HOW ETHICAL PRINCIPLES APPLY TO THIS WORKSHOP

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SETS OF ETHICAL PRINCIPLES

Al Jonsen, Clinical Ethics 1982

Beneficence
Non-Maleficence
Justice
Autonomy
Utilitarianism: The intention to effect a greater balance of pleasure over pain in the experiences of a person, of a population, or in the world.

Joseph Fletcher Introduction to Clinical Ethics 1993

Beneficence
Non-Maleficence
Justice
Autonomy
Norms of Family Life
Relationship between Clinician and Patient
Professional Integrity
Cost Effectiveness
Issues of Cultural and/or Religious Variation

Beauchamp and Childress, Principles of Biomedical Ethics 1989

Beneficence
Non-Maleficence
Justice
Autonomy

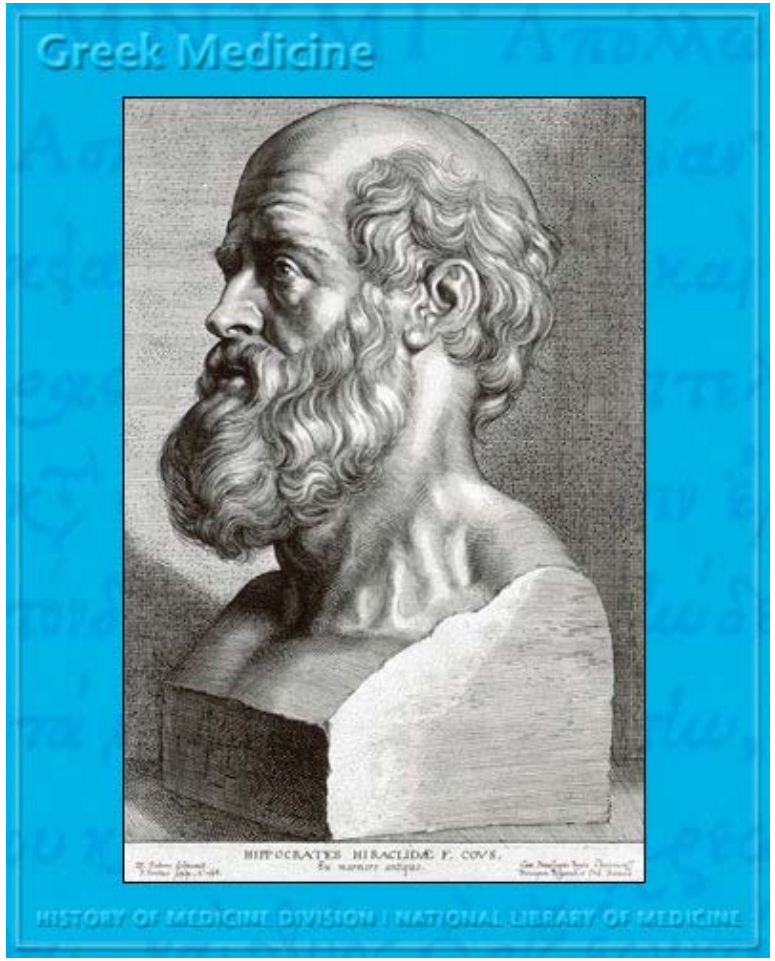
ONLY THREE PRINCIPLES NEEDED TO CAPTURE THE MAIN ETHICAL ISSUES

Non-Maleficence

Autonomy

Justice

NON- MALEFICENCE IS BEDROCK OF MEDICINE



The Hippocratic Oath, circa 500 BC, defined the essential values of Medicine:

To Benefit the Sick

First Do No Harm

IF A PHYSICIAN HAS NO EVIDENCE, HOW DOES HE/SHE DECIDE TREATMENT?

Best Clinical Judgment

“the elderly receive either untested treatments, inadequate treatment, or even none at all, at the **whim** of their clinician**”**

Fentiman, *et al.* Cancer in the elderly: why so badly treated? Lancet, 1990

“**Arbitrarily** decrease the dosage of conventional chemotherapy”

Lipschitz DA et al Cancer in the elderly: basic science and clinical aspects. Ann Intern Med, 1985

“…treatment decision-making based on **assumption, observation, conjecture and even bias.”**

Kearney, N., & Miller, M. Elderly patients with cancer: An ethical dilemma. *Critical Reviews in Oncology/Hematology*, 2000

LACK OF EVIDENCE MAKES "DOING NO HARM" EXTREMELY DIFFICULT

"Lack of evidence affects cancer care on multiple levels. It impedes the ability of oncologists to deliver optimal treatment to older patients by forcing them to extrapolate from data collected in younger, healthier patients; places older adults at serious risk of negative health consequences"

Levit, L. A., et al, . Expanding the evidence base in geriatric oncology: action items from an FDA-ASCO workshop. *JNCI: Journal of the National Cancer Institute*, 2018

PATIENT AUTONOMY

RIGHT OF ADULTS TO MAKE INFORMED DECISIONS ABOUT THEIR OWN **MEDICAL CARE**

AUTONOMY IS NOT AN ANCIENT PRINCIPLE: HIPPOCRATIC DECEIT

"Perform these duties calmly and adroitly**, concealing things from the patient** while you are attending to him. Give necessary orders with cheerfulness and serenity, turning his attention away from what is being done to him; sometimes reprove sharply and emphatically, and sometimes comfort with solicitude and attention, **revealing nothing to the patient's future or present condition."**

Hippocratic Corpus in Decorum 4

AUTONOMY IS CONTINGENT ON HAVING CAPACITY

Medical Capacity:

Understand the benefits, risks and alternatives to a treatment or trial

Assess these given one's own values

Make and express a choice

IT IS WRONG TO ASSUME THAT AN INDIVIDUAL LACKS CAPACITY JUST DUE TO AGE

NONE OF THESE NECESSARILY MEAN LOSS OF CAPACITY

Inability to perform tasks of daily living

Physical disabilities

Being frail

Confused by medical jargon

Wanting a medically counter-indicated treatment

Relying heavily on family members' input

ANOTHER FAULTY ASSUMPTION THAT THREATENS AUTONOMY:

IT IS WRONG TO ASSUME THAT OLDER PATIENTS DO NOT WANT TO PARTICIPATE IN CLINICAL TRIALS

SWOG study followed 909 patients

364 eligible for a clinical trial >65 less often eligible

(78%<65 v 65%>65 p.004)

142 consented – **no difference by age**

(40%<65 v 34%>65 p =0.32)

Older patients more concerned about side effects of trial p=0.02

Javid SH, et al. A prospective analysis of the influence of older age on physician and patient decision-making when considering enrollment in breast cancer clinical trials (SWOG S0316). *Oncologist*. 2012

FACTORS, WHICH MAY HINDER AUTONOMY, MUST BE ADDRESSED

- Impaired hearing or sight
- Loss of independence and reliance on family

  Daher, M. Ethical issues in the geriatric patient with advanced cancer 'living to the end.' 2013

- Tendency " to ask for less information and to delegate decisions to their doctors or caregivers"

  Surbone, A. Ethical considerations in conducting clinical trials for elderly cancer patients. *Aging Health* 2008

- Reluctance to ask for clarification if don't understand

  Strohschein FJ, Newton LJ. Mobilizing purpose and passion in oncology nursing care of older adults: *Can Oncol Nurs J*. 2018

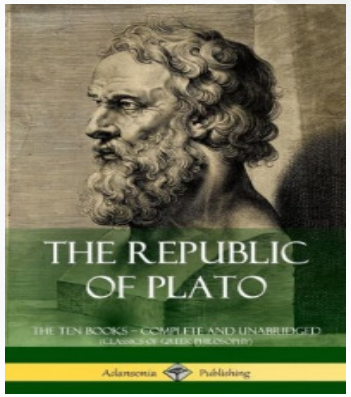
JUSTICE:

Healthcare professionals have a duty to act with fairness giving every individual his or her due.

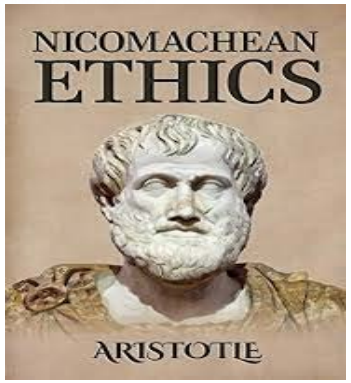
Rawls and Beachamp/Childress

JUSTICE IS AN ANCIENT PRINCIPLE

Justice is examined in length in Plato's *Republic*



Aristotle considered justice a central virtue between the "vices of excess and defect" and *opposed to* a desire for maldistribution of "goods of fortune." *Nicomachean Ethics* V



JUSTICE IS THWARTED IF THERE IS NEGATIVE DISCRIMINATION BASED ON ADVANCED AGE

FOUR TYPES OF DISCRIMINATION BY AGE: AGEISM

KAGAN, SH, AGEISM IN CANCER CARE, *CANCER CARE IN VULNERABLE POPULATIONS*, 2008

1. **Negative ageism:** judgments that disrespect, denigrate and isolate older people. Focusing on chronological age, without consideration of performance status and comorbidities

Strohschein FJ, Newton LJ. Mobilizing purpose and passion in oncology nursing care of older adults: *Can Oncol Nurs J*. 2018

2. **Ageist self-stereotyping:** an older patient says he is “too old” to do a treatment or join a clinical trial. Based on misunderstandings about older age.

3. **Positive ageism:** certain forms of discrimination have advantages for older adults: Medicare and Social Security

Coined by Palmore EB, Positive Ageism?, *Gerontologist*, 1992

4. **Beneficent ageism:** discrimination by caregivers, clinicians and others with the intent to help the older person

BUT THIS IS PATERNALISM – Violates Autonomy

NEGATIVE AGEISM IN ONCOLOGY

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Kogan's Old People Scale filled out by 197 oncology professionals (medical:34,nursing:102,radiology 61)

Lower score is more negative view of older adults. Score of 101 is neutral

Mean score: 81

No statistical difference (p= 0.86) for different roles: medical (83), nursing (80) and radiology(82)

No statistical difference by gender p= 0.096

Kearney, N., et al, Oncology healthcare professionals' attitudes toward elderly people. *Annals of Oncology,* 2000

AGEISM IN ONCOLOGY OR JUST LACK OF EVIDENCE?

SWOG study following 909 patients

Physicians interviewed if patient eligible for trial but did not enroll.

Age a factor in whether the trial was even discussed: 58%> 65; 76%<65 p=0.008

Age a factor in whether or not the patient enrolled 14%>65; 3% <65 p=0.002

"Our results suggest that advancing age remains an independent barrier to trial enrollment" **Reason suggested – lack of evidence about toxicity and efficacy. Or is this implicit bias?**

Javid SH, et al. A prospective analysis of the influence of older age on physician and patient decision-making when considering enrollment in breast cancer clinical trials (SWOG S0316). *Oncologist*. 2012

SUBTLE NEGATIVE AGEISM

1. Inappropriate presentation of information

40 healthcare workers recorded a podcast on endocrine therapy for a 40 yo and a 70yo. More Elder Speak with 70 yo and correlated with negative views of aging. Elder Speak: short sentences, repeat information, talk slow.

Schroyen, S, Adam, S, Marquet, M, et al.Communication of healthcare professionals: Is there ageism? *Eur J Cancer Care*. 2018

2. Inaccessibility of healthcare environments

3. Lack of access to screening and treatment – not just for older adults!

Strohschein FJ, Newton LJ. Mobilizing purpose and passion in oncology nursing care of older adults: *Can Oncol Nurse J*. 2018

HOW DO WE MEET THESE ETHICAL CHALLENGES?

Non-Maleficence

Implement the recommendations of this workshop.

More evidence!

AUTONOMY

- Simpler consent form and better educational tools
- Encourage questions and discussion of concerns – draw older adults out if need be
- Assistance from geriatric specialists
- Offering hearing and visual assistant devices
- Remote data collection was suggested to overcome transportation barriers for older adults
- Make personnel available in the clinic to explain clinical trials to elderly patients and their families

Kornblith, A. B. et al Survey of oncologists' perceptions of barriers to accrual of older patients with breast carcinoma to clinical trials. *Cancer*, 2002 *95*(5), 989-996

JUSTICE – MUST COMBAT NEGATIVE AGEISM

Not easy since negative ageism is prevalent in Western Cultures

Berger, R. (2017). Aging in America: ageism and general attitudes toward growing old and the elderly. *Open Journal of Social Sciences*, *5*(08), 183.

Study of implicit and explicit bias against older adults (n=704,151)

77% of sample from the US

Participants of **all ages preferred younger people** using both explicit and implicit bias tests, though older adults implicit bias was larger than their explicit bias.

Chopik, WJ et al Age Differences in Explicit and Implicit Age Attitudes Across the Life Span, *The Gerontologist*, 2017.

CHANGING CULTURE IS VERY DIFFICULT

The COVID hashtag: #BoomerRemover

DISCUSSION AND QUESTIONS

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