Protecting trust in a patient-physician relationship in the changing era of modern bioethics

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Introduction

- Medical profession is existing for thousands of years
- Hyppocratic oath exists for approximately 2300 years
- In medical shools physicians-professors teach medical students not only medical knowledge and skills but also nurture values as humanity, respect, humility, fighting for the patient's best interest
- With the advances of modern medicine in the 20th century, after WWII and later, new medical and ethical challenges have arisen, leading to the birth of modern bioethics whose priorities and views in some segments are different from the old ones

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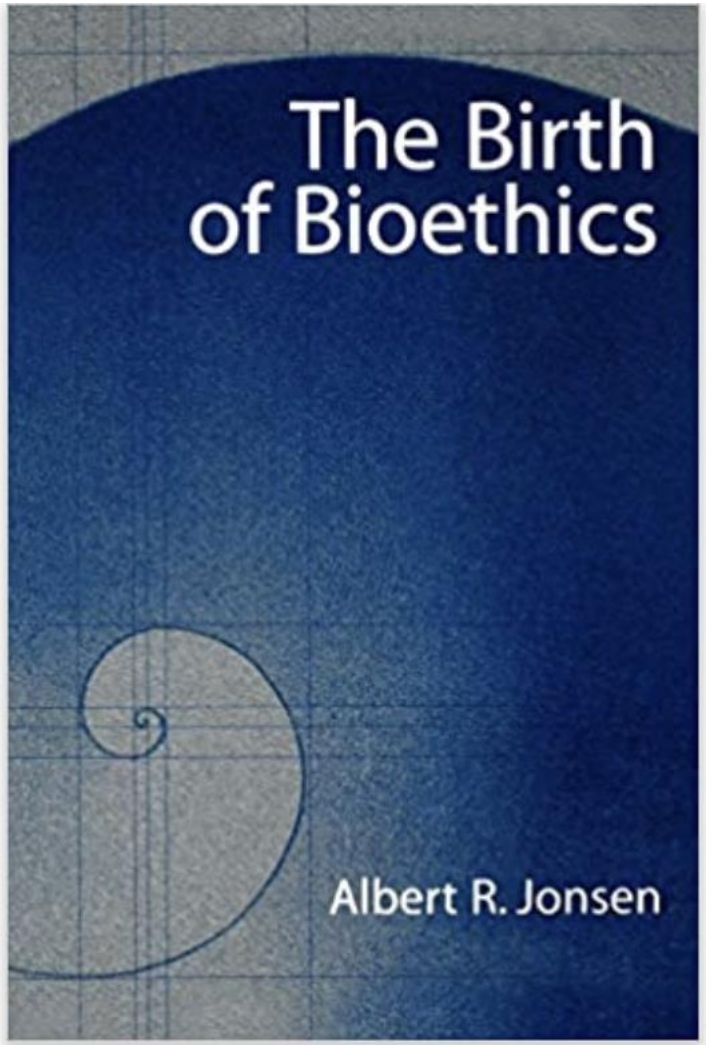

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Part II: **Bioethical Beginnings: The Problems**

http://www.nephjc.com/news/godpanel

Life Magazine, November 9, 1962: Shana Alexander

Seattle God's committee: who should receive maintenance hemodialysis therapy

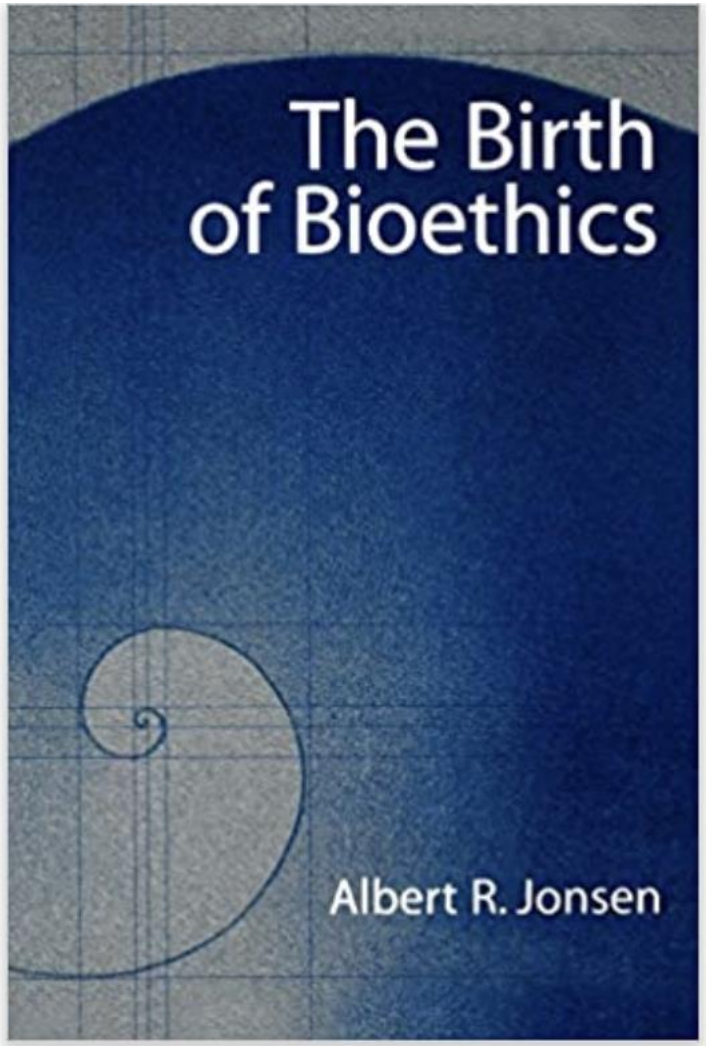
- 7 members (6 males, one female): layer, priest, syndicate representative, banker, public servant, and a physician (surgeon)
- Age limit: 45 years
- Children were not accepted to hemodialysis (supposing that hemodialysis would be too traumatizing)
- Prescription of dialysis 2x12 hous per week

http://www.nephjc.com/news/godpanel

Life Magazine, November 9, 1962: Shana Alexander

Seattle God's committee – criteria for acceptance to the hemodialysis program

- Sex, marriage status, number of persons to care for
- „Net worth"
- Emotional stability, profession
- „Past performance, future potential"
- Medicare Kidney Disease Entitlement: The 1972 Amendments to the Social Security Act extended health insurance coverage to people who have Chronic Renal Disease (CRD) and require dialysis (including peritoneal dialysis) or kidney transplantation.
- **President Nixon signed the bill on October 30, 1972**



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- Respecting patient's autonomy
- Beneficience
- Non-maleficience
- Justice/Fairness

Informed consent as a guarantee for patients autonomy
Physician's "paternalism" is viewed negatively, as interfering with patient's autonomy

Weight put on each bioethics principle is critical

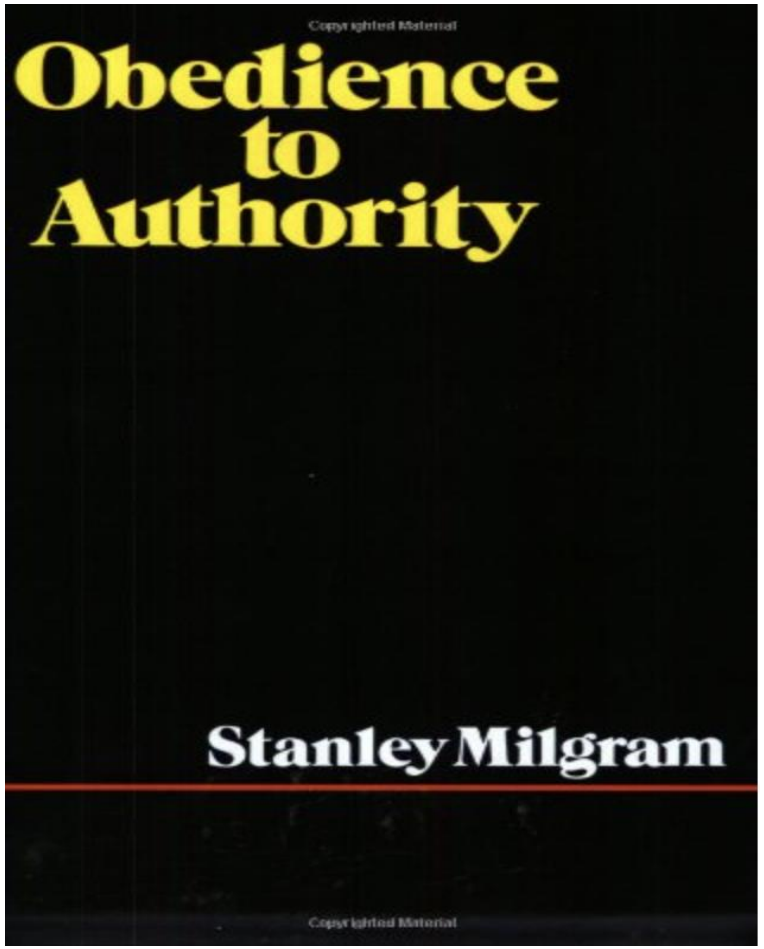
- As generally in life and medicine, right balance (“prava mera”) is critical to find the optimal solution and reach optimal decision
- However, weight put to the principle of “autonomy” has become occasionally, or more and more often, too disproportionate in medical decision-making
- Wise interference or suggestions from physicians in the best interest of the patient may be stigmatized and condemned as “paternalism”
- In increasing number of countries when patient request from physician to terminate his life or perform mutilation and irreversible surgery, even in a minor to change gender, is considered ethical, all in the context of respecting patient’s autonomy, neglecting the fact that, for example, brain maturation in minors is not completed, or that patient can change his mind in future, or that “sickness is the biggest thief of autonomy”*

MEDICAL ETHICS

Consent or Obedience? Power and Authority in Medicine

Eric J. Cassell, M.D.

N ENGL J MED 352;4 WWW.NEJM.ORG JANUARY 27, 2005



- We are responsible for knowing, what patients are doing out of obedience rather because it is best for them
- The biggest thief of autonomy is sickness
- **One of the functions of medical care is to help patients reassert their autonomy including their ability to make authentic decision**

From legal point of view (civil law) physician - patient relationship in the context of autonomy is viewed as consumer - provider contract

- However, signed informed consent before high risk procedure does not release physician or hospital from responsibility
- Explanatory duty from “unbiased” physician today is very demanding (from legal point of view), requiring a lot of time that does not exists in busy physician’s schedule
- Who is “unbiased” physician? Do patients want ”unbiased” physician?
- I want physician to tell me what he will choose for himself or his nearest they would be in my situation
- I want physician who cares for me, who understands and respects me as a whole and unique person and not physician blindly following momentary guidelines for a specific diagnosis that addresses “average” patient that doses not exist
- That’s why we need physicians, otherwise virtual person or artificial intelligence could offer treatment options to be chosen
- I want physician who will fight for me, as I fight for my patients and teach my students to do so
- The final decision would be mine anyway, my autonomy would not be jeopardized by his “paternalism”

Caplan AL. Why autonomy needs help? J Med Ethics May 2014; vol. 40, No5

bioethics

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DOCTORS HAVE NO RIGHT TO REFUSE MEDICAL ASSISTANCE IN DYING, ABORTION OR CONTRACEPTION

JULIAN SAVULESCU AND UDO SCHUKLENK

Keywords
autonomy,
professionalism,
interests,
justice,
law,
euthanasia

ABSTRACT
In an article in this journal, Christopher Cowley argues that we have 'misunderstood the special nature of medicine, and have misunderstood the motivations of the conscientious objectors'.[1] We have not. It is Cowley who has misunderstood the role of personal values in the profession of medicine. We argue that there should be better protections for patients from doctors' personal values and there should be more severe restrictions on the right to conscientious objection, particularly in relation to assisted dying. We argue that eligible patients could be guaranteed access to medical services that are subject to conscientious objections by: (1) removing a right to conscientious objection; (2) selecting candidates into relevant medical specialities or general practice who do not have objections; (3) demonopolizing the provision of these services away from the medical profession.

But isn't the consience the soul of medical profession?

RESEARCH LETTER JAMA Pediatrics Published online October 17, 2022 E1

Gender-Affirming Chest Reconstruction Among Transgender and Gender-Diverse Adolescents in the US From 2016 to 2019

Illustration of patients' autonomy in real life

Rishub Karan Das, BA
Galen Perdikis, MD
Nyam Al Kassis, MD
Brian C. Drolet, MD

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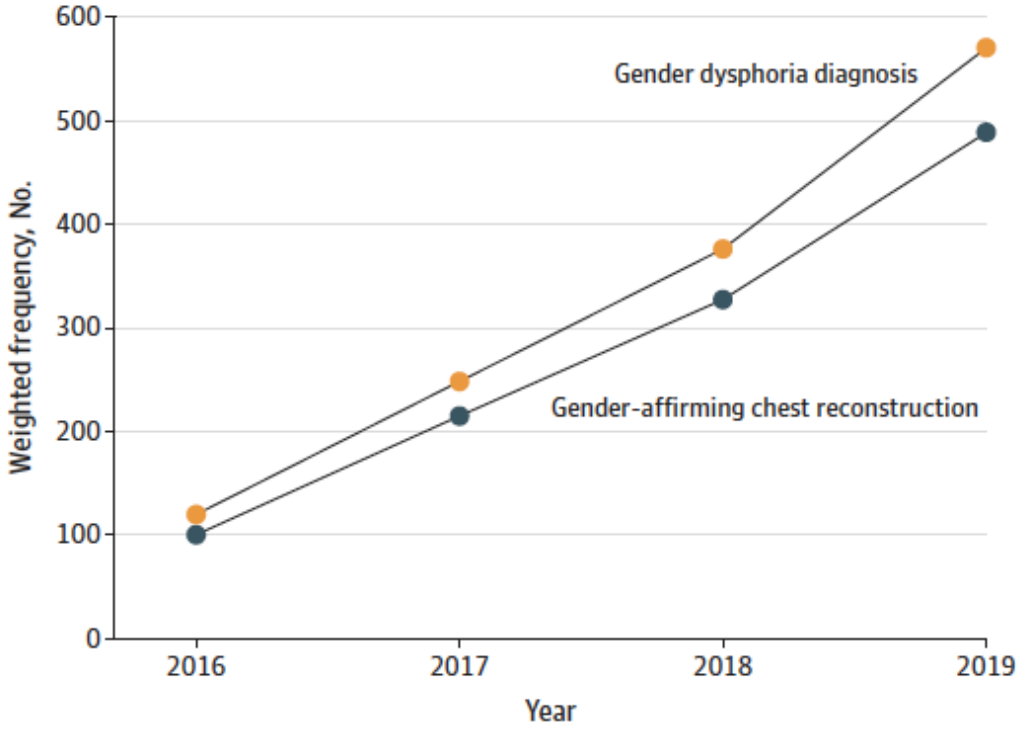
Figure. Temporal Trends in Ambulatory Gender-Affirming Chest Reconstruction in Adolescents From 2016 to 2019



Results | A weighted estimate of 1130 encounters (1114 [98.6%] masculinizing and 16 [1.4%] feminizing) for chest reconstruction were included. Between 2016 and 2019, the annual number of gender-affirming chest surgeries increased by 389% (100 in 2016 vs 489 in 2019; $P < .001$) (**Figure**).

Most gender-affirming chest surgeries were covered by private health insurance (61.1%; 95% CI, 52.0%-69.4%) (**Table**). There was no significant change in health insurance coverage during the study period. The median (range) age for gender-affirming chest reconstruction was 16 (12-17) years. Of the

News > Medscape Medical News

Doctors Have Failed Them, Say Those With Transgender Regret

Alicia Ault

March 14, 2022

Don’t trust therapists

Therapists and physicians who help them transition are harming them for life based on something they would have grown out of or overcome without permanent damage

- Lack of evidence-base, informed consent without proper explanatory duty
- You need a really, really good evidence base in place if you’re going straight to an invasive treatment that is going to cause permanent damage to your body
- **Activist-driven, not evidence based medicine**
- **A huge feeling of institutional betrayal**

https://www.medscape.com/viewarticle/970223

Motivation and Emotion, Vol. 29, No. 4, December 2005 (© 2005)
DOI: 10.1007/s11031-006-9017-x

Imagining the End of Life: On the Psychology of Advance Medical Decision Making[1]

Peter H. Ditto,[2,5] Nikki A. Hawkins,[2,3] and David A. Pizarro[2,4]

Published online: 20 July 2006

Near the end of life, individuals often become too ill to express their wishes about the use of life-sustaining medical treatment. Instructional advance directives (i.e., livings wills) are widely advocated as a solution to this problem based on the assumption that healthy people can predict the types of medical treatment they will want to receive if they become seriously ill. In this paper, we review a large body of research from the psychological and medical literatures that challenges this assumption. This research demonstrates that across a wide variety of decision contexts people show limited ability to predict their affective and behavioral reactions to future situations. We outline several ways that policy and law regarding the use of advance directives could be informed by this research, and suggest a number of issues involved in advance medical decision making that could benefit from additional empirical and conceptual attention.

KEY WORDS: advance directives; medical decision making; predictive accuracy; affective forecasting.

The story of administrative assistant

10+ years ago, University Medical Centre Ljubljana, Outpatient Unit “Poliklinika”

- Friday, approx 1.30 p.m., two nephrology outpatients unit working
- Nephrologist with a nurse and administrative assistant work in each unit
- Unit 1 has just been closed, nephrologist has left
- The last patients in Unit 2 has been examined, the report is to be completed
- Administrative assistant from unit 1 entered unit 2 office, bringing patient’s documentation and saying: “Doctor, please do sometnih, young women will die, she refuses dialysis, she has signed all the papers and is now waiting for tranfer to go home. Her potassium is high, she may not survive until Monday”

- After brief look at the lab and ultrasound data, it was obvious that the it is end-stage kidney disease (kidneys completely shrunken). The lady urgently needed hemodialysis.
- Administrative assistant said that all of them have tried to persuade the lady to go to dialysis, but her refusal was very determined.
- At the hallway, the lady and her husband were waiting for the transfer to home
- I have approached them, tried to explain her that she urgently needed hemodialysis or will die soon, however, she said she would rather die, the husband fully supported her
- I decided to call head nurse from transplantation centre, ask her to come to outpatient unit immediately, explaining the situation and asking her to take the lady to catheter insertion and hemodialysis procedure as soon as possible, without extensive discussion

- Nurse has come immediately, kindly hugged the patient and took her to dialysis center in the main building of our hospital, with husband following them
- Interventional nephrologist was already waiting for her in the dialysis center intervention room, hemodialysis catheters were inserted, dialysis monitor was already prepared in the “grey zone” of dialysis center, and hemodialysis was started
- All intervetions were performed without any resistance from the patient, she was fuly cooperative
- Dialysis procedure was completed after 3 hours, without adverse events, the lady has received her regular hemodialysis schedule and transfer to and from dialysis center arrangement
- After completing first hemodialysis session, the lady has left dialysis centre, coming regularly 3 times per week, never missing a session
- Few weeks later we have started work-up for the waiting list for kidney transplantation from a deceased donor

- Approximately a year later she received a kidney from a deceased donor, still functioning well today

- I’ve met her many times, she always looked happy, full of life, smiling. We had always some “small talk”, never mentioning “that” Friday.

Who saves one life saves the world entire....

- Key person saving lady's life was administrative assistant from our hospital. She was not focused only to her administrative job, she cared for the patients, she was determined to fight for the patient's life
- However, full responsibility for NOT respecting patient's directive was physician's
- Have we respected patient's autonomy?
- Were we paternalistic?
- Was it "good" paternalism? Or bad?*
- Have we actually given her a chance to fully take advantage of her autonomy?
- Should we be stopped by the piece of paper signed by a patient in stress, scared and confused? ("The biggest thief of autonomy is sickness.")
- Would it be better for us to say: It's Friday, let's go home, she made and signed her decision, we should respect that....?

*Caplan AL. Why autonomy needs help? J Med Ethics May 2014; vol. 40, No5

Instead of conclusions

- Trusting patient-physician relationship is core value of medicine and should remain so
- Physician-patients relationship is under great pressure in the era of modern medicine and modern bioethics
- Administrative, legal, insurance and other burdens to physicians are leading to burnout, including measuring individual physician's efficiency
- Hyperproductive medicine cannot protect and enhance trust in a patient-physician relationship
- We should fight to protect trusting relationship together with our patients
- The focus for the fight in this moment is also the fight for the protected time and space for an intimate talk with the patient, being in harmony with the legal obligation of explanatory duty
- "The fact that the patient gave an informed consent usually will not prevent him from suing; a warm relationship with a competent and caring physician usually will."*

*Kenneth Boyd. The imposibility of informed consent? J Med Ethics 2015; 41: 44-47. doi: 10.1136/medethics-2014-102308

- At University Medical Center we’re fighting to increase the number of hospital physicians, to improve quality of care and to decrease the burden to individual physician and avoid burnout
- From January 3, 2018, until October 31, 2022, we have increased the number of specialists from 863 to 1012
- During these difficult times we have fought together, medical directors and heads of our departments, to employ young physicians, one by one
- I believe that we have very good balance between senior and junior physicians and all in between, to exchange our knowledge, skills, experience and our values
- I believe we should continue in this direction, fighting to protect trusting physician-patient relationship for generations to come

Philosopher assisted suicide and euthanasia

Carl Elliott

Legal euthanasia and assisted suicide are beginning to look inevitable, yet many doctors seem uncomfortable with the idea. The BMA has opposed legalising euthanasia and so have many states and national medical organisations in the United States. A recent bill making Australia's Northern Territories the world's first jurisdiction to legalise active euthanasia was bitterly opposed by the Australian Medical Association. Even doctors who want to make euthanasia legal often say that they would not want to participate.

In this, as in other things, philosophers think differently. While there is certainly not unanimity among them—some moral philosophers express deep concerns about euthanasia—academic philosophers have been prominent among those arguing for ethical and legislative changes in current euthanasia policies. Philosophers have rightly pointed out that euthanasia brings about a quicker death for patients who are suffering, and on humanitarian grounds this is preferable to a more prolonged death. Philosophers have also argued, again persuasively, that it is difficult to make rational moral distinctions between withdrawal of life sustaining treatment, which doctors have come to believe is ethically acceptable, and active euthanasia, which many doctors apparently believe is not. Philosophers rather than doctors reflect the views of the public, which in many countries seem sympathetic to the idea of physician assisted death.

When a majority of the public and philosophers support euthanasia and assisted suicide but doctors do not, there is a clear solution: let philosophers do the job. Legislation should authorise philosophers to perform euthanasia and assisted suicide. Lethal injection is a technically uncomplicated procedure that philosophers could easily learn to perform. It is already employed in several United States jurisdictions as a means of capital punishment without the aid of doctors. Assuming that the customary safeguards proposed to prevent abuse of a euthanasia policy could be implemented, this proposal would remedy the problems that make doctors worry about a policy of active euthanasia and assisted suicide.

The reasons many doctors give for opposing active euthanasia have become familiar: it would contravene professional oaths and codes of ethics, violating the moral norms of a long professional history; it would damage the relationship between doctors and patients, casting doubts in the minds of patients about the goals of life and health to which their doctors are committed; and it would be a step down a slippery slope leading to morally objectionable forms of euthanasia, such as involuntary euthanasia for the disabled.

"Legislation should authorise philosophers to perform euthanasia and assisted suicide."

slide down the slippery slope. And they have the additional advantage of failing to see the distinctions that doctors see between withdrawing life sustaining treatment and administering a lethal injection that prevents doctors from endorsing the latter.

Some philosophers may think that their background and education have not supplied them with the training necessary to carry out euthanasia. This may well be a legitimate worry. But many doctors feel the same way.

Euthanasia has not traditionally been a major focus of medical education. Indeed, apart from the technical knowledge that would ensure that death is swift and painless, it is not entirely clear what the relevant skills to perform euthanasia would be. Whatever

As many philosophers also realise, there is a difference between thinking it best that something should happen and thinking that you should do it—between thinking that it would be best if a person were to die and thinking that you ought to kill him or her. The latter involves questions of personal moral responsibility for ending a human life that philosophers may be reluctant to take on. If

"Euthanasia has not traditionally been a major focus of medical education."

Physicians should never forget…

- That we’re part of the team, that all our doings are observed and critically discussed not only by patients but by all surroinding us, nurses, administrative assistants, cleaning ladies etc, our reputation depends on all of them (“word of mouth”)
- Legal obligation of explanatory duty is an opportunity, to enhance trust of the patient who needs us
- This trust is buoid by telling the truth respectfully and understandably, by ackowledging that prognosis at the level of individual patients is never 100%, to give aupanje utrjujemo s tem da na spoštljiv in razumljiv način govorimo resnico, da se zavedamo da na ravni posameznika prognoza pogosto ni možna, da bolniku ki je v stiski dvignemo moralo, da mu pokažemo, da nam je prav za tega konkretnega bolnika ki sedi pred nami mar, in da ga ne jemljemo kot še enega na tekočem traku
- Za to potrebujemo pogoje, potrebujemo čas, in za te pogoje se moramo boriti in si jih priboriti

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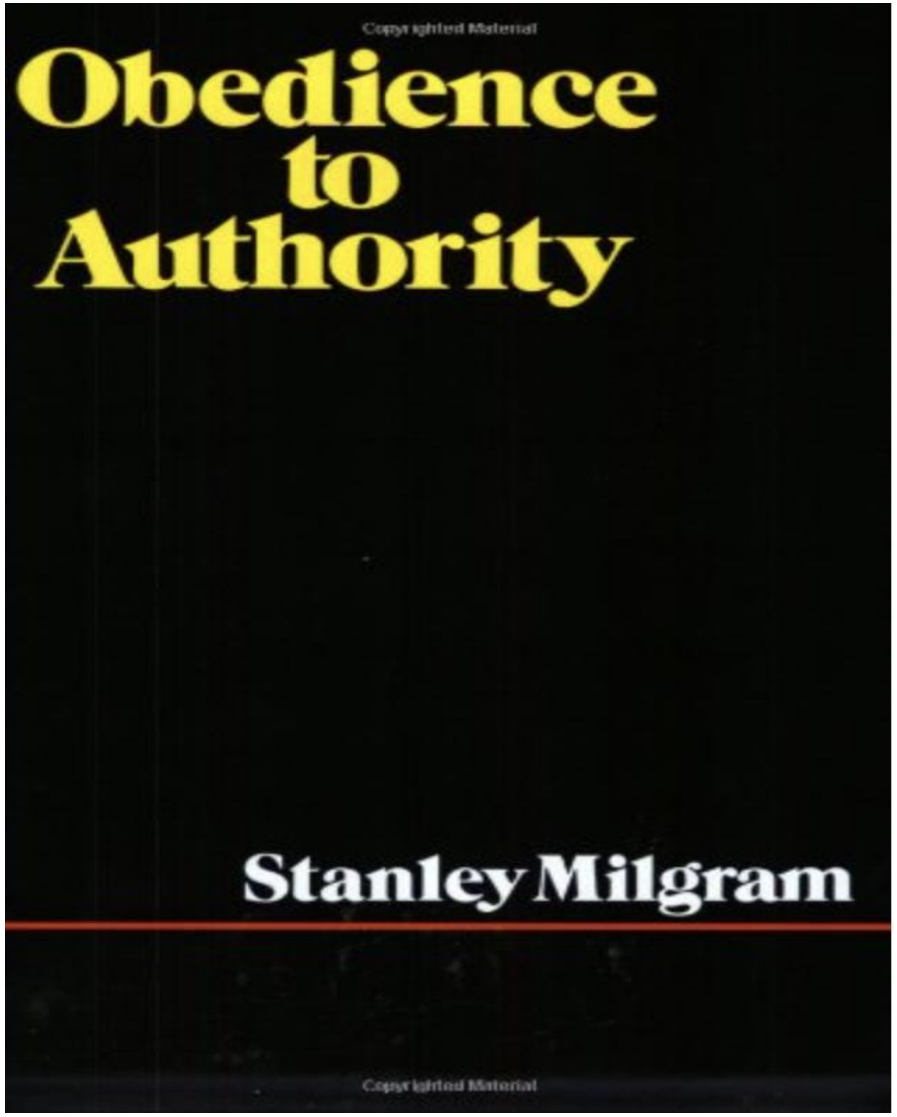

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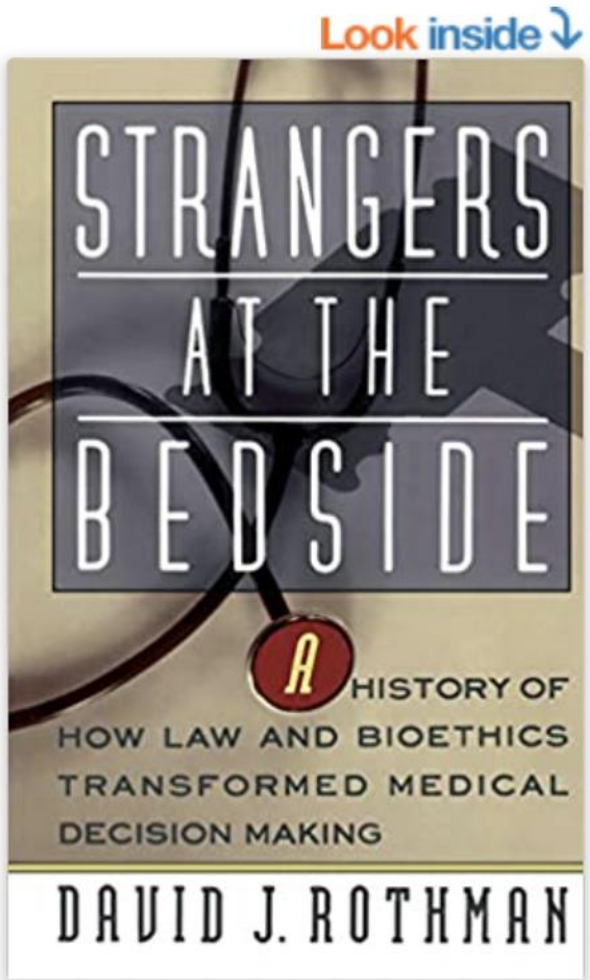

Strangers At The Bedside: A History Of How Law And Bioethics Transformed Medical Decision Making

by David J. Rothman (Author)

★★★★★ 14 ratings

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What caused physicians in the USA to confront committees, forms, and active patients? Tracing the revolution that transformed the doctor-patient relationship, this book takes the reader into the laboratory and the examining room, tracing the development of new technologies and social attitudes.