

Patient Rights and Ethics: Regional challenges and way forward



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Faculty of Medicine

Salim El-Hoss Bioethics and Professionalism Program

المركز الطبي في الجامعة الأميركية في بيروت
برنامج سليم الحص للأخلاقيات الاحيائية والاحتراف

Patients have rights

- We all agree.
- Too wide a topic
- I will focus on a core point, albeit often ignored, stemming from my work with patients.

PATIENT
BILL OF RIGHTS



Human rights in patient care

Right to health

Right to non-discrimination and equality; Right to health

Right to information

Right to bodily integrity; Right to liberty and security of person; Right to freedom from torture and cruel, inhuman, degrading treatment; Right to privacy; Right to health

Right to bodily integrity; Right to liberty and security of person; Right to freedom from torture and cruel, inhuman, degrading treatment; Right to privacy; Right to health

Right to privacy

Right to health

Right to health; Right to life

Right to health; Right to life

Right to health; Right to enjoy the benefits of scientific progress

Right to health; Freedom from torture and cruel, inhuman, degrading treatment

Right to health; Right to non-discrimination and equality

Right to a remedy

Right to a remedy

Absent are

- Right to values
- Law vs Ethics (e.g.. Decision regarding DNR, etc.)

At the core of other rights

- Patients have the right to be involved in decisions about their healthcare.
- For this to happen, patients (and/or their families) need to be involved in deliberations and decisions on matters pertaining to their health which takes into considerations their values, preferences, fears, hopes, etc.
- Unfortunately, although many hospitals in the region speak of patient's rights, they are generally marked by medical paternalism.



- The patient's rights movement has played an important role since the late 1970s in the West
- A voice hardly been heard in other areas of the world marked by medical paternalism.
- This presentation highlights the role of clinical ethics in better patient centered care, a care that takes their rights into consideration.



A Whispering Voice Among A Sea Of Silence
Ric Nagualero
Painting - Acrylic On Canvas

- Most hospitals in Lebanon are now required to have an ethics committee but **none of them offers bedside ethics consultations (clinical ethics consultations).**



- Clinical Ethics plays an important role ensuring patients' rights are respected, patients are better treated and care is better provided (healing vs. curing).



Hospital Ethics Committee?

Final treatment decisions are made between the attending physician and patient or surrogate-decision maker.

However, it is my contention that the role of the EC is wanting without bedside ethics visits and consults.

- Work of the HEC remain detached, unqualified, unskillful and theoretical unless educated by the **voices of patients and members of the healthcare team.**
- They are akin to teaching ethics through case-vignettes. The particulars are lost and hence decision making is wanting and the patient is betrayed.*

* Arawi, T. Using Medical Drama to teach biomedical ethics to medical students in *Medical Teacher*, 2010, 32: 2205-e210.



A Closer Look at Case Consultations



- “The central purpose [of an ethics consultation] is to improve the process and outcomes of patient care by helping to **identify, analyze, and resolve ethical problems.**”



John C. Fletcher, Ph.D., quoting the consensus statement of the Consortium for Evaluation of Ethics Case Consultations, Chicago 1995. Journal of Clinical Ethics 7(2) 1996.

Director of the Center for Biomedical Ethics at the
University of Virginia

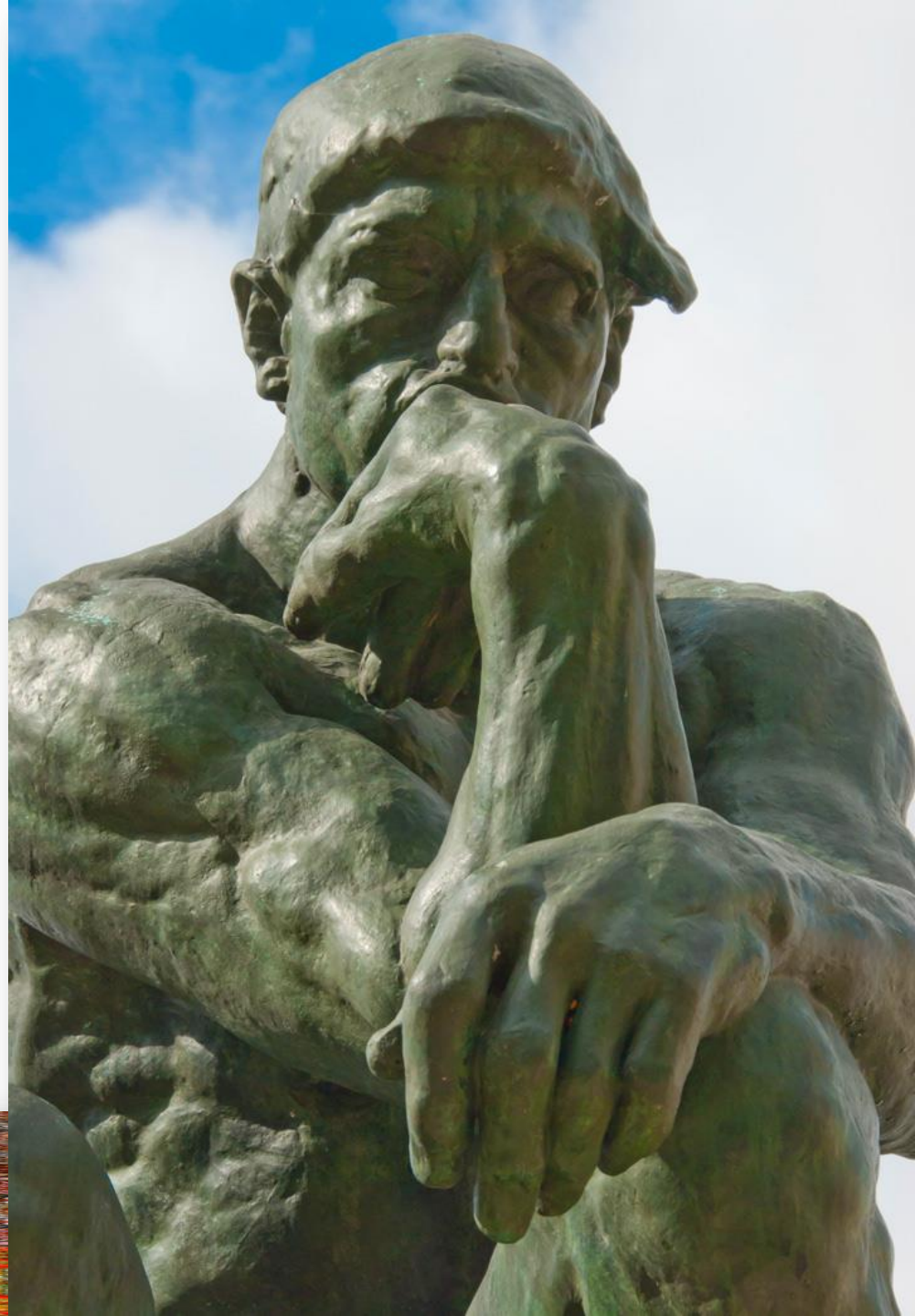


This necessarily means that:

- All members of the healthcare team working with the patient listen to each other
- .. and to patients



Listening is an
“active verb” and
requires being
attuned to cues.



AUBMC-MCEC



AUBMC-MCEC

- An advisory group **appointed by the Medical Board upon the recommendation of the Chief of Staff.**
- Multidisciplinary



Functions of a Clinical Ethics Committee

Education

facilitate educational opportunities for health care professionals, patients, and their families.

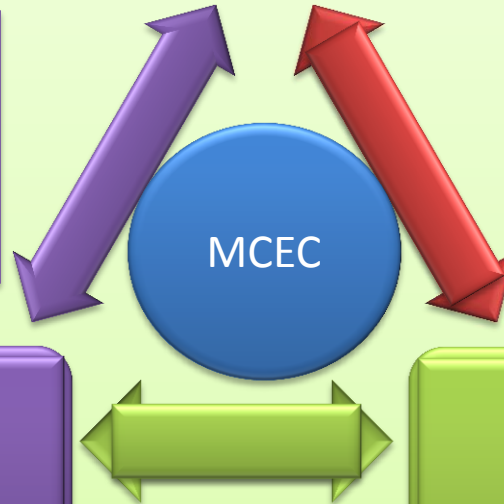
provide consultative services regarding ethical issues pertaining to a specific patient.

Case Consultation

MCEC

discussion and evaluation of policies and procedures having ethical implications.

Policy



AUB-MC Medical Center Ethics Committee

Between 2005 and 2011, 5 cases were referred to the medical center Ethics committee for recommendation.

**All related to
removal of life
support.**



**Facing an ethical dilemma while caring for your patient
or while being cared for? You are not alone!**

Consult the Medical Center Ethics Committee (MCEC)

Contact:

Chief of Staff (Dr. Hassan El Solh, Pager 0619, Ext. 5995, email
hassan.solh@aub.edu.lb)

Chairperson of the MCEC (Dr. Adnan Mroueh, Ext 5612, Pager 575, email
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Secretary and Social Service Manager (Mrs. Wafa Khansa, Ext 6713, Pager 1603,
email wk09@aub.edu.lb)

For more information, visit our website <http://www.aub.edu.lb/fm/shbpp/mcec/Pages/index.aspx>

AUBMC leading in Bedside Ethics Consultations-

<http://www.aubmc.org.lb/Pages/AUBMC-leading-in-Bedside-Ethics-Consultations.aspx>



December 2013- December 2015

- 50 bedside ethics consultations
- Called for by:
 - Attending physicians
 - Residents
 - Nurses
 - Patients
 - Not counting informal consults by med 3-4.

End of Life Issues
DNR
Feeding
Tracheostomy?
Going ahead with surgery
Bed sores
Termination of pregnancy
Healthcare and severe depression
IVF
Ambiguous genitalia
AMA
Malpractice?
Decision making-competency
Euthanasia
Postmortem (?) sperm retrieval
Transplant
Overdose
Surrogacy...

As a member of the medical team, the CEC often serves as a facilitator and negotiator, a listener and a guide.

Unveils concerns and salient ethical issues

Joins forces to offer a set of possible scenarios/solutions for the patient and attending

One case will be shared to illustrate this



Walking the
extra mile.. Is
it really an
“extra mile”?

The case of Baby Sami



Baby A

- 5 years and 6 months of age.
- Born with ambiguous genitalia, mentally challenged, nearly blind, cannot communicate, hardly hears, does not respond except with a few smiles. He cannot eat or move. Has several strong seizures, developed hypothyroidism, reflux, underwent fundoplication, is fed via gastrostomy tube.
- He also suffers from cardiomyopathy



- Neurogenic bladder, urine infection, diarrhea, dehydration and respiratory distress, becoming overweight though on low calorie diet.
- Presented to the ED ashy and hypotensive and bleeding from upper GI.
- Always in need of intubation (on a 6 month basis, then 3 month basis, then 2 months, by the time of the consult, every 20 or 15 days, he gets ill, admitted to ED, and intubated.
- Tracheostomy ?
- Consult called for by Psychiatrist and Pediatrician



Clinical Ethics Consult

- Parents religious people and sole caregivers.
- Abandoned by their respective families who refuse to see the boy.
- In financial debt, conjugal life affected (this is their first baby).
- Mother attempted suicide.
- They are depressed and seeing a psychologist.
- Father studying religion under one sheikh to whom you insert a tube even if it will prolong life for one hour or one day. That Sheikh refused to listen to any background information, even to the medical facts of the case.
- → troubled and confused parents.



What was done

- Meetings with team
- Meeting with parents
- Moral tension (medical, psychological, trumped by religious): → Dar El Fatwa and gave the medical psycho-socio-economic and medical background.
- Meeting at with Sheikh: healthcare team (CEC, attending, resident, parents).



Parents

- Father: “we do not want to be involved in decisions, just make them, we do not want that burden” -this was discussed during the consult and they understood the importance of shared decision making for them and for the team. They also appreciated it and thanked us for involving them.
- “Thank you for surrounding us and listening to us.. We had concerns.. We were not comfortable”.



The consult helped in bringing the medical team and the parents closer to each other in terms of understanding the situation on both sides.

The **process** *of the consult and discussion helped all people involved to take time and reflect on what they were thinking and what decisions they were making. At the end, everyone was comfortable with the course taken.

Attending of the case

* *My emphasis*



We felt understood, dignified and
cared for.. That our son was cared
for.

We do not know how to thank
you.. Words fail us..



The wishes/values/preferences of the patient/family should be taken into serious consideration. If not, consent is elusive and autonomy undermined.

Sensitive probing and discussion might allow the patient/family a chance to think them over again and to appreciate that the medical team is on their side.

- Average consult time - 3 hours. Often several meetings.
- Chart

- Parents, physicians, nurses, etc. call on personal mobile whenever they need to. They often contact the CB for discussion of related concerns and urgent issues. → Finances → MCEC.

Success stories because of the commitment and dedication of the medical team to the entire process.



- At the age of 13, Sami died.. Just when his parents brought to life a new baby girl.
- They wanted the entire same team to care for the pregnancy, for the delivery and insisted on having the clinical bioethicist there.. And all through the care of their daughter.
- Replacing attending ... fear... CEC role... Thanks.



Symphony

- When healthcare teams (regardless of their dedication) work in isolation, the process of resolution of an ethical issue does not really materialize.
- It is only when ALL voices are heard that the tunes fit together to create the needed harmony that will lead to better choices, better decisions and greater patient satisfaction.



Lessons Learned



- No two *cases* are exactly alike
- Patients have concerns that they are “afraid” or “shy” to talk about. These affect their understanding and decisions.. They need to feel a safe space.
- Important to be able to read the non-verbal cues. These are the hidden but important thread in the tapestry.
- Family members might be overpowered by one member (or vice versa). Their voice will not be heard. They await for the right moment to be probed, to feel it is OK to speak up. If not, they will carry the burden and the guilt and whatever decision they make, it will not be really free.



Unhappy stakeholders





The CEC is like a steersperson

- Reflecting on his paintings Monet once said that it is the parts that give insight into the whole. The same can be said about our experience of ethics consultations.
- The voice of the patient and/or his/her family (along with that of the healthcare team) are the fabric that constitute the tapestry.
- One hole/ flaw and the tapestry is either damaged or completely destroyed.





Thank you

- Arawi, T. Using Medical Drama to teach biomedical ethics to medical students in Medical Teacher, 2010, 32: 2205-e210.
- John C. Fletcher, Ph.D., quoting the consensus statement of the Consortium for Evaluation of Ethics Case Consultations, Chicago 1995. Journal of Clinical Ethics 7(2) 1996.\
- Judith Andre, Bioethics as Practice (UNC Press, 2002), pp. 17-18.
- Patricia Talone, “Catholic Health Care Ethics Consultation: A Community of Care,” HEC Forum. 2003; 15(4): 323- 337
- AUBMC leading in Bedside Ethics Consultations-
<http://www.aubmc.org.lb/Pages/AUBMC-leading-in-Bedside-Ethics-Consultations.aspx>
- Can you read people’s emotions? New York times,
http://well.blogs.nytimes.com/2013/10/03/well-quiz-the-mind-behind-the-eyes/?_php=true&_type=blogs&_r=0
- Hospitals in Lebanon, Banque Bemo, June 2013,
<http://www.bemobank.com/files/Hospital%20Industry%20Report.%20June%202013.pdf>
- WHO, Lebanon National Health Accounts, 2000
http://www.who.int/nha/docs/en/Lebanon_NHA_report_english.pdf
- Cohen, J and Ezer Tamar; Human Rights in Patient care: A theoretical framework. Health and Human Rights, 15 (2) 2013. pp.7-19.