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Decision-Making in Artificial Nutrition and Hydration: Ethical and Legal Considerations for Minors and Incapable Patients

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Abstract. The complex issues surrounding the administration of Artificial Nutrition and Hydration (ANH) in cases involving minors or individual's incapable of understanding and willing are examined, focusing on who should make the relevant decisions and the ethical, deontological, and legal aspects involved. Challenges in obtaining informed consent from minors and incapable individuals are highlighted, emphasizing the importance of considering the best interest of the patient. Advocating for a therapeutic alliance, the involvement of the minor, the guardian, and the physician in the decision-making process is recommended to ensure the patient's rights and dignity are respected. The need for a multidisciplinary approach in evaluating the benefits and risks of ANH is addressed, stressing the principles of proportionality and beneficially to prevent unnecessary suffering. The role of the healthcare provider in navigating these ethical dilemmas and the importance of collaboration among medical staff, legal guardians, and families are underscored to ensure ethically and clinically appropriate care.

Key words: artificial nutrition and hydration, bioethics, ethical considerations, medical decisio-making, patient autonomy

Introduction

Regarding the administration of Artificial Nutrition and Hydration (ANH), the most significant difficulties seem to arise when the patient is a minor or an individual incapable of understanding and willing (1). In such circumstances, the question is who should make the related decision. Specifically, when considering minors, the issue is complex, involving not only ethical but also deontological and legal aspects. There is a debate on whether informed consent given by a minor (2), who possesses natural capacity and discernment, is sufficient for the administration of the medical treatment (3) and at what age such a significant decision, laden with responsibility, can be reasonably placed on them (4-5). Even more problematic is the case where the minor is incapable of understanding and willing (6).

Discussion

It is necessary to preface that patient in general, whether minors or adults, who are incapable of understanding or willing or who lack consciousness (7), are those who are unable to express their own will. Hence, in the case of both minors and incapable adults, there is a discussion on the conduct that the healthcare provider should adopt when there is a discrepancy (8) between the consent given by the parents or legal representative and the best interest of the patient (9). Indeed, it can happen that the consent given, in order to prolong the continuation of the ongoing medical treatment (10-11), is contrary to the opinion given by the attending physician (12). Thus, the question arises whether such a request is equally legitimate (13) or whether it should not be followed, as it does not meet the "best interest" (14) of the patient (15). Regarding minors in healthcare, there seems to be a so-called “adult-centric” vision (16), where the patient’s illness (17) and possible suffering are (18), so to speak, reserved for adults. In this sense, there is a sort of denial of the child’s subjectivity (19) in decision-making, either out of fear and a desire for protection by the adult or due to the minor’s lack of maturity (20). For this reason, the consent for ANH is requested from the guardian (21). However, the minor has the right to be heard, to express their own opinion (22-23), and to participate and be involved in decisions that concern them. Therefore, the request for informed consent aims at adopting a shared decision among multiple parties (24), including the minor, the parent, and the physician, to achieve a “therapeutic alliance,” (25) which is considered the optimal form of care (26). For these reasons, the decision regarding the administration of ANH should be made by the guardian, who should involve the minor, understand their experiences, and provide an appropriate space for listening (27). The minor should be involved in the potential therapeutic treatment without being burdened with excessive responsibilities (28) beyond their capacity, which could cause trauma or wounds that are difficult to heal. In this sense, it can be said that involving the minor should not transform into a request for “co-responsibility (29).” The consent for treatment should always be provided by the parents, albeit in the best interest of the minor (30). In reality, it is not always easy to understand what the best interest of the child or the incapable adult might be, especially when they are in a terminal condition with no possibility of improvement. The best interest should be understood as a general clause prescribing a course of action to ensure the respect of the fundamental rights of the minor or the incapable individual (31). Specifically, the “best interest” represents a summary formula capable of evoking the values based on which adults or legal representatives (32) should make their decisions, directing them towards reasonable and just choices, considering the peculiarities of individual cases. This is precisely the ground on which paediatric or incapable patients risk suffering the worst consequences of drastic decisions made by others, especially when motivated by ideological and/or emotional reasons that may not align with the best interest of those who should be protected (33). To prevent such risks, it is required that healthcare treatments, especially when administered to minors or incapable individuals by the choice of parents or legal representatives, are guided by the principles of proportionality and beneficially, ensuring that medical interventions provide some benefit to the patient and never become a tool for an unreasonable prolongation of suffering of the most vulnerable. Specifically, Article 37 of the Deontological Code stipulates that, in the case of a minor or incapable patient, the physician is required to obtain informed consent or dissent from the legal representative but must also report to the competent Authority any opposition expressed by the minor or those exercising parental authority to a therapeutic intervention deemed necessary. In such a case, the healthcare provider (34), considering the patient’s clinical conditions, is still authorized to intervene promptly, administering the necessary and urgent care. Additionally, it is important to emphasize that the administration of ANH should never be seen as a mechanical obligation but as a considered decision that takes into account the specific circumstances and needs of the patient. The evaluation of benefits versus risks and consideration of the patient’s quality of life should always be at the center of medical decisions. Moreover, the decision-making process (35) should involve a multidisciplinary team, including not only attending physicians but also psychologists, social workers, and legal experts, to ensure that all perspectives are considered and that the patient receives the best possible care.

Conclusion

Collaboration among medical staff, legal guardians, and families is crucial to ensure that every decision is made in the patient’s best interest, respecting their dignity and fundamental rights. Active involvement of patients and their legal representatives in decisions about their care is essential to build trust and ensure that therapeutic choices are aligned with the patient’s values and preferences. This way, ANH can be administered in an ethically and clinically appropriate manner, contributing to the overall well-being of the patient.

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