No Man (or Woman) Is an Island?

Michael A. Ashby

Published online: 12 October 2020
© Journal of Bioethical Inquiry Pty Ltd. 2020

Keywords Autonomy · Genetic testing · Truth-telling · Physician-assisted death · Organ donation · Disability · Advance directives · Resource allocation · Responsibility · Pathography

No man is an island entire of itself; every man is a piece of the continent, a part of the main; if a clod be washed away by the sea, Europe is the less, as well as if a promontory were, as well as any manner of thy friends or of thine own were; any man's death diminishes me, because I am involved in mankind.

And therefore never send to know for whom the bell tolls; it tolls for thee.

(MEDITATION XVII Devotions upon Emergent Occasions. John Donne [1572–1631])

Ignoring gender and geographical references of its time, these famous words by the English metaphysical poet echo through our times and several of the papers in this issue. In this era marked so heavily in every corner of the world by the COVID-19 pandemic, with nearly 25 million cases and 900,000 deaths, it is all too easy to

be overwhelmed by the magnitude of death and disease-related suffering that mask the myriad individual journeys of grief, loss, and unaccompanied death. To the fact of death on this scale, is added the anguish of potential avoidability, dying by oneself away from family and friends, and a small funeral or none at all. Apart from showing its empathy and concern, all a journal can do is write: “a writer always writes.” The next edition of *Journal of Bioethical Inquiry* will be dedicated to the pandemic (Volume 17(4) forthcoming; articles currently available at <https://bioethicalinquiry.com/symposium-social-and-ethical-implications-of-the-covid-19-pandemicpart-1/>).

Respect for each human life and promotion of the interests and freedom of every person is fundamental and non-negotiable in bioethical inquiry. Autonomy is the most prominent of principles in bioethics and underpins most ethical and legal deliberations. This can almost make it seem like a settled concept, that when the word is deployed everyone knows what it means and will agree. Like all ethical concepts, it can be taken to extremes and autonomy taken to mean that the individual's wishes, needs, and wants supersede all other considerations. However, as Donne points out, no person exists in a social vacuum, especially at the beginning and end of life, when ethics is most often invoked (and once gain the pandemic, of course, has challenged this head-on everywhere). In several of the articles in this edition, it is seen that autonomy has boundaries and hurdles in both theory and practice. Despite its almost universal pre-eminence and acceptance, it can, and

M. A. Ashby (✉)
Cancer, Chronic Disease and Sub-Acute Stream, Royal Hobart Hospital, Tasmanian Health Service, School of Medicine, Royal Hobart Hospital, University of Tasmania, Hobart, TAS 7000, Australia
e-mail: michael.ashby@ths.tas.gov.au

should be questioned, and, where necessary, balanced against other considerations.

In the regular legal column, Recent Developments, Pandos (2020) considers the growing availability of “do it yourself” genetic tests. The paper considers three test kits and shows how two unregulated tests were harmful, particularly when done without adequate medical input and genetic counselling support, and worst of all, based on unscientific advertising claims. By contrast and U.S. FDA-approved cancer gene kit is safe and gives access that might be considered to support patient autonomy due to proper regulatory scrutiny. The author also briefly reviews Australian regulatory scrutiny through the Therapeutic Goods Administration (TGA). Staying with genetics, Shupmann, Jamal, and Berkman (2020) review genetic counselling, and argue that, based on the primacy of autonomy, a “non-directive” approach evolved that is problematic in the modern “genomic” era. They show that where the four principles collide the “doing” of ethics starts and that to get the best outcomes for patients skilled guidance is needed and that providing the patient with what they want may not.

It has always been clear that there are large international differences in cultural and political interpretations of autonomy. Zhang and Min (2020) write about the challenges of truth-telling in China. Legislation does require truth-telling but also includes a responsibility for adverse consequences. Family consultation about what to disclose to seriously ill and dying patients is the norm, due to a more collectivist and family-based tradition. Paternalism is still common. The authors recommend a sensitive consultative pathway to handling a poor prognosis, that actually sounds not dissimilar to the way medical and palliative care services mostly proceed in western countries, like Australia, where bad news is often conveyed at family meetings (which are nonetheless only called with patient consent and, where possible, involvement).

Davis and Mathison (2020) investigate the principles at play in physician-assisted death and make a case for what they term an “autonomy-centred” view. They argue that both autonomy and welfare considerations are usually taken into account and written into legislation. In order to qualify for assistance, a person must have evidence of, for instance, suffering and/or a life-limiting condition that is likely to result in death anyway in the foreseeable future. The authors conclude that the suffering (welfare) component of what they call the “joint” view in these

matters, actually collapses into the autonomy component, so autonomous considerations are the best basis alone for determining whether assistance should be rendered, welfare considerations being both subjective and determined by the person themselves (what is intolerable for me).

Albertsen (2020) considers four models for transplant organ provision incentives and focuses on one: the family rewards future market model whereby organs are “sold” for future harvesting after death and the family are paid after death of the person. The authors favour this as the least bad model of paid organ donation but concede that it would have poor uptake.

Gould argues that intellectual disability as grounds for abortion in the United States is often based on exaggerated claims about potential quality-of-life disadvantages. Kolmes and Boerstler (2020) delve into difference in pain management between men and women, and their empirical study involving 982 subjects supported the hypothesis that the gender pain gap, about much has been written, was not due to a failure of self-advocacy.

Much hope for better decision-making when people lose capacity, especially when they are dying, has been invested in advance directives (ADs). The problem has been implementation. Herreros et al. (2020) undertook a focus group study of medical, nursing, and allied health staff in four Madrid hospitals. Their findings suggest that knowledge and experience with ADs was low but the staff liked the idea of them and supported the concept and also that public engagement was poor. This provides further evidence that ADs need to be well embedded in the health system and backed up with public health interventions to inform the public.

Close, White, and Willmott (2020) have conducted a survey of professional guidance policies in Australia concerning resource allocation and life sustaining treatment. They found eight policies that met their inclusion criteria out of twenty-three such policies. The findings were that although there was some broad agreement about transparency, and abating treatments where results were likely to be very bad (futility), most “pulled the punches” when it came to how and when to deny access, outside situations of absolute scarcity, when triage is required. The legal basis of favouring those patients who are most likely to benefit is also found to be untested at law.

Davies and Savulescu (2020) again tackle the issue of taking responsibility for one’s own health and how

resources should be directed when people fail to do so. They conclude that there is a case for ensuring that a person who fails to show “sufficient” responsibility should not displace someone who does.

Lastly, Komesaroff (2020) reviews John Wiltshire’s book, *Frances Burney and the doctors: Patient narratives, then and now* (United Kingdom: Cambridge University Press, 2019). The book tells the story of the evolution of “pathography,” the writing of patient narratives and their encounters with the health system. Although there are a large number of such books, podcasts, and social media accounts published now, the long history of this genre is traced back to the seventeenth century in England, in this case retelling the account of a mastectomy without anaesthetic by the writer Frances Burney in 1811. A rich understanding of the evolution of modern medicine in all its social and ethical dimensions emerges, tracing the struggles for the patient’s voice to be heard.

The Journal of Bioethical Inquiry aims to reach all islands, small and large, and, in its own small way, to join them in conversation, as the bell tolls for all of us.

References

- Albertsen, A. 2020. If the price is right: The ethics and efficiency of market solutions to the organ shortage. *Journal of Bioethical Inquiry* 17(3): <https://doi.org/10.1007/s11673-020-09981-y>.
- Close, E., B.P. White, and L. Willmott. 2020. Balancing patient and societal interests in decisions about potentially life-sustaining treatment. *Journal of Bioethical Inquiry* 17(3): <https://doi.org/10.1007/s11673-020-09994-7>.
- Davies, B., and J. Savulescu. 2020. From sufficient health to sufficient responsibility. *Journal of Bioethical Inquiry* 17(3): <https://doi.org/10.1007/s11673-020-09992-9>.
- Davis, J., and E. Mathison. 2020. The case for an autonomy-centred view of physician-assisted death. *Journal of Bioethical Inquiry* 17(3): <https://doi.org/10.1007/s11673-020-09977-8>.
- Herreros, B., M.J. Monforte, J. Molina, M. Velasco, K. Olaciregui Dague, and E. Valenti. 2020. The use of advance directives in specialized care units: A focus group study with healthcare professionals in Madrid. *Journal of Bioethical Inquiry* 17(3): <https://doi.org/10.1007/s11673-020-09991-w>.
- Kolmes, S.K., and K.R. Boerstler. 2020. Is there a gender self-advocacy gap? An empiric investigation into the gender pain gap. *Journal of Bioethical Inquiry* 17(3): <https://doi.org/10.1007/s11673-020-09993-8>.
- Komesaroff, P. 2020. John Wiltshire, *Frances Burney and the doctors: Patient narratives, then and now* (United Kingdom: Cambridge University Press, 2019). *Journal of Bioethical Inquiry* 17(3): <https://doi.org/10.1007/s11673-020-09985-8>.
- Pandos, O. 2020. DIY genetic tests: A product of fact or fallacy? *Journal of Bioethical Inquiry* 17(3): <https://doi.org/10.1007/s11673-020-09995-6>.
- Schupmann, W., L. Jamal, and B.E. Berkman. 2020. Re-examining the ethics of genetic counselling in the genomic era. *Journal of Bioethical Inquiry* 17(3): <https://doi.org/10.1007/s11673-020-09983-w>.
- Zhang, Z., and X. Min. 2020. The ethical dilemma of truth-telling in healthcare in China. *Journal of Bioethical Inquiry* 17(3): <https://doi.org/10.1007/s11673-020-09979-6>.

Publisher’s note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.