



# Health Ethics Today

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## Editor's Forum

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In this issue of *Health Ethics Today* we discuss how some health care objectives can go wrong.

Laura Shanner asks us to think about the interplay between ethics and public health in a new way. She points out the importance of recognizing ethical aspects of health and health care within a broader context. She maintains that the view from public health can educate all health care professionals (HCPs) in this undertaking. This idea is illustrated with examples ranging from narrow issues such as confidentiality, through broader questions about professional integrity, to the often misunderstood data on the socioeconomic determinants of health. She questions our tendency in ethics to focus on individual autonomy as the most important influence on decision-making, given the wealth of public health information to the contrary.

Wendy Austin illustrates the professional risks involved when HCPs are not held accountable to a standard of care supported by evidence of benefit to patients. Her infamous examples make us angry, especially as she reminds us that these treatments were undertaken in academic medical science centers. The examples illustrate the danger of patient treatment being driven solely by science and technology. The treatment must involve care for and about the patient in

order for patients to retain their humanity. I point out in my article that this attention to care is easily lost in today's often disjointed delivery of treatment despite a "seamless health record". It is a necessity for day to day clinical practice as well as for high profile state of the art technological treatment. It is at the individual level of respect

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for the patient that we prevent these outrages rather than by policy from above. Health care professionals need to remember the value of caring as well as finding cures for patients. Professional ethics codes are important but education of all HCP students in basic respect for patients is more effective. It is the best way to ensure protection of the most vulnerable.

Dick Sobsey discusses the problems of our most vulnerable in terms of risks for individuals who cannot decide for themselves. While we allow a wide range of risk tolerance for autonomous persons in daily life we are more restrictive for those who lack decision-making capacity. The protection of the vulnerable from harm is rooted in traditional paternalism and the ethic of care across the professions. And yet, as Dick illustrates our conception of harms and need for protection

needs thoughtful reconsideration in today's world. We need to clarify *who* is being really protected, as well as *how* and *why*.

The need for vigilance in intensive care units (ICUs) is the focus of my paper about the potential dangers of life-saving treatment. A physiological and clinical basis for treatment is now expected to be evident before a patient is subjected to it. Even with such support many ICU treatments have serious side effects. And yet there are patients who receive treatment without any prior evidence suggesting benefit. This ICU tradition of trying untested "innovative" treatment in often futile situations has been justified on the basis of "doing everything to save life". The balance between the wishes and needs of the patient and the evidence to support treatment require careful consideration in each and every case. ■

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## Lost in the Crowd: Individuals in Public Health and Health Policy

**Laura Shanner, PhD**

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Bioethics has much to offer – and to learn from – the field of public health. Although the utilitarian and communitarian roots of population health initiatives were identified in the 1980's (Beauchamp, 1985) and the ethical challenges of HIV-AIDS were discussed widely through the 1990's, it took the SARS outbreak to focus bioethics attention on broader ethical matters in community health practice, health protection policy, epidemiological research, occupational medicine and environmental health.

Larry Gostin (2001) suggests that the phrase "public health ethics" can refer to ethics *in* public health, ethics *of* public health, and ethics *for* public health. Ethics *in* public health, like most bioethics activity, addresses foundational ethical frameworks and

practical dilemmas. Some old problems take a new twist: what standards of confidentiality are appropriate for disease surveillance and contact tracing? (Bayer and Fairchild, 2000) What does gene mapping mean for populations, not just individuals? (Clayton, 2002) Some unique problems emerge: Is it unethical to refuse immunization if an epidemic is likely? (Holland, 2007) Should health education promote truly informed, voluntary choices about risky behaviors, or should we keep "educating" until risk-takers change their ways? (Cole, 1995) Do traditional bioethics principles effectively address public health dilemmas, or are new principles needed? (Upshur, 2002; Childress et al., 2002)

Ethics *of* public health involves the professional in-

tegrity and trustworthiness of public health workers and mirrors other professional virtues and codes, but requires greater attention to leadership and advocacy roles. Patients initiate most clinical encounters, but professionals initiate most public health efforts: health surveillance requires accessing vast amounts of confidential information without Research Ethics Board review; intervention programs are targeted to communities in need; legislation may be advocated, as for banning cell phone use in cars. Who *are* these instigators, and why should we listen to their advice? Community confidence in public health leadership is essential for health protection/promotion efforts to succeed, as we are quite unlikely to change our public policies or personal behaviors unless we trust those who advise us to do so. A loss of public trust can be catastrophic in a crisis; conveying urgency while simultaneously quelling panic demands unique leadership ability.

Ethics *for* public health calls attention to a well known but still startling fact: socioeconomic disparities are the primary determinant of health, accounting for at least 50% of our life expectancy and health quality (Senate of Canada, 2008). All clinical interventions combined actually have very little effect on our health status; biotechnology is worthless to those lacking access to safe food, water, shelter, education, basic health services, and personal security. Human rights violations typically have negative health consequences (Mann, 1999), and climate change will likely cause global public health catastrophes (Soskolne et al., 2007). In short, public health is inherently threatened if we lack a solid foundation of human rights, social and distributive justice, and global responsibility. The advocacy role of public health thus extends beyond specific health policies or behaviors to the most sweeping socio-political decisions.

A challenge for public health is that individual human beings tend to get lost in the masses of data and health indicators; people become amorphous data points in health statistics, in populations to be educated or vaccinated, or in health protection policies



adopted across jurisdictions. There is no point to collecting mortality data, though, unless one is acutely aware that each data point represents a lost person and grieving family. As Howard Brody (1992) wisely noted, this would be “a classic case of the measurable driving out the important.” Public health workers and researchers must never lose sight of the humanity behind the numbers, and bioethics must give voice to the complex individual experiences and values at stake.

A paradox of public health is that, while we focus on groups in which individuals often disappear, we nevertheless tend to hold individuals responsible for their health. We say that YOU should change your diet, get more exercise and stop smoking, despite overwhelming evidence that socioeconomic disparities not only affect health far more than individual lifestyle choices do, but also shape the options available to be chosen in the first place. How can you choose to eat a healthier diet if you just can’t afford fresh produce? This paradox challenges some traditional bioethics assumptions: as a practical public health matter, how important is individual autonomy, really? (Wikler, 1987)

It is my hope that this recent attention to public health will infuse bioethics with renewed urgency and activism: social justice is literally good for us (Daniels et al., 2000), but achieving equity requires more than theoretical evaluations and interesting case studies, and has nothing to do with exciting medical technologies. We must all become advocates for human health and thriving, exercising political will and commitment to action across the gamut of environmental, socioeconomic and individual determinants of health. Ethics is a critical foundation for better public health, and public health just might be a rejuvenating focus for the field of bioethics. ■

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# "What Were They Thinking?": How Appalling Acts Can Spring from Good Intentions

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*"He who would do a great evil must first of all convince himself he is doing a great good."*  
(Gandhi)

History provides many examples of unethical, or ethically questionable, acts that were undertaken by people in the health sciences community whose stated intentions were to do "good". Unfortunately, rather than holding these actions before us and

learning from them, the tendency has been to maintain silence. We need, however, to pay attention to our history. Pellegrino (1997) argues that to think the gross malfeasance of the Nazi physicians could never happen again is dangerous. Nazi physicians "believed they were doing the right thing" and "made constant allusions to medical ethics" at their Nuremberg trials (Pellegrino 1997, p. 307). By using examples from psychiatric care and research we can illustrate how

good intentions can go horrendously astray, note commonalities, and point to some things happening today that may shock and dismay future generations.

***Some extreme examples from which to learn***

- **Benjamin Rush**, the father of American psychiatry, believed all disease stemmed from a fundamental pathology. On the medical staff of the Pennsylvania Hospital from 1783 to 1813, Rush sought cures for mental illness by reducing blood flow to the brain by such means as rotational therapy (spinning people suspending from the ceiling) and the Rush Chair, despite the visible anguish incurred by those so treated (Penfold & Walker, 1983).
- **Henry Cotton**, at Trenton Psychiatric Hospital (originally known as the New Jersey Lunatic Asylum and founded at the urging of Dorothea Dix, the famous advocate for humane care), was convinced psychiatric patients suffered from toxic products of unrecognized infections. Between 1918 and 1930, Cotton removed teeth, tonsils, gallbladders, genitalia, parts of stomachs and colons from hundreds of patients, many of whom died in attempts to cure them (Scull & Madhouse, 2006).
- **Walter Freeman** performed 3,500 lobotomies during the 1950's (mostly with an ice pick and hammer after the person was made unconscious by Electro-Convulsive Therapy (ECT)), which made the cover of Time and Life magazines. His youngest patient was 4 years old. Responding to claims that lobotomies cause lethargy and lack of spirit, Freeman said that "even if a patient is no longer able to paint pictures, write poetry, or compose music, he is, on the other hand, no longer ashamed to fetch and carry, to wait on tables or make beds or empty cans" and that he changed "taxeaters" into "taxpayers" (El-Hai, 2005; Pressman, 1998).
- **Germany's National Socialist Public Health's** eugenics program resulted in the systematic killing of psychiatric patients who were deemed to be suffering with lives unfit for life and as useless eaters (Bachrach, 2004).



- **Ewen Cameron**, in Canada, during the 1950's and 1960's attempted to "de-pattern" patients' memories via drug-induced sleep, multiple ECT treatments, and LSD injection. To insert new thoughts, he forced patients to listen to a tape of his voice saying a few sentences repeatedly (Collins, 1998). At least nine of his patients who lost the memory of their pre-Cameron treatment lives won law suits against the American and Canadian governments.

***What were they thinking?***

Looking across these disparate examples, we can

begin to see some commonalities that may help us understand what went so wrong.

There was recognition of a desperate need. Lobotomies, for instance, were introduced at a time of overcrowded and understaffed hospitals where ECT and insulin coma were the primary treatments. Rush, Cotton, Freeman and Cameron were all known for their compassion and concern for the suffering of their patients.

The belief that science needs to be conducted objectively (i.e., without emotion or empathy) has meant that the suffering of persons can be seen as necessary for the greater good and that it ought not to sway the clinical scientist from pursuing important therapeutic goals.

The lure of technology can be so strong that, as Gadamer (1996, p. 24) warns in *The Enigma of Health*, it “encounters an unprepared humanity”. Our social-political consciousness is failing to keep pace with our scientific and technological progress. There seems to be little time or inclination to address the significant social, legal and moral questions of our technical advances both at the individual and societal levels.

The temptations of power and certainty are evident in each of the above cited examples, suggesting that hubris, as well as dreams of fame, motivated professional actions. Wiesel (2005) has noted that officers of Nazi death camps held university degrees (e.g., doctorates in philosophy, history, and theology) yet their education did not shield them from or repel the temptation of cruelty: “This question haunts me still” (Wiesel, 2005, p.1513).

**Othring** – the idea that some persons are so different from oneself that different moral rules apply; they are not part of one’s moral community – means that basic principles, even “do no harm”, can be set aside in relation to others. Persons who are seen as “not like us” are highly vulnerable to having their rights suspended to allow researchers to use them as subjects for experimentation. The appalling historical record of abusive practices seems to reflect less about

individual clinical scientists gone wrong than it does about societal values.

### ***Some ideas on what we are doing that will shock and dismay future generations***

We are engaging in pharmaceutical memory blocking and enhancement; we risk creating mental health epidemics through diagnosing life experiences or conditions as disease (sadness is labeled depression; shyness as social phobic disorder). We increasingly accept conflicts of interest in the funding of research (Angell, 2000). Molecular biology driven prenatal eugenics seems to be promising human perfection. Health professionals are involved in hostile interrogations in the post-9/11 world (Annas, 2005; Lifton, 2004).

Perhaps we should stop to consider: ***What are we thinking?*** ■

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# Perils of Protection

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Fictional superheroes fight evil and usually save the day. Rarely, on TV or in the movies do we see the good guys failing in their mission, or even having their attempts to make things better result in making things worse. Protecting vulnerable people in health and rehabilitative services is rarely that simple. Here are a few ethical considerations.

**Justifiable Risk** Every protective intervention will produce its own new set of problems. A worthwhile protection is one that clearly has a net positive effect. For example, vaccination poses real risks, but most vaccinations are acceptable based on two considerations. First, the risk of being vaccinated is typically much lower than the risk of the disease we are vaccinated against, so there is a net gain. Second, we also have to ask ourselves if another form of prevention would impose more or less risk. In order to justify any protective measure, we need to determine that it has net effect of reducing harm or risk and that the risk imposed by this form of protection is not substantially greater than potential alternatives.

**Dignity of Risk** Some risks are necessary and acceptable. Most of us determine which risks we are

prepared to take for ourselves. Unfortunately, some individuals lack the capacity to make independent decisions about some kinds of risk. Children and adults with cognitive or emotional disabilities may need assistance in making some of these decisions. When a guardian or an agency makes the decision for such an individual, there is a strong tendency to err on the side of safety, even when doing so interferes with the individual's freedom, function, or enjoyment of life. As an example, many families of individuals with developmental disabilities resisted deinstitutionalization, citing fear that their loved ones would be victimized or exploited in the community. Life in the community does have some degree of risk, but the vast majority of individuals leaving institutions reported being much happier in the community (e.g., Young & Ashman, 2004). Of course, this does not mean abandoning all efforts to keep people safe in the name of the dignity of risk. A concern arises that such a policy does not consider an individual's likely choices, recognizing that some reasonable risks are acceptable.



**Whose Risk, Whose Protection?** Sometimes it is important to recognize who is at risk and who is being protected. Protecting patients from risk and harm may sometimes require exactly the same measures as protecting health-care agencies and providers from legal and financial responsibility for doing harm. At times, however, institutional risk management drives towards different outcomes than the protection of patients. At such times, those involved in ethical decision making must be clear about whose interests they represent and whose interests are in need of protection. For example, in the absence of clinical signs of brain injury, the risk to the patient of a covert skull fracture may be so low that it does not warrant x-ray exposure. In some cases, a decision to x-ray may be driven in part by the desire to protect the physician or health facility from the potential consequences of a missed diagnosis rather than the desire to protect the patient.

**Unintended Consequences** It is sometimes difficult to determine all of the consequences of a protective measure, especially when several measures may interact in ways that are difficult to foresee. For example, child safety-locks on the rear doors of automobiles reduce the risk of children falling out of moving vehicles. Newer electronic versions allow the driver to lock both the rear doors and windows. Safety shields provide a degree of protection for taxi drivers, who have often been victims of violence committed by passengers. Each has public health value in reducing accidental or intentional injury. Together, however, these two have had an unintended effect. Passengers may be essentially captives from the moment that the automobile door closes. As a result, children may not be able to escape from an accident or there is the risk of passengers being taken against their will to remote locations, and victimized.

**Illusion of Protection** Sometimes protective measures are more apparent than real. For example, many health-care and other staff working with vulnerable people require a criminal record background check. Many people might assume that this would mean

that any person who has been convicted of serious crime could not be hired into a position working with children or vulnerable adults. However, at the same time that more agencies require checks, the granting of pardons has also increased. In Canada, young offenders (about 50,000 per year) do not have criminal records. Approximately 55,000 adult offenders are automatically pardoned each year because they receive absolute or conditional discharges. In 2003, for example, these offenses included more than 15,000 assaults and almost 500 sex crimes. In addition, all others who complete their sentences can apply for pardons. To illustrate this, in 2006-2007 more than 26,000 Canadian offenders applied for pardons and more than 99% of their applications were granted. In total, about 130,000 criminal convictions, are expunged from the record each year. According to Public Safety Canada (2000), the “automatic denial of pardons to sex offenders would unnecessarily curtail the liberties of the many ex-offenders who remain crime-free.” They estimate that 4,883 sex offenders were pardoned in Canada between 1970 and 1998. The screening of criminal records may appear to provide more protection than it really does. This does not suggest that criminal record checks are without value, but it does mean that too much reliance on them as a means of protecting vulnerable individuals is more risky than it appears to be.

These are some of the ethical issues for consideration in the risky business of protecting vulnerable people. It might be tempting, in view of these pitfalls, to simply give up, on trying to the control risks. This is not an option from an ethical or legal perspective. Rather, we need to proceed cautiously and thoughtfully with the important endeavor of risk management while recognizing that there are few easy and no perfect solutions. ■

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# Can We Do It? – Yes We Can! – (but Ought We?)

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The modern era of Health Science centers dominating state of the art “high tech” treatments in an ever increasing range of sub-specialties has evolved over the past 30 years. In marked contrast to the recent past the majority of medical students today opt against a career in family practice in keeping with this new vision of multiple specialist treatment and care. The extraordinary success of tertiary care at curing individuals of life threatening illness is seen across all age groups from tiny premature infants to very elderly patients. New high tech treatments abound; bypass machines and mechanical hearts for kids and adults, lifelong dialysis over decades, organ transplants and joint replacement; have all become part of the medical treatment arsenal. The success of such treatments causes them to become gradually integrated into what is offered as “Standard Care”. The public and the health care professionals (HCPs) acceptance of this technology driven treatment as uniformly beneficial leads to very high expectations, especially in a single payer (government) health system such as exists in Canada. The short term effectiveness of many high tech interventions are well established with respect to improved early survival but longer term outcomes are less clearly beneficial. And yet as Laura Shanner described in her article above, it is the broader socioeconomic demographics of persons that truly reflect their lifelong health, rather than specific treatments.

Life-saving treatment in intensive care units (ICUs) is improving at such a rate that even medical textbooks are out of date by the time they are published. But is this success of emergency life saving treatment as clear cut as it seems? Depending on what is valued in terms of success (lets avoid the hunt for definitions) and by whom the question is answered, the answer is a **yes, no or maybe**. **Yes**, because many individuals survive previously fatal illnesses due

to extraordinary skill, technology and care, and go on to live long and happy lives. **No**, because we see enormous amounts of time, expertise, care and resources expended on people who die within hours or days, of the treatment. Or sometimes the result is weeks or months of bare survival, with no hope of eventual recovery, after this life-saving treatment. Is it possible to distinguish between those critically ill patients who will benefit from such treatment to the extent that they will be discharged home in relative health rather than to merely survive “at all costs”, and die a complicated slow death soon afterwards? **Maybe**.

**Maybe**, because a variety of clinical and test based scoring systems allow survival or death to be predicted with some degree of certainty. Across a range of illnesses and demographics a high risk of death can be predicted. However, the “exceptional case” undermines this data based approach to prognostication. Are we willing to doom the occasional, “exceptional potential survivor” based on the overall statistics for the group? Are we willing to refuse to begin life saving attempts or to discontinue treatment based on a futility argument? Usually we are very reluctant to embark on this nihilist road despite the widespread acceptance of evidence based medicine (EBM) as the basis of treatment. This so called EBM is now firmly established in medical undergraduate and residency education. The view of the expert clinician as one possessing a mysterious art born of learning and experience, who can prescribe treatment solely on that basis, has become obsolete. Aside from the appalling examples Wendy Austin described in her article, many more treatments used by experts without good evidence have caused widespread suffering and death. Despite this fact we continue to see “miracle cases” where treatments are used against all the odds (and against the evidence too) and the



patient survives. These patients re-enforce the Yes We Can and So We Must schools of medical treatment. Physicians tend to present these cases as triumphs over the EBM dogma. There is reluctance to discuss similar patients who die other than to say death was predictable anyway.

How can we deal with this conflict between the welfare of the immediate patient and the requirement to only utilize treatments supported by best

evidence? This conflict is more apparent than real in most cases. There is no ethical obligation to undertake a course of treatment in the absence of evidence to support benefit. Often a patient or surrogate will request, demand or insist that “everything must be done” to save the patient’s life. In clinical practice, doing everything can have different meanings depending on the conditions of care: the patient condition, the patient’s wishes and beliefs, the diagnosis, the risks and benefits of life saving treatment. “Everything” may involve extraordinary treatment including surgery, extracorporeal membrane oxygenation (ECMO), transplantation, etc. or it may mean high quality compassionate end of life care. In patients with clearly expressed or previously expressed wishes (verbal or written) the decision-making about treatment must be guided by their wishes. But these expressed wishes and this guidance is not unqualified. A wish to have “everything possible done” to save life does not include consideration of treatment with no biological basis or clinically demonstrable benefit. Terminal respiratory failure from metastatic cancer should not be treated by lung transplantation irrespective of what a patient or family requests.

Treatment judgments become difficult in situations where new evidence is beginning to accumulate, but is not yet conclusive. In the ICU setting this is frequently the case. A small number of patients may demonstrate improved outcomes with a novel treatment, but widespread clinical experience or appropriate research (randomized or other trials) has not yet occurred. The academic medical response to this dilemma at the bedside is either to enroll the patient into an appropriate study or proceed with “innovative treatment”. But what if there is no research study available? The clinicians may embark on innovative treatment if there is even a small probability of benefit and if the patient / surrogate agree. Unfortunately, physicians’ ability to predict outcome accurately in an individual patient with complex life threatening illness is poor. Databases on outcomes, scoring systems, and collective experience assist in this prediction but do not readily apply to the excep-

tional survivor. This underscores the necessity to be extremely cautious whenever we depart significantly from the standard approach to treatment because of the potential to do great harm to the patient. Every “miracle cure” is always memorable but not always helpful to the patient in the long term or to the HCPs in terms of learning. The difficult question of whether we ought to do many of the things we do in the

name of saving life cannot be answered in general terms. Only by remembering the importance of caring for and about each patient as well as trying to cure them will we approach an ethically acceptable answer. ■

## References

References available upon request.

## Upcoming Events

### New Adult Guardianship and Trusteeship Act Workshop:

Repeat Offer by John Dossetor Health Ethics Centre and Public Guardian’s Office

29 January 2010, 8:30 am – 3:30 pm

Bernard Snell Hall, Walter Mackenzie Health Sciences Centre, University of Alberta Hospital

### Dossetor Centre Health Ethics Seminars:

- 22 January 2010  
David McConnell, PhD, Associate Professor, Faculty of Rehabilitation Medicine, University of Alberta. *Disability, Parenting and the Rights of the Child.*
- 26 February 2010  
Victoria Seavilleklein, PhD, Ethicist & Policy Director, Provincial Health Ethics Network. *Newborn Screening...Just because we can?*
- 19 March 2010  
Wendy Austin, RN, PhD, Professor & Canada Research Chair, Faculty of Nursing & John Dossetor Health Ethics Centre and Owen Beattie, PhD, Professor, Faculty of Arts, University of Alberta. *Organ Donation and Presumed Consent: Recent immigrants’ perspectives.*

All seminars take place in Room 2-07, Heritage Medical Research Centre, 12:00 – 12:45 pm. Please check the John Dossetor Health Ethics Centre website at [www.ualberta.ca/BIOETHICS/](http://www.ualberta.ca/BIOETHICS/) for complete details.

### Health Ethics Week:

Theme: Hope & Healing: Creating a Moral Climate for Well-Being

1 – 7 March 2010

More information available at: [www.ualberta.ca/BIOETHICS/](http://www.ualberta.ca/BIOETHICS/)

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# Health Ethics Today

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