Stem Cell Intersections: Perspectives and Experiences

Aditya Bharadwaj

Introduction

Global Perspectives on Stem Cell Technologies is an exploration of social science, patient, and biomedical perspectives on stem cell technologies. This unique engagement takes as its starting point a humble cell lying on an intersection of ideas as diverse and interlaced as life, knowledge, commerce, governance, and ethics. While natural sciences have focused on the bio-anatomy and unique therapeutic promise of stem cells, social science disciplines such as anthropology and sociology in large part endeavor to reveal the 'cultural contours of interlocked sociotechnical assemblages framing stem cell isolation, generation and application' (Bharadwaj 2012, p. 304). These are shown to range from scientific production, political contestations, and economic calculations to ethical variations, religious objections, and social mobilization around the globe (ibid.). These complex processes and relationships have not only amassed around the scien-

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A. Bharadwaj (✉)
Department of Anthropology and Sociology, Graduate Institute
of International and Development Studies, Geneva, Switzerland

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tific possibility of purging the cellular form of therapeutic promise but also increased levels of promissory hope and indorsed hype in the cellular form.

This book is an engagement with an emerging but vital area of science spanning geopolitical, socio-economic, and techno-scientific as well as bioethical dimensions. The endeavor is to deepen our understanding of stem cell entities and the concerns, hopes, and aspirations that shape them and make them imaginable as viable therapeutic entities. 'Several key intersections between individual, group, and institutional relationships have become central to locating and debating the production of stem cells' (Bharadwaj 2012, p. 306). Gradually, stem cells are emerging as biogenetic objects bestriding intersections as diverse as ethical/unethical, science/commerce, religious morality/secular governance, somatic/embryonic through to utopian hope and dystopian despair. There is, however, a paradox at the core of stem cell intersectionality: stem cells can be imagined and materially deciphered across a variety of sites. That is, the culturally ascribed identity of stem cells acquires value precisely because stem cells can be imagined as 'both like and not like human beings' (Squier 2004, p. 4). It is on the precise intersection of shifting individual, group, and institutional relationships that stem cells continually renew to mean different things and embody different moral, ethical, economic, and therapeutic values.

The millennial turn saw the rise of the biotechnology of stem cells in nations of the 'South' such as India and beyond. The rapid globalization of stem cell research and clinical application is producing an uneven landscape of opportunity to research, regulate, promote, and debate the cellular form. These moves are also rapidly problematizing long-established oppositions of global North/South, First/Third worlds, developed/developing economies, and Western/Eastern cultures (Bharadwaj 2009; Bharadwaj and Glasner 2009). What is to count as local and global is rapidly dislocating. In large part, this also means that the twentieth-century-development discourse that privileged the unidirectional flow of knowledge from the 'global' North/developed to the 'local' South/developing is disintegrating. As long argued, this geopolitical worldview is now both an untenable orthodoxy and an unsustainable project (ibid.). It is in this world order in which twentieth-century geopolitical stability is rapidly shifting and intersecting in ways previously unimaginable that stem cells have begun to proliferate and mutate to body forth culture-specific responses to certain core and contested arenas.

The book addresses three overarching arenas of concern: (1) regenerating the very notion of regulation and ethics, (2) emerging therapeutic horizons, and (3) patient positions. In large part, these concerns have framed the research focus and lived experience of the authors in this book. These concerns are continually 'co-produced', to use Sheila Jasanoff's apt phrasing, to mean different things in different global contexts. For example, as the accounts in this volume show, while there is emerging evidence of growing social and regulatory concerns around stem cell research and clinical interventions from the United States, the United Kingdom, and Japan, stem cell therapies have become firmly embedded as therapeutic practice in global locales like India. Similarly, in some parts of the world, regulatory and ethical concerns are focused predominantly on the clinical manipulation of the embryonic form and sourcing of reproductive gametes for research (Sperling 2013). In some other global locales, the impact of invasive extraction practices to procure such biogenetic tissues and exploitation of vulnerable populations is being framed as a major area of concern (Waldby and Cooper 2010). The global political economy of such biotechnological developments along with the commercial exploitation of future therapeutic possibilities is also causing alarm and mobilization. While the origins and ethical objections to using embryos for stem cell research can be traced back to the religious domain in specific Euro-American formations (Bharadwaj 2009), the global variability notwithstanding, creation of human embryos for fertility treatments and stem cell research alike have become core bioethical subjects as ethical concerns and, to borrow from Sarah Franklin's insightful analysis, are 'built into' new life forms (2003, 2013). The question of ethics covers a spectrum of issues ranging from scandals involving unethical stem cell research (chapter 'Staging Scientific Selves and Pluripotent Cells in South Korea and Japan') to what Clare Williams and her colleagues have shown to be 'ethical boundary work' (Wainwright et al. 2006) within stem cell laboratories and clinical application of stem cells in specific global locales to the ethics of gamete and embryo sourcing for research through stem cells.

The emerging treatment modalities in a globalized research and therapeutic landscape are similarly mired and caught up in the crude but readily available intersection between good and bad science (Bharadwaj 2015). The conversation this book seeks to instigate significantly involves one notable example of an emerging embryonic stem cell treatment modality in India (see chapters 'Establishment and Use of Injectable Human Embryonic Stem Cells for Clinical Application', 'Pre-blastomeric regeneration: German patients encounter human embryonic stem cells in India', and 'Accidental Events: Regenerative Medicine, Quadriplegia and Life's Journey'). In large part, the intent is to let the voices of those most intimately involved in this breakthrough—from the clinician scientist and author of this unique breakthrough to international interlocutors ranging from physicians to patients embodying the cellular therapy—put forward their perspectives. For too long, these voices have been marginalized in bioscience and social science literature as fringe, guileful, or gullible (cf. Bharadwaj 2013a, b, c, 2015). However, as decade-long anthropological analysis has shown that to the purveyors and surveyors of normative 'good science', clinical breakthroughs in India may seem problematic because they perceive human embryonic stem cells (hESCs) to be digressing from what is often seen as adjudicated and consensible science (Bharadwaj 2013a). Nonetheless, hESC interpolations achieved in the Indian clinic amply illustrate ways in which the slow-paced but high-stakes, capital-saturated, Euro-American forays into stem cell research produce structural conditions that allow the tropic notion of 'bad name science' to solidify on the intersection of states, capital, and science (see Bharadwaj 2015). However, we must remain alert and not lapse into a just as radially available and tempting essentialism that could recast the critique of hESC in India, for example, as mere evidence of a 'West versus the rest' mindset. Rather, it seems the politics of life and science (in that order) paint a more complicated portraiture that takes as their rhetoric of persuasion the notion 'first in the West then elsewhere' (see Chakrabarty 2000, p. 6). Let us also be clear that the emerging global intersection of state, science, and capital is bringing together a collation of strange bedfellows. For instance, the emerging regulatory guidelines in India have more in common with the standardized regulatory norms long fantastically fantasized in the Euro-American landscape as establishing a global gold standard in which biogenetic tissue could become normalized as intellectual property, commercial transaction, standardized therapeutic protocol, and normative bioethical compliance. Put another way, these imagined 'tracks' are fast becoming essential for the smooth shuttling of capital-fueled biotechnological locomotion. The emerging binary between the hESCs and somatic cells in Indian regulatory thinking is a fine reflection of this purportedly globally standardized view on human embryonic source of stem cell as inherently unethical, dangerous (cancerous), and difficult to regulate (chapter 'Biocrossing Heterotopia: Revisiting Contemporary Stem Cell Research and Therapy in India'). It seems the very notion of regulation is in a double bind: how to regulate embryonic stem cell proliferation in petri dishes and across the globe and how to regulate (and not proliferate) ethical, moral, and political issues. Yet, hESCs are proliferating in India and attracting patients from around the globe (see chapters 'Pre-blastomeric regeneration: German patients encounter human embryonic stem cells in India' and 'Accidental Events: Regenerative Medicine, Quadriplegia and Life's Journey'). The so-called regulatory vacuum, as some argue (Sleeboom-Faulkner and Patra 2008), is purportedly allowing this proliferation to go unchecked. The reason this collection includes the Indian hESC breakthrough prominently is because the Indian case is quite possibly the only contemporary example in the world where hESCs are being used clinically with accumulating patient data and testimonies that render problematic the spectral fears of dangerous proliferating potential of embryonic cellular form (Widschwendter et al. 2006).

Against this backdrop, the growing movement of people from around the world in search of stem cell therapies becomes yet another emerging arena of concern. Stem cell tourism, as global therapeutic travel is frequently euphemized, has expanded to include India as a major hub. The so-called stem cell tourists are part of the conversation this book seeks to set in motion, and only their voices can best complicate the problematic nature of the 'tourism' euphemism. It would be erroneous to view this as a mere experimental moment in charting the rise of an innovative biotechnology. Instead, this book's main orientation is a belief that no matter how noble our intentions as social science researchers, we cannot truly give voices to people we 'study' be they scientists, clinicians, or patients.

Instead we can merely create conditions for voices to emerge. Taken together, these developments turn stem cells into a 'spectacle ripe for … analysis' (Hogle 2005).

Stem Cell Theory Machine

Stem cell intersections offer a unique opportunity to revisit Galison (2003) and Helmreich's (2011) notion of the 'theory machine' (also see Bharadwaj 2012), that is, 'an object in the world that stimulates a theoretical formulation' (Helmreich 2011, p. 132). Helmreich explains that for Galison, 'networks of electrocoordinated clocks in turn-of-the-twentieth-century European railway stations aided Einstein's thinking about simultaneity'. Similarly, 'animal husbandry provided a theory machine for Darwin' (ibid.). Retooling Galison, Helmreich focuses on theory as neither fixed above the empirical nor deriving from it in any straightforward sense but rather as crossing the empirical transversely (also see Helmreich 2009, p. 23–25). Thus argued, theory becomes at once an abstraction and an object in the world. In Helmreich's formulation, 'theories constantly cut across and complicate our paths as we navigate forward in the "real world"' (Helmreich 2011, p. 135).

Manifestly a humble stem cell is a theory machine par excellence. As a quintessential 'emergent form of life' (Fischer 2003), a stem cell is at once constricted in the specific context of its cultural medium and dispersed as a 'global biological' entity (Franklin 2005). The theory machine potential of a stem cell is thoroughly realized in its cultural capacity to manifest as the progenitor idea that transforms the notion of 'life' as not only emergent but also simultaneously regenerating. It is the regenerating potential of stem cells, both therapeutically and the social, economic, political regeneration such therapeutic promise sets in motion that further complicates the symbiotic and semiotic emergence of a vital concept: life.

As an abstraction and a real object, a stem cell is rapidly becoming vital to the vitality of the emerging notion of life as regenerative and its evolving institutional and structural framing in the new century. One can argue that the stem cell theory machine crosses sharply athwart the empirical terrain of life. This produces complications. In other words, stem cells are abstractions with real-life consequences. The athwart movement of cells through everyday lived complexities that imbricate science and suffering, as well as regulatory necessities and ethical contingencies, can be seen tropically instantiating a 'biocrossing' (Bharadwaj 2008). As a conceptual trope, the notion of biocrossing alerts us to 'crossings' achieved 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 (ibid.). A crucially important way to examine these complexities is to become attentive to ways in which biocrossings traverse the heterotopic spaces in which utopian promise and dystopian angst are reflected and refracted (see Foucault 1986; chapter 'Biocrossing Heterotopia: Revisiting Contemporary Stem Cell Research and Therapy in India', this volume). These reflected sites produce counter-sites within cultures that allow life to assert its vitality within a set of circumstances and material conditions that run counter to individual or shared ideas about life. The theory machine of stem cells is uniquely placed to operate in and as heterotopias: manifest entities and discursive sites suffused with real and imagined, utopic, and dystopic alterations made evident as 'biocrossing gain traction between the biogenetic, technoscientific, socioeconomic, and geopolitical landscapes of possibilities' (ibid.). To be clear, heterotopias are not negative spaces per se but rather multiple concrete and discursive counter-spaces that can be experienced. While Foucault neglected to unpack the notion of heterotopia in any meaningful detail, a close reading of his limited musings on the topic suggests that the notion of heterotopia allows life to unfold and accumulate temporally and spatially even in the face of structural conditions seemingly not conducive to nor sufficient for life. For example, in Foucault's formulation, both prison and museum would typify a heterotopia. While the latter would accumulate time and space indefinitely, the former could become transitory surveyed time and panoptic space. In a similar vein, the temporal and spatial vitality inhered in the cellular form and the vital force of human life itself become equally heterotopic. As counter-spaces, heterotopias contain the potential to operationalize life and enable life to willfully accumulate or dissipate by 'juxtaposing in a single real place several spaces, several sites that are in themselves incompatible' (Foucault 1986, p. 25). These spaces can range from the human corporeal form, stem cells ensconced in a petri dish, hospitals, and laboratories to conference halls, classrooms, and national parliaments promoting or neglecting panoptic ethicality through to international stock markets and pharmaceutical corporate entities. These sites, incompatible in scale, temporality, and power, are importantly reflected and rendered vibrant as they interact and counteract over time and space to produce dynamic shifting social arrangements that ironically sustain and curtail stem cells. Foucault reminds us that 'the heterotopic site is not freely accessible like a public place' (1986, p. 26). The entry into a heterotopia is either compulsorily overseen (e.g., barracks or a prison) or via rites and purifications. This unique heterotopic character isolates as well as renders accessible a counter-site. The purification of stem cells as ethical objects and shards of hermetically isolated and panoptically surveyed biogenetic tissue (imprisoned in a laboratory) further behooves us to inspect the open and closed character of stem cell heterotopia.

The ethical space framing stem cells has a discursive presence. However, the theory machine of stem cells concertizes the discursive and specializes it to hone and 'home in' on competing social orderings that not only harden to become canonical practices and pronouncements but also end up subordinating ethical practices that materialize in response to mundane encounters with life and living. The ordering of good and bad science, however, makes the moral binary factitious. In Thompson's brilliantly insightful account of ethical choreography surrounding stem cell science, she shows that a truly good science with ethics would do more than conceive best scientific and ethical practices as mere instruments for overcoming ethical barriers to research (or for that matter clinical application). Instead Thompson eloquently argues that:

> … dissent and assent and other interests in relation to fields of science should be solicited, not shut down by scientists and ethicists and administrators; that criticism of science should open up, rather than shutting down avenues of research; that the process and procedures of ethical inquiry should be honored; and that multiple forums for ethical deliberation should be developed, recognized, and made integral to robust science. (2013, p. 64–65)

Perhaps it is time to embrace and advocate the open-ended nature of ethical deliberations, broadly participatory and somewhat democratic, as emerging cellular potential gets realized and theorized around the globe. The alternative and slightly closed and inward-looking bioethical farming merely bureaucratizes ethics to mean something altogether specific. The true answer is perhaps to be (re)searched on the intersection of these competing ethicalities. The theory machine potential of stem cell and its ethical pluripotency is uniquely placed to achieve and propagate this integration.

Regulating Pluripotency

The global stem cell landscape can be imagined as inherently pluripotent. This inherent pluripotency gives rise to much more than vibrant cellular forms—that is, the science and emerging political economy of stem cell technologies around the globe are producing distinct culture-specific responses. It is as if by virtue of differentiating in divergent cross-cultural mediums, stem cell science has become an arena in need of robust standardized regulation. Yet, the notion of regulation remains a slippery concept in much of the social science scholarship and state response to stem cells these accounts focus on as their empirical base. There is an unwitting assumption that greater regulation would somehow rein in the euphemistic pluripotency from assuming dangerous proportions (Salter 2008; Patra and Sleeboom-Faulkner 2009).

Sheila Jasanoff shows that 'biotechnology politics and policy are situated at the intersection of two profoundly destabilizing changes in the way we view the world: one cognitive, the other political' (2005, p. 13). Science has historically maintained its legitimacy by cultivating a careful distance from the politics (Jasanoff 2005, p. 6). She argues that as state-science relations become more openly instrumental, we can reasonably wonder whether science will lose its ability to serve either state or society as a source of impartial critical authority (p. 6). In other words, Jasanoff (1990, 2004, 2005) equips us to ask how inventions, both scientific and social, relate to public and private actors in (predominantly democratic) nations and assist in the production of new phenomena through their support for biotechnology and how they reassure themselves and others about the safety of the resulting changes—or fail to do so (2005, p. 6). Broadly speaking, the notion of 'pluripotent stem cell' encapsulates this troublesome complexity. The issue of unregulated invention and science with its normative inversion—compliant and adjudicated science—circumscribed by state-science consensus in public and private realms produces a shared sense of belonging to an epistemological and regulatory technology. The technoscientific act of honing cells co-produces (Jasanoff 2004) the equally complex task of honing the technoscientific procedure itself. Similarly, the act of reassuring selves and others becomes a manifestly political act of forging a consensual polity of instrumental and ethical action. Moves to standardize and universalize ethical and epistemological procedures are intimately connected to such impulses interested in honing the pluripotent potential of stem cells.

Regulating the social and scientific pluripotency in a globalized research and therapeutic system is a complex task. In the late twentieth and early twenty-first centuries, these moves have birthed the triumvirate of state-science-capital. Increasingly, this troika works to contain, curtail, and cultivate zones of consensible epistemology, shared ethicality, and commercial viability (see Bharadwaj 2013a)—as if anything proliferating outside this consensible vision of a globalized stem cell terrain becomes, like stem cells themselves, peripherally dangerous. The failure to coax cells, science, and society into an orderly development becomes a failure to foresee and prevent a malignant disruption. However, it would be erroneous to assume that some monopolistic state-science machine of global domination is circumscribing stem cells from proliferating 'unregulated' in nation-states and petri dishes. On the contrary, it is becoming increasingly difficult and complex to determine how democratic nations function and respond in the context of the emerging global politics of science and technology around stem cells. For example, Sperling's rich ethnography on the bioethics debate in Germany offers a peek into the established presence of a pronounced sense of 'German' and 'un-German' modes of doing stem cell research (Sperling 2013). The boundaries around German research at best remain ambiguous even as bioethicality posits research inside and outside Germany by German scientists or research on stem cell lines imported rather than indigenously developed as the threshold for precarious border [bio]crossing of the ethical terrain. The Euro-American terrain is internally diverse and distinct. The national cultures of stem cell research and regulation do depart on occasion significantly. However, regulatory protocols and bioethical thinking in the Euro-American formations, differences, and digressions notwithstanding share a distinct philosophical and ideological provenance. While these manifest differently in different nation-states, for example, at the level of the European Union as opposed to individual member states, they do pose problems, as they travel globally. In India alone one finds that while stem cell scientists effortlessly incorporate Western biomedical training and biotechnological developments into their indigenous stem cell tool kits, they do struggle to make sense of normative injunctions around ethics and new regulatory concerns around human embryonic forms. The resounding pushback observed for over a decade can simply be paraphrased to read that the human embryonic form is neither a religious nor a moral nor ethical 'hot potato' in India. Yet, the moves by the Indian state to problematize the destruction of an embryo as an ethical concern, the creation of hESC lines as inherently perilous, and the regulation of such embryonic entities as exceedingly complex reflect the consensus in the Euro-American formations on the subject. More important, the emerging regulatory concern of the Indian state is seeking to transform the stem cell terrain in India by stemming the therapeutic viability of the pluripotent embryonic cell while proactively coaxing the proliferation of autologous cellular research and therapies (see chapter 'biocrossing Heterotopia: Revisiting Contemporary Stem Cell Research and Therapy in India'). Manifestly, it is no surprise that the emerging stem cell nations like India are seeking to create global reach and access by co-opting and building into the stem cell entities ethical, moral, and regulatory thresholds of their probable lay and professional consumers and future markets (see Bharadwaj 2009). The triumvirate of state-science-capital necessitates that political regulation, scientific consensus, and economic calculation seamlessly align if nascent entities like stem cells are to become viable as ethical, therapeutic, and commercial objects. To read these emerging socio-political complexities as mere standardized regulatory and bioethical practices or in some unique sense hallmark good science would be hugely one dimensional.

Policy and regulatory thinking that assumes simplistic divisions such as good/bad and ethical/unethical often miss the nuanced complexities routinely imploding such binaries. If we subject prefixes such as 'good' and 'bad', usually appended to an idea of science, to critical scrutiny, we soon discover that these prefixes curiously circulate and mutate as they converse with their immediate and distant 'environments' and in so doing attach and detach from the very idea of 'science'. Take, for example, the controversy surrounding Proposition 71 of 2004 (or the California Stem Cell Research and Cures Act), a law enacted by California voters to support stem cell research, most notably embryonic stem cell research, in the state. The California Institute for Regenerative Medicine (CIRM) became the state agency brought into existence by the passage of Proposition 71. Funded by state bond funds and backed by taxpayers to the tune of three billion over ten years, the CIRM became a unique holding space for hype/hope, promise/despair, risk/reward, and intractable diseases/promissory cures (Bharadwaj 2015, p. 4). However, the promissory value of the CIRM was somewhat tarnished when local media began highlighting its 'insular' and 'insider-like' way of doing business (*Los Angeles Times* 2014). The main bone of contention was the CIRM's former president's unethical practices and the subsequent CIRM-sponsored cover-up. From its very inception, the CIRM was to be the crucible of good science, and its remit was to find cures for humankind's worst afflictions. This 'procurial' remit, to use Charis Thompson's felicitous framing, was the defining feature of the CIRM's rapid and unprecedented rise. However, the 'procure' rhetoric of 'good science' that enabled the CIRM to come into existence in the first place paradoxically bore fruit in distant India. The fact of stem cell therapies in India can achieve and deliver results that elude good science elsewhere remains an enduring irony. This is because the critique often encountered in the Indian stem cell terrain has in large part focused on imagined violations of an epistemic kind: no animal models or clinical trials and/or no standardized ethical choreography prefiguring good scientific performativity. In this respect, following Shroff's work (chapter 'Establishment and Use of Injectable Human Embryonic Stem Cells for Clinical Application') is illuminating in one crucial respect: it lays bare the pursuit of 'local good' circumscribed by contingent ethics produced in relation to sensibilities populating the everyday engagement with life (see Das 2015). For instance, in all my interactions with Geeta Shroff, I have found her to see placebo-controlled trials as unethical since stem cells at her clinic are used to treat only terminal and incurable conditions:

> We never opted for a clinical trail because we are against giving placebos. The patient is the control because there is chronicity, and it is not fair to treat a patient with placebos especially if a motor-neuron-disease patient is coming to you who is going down every day. The institutional ethics committee took this decision a very long time ago that there will be no placebo, as it is against our ethics; we can't stand back and watch a motor-neuron-disease patient rapidly worsen and die. It is against our ethics. (Bharadwaj 2015, p. 13)

How do we then accommodate this call for localized ethical contingency in the grand narrative of bioethics? In the register of everyday ethics that Veena Das (2015) has brilliantly illuminated through her work, the contingency and frailty of the human condition and its unpredictable social trajectory render untenable a scientific and bioethical commitment to standardized epistemic choreography. However, procedures and processes are changing. As Hogle shows within the purview of the Twenty-First-Century Cures Act in the United States, the law is instructing the FDA in no uncertain terms to use observational data in the evaluation of drugs, biologics, and devices. This data, Hogle explains, could come, in addition to other sources, from case histories and patient narratives about their own experience (chapter 'Ethical Ambiguities: Emerging Models of Donor–Researcher Relations in the Induced Pluripotent Stem Cells'). While these moves stop far short of a watershed moment in eliciting evidence, newer and older notions of appropriate evidence are likely to become more hybrid (ibid.). Nevertheless, these developments can only give hope. For now, it seems, the mode of building and doing 'good science' as envisioned by Thompson seems a step closer to realization.

On the question of regulation, certain expedient logics appear to underscore the rise of science policy and governance around the globe today. This expediency, I think, is an unwitting corollary (and on rare occasions a willful manifestation) of processes that both operate and are operationalized as the global circulation of intellectual and monetary capital gain traction. We need to pay particular attention to such an emergence within the policy landscape, national and regional differences notwithstanding. We should also remain somewhat ambivalent in the face of two popular and explicit suggestions embedded in the existing social science literature on stem cells that see robust governance of stem cells predicated on common acceptable principles and mechanisms as facilitating good scientific practice and international collaborations and the standardization and globalization of ethical concerns. In my view one of these aims, international collaborations encouraging good scientific practice, is often unattainable given the woeful lack of a level global playing field; the other, the standardization of ethical concerns, is undesirable. This is because in order to understand science policy and regulation, we also need to understand how power structures set definite limits to individual and collective negotiating capacities. The resulting negotiating choreography produces seemingly new norms, but these reassert the hegemonic view that either seeks to co-opt the emerging new in its own image or reject it altogether, a sense of 'our way or the highway'.

The foregoing policy, scientific, ethical, and regulatory concerns often eclipse one important stakeholder in the global stem cell landscape: patients suffering from chronic and degenerative medical conditions. Ironically, the manifesto of 'good science' that Thompson troubles and expands to include a diverse pool of concerns and ethicalities takes as its point of departure a strong 'pro-cure' stance as the main justification for intensified research, enhanced funding, and procuring access to biogenetic tissue. The affect saturated call for this intensification takes human suffering and progressive and degenerative afflictions as the only humane justification for developing and delivering therapy-grade stem cell technologies. The suffering patient thus co-opted in the triumvirate circuit of state-science-capital paradoxically serves to obfuscate the troika at the cost of her own obfuscation. The suffering patient and her suffering is deferred, disappeared, and dispersed into a promissory therapeutic future. The certainty of her suffering and eventual end in the present assumes a totemic quality: a sacrifice that guarantees promised future returns on the investment elicited in her name from state, science, and capital.

I have had the rare privilege of documenting and following biographies of stem cell treatment seekers for nearly a decade. I am delighted that rather than represent them, some of these inspirational pioneers will represent themselves and their experiences in the pages of this book. As noted previously, it is my firm belief that no matter how noble our intention as researchers we cannot truly give voices to people. Instead we can merely create conditions for voices to be heard.

Through the course of my research, I have encountered numerous patients reporting reversals in their rapidly worsening conditions post-stem cell interpolations and voicing deep frustrations on being seen as either psychosomatic or responding to mere placebos (Bharadwaj 2013b). For example, many patients had to contend with well-meaning but unsupportive biomedical opinions advising against stem cell treatments in India. Patients were continually asked to wait for therapeutic alternatives to emerge within their home countries in Europe or the United States. The well-meaning tropic construct of desperate gullible dupe in need of protection from a guileful maverick often silenced the enduring frustration patients articulated. To these intrepid treatment seekers, the ethical stance of principled good science seemed callous and inhuman. As one treatment seeker told me, 'They [purveyors of bioethically settled stem cell science] appear to be saying we rather you die than try'. In a similar vein, a young man told Thompson (2013) he would travel abroad for stem cell treatments if he could. He couldn't understand why there were concerted efforts to demonize countries offering treatments even if those interventions were largely experimental. To the young man, the demonized experimental nature of stem cell treatment modality abroad was more desirable than dying waiting for the FDA in the United States (Thompson 2013, p. 16).

It appears the figure of an independent, autonomous, free, rational, and calculating subject—routinely resurrected in ethically adjudicated consent procedures—is rendered problematic, as a decision to seek stem cell treatments around the globe cannot be captured under the sign of a clinical trial or some form of normative treatment seeking. It appears outside the state-science-capital circuit; autonomy, consent, and choice add up to mean something rather specific—gullibility and desperation. Alternatives to what I am calling the triumvirate-sponsored biomedical science are rendered untenable. And yet therapeutic migrations from over 50 countries to India have continued to seek out stem cell treatments for over a decade (chapters 'Establishment and Use of Injectable Human Embryonic Stem Cells for Clinical Application', 'Pre-blastomeric regeneration: German patients encounter human embryonic stem cells in India', and 'Accidental Events: Regenerative Medicine, Quadriplegia and Life's Journey').

In highlighting the complex pieces making up the pattern of global stem cell initiatives, this book is seeking to initiate and invite conversation. The chapters that follow might offer a template for future engagement and forays into the cellular terrain populated by multidisciplinary stakeholders.

The Book

This book aims to instigate conversation. In so doing we need to remain alert and open to asking what kinds of science, politics, and ethicality are at stake as stem cell science and therapies throw roots around the globe. This will entail crossing disciplinary, ethical, geopolitical, and cultural borders. The chapters that follow offer remarkable insights into groundbreaking research from across disciplines. These perspectives reinforce a call for methodological immersion that is longitudinal, sustained, and multi-sited in order to reveal everyday complexities at the heart of these emerging stem cell challenges around the globe.

The chapters that follow offer illustrations into the emerging life of stem cell technologies in an interconnected world. These examples are unique, and given the prevailing contentious bioethical framing of stem cell entities, some of these illustrations may even be perceived as controversial. One of the primary aims of this collection is to jolt us out of our epistemic comfort zones and facilitate a dialogue on a disciplinary and experiential intersection. As noted previously, the book is held together by three distinct and yet connected thematic sets.

The first major thematic group is concerned with the notion of regenerating regulation and ethics. Franklin (chapter 'Somewhere Over the Rainbow, Cells Do Fly'), Hogle (chapter 'Ethical Ambiguities: Emerging

Models of Donor–Researcher Relations in the Induced Pluripotent Stem Cells'), and Middlebrooks and Shimono (chapter 'Staging Scientific Selves and Pluripotent Cells in South Korea and Japan') illustrate the regulatory and ethical precarities as well as glimpses of emerging new stability in vastly different contexts in the United Kingdom, the United States, South Korea, and Japan.

Franklin argues that cell therapy and regenerative medicine are tied to translational ambitions seeking to deliver improved healthcare. These moves often manifest as 'pipeline models' of delivery and congregate around the discourse of 'impact'. Franklin shows that the pipeline idiom is 'inadequate to encompass the iterative, loping, and often circuitous realities of "translating" knowledge into products and applications'. Drawing on longitudinal ethnographic immersion and proactive conversations with cell-therapy advocates and stem cell researchers, she shows how, when discussions of impact are examined alongside humanities scholars, many common themes begin to emerge. Franklin calls for a move away from linear models of progress to incorporate 'churn', 'circularity', and 'conversations' as the 3Cs in the co-produced future of science and social science. In so arguing, she maps out the various 'intersections' between social and basic science. Franklin expertly troubles the irony underscoring 'promotional' and 'aspirational' idioms impeding 'the very flows they are allegedly designed to accelerate'. She argues that good solutions require a much more circular process. In the final analysis, she calls for better models than 'pipelines' and 'impact' to help appreciate the complexity of technological change. Following Franklin, we can argue that the current-event horizon of stem cell science is ironically birthing variegated rainbows. And perhaps if we fly high enough over the rainbow, a globalized consensus on how to culture, restrict, and circulate stem cell biogenetic entities might become realizable.

Hogle delves into the world of stem cell and regenerative-medicine governance. She examines the contemporary debates over regenerative-medicine implementation and governance in the context of emerging thinking on producing evidence in contemporary biosciences and medicine. She persuasively argues that stem cell and regenerative-medicine governance has largely been circumscribed by technological zones and limited to: what is or is not allowed by regulatory authorities in specific locales, what is or is not an ethical therapeutic application, and the variances across societies. She shows how this approach largely ignores intersections with economic, political, and other kinds of technological zones. Hogle makes a ground-breaking intervention by problematizing the category of evidence itself. She shows how stem cells upset stable categories set forth by evidence-based medicine and policy because of their 'complexity and recalcitrance to existing ways of measuring evidence'.

Hogle offers a fascinating insight into the current state of flux where the following are ongoing: a shift toward patient-generated data and patient entitlements to choose experimental treatments; a push to speed up product approvals circumscribed by differing attitudes toward risk and patients' roles in decision-making; an uptake of new techniques such as Big Data analytics and predictive computation that aid economic calculations for systems as a whole well beyond the production of data for specific innovations; and actions built on platforms serving broader political and economic purposes. In this climate of change she rightly impels us to ask what work we are expecting evidence to do in the ethically ambiguous stem cell terrain.

Middlebrooks and Hazuki explore how prominent Japanese and South Korean scientists Obokata Haruko's and Hwang Woo-suk's public personas and self-presentations produced the credibility of their stem cell research narratives. The chapter offers a gripping account of ways in which extensive media coverage of both scientists' stem cell successes and subsequent stem cell research scandals dovetailed their public personas to the 'ontological possibility of their promised stem cells in fluid yet persistently gendered ways'. Middlebrooks and Hazuki argue that the Stimulus-Triggered Acquisition of Pluripotency stem cell research scandal in Japan and the human embryonic somatic cell nucleus transfer or cloned stem cell research scandal in South Korea link the perceived integrity of mass-mediated scientific personas with the 'integrate-ability' of their stem cell research results. The chapter lays bare the vulnerability of ethical and regulatory oversight in the face of stage-managed 'scientific selves' via personalized public performances in sustaining public support for stem cell science.

The second thematic segment takes the reader into the biomedical terrain of human embryonic stem cell innovation in India. Despite much promissory hope and hype invested in therapeutic viability in the Euro-American formations, the Indian example complicates our understanding of stem cell therapies in a globalized research system. Shroff, through her extensive work treating spinal cord injury with hESCs, argues how despite their great potential in curing chronic conditions such as spinal cord injury (SCI), hESCs have not been used extensively in humans. She shows that current research on treatment options for traumatic SCI aims at regaining the lost functions of the spinal cord by promoting remyelination (material surrounding nerves) with oligodendrocytes (concerned with the production of myelin [an insulating sheath around many nerve fibers] in the central nervous system) and formation of neurons. The case studies detailed in this chapter are the first of their kind to demonstrate the adequate efficacy of hESCs in SCI patients with a good tolerability profile. Shroff draws on accumulated data to show how patients gained voluntary movement of the areas below the levels of injury as well as improvements in bladder and bowel sensation and control, gait, and handgrip. The chapter offers potentially landmark insights into the therapeutic potential of largely misunderstood hESC transplantation in SCI patients.

After seeing a successful hESC case at a conference in Germany, Hopf-Seidel accompanied 12 patients from 20 to 73 years of age with chronic conditions such as Lyme, amyotrophic laterals sclerosis, arthritis, and macular degeneration to India for treatment. Faced with intractable and debilitating conditions in her patients, she recommended pre-blastomeric embryonic stem cell therapy in India. The chapter details the outcome of three intensive trips to the clinic between 2012 and 2014 with patients who could not experience any improvement through previous conventional medical treatments. The chapter traces the journey and illustrates the outcomes based on photographic and biomedical evidence gathered on these trips and subsequent follow-ups in Germany.

The third and final segment takes us into the world of patient positions on stem cells. Singh as well as Davis and Davis show in their respective chapters how these positions offer literal examples of patience and resilience, while Appleton and Bharadwaj draw on patient and practitioner experiences in the larger context of engineered shifts in the Indian policy landscape.

The notion of ‘active parent’ blurs the lines between parental and professional activism. Singh explores this complex intersection to show how active parents and parental activism intersect to produce a unique biography of an emerging stem cell intervention. The chapter documents the personal journey of Singh as a working professional who took on the seemingly impossible task of finding a cure for his four-year-old son, who in 2005 was diagnosed with Duchenne Muscular Dystrophy, a muscle-wasting condition. The chapter traces the deeply personal account of accepting, resisting, and rejecting the diagnosis and the intractable finality it presented. This account emerges from an autobiographical space and narrates the birth of an ‘active parent’ who with 10 other ‘active parents’ (connected to more than 200 parents) took on the challenge of finding an adipose stem cell-based cure. The chapter charts the failures and successes on the path to directing and driving the study and how parents coped with the demands of laying down the complete study protocols through to ensuring the safety and efficacy of the study to secure some semblance of therapeutic value for their children.

When Shannon Davis became quadriplegic after a devastating and life-altering car accident, she sought treatment in India from Dr. Shroff. In the first three months of treatment, Shannon showed improvement in all muscle groups and was able to stand upright with leg and abdominal calipers for longer and longer periods. In this chapter, the Davises argue that while the potential of stem cells to transform medicine will be a reality one day, for families in need of help today (or yesterday), the urgency to make decisions plays a critical role. The account shows how parents of desperately ill or injured children, especially those for whom no established treatment exists, search for and are often willing to engage in treatments in far corners of the world with potential positive outcomes. In the final analysis, they share the process of their travel to India and the experience of receiving positive results via human embryonic stem cell treatment.

Appleton and Bharadwaj show that the fraught and contested terrain of stem cell research and therapies is an undulating landscape of utopias and dystopias. While dystopic scenarios of stem cell research and therapy in unregulated and unregimented nation-states include fear of mass epidemics of cancerous growths in uninsured, ill-informed, and gullible patients, the utopic scenario imagines personalized medicine without multi-national pharmaceutical profit motivations or leading hospitals and physicians acting as gatekeepers for accessible care. Extending the tropic notion of 'biocrossing' (Bharadwaj 2008), the chapter articulates the faint traces of utopic and dystopic logics underscoring these 'crossings' and the evolving biography of a contested terrain this (re)scripts. Appleton and Bharadwaj engage with ethnographic immersion into the lives of physicians, researchers, policymakers, and patients to conceptualize evolving scenarios that remain divergent and yet the source of emergent but shifting utopias and dystopias that often are experienced as a heterotopia.

* * *

This book produces a unique account of the emerging research/therapy interface in order to explicate the high-risk and high-gain production of stem cell biotechnologies around the globe. The collection situates these developments in the context of larger global developments, most notably, the United States, Europe, and Asia to excavate the multi-national and multi-sited nature of contentious innovation culturing the stem cell technology landscape. Our hope is to provide an insightful account detailing arenas of stem cell research; local and global trajectories of therapeutic application and scientific collaborations; lines of public- and private-sector intersections; zones of ethical contestation; implications for private- and public-sector investments in science and biotechnology; and the tenuous nature of governance and its implications for both Euro-American science and burgeoning regenerative biotechnology sectors in India. In other words, this book is small but has big aspirations. It's a dialogue across cultures: social sciences and biosciences, Indian science and Euro-American science, clinical scientists providing stem cell care, and patients embodying these scientific breakthroughs. The common denominator is the word 'science': it brings us together, binds us together. While science is curiosity and the pursuit of knowledge and ideas, our points of departure and cultures of practice are deeply informed by how and where we are located: institutionally, culturally, as well as geographically. Much like stem cells and their regenerative capacity, our work practices and thought processes also gestate in a distinct cultural medium. Our sincere hope is that this book will be the starting point of a unique mixing of cultures seemingly removed from each other. It seeks to inaugurate a conversation across disciplinary and national boundaries and share outcomes of research-led understanding and interdisciplinary collaborations. While we remain embedded in our respective cultures of knowing, problem-solving and playing to our inimitable strengths and unique approaches to understanding the cellular form would, I strongly feel, succeed in enabling a shared understanding of what collaborative effort can achieve. It is in this spirit of collaboration and common interest in the cellular form that we ought to attempt moving forward.

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Aditya Bharadwaj is a professor at the Graduate Institute of International and Development Studies, Geneva. He moved to the Graduate Institute, Geneva, in January 2013, after completing seven years as a lecturer and later as a senior lecturer at the School of Social and Political Studies at the University of Edinburgh. He received his doctoral degree from the University of Bristol and spent more than three years as a postdoctoral research fellow at Cardiff University before moving to the University of Edinburgh in 2005. His principal research interest is in the area of assisted reproductive, genetic, and stem cell biotechnologies and their rapid spread in diverse global locales. In 2013, he was awarded a European Research Council Consolidator Grant to examine the burgeoning rise of stem cell biotechnologies in India. Bharadwaj's work has been published in peer-reviewed journals such as *Medical Anthropology*; *Ethnos*; *BioSocieties*; *Social Science & Medicine*; *Anthropology & Medicine*; *Health, Risk & Society*; and *Culture, Medicine and Psychiatry* and he has contributed several chapters to edited collections. He has co-authored *Risky Relations, Family Kinship and the New Genetics* (2006) and is the lead author of *Local Cells, Global Science: The Proliferation of Stem Cell Technologies in India* (2009). His sole-authored research monograph is titled *Conceptions: Infertility and Procreative Technologies in India* (2016).