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EDITORIAL

Nature of Suffering, Anarchy, Life and Liberty: Is the Cure Worse Than the Disease?

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As previously argued in this column, the COVID-19 pandemic has revealed and magnified all the old potholes, the existing inequalities, deficits, state failures, discrimination, and vulnerabilities, rather than, for the most part, creating new problems. It is true that all people across the world–including doctors, nurses and other health workers–have had to learn a new respect for infectious diseases, and massively revise their day-to-day anti-contagion measures. Infections, which seemed to have been overtaken by cancer and chronic diseases, can and do kill you, especially if you are elderly and/or have underlying health problems. Perhaps the bigger but less visible impact has been on regimes of truth, and the culture wars around prevention of death on the one hand and individual freedom on the other.

The pandemic has certainly raised serious issues about compliance and state power. Opposition to COVID-19 public health measures is mainly seen as fringe mob rule, with violent undertones, epitomised by the awful scenes from the storming of the US Capitol in 2021. Violent libertarian extremist behaviour has given philosophical anarchy a bad name that makes it hard to raise important questions about the extent of state power, and the rights of individuals to dissent and protest. (to move beyond the purely pejorative, for a history of anarchy as political movement, see Marshall 1993).

Ryan Essex of the University of Greenwich, England, explores how resistance to authority and policy implementation can be a force for good in a society, although this must depend on what is being resisted and by whom (Essex 2022). He lists various behaviours, demeanors and actions: disobedience, insubordination, misbehaviour, agitation, advocacy, subversion, and opposition, all of which may be a healthy counterbalance to power. How then can we show dissent without being aggressive or endanger others, and who is the arbiter of the "just" cause? The author suggests that the expression of dissent may be beneficial and that internal tension always exists in human organizations. The resulting tensions need to find expression for healthy differences to be resolved, or at least consciously lived with. Leslie (2021) has recently written a book suggesting that internal organizational conflict can tear you apart, but also may be constructive if it allows healthy expression of difference, as any Tavistock Leicester conference will attest (https://www.tavinstitute.org/what-we-offer/professional-development/leicester-conference/). Indeed ,buried unspoken and often unconscious tensions can cause long term unhappiness, dysfunction and possibly impaired safety in human service organsiuations, especially in health.

In his wonderful podcast series offered during the pandemic (2020), and honed into a recent book (2021), David Runciman considers state power by starting with Thomas Hobbes and his landmark book *Leviathan*. He points out that for Hobbes, having seen the awful effects

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of the European wars of religion and the English civil war, a strong state is always needed in order to maintain safety. Safety then in a "brutish" world was given precedence over liberty. How resonant this is with the politics of the pandemic, where death anxiety has fueled denunciations, deep rifts even among friends and families, and frightening regimes of truth, especially about lockdowns, mask wearing and social distancing. It is clear that modern Hobbesians have placed the voice of science (epidemiology and infectious diseases) above individual freedom and civil liberties. Logic has won the day, but just as we thought that it had delivered liberal individualism as the high point of our political development (Fukuyama 1989, 1992; Dunt 2020), it turns on us and, in our fear, locks us up for our own good!

Complex political and social inequalities are highlighted by Dineen et al. (2022) when they reflect on the treatment of meat workers in the US during the pandemic. The food industry is usually protected in a war or crisis for good reasons, as the provision of food is rightly deemed to be an essential industry, and therefore needs to keep producing food in conditions that are dangerous for low paid workers who are therefore very vulnerable, inadequately protected and poorly paid.

The limits of philosophical liberalism are further exposed in the African context where work on attitudes about HIV testing and prevention strategies show that the public good is often valued above individual autonomy. Kasoka and Weait (2022) report on a qualitative study in Zambia where notions of interdependence and care about others was valued highly by a wide range of survey respondents, and these data are put forward to inform what these authors hope will be a more contextual, respectful and ethical approach in HIV testing policies in that country. These findings are consistent with the pervading view that the Western emphasis on autonomy, and hence strong defence of confidentiality (often taken to ridiculous extremes, and, for instance, to the detriment of care transfer in countries like Australia), are not as strongly held in non-Western countries where there is more communitarian emphasis.

Most everyday users of software and social media are unaware of the commercial influences at play when they are going about their daily business. Whether it is advertising, sponsorship, data sharing, algorithms or subliminal influences, it is often not obvious that we are being "influenced", spied on or used in some way for corporate interests without consent or even knowledge. People vary enormously in their degree of online caution, vigilance and suspicion. In our regular legal Recent Developments column, Megan Prictor of the Melbourne Law School, reports on the United States "Practice Fusion" case, where a clinical decision-making software tool company was found to be receiving financial kickbacks for promoting the prescription of opioids. Prictor warns of the dangers of the relative absence of regulation in the area of clinical software design and use, with the real threat of commercial bias being built into such systems.

At the height of the pandemic, travel bans and visiting (visitation sounds more like bishop or king's progress!) restrictions made for harrowing stories for friends and relatives of very sick people, and added enormously to the stress and moral injury for staff, especially in palliative care and aged care services. One of the marching tunes of the hospice and palliative care movement has been that "nobody should die alone". During the COVID-19 pandemic, this has been explicitly honoured in the breach. One of the most painful consequences of the public health measures to prevent death was to ensure that many thousands of people around the world did indeed die alone despite the best efforts of stressed and overworked care teams in wards, intensive care units and nursing homes. Russell, William and Chapman (2022) have reported on an Australian framework for visitation (for the Australian and New Zealand Society for Palliative Medicine-ANZSPM-COVID-19 Special Interest Group). It considers the prevailing epidemiological conditions, the COVID-19 status of patients and visitors and the proximity to death. This last factor may be a problem, as waivers to strict visitor bans have tended to be granted to imminently dying people, whereas the most valued time may be earlier in the patient journey when there is enough energy to talk and relate. The downstream effects of these bans, however well-reasoned, will probably never be known, but those working with dying people will testify to the misery and additional grief they caused.

These sentiments are echoed in a Romanian/Swiss collaborative paper by Voinea, Wangmo and Vică (2022) who reflect on the dignity and welfare of older people during the pandemic. It has been said more than once that there is "more to life than being alive". In well-intentioned attempts to prevent death, elderly nursing home residents were subjected to benign incarceration, indeed not dissimilar to that experienced in prisons, and frail elderly people at home have been effectively subjected to prolonged periods of solitary confinement.

These authors point out the systemic problems for elderly people that have been exacerbated by the pandemic, and ways to address barriers to quality of life and social integration for senior citizens.

Zayegh (2022), of The Royal Women's Hospital in Melbourne (Australia), asks how we understand suffering in children who presumably lack the language to tell us how they are feeling. Medicine has put much store by the objective measurement of pain, suffering and quality of life, but the subjective elements are more ephemeral. By virtue of their absence of quantification, these aspects are open to speculation and interpretation, and are, hopefully, guided by moral considerations. For instance, assuming that pain may be present even if there are no verbal clues. For this reason, pain specialists have developed tools to try and assess pain for the very young and the elderly who lack the capacity to report. It is now many years since Eric Cassell (1991) first drew our attention to the nature of suffering as it is understood, and not understood, in medicine. Perhaps the best we can say is that even if we cannot see or measure an infant or young child's suffering, we might need, as an ethical imperative, to assume it may be present and act accordingly. This may, for instance, mean a trial of analgesia and behavioural response monitoring in situations where it is unclear. It also means that if the disease data fail to tell us what is going on for a person, we should always ask who the patient is, as Cassell urges us to.

The rescue of twelve boys from a flooded underground cave gripped the world in 2018, with enormous relief, and admiration for the rescue team when they were brought out safely. After such a heroic intervention with a good outcome, it may seem odd to some to raise any ethical dimensions about the rescue plan. However, this is exactly what Irwin (2022) does in a gripping article in which consent and risk are explored. The rescue required a prolonged submerged swim with each boy anaesthetized and accompanied by a rescue diver. There were therefore enormous risks involved and informed consent would need to cover the very real possibility of death during the rescue. Any such exercise requires careful balancing of psychology and morale. Compromises are required. So, sometimes in extreme circumstances it really is a matter of "whatever it takes"–maybe ethical procedures are modified by paternalistic rescuers, and there is great reliance on the virtuous practitioner? This is confronting for bioethics as informed consent and respect for autonomy are paramount and universal. Yet, if we are drowning or in an accident, do we not hope that our rescuers will do what is necessary when we are in no position to make a decision ourselves, and our fate is in their hands, reliant utterly on their goodness? And how many times do we see in the movies, and in life, that "in the hazard", we need to accentuate the positive.

Reichlin (2022), from San Raffaele University, Italy, writes that conscientious objection (CO) for health professionals needs to be assessed through a standard of reasonableness. The notion of moral integrity that is mobilized to justify non-referral for abortion and assistance in dying, for instance, where these are lawful, is not defensible. Appeal is made to good standards of medical practice, and absolutist CO positions are seen to mitigate against such standards, but on the other hand the idea that CO cannot be compatible with good medical practice is also rejected in favor of reason.

Zohny, Earp and Savulescu (2022) contribute to the gender enhancement debate in which surgery and hormone manipulation are deployed. This has become such a political flash point, in which those with strong, and usually religiously based, views oppose any such changes to the body "you were given". Consent to medical treatment is usually for interventions to treat a pathological process, rather than for body enhancement. These authors have argued that enhancement should also be recognized, in its own right, as justification for medical and surgical interventions, subject of course to rigorous standards of consent and practice. Using a welfarist lens, they propose a conceptual framework to progress these issues in what is sometimes a hostile political environment where logical analysis and needs of individuals may be side-lined.

It is hard enough for a competent adult to consent to a clinical trial where equipoise is assumed, and therefore there may be exposure to adverse effect risk, and no benefit. Różyńska (2022), from the University of Warsaw, takes on the problem of consent for research in paediatrics, where the patient cannot give informed consent and the treatment in question may confer no benefit on that individual. It is argued that none of the hitherto published ethical "solutions" to this problem are effective, and a new formulation of the primacy of the person is proposed.

Dementia is feared by everybody, and with good reason, especially as it is becoming a major contributory cause of death around the world, particularly in relatively wealthy countries (for example, dementia is now the commonest cause of death in women in Australia). It potentially robs the individual of the kind of mental capacity that is required for a modern fulfilling life, with inevitable losses of much treasured autonomy and meaning. Smedinga et al. (2022) from The Netherlands employ reflective equilibrium as a technique to analyse the ethical aspects of biomarker testing for dementia, and the great potential for harm that such foreknowledge of dementia risk might generate.

Lysaght et al. (2022) from Singapore propose the Professional Oversight of Emergency-Use Interventions and Monitoring System (POEIMS) as a means of trying out new treatments for infectious diseases in the acute setting outside of clinical trials. High standards of data recording and professional integrity are required to ensure that beneficial results are truthful, and adverse effects are rigorously assessed and reported.

Ergin et al. (2022) report a study correlating emotional intelligence and ethical sensitivity tool scores for Turkish nursing students. They found that those who are happy in their career choice had the highest ethical and empathetic scores. Discomfort around ethical dilemmas was shown, but high scores were found for interpersonal orientation. The study also suggested that family background and socio-economic factors also had a significant influence on ethical attitudes.

So much of life, and hence bioethics, is a tussle between perceived polarities: good and bad, ethical and unethical, fact or fiction, and so on. The papers in this edition of the *JBI*, and a great deal of other wisdom, would suggest that we spend too much time being seduced by notions of certainty, or dreaming of what we want to happen, rather than curiously investigating the "is". Just as the Tavistock Institute's Leicester Conference[1] creates a temporary learning institution, with a strong emphasis on the nature of authority–"a safe space where we can study [those] feelings, thoughts and assumptions; test them, and find new ways to work in, with or around them"–so the JBI can maybe aspire to do the same, especially where authority is so much in question.

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[1] https://www.tavinstitute.org/what-we-offer/professional-development/leicester-conference/

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