Ethics in Disorders of Consciousness

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Introduction

The introduction of the mechanical ventilator in the 1950s and the development of intensive care in the 1960s permitted many patients to sustain their vegetative functions and survive severe injuries. Despite such advances, in many cases patients were found to suffer from altered states of consciousness which had never been encountered before as these patients would normally have died from apnea [1]. The imminent ethical impact of these profound states of unconsciousness was reflected in the composition of the first bioethical committees discussing the redefinition of life and the concept of therapeutic obstinacy. In 1968, the Ad Hoc Committee of Harvard Medical School published a milestone paper for the redefinition of death as irreversible coma and brain failure [2]. The committee was comprised of ten physicians, a theologian, a lawyer and a historian of science, betokening the medical, legal and societal debates that were to follow. We will here give a brief overview of some ethical issues related to the concept of consciousness and the medical management of patients with disorders of consciousness, such as comatose, vegetative and minimally conscious states that may be encountered in the intensive care setting. We will emphasize the problem of pain management and end-of life decision-making.

Ethical Issues in Clinical Management

Confusions and controversies are often related to the way we define things. One such multifaceted term is consciousness, which has many divergent connotations [3]. The way we define consciousness is crucial, as it may govern our attitudes towards medical management of disorders of consciousness. For example, in a survey among medical and paramedical professionals (n = 1858), compared to a student population (n = 250), we recently found that although the majority of health-care workers denied a distinction between consciousness and the brain, more than one-third of medical and paramedical professionals still regarded the mind and brain as separate entities (**Fig. 1**). Such dualistic opinions may have implications in the formulation of scientific questions about the nature of consciousness, in the clinical management of disorders of consciousness, and in the reception of both by the general public [4]. We here adopt a perspective where consciousness is clinically defined as having two components, wakefulness and awareness [5]. Under this definition, many variant altered states of consciousness may be hosted. The most transient and most familiar to us all is the transition

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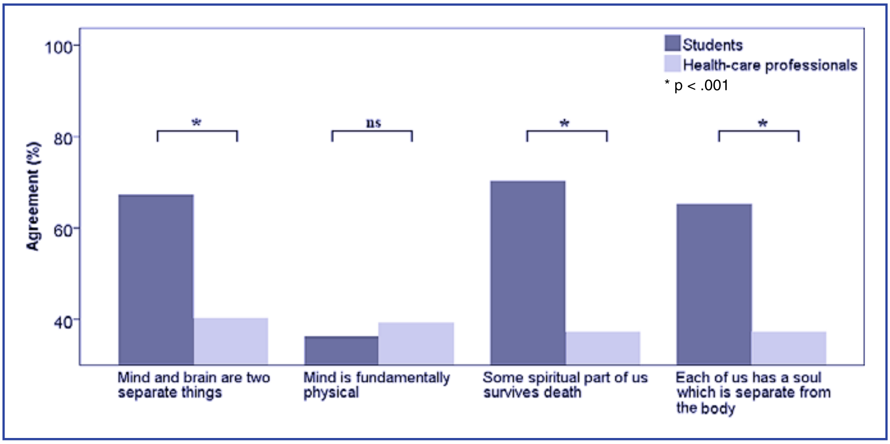

Fig. 1. Dualistic attitudes towards the mind-brain relationship among students (Edinburgh survey, n = 250) and health-care professionals (Liège survey, n = 1858). Adapted from [4] with permission.

from conscious wakefulness to deep sleep; the drowsier we become, the less aware we get of our surroundings and of ourselves. This implies that patients in coma and under anesthesia (i.e., pharmacological coma) are unaware because they cannot be awakened, even after noxious stimulation. The vegetative state is defined as 'wakefulness without awareness', in which patients may open their eyes but will never exhibit non-reflex voluntary movements [6]. A patient in a minimally conscious state may show some signs declaring awareness (e.g., visual pursuit, orientation to pain or non-systematic command following) but is unable to communicate his or her thoughts or feelings [7]. Because these behavioral signs of consciousness are often small and fluctuating in time, this condition may be challenging to diagnose and differentiate from vegetative state [8]. It has been suggested that once conscious awareness has been identified and its quality is estimated in a non-communicating patient (e.g., see [9, 10]), this may well be a good reason to preserve life-sustaining aids [11]. However, the moral significance of preserved consciousness has been questioned on the grounds that it may not always be in a patient's best interest to continue a severely handicapped life [12].

One challenging issue in this debate is the conscious perception of pain in these patients. As defined by the Multi-Society Task Force on persistent vegetative state (PVS), 'pain and suffering refer to the unpleasant experiences that occur in response to stimulation of peripheral nociceptive receptors and their peripheral and central afferent pathways or that may emanate endogenously from the depths of human self-perception' [13]. Thus, pain constitutes a conscious experience with a physical (nociception) and a psychological counterpart (suffering), suggesting that nociception by itself is not sufficient to cause suffering. The management of pain in patients with disorders of consciousness is challenging because patients in a vegetative or minimally conscious state cannot verbally or non-verbally communicate their feelings or experiences [1]. This is reflected in how clinicians perceive pain in these patients. According to recently surveyed attitudes among health-care professionals, there was unanimous support that patients in a minimally conscious state (96 %) perceived pain whereas opinions were less clear for the patients in a vegetative state (56 %) [14]. Considering these results on varying beliefs about pain perception in disorders of consciousness, physicians and health-care workers' views on analgesia and symptom management may also be affected. Since nearly half of the surveyed doctors stated that vegetative state patients do not feel pain, these physicians could be expected to act accordingly, for instance, by not providing analgesic medication to these patients during care or during the dying process after withdrawal of artificial hydration and nutrition [15], the latter on the grounds that these patients do not experience suffering from hunger or thirst [16].

How are clinicians supposed to determine whether patients in a vegetative or minimally conscious state feel pain or suffering? At the patient's bedside, we are limited to evaluating the behavioral responsiveness to pain: If patients show no signs of voluntary movement (i.e., localizing the source of pain) in response to a noxious stimulus, it can be concluded that they do not experience pain. Conscious but paralyzed 'locked-in syndrome' patients, who classically show absent or 'decerebration' (i.e., stereotyped extension) or 'decortication' (i.e., stereotyped flexion) movements, teach that this need not necessarily be the case. In response to noxious stimulation, patients with disorders of consciousness will frequently show increased arousal levels (evidenced by opening or widening of the eyes), quickening of breathing, increased heart rate and blood pressure, or grimace-like or crying-like behavior. As all these abilities are also seen in infants with anencephaly [17], they are considered to be of subcortical origin and not necessarily reflecting conscious perception of pain. However, the absence of a behavioral response cannot be taken as proof of the absence of conscious perception [18] and the inference of pain and suffering merely by observing behavioral responses may be misleading. Repeated clinical examinations by experienced examiners with standardized tools such as the recently proposed 'coma nociception scale' (e.g., [19]) are paramount for the behavioral assessment of pain. Additional information coming from functional neuroimaging studies may assist in the formulation of a clearer clinical picture. For example, in a positron emission tomography (PET) study, it was shown that patients in a vegetative state may show cerebral processing of the incoming noxious stimulus (activation of primary somatosensory areas), but the observed neural activity was isolated and disconnected from higher-order associative brain areas which are considered necessary for conscious perception of pain [20]. It is important to stress that very different results were obtained in patients in a minimally conscious state in whom functional neuroimaging studies have shown more widespread activation in the cerebral network compared to patients in vegetative state, but similar to healthy controls, suggesting potential pain perception these patients [21]. In light of the incomplete picture of pain perception in patients in vegetative state, the existing risk for misdiagnosis [8], the inconclusive drug-related effects in disorders of consciousness [22], and the limitations of interpreting neuroimaging results [23], pain prophylaxis and drug treatment have been proposed for all patients suffering from disorders of consciousness [24].

In intensive care settings, medical doctors and assisting staff are confronted daily with situations where clinical decisions are still more critical, such as continuing or withdrawing life sustaining treatment. Treatment limitations can be viewed as having two directions depending on whether the decision is made preoperatively or after an intervention [25]. In the former case, it may come as a refusal of cardiopulmonary resuscitation (CPR) in case of cardiopulmonary arrest; in the latter case, it most usually comes as a decision to withdraw treatment, such as the artificial respirator or artificial nutrition and hydration. CPR is almost automatically performed as an emergency therapy in order to restore heartbeat and ceased breathing, unless the patient or the legal representative have refused it in advance in a form of a do-not-resuscitate order (DNR). Nevertheless, it should be noted that DNR orders do not necessarily prohibit other therapies; they rather authorize the physician to act on this specific manner of therapy [26]. When the clinical condition of a patient has been stabilized and denoted as irreversible, decisions about artificial nutrition and hydration limitation may come into play. From a bioethical standpoint, withdrawing artificial nutrition and hydration is comparable to withdrawing mechanical ventilation, even if emotionally these two actions may be perceived differently. In the intensive care unit (ICU) setting, the majority of deaths are the result of a medical decision to withhold or withdraw treatment [27]. Such decisions are evidence-based and rely on validated clinical or paraclinical markers of bad outcome ([e.g., for anoxic coma see [28]). Despite the controversy as to whether artificial nutrition and hydration constitutes a medical treatment [29] and thus should never be withdrawn from patients [30], most of the medical community (especially Anglo-Saxon) would agree with its being a medical therapy which can be refused by patients and surrogate decision makers [31]. Such decisions in vegetative state patients are only justified when a case is denoted as irreversible [32]. Guidelines with regard to temporal determination of a definitive outcome in vegetative state currently state that if no recovery is observed within 3 months after a non-traumatic or 12 months after a traumatic accident, the condition of the patient can be denoted as permanent [13].

The controversies around the clinical management at the end-of-life in patients with disorders of consciousness were reflected in a recent European survey (n = 2475), where the majority of health-care professionals (66 %) agreed to withdraw treatment from chronic vegetative state patients whereas only 28 % agreed to do so for chronic minimally conscious state patients; additionally, most clinicians wished not to be kept alive if they imagined themselves in a chronic vegetative state (82 %) and a similar proportion (67 %) agreed if they imagined themselves in a chronic minimally conscious state [33]. Geographical region and religion were among the factors that explained most of the variance in the responses and these results are in line with previous surveys in which physicians' characteristics (i.e., age, religion and geographic region) seem to play a critical role in governing such options [34]. The detected differences between the two states could be due to the existing legal ambiguity around minimally conscious state which may have influenced the surveyed participants to differentiate between expressing preferences for self versus others, by implicitly recognizing that the latter could be a step on the slippery slope to euthanasia.

Clinicians' opinions appear much more uniform with regard to brain death [35]. As mentioned earlier, the Ad Hoc Committee of the Harvard Medical School went on to the redefinition of death as a consequence of the technological advancements in intensive care, where patients could sustain severe injuries but maintain the function of vital organs [2]. It was, therefore, possible to dissociate between cardiac, respiratory and brain functions which in turn required an alternative definition of death, moving from a cardiorespiratory towards a neurocentric formulation (i.e., irreversible coma). According to the latter, death can be viewed either as death of the whole brain or of the brainstem [36] or as neocortical [37]. The first two are defined as the irreversible cessation of the organism as a whole, differing in their anatomical interpretation [38], whereas the last solely requires the irreversible loss of the capacity of consciousness and social interaction but has never convinced medical or legal scholars. The main utility of the introduction of brain death is that it permitted vital organ procurement for transplantation with the application of ethical restrictions, such as the dead donor rule (i.e., a patient has to be declared dead before the removal of life-sustaining organs). Based on the neocortical definition of death, however, both vegetative and minimally conscious state patients can be declared dead. It has been argued that the neocortical definition is conceptually inadequate and practically unfeasible, especially with the lack of a complete understanding of higher-order conscious functioning; hence, patients with disorders of consciousness are not dead [27] and organ donation options in these patients should be excluded since they violate the dead donor rule [39] – despite opposing opinions to abandon this ethical axiom [40].

Legal Issues in Disorders of Consciousness

Disorders of consciousness have posed not only medical challenges but in many cases they required the mediation of legal authorities in order to regulate ambiguous and controversial issues, such as end-of-life decisions. When end-of-life wishes have not been earlier formulated in the form of an advanced directive (i.e., written statement completed by a competent person in anticipation of her/his future incompetence, expressing personal treatment preferences and formal surrogacy appointment), then a surrogate decision maker is eligible to take responsibility for the patient's clinical management. The way the legal representative should act on behalf of the patient is a progressive one. The surrogate should first attempt to follow the wishes of the patient as closely as possible, in the way in which they were expressed before the accident, either orally or in the form of advance directives. When the wishes are unknown and an advance directive is not available, the surrogate decision maker should try to reproduce the patient's preferences based on their history and personal values. When this is not possible, decisions should rely on more objective markers that determine the patient's best interest (e.g., likelihood of recovery, pain management, impact on family) [25, 41]. The proxy decision maker should mediate trying to maximize the patient's self-determination and protect their interests using the principles of beneficence and non-maleficence [42].

The use of advance directives could also be considered as a means to regulate cost savings in the end-of-life; once the wishes of a terminal patient are known, care can be taken to constrain extraordinary means and spare the available resources for other urgent cases. However, no such rationale corresponds to the reality and advance directives, together with hospice care and the elimination of futile care, have not contributed to the effective regulation of the economics of dying [43]. Treatment resources are not unlimited and despite care for a good death sometimes physicians need to make do with the means they have available. The allocation of resources and the economics at the end-of-life have not yet been fully determined for patients with disorders of consciousness. In intensive care medicine, some unwritten rules can facilitate decisions as to who is to be treated, like the 'first come' principle or 'who will most likely benefit from intensive care' [44]. However, for chronic disorder of consciousness cases, information on resource allocation is often lacking. This may be due to the nature of patients with chronic vegetative or minimally conscious state. These are severely brain-damaged patients for whom the dilemma on treating becomes crucial either because treatments are not guaranteed as successful (i.e., the condition is too bad to be treated) or unkind (i.e., the quality of life of those surviving is not acceptable) which may lead to an unwise way to allocate available resources [44].

The legal provisions concerning end-of-life issues in disorders of consciousness differ from country to country. In the United States, where a patient-centered medical framework has been adopted, the patient is allowed to participate in the regulation of her/his own course of the disease. In the case of disorders of consciousness, legal representatives in close collaboration with the clinical staff and in line with the patient's previously expressed wishes may decide together about the long-term care of irreversibly comatose patients. There are times, however, when conflicts of interests arise while making such decisions, either between family and physicians, such as in the Quinlan case [45], or among family members, like the more recent Schiavo case [46]. As most often such cases require the mediation of the court, they may have a wider publicity in which public opinion can come into play and may lead to societal movements on pro-life versus right-to-die action groups [47]. In Europe, there are more subtle differences in the way treatment limitation is perceived, especially between Northern (more right-to-die oriented) and Southern (more pro-life positioned) European countries [33]. In general, decisions for treatment limitation (usually concerning artifical nutrition and hydration) need to be taken after reference to the court. Exceptions are the Netherlands, Belgium, Switzerland and Scandinavian countries where no court mediation is needed for limiting treatment in disorders of consciousness [48]. Considering these different attitudes within and out of Europe, it has been suggested that an international consensus regarding standards of care for patients with disorders of consciousness needs to be reached [49].

Conclusion

The ethical issues accrued from the study and management of patients with disorders of consciousness are variant and multi-faceted. Medical, legal and public controversies are partly shaped by how different people think about these issues and in many cases are country-dependent. It is, therefore, evident that a uniform ethical framework needs to be shaped to guide clinicians and caregivers in terms of clinical outcome, prognosis, and medical management.

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