

More than Words

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This work is borne of shared frustration: frustration over seeing many specific instances of bad behavior, poor judgment, dangerous ignorance, harmful cultures, or outright injustices in contemporary medical care and medical research; frustration over medical systems punishing whistle-blowers and agents of positive change while rewarding bad actors and interest-conflicted parties; frustration over the public being distracted by sexy bioethics micro-punditry while so much harm is accruing, largely unacknowledged, at a much larger scale; frustration especially at how “bioethics” has come to be understood – within the academic realm as something that is increasingly measured by external grants and (secondarily) peer-reviewed publications, and within the public realm as sporty commentary on oversimplified medical controversies purposefully dramatized to increase media outlets’ ad revenues.

The bioethics we have known personally, in our own work and our collaborations, is largely different from this. A few years ago we labeled our kind of bioethics “Impact Ethics.” In our conception, Impact Ethics is fundamentally oriented toward public service, and, as such, it often challenges the “powers that be” in a direct fashion. Consider, for example, an early, apt meditation on Impact Ethics penned by our colleague Barry Hoffmaster:

Impact Ethics is a way of doing bioethics.
 It is not a definition of bioethics.
 It is not a theory of bioethics. It is not a scholarly analysis of bioethics.
 It is a bioethics that is faithful to its origins, not its patrons.
 It is a bioethics that is embedded, not abstracted.
 It is a bioethics that is critical, not accepting.
 It is a bioethics that is creative, not conventional.
 It is a bioethics that is risky, not secure.
 It is a bioethics of commitment, not resignation.
 It is a bioethics of engagement, not passivity.
 It is a bioethics of devotion, not recognition.
 It is a bioethics of the marginalized, not the established.

It is the bioethics of a calling, not a career.
 It is the bioethics of the advocate, not the consultant.
 It is the bioethics of the activist, not the apologist.
 It is the bioethics of the whistleblower, not the muckraker.
 It is a bioethics for the humble, not the aggrandizing.
 It is a bioethics for the vulnerable, not the powerful.
 Impact Ethics disappoints more than it rewards.¹

Why does Impact Ethics “disappoint more than it rewards”? Because it is the kind of work that pushes against powerful forces and against the reward systems those forces have established to protect themselves. The work of Impact Ethics does not lack academic research and theorizing, but it is so much more than this. The outcome(s) that matter are not lines in a resume, dollars in research accounts, numbers of appearances on television or talk shows, or service activities that primarily aim to please one’s university administration. That is, the outcomes that matter are neither career advancement nor popularity. The outcomes that matter are witnessing and ending injustices, improving patients’ lives, defending and protecting research participants’ rights, and contesting entrenched (and too often accepted) structural conflicts of interests. This is often, as this volume shows, deeply uncomfortable and personally costly work; Impact Ethics is not easy work.

Why would anyone take this on? As the contributions to this volume show, there are a variety answers to this question. Some of us have attempted ethical interventions in medicine and medical research because we personally experienced an injustice that we realized was part of a larger web of injustice also harming others. Some of us have attempted ethical interventions because we discovered something in our research that we felt should not go unaddressed. Some of us are naturally inclined toward social and political engagement. And some of us have personality types that make it difficult for us to let go when we see harmful systems that we feel require public exposure, accountability, and change.

What all of the stories in this volume have in common are attempts to approach ethics not as something to just *talk about*, but as something to *do*. Paradoxically, this is what people outside the academic field known as bioethics often assume is what the field of bioethics *normally* involves; after all, bioethics *is* applied ethics. Indeed, many physicians, nurses,

¹ B. Hoffmaster, “What is impact ethics?,” *Impact Ethics*, November 18, 2013, available at: <https://impactethics.ca/2013/11/18/what-is-impact-ethics/>. Accessed on: February 21, 2018.

other healthcare professionals, patients, research participants, and their families assume that what academic and clinical bioethicists do through words and deeds is advocacy on behalf of patients and medical research participants. Indeed, it is not uncommon for academic and clinical bioethicists to be approached by individuals hoping they will be of help with actual medical ethics problems, policy gaps, or injustices actively occurring within the modern medical-research industrial complex.

But in practice, many bioethicists do not actively work to defend or protect specific vulnerable individuals or groups. Some theorize and write about justice but are of the view that engaging in translational or direct interventional work is the role and responsibility of others, such as lawyers, investigative reporters, professionalized activists, and administrators charged with ethics oversight. Other bioethicists advance ideas on specific topics and then, in the wake of controversy concerning their theorizing, have the audacity to suggest that they were merely exploring ideas and did not mean for their ideas to influence the “real” world of patients, families, and health-care providers.

Yet bioethics has also naturally drawn to its venues people like the authors in this volume, people we might call *doers*. These are people who wish to try to *enact*, and not just *discuss*, justice – often with a specific concentration on social justice concerns – in medicine, medical research, and public health. These include people who are primarily academics in bioethics and allied fields like health law, academic medicine, and history of medicine and science, but also those who are public sector advocacy lawyers, nonprofit activists, and investigative journalists. These are people who have, by their orientation, grown increasingly intolerant of people called bioethicists who advocate *not* primarily on behalf of patients or research participants but on behalf of those who fund the bioethicists – in some cases, drug, device, or vaccine makers, in other cases, research groups empowered by and empowering the medical-industrial research complex.

As a consequence of all of this, an active schism – or at least an uncomfortable implied debate – appears to be forming within academic bioethics over the question of what the roles and responsibilities should be for those who are identified as bioethicists. A sign of this rift is a fundamental divergence in views about how and what bioethics should contribute to public discourse and debate, practice, and policymaking. The different perspectives reflect a fundamental contrast between what bioethics has predominantly become in academia and what bioethics could be in the world.

This emerging tension in bioethics is more broadly reflected in our culture at large, particularly with regard to the roles of academics, healthcare professionals, journalists, politicians, and other thought leaders. The following question is of pivotal importance. Working in fields where recognizing injustices is expected as part of the knowledge required for being a professional, is it enough to aim at being a competent knowledge-producer or is there an attendant duty to act (when possible) on this knowledge, in a committed and sustained fashion?

The contributors to this book share in the belief that producing knowledge is not enough. Their writings begin and end with the assumption that, amid the plurality and often conflicting needs of the various parties involved with modern medicine and medical research, the needs of actual and future patients and medical research participants must be made primary, and their rights must be respected, preserved, and even enhanced. The contributors to this book also share the view that too many people are going unprotected, misunderstood, used, and even abused in the modern medical-research industrial complex, and that it is imperative to work, in small and large – local and global – fashions to improve the clinical and research systems that are centered on the bodies of sometimes vulnerable people.

The institutionalization of bioethics in its providing of structures for keeping the needs of patients and medical research participants visible, along with institutional mechanisms to ensure respect for their rights, may contribute to this moral advance. But the institutionalization of bioethics has in practice also had the effect of diluting, inhibiting, and constraining respect for this fundamental moral requirement. Systemic, institutionally sanctioned inattention and even corruption is not uncommon in medicine and medical research. The contributors to this book insist that academic bioethics itself be held accountable for what it is and isn't doing. Moreover, the field needs to resist the all too common tolerance, or even support, for careers made merely through analysis and commentary – a kind of intellectual (and sometimes public) punditry that can feel like secondary abuse of patients and research participants who have already been harmed or are at risk of future harm.

In providing this topic-diverse collection of first-person narratives of bioethics in action, our goals as editors are multiple: to provide models, inspiration, warnings, and hard-won insights for those who might do the kinds of work the authors do; to issue a moral calling to those with

enough privilege to act so as to protect and defend patients and medical research participants; and to better educate the public on the differences and relationships between what might be called punditry bioethics and bioethics-based advocacy.

The stories that comprise this volume are an intentional sampling of the kinds of work people are doing in specific instances and specific institutions as they try to make known and also fix medical ethics failures. By no means is this volume meant to be understood as the only example available; there is much good work being done in this area, and in some ways it was difficult to decide whom to invite to contribute. The contributors to this volume are purposefully drawn from many walks of life, including academic bioethics, history, and philosophy, but also public sector health advocacy, medicine, and politics. Some have had their stories covered in major media outlets, but this is the first time a group like this has come together to present what we see as a gripping collection of personal stories – some of failure, some of success, many of hardship. The stories presented in this collection include not only riveting accounts of medicine or medical research gone awry, but also honest reflections regarding which techniques worked or didn't work, how action might have been smarter or more effective, and where individuals (including the authors) and systems failed. As such, these stories are both inspirational and cautionary, not always in equal measure.

In Chapter 2, Françoise Baylis and Jocelyn Downie, scholars in philosophy, bioethics, and health law/policy, detail how they attempted to undo the appointment of a pharmaceutical representative to the Governing Council of the Canadian Institutes of Health Research (CIHR), the Canadian national funding agency for health research. Along with international leaders in patient advocacy, Baylis and Downie recognized the appointment as involving an untenable structural conflict of interest given the Governing Council's mandate to "shape the strategic directions, goals, and policies of federally-funded health research in Canada." The authors explain how they attempted to mobilize elected officials, fellow bioethicists, leaders within CIHR, and the public in an effort to stop having corporations with seriously checkered ethics histories from literally having a seat at the table of national health research policymaking.

In Chapter 3, Susan M. Reverby, a historian of medicine, explores how she has tried to produce history that can meaningfully inform our contemporary health-care systems. Reverby is a leading historian of the infamous Tuskegee syphilis study and was the researcher who discovered

the US government's studies involving the intentional infection of prisoners with gonorrhea and syphilis in Guatemala. Reverby explains how she has tried to make known her findings of unethical medical research while avoiding unnecessary harm to public health institutions – not an easy scene when dealing with the modern media machine, which loves to simplify and sensationalize stories involving unethical behaviors. She also explores the politics of public apologies and the problem of how history of the dead is often reframed for the glory – rather than for the edification – of those living. She concludes that “doing the best history we can matters, but this will never be enough,” and suggests what more must be done.

In Chapter 4, Alice Dreger, a historian and philosopher of anatomy, explains how she came to be a leader in the intersex patient rights movement, including as one of the heads of the Intersex Society of North America. She recounts what techniques she and her collaborators used to try to bring about a more rational and just system of care for children born with body types that do not fit sex norms, and she carefully points out where they succeeded and failed.

In Chapter 5, Ruth Macklin, a philosopher and bioethicist, details how she has actively collaborated with the nonprofit organization Public Citizen's Health Research Group in the United States to push for the rights of participants in clinical trials conducted nationally and internationally. Macklin shows how difficult it can be to bring about the alignment of research practices with what we generally think of as long-agreed-upon core principles.

In Chapter 6, Miriam Zoll explains how in her experience the reproductive medicine system is “a profit-driven medical marketing trap, a cultural trap, a trap of misinformation; a trap that intentionally preyed upon the naiveté and vulnerability of anxious couples.” From this revelation, she explains how she moved on to become a vocal and highly effective critic of the “global repro tech industry.” We include Zoll's story not only to show how iatrogenic trauma can lead to patients fighting back, but also because we believe it is important to remember that much of medical advocacy begins with patients who become politically conscious enough to wake others who may then assist. The chapters by Dreger, Macklin, and Zoll each cover decades of work and showcase how the work of challenging the medical industrial complex is not getting easier, even though it does seem to be becoming more urgent.

Chapters 7–9 provide first-person case histories of academics who have tried to help develop more educated, more compassionate, and

more just systems by working within hospitals, medical schools, and governmental systems, including regulatory agencies, the judiciary, and legislative bodies. In each of these instances, the authors have identified knowledge and/or practice failures that might be fixed through direct, positive engagement. All also recognize that trying to effect this kind of systematic change requires novel collaborations and sustained efforts that ultimately require deep support from administrators who control reward systems, resources, and missions.

In Chapter 7, physician and ethicist Joel Frader tells the story of how institutionally challenging it has been to establish pediatric palliative care. His is a classic story of how good intentions can get in the way of optimal patient care, in this case in hospital settings. Frader demonstrates the kind of sustained effort required to enact meaningful change in recalcitrant systems. In Chapter 8, historian and philosopher of science Jane Maienschein describes how a highly supportive administrative system at Arizona State University in the United States has empowered her to do socially engaged work, educating judges and legislators about embryology (relevant to abortion debates), cloning (relevant to potential legislative bans on research and technology), and the like. Maienschein describes how she has set up an educational system around this outreach work in order to expand and sustain this kind of public service. Finally, in Chapter 9, physician and medical educator Aron Sousa tells the story of how he worked as a medical school dean at Michigan State University in the United States to support his faculty who were engaged with the Flint Water Crisis – a massive and protracted public health emergency caused by bad politics around drinking water. Sousa's account demonstrates how difficult it can be to manage research, care of patients, and public health when working within systems thick with politics, persistent inequities, and bureaucracy.

We are sure readers will see, as we do, that there are many questions raised by the personal narratives included in this collection. What is the difference between what is called “advocacy” and what is called “activism,” besides that the former is often used as a term of admiration in medicine and public health and the latter, one of derision? What is the right way to understand academic freedom when one academic uses hers to call out another academic researcher for allegedly objectionable behavior? How do we ensure that scholarship is not weakened by ideology and missions of justice? How do we recognize that the personal is political while also understanding the limits of first-person accounts? How do we move people past simplistic stories of good and evil while

also recognizing that sometimes we are dealing with cases of injustice so outrageous as to constitute a kind of evil? How do we remain morally sensitive without constant frustration and exhaustion?

We hope that this volume will spur conversations on these and many other questions with which many of us are now struggling. But even more than spurring conversation, we hope this volume conveys the sense shared by all of the contributors that actions speak louder than words.