



Navigating difficult decisions in medical care and research

doi:10.1136/medethics-2020-106410

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The articles in this issue explore a number of difficult choices in medical care and research. They investigate ethical complexity in a range of decisions faced by policymakers and clinicians, and offer new evidence or normative approaches for navigating this complexity.

In this issue's feature article, Ford and colleagues engage with an ethical challenge faced by policymakers in relation to health research: should free text data contained in medical records be shared for research purposes?¹ While some types of data from electronic medical records are used widely in health research, privacy concerns have limited the use of free text data specifically. Ford and colleagues highlight the richness of the clinical information in free text and its centrality to some areas of healthcare such as mental health and primary care. In their view, while text analytic technology is developing rapidly, 'policy makers routinely judge that the risk of re-identifying patients from text data is too high for these data uses'. Their citizens' jury study in the UK found that participants were largely in favour of medical free text data being shared outside the NHS for research using an opt-out model: 'the majority of jurors believed the benefits of sharing data for research outweighed the privacy risks'.

In their commentary on this research, Largent and Morain raise some important issues about policymakers' use of empirical findings about public preferences, and the challenges of this type of approach.² In depth deliberative methods such as those used in Ford and colleagues' study involve extensive information provision and structured reflection for participants. Largent and Morain ask 'how a policy that incorporates informed and reflective preferences elicited from a small group of jurors can effectively engender trust among members of the broader public who have not had the benefit of deliberative methods?'

Similarly focused on ethical questions faced by policymakers, two articles in this issue look at difficult choices about medical assistance in dying. Singh, Macdonald and Carnevale explore extending Canada's legislation allowing medical assistance in

dying to include mature minors and potentially minors more broadly.³ The concept of children's voices is central to their analysis. They argue that children's voices can provide insights into their illness experiences that are crucial to determining eligibility for MAID in the Canadian approach. In the German context, Horn reports on the Constitutional Court's recent ruling on assisted suicide which emphasised autonomy and self-determination.⁴ Horn suggests that, while the Court overturned the ban on assisted suicide, the task of providing clear guidance on how to regulate assisted suicide remains.

As well as ethical choices for policymakers, several articles in this issue address challenging decisions for clinicians. Again focusing on minors, Turnham and colleagues investigate whether minors who are parents have the same ethical entitlements in relation to medical decision-making for their children as other parents do.⁵ Their analysis focuses on a case in which an unwell infant's mother is herself a minor. The 'minor-parent' is refusing an intervention for the infant that the medical team recommends. Should the clinicians approach this situation in the same way that they would if the parent was an adult? Turnham, Binik and Wilkinson argue that a minor-parent's decision-making authority for an infant is comparable to that of other parents, insofar as the minor-parent is undertaking the duties of parenthood and shares the consequences of medical decisions made for the child. They suggest that, even though there are limitations on the medical decisions that minors are permitted to make for themselves compared with adults, minor-parents should not have greater restrictions on their 'zone of parental discretion' in relation to medical decision-making for their children. This is, these authors argue, because 'the restricted authority that teenagers are granted to make medical decisions for themselves looks very similar to the restricted autonomy of all parents' – limited by the harm threshold. Bersani, Pacitti and Iannietelli also investigate a clinical ethics issue: complexities of consent for electroconvulsive therapy.⁶ They argue that this type of treatment

highlights the distinction between an expression of consent and valid informed consent.

Continuing the focus on clinicians' difficult choices, two other articles in this issue look at ethical challenges related to the COVID-19 pandemic. McConnell analyses the hard choices faced by clinicians attempting to balance their duty to treat patients with their duty to protect their families from COVID-19 infection.⁷ He argues that it is morally permissible for a healthcare worker to abstain from work when their role-based duty to treat patients is outweighed by the risks and burdens of their work, which include the risks of COVID-19 infection for any particularly vulnerable members of their family. Mannelli looks at allocation of scarce healthcare resources in the pandemic, specifically intensive care specialists in the northern area of Italy 'facing overwhelming decisions about who should be provided with ventilation'.⁸ Mannelli argues that, despite the public outcry, prioritisation for scarce health resources is not a new phenomenon; what is new in the COVID-19 situation is the vast number of people affected by prioritisation.

Two other papers in this issue address phenomena that are genuinely new, and the ethical issues associated with them. In the first, Fabiano explores whether technological moral enhancement is a unique area of human enhancement, with a different level of justification compared with other types of human enhancement.⁹ This paper takes as its starting point the argument that moral enhancement is unnecessary: that traditional forms of moral education are sufficient to enable our presently inadequate morality to develop in ways that would enable us to tackle co-operatively the new global risks to human lives such as climate change and pandemics. Fabiano critiques this view, arguing that its assumptions about the efficacy of traditional moral progress are too bold and that '[t]raditional moral progress could use some assistance from non-traditional means in order to face new challenges'.

Kim and colleagues investigate the new possibilities raised by technologies that

remotely monitor patients' adherence to medications.¹⁰ In a 'learning health system' where clinical care and research are closely integrated, do patients have a responsibility to use technologies that enable remote monitoring of their medication adherence and to share their data? Using a framework of seven obligations specific to learning health systems, Kim and colleagues argue that patients do have a conditional responsibility to use available novel medical adherence monitoring systems when important new knowledge can be generated. However, these authors suggest, this responsibility is limited by considerations around intrusion, privacy, coercion and data ownership.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; internally peer reviewed.

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