

“Modernization”, “Re-balancing” and “States of Exception”: the Multi-Pronged Attack on Fundamental Patient Autonomy Rights

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Introduction

I am going to discuss some of the discursive and rhetorical devices and constructs that are currently undermining fundamental patient rights. A theme that I will highlight at the outset is that we are seeing the language and concept of rights co-opted and contorted. As a character says in Tom Stoppard’s play “Rock n’ Roll”:

We have to begin again with the ordinary meaning of words.
Giving new meanings to words is how systems lie to themselves...

I would like to talk about how our narratives, our understanding of patient rights and the framework of patient rights is being very decidedly shifted and how the new “rights discourse” is reflected in and augmented by the broader developments of neoliberalism and the national security state.

Drivers

To absolutely no one’s surprise, economics is a major driver of the shift in patient rights. As David Harvey (2010, 98) notes in *The Enigma of Capital*, bets are on that the next innovation-led speculative bubble will come from biomedical and genetic engineering.

The embrace of the so-called “knowledge economy” has created tremendous momentum for grand scale government information technology schemes to capture, use and commodify citizens’ data.

The United Kingdom is generally considered the prime example of the “database nation” approach to the knowledge economy (also known as “transformational government”, “horizontal governmental” or “e-government”) which is unavoidably in tension with fundamental citizen rights, for example, in the uses and abuses of centralized electronic health care records (Anderson et al. 2009).

Dr. Helen Wallace (2009) of GeneWatch has noted that the ultimate plan for the UK's electronic health records program involved linking all patient records with the national DNA database to allow Britain to take the lead in commercializing the human genome and use this vast repository of patients' confidential medical information for genetic and medical research which would be achieved by the government giving patient data to industry.

Only an absolutely heroic lobbying effort in 2009 by British privacy and patient advocates beat back (at least to date) a sneaky provision in The Coroners and Justice Bill that would have allowed ministers to disclose any data – including citizens' genetic information and confidential medical information – to *anyone* they cared to, public or private sector, domestic or foreign, without citizens' knowledge, let alone consent (GeneWatch UK 2009).

I come from the Canadian province of British Columbia, which is (rather ironically, given our name) increasingly determined to follow the lead of the UK in this realm. The government of BC is devoting hundreds of millions of dollars to an unprecedented, and possibly unconstitutional, consolidation of citizen data held by different ministries with an additional data grab of citizen information from private sector entities ranging from private medical laboratories to community-based counseling services (BC Freedom of Information and Privacy Association 2010).

The reasons given for this government commandeering of citizens' private, personal information are efficiency, administrative stewardship and research (British Columbia 2010). I submit that none of these justifications for mass privacy violations withstands genuine scrutiny, but for our purposes we need only note the explicit research agenda of the government.

Like the UK, this research agenda is linked to economic investments in genomic medicine and more broadly to “developing health research enterprise” to boost “BC's knowledge economy” (Cassels 2010).

The current climate of increasing commercialization of research will not be news to anyone in this audience.

A recent *New York Times* article commented on the growth in the US of a new style of graduate studies that combines mathematics or science (usually

biotech) and business management courses. Trend-spotters are calling this transparent bid for increased industry revenue and obvious deepening of schools' partnership with industry, "the new MBA". It is telling that the first universities to have adopted this model outside of the United States are the Open University in Britain, the University of Queensland in Australia, and the University of British Columbia (Rosenbloom 2010).

Another notable aspect of the climate of commercialized research and health policy is what Abby Lippman, Professor of Epidemiology at McGill University, terms "neomedicalization".

Neomedicalization is an expansive incarnation of disease-creation. This process involves the corporate creation and marketing of diseases to sell drugs, as well as framing of natural experiences as causes of future diseases. In other words, the emphasis is on one's supposed risk of developing a problem, and, in its most pernicious form, in making being "at risk" itself a disease state (Lippman 2006, 18).

Neomedicalization's focus on "risk management" fits perfectly within a broader discourse of risk and securitization, which is at the heart of the shift in ideas about patients' rights.

Rhetorical Shift

The focus of my discussion is about how citizens are being sold this idea. What are the components of the campaign for the hearts and minds of the citizenry to support the erosion of our own rights?

Unsurprisingly, many of the components are essentially the same devices used to "sell" the idea that diminishment of citizens' rights was necessary after 9/11. The standard post-9/11 conceptual device was (and still is) "security vs. liberty", as a zero sum game, whereby less of one must mean more of the other. This is echoed in the realm of patient rights in a framework that I am seeing evoked more and more frequently: "social responsibility vs. individual rights", also imagined as a zero sum game, and most obvious in the context of legal and ethical discussions about infectious diseases and vaccines.

Both frameworks – security vs. liberty; social responsibility vs. individual rights – are very much in evidence in debates about the purported need to “re-balance” citizens’ rights in light of current “realities”.

“Rebalancing” is a buzz word; code, in fact. Rebalancing, despite its facial neutrality, is not at all neutral. Rebalancing is entirely unidirectional. It only goes in the direction of fewer and weaker rights, never more and stronger rights. It is also notable that “rebalancing” does not typically involve small, cautious, incremental, tightly prescribed, time-limited changes. Very often it involves radical departures from long-standing legal and ethical norms and constitutional values.

Typically the justification is the “emergency”, the “new reality” that invokes the state of exception from previous norms. But without proactive resistance, the state of exception quickly becomes the new normal. That “going back” is not a legitimate option is implicit when the re-balancing discussion comes even more tightly packaged and is simply described as “modernization” or “current realities given technological advances” - both of which invoke the arrow of progress to indicate that there will be no going “back” because we are naturally and assuredly going “forward”.

“Modernization” is a particularly invidious label for these changes as it harnesses the glamour of contemporary technology to mask highly regressive roll-backs of citizens’ rights.

National security rebalancing rhetoric attempts to justify blatant rights violations ranging from mass surveillance to torture. Likewise, rebalancing rhetoric is being used to justify a movement away from established principles and norms in patient rights, seen in developments such as:

- forced testing of suspected source patients in occupational HIV exposure situations (Elliott 2007);
- mandatory knife wound and gunshot reporting (General Medical Council 2009); and
- insistent calls for a “revisioning” (another buzz word) of informed consent for medical testing, research and for inclusion in bio-banks and electronic health records databases (Kegley 2004).

Like the national security rhetoric, these are calls for compulsion and surveillance mechanisms that purport to be for a public good and necessitate a violation of citizens' autonomy and privacy rights.

Who is the “public” in the “public good”?

The new “public good” story is getting a great deal of play in the media and is showing up in a startling number of different guises. It is worth remembering just how starkly the story - “public good must trump patients' rights” - contrasts with the dominant norms of only a very short time ago.

The work of Jonathan Mann, the former head of the World Health Organization's AIDS program, for example, helped to develop a consensus among global health bodies that rights are supportive of population health, not at odds with it (Gostin 2001). This view aligned with Health Promotion theory, which was supported by an impressive body of research investigating the social determinants of health (Wilkinson 1996).

However, the ascendancy of neoliberal ways of thinking about the role of the citizen and the state was increasing at odds with the evidence in support of the social determinants of health and a rights-based approach to health.

The neoliberal state minimizes the provision of services to citizens and places extraordinary emphasis on protecting the public from risks. Risk analysis and risk management are absolutely central features of the role of the neoliberal state; arguably the very essence of the neoliberal state's purpose. The result is that the social construction of public health risks, like national security risks, has become seriously distorted.

Granted, as medical historians have noted, the social construction of public health risks has never been unproblematic. New and emerging infectious diseases in particular have historically galvanized responses that are in essence moral panics (Gilman 2010), and which have a long and inglorious history of serving political agendas, like targeting recent immigrants as vectors of disease (Leask, et al. 2006; Parmet 2009).

While the social construction of public health risks is generally problematic and subject to political manipulation, the increased focus on securitization in public health discourse is particularly dangerous.

The securitization paradigm is a central feature of the decided shift in the relationship between rights and health. The shift, according to Wendy Parmet (2009), has taken public health out of alignment with human rights and into alignment with social control theory.

As Parmet notes:

Laurie Garrett's influential paper, *The Return of Infectious Disease*, explicitly linked the threat of emerging infections to economic and security interests, a tactic that helped researchers attract both funding and the avid interest of policymakers (Parmet 2009, 15).

Parmet further notes that the US anthrax attacks:

helped to transform the emerging epidemic perspective into one which emphasized the similarities between natural occurring infections and bioterrorism (Parmet 2009, 16).

In other words, the conceptual filter of "national security" has facilitated the adoption of a social control and surveillance model over a citizens' rights model.

This conflation of health and national security is so prevalent that it has spawned its own terminology, like "bio-security", which is a key aspect of the enveloping concept of "emergency preparedness".

As an aside I note that, for maximum disorientation, the militarization and securitization of public health coincides with a troubling new therapeutic discourse in actual military occupation. As Derek Gregory (2010) points out, the new US centre for counterinsurgency promotes the image of counterinsurgency as intrinsically therapeutic- 'armed social work' - and uses medicalized terms to describe project stages like "stop the bleeding", "inpatient care" and "outpatient care". This is a view Gregory describes as an invitation to "step through the back of the wardrobe into a martial Narnia".

I like this term so much I need to borrow it to discuss a brief case study in the re-visioning of patient rights. I'm going to say a few words about the HIV testing situation in British Columbia, which I'm going to use an example of medical Narnia.

Medical Narnia

Snapshot: In December 2009, if a resident of British Columbia wished to be tested for HIV, she could do so nominally or non-nominally. CDC guidelines on pre-and-post test counseling help to ensure informed consent to testing. If the test was positive, it would be reportable to Public Health, but no further disclosure of the test result would be allowed without the written consent of the patient, as per the *Health Act Communicable Disease Regulations*. Almost assuredly there would not be even one patient out of a thousand who would be likely to know such details; but there is, nevertheless, broad understanding and trust that HIV testing is confidential.

Snapshot: Same scenario December 2010 – one year later. This patient's positive test result is no longer protected by the Communicable Disease Regulations privacy provisions which have been quietly repealed to allow the government to take the lab results into a longitudinal database repository of citizens' laboratory test results that will be available throughout the province to a broad range of health care providers, government bureaucrats and researchers, and eventually slated to be linked to the information systems of other government ministries (Province of British Columbia Order of the Lieutenant Governor in Council 2010; Vonn 2009).

In this latest scenario, the only privacy protection available is called a disclosure directive, which provides for a limited ability to mask records, but the patient will not be told this. Unless she just happened to be surfing obscure corners of the Ministry of Health website, the patient has no effective means of knowing the system is no longer confidential or that she has some even limited means of trying to protect her privacy (Vonn 2009).

Further, she may or may not have even understood that she was being tested for HIV, or may face a de facto 'opt out' of testing rather than an informed 'opt in'. This is because her health care provider may have lumped in the test with other "routine" tests following the new HIV testing recommendations issued by the Medical Health Officer. The memorandum issued by the Medical Health Officer to physicians cites the "opportunity" of a controversial local research project that is dependent on increased HIV testing to urge more HIV testing and offers "a practical way to add routine HIV testing to your practice" (Physicians Update from the Office of the Chief Medical Health Officer 2010).

By any measure you choose, these snapshots describe a profound undermining of fundamental patient autonomy and privacy rights. But not according to the new rights discourse, which makes the same words mean something different.

The controversial research project I am referring to is a treatment-as-prevention strategy known locally as “Seek and Treat”. The theory is that since high viral load increases infectivity, if treatment can reduce the viral load of a sufficient number of patients, new HIV infections will be greatly reduced or even eliminated. While traditional rights language is used in describing the “Seek and Treat” program – which explicitly invokes “the right to treatment” – treatment per se is not the focus, but rather treatment as de facto vaccination (Nguyen et al 2010).

As Cindy Patton, Canada Research Chair in Community, Culture and Health writes:

Although superficially cloaked in rights-resonant language, the treatment-as-prevention approach quickly slides from “vulnerable populations” to “at risk populations” to actuarial claims about the number of “infections” the program might avert, and at what dollar investment and savings, with little further consideration of the realities of living with HIV on the ground (Patton n.d., 22).

The case for treatment-as-prevention is made by rhetorically jumping scale from the image and language of the vulnerable person with AIDS to the dubious right to be free of virus at the level of population, and then sell this population-eye view of HIV back to publics as a health value that scales down equally to all members.

But in the shock and awe of statistical modeling that cloaks itself in the ethos of rights, how can we remain attentive to the possibility of the wrongs that will be occurring to individuals who will be the “targets” of a program? (Patton n.d., 23-24)

This then would be a novel articulation of a theme that plays out continually in discussions of vaccines: a minimizing of traditional, individual patient rights and an emphasis on a new rights formulation – the “right” to be protected from communicable diseases, ergo protected from people with communicable diseases or at risk of contracting communicable diseases.

This is often what we find at bottom of a new “rights” formulation: an underlying story about Us vs. “Them; about the rights of Others vs. Our alleged higher good/protection/etc.

“Other-ing”, of course, has long been a popular trope in the social construction of communicable diseases. For example, a company called Global Viral Forecasting and its monitoring of “the emergence of deadly viruses from the jungles of Central Africa” was recently the subject of a *New Yorker* article floridly titled “The Doomsday Strain” (Specter 2010). I have no reason to think there is anything wrong with the scientific research that is being conducted in the jungles of Central Africa. But I have every reason to think that no equal amount of media ink or fawning Indiana Jones-type personality profiles are being employed to describe scientists investigating potentially deadly viruses incubating in North American factory farming, for example. That plays against type. The narrative is that “deadly viruses” come from elsewhere.

There is an extensive and important literature that critiques this narrative of infection from elsewhere/outside invading the body/body politic, and how this view inculcates in health generally the language and imagery of war and secured borders (e.g. Patton 1986). As I say, these narratives are not new, but they are being heavily drawn upon in the “securitization make-over” of health and patient rights.

Getting back to the case study of HIV testing in British Columbia, I called the Chief Medical Health Officer for Vancouver about the memo urging “routine HIV testing”. This was shortly before the Office of the Medical Health Officer began its *public* campaign, which resulted in news articles with titles like “BC health officials want virtually everyone to get an HIV test” (Lazaruk 2010). The Chief Medical Health Officer took the position with me that despite referencing the Seek and Treat research project (also known as the Stop HIV/AIDS Project) in the *first sentence* of the memorandum to physicians, there was no connection whatsoever between public health officials calling for doctors to test everyone and a high profile

research project entirely dependent on aggressive levels of testing (Daly, personal interview, Dec 4, 2010).

No connection.

Likewise, no connection between public health officials call to test virtually everyone in the province and the quiet repeal just two weeks earlier of the Communicable Disease Regulations in order to flow all test results into the new government health data repository. And this may well be true, but there was also, at least at the time of the discussion, no plan for informing either patients or physicians of this critically important information affecting patients' rights.

In this scenario, it is not only that patients' rights are being given incredibly little weight, which is obviously true, but it is also that the very nature of rights is being redefined.

In her comments to the press, the Chief Medical Health Officer states that she wants a massive expansion of HIV testing *despite* her assessment that the vast number of the people they will be testing will be at no risk of contracting HIV; risk groups in her assessment of the situation in British Columbia currently being confined to men who have unprotected sex with other men and injection drug users (Lazaruk 2010).

So why exactly should the vast majority of the population who are outside of the narrowly drawn risk groups submit themselves to the state for HIV surveillance for almost assuredly no health benefit to themselves and guaranteed wasting of our province's precious public health dollars?

Because, according to the Chief Medical Health Officer, everyone testing all the time will reduce the stigma of testing and make testing more accessible for the others who are at risk: "That's the real reason why we're doing it" (Lazaruk 2010).

Leaving aside the highly dubious assumptions on which this construction rests... in essence, the overarching plan looks like this: those in risk groups need to test so they can get on treatment that will act like a vaccine to protect everyone else (the public good); and everyone else needs to test so that the risk groups will get tested and get on treatment that will act like a vaccine to protect everyone else (the public good).

In other words, the only “right” in evidence in any of this formulation is the right of an abstract “public” to be protected from risk. In this construction individual citizens have responsibilities and the abstract public has rights.

That’s the new “rights” paradigm in a nutshell.

Appropriate Policies

The shifts that I have been describing are particularly important in the context of coercive actions that can be undertaken in the name of public health. Genuine public health emergencies involving contagious diseases have a different ethical and legal calculus than ordinary patient treatment scenarios. This potential for highly coercive social control obviously must be informed by the best available science. But in addition, there is an urgent need to address this new regressive view of patients’ rights because, as Parmet notes, even the best science is not going to be able to definitively address the appropriateness of any given policy.

...[S]cience cannot decide the value that should be placed on either any particular risk or any human right. Thus science cannot decide whether any particular reduction in the risk of transmission warrants a ban on immigration, the denial of asylum, the abandonment of privacy...[T]he fundamental question whether a particular risk, whose magnitude is invariably uncertain, justifies the deprivation of any individual liberty, is ultimately a social judgment to which there is no neutral scientific answer (Parmet 2009, 52).

The current health securitization narratives do not bode well for public health responses that properly weigh patients’ rights.

Alongside the science, we must publicly question and oppose the biosecurity perspectives which “are priming the world for public health panics and laying the foundation for the unnecessary restriction of human rights” (Parmet 2009, 55).

This includes challenging the zero-sum game framework of “individual rights” vs. “social responsibility” and the increasingly promulgated notion that individual rights need to “evaporate in the face of a public health emergency” (Parmet 2009, 56).

References

- Anderson, Ross, Ian Brown, Terri Dowty, Philip Inglesant, Willian Heath and Angela Sasse. 2009. "Database State", report commissioned by the Joseph Rowntree Reform Trust Ltd.
- British Columbia Freedom of Information and Privacy Association. 2010. "Culture of Care... Or Culture of Surveillance? Personal Privacy and the BC Government's Integrated Case Management System: Legal, ethical and procedural implications for independent community service organizations", report.
- British Columbia Government Submission to the Special Committee to Review the *Freedom of Information and Protection of Privacy Act*, 2010.
- Cassels, Alan. 2010. BC's new love affair with biotech. *Common Ground Magazine*, May 1, 2010.
- Daly, Patricia. Personal Interview December 4, 2010.
- Elliott, Richard. 2007. "Undue Force: An Overview of Provincial Legislation on Forced Testing for HIV". Canadian HIV/AIDS Legal Network report. Online at www.aidslaw.ca/testing.
- General Medical Council. 2009. "Confidentiality: Reporting Gunshot and Knife Wounds". Online at: http://www.gmc-uk.org/static/documents/content/Confidentiality_reporting_gunshot_wounds_2009.pdf.
- GeneWatch UK. 2009. "The Coroners and Justice Bill: A DNA database by stealth". Parliamentary briefing, January, 2009. Online at: http://genewatch.org/uploads/f03c6d66a9b354535738483c1c3d49e4/MPs_brief_CJB_fin_1.pdf
- Gilman, Sander. 2010. "Moral Panic and Pandemics". *The Lancet*, 375 (9729): 1866-1867.
- Goslin, Lawrence. 2001. "Public health, ethics and human rights: A tribute to the late Jonathan Mann". *The Journal of Law, Medicine and Ethics*. July 1, 2001. <http://www.allbusiness.com/legal/3586793-1.html>
- Gregory, Derek. 2008. "The Cultural Turn in Late Modern War and the Rush to the Intimate". Online at http://www.radicalphilosophy.com/print.asp?editorial_id=26755.
- Harvey, David. 2010. *The Enigma of Capital and the Crisis of Capitalism*. London: Profile Books Ltd.
- Kegley, Jacquelyn. 2004. "Challenges to Informed Consent: New Developments in Biomedical Research and Healthcare May Mark the End of the Traditional Concept of Informed Consent". *EMBO reports* 5 (9): 832-836
- Lazaruk, Susan. 2010. "BC health officials want virtually everyone to get an HIV test". *Calgary Herald*. December 6, 2010.

Leask, Julie, Mohamud Sheikh-Mohammed, C. Raina MacIntyre, Alexander Leask and Nicholas Wood. 2006. "Community Perceptions About Infectious Disease Risk Posed by New Arrivals: A Qualitative Study". *MJA* 185 (11/12): 591-593.

Lippman, Abby. 2006. "The Inclusion of Women in Clinical Trials: Are We Asking the Right Questions?". On line at: <http://www.whp-apsf.ca/pdf/clinicalTrialsEN.pdf>.

Nguyen, Vinh-Kim, Nathalie Bajos, Francoise Dubois-Arber, Jeffrey O'Malley and Catherine M. Pirkle. 2010. "Remedicalizing an epidemic: from HIV treatment as prevention to HIV treatment is prevention". *AIDS* 24 (00).

Parmet, Wendy. 2009. "Public Health and Social Control: Implications for Human Rights, International Council on Human Rights Policy". Online at: http://www.ichrp.org/files/papers/173/public_health_and_social_control_wendy_parmet.pdf.

Patton, Cindy. n.d. "Rights language and HIV treatment: universal care or population control?"

Patton, Cindy. 1986. *Sex and Germs: The Politics of AIDS*. Boston: South End Press.

Physicians' Update from the Office of the Chief Medical Health Officer, November 30, 2010, Vancouver Coastal Health.

Province of British Columbia Order of the Lieutenant Governor in Council, Order in Council No. 726, November 18, 2010.

Rosenbloom, Joseph. 2010. "A Master's for Science Professionals Sweeps U.S. Schools". *The New York Times*. December 26, 2010.

Specter, Michael. 2010. "The Doomsday Strain: Can Nathan Wolfe thwart the next AIDS before it spreads?" *The New Yorker*. December 20-27, 2010.

Vonn, Micheal. 2009. "The Real Impact of the E-health Act". *The Advocate*, 67 (6): 753.

Wallace, Helen. 2009. Q & A on the House of Lords Science and Technology Committee's forthcoming Genomic Medicine Report. Genewatch UK, June 2009.

Wilkinson, R.G. 1996. *Unhealthy Societies: The Afflictions of Inequality*. London: Routledge.

