AUTONOMY, CAPACITY, AND CONSENT

Why study biomedical, esp. psychiatric ethics?

Philosophical interest:
- offers test or limit cases for central normative concepts, their possible interactions, and respective limitations, e.g. autonomy, right, coercion, and obligation.
- brings to the fore the action-guiding character of ethical considerations and urge us to face some inconsistencies of our ordinary moral intuitions, which otherwise may remain unaddressed.

Course outline:
Lecture 1: Personal and patient autonomy
Is the right to self-determination a promising or even coherent way of conceptualising the autonomy of persons, esp. patients?
Lecture 2: Decisional capacity
Could a notion of decisional capacity in terms context-dependent threshold help address some of the sceptical challenges faced by personal viz. patient autonomy?
Lecture 3: Varieties of consent
Is consent normatively significant? How exactly does it affect the permissibility or impermissibility of some actions?
Lecture 4: Incentives for health
Do incentives for health form a coherent category? Can they be reliably distinguished from coercive offers?

LECTURE 1: PERSONAL AND PATIENT AUTONOMY

Three background assumptions about personal autonomy that also affect patient autonomy:
- liberal concept, strong link to privacy;
- agency concept, strong link to freedom;
- incompatible at least with severe mental disorder.

There seems to be an implicit tension between assumptions. Consider the Wooltorton case:
Upon admission to hospital, a young woman who has ingested antifreeze refuses to receive lifesaving treatment and insists that all she wants is to die in a situation where she is not alone and where
comfort care is provided. She has ingested antifreeze on nine previous occasions but has accepted lifesaving treatment afterwards.

R.1: “A doctor who imposes treatment in the face of a competent refusal would be guilty of assaulting the patient.”

R.2: “The right to self-determination is not the right to drink antifreeze and not be treated.”

Two rival interpretations of the relationship between autonomy- and health-based considerations:

1. *Autonomy trumps health*, i.e. autonomy functions as a constraint to the promotion of health, incl. lifesaving treatment.

“A mentally competent patient has an absolute right to refuse to consent to medical treatment for any reason, rational or irrational, or for no reason at all, even where that decision may lead to his or her own death.” (*Re MB* [1997] 2 FLR 426)

“If a person possesses any tolerable amount of common sense and experience, his own mode of laying out his existence is the best, not because it is the best in itself, but because it is his own mode.” (J.S. Mill, *On Liberty*)

The underlying conception of autonomy here is *right to self-determination*, viz. independence from others, and it presupposes a *capacity for self-determination*, e.g. a ‘tolerable amount of common sense’, ‘mental competence’, or decisional capacity (current term), cf. the following lecture.

In medical contexts, this capacity is understood as a capacity to give (or refuse to) consent to specific treatments. If a person is deemed to lack such capacity with respect to a decision, then autonomy-based considerations do not come into play.

2. *Autonomy not always trumps health; sometimes health trumps autonomy*, i.e. in medicine hard paternalism is not out of place.

**Paternalism:** there is an obligation to protect people from the harmful consequences of their own choices, if necessary, by curtailing these choices. A refusal to consent to receiving lifesaving treatment is an obvious example of a potentially harmful choice.

**Soft paternalism:** there is such an obligation to protect people from the harmful consequences of their choices, but only if these choices are not fully voluntary, e.g.

- made in the absence of decisional capacity or
- instances of uninformed consent or refusal to consent, although capacity is present.

Soft paternalism is consistent with autonomy as specified in 1) above, i.e. a right to self-determination protecting the exercise of a capacity for self-determination.
**Hard paternalism:** there is such an obligation to protect people from the harmful consequences of their choices even when these are fully voluntary. Unlike soft paternalism, hard paternalism does violate autonomy as specified above. How could this be justified?

A possible argument in defence of hard paternalism is as follows:

1. autonomy and beneficence are two equally fundamental moral principles, which may clash because
2. autonomy requires deference to other people’s past and/or present values concerning how they should live their lives whilst
3. beneficence requires that we reckon what is good for others in a way that is temporally neutral as regards present and future
4. when the two principles clash, beneficence sometimes overrides autonomy (Scoccia 2008).

Autonomy is understood here as a right to self-determination consistent with soft but not hard paternalism.

Beneficence is about the promotion of prudential values, e.g. health that would make another person’s life go better from this person’s evaluative perspective but conceived in temporally neutral terms. More precisely, the beneficence principle: “identifies one’s prudential good with the satisfaction of one’s self-regarding desires or fulfilment of whatever views one happens to hold about what will make one’s life go best. It implies that you can be mistaken about what’s best for you over the long run because your preferences or views can change in ways that you fail to anticipate” (p. 362)

This is to differentiate justified hard paternalism from unjustified or moralised paternalism which ignores the intended beneficiary’s evaluative perspective.

Paradigm case of justified hard paternalism: rejection of physician-assisted suicide demands made by persons who are “better off alive than dead notwithstanding their belief to the contrary” (p.367).

Paradigm case of unjustified hard paternalism: forced blood transfusion to adult Jehovah’s Witnesses because it would violate a more specific and substantive right, e.g. freedom of religion, not just autonomy as an abstract right to self-determination.

**Returning to the Wooltorton case:**

One way of locating the point of contention between the two responses is with respect to the nature and scope of autonomy as a right:

**R1.** Treatment without a patient’s informed consent in the presence of capacity amounts to assaulting the patient. It is a violation of the right to self-determination as *expression of a person’s will.*

**R2.** The right to self-determination is merely a placeholder for more specific and substantial rights. Lifesaving treatment against a patient’s will in circumstances like the case at issue does not violate the right to self-determination, for the purpose of this right is to ensure *protection for a person’s significant interests* (and the chance to drink antifreeze and not get treated is not such an interest).
However, the above does not do justice to another important cluster of intuitions at play, namely about the nature and significance of health. There are at least three alternative approaches worth considering:
- Biological: health is absence of disease and dysfunction
- Holistic: health is complete well-being, physical, mental, and social
- Capability approach: health is foundations of achievement

The appeal of both responses above greatly depends on which of these perspectives on health we assume. This becomes particularly salient if we consider cases where the lifesaving treatment at stake has to do with mental health issues. Hence, the topic of the next lecture: decisional capacity assessment and the right to refuse treatment in the context of mental disorder.

**Suggested readings:**


*Heal, J. “Mental disorder and the value(s) of ‘autonomy’. In L.Radoilska (ed.) Autonomy and Mental Disorder. Oxford: OUP.*


Starting point:
Autonomy as right to self-determination presupposes a capacity for self-determination.
Decisional capacity (mental/ legal competence) is conceived as a context-dependent threshold.

Underlying question:
Could a notion of decisional capacity in terms context-dependent threshold help address some of the sceptical challenges faced by personal viz. patient autonomy?
Autonomy functions as a constraint to the promotion of health and other desirable outcomes. It is construed as an independent and overriding, though limited in scope justification for refraining from certain actions, which in the absence of autonomy-considerations are morally (and often legally) required: e.g. the Wooltorton case:
- potential constraint on beneficence viz. barrier against unjustified hard paternalism;
- but also: grounds for justified soft paternalism;
- hence, helps define both rights and obligations with respect to protection from harm and self-harm, esp. harmful consequences of one’s choices.

The Mental Capacity Act (2005):
An adult is deemed to lack capacity with respect to a decision if he/she cannot – due to an impairment of or a disturbance in the functioning of the mind or brain – do the following at the time of decision-making:

a) understand the information relevant to the decision,
b) retain that information,
c) use or weigh that information as part of the process of making the decision, or
d) communicate his/her decision (by talking, using sign language or any other means).

Underlying tension:
1: “A person is not to be treated as unable to make a decision merely because he/she makes an unwise decision.” Yet:

2. The information relevant to a decision (cf. a and c above) is about reasonably foreseeable consequences of deciding one way or another and failing to make the decision.
Compare:

1. “A mentally competent patient has an absolute right to refuse to consent to medical treatment for any reason, rational or irrational, or for no reason at all, even where that decision may lead to his or her own death… Irrationality is here used to connote a decision which is so outrageous in its defiance of logic or of accepted moral standards that no sensible person who had applied his mind to the question to be decided could have arrived at it.” (Re MB [1997] 2 FLR 426)

2. “… panic, indecisiveness and irrationality in themselves do not as such amount to incompetence, but they may be symptoms or evidence of incompetence.” (ibid.)

Two rival interpretations of decisional capacity:

Value-neutral: focus on cognitive failures (narrowly understood), e.g. misperception of reality, mishandling of evidence to the exclusion of substantive evaluative commitments:
- Motivation: to protect unpopular choices and pre-empt a tyranny of the majority
- Underlying assumption: means-ends account of practical rationality
- Paradigm cases: life-saving treatment refusals on religious grounds
- Difficulty: some mental disorders do not seem to affect a person’s cognition narrowly understood, but his/her capacity to value:
  - Anorexia: ‘abnormal’ or ‘pathological’ evaluative commitments but no cognitive failures in the sense above
  - Depression: ‘abnormal’ or ‘pathological’ detachment from what one cares about
  - Manic-depression: overwhelming but transient attachment to projects one does not identify with.

The capacity for self-determination seems undermined in a way that cannot be registered by a narrowly cognitive (value-neutral) model.

Value-laden: expands the capacity assessment to include substantive evaluative commitments
- Underlying assumptions:
  - substantive account of practical rationality
  - autonomy is practical rationality
- Concerns:
  - resolves the difficulty above at the expense of introducing reasonableness requirements that life-saving treatment refusals on religious grounds cannot satisfy;
  - opens the door for various kinds of tyrannies (cf. Berlin on positive freedom);
  - misses the point of capacity as a threshold condition whose target is sufficient voluntariness not ideal rationality;
  - inappropriately substitutes one autonomy conception with another.
Possible solutions:

(1) Reject the conception of patient autonomy as right to self-determination protecting a capacity to self-determination that Decisional capacity tests are meant to track/ascertain.

‘Respect for autonomy might require that we respect a treatment decision even when the person “unreasonably” retains that [religious] belief in spite of compelling counter-evidence – even when the belief renders her incapacitated.’ (Martin 2007, 37)

The right to self-determination covers more specific and substantive rights, e.g. freedom of religion, not an abstract capacity for self-determination (cf. Scoccia 2008).

(2) Reject the underlying assumptions of a value-laden interpretation of capacity, hence: no reasonableness requirements in the absence of mental disorder. Again: proposed dissociation of autonomy and capacity.

Is mental disorder a clear-cut category?

Philosophers often assume that it is esp. in the context of physician-assisted suicide, e.g. finding one’s life no longer worth living vs. willing to die because one is depressed: Feinberg (1986); Warnock and Macdonald (2008).

However, the concept of mental disorder exhibits the same tensions as that of decisional capacity:

“Each of the mental disorders is conceptualized as a clinically significant behavioural or psychological syndrome or pattern that occurs in an individual and that is associated with present distress (e.g., a painful symptom) or disability (i.e., impairment in one or more important areas of functioning).” (American Psychiatric Association DSM-IV, 1994, xxi)

Discussion:

Consider the following case study. In light of the vignette provided, would you interpret it as an instance of religious experience or the onset of a mental disorder (psychosis)?

A case study: Simon, aged 40, lawyer

Simon was a senior, black, American lawyer from a middle-class, Baptist family. Although not a religious man he had had occasional relatively minor psychic experiences that had led him from time to time to seek the guidance of a professional ‘seer’. Otherwise his career and life generally were going well.

Then, out of the blue, he was threatened by a malpractice legal action from a group of his colleagues. Although he claimed to be innocent, mounting a defence would be expensive and hazardous. He responded to this crisis by praying in front of an open bible placed on a small altar that he set up in his front room. After an emotional evening's ‘outpouring’ he found that wax from two large candles
on the altar had run down onto the bible marking out various words and phrases (he called these wax marks ‘seals’ or ‘suns’). He described his experiences thus. “I got up and I saw the seal that was in my father's bible and I called my friend John and I said, you know, ‘something remarkable is going on over here.’ I think the beauty of it was the specificity by which the sun burned through. It was ... in my mind, a clever play on words.”

From this time on, Simon received a complex series of ‘revelations’ largely conveyed through the images left in melted candle wax. They meant nothing to anyone else including Simon’s Baptist friends and family. But for Simon they were clearly representations of biblical symbols particularly from the book of Revelations (the bull, the 24 elders, the arc of the covenant, etc.) signifying that “I am the living son of David ... and I'm also a relative of Ishmael and ... of Joseph”. He was also the “captain of the guard of Israel”. He found that this role carried awesome responsibilities: “Sometimes I'm saying - Oh my God, why did you choose me, and there's no answer to that”. His special status had the effect of “increasing my own inward sense, wisdom, understanding, and endurance” which would “allow me to do whatever is required in terms of bringing whatever message it is that God wants me to bring”. When confronted with scepticism, he said simply: “I don't get upset, because I know within myself, what I know”.


Suggested readings:
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LECTURE 3: CONSENT

Why does consent matter?
Affects the permissibility/impermissibility of certain actions
E.g. Wooltorton case: “A doctor who imposes treatment in the face of a competent refusal would be guilty of assaulting the patient.” Also: biomedical research; use of someone else’s property; disclosure of sensitive information; dangerous sports.
Core idea: consent as a kind of permission; however, disagreement about its nature and scope
E.g. pre-commitment: advance decisions/directives also known as living wills (when capacity is absent) and Ulysses arrangements (when capacity is present).

The permissibility of what kinds of things can be subject to consent? What constitutes valid consent?
Health and personal welfare, but:
- consent cannot legitimise infliction of harm above certain level, e.g. as in assault (criminal offense)
- no advance directive can be used to refuse basic nursing care

Two accounts of valid consent:

A.1: Consent as authorisation
A.2: Consent as waiver

A.1. Consent as primary normative concept: exercise of the right to self-determination. But does capacity suffice?

Re SA (Vulnerable Adult with Capacity: Marriage) [2006] 1 FLR 867:

“A vulnerable adult who does not suffer from any kind of mental incapacity may nonetheless be entitled to the protection of the inherent jurisdiction if he or she is, or is reasonably believed to be, incapacitated from making the relevant decision by reason of such things as constraint, coercion, undue influence or other vitiating factors.”

“In the context of the inherent jurisdiction I would treat as a vulnerable adult someone who, whether or not mentally incapacitated, and whether or not suffering from any mental illness, or mental disorder, is or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation.”

Vulnerability as ground for special protection, the general point being: absence of force, coercion, deceit, and manipulation are prerequisites for valid consent, in addition to capacity:
‘Informed consent’ may be a misnomer.

A.2. Consent as secondary normative concept: justifies certain actions only against the background of other, more fundamental norms and expectations.

A critique and alternative to informed consent as exercise of the right to self-determination:

- informed consent is no reliable barrier to abuse and exploitation but is consistent with institutional complacency and indifference
- alternatively, unjustified paternalism may be introduced via vulnerability considerations, e.g. implicit substitution of voluntariness with reasonableness
- hence, need to go beyond individual or ‘Millian’ autonomy: healthcare and biomedical research are public goods, e.g. quarantine; vaccination; health and safety measures; research funding

Two alternative conceptions of autonomy:

Principled or ‘Kantian’ autonomy

- does not apply to persons but to reasons and principles, cf. the Categorical Imperative as expressed in the Formula of Autonomy:

  “Autonomy of the will is the property of the will by which it is a law to itself (independently of any property of the objects of volition). The principle of autonomy is therefore: to choose only in such a way that the maxims of your choice are also included as universal law in the same volition.” (Groundwork 4:440)

Relational autonomy

- primarily a social-relational status, not a psychological capacity

  “… to be autonomous is to stand in a certain position of authority over one’s life with respect to others” (Oshana, M. 2006. Personal autonomy in society. Aldershot: Ashgate)

A more radical alternative: vulnerability not autonomy should be our central concept because:

- vulnerability is more universal than autonomy: it reflects our embodied humanity and ‘the present potential for each of us to become dependent based upon our persistent susceptibility to misfortune and catastrophe’ (Fineman 2008/09)

- autonomy cannot provide a helpful focus for our political institutions: by trying to respect autonomy, we lose sight of the various kinds of possible harms that are not autonomy-related, yet are extremely damaging to us as human beings.

- the exclusive focus on autonomy follows from a misleading idealisation of the human condition whereby individuals are depicted as independent, self-reliant, and self-sufficient (Anderson and Honneth 2005)
But is vulnerability an alternative to all autonomy conceptions or is it levelled against a specific and contested conception of autonomy?

A logical reconstruction of some arguments in favour of vulnerability vs. autonomy:

1) autonomy means self-determination;

2) self-determination excludes determination by others;

3) therefore, autonomy requires independence from others;

4) however, human beings are not self-sufficient: in fact, it is implausible to imagine human life without various personal interactions which make mutual dependence both inescapable and valuable to us;

5) a relationship of mutual dependence is incompatible with the self-determination of the parties;

6) therefore:

   a) autonomy presents an impoverished if not impractical ideal of human life, and

   b) vulnerability offers the needed correction as it acknowledges the significance of mutual dependences in society.

A possible concern: could vulnerability ground other-regarding obligations over and above the Harm Principle, and if so, wouldn’t these collapse into a form of hard paternalism?

Suggested readings:

Altzheimer’s Society (2010) Factsheet on Advance Directives, at:

http://www.alzheimers.org.uk/factsheet/463


Wide range of initiatives: smoking cessation; adherence to prescribed medication; STD testing.

Two sets of questions:
- Normative: Are incentives for health morally permissible/ desirable? Or patronising/ coercive/ unfair?
- Conceptual: Do incentives for health form a coherent category? Is the moral appraisal of one kind of incentive indicative of/ necessarily linked to that of (all) others?

1. Egalitarian intuitions about health

Are these compatible with the use of (some) incentives for health?

Cf. different approaches to health: biological, holistic, and capability (lecture 1).

1.1. Specific egalitarianism

Health is *sui generis* (and intimately related to well-being); it should be distributed less unequally than other goods.

Specific egalitarianism seems independent from general theories of justice. Yet, it relies on an overlapping and possibly superficial consensus about the significance of health.

Could health be interpreted as an overarching value and its promotion employed as an overall criterion for good social policy?

Some epidemiologists think so. However, at a closer look, health turns out to be an unlikely candidate: health is not only valuable for its own sake, but also for the sake of further valuable pursuits.

There is an all-purpose means aspect in health as a value, which is at odds with its alleged status of an overarching value.

1.2. Fair equality of opportunity

*Access to healthcare services* should be distributed according to the principle of fair equality of opportunity: disease and disability may be *obstacles to full participation* in a society just as race, gender, and class.

Hence, a liberal state ought to provide special protection for its citizens’ health.
Is universal access to *healthcare* and the enforcement of adequate health and safety measures enough?

Looking at the social gradient of *health*, arguably not:

- strong correlation between relative poverty and lower socio-economic status, on the one hand, and ill health and shorter life-expectancy, on the other;
- the overall impact of inequality is also negative; cf. the catchphrase: “Justice is good for our health”.

1.3. Luck egalitarianism

*Health inequalities* are only unfair if they reflect differences in brute luck as opposed to individual *choice* and *effort*.

Hence, the state should focus on tackling adverse health outcomes that are beyond a person’s control.

But is choice vs. circumstance a reliable/relevant distinction?

Cf. life-style sensitive conditions incurred by people with different socio-economic status.

What is the burden that these three conceptions of equality aim to distribute fairly across society?

Risks to health or the financing of health services?

2. Revisiting Mill’s Harm Principle?

- Libertarian paternalism (Thaler and Sustein 2008). Only ‘nudges’, but no use of the criminal law (punishment by the state) for being imprudent.

- Coercive paternalism (Conly 2012): criminal law should be employed to prevent significant harm to self.

Data from the behavioural sciences: our cognitive and affective capacities are limited and flawed in many ways, and we as agents are not well-suited to correct these biases on our own. E.g. ‘paternalism is more justified than we normally think. We know now that we are intractably irrational, and this can't be rectified by simple care and introspection’ (Conly 2012, p. 7)

3. Coercion and coercive offers

Could (at least some) incentives for health be impermissible by virtue of being coercive?

Could offers be coercive at all?

According to an influential account, coercion takes place only when a person

1) is faced with an imminent danger of being made considerably worse off should he/she decline to do what the coercer would like him/her to do, and

2) actually acquiesces to the coercive request.
However, coerced actions may not always be responses to credible threats.

- Arguably, the notion of being made worse off is ambivalent: and so, offers are sometimes hardly distinguishable from threats;

- Domination does not have to rely on explicit demands backed up by threats: e.g. self-censorship of the oppressed.

In addition, more choice options are not always better than less.

- In circumstance of increased complexity, it becomes more burdensome to make a choice;

- The perceived availability of options imposes new responsibilities on the choosers;

- The variety of choice options might be effectively trivial and concealing the lack of meaningful choice from the choosers; and

- The circumstance of choice may be manipulated, e.g. switching to healthier default options. But is this kind of manipulation reprehensible at all, especially if it is explicitly undertaken?

4. Adaptive preferences

Adaptive preference formation is a mechanism of psychological adjustment to oppressive norms, which is often sub-conscious; e.g. strong correlation between cumulative disadvantage and limited aspirations, incl. lack of self-trust.

Besides being harmful, adaptive preference formation casts doubt on the authenticity or autonomy of the preferences thus formed.

Should (at least some) incentives for health be upheld as contravening adaptive preferences rather than autonomous choices?

A possible example: financial incentives for smoking cessation targeted at groups with strong anti-establishment peer-pressure.

Suggested readings:


