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The concept of a surrogate is ill adapted to intensive care: Criteria for recognizing a reference person

Jean-Philippe Rigaud, MD, PhD [a,*], Jean-Baptiste Hardy, MD [a], Nicolas Meunier-Beillard [b,c], Hervé Devilliers, MD, PhD [d,e], Fiona Ecarnot, MSc [f], Corinne Quesnel, MD [a], Stéphanie Gelinotte, MD [a], Pierre-Louis Declercq, MD [a], Jean-Pierre Eraldi, MD [a], François Bougerol, MD [a], Jean-Pierre Quenot, MD, PhD [b,e,g]

[a] Department of Intensive Care, Dieppe General Hospital, 76202 Dieppe, France
[b] Department of Intensive Care, François Mitterrand University Hospital, 21079 Dijon, France
[c] UMR 7366 CNRS, University of Burgundy, Dijon, France
[d] Department of Internal Medicine, François Mitterrand University Hospital, 21079 Dijon, France
[e] INSERM CIC 1432, Clinical Epidemiology, University of Burgundy, Dijon, France
[f] Department of Cardiology, EA3920, University Hospital Jean Minjoz, Besançon, France
[g] Lipness Team, INSERM Research Center UMR 866, University of Burgundy, Dijon, France

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ABSTRACT

Purpose: In the intensive care unit (ICU), caregivers may find it difficult to identify a suitable person in the patient's entourage to serve as a reference when there is no official surrogate.
Methods: We developed a 12-item questionnaire to identify factors potentially important for caregivers when identifying a reference person. Each criterion was evaluated as regards its importance for the role of reference. Responses were on a scale of 0 (not important) to 10 (extremely important). We recorded respondent's age, job title, and number of years' ICU experience. The questionnaire was distributed to all health care professionals in 2 French ICUs.
Results: Among 144 staff, 128 were contacted; 99 completed the questionnaire (77% response rate; 20 physicians [11 residents], 51 nurses, 28 nurse's aides). Items classed as most important attributes for a reference person were knowledge of patient's wishes and values, emotional attachment, adequate understanding of the clinical history, and designation as a surrogate before admission. There were no significant differences according to respondent's age, job title, or experience.
Conclusion: Caregivers identify a reference person based on criteria such as knowledge of the patient's wishes, emotional bond with the patient, an adequate understanding of the clinical history, and designation as surrogate before admission.

1. Introduction

The French law dated March 4, 2002, relating to the rights of patients and the quality of the health system introduced the concept of a surrogate. A surrogate is a person designated by the patient who can accompany the patient through the health care process but who can also testify to the patient's wishes in case the patient becomes unable to express his or her own wishes [1]. Unfortunately, this law is often particularly difficult to apply in critical care for 2 reasons, namely, the emergency nature of the situation and the clinical state of the patient (coma, shock, mechanical ventilation, sedation), which make it impossible for the patient to designate a surrogate.

The absence of a designated surrogate before hospitalization poses several problems. First, providing sensitive medical information to a nondesignated person is in breach of medical secrecy. Second, the intensive care unit (ICU) team might not choose the same person to be their reference as the patient would have designated [2]. Third, nominating a member of the family, preferably the spouse, is not necessarily the best choice in the patient's view [3-5]. Lastly, the reference person designated during hospitalization in the ICU is not necessarily prepared for this responsibility, particularly if there are difficult choices to be made, such as initiation of complex and burdensome therapies, or decisions on withdrawal and/or withholding lifesaving therapies.

Usually, the caregivers in the ICU identify a suitable person among the patient's next of kin to serve as the reference person, in the absence of an officially designated surrogate. To date, there has been no

* Corresponding author at: Réanimation Polyvalente, Centre Hospitalier Dieppe, Avenue Pasteur, BP 219, 76200 Dieppe, France. Tel.: +33 232 147 550; fax: +33 232 147 436.
E-mail addresses: JRigaud@ch-dieppe.fr (J.-P. Rigaud), jeanbaptistehardy@hotmail.fr (J.-B. Hardy), nicolas.meunier-beillard@u-bourgogne.fr (N. Meunier-Beillard), herve.devilliers@chu-dijon.fr (H. Devilliers), fiona.ecarnot@univ-fcomte.fr (F. Ecarnot), cquesnel@ch-dieppe.fr (C. Quesnel), sgelinotte@ch-dieppe.fr (S. Gelinotte), pldeclercq@ch-dieppe.fr (P.-L. Declercq), jeraldi@ch-dieppe.fr (J.-P. Eraldi), fbougerol@ch-dieppe.fr (F. Bougerol), jean-pierre.quenot@chu-dijon.fr (J.-P. Quenot).

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investigation of the criteria that ICU caregivers apply to identify the person most capable of representing the patient's best interests. In this context, we aimed to evaluate, among ICU caregivers, the level of importance that they accord to the various characteristics that a person is expected to present to qualify as a suitable reference person.

This work was partially presented as an oral presentation at the 45th congress of the French Intensive Care Society, Paris 2015.

2. Methods

A questionnaire (Supplementary file 1) comprising 12 questions was constructed by 2 ICU specialists (JPQ and JPR) and a sociologist (NMB). The empirical data used to build the questionnaires items were obtained from a preliminary qualitative study among 15 health care professionals working in a single ICU (7 nurses, 5 nurse's aides, 3 ICU physicians). This exploratory phase used in situ observations and semidirective interviews to identify factors that were potentially important for caregivers when identifying a reference person for patients without an officially designated surrogate. Interviews were conducted until saturation; that is, interviews were stopped when the last interview yielded no new information likely to add to the empirical data already recorded. After these interviews, the items that came out of the discourse were rephrased to achieve maximum readability (using the Flesch readability test and the Flesch-Kincaid grade level). Next, the expert panel method was applied to reduce the number of items present in the final questionnaire [6]. Each of the criteria was to be evaluated by the health care professional as regards its importance for the role of reference person. Responses were given on a scale of 0 (criterion not important at all) to 10 (extremely important criterion). To be considered as "important," an item had to receive an average score more than 7 in each age category, to ensure that, regardless of the respondent's experience in intensive care, the choice of an appropriate surrogate was made in the same way and giving precedence to the same attributes. Lastly, there were 3 questions relating to the respondent's age, job title, and number of years' experience in ICU. Age was classified in 4 categories (20-30, 31-40, 41-50, and >50 years), and the number of years' experience was also grouped in 4 categories (<5, 5-10, 11-20, and >20 years). Three job titles were identified, namely, physician (including residents), nurse, and nurse's aide.

The questionnaire was distributed to all health care professionals working in 2 ICUs (mixed ICU of the nonacademic General Hospital of Dieppe, France, and the medical ICU of the François Mitterand University Hospital, Dijon, France). All questionnaires were anonymous.

2.1. Statistical analysis

Responses to each question are expressed as mean ± SD or median (interquartile ranges). Responses were also analyzed according to age, job title, and number of years' experience of the respondents. The Kruskal-Wallis test was used to compare responses between groups.

Relations between item responses were examined using Spearman's correlation coefficient. Principal component analysis (PCA) was performed to identify response profiles for the different questions. $P < .05$ was considered statistically significant. All analyses were performed using SAS version 9.3 (SAS Institute, Inc, Cary, NC).

3. Results

3.1. Characteristics of the respondents

At the time of the study, the total combined headcount of the 2 participating ICUs was 144 persons. Among these, a total of 128 health care professionals across both ICUs were contacted during April and May 2014 (contact rate, 88.8%), and 99 completed the questionnaire (response rate, 77%). The reasons for nonresponse of the other 29 included sick leave, holiday leave during the study period, or failure to return the questionnaire by the deadline for study end. No health care professional refused to answer the questionnaire.

Among the 99 respondents, there were 20 physicians (of which 11 were residents), 51 nurses, and 28 nurse's aides (Table 1).

The items that were classed by the respondents as being the most important attributes for a reference person were the following: knowledge of the patient's wishes and values, emotional attachment to the patient, adequate understanding of the clinical history, and the fact of having been designated as a surrogate by the patient before admission (Fig. 1). There were no significant differences in the attributes considered important according to the age, job title, or experience of the respondents (Supplementary Figs. S1-S3).

Principal component analysis and the matrix of correlations identified moderate correlations between (1) frequent telephone contacts and the first person to make contact ($r = 0.52$), and regular visiting ($r = 0.52$); (2) good knowledge of the patient's family history and a good understanding of the clinical situation ($r = 0.57$) and information from outside the ICU ($r = 0.53$); (3) a surrogate officially designated before admission to the ICU and knowledge of the patient's wishes and values ($r = 0.56$). All other correlations were weak.

By PCA, 2 distinct groups of attributes could be distinguished for caregivers to identify a reference person. The first group of attributes included the first person to make contact, frequent telephone contacts, presence at the time of admission, regular visitor, member of the patient's family, or person already designated surrogate before admission to the ICU or during a previous hospital stay. The second group of attributes included self-nomination as reference person, a person with a good understanding of the patient's clinical situation, good knowledge of the patient's family history, and information from the hospital admissions office.

4. Discussion

To the best of our knowledge, this is the first study to evaluate the importance of certain attributes in identifying a reference person for a patient hospitalized in the ICU, in the absence of an officially designated surrogate. Among the 12 items proposed on the questionnaire, 3 characteristics were found to be predominant, namely, knowledge of the patient's wishes and values, an emotional relationship with the patient, and designation as a surrogate prior to admission. There was no difference in the importance accorded to these attributes depending on the respondents' age, function, or level of ICU experience.

These results show that health care professionals in the ICU can recognize attributes or behaviors in a person from the patient's entourage that make that person a suitable surrogate, in their opinion, and they can rank these specific attributes according to their importance. The characteristics identified in our study are line with those recommended by current legislation in France, namely, knowledge of the patient's

Table 1
Characteristics of the respondents to the questionnaire (n = 99)

Variable	n (%), n = 99
Age (y)	
20-30	32 (32.3)
31-40	39 (39.4)
41-50	21 (21.2)
>50	7 (7.1)
Job title	
Physician	20 (20.2)
Nurse	51 (51.5)
Nurse's aide	28 (28.3)
No. of years' experience in ICU	
<5 y	47 (47.5)
5-10 y	27 (27.3)
11-20 y	18 (18.2)
>20 y	7 (7.1)