End-of-life decision making
concerning patients with disorders of consciousness

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Chronic disorders of consciousness
Chronic disorders of consciousness (CDC) are states of illness that are notorious for provoking substantial ethical quandaries. The fiction literature, cinema and theater abound with stories of individuals who have been lying in coma for months or years until they eventually (and miraculously) wake up to see a world that has significantly changed. Famous examples are Pedro Almodóvars Habla con Ella, Wolfgang Beckers Goodbye Lenin or Alex Garlands The Coma.

Coma is a borderline state of human existence. The word “coma” originates in ancient Greek where it means “deep sleep”. In medicine, it has come to signify a state of deep unconsciousness, where a person cannot even be awakened by intensive stimuli like pain. Usualy, coma is a transient state after an accident, in the crisis of a grave disease or, artificially provoked, in narcosis during surgery. A non-artificial coma usually lasts for up to three weeks until the patient either recovers and slowly regains consciousness or deteriorates and dies.

Recovery can, however, come to a standstill at a very basic level of brain functioning. This is the level of the so-called vegetative state (VS), in which the functions of the evolutionarily ancient brainstem are intact, but the evolutionary younger and more vulnerable cerebral cortex lacks regular function. These patients (their state is also called apallic syndrome, wakefulness coma or coma vigile) show sleep-wake cycles with open eyes during daytime, reflex motor activity, spontaneous breathing and integration of vegetative bodily functions like the hormone system, blood pressure and body temperature. They do not display, however, any intentional behavior, any consistent responses to stimuli or any purposeful interaction with the environment.

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If the recovery of brain function proceeds to a point where certain systems of the cerebral cortex resume basic functions, neurologists speak of a minimal conscious state (MCS). These patients show at least some subtle and intermittent signs of awareness, e.g. voluntary motor activity like fixating and tracking objects with their eyes, but also following simple commands or sometimes even uttering single words. Yet, these patients are usually unable to uphold a meaningful communication and interaction with their environment. Both states, VS and MCS, are jointly referred to as chronic disorders of consciousness. They can be chronic because these patients receive life-sustaining medical treatment that replaces those lost brain functions that are necessary for life, especially the ability to eat and drink. This is why such states were exceedingly rare and rather short before the invention of the feeding tubes that allow long-lasting artificial nutrition and hydration directly into the stomach of the patients.

Ethical questions
There are numerous ethical questions surfacing in the context of CDC patients. A basic and rather meta-ethical point is the question what the moral status of these patients is and whether they can and should be regarded as persons with all rights and responsibilities, which obviously depends on the controversial definition of person and the rules of ascribing moral status. In addition, there are justice questions that mainly touch on the issue of fair resource allocation, as these are disorders with a low prevalence, but a relatively cost-intensive care. Another public ethics issue is the question how these patients should be institutionalized and cared for (e.g. in nursing homes, rehabilitation centers, special facilities etc.). In the past, there have been many media reports on CDC patients of a scandalizing, distorting or manipulating nature, so responsible media portrayal of these disorders is another crucial issue. As many CDC patients are young and fall ill in the context of building a family, there are issues of reproductive ethics: How should we deal with pregnant women that suddenly suffer accidents leaving them in a CDC? What about CDC patients that have stored gametes or zygotes for in-vitro fertilization or partners who want to get children with the help of sperm-
retrieval from their CDC patients? For partners of CDC patients the question of intimacy and sexuality may also be a big issue, as are sexual assaults of these totally unprotected by caregivers or others.

End-of-life decisions: illustrious cases
This is only a selection of ethical issues that have been discussed in relation to CDC patients. The most widely and intensely debated issue, however, is undoubtedly end-of-life decision making. Since the commencement of modern bioethics, controversial cases of CDC patients have regularly been in the spotlight of international attention. This started in 1975 with Karen Ann Quinlan, a 21-year-old woman from New Jersey, USA, who suffered respiratory failure on a party after ingestion of alcohol and sedative drugs. Because of delayed resuscitation she eventually remained in a state of wakeful unresponsiveness and was kept on life-sustaining mechanical ventilation. Her catholic adoptive parents asked for the ventilation to be withdrawn. After long judicial proceedings against the hospital the court granted the request, but Quinlan unexpectedly survived the withdrawal of ventilation, lived with the assistance of a feeding tube for another nine years and finally died from pneumonia.

In 1983, the 26-year-old Nancy Cruzan from Missouri, USA, had a car accident and suffered a cardio-respiratory arrest. After having been resuscitated by paramedics she also ended up in a VS state. During the following four years, her state did not improve, and the parents fought a three-year court battle for stopping the artificial nutrition and hydration. The case went through all levels of jurisdiction, and the final court decision in 1990 saw clear and convincing evidence for patient preferences against life-sustaining treatment.

Around the same time the 18-year-old football supporter Anthony Bland was caught in the 1989 mass panic in the Hillsborough stadium in Sheffield and suffered brain hypoxia due to lung injuries. Despite intensive rehabilitation care he remained in VS which led the parents and the treating physician to apply for withdrawal of life-sustaining measures. The English
courts including the House of Lords granted this request, stating that prolonging that state of life would not be in Bland’s best interest.

The most famous VS case was that of Terri Schiavo from Florida, USA.\textsuperscript{12} She was 26 years old when she had a cardiac arrest in the context of bulimia. She then lived in VS for 15 years. The controversies began in a family feud between the husband who wanted his wife to be allowed to die, based on her alleged prior expressions, and her parents who had strict pro-life attitudes. The 8-year lawsuit instigated a fervid public and media debate that also included church authorities and the highest politicians. The feeding tube was twice removed and replaced following court orders before Schiavo ultimately died after a definitive court order to remove the tube.

The European counterpart to the Schiavo case concerned Eluana Englaro from Lecco in North Italy.\textsuperscript{13} She was 21 when she had traumatic brain injury due to a car accident, leaving her in VS for 19 years. The main divide in this case was between Englaro’s father who pleaded the courts to allow his daughter to die and political and clerical authorities in Italy and the Vatican. The father ultimately won the lawsuit, and his daughter died a few days after stopping artificial nutrition and hydration.

\textit{Reasons for ethical controversies}

Summing up these cases, there are some remarkable points to be made: (1) all cases concerned young, attractive people, mostly women, who suddenly and unexpectedly fell into VS; (2) all lived in VS for several years with no significant rehabilitative success; (3) the moral debate surrounded, with the exception of Karen Ann Quinlan, artificial nutrition and hydration; (4) long, multi-level court proceedings led to intense public debates; (5) while the jurisdiction showed a more liberal stance, strengthening the right to die, political and clerical leaders put more emphasis on the value of life.

Although there may have been specific situational and personal factors that led to these cases becoming so publicly prominent, it is certainly also a consequence of true ethical conflicts. While the general conflict between letting die and saving life is difficult enough, there are some complicating features attached to CDC patients: (1) The patients are unable to make health
care decisions for themselves, so surrogate decision making is necessary;\textsuperscript{14} (2) CDC are puzzling disorders with a high rate of misdiagnosis\textsuperscript{15} and very little prognostic knowledge,\textsuperscript{16} and the segregation of wakefulness and awareness is hard to grasp for the ordinary observer; (3) media reports on miraculous awakenings from coma\textsuperscript{17} or fabulous new brain imaging data showing surprisingly normal brain activation\textsuperscript{18} unsettle the public; (4) mental events are, as a matter of principle, not amenable to objective scientific proofs, opening up room for speculation.

\textit{Life-sustaining treatment}

The standard bioethical account of letting a patient die has one necessary condition: it is only possible if there is at least one life-sustaining treatment currently being administered. In other words: Life-sustaining treatment is defined counterfactually, meaning that any treatment without which the patient would die from a life-limiting disease within a foreseeable time frame can be defined as life-sustaining treatment. Usually, there is a substantial difference of prognosticated survival time with and without the life-sustaining measure. The time between foregoing the treatment measure and the ensuing death varies according to the kind of treatment and the underlying course of the disease. It is usually only a few minutes for removal of mechanical ventilation or withholding of cardiopulmonary resuscitation, but it can be several weeks for withdrawing hemodialysis or artificial nutrition. Most treatment forms that are considered life-sustaining lead to death within a few weeks if they are discontinued.

If the time interval becomes longer and the causal connection gets weaker, speaking of life-sustaining treatment forms becomes arguable. This applies, for example, to chemotherapy that may statistically extend survival for a few months, and abstaining from it may therefore lead to an earlier death, but this can still be many months or years away in the future. And finally, there are treatment forms that may have a significant life-prolonging effect, but only in the distant future, while there may be many other reasons for a death in between. This is the case for pharmacological treatment of high blood pressure or antiretroviral treatment against HIV: a correct therapy
statistically leads to survival times that are several years longer than without that treatment, but death due to consequences of the disease usually lies many years ahead in the future, and the patient may die from other causes earlier.

As a bottom line, I would suggest defining life-sustaining treatment for pragmatic reasons as a treatment without which the patient will most likely die within six months, while he would live substantially longer with that treatment. Six months is also the estimated survival time, below which hospices and palliative care institutions usually accept patients.

Of note, life-sustaining is not an abstract attribute that may permanently be attached to a certain form of treatment. It is therefore not correct to say that antibiotics are per se life-sustaining treatment. It depends on the situation and on the prognosis with and without that treatment. In CDC patients, the most common form of life-sustaining treatment that nearly all patients constantly need is the artificial nutrition and hydration, usually via a feeding tube (PEG tube). This is because all other vital physiological functions are preserved (breathing, cardio-circulatory system, hormonal system etc.), and the ingestion of food and water is the only vital function that in human beings needs an intact cerebral cortex and cannot be implemented by the brainstem alone.

The second group of life-sustaining treatment that CDC patients often need is treatment of infections. As they often get infectious complications like pneumonias, PEG tube infections, decubitus ulcers, urinary tract infections or septicemias, they often need antibiotics, sometimes small surgeries and even intensive care measures. Other life-threatening complications of CDC are pulmonary embolism, status epilepticus and gastrointestinal obstruction. In addition, CDC patients may also have unrelated life-limiting diseases like cancer, renal failure or stroke that may need life-sustaining treatment.

**Decision-making criteria**

Now that we have seen why end-of-life decision making is particularly difficult in disorders of consciousness and which are the concrete treatment decisions that most frequently need to be made, we have to address the
normative question how these decisions should be made and which criteria should be used.

Decision-making criteria can be heuristically identified if we concentrate on the four principles of biomedical ethics\textsuperscript{19} and the values they entail: Beneficence and non-maleficence refer to the value of patient wellbeing, respect for autonomy is of course based on the value of patient autonomy, and justice is the third core value that is at stake. These three are the core values that form the basis of decision-making criteria in medicine generally and in end-of-life decision making specifically.

*Patient wellbeing*

Let’s start with the most difficult, but also the most relevant criterion in end-of-life decision making for CDC patients: promoting the patient’s wellbeing. Before looking at the specific problems in CDC patients, it is worth noting some general points. Wellbeing in the ordinary language means that someone is doing well. This is a very vague and ill-defined concept,\textsuperscript{20} and usually it is up to the person herself to define what wellbeing means to her. Generally speaking, wellbeing is both a holistic concept (it refers to all aspects of a human being) and a time-transcending concept (it mainly refers to the present state, but is indirectly affected by remnants from the past and prospects into the future).

This translates into ethical obligations: if you want to promote another’s wellbeing, you have to consider the person with all her dimensions and have in-depth knowledge of that person, and you have to regard the person’s past and future. Applied to health care, this means that proxy decision-makers should get to know the patient and talk to the patient’s relatives and friends, and they also should be attentive to a correct diagnosis, the illness history and an extremely thorough prognosis.

The ordinary understanding of promoting another’s wellbeing also implies that the person promoting the wellbeing has benevolent intentions and motives, so it clearly transcends a purely consequentialist view.

If we focus on CDC patients, there are two pivotal questions: (1) Which patients have what level of awareness? (2) Is awareness a necessary condition
for wellbeing? The first question is one that touches on the mind-body-problem. Without going too much into detail, it suffices to say that awareness is usually detected interpersonally via communication and empathy. If aware patients have no ability to communicate and express themselves due to paralysis (like patients in a complete locked-in state) there is no reliable and doubtless method to identify that awareness. This is because awareness is a subjective category that is not directly amenable to objective measurement from the outside. There are two methods how neuroscience tries to solve this problem: (1) some researchers try to establish routes of communication that bypass the motor system, using brain-computer interfaces;\(^2\) (2) others try to find surrogates and correlates of awareness, e.g. certain activity patterns in functional brain imaging.\(^2\) The dominant view among neuroscientists is that VS patients are not aware of themselves or their surroundings due to extensive cortical damage, whereas MCS patients (as the name already reveals) have at least sometimes some basic level of awareness including pain perception.\(^2,3\)

The diagnosis of awareness would become less relevant if we held that awareness is not a necessary condition for wellbeing and that a completely unconscious person can have wellbeing. This is a defensible position that I will call the *transmentalist view*. Proponents of this view will, however, need to explain what wellbeing means, what its conditions are and whether we can speak of the wellbeing of unconscious lower animals, plants or even objects. The more often held position is the *mentalist view* that regards wellbeing as a state of mind and therefore presupposes awareness. According to this view, it is nonsense to ask about the wellbeing of an unconscious person. This view, however, is challenged by transient states of unawareness: If a patient is unaware, but can easily regain his awareness, helping him to come aware again surely promotes his wellbeing.

The clinical consequences of these two views are far-reaching: the mentalist who does not see any sense in asking about the wellbeing of unaware persons will have to oppose life-sustaining treatment for VS patients, because it is usually not considered ethical to perform a treatment that does not benefit the patient in any way. As MCS patients are considered minimally
aware, he will have a more positive stance towards life-sustaining treatment for these patients. The transmentalist, on the other hand, judges wellbeing irrespective of the question of awareness. Therefore, he will not make a general normative distinction between the treatment for VS and MCS patients. Whether they should receive life-sustaining treatment will depend on how he judges wellbeing in these states and whether it is estimated to be preferable to death.

This brings us to another important metaphysical aspect that should be considered in the context of end-of-life decision making. Decisions are always between at least two options, and the two basic options in end-of-life decisions are to sustain life (A) or to allow dying (B). If promoting the patient’s wellbeing is a crucial criterion in end-of-life decision making, we have to ask what wellbeing means both for option A and for option B. If we isolate the criterion of wellbeing, life-sustaining treatment should be continued if the wellbeing associated with the option A is superior to wellbeing associated with option B.

Let’s concentrate first on the option of sustaining life (option A). Here, the current wellbeing of the patient ($W_{\text{curr}}$) must be combined with the prognosis of the disease. What will be the best possible future scenario regarding wellbeing ($w_{\text{best}}$) and what is the probability ($p$) of this state? We can abbreviate this option A using the following term:

$$W_{\text{curr}} + (p \times w_{\text{best}})$$

But this is not yet a comprehensive formulation of option A. If we compare life to death, we can argue that life carries an added value by itself, irrespective of the state of wellbeing of the person living that life. This added value is attached to the mere biological liveliness and therefore also relevant for unconscious patients. Does life in itself have a positive value ($v_{\text{biol}}$)? It surely has a metaphysical value, but does it have an ethical value or is it rather ethically neutral? I think that there is indeed some ethical value in pure biological liveliness, because it is a conditional value: life is the basic condition for any moral good, even for morality and ethics in general. As a conditional value (just as other conditional values like health or knowledge) it has a relatively high ethical value, but it should never be seen as an absolute value.
Otherwise we would run into vitalism, which means that preserving biological life trumps every other consideration and life-sustaining treatment is imperative in each and every case and situation. Our term for option A now looks the following:

\[ W_{\text{curr}} + (p \times w_{\text{best}}) + v_{\text{biol}} \]

If we come back to CDC patients, we now see that the problem is not only the difficulty judging the current state of wellbeing, depending in part on the stance towards awareness, but also predicting what the best possible state would be and how probable this is. Prognostication is generally a vague project, but in CDC it is most complicated. Conclusive data on clinical predictors that reliably distinguish between different severities of the disease and foresee the future outcome are lacking. There is the additional problem of anecdotal reports of late recovery from CDC after years or decades. Treatment effects are still poorly researched and there is no effective standard treatment regimen, but some drugs or invasive procedures like deep brain stimulation may have prognosis-modulating effects in at least some patients.25 The lack of ongoing rehabilitation measures and regular expert follow-up examinations in the long-term care phase (e.g. in nursing homes) hampers a good understanding of prognosis. In addition, prognosis is biased by the mechanism of self-fulfilling prophecy: if physicians think that prognosis is poor, they will soon withdraw life-sustaining treatment with the effect that the further course of the disease will not become known and the prognosis might be systematically judged too poor.4

Let us now turn to option of letting the patient die (option B). As all humans eventually die, this option is really about the time of death. In other words, the question is whether, at a given moment, sustaining life until the eventual death or allowing death to occur already now is preferable. Option B totally depends on the personal meaning of death to the individual patient (and the relatives). If the patient thinks that death is simply the end of life and there is no existence afterwards, option B becomes irrelevant and it all hinges on the positive or negative evaluation of option A. Yet, if life after death is not negated (\(u\)-topia), but regarded as a paradise (\(eu\)-topia) or as a horrible place
of torture and suffering (dys-topia), the ethical assessment also depends on the value of life after death (v_{LAD}). The full equation of the criterion of patient wellbeing now looks the following way:

Life-sustaining treatment is warranted if:

\[ w_{\text{curr}} + (p \cdot w_{\text{best}}) + v_{\text{biol}} > v_{\text{LAD}} \]

with \( w_{\text{curr}} \) being the current state of wellbeing, \( p \) being the probability, \( w_{\text{best}} \) being the best possible future state of wellbeing, \( v_{\text{biol}} \) being the value of biological life as such, and \( v_{\text{LAD}} \) being the value of life after death. The problem is that nobody knows what death really is and whether there is some form of life after the dying phase. So the only possibility to include this thought in our ethical evaluation is to honor the patient`s belief regarding life after death. Now we already arrived at the second major ethical criterion for end-of-life decision making, the patient autonomy.

*Patient autonomy*

The primary form a patient autonomy – the self-determination of an informed, competent patient – is not possible in CDC. Both VS and MCS patients do not achieve the necessary level of awareness and cognitive capacities to exert this form of instantaneous personal autonomy. This already follows from the fact we cannot determine whether a CDC patient adequately understood the information that is conveyed to him about the different treatment options. Moreover, another condition that is not met by CDC patients is the ability to communicate one’s preferences, intentions and decisions in an unambiguous and effective way.

In practice, however, it is often found that relatives and health care professionals interpret certain patterns of patient behavior as expressions of a `natural` will.\(^{26}\) If CDC patients smile or clench their fist when others hold their hand, this may be interpreted as signs of a will to live. Moaning or turning away the head, on the other hand, may be construed as signs of a will to die. These examples already show how nebulous and dubious this concept is. Neurologists know that CDC patients show complex brainstem reflexes and disconnection syndromes that may mimic behavioral responses (like smiling,
clenching the fist, moaning etc.). Yet, how should we differentiate between a reflexive and a volitional origin of a phenomenologically indiscriminate behavior? In addition, if such behavioral signs present without a verbal expression, they are often ambivalent and can be interpreted in both ways. Weeping, for example, can be seen as a sign of affection, joy and the will to live, but it can also be interpreted as a sign of suffering, despair and the will to die. The same is true for clenching the fist. Such behavior is surely important to recognize and consider in making healthcare decisions, but they are to be seen as expressions of comfort and discomfort facilitating the judgment about the patient’s wellbeing and not as expressions of a will that could adequately answer complex questions on end-of-life treatment.

We have seen that there is no actual, instantaneous autonomy by verbal or behavioral expressions that could guide decisions for CDC patients. But there are two auxiliary forms of autonomy that can also inform decisions regarding patients without decision-making capacity: prospective autonomy, based on prospectively stated preferences, and substitutive autonomy, based on substituted judgment regarding the presumed will of the patient.27

The institutional form of prospective autonomy is the instructional advance directive, also called the living will. It has been praised as the best solution when controversies on the presumed will have proved insurmountable, particularly in CDC patients.28 Many check-box forms of advance directives do indeed contain passages on states of unconsciousness, but they rarely differentiate between coma, prolonged coma, VS, MCS and other states – so, for example, the most frequently used form in Germany.29

The objection is often heard that such an extreme state of health like VS or MCS could never be adequately anticipated, which must be the case if the advance directive should adequately represent the true preferences of the patient. A recent empirical study compared check-boxes in advance directive forms with qualitatively explored patient preferences and found a rather low level of congruence.30 Interestingly, the congruence for the extreme state of coma after stroke was not lower but higher, arguing for the fact that advance directives might be more suitable for CDC than for other kinds of illness.
The objection is also vulnerable at another side, because it is based on a wrong premise. It is not necessary to anticipate fully how it will feel to live without awareness, perceptions, thoughts and other mental events. It is sufficient to know how it feels to live with these mental capacities now and to value them for their significant contribution to one’s quality of life. This is enough to be able to judge what a possible loss of these capacities would mean for oneself. It is true that many patients who suffer from chronic non-psychiatric diseases like a tumor or a stroke are able to adjust to the new situation with certain disabilities and find more quality of life than they did before. Yet, this “response shift” is a highly creative way of compensation that requires intact cognitive, emotional and volitional capacities. It may well be performed by locked-in patients who don’t have any damage to the cerebral cortex, but not by CDC patients with no or only minimal awareness.

A more practical problem surrounding advance directives is their scarcity in CDC patients and their implementation. As many CDC patients are young and fall ill due to an accident or sudden disease, very few of them have written advance directives – in contrast to elderly patients with chronic or progressive diseases. Motivating young people to write advance directives is known to be extremely difficult, as the only reliable predictor for writing directives are experiences with death and disability in the own family. Even if patients have written advance directives, it is still not guaranteed that they will be treated accordingly. Relatives may not find the directives in due time or hold them back, physicians may not be willing to implement them, or the directives may be written too vaguely or too specifically to apply them to the current situation.

If there is no advance directive or it is not implemented, there is still the criterion of substituted judgment according to the patient’s presumed will. In principle this is an ethically appealing criterion that purports to safeguard patient autonomy. Numerous empirical studies, however, have found that even the closest relatives only achieve an accuracy of 68% in substituted judgments. In parallel to the data on advance directives, it has also been found that the accuracy is somewhat higher (70%) for extreme states of health like coma states. Another problem is that many legal systems have rather
strict evidence rules for substituted judgment and require clear and convincing evidence from relatives who purport to report the patient’s presumed will. This evidence is mainly found in previous statements on specific healthcare preferences, and these are rarely identified in young CDC patients’ past. It is also known from empirical studies that proxy decision-makers often consider their own values and interests and do not solely decide according to the patient’s presumed will, but this is very difficult to ascertain by others.

**Justice criteria and other considerations**

End-of-life decisions should primarily be discussed from the perspective of individual ethics. Because such intimate and high values as life and death of the patient are at stake, the patient should be the primary concern of all actions. But this does not mean that we can totally eliminate the perspective of social and public health ethics. First, there are also relatives, friends, healthcare professionals involved who have their own moral rights and valid interests. Second, such decisions can have far-reaching impacts on other vulnerable groups of society. The slippery-slope argument that decisions to let patients die might slowly lead to a social pressure on vulnerable patient groups like the disabled or demented has to be taken seriously. Third, there are numerous other interests of society, and scarce public resources have to be allocated fairly between citizens and their interests.

The area of ethically defensible options is certainly restricted by the prohibition to instrumentalize human beings that has been cogently formulated by Kant in his Categorical Imperative. According to this rule human beings should never been treated exclusively as means for other ends, but always also as ends in themselves. A complete instrumentalization of patients is a particular danger in highly vulnerable groups such as CDC patients who cannot defend themselves in any way. It can happen in both directions: proxies or healthcare professionals may sustain life solely for their own purposes (be it financial, emotional or other purposes), and they may allow death merely for their own purposes (again these may be financial, emotional or other ones). Hence, it should always be paid meticulous
attention whether and how a decision respects the patient as the final end and not just as a means to further other ends.

Another consideration frequently mentioned by lawyers and theologians is the principle of proportionality. It has to be asked whether it is proportionate to sustain life of a CDC patient by using feeding tubes, cardiopulmonary resuscitation, large surgeries or intensive care measures. This requires a careful balancing of the pros and cons of all means for this end. The principle of proportionality forms the basis of the catholic differences between *remedia ordinaria* and *remedia extraordinaria* that was brought into the discussion by Pope Pius XII. According to this teaching, ordinary means like giving nutrition, hydration, nursing care and shelter are morally obligatory to help these patients, but extraordinary means like intensive care treatment, mechanical ventilation and resuscitation are not obligatory – not even to save life – because they may carry a disproportionate burden on the person or others. Ethically scrutinized, the distinction between ordinary and extraordinary means or natural and artificial means becomes highly questionable and some philosophers even argue that amounts to a natural fallacy. Moreover, medical nutrition and hydration via feeding tubes has to be classified, contrary to the Vatican’s traditional position, as an extraordinary means and not as an ordinary one. A tube might be easy to place and handle, but it undoubtedly requires medical skills and a surgical procedure and can have relevant adverse effects. The effect of prolonging life by decades in CDC patients who would have died before the invention of these feeding tubes actually argues against its ordinary nature and makes it a highly effective technique that should only be used with good reasons.

Finally, I would like to address another aspect that is often used in the context of end-of-life decision making and CDC patients. This is the rule *in dubio pro vita* that is frequently employed by judges, especially in Germany. It means that in cases of doubt the decision makers should tend towards sustaining life. The rationale behind this rule is that a pro-life decision carries fewer risks if it turns out to be wrong, because it is reversible (letting the patient die later) while the pro-death decision is not (resuscitating the dead patient is only possible within the first minutes). This is, however, only
roughly true, because even the pro-life decision is not fully reversible: If the pro-life decision turns out to be wrong, the time between the decision and realization of a mistake may have been associated with substantial unwanted suffering for both the patient and his family, and it might be the case that the opportunity to allow death has gone away if there was only a single life-sustaining procedure necessary, for example a life-saving surgery. Erroneous decisions to sustain life may also lead to increased suffering in the future, as in the frequent case of resuscitation. In addition, the rule *in dubio pro vita* can easily be misused, because doubt is a subjective category that can simply be alleged by the decision-maker. What is more, doubt is inherent in CDC as we can never be sure about the subjective presence of consciousness without adequate options of communicating with the patient. This would mean that the rule would apply in all cases of CDC and that, as a consequence, all CDC patients would have to be treated with life-sustaining measure indefinitely. This is surely a consequence that not even the proponents of this rule intend. The rule *in dubio pro vita* might be a *prima facie* rule of prudence that may be considered in addition to the ethical criteria, but it is can hardly be considered an ethical criterion per se.\(^4\)

*Summary*

As a summary, we have seen that CDC carry numerous ethical problems, but end-of-life decision making is the ethical problem that, for good reasons, has attracted most attention. Patients with CDC need diverse forms of life-sustaining treatment; most of them need artificial nutrition and hydration as a continuous form of life-sustaining treatment. End-of-life decision making needs reliable ethical criteria, but we have seen that the criteria of promoting patient wellbeing, respecting patient autonomy and considering justice arguments are not straightforward in CDC due to the nature of the disorder. Other considerations like the prohibition of instrumentalization, the principle of proportionality and the rule *in dubio pro vita* are only partially helpful and may only be regarded as second-order criteria. Ultimately, we cannot eschew making decisions, but we can at least ensure that the decisions are made
transarently, responsibly and after a careful assessment of all relevant ethical criteria and considerations.

**Literature**


