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Ethical Dilemma of Pediatric Traumatic Brain Injury

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Abstract

Head trauma is still globally one of the major causes of children's death. A child seriously injured and suffering from severe head trauma is not only a medical problem for that unfortunate child, but it is a catastrophic problem for the whole child's family. The uncertainty of the outcome and prognosis of such trauma is a fact. Good, prompt, and efficient medical and neurosurgical management should start at the accident site, be maintained during transport to the hospital, and continue to the fullest extent possible, using the best available technology in the hospital. The health care provider should approach the victim's family with sympathy, empathy, and compassion. The treating doctors should employ especially high-level tactics that go beyond basic communication and interaction to calm the family's uncontrolled emotions; however, at the same time, ensure clarity in that complex situation, avoiding false hope or a presumed pessimistic view. Such complex communication skills are badly needed throughout the patient's management.

The aim of this study is to identify, analyze, and discuss the ethical challenges of the management of severe pediatric traumatic brain injury. We also try to reach a consensus on the ethical and professional approaches to such cases.

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INTRODUCTION

Globally, Traumatic Brain Injury still has the highest incidence of all neurosurgical disorders. TBI has a serious impact on the victims, their families, and has a significant burden on the health care system and education systems in all societies and countries. (1)

The adolescent and pediatric age group (0-18 years) has the second-highest number of hospital admissions in European and US hospitals (34). The Years of Life Lost (YLL), the key metric used to quantify the burden of TBI mortality, indicates 184 YLL per 100,000 persons in Europe. The pediatric mortality caused by TBI in Europe is estimated to be 200,000 YLLs. (2)

In the last few decades, researchers at various centers have sought more accurate methods to predict the outcome of TBI. Each type of head trauma seems to have its own characteristics and problems. In cases of pediatric mild head trauma, complete recovery is expected within 6 weeks of the injury; however, 60 % may have persisting symptoms of headache or irritability or other mild symptoms for 30 days, 10% of those cases may continue suffering for 3 months, and 5% they will have several symptoms for a year (3). Not so much is known about how mild head trauma may affect school performance, social integration, and sleeping patterns.

There are several factors which each is having direct impact on the management and outcome of pediatric head trauma, such as:

i. Factors related to the trauma:
   a. Severity of the trauma
   b. Mechanism of the injury
   c. Time span between the trauma and arriving at the hospital to receive medical management

ii. Factors related to the child:
   a. Age
   b. General condition and previous medical problems

iii. Pre-hospital care

iv. The method of transportation and the quality of ambulance service and paramedics

v. Receiving hospital, facilities, and manpower

vi. Initial management in the Casualty Department

vii. The management (OR, ICU)

viii. Rehabilitation (physical, psychological, social)

ix. Follow up

x. Parents and family partnership and support in management

xi. School and friends

In cases of severe head trauma, the problem is serious and has an impact on different facets of the children's and the family's life. From an ethical point of view, the exploration and study of such issues should cover these subjects:

1. Ethical issues related to pediatric patients in particular (emergency management, prognostic uncertainty, long-term follow-up, and outcome)
2. Ethical and professional approaches to the patient's family
3. Cognitive functions and brain development after head trauma
4. Rehabilitation
5. Brain death

One of the basic principles for correctly implementing medical ethics is having a clear understanding of all the facts about any medical condition. It has been said, "Good facts make good ethics". Therefore, in cases of children suffering severe head trauma, when there is uncertainty about the management and prediction of the long-term outcome, there are serious ethical challenges to be dealt with.

Illustrative case:

A 14-year-old, a precious son of middle-aged parents, was a victim of a severe RTA. He was brought to the hospital in a coma, GCS 4, left pupil was dilated but still reacting to light, right eye was not examined because of the severe eyelid edema and subcutaneous tissue. CSF and lacerated pieces of brain were oozing out of his right frontoparietal lacerated wound and fractured skull. The patient was intubated and rushed for a Brain and full-body CT scan. The

CT-Scan showed multiple areas of contusion and gray-white matter loss of differentiation, suspicious of tonsillar herniation and intraventricular hemorrhage **(Figure 1.A)**. The opinion of the attending trauma team was that the patient was potentially in brain death, so there was no need for surgical intervention. So they decided to admit the child to the ICU and treat him conservatively. Both parents utterly refused to accept the notion of brain death and urged to do everything possible for the patient. I was called, and after a tense and emotional discussion with the patient's parents, we pushed the child to the operating room for a decompressing craniectomy and insertion of EVD. We made it very clear that this was the maximum we could do and that we were not very optimistic about the outcome.

After surgery, the patient remained in the ICU and started to show signs of slow recovery. CT-Scan a day after surgery, showed the decompressing craniectomy, injured brain tissue was herniating through the craniectomy site and large areas of law density and contusions, **(Figure 1.B)**. 22 days later, the patient deteriorated, both pupils became dilated, and he was rushed to CT-Scan which revealed a large area of hemorrhagic infarction in the right frontal area, and signs of brain

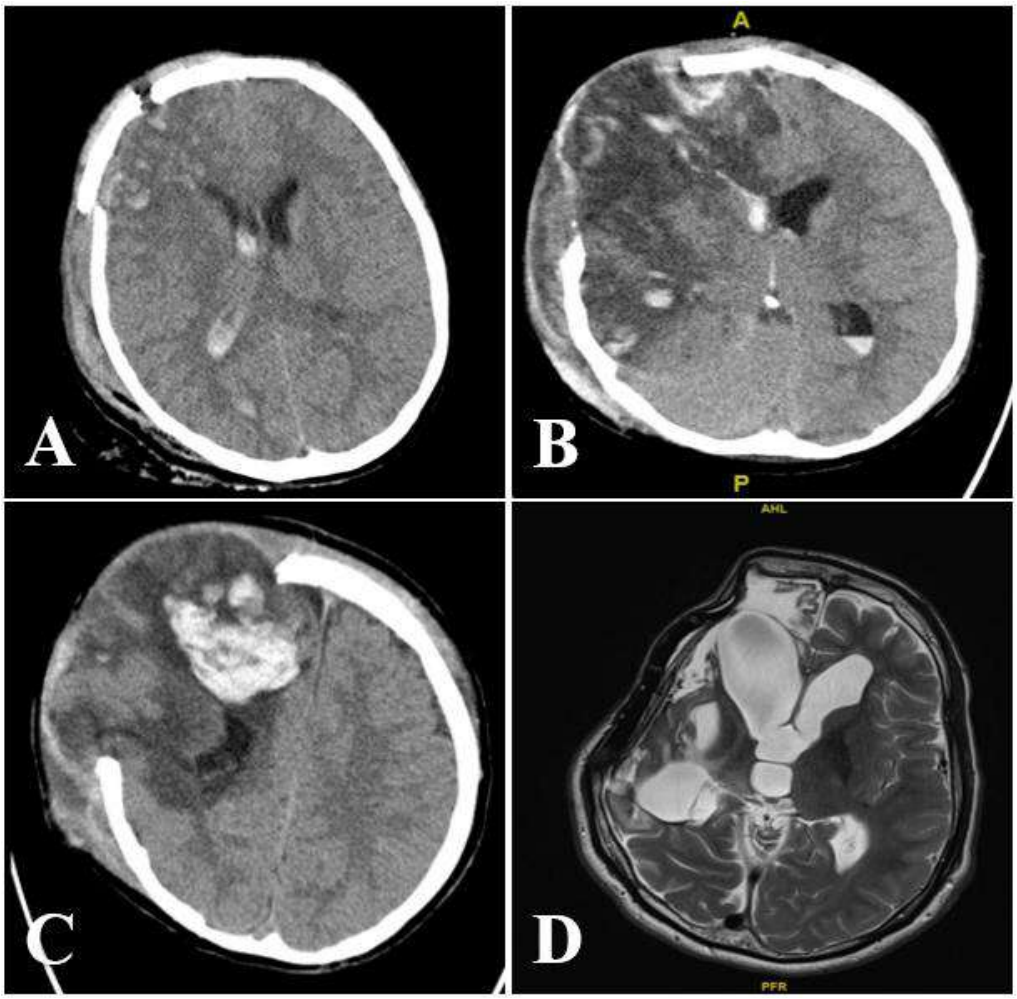

Figure 1: Serial CT scans of a 14-year-old boy, victim of severe head trauma, over 2 years.
Figure 1.A: The CT-Scan showed multiple areas of contusion and gray-white matter loss of differentiation, suspicious of tonsillar herniation and intraventricular hemorrhage.
Figure 1.B: CT-Scan a day after surgery, showed the decompressing craniectomy, brain tissue herniating through the craniectomy site, and large areas of low density and contusions.
Figure 1.C: CT-Scan, which revealed a large area of hemorrhagic infarction in the right frontal area, and signs of brain herniation.
Figure 1.D: MRI after 14 months showed the cranioplasty. The right frontal and temporal lobes are severely damaged; the patient is walking with support and talking.

herniation, **(Figure 1.C)**. We refused to surgically intervene, and the patient was treated with maximum dehydration and methods to reduce the ICP. The child responded, and he remained in the ICU for more than 6 months. The mother resigned from her job, and the father took one year of unpaid leave, which was extended to 30 months of unpaid leave to stay in the hospital near the child almost 24 hours. The patient made a slow recovery.

A year later, the patient started to open his eyes and obey orders, the tracheostomy was removed, and a cranioplasty was performed. The family took the child home and prepared a room for him, stocked with the necessary equipment, such as suction and oxygen. They hired two physiotherapists to provide the child with 2 physiotherapy sessions daily. Six months after discharge, the child came to visit us in the hospital walking, with support, with a marked weakness in the left side, talking, with a disfigured face, neck, and head, and an obvious neurological deficit. The parents were very happy with the outcome, very proud of their child, and continued their own rehabilitation and education at home. 14 months after the trauma, the patient suffered severe sinking skin flap syndrome, so he was operated on for cranioplasty as seen in **(Figure 1.D)**.

This case highly illustrates the medical and ethical dilemmas of pediatric head trauma and the uncertainty of the long-term outcome. It also demonstrates the positive impact of the parents' determination to save their precious child. This case may demonstrate the role and determination of parents to help their child who suffered severe head trauma.

1. Ethical issues should be considered during the management of pediatric head trauma

1.1 The Doctor-family- child complex relationship

The Doctor-family relationship can't be more complex than it is in the cases of severe pediatric head trauma. The emotions, anger, fear, helplessness, anxiety, and sympathy are overwhelming feelings occupying the parents' brains and controlling their behavior and attitude. The treating team facing the emergency should make the right decision at the right time and be prepared to calm the parents and respond to their agony. The general principle of the patient–doctor relationship in adults is that it is a direct relationship; the patient has the autonomy to accept or refuse treatment and to consent to any intervention **(Figure 2)**. In pediatric patients, the patient–doctor relationship must go through the parents or guardians (4,5,6) **(Figure 3)**.

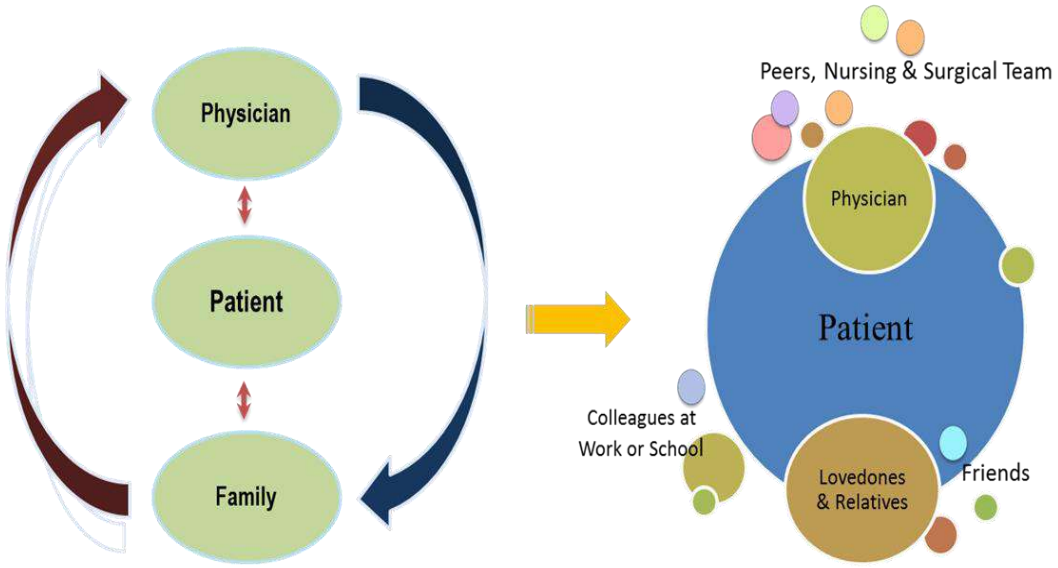

Figure 2. The evolution of the patient-physician relationship, in most cases, should be a direct relationship

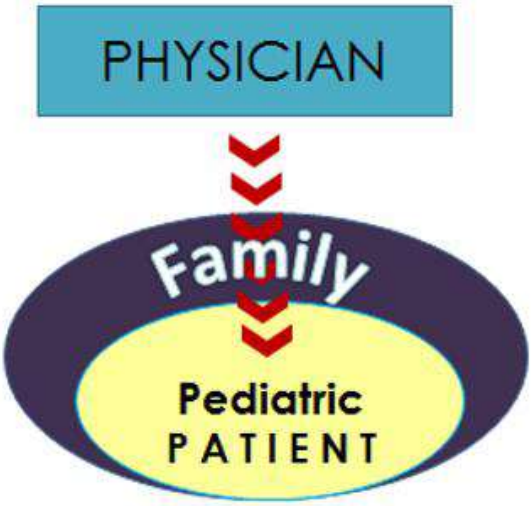

Figure 3. The core of the medical relationship in cases of neonates and young pediatric patients

1.2 Ascertaining the immediate outcome and long-term prognosis

The nature and pathophysiology of variable types of severe head trauma may not help the neurosurgeons to ascertain an accurate prediction of the prognostic outcome of a severely injured child (7,8,9,10,11). Sometimes an accurate or decisive answer can be out of reach. This, unfortunately, is not a rare condition that complicates the discussion, communication, and relationship between the medical team and the patient's family. In most cases, families are agonized and extremely apprehensive, as they are eager to hear answers to their painful questions. It is vital to reach the right diagnosis and full knowledge about the status of such an injured child. (12). The right diagnosis is always the fundamental basis not only for the medical and surgical management of the patient, but also as the base for proper, ethical, and professional communication with the child's family. Usually, families, regardless of their age, culture, religion or race, have similar nagging concerns such as:

- ***Will our child survive the trauma?***
- ***When does our child wake up?***
- ***Can you do something more to help?***
- ***Is there anyone anywhere who can do more? Or is there a better-equipped center to treat this case?***
- ***What is the long-term outcome?***
- ***What kind of neurological deficit may he suffer?***
- ***Will my child be able to go to regular school?***

These questions and others should be expected and answered clearly on a scientific basis, without being pessimistic or optimistic or providing false hope (13,14). The answers should be based on facts, avoiding false hope or unfounded pessimism. The members of the medical teams involved in treating such children should agree between themselves on what to say to the family to avoid any confusion or conflicting answers to the same question. Therefore, it is advisable that the medical team choose one experienced and specially trained to communicate with apprehensive parents. The answers should be evidence-based as much as possible. Unfortunately, there is no class A evidence to predict, with a high degree of certainty, the nature of the outcome at the early hours of TBI (15.16).

1.3 Treating team's ethical obligations

Neurosurgeons, in particular, and the treating team in general, have several ethical obligations in supporting parents. These obligations are summarized as follows:

1. To absorb the parents' shock by offering sympathy, compassion, understanding, and care.
2. Good communication and answering the parents 'questions as clearly, accurately, scientifically and simply as possible.
3. Physicians should make efforts to understand the families' values, concerns, and what they would deem an acceptable quality of life for their child. By doing so, the physician will be able to professionally help implement a mutually agreed-upon care plan that is most consistent with the family's values and wishes for their child.
4. This shared decision-making model encourages ongoing dialogue between the physician and the child's family, and it has been endorsed by

many professional organizations and the Institute of Medicine (4,5,17)

Meeting these obligations is not easy; it hinges on:

a. Developing trust between the patients and their families and the treating medical team.
b. Recognizing and elucidating the parent's values for their badly injured child,
c. Estimating the prognostic accuracy and certainty before making any decision, which can be very difficult task,
d. Effective and continuous communication with the parents to discuss every step of the management and to deliver the prognostic information to the family. This effective communication has a profound influence on decisions regarding goals of care and clinical management of the child, especially when Prognostic information is clouded by uncertainty.

1.4 The certainty of uncertainty- Can the neurosurgeon influence the decision of the parents?

In such situations of acute severe head trauma, parents and loved ones are in the denial stage, refusing to hear the possibility of losing their child. Therefore, the physician or neurosurgeon who directly deals with these families to obtain consent or to involve them as partners in making serious decisions should consider only the medical facts. Parents, as well, are seeking facts to make decisions. Scientifically and clinically, there is very little evidence about the definite outcome of severe pediatric Traumatic Brain Injury. Therefore, the neurosurgeons or the attending physician must provide answers based primarily on personal, local, or, at times, international experience. In general, the trapped neurosurgeon in that situation may have one of two personalities: one that emphasizes the uncertainty of outcomes, or one that emphasizes certain outcomes based on their own experience. Both attitudes of the medical teams may influence the parents' decision and sometimes confuse them. The treating neurosurgeons and physicians should avoid claiming prognostic certainty in uncertain matters to avoid directing the parents' decision. At the same time, they should avoid confusing the stressed parents by giving false hopes (18,3).

Therefore, it is not ethically right to direct the parent to consent to a debatable procedure without explaining the different management options. It is also unethical to provide the patient with incomplete or contested opinions, as these are facts regarding their patient's medical condition, management, and possible outcomes (19,17).

1.5 Parents and neurosurgeons' disagreement- How far should the neurosurgeon go?

In some cases of disparate conditions, parents feel disparate, helpless, and ask the neurosurgeon to do everything possible and impossible to save their child. Sometimes, no reasoning, just a refusal to accept facts and live in a state of denial. Would the neurosurgeon go with them, or face them with facts/ what about if they disagree! In these cases, it is advisable to ask the family to have a second opinion. A second opinion is very welcome in such situations.

2. Effective Communication with Families

2.1 Understanding, appreciating, and respecting parents' values and feelings

Families of critically injured children are emotionally overwhelmed, looking for hope and struggling to navigate a way to help their children overcome the event. There is evidence that a considerable number of these unfortunate families suffer from post-traumatic stress syndrome. (20,21 ,22) Therefore, it is strongly advisable that all the medical teams receiving and dealing with trauma should be trained to deal with and care for such families professionally and ethically. The skills of delivering bad news are important skills to gain and practice. In the literature, there is no consensus on how to deal with heartbroken and emotionally disturbed families. Some researchers favor a direct, rational manner of stating the facts as seen and expected at that

critical time. Others favor a soft approach, acknowledging the disturbed emotional state of these families (17). We favor such a soft, empathic approach.

Effective communication has a profound impact on preparing families to accept difficult decisions, such as withholding resuscitation attempts, and on markedly reducing the risk of medical litigation and being sued later. It is important to be trained to recognize, plan, and document how to introduce the treatment team, inform them about the current clinical condition, what has been done as initially necessary management, what the plan is, and why the medical team chose that plan. (23).

The effective communication strategies should consider several important elements, which are:

1. The language, tone, and way of communication and discussion
2. The venue of the meeting to discuss the case.
3. The family's behavior and attitude, the denying and shocked families, should be recognized.
4. The seriousness of the clinical status of the patient
5. The accurate information about the patient's condition
6. The availability of different methods of diagnosis and management.
7. The attitude of the treating team and their eagerness to do everything possible for the best of the patient. The team should demonstrate that they trust their own skills and knowledge and have prior experience working with such patients.

2.2 Consent, autonomy, and the medical decision

So far, in almost every country, minors and children are not permitted or authorized to make decisions or approve and consent to certain management plans. Parents and guardians are presumed to consider their child's best interests as their primary goal. It is very difficult, even impossible, in such critical situations to expect the parents of a critically injured child to separate their emotions and fears of losing their own child and think rationally for the future of their child. The treatment teams may have an opinion, while families may have different opinions and expectations (24).

Neurosurgeons/ pediatric neurosurgeons, intensivists, ER physicians, and other involved teams should and must respect the patient's and the patient's parents' right to autonomy and consent for the management plan and procedures.

3. Brain Death

The neurosurgeons should be aware that the diagnosis of brain death is not just a simple, regular medical diagnosis. The ICU physicians or neurosurgeons should clearly understand and appreciate that when they write the term brain death in the patient's file, they are, in fact, writing the first sentence of a death certificate with all the emotional, social, and familial litigation consequences. The brain death diagnosis should be confirmed by another team. The neurosurgeons should learn and master the skills of delivering bad news. The family should be taken to a separate room or a quiet corner and be informed about the brain death in clear words without any ambiguous sentences. The parents' feelings should be respected, and their anger should be absorbed.

DICUSSION

Good modern medical practice is popularized as following the principles of Evidence-Based Medicine (EBM). However, good medical practice throughout human history has been, and will be, based on sound values. It is not unusual in daily practice to face a medical problem when the line between right and wrong is unclear. In such a state of confusion, it is important to closely follow the principles of medical ethics and Values-Based Medicine (VBM) (5). The management of pediatric severe Traumatic Brain Injury is a medical, ethical, and professional challenge. Each case should be approached and treated according to its own conditions and to the best abilities and

experiences of the treating team. A good, efficient doctor-family-child relationship is sometimes the cornerstone of successful management of such cases.

One of the serious challenges that the clinicians who are dealing with severe pediatric Traumatic Brain Injury are facing is: How to calm down and answer the questions of the apprehensive and angry families of such children? The families' expectations and hopes for the recovery of their children do not necessarily need to be the same as the expectations and predictions of the treating clinicians. It is rather common to see treating clinicians or neurosurgeons trapped between being unfoundedly optimistic and giving false hope, and being realistic and pessimistic. (25,26,27) The key to unlock such a trap is for treating clinicians to show the family that they do their best, meticulously follow their patients daily, and exercise their autonomy rights to bring the family from watching from the side to being partners in sharing in the decisions regarding the course of treatment for their patient. It is so vital that the treating clinicians show compassion, empathy, and respect for their deep sadness and anxiety. Respecting patients' and families' cultures and values is also important in such situations.

Ethical and professional communication with families should be precise, and words should not have more than one meaning. The ambiguous chat with the patient's family is unethical and unprofessional. The meaning of a good outcome may differ greatly between what clinicians mean and what families expect. Clinicians usually see good outcomes in terms of consciousness, mobility, speech, and recognition of family members. However, higher brain function, cognitive abilities, and the ability to pursue higher education and a future may not be included in that "good outcome" in that context. However, from a family's perspective, these issues are very much in mind, and so is understanding the meaning of "good outcome." (28)

Managing TBI patients who are admitted to the ICU, intubated, and may stay there for a long period, as our illustrated case did! That long stay in the ICU and the occupation of those always-needed beds may place a great burden on that hospital and the health care system in that region. However, acute severe impairment does not always imply poor functional outcome. Some patients with very severe brain injuries can achieve favorable outcomes over time. (29) The management of severe pediatric Traumatic Brain Injury patients in the intensive care unit should be based on the six principles of Values-Based Medicine, which are: autonomy, beneficence, non-maleficence, justice, dignity, and honesty (5)

Another dimension of ethics and management of pediatric TBI is the longstanding sequelae, such as cognitive function deficits, mood and psychiatric disorders, motor deficits, epilepsy, and other medical problems, which show up gradually over time. Ethics advises observing the medical ethics principles and the VsBM principles, and respecting the patient's right to know and participate in decision-making regarding their case. Respecting patients' dignity should be the core of professional medical short and long-term, acute or chronic management and care for this patient. (30,31,32, 33)

It is an ethical responsibility and professional duty to plan for lifelong management of children who have suffered severe or even moderate TBI. Ethical obligations go beyond medical treatment, and hospital care requires societal awareness about the scope of those problems and the required needs of such unfortunate. It is a societal duty to accommodate such children and help them overcome future difficulties,

The withdrawal of medication and turning off the ventilators is in a case of brain death require absolute observation of the international criteria of brain death and avoidance of premature decisions on withdrawal of life-sustaining measures when prognosis is uncertain. It also

requires an ethical and professional dialogue with the victim's family. (34,35)

CONCLUSION

Collaborative efforts are momentous in interprofessional clinical specialties involved in TBI management as emergency, critical care, pediatric, neurosurgery. Clinicians in general, and neurosurgeons in particular, have a duty to treat and manage every neurosurgical patient, including those with severe TBI, to the best of their abilities. During medical and surgical management, they are obliged to support the patients' families. A good and professional commission is key to properly dealing with the families of severely injured children. The treatment teams should be trained, gain the skills to do so, and find a good time to answer frustrated parents' questions about the current clinical condition, medical and surgical plans, and long-term outcomes. The answers should be based on scientific facts and take into consideration the emotional status of the parents who are in fear of losing their child. The questions should be answered very carefully and ethically. Giving false hope should be avoided, as should very pessimistic outcomes without solid, proven evidence. All clinicians should be aware of the uncertainties in the short- and long-term outcomes of pediatric severe TBI. The clinicians should be trained to learn and use the ethics of management of children who suffer severe TBI. A validated set of ethical guidelines should be available and taught to all medical and paramedical staff who may be engaged in receiving and managing severe TBI. The precision medicine approaches should be carefully implemented in such cases.

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