

What are the ethical issues in relation to the role of the family in intensive care?

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Abstract: A large proportion of patients admitted to the intensive care unit (ICU) are unable to express themselves, often due to acute illness, shock or trauma, and this precludes any communication and/or consent for care that might reflect their wishes and opinions. In such cases, the only solution for the ICU physician is to include the patient's family in the healthcare decisions. This can represent a significant burden on the family, on top of the psychological distress of the ICU environment and hospitalisation of their relatives, and many family members may suffer from anxiety, depression or symptoms of post-traumatic stress disorder (PTSD) during or after the hospitalisation and/or death of a loved one in the ICU. Good communication remains the cornerstone of family satisfaction in the ICU. Information imparted to the patient and/or family should cover diagnosis, prognosis and treatment. Information should be given orally, in person, using accessible language. Several other measures that can lessen the burden on the families of patients in the ICU and help to reduce anxiety and stress are also detailed in this review. Overall, family-centred care in the ICU requires a systematic communication strategy within the healthcare team, combined with an environment that is as amenable as possible to the family's presence and involvement, in order to maximize family satisfaction with ICU care, and ensure that the patient's values and preferences are respected.

Keywords: Intensive care unit (ICU); family; satisfaction; communication; ethics

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Introduction

Intensive care is unique in that it enables critically ill patients to get through an acute phase of disease that they would not otherwise survive, without the life-sustaining therapies that are available today. However, intensive care may also be a source of physical, functional or cognitive handicap. Therefore, intensive care physicians must try to

ensure that after-effects are minimized as far as possible, by constantly weighing the risk-benefit ratio in the intensive care unit (ICU) in terms of future quality of life that can be expected for the patient (1-3). The interpretation of "quality of life" is highly individual, and thus, extremely difficult to define, because it depends on a range of factors such as the patient's age, life course and healthcare pathway before admission (4). A further specificity of intensive care is that

most of the time, patients are not capable of expressing themselves, often due to coma (artificial or otherwise), and this precludes any communication and/or consent for care that might reflect their wishes and opinions regarding the initiation of complex intensive care therapies (5). In such cases, the only solution for the ICU physician is to include the patient's family in the healthcare decisions, firstly to avoid any unreasonable obstination, and secondly, to ensure that the patient's wishes and values are respected. This can represent a significant burden on the family, on top of the psychological distress of the ICU environment and the (often sudden) hospitalisation of a loved one. This in turn can engender anxiety, depression and a state of post-traumatic stress; symptoms collectively termed "postintensive care syndrome" (6). In addition, one must not overlook the additional burden of care that families have to shoulder once the patient is discharged from hospital to home; indeed, 50% of patients leave the ICU with varying degrees of persisting impairments (7).

In this context, the place of the family in intensive care raises a number of ethical questions that need to be taken into consideration by the caregiving team, within the wider framework of so-called "family-centred care". This approach is based on the principle that each family is unique and possesses special expertise in identifying the patient's needs. Here, family is defined by the patient or, in the case of minors or those lacking decisional capacity, by their surrogates. In this context, the family may be related or unrelated to the patient. In general, it includes persons who provide support and with whom the patient has a significant relationship. Family-centered care is therefore an approach to healthcare that respects, and responds to individual families' needs and values (8).

Promoting communication: the cornerstone of family satisfaction

The main questions that should systematically be raised regarding families are: who knows the patient best, especially his/her values and preferences? Who is impacted the most, on a personal level, by the medical decisions? If the patient were to die, who would suffer the most from his/her death? (who would find it most difficult to accept the death?).

The reasons these questions are foremost is that the ICU must be able to answer them. One of the first answers that needs to be provided concerns the family's desire for

information about their loved one's state of health. Very often, the family's stress may also perturb the caregiving team, and this may not only be a source of conflict within the healthcare team (9), but can also increase the risk of burn-out among staff (10). This raises the question as to what is the "appropriate distance" to be kept with families, that nonetheless reconciles the need to know more about the patient through identification, empathy and trust, with the risk of a feeling of persecution among the family, which may rapidly make the family appear overbearing or aggressive. Yet, the presence of the family is essential, since a fruitful patient-carer-family triad contributes to humanizing the caregiving relation with the patient, with, in return, adequate recognition of the professional identity of the caregivers.

The quality of communication between the ICU caregiving team and patients/families has become a focus of attention, because it is now clear that this corresponds to a major need of the families (11). Information imparted to the patient and/or family should cover diagnosis, prognosis and treatment. Information should be given orally, in person, using accessible language (explain using analogies, use simple words, repeat the main message often, repeat explanations at each interview). Ideally, meetings with the family should take place in a dedicated room in order to preserve the confidentiality and intimacy of the physician-to-family relationship, and the meeting should also be noted in the patient's medical file.

Patient information leaflets given at admission are a simple yet useful pedagogical tool for providing basic information both about the ICU (visiting hours, contact phone numbers, typical work patterns etc.), and about the type of life-support therapies given there (additional information). Clearly, providing appropriate and sufficient information is quite a job, and many ICU physicians have no specific training in this area, meaning that they must permanently make an effort to meet the appropriate communication criteria: i.e., pay attention to the language and words used, and to the cadence and speed of speech, repeat and rephrase basic information, etc. In addition, in end-of-life situations, communication becomes increasingly difficult as the emotional context intensifies. Communication in all its forms is therefore of paramount importance to the family, and when delivered in a clear, transparent and appropriate manner, enables the patient and/or family to understand better, and thus to accept death more easily, in turn facilitating the grieving process. Lastly,

good quality information also contributes to significantly reducing the violent nature of the situation that the families find themselves in when a loved one is hospitalized and in danger of dying.

The specific situation of end-of-life decisions

The paternalistic model of communication (“telling rather than asking”) (12,13) that previously predominated in Europe has progressively given way to a model allowing for greater patient autonomy (14,15) (see also the article on collegial decision-making procedures in this issue). This new approach allows for greater involvement of the patient (if competent), and also the patient’s family, by means of structured interviews (in particular with the caregivers in charge of the patient) in the decision-making process, especially as regards decisions to limit or withdraw life-sustaining therapies. According to the criteria proposed by Appelbaum and Grisso, decisional capacity should be considered to cover the ability to receive and understand information, appreciate one’s own situation and potential outcome, make a conscious decision, and then make that decision known by communicating one’s wishes to the entourage (16,17). In France, legislation regarding patients’ rights at the end-of-life have placed considerable emphasis on the designation of a surrogate (or healthcare proxy), who may be a member of the family or other member of the patient’s close entourage, whose primary role is to inform the physicians about the patient’s wishes and values (18–20), particularly in end-of-life situations. The laws stipulate that the surrogate must be designated before admission to the hospital, which is actually rarely the case in real-life practice. Surrogates often have little awareness of their role and tasks, even though these may be important in the ICU context, and they also often misunderstand the disease and the therapeutic issues that arise (21,22). The healthcare teams can then find themselves treating patients who never gave any indication of their wishes or preferences to their family or entourage, and surrounded by families who (consciously or unconsciously) make decisions for those patients without understanding the stakes, or even putting their own interests before those of the patient (23,24). In these circumstances, it is understandable that the involvement of the family in end-of-life decision-making should be properly organised within the ICU. To this end, the VALUE approach (i.e., value the family’s statements, acknowledge the family’s emotions, listen to the

family, understand the patient as a person, elicit the family’s questions) has been shown to reduce symptoms of anxiety, depression and post-traumatic stress disorder (PTSD) at 3 months among the families of deceased patients (25,26). A recent study by our group (27) showed, using a questionnaire completed by caregivers in two ICUs, that the ideal “reference” person among the patient’s entourage should have the following characteristics: knowledge of the patient’s wishes and preferences, an emotional bond with the patient, good knowledge of the patient’s clinical history, and ideally, should have been designated as an official surrogate before the patient’s admission to the ICU. The objective of identifying a person with these qualities is to avoid what regularly happens in routine practice, namely “automatic” designation of the spouse as the intermediary. Indeed, the spouse is not always the most appropriate person to act as a reference in the context of ICU care, in the same way as a surrogate designated on the spur of the moment during the hospitalisation is not always prepared for the task entrusted to them (28,29).

Through several surveys performed heretofore, it has been shown that the satisfaction of families with ICU care is directly linked to their involvement in care, strategic discussions and decision-making procedures, all the more so when the quality of information is satisfactory (30,31). In France, more than half of families do not participate in medical decisions, whereas more than 90% of patients would like their families to participate in decision-making if they (the patients) were admitted to the ICU (24,28). In a landmark study by Ferrand *et al.* concerning end-of-life in the ICU, only 40% of family members were found to participate in the end-of-life decision-making process (5). Furthermore, the factors that give rise to dissatisfaction with ICU care among the patients’ families are well established, and logically, are mostly the mirror image of the causes of satisfaction, and include the communication between the physician the families in the patient’s room, conflict between the families and the caregiving team, family financial difficulties, and restricted visiting hours (32,33). It has also been shown that the involvement of families in the decision-making process can create an increased state of post-traumatic stress 3 months after the death, especially when the families received conflicting information or when they felt the decision was not the right one (34). A recent North-American multicentre, randomized, controlled study (35) evaluated the utility of family informational and emotional support meetings led

by palliative care clinicians in improving family anxiety and depression. The meeting team consisted of a palliative care physician (except study investigators) and nurse practitioner, and could also include social workers, chaplains, or other disciplines as required. The primary endpoint, measured at 3 months after the patient's discharge or death, was Hospital Anxiety and Depression Scale (HADS) symptom score, while the secondary endpoint was PTSD symptoms of the surrogate decision maker at 3 months as assessed by the Impact of Event Scale-Revised (IES-R) score. Overall, among 312 family surrogate members with outcome interviews, the authors observed no significant difference in the primary endpoint between those who had palliative-care led informational and emotional support meetings, and those who had not. However, there was a significantly higher risk of developing PTSD in the intervention group. Therefore, this begs the question of whether information that is too direct and open may not actually be deleterious and traumatic for the families, by highlighting the gravity of the situation to them, and by breaking down their coping mechanisms (36), particularly in cases where the prognosis is very poor. Similarly, addressing the question of the patient's preferences can also underscore the family's lack of knowledge of their loved one in this regard, bringing an increased feeling of responsibility to bear on them. Carson's study, as other studies before it, therefore raises several important questions. Should the role of the ICU physician not be to inform and support the family, rather than bring in outside representatives who do not participate in the patient's daily care (37). On the contrary, it appears that a proactive strategy of ICU consultations by the palliative care team can reduce the length of ICU and hospital stay in selected patient populations (advanced dementia, stroke occurring after cardiocirculatory arrest, prolonged ICU stay, neurological disease with dependence on mechanical ventilation) (38,39). In a recent study (40), Curtis *et al.* showed that communication facilitators may be associated with decreased family depressive symptoms at 6 months, but there was no significant difference at 3 months, or in the levels of anxiety or PTSD. The presence of facilitators to support communication between physicians and families, and to mediate conflict reduced both costs and length of stay, especially among decedents. This important study is the first to report a reduction in the intensity of end-of-life care, at similar or improved levels of family distress. Clearly, palliative care strategies need to be integrated into routine practice in ICUs, especially for end-of-life situations,

and the caregivers should receive special training for this purpose (41).

Anticipating the families' wishes: simple measures to put in practice

While good communication remains the cornerstone of family satisfaction in the ICU, there are also other simple measures that can be put in place to ensure that families are satisfied with their experience of the ICU.

One such measure is to facilitate the presence of the family at their loved-one's side at all times, by involving the family, where possible, in the caregiving process and in decisions concerning treatment, particularly end-of-life decisions. This does require a certain level of organisation and reflection before implementation, as it may call for a change in practices, or even increase the workload for some staff members (42). Although there have been no randomized, controlled trials to date, it would appear that restricting visiting hours gives rise to dissatisfaction among family members, whereas unlimited visiting strengthens the bonds with the caregiving team (43,44).

Another simple yet effective measure is to keep an ICU diary. The concept of an ICU diary was first introduced in 1980 in Northern Europe for nurses to share the presence of the families, the investment of the caregivers, and the family history, and more generally, as a support and encouragement for the patients and their families during the ICU stay. Families often have difficulty understanding and integrating the information they receive in the ICU, and often have questions that remain unanswered (45,46). The ties that can remain after the ICU stay within the patient-caregiver-family triad can be based on the written evidence of the timeline of the medical events, and can help to situate the patient's timeline within the real-world context of the surrounding environment. The diary entries punctuate the continuity of the patient's life, and present an opportunity to express feelings and emotions, but also support and encouragement. Each person who comes into the room can write in the diary, maybe a few lines about the patient, the care delivered, or anything else that happened during the ICU stay, and photos can be added. Both qualitative (47,48) and randomized studies (49,50) have suggested the utility of ICU diaries in terms of reducing PTSD at 3 and 12 months among families.

The availability of other healthcare professionals, such as psychologists (51), social workers (52) or ethics

consultations (53) in a multidisciplinary team setting can also contribute to increasing family satisfaction with encounters with the ICU caregivers, and is recommended, albeit with a low level of evidence, in recent guidelines for family-centred care in the ICU (8). Similarly, families can be offered the possibility to see a chaplain or other religious representative to accompany them in accordance with their religious beliefs, particularly in situations where the prognosis is poor.

The patient's environment is also important for the family, and especially respect for their privacy. Background noise should be kept to a minimum, care procedures should be adapted to the family's visiting times and the presence of children should be accommodated and encouraged.

Beyond the requirements of specific indications, the level of sedation should allow communication between the patient and the family, where possible. In some circumstances, it may also be possible to invite the family to participate in the care procedures, with or without the help of the healthcare professional (54). As far as possible, families should be allowed to stay overnight at their loved-one's side, especially in end-of-life situations. Several international professional societies have issued guidelines for the involvement of families with a view to reducing potential for conflict and improving family satisfaction (55-58).

Conclusions

Family-centred care in the ICU requires a systematic communication strategy within the healthcare team, combined with an environment that is as amenable as possible to the family's presence and involvement, in order to maximize family satisfaction with ICU care. The aim is to respect the patient's values and preferences as far as possible, by constructing a culture of care based on a multidisciplinary model that includes a palliative care dimension.

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Footnote

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