Ethical dilemma in pediatric neuro oncology

Ahmed Ammar, MBChB, DMSc, FICS, FACS, FAANS

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Dr. Admed Ammar
Coordinator, Neurosurgery Dept.
King Faisal University Hospital
P.O. Box 40040
AL-KHOBAR 31952
SAUDI ARABIA

Dear Prof. Ammar,

I have great pleasure in sending you a copy of the 4th draft of the “Guidelines for a good practice in Neurosurgery”. I think that the draft will be approved by the Executive Committee of the EANS during the Winter Meeting, to be held in Istanbul next February.

However, I understand that these Guidelines could be modified in some aspects by neurosurgeons from other countries, due to different points of view. There is time for including comments and remarks coming from other neurosurgeons from other areas of the World.

A few months ago, Prof. Samii, President of the WFNS, has nominated me again as Chair of the Committee for Ethics and Legal Affairs. I’d like you to continue as member of this Committee. I’ve included your name in the list of contributors to these Guidelines. I thank you, in advance, for your kindness. Perhaps, in the near future, we’ll have to develop other activities, concerning these issues. The field is open to suggestions.

With my best wishes for 1998.

Looking forward to hearing from you soon.

Yours sincerely,

Maximo TOZA, M.D., Ph.D.
Chairman of the Committee for Ethics and Legal Affairs of the WFNS
Gran Vía Satrilea, 62-11 H.
30005 MURCIA (Spain)

Fax: 34/48 36 96 78

World Federation of Neurosurgical Societies. European Association of Neurosurgical Societies
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Good Practice: A Guide for Neurosurgeons

Membership of the Committee and Acknowledgements

The Committee for Ethics & Legal Affairs of the WFNS

Professor M. Toza, Murcia, Spain (Chairman)
Dr. G. Ashton, Baku, Azerbaijan
Professor A. Ammar, Alkobar, Saudi Arabia
Dr. J. Bennani, Rabat, Morocco, Argentina
Professor A. K. Banerji, New Delhi, India
Professor P. M. Black, Boston, USA
Professor M. B. Francis, Wollongong, Australia
Professor J. Mendoza-Vega, Santa Fe de Bogota, Columbia
Dr. J. P. Perez-Anton, Italy
Professor L. Rosenthal, Stockholm, Sweden
Professor D. M. Velasco-Sanchez, Mexico
Professor T. Yoshimoto, Sendai, Japan
Professor Y. Zhao, Beijing, People’s Republic of China

The Ethical Committee of the EANS

Mr. R. H. Binnington, London, UK (Chairman and Editor)
Professor H. Arnold, Labeck, Germany
Dr. D. Augustepont, Athens, Greece
Dr. P. Bocci, Budapest, Hungary
Professor A. Cometti, Bagnacavallo, Bologna, Italy
Professor B. Cifaldi, Rome, Italy
Professor G. Greli, Basel, Switzerland
Professor I. Kratochvil, Szczecin, Poland
Professor F. Lemiere, Paris, France
Professor S. M brainstorm, Athens, Greece
Professor G. Schurch, Stockholm, Sweden
Professor B. Schumacher, Vienna, Austria
Professor T. Tonto, Ljubljana, Slovenia
Dr. J. Wall, London, UK

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Mr. C. Ward, Consultant Plastic Surgeon and Honorary Senior Lecturer in Medical Ethics, Imperial College of Science, Technology & Medicine, London, UK.
Professor G. M. Tindale, Institute of Neurological Sciences, University of Glasgow, UK, on the Ethics of Surgical Research.

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Introduction

The relationship between patient and doctor is governed by a number of principles. Above all there is the right of each individual to decide what is done to his or her person. There are the obligations to avoid doing harm to patients, and for any treatment to be potentially beneficial. There is also an obligation to society to use medical resources to provide effective treatment for the greatest number of people in need. These principles may raise difficulties for the practice of neurosurgery, which has the potential to leave patients substantially worse or even disabled after treatment which may have achieved its surgical goal. Further, the resources often used are expensive, thus raising an issue about using these resources fairly and effectively for the greatest number of people. This guide has been produced by the Committee for Ethics and Legal Affairs of the World Federation of Neurosurgical Societies, and the Ethical Committee of the European Association of Neurosurgical Societies to help neurosurgeons to resolve these problems.
Good neurosurgical practice is based not only on evidence, guidelines, and equipment, but also on good judgment. Young neurosurgeons often ask about this and believe they learn the behavior of their teachers in different situations, but for several reasons, this is not enough. This book discusses the ethical issues that arise during the daily practice of neurosurgery. It will be especially informative for neurosurgeons and other surgeons, physicians, residents, medical students, and allied health care providers. The book is not a descriptive expose but an easily readable and highly practical tool map on how to navigate ethically challenging situations in neurosurgery and other practice.

The book is divided into five parts, reflecting general issues, patients rights, end of life issues, neurosurgical specialties, and neurosurgical and society. The chapters are organized to provide an overview of ethical issues in neurosurgery and other disciplines, including general principles and ethical issues in different specialties. They are designed to help neurosurgeons and other health care professionals better understand the ethical issues they face in their work.

The book is a valuable resource for neurosurgeons and other health care professionals who need to navigate the ethical challenges of their daily practice. It provides a comprehensive overview of the ethical issues that arise in neurosurgery and other specialties, and offers practical guidance on how to approach these issues in a way that is ethical and consistent with the best interests of patients.
Major branches of ethics

- **Applied ethics**: about how moral outcomes can be achieved in specific situations;
- **Meta ethics**: about how to determine the meanings of true values;
- **Descriptive ethics**: what people really want that moral values are met;
- **Normative ethics**: about the practical meanings of what is right and what is wrong.
Bioethics

- **Autonomy:** the patient has the right to refuse or choose their treatment.
- **Beneficence:** a practitioner should act in the best interest of the patient.
- **Non-maleficence:** "first, do no harm".
- **Justice:** (fairness and equality).
- **Dignity:** the patient (and his treating team) have the right to be treated with dignity.
- **Truthfulness and honesty.**
Autonomy

Beneficence

Justice

Dignity

Non-maleficence

Truthfulness and Honesty
Child’ autonomy

Case 1

• 13 years old girl, lives with her mother, active intelligent, play regular gymnastic, complaints off and on headache
• MRI showed posterior fossa tumor
• Operated some where; less than 10% of the tumor was removed
• Pathology astrocytoma grade II
• Mother refused to inform the child that there are residual of the tumor
Preoperative

Postoperative
Ethical questions

• Does the child has the right to know (autonomy)
• Is there difference between legal age (age of majority) and ethical age?
• Does the biological father has any thing to say in that matter if he may has different opinion?
Emancipation

- Minors are under the control of their parents or legal guardians, until they attain the age of majority, at which point they become legal adults.

- In most states this is upon turning 18 years of age. However, in special circumstances, minors can be freed from control by their guardian before turning 18.
The exact laws and protocols for obtaining emancipation vary from country to country and even from state to state. In most states, minors must file a petition with the family court in the applicable jurisdiction, formally requesting emancipation and citing reasons it is in their best interest to be emancipated.
• Emancipation is not easily granted because of the subjectivity and narrowness of the definition of "best interest".
• In most cases children are victims of abuse.
• state's department of child services takes very valuable time!!
• What about life and death decision!!
• Is it possible to solve such dispute in the hospital?!
Facts to be considered

• There is no global consensus about the age of majority/ responsibility /adulthood
• Calendar age
• Mental capacity age
• Ethical age *(Best Interest)*
• Family ties and care. Parents love and concern should be considered as well
• Priority is for child’s well being and health
• Is it not strange that there are clear laws about driving cars, open bank account and there is no clear law about the growing children (teenagers) rights to decide for their own health problem and life and death
Health Care System & Medical-Industrial Complex

- Physician
- Patient
- Family

- Peers, Nursing & Surgical Team
- Colleagues at Work or School
- Friends
- Loved Ones & Relatives
Parents/Guardians

Medical Team

Child as a Patient
<table>
<thead>
<tr>
<th>Parents/Guardian</th>
<th>Child as Patient</th>
<th>Medical Team</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Family status</td>
<td>• Cut Age?</td>
<td>• Is the operation necessary?</td>
</tr>
<tr>
<td>• Level of education</td>
<td>• Around 10?</td>
<td>• Is there any other alternative treatment?</td>
</tr>
<tr>
<td>• Emotional and psychological stability</td>
<td>• Mental Capacity</td>
<td>• Is there any way to reduce the risks?</td>
</tr>
<tr>
<td>• Several meeting involving the social worker and patient relation</td>
<td>• Psychological and emotional status</td>
<td>• Second opinion</td>
</tr>
<tr>
<td>• Social workers, Psychologists and Lawyers should be involved</td>
<td>• School performance</td>
<td>• Is the team prepared, qualified and experienced to perform such a risky procedure?</td>
</tr>
<tr>
<td></td>
<td>• Relationship with parents/guardians</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Several meeting with the child to ensure that the child understand fully</td>
<td></td>
</tr>
</tbody>
</table>
Consensus Meeting

• Meeting with the child, parents/guardian, the treating team, pediatric psychologist, social worker and patient relation.
Case 2

- 4 years old girl suffered a sudden attack of severe headache and right side hemi paresis.
- Patient was brought to the ER
- On examination, fully conscious but drowsy girl. She was suffering headache.
- Right side XI and XII nerves palsy
- Right side hemi paresis
- Emergency operation was offered.
Ethical issues

• Informed consent, the child and family have right to ask these questions?
• Special care to answer all the questions with facts and in simple and clear manner
• Psychological and emotional status of the child should be considered
Informed consent

• How to obtain informed consent of patient under 16 years old?
• Witnesses are mandatory
• Who are the witnesses
Family’s demands

Case 3

• Myelomeningocele neoborn is paraplegic and double sphincter incontinent and hydrocephalus.
• Patient was operated to repair the myelomeningocele and V-P shunt.
• The parents requested and insisted to operate their son with insertion of the stem cells, as we have running program for stem cell
• We refused as we had no previous experience with such cases and we don’t have evidence that this method may help.

• The father insisted to take the child abroad and sued the hospital and sued me for refusing treatment their son.

• He requested the government to pay for the coast of treatment abroad!
Ethical issues

- The experimental surgery
- The options for well known and documented bad outcome cases- Is there a hope!
- The media
- The commercial, advertisement and reports on the internet.
- Does the patient right to seek hope even unrealistic hope
- Is it ethical to burn down that hope!
Case 4

- 27 months old girl with gradual decrease of vision.
- MRI showed hypothalamic optic glioma
- We offered biopsy and Chemotherapy
- Family insisted for surgery
- We refused and explained why
- Patient went abroad
Ethical questions

• Neurosurgeons have the right to refuse to operate patients for the **best interest of the child**
• If the family are not satisfied, they should be helped to seek second opinion
Expert witness
Case 5

• If you have been requested by the court to be expert witness and you know about the case and already have your opinion about the case would you accept to write the report?
A GUIDELINE OF QUESTIONING BEFORE BEING CONSIDERED TO BE AN EXPERT WITNESS

- Do you consider yourself as an expert in this field? **YES**
- Do you have access to all relevant materials? **NO**
- Are you knowledgeable about the local legal system? **YES**
- Are you familiar on writing a professional, scientific, legal and factual report? Can you do it? **NO**
- Are you ready to answer all the questions and defend your answers or report in the court? **YES**

Accepted to be an Expert Witness
Conclusion

• Ethical dilemmas are challenge for everyone in his daily practice.
• It is very difficult to make a clear line in some cases between which is ethical and which is breaching the ethics.
• There is need to highlight, workshops, sessions to learn about bioethics.
• Medical Practice in general and neurosurgery in particular is practice based on values and evidence.
• There is a lot of work is needed to clearly define the emancipations laws in health care systems
“Value has a value only if its value is valued”

Bryan Dyson
Case 5

Under treatment and safe surgery

• Can biopsy considered under treatment!
• Partial removal of tumors can be considered under treatment
• Safe surgery! Safe for whom? The patient or the surgeon or both?
• Is safe surgery sort of undertreatment?
Modern Neurosurgical practice should be based on Evidence based medicine and Value Based medicine.
Resolution of Ethical Dilemmas

- Principles
- Ethical codes
- Clinical judgment
- Reasoned analysis
- Ethical committees
- Ethical tests

- Declarations
- Oaths & Pledges
- Commonsense
- Debate
- Ethical Consults
- The Law
Bioethics

• **Autonomy:** the patient has the right to refuse or choose their treatment. (Voluntas aegroti suprema lex.)

• **Beneficence:** a practitioner should act in the best interest of the patient. (Salus aegroti suprema lex.)

• **Non-maleficence:** "first, do no harm" (primum non nocere).

• **Justice:** concerns the distribution of scarce health resources, and the decision of who gets what treatment (fairness and equality).
• Dignity; the patient *(and his treating team)* have the right to be treated with dignity.

• Truthfulness and honesty.
The scope of Medical Ethics

1. development of ethical codes and guidelines
2. promotion of ethical practice
3. prevention of ethical breaches
4. recognition of ethical dilemmas
5. resolution of ethical conflicts
Major branches of ethics include

- Meta-ethics; about the theoretical meaning and reference of moral propositions and how their **truth values** (if any) may be determined;
- Normative ethics; about the practical means of determining a moral course of action (what is right and what is wrong);
Case 3

- 4 years old Saudi patient has been complaining of headache, weakness in the right side and VII, IX, X nerves palsy
- MRI showed brainstem tumor (Diffuse pontine)
- Surgery was offered.
- Informed consent