What is a good discussion about risk and information sharing?

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2017

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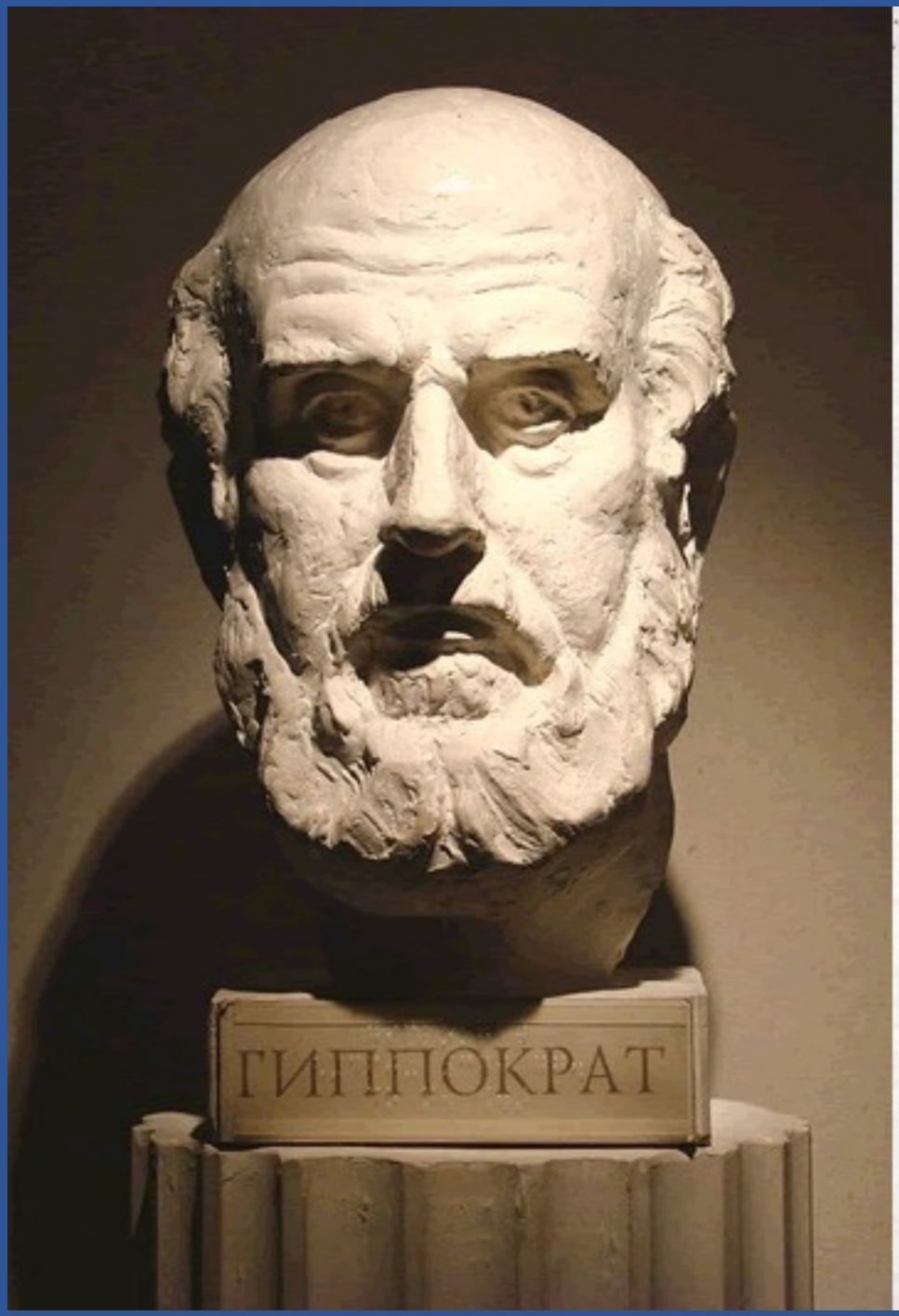
In this talk:

- The duty of confidentiality: history and scope
- Limits to confidentiality and secrecy
- Information as possession
- Risk of harm and information sharing
- Duties to disclose and whistle blowing

- Acknowledgements: Professors Deborah Bowman, Bill Fulford and Nigel Eastman. Thanks also to Dr Brian Robinson and Mr Dan Ferris.



ΙΠΠΟΚΡΑΤΟΥΣ

ΚΩΟΥ ΙΑΤΡΟΥ ΠΑΛΑΙΟΤΑ=

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HIPPOCRATIS COI MEDICI

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BASILEAE

M D XXXVIII

The Hippocratic corpus: secrecy in medicine

Whatever, in connection with my professional service, or not in connection with it, I see or hear, in the life of men, *which ought not to be spoken of abroad*, I will not divulge, as reckoning that all such should *be kept secret*.

Why secrecy as a duty?

- In classical culture, value of wives/slaves might alter if heads of household know them to be ill
- Kinship structures and alliances with pregnancy
- A holy mystery?
- Secrecy promotes disclosure of shameful things

Traditional basis for duty of confidentiality

- People seeking care when suffering or worried are vulnerable
- Need assurance that doctor will not exploit vulnerability
- Therapeutic relationships need openness and honesty, which can only be based on trust
- Trust is supported by an agreement of privacy and containment of knowledge
- Protection against gossip: ruinous in small communities

Information control as a human right

- Article 8 ECHR: the right to a private life includes control over personal information
- Campbell vs MGN Ltd
- Medical Records are part of private life; and each person has right to control that information
- Other cases?
- Rights to information control replaces a duty to keep secrets
- Caldicott principles and Guardians

Confidentiality and information management

- Personal information treated as data to be collected and stored
- Information as a commodity in market economies: financial implications
- Individuals own their information: no disclosure without consent
- Data Protection Act and Information governance

But… what about…?

- Secrecy can be harmful to communities: secrecy can support exploitation of the vulnerable
- Secrecy is harmful in relation to occupational and communicable diseases
- What about the scope of the duty? How far does it extend? And for how long?
- Can there be protection of privacy without secrecy?
- Could there be a duty to disclose to prevent harm to others?


JUSTICE

Confidentiality: individuals vs communities

- 19C: introduction of public health laws that restrict movement of people with communicable disease
- Introduction of concept of occupational health, and health and safety at work
- Role of doctors in public health: duties to communities and groups, not individuals
- Medicine not purely a private relationships between two parties: so justice is involved

Duties to disclose: risk of harm to others

GMC advice in the 1980s in response to AIDS

If a person who is HIV positive refuses to disclose this to named and identified sexual partners, a doctor may disclose this to those partners in the face of a flat refusal

A breach of the duty of confidentiality is justified by the prevention of serious harm to others

OR

The duty to prevent harm to others trumps professional duties to individuals .

Risk/harm reduction as clinical outcomes and ethical goal

- Medicine's utilitarian framework: a duty of beneficence implies a duty to always do that which brings about the best outcome for as many people as possible
- And to reduce harm
- But what if attention to these duties means breaching others?
- Which potential benefits and harms will matter? Who gets to decide?
- What about bad outcomes in the pursuit of a good outcome? The Doctrine of Double Effect
- What about a focus on duties not outcomes?
- What about justice?

The Minimally Helpful Samaritan?

- Set out in Judith Jarvis Thompson's defence of abortion
- We cannot expect people to be Good Samaritans but we might expect them to be minimally helpful
- If their refusal to help costs them little but costs others a lot, then this is unreasonable and morally unsustainable
- Is there a parallel here with information sharing?
- Who decides the costs?

Tarasoff vs Regents of University of Berkeley CA

- The case that launched a thousand writs
- Miss Tarasoff & Mr Poddar were students at Berkeley. They had a brief relationship, but Miss T broke it off. Mr P became depressed and he started to stalk Miss T. He saw a campus counsellor for therapy; and told her that he was thinking of killing Miss T. if he could not be her BF. He then dropped out of therapy.
- The counsellor was alarmed; and told the campus police who spoke to Mr Poddar about his intent to harm Miss Tarasoff. He denied this and no further action was taken.
- Three weeks later, Mr Poddar shot Miss Tarasoff dead. He was tried for murder; found NGRI and after spending time in hospital was deported back to his native India.

Tarasoff vs Regents of University of Berkeley CA (2)

- Miss Tarasoff's parents sued the University, claiming that they had failed in their duty of care to Tatiana by not telling her she was in danger from Poddar. The University claimed that their counsellor had a duty of confidentiality to Mr Poddar; and no duty to Miss Tarasoff, because she was not a patient.
- The California supreme court heard the case twice!
- They found that the duty to keep confidence was not absolute; and that the University did have a duty to (a) warn and (b) protect those identified at risk.

A duty to disclose information that would reduce risk of harm

- *Tarasoff* founded a new duty for health care professionals; and effectively abolished secrecy as basis for confidentiality duty
- Key issues: identifiable victims and foreseeability of violence risk
- Generated research into the link between mental disorders and violence
- *Identifiability* of a person at risk creates a duty to protect

From the Tarasoff Judgement

“Protective privilege ends where public peril begins”

Dr Egdell and Mr W (1990)

- Mr W was a patient in a secure hospital who wanted to be released at a Tribunal hearing. His lawyers instructed Dr Egdell to provide a report about W's risk. W told Dr Egdell about his continuing interest in 'explosives', and Dr Egdell formed the view that W still posed a risk of harm to others as a result of his mental illness. The lawyers thanked Dr Egdell for his report; and decided not to use it at the hearing. Dr Egdell sent his report to W's doctors; and the report eventually found its way to the Home Office. W sued Dr Egdell for breach of confidentiality.
- The court found that there had been a breach of confidentiality, but it was justified by the duty to ensure risk reduction. The court also commented that there might be a duty on doctors to breach confidentiality in such circumstances.

Palmer vs Tees Health Authority [1999] EWCA Civ 1533

Rosie Palmer was killed by a patient released from a psychiatric hospital; who had talked about having thoughts of harming children. Her family argued that the HA had a duty to Rosie; but the court found that there could be no duty to unidentifiable classes of people, because of the burden it would put on services.

Risk of what and to who and when

- NHS code of confidentiality (2003) imposes duty to disclose medical information in the '*prevention, detection and punishment of serious crime*'
- Separate duties for child protection: DoH guidance, Local Authority safeguarding procedures, GMC guidance
- Risk assessment for every patient in mental health; includes attention of risk to others
- Risk to others is one criteria for detention under mental health law

Example: justice, fairness and confidences

Mr Jenkins killed his wife when he was mentally ill. He was sent to a secure hospital for treatment instead of a prison sentence and spent 20 years there. He is now well enough to be transferred to a less secure service near his home area, which he knows well, and where he has some supportive friends. However, legislation for crime victims states that his family members must be told of his planned transfer; and his adult children oppose his move, saying they will tell local newspapers, complain to the MP and even threaten to kill him if he comes back to the local area.

Risk management involves moral reasoning

- Why does Mr Jenkins have no claim to confidentiality? What about a claim to justice?
- Why do his family members get to decide about his care?
- Risk assessment is not about imagining what might happen: but weighing up of chance and probabilities
- Hard to do with low base rate events: Empirical evidence suggests the risk is low
- Risk = Hazard x Outrage

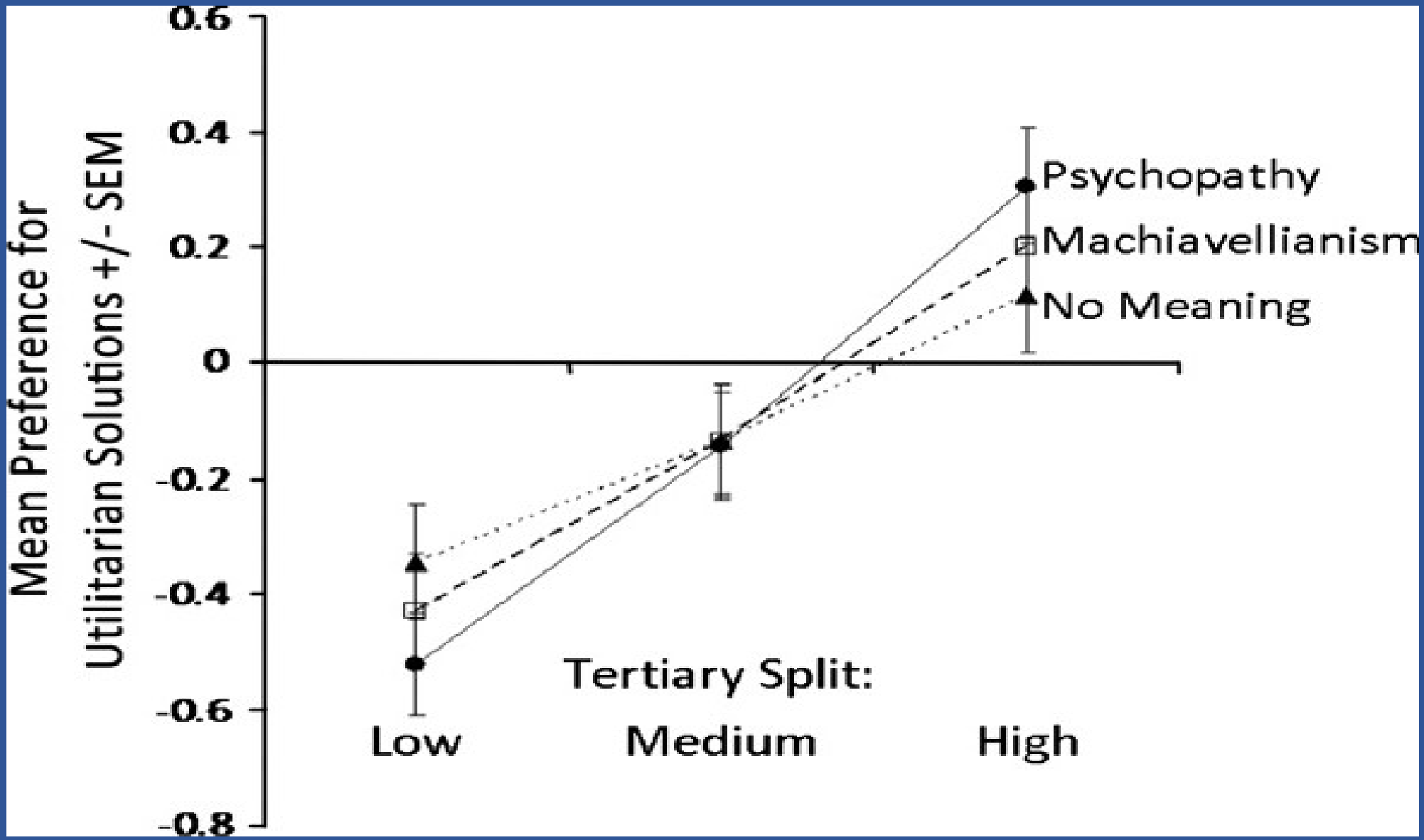
Different approaches to confidentiality for different people?

- If you are an ordinary patient with a medical disorder, no-one can disclose any information about your condition without your express consent
- This includes people with criminal records
- But if you are a patient with a mental disorder, who has been violent in the past, information about you can be shared without your consent, without your knowledge and even if you refuse consent
- Fatal child abuse inquiries make it clear that professionals are still reluctant to share concerns about adults who might pose a risk to children

Is this a version of the trolley problem in mental health?

- One person's privacy and confidentiality is breached to reduce the risk of harm to others
- How many others? What if they just *feel* safer?
- What if only the professionals and their employers feel safer?

Bartels & Pizarro 2011



Information and relational ethics

- Is what a man says in therapy a type of personal *object* that he *owns*?
- The knowledge people have of each other is crucial to intimacy, trust and attachment
- Real dilemmas about treating personal information as a commodity
- Especially when people are elderly and dependent on others; young and dependent on others; end of life care, when relationships are crucial
- Information as *communication*

How to think about these challenges?

- Change the emphasis on what people say about themselves from a market approach to a relational approach
- Ask people early on in their care who is important to them and their identity and how they want others to be involved in their care
- Teach staff about the values of good communication and sharing of information as part of care
- Health care as a conversation, not a transaction

Montgomery decision: shared decision making

- Informed consent is not a medical technical issue
- Shared decision making: paying attention to

(a) The perspective of the reasonable person in the patient's position

(b) The perspective of the reasonable clinician thinking about the patient's condition

Dialogue between the patient and the clinician who must pay attention to the values of this particular patient: even if the clinician is not especially skilful or feels they have time

Risky business: when information is distressing

- A patient is diagnosed with a severe medical condition that is genetically transmitted.
- Information about this condition means that his doctors now know important information with significance and salience for others e.g the patient's children and relatives
- Who should tell who what? And who gets to decide?
- Especially if the process of disclosure may be distressing; and the outcome life changing.

Dheensa et al (2016; 2017)

Studies of what patients and professionals say about these dilemmas in genetic medicine

Patients say: this doesn't feel like my information to be kept to myself

Professionals say: I don't want to disclose because it might upset family dynamics and cause distress

If a patient doesn't want to tell his family, I can't make him do that: it's his right to make a decision that hurts others

ABC vs St George's NHS Trust [2015] EWHC 1394 QB

- A real case: Mr A killed his wife while mentally ill and went to a secure hospital. He had family therapy with his daughter Ms C to discuss his offence and the impact on their family.
- Mr A was diagnosed with Huntington's Disease. This meant that Ms C had a 50: 50 chance of having the disease herself; and any off spring of hers might also be affected.
- Ms C was pregnant; but Mr A refused to have his condition disclosed to her in case she decided to have an abortion. Ms C had a baby daughter.
- Ms C accidentally found out that her father had HD; and that the hospital had known for some time. She sued in negligence, saying that the hospital had failed in its duty of care to her.
- The court found that there was no case to answer as the hospital had no duty to her; because she was not a patient.
- **Ms C appealed in 2016**

BUT…

- Do we really ‘own’ information about ourselves in this way?
- How can we help people to communicate about distressing and frightening matters?
- Justice may be more important than welfare in the long term
- March 2017: The Court of Appeal in ABC found for Ms C: the Trust did have duty of care to her because of the harm caused by the failure to disclose.

Conclusion

- Health information is not just the property of an individual patient
- Information sharing is expected as part of getting consent to interventions
- Health care professionals need to get better at communication, dialogue and reflection
- Therapeutic conversations: not just outcomes but identities and relationships
- Especially in health care decisions that affect others and their identities : OBGYN, genetics

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