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Global Perspectives on Stem Cell Technologies

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Afterword

Marcia C. Inhorn

“Bio-crossings”—a term coined by editor Aditya Bharadwaj—is an apt neologism for this remarkable volume, which focuses on a miniscule biological entity, the stem cell, and the momentous ways in which this once-inconsequential bio-form has now become a powerful bio-technology, touching the lives of many people across the globe. These include scientists, clinicians, regulators, policymakers, patients, parents, advocates, anthropologists, and sociologists—many of whom have crossed national borders and disciplinary boundaries in their pursuit of stem cells as a new field of science and discovery, a powerful cure for some of the world’s most dreaded afflictions, and a platform for regenerative medicine in the twenty-first century.

Yet, rarely do these stem cell stakeholders come together, which is exactly why this volume is so path-breaking and important. This book emerged from a one-of-a-kind, international conference held in Geneva, Switzerland, and called “Intersections: Social Science & Bioscience Perspectives on Stem Cell Technologies.” The goal of that unique conference was to bring together five major groups of stakeholders:

1. Scientists who produce stem cell research, mostly but not exclusively in the global North;
2. Clinicians who use stem cells to treat sick patients, almost always in the global South;
3. Sick patients and their supporters, primarily their parents, who seek stem cell treatments for debilitating conditions;
4. Professional associations and their representatives, who attempt to provide ethical guidance and regulatory oversight; and
5. Social scientists who are charting the “social life” of stem cells as they reach many different corners of the globe.

This book thus reflects these various perspectives. It begins with fundamental insights made by two of the world’s leading technoscience scholars, Charis Thompson of the University of California, Berkeley, and Sarah Franklin, of Cambridge University. In her chapter, Franklin reminds us that *in vitro* fertilization (IVF), which was invented and introduced in England in the late 1970s, has become the “platform” technology for much that has followed (Franklin 2013). Human embryonic stem cell (hESC) lines were first created from excess embryos in IVF labs. To use Franklin’s excellent analogy, IVF was the original “steam engine” in the reprogramming of reproductive biology, leading to the development of many other forms of “biological equipment.”

However, as Franklin also notes in her chapter, these powerful “bio tools” have also created much controversy and “technological ambivalence.” In the US, for example, early stem cell debates centered around America’s abortion politics and the religious disagreements over the status of the human embryo. Thus, ethical restrictions on stem cell research quickly emerged during the George W. Bush years, reflecting a “Christian right” view of morality and ethics. However, as Thompson argues based on her many years as a social scientist observing the US stem cell sector (Thompson 2013), “good science” can only emerge from a more capacious view of ethics and a “multi-vocal,” democratic, and participatory scientific process. In other words, Thompson asks us to reconsider what constitutes good science and good ethics.

This very question—what constitutes good, ethical stem cell science—is at the heart of this volume. One chapter by Linda Hogle takes up this

question by examining standards of evidence. In 2015, a policy document emerging from President Barack Obama’s White House argued for a more “fluid,” flexible approach to biomedical innovation, to undo some of the more cumbersome aspects of the US regulatory process. However, as Hogle shows, such flexibility is difficult to achieve under US standards of evidence-based medicine (EBM), which has become established in the West as an “organizing principle” for assessing new medical technologies. In order to meet the standards of EBM, clinical efficacy and safety must be proven through large-scale, randomized clinical trials (RCTs). In the West, RCTs are now *sine qua non* for “proving” both safety and efficacy. However, these large-scale trials, employing computerized “big data,” are difficult and expensive to produce, and are often funded by pharmaceutical companies, creating the potential for conflict of interest. Thus, the question remains: Are RCTs always necessary? Or, are other forms of evidence, such as those based in clinical practice, also useful?

RCTs also pose ethical quandaries that are questioned in this volume. For example, several of the authors question the validity of placebo-controlled trials, when giving a placebo to a very sick patient seems unethical, even morally unconscionable. Much is at stake for very sick patients, when they have no other options. Thus, Thompson calls attention to “ethical choreographies”—or the ways in which different stakeholders come to understand and enact ethics. The assumption that only one moral universe exists based on four ethical principles—respect for autonomy, nonmaleficence, beneficence, and justice—may be inadequate in capturing what is at stake and what really matters in people’s everyday local moral worlds (Kleinman 2006).

This is an important insight when it comes to stem cell medicine, especially as it is being practiced in Asia. In India, but also in China (Song 2017), therapeutic stem cells have been deemed a “breakthrough” technology—a veritable “revolution” in the treatment of otherwise chronic, incurable diseases and injuries. Such Asian centers of stem cell therapy are attracting stem cell “tourists” from around the world, including many from America and Europe. It is important to emphasize that in the West, stem cell therapy is not available for clinical use, for as described above, the evidentiary standards required to prove safety and efficacy through RCTs have not yet been established. In the US and Europe, then, stem

cells constitute a kind of distant mirage—a treatment “on the horizon,” but still many years down the road. Given this foreclosure, many sick Western patients—who have nothing else to lose and potentially much to gain—now make heroic journeys, often wheelchair bound, to stem cell clinics in Asia.

These Asian stem cell scientists and practitioners have been largely discredited by the international scientific community. For example, the chapter by Marcia Middlebrooks and Hazuki Shimono explores the “scandals” that took place in South Korea and Japan involving two separate stem cell scientists. Such individuals have been cast by the international community as “rogue” scientists or charlatans. Furthermore, attempts within different Asian countries to actually treat patients with stem cells are cast as “quackery,” or the commercial exploitation of those who are desperate and suffering.

However, most of the chapters in this volume chart a far different Asian story, one that belies this kind of scientific disbelief and the frank paternalism on the part of the Western biomedical community. Part II, “Therapeutic Horizons” and Part III, “Patient Positions” focus specifically on India, a nation that has gained an international reputation—if not a scientifically accredited one—as the world’s global stem cell “hub.” As shown by Appleton and Bharadwaj in their major study of India’s stem cell industry, clinics offering therapeutic stem cell treatments now operate all over India, in the major tier-one cities such as Delhi and Mumbai, as well as smaller, provincial, tier-two cities. There, physicians offer stem cell treatments for conditions ranging from rheumatism to optic nerve damage to amyotrophic lateral sclerosis (ALS), the deadly disease also known as Lou Gehrig’s disease and made famous by the case of Nobel-prize-winning physicist Stephen Hawking.

Part II begins with the detailed work of Dr. Geeta Shroff, India’s most well-known stem cell physician, who has been offering patients treatment since the early 2000s. Shroff charts the clinical history of her therapeutic stem cell line, which was derived from a single human embryo. Over the past decade and a half, Shroff has treated hundreds, if not thousands, of patients, many of them coming from Western countries, often with incurable, degenerative conditions. In her chapter, Shroff describes the treatment she offers to patients suffering from spinal cord injuries (SCIs)

and the sometimes subtle, but often substantial improvements that she has documented in both quadriplegic and paraplegic patients. In the next chapter, Dr. Petra Hopf-Seidel, a German psychiatrist and neurologist, describes the journeys she has made to Dr. Shroff’s clinic accompanying her very sick German patients, including those suffering from the neurological effects of chronic Lyme disease and ALS. Among the Lyme patients but less so among the ALS sufferers, Hopf-Seidel has seen some remarkable improvements, even full recovery. Thus, she continues to advocate stem cell therapy for her neurologically impaired patients, especially those who have few other treatment options.

The final section of this book, *Patient Positions*, is, in my view as an anthropologist, the most powerful and thought-provoking. Taking patient subjectivities and voices very seriously, Bharadwaj sought in this volume to include the perspectives of those who have actually sought out and used stem cell therapies in India. Thus, in this section, one chapter features an interview with a mother and daughter. Shannon Davis, a young American woman, was rendered quadriplegic by a horrifying auto accident. Her mother Lola did everything she could to support Shannon. Through research on the internet, Shannon and Lola discovered that their only hope for stem cell therapy was in India with Dr. Shroff. Thus, they made the trip together several times for stem cell treatments, which were delivered via injection and spinal infusion. Once immobile from her chest down, Shannon can now function on her own. She feeds herself, dresses herself, moves herself from her wheelchair into her specially adapted car, and drives herself to work, where she is employed in the job that she held before the accident. The Davis’ mother-daughter conversation serves as a powerful testimonial to the regenerative efficacy of stem cell therapy, which in the case of Shannon has led to vast improvements in her quality of life.

In the moving chapter by Ripudaman Singh, he recounts how he became a parent activist, when his young son was diagnosed with the degenerative and ultimately deadly condition known as Duchenne muscular dystrophy (DMD). Heartbroken but determined to do something for his beloved son, Singh becomes a kind of “lay expert” in stem cell therapy. Along with several other Indian DMD parents, Singh and his compatriots self-fund the Adipose Stem Cell In-Vitro Lab Study, in

which they enroll their sons (because DMD is a sex-linked genetic condition, primarily affecting boys). Although Singh faces criticism for turning his son into an experimental subject, he is supported by wife, his family, and his physician in-laws. To date, his son has suffered no ill effects, although also no marked improvements. As Singh explains so poignantly, without these kinds of “patient-driven” studies, there is literally no hope for DMD patients in India. Singh laments what he sees as the lack of concern for the disabled: “In India, the reality is that nobody cares about a disabled child, and even if I were to narrate my story, nobody cares. It is ironic that India is a spiritual country but it has so much apathy.”

Thus, the heartbreak and desperation, the hopes and fears, the need for compassion and for evidence, and ultimately the desire for a cure ring out in this final poignant section. Unlike so many other ethnographic volumes, in which social scientists speak “for” their interlocutors, this volume is remarkable in letting patients and their parents speak for themselves. It reveals their struggles, their heartbreaks, their desires, and their hopes. These chapters attest to the fact that patients and their advocates *must* be part of the stem cell conversation.

Finally, it is important to end on the theme of social justice. In a country like India, where poverty is rampant and the public health system is broken down, stem cell therapy exists in the world of private, fee-for-service medicine, where patients must pay, sometimes high prices, for stem cell services. It is thus not surprising that many of the beneficiaries of stem cell treatments in India are arriving from the global North. Or, like the Indian parents who funded the DMD study, they are educated elites within their own society. The advent of stem cell therapies in India and other Asian settings raises thorny questions about healthcare access and social justice, including how patients arriving from the global North may benefit at the expense of those from the global South. In an era when stem cell therapies are still globally inaccessible, questions of prioritization, triage, equity, and justice become paramount.

Although this book is being published decades after the first stem cell lines were established in the West, therapeutic stem cells are far from being offered in Western clinical practice. Indeed, the slow pace of development in the West has led to other global trajectories, intersections, and perspectives. This book has admirably captured this lively and important

domain of biomedicine outside of the West in a part of the world that is showing itself to be a lively site of technoscientific invention. The book is timely and thought-provoking foray into this world, and the global circulations that are making it possible.

Anyone interesting in stem cells should read this book.

For anyone interested in stem cell treatment, reading this book is a must.

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