INTRODUCTION

LIGHTS BLAZING AND SIRENS SCREAMING, the honor convoy of fire engines and ambulances launched Jeff Dunn on his transnational quest for medical treatment. The thirty-three-year-old Colorado firefighter and his wife, Cyrilla, were bound for China’s capital city, leaving their toddler son in safekeeping as they embarked on their biomedical odyssey. Jeff had been diagnosed a year earlier with amyotrophic lateral sclerosis (ALS), the same disease that had terminated the lives of American baseball star Lou Gehrig and allegedly China’s revolutionary leader Mao Zedong. ALS was a death sentence inexorably taking away the firefighter’s ability to walk, talk, and ultimately breathe. Jeff’s American doctors had told him that there was no cure for the disease that was destroying the motor neurons in his brain and spinal cord. All they could offer him was a bottle of Rilutek—the only FDA-approved treatment for ALS—that slowed the course of the neurodegenerative disease by a few months at a cost of thousands of dollars. Jeff’s doctors advised him to complete a last will and testament. They sent him home with a prescription for sleeping pills.

Jeff was now traveling six thousand miles from his home to seek an experimental therapy devised by a neurosurgeon in Beijing—and blogging each step of the way about the procedure that would transplant fetal olfactory bulb cells into the deteriorating corona radiata (white matter) of his brain. Jeff’s fellow firefighters and paramedics had set up a blog on their official brigade website to raise awareness about their comrade’s plight. Initially a way to solicit donations for Jeff to help him manage the fatal disease, the blog had now become Jeff’s digital lifeline to his friends and family back home as he journeyed halfway around the world.

Jeff was not alone in his quest for treatment. Galvanized by the potential of fetal cells to regenerate damaged neurons and restore lost bodily functions, thousands of people from more than eighty countries have journeyed to China since 2001 to undergo experimental treatment. Despite the warnings of doctors and scientists back home, hundreds of people paralyzed by spinal cord injuries and brain damage have sought fetal cell transplantation in Beijing, including a
teenager from California who had broken his back snowboarding, a middle-aged man from Istanbul who had fallen sixty feet down an empty elevator shaft, a young lawyer from the Philippines crippled in a motor vehicle accident, a salaryman from Japan struck down by a stroke, and a three-year-old girl from Romania born with cerebral palsy. Hundreds more suffering from neurodegenerative disorders like Jeff have staked their lives on this experimental therapy, including a golf pro from Florida trying to maintain his weakening grip, a newspaper columnist from Utrecht seeking more time with her family, a police officer from Belgium immobilized in a wheelchair, and a schoolteacher from Italy rendered speechless by ALS. I met these people and many more online and in Beijing, all with individual biographies of busy lives arrested by disease or injury.

This book is an ethnographic account of these biomedical odysseys, of why and how people like Jeff—and Derek, Nedim, Michael, Takeshi, Denisa, Doug, Loes, Patrick, and Maria—have entrusted their bodies to Chinese neurosurgeons operating on the cutting edge of experimental medicine. I invoke the metaphor of “cutting edge” in three distinct ways throughout the book: to suggest the latest advances in biomedical science, to focus attention on the embodied experiences of surgical intervention, and to allude to the borderline nature of experimental therapies occurring at the limits of ethics and legality. In a world in which technologies and risks are moving faster than our ethics and laws can keep pace, we need to take a closer look at what we mean by “cutting edge” medicine by examining the experiences of those on the front lines of these experimental developments.

The easy story here is the standard one of exploitation: of desperate patients duped by medical charlatans peddling false hope with their quack therapies. This is the story reiterated by journalists, international medical experts, and other outside critics—but challenged repeatedly by thousands of patients whose very lives are at stake and the Chinese neurosurgeons who have cared for them. This book follows these patients and clinicians from online discussion forums to Chinese hospital wards in order to understand the hopes, frustrations, and possibilities that experimental therapies offer those living with conditions deemed incurable. I bracket my own normative impulse and delve beneath headline news hyperbole in order to investigate the core issues from the diverse perspectives of the participants involved. What convinced Jeff to travel halfway around the world to undergo experimental surgery? What prompted his Chinese neurosurgeons to try out laboratory procedures on human patients? What motivated the Chinese clinic staff—nurses, neurologists, acupuncturists, scientific researchers, information technology specialists, patient coordinators, custodial workers—to work in this experimental setting? Focusing on the participants’ perspectives is a necessary methodological and ethical position for studying such a fraught phenomenon in which the stakes are so high.

For people whose futures have been cut short by diagnoses of paralysis and degeneration, what does it mean to take their hopes seriously? Although some
patients lived in suburban housing tracts while others inhabited crowded ten-
ments, some were long retired while a few had barely begun life, some had never
flown on an airplane before while others frequented business class lounges, they
all shared similar stories of frustration from their fruitless encounters with the
medical establishment back home. Written off by busy doctors and insurance
companies, these patients and their families had turned to the Internet to pursue
alternative possibilities. Through online discussion forums, email listservs, pa-
tient blogs, and other social media channels, they had discovered a new fetal cell
transplantation surgery in Beijing. By undergoing an experimental procedure
in a foreign country, each of these medical pioneers was seeking to overturn the
prevailing medical consensus that had written them off as hopeless cases.

Facing the limits of conventional medicine and regulation in their home
countries, they have not acquiesced to what others consider the inevitable:
resignation, hopelessness, death. In the face of overwhelming neurological
catastrophes, their hopes have oriented them to life. Their orientation toward
a hopeful future is particularly significant given the expanding politics of resig-
nation following in the wake of corporate capitalism around the world (Benson
and Kirsch 2010). Instead of giving up, they have tried to maintain what phi-
losopher Ernst Bloch (1986 [1959]) has described as the “not-yet,” an orienta-
tion toward what has not yet come into being. Bloch’s work focuses attention on
the temporal dimensions of hope in generating desires about the future. I bring
this inquiry specifically into the realm of Internet-mediated health, seeking to
examine how the differential chronicity of illness experiences intersects with the
temporal variability of digital communication technologies.

In the chapters that follow, I develop an anthropology of transnational re-
generative medicine that documents how hope is produced and troubled both
online and through physical encounters with experimental therapies transpir-
ing on the fringes of biomedicine. By framing hope as an important affect or-
ganizing human engagements with “cutting edge” medicine, I seek to recast our
understanding of the experimental in light of a changing political and moral
economy in China that enables novel medical practices. I demonstrate how
the production of hope is entangled in differences in ethical values, regulatory
frameworks, and politico-economic histories that stoke border-crossing quests
for regenerative medicine.

THEORIZING A NEW BIOLOGY OF HOPE

As technological innovations enable alternate futures and the processes of glo-
balization accelerate contact between people in far-flung corners of the world,
new social relations and subjectivities have emerged that extend far beyond
the conventional dyad of the doctor-patient relationship. The new forms of
social experience coalescing around biomedical technologies and therapies of-
er us a critical opportunity to explore the interactions between biological and
cultural processes. Researchers studying the social uses of DNA have highlighted the new relationships and subjectivities engendered by genetic knowledge (Rabinow 1996, 1999; Simpson 2000; Novas and Rose 2000; Rapp, Heath, and Taussig 2001; Lee, Mountain, and Koenig 2001; Rose 2007; Wagner 2008; Sleeboom-Faulkner 2010; Montoya 2011; TallBear 2013). But more than half a century after James Watson and Francis Crick discovered the chemical structure of DNA (in 1953) and over a decade since the completion of the Human Genome Project (in 2003), new modes of analysis are being devised as scientists move beyond sequencing DNA and identifying genes to integrating them with the cellular mechanisms of life. In his testimony supporting stem cell research before the U.S. Senate Committee on Health, Education, Labor and Pensions on September 5, 2001, Harvard biologist Douglas Melton (founding director of the Harvard Stem Cell Institute) urged senators to remember that “the unit of life is not DNA nor the gene, but rather the unit of life is the cell. . . . Whereas the last century of biology can be said to have focused on the gene and the sequence of DNA, I believe this century will see biologists come to understand and harness the unit of life: the cell, specifically stem cells” (Melton 2001). Social scientists working at the intersection of anthropology and science studies have examined the ramifications of these new cellular forms of life in the contexts of laboratory culture (Landecker 2007; Hogle 2010), animal cloning (Franklin 2007), and assisted conception (Franklin 2013).

As the cell displaces the gene as the central unit of analysis for both biomedical researchers and social scientists in the twenty-first century, we need to rethink how an alternative form of biological knowledge is reshaping human relations and futures. Two decades ago, Paul Rabinow (1996, 1999) launched a deluge of exciting anthropological scholarship on the formation of new collectivities around shared genetic markers. But what different forms of biosociality emerge when we shift our analytical focus from deterministic “markers of identity” to dreams of “pluripotency”? As Aditya Bharadwaj notes in his comprehensive review of anthropological engagements with stem cells in the first decade of the new millennium, a proliferating body of anthropological work has begun to recognize the importance of “theoretically unpack[ing] and ethnographically illustrat[ing] cultures of stem cells both as a medium for gestating cellular form as well as a new medium for exploring ideas about life, knowledge, commerce, governance, and ethics” (2012, 304–5). Rather than the splintering of divergent interest groups along various genetic differences and restriction loci, I argue in this book that the hope embodied by emerging cellular therapies is rallying together disparate groups that may never have come into contact otherwise—from Beijing nurses and former mayors in South Dakota to Kuwaiti princes, Dutch grandmothers, and military-trained Chinese surgeons.

While the Human Genome Project engendered metaphors of a “master plan” or “the book of life” determining our identity (Nelkin and Lindee 2004 [1995]; Kay 2000; Fox Keller 2000), regenerative medicine in the twenty-first century
INTRODUCTION

offers a different outlook on human life. Stem cell science and its application in regenerative medicine promise the exciting possibility of transforming our destinies. Endowed with the twin capacities of renewing themselves and differentiating into other cell types in the body (the scientific definition of “pluripotency”), stem cells have proliferated in scientific, economic, and social imaginations. Described as “one of the most fascinating areas of contemporary biology” by the National Institutes of Health (2015), stem cells hold enormous potential for unlocking the secrets of embryonic development and for restoring diseased, damaged, or aging cells and tissues in the human body—the holy grail of the broader field of regenerative medicine. In a fact sheet intended to educate the public on the past, present, and future of regenerative medicine, the U.S. National Institutes of Health (2010) asks us to “imagine a world where there is no donor organ shortage, where victims of spinal cord injuries can walk, and where weakened hearts are replaced. This is the long-term promise of regenerative medicine.” The power of the stem cell thus lies in its potential—from producing neurons to generating new organs and replacing failing body parts. As a creative entity with the capacity of transforming itself into seemingly endless possibilities, the stem cell can be understood as the biological instantiation of hope itself.

Hope has been a key analytic for social scientists who study biomedicine and biotechnology. Drawing on her work on the culture of American clinical oncology, Mary-Jo DelVecchio Good suggests that the “political economy of hope” (Good et al. 1990) generated by biotechnology envelops all of us in a “biotechnical embrace” (Good 2001) that leads patients suffering from cancer to pursue experimental therapies and encourages nations to invest billions in medical research. Carlos Novas (2006) examines the “capitalization” of hope by analyzing the efforts of patient advocacy groups that have accelerated research initiatives for rare genetic disorders. Comparing the genomics research industry in the United States and India, Kaushik Sunder Rajan (2006) has articulated the “promissory horizon” of biotechnology as both a “therapeutic realization” on the level of personalized medicine and a “commercial realization” for corporate, academic, and state actors. These approaches emphasize both the financial and affective dimensions of biotechnology by showing how hope in the possibility of a cure is linked to the public and private funding of research, the professional ambitions of scientist-clinicians, the business dreams of entrepreneurs, and the subjective experiences of patients and their families.

The proliferation of clinics offering experimental stem and fetal cell therapies in China capitalizes on the biological potentiality to sell imagined futures in which damaged tissue may be regenerated, lost function may be regained, and previously irreparable organs may even heal themselves. For patients from North America and Europe, these new forms of experimental biomedicine circulating in China leverage their expectations of familiarity for biomedical treatment with the radical othering of a different cultural, legal, and ethical context to produce new horizons of hope. While pursuing the latest technological advances
in regenerative medicine abroad, these patients simultaneously circumvent the legal restrictions and ethical qualms stymieing stem and fetal cell research in their home countries. These experimental fields of activity ultimately deepen our understanding of the political and moral economy of hope by illuminating the ways in which regenerative medicine intersects with technology, travel, and the political economies of health care and medical research in a global era.

THE GEOPOLITICS OF STEM CELL SCIENCE AND FETAL TISSUE RESEARCH

The biomedical odysseys documented in this book have been enabled by differing political climates, regulatory regimes, religious values, ethical controversies, and financial considerations in various countries. In Europe, a diverse regulatory continuum has ranged from the outright ban of research on embryos in Austria (Austrian Bioethics Commission 2009), to the criminalization of embryonic stem cell derivation within German borders but permission to import cell lines from other countries (Germany Federal Law Gazette 2002), to British authorization for creating human embryos for research purposes including cloning (United Kingdom 2008). The Catholic Church has played a key role in exerting political pressure on European Parliament members to oppose the use of human embryos in medical science (Pontifical Academy for Life 2000; Minkenberg 2002; Salter and Salter 2007).

In the United States, advances in stem cell science have collided with political and religious controversies surrounding the moral status of the embryo. Although American researchers were the first to cultivate human embryonic stem cell lines successfully in 1998 (Thomson et al. 1998; Shamblott et al. 1998), the excitement surrounding the therapeutic potential of stem cell science ran headlong into President George W. Bush’s 2001 executive order restricting federal funding for stem cell research involving the destruction of human embryos (Bush 2001). Although individual states—most notably California (Benjamin 2013; Thompson 2013)—tried to fill the gaps with state-level funding initiatives, the restrictive federal policies stoked fears of a “brain drain” of stem cell researchers to other countries with more welcoming policies (Kahn 2001; BBC 2001; Watt 2006; Longstaff et al. 2013; Thompson 2013). Scientists have not been the only ones looking beyond American borders. The therapeutic potential of stem cells has conjured up previously unimaginable hope for suffering patients awaiting regeneration and repair of damaged body parts. Frustrated by regulatory restrictions and the slow pace of research, increasing numbers of American patients have decided to take matters into their own hands by traveling abroad to other countries such as China to obtain experimental fetal and stem cell therapies.

While pro-life lobbyists, religious fundamentalists, and “compassionate” conservatives have stymied stem cell research in the United States, the prospects for regenerative medicine look very different from the perspective of a country
INTRODUCTION

where abortion is a routine practice and where atheism itself is the reigning paradigm of the ruling party. Responding to American religious and regulatory scruples constraining research on human embryos and fetuses, Chinese scientists and clinicians have leveraged a different ethical and legal terrain to offer experimental therapies not possible in the United States (Song 2011; Zhang 2012; Rosemann 2013; Sui and Sleeboom-Faulkner 2015).

The practice of radically new and potentially dangerous therapeutic interventions in China has emerged at a particular historical moment, as a market-driven development agenda collides with the remnants of socialist ideology. From “serving the people” (为人民服务 wèi rénmín fúwù) to “getting rich is glorious” (致富光荣 zhìfù guāngróng), Chinese healthcare workers have found themselves caught between conflicting ideological slogans and institutional practices from different political eras. As the former emphasis on preventive medicine during Mao’s era of collectivism has given way to a market-driven push for high-tech interventions and financial profitability, Chinese clinicians have faced increasing threats to their professional identities and their very livelihoods. These economic and political changes have heightened doctors’ anxiety and sense of besiegement, but they have also enabled unparalleled opportunities for profit-making and success. Accelerating privatization (Zhang and Ong 2008) and a growing sense of moral crisis (Kleinman et al. 2011) in the twenty-first century are transforming entrepreneurial medicine in urban China on a transnational scale.

The Chinese party-state has sought to promote “scientific and technological modernization” (科学技术现代化 kēxué jìshù xiàndàihuà) as the engine for economic growth and its source of political legitimacy, encouraging scientists and clinicians to experiment with innovative medical therapies. The hype over stem cells and regenerative medicine has created new futures and careers for ambitious Chinese neurosurgeons and other health care professionals in China’s urban metropolises. These urban clinicians interpret experimental medical interventions for foreign patients as their ticket to personal survival and professional success in an uncertain environment where increasingly profit-driven hospitals and restructured government priorities have left former state-employed medical workers to fend for themselves.

Differences in ethical values, regulatory frameworks, and politico-economic histories between China and other countries have enabled shrewd Chinese clinicians to attract patients from around the world. These transnational variations have opened up new promissory horizons for these clinicians and their foreign patients—who may not be willing or able to wait for the uncertain course of biomedical research to wind its way through years of animal testing and multi-stage clinical trials. Yet these same differences have also served as fodder for critique. Charis Thompson observes that the American scientific community has dismissed stem cell tourism as an “off-shore hazard to good science” marketed by “rogue” clinicians (2013, 118)—but she points out that “a rhetoric of
East versus West, or good versus bad science is much too crude and inaccurate (and, to many, offensive) to capture the geopolitics of the science or the ethics” (2013, 148). As ambitious Chinese clinicians have “surged ahead”\(^\text{18}\) of their more constrained and cautious counterparts in North America and Europe, they have faced accusations of being charlatans who exploit desperate patients. Margaret Sleeboom-Faulkner and colleagues (2016, 241) have also challenged these “hackneyed” dichotomies, noting that the stark delineation between “bona fide science” and “snake oil traders” operates as a form of “boundary work” (Gieryn 1983) that establishes epistemic authority and claims scientific integrity for a small group of elite researchers while dismissing the rest. These suspicions must also be situated against broader anxieties about academic fraud (Lancet 2010; Economist 2013; Hvistendahl 2015) and contaminated foods and medicines (Chen 2014) plaguing intellectual and material production in China. Given these serious concerns, why have thousands of patients from around the world undergone experimental stem and fetal cell transplantation in China? My book takes on this question by following the science out of the lab and into hospital wards in order to examine the embodied dynamics and lived experience of clinical experimentation. I leverage an ethnographic perspective based on long-term, situated fieldwork to illuminate the stories and life trajectories of patients and clinicians on the front lines of regenerative medicine.

**FETAL CELL EXPERIMENTS IN CHINA**

The experimental fetal cell therapy sought by Jeff and thousands of other patients suffering from neurodegenerative conditions—and the central focus of this book—was developed by Dr. Huang Hongyun, a military-trained neurosurgeon based in Beijing. His experimental procedure involved injecting a suspension of cultured fetal cells around the area of neurological damage. The injected fetal cells were a special type of nerve support cell extracted from the olfactory bulbs of aborted human fetuses, a controversial source I will describe in more detail in subsequent chapters.\(^\text{19}\) These olfactory ensheathing glial (OEG) cells had shown potential in laboratory experiments he had conducted as a postdoctoral researcher in the United States for restoring functional recovery in rats after spinal cord injury. Dr. Huang began testing this experimental therapy on Chinese patients with spinal cord injuries upon his return to the Naval General Hospital in Beijing in 2001. His initial clinical successes enabled him to move to a larger public hospital and eventually to set up his own regenerative medicine clinic based in a rehabilitation hospital in western Beijing.

Dr. Huang’s experimental fetal cell therapy has garnered extensive attention from media outlets around the world, including China Central Television (CCTV 2002), the *Wall Street Journal* (Regalado 2004), *TIME* magazine (Forney 2004), the *New Zealand Herald* (Macbrayne and Rowan 2005), and the Madrid-based daily newspaper *ABC* (Mediavilla 2006), as well as prestigious scientific journals.
such as *Nature* (Cyranoski 2005) and the *New England Journal of Medicine* (whose editor-in-chief, Jeffrey Drazen, paid a personal visit to the Chinese neurosurgery clinic in March 2005). Many of these news reports emphasized the high hopes of patients, publishing glowing praise from the neurosurgeon's satisfied customers from around the world: “My husband’s tremors ceased the day after surgery. He could shave by himself. He was ecstatic. My husband could barely talk, swallow or drink. Now he can do all of that,” declared one American patient’s wife to the Beijing bureau chief for Knight Ridder Newspapers, whose story was picked up by newspapers throughout North America (Johnson 2004). Other accounts portrayed the neurosurgeon with skeptical caution, suggesting that the procedure smacked of quackery: “Snake oil is not too strong a word,” warned a disapproving neurologist at Northwestern University quoted in the *Chicago Tribune* (Lev 2004). Much of the media coverage oscillated between these extremes. As a journalist for London-based newspaper the *Guardian* proclaimed with biblical excess:

They come to him in search of miracles. The lame, the sick and the dying; young and old; Christians from the US, Muslims from the Middle East, Buddhists from Japan, agnostics from Europe. Some have been in wheelchairs for years and believe he can help them walk; others are kept alive by respirators, yet hope he can make them breathe. The voiceless have heard he can bring them speech. The terminally ill seek nothing less than more life. In many cases doctors and friends advise them to stay at home, not to waste their money, and warn them of potential risks. For they come in search of one of the most pioneering—and controversial—medical procedures on the planet: the injection of cells from aborted foetuses into the brains and spines of the sick. And the object of their faith is a Chinese surgeon who spent many of his university years labouring as a peasant and is now conducting trial-and-error experiments on live subjects despite his research being rejected by the western medical establishment. (Watts 2004)

Dramatizing the life-and-death stakes of the controversial Chinese medical procedure, international media coverage tended to fluctuate between giddy talk of miracles and dire warnings about apocalyptic consequences. But the patients, caregivers, and medical professionals I met in the hallways of New Century Hospital avoided these sensational terms in describing their experiences. Most of the foreign patients preferred instead to speak about “small victories” and the incremental steps toward recovery they hoped to make: improvements in finger dexterity so they could grasp utensils and feed themselves; increased sensation in order to feel the touch of loved ones. This focus on the ordinary activities that their injuries and illnesses had disrupted rather than the sensational aspects of the procedure provided patients and their families with a practical framework for incorporating their extraordinary experiences in China into their everyday lives.
I follow these patients’ lead by focusing on the everyday dimensions of hope that materialize in the grounded interactions of transnational biomedicine, from online debates about the efficacy of experimental fetal cell therapies to cross-cultural miscommunications on the operating table. Both patients and clinicians deploy hope in experimental medicine as a survival tactic to transcend the uncertainties threatening their lives and futures. The proliferation of high-tech therapies in China has become a fount of hope for patients worldwide suffering from conditions that have been written off as incurable in their home countries. But those who have entrusted their bodies to Chinese clinics such as New Century have had to reconcile the elusive promises of regenerative medicine with the corporeal experiences of undergoing experimental surgical procedures while navigating an unfamiliar health care system. Meanwhile, the allure of biotechnology and the globalization of medicine have also created new futures and careers for ambitious Chinese neurosurgeons and other health care professionals. The transformation of health care into a business, combined with an unpredictable regulatory landscape, has encouraged urban Chinese surgeons to experiment with lucrative biomedical interventions with uncertain therapeutic efficacy.

The Chinese fetal cell therapies I examine in this book can be considered experimental from both a biological and a regulatory perspective. On the biological level, Chinese clinicians are translating laboratory findings into novel forms of care as their foreign patients try out therapeutic innovations and develop new methods of self-tracking to monitor potential neurological change and functional recovery. This field of experimental activity in the biological realm is simultaneously accompanied by experimentation on the regulatory level as Chinese clinicians and their foreign patients engage in bureaucratic forms of practice that mitigate regulatory scrutiny and deflect charges of illegality. While Adriana Petryna (2009) maps out the contours of experimentality emerging from the opportunistic activities of pharmaceutical corporations offshoring their clinical trials industry to poorer countries, my ethnographic materials demand a different theoretical and ethical intervention on the experimental.

For people around the world with incurable neurodegenerative conditions who actively seek experimental cellular therapies in Beijing, the ethics, science, and politics underlying their transnational odysseys are not so clear-cut. As we will see in the following chapters, enterprising Chinese neurosurgeons and foreign health care seekers are coming together in new configurations and in new spaces, both online and in clinical settings in China’s urban metropolises. Their encounters at the margins of medicine vividly capture the hopes engendered by new biomedical and communication technologies. By tracking these biomedical odysseys from cyberspace to China, my goal is to illuminate the moral, socioeconomic, and geopolitical fault lines of hope at the limits of medicine.
This book is based on a decade of ethnographic research on experimental stem and fetal cell therapies in China, including twenty-eight months of sustained fieldwork in Beijing conducted between 2004 and 2007 and several shorter research trips to various sites of experimental medicine in urban China carried out through 2015. The chapters that follow provide a detailed account of one of the most successful experimental regenerative medicine clinics to date: the New Century Hospital Neurological Disorders Research and Treatment Center in Beijing. Located in Shijingshan district on the western outskirts of China’s capital city, this experimental neurosurgery clinic was housed in a former worker’s sanatorium, hoping to become a state-of-the-art rehabilitation hospital. Typical of other state-owned health facilities in post-Deng China, New Century Hospital faced growing budget deficits at the beginning of the new millennium that encouraged hospital administrators to remake the neglected health facility into a profitable institution that could provide advanced medical services and new technologies to more lucrative patrons. Recruiting Dr. Huang Hongyun, the neurosurgeon sought out by Jeff and eventually thousands of other non-Chinese patients, to set up a regenerative medicine clinic played a key role in the hospital’s revamped agenda.

The New Century Neurological Disorders Research and Treatment Center provided a crucial vantage point for researching the transnational dimensions of experimental medical treatment. Nearly two thousand people from more than eighty countries around the world have undergone Dr. Huang’s fetal cell therapy procedure since 2001 (figure 1.1). As a Chinese American anthropologist who spoke English and Mandarin fluently, I focused primarily on the experiences of the Chinese staff (including doctors, nurses, scientists, and administrative workers) and their English-speaking patients. With the help of dog-eared dictionaries, digital translation software, and interpreters, I also interacted with people of many other linguistic backgrounds seeking treatment in Beijing. By the time I started conducting my fieldwork, Dr. Huang had decided to focus almost exclusively on foreigners and treated very few Chinese patients at New Century Hospital. As I will explain later in the book, this focus on foreign patients reflected local institutional and financial motivations as well as larger geopolitical processes.

My ethnographic research methods at New Century Hospital included participant observation, formal and informal interviews, surveys, and textual analysis of medical and scientific documents. As other anthropologists who have worked intensively in clinical settings have illustrated so vividly (Garcia 2010; Livingston 2012), my work with the Chinese staff and foreign patients entailed forms of engagement that extended beyond the confines of a typical workday. I shared an office on the patient ward with a junior neurosurgeon and a neurologist, often keeping them company as they worked late into the night past their
Figure 1.1. Geographic distribution of Chinese neurosurgeon Huang Hongyun’s fetal cell therapy recipients by country of origin (map designed by Oikeat Lam).
scheduled hours. I lived in a two-room apartment in the hospital dormitory with the clinic’s acupuncturist and the head cleaning woman, which enabled me to experience the dimensions of off-duty life for the clinic’s employees. My proximity meant that I was called in at all hours to help nurses straighten out garbled “Chinglish” instructions to their foreign patients, plan impromptu shopping trips with foreign caregivers who had run out of snacks and entertainment options in the secluded hospital, coach administrative staff on their American pop culture know-how, place orders for digital pulse oximeters and mechanical ventilators, and edit research papers the clinical staff hoped to submit to prestigious international medical journals.

I complemented my research at New Century Hospital with shorter periods of participant observation at several other sites of elite high-tech medicine in China conducted between 2004 and 2015. These sites included the emergency department and “special needs” outpatient center at one of Beijing’s most prestigious hospitals, a VIP treatment ward of a public hospital that was rented out to foreign businessmen in Shenzhen (China’s first designated Special Economic Zone located just across the border from Hong Kong), an elite neurosurgery ward devoted to foreign patients at a for-profit hospital that eventually went bankrupt in Qingdao (another coastal city granted more flexibility by the central Chinese state in setting market-oriented economic policies), an orthopedic surgery department in Shanghai (my work there included accompanying surgeons on follow-up visits to patients with spinal cord injuries in the Zhejiang countryside), and the China Spinal Cord Injury Network (a consortium of medical centers in mainland China, Taiwan, and Hong Kong funded by the Hong Kong Spinal Cord Injury Fund and managed by the Clinical Trial Centre at Hong Kong University).

Online activities figured prominently in the experiences of the foreign patients and caregivers who journeyed to China for high-tech therapies. I quickly discovered that almost every foreign family who came to Beijing remained in constant contact with relatives, friends, and even strangers back home and throughout the world—via the Internet. They posted updates about their cross-cultural encounters to online discussion forums, uploaded digital videos that documented their post-surgical changes to journalists tracking their progress for viewers back home, and vented their frustrations about language barriers and hospital food on their personal blogs. Although their online activities often got bogged down by slow connection speeds or were even blocked by Chinese Internet filters (as with most popular blog-hosting services), many patients and caregivers spent more time in front of their computer screens during their sojourns in Beijing than they did hanging out with their hospital ward neighbors in the communal activity room.

As their mediated experiences bear witness, the Internet is playing an increasingly significant role in the lives of Americans grappling with challenging disabilities and terminal illnesses. The Pew Internet and American Life Project
CHAPTER 1

has tracked the “online health care revolution” since 2000, calculating in its inaugural report that 52 million American adults searched online for health information (Fox and Rainie 2000). These numbers more than tripled a decade later (Fox 2011). Another national poll monitoring online health behavior since 1998 calculated that these “cyberchondriacs” comprised 74 percent of the American adult population in 2011 (HarrisInteractive 2011). Through the Internet, patients and their family members can obtain instant information on troubling symptoms from a variety of sources ranging from other patients’ blogs to clinician-managed health websites, advocacy organizations’ discussion forums, and pharmaceutical companies’ social media accounts.

The Internet is not just a source of information, however; it is also a mediator of social experience. By broadening access to information on an unprecedented level and bringing people in far-flung corners of the world into contact with each other, the Internet creates opportunities for new forms of social engagement. In the medical realm, ethnographers and digital media scholars have called attention to the Internet’s role in transforming patients and their caregivers into active participants in the quest for health. For example, people living with contested “sociomedical disorders” such as attention deficit hyperactivity disorder and chronic fatigue syndrome have taken control of their identities by sharing strategies online for dealing with medical bureaucracies unwilling to acknowledge their suffering (Dumit 2000, 2006). While living in a digitally mediated world can empower patients, it can also further entrench existing financial and technoscientific interests. The ability to access information online has intensified cancer patients’ emotional attachment to high-technology treatment options, fueling the lucrative American oncology enterprise (Good 2001).

More recently, digital mediation in the health realm has encompassed a growing trend for individuals to engage in self-tracking and quantification practices. From wristband activity trackers such as FitBit to patient-networking websites such as PatientsLikeMe.com, these new forms of digital mediation are leveraging patient-generated data to drive therapeutic regimens and medical innovation. Olivia Banner (2014) observes that these digital practices of self-quantification transform contested subjective experience into legitimate statistical data. By tracking changes to their physical and mental states online, women living with fibromyalgia and other contested conditions generate hard evidence not so easily dismissed by skeptical medical professionals. Banner argues that this type of “informatic subjecthood” (2014, 199) is ultimately a Foucauldian project that transforms these women into biomedicalized subjects, encouraging a cybersociality that enmeshes them in biomedical discourses.

 Whether emancipatory or hegemonic, these emergent forms of “biomediation” (Thacker 2004) warrant closer investigation as various biological conditions become increasingly refracted through digital modes of representation. As scholars of virtuality have noted, we must “disaggregate … the monolithic
medium called ‘Internet’” (Miller and Slater 2000, 14) into its component technologies in order to understand the complex dynamics of mediation. What we call the “Internet” serves as a convenient but obfuscating shorthand for an assemblage of technologies that enable but also constrain social action in particular ways. Seductive terms like the “World Wide Web” and “Information Superhighway” make it all too easy to take the “global reach” of the Internet for granted. But as Anna Tsing (2005) highlights with the metaphor of friction, these connections do not happen seamlessly. In order to understand how “global connections” emerge in practice, we need to take a closer look at how contingent alliances and unstable interactions shape health-based cyberspace networks. A key aspect of this analytical project involves understanding the form and function of specific digital technologies that underpin online activities, from web browsers and email clients to online forum platforms and blogging software. This approach dovetails with the “technological turn” characterizing studies of the virtual (Nardi 2015), which examines how specific properties of different technologies constrain and enable digital activity. These studies have also recognized the historical situatedness of these technologies, noting that the Internet of today is different from the Internet of a decade ago (Karpf 2012; Nardi 2015). As a loose collection of haphazardly connected nodes and affiliated technologies, the Internet enables a diversity of social practices, modes of representation, and forms of interaction that must be situated in historical and technological context.

Accounting for the online lives of my informants has demanded critical innovations in ethnographic methodology and writing practices in order to trace the emergence of new cultural forms and modes of biosociality online. When I first began researching digital health practices, Mark Zuckerberg had yet to launch Facebook. Although ethnographers were becoming interested in the social implications and methodological challenges posed by Internet communication technologies (cf. Markham 1998; Hakken 1999; Heath et al. 1999; Hine 2000; Miller and Slater 2000; Kendall 2002; Wilson and Peterson 2002; Sveningsson 2003), many of the foundational ethnographies and handbooks on virtual worlds and social media were yet to come (Taylor 2006; Boellstorff 2008; Fielding, Lee, and Blank 2008; Gershon 2010; Nardi 2010; Boellstorff et al. 2012; Horst and Miller 2012). The digitally mediated quests for experimental therapy that I analyze in this book began in 2001, several years before the advent of popular social media platforms such as Facebook in 2004, Twitter in 2006, and Instagram in 2010. Without the existence of major social media platforms dominating the market, patients in the early 2000s leveraged a wide assortment of online communication tools that I will examine in greater detail in the following pages. Over the past decade, I have logged thousands of hours online participating in health discussion forums devoted to neurodegenerative conditions, performing content analysis on the websites of hospitals and health regulatory agencies, and studying the blogs of patients and caregivers who have chronicled...
their experiences online. As I tracked the emergence of new cultural forms and modes of sociality online, the Internet became not only a crucial research tool but also a key subject in my ethnographic analysis.

The electronic archiving function of the Internet has given researchers unprecedented access to people’s online lives—and raises critical questions about the ethical dilemmas of conducting research and representing others in a digital age. Although I observed some discussions about experimental medical treatments in China as they occurred online, the archiving function of many Internet discussion forums enabled me to reconstruct conversations and debates that happened earlier. My research in cyberspace often resembled more archival sleuthing than conventional ethnography. Unlike survey respondents and interviewees who actively agree to participate in research studies and sign consent forms acknowledging their status as research subjects, some of these online denizens became inadvertent participants in my after-the-fact study of their digitized activities. I struggled with conflicting obligations of research: Should I credit my sources as authors in their own right? Or should I disguise their identities in order to protect them as vulnerable subjects?

In navigating the ethical and methodological challenges of conducting research online, I have chosen to cite the source of materials that were posted in the public domain in order to give due credit to authors who wrote eloquent narratives and detailed explanations that they clearly put much time into crafting. Of course others typed out less careful replies, often in the heat of an impassioned debate. Site administrators of one of the main online health discussion forums I analyzed warned members that “everything posted on public forums such as CareCure can be seen by anybody and is often archived elsewhere on the Internet” (Young 2007). In my quotations of publicly accessible forum discussions, I have thus attributed this material to the online noms de plume under which members have posted their messages, rather than disguising them with additional pseudonyms. Furthermore, I have reproduced quotations verbatim as they appeared online, without editing for grammar and spelling errors (with the exception of a few obvious typos that I corrected in order to improve readability). I also have kept the original punctuation and capitalization; quadriplegics using typing sticks controlled by their mouths often write in all lowercase letters since they can only press one key at a time. While some toil over multiple revisions of a single post, others dash off hasty replies in seconds, concerned more about getting their point across than following formal grammar rules. My goal is to capture the tenor of the online discussions as faithfully as possible in order to remind us of the embedded and embodied dimensions of Internet-mediated lived experience.

I recognize the fraught politics of knowledge production, in which my presence provides an additional degree of legitimacy to the experimental enterprises I describe in this book. Over the past decade, neurosurgeon Huang Hongyun has relished highlighting my institutional affiliations as an index for his own
status. Although he always called me Little Song (小宋 Xiǎo Sòng) during private conversations and among his staff members, he enjoyed referring to me as his “American brand-name university Ph.D.” (美国名牌大学博士 Měiguó míngpái dàxué bóshì) in front of visiting dignitaries—while toasting a municipal health official during a holiday banquet or shaking hands with a foreign scientist touring the facilities, for example. To resist being co-opted by other people’s agendas, I have thus chosen to use a selective mix of actual names, online screen names, and pseudonyms for the institutions and clinicians I discuss in this book. This has also served as a strategic way to balance often conflicting norms of scholarly acknowledgment and the protection of my interlocutors’ privacy. While determined readers may be able to deduce the identities of some of the pseudonymous individuals and institutions discussed in this book, I maintain the fiction of pseudonymity in order to keep their names from being indexed on search engines and out of general circulation. I do this for two important reasons: first, to avoid serving as an unwitting mouthpiece for these experimental clinics’ marketing departments, and second, to provide the involved parties with plausible deniability. Given the renewed crackdown on corruption and the growing censorship dragnet implemented by Chinese president Xi Jinping, anthropologists and our interlocutors working in China face heightened stakes of disclosure.

ORGANIZATION OF THE BOOK

The chapters that follow tell a story of how people facing devastating disabilities and terminal illnesses around the world have sought fetal cell transplantation surgery from enterprising neurosurgeons in China.26 As I have already begun to show, the conjunction of Internet-based communication technologies and market-driven health care reforms has enabled a global search for high-tech cures stretching from computer screens in Colorado to hospital wards in Beijing. Part 1 of this book, “Online Mediations,” theorizes the digital mediation of health-seeking by exploring how and why American and European patients with spinal cord injuries and neurodegenerative diseases have pursued experimental fetal cell transplantation in Beijing. Over the next three chapters, I highlight the ways in which different Internet communication technologies have transformed patient activism in a transnational era.

Chapter 2, “Mobilizing the Paralyzed Online,” traces the spatial and temporal dynamics of CareCure—an online discussion forum devoted to research and treatment for spinal cord injury (SCI). Created from a U.S. neuroscientist’s experiment in caring and curing, the CareCure website links the scientific pursuit of the cure with the construction of a community for those living and dealing with SCI. The cybersociality engendered by CareCure has produced a new form of mobility that might otherwise be lost in the offline, visceral world of chronic paralysis. I demonstrate how this virtual forum has fostered a technologically
mediated social movement of patients, families, researchers, and doctors who pursue experimental therapies for conditions considered incurable by conventional medicine.

Chapter 3, “Cyberanatomies of Hope,” explores how the embodied dynamics of illness and chronicity shape online modes of health-seeking by comparing the experiences of people living with spinal cord injuries to those of people suffering from amyotrophic lateral sclerosis (ALS). As diverse biological conditions become increasingly mediated by digital modes of representation, these emergent forms of “biomediation” (Thacker 2004) catalyze new hopes and possibilities for those seeking to challenge orthodox prognoses and bodily limitations. While the chronic nature of SCI enables the formation of robust and stable online communities such as CareCure, the cybersociality cultivated by people living with the immediate threat of ALS is much more contingent and ephemeral. The kinds of social connections forged online in turn shape the forms of mobilization and digital pathways to experimental medicine.

Chapter 4, “Where the Virtual Becomes Visceral,” explores how the online and offline experiences of illness and mobilization converge and collide on the operating table and in the corridors of Huang’s experimental neurosurgery clinic in Beijing. I follow the digitally mediated trajectories of several American and European patients who underwent experimental fetal cell transplantation, providing ethnographic insight into their embodied experiences of transnational health-seeking. By comparing these distinctive digital pathways to experimental biomedicine, the chapters in part 1 illuminate how dynamics of illness and chronicity map onto patterns of endurance and ephemerality that characterize different forms of digital technology. I ultimately show how various modes of mediation open up alternative horizons of hope for those facing incurable neurological catastrophes.

Part 2 of this book, “Chinese Experiments,” shifts perspective to consider these transnational encounters from the standpoint of the Chinese clinicians. I examine how urban medical entrepreneurs have responded to the proliferating political uncertainties and economic anxieties in a complex regulatory landscape where rules are flexibly interpreted and arbitrarily enforced. The experimental forms of health care that they practice are turning China’s urban medical system into a laboratory for entrepreneurial tactics.

Chapter 5, “Medical Entrepreneurs,” examines how changes in the political economy of health care have encouraged enterprising Chinese clinicians to experiment with lucrative biomedical interventions for foreign patients. I follow the career trajectory of New Century Hospital’s lead neurosurgeon, Dr. Huang Hongyun, and contrast his experiences with those of other clinicians in order to illustrate the ethnographic contours of medical entrepreneurialism in urban China. Recounting their struggles to balance individual interests, professional ethics, and global ambitions, I demonstrate how the pursuit of high-tech therapies by medical entrepreneurs is not just about making money but also about