22 Ethical Aspects and Communication

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Recommendations

Level I

Data are insufficient to support Level I recommendations for this subject.

Level II

Data are insufficient to support Level II recommendations for this subject.

Level III

Effective communication is an essential nontechnical skill for all intensive care clinicians.

Training, practice, preparation, and reflective review may improve performance when conducting family meetings and lead to better outcomes for patients and families.

Decision-making regarding organ donation depends heavily on the family's trust in the healthcare professionals, on the professional's communicative skills, and on the family's understanding of (brain) death.

Tips, Tricks, and Pitfalls

- The decision to limit or withdraw treatment is clinically based and is always the medical doctor's responsibility, never the relatives.
- When treatment is withdrawn, the healthcare professionals should avoid making decisions on behalf of the relatives. The patient's last hours or days belong to the family and they should be informed and, if they want to, also involved in interventions.
- Organ donation is an option and not a burden. Present the relatives with the possibility for organ donation when this is an option.
- Be honest about what you know and what you don't know.
- Be true.

22.1 Overview

The aim of this chapter is to overview considerations regarding communication with relatives and surrogate decision-makers in the ICU setting. A recommendation is to undergo regular training of nontechnical skills.

Patients with severe TBI need, by definition, both acute and intensive care. The situation is

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© Springer Nature Switzerland AG 2020
T. Sundstrøm et al. (eds.), *Management of Severe Traumatic Brain Injury*,
https://doi.org/10.1007/978-3-030-39383-0_22

often more or less chaotic, and we, as healthcare providers, are busy saving the patient's life and minimizing the evolvement of secondary injuries. Finding time to inform the relatives is important, but challenging in the acute phase. Prioritizing the patient is number 1 at all times, something that the relatives expect. Nevertheless, they have some basic needs we should consider:

- What has happened?
- Is he/she going to survive?
- Are you doing everything you can?
- Can we see him/her?
- Can I trust you?

Communicating is a multidisciplinary task. Informal communication is as important as formal. The nurse talking with the relatives while nursing the patient is the typical example of an informal situation. It is, however, important to initiate and maintain the formal communication in a formal setting. Preparation is crucial:

- Be sure to have a thorough overview of the patient's history.
- Know what has been done and what is going to be done.
- Know what the nurse knows about the relatives, the way they are related to each other, what they may have expressed concerns about, etc.
- Prepare for the dialogue in the multidisciplinary team (anesthetist/intensivist, neurosurgeon/neurologist, patient-responsible ICU nurse): Who does what/who leads the dialogue? Where are we? What is the short-term plan?

Good/effective communication, especially in the acute phase and in the situation where treatment is withdrawn, depends primarily on:

- Trust.
- Sensitivity overrules effectivity.
- The patient is a *person* (son/daughter/brother etc.), not a complex traumatic brain injury case.
- Thorough information, understandable/simple and in small portions.
- Physical surroundings, tidy room, closed door (not standing around the ICU bed or in the hallway).
- Honesty - not creating false hope, tell what you know and be honest about what you do not know.
- Competence. Everything is done to save the patient's life.
- Leaving room for the relatives to react and speak their minds.
- Time to consume the information and a possibility to have a talk again.
- Keeping your personal opinion apart from the ethics. What is right for you is not necessarily right for this patient and this family. Decisions involving beliefs, feelings, rituals, etc. are for the relatives to make.
- The medical doctor decides to end the treatment. The relatives are to be informed and heard. They are not the ones responsible for ending their relative's life.
- Be present. Turn off your phone or let somebody else outside the room hold it and take notes for you.

It is important to document a summary of the dialogue in the patient journal. It helps your colleagues to take over, and it is crucial for the relatives' impression of coherence that the next dialogue is a continuation of the former. Official documentation of specific treatment limitations should be made, including that relatives have been informed of these decisions.

Consider to offer counseling to the relatives. The chaplain or psychologist has the advantage of not being part of the team treating their relative and can help them to deal with their thoughts and concerns. This is not only helpful in cases, where the patient is going to die, but also in other situations where a patient is critically ill, the family structure is complex, children are involved, etc.

22.2 Background

Understanding the relatives' needs and what they understand are not something that is in every medical doctor's genes. Effective com-

munication is an essential nontechnical skill for all intensive care clinicians, and there is a still growing acknowledgement for the importance of this (Quinn et al. 2017). Interviewing the experts, i.e., the relatives, has revealed that they go to the clinician primarily for the truth and to seek hope elsewhere (Quinn et al. 2017; Apatira et al. 2008). When treating TBI patients, it is seldom possible to say anything definite about the future—even in the short term. The uncertainty is the most difficult thing to cope with for the relatives. The only way to help them is to give them insight in our plans for the nearest future and our reasons for choosing this path in this specific case. Especially important is it for parents to an injured child to have insight and a role in care (Roscigno et al. 2013). Avoiding discussions about prognosis is an unacceptable way to maintain hope, and being able to prepare emotionally and logistically for the possibility of a patient's death is essential. To understand that the patient is treated with the highest level of care, both as a trauma patient and as a person, has important consequences for the relatives' ability to cope with the situation here and now, as well as in the future (Jensen 2011; Apatira et al. 2008; Warrillow et al. 2016).

Relatives to a potential organ donor have the same needs as anybody else, but a few important details demand special consideration. Jensen (2011) refers to a series of relatives to organ donors after brain death. They all expressed that it is crucial to understand that the patient is actually dead, even though there is visible breathing movements, heartbeat, warm skin, and not seldom involuntary reflexes. Even if the doctor has explained brain death in understandable terms, the relatives first realize the truth when they see the clinical examination for brain death. It is helpful to give the information about brain death and information about organ donation in two separate occasions, as it is important to understand that the patient is going to die before the relatives can consider what to do when death has occurred. Some relatives will, however, mention the possibility themselves during the first dialogue. In the same study, the relatives mentioned that it was important for them to see the organ donation as a gift and that the healthcare professionals remembered to treat the patient with respect as a dying person and not simply as an organ donor (Jensen 2011).

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