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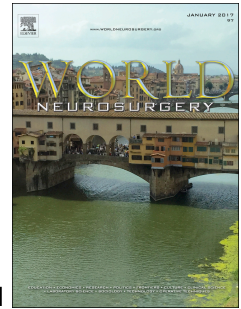
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Title: When time is critical, is informed consent less so? A discussion of patient autonomy in emergency neurosurgery

Short title: Ethics of emergency neurosurgery

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1 Abbreviations:

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

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6 Abstract:

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

18

19 Introduction

20 Time is of the essence for many neurosurgical procedures that often must be done on
21 an emergent basis to mitigate the extent of patient morbidity and mortality.¹ Compared to
22 non-emergent procedures, emergency surgeries are independently associated with increased
23 post-operative morbidity and mortality¹. In addition, they are associated with additional
24 ethical challenges, specifically related to patient autonomy and beneficence. Unfortunately,
25 no formal guidelines or statements exist that specifically describe how to mitigate the ethical
26 challenges in an emergency setting for neurosurgery. Ethical management of emergent
27 neurosurgical situations requires the neurosurgeon to be aware of all potential ethical issues
28 involved. In this perspective piece, we discuss the ethical questions that may arise in an
29 emergency neurosurgery related to respect for autonomy and propose methods to address
30 them.

31

32 Respect for autonomy in an emergency setting

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

35 *Lack of time*

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

43 *Lack of capacity to make autonomous decisions*

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

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

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

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

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

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

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

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

90 Management of ethical challenges related to emergency neurosurgery

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

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

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

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

111 *Disagreement between patient and neurosurgeon*

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

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

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

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

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

158 *Emergency neurosurgery in an innovative or research setting*

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

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

175

176 *Ethical care for patients in emergency neurosurgical scenarios*

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

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

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

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

213 Conclusion

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

The corresponding author declares on behalf of all authors that there are no competing interests.

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