Chasing Certainty After Cardiac Arrest: Can a Technological Innovation Solve a Moral Dilemma?

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Abstract When information on a coma patient's expected outcome is uncertain, a moral dilemma arises in clinical practice: if life-sustaining treatment is continued, the patient may survive with unacceptably poor neurological prospects, but if withdrawn a patient who could have recovered may die. Continuous electroencephalogram-monitoring (cEEG) is expected to substantially improve neuroprognostication for patients in coma after cardiac arrest. This raises expectations that decisions whether or not to withdraw will become easier. This paper investigates that expectation, exploring cEEG's impacts when it becomes part of a socio-technical network in an

Intensive Care Unit (ICU). Based on observations in two ICUs in the Netherlands and one in the USA that had cEEG implemented for research, we interviewed 25 family members, healthcare professionals, and surviving patients. The analysis focuses on (a) the way patient outcomes are constructed, (b) the kind of decision support these outcomes provide, and (c) how cEEG affects communication between professionals and relatives. We argue that cEEG can take away or decrease the intensity of the dilemma in some cases, while increasing uncertainty for others. It also raises new concerns. Since its actual impacts furthermore hinge on how cEEG is designed and implemented, we end with recommendations for ensuring responsible development and implementation.

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Aim and Motivation

“My husband, Chris, had been alone since 9 am. We had almost reached home when he called me in distress ‘Where are you? I need you’. I immediately had this feeling; this isn’t right, this *really* ain’t right. We raced home as I said ‘Hold on. We’ll be home in three minutes.’ Meanwhile, my daughter called 911. Chris was

still sitting at the table when we ran in but as we reached him, he collapsed. My son and I started reanimation but Chris started vomiting and his head was quickly turning blue. I got really scared that he wasn't getting the oxygen we tried to give him through mouth-to-mouth breathing. It took the ambulance seven minutes to arrive. Reanimation took a long time and after several defibrillations and lots of medication, Chris was stable enough to go to the hospital. But even on the way to the hospital he had another cardiac arrest and more defibrillation." (Vanderbilt's wife)

Chris Vanderbilt remained in intensive care for weeks. An experimental neuroprognostic tool which was then still under investigation indicated a poor outcome yet, overall, neuroprognostication remained subject to a significant degree of uncertainty. The Vanderbilts managed to convince the physicians to continue treatment by pointing to video footage that demonstrated signs of consciousness, indicating that withdrawing life-sustaining treatment might arguably strip Chris of a viable chance. Even so, both family and treating physicians were aware of the danger continuation of care might hold for the patient and their quality of life; Chris could survive in ways he might consider worse than death.

The (im)permissibility of withdrawal or withholding of life sustaining treatment [1–3], as well as the difference between the two [4–10], have been extensively discussed in the philosophical literature. Since many countries legalized withdrawal of life-sustaining treatment (WLST) when treatment is considered futile, however, the ethical issues in those countries shifted to the level of medical practice, where they reappear in a more practical form. Medical professionals as well as relatives of patients in coma after cardiac arrest now have to answer the question 'Should we continue treatment for this particular patient or not?'.

Any answer to this practical question has to address two sub questions. On the one hand, one needs to know the minimum quality of life that should be achieved to make continued living worthwhile. In practice, our empirical study shows this normative criterion is usually inferred from what is known about a specific patient's wishes and values but it is also dependent on cultural and political context [11].

On the other hand, information is needed about the chances that a particular patient will be able to attain that minimum level – that is, about a patient's prognosis. As seen in the example above, current prognostic practices for patients in coma after cardiac arrest show that if a patient's prognosis is uncertain or lacking, the option to discontinue care has created a moral dilemma. Medical practitioners and families are forced to choose between two potential harms: continuing care with the risk that the patient will survive with unacceptably poor neurological prospects, or withdrawing care with the risk of allowing the patient to die, never knowing if they could have recovered.

It need not surprise, then, that there is a strong urge to reduce the uncertainty underlying this dilemma by developing and further improving neuroprognostic tools. In the case of prognostication of patients in post-anoxic coma, continuous electroencephalogram (cEEG) monitoring was recently shown to reduce prognostic uncertainty. It not only provides reliable predictions of poor outcome, but also enables a robust predictor of good outcome [12–15]. The promise of increased certainty also raises expectations regarding care. If results are more certain, they might (a) provide more clear-cut information for medical professionals, (b) offer better guidance for decision-making, and (c) be easier to communicate to relatives.

Obviously, a reduction of prognostic uncertainty is desirable, especially given the high stakes. Moreover, it might indeed positively impact professional understanding, decision-making processes, and communication. However, past research from philosophy of technology and science and technology studies has shown that new technology usually does both much more than, as well as things different from, what it is intended to do [16–20]. These broader impacts can furthermore considerably influence the societal and ethical acceptability of a new technology. In this article, we therefore explore the broader, unintended effects of cEEG-monitoring on care practices in intensive care units (ICUs) and conclude with an inventory of issues that need to be addressed to ensure responsible development and implementation of cEEG.

We first introduce current practices of prognosticating for patients in coma after cardiac arrest and the promise of cEEG monitoring and then provide more background regarding our theoretical framework and methods. We subsequently discuss our findings, which roughly cluster around three themes:

the construction of patient outcomes (a); the decision support provided (b) and the communication of results (c). We show that in each case the increase in certainty that cEEG offers comes at the cost of newly emerging uncertainties (often of a different type) elsewhere. We end by discussing implications for the design and implementation of cEEG in the ICU.

Neuroprognosticating Postanoxic Coma: Old Tools and New Ones

For about nine in ten patients, out of hospital cardiac arrest (OHCA) is lethal [21, 989]. Patients who are successfully resuscitated usually remain unconscious in *postanoxic coma*, meaning coma after oxygen deprivation. When these patients arrive at the ICU they are sedated, intubated, and their body temperature is often controlled to prevent fever which could otherwise further brain damage (989). About half of these patients survive with favourable neurological function (989). Valid neuroprognostication is vitally important because patients who die after the first twenty-four hours, mostly die from WLST in anticipation of severe neurological damage (989, 994).

Existing neuroprognostic indicators commonly include the pupillary reflex test, the corneal reflex test, and the Somato-Sensory Evoked Potential (SSEP) test.¹ These must be performed at least 72 h after the arrest (991). All three tests look for a response from the patient: changes in pupil width after a light stimulus, movement of the eyelid after a touch stimulus, and electrical activity in the brain after an electrical stimulus of the wrist, respectively. If such responses are bilaterally absent, recovery is highly unlikely. However, these tests only predict poor, not good outcome and only for up to half of patients with poor outcome [22–24]. In practice this means that in the vast majority of cases, relatives are told to ‘wait and see’ whether a patient will wake up.

Several studies have shown the added value of EEG-monitoring. Highly malignant EEG after 72 h reliably predicts outcome for half of the patients with poor outcome [25]. Furthermore, the addition of cEEG enables an overall prediction for up to half of *all* patients, in some studies as soon as 12 to 24 h after reanimation [12, 14, 15]. The increase in predictive capacity is largely due to cEEG’s ability to predict good outcome.

The cEEG-based test requires that non-invasive sensors are attached to the patient’s head, preferably as soon as the patient arrives at the ICU. These sensors register electrical activity in the brain. The registrations are stored and represented in the form of graphs on a monitor. This monitor may be at the bedside or available off-site. In order to predict good and poor outcomes, interpretation of the cEEG graphs requires that specific patterns are identified. This can be done in three ways:

- (1) qualitative: through visual observation by a doctor (typically a neurologist);
- (2) computer-assisted: using human extracted quantitative features to create manmade algorithms which translate the specific features into a prognostic score;
- (3) machine learning-based: (a) including traditional machine learning in which predictive models are created after explicit features were provided (b) including deep learning techniques in which a neural network is trained to independently predict without being fed explicit features.

The third option has only emerged very recently [26, 27]. The predictive value of cEEG slightly varies depending on the mode of interpretation. Recent publications suggest that computer-assisted interpretation is better at predicting outcomes than visual interpretation, while machine learning techniques may eventually outperform both [26–28].

In sum, cEEG-monitoring seems to have several advantages. Its addition to existing prognostic tools allows for:

- increased reliability of prognostication of poor outcome
- prognostication of good outcome
- a faster provision of the prognosis (at 12 or 24 h, instead of at 72 h)

¹ Other imaging technologies like CT and MRI as well as biomarkers (eg neuro-specific enolase, protein S-100B, and the axonal injury marker tau) can be used to complement the multimodal prognostic assessment but should not be used in isolation [21].

Based on the evidence available, cEEG monitoring was recently considered sufficiently robust to be included in the Dutch clinical guidelines for prognostication of patients in post-anoxic coma [29]. Other countries also increasingly include cEEG in their multimodal prognostication [30].

Technology: its Performativity and Architecture

Inclusion of the technology in guidelines does not imply that seamless integration in practice will follow automatically. Technology assessment for the development of clinical guidelines tends to focus on a narrow set of outcome measures, linked to the technology's intended purpose [31]. In the case of prognostic technologies, validity, reliability, and predictive value are considered most important in the decision to implement. As research in science and technology studies (STS) has amply shown, however, technologies tend to do much more than intended. They are *performative* [32–37]: while aiming to measure aspects of the world, they also reconfigure that world. For instance, as we shall demonstrate in this article, when measuring the state of a patient's body, technologies also reconfigure the interaction between a patient and a doctor, the way health is experienced, and even the concepts of health and disease themselves.

Several concepts put forward in STS highlight these performative effects. First of all, Akrich pointed out that technological devices have a *script* that defines, among many other things, roles and responsibilities of users, what type of actor can be a user, and what values are important [16]. Moreover, these devices need to become embedded in sociomaterial networks to fulfill their function. As Parthasarathy [18, 38] has shown, what a test actually is and does depends on the way it becomes embedded in such a network. Rather than asking how a test impacts medical and social practices, we should ask how a new testing modality and existing practices *configure each other* and lead to new *testing architectures*. Finally, answers to these questions are not always straightforwardly available when the more complex parts of the technology are black boxed and only input and output are visible [39]. We must therefore unpack,

as much as possible, the ways in which inputs are turned into outputs.

When considering the desirability of new technologies, the point is that desirability does not depend only on the effectiveness with which intended aims are realized. Rather, overall impacts on clinical and social practices are crucial. To enable timely reflection on the social and ethical desirability of cEEG-monitoring, we must investigate the performative effects of cEEG in practice.

Fieldwork: Practices and People

Investigating cEEG in practice is possible by looking specifically at ICUs that have already installed cEEG for research purposes. Although cEEG-based information in these contexts should not be used for prognostication due to its experimental status, such *liminal innovation practices* [40] already show how the technology influences—and is itself influenced by—the sociomaterial network it becomes part of. Thus, Mertens conducted ethnographic fieldwork in two Dutch hospitals and, in order to contextualize the findings in Dutch practice, one hospital in the United States.² All three hospitals had introduced cEEG-monitoring for postanoxic patients for research, before it was included in guidelines for clinical decision-making. Over twenty patient cases were followed and analysed and four were selected for in-depth analysis. This particular selection was motivated by the empirical insight that concerns greatly varied depending on the predicted outcome, and even more so in retrospect, when compared to the actual outcome. The four selected cases thus aimed to capture the widest possible diversity³ in, and combinations of, predicted and real outcome (see Table 1), as these variations offered the greatest variety of concerns.

² We do not compare the neuroprognostic practices of the NL and the US as a whole. By only comparing the US practice with regard to the way it implements cEEG as part of the liminal innovation practice, the comparative component in this article is substantially limited.

³ Our study contained only one case where cEEG predicted a good outcome, when the actual outcome was poor. However, the death of the patient was not due to neurological damage and therefore, it was not included for in-depth analysis.

Table 1 Predicted and actual outcome of the 4 case studies (*patient names were changed)

Cases	Prediction based on existing practice	cEEG-based prediction	Actual outcome
Reinhart	poor	poor	passed away after withdrawal of life support
Willems	good	good	lived without severe neurological damage
Vanderbilt	uncertain / optimistic	poor	lived with severe neurological damage
Felts	uncertain / pessimistic	poor	lived without severe neurological damage

To limit contextual variety for comparative purposes, all four cases were taken from the Dutch settings. Since cEEG was part of the research practice, the standard care protocol was followed for decision-making regardless of the outcome predicted by cEEG. Where relevant, we expand the comparison with the US practice.

For each case, Mertens held open, semi-structured interviews with the healthcare professionals involved, surviving patients (when possible), and family members. Twenty-five respondents were interviewed, including four intensivists, five neurologists, two rehabilitation doctors, one IC-nurse, one technician, two patients, four partners of patients, and five of their children. Several medical interviewees were also key contributors to the development of cEEG as a prognostic tool. We obtained informed consent from all participants. All interviews were transcribed, personal data were anonymised, and names changed. Approval was granted by the Ethics Committee of the University of Twente and approved by the individual hospitals' ethics boards.

All data were analysed in Atlas-ti, combining inductive and deductive coding. The starting point was the question: "what are people concerned about?" Initially we coded inductively, allowing matters of concern to emerge from the data. Once we developed a list of concerns, we analysed mostly deductively. For this article, we focused primarily on concerns related to the new prognostic technology. Additionally, the observation reports and interviews comprised the basis for conceptual analysis of the technology's performativity. For valorisation purposes, we presented our findings to an expert panel and organised a multi-stakeholder workshop. Participants' responses were included in the data set.

cEEG in Practice: Challenges and Unintended Effects

We clustered our findings into three groups, each relating to expectations raised by the increased prognostic certainty cEEG offers:

- test results will offer more clarity about a patient's neurological state (a. facilitating interpretation)
- decision-making on individual cases will be easier (b. facilitating decision-making)
- communication with relatives will be easier (c. facilitating communication)

In all three respects, our observations of how cEEG works out in practice indicate that the technology does not fulfill these expectations in a straightforward way.

Facilitating Interpretation (a)

As indicated above, current prognostic tests for postanoxic coma have low predictive value. The evidence available shows that the addition of cEEG improves predictive value and may thus reduce uncertainty. When inquiring how the results of cEEG are produced in practice, however, it became clear that in the process many other uncertainties emerge that need to be addressed. Moreover, the resulting practices inevitably, yet invisibly, embed specific norms and values. In what follows, we will unpack both issues by reconstructing what is required to produce cEEG-based test results.

Identifying Patterns

Prognostication based on cEEG-monitoring requires identifying patterns. The evolution of patterns over

Table 2 Categorization of cEEG-patterns to prognosticate patients in postanoxic coma—in Dutch scientific research

Pattern name	Amplitude	Dominant frequency	Characteristics or other distinctions
Iso-Electric	/	/	No brain activity recorded (flatline)
Low Voltage	< 10 microvolt		Amplitude of signal is low
Burst suppression	< 10 microvolt & bursts > 10 microvolt		Identical and non-identical bursts are above 10 microvolt, rest is suppressed
Diffusely Slowed	> 10 microvolt	< 8 Hertz	Normal amplitude, but frequency is lower than normal
Normal	> 10 microvolt	> 8 Hertz	Continuous activity, normal amplitude and frequency
Generalised Periodic Discharges (GPD)	Epileptic activity		Discharges occur simultaneously on all channels and at regular intervals
Epileptiform	Epileptic activity		Constant epileptic discharges

time will form the basis of the prediction. It is not obvious how these patterns should be distinguished, however. EEG merely registers electrical activity in the brain. The main variables researchers look at are amplitude and frequency of the electrical activity, as well as (ir)regularities. This process can lead to different categorizations of patterns. Table 2 summarizes categorizations used by the researchers in the practices we observed.

Willems' neurologist, also a cEEG researcher, explains:

"I have to add that these categories, to an extent, they're arbitrary. This is just what *we've* come up with. It isn't so that these are *the* generally accepted categories in which you can classify the EEG for this patient group, but rather *a way* of categorizing."

He added that there is, for instance, disagreement whether or not to distinguish between GPD and epileptiform. The relevant categories have thus not been fully standardized yet. Other research groups, for instance in the US, Italy, and South Korea, use slightly different classifications [14, 41]. Accordingly, there is uncertainty regarding whether the patterns currently used are the most informative ones. There may also be other patterns that have not been identified yet.

Classifying EEG-Measurements

Interpreting the cEEG-measurements also poses challenges. Traditionally, EEGs are interpreted in a qualitative way by looking at the graphs. However, both

interrater and intrarater reliability for visually interpreting EEG-patterns are generally low [42, 43]. In our interviews, this was acknowledged as a challenge for cEEG-based prognostication:

"The expectations are really high, while in daily practice... Don't forget, the average doctor isn't capable of interpreting this machine. [...] Our experience shows that even an average neurologist can hardly interpret." (Willems' intensivist)

In the ICU's studied, this issue was not that pressing; clinician-researchers (in all cases neurologists) specialised in cEEG were available. However, this definitely will not be the case when cEEG is implemented in non-research hospitals.

Additionally, it was clear from our observations that even experts go about interpretation in different ways. Dutch clinician-researchers would be called to the ICU to interpret the raw cEEG-patterns by the bedside, or look at them remotely in their offices. Either way, they visually assessed the activity at 12 and 24 h after cardiac arrest. There is no standard procedure for this evaluation. The US clinician-researchers, in contrast, scroll through all data of the entire 12 h that preceded their shift in an offsite lab. Unusual patterns, spikes, and flat parts are studied more closely. Thanks to the addition of video monitoring, they can observe the corresponding activity at the bedside. Next, for all cases they take a 2 h interval they consider representative and analyze it in detail. Finally, interpretations are discussed in detail as a team.

Obviously, the American procedure is very time-consuming, labour-intensive, and hard to implement

Table 3 Cerebral Performance Category Scale and outcome classification

CPC	Activity level	Classification
1—Full recovery	Conscious. Can lead normal life and work. May have minor deficits	Good
2—Mild Cerebral Impairment	Conscious. Cerebral function adequate for part-time work in sheltered environment, or independent activities of daily living	Good
3—Severe Cerebral Impairment	Conscious. Dependent on others for activities of daily living	Poor (roughly since 2006); Good (before 2006)
4—Coma or vegetative state	Not conscious. No interaction with the environment	Poor
5—Death	Brainstem dead or dead by traditional criteria	Poor

in non-research hospitals. Dutch researchers are therefore seeking other solutions. They hope to reduce interrater and intrarater reliability through computer-support. Advantages of automated analysis are standardization and efficiency. Broadly speaking, there are two ways computers can be used to analyze the data from cEEG monitoring. One is as an aid to quantify differences among measurements, using pre-set rules, specified by human researchers [28]. The other is based on machine learning techniques that allow the computer to identify regularities programmers did not anticipate. Thus, machine learning may potentially address the challenge regarding the comprehensiveness and precision of the list of patterns mentioned in the previous section. Recent publications show that machine learning techniques could further increase the ability to accurately predict neurological outcome after cardiac arrest, thus reducing uncertainty for an increasing number of patients [26, 27, 44, 45]. A major problem with unsupervised machine learning techniques, however, relates to transparency [46, 47]. Human experts can check whether they come to the same conclusion in particular cases by looking at the patterns themselves but they would not know *how* the computer produced the prediction. Moreover, machine learning is prone to exacerbating self-fulfilling prophecies⁴ due to feedback loops. The problem of self-fulfilling prophecies in neuroprognostication requires in-depth analysis which we present elsewhere [11, 48].

⁴ Self-fulfilling prophecies are recognized to be a general problem in intensive care [56] and in neuroprognostication specifically, especially for patients after cardiac arrest [57, 58]. Discussing, in this article, the ethical and epistemic challenges they pose will take us too far afield but we discuss these problems elsewhere [48].

In summary, the work involved in classifying EEG-measurements requires expertise that will not be generally available. This poses serious challenges for the reliability of the resulting predictions, which researchers hope to tackle by developing computerized assistance. Depending on the technique used, such computer support may have challenges of its own.

Linking Measurements to Outcomes

The last step in producing a cEEG-based prognosis is linking EEG measurements and their development over time to neurological outcomes. Here, the first thing to note is that cEEG-based prognosis (like other prognostic technologies for this patient group) uses only two outcome categories: ‘good’ or ‘poor’. When researchers call surviving patients after 6 months or one year to check their neurological functioning, they often register outcomes in terms of the 5 categories on the Cerebral Performance Categories-scale (CPC, see Table 3 above). This scale classifies functioning on five levels, which are dichotomized for prognostic purposes. Recently, there have been pleas to shift to more fine-grained scales when measuring neurological functioning in research on outcomes after cardiac arrest [49–51]. However, since it is not possible to link cEEG-patterns to the 5 categories of the CPC-scale, let alone to more fine-grained categorizations of outcome, results are reduced to two classes: good or poor outcome.

Evaluating outcomes in terms of ‘good’ or ‘poor’ clearly represents a value judgment, in this case pertaining to a patient’s future neurological state. Interestingly, as Sandroni et al. [22, 151] show, the criteria used internationally to distinguish good from poor

have changed over time (see Table 3). Whereas in the past CPC 1–3 were classified as ‘good’ outcome and CPC 4–5 as ‘poor’, CPC 3 in the scientific literature and clinical practice guidelines has gradually come to be perceived as ‘poor outcome’ [52]. As such, ‘poor outcome’ before 2006 was generally understood as referring to vegetative state and death, ‘good outcome’ usually referred to normal functioning and moderate and severe neurological disability. After 2006, most studies included severe disability in ‘poor outcome’. This particular change suggests a shift from ‘regaining consciousness’ as the main criterion distinguishing good and poor quality of life, to recovering sufficient cognitive and motoric capacity to allow independent daily living.

This points to the question of who should determine what counts as ‘good’ or ‘poor’ quality of life, and how to draw the line between the two. Since the shift visible in research also fed into clinical guidelines, it represents at least a change in medical-professional norms. It is less clear to what extent this professional change reflects a broader shift in societal norms. The results of a national survey presented elsewhere at least suggest that there may be a divide between clinician and public perspectives [11]. Even if the shift reflected the norm, such a shift was probably more clearly present in some countries, rather than others. Clearly, there is ample room for interesting historical research here.

In summary, even though cEEG-patterns enable reliable classification of more patients, the categories ‘good’ and ‘poor’ still cover a wide range in outcomes – as they do with existing prognostic technologies. Moreover, the boundary between the two is not self-evident and has changed over time. Predicting how a patient will experience the neurophysiological outcome is far from straightforward, even with cEEG-results predicting what that outcome will be [11]. Rather, the binary outcome measure obscures that outcomes vary in several respects, for example, with regard to mental and physical functioning. Moreover, it obscures that outcomes can be evaluated differently. While these remarks are not specific to cEEG, they do put the hopes raised by cEEG in perspective.

In conclusion:

- Prognosis based on cEEG faces several limitations and uncertainties due to arbitrary pattern identification and variation in interpretations of patterns, which make its use far from straightforward.
- In practice, these limitations and uncertainties are addressed by (1) developing extensive interpretation practices requiring expertise and time which are not widely available, or by (2) developing computer support, the workings of which may not be fully transparent to users and which may be hampered by feedback loops – all of which challenge the reliability of the technology. This implies, as Parthasarathy [18, 38] also showed in her discussion of BRCA-testing in the USA and the UK, that there is not one ‘cEEG-based prognostic test’. Rather, different countries make different choices in how to organize cEEG-testing, particularly with respect to the roles and responsibilities ascribed to medical professionals and, more recently, to machines. The various distributions of roles and responsibilities, in this case, are different responses to the epistemic uncertainty involved in translating cEEG-patterns into predictions of a patient’s future functioning, which do not seem shaped so much by national political culture (as in Parthasarathy’s study) but by differences in ethical culture.
- Interestingly, however, differences in ethical culture are not visible in the way evaluations of predicted outcomes have been inscribed in the technology. cEEG-patterns are classified in ‘good’ and ‘poor’ outcomes in the same way everywhere, although the boundary between the two changed over time. Since the basis for this evaluation is not visible, cEEG, like other prognostic technologies in postanoxic coma, has an inherent normativity that is not transparent to users.

Facilitating Decision-Making (b)

We discussed how cEEG-monitoring produces predictions of ‘poor’ or ‘good’ quality of life. Importantly, results are often uncertain. Our fieldwork suggests that, even though cEEG definitely provides prognostic information for substantially more patients, the connection with decision-making for each prognostic result is far from straightforward. Below, we highlight why this is the case for each type of outcome respectively.

Responding to ‘Poor’ Outcomes

Decisions about whether or not to withdraw life-sustaining treatment requires a combination of normative criteria and predictive information [11]. The former entails the question ‘What is a life worth living?’ The latter requires answering ‘What neurological outcome is to be expected for this particular patient?’. Above, we showed how cEEG-monitoring provides the second type of information but also implies a specific norm as to what is or is not a life worth living. To be clear, in no way does this imply that this specific norm is automatically applied to all patient cases. Physicians have to make a dedicated effort to clarify how the patients themselves would value their life with particular limitations.

Legal declarations of which actions should be taken when the person in question can no longer express their wishes can be very helpful. However, since such advance directives are often missing, relatives are usually the most important source of information in this regard. The patient may have explicitly discussed their preferences. Mr. Reinhart, for example, had talked extensively about his views on a life worth living. His son recounted that any physical disability was a price his father would be happy to pay if it meant more time with his family. His father made it clear though, that if he would no longer recognize his wife or children, if he would lose the memories of who they were to him, they *had* to let him go. To him, that seemed a fate worse than death. His wife added that his wish made it impossible for her to keep him alive even if she wanted to. She felt that would be selfish. Such clear statements are often missing, however. Family and physicians then resort to reconstructing a patient’s preferences from their more general views of life and previous experiences.

It is clear that cEEG cannot, and does not aim to, solve the problem of how to infer which choices a patient would have made in this particular situation. However, regardless of how sure relatives are about what a patient would have wanted, connecting these views to a cEEG-based prognosis may be challenging. Our observations indicate that both patients and relatives tend to think about (un)acceptable quality of life in different and in more nuanced terms than cEEG-monitoring allows for. This is clear in Reinhart’s case, who made a distinction between physical and cognitive or emotional capacities. Similarly,

Willems insisted that interaction with others was most important to him. Losing the ability to express himself, to have meaningful exchanges, he no longer saw the point to go on living.

Both Reinhart and Willems thus had very specific damages in mind that to them would make continued living unacceptable. This nuanced way of thinking emerged quite frequently in our interviews and observations [11]. Yet, even when referring to the underlying categories of the CPC and abstaining from the normative judgment of what is a poor or a good outcome, the CPC categories do not allow for distinguishing among different types of damage that are described by the patients above. CPC3, in particular, covers a very wide range of function losses. Thus, the type of outcome predictions offered by prognostic technologies, including cEEG, would not offer the qualitative information that our respondents are looking for.⁵ For now, the precision that our respondents are interested in cannot be provided. In practice, this implies that medical professionals have to put a lot of effort into explaining what a poor prognosis actually predicts.

Summing up, when cEEG predicts poor outcome, this does not provide the type of information that allows linking the prognosis to patients’ and relatives’ views of a life worth living. The technology, like all other available prognostic tools, thus facilitates decisions about whether or not to withdraw life-sustaining treatment in a fairly limited way.

Responding to ‘Good Outcome’

One of the specific advantages of cEEG is that it offers early and robust prediction of *good* neurological recovery. The recently published new Dutch national guideline for postanoxic coma states that “although this information does not yet yield treatment decisions, it is of great value to the treating physicians and the family of the patient” [29].

The value referred to concerns, first of all, the knowledge that the patient is likely to recover. This information justifies continuation of life-sustaining

⁵ We are not suggesting that these distinctions are necessarily informative for normative arguments about whether or not to discontinue someone’s life support. Our focus lies on the concerns and considerations that surface in practice, regardless of whether these lead to morally justifiable decisions.

treatment, thus pre-empting the need to consider whether or not to withdraw it. This relieves both physicians and relatives from the heavy burden discussed in the previous section.

Second, our study showed yet another way to use good outcome predictions. Many medical respondents indicated they see it as their duty to provide sensible care. One respondent specified that aggressively treating infections or organ failures in a patient who may remain in vegetative state seems nonsensical to them. Our clinical observations revealed that in case of a good prognosis, in contrast, intensivists find it self-evident to treat these ailments more aggressively.

In the same spirit, good news could result in more proactive care decisions aligning with the prediction, such as stopping the cooling and sedation and aim for early awakening. Several medical professionals suggested that research ought to be done on the benefits of early awakening of patients with a good prognosis.

In a nutshell, rather than ‘just’ being good news, cEEG’s capacity to predict good neurological outcome has multiple values for decision-making. It justifies continuation of treatment and preempts the need to decide about the life and death of the patient. Moreover, the health professionals among our respondents indicate that there may be unexplored potential regarding treatment decisions for these patients.

Responding to Uncertain Outcomes

An additional, yet unexpected, effect of cEEG’s capacity to predict good outcomes is that cEEG now also creates a more distinctive category of ‘uncertain’ measurements. Existing tests produce a prediction half of the time but only for patients with poor outcome. For the majority of cases they do not produce any prediction and for those patients, the advice is always to ‘wait and see’.⁶ While cEEG does not allow for a prediction in only half of *all* cases approximately, the meaning of the failure to provide a prediction is likely to be different in a number of ways.

First, the meaning of uncertain results in case of cEEG is qualitatively different because uncertain

now implies ‘neither clearly poor, *nor* clearly good’, whereas before the lack of a positive test result meant merely ‘not clearly poor’. Even though physicians in these latter cases try to temper premature optimism by making explicit that the lack of a positive test result is not necessarily a good sign, families nevertheless experience the message of ‘wait and see’ as positive. This is due to the impact a positive test result has, namely, withdrawal of life-sustaining treatment and, subsequently, the death of the patient. The fear and anxiety in anticipation of such bad news fall away temporarily. Vanderbilt’s wife, for instance, was told that if the SSEP-test predicted poor outcome, medical treatment had to be stopped. When that wasn’t the case, she said: “That was again a positive, very weakly positive, sure, but nevertheless, in the sense that the continuation of medical [treatment] could take place.” There is a signal, and even if it’s hard to say what that means, there is reason for hope: at least it is not ‘clearly poor’. With cEEG’s ability to predict good outcomes as well, even if the advice for uncertain cases will still be to ‘wait and see’, it structures the anticipation of possible outcomes in a different way – for both physicians and relatives. The continuous character and the visibility of the EEG-measurements also contribute to this, as we will discuss in the next section.

Second, the composition of outcomes in the ‘uncertain’ category changes depending on how many good and poor outcomes can correctly be identified. Although ultimate survival to discharge rates show substantial international as well as regional variation [53, 54], chances of functional survival after successful reanimation and admission to the ICU, at least in the Netherlands, are more or less fifty-fifty [15]. This means that without prognostic information, outcome in all patients is uncertain. About half of these patients will have a poor outcome and the other half will have a good outcome. Once predictions can be made for *some* patients, the ratio of good to poor outcome expectancy for the remaining patients changes.

Before cEEG was implemented the SSEP-test was able to identify 30–48% of patients with poor outcomes [22–24]. Overall this implies outcome could be predicted for 15–24% of all patients. Let’s take the most optimistic view, which is that poor outcome can be predicted for nearly a quarter of the total population, leaving the prospects of the remaining three quarters of the population uncertain (see Table 4). Uncertain at that point means there is up to twice as

⁶ Technically, this strategy can also be understood as a form of ICU-test [59] or time-limited trial of intensive care treatment (TLT) [60, 61] but this was never communicated as such. Other studies confirm this is not unusual. Even when offered, TLTs are typically not sufficiently discussed [62].

Table 4 Prediction ratio, outcome prediction (good/poor) versus no outcome prediction (ratio good/poor)

Prognostic ratio	Good / Poor outcome	Uncertain outcome (ratio good + poor)	
No prognostic tools	0% / 0%	100%	= 50% good + 50% poor
SSEP	0% / 24%	76%	= 50% good + 26% poor
cEEG	25% / 25%	50%	= 25% good + 25% poor

much chance of recovery than there is a chance of poor outcome. These chance calculations (which may include estimates based on length and circumstances of reanimation) are relevant in cases where no neuro-prognostic information is available—as with patients in the intermediate category—simply because a decision is eventually made based on probability.

With the introduction of cEEG, however, filtering out both poor and good outcomes in equal measure means that chances of recovery for those with uncertain results are back to fifty-fifty. In essence, by filtering out both good and poor outcome, cEEG increases the ambiguity for patients in the uncertain category to the situation before any neuroprognostic tests existed. While these shifts in probabilities do not change the actual outcome of an individual patient, they can increase or decrease the clinical dilemma, making decision-makers more or less confident about what to do. In practice, all uncertain cases are considered equally uncertain, and relatives are still told: “We don’t know, we must wait.” However, as we’ll see in the next section, both predictive and uncertain measurements are prone to invite interpretation, depending on how visible the continuous measurements are. Their ultimate impact will depend on how and to whom uncertain results are made visible.

Finally, the question arises whether cEEG does not also filter out the very worst and the very best. Patients for whom cEEG does not provide predictive results (‘not clearly good, nor clearly poor’) may also be the patients with the most ambiguous *kind* of damage, for example, limited cognitive capacity, including a limited sense of personhood, while retaining motoric function. Since this is a hypothesis, further research into the long term outcome of patients for whom cEEG does not produce a clear prediction seems advisable. One cEEG researcher we spoke to confirmed they would be interested in conducting such research. If the hypothesis would be confirmed, this would justify the development of dedicated care approaches for this particular group of patients and their relatives.

Summing up, cEEG does not only predict good and poor outcome. It also creates a third group of patients, for whom the lack of cEEG results actually increases ambiguity and may decrease hope, even though treatment policy does not change. Pending further research, specific support for the relatives of patients in this group may be warranted.

In conclusion, with regard to facilitating decision-making, cEEG does both more and less than initially expected:

- Although it increases the reliability of predictions of poor outcome, it does not provide the detailed information stakeholders need for well-considered decision-making on WLST.
- On the other hand, cEEG’s predictions of good outcome *does* impact treatment and may enable even more directions for moving forward than currently acknowledged, for instance, by allowing early awakening or active neurostimulation.
- Finally, cEEG distinguishes a third category of patients for whom the anticipated future becomes more ambiguous than before the introduction of cEEG. In particular, this latter effect is a good example of the performative impact testing technologies have on the stratification of patients. Moreover, it shows how this performativity comes with ethical challenges that need to be addressed in the design of the overall testing architecture. If pursuing increased certainty for all comes at the cost of creating more (and possibly different) uncertainty for some, reconsideration of current architectures seems required. Different elements of the architecture can be adjusted to deal with this novel uncertainty. As we will discuss in the next section, whether decision-making about the intermediate group requires dedicated support largely depends on how the information about this category is made available to relatives and physicians.

Facilitating Communication (c)

Aside from expecting cEEG to facilitate interpretation and decision-making, it seems reasonable to expect that communication with relatives about the patient and how to proceed will become easier once there is less uncertainty. Yet, our fieldwork shows, once again, that actual impact on communication practices may be more complicated and ambiguous than first anticipated. The continuous character and bedside location of the EEG measurements in particular pose specific challenges. Two aspects deserve further discussion: the visualization of measuring results as well as the timing of communication.

Visualization of Results

Any presentation of results will inevitably have an impact. As such, no presentation of information is ever completely neutral. Available information *will* be interpreted, and this influences decision-makers' expectations and, ultimately, their decision-making process. It is therefore crucial to consider how exactly specific presentations may help or hinder accurate interpretations and good patient care.

Traditionally, EEG measurements are visualized in graphs on a monitor. The use of continuous EEG implies that the monitor displays results in real time, like many other instruments at the ICU do. These may be the traditional graphs (considered 'raw data'), analyzed data, or both. The monitor can be at the bedside or elsewhere. The first thing to note here is that *if* the monitor is visible for anyone who happens to be at the ICU, as it was in one of the hospitals where we observed, this unavoidably invites interpretation. Willem's wife recounts:

I received no explanations. But I'm quite stubborn, so I go and look at the machine, to see, what does this do exactly? And I *got* that all we can do is wait at that point. They said so, too. But I also figured, if there's brain activity everywhere, even if just a little bit, then that is at least *something*. I mean, the moment I would see straight, flat lines, I would have rung the bell and told the doctor 'Hello, there are 3 straight lines here, that doesn't seem right to me. Either that thing is not connected very well, or there's no activity. But I would've appreciated getting a bit more explanation.

What interpretations are invited and what impacts they have depends on the way the monitor visualizes results. This part of the technology's design was still in development when we did our fieldwork, so we reflected on the different options considered by the software developers and discussed them in a multi-stakeholder workshop. As mentioned above, tech developers aim to increase intra- and interrater reliability of EEG interpretation via quantitative analysis. This generates a number of choices regarding the representation of the results on the screen. They can be displayed graphically or with a number, in real-time or refreshed at pre-set moments. Interpretation can be facilitated by using colour coding. Each choice has specific implications.

Visualization furthermore inscribes who can use the information offered. The developers consider it desirable to extend the potential user group beyond the neurologist, as this facilitates implementation of the technology. Most hospitals have the equipment for EEG measurements, but they may lack sufficient neurological expertise. Simplifying the display of patterns means that other users besides the neurologist can make sense of the screen, like the intensivist, nurses, and other medical professionals—but also relatives.

In addition, simplification can be achieved in different ways, with different effects (see Fig. 1). When the display indicates that the pattern matches a pattern considered relevant (for example by colouring epileptiform patterns blue), it enables a first *descriptive* layer of interpretation by differentiating among a variety of patterns, without implying how to use this information. It still takes an expert to grasp what meaning these distinctions have and how to put them to use. When the visualization distinguishes patterns of a quantitative indicator (like the Cerebral Recovery Index (CRI): a number indicating chances of recovery [26, 28]) indicating 'poor' and 'good outcome', it is *predictive* and already invites prognostication, which no longer requires specific expertise. Finally, designs using a traffic light model to distinguish outcomes tend to have a *prescriptive* effect. The colours convey 'stop', 'continue', or 'caution'. Now the technology *tells* the user what to do with the patient.

The version we observed in practice combined display of raw, real time cEEG measurements with options for researchers to pull up other features like the graphical display of the development of the CRI. The developers were considering the use of red and green zones to distinguish good from poor results,

When we discussed our analysis of design options with a panel of experiential experts, we received conflicting input. Two ICU-nurses criticized the idea of prescriptive visualisation. They were worried that families seeing a curve in a red zone would jump to conclusions. They warned that it would likely raise a lot of worries and additional questions, giving the nurses more work. In contrast, the neurologist and intensivist initially argued that the sooner the family is aware of the critical situation, the better. Yet, when

Another potential effect of visualization is that the ‘uncertain’ results become more visible than before and are more likely to be interpreted as having an ‘intermediate’ prognosis. This may reinforce relatives’ (often already present) tendency to look for ‘proof’ of a patient’s improvement.⁷ In Vanderbilt’s case,

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the family made a video of the patient. It showed the father lying in bed, reaching out to his daughter with his arm, seemingly attempting to stroke her face. The family showed this video to the intensivist, who then responded, seemingly convinced by the ‘evidence’, by saying: “The truth is lying in bed”. Hence, care for the patient was continued. The doctor’s response returned repeatedly in the interviews with Vanderbilt’s partner and children. It was the point they remembered as winning a negotiation process. When the monitor visibly indicates an uncertain outcome, this explicit ambiguity invites a desire to postpone WLST and such negotiations may actually become more frequent. All medical professionals we spoke to agree that trust and rapport between the physician and family is crucial to reach agreement on treatment decisions. Yet, the visibility of uncertainty suggests that uncertain cEEG-based prognoses are a third explicit result next to the good and poor results rather than no result at all (merely implying ‘yet to be determined’). As our example shows, explicit uncertainty can stall expert decision-making and lead to negotiations that undermine the relationship between physicians and family.

Visualization may also *hide* certain aspects from view. In particular, the source of the analysis is not visible on the screen. For instance, an interface using color-coding could represent a human steered analysis based on preselected features and predefined algorithms, or it could be based on deep learning. The interface would look exactly the same. As such, the epistemic difference between the two is opaque to the user. The same goes for the CRI, which is represented by a number ranging between 0–1.⁸ Initially that number reflected as much as possible the experts’ understanding [28]. It was then further developed using machine learning training [26] and most recently is based on deep learning techniques [27, 44]. Although these interpretative processes are significantly different, the CRI user is currently not made aware of this.

Clearly, different visualizations offer different functions, with different degrees of transparency for different people which impact how users understand, communicate and use the results. Since different stakeholders will value different functions of the

technology, tradeoffs may be hard to avoid here. As a start, designers need to consider whether *everything* should be communicated to *everyone*, for *all three* outcome types, in the same *way*, at the same *time*.

As the family members we interviewed indicated repeatedly, the *way* bad news is delivered is key. Doctors and nurses in an ungarded moment commenting on a patient’s state can cause traumatic experiences. However, medical professionals can be attentive and responsive to relatives’ needs in a way a display never is. Likewise, when medical staff communicates positive news, they can contextualize and add nuance to the prediction, guarding recipients for disappointment, in ways that color-coded graphs on the monitor can’t. Naturally, such responsiveness also depends on the communicator’s ability to understand the prediction and the interpretive process that resulted in the prediction. As we have pointed out, some interpretative methods prevent such understanding.

In conclusion, although there may be a strong desire to be transparent about prognostic information, the *way* this transparency is achieved is even more important. It is not just a matter of designing ‘transparency’ into the technology’s user interface. Rather, the interplay of the design and implementation of cEEG on the one hand and communication with families on the other needs careful consideration. Thinking about design and implementation in terms of shaping a testing architecture invites consideration of a broad set of elements that can be ‘tweaked’ to invite good professional behavior. It is important, however, to keep in mind the limitations of this way of thinking. Whether a medical professional is actually attentive and caring in their communication with relatives also depends on internal dispositions and capacities and the specific situation.

Timing of Disclosure of Prognostic Outcome

At some point, the physician will discuss the patient’s prognosis with the next of kin. One of the promises of cEEG monitoring is that it might provide a prognosis earlier than existing technologies. Research results thus far show that the technology may indeed provide a reliable prognosis within 12 to 24 h after reanimation. The current Dutch and European clinical guidelines, however,

⁸ Deep learning does not currently allow a continuous calculation but only one at set times, currently at 6 h and 12 h after reanimation.

advice to postpone communication of the prognosis till results from other tests are also available [29, 30]. This may be quite challenging if the monitor is visible for relatives and the interface easy to understand. Leaving this issue aside for now, cEEG raises the question whether it is desirable to inform relatives who have just heard that their loved one had a cardiac arrest about the prognosis as soon as possible?

Generally speaking, our respondents strongly emphasized the desirability of open communication, honesty, and transparency. Both family members and physicians expressed a preference for full disclosure of the prognosis as soon as information is available, even when a technology is still experimental, as Willems' wife insisted:

"I certainly hope that the moment a doctor or researcher sees something, that they'll enter into conversation with the family or partner of the patient. 'Yes, this is experimental research, this isn't a given, of course. But we see some reason for worry.' That way, you at least create a bit of awareness, as in, keep in mind that someone doesn't get out of this the way you *think* they will."

Notice, however, that her reference to 'reason for worry' and preparing for unmet expectations imply that she is focused on transparency regarding *negative* information. Although early predictions of poor outcome are more controversial, since they may hasten the death of the patient, simply communicating the pessimistic prediction helps family prepare for the worst and is therefore always appreciated. In our discussions with family and practitioners they seemed much less sure that communicating early predictions of good prognosis is desirable as well. Communicating an optimistic prediction, after all, doesn't have the same positive effect. Willems' wife elaborates:

"Personally, I imagine it would be pleasant for the people around the patient to know 'we suspect some constraints or disabilities when he wakes up'. The suspicion of limitations means you'll be totally, super happy when the patient wakes up without limitations. If you have to wait until someone finally wakes up but then you're being told, 'there are limitations'... It's better to be prepared for bad news and get good

news than to think, 'everything is going well' and then get smacked in the face later."

As long as a degree of uncertainty remains, family members indeed see an advantage to hearing an early negative prediction ahead of time which, if correct, prepares them for the pain and struggle that is to come, allows them some time for mental and practical preparation and to say goodbye to the patient. If the prediction turns out to be incorrect, that would simply be a source of happiness. However, such scenarios require delaying WLST based on the prediction, long enough for the patient to show signs of recovery. Family members further indicated that if that decision came too soon, they might reject the prognosis altogether.

Communicating an optimistic prediction early on, in contrast, raises expectations which can lead to disappointment if it proves incorrect, or if the patient dies from other causes than neurological damage. In these situations, the chance or time left to say goodbye may have been reduced significantly. We observed a similar response in our discussions with professionals. When asked whether they would be transparent about pessimistic preliminary findings early on, they only argued about the *best way* to deliver the bad news. When the preliminary findings were optimistic, however, they were reluctant to share their expectations, unless it could be made *very* clear that the prognosis was 'tentative'. This would guard the family against overly optimistic expectations about the outcome.

In contrast to what might be expected, then, early communication of a good prognosis is not necessarily appreciated. Different prognostic predictions seem to require different timing. To accommodate this requirement, both the design of the user interface and the communication policies that are part of the testing architecture need to be sufficiently specific. Like before, however, the personal disposition and capacities of the professional play a role that no testing architecture can fully 'inscribe'.

Summing up and Looking Forward

In view of the life or death decisions that are being made, reducing uncertainty regarding the future perspectives of a patient in postanoxic coma is important.

Providing substantially more patients with a prognosis, as cEEG does, is therefore a desirable aim to pursue. The preceding analysis also shows, however, that the added value of cEEG in practice is less straightforward than one would expect. Fieldwork in ICUs where cEEG was implemented for research purposes indicates that expectations of the new technology's ability to facilitate interpretation, decision-making, and communication, are not always met. Increased certainty does not necessarily produce 1) clear-cut information for medical professionals, 2) better guidance for decision-making, or 3) easier communication with relatives.

1. Regarding information provision, opening up the work and the choices underlying the production of cEEG results shows that cEEG faces several limitations and uncertainties regarding the identification and classification of patterns and how these are linked to outcomes. The different ways these issues of reliability are addressed, whether by additional resources or automation, pose their own challenges. Moreover, the technology has a built-in normativity that is rather crude and not immediately transparent.
2. This built-in normativity has implications for the way cEEG-results impact decision-making. Regarding poor outcome predictions, users feel the resulting prognosis still lacks the level of detail that they feel is required to decide whether or not to withdraw life-sustaining treatment. In contrast, good outcome predictions may actually have more action potential than has been acknowledged thus far. Most surprisingly, the technology also produces a new category of patients for whom the future appears more, rather than less ambiguous.
3. With regard to communication, the early availability and potential accessibility of the prognostic information can foster, but also hinder, good communication with relatives. Although the design of cEEG may suggest that information is transparent to all, relevant nuances and assumptions are easily overlooked. Regarding timing, it is important to note that, even though cEEG provides a good prognosis earlier than a poor one, early communication of a poor prognosis may be more desirable than that of a good prognosis.

These observations are based on a limited set of observations and interviews in a limited number of settings in the Netherlands. We do not claim that the use of cEEG will always work out in this way. On the contrary, our comparative investigation of the liminal use of cEEG in a US hospital shows that, in other settings, cEEG will be a different technology, with different impacts.⁹ Whether the different ways in which epistemic uncertainty is addressed are somehow related to differences in ethical culture needs further investigation, especially since the latter do not seem to impact the way normativity is inscribed. Our findings do show, however, that this technology can bring along a number of social and ethical issues and challenges that need to be addressed to increase its acceptability. We hope that our analysis demonstrates how approaching design and implementation of cEEG as the building of a testing architecture helps to see how many different elements can be adjusted to avoid or address these challenges. It also helps to become aware of their interdependency. At the same time, it is important to remain aware that adjusting this architecture is not a panacea to prevent inattentive and uncaring professional behavior.

When further developing the technology's overall architecture, attention should be paid to safeguarding reliable interpretations: how to align the design of the technology, the working procedures to interpret measurements, and arrangements as to who is allowed to interpret. This includes careful consideration of the (dis)advantages of human versus machine-supported versus machine-based interpretation. Different decisions will come with varying trade-offs for transparency.

Importantly, user interface must be designed and implemented in such a way that it allows for human-mediated ways and multiple timings of communicating the prognosis with relatives. For some practices, this may mean that relatives are prevented from seeing the screen altogether.

In addition, efforts must be made to nuance outcome measures, or (as long as this is not possible) transparency about what outcome categories imply must at least be increased, to allow for open discussion and for more informed decision-making. Investigating whether cEEG predictions are filtering out

⁹ Further study is needed to analyse how exactly cEEG will impact US neuroprognostic practice as a whole.

the very best and very worst outcomes by examining the uncertain category is thought to be a worthwhile endeavor in that regard.

Finally, furthering research on what additional proactive care can be offered to patients with a good prognosis, as well as what tailored support can be offered to patients with an uncertain (or ‘grey’) prognosis and their relatives, would increase the benefits of cEEG-based prognosis.

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References

1. Ko, D.N., and C.D. Blinderman. 2015. Withholding and withdrawing life-sustaining treatment (including artificial nutrition and hydration). In *Oxford textbook of palliative medicine*, ed. N. Cherny, M. Fallon, S. Kaasa, R.K. Portenoy, and D.C. Currow. Oxford: Oxford University Press. <https://doi.org/10.1093/med/9780199656097.003.0108>.
2. Rydvall, A., and N. Lynöe. 2008. Withholding and withdrawing life-sustaining treatment: A comparative study of the ethical reasoning of physicians and the general public. *Critical care* 12 (1): R13.
3. Welie, J.V., and H.A. Ten Have. 2014. The ethics of forgoing life-sustaining treatment: theoretical considerations and clinical decision making. *Multidisciplinary respiratory medicine* 9 (1): 14. <https://doi.org/10.1186/2049-6958-9-14>.
4. Cartwright, W. 1996. Killing and letting die: A defensible distinction. *British Medical Bulletin* 2 (2): 354–361.
5. Foot, P. 2002. Killing and letting die. In: *Moral Dilemmas: and other topics in moral philosophy*. Published to Oxford Scholarship Online: November 2003. <https://doi.org/10.1093/019925284X.001.0001>
6. Husak, D.N. 1979. Killing, letting die and euthanasia. *Journal Medical Ethics* 5 (4): 200–202.
7. Levin, P.D., and C.L. Sprung. 2005. Withdrawing and withholding life-sustaining therapies are not the same. *Critical care* 9 (3): 230–232.
8. Rachels, J. 2001. Killing and letting die. In: the Encyclopedia of ethics, 2nd edition, ed. Lawrence.
9. Thomson, J. 1976. Killing, letting die, and the trolley problem. *The Monist*, 59(2): 204–217. Retrieved from <http://www.jstor.org/stable/27902416>.
10. Tooley, M. 1980. An irrelevant consideration: Killing versus letting die. In *Killing and letting die*, ed. B. Steinbock, 56–62. Englewood Cliffs: Prentice-Hall.
11. Mertens, M. (2021). *Responsible prediction under critical uncertainty: an epistemic analysis of neuroprognostic innovation practices after cardiac arrest*. Enschede: Ipskamp (forthcoming).
12. Hofmeijer, J., T.M.J. Beernink, F.H. Bosch, A. Beishuizen, M.C. Tjepkema-Cloostermans, and M.J.A.M. van Putten. 2015. Early EEG Contributes to Multimodal Outcome Prediction of Postanoxic Coma. *Neurology* 85 (2): 137–143.
13. Ruijter, B.J., M.C. Tjepkema-Cloostermans, S.C. Tromp, W.M. van den Bergh, N.A. Foudraïne, F.H.M. Kornips, G. Drost, E. Scholten, F.H. Bosch, A. Beishuizen, M.J.A.M. van Putten, and J. Hofmeijer. 2019. Early EEG for outcome prediction of postanoxic coma: A prospective cohort study. *Annals of Neurology*. <https://doi.org/10.1002/ana.25518>.
14. Spalletti, M., R. Carrai, M. Scarpino, C. Cossu, A. Ammannati, M. Ciapetti, L. Tadini Buoninsegni, A. Peris, S. Valente, A. Grippo, and A. Amantini. 2016. Single electroencephalographic patterns as specific and time-dependent indicators of good and poor outcome after cardiac arrest. *Clinical Neurophysiology* 127 (7): 2610–2617.
15. Tjepkema-Cloostermans, M.C., J. Hofmeijer, R.J. Trof, M.J. Blans, A. Beishuizen, and M.J.A.M. van Putten. 2015. Electroencephalogram predicts outcome in patients with postanoxic coma during mild therapeutic hypothermia. *Critical Care Medicine* 43: 159–167.
16. Akrich, M. 1992. The de-scription of technical objects. In *Shaping technology/building society: Studies in sociotechnical change*, ed. W. Bijker and J. Law, 205–224. Cambridge: MIT Press.
17. Geels, F.W., and W.A. Smit. 2000. Failed technology futures: Pitfalls and lessons from a historical survey. *Futures* 32 (9–10): 867–885.
18. Parthasarathy, S. 2005. Architectures of genetic medicine: Comparing genetic testing for breast cancer in the USA and the UK. *Social Studies of Science* 35 (1): 5–40.

19. Verbeek, P.P. 2005. *What things do: Philosophical reflections on technology, agency, and design*. University Park: The Pennsylvania State University Press.
20. Verbeek, P.P. 2008. Morality in design: Design ethics and the morality of technological artifacts. In *Philosophy and design*, ed. P.E. Vermaas, P. Kroes, A. Light, and S. Moore, 91–103. Dordrecht: Springer.
21. Hassager, C., K. Nagao, and D. Hildick-Smith. 2018. Out-of-hospital cardiac arrest: In-hospital intervention strategies. *The Lancet* 391 (10124): 989–998. [https://doi.org/10.1016/s0140-6736\(18\)30315-5](https://doi.org/10.1016/s0140-6736(18)30315-5).
22. Sandroni, C., S. D'Arrigo, and J.P. Nolan. 2018. Prognostication after cardiac arrest. *Critical Care* 22 (1): 150. <https://doi.org/10.1186/s13054-018-2060-7>.
23. Zandbergen, E.G.J., R.J. de Haan, C.P. Stoutenbeek, J.H.T.M. Koelman, and A. Hijdra. 1998. Systematic review of early prediction of poor outcome in anoxic-ischaemic coma. *Lancet* 352: 1808–1812.
24. Zandbergen, E.G.J., J.H.T.M. Koelman, R.J. de Haan, and A. Hijdra. 2006. SSEPs and prognosis in postanoxic coma: Only short or also long latency responses? *Neurology* 67: 583–586.
25. Westhall, E., A.O. Rossetti, A.F. van Rootselaar, T. WessenbergKjaer, J. Horn, S. Ullén, H. Friberg, N. Nielsen, I. Rosén, A. Åneman, D. Erlinge, Y. Gasche, C. Hassager, J. Hovdenes, J. Kjaergaard, M. Kuiper, T. Pellis, P. Stammet, M. Wanscher, J. Wetterslev, M.P. Wise, T. Cronberg, and TTM-trial investigators. 2016. Standardized EEG interpretation accurately predicts prognosis after cardiac arrest. *Neurology* 86: 1482–1490.
26. Tjepkema-Cloostermans, M.C., J. Hofmeijer, A. Beishuizen, H.W. Hom, M.J. Blans, F.H. Bosch, and M.J.A.M. van Putten. 2017. Cerebral recovery index: Reliable help for prediction of neurologic outcome after cardiac arrest. *Critical care medicine* 45 (8): e789–e797. <https://doi.org/10.1097/CCM.0000000000002412>.
27. Tjepkema-Cloostermans, M. C., C. da Silva Lourenço, B.J. Ruijter, S.C. Tromp, G. Drost, F.H.M. Kornips, A. Beishuizen, F.H. Bosch, J. Hofmeijer, and M.J.A.M. van Putten. 2019. outcome prediction in postanoxic coma with deep learning. *Critical Care Medicine*. (Online first).
28. Tjepkema-Cloostermans, M.C., F.B. van Meulen, G. Meinsma, and M.J.A.M. van Putten. 2013. A Cerebral Recovery Index (CRI) for early prognosis in patients after cardiac arrest. *Critical Care* 17 (5): R252. <https://doi.org/10.1186/cc13078>.
29. Horn, J., C.W.E. Hoedemaekers, J. Hofmeijer, L.S.D. Jewbali, J.H.T.M. Koelman, and W. de Ruijter. 2019. *Richtlijn Prognose van postanoxische coma*. Utrecht: Nederlandse Vereniging voor Neurologie.
30. Nolan, J.P., Sandroni, C., Böttiger, B.W., Cariou, A., Cronberg, T., Friberg, H. et al. (2021). European resuscitation council and european society of intensive care medicine guidelines 2021: post-resuscitation care. *Intensive Care Medicine*, 47(4), 369–421.
31. Boenink, M. 2012. Debating the desirability of new biomedical technologies: Lessons from the introduction of breast cancer screening in the Netherlands. *Health Care Analysis* 20 (1): 84–102.
32. Berg, M., and A. Mol. 1998. *Differences in medicine: Unraveling practices, techniques, and bodies*. Durham: Duke University Press.
33. Law, J., and V. Singleton. 2000. Performing technology's stories: On social constructivism, performance, and performativity. *Technology and Culture* 41 (4): 765–775.
34. Licoppe, C. 2010. The “performative turn” in science and technology studies. *Journal of Cultural Economy* 3 (2): 181–188. <https://doi.org/10.1080/17530350.2010.494122>.
35. MacKenzie, D.A., F. Muniesa, and L. Siu. 2007. *Do economists make markets? On the performativity of economics*. Princeton: Princeton University Press.
36. Pickering, A. 1995. Beyond constraint: The temporality of practice and the historicity of knowledge. In *Scientific practice: Theories and stories of doing physics*, ed. J.Z. Buchwald, 42–55. Chicago: University of Chicago Press.
37. Wallenburg, I., J. Quartz, and R. Bal. 2019. Making Hospitals Governable: Performativity and institutional work in ranking practices. *Administration & Society* 51 (4): 637–663. <https://doi.org/10.1177/0095399716680054>.
38. Parthasarathy, S. 2012. *Building genetic medicine: Breast cancer, technology, and the comparative politics of health care*. Cambridge: MIT Press.
39. Latour, B. 1987. *Science in action: How to follow scientists and engineers through society*. Cambridge: Harvard University Press.
40. Mertens, M. 2018. Liminal innovation practices: Questioning three common assumptions in responsible innovation. *Journal of Responsible Innovation* 5 (3): 280–298. <https://doi.org/10.1080/23299460.2018.1495031>.
41. Oh, S.H., K.N. Park, Y.-M. Shon, Y.-M. Kim, H.J. Kim, C. S. Youn, ... S. C. Kim. 2015. Continuous amplitude-integrated electroencephalographic monitoring is a useful prognostic tool for hypothermia-treated cardiac arrest patients. *Circulation*, 132(12): 1094–1103.
42. Grant, AC., Abdel-Baki, S.G., Weedon, J., Arnedo, V., Chari, G., Koziorynska, E., Lushbough, C., Maus, D., McSween, T., Mortati, K.A., Reznikov, A., Omurtag, A. (2014). EEG interpretation reliability and interpreter confidence: A large single-center study. *Epilepsy & Behavior*, 32, 102–107.
43. Benbadis, S.R., LaFrance, W.C., Papandonatos, G.D., Korabathina, K., Lin, K., Kraemer, H.C. (2009). Inter-rater reliability of EEG-video monitoring. *Neurology*, 73 (11), 843–846.
44. Nagaraj, S.B., M.C. Tjepkema-Cloostermans, B.J. Ruijter, J. Hofmeijer, and M.J.A.M. van Putten. 2018. The revised Cerebral Recovery Index improves predictions of neurological outcome after cardiac arrest. *Clinical neurophysiology* 129 (12): 2557–2566.

45. Van Putten, M.J.A.M., J. Hofmeijer, B.J. Ruijter, and M.C. Tjepkema-Cloostermans. 2017. Deep Learning for outcome prediction of postanoxic coma. In *EMBECE & NBC 2017. EMBEC 2017, NBC 2017. IFMBE Proceedings*, vol. 65, ed. H. Eskola, O. Väisänen, J. Viik, and J. Hytinen. Singapore: Springer.
46. Mittelstadt, B.D., P. Allo, M. Taddeo, S. Wachter, and L. Floridi. 2016. The ethics of algorithms: Mapping the debate. *Big Data & Society* 3 (2): 205395171667967. <https://doi.org/10.1177/2053951716679679>.
47. Silva, S., and M. Kenney. 2019. Algorithms, platforms, and ethnic bias. *Communications of the ACM* 62 (11): 37–39.
48. Mertens, M., King, O.C., van Putten, M.J.A.M., & Boenink, M. (2021). Can we learn from hidden mistakes? Self-fulfilling prophecy and responsible neuroprognostic innovation. *Journal of Medical Ethics*. <https://doi.org/10.1136/medethics-2020-106636>.
49. Balouris, S.A., Raina, K.D., Rittenberger, J.C., Callaway, C.W., Rogers, J.C., & Holm, M.B. (2015). Development and validation of the cerebral performance categories-extended (CPC-E). *Resuscitation*, 94, 98–105. <https://doi.org/10.1016/j.resuscitation.2015.05.013>.
50. Haywood, K., Whitehead, L., Nadkarni, V.M., Achana, F., Beesems, S., Böttiger, B.W. et al. (2018). COSCA (core outcome set for cardiac arrest) in adults: an advisory statement from the international liaison committee on resuscitation. *Circulation* 137.
51. Tong, J.T., Eyngorn, I., Mlynash, M., Albers, G. W., & Hirsch, K. G. (2016). Functional neurologic outcomes change over the first 6 months after cardiac arrest. *Critical Care Medicine*, 44(12), e1202–e1207. <https://doi.org/10.1097/CCM.0000000000001963>.
52. Sandroni, C., and J.P. Nolan. 2015. Neuroprognostication after cardiac arrest in Europe: New timings and standards. *Resuscitation* 90: A4–A5. <https://doi.org/10.1016/j.resuscitation.2015.02.020>.
53. Myat, A., Song, K-J., Rea, T. (2018). Out-of-hospital cardiac arrest: current concepts. *The Lancet*, 391(10124), 970–979.
54. Kudenchuk, P.J., Sandroni, C., Drinhaus, H.R., Böttiger, B.W., Cariou, A., Sunde, K. et al. (2015). Breakthrough in cardiac arrest: reports from the 4th Paris International Conference. *Annals of Intensive Care*, 5 (1).
55. Koren, J. P., J. Herta, F. Furbass, S. Pirker, V. Reiner-Deitemyer, F. Riederer ... C. Baumgartner. 2018. Automated long-term EEG review: Fast and precise analysis in critical care patients. *Frontiers in Neurology*, 9, 454. <https://doi.org/10.3389/fneur.2018.00454>.
56. Wilkinson, D. 2009. The self-fulfilling prophecy in intensive care. *Theoretical Medicine and Bioethics* 30 (6): 401–410.
57. Gold, B., L. Puertas, S.P. Davis, et al. 2014. Awakening after cardiac arrest and post resuscitation hypothermia: Are we pulling the plug too early? *Resuscitation* 85 (2): 211–214. <https://doi.org/10.1016/j.resuscitation.2013.10.030>.
58. Geocadin, R.G., M.A. Peberdy, and R.M. Lazar. 2012. Poor survival after cardiac arrest resuscitation: A self-fulfilling prophecy or biologic destiny? *Critical Care Medicine* 40 (3): 979–980.
59. Vincent, J.L. 2005. Withdrawing may be preferable to withholding. *Critical Care* 9: 226–229.
60. Quill, T.E., and R. Holloway. 2011. Time-limited trials near the end of life. *Journal of the American Medical Association* 306: 1483–1484.
61. Vink, E.E., E. Azoulay, A. Caplan, E.J.O. Kompanje, and J. Bakker. 2018. Time-limited trial of intensive care treatment: An overview of current literature. *Intensive Care Medicine*. <https://doi.org/10.1007/s00134-018-5339-x>.
62. Schenker, Y., G.A. Tiver, S.Y. Hong, and D.B. White. 2013. Discussion of treatment trials in intensive care. *Journal of Critical Care* 28: 862–869.
63. Schembs, L., M. Ruhfass, E. Racine, R.J. Jox, A. Bender, M. Rosenfelder, and K. Kuehlmeier. 2020. How does functional neurodiagnostics inform surrogate decision-making for patients with disorders of consciousness? A qualitative interview study with Patients' Next of Kin. *Neuroethics*. <https://doi.org/10.1007/s12152-019-09425-4>.

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