

## Wicked Problems, Complex Solutions, and the Cost of Trust

Medicine interacts with social, legal and political elements of life. For example, UK homelessness leads to a reduction of life-expectancy of around 30 years<sup>1</sup>. This issue is a daily reality for practising clinicians. In research and research ethics, vulnerable groups, including socially vulnerable, are frequently excluded from research. Whilst there are good reasons for this, this can mean exclusion from benefits as well as from risks.

In our Feature Article this month, Dawson et al. make a compelling and nuanced case —and a practical proposal— for designing research protocols for HIV prevention measures that allow for the inclusion of people who inject drugs (PWID) without compromising their safety from a legal and social perspective as well as a medical one. Along the way, they reference some of the public health damage caused by legal and social policy. To take one example: “if police beatings were eliminated in Odessa, Ukraine, HIV incidence among PWID would decrease up to 19% over a 5-year period”<sup>2</sup>. For those of us in the University sector, “Impact” has become a major, and sometimes controversial, way that our output is judged. This paper highlights the real-world importance of research impact as well as the kinds of difficulties researchers face.

A series of commentaries probe the practical proposal put forward in Dawson et al’s paper. Lavery applies Rittel and Webber’s concept of “wicked problems” to the dilemmas facing researchers in this context:

“Wicked problems have 10 defining characteristics: (1) they are not amenable to definitive formulation; (2) it is not obvious when they have been solved; (3) solutions are not true or false, but good or bad; (4) there is no immediate, or ultimate, test of a solution; (5) every implemented solution is consequential, it leaves traces that cannot be undone; (6) there are no criteria to prove that all potential solutions have been identified and considered; (7) every wicked problem is essentially unique; (8) every wicked problem can be considered to be a symptom of another problem; (9) a wicked problem can be explained in numerous ways and the choice of explanation determines what will count as a solution and (10) the actors are liable for the consequences of the actions they generate.”<sup>3</sup>

Clinicians and researchers in a variety of fields will be familiar with the tentacles of this kind of problem. The lack of easy answers or easy measurements is not a reason to ignore such problems, or the communities who are affected by them. It *is* a reason, as the authors and commentators here have presented, to design and evaluate research with extraordinary care.

I have a personal story that I sometimes share to illustrate the importance of good communication. In 2001, I broke my leg badly in a skiing accident. I ruptured the anterior

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<sup>1</sup> <https://www.gov.uk/government/publications/homelessness-applying-all-our-health/homelessness-applying-all-our-health>

<sup>2</sup> Dawson L, et al. J Med Ethics 2016;0:1–10. doi:10.1136/medethics-2015-102895, page 2

<sup>3</sup> Lavery JV. J Med Ethics Month 2016 Vol 0 No 0, page 1

tibial artery and suffered a compartment syndrome and nearly lost my leg. Thanks to an incredible medical team I am able to go around risking my legs on ski slopes to this very day. When I was admitted to hospital, I made a non-standard request. Having worked as a doctor and also done considerable research on Jehovah's Witnesses, I felt many transfusions were unnecessary. I also felt that infection testing could never be 100%. I nevertheless appreciated that it is a life-saving intervention in some circumstances. I therefore asked that I did not receive a blood transfusion unless I lost more blood (my Hb was stable at 5) and it was necessary to save my life. When I saw my notes, this had been translated as an outright refusal of blood as a medical treatment due to religious reasons. My reasons were self-interest, not religion. This month, the story came to my mind for different reasons. Verweij and Kramer's article makes a case for *less* rather than *more* screening against infectious diseases in blood transfusions. This argument is a confronting one for me given my own risk-averseness, but their argument is persuasive. The cost per Quality Adjusted Life Year (QALY) is a broadly accepted measure of the cost effectiveness of a treatment, and is used to justify or exclude the provision of treatments in health services. The cost per QALY that a health service will accept varies service by service according to its resource base, but to give one example cited in the paper, for the UK's NHS, it is £20-30k per QALY. Against this context, the calculated cost of state of the art nucleic acid testing is indeed fairly astounding: "€5 199 220 per quality-adjusted life-year (QALY)"<sup>4</sup>. Furthermore, "Serological screening for human T-cell lymphotropic virus (HTLV-I/II), a virus that causes disease in a minority of infected persons, was in the Netherlands even estimated to cost €45 182 666 per QALY."<sup>5</sup>

Even after some rough and ready common sense measures, the cost is still extremely high:

"after switching from testing all donations to testing new donors only...the cost-effectiveness ratio is still over €2 000 000 per QALY"<sup>6</sup>

Verweij and Kramer investigate and exclude some common justifications for allowing this type of treatment a free pass from the QALY regime. Whilst we do not expect medical treatment to *cause* harm, they point out that there are few -- if any-- medical treatments that do not include a risk of side effects. Then there are resource allocation issues. Money spent in one place is money that can't be spent in another. As with some of the problems facing HIV research, it might be that politics, stigma and fear are ousting good evidence. Nevertheless, Verweij and Kramer do allow for a view of resource allocation that goes beyond the stern inflexibility of the QALY regime. What price is trust in healthcare? Then there is the patient. My clinician friends sometimes mock my decision to risk a low hemoglobin level instead of taking the smaller risk of infection. They call me irrational, which they enjoy all the more given my profession. Perhaps it was. In the words of Verweij and Kramer:

"There might be something 'irrational' in the general public's perception of blood risks, but in a pluralistic and democratic society it cannot be ignored completely."<sup>7</sup>

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<sup>4</sup> Verweij M, Kramer K. J Med Ethics 2016;0:1–5. doi:10.1136/medethics-2015-103338 page 1

<sup>5</sup> Ibid.

<sup>6</sup> Ibid.

<sup>7</sup> Verweij M, Kramer K. J Med Ethics 2016;0:1–5. doi:10.1136/medethics-2015-103338 page 4

Dawson et al. and Verweij and Kramer raise big and complex questions about medicine and research in the real world. Dawson et al. present the need to adjust research protocols to fit the world rather than withdrawing. Verweij and Kramer challenge us to find the price we are willing to pay for our collective peace of mind.

I would add though, one word of caution. Trust is fragile. One of the reasons research ethics has excluded vulnerable populations is because in the past research has exploited them. And one of the reasons that we do not trust assurances of safety of the blood supply is that in the past, the public has been fobbed off with false assurances (Verwij and Kramer quote assurances that the risk of HIV infection was “one in a million” when it was later found to be-- at that time-- “more like 1:100”<sup>8</sup>.) In the words of Warren Buffet, “It takes 20 years to build a reputation and five minutes to ruin it. If you think about that, you'll do things differently”<sup>9</sup>.

Where Dawson et al address the interaction of social and political factors in research, and Verwij and Kramer address related issues in healthcare policy, a paper by Dominicé Dao illustrates the complexities of clinical care that arise from a similar problem. Dominicé Dao presents a clinical team and a mother, Sonia, in conflict over the treatment of a baby boy, Justin, who required surgery for a complication arising from a previous surgery addressing a congenital malformation. The case highlights how unemployment, homelessness, language barriers, the harsh realities of life as an illegal immigrant, and even the broader global economic situation act as barriers to the best medical care. Consciously or unconsciously, these factors and the kinds of biases that they might engender, may also affect the care that doctors offer. Workloads, like QALYs, are sadly unresponsive to lived human reality. Dominicé Dao draws on evidence to show that:

“This ‘extra bit’ that is often required to care for migrant patients might also kindle negative attitudes in health professionals, which may be amplified in contexts of economic constraints experienced in many public institutions.”<sup>10</sup>

For example:

“Requesting procedures that are unfamiliar to clinicians, such as writing a medical certificate to give grounds to a humanitarian permit or working with an interpreter, calls for specific competence that may bring clinicians out of their ‘comfort zone’... functional neuroimaging research shows that stereotypes are triggered by negative emotions, heavy workload and time pressure; they are decreased by prompts to individualise stereotyped images.”<sup>11</sup>

Furthermore, we can be affected by views that are widespread in public and political discourse, even those we actually reject:

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<sup>8</sup> Verweij M, Kramer K. J Med Ethics 2016;0:1–5. doi:10.1136/medethics-2015-103338 page 1

<sup>9</sup> <https://www.forbes.com/sites/jamesberman/2014/04/20/the-three-essential-warren-buffett-quotes-to-live-by/#78bf8ad46543>

<sup>10</sup> Dominicé Dao M. J Med Ethics 2016;0:1–4. doi:10.1136/medethics-2015-103337,page 3

<sup>11</sup> ibid

“Grove and Zwi also describe how public and political discourse of ‘othering’ refugees and forced migrants distances, marginalizes and disempowers migrants by portraying them as deviant from the host society and a threat to national security, scarce resources and public health. ... the expectation is that migrants must be content with their fate of poverty, hardworking, pursuing integration, respectful of authority and compliant with procedures. ... Sonia’s refusal of the intervention and proposed housing solutions, her multiple and sometimes aggressive requests, and the ‘suspicious’ inaccuracies of her narratives to different healthcare providers paint a portrait far from the expected one. In such cases, deviating from the expected norm can have a negative impact on the provision of empathy, explicitly or implicitly, even despite the skills and good intentions of health professionals.”<sup>12</sup>

Like me, Sonia was not an ideal or easy patient and it is clear from Dominicé Dao’s article that the treating team had enormous care for Justin and concern for his well-being. This is not an accusatory article or a case study picking apart a failure, but an article that addresses some of the ways in which social, political, legal and interpersonal factors complicate patient care. In this case in fact, the clinical team recognized that non-medical aspects of the case were restricting their ability to care for Justin and called for Transcultural Consultation. This strategy assisted with breaking the impasse, and the second operation went ahead and was a success.

Each of these articles makes progress on understanding and addressing a complex problem. But together they highlight the way the community affects individuals in a way that has perhaps been underestimated. Medical Ethics and clinical practice has made huge strides as paternalism has given way to autonomy, but perhaps it is time to pan out a bit more to understand the broader picture.

In addition to understanding the broader sociopolitical context of medical ethics, good medical ethics also requires good philosophy. Solberg et al's article, “The disvalue of death in the global burden of disease”, is a fine example. They expose the widely used instrument, Disability Adjusted Life Years (DALYs) to philosophical scrutiny. They uncover highly controversial assumptions and show that the best way to resolve internal tensions is to utilise a counterfactual account of harm. The badness of premature death is then measured according to how many years life fall short of some ideal standard. But what should this ideal standard be? This remains a deep ethical question upon which the whole DALY enterprise is founded.

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<sup>12</sup> ibid