UNDERSTANDING THE DISEASE

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Understanding ethical decisions for patients on extracorporeal life support

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Modern extracorporeal life support [veno-venous (vv) or veno-arterial extracorporeal membrane oxygenation (vaE-CMO)] is generating increasing interest throughout the world. Despite the significantly increasing use of ECMO in recent years, in-hospital mortality remains high [1]. Furthermore, clear inclusion criteria for ECMO treatment are lacking, resulting in a call for further investigation [2], especially in specific areas such as vaECMO for rescue cardiopulmonary resuscitation, where the rate of survival with good neurologic recovery is poor in some settings [3].

With increasing use of ECMO as a technology to maintain, or even replace, basic biological functions [4], the question we will hear sometimes at bedside rounds is: 'Do we want to continue ECMO if recovery with any quality of life is unlikely or perhaps impossible?' [5]. While the broad application of new technologies like ECMO no doubt saves lives in many cases, these innovations create a new thinking about medical ethics [6]. Traditional ethical principles (autonomy, beneficence, nonmaleficence, justice) may not be easily applied to some ECMO patients: What is the meaning of "well-being" in situations where, for instance, patients on ECMO are not recovering and there are no other therapies to offer? In recent years, we have increasingly engaged with families in "shared decision-making". In a recent survey of physicians' attitudes toward decision-making authority for the initiation and withdrawal of vaECMO [7], the majority of physicians who self-reported as very specialized in vaECMO treatment felt that physicians should have the right to discontinue vaECMO over a family's objection. Such a point of view cannot be left unchallenged. Shared decision-making brings its own set of ethical challenges in ECMO patients:

Who decides? When ECMO no longer seems to provide hope of recovery, should the decision to discontinue ECMO be a shared decision, or should clinicians alone decide when to stop? Shared decisions may enhance autonomy. Yet, there is a downside to deferring these decisions to a patient or surrogate. The burden of the decision, in the setting of great medical complexity, may overwhelm the very people we are trying to help; their experience of the decision-making process may be laced with feelings of profound guilt, anger or fear [6].

Can we enact our decision? In the event that the cessation of ECMO will result in immediately linked cardiocirculatory collapse and death, some surrogates—or even some members of the intensive care staff—may experience those situations as a profound burden.

Are intensivists prepared to address ethical questions related to this evolving technology? A new context for common ethical questions and new issues per se are associated with novel technologies like ECMO [6], and here we offer recommendations based on literature [6, 8, 9] and our own experiences:

'Close guidance' of the relatives:

The intensivist must help ensure, preemptively, that the ECMO treatment is consistent with patient preferences and goals of care. In contrast to other organ-replacement procedures (mechanical ventilation or renal replacement therapy) ECMO creates unique challenges. For instance, vaECMO, by providing circulatory support, may at times preclude circulatory death despite evident cardiac death. This creates confusion about the state of the patient; is she alive or is she dead? This is more than a technical matter. It raises complex issues regarding the futility of ongoing therapy. If further cardiac mechanical support is not being offered, should ECMO simply be withdrawn? Discussions with the surrogates must consider autonomy in decision-making and yet pass the fine line between therapy with a goal and a device that is merely preventing

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the dying process from taking place. It is crucial to strike the right balance to inform decision-making.

'Preventive ethics' [5, 6]:

- Daily interdisciplinary rounds—from the beginning of ECMO treatment—should carefully address the following: Is ECMO potentially a bridge to recovery, a guarantee of a status quo, or just prohibiting dying?
- Advance care planning (ACP) [10]: A process in which relatives receive information early after initiation of ECMO about the ongoing therapeutic process, the prognosis and specific consequences of continuation or discontinuation of ECMO. ACP should include a discussion of values, appropriate goals and fears; the patient's preferences should be articulated, and ACP may include a written prospective contract with surrogates among possible future scenarios (e.g., discontinuation of ECMO in irreversible organ failure).
- Conflicts about treatment benefits and burdens, and discussions on futility may arise in patients on ECMO. A mandatory ethics consultation policy [11], as an example, will increase the frequency and quality of ethics consultant—physician interaction, and increased awareness among physicians and nurses of potential ethics support. A precondition for such a policy is the institution's presence of a well-established ethics consultation service with consultants who understand the rudiments of ECMO technologies and the associated ethical issues. Mandatory palliative care consultation [12] might also be considered, especially in cases of great medical complexity and prognostic uncertainty.

Support by spiritual and palliative care providers:

Emotional support of patients and surrogates is essential with a focus on listening carefully to their concerns, and on providing technical details of the patient's course. Their reactions may be anger as an expression of helplessness, confrontation as a manifestation of extreme stress. Clinicians must not take such expressions personally, but place them in context and react with empathy to the greatest extent possible. Furthermore the utility of exploring spiritual issues with critically ill patients who have difficulty communicating, using a chaplain-led pictureguided tool for spiritual care [13], was demonstrated.

In our approach to such patients, ECMO is different from other forms of life support, since our ability to push the limits of life and stave off death (even if only temporarily) is that much greater and therefore that much more fraught with potential ethical complications. In that context, the rapid development and use of ECMO is an illustration of the fact that new technologies in medicine deserve carefully crafted approaches to medical ethics [6, 8, 9]. Furthermore these changes need systematic

research to better understand the demands of patients, relatives, and medical staff, and to propose solutions for potentially complex ethical dilemmas.

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Compliance with ethical standards

Conflicts of interest

TB is member of the Medical Advisory Board of the Xenios/Novalung Company, Heilbronn, Germany, and he received honoraria. DB is currently on the medical advisory boards of A Lung Technologies and Kadence. All compensation for these activities is paid to Columbia University.

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