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Criteria deemed important by the relatives for designating a reference person for patients hospitalized in ICU

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Abstract

Purpose : We investigated the criteria that patients' relatives deem important for choosing, amongst themselves, the person best qualified to interact with the caregiving staff.

Methods : Exploratory, observational, prospective, multicentre study between 1st March and 31st October 2018 in 2 intensive care units (ICUs). A 12-item questionnaire was completed anonymously by family members of patients hospitalized in the ICU 3 and 5 days after the patient's admission. Relatives were eligible if they understood French and if no surrogate had been appointed by the patient prior to ICU admission. More than one relative per patient could participate.

Results : In total, 87 relatives of 73 patients completed the questionnaire, average age of relatives was 58 ± 15 years, 46% were the spouse, 30% were children/grandchildren. Items classed as being the most important attributes for a reference person were: good knowledge of the patient's wishes and values; an emotional attachment to the patient; being a family member; and having an adequate understanding of the clinical status and clinical history.

Conclusion : This study identifies the attributes considered by relatives to be most important for designating, amongst themselves, a reference person for a patient hospitalized in the ICU.

Keywords: Ethics, reference person, proxy, intensive care unit.

INTRODUCTION

One of the major developments of intensive care in recent years has been the increasingly frequent admission of ever older patients, with more comorbidities, and consequently, more unfavourable prognosis. This trend towards older, sicker patients has made the decision-making process more difficult for intensive care unit (ICU) physicians, both at the time of admission of the patient to the ICU, and during the stay, when decisions need to be made about the level of therapeutic engagement [1]. ICU physicians have to take account of considerations such as the patient's frailty [2], life trajectory [3], healthcare plan and wishes for overall management, particularly any preferences regarding end-of-life care [4-6]. Unfortunately, patients' wishes and preferences regarding their end-of-life are often poorly documented or totally unknown at the time of admission to the ICU [7]. Indeed, although legal dispositions do exist for expressing one's desires about end-of-life care, for instance in the form of advance directives [6, 8, 9], patients who actually have advance directives are very rare in routine practice [10]. In this context, family-centred care, which is an approach focusing on the central role of the family in the patient's care and recovery, can help to clarify the patient's aspirations and values [11]. However, family members may sometimes make decisions (whether consciously or not) without fully understanding what is at stake, or in a manner that prioritizes their own interests rather than those of the patient [12].

Against this background, successive French laws relating to patients' rights at the end of life have provided for the designation of a surrogate. A surrogate is a person who is officially designated by the patient to accompany the patient along their healthcare pathway, and to make decisions on the patient's behalf should the patient become too ill to express their own wishes [6, 13, 14]. In practice, it is difficult to apply this legislation in the ICU because admissions often take place in an emergency context, and the patient in a clinical state that

precludes designation of a surrogate. The healthcare team in the ICU must then identify, among the patient's entourage, a suitable person to act as the reference person, in the absence of an officially designated surrogate.

We previously described the criteria that caregivers use to identify a suitable reference person among the patient's entourage [15], but no study to date has investigated the criteria that the patient's relatives deem important for choosing, amongst themselves, the person best qualified to interact with the caregiving staff and most capable of representing the patient's best interests.

In this context, we aimed to evaluate, among the relatives of patients hospitalized in the ICU, the level of importance they accord to the various characteristics that a person is expected to possess in order to qualify as a suitable reference person.

METHODS

We performed an exploratory, observational, prospective, multicentre study between 1st March and 31st October 2018. A questionnaire composed of 12 questions was constructed by two senior ICU physicians (JPQ, JPR) and a sociologist (NMB) using a methodology previously described elsewhere [10, 15-17]. The empirical data used to build the questionnaire items were obtained from a preliminary qualitative study among 15 healthcare professionals [15] working in a single ICU (7 nurses, 5 nurses' aides, 3 ICU physicians). The questionnaire was validated for use in the present study by a panel of 15 relatives of hospitalized ICU patients, using semi-directive interviews. In the present study, the importance of each criterion for the role of reference person was to be ranked by the relatives. Responses were given on a scale of 0 (criterion not important at all) to 10 (extremely

important criterion). In order to be considered as “important”, an item had to receive an average score >7. Lastly, there were three questions about the relatives’ characteristics, namely their age, relationship with the patient and socio-professional category.

The questionnaire was distributed to the relatives of patients hospitalized in the ICU by the investigating physicians in two ICUs (one mixed ICU in a non-academic general hospital, and one medical ICU in a university teaching hospital) between the 3rd and 5th day after the patient’s admission to the ICU. All questionnaires were anonymous. Relatives were eligible to participate in the study if they had a good understanding of the French language and if no surrogate had been appointed by that patient prior to intensive care. More than one relative per patient could complete the questionnaire. The study was registered with ClinicalTrials.gov under the identifier NCT03261258.

The institutional review board (Comité de Protection des Personnes Est I, Dijon) approved the protocol, and considered it to constitute routine clinical practice. The need for informed consent was waived, but all relatives were given clear information about the study, and their non-opposition was obtained. Collection of nominative data was approved by the national authority for the protection of privacy and personal data.

Data sources

The following data were recorded for each patient: socio-demographic characteristics, indication for admission in ICU, co-morbidities evaluated by the Charlson index [18]; Katz’s Activities of Daily Living (ADL) [19], severity of disease calculated using the Simplified Acute Physiology Score (SAPS) II [20] and Sequential Organ Failure Assessment (SOFA) score [21] at ICU admission, length of ICU and hospital stay, and in-ICU death.

The following data were recorded for each relative: age, socio-professional category and relationship with the patient.

Dedicated clinical research assistants collected all data using a standardized electronic case report form. Automatic checks were generated for missing or incoherent data. Data was independently managed by the Centre for Clinical and Epidemiological Investigation (Centre d'Investigation Clinique et Epidémiologie Clinique, CIC 1432) (EK).

Statistical analysis

Continuous variables are expressed as mean \pm standard deviation or median [interquartile range], and categorical variables as number (percentage). For each question, responses from all respondents are expressed as mean \pm standard deviation, or median [interquartile range]. Relations between item responses were examined using Spearman's correlation coefficient. Principal Component Analysis (PCA) on standardized data was performed in order to summarize item information. Mixed models were used to assess the association between the PCA axis and population characteristics. The subject was considered as a random effect and population characteristics as a fixed effect. Each characteristic was analysed in a separate model.

A p-value of <0.05 was considered statistically significant. All analyses were performed using SAS version 9.4 (SAS Institute Inc., Cary, NC, USA).

RESULTS

A total of 87 relatives completed the questionnaire for 73 patients consecutively admitted to the 2 ICUs. The main characteristics of the 73 patients are given in Table 1.

The average age of the relatives was 58 ± 15 years. Almost half (46%) were the patient's spouse (or ex-spouse), 30% were children/grandchildren of the patient, and 24% were a sibling of the patient. Regarding the socio-professional category of the relatives, 12 were retired (14%), 25 were manual workers (29%), 25 held intermediate professions (29%), 15 were upper-level managers (17%) and 10 had no profession (11%).

The items that were classed by the respondents as being the most important attributes for a reference person were the following: good knowledge of the patient's wishes and values; having an emotional attachment to the patient; being a family member; and having an adequate understanding of the clinical status and clinical history (Figure 1). There were no significant differences in the attributes considered important according to age, socio-professional category and type of relationship with the patient.

The matrix of correlations identified moderate correlations between: (1) frequent telephone contacts and being present at the patient's admission ($r=0.62$); (2) frequent telephone contacts and being a regular visitor ($r=0.59$); (3) being a regular visitor / family member ($r=0.54$) and information from the hospital admissions office about the existence of a surrogate ($r=0.58$), (4) Information from the admissions office, and presence of a designated surrogate before admission ($r=0.51$). All other correlations were weak.

The first 3 axes of PCA were retained, because taken together, they summarized 62.7% of the total variability. The first group of attributes (axis 1) included frequent telephone contacts, presence at the time of admission and being a regular visitor. This axis explained 37.5% of the overall variability.

The second group of attributes (axis 2) included having a good understanding of the patient's clinical situation and good knowledge of the patient's wishes and values. This axis explained 14.2% of the overall variability.

The third group (axis 3) included being self-designated as the reference person, and being the first person to make contact. This axis explained 11% of the overall variability. This last axis juxtaposed self-designation among the patient's entourage as the reference person (correlation with the axis = 0.64) against being the first person to make contact with the ICU (correlation with the axis = -0.61). Accordingly, a high score on this axis indicates that relatives consider self-designation to be more important, and being the first person to make contact as less important attributes in the choice of the reference person for their loved-one.

The contributions of the individual items on the questionnaire to each of these three axes is detailed in Table 2.

No significant association was found between PCA axes and population characteristics.

DISCUSSION

This study attempted to provide answers to some of the questions that systematically arise during meetings with the relatives of patients hospitalized in the ICU when no official surrogate, as defined in French legislation [6, 13, 14], has been designated before admission. It is not easy to identify who, in the patient's entourage, knows the patient best, or who, when called upon to make medical decisions for the patient, might best know what the patient would want. In critical situations, who is most capable of grasping the issues at stake in the ICU? And who will be most involved if end-of-life decisions need to be made?

The results of the present study may appear to be largely similar to those of our previous investigation of the same question, considered from the point of view of the caregivers [15]. However, it is noteworthy that this is the first study to investigate the relatives' viewpoint on the choice of a reference person from among their ranks. We found that the most important attributes were a good knowledge of the patient's wishes and values; the fact of having an emotional attachment to the patient; the fact of being a family member and having adequate a good understanding of the clinical status and clinical history. There were no significant differences in the attributes considered important according to age, socio-professional category or type of relationship with the patient.

Principal components analysis makes it possible to summarize groups of similar variables in thematic axes, and is a particularly useful approach when there are large amounts of quantitative data, as in this study. Here, principal components analysis illustrated that the attributes relatives found important were clustered into groups; for example, frequency of contacts (axis 1), knowledge of the patient (axis 2) and volunteering to act as surrogate (axis 3). These findings are in line with those of Majesko et al, who reported that family members who had not had discussions with the patient in the past about treatment preferences felt significantly less confident in the role of surrogate [22].

Designation of a surrogate is often proposed at the beginning of the hospital stay, without any specific procedures. In real-life practice, designating a surrogate is often done along with a range of other administrative procedures that are required at admission or during the hospital stay. In many, not to say most cases, the relative who gets designated as the surrogate during these administrative tasks is often unaware of the role to which they have been appointed. Even when they are informed that they have been designated as a surrogate, the relative is often unaware of what that entails, exactly, and the responsibility it confers on

them vis-à-vis the patient. With the exception of a few very well informed patients, there is also usually no time accorded to reflection on the weighty decision that is the designation of a surrogate for oneself.

In emergency situations, especially in the ICU, where access to medical files is not always available 24/7 and contact with another health professional involved in the patient's care may not be easy, the only solution available to ICU staff seeking to discuss the patient's clinical situation is to consult the relatives who are present and available, when the patient is unable to communicate. This is of paramount importance to avoid unreasonable therapeutic obstinacy by pursuing treatments that the patient would not want (e.g. respiratory assistance if weaning is likely to be impossible), but also to know what the patient would want, so as to avoid loss of opportunity, which is equally as reprehensible. Asking the relatives about the patient's values and wishes, especially when the patient had expressed views on the matter before admission, is essential to ensuring that those wishes are respected. In this context, the relatives are thus called upon to bear substantial responsibility, often compounded by the worry, anxiety and prognostic uncertainty engendered by the patient's presence in the ICU. Indeed, these conditions can even culminate in post-intensive-care syndrome in certain cases [23].

Therefore, the absence of a designated surrogate prior to hospitalization raises several problems. Firstly, providing sensitive medical information to a non-designated person is a breach of medical secrecy, although it is generally acknowledged that family members are, by definition, well-meaning towards the patient and the physician cannot ignore the relatives' need to know. It would not be benevolent on the part of the physician to leave a family member, even one who is not designated as a surrogate, in the dark about important medical information regarding their loved one solely on the pretext that it is a breach of medical

secrecy. This is particularly true when the medical information concerned is likely to have repercussions for that relative's personal life, especially if it is a question of sequelae resulting from decisions made during the ICU stay [24, 25]. Secondly, the ICU team might not choose the same person to be their reference as the patient would have designated [26]. On the contrary, it is quite possible that the patient designated someone who was not the "right" person – namely, not the person best qualified to relate the patient's values and testify to the patient's preferences. Thirdly, nominating a member of the family, preferably the spouse, is not necessarily the best choice in the patient's view [27-30]. Lastly, the reference person designated during hospitalisation 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 of lifesaving therapies.

Family satisfaction with care after the hospitalized of a loved-one in the ICU is directly related to their degree of involvement in care, meetings and decision-making, and all the more so when the quality of the information given to the family is satisfactory [31, 32]. Conversely, providing the family with information, and having them participate in medical decisions are two entirely distinct issues. Relatives, whether officially designated surrogates or not, can only contribute to the care plan and medical decisions within the limits of their knowledge of the patient, the knowledge given by the ICU team, and the extent of what the patient has confided in them. Therefore, if the question of ICU admission or possible re-admission is raised in advance, during the discussion of the healthcare plan with the patient and his/her relatives before an acute event occurs, then this would relieve the relatives of this responsibility, and would avoid uncertainty among the healthcare team [33, 34]. Beyond considerations such as the patient's age and comorbidities, other factors would also be taken adequately into consideration, such as the patient's autonomy and/or previous and anticipated quality of life post ICU, and more generally, the patient's overall life trajectory [3, 35]. Future

hospitalisations or consultations performed during the follow-up of chronic diseases are ideal opportunities to address the patient's options in terms of healthcare plan (curative or palliative), once clear and transparent information has been given to the patient and/or relatives about the prognosis and expected course of disease. In such situations, it is legitimate to expect that anticipating these decisions outside the context of acute events [7] could on the one hand avoid non-beneficial admissions to the ICU [36], or on the other hand, enable ICU admissions with a clear therapeutic plan for the patient, thereby alleviating the involvement and responsibility of the family members in weighty decisions [37].

The findings of this study open interesting avenues for future research. Firstly, it would be interesting to organise a follow-up session, for example using concept mapping methodology, to rank the importance of the different criteria. Second, a larger scale, multicenter study would be helpful to validate the criteria identified here and ensure that the findings are not centre-specific. A multicenter design would also allow for controlling of potential confounders. Finally, a booklet or information leaflet explaining the role of surrogate (what it involves, how to name one etc) could be produced and made available at the admissions office and in patient's rooms and waiting areas. Its efficacy in informing families could be evaluated in a before-and-after study. Further studies are warranted to explore these, and other perspectives.

Study limitations

This study suffers from several limitations. Firstly, the study was performed in only two ICUs with a limited number of respondents. The narrow confidence intervals around the estimates for each item support the posit that a larger number of respondents would not significantly alter the results. Secondly, other characteristics of the relatives that were not

recorded here may have had an impact on the results (e.g. the number of children relatives had, the relatives' own personal history of serious illness and hospitalization, or their previous experience of acting as surrogates). Thirdly, we cannot exclude the possibility that our questionnaire was not exhaustive, and that other factors exist that were not taken into account. Lastly, the time at which the relatives completed the questionnaires may have influenced their responses due to the stress generated by the ICU environment.

Conversely, our study also presents several strengths. The questionnaire was developed using methodologically robust qualitative methods based on semi-directive interviews conducted until saturation. In addition, the data recorded here can be judged robust, since the PCA found them to explain more than 60% of the total variance across three axes, with quite strong ($r > 0.5$) correlations. Similarly, the results remained unchanged regardless of the age, socio-economic category and relationship of the respondent with the patient.

CONCLUSION

This study confirms that the values considered by relatives to be most important for designating a reference person for ICU patients are the knowledge of the patient's wishes, and the existence of emotional and family attachments to the patient. These findings could be a starting point for reflection among the family regarding the development of a therapeutic plan for their loved one, particularly before the occurrence of acute events, such as admission to the ICU. More than just changes in the legislation, these findings call for a change in the paradigm of care planning, by anticipating and integrating possible ICU admission into plans

for care. This could help to alleviate the burden on relatives and caregivers when a loved one suddenly becomes an ICU patient.

Table 1: Characteristics of the 73 patients whose relatives (n=87) responded to the questionnaire

Variable	All (N=73)
Age, years	66±17
Female sex, n (%)	21 (29%)
Charlson comorbidity score	2.3±2.3
SAPS II score	46±19
SOFA score	6.7±4.3
ADL de Katz	5.2±1.3
Main reason for ICU admission, n (%)	
Respiratory	29 (40)
Sepsis	17 (23)
Cardiac	14 (19)
Renal	5 (7)
Neurological	4 (5)
Other reasons	4 (5)
Length of ICU stay	17.3±20.8
In-ICU Death, n (%)	8 (11)

In-hospital Death, n (%)	9 (12)
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Quantitative continue variables are expressed as mean±SD

SD, Standard deviation; 95%CI, 95% confidence interval; ICU, intensive care unit; SAPS II, Simplified Acute Physiology Score II; IQR, interquartile range.

Table 2: Contribution of the individual questionnaire items to each of the three axes retained by principal components analysis.

	Axis 1	Axis 2	Axis 3
	Contribution	Contribution	Contribution
First person to make contact	5.82	1.24	28.64
Frequent phone contact	15.5	0.19	0.54
Present at patient's admission	13.37	0.002	0.24
Regular visitor	12.48	2.55	5.27
Family member	9.09	0.23	0.09
Emotional bond	9.73	9.04	4.35
Self-designated	7.24	0.34	30.79
Understands clinical status	0.38	38.22	0.47
Good knowledge of family history	7.85	5.14	6.88
Good knowledge of patient's wishes & values	1.17	33.04	0.55
Information from outside the ICU	9.69	7.65	0.002
Designated surrogate before admission	7.69	2.38	22.17

The items that contributed the most to each axis are highlighted in bold. The sum of contributions for each axis is 100%.

Figure Legends

Figure 1: Average level of importance accorded to each item on the questionnaire by the 87 respondents.

Conflict of interest statement

No author has any conflict of interest to declare.

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