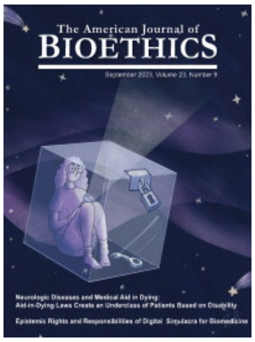

Taylor & Francis
Taylor & Francis Group

The American Journal of Bioethics

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/uajb20

Care Depersonalized: The Risk of Infocratic "Personalised" Care and a Posthuman Dystopia

Matthew Tieu & Alison L. Kitson

To cite this article: Matthew Tieu & Alison L. Kitson (2023) Care Depersonalized: The Risk of Infocratic "Personalised" Care and a Posthuman Dystopia, The American Journal of Bioethics, 23:9, 89-91, DOI: 10.1080/15265161.2023.2237472

To link to this article: https://doi.org/10.1080/15265161.2023.2237472

THE AMERICAN JOURNAL OF BIOETHICS
2023, VOL. 23, NO. 9, 89–91
https://doi.org/10.1080/15265161.2023.2237472

Taylor & Francis
Taylor & Francis Group

OPEN PEER COMMENTARIES

Care Depersonalized: The Risk of Infocratic “Personalised” Care and a Posthuman Dystopia

Matthew Tieu and Alison L. Kitson

Flinders University South Australia

Much of the discussion of the role of emerging technologies associated with AI, machine learning, digital simulacra, and relevant ethical considerations such as those discussed in the target article, take a relatively narrow and episodic view of a person’s healthcare needs. There is much speculation about diagnostic, treatment, and predictive applications but relatively little consideration of how such technologies might be used to address a person’s lived experience of illness and ongoing care needs. This is likely due to the greater weight or priority given to acute care needs and the role of medical treatment in care provision, but it may also reflect the limitations of current technologies and our limited vision of their potential application. Such limitations are not surprising given that we are still grappling with the complexities and nuances of achieving the ethical and humanistic ideals of care, namely, care that addresses the hermeneutical, relational, contextual, temporal, and agential dimensions of a person’s health and wellbeing. However, it is foreseeable, that emerging technologies will eventually have applications across broader domains of care and thus help to promote those ideals. The ethically relevant question then is whether we are doing enough to develop those technologies, envisaging their application accordingly, while also anticipating and navigating potential ethical pitfalls.

Regarding the use of digital simulacra and other “data-first” approaches in health research and care, Cho and Martinez-Martin (2023) have highlighted the problems of bias and misrepresentation that result in misdirected care, “epistemic injustice” and marginalization of certain populations. They also point out that it shifts “moral obligations in health research toward digital simulations and away from the people on whom the simulations are based” (45). Building on these concerns and viewing them through a humanistic care lens, we point out that our current vision of the application of emerging technologies in care is an infocratic one in which the general goal is to defer much of the responsibility of understanding, learning, planning, and decision-making to such technologies. This can have an objectifying and depersonalizing effect on those in need of care and may also promote a return to institutional and biomedical models of care, undermining decades of progress in shifting toward biopsychosocial, person-centred, and integrated life course models (Engel, 1977; Kitwood, 1997; Kitson et al. 2022). Despite the possibility (and rhetoric) of greater “personalisation” and treatments better tailored to the individual, we contend that a “data-first” approach risks *completely* misdirecting care and marginalizing *all* people in need of care. In this regard, we echo the views of Boris Groys who in his book, *Philosophy of Care*, points out that our dependence on the technology and institution of care itself (the “machine of caring”) entails that we must continuously grapple with the goal of caring for our selves (our bodies) and caring for the projections and representations of our selves (our “symbolic bodies”) (Groys, 2022).

A POSTHUMAN DYSTOPIA IS NOT INEVITABLE

Concerns about the existential threat posed by technology abound in various forms, a noteworthy example being the recent statement issued by the Center for AI Safety, that “mitigating the risk of

CONTACT Matthew Tieu matthew.tieu@flinders.edu.au College of Nursing and Health Sciences (Flinders University), GPO Box 2100, Adelaide 5001, South Australia; Alison Kitson alison.kitson@flinders.edu.au College of Nursing and Health Sciences (Flinders University), GPO Box 2100, Adelaide 5001, South Australia.

extinction from AI should be a global priority alongside other societal-scale risks such as pandemics and nuclear war."[1] Such concerns may indeed be well founded, but rather than opposing the emerging technologies or accepting the inevitability of a post-human dystopia, we acknowledge their potential to dramatically improve our lives, particularly through enabling us to provide better care and create better systems of care. It is therefore ethically incumbent upon us to ensure that emerging technologies are created and applied accordingly.

Technologies such as digital simulacra reflect the abundance and ubiquity of personal information and the power to harness it in ways that enable a better understanding of human beings and greater sophistication and nuance in care provision (e.g., ranging from precision medicine to personal care planning across the lifespan). As Cho and Martinez-Martin (2023) point out, digital simulacra bridge "the gap between population-level data and the individual and the problem of applying research findings derived from groups to a single patient" (44), which has implications for clinical care of individuals. As care systems trend toward consumer-centred models that increasingly rely on self-care and self-management of illness (particularly of chronic illness and multi-morbidities) we increasingly become consumers of the emerging care technology itself. We have argued elsewhere that consumerist models of care tend to ignore the relational, contextual, and humanistic aspects of a person's care needs, which can lead to dramatic failures in providing the most basic forms of care (or what we refer to as "fundamental care") to vulnerable people (Tieu et al. 2022). However, given that individual or personal-level data will also increasingly inform population-level data, it provides an avenue by which care systems and policies can be shaped appropriately. As a case in point, we refer to work by our colleagues who have developed a method informed by complexity science to measure the presence of fundamental care and its interconnections with elements of a person's care environment. It utilizes patient experiences and narratives of care to identify elements of fundamental care associated with the integration of physical, psychosocial, and relational aspects of care, and broader system and policy-level determinants of care. Such a method can be used for monitoring and assessing care quality, tailoring care provision to meet patient needs, training and professional development, and creating care systems and policies that better enable the provision of fundamental care. There is potential for further development of the method for higher throughput using app-based technology and artificial intelligence (Conroy et al. 2023).

A PERSON-FIRST APPROACH

Emerging technologies draw from vast amounts of personal information to provide us with an unprecedented understanding of ourselves but for now and the foreseeable future they do not adequately capture the hermeneutical aspects of self-understanding. We experience health, illness and care through an interpretive and evaluative lens, striving to make sense and find meaning out of our condition, and in ways that often have a moral and spiritual character. Our interpretations and evaluations are also shaped by context, including interpersonal and social contexts, and are ultimately subject to ongoing revision over the course of our lives. Digital simulacra are highly sophisticated and detailed digital representations of people, but they do not adequately capture the hermeneutical, relational, contextual, temporal, and agential dimensions. Thus, expanding on the point about epistemic humility raised by Cho and Martinez-Martin (2023), we point out that the issue is also one of epistemic adequacy. The ethical development and application of digital simulacra and other emerging technologies in care require consultation and partnership with patients themselves so as to ensure that personal information is adequately and accurately captured, and utilized in ways that uphold their dignity and agency as human beings.

A "data first" approach represents an inherent shift away from the person and thus an inherent shift away from person-centred approaches to care. It ignores the fact that humans are hermeneutical and relational beings that utilize sociobiographical information to construct meaning, purpose, agency, and identity (Tieu, 2022). If we lose sight of this in how we develop and apply emerging technologies we lose sight of what actually matters in care, the person. Viewing the role of emerging technologies from a humanistic care lens enables us to identify a wider range of ethical concerns, which if adequately addressed can help us shape the future of care in ways that genuinely improve the lives of all people. Our reliance on technology need not yield a dystopian future in which the anti-humanistic aspirations of critical posthumanists (Braidotti, 2013; Petrovskaya, 2023) are realized by technologies and institutions that displace humanism

---

[1] The statement has thus far attracted hundreds of signatories including many high profile CEOs, AI researchers and academics. https://www.safe.ai/statement-on-ai-risk#open-letter

in care, but we need to remain vigilant and proactive amidst the ubiquity of emerging technologies.

FUNDING

The author(s) reported there is no funding associated with the work featured in this article.

ORCID

Matthew Tieu http://orcid.org/0000-0003-3578-6579
Alison L. Kitson http://orcid.org/0000-0003-3053-8381

REFERENCES

Braidotti, R. 2013. Posthuman humanities. *European Educational Research Journal* 12 (1):1–19. doi:10.2304/eerj.2013.12.1.1.

Cho, M. K., and N. Martinez-Martin. 2023. Epistemic rights and responsibilities of digital simulacra for biomedicine. *The American Journal of Bioethics* 23 (9):43–54. doi:10.1080/15265161.2022.2146785.

Conroy, T., M. A. Pinero de Plaza, A. Mudd, M. Mitchell, and A. Kitson. 2023. Measuring fundamental care using complexity science: A descriptive case study of a methodological innovation. *Journal of Clinical Nursing* 32 (11-12):2903–12. doi:10.1111/jocn.15905.

Engel, G. L. 1977. The need for a new medical model: A challenge for biomedicine. *Science* 196 (4286):129–36. doi:10.1126/science.847460.

Groys, B. 2022. *Philosophy of Care*. United Kingdom: Verso Books.

Kitson, A., R. Feo, M. Lawless, J. Arciuli, R. Clark, R. Golley, B. Lange, J. Ratcliffe, and S. Robinson. 2022. Towards a unifying caring life-course theory for better self-care and caring solutions: A discussion paper. *Journal of Advanced Nursing* 78 (1): E 6–20–e20. doi:10.1111/jan.14887.

Kitwood, T. 1997. *Dementia reconsidered: The person comes first*. United Kingdom: Open University Press.

Petrovskaya, O. 2023. Farewell to humanism? Considerations for nursing philosophy and research in posthuman times. *Nursing Philosophy* 24:e12448. doi:10.1111/nup.12448.

Tieu, M. 2022. *Self and Identity: An exploration of the development, constitution, and breakdown of human selfhood*. United Kingdom: Routledge.

Tieu, M., A. Mudd, T. Conroy, A. Pinero de Plaza, and A. Kitson. 2022. The trouble with personhood and person-centred care. *Nursing Philosophy* 23 (3):e12381. doi:10.1111/nup.12381.

THE AMERICAN JOURNAL OF BIOETHICS
2023, VOL. 23, NO. 9, 91–93
https://doi.org/10.1080/15265161.2023.2237467

Taylor & Francis
Taylor & Francis Group

OPEN PEER COMMENTARIES

Check for updates

Digital Simulacra and the Call for Epistemic Responsibility: An Ubuntu Perspective

Brandon Ferlito and Michiel De Proost

Ghent University

Cho and Martinez-Martin (2023) discuss the ethical challenges associated with the use of digital simulacra (also known as digital twins) in biomedicine, specifically focusing on the issue of epistemic rights and responsibilities. However, they are unclear about which kind of responsibility concept to use when discussing the ethically salient characteristics of digital twins. While we agree that achieving the ethical development of digital simulacra requires epistemic responsibility, we propose the inclusion of the Ubuntu perspective as an addendum to strengthen the argument for epistemic responsibility in this context. Ubuntu, a pan-African philosophy, could specify how to conceptualize epistemic responsibility by highlighting the importance of forward-looking collective responsibility. In the rest of this commentary, we will argue that this is an ethically fruitful orientation in the context of digital twins.

Ubuntu is a concept originating from Southern Africa that encourages close connections and mutual reliance between people in a society (Metz 2007). The word "Ubuntu" is frequently used in the IsiZulu

CONTACT Michiel De Proost michiel.deproost@ugent.be Department of Philosophy and Moral Sciences, Ghent University, Gent, Belgium.