MRS. FEDERICA MERLO (Orcid ID : 0000-0002-6201-6206)
PROF. CLAUDIO L BASSETTI (Orcid ID : 0000-0002-4535-0245)

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Physicians' decision-making when managing pediatric patients with prolonged disorders of consciousness: A qualitative study

Federica Merlo[1,2], Roberto Malacrida[1], Samia Hurst[3], Claudio L.A. Bassetti[4,5], Emiliano Albanese[2], Marta Fadda[2]

Sasso Corbaro Foundation, Bellinzona, Switzerland
[2]Institute of Public Health, Università della Svizzera italiana, Via Buffi 13, 6900 Lugano, Switzerland
[3]Institute for Ethics, History and the Humanities, University of Geneva, 24 rue du Général – Dufour, Geneve, Geneva, Switzerland
[4]Department of Neurology, Inselspital, University of Bern, Bern, Switzerland
[5]Department of Neurology, Sechenow University, Moscow, Russia

*Corresponding author: federica.merlo@usi.ch

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Abstract

Background: Advances in medicine have resulted in treatments that can extend the survival of patients with prolonged disorders of consciousness (PDOC) for several years. However, several diagnostic and prognostic uncertainties remain particularly in the care of pediatric patients. In the absence of international guidelines, we aimed to explore physicians' decision-making when managing pediatric patients with PDOC.

Methods: We conducted a qualitative study using semi-structured, individual interviews and employed an inductive thematic analytical approach to explore physicians' subjective experiences and decision-making when managing pediatric patients with PDOC. We recruited a purposive sample of 19 Italian-speaking physicians currently or previously employed in intensive care unit, pediatric, internal medicine, or neurology departments in Switzerland.

Results: Participants stated that making clinical decisions involving pediatric patients with PDOC is extremely challenging because the decisional process requires finding a balance between several contending factors. We found that physicians experienced ambivalence in three domains of care (time, goals of care, and target of care), and that they were aware of the risk of self-fulfilling prophecies for both prognosis and main clinical outcomes.

Conclusions: Our study confirmed that experienced clinicians acknowledge the complex nature and challenge of clinical decision-making of pediatric patients with PDOC. More research is warranted to improve and expand existing guidelines aimed at assisting and facilitating clinical and ethical decision-making, and improving physicians' awareness of the factors affecting their decisions when dealing with patients with PDOC.

Introduction

Current medical treatments can extend for several years survival of patients with prolonged disorders of consciousness (PDOC), namely unresponsive wakefulness syndrome (UWS), also known as vegetative state (VS), and minimally conscious state (MCS)[1,2]. However, due to many diagnostic and prognostic uncertainties, particularly in pediatric patients, physicians dealing with them face several clinical, ethical and legal challenges[3,4]. Decisions following deterioration in the clinical condition are likely to entail ethical dilemmas and, sometimes, legal issues[5–9].

In 2018, a Committee of the American Academy of Neurology (AAN) published recommendations for patients with PDOC[10]. Recommendations number 16, 17 and 18 highlight the absence of pediatric-specific evidence and advise clinicians to adopt the same diagnostic

recommendations that apply to adult populations, and inform families that the natural history and prognosis of children/adolescents with PDOC is not well defined, and that there are no established therapies for this population[10]. More recently, the European Academy of Neurology (EAN) published a comprehensive guideline for the diagnosis and classification of coma and other PDOC based on the best available scientific evidence[12]. The EAN guideline recognizes that misclassification may lead to major ethical issues for patients and their caregivers, including prognosis, treatment, resource allocation and end-of-life decisions[12]. The Swiss Academy of Medical Sciences (SAMS) has issued guidelines that address the ethical challenges posed by caring for both adult and pediatric patients with PDOC[11]. The SAMS guidelines recognize that, since special characteristics apply to children and adolescents, clinical decisions, must be made on a case-by-case basis. The decision-making process should take into account each patient's individual prognosis, their presumed wishes and character, ponder the therapy's anticipated benefits against its disadvantages and consider the emotional burden that parents/caregivers may face when asked to make life and death decisions for the patient[11].

However, the AAN, EAN and SAMS guidelines are suboptimal in at least three stances. First, they do not offer a comprehensive ethical framework for physicians to consult and navigate during the decision-making process. Second, they do not provide actionable information on the multitude of factors that may influence the decision-making process. Third, they make no explicit reference to how physicians should balance the interests and presumed wishes of the child with the will of the parents. The literature has repeatedly highlighted the presence of such grey areas where, despite the many legal treatment options available, only few can also be considered morally acceptable[13]. The difficulty of having well-defined procedures when dealing with suffering children and adolescents is partly due to the high variance in individuals' point of view regarding what it means to live "a good life"[14]. The main aim of this study was to explore physicians' decision-making when managing pediatric patients with prolonged disorders of consciousness, with a special look at the ethical issues they may encounter. In particular, we aimed at uncovering physicians' moral reasoning regarding decisions on, e.g., diagnostic procedures, evaluation of prognosis, treatment withdrawal/withholding, and the management of acute episodes within chronic conditions.

Methods

We conducted a qualitative study using semi-structured, individual interviews to explore physicians' decision-making when managing pediatric patients with PDOC. The method and reporting followed the Consolidated Criteria for Reporting Qualitative Research (COREQ)[15].

Sample

To capture a wide range of perspectives, we recruited a representative sample of 19 Italian-speaking physicians employed in either an intensive care unit (ICU), pediatric, internal medicine, or neurology Swiss hospital department. We selected participants based on our knowledge of their past/current clinical activity and, at the beginning of the interview, we asked participants to confirm they had experience in managing patients with PDOC. We interrupted recruitment when we reached thematic saturation[16]. A snowball sampling technique was used to identify potential participants, starting from a pool of six participants with whom one of the authors (FM) had already work-related contact. No one refused to participate.

Data collection

Interviews were conducted between January 2019 and January 2020, and lasted between 25 and 59 minutes. The interviewers (FM and MF) were two researchers trained in qualitative research. At the time of the interviews, FM was a social worker trained in bioethics and employed in a pediatric department that caters for children affected by PDOC, while MF was a qualitative researcher trained in bioethics. To reduce possible social desirability bias, both the interviewers adopted techniques such as open-ended and nominative questions and employed a non-judgmental and non-leading approach to questioning. To guide each interview, a flexible interview guide was developed based on the literature and expert consultation. Topics included participants' definition of PDOC, a description of the main clinical decisions involving adult and pediatric patients with PDOC and the related criteria for decision-making (Appendix 1). We initially prompted our participants to consider different etiologies when reflecting on their moral reasoning behind decisions. Time was devoted to eliciting criteria that may not be included in the list. After participants' oral informed consent, interviews were audio recorded and transcribed verbatim. Debriefing among the two interviewers took place within one week following each interview based on transcripts and notes.

Data analysis

Two researchers (FM and MF) and a student assistant employed an inductive thematic analysis to extract meaningful themes from the data[17]. Initially, the two researchers read the transcripts multiple times to become familiar with the content and independently highlighted meaningful quotes. Subsequently, they summarized the quotes under labels by comparing their interpretations and organized the generated labels hierarchically. This was done at a vertical level first, and at a horizontal level at a later stage. The initial labels were re-coded in a list with themes and concepts on a more abstract and conceptual level. Finally, the coders applied the code list to the transcripts and generated a more abstract list of themes. The resulting themes were discussed among the coders through reference to the interview transcripts until consensus was reached. The transcripts were analyzed using NVivo version 12 software[18].

Results

Among the 19 included physicians, three were employed in ICUs, eight in pediatric, seven in neurology, and one in internal medicine department (Table 1). The mean age was 57 (SD=8) and the average years of experience was 30 (SD=7). In addition, participants listed precise etiologies for PDOC, and clearly understood and highlighted the difference between an inborn condition due to a genetic background, or pre- or perinatal complication or a later acquired brain damage (traumatic or hypoxic). However, they consistently reported that the PDOC's etiology isn't the main factor influencing decision-making process. Rather, the latter is guided by the child's clinical condition. Exemplary quotes from the interviews can be found in Table 2.

The struggle to find a balance

All participants stated that making clinical decisions involving pediatric patients with PDOC is extremely challenging, since the decisional process requires finding a balance between multiple factors that are not always compatible with each other (Q#1). One of the challenges identified by most participants is to adapt to a high level of variability in terms of both patients and contexts and, at the same time, dealing with the lack of precise ethical guidelines (Q#2, Q#3). Indeed, they reported that clinical decisions in these situations have always a major ethical component and they underlined that science only provides the "how to", but the decision on "whether to" does not depend only on scientific criteria but also on humanistic and philosophical reasoning (Q#5). Making clinical decisions for these patients requires taking into account what the public opinion is on when it is no longer worth living, and physicians need to anticipate the societal implications of

their decisions (Q#6). An additional difficulty lies in the fact that decisions need to be made fast, especially when it comes to acute events (Q#7). Participants recognized the need to acknowledge one's own feelings, religious and cultural beliefs, and expectations in relation to the type of clinical decision that needs to be made and account for their possible influence (Q#8).

Time is needed for an appropriate qualitative evaluation

In the decision-making process, participants agreed that the three most important variables to evaluate are the etiology, diagnosis, and prognosis of the patient's disease. However, they added that the evaluation of these factors is extremely problematic because it requires a qualitative rather than a quantitative approach, with some referring to diagnosis and prognosis as "fluid factors" (Q#9). Almost half of the participants stated that the evaluation of the patient's consciousness is the most important factor contributing to the path towards the diagnosis of PDOC. However, participants noted that it is the very idea of consciousness that is open to debate and requires a philosophical approach to understand its nature. Again, they noted the need to avoid reducing patients to single categories, but to describe their situation in a qualitative way (Q#10, Q#11). As explained by several participants, such a qualitative approach requires an investment in terms of time (Q#12). The concept of time was reported to be key in allowing both a careful evaluation of the evolution of the disease and their understanding of the relationship between the etiology and the prognosis and how they can be accurate making a prognosis (Q#14).

Between patient's and family's quality of life

Participants reported frustration about the fact that they often do not know enough of the patients' life before the event that lead to PDOC to interpret their presumed wishes (Q#15, Q#16). To fill this gap, half of the physicians stated that they usually consult families, nurses and social workers to get to know the child better (Q#17, Q#18). In the absence of information on the child's identity and alleged will, most participants cited the patient's past, present, and expected quality of life as a major factor to take into account in the decision-making process. Present and expected quality of life was mainly conceptualized as the degree of sufferance the patient might be experiencing, while they reported that past quality of life refers to the activities that the patient was able to carry out prior to the brain damage. However, all participants recognized the subjective nature of the concept of quality of life, stating that its interpretation is often left to those who supposedly know the patients best (Q#19). Most participants stressed the importance of evaluating each single case

within the individual-specific social context where he or she comes from, as it might be difficult for physicians to decide whether to weigh decisions according to patients' quality of life or their families' one (Q#20, Q#21). For a quarter of participants, family's quality of life weighted more than the child's in the evaluation of clinical decisions (Q#22, Q#23). Few participants explained that this was due to the emotional burden of family members (Q#24, Q#25). For other participants, this was justified by the fact that the patient's mother may create a symbiotic relationship with the child (Q#26). However, some argued that this type of symbiotic relationship may result in the exclusion of all other members of the family, including patients' siblings (Q#27, Q#28).

The risk of self-fulfilling prophecies

Participants also reported a high risk of self-fulfilling prophecies (Q#29, Q#30). According to half of the participants, this risk may be managed by physicians by acknowledging what value they attribute to life and the features that life should have to be considered a "good" life, with some arguing that life is not "an absolute value" (Q#31, Q#32, Q#33). In addition, few participants noted that physicians need to acknowledge and respect the value of the patient's family attribute to the patient's life, even when this does not correspond to their own (Q#34).

Discussion

The main aim of this study was to explore physicians' decision-making when managing pediatric patients with PDOC. We found that physicians experienced ambivalence in several domains of care, i.e., time (need to act fast vs. need to wait), goals of care (extending life as a value *per se* vs. avoiding medical futility), and targets of care (patient vs. caregiver), and that they were aware of the factors that may influence their decision-making process.

Our finding that physicians experience ambivalence towards time resonates with evidence that time is a crucial dimension of decision making in the ICU: participants experienced a "moral challenge" in managing the interplay between the two notions of 'Need to wait' and 'Need for action'[19]. Our findings extend this evidence to physicians caring for pediatric patients with chronic conditions mostly managed outside the ICU. Another study that investigated contextual and relational aspects affecting decision-making for patients with DOC identified time as a key aspect[20]. Unlike our results, this study found that physicians experienced a moral tension between the need to give families the time to grasp the events and the need for fair allocation of

resources[20]. Evidence from Ticino highlights physicians' need to find both "enough" time and the "right" time to explain information honestly and efficiently while maintaining patient's hope[21].

We also found that physicians experienced a tension between treating to provide medical benefit vs. treating to preserve life at any cost. As a result, physicians' perception of futility is variable because the decision-making process is highly subjective and likely to fluctuate based on several factors related to the physician involved[22]. Moral distress may result from providing futile treatments when this honors families' wishes[23-27]. Our study provides novel insights by reporting the widespread, accepted tendency by physicians to allow futile treatments in the context of PDOC pediatric patients, when these are requested by their guardians. Our participants seemed to experience a cognitive dissonance. On the one hand, they felt that they must adhere to the concept futility even if it applies to the pediatric patients with PDOC and consequently they would prefer not to pursue certain treatments that may be requested or demanded by patients' families in case of very bad prognostic estimates. On the other hand, they felt that – when it comes to children and adolescents – life should be prolonged at any cost.

We also found that physicians experienced a tension regarding whom their decisions should target. Many participants accepted to prolong life-sustaining treatments despite their futility because withdrawing them could cause detrimental consequences to the patient's legal guardian(s) and their long-term quality of life. This echoes previous evidence describing physicians' full support of parents when the latter were unable to accept the limits to treatment proposed by the former[28], despite frameworks provide justifications for overriding parental decisions[29]. Another study found that parents' feelings of guilt and perceived duty of supervisions play an important role in the long-term quality of life of the families of children with a diagnosis of UWS[30]. Some guidelines advise that the best interest of the patient should correspond with that of the caregiver[31,32]. One study showed that two or more formal meetings would be required to reach a consensus with children's caregivers regarding waiver of therapy, while agreement would be much more immediate, under the same clinical circumstances, if patients were adult[33]. Our results stress the tension between acting in the best interest of the patient vs. preventing harm to his/her carer(s).

A second finding is that most participants were aware of a possible error of undertreatment and its influencing factors, with some of them referring to the risk of a self-fulfilling prophecy. A study finding that nearly 43% of patients diagnosed with a PDOC showed signs of awareness after repeated examination, suggested that factors other than lack of standardized assessment

approaches may influence diagnostic accuracy[34]. The literature has already shown that pessimistic assumptions (or a pessimism bias) regarding prognosis for PDOC patients may become self-fulfilling if premature life-sustaining treatment or resuscitation are withheld on the basis of that negative prediction[35–39]. Other studies suggest that adopting a nihilist perspective by some clinicians with patients with moderate-severe traumatic brain injury may result in self-fulfilling prophecies[39]. In addition to this evidence, our participants reported to have reflected on the possible factors leading to this risk, which include their own cultural and philosophical beliefs as well as their past experiences regarding end-of-life. The literature has found that different physicians' bias may affect clinical decision-making, significantly influence prognostication and early withdrawal-of-care[40–43]. Our finding that some of our participants engaged in a reflective reasoning constitute an element of promising novelty, which takes place rarely, has been shown to counteract the impact of cognitive biases by improving diagnostic accuracy[44].

Physicians' ambivalence towards time can be explained by analyzing the tension between two aspects of the very nature of time. Physicians spend only 20% of their time on bedside care and education[45,46]. To achieve a humanization of patient's care, many have called for the current understanding of time to leave more emphasis on its quality rather than its quantity[47]. This translates in placing more emphasis on active listening of patients and family members[47,48]. Regarding physicians' ambivalence towards goal of care individuals may perceive commission/omission errors concerning pediatric patients to be more morally condemned than with adult patients[49]. As for their ambivalence towards target of care, our findings are plausible because in treating children with PDOC, clinicians are confronted not only with the child's clinical situation but also with the painful experience of the family. It does not surprise that most physicians would be against discontinuing treatment when clinically appropriate, if this was against the wishes of the families[25,50]. Regarding physicians' pessimism bias, the literature recognize the existence of several cognitive biases associated with medical decisions, such as lower tolerance to risk, anchoring effect, commission and omission biases, and information and availability biases[51,52]. Interventions that might reduce the likelihood of cognitive errors include interventions aimed at improving clinical reasoning and decision-making skills, such as reflective practice and active metacognitive review[53]. Beyond the cognitive explanation, philosophy finds in clinical or therapeutic nihilism a possible basis for self-fulfilling prophecies[54]. Doctors are required to avoid the twin traps of overtreatment, on the one hand, and therapeutic nihilism, on the other[44]. False positive or omission errors with pediatric patients are, generally more morally

condemnable. However, it may be equally morally condemnable to add years of suffering to younger than to older individuals. Rather than identifying the "correct traps", physicians should find the "correct prognosis". Our participants seemed to be aware that, to avoid the influence exerted on their judgment by factors that are unrelated to the specific problem, they may have to practice deliberate reflection on such factors[44].

Our results have some implications. From a practical point of view, guidelines should be strengthened by including more details regarding both clinical and ethical management, and address the ethical issues posed by the most recent clinical and technological developments that may further extend PDOC patients' survival. They should present advance care planning as a mandatory criterion for decision-making, and have the removal of suffering at their core. Awareness of the decision-making process should be promoted while meta-disciplinary solutions are implemented through the advice of interprofessional groups and expert ethics committees to protect those who have additional vulnerabilities. The presence of a trained professional in the team would facilitate the development of self-awareness among team members and improve ethical decision-making. In turn, constant, collective decision-making would prevent falling in either the traps of over- or under-treatment. Considering the role of reflective practice and active metacognitive review to reduce medical errors and improve ethical decision-making, medical training curricula should be increasingly focused on developing reflection skills. Physicians treating pediatric patients with PDOC are at higher need for psychosocial support and interpersonal skills training, which would help them provide parents with emotional support and advocacy, limit the risk of cognitive bias, and avoid emotional burnout. Patients and healthcare professionals need 'their' time to arrive at an agreed-upon and ethically justified clinical decision[19]. From a more theoretical point of view, our results ignite the debate on what makes life worth living and raise the question on what qualifies surrogates who are not knowledgeable about patients' wishes[55].

Some limitations of our study are worth noting. A first limitation is that we only included Italian-speaking physicians. The results may thus reflect culture-specific beliefs. However, this allowed participants to communicate in their native language and, thus, freely express their thoughts and lived experiences in a vivid manner. Also, some physicians have been active outside the Italian part of Switzerland/Ticino for years. Furthermore, current SAMS guidelines apply to all physicians based in Switzerland. Second, most of our participants are employed in hospitals in the Canton of Ticino, where cases of patients with PDOC are extremely limited. To address this

limitation, we ensured that Ticino participants had gained substantial experience with this patient population outside of this Canton. Finally, being this a qualitative study with a small sample based in Switzerland, our results cannot be generalized to other geographical contexts, where the decision-making process among physicians may be different both in terms of themes and from an inter-professional perspective.

Conclusions

Our study confirmed that experienced clinicians acknowledge the complex nature and challenge of clinical decision-making of pediatric patients with PDOC. It also highlights the difficulty not only to estimate the patient's prognosis but also to manage risk and uncertainty. Improving current guidelines could facilitate successful ethical and clinical decision-making and increase physicians' awareness of the plethora of factors affecting their decisions. More research should be conducted on what extent being aware of one's own feelings, beliefs and cognitive bias may help decrease their impact, and on opportunities and limitations of disclosing one's own ethical reasoning.

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Conflict(s) of Interest Statement

Disclosure: none

Availability of data and material

The datasets generated and/or analysed during the current study are not publicly available due privacy reasons but data summaries are available from the corresponding author on reasonable request.

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Tables

Appendixes

Table 1. Characteristics of study participants (N=19)

Variable	
Gender	
Female	3 (15.8%)
Age	M= 57 (SD= 8.4; range: 45-79)
Specialty	
Pediatrics	8 (42.1%)
Neurology	7 (36.9%)
Intensive care	3 (15.8%)
Internal medicine	1 (5.3%)
Role	
Medical director	9 (47.4%)
Head of unit	6 (31.6%)
Former head of unit	4 (21%)
Years of experience*	M= 30 (SD= 7.2; range: 19 –45)

*Years of experience are counted since obtaining medical degree

Table 2. Exemplary quotes from the interviews

Themes	**Quotes**	**#**
The struggle to find a balance	*You are walking along a tightrope. You have to take into account social justice, you need to avoid being too invasive, you need to consider the welcoming aspect itself, and it's very difficult to strike a balance between all these.* Interview 12, Pediatrician, age range 51-60	1
	The problem is that there is so much variance among subjects. Contexts are so different, and that makes it is extremely difficult. Interview 16, Intensive care specialist, age range 51-60	2
	We don't have any ethical guidelines for patients who arrive in vegetative state, so issues are addressed on a case-by-case basis; the only guideline is that these cases need to be discussed. Interview 4, Intensive care specialist, age range 51-60	3
	The paradigm is "not being able to communicate as it is usually done". Communication occurs through channels and processes that must necessarily be adapted to the communicative level, which in turn corresponds to the cognitive one. Interview 17, Intensive care specialist, age range 51-60	4
	Science is evaluative, so if a complication arises, science does not tell us if and what to do. It tells us what to do if we decide to do it. But deciding if to do it is an ethical evaluation, not a scientific one. If we decide to do it, science tells us how to do it. Interview 19, Neurologist, age range 71-80	5
	Deciding when life is worth living and when it's not is an extremely difficult and dangerous decision for its impact on society. However, we tend to be a bit	6

	bigoted… On the one hand, we offer simple prenatal screenings for trisomy 21 so that people can decided whether to have an abortion and, on the other hand, we do not want to discuss when life is not worth living. Interview 11, Pediatrician, age range 41-50	
	When you realize the magnitude of the [brain] damage, you have to make a rapid decision. Interview 9, Neurologist, age range 41-50	7
	Every decision is very personal. It may not decide in the same way as a family member or another surrogate. There are situations that must be projected within oneself and need to be contextualized to a larger container that has many things inside: feelings, religious beliefs, our cultural features, our expectations and whatever we have absorbed over time. Interview 12, Pediatrician, age range 51-60	8
Time's asset in facilitating a qualitative evaluation	*That's one of the liquid factors, and liquid is also the prognosis factor because it's aleatory and it's not measurable. Even though there are better and worse criteria for determining prognosis, but in the end, it boils down to something that has a certain extent of arbitrariness, as the quality of life and real vs. presumed patient's will.* Interview 17, Intensive care specialist, age range 51-60	9
	For me being awake, but not self-aware, does not correspond to being alive in the human sense. Life loses the human quality. So, self-awareness, in my opinion is part of this quality. What makes us human? Is self-awareness necessary? Is it sufficient? You need a philosopher here to help you understand. For me, in my vision, self-awareness is necessary. I should have a sufficient level of self-awareness to live, at least in my vision. There should be self-awareness and no	10

	suffering. If I'm self-aware and suffering, no! If I'm not self-aware, no! Then, how much self-awareness you need, where to draw the line, I don't know. Is self-awareness only qualitative or quantitative? We don't know. Interview 1, Neurologist, age range 51-60	
	Basically, you have to understand three or four things. One is to understand the seriousness of the state: when we say coma, when we say vegetative state, when we say minimally conscious state, these are categories, as we said before, and it is our daily task not to give a label, but an as accurate as possible description of the situation. Because, as I said before, leaving aside the psycho-social aspect, where the patient comes from, his/her age… let us stick to the clinical aspects: the clinical situation of each patient is different. Interview 7, Neurologist, age range 61-70	11
	You need to know how to perform the evaluation. For instance, you need to know how to wait. After a head trauma, I can ask a patient to hold my hand tight, but s/he will never do it the way you would do it if I were asking you. You need to wait 20 or 30 seconds and then the patient reacts. Then you need to try more to understand if it was by chance or if it was a real response. So, if one doesn't know that you need to spend time with these patients maybe s/he will say that the patient doesn't react, but instead the patient feels more, s/he just doesn't have fast enough connections to respond in time so that the other understands. Interview 11, Pediatrician, age range 41-50	12
	It depends on the damage and the reason… it depends on the etiology. Whether the vegetative state is caused by a head injury, a tumor, or a prolonged cardiac	13

	arrest. It depends a lot on the etiology, but also on the time between the event and the current situation, so if one day has passed it is one thing, if six months have passed it is another. Interview 13, Neurologist, age range 41-50	
	Let me say something very important: it is always a temporary assessment. If one has taken benzodiazepines, s/he might be very different after six hours. If one has had a stroke maybe.... (short pause) so the assessment needs to be repeated. To be able to evaluate well, especially if you are moving towards the third aspect that is the prognosis, you must see a progress, and this is the third element of the evaluation. Interview 7, Neurologist, age range 61-70	14
Between patient's and family's quality of life	*To what extent do you want that person to survive because it's your need, or because you think that he or she considers his/her life worth living?* Interview 1, Neurologist, age range 51-60	15
	How can you make a decision, when you look into the patient's eyes, when he/she has pneumonia and is sick, if you don't know anything about him/her? And, often, you know nothing or very little. Interview 7, Neurologist, age range 61-70	16
	Usually, in these chronic situations, we tend to rely on parents because, in spite of everything, they are usually the ones who know the patient best, they can pick up on the little nuances. Interview 5, Pediatrician, age range 51-60	17
	In fact, those who are closest to them, that is, parents, or those who work in institutions such as the social workers, are often able to perceive more elements than what a professional such as a doctor might perceive. Interview 6, Pediatrician, age range 41-50	18

	This is such a huge and sensitive issue, because it's such a subjective variable. In the end, it's the family member who interprets the patient's quality of life. Interview 16, Intensive care specialist, age range 51-60	19
	Should we evaluate the quality of life of the family, the mom's, the dad's, or should we evaluate the quality of life of the individual? Here, again, it's very, very difficult. Interview 6, Pediatrician, age range 41-50	20
	You can never say "this is appendicitis" but you need to say "this is appendicitis in a child with this kind of clinical context and this kind of social context". Interview 17, Intensive care specialist, age range 51-60	21
	Therapy is often done for a number of compromises. Treating a patient is something that is done for the benefit of the patient. However, that is also interpreted by the patient's social context, especially family members, and also therapists, social workers, all those who take care of or who want to do the best for these patients. Interview 12, Pediatrician, age range 51-60	22
	These children are in a situation of great precariousness, in the sense that they cannot defend themselves and cannot assert their advance directives or presumed will. Therefore, the patient was represented by the person who was closest to him, i.e., his mother or the social workers who had been following him for years. On the one hand, one might think that because no one is protecting them from their suffering and because they cannot express themselves, it is the duty of the caregivers to "defend" them and make sure that they no longer continue to suffer; on the other hand, however, in the real life, we were so	23

	impressed by the tragedy experienced by his mother that it seemed to us that going against her wishes… she had followed her child with immense love and sacrifices for years… here the beneficence towards his mother, who represented him, prevailed… as if our compassion was stronger towards the mother than the child. Interview 15, Intensive care specialist, age range 71-80	
	On the one hand, I wonder how I can judge this; on the other hand, I have a feeling that people who are very close to these patients, for example, family members and social workers, are not very rational. Interview 2, Internal medicine specialist, age range 51-60	24
	Sometimes, parents' suffering is overwhelming and shattering. Interview 14, Pediatrician, age range 51-60	25
	Sometimes, you need to decide together with the family whether to institutionalize the patient or not. Because, in some cases, families take full care of the patient at home and one of the family members is usually completely devoted to these individuals. Interview 9, Neurologist, age range 41-50	26
	There's not only the issue of the mother, but also the dad and siblings who, it's true, are of lesser importance than the baby and the mother… but they exist too! So, we have something related to beneficence that we are not so sure of, and something related to maleficence that is certainly greater than zero. Interview 4, Intensive care specialist, age range 51-60	27
	It is extremely important to understand and describe what it means to keep a child alive and the consequences of doing it at home. This means intensive	28

	care at home with alarms every two or three minutes, even during the night. A nurse may not available 24/7. You need to also consider the impact this can have on brothers and sisters - who are often forgotten. Interview 11, Pediatrician, age range 41-50	
The risk of self-fulfilling prophecies	*It's quite complicated. We often direct decision towards the negative and not the positive, particularly in severe cases. There is a sort of self-fulfilling prophecy: you move towards the negative, and this prediction affects the outcome because the meaning and behavior align with that and eventually affect all actions. This self-fulfilling prophecy, funnels and influences future decisions, especially in the post coma. And this can create conflicts with the patient. If you can't bring everyone to a shared opinion, it may be that family members want a tracheotomy or so, and often you pursue this desire in order not to break this alliance with the family. The self-fulfilling prophecy is always present and has always a negative meaning. And the problem is that there is big gray area.* Interview 10, Neurologist, age range 41-50	29
	As a statement published in 2007 – but still valid – well puts it, this could be a self-fulfilling prophecy, as expressed by colleagues in the US. In other words, in accordance with objective observations (brain images showing extremely severe and unrecoverable brain damage), physicians made the diagnosis of vegetative state, claiming that the patient has no signs of awareness. Presenting some cases, the authors of the article demonstrated instead evident signs of awareness, although these were not expressed in words. Interview 18, Neurologist, age range 71-80	30

	Where is the limit? I don't know if there is a limit, but we are at very edges of the limits, if any. [...] If life is a value in itself, and that is the only element which you base all your reasonings on, then everything else gets lost. Interview 1, Neurologist, age range 51-60	31
	One of the fathers of resuscitation used to say that we perform excessive treatments on every patient. That is, something that is potentially unacceptable but becomes acceptable only because we save his or her life and, in this way, we justify our actions. [...] With regards to the population under investigation [pediatric patients], it becomes even more complicated because a justification can be easily found with an adult patient: he or she is giving us the mandate to save his or her life. Therefore, even from a moral point of view, we feel justified to harm this patient as long as we save his or her life. A child may have already been through big things, orthopedic surgeries, and now something huge like this... The problem is that the line is extremely subjective. Interview 16, Intensive care specialist, age range 51-60	32
	That is not accepted by everyone, just as the fact that life is, in itself, regardless of an absent neurological state, a value. [...] Speaking of the vegetative state, the problem lies precisely in understanding what good I am doing by keeping the person alive, i.e., is the life of these people a good or not? Does life, as an object of love, have value? Interview 4, Intensive care specialist, age range 51-60	33

Appendix 1. Interview grid

Theme	Question
Definitions	
Persistent Vegetative State (PVS)	• How would you define the Persistent Vegetative State?
Minimally Conscious State (MCS)	• How would you define the Minimally Conscious State?
Comparison between the two conditions	• What are the main differences between the two conditions?
Main clinical decisions in adult patients	
PVS	• Which are the main clinical decisions when managing adult patients in PVS?
MCS	• Which are the main clinical decisions when managing adult patients in MCS?
Main clinical decisions in children patients	
PVS	• Which are the main clinical decisions when managing pediatric patients in PVS?
MCS	• Which are the main clinical decisions when managing pediatric patients in MCS?
Criteria for decision-making	
	• Why do you think different clinical decisions are made in similar clinical situations, but in different hospitals or departments? • Are there guidelines for clinical decision-making with PVS and MSC adult/pediatric patients in your hospital (or in other hospitals in which you worked)? If so, what role do they play in your decision-making process? • Can you think of factors that play a role during your decision-making process and that challenge such guidelines?

Quality of life/health status	
	• What do you take into consideration when evaluating the child's/adolescent's quality of life prior to the trauma/event? • What role does the initial health status of the child/adolescent play in your evaluation of his/her quality of life prior to the trauma/event? • How would you define the quality of life of a child/adolescent in PVS/MCS from birth?
Etiology	
	• What role does etiology play on your decision-making, compared to prognosis? • Think about different etiologies: what difference does it make if the patient had traumatic or non-traumatic (hypoxia) brain injuries from birth?
Diagnosis	
	• What role does diagnosis play on your decision-making, compared to prognosis?
Prognosis	
	• What do you take into account when making a prognosis?
Treatment	
	• What do you consider to be an "aggressive treatment"? • How do different treatments affect PVS/MCS patients' quality of life? • When deciding for treatment, would it make a difference whether the child/adolescent has been in PVS/MCS since birth? If so, how?
Role of family members	
	• Think about the role of PVS patients' family members on your clinical decision-making process: what comes to your mind?

	• Think about the role of MCS patients' family members on your clinical decision-making process: what comes to your mind?
Distributive justice	
	• Do you do anything to ensure that management/treatment costs are equally distributed? If so, what?
Autonomy	
	• What do you think is the best way to respect the autonomy of a child/adolescent in PVS? What do you do? • What do you think is the best way to respect the autonomy of a child/adolescent in MCS? What do you do? • Who should be the guardian of this autonomy? Who, in fact, is?

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