

# Ethical issues in the treatment of patients with acute Stroke

## Abstract

The treatment of patients with stroke raises several ethical issues. The impact of a stroke on a patient's cognition, communication, and understanding can hinder their ability to make decisions about their treatment. Often, strokes occur suddenly and unexpectedly, leaving both the patient and their family unprepared for decision-making. Key concepts such as decision-making capacity, identification of a healthcare proxy, and informed consent are critical during the acute phase of stroke treatment and throughout short- and medium-term care. Treatment decisions encompass various options, ranging from initial therapies like thrombolysis or thrombectomy to invasive procedures, resuscitation, palliative care, and others. Prognosis inevitably plays a role in decision-making, and although various tools aid in this process, some reservations remain.

The recommended approach involves integrating information provided by clinicians, considering the patient's preferences, and considering the input of family members or the designated healthcare proxy. Effective, straight forward, and objective communication with the patient and their family is essential to prevent and resolve conflicts. Familiarity with these ethical concepts is crucial for all physicians and healthcare professionals involved in caring for stroke patients.

**Keywords:** decision-making capacity, ethical issues, healthcare proxy, informed consent, treatment decisions

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## Introduction

The provision of healthcare to patients affected by Stroke is complex and can give rise to a variety of ethical questions. The impact of a stroke on cognition, communication, and comprehension can affect the patient's capacity to participate in decision-making, whether it pertains to the treatment of the stroke or other matters. In most cases, the event is sudden and unexpected for the patient and their family, catching them off guard and ill-prepared for the decision-making process, both from the patient's perspective and as formal caregivers. Concepts such as decision-making capacity, identification of a healthcare proxy, and informed consent are of utmost importance not only in the acute phase of stroke treatment but also in short- and medium-term care. Treatment decisions range from initiating therapies like thrombolysis or thrombectomy to invasive procedures, resuscitation, palliative care, and nowadays, several tools are available to assist with this, though some reservations exist.

Recommendations emphasize making decisions based on the integration of information provided by clinicians, the patient's preferences, and the contributions of family members or the healthcare proxy. Clear, direct, and objective communication with the patient and their family is vital in preventing and resolving conflicts. A solid understanding of these ethical concepts is essential for all physicians and healthcare professionals providing care to stroke patients.

## Decision-making capacity

The capacity for decision-making is based on the ethical principle of Autonomy, which upholds the right of patients to make choices based on their values and beliefs.<sup>1</sup> All adult patients are presumed capable of making decisions unless an evaluation determines otherwise. Typically, such an assessment should be conducted by one or more physicians and ideally by a psychologist as well. To be considered capable of decision-making, the patient must be able to comprehend

relevant information, understand its significance and implications in their situation, consider the presented options, and formulate and communicate a choice.<sup>2</sup> The capacity may also fluctuate during hospitalization, making it a dynamic decision.

There exists a broad spectrum of decision-making capacity. For example, a patient may not be capable of making judgments about which treatment option to choose in a decision scenario but may still be able to identify and name their family member responsible for the decision.

Following a stroke, alterations in consciousness, cognition, and communication can impact the patient's capacity for decision-making. A patient in a coma is clearly unable to make decisions. However, even minor cognitive changes can impede information processing and decision-making, necessitating a thorough cognitive assessment. Severe dysarthria or aphasia may compromise communication and understanding. Speech therapy can play a significant role in this context by developing strategies to overcome the challenges presented by the patient's condition.<sup>3</sup>

## Identification of the healthcare Proxy

For patients who lack decision-making capacity, the identification of the healthcare proxy is a fundamental pillar. If the patient has completed an Advance Healthcare Directive (*Testamento Vital* as it is called in Portugal), the appointment of the healthcare proxy is part of its content. Law no. 25/2012 of July 16, 2012, regulates advance directives of will (DAV in Portuguese), including the form of an advance healthcare directive, and the appointment of the healthcare proxy, establishing the National Registry of Advance Healthcare Directives (RENTEV).

In cases where an Advance Healthcare Directive exists, this requirement is naturally fulfilled. However, a significant portion of the population, particularly the elderly and those with limited awareness,

may not have completed their advance directives due to lack of awareness or disinterest. In the absence of an advance directive and when the patient is unable to make decisions, the usual practice is to turn to the closest family member, as they are typically the ones who know the patient's preferences and beliefs best.

## Informed consent

Patients with decision-making capacity or healthcare proxies for incapacitated patients have the right to consent to or refuse treatments through the process of informed consent. For informed consent to occur, individual decision-making capacity must be present. Relevant information about the treatment process should be provided, understood by the patient or their proxy, and the authorization decision should be voluntary. The process is typically recorded and signed, but informed consent is more than just a document; it is a communication process between the healthcare provider, patient or proxy, where risks, benefits, and alternatives to a specific treatment are evaluated.<sup>4</sup>

There are several specific factors related to stroke treatments that make informed consent more complex, including the emotional impact of a sudden illness, an unexpected event, and the short therapeutic window for some treatments, particularly arterial recanalization, either through thrombolysis or thrombectomy. Respecting the principle of autonomy and applying informed consent must be done efficiently to avoid delays. Other ethical principles are also involved, such as beneficence (timely treatment increases the likelihood of a better outcome) and non-maleficence (timely treatment may reduce the risk of complications). In 2011, the American Academy of Neurology outlined that obtaining informed consent for thrombolysis with alteplase should be obtained and documented whenever possible, but written and signed consent is not required.<sup>5</sup> In cases where stroke patients lack decision-making capacity, treatments may sometimes occur before a healthcare proxy is identified to prevent severe harm or death. In such cases, it is ethically acceptable for physicians to provide interventions consistent with the best available medical treatment, with implicit consent for emergency treatment.<sup>6</sup> The decision to proceed under implicit consent aims to prevent death and severe consequences, but it should not in any way preclude efforts to locate a healthcare proxy or close family member.

## Prognosis

Some ethical decisions after a severe stroke are based on prognosis, which relies on the accurate interpretation of the patient's condition and potential outcomes. Healthcare professionals rely on their clinical experience and existing evidence (predictive models) to determine prognosis, but there are several limitations, such as insufficient clinical evidence, distorted beliefs, clinical biases, generalization of inconsistent scientific knowledge, among others.<sup>7</sup>

Often, intensive care or intermediate care physicians do not follow the patient throughout their entire hospital stay, limiting their ability to predict potential outcomes. This can result in less aggressive treatment decisions or recommendations for comfort care or do-not-resuscitate orders. If clinical judgment is based on incomplete or incorrect information about the potential for recovery, the patient's outcome will be negatively affected. The Neurocritical Care Society recommends repeated clinical examinations to improve prognostic accuracy and the maintenance of intensive therapies to achieve physiological stability in the first 72 hours, allowing time for prognostic evaluation, care planning, and consideration of organ donation.<sup>8</sup>

There are predictive models for stroke, but these models have significant limitations. Most are based on outcome studies conducted

in a limited number of centers, limiting their generalizability due to possible differences in potential treatments in other contexts. Another limitation of predictive models is that treatments evolve, and outcomes should also change accordingly. Predictive models forecast outcomes for populations of patients, but the goal of establishing a prognosis in the clinical context is to provide information about the possible outcome for an individual.<sup>9</sup>

Prognostic models may not reflect the outcomes that are important to patients and their families. Patients with severe brain injury and their families typically want information about functional outcomes,<sup>10</sup> which is more difficult to determine as outcomes vary widely and are more complex to evaluate. The described outcomes may not be meaningful to the patient and their family. One limitation of these prognostic models is that they may not reflect the natural evolution of stroke in the context of intensive therapy. Many studies include patients for whom decisions for supportive measures were made, creating a kind of self-fulfilling prophecy, where many end up dying after support therapies are withdrawn. In this regard, considering the impact of this aspect on prognostic models, the American Heart Association / American Stroke Association issued guidelines for intracerebral hemorrhage, recommending initial intensive treatment and deferral of don't resuscitate orders until the end of the second full day of hospitalization.<sup>11</sup>

In establishing a prognosis, transparent communication is essential, creating an opportunity for the patient, caregivers, and family to share their values and beliefs and providing information about the prognosis while maintaining honesty about potential uncertainties. Predictive models have the potential to refine prognosis but should be used in combination with other factors, such as clinical experience and knowledge of the patient's most important values and expectations.

## Shared decisions

The implementation of intensive therapies in stroke aims to improve outcomes, but often leads to increased survival with increased disability. As such, many of the decisions made should be based not only on clinical evidence but also on the preferences and values of the patient, caregivers, and family. Interventions such as intubation, mechanical ventilation, tracheostomy, hemicraniectomy, and gastrostomies are examples that require clear communication and effective communication with patients and their families.

The patient and the family should provide information about their preferences, values, and beliefs to healthcare professionals, while the professionals provide information about the medical condition, prognosis, and treatment options. Shared decision-making allows for the development of a joint plan based on preferences and realistic goals. There are also patients and families who prefer healthcare professionals to take on a more predominant or even exclusive role in decision-making.<sup>12</sup>

Patients' perspectives on quality of life vary significantly from patient to patient. Some patients value life despite severe disabilities, while others see death as the preferred alternative and choose to forgo intensive and supportive therapies. In stroke, patients often lose the ability to express their perspectives, thus not participating in the decision-making process. It often falls to healthcare professionals, caregivers, and families to predict the patient's quality of life based on often limited prognoses and make decisions based on their perception of what would be an acceptable quality of life for the patient.<sup>13</sup>

Advance Healthcare Directives contain information about the patient's preferences and values in the event of the patient losing

decision-making capacity. However, Advanced Healthcare Directives do not provide specific information in the case of a stroke. The document has information about the patient's wishes regarding a "terminal condition" or "conditions with no possibility of recovery," which can be difficult to determine in the acute phase of a stroke. In such cases, Advanced Healthcare Directives can be a good starting point for discussion with family members and caregivers about the patient's preferences and values.

In the absence of Advanced Healthcare Directives, it falls to the caregiver or family member to make decisions for the patient based on what they believe would be the patient's beliefs and preferences, even if they differ from their own. Decisions should be made in what is believed to be the best interest of the patient. In some cases, patients may have previously expressed their wishes regarding states of disability or dependence. While useful, this information should be interpreted with care by family members, as values and beliefs may change over time, especially in situations where they are confronted with the choice between life with disability and death.

## Conclusion

It is the role of healthcare providers in stroke care to prevent ethical conflicts and resolve ethical issues when they arise. There are a set of strategies that facilitate ethical decisions at the point where doubts arise. The existence of legislation that provides for the identification of a healthcare proxy promotes shared decision-making based on individual knowledge of patients, respecting their wishes. The shared decision-making model is preferred for sensitive decisions following a stroke. This model should be based on accurate clinical information about treatment options and prognosis, as well as an understanding of the patient's values, preferences, and beliefs.

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## Conflicts of interest

The authors declare no conflicts of interest.

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