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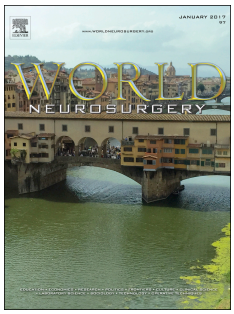

When time is critical, is informed consent less so? A discussion of patient autonomy in emergency neurosurgery

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- DPA: Durable power of attorney
- NHS: Health Services (NHS)

Abstract:

Neurosurgical interventions frequently take place in an emergency setting. In this setting, patients often have impaired consciousness and are unable to directly express their values and wishes regarding their treatment. The limited time available for clinical decision making holds great ethical implications as the informed consent procedure may become compromised. The ethical situation may be further challenged by different views between the patient, relatives and the neurosurgeon; the presence of advance directives; innovative procedures; or if the procedure is part of a research project. In this moral opinion piece, we discuss the implications of time constraints and a lack of patient capacity for autonomous decision making in emergency neurosurgical situations. We also discuss potential solutions to these challenges that might help to improve ethical patient management in emergency settings.

Introduction

Time is of the essence for many neurosurgical procedures that often must be done on an emergent basis to mitigate the extent of patient morbidity and mortality.[1] Compared to non-emergent procedures, emergency surgeries are independently associated with increased post-operative morbidity and mortality[1]. In addition, they are associated with additional ethical challenges, specifically related to patient autonomy and beneficence. Unfortunately, no formal guidelines or statements exist that specifically describe how to mitigate the ethical challenges in an emergency setting for neurosurgery. Ethical management of emergent neurosurgical situations requires the neurosurgeon to be aware of all potential ethical issues involved. In this perspective piece, we discuss the ethical questions that may arise in an emergency neurosurgery related to respect for autonomy and propose methods to address them.

Respect for autonomy in an emergency setting

In an emergency surgical setting, respect for the autonomy of the patient may be challenged for two main reasons: a lack of time and questionable capacity.

Lack of time

In an emergency setting, patients are often unable to make an autonomous decision because of time constraints.[2,3] The limited time compromises the ability of the patient to weigh the benefits and risks, to appreciate the gravity of the situation, and to consider all treatment or non-treatment options and divergent outcomes. Fear and misunderstanding, in addition to the sparse time to make autonomous decisions, further limit patients to make autonomous decisions.[2,4] At the same time, in an emergency situation, neurosurgeons have less time to prepare for surgery and moral deliberation.[5]

Lack of capacity to make autonomous decisions

In addition to a lack of time for informed consent, acute neurosurgical diseases may limit the capacity of a patient to formulate or express an autonomous decision. Three scenarios may arise: 1) the patient has capacity to make an autonomous decision before surgery, 2) the patient lacks capacity to make an autonomous decision and relies on surrogate decision maker, 3) a patient lacks capacity to make an autonomous decision and has an

advance directive for medical emergencies, or 4) the patient is comatose and family members are unavailable (**Table 1**).

In the first scenario, effectively communicating and providing informed consent is the main challenge in emergency surgery given a relative lack of time. An example of this scenario may be a patient with an epidural hematoma who provides informed consent for surgery during a lucid interval. In the second -very common- scenario, a patient that requires emergency surgery has impaired level of consciousness and is no longer capable of autonomous decision making. This may be the case for a patient that presents with an acute subdural hematoma. Hence, decision-making relies on a surrogate decision-maker (often a family member) if available.

In the third scenario, the patient who is unable to make a decision before surgery has an advance directive for medical emergencies. This can be a living-will that provides directions in specific circumstances and/or a durable power of attorney (DPA) in which the authority of the patient is carried over to another person through a legal document. Living wills offer a clear direction to take for the neurosurgeon and following this direction would respect the patient's autonomy. A clear and reasonable wish in a specific circumstance may seem relatively easy for a neurosurgeon to follow. This may be the case for an elderly patient with a severe traumatic brain injury and living will that states that no surgery should be pursued. However, even though this scenario might seem straightforward, it often not really is. For instance, society and the neurosurgeon may value the sanctity of life more that the respect for autonomy in certain situations.

Also, a living will should describe a well-defined scenario in which medical intervention is or is not to be pursued. This scenario may, however, not be fully or only partially applicable to the situation at hand, which raises questions regarding whether the living will should be followed. For example, an elderly patient that whishes no surgery to be performed under any circumstance for fear of bad outcomes might greatly benefit from the removal of a chronic subdural hematoma when compared to conservative management. Indeed, a survey among neurosurgeons showed that half of responding neurosurgeons would decline to operate on patients with an advance directive that limits post-operative life-supporting therapy.[6]

In addition to a living will, a Durable power of Attorney (DPA) may also provide guidance in the decision-making process for emergency surgery. A DPA is appointed by the

patient and should be familiar the patient's values and wishes. However, the DPA may be unavailable in an emergency situation and the patient's wishes may have changed since the DPA was appointed.

In the final scenario, a patient is unable to make an autonomous decision and has no available surrogate decision maker or known living will. In that case, the neurosurgeon becomes the sole responsible person to make a decision that is in the patient's best interest. When a patient cannot be expected to make a rational decision despite not being cognitively impaired, e.g. a comatose patient, the neurosurgeon might be required to take the decision on behalf of the patient.

Management of ethical challenges related to emergency neurosurgery

In emergency settings, lack of time and compromised capacity can challenge respect for autonomy. Here, we discuss how neurosurgeons may balance lack of time, compromised capacity of the patient and respect for autonomy and propose potential solutions to help guide management in these scenarios. Recommendations for ethical management of an informed consent procedure in neurosurgery are summarized in **Table 2**.

Balance between limited time, incapacitated patients, and respect for autonomy

In emergency situations, the neurosurgeon has to balance informed consent with minimal delay of the surgery. As a result, the formal informed consent procedure may be waived in acutely life-threatening scenarios like an evolving epidural hematoma causing uncal herniation. The ability to act fast maximizes beneficence to potentially incapacitated neurosurgical patients whose prognosis worsens with each minute of inaction. Most situations, however, will offer some – though limited - time to discuss treatment options but will still result in a compromised informed consent. All efforts should be made to obtain informed consent that is as complete as possible from the patient or surrogate decision-maker.

In the case of a patient that is incompetent to make an autonomous decision, the neurosurgeon should first consult the DPA or surrogate decision maker to guide decision-making. A living will may very well guide this process but should only aid decision-making if it provides a specified plan of action for the medical scenario. As indicated above, the decision to operate ultimately rests on the neurosurgeon's shoulders if no surrogate decision maker, DPA, or living will are available.

Disagreement between patient and neurosurgeon

We argue that neurosurgeons should in general regard the patient capable to make an autonomous decision when determining the patient's decision-making potential for emergent surgery. Only when the neurosurgeon has reasonable doubt regarding the patient's capacity to make autonomous decisions after discussion between multiple members of the neurosurgical team may operating without consent be ethically justified. Choosing to perform surgery without consent may be justified if the patient lacks capacity, has an unknown or unreachable health care proxy, has no living will or DPA prepared, and requires an urgent operation. This cautious management leans on the side of saving a life when it is not completely clear that a patient has capacity to make an autonomous decision.

On the other hand, if a patient is capable to make an autonomous decision and does not change his or her mind over a reasonable amount of time, then the patient's decision should be respected despite potential detrimental outcomes. There may, however, be no time to be sure that the patient is consistent in his or her reasoning over a longer period of time and the patient may also have chosen differently if the choice was not presented in an emergency scenario. Prioritizing beneficence over respect for autonomy may be ethically justified if respect for autonomy is viewed as a value or a relative right instead of an absolute right. In this instance, beneficence (e.g. saving the patient's life) is highly likely to strongly outweigh respect for autonomy under the patient's own value system.[7] In this situation, the neurosurgeon tries to act in the patient's best interest, which could be regarded as experience-based paternalism.[8] However, the neurosurgeon should be aware that he/she runs the risk of incorrectly assuming a patient's values and wishes based on his or her own social, cultural and religious background, which has a great influence on the decision making process. Therefore, this approach should be applied with caution and may not be justifiable if there is time available to further discuss treatment options with the patient or surrogate decision-makers.

Another example of disagreement between patient and neurosurgeon exists when there is disagreement about what constitutes a good outcome. For example, predicted outcomes after decompression malignant middle cerebral artery infarction might be acceptable for some, but not for others.[9,10] Indeed, for most (malignant middle cerebral artery infarction) patients and their families quality of life and functional outcomes are very valuable.[11,12]

The difficulty in weighing respect for autonomy and beneficence in complicated scenarios like these highlights the necessity for neurosurgeons to comply with the highest professional standards, be fully informed, and be sufficiently trained to avoid or take paternalistic positions. Conversely, respect for the autonomous decision to forgo surgery may outweigh the beneficence conferred by the surgery when the neurosurgeon wants to pursue surgery. Examples of these are surgeries with minor expected benefits, a high risk of poor outcome, and great uncertainty regarding difference in outcomes between surgery and conservative management.

A surgeon may also decide to refuse to offer surgery to the patient, while the patient or the surrogate wants an operation. Ethical justification for this practice requires reasonable certainty regarding the outcome and thorough explanation to the patient or surrogate decision makers. An example is a family demanding decompressive surgery for an elderly patient with a severe traumatic brain injury with expected very poor outcome. The neurosurgeon should nevertheless try to pursue a treatment plan that respects the values and follows the wishes of the patient as closely as possible whilst ensuring an optimal outcome for the patient. Fellow neurosurgeons may be consulted for a second opinion in these instances.

Emergency neurosurgery in an innovative or research setting

Respect for autonomy in an emergency situation becomes even more challenging when the procedure is innovative or takes place in a research setting. The uniqueness of an emergency case may pressure the neurosurgeon to perform the relatively unproven or innovative procedure and require a more extensive informed consent process.[13,14] This, therefore, requires a more extensive description of the procedure by the neurosurgeon postoperatively and a disclosure that the procedure was in fact innovative. This should, however, not result in neurosurgeons refraining from innovating in an emergency scenario when necessary. Innovation may also take place in a research setting which requires an extended informed consent. These patients may not be suitable research subjects as they are not able to provide consent, but outcomes of future patients may only be improved through formal research and there may be no other ways investigate certain treatments. One survey showed that the vast majority of the public would find it acceptable if a surrogate or their next of kin provided consent for a trial in an emergency setting.[15] The Rescue ICP and RESCUE-ASDH trials demonstrates that formal research in incompetent patients in an emergency

setting can be done safely and ethically.[16–19] However, there are currently no guidelines or specific requirement for the informed consent procedure for emergency neurosurgery.

Ethical care for patients in emergency neurosurgical scenarios

We argue that greater awareness of the importance of autonomy as well as open communication between the patient and neurosurgeon will ensure that emergency neurosurgical scenarios are managed in an ethically sound manner. Here we outline several ways for all parties involved in emergency neurosurgical care to achieve this.

A mandatory post-operative notification could be an additive to an incomplete informed consent procedure for an emergent case. The patient or family should be made aware of what the procedure entailed and what the reason was for choosing a particular procedure or to refrain from one. This should ideally take place when the patient has recovered to a state that could be considered competent to make an autonomous decision. The representatives or family members could be informed earlier if the patient remains cognitively impaired or needs extensive recovery. Guidelines could help in this scenario by suggesting what should be communicated at a minimum. Specific training for obtaining optimal informed consent in an emergency setting and communication with patients in emergency scenarios and afterwards could be included in the neurosurgical (ethics) curriculum. In addition, to create awareness and encourage advance directives, (potential) patients could be notified that the informed consent process may be partially or completely waived in an emergency situation. This could take the form of a notification in the emergency room or a brochure.[20] This notification could also state that the course of action will be explained to the patient afterwards. Such a notification has been implemented by the National Health Services (NHS) in the UK.[21] A downside to this approach is that patients may ignore this notification or that patients or families will only notice this notification when requiring emergency surgery. However, we believe that greater awareness among patients may stimulate them to discuss values and wishes with family and other potential surrogate decision-makers or even provide advance directives.

On a policy level, surgical societies could engage with patient advocates and hospitals to come up with guidelines, statements, or a form of oversight for emergency neurosurgery. These guidelines could reflect the difficulties that may arise and how these may be managed

by neurosurgeons. We believe that these policies could improve awareness among patients and could increase the trust patients place in neurosurgeons when they seek emergency care. These proposals may, however, only result in a reduction of the number of ethically challenging emergency neurosurgical scenarios. Every emergency neurosurgical scenario will remain unique and present the neurosurgeon with difficult ethical challenges where guidelines, patient awareness, and previous training will only be of partial benefit. Ethical handling of such situation will continue to rely on the neurosurgeon's professionalism. We regard professionalism as an ethical obligation of the neurosurgeon, and is a result of good mentoring, continuous personal reflection, and understanding of patients' values and wishes.

Conclusion

Emergency neurosurgery challenges the respect of autonomy of the patient. The emergent nature compromises the respect for autonomy due to a lack of time, especially if the patient lacks capacity to make an autonomous decision. The neurosurgeon needs to possess robust knowledge of the inherent risks and benefits of various emergency scenarios, excellent communicational skills to balance the time allotted and informed consent, and prowess to ethically handle disagreement. The situation may be improved by a post-operative notification, specific training of the neurosurgical team, and greater awareness among patients. However, most scenarios will continue to rely on the neurosurgeon acting in a professional way to manage each unique scenario in an ethically sound manner.

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Table 1: 4 scenarios in emergency neurosurgery.

Scenario	The patient is able to make autonomous decisions:	Other available parties or materials to guide decision-making.	Decision-maker.	Example.
1	Yes	Not necessary.	The patient.	An adult patient with a traumatic vertebral fracture that needs urgent stabilization.
2	No	A surrogate decision-maker such as a family member.	The surrogate decision-maker.	A pediatric patient with an epidural hematoma that requires emergent evacuation.
3		An advance directive: DPA or living will.	The neurosurgeon, guided by the Advance directive.	An elderly patient that has stated in a living will that no surgical procedure should be pursued but requires emergency evacuation of a subdural hematoma.
4		Not available or enough time does not exist (e.g. patient with unilateral mydriasis and EDH)	The neurosurgeon.	A comatose patient with severe TBI that is brought in by emergency services and whose name and family are unknown to the neurosurgeon.

Table 1 legend: Abbreviations: EDH: epidural hematoma, DPA: Durable power of attorney, TBI: traumatic brain injury.

Table 2: Recommendations for ethical management of an informed consent procedure in emergency neurosurgery.

Recommendations
1. An autonomous decision by a capable patient should always tried to be respected, even if it is not the decision recommended by the neurosurgical team. 2. The informed consent procedure should only be waived when benefit is expected from the procedure and any delay would result in inferior outcomes in incompetent patients. 3. The neurosurgeon should provide a post-operative notification is the informed consent was (partially) waived. 4. The neurosurgeon should ensure that the highest professional standards are followed in complex situations where no clear course of action is available. 5. The neurosurgeon should possess knowledge of the risks and benefits of various emergency scenarios and communicational skills. 6. The neurosurgeon should ensure the values and wishes of the patient and the family, which may be very different from the neurosurgeon's, are followed as closely as possible in all circumstances (especially when in a paternalistic position). 7. The decision to operate in complex situations should lean on the side of saving a life. 8. The neurosurgeon should incorporate a more extensive informed consent process when the surgical procedure is innovative or takes place in a research setting.

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