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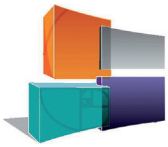

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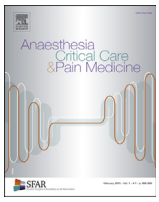

Original Article

How patient families are provided with information during intensive care: A survey of practices☆

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ABSTRACT

Background: Many critically ill patients are incapable of receiving information or expressing their own opinion on treatment decisions due to the severity of their disease, or because they are under sedation. French legislation requires that when a physician proposes further tests or treatment for a patient, this proposal should be accompanied by clear and honest information that is appropriate in view of the circumstances and the patient's state of health, and the physician must obtain the patient's consent before proceeding. However, this is often impossible in critical care. We evaluated whether provisions for surrogates are adequate in meeting information needs of patients and families in critical care.
Methods: Survey of intensive care physicians by electronic questionnaire in December 2010 and January 2011 to evaluate actual practices. The questionnaire comprised 6 domains covering various aspects relating to the information of patients' relatives as regards diagnostic testing in critical care, when the patient was unable to be appropriately informed. We recorded responders' socio-demographic data (age, how long in practice, where they practised).
Results: Among 1279 physicians contacted, 139 (10.8%) from 98 critical care departments (France, Belgium, Switzerland) responded. A total of 66.2% said they believed it is possible to perform diagnostic tests without informing the patient's relatives. Invasive or high-risk tests, time available to provide information, and quality of prior relations with the patient's family were factors likely to prompt the physician to inform the family, while potentially serious implications for the relatives, and degree of relation of the family member to the patient were reported to make the physician more reluctant to inform relatives. Less than 6% considered routine procedures to require provision of information to relatives.
Conclusion: Our results suggest that modalities for providing information to families and relatives, as defined by current French legislation, are not suitable to the context of critical care.
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1. Introduction

Patients admitted to the Intensive Care Unit (ICU) usually present with the life-threatening failure of at least one major organ. In most cases, these patients are incapable of expressing their own opinion on treatment decisions due to the severity of their disease, or sedation.

Current French legislation relating to patient rights and the quality of healthcare stipulates that when a physician proposes further tests or treatment for a patient, this proposal should be

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accompanied by clear and honest information that is appropriate in view of the circumstances and the patient's state of health, and the physician must obtain patient consent before proceeding (Article L.1111-2 of the Code of Public Health) [1–3].

These principles raise some questions in the many clinical situations where they simply cannot be applied. In this context, legislators in France decided to allow a close relative, or a third party in a close relationship with the patient, to mediate on behalf of, and represent the patient, when the patient himself/herself is unable to act autonomously, or even if the patient simply does wish to make an important decision on his/her own. Moreover, this designation should be written and signed by the patients themselves.

In the ICU, emergency situations and disease severity (coma, shock, mechanical ventilation, sedation) result in a situation where the patient is unable to designate a surrogate. Therefore, ICU physicians are often unable to comply with the principles of clear and complete delivery of information to patients or relatives. When an official surrogate is not designated, informing the patient's family is problematic since the physician is obliged to observe professional secrecy, which considerably limits the extent of information that can be released.

To date, there has been no investigation on the type and/or amount of information that should be given to the relatives of patients in critical care as regards diagnostic testing. In this context, our goal was to describe the perceptions of ICU physicians regarding the delivery of information to patient relatives, in light of current legislation, and regarding diagnostic testing performed during the hospital stay for ICU patients.

2. Methods

We performed a survey of practices using an electronic questionnaire sent to all the members of the Société de réanimation de langue française (SRLF) in December 2010 and January 2011. The questionnaire comprised 6 domains identified by prior thematic analysis of discourse from semi-directive interviews with 19 critical care physicians from 3 hospital units. The questions covered various aspects relating to the delivery of information to relatives as regards diagnostic testing in the ICU (when the patient was unable to be appropriately informed). Each response modality for each question could be commented by the responding physician. The respondents' socio-demographic data were recorded (age, practice location, duration of their ICU experience). If the questionnaire was incomplete, the responding physician was contacted again in order to complete missing data. Physicians were considered as non-responders if no answer was obtained after one reminder.

Five questions dealt with the utility of providing information about diagnostic testing, the situations likely to result in information being limited, and the real delivery of information to relatives. A sixth question explored the impact of the existence of guidelines or rules for delivering information to relatives. The questions were as follows:

1) outside of emergency situations, do you think it is possible nowadays to perform a diagnostic test in the ICU without informing the patient's relatives?
2) for each of the following diagnostic tests, please classify your obligation (by choosing yes or no) to provide information to ICU patient relatives: colonoscopy, gastroscopy, bronchial fibroscopy, computed tomography with and without injection of contrast medium, angiography, echography, pleural and lumbar punctures, diagnostic laparoscopy and laparotomy, chest x-ray, blood sample, scientific autopsy, post-mortem tissue sampling, post-mortem imaging;
3) for the same diagnostic tests as in question 2, please indicate (by choosing yes or no) whether you provide information to relatives in practice, outside of emergency situations;
4) in practical terms, please state, for each of the following reasons, whether it might lead you to limit the information you provide to patient relatives about a test? (Please answer yes or no for each option) (options listed in online supplementary material);
5) irrespective of the type of test, do you think that the relatives should be informed about the practical aspects of the test (e.g. need for intra-hospital transport, test performed in the operating theatre, use of contrast medium etc.)?
6) in your opinion, "Good practice" (as laid down by guidelines, consensus documents etc.) in terms of diagnostic testing (e.g. lumbar puncture in suspected meningitis) requires…: (please tick yes or no for each option):
   - that relatives be informed before the test is performed?
   - that relatives provide consent before the test is performed?
   - that relatives be informed after the test has been performed?
   - that the test be performed even if the relatives refuse to consent?

2.1. Statistical analysis

Qualitative variables are expressed as numbers (percentages) and quantitative data as medians (ranges) with (interquartile ranges [IQR]). Qualitative variables were compared using the Chi square or Fisher's exact test as appropriate, and quantitative variables using the Wilcoxon test. Bonferroni's correction was applied to account for multiple comparisons. All tests were bilateral and a P-value of < 0.05 was considered statistically significant. All analyses were performed using SAS version 9.1 (SAS Institute Inc., Cary, NC, USA).

3. Results

3.1. Respondent characteristics

Subsequent to the 1279 questionnaires sent, 139 (11%) physicians responded from 98 ICUs in France, Switzerland and Belgium. Among the 139 responses, 37 questionnaires (27%) had accompanying comments. The characteristics of the respondents are shown in Table 1.

In response to question 1, 92 (66%) respondents reported that it is possible to perform diagnostic tests without informing the patient's relatives.

The factors reported to make the physician more likely to inform the family were:

- invasive or high-risk tests;
- the time available to provide appropriate information;
- the quality of the prior relations between the physician and the patient's family.

Conversely, the factors likely to make the physician think twice before providing information to relatives about the diagnostic tests being performed included:

- potentially serious implications for the relatives;
- degree of relation of the family member to the patient.

The responses to questions 2 and 3 are summarized in Table 2. Over 95% of participating physicians responded that relatives had to be informed about post-mortem autopsy, tissue

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