



Making concepts work

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The articles in this issue direct our attention to the role of concepts in medical ethics. The issue includes research that defines a concept,¹ research that applies concepts to illuminate the moral aspects of various elements of medicine,^{2,3} and research investigating the appropriate set of concepts to teach medical students.⁴

In their in-depth exploration of the concept of disease in this issue, Powell and Scarffe argue that our understanding of a concept should be 'tailored to the role that the concept plays in the institutional settings in which it is deployed'.¹ Their methodology takes seriously the institutional context in which a concept operates. This approach to thinking about concepts is potentially applicable very broadly in medical ethics. What is the institutional role that a concept plays? What is the work that we need the concept to do?

The feature article by Powell and Scarffe proposes a new definition of a foundational concept in medicine, that of disease. On their view, 'a biomedical state is a disease only if it implicates a biological dysfunction that is, or would be, properly disvalued'.¹ They describe their definition as involving both a moral criterion (of being 'properly disvalued') and a biological criterion (of biological dysfunction).

A number of commentators engage with Powell and Scarffe's proposal. Tekin focuses on the moral criterion, through the example of grief and depression. By investigating 'whether complicated grief is a disease', Tekin endorses an inclusive process to decide whether a state is properly disvalued.⁵ Any process of moral justification must, on Tekin's view, include perspectives beyond scientists and doctors and incorporate the views of those with lived experience. Carel similarly highlights 'the problem of who deliberates', drawing attention to the importance of patient views and preferences.⁶ In asking 'which values are the ones to be taken into account?', Carel raises the concern that the proposed account 'does not include a requirement that first-person patient views are included in, or should feed into, debates on how to classify a particular condition'.⁶

The final commentary, by Agar, engages with a different aspect of Powell and Scarffe's proposal: their recommendation that an account of disease need not be

universally applicable across all domains. Powell and Scarffe argue for 'disease concept pluralism between medical and biological sciences to allow the concept to serve the different epistemic and institutional goals of these respective disciplines'.¹ They see their definition of disease as applicable across 'the broad domain of human healthcare'.¹ However, Agar argues that mental health is importantly different to other areas of healthcare – 'brains are not like pancreases' – to the extent that eliminating the concept of disease from mental health is appropriate.⁷

Other articles in this issue work with concepts in a different sense: applying existing concepts to generate new insights into aspects of healthcare. Parker takes the concept of moral exploitation and uses it to illuminate the position of junior doctors in the medical hierarchy and health system.² Hanna and Robert argue that the concept of dignity is an important lens through which to view practices of limb disposal, in the wake of a recent UK scandal in which patients' amputated body parts were stockpiled.³

Ethical concepts are also central to the argument put forward by Finlay, Choong and Nimmagadda in their analysis of UNESCO's *Undergraduate Bioethics Integrated Curriculum*. While seeing the creation of an integrated curriculum as an laudable achievement, they have concerns about the nature of the concepts contained in this curriculum which is aimed for first use in Indian medical schools. They argue, in part, that the curriculum 'sees bioethical issues, problems and solutions through the philosophical traditions of the West'.⁴ These authors advocate an alternative approach in which 'concepts from the Western model of bioethics may form a vital part of the instructors' toolkit, (but) they and their students may also draw from their own cultural-religious frame of reference'.⁴

The concept of privacy in the digital age is the focus of the article by Aboujaoude. Aboujaoude argues that the 'assault on privacy' associated with Internet-related technologies renders users 'psychologically vulnerable'.⁸ As a result, in his view, medical professionals' ethical obligations in relation to privacy now extend beyond simply appropriate handling of patient information: 'clinically relevant privacy

breeches now go well beyond violations of the medical record' and thus advocating for digital privacy should be a priority for clinicians.⁸

A different ethical impact of digital technologies is explored by Fiske, Prainsack and Buyx: the expansion of 'citizen science'. These authors discuss the ethics of this approach to knowledge production, understood as the participation of non-professionals (such as patients) in scientific research. Fiske, Prainsack and Buyx identify a range of ethical issues raised by citizen science which are not well-addressed by standard established frameworks of research ethics, particularly in relation to power disparities. They argue specifically that 'benefits need to be both accessible and actionable by participants – in particular those who are resource-poor, located outside of service networks, non-white/western, or have been historically marginalised by biomedicine'.⁹ They put forward a set of key questions to support ethical decision-making by all involved with citizen science initiatives.

This issue also contains an empirical study that aims to contribute to addressing 'a lack of conceptual and normative clarity' about the form of clinical ethics support known as moral case deliberation.¹⁰ Moral case deliberation is 'a facilitator-led collective moral inquiry into a concrete moral question connected to a real case made by healthcare professionals in their practice'.¹⁰ Svantesson and colleagues conducted a survey of healthcare professionals drawn from 73 healthcare workplaces in the Netherlands, Norway and Sweden, to increase understanding of health professionals' views about the outcomes of moral case deliberation. These researchers focused on which outcomes were perceived as most important by health professionals prior to participating in moral case deliberation. They found that participants perceived enhanced collaboration among co-workers, and concrete action-focused results as the most important outcomes of this method of clinical ethics support.

The final piece in this issue is an excellent student essay by Epanomeritakis which presents a detailed ethical analysis of the UK's Cancer Drugs Fund. This initiative was introduced to enable access to efficacious

cancer drugs which were not available through the NHS due to cost ineffectiveness. Epanomeritakis argues that setting up a cancer-specific fund is not defensible on grounds of distributive justice: '[i]t creates a healthcare system which is partial to the purchase of cancer drugs over other drug-types'.¹¹ However, the fund cannot reasonably be disestablished as this would involve 'levelling down', and has a justifiable internal procedural structure.¹¹

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