

Global Perspectives on Stem Cell Technologies

“Stem cells circulate the globe today in settings where patient desperation confronts regulatory confusion and commercial expectation bumps up against ethical ambiguity. In Bharadwaj’s fearless editorial hands, the intersection of these forces, centering on novel Indian therapies, comes alive through voices ranging from academic and reflective to passionate and deeply personal. The book may haunt, destabilize or challenge. It will not bore.”

—Sheila Jasnoff, *Pforzheimer Professor of Science and Technology Studies at Harvard University’s John F. Kennedy School of Government*

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Foreword: *Good Science, Better Patients*

In my 2013 book, *Good Science: The Ethical Choreography of Stem Cell Research* (MIT Press),¹ I characterized the current era as one in which two kinds of “good science” go together to drive highly capitalized biomedical innovation: “good science” as in reproducible, reliable, and robust method and knowledge, and “good science” as in freighted with ethical questions such as the moral status of embryos or how to compensate egg donors or find cures. I investigated this intertwining of the moral and technical in bio-innovation economies through the example of US and California pluripotent stem cell research during the 15 years from the first successful derivation of human embryonic stem cell lines until the political and technical stabilization of induced pluripotent stem cell research. I developed a mixed ethnographic/archival/participatory method I called “triage” to collect data with the intent of bringing to light processes whereby some lives come to matter more than others in relation to an emerging technology. I examined US Democrats’ and Republicans’ competing framings of stem cell research; stem cell research’s geographies and geopolitics as seen from California, especially federal and state dynamics in the USA; putative brain drains to the UK and Singapore; and a short-lived rivalry with South Korea over somatic cell nuclear transfer cloning. I also looked at novel public–private funding and governance structures that were being erected for dealing with the ever-present risk of market failure around human cellular technologies at this time, and at how

poorly the technical and moral challenges of stem cell research were addressed by the post-war ethics of what I called the “substitutive research subject.”

To demonstrate the way that ethical and technical challenges were articulated together throughout research, and not just before beginning the research and after the research is let loose upon the social sphere to have implications or impact, I highlighted California’s “procurial” frame for human pluripotent stem cell research: *pro-cures* as the overwhelming moral mandate and technical challenge; *procurement* as the simultaneous ethical roadblock and technical feedstock; and *bio-curation* as the process of moving (de)identified characterized tissue and bio-information between formats and in accounted-for chains of custody. In order to achieve both epistemologically and morally good science, I argued for upstream, interactive, and iterative technical, economic, and ethical innovation, expressed in terms that make sense within the political repertoire of a given jurisdiction. I also argued for the iterative, participatory, and upstream inclusion of distributive justice goals so as to disrupt the systems-entropy whereby discrimination characteristic of a history, time, and place is materialized into technologies and their corresponding ethical instruments. I pushed against the blindness to stratification of the individualism of much of bioethics, and against the species and mind-over-body exceptionalism of humanism. I also called for a radical updating of the epistemologically entrenched and globally circulating and differentiating category of the substitutive research subject. This work has had concrete outcomes, ranging from invitations to teach animal research ethics to engagement with human rights lawyers, and the launch with colleagues of the Science FARE (feminist, anti-racist, equity) initiative to urge technical infrastructures to embed social justice goals.²

This important edited collection, *Global Perspectives on Stem Cell Technologies*, takes up good science in ways that resonate with my own development of the term, as well as in quite other ways. In close kinship, this collection focuses on connections forged by cellular technologies through “the twin processes of extraction and insertion of biogenetic substance across multiple terrains ranging from geopolitical borders to areas between biology and machine, governance and ethical dilemmas, everyday suffering, and religious as well as secularized morality,” (“Introduction:

Stem Cell Intersections: Perspectives and Experiences”) that Aditya Bharadwaj felicitously refers to as “bio-crossings.” Nayantara Sheron and Bharadwaj argue in “Bio-crossing Heterotopia: Revisiting Contemporary Stem Cell Research and Therapy in India” that “science and emerging political economy of stem cell technologies around the globe are producing distinct culture-specific responses” (introduction). Sheron and Bharadwaj compellingly reimagine stem cells in India “as heterotopias: manifest entities and discursive sites suffused with real and imagined, and utopic and dystopic alterations made manifest as bio-crossings gain traction between the biogenetic, technoscientific, socioeconomic, and geopolitical landscapes of possibilities.”

Sheron and Bharadwaj demonstrate, as I did for the American Medical Association’s guidelines on medical tourism, how two sets of 2013 Guidelines in India ended up with the consequence of an “automatic ‘good/permisible’ science versus a ‘bad/rogué’ science,” between human embryonic stem cells (hESC) and somatic autologous cells. In their chapter, “Staging Scientific Selves and Pluripotent Cells in South Korea and Japan,” Marcie Middlebrooks and Hazuki Shimono show how important the genre of scientific biography is to establishing good science, which cannot happen without good scientists. As I did in *Good Science*, they reconstruct the portrayal of South Korea’s Hwang Woo-suk before and after the somatic stem cell cloning scandal. They go further and fruitfully compare portrayals of Hwang with portrayals of Japan’s Haruko Obokata during and after the stimulus-triggered acquired pluripotency (STAP) scandal. When Hwang and Obokata were national heroes, traditional biographical vignettes were afforded great nationalist significance. Obokata’s grandmother’s apron in the place of a lab coat, and Hwang’s cow with whom he shared bucolic roots as a boy, assured their goodness as moral scientists. Once the scandals broke, however, these same “moral maternal” tropes began to be treated as evidence of the very flaws that led to their downfall.

Where I focused on the problems of extending the ethics and epistemology of substitutive human and animal models to regenerative medicine, Linda Hogle (“Ethical Ambiguities: Emerging Models of Donor–Researcher Relations in the Induced Pluripotent Stem Cells”) draws our attention to a different ethical and epistemological limitation

emerging in stem cell research: the changing nature of trials and how they advance evidence-based medicine. She draws on her own previous work to show that “for cell-based products, large-scale trials pose challenges, blinding is virtually impossible, and endpoints are difficult to establish.” She convincingly argues that the previous gold standard of good science, the double-blind randomized controlled trial, is being superseded by patient activism and computational tools in an emerging assemblage of evidence-based medicine for the pro-cures era.

Sarah Franklin (“Somewhere Over the Rainbow, Cells Do Fly”) adds a vital element to the epistemological and geopolitical landscape by zeroing in on regenerative medicine and its associated industries in the UK. As she shows, stem cell technologies are increasingly powerful and “disruptive” because they are part of the “technological platform that enabled the reprogramming of reproductive biology.” “Stage 3 clinical trials in a wide range of fields,” and “combination products that integrate cells with medical devices, such as patches and scaffolds,” lead to “a far-ranging vision of induced plasticity delivered through signalling factors extracted from pluripotent cells and repurposed to trigger in situ cellular reorganisation.” Franklin points to these technical breakthroughs as well as to smaller yet higher impactful by-products of changing practice. For example, the trend to freeze embryos at a later stage in fertility medicine has meant that scientists have a diminished source of leftover embryos suitable for hESC derivation. Similarly, the development of stem cell product derived patches that lose many of the cellular properties is making the delivery of cellular products easier. Franklin challenges readers to consider what contribution the social sciences might play. If there are social aspects of regenerative medicine throughout the research, development, and application process, downstream models of social science impact are likely wrong, too. She argues that we need to develop equally sophisticated models to measure and promote our own research impact.

I want to now turn to another fascinating aspect of this edited collection. In the title to this Foreword, I have gestured at it with the phrase, “better patients.” This is a play on the moral and epistemological work patients and their physicians and advocates do³ which makes the science better and thus makes their treatment work better, and on the sense of “being, feeling, or getting better” that we apply to patients who are on the

road to recovery or have reduced symptoms and/or improved quality of life. The remaining chapters in this collection concern the kinds of good science captured by this double meaning of “better patients.” Dr. Geeta Shroff’s chapter, “Establishment and Use of Injectable Human Embryonic Stem Cells for Clinical Application,” documents her reasons for choosing a particular population of chronic spinal cord injury (SCI) patients for hESC-derived transplantations in her Indian embryonic stem cell transplant clinic. She focuses on the needs of those “less likely to suffer opportunity costs from study participation” for whom there are few treatment alternatives, and rightly casts this as its own moral imperative. Shroff displays the methodological virtues of her protocol: its simplicity, the regenerative nature of the cell line she uses, and the cell culture; freedom from animal products. The chapter takes time to demonstrate the treatment’s scientific legitimacy in highly recognizable terms, but the emphasis is on small clinical improvements that contribute to wellbeing and more productive life, however manifested, rather than on cures or increased survival. Petra Hopf-Seidel, in her chapter “Pre-blastomeric Regeneration: German Patients Encounter hESC in India,” likewise explains that “each of my patients improved in one way or other, some visible and measurable, others more invisible with improved stamina, better moods, or more muscle strength. No one had adverse effects, so I can say confidently that I was surrounded by happy patients.” Better treatments are ones that lead to better patients however measured.

Finally, Ripudaman Singh’s chapter, “Active Parents, Parental Activism: The Adipose Stem Cell In-Vitro Lab Study,” and Lola and Shannon Davis’ chapter, “Accidental Events: Regenerative Medicine, Quadriplegia and Life’s Journey,” take us to the heart of the work done by patients and their parent activists to bring treatments in to being in ways that promote good science and lead to better patients. Singh, his wife, and son all worked tirelessly with their fellow families to improve their children’s conditions of life in a country where “nobody cares,” least of all the Indian Medical Council, which took the dismissive attitude that “stem cells are just placebos.” The “parents did most of the research and determined the protocols, such as how many cells we wanted and the number of infusions,” and, at the very least, knowledgeably and actively bought “time until something better came along.” In their chapter, Shannon and Lola

Davis emphasize the progress made through being a patient of Dr. Shroff when nothing else had worked. Shannon's mother describes the range of incremental improvements in function and quality of life, rather than total cure, offered by the treatments, and sums it up by noting that "her life has become as normal as it can be." Shannon herself underlines the "rigorous medical attention to treatment protocol," as a "deciding factor" in traveling to India for treatment, and also sets the bottom line in terms of efficacy of the treatment in the absence of alternatives, noting that "there is no other place in the world to help me."

Overall, *Global Perspectives on Stem Cell Technologies* was a pleasure to read and learn from. It resonated deeply with my own work, while also taking me much beyond. Good stem cell science and regenerative medicine has much in common around the world, but also crucially differs according to local political and ethical and scientific repertoires, economic circumstances, governance and regulation or the lack thereof, and the institutional structure and funding of science. Narratives of moral and epistemological goodness are produced in and in turn produce scientific and biomedical innovation. Market failures and a completely new understanding of the biological are leading to innovation stretching from clinical trials to patient activism. Cures and care promise, eventually, to be the better for it.

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Professor, LSE.
June 2017

Charis Thompson

Notes

1. Charis Thompson, 2013. *Good Science: The Ethical Choreography of Stem Cell Research*. MIT Press.
2. See *Nature* 538, 371, 2016, Science FARE <http://www.nature.com/nature/journal/v538/n7625/full/538317b.html>
3. See, for example, these founding works: Steven Epstein, 1998. *Impure Science: AIDS, Activism, and the Politics of Knowledge*. University of California Press, and Rayna Rapp, 1987. *Moral Pioneers: Women, Men and Fetuses on a Frontier of Reproductive Technology*. *Women Health* 1987;13(1-2):101-116.

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