When Doctors Become Patients: What is bioethics and Why is it important?

Robert Klitzman, MD Director of Masters in Bioethics Program Professor of Clinical Psychiatry College of Physicians & Surgeons & Mailman School of Public Health Columbia University New York, NY Advances in biotechnology and biomedicine are increasing

## But pose complex ethical, legal and social questions

– e.g., What we can do vs. what we should do







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# THE CASE FOR KILING EXCESSIVE END-OF-LIFE CARE

CURBING EXCESSIVE END-OF-LIFE CARE IS GOOD FOR AMERICA BY EVAN THOMAS

I WAS A TEENAGE DEATH PANELIST BY JON MEACHAM

PLUS

THE WAY OUT OF AFGHANISTAN BY FAREED ZAKARIA THE ROOTS OF THE NEXT CRASH BY NIALL FERGUSON OBAMA'S CREDIBILITY GAP BY GEORGE F. WILL

## **Difficult Choices**

- Genetic testing
  - Who should know your genetic results?
- "Designing babies"
- Editing genes of embryos
- Enhancement ( "Steroids in Sports")
- Drug Company Scandals
- End-of-life care
  - Whether one should "pull the plug"

## Difficult Choices (continued...)

- Preparing for epidemics the next Ebola, SARS, or...
- Rationing of health care
  - Who should get ICU beds?
  - How much health care, if any, should governments provide to everyone?
- How much should we decrease health inequities?
- How much should the government oversee or regulate research?

## **Genetic Testing**

- When should genetic testing be used?
- What if low predictive value/only slightly increased risk of disease?
- What if low or no clinical utility?
  - How low in each case warrants use?
- Examples:
  - Alzheimer's disease?
  - Autism?
  - Traits such as intelligence?
  - Musical ability?
  - Athleticism?
  - Homosexuality?
  - Risk taking?

## **Public Health Ethics**

#### Disaster preparedness

- Rationing/triage
  - How do and should decisions be made?
- Public health vs. clinical ethics
- Questions of justice
- Role of the state vs. individual liberties?
   How much?
- Who should be quarantined and when?
- Definition of a health "crisis"?
  - What if ongoing? (e.g. AIDS)

Who should decide, and how?

 Need for public engagement
 Transparency
 Not increasing disparities

 Can contribute to better understanding of health and medical practices

### Neuroethics

fMRIs as "mind reading"
"Lie detecting"
Revealing subconscious thoughts and prejudices

## Moral and Ethical principles

- 1. What are our moral and ethical principles?
- 2. Where do our moral and ethical principles come from?
- 3. What do we do when they conflict with each other or with other goals?

## **Hippocratic Oath**

Classic translation of the English:

- "I swear by Apollo the Physician and Asclepius and Hygieia and Panaceia and all the gods, and goddesses, making them my witnesses, that I will fulfill according to my abilities:
- What I may see or hear in the course of treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep myself holding such things shameful to be spoken about.

#### I will keep the sick from harm and injustice.

- I will neither give a deadly drug to anybody if asked for it, nor will I make a suggestion to this effect.
- Similarly I will not give to a woman an abortive remedy.
- Whatever houses I may visit, I will come for the benefit of the sick, remaining free of all intentional injustice, of all mischief and in particular of sexual relations with both female and male persons, be they free or slaves.

If I fulfill this oath and do not violate it, may it be granted to me to enjoy life and art, being honoured with fame among all men for all time to come; if I transgress it and swear falsely, may the opposite of all this be my lot."

## Non-Western Medical Ethics

#### Shamans:

- Not systematic texts
- Explanatory systems often belief in "magic"

#### India:

- Ayurveda
- Classic Sanskrit texts
- Buddhist beliefs and practices

#### China:

- Confucius texts
- Other ancient medical texts
- Tao (e.g., Yin/yang)
- Buddhism

## Non-Western Medical Ethics

#### Similarities:

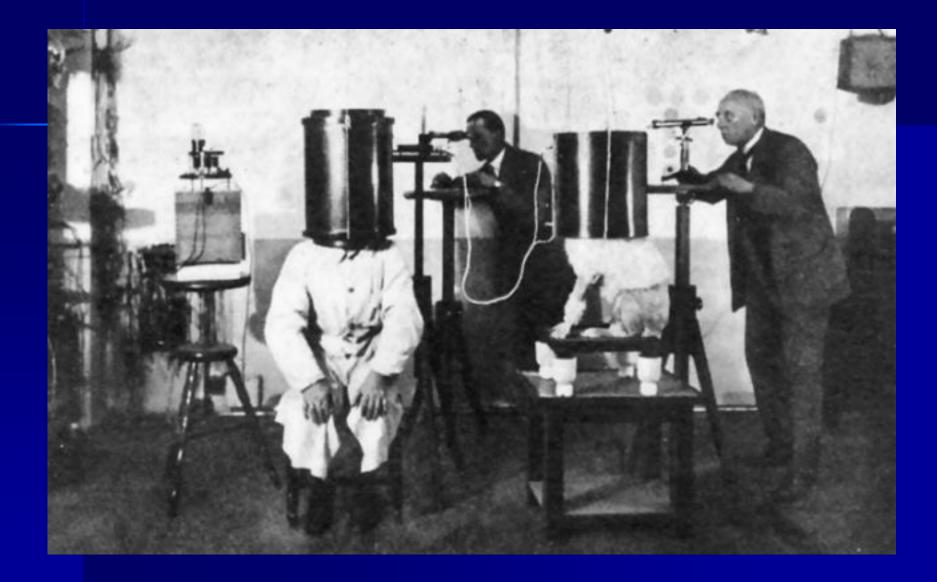
- Broad ethical principles:
  - Practice of medicine as a moral enterprise
  - Importance of "truth," "compassion"
- Differences:

- No formal social organization of a "profession"
- No notion of "autonomy"
- Differing applications in certain situations:
  - Do not treat enemies of the king
  - Respect for cows
  - Treat only your own social class

## Non-Western Medical Ethics

#### Questions:

- When, how change "tradition"/culturally sanctioned practices and beliefs?
  - e.g., Precepts against abortion
    - Established before "modern", safer techniques



## Japanese Army Unit 731





## Importance of medical professionalism

Professional competence is the habitual and judicious use of communication, knowledge, technical skills, clinical reasoning, emotions, values, and reflection in daily practice for the benefit of the individual and community being served. – — Epstein and Hundert (1)

## **Belmont Report**

Prepared in 1979
 Basic ethical principles and guidelines:

 Boundaries between practice and research

Basic ethical principles applications

## **Basic Ethical Principles**

- Autonomy/Respect for Persons
  - Individuals should be treated as autonomous agents
  - Individuals with diminished autonomy are entitled to protections
- Beneficence
  - Do not harm.
  - Maximum possible benefits, and minimize potential harms
- Justice
  - Fair distribution of burdens and benefits of research.

## Questions about Ethical Principles

- How to integrate and apply them in specific situations?
- Can reasonable people disagree in their interpretation and applications of these principles, if so, which should be done?

## **Other Principles**

Justice
Dignity?
Communitarianism?

## How should principles be weighed?

Virtue ethics

 Be a "righteous person"

 Deontology

 Do what is inherently right

 Consequentialism/Utilitarianism

 Maximized benefit

## **Critical questions**

How do these priniciples apply:

- In the work and lives of health care providers
- In interactions and communication with patients
- In health policy (e.g., distribution of resources)

## Needs for multi-disciplinary approaches

Importance of understanding the viewpoints of others

- To enter into others' points of view
- Can help providers
  - Understand their patients' points of view
  - Reflect on their patients' experiences
  - Can promote empathy and professionalism

#### WHEN DOCTORS BECOME PATIENTS



ROBERT KLITZMAN

### **Goals:**

- To understand the experiences of physicians when they become patients due to serious illness
- What challenges they face
- How they address these
- What insights and lessons do they provide:
  - For other physicians
  - For patients

### Methods

Interviewed 75 physicians with serious illnesses

Semi-structured qualitative interviews

Used Grounded Theory

## Results

A series of challenges:

- Becoming a patient
- Being a patient
- Treating other patients

## **Becoming a patient**

- Resisting the role:
  - Perceived stigma of illness
    - "I wear a magic white coat"
  - Often delay seeking treatment
  - Post-residency disease
  - Not taking good care of themselves or seeking help from others
  - Not getting regular check ups
  - Seeking help=inability to cope or perform their job

## **Being patients**

- Becoming more aware of patients' perspectives and challenges:
  - Screw-ups in care: medical errors
  - "Non-specific" symptoms and "routine" tests
  - Physical plant
  - Hospital food
  - Loss of dignity
  - Poor communication
  - Desires to please doctors
  - Importance of touch
  - Definitions of a "good patient"
    - Not complain

Changed awareness: experiences of time

Patient time vs. doctor time
Waiting rooms
Experiences of time

How soon is soon?

Getting results to patients sooner
Waiting = Suffering

#### **Psychiatric problems**

Depression
Anxiety

"I've become like a social worker"

Sexual side effects

Looking at <u>risks and benefits</u> differently:

 "Research-level" medicine?
 Double standard?

 Not ignoring side effects
 Seeing errors
 Second opinions as taboo

## Coping

#### Taboos

- Depression
- Anxiety
  - "I've become like a social worker"
- Being "Macho" vs. okay to cry
- Stigma of seeming "weak"

#### **Self-doctoring**

- Self-diagnosing
  - "I didn't look at myself as I would a patient"
- Self-treating
- Self-prognosticating
- Questions of professionalism

#### Denial systems/collusion

- Wearing scrubs in the hospital
- Preping one's own chemo
- Bringing one's laptop to the ICU
- Colleagues don't confront the "doctorpatient"
- Doctors' families cannot successfully challenge them

#### **Choosing doctors**

- Empathy is more important than they had thought before-hand
  - Except in certain surgeries
- Reputations not born out
- VIP treatment vs. Loss of privacy
- Picking doctors
  - What is a good doctor?
  - "Good taste"
  - Different styles

## **Telling others?**

Disclosure difficult to: - Colleagues - Work-friends - Bosses "Don't want to know too much" - Patients Peripheralization

## Workaholism

- Being "super-doc"
  - "If I busy helping others, I won't get sick or die"
- Gives meaning
- Structure
  - Got rewards
- Self-perpetuating
- Excuse not to have a social life/deal with family
- But shortcomings
- Worked while they were sick
  - The few that took a sick day felt guilty
- Health viewed as reflection of competence

#### Interacting with patients: "Us" and "Them"

- Trying to reduce the hierarchy
- But still important
- How close to be
- Detached concern/questions of boundaries
- Changes made
  - Adherence: less hard
  - Not practicing what one preaches

## **Spirituality & religion**

Some doctors had dismissed it
 Not easy

 "I wish I could believe"
 But most believe in something

#### Themes concerning spirituality

Continuum of contents of beliefs

- Following a religious tradition
- Wariness of organized religion
- Ritual without acknowledging belief
- Mixing beliefs
- Non-specific beliefs
- Spirituality as involved in health events

#### Continuum of forms of spirituality

- Being spiritual to start, and not changing much
- Seeking and becoming more spiritual
- Spirituality despite oneself
- Being spiritual, but not thinking of oneself as such
- Wanting, but being unable to believe
- Continuing to doubt

## Implications:

Importance of understanding:

- Cultural contexts, views, representations and framing of disease and treatments
- Others' perspectives on these phenomena
- How views of disease and treatment have changed over time

## Helping patients

- Empathy: Can it be taught?
  - Yes/No
    - But can teach skills
  - No "routine" tests
- Giving results sooner
- Giving bad news:
  - <u>Not</u>: "There is nothing we can do for you"
  - <u>But</u>: "Your life will be different"
- Empathy as a daily challenge:
  - <u>Not</u>: "Do you have any questions?"
  - <u>But</u>: "I'm sorry I've kept you waiting"
- Sitting down with chart
- Play acting empathy/the caring doctor

## **Implications for:**

Medical Practice: - Individual physicians - Health care institutions Education of: - Providers – Patients - Institutions Research

# Important aspects of professionalism

What are the appropriate roles and responsibilities of physicians? - Coping and self-care: Not taught in medical school Discouraged by much of the medical profession Essential

#### Needs for research:

- How doctors and patients do and should make decisions about these issuesHow policy makers should make decisions about these areas
  - What unintended consequences may occur?
- Do these issues vary across individuals and cultures, and if so, how?

# What Can be Taught in the Bioethics

- Philosophy of Bioethics
- History of Bioethics
- Clinical Ethics
- Research Ethics
- "Genethics"
- Public Health Ethics
- Neuroethics
- Reproductive Ethics
- Global Bioethics
- Law and Bioethics
- Empirical bioethics

## Conclusions

#### Bioethics:

- Rapidly expanding field
- Integral part of clinical medicine and public health
- Can contribute much through:
  - Practice/care
  - Education
  - Research
  - Policy

#### WHEN DOCTORS BECOME PATIENTS



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#### **Questions?**

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## "Best practices"

Physicians should:
Select a personal physician who can perform regular check-ups
Individual physicians lack self-treatment or self-medication

## Retirement

- Difficult to confront
- Ambivalence
  - Some worked harder when they became sick
- If not working, what are you?
  - Are you what you do?
- Some:
  - Reinvented themselves
  - Volunteered
  - Taught others
  - Used skills in other ways.
  - Spend more time with family

#### The medical profession should

- Promote health and wellness among physicians
- Establish appropriate mechanisms to detect impairment
- Intervene in a supportive fashion
- Refer and/or report impairment if necessary