

Bonnie Steinbock University at Albany (emerita) CUHK Centre for Bioethics Oct. 17, 2015

AUTONOMY

- Different meanings of autonomy
 - A capacity: the ability to understand and make decisions
 - A right: the right of individuals to make their own medical decisions based on their own values
 - A value: autonomous beings persons -- have a special moral status

A NEW CONCEPT IN MEDICINE

- Respect for autonomy as the right to make one's own medical decisions is not part of traditional medical ethics
- Hippocratic tradition
 - No expectation of patient participation in medical decision making
 - Physician should do what is best for the patient, based on physician's superior medical knowledge and expertise

PATERNALISM

- Coercing/forcing/manipulating people for their own good
- Traditional Hippocratic ethic is overtly paternalistic, particularly as regards giving information/withholding truth
 - Conceal what you are doing to avoid upsetting the patient
 - Truth may be withheld or shaded if telling the truth likely to cause harm
 - cause distress
 - lead to rejection of treatment physician recommends

WHAT'S WRONG WITH PATERNALISM?

- John Stuart Mill:
 - Individuals know what's best for them
 - They know more about their individual
 - More concerned with their own welfare than others
 - People have a right to make decisions about what affects their bodies and lives – even when others regard them as foolish, misguided, wrong
 - Forcible interventions warranted only to prevent "harm to others"

FROM PATERNALISM TO AUTONOMY

- 1960s and 70s a time of social upheaval
 - Civil rights
 - Feminism
 - Student movement
- General questioning of authority and emphasis on individual values
- Emergence of applied ethics

THE BELMONT REPORT,

1979

- Congress asked the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research for the basic ethical principles that should guide human subject research.
 - Respect for persons
 - Beneficence/nonmaleficence
 - Justice
- Became the basic principles of bioethics generally
- Respect for persons became respect for autonomy

UNDERSTANDING PATERNALISM

- Not all coercion for the person's own good counts as paternalism
 - Restricted to competent adults
 - Compelling children or cognitively impaired doesn't count as paternalism
 - Compulsion not paternalistic where choice is not free due to ignorance
 - Mill's bridge example

IS PATERNALISM EVER JUSTIFIED?

- Paternalism most objectionable when people are forced to do what is contrary to their own values
- Paternalism may be justified if:
 - Coerced action required by or consistent with the person's own values
 - Harm threatened is certain, severe, and irreversible
 - Burden inflicted by the restriction is relatively minor
 - Seat belt laws

IN FAVOR OF MEDICAL PATERNALISM

- Patients cannot exercise genuine free choice because they:
 - Are sick and vulnerable
 - Lack medical training and expertise
 - May be emotional and fearful, unable to make objective judgments
 - They often want their doctors to decide for them
- Health and prolongation of life take priority because necessary for realization of other values
- Truth may depress patient and lessen chances of cure

AGAINST MEDICAL PATERNALISM

- Prolonging life not necessarily most important value
 - Patient may reasonably prefer less life to life of poor quality
- Participating in medical decisions is a fundamental moral/legal right
- Having truthful information essential to such participation

WHY PHYSICIANS WITHHOLD TRUTH

- Physician discomfort
- Physicians reluctant to acknowledge uncertainty
- Lack of compensation
- Lack of training

HARD CASES

- Respect for patient autonomy now mainstream
 - Idea that doctors should lie to patients "for their own good" rarely defended
- But what if the patient's family asks for truth to be concealed?
 - Cultural relativism and cultural sensitivity
 - Case study: Request for placebo so father doesn't lose hope
- Can truth telling be a "charade of autonomy"?
 - Waking up Monica

INFORMED CONSENT

- Central to clinical ethics
- Touches on many other important topics
 - Autonomy and paternalism
 - Harm and beneficence
 - Competence to give/withhold consent
 - Communication and trust between doctor and patient

LEGAL (NOT MEDICAL) CONCEPT

- Two parts: consent and informed
 - Consent: the patient must agree to the procedure
 - Exception: emergency, when procedure necessary to preserve life or health and patient is unconscious
 - Informed
 - How much information is a doctor required to give?
 - Not all risks, no matter how remote
 - Information a patient would want in order to make reasonable decision
 - Physicians not permitted to conceal information to get patient to accept procedure

PROBLEMS WITH LEGALISM

- Regarding informed consent as legal requirement distorts doctor-patient relationship
- Emphasis is on, what information do I need to give to avoid being sued?
 - "Consent" as a transitive verb: Did you consent that patient?
- Right question: what information does my patient need to participate intelligently in decision making?
- How can I best convey this information?

HOW TO RESPECT AUTONOMY

- The wrong way
 - Dump poor prognosis on patient and leave
 - Provide technical information and ask, what do you want to do?
- The right way
 - Communication skills essential
 - May take several conversations before patient really understands diagnosis, prognosis, and treatment options
 - Give as much information as the patient can accept at the time
 - Do not abandon your patient