderate	19	18	14	0	
Serious	26	20	14	0	.52
Care provided in ICU					
Very good	83	73	79	100	
Good	17	27	14	0	
Satisfactory	0	0	0	0	
Bad	0	0	7	0	.83
Prognosis					
Very good	4	6	0	0	
Good	24	25	36	0	
Satisfactory	20	20	14	0	
Bad	46	45	36	100	
Unknown	6	4	14	0	.83

In this study, pre-admission autonomy, which favored the preference for physician-decision-making, 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 (United States and northern Europe), around the principle of autonomy (or patient/family compromise),²² whereas in southern European countries the principle of beneficence is still ascendant. In the daily exercise of medicine a confrontation exists between the perception and practice of these 2 principles: beneficence and autonomy. Of late, in the southern European medical community the principle of autonomy is slowly making inroads in the behavior of physicians. In our opinion this rise 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 the present study patient autonomy prior to admission seemed to statistically influence decision-making preferences. 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."²³ 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. Our goals were to find out which option the surrogate would prefer regarding the responsibility of decision (physician, shared, or family decision) and if that choice would depend on the patient's competency and the influence of certain variables—the patient, the surrogate family member, and the circumstances of the situation. Our data analysis suggests that for family members of incompetent patients, the principle of autonomy can be exercised by delegating to the physician, alone or together with the family member, the responsibility of decision. Further, only one variable, autonomy prior to admission, had a statistically significant influence on that choice. Other variables need further study. A greater knowl-

edge, considering each country's cultural and social reality, is fundamental to understanding the process of decision-making to avoid or at least minimize potential ethical conflicts in ICUs.

Limitations

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 2 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 preferences, 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 we made efforts to put the family members at ease, it is not always possible for people to exchange their views in an open and sincere manner. Third, a variable that was not considered but that might influence the respondents' preferences is the economic impact of disease on 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 in some 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.

Conclusions

The majority of families preferred to rely on the physicians, whereas some 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 family's preferences.

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.

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