The relevance of healthcare inequalities for clinical ethics committees

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• Healthcare inequalities pose ethical questions.

• Clinical ethics committees are in a position to address some of these questions.

• But a large gap remains in the translation of ethical principles and ethical awareness into good clinical practice.

• In particular, clinical ethics committees are limited in their ability to address issues such as those raised by healthcare inequalities by
  – Organisational structures;
  – Traditional conceptions of what it is to ‘do clinical ethics’.
Healthcare inequalities pose ethical questions

Difference is not necessarily a moral concern.

But differences between people, and the way people are dealt with in healthcare systems, create variation in outcomes - and *this* is an ethical issue.

Some of this variation is ‘prior’ to the care we give in healthcare settings; some occurs within the healthcare setting.
Inequality in the provision of care leads to different patient choice and different outcomes

RR=0.76 (0.6, 0.9)

O’Connor et al., *Cochrane Library*, 2009
Better information and involvement in decision making affects patient choice and outcomes.

- Prostatectomy rates decreased 40% to a rate lower than all but one of 306.
- CABG rates decreased 26% to a rate lower than all 306 regions.

Impact of better decisions on surgery rates: BPH & CHD
Where there is clinical uncertainty about the best course of action, variation is high - and unlikely to be led by patients.

Consensus about evidence / necessity

Importance of patient preferences
Cultural differences and language barriers can affect clinical outcomes


In decisions about renal replacement therapy, the use of family members to interpret for people approaching end stage renal failure can cause tension and limit access to information and support.
Health literacy affects clinical outcomes

Among patients with heart failure, low health literacy has been shown to be associated with higher all cause mortality.

Peterson P et al *Health Literacy and Outcomes among patients with heart failure* JAMA 2011; 305: 1695-1701
Questions of equality often arise in the allocation of scarce resources - and ethics committees have been here before

“They decide who lives, who dies: medical miracle puts moral burden on a small committee”

‘the story captured the inherently dramatic nature of the artificial kidney program: the frankly experimental nature of chronic dialysis; the dependence of the patient on the workings of a machine …. and, above all, the radically unorthodox step of involving laymen in making life-or-death decisions about a candidate’s acceptability for this medical procedure.’

Renee Fox and Judith Swazey The Courage to Fail
Univ Chicago Press 1978
Clinical ethics committees do address issues relating to inequality

- Review of policies and guidelines.
- Exploring issues of equality with clinical teams in the consideration of individual cases.

But…..
... there are obstacles to addressing inequalities

• The organisational structure and perceived role of clinical ethics committees.

• Traditional conceptions of what it is to ‘do clinical ethics’.
The organisational structure and perceived role of clinical ethics committees.

- Individual cases.
- Clinicians bring cases: preaching to the converted?
- The gap between policies/principles and clinical practice.
The social construction of what it is to ‘do clinical ethics’.

• A comparison: ‘patient-centred care’.
Bioethics can be criticised in much the same way as biomedicine has been criticised

The prevailing ‘limited view of what an ethical problem is and how it is solved is one that allows the bioethicist to work closely with physicians without changing the prevailing structural arrangements of health care’.

There are alternative ways of doing clinical ethics and clinical ethics committees can and do use them

‘there is a deeply troubling question in the philosophical formulation of an ethical problem as rational choice among abstract principles, because that problem is always the burden of a man or woman’s particular world of pain and possibility. That social space contains the flows, routines, and everyday practices of moral experience. Ethnography, biography, social history, literature – all contain methods of entering those local social spaces. They see moral issues from inside of experience, where those issues appear as they are so often lived, as fragments, incoherences, things beyond one’s control.’

Can we address what is perhaps the ultimate healthcare inequality: the personal vs the medical?

‘..when we have a pattern of day-to-day healthcare, which creates discomfort, pain, and even fear for several patients at once, the clinicians stay silent. Someone needs to give those clinicians a tool with which to attack the system in which they are trapped. For it is a world whose everyday habits demean those who work in it as much as they harm patients. Maybe ethicists could help change that world.’

Updale, E. 2008, "The ethics of the everyday: problems the professors are too posh to ponder?", *Clinical Ethics*, vol. 3, no. 1, pp. 34.
Bridging the gap between ethics and clinical practice: what does it look like?

TRADITIONAL
• Extrinsic motivation
• Governance
• Traditional bioethics
• Principlism
• Reactive
• Post-hoc analysis

IDEAL
• Intrinsic motivation
• Ethics
• Activism
• A socially informed, cross-disciplinary ethics
• Proactive
• Pre-emptive training
And what does that mean in practice?