

What are the ethical questions raised by the integration of intensive care into advance care planning?

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Contributions: (I) Conception and design: JP Quenot, JP Rigaud; (II) Administrative support: None; (III) Provision of study materials or patients: None; (IV) Collection and assembly of data: JP Quenot, F Ecarnot, N Meunier-Beillard, A Dargent, A Large, P Andreu; (V) Data analysis and interpretation: JP Quenot, F Ecarnot, N Meunier-Beillard, A Dargent, A Large, P Andreu; (VI) Manuscript writing: All authors; (VII) Final approval of manuscript: All authors.

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Abstract: A major goal of intensive care units (ICUs) is to offer optimal management, but for many patients admitted to the ICU, they are unlikely to yield any lasting benefit. In this context, the ICU physician remains a key intermediary, particularly when a decision regarding possible limitation or withdrawal of life-sustaining therapy becomes necessary. The possibility of admission to the ICU, and the type of care the patient would like to receive there, should be integrated into the healthcare project in agreement with the patient, regardless of the stage of disease that the patient suffers from. These dispositions should be recorded in the patient's file, and should respect the progressive nature of both the disease itself, and the discussions necessary in such complex situations. The ICU physician can serve as a valuable consultant for the treating physician, in particular to guide patient choices when formalizing their healthcare preferences in the form of advance care planning (ACP) or advance directives (AD). Ideally, the best time to address this issue is before the patient's clinical situation deteriorates towards an acute emergency, and providing complete and transparent information to inform the patient's choices.

Keywords: Intensive care unit (ICU); advance care planning (ACP); ethics

Submitted Mar 13, 2017. Accepted for publication Jul 21, 2017.

doi: 10.21037/atm.2017.08.08

View this article at: <http://dx.doi.org/10.21037/atm.2017.08.08>

Introduction

A major goal of intensive care units (ICU), particularly in developed countries, is to offer patients optimal management that will ensure survival and quality of life that is accordance with their wishes and values (1). However, in a substantial proportion of cases, artificial life support will not yield an enduring benefit for the patient, and will engender physical, emotional, spiritual and financial burdens on the patients, their families and society in general (2). Although a number of consensus documents and recommendations for end-of-life

situations have been published (3,4), which have undoubtedly improved our practices in this domain (5), ICU physicians still have two major goals for patient management, namely to anticipate ICU admission where prognosis would be highly unfavourable, and to limit the use of certain life-sustaining therapies in the ICU (e.g., proposing non-invasive ventilation, but not intubation). In the literature, different approaches have been proposed for meeting these objectives, in particular advance care planning (ACP), ethics consultations, and palliative care consultations (1,6-9). Despite these various proposals, it is clear that the ICU

physician must remain the preferred intermediary in the decision to admit a patient to the ICU (or not), as well as for decisions regarding possible limitation or withdrawal of life-sustaining therapy (4,10). There are several reasons that support this position (11). Firstly, the intensivist has the best knowledge of the ICU and the life-support therapies that can be offered to the patient there. Secondly, the intensivist is also best placed to evaluate the patient's prognosis according to the presence or absence of organ failure. Finally, the intensivist is the most qualified to explain to the patient, as well as families and loved ones, the limitations and possible outcomes of ICU care. In this article, we will address the ethical issues and practical consequences of a decision to include ICU considerations in patients' healthcare projects via ACP.

How can we anticipate what patients will want?

In daily practice, for any patient admission, a number of ethical questions arise that will have practical consequences: (I) how can we be sure, in an emergency setting or otherwise, that it is appropriate to proceed with heavy levels of care, or on the contrary, not to engage in such care, while at the same time respecting the patient's wishes? (II) How will the patient and their family accept a situation of increased vulnerability, even extreme vulnerability, which is the reflection of the advanced stage of the disease? (III) In this day and age, how can we envisage palliative care for a patient who is dependent on multiple life-support therapies? (IV) How can we imagine that in a healthcare system that suffers increasing budgetary constraints, there is no advance discussion before an ICU admission that is unjustified by the clinical status and undesired by the patient and their family?

The questions that the ICU physician faces relate, on the one hand to anticipating an acute deterioration in the health of the patient, and on the other hand, to respecting the patient's wishes and preferences for such circumstances. The medical literature reports several difficulties encountered by intensivists in dealing with these questions. Firstly, physicians often find it difficult to give an accurate prognosis for their patient's outcome, and this is compounded by their well-meaning optimism (12-14). Secondly, the physician often lacks sufficient information about the patient's clinical state, prior medical history, previous level of quality of life, and healthcare trajectory. Third, informing patients and families of an acute health event that is usually rare and unexpected is not an easy task

for many physicians. Finally, some physicians may have a lack of knowledge of very high levels of care that are possible, particularly in the ICU (15,16).

To address these issues, many Anglo-Saxon countries, such as the United Kingdom, USA, and Australia have long since turned to the practice of ACP, encompassing the preparation of advance directives (AD).

The concept of ACP

The concept of ACP originates from the move towards consumer (and patient) protection in the USA in the 1960s and 70s. Since then, the American Supreme Court has recognized each citizen's constitutional right to refuse or interrupt therapy. This right equally applies to patients without decisional capacity. In 1990, the "Patient Self-Determination Act" was passed, which encouraged all stakeholders in the healthcare arena to introduce programmes to enable patients to learn about their rights relating to their own healthcare decisions (17). This included, in particular, the right to participate in discussions and partake of decisions relating to their healthcare, the right to refuse treatment, and the right to formulate AD. The Patient Self-Determination Act also made it unlawful for healthcare establishments to discriminate against patients who had not formulated AD.

What exactly are ACP and AD?

ACP is a dynamic process in which the patient is encouraged to discuss and identify his/her values, beliefs and life goals, especially the healthcare trajectory he/she wishes to follow. This process implies that the patient must be able to adequately formalize their own thinking on the subject, and share it, not only with their family and loved ones, but also with the caregiving team. Overall, ACP is a proactive and dynamic process that can evolve over time, particularly when major health events occur during the course of the disease. The main goal leading to the formulation of ACP is to ensure that the healthcare the patients receives, or will receive in the future, is in accordance with their values and preferences regarding their own health. ACP can also be accompanied (or not) by the preparation of AD.

AD are a written document, available in many countries, that a patient may prepare to consign, in writing, their wishes regarding end-of-life care, in case they subsequently become incompetent and unable to communicate their preferences (3,4). This ensures that for patients who lose

decisional capacity (a frequent situation in the ICU), their wishes will be respected, particularly as regards guiding therapy. The ICU physicians can integrate the AD, notably in cases where a decision to limit or withdraw therapy is being considered.

Despite numerous international recommendations and legislation formalizing AD in many countries (3,4), uptake of AD remains poor in the general population. The main problem likely concerns the fact that many patients find it hard to envisage their own demise, and are unable to say in advance what they might want at the end-of-life. For example, since the adoption of the Patient Self-Determination Act in the USA in 1991, only 10% of patients have prepared AD (18). Similar rates of uptake have been reported in Germany (19), the Netherlands (20), and the United Kingdom (21). Rates are reportedly even lower in Australia, at 0.2% to 7.9% (22) and Spain (<1%) (23). In France, less than 2% of the population has prepared AD according to the national institute for demographic studies (24,25).

In the province of Alberta, Canada, a survey performed in 2013 reported that 43.6% of patients had AD or a living will, and that 42.1% intended to complete them (26).

Certain patient characteristics seem to be associated with a higher rate of AD preparation, such as age, Caucasian origin, chronic disease, a higher socio-economic status or level of education, and also better knowledge of end-of-life options (19,27-29).

Pros and cons of ACP and AD

The ACP process requires that patients be accompanied, first by the physician caring for the patient, but also for the administrative follow-up to ensure that the process is efficacious and beneficial. It is currently recommended that healthcare systems around the world adopt a universal system for identifying the presence of AD for a given patient in the population, which would make it possible to find the AD and consult them efficaciously and rapidly, particularly in emergency situations (3). In the USA, for example, an AD registry has been implemented that helps to alleviate the problem of accessing AD. Indeed, some states have established an electronic registry, in addition to certain commercial registries (for example for living wills) (17). One major challenge of such registries is ensuring that they are kept up to date. France is moving towards a similar system with the introduction of new rights for patients at the end-of-life into the legislation in 2016 (30).

An important quality of ACP and AD is the fact that they can evolve over time. Indeed, it is important to verify with the patient at regular intervals that their preferences have not changed, particularly when there is a significant change in the patient's health status. A meta-analysis published in 2014 (31) reported that decisions consigned in ACP and AD were relatively stable over time, particularly concerning the following points:

- (I) The preference for having AD prepared, rather than not having any;
- (II) The preference for rejecting rather than accepting treatment;
- (III) The preference for accepting treatment in very mild disease conditions, and rejecting it in very severe conditions.

Beyond simply ensuring that the patient's preferences are respected, numerous other advantages have been ascribed to ACP in the literature (32-35). These include: (I) an increase in the rate of AD use; (II) greater compatibility between the healthcare delivered and the patient's wishes; (III) guidance for families concerning the most appropriate care, and reduction of their emotional burden; (IV) an increased likelihood that the caregiving team and the family understand what the patient would have wanted; (V) respecting the patient's place of death; (VI) greater satisfaction with the quality of care by improving communication between the patients, their families and the healthcare professionals; and (VII) a reduced feeling of stress, anxiety and depression among the family and/or loved ones.

A meta-analysis performed in 2014 (32) also reported that the terms "Do Not Resuscitate" and "Do Not Hospitalize" respectively decreased use of cardiopulmonary resuscitation and increased use of palliative care, but also reduced the number of hospitalizations, particularly for end-of-life and ICU admissions, with a corresponding increase in the number of deaths occurring at home. A recent literature review (36) investigating the impact of palliative care interventions and ACP on ICU utilization, brought together 22 studies (9 randomized and 13 non-randomized studies) and showed an overall reduction in ICU admissions and the length of stay with the use these interventions.

As regards the economic evaluation of the impact of ACP, in particular its cost-efficacy, data are sparse in the literature. To date, economic studies in this area have mainly focused on healthcare establishments caring for patients with dementia and/or highly dependent patients at the end-of-life (37). Importantly, ethical considerations must remain

to the forefront during discussions of management options in patients at the end-of-life, and economic conditions must not be allowed to influence patient autonomy (38).

The intensivist in a stalemate

The position of the ICU physician can be difficult in certain clinical situations where the doctor is torn between the duty and/or obligation to provide care for a patient in great medical need on the one hand, and the prohibition of “unreasonable obstinacy” on the other hand (3). It is established that patients who survive a stay in the ICU may suffer from long-term repercussions, in physical, emotional, and cognitive and financial terms, and these may impact on the patient, their family and society as a whole (39-43). The emergency nature of the situation, a lack of anticipation or discussion before the emergency occurs, and night-time or weekend admissions all concur to make it difficult to take calm and well-thought-out decisions in the patient’s best interest. Other factors may also enter into play in the decision to resuscitate a patient, such as physical and/or moral distress of the family or entourage, stress in the caregiving team, an inappropriate hospital environment, absence of usual intermediaries from the medical team, lack of knowledge regarding the patient’s healthcare pathway and medical file, scanty information in the file regarding end-of-life wishes, lack of knowledge of the patient’s preferences or those of the family, isolation of the physician, or the impossibility of organizing a collegial decision-making procedure. All these factors count among the difficulties faced by intensivists in daily practice (11).

In such situations, the ICU physician can experience very negative feelings, at the extreme end of the spectrum, may feel that they are stuck in a stalemate situation. Indeed, the fear of being at the root of a loss of opportunity for the patient is as salient as the fear of engaging disproportionate levels of care. In the current climate of care, it is complex to have to make such weighty decisions once the patient has been admitted to the ICU, in the context of known disease likely to lead to multiorgan failure, especially when these issues could have been anticipated and discussed in advance, before the situation became urgent. In some cases, a sudden and dramatic change in the therapeutic project may be taken badly, not only by the patient, but also their family and the caregivers. This can lead the patient and family to feel that they have been abandoned, and may give rise to symptoms of burnout in the caregivers. In other cases, the fact that the patient is admitted to the ICU could itself be

seen as unreasonable obstinacy. Indeed, in some clinical situations where it is established that life-support therapies, such as mechanical ventilation, can be considered futile (e.g., severe pulmonary fibrosis), it is imperative to anticipate possible outcomes, and reflect on the preferences for care in advance. The ICU physicians could provide input to this reflection by explaining possible approaches for dealing with intercurrent events that destabilise the underlying chronic disease.

The intensivist as an outside consultant to guide informed decisions by the patient and their families

Again, the idea of anticipating end-of-life decisions remains crucial, and requires the involvement of the ICU physician before the occurrence of an acute emergency, for example by consulting a team for a quick response regarding end-of-life situations (11,44). Firstly, it is a pity that the possibility of ICU admission is not more frequently addressed with patients, especially in today’s climate of increased implication of the patient in their own therapeutic project. This is reflected by the increased emphasis in the public arena on the preparation of AD, as is the case in France with the use of public information campaigns (30). Defining a therapeutic project together provides a unique opportunity to address the potential course of the disease towards an incurable stage, with the possibility for palliative treatment or life-support. Indeed, it has been shown that the trajectory of elderly patients after a stay in the ICU can be anticipated using simple instruments measuring, for example, the basic activities of daily living (e.g., bathing, dressing, walking across a room and transferring from a chair). The patients who have lost the most autonomy in the activities of daily living have the highest risk of death within the first year after hospitalisation in the ICU (45). However, the possibility of acute organ failure leading to ICU admission must also be considered, especially in patients with chronic disease. In this case, the possibility of preparing AD could be raised with the patient, as AD reflect the fruit of their reflection on the subject well in advance, when they have the time to include their families and other important figures from their entourage in the discussions. As a pre-requisite, the patient must be fully informed about the risks related to the likely course of the disease, but also about available therapeutic options. In addition to standard management of the disease, it would also be useful to reserve a dedicated time slot, for example during

multidisciplinary team meetings, to discuss the possibility of acute decompensation of the disease, and what to do if this occurs. In this meeting, where the intensivist should of course be invited to participate, all the possible outcomes, benefits and constraints of initiating life-support therapies could be discussed. The level of therapeutic engagement, the relevance of life-support therapies at specific timepoints through the healthcare pathway, the justification for repeated implementation of life-support etc., could be defined. Over the course of the patient's experience, these discussions could be enriched by including the patient's perceptions, feelings, experience and wishes. Indeed, it has been shown that appropriate ICU care (e.g., for decompensated COPD or heart failure etc.) can revive the patient sufficiently for him/her to be willing to talk about a healthcare project (either for the first time or again), or even a life-project, thanks to the improvement in their physical and/or psychological quality of life (33). Unfortunately, these patients often slip into a vicious circle, sometimes refusing care, because their situation of frailty and clinical deterioration prevents them from having a positive outlook towards the future. The patient could then prepare AD that would be more valuable than if they were prepared without the enlightening contribution of the intensivist.

In the minds of the public, writing AD is akin to refusing overly aggressive therapy, but is it not possible to envisage the preparation of AD with a view to guiding therapeutic engagement, oriented towards initiation of life-support therapy, so as to ensure survival that is acceptable to both the patient and their family? Naturally, only the patient him/herself is qualified to assess how valuable their own life is, but the caregivers must provide the factual elements that will enable the patient to make that assessment. Expressing the desire for organ failure to be managed according to pre-defined modalities, with a given level of therapeutic engagement, all decided in advance through consensual and shared decision-making, reflects the patient's consent for active care and/or support, and a refusal of unreasonable obstinacy. It is the quality of the information provided to the patient and their family that allows a truly "informed" decision, thereby conferring immeasurable value on the consent. It has previously been shown that when physicians address end-of-life issues with patients, there is subsequently a greater likelihood that the patient's preferences will be respected, and there are lower levels of anxiety, stress and depression among the family (33). To this end, it is essential for the patient and family to be able to come together to deliberate at a quiet time, when

emotions are not running high, and outside the context of acute events, and together with the intensivist, so that this latter may explain the therapeutic options available in case of organ failure, and also so that the patient and family may communicate their preferences for such a situation (46). Explaining what can be done implicitly suggests what will not be done. The approach is not the same, and while the first part seems more positive in its formulation, the second part should not be overlooked either. Explaining clearly what will not be done in a given scenario, and why (i.e., why it would not be reasonable to do it), makes it possible to re-orient the discussion towards the available options for what can and will be done. It is above all essential to ensure that neither the patient nor the family feel abandoned by the caregiving team, regardless of the outcome. Therefore, the therapeutic project should clearly address the question of ICU admission (or re-admission), and allow the patient to participate in choosing among the options that may be proposed. Indeed, it is unreasonable to expect a patient to make a decision regarding their own end-of-life when the physicians have not even defined the management strategy for any potential organ failure. This also implies that the physicians should not propose any care options, including in the ICU, that could be considered unreasonable. Finally, it is also necessary to address the possibility of dependence on life-support. Only physicians who have experience in these areas are qualified to discuss these very specific aspects with patients.

Life project and end-of-life

The occurrence of organ failure justifying initiation of life-support therapy is a crucial turning point, but one that is extremely difficult to pinpoint. The occurrence of organ failure, even in the context of chronic or incurable disease, does not necessarily equate with the end-of-life. It is naturally difficult to apprehend these considerations with detachment and flexibility when the patient is in a situation of distress. Repeated episodes of acute pulmonary oedema in the context of heart failure is a situation that can lead to discussions about whether to limit or withdraw therapy, but at what exact time should this be materialised? After a number of decompensation episodes? If so, how many? The next time? In situations of this type, it is impossible to make concrete decisions without involving the patient and their family in the discussion about the therapeutic project. This project should include dispositions for accompanying the patient, and providing comfort care, with an important role

for palliative care. Decisions to limit or withdraw treatment cannot be made without taking account of the patient's quality of life and will to live, and what one might term his/her "life project". After all, in the end, the appreciation of their own quality of life lies with the patient and their family.

Conclusions

The possibility of admission to the ICU, in the same way as refusal to admit or re-admit to the ICU, should be integrated into the healthcare project in agreement with the patient, regardless of the stage of disease that the patient suffers from. These dispositions should be recorded in the patient's file, and should respect the progressive nature of both the disease itself, and the discussions necessary in such complex situations. The ICU physician can serve as a valuable consultant for the treating physician, in particular to guide patient choices when formalizing their healthcare preferences in the form of ACP or AD. Ideally, the best time to address this issue is before the patient's clinical situation deteriorates towards an acute emergency, and providing complete and transparent information to inform the patient's choices.

Acknowledgements

None.

Footnote

Conflicts of Interest: The authors have no conflicts of interest to declare.

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Cite this article as: Quenot JP, Ecarnot F, Meunier-Beillard N, Dargent A, Large A, Andreu P, Rigaud JP. What are the ethical questions raised by the integration of intensive care into advance care planning? *Ann Transl Med* 2017;5(Suppl 4):S46. doi: 10.21037/atm.2017.08.08