

Signposts in a Familiar Land?

A Second (or Third or Fourth ...) Look at Lingering Bioethical Concerns

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In comedy and humor it is often said that we laugh at what we find most difficult: sex and death and social taboos. In bioethics, we struggle to control—or at least order and contain—ultimately that over which we have no control: our “coming hither” and “going hence” (as *King Lear* has it). Perhaps increasingly today, we might also add the many ways in which we manipulate the body. These are the threads of life.

Canadian author and politician Michael Ignatieff, in the aptly named work, *Scar Tissue*, that describes the dying process of a mother with dementia, poignantly sums up the human tendency to attempt to control or tame our existential boundaries:

The real problem, of course, is what we are to think of death. People like us who live by the

values of self-mastery are not especially good at dying, at submitting to biological destiny. The modern problem is not death without religious consolation, without an afterlife. The problem is that death makes the modern secular religion of self-development and self-improvement appear senseless. We are addicted to a vision of life as narrative, which we compose as we go along. In fact, we didn't have anything to do with the beginning of the story; we are merely allowed to dabble with the middle; and the end is mostly not up to us at all, but to genetics, biological fate and chance (Ignatieff 1994, 68).

How does this relate to bioethics and what does it say about the communities bioethics attempts to serve? Firstly, it is suggested that our greatest moral discomfort is with causality in the begetting and ending of life. It is perhaps a positive endorsement of our deontological traditions (whether you are guided by them or not) that we have deeply embedded concern and moral intuition about human agency in the creation of new life and the cessation of existing life. It would indeed be disquieting if we had no qualms about intervening in matters of our very existence. On the other hand, those who see no basis for deontological derivation of morality, and usually employ consequentialist methods of argumentation and ethical analysis, view this deontological tradition as an obstruction to human progress and individual liberty and, perhaps, mere logical nonsense.

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But the fact remains that, as bioethicists, it is in beginnings and endings (and more than just those related to birth and death) where we spend much of our time, because, one way and another, these beginnings and endings offer real or perceived difficulties. The interdisciplinary (and sometimes amorphous) field of bioethics is seen to provide ways forward or, at least, offer in relation to life's challenges crucial insights and greater understanding (in both senses of the word).

Secondly, Ignatieff's perspective steers very much toward a bioethics of dilemma. At the *Journal of Bioethical Inquiry*, we try to avoid the notion of bioethics as but a vehicle for maneuvering through the rough terrain of sticky situations; rather, it is a conduit and catalyst for deeper discernment of the issues and principles at stake, in the (utilitarian) hope that we thereby prevent the sticky situations more often through improved conceptualizations, perspectives, and analysis, especially related to "difference."

Bioethics, however, is relatively young (despite the fact that today's university students would never dare consider the mid-20th century the "recent past"). Rapid advances in the "new biology" in the last three decades, particularly with regard to organ transplantation, assisted reproduction, cloning, genetics, and nanomedicine, also have made bioethics a popular topic of interest. Courses and content related to ethics abound beyond the purview of philosophy departments, having been added (sometimes with crowbar force and sometimes still as an afterthought) into medical school curricula and cropping up in other clinical and nonclinical health programs. Moreover, bioethical conundrums have become dinner-table conversations: They are regularly reported in the news and depicted in film and fictionalized television shows. Everyone today seems to be serving up a piece of the "ethics" pie, although not all portions come with a firm philosophical crust.

There remains much work to do in bioethics and not simply because biotechnologies increasingly come in a variety of offerings that may be marketed before they have sufficiently been reviewed. "Hot" topics are hot for a reason: indicating that we have not taken (or desired) the time to allow them to cool by way of thorough analysis and discourse. Of course, some are imbued with such fundamental and complex dilemmas they smolder regardless, retaining an ability to "burn" despite our efforts.

Practitioners, policymakers, and the public alike must not only keep pace with current and future advances in biotechnology but also revisit and reevaluate issues that are seemingly settled or even long forgotten.

The papers presented in this issue, although not formally part of a symposium, thematically center around the latter—offering fresh perspectives on old recipes and calling for bioethical concoctions we all can, and should, swallow.

Thalia Arawi and Philip M. Rosoff's "Competing Duties: Medical Educators, Underperforming Students, and Social Accountability" and Ami Harbin, Brenda Beagan, and Lisa Goldberg's "Discomfort, Judgment, and Health Care for Queers" focus on medicine's "bakers"—the training of health care practitioners in relation to the provision of (medically competent and socially just) care and duties owed to patients and society.

Arawi and Rosoff (2012) tackle, from an ethical standpoint, the problem of medical students who ought not graduate or practice (in the interest of patient safety) and the strong rights-based culture that impedes the exclusion of those who have a high chance of professional failure.

Revisiting the historical development and existing state of medical school admissions criteria as well as school- and profession-based evaluation and governance mechanisms, these authors argue that a "lack of competency"—in terms of "academic mastery, clinical acumen, [and/or] professionalism"—"can often be detected very early in a student's career and may or may not be immune to remediation efforts" (Arawi and Rosoff 2012, under "Abstract").

"It is a trivial claim, but nonetheless true," Arawi and Rosoff note, "that some people admitted to medical school should not become doctors" (2012, ¶6 under "Introduction and Background"). While mechanisms, both good and bad, exist to assist those who encounter academic difficulties (sometimes matriculating students who perhaps should not be allowed or enabled to do so), there are few in place that effectively assess and inculcate students' "professional" abilities. Arawi and Rosoff write:

Recognizing, uncovering, and responding to difficulties with what we now call "professionalism" is more of a challenge, and it is unclear if there have been any successful attempts to correct what may actually be, in some cases, character flaws, or if any such endeavors have been

made using the most appropriate and effective approaches (2012, ¶6 under “Introduction and Background”).

Medical education, we now know (even if acknowledgement of such continues to be plagued with a “postmodern” stigma), must encompass more than the mechanics of bodies. Health care practitioners not only serve the whole patient (and not the disease) but also the whole of society. Increasingly, clinicians stand at the forefront of bioethical frontiers, leading or blocking the way. Likewise, medical educators are tasked with “a dual and, at times, competing set of duties. On the one hand, they have a responsibility to the student to ensure that she is offered every possibility for achieving success. ... On the other, faculty members are obliged to the institution and the society that warrants that school” (Arawi and Rosoff 2012, ¶2 under “Introduction and Background”).

Thus, there is a need to reexamine the training of clinicians, even if this means closing the professional doors to those who cannot meet the standards of care in a broad sense of the term. This may be both a challenging and a delicate task. One need only revisit the modification and standardization of medical schools and practice in the 1800s and early 1900s as well as the motives and means behind the Flexner Report—a study funded by the Carnegie Foundation on the state of medical education in the United States and Canada (Flexner 1910). While certain positive changes accrued in the practice of biomedicine, Flexner’s methods proved to be substandard and social prejudices further disenfranchised already-marginalized populations seeking medical education and/or medical care such as African Americans and women (Beck 2004).

Harbin, Beagan, and Goldberg also call for changes in clinical training, particularly in relation to lesbian, gay, bisexual, transgender, and queer (LGBTQ) patients. They note that standard cultural competence training, a popular and widely used tool designed to improve attendance to the whole patient, fails in both its methods and its assessment: While the goal of cultural competence education is for practitioners

to learn about the beliefs, values, and practices of cultural groups, enhance cross-cultural communication skills, and develop tolerance and appreciation for others ... dominant models of cultural competence training fail to address power relations, systemic sources of social inequities, and

connections between social inequities and normative assumptions. Moreover, the measure of successful learning, the hallmark of “cultural competence,” tends to be increased comfort and confidence among learners, rather than skills in critical reflexivity (Harbin, Beagan, and Goldberg 2012, ¶2 under “Theoretical Approach: Feminist Bioethics, Cultural Competence, and Queer Contexts”).

Instead of improving doctor–patient relations, particularly those that challenge notions of hetero- and gender-normativity, this enables “unconscious assumptions and biases about queer and trans patients ... [to] persist” (Harbin, Beagan, and Goldberg 2012, ¶1). Alternatively, Harbin, Beagan, and Goldberg call for training and professional interaction that allows for, rather than prohibits, the expression of and attendance to “discomfort.” This does not mean, the authors carefully emphasize, the “unqualified endorsement of physicians unreservedly expressing discomfort with queerness to their queer patients” or “a focus on the discomfort of practitioners alone” (2012, ¶9 and ¶10, respectively, under “Critically Evaluating Comfort”). Rather, new “strategies for restoring comfort” should address not only the patient as a whole but the whole provider–patient relationship as well.

The recurring theme of the “internal” nature of medical ethics is once again on the table.

Similarly, there is a need to reappraise some of the foundations of medical and bioethical practices. Georg Spielthener, for example, reexamines “Risk–Benefit Analysis: From a Logical Point of View,” arguing that the “popular” (and often applied) approach to risk–benefit calculations is “logically faulty,” particularly “if ‘risk’ and ‘benefit’ are taken in their absolute sense” (2012, under “Abstract”) or when risk–benefit analysis is conceptualized as “a process of weighing the advantages of an option against its disadvantages” (2012, ¶6 under “Some Preliminaries”). In this light, the right action may not always be the “option whose benefits exceed its costs” (2012, ¶6 under “Some Preliminaries”). Spielthener offers easily comprehensible and compelling examples that illustrate *incremental* risk and benefit estimation in a model that can withstand the inherent uncertainties of medical decision-making and its significant qualitative nature (where formal logic also runs out of road).

In a discussion of “Word Games or War Games,” Sam Rys, Reginald Deschepper, Freddy Mortier, Luc

Deliens, Douglas Atkinson, and Johan Bilzen unpack the slippery meanings of terms related to euthanasia and investigate “The Moral Difference or Equivalence Between Continuous Sedation Until Death [CSD] and Physician-Assisted Death [PAD].” The debate about the moral acceptability of the former versus the latter, the authors discover from analyzing opinion pieces written by clinicians in academic journals, “is first and foremost a semantic rather than a factual dispute” (2012, under “Abstract”) and one in which these supposed “antinomies” are not equally and fairly opposed—where ambiguity about terminology is often tactical and value-laden in itself.

For instance, arguments for and against a moral difference between CSD and PAD “refer basically to the same ambiguous themes, namely intention, proportionality, withholding artificial nutrition and hydration, and removing consciousness” (Rys et al. 2012, under “Abstract”). There are, however, misunderstandings of and deficiencies in these concepts that can be used to serve either side. For instance, the authors ask:

Is “intention” strong enough as a concept to define and dissociate both practices? Or, more importantly, can it safeguard medical practice? We submit that there are several flaws in the concept of intention, not only practical aspects (such as the external validation of physicians’ intentions) but also theoretical and definitional aspects. One of the main problems with intention is its ambiguity. ... For example, practically all guidelines on CSD declare that the intention of CSD is not to shorten patients’ lives but that it is ultimately done for the sake of relieving suffering. But the same can be said about euthanasia (PAD)—that it is ultimately done for the sake of relieving suffering and that its ultimate aim is not the death of the patient (Rys et al. 2012, ¶2 under “The Ambiguity of Concepts”).

Rys and colleagues conclude that the “semantic elasticity” of these types of concepts and terms, particularly if ignored or misunderstood, may make for a fragile—and perhaps unclear, invalid, and unsafe—medical and ethical framework: one that is “vague and hypocritical, publically rejecting PAD while at the same time keeping the door open for ambiguous practices under the guise of CSD” (Rys et al. 2012, ¶1 under “The Semantic Elasticity of CSD”). For example, the use of sedation in response to agitated delirium

in the last hours of death (so-called “terminal restlessness”) is surely relatively uncontroversial; however, sedation of people who are not in the terminal phase, what has sometimes been termed “pharmacological oblivion,” is more contentious and certainly amenable to moral struggle.

No progress can or will be made in such debates, Rys et al. argue, until this moral struggle and the ambiguity in and asymmetry of concepts are brought into the light.

Jennifer Sarah Moore notes a similar trend in “New Zealand’s Regulation of Cosmetic Products Containing Nanomaterials.” Although amendments proposed to the New Zealand Cosmetic Products Group Standard (NZCPGS) move beyond an initial and relatively “toothless” focus on regulatory agency “notification”—and instead call for mandatory labeling of products—difficulties persist in how to define “nanoparticles,” “manufactured nanomaterials” (mNM), and “nanotechnology.” Moore explains: One of the problems with the definition of “nanoparticle” as set forth in the EU Cosmetics Directive, on which the NZCPGS is based,

is that nanoparticles can form aggregates. The size of the aggregate can be greater than 100 nanometres, thus falling outside the EU and New Zealand definition. The current definitions of mNM are not perfect. For example, they focus on size instead of including other physio-chemical characteristics such as shape, charge, and surface properties (Moore 2012, ¶1 under “Definition Challenges”).

Even if consistent and coherent definitions could be crafted, questions will remain about whether labeling will or can be effective in protecting populations and the environment from potential mNM risks, particularly when the larger public knows little of or about the mNM debate.

Likewise missing from the public forum is discussion regarding the use of dried blood spots originally collected as part of newborn screening (NBS) programs for other research purposes, despite the fact that such screening has been in existence for at least half a century. Li-Ming Gong, Wen-Jun Tu, Jian He, Xiao-Dong Shi, Xin-Yu Wang, and Ying Li surveyed Chinese parents’ attitudes regarding the storage of NBS blood samples and their use in research and found that parents are more likely to consent if they are given the

opportunity to choose. “These findings emphasize the importance of considering parental permission in future plans to use NBS samples for research” (Gong et al. 2012, ¶1 under “Discussion”) and that autonomous decision-making, particularly with regard to the body and bodily tissues, is clearly a global trend regardless of history or culture.

What is more revelatory, however, is the fact that there have been few examinations (and none, in some regions) of parental attitudes regarding the storage and use of NBS samples. Within the scientific, medical, and bioethical communities, we have not lacked the time to engage in such inquiries; rather, it seems we have lacked the mindfulness to engage with individuals and families in discussions about their bodies and tissues. Moreover, the finding that some parents would not consent to the storage or use of their infant’s NBS samples for research even with parental permission raises important concerns about privacy and the safeguarding of bodily and medical information.

Gong et al. make a seemingly obvious but long overdue appeal: “While NBS samples represent a public health resource, we also have the responsibility of engaging the public in discussions about policies and procedures regarding their use and the personal and health-related information that may be involved” (2012, ¶6 under “Discussion”).

Finally, Aaron G. Rizzieri asks us to reconsider whether “Stem Cell Research on Embryonic Persons Is Just.” There is a strong view held by most of those who oppose embryonic stem cell research (ESCR) that embryos have the full moral rights of personhood, often backed up by arguments of life potential. These views, especially when based on religious teaching, tend to be immutable. Rizzieri argues that “embryonic stem cell research is fair to the embryo, even on the assumption that the embryo has attained full personhood and an attendant right to life at conception ... because the only feasible alternatives open to the embryo” are brief unconscious existence and death after research or nonexistence from the start (Rizzieri 2012, under “Abstract”).

While some may “remain unconvinced” of his stance, which is “modeled on Rawls’ concept of the original position” as well as Kantian notions of justice and fairness (2012, ¶5 and ¶6 under “Introduction”), Rizzieri’s paper also raises several important and perhaps overlooked considerations about Kant’s second categorical imperative (treating others never merely as

means but always as ends) that often is invoked in the embryo debate. “A well-known difficulty with Kant’s maxim—indeed with any interesting general moral rule,” Rizzieri writes, “is that it has to be interpreted and applied despite its general and somewhat vague content” (2012, ¶1 under “Kant’s Kingdom of Ends and Human Dignity”). Moreover, and more importantly, Rizzieri presents a line of reasoning that permits him, and us, to consider the idea that prior to engaging in ESCR “one *has* treated the embryo as an end in herself by taking her interests into account” (Rizzieri 2012, ¶2 under “Kant’s Kingdom of Ends and Human Dignity,” *emphasis added*).

If we were to add a label to this unplanned compilation of papers, we might suggest something about *Signposts in a Strange Land* (to borrow from Walker Percy 1991) or, rather, “Signposts in a Familiar Land”—a much-needed second look (or third or fourth ...) at matters that some may think no longer matter or do not readily register on our policy and practice radars.

Whether in relation to the old or the new, bioethics offers both a space to explore and a place to return. Far from a positivist science that conceives of experiments or progress in a linear fashion, it is by nature iterative, regularly demanding a qualitative and circuitous path that must revisit the past even while it envisions the future.

We hope this issue of the *JB* provides such an opportunity, knowing that though we may desire cohesive narratives and comprehension of and control over our beginnings, middles, and ends, there will always remain something about life-as-lived that is beyond our storytelling grasp (Mattingly 1998).

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