

# **AUTONOMY & INFORMED CONSENT IN MEDICINE – ETHICAL PERSPECTIVES**

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# AIMS

- ❑ To explore different models and ethical (& legal) perspectives for autonomy and consent in the context of medical practice.
- ❑ Critical evaluation of these two foundational concepts in modern medical ethics.

## A Case

A 93 year old woman (Mrs P) is admitted to hospital with acute liver failure having taken an overdose of paracetamol & codeine over three days. She was found by a neighbour who had been called by Mrs P's worried daughter (who lives abroad). Mrs P had made extensive preparations for her suicide. According to her family, for 50 years she had expressed her intention to end her life when she became less independent. Up till now she had lived an independent & active life. A month before she had signed an AD stating that she did not wish to receive any life saving or prolonging treatment.

## Case - Continued

After she had been treated and recovered from her acute illness, the psychiatry team assessed her. She had no mood disorder & no symptoms of depression. She had mild cognitive impairment (MoCA score) but was lucid & articulate and her short-term memory reasonably intact.

She expressed no regrets regarding her decision, apart from causing distress & bother to others. She felt proud of her lifetime achievements but felt that it was the 'right time to go'. She is now refusing further treatment & is asking to be discharged.

# Questions

1. Does Mrs P have capacity to refuse treatment?
2. Is the advance directive valid? Mrs P had not refused to have antibiotics for a UTI (when she became temporarily delirious).
3. Is it ethical to discharge the patient? She says she would be 'happy to die in her sleep', but for the time being will not attempt suicide again.
4. Can suicide ever be rational?

# WHAT IS AUTONOMY?

Greek *autos* (self) & *nomos* (rule) “Self-rule”

Dworkin: “*Many definitions, but all agree it is a desirable quality to have*”. [The theory and Practice of Autonomy, C.U.P, 1988]

O’Neill: “*Autonomous action, understood literally, is self legislated action. It is the action of agents who can understand and choose what they do. When cognitive or volitional capacities, or both, are lacking or impaired, autonomous action is reduced or impossible.*” [O’Neill: Paternalism and partial autonomy. *JME* 1984;10:173-178]

# Three types of autonomy

1. Autonomy of THOUGHT – thinking for oneself.
2. Autonomy of WILL – freedom to decide on the basis of one's deliberations.
3. Autonomy of ACTION – is physically unconstrained to act upon his/her decision.

[Gillon R. *BMJ* 1985. Autonomy & the principle of respect for autonomy]

## Len Doyal: Moral inderterminacy Weak and Strong Autonomy

‘Strong’ or ‘critical’ autonomy requires careful and critical deliberation, with both intellectual and emotional competence as well as the objective opportunity for action. Doyal argues that in the case of sick patients, this may not always be realistic.

*”For in assuming that patients are critically autonomous we may be mistaken and the mistakes may could be dramatic enough to cost them their lives...To make an optimally informed choice, patients require active help – respect for their positive and negative freedom.”*

[Doyal: Paternalism and the right to informed consent. J Law & Society 1990;17(1)1-15]

## **'Positive' and 'negative' autonomy**

### **Negative autonomy**

John Stuart Mill: One should not interfere with another person's freedom to think/act as they wish so long as they do not harm others.

In medicine this represents the right to refuse treatment, even if this means one may die.

### **Positive Autonomy**

Having the conditions that enable one to express (& enact) one's autonomy

## AGENCY & AUTHENTICITY

The capacity to make a choice. Kant – to “set ends”, to accept or reject our desires and to be independent of them – autonomy vs heteronomy. [*Metaphysics of Morals*]. AGENCY – **momentary** achievement.

Living ones' life in accordance with one's distinctive values and beliefs. “It is the privilege and proper condition of a human being, arrived at the maturity of his faculties, to use and interpret experience in his own way” [John Stuart Mill – *On Liberty*]  
AUTHENTICITY – **sustained** achievement

## Which desires do we respond to?

Will Frankfurt – First and second (and third) order desires e.g. the smoker or addict who wishes to give up. Which represents the ‘true’ person?

*Freedom of the will and the concept of the person.1971*

# The Rugged (rational, self-interested) Individual



## Feminist & Communitarian Ethics & Autonomy

Critique of individual autonomy:

*“This vision of the autonomous individual as one securely isolated from his threatening fellows seems to me to be a pathology that has profoundly affected western societies for several centuries.”*

Nedelsky J. *Reconceiving autonomy: Sources, thoughts and possibilities.*  
HeinOnline. 1 Yale J.L. & Feminism 1989

## A Personal view from a Bioethicist

“The notion of people as separate, rational and self-determining beings seems to overlook the connectedness and relationships that shape not only our choices, but also inform what it is to be part of a flourishing community”. ...

“Fundamentally, autonomy is relational. It is not solely intellectual. It is predicated on interaction and exchange. It does not and cannot exist without the kindness, patience, sensitivity, wisdom, honesty, commitment and expertise of professional staff.”

*Professor Deborah Bowman on Autonomy.*

## THE LINK BETWEEN CONSENT & AUTONOMY

*“The underlying ethical principle of informed consent is that one should respect the patient’s autonomy: the capacity to think, decide and act upon one’s own thoughts and decisions freely and independently. This is done within a set of personal values and goals, which will be different for different people.”*

Jones M. Informed consent and other fairy stories. *Med Law Review* 1999 7:1-3-134

## VALID & INFORMED CONSENT

*“Consent means a voluntary, uncoerced, decision, made by a sufficiently competent or autonomous person on the basis of adequate information and deliberation, to accept rather than reject some proposed course of action.” [Gillon, 1986]*

Informed consent is the pillar of modern clinical practice reflecting trust, shared understanding and respect for autonomous choices. Much emphasised in the law.

# Implied consent & Presumed consent

## IMPLIED?



## PRESUMED: “OPT-OUT”

Organ donation: Failure to opt out unrepresentative of valid consent?

*“It must also be the case that all residents understand that their silence constitutes a token of consent to donation.”*

EU survey: Only 28% knew regulations re organ donation in their country.

[McKay D. Opt-out & Consent. *JME* 2015 0:1-4.]

## How much information? The move away from doctor centredness (paternalism) to patient centredness

- Professional standard (Bolam) “reasonable doctor”
- Reasonable/prudent person standard
- Subjective standard – enables *this particular* person to make an informed choice based on their values and personal preferences.

## THE MONTGOMERY CASE (2015)

Nadine Montgomery small stature, type 1 diabetes – baby son born with cerebral palsy and other disabilities resulting from shoulder dystocia/anoxia. Had vaginal vs caesarian section.

Supreme court upheld Mrs M's appeal (£5.25 mill. damages)

*Montgomery v Lanarkshire Health Board 2015.*



## MONTGOMERY – 2 CONFLICTING OPINIONS

1. Farrell AM & Brazier M. *JME* 2015

*“...will make little difference to healthcare practice & consent in UK, which for over 10 years has focused principally on a reasonable patient test”.*

2. Montgomery J, Montgomery E. (no relation!) *JME* 2015

Flawed decision making – *“the implications of the decision for the legal regulation of clinical judgement are more radical and more wide-ranging than the court claims.”*

‘Infantilising the patient, demonising the doctor’: *“Stereotype of an intimidated patient as the foundation of its decision”* vs *“an intelligent, educated, independent, articulate, and well supported woman”*.

# GMC – DECISION MAKING & CONSENT

## November 2020 – Key points

- **Meaningful dialogue** – exchange of information specific to individual patient in an ongoing process.
- Doctors must find out **what matters to patients** – their needs, values and priorities - so they share relevant information re harms/benefits and reasonable alternatives, including taking no action.
- Doctors must give patients clear, accurate and up-to-date information **based on the best available evidence**, about potential benefits, risks of harm of each option. **Tailor discussion to each individual patient.**
- **Ensure they have understood the information given.**

How realistic is this in the real world of medical practice?

## What does capacity (competence) entail?

### ➤ PRESUMPTION OF COMPETENCE

Ability to:

1. Understand relevant information
2. Retain that information
3. Use or weigh up that information
4. Communicate that decision

## COMPETENCE & VALID CONSENT

- Patient must be competent & uncoerced for valid consent.
- Competence can fluctuate
- Competence to X – *decision-specific*
- The graver the decision, the higher the bar for accepting capacity e.g. refusal of life saving treatment.

## How 'rational' do patients' decisions have to be?

In UK law “*Competent adult patients have a right to refuse treatment for reasons which are rational, irrational or for no reason.*”

Per Lord Templeman in *Sidaway* (1985).

## SHOULD DOCTORS SUPPORT 'IRRATIONAL' DECISIONS?

Savulescu and Momeyer (1997) argue that:

“Some of what purports to be medical deference to a patient’s values is not this at all: rather, it is acquiescence to irrationality. Some of what passes for respecting patient autonomy may turn out to be less respect than abandonment” ...

“We do not respect autonomy when we encourage people to act on irrational beliefs. Rather, such beliefs limit a person’s autonomy.”

“Physicians must concern themselves with helping patients to deliberate more effectively and, ultimately, must themselves learn to care more about theoretical rationality”.

## WHAT ARE THE DANGERS IF WE INSIST ON 'RATIONALITY'?

If we set the bar too high – we may paradoxically undermine autonomy.

Isaiah Berlin. *Two concepts of Liberty. In Four Essays on Liberty.* (1958) Rationality may become coercive - forcing people to obey as 'they do not know what is good for them'.

Do we sometimes say patients are 'irrational' and question their capacity when we disagree with them?

## Critical view of Purpose & Process of Informed Consent

O'Neill:

*“Genuine consent is not a matter of overwhelming patients with information, arrays of boxes to tick or propositions for signature.”*

Jackson 2021:

*“My claim is that a good informed consent process should not assume that a neutral presentation of information about material risks and alternatives will seamlessly produce informed patients making informed decisions”.*

*Challenging the comparison in Montgomery between patients and consumers exercising choices. MLR 29(4):595-612*

# A personal example

## Does 'rational choice' theory stand up to scrutiny?

“Scientific research into decision-making shows that people make decisions in much less rational and well-considered ways than was often assumed.”

“These findings can have serious implications for the ethical doctrine of informed consent...

“We need to combine deliberative and intuitive choice processes”.

[Vos, Schermer & Bolt. Recent insights into decision-making and their implications for informed consent. *JME* 2018, 44:734-738]

# UNDERSTANDING PATIENTS' DECISIONS: COGNITIVE & EMOTIONAL PERSPECTIVES

- 'ENCHANTING APPEAL OF ZERO RISK'
- FRAMING & PRESENTATION
- HINDSIGHT BIAS & ANTICIPATED REGRET
- LOSS AVERSION AND PREFERENCE FOR STATUS QUO
- UNRELIABLE PREDICTION OF FUTURE FEELINGS
- UNDUE SALIENCE TO PAST MEMORIES
- IRRATIONAL CONCERNS
- COGNITIVE BIASES IN RISK PERCEPTION e.g immediate vs longer term harms, 'safe' and 'dangerous' labels

**Conclusion: Doctors need to help patients identify pitfalls in reasoning and to recognize the role of emotions.**

## **EMPIRICAL STUDIES**

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The empirical literature often shows a lack of shared understanding between clinicians and patients.

## EXAMPLE : HAEMATOLOGY

Qualitative study of 25 patients undergoing stem cell transplantation.

“Information about treatment procedures and protocols can be satisfactorily communicated, but personal experience of suffering defies communication. This finding has serious implications for the practices involved in obtaining informed consent and for the very notion of informed consent.”

## INFORMED CONSENT & MEDICAL ORDEAL

Patient 'Colin' who had found initial information given very helpful. At second interview after the treatment:

“No, I was not prepared. I mean I was not prepared...I never thought how bad it could be or how dangerous it could be, how life threatening it could be...I could never ever comprehend what I was going through at the time’...

Informed consent and medical ordeal: a qualitative study. Little M et al. *IntJMed* 2008;38:624-628

## Example: Obstetrics & Gynaecology

Qualitative study of 25 women having elective or emergency O&G procedures. Of these 9 were opposed or ambivalent to surgery but they felt obliged to submit to the 'rules of the game'.

*“Our study suggests that the consent process not only fails to operationalize bioethical ideals such as respect for autonomy and a challenge to paternalism, but through its enactment may actively contribute to the disempowerment and disenfranchisement of patients.”*

[Dixon-Woods M et al. *Clinical Ethics* 2006;1:153-8]

## **Example: Palliative Care: What oncologists tell patients about survival benefits.**

Qualitative study (27 patients and 9 doctors) of consultations where treatment decisions made.

In most consultations (26/37) discussion of survival benefit of palliative chemotherapy was vague or non-existent.

Patients will often risk negative impacts on QOL for survival gain.

*“By sensitively narrowing the gap between unrealistic expectations and current evidence, oncologists can be closer to fulfilling their responsibility of assisting patients to make informed decisions”.*

Audrey S et al. *BMJ* 2008;337:a752

## THE WAY FORWARD? “COLLABORATIVE COGNITION”

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*“Collaborative cognition depends on physicians being mindful not only of patient’s values, thoughts, and feelings but also his or her own.”*

[Epstein and Peters. Beyond information: exploring patients’ preferences. *JAMA* 2009;**302** (2):195-7]

## Four models of the doctor-patient relationship

<p><b>PATERNALISTIC</b> Doctor “knows best”. Selects information and strongly recommends the ‘best’ treatment. Patient assents.</p>	<p><b>INFORMATIVE</b> Engineering or consumer model. Gives all the relevant information. Patient decides &amp; controls decision making.</p>
<p><b>INTERPRETIVE</b> Dr provides the information but helps the patient to decide what aligns best with his/her values. Acts as counselor.</p>	<p><b>DELIBERATIVE</b> Dr has dialogue with patient to choose the best health-related values that can be achieved. Acts as teacher or friend.</p>

*Emanuel EJ and Emanuel LL. Four models of the physician-patient relationship. JAMA 1992;267:2221-6*

## SHARED DECISION MAKING (SDM) & PATIENT-CENTREDNESS

“Unlike the conversational dance in SDM that requires a human connection of careful and kind care, informed consent procedures call for a more technical and mechanical approach, a formal one-way provision of information in which boxes of topics addressed are to be metaphorically ticked for administrative and legal purposes...

SDM should be a manifestation of advanced patient-centred care.”

When patient-centred care is worth doing well: informed consent or shared decision-making. Kunneman M & Montori VM, *BMJ* 2017;26:522-524

## Back to the case...

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# CONCLUSION

- ❖ Standard 'Western' models of individual autonomy and informed consent based on rational deliberation do not appear to adequately reflect 'lived experience', or neuroscientific & empirical evidence.
- ❖ Gaining consent should involve conversation, not just information. Offering care, not just choice.
- ❖ Choices consistent with patients' goals are most likely to emerge when emotions and logic work in concert. Clinicians can help patients construct preferences. But it's not easy!

## ANY QUESTIONS OR COMMENTS?



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