Biotech Pilgrims and the Transnational Quest for Stem Cell Cures

Priscilla Song

Thousands of patients with incurable neurodegenerative conditions from more than 60 countries have sought fetal cell transplants in China since 2001. Drawing on 24 months of ethnographic fieldwork, I investigate these transnational encounters occurring in the realm of experimental medicine. Critiquing popular notions of “medical tourism,” I develop the alternative concept of “biotech pilgrimage” to reveal how faith intertwines with technology, travel, and the political economies of health care and medical research in a global era. Insights from pilgrimage theory enable us to question assumptions of leisure embedded in claims of tourism while also exploring new biopolitical practices that extend beyond the borders of the nation-state. I also demonstrate how materialist visions of salvation underlie medical practice and contribute to China’s rising influence as a global technological leader.

Key Words: China; globalization; Internet; medical tourism; pilgrimage

At the entrance of the Neurosurgery Ward for Foreigners at West Hill Hospital,1 framed montages of smiling patients greet visitors to this former workers’ sanatorium on the outskirts of western Beijing. Since 2001, thousands of patients from more than 60 countries have sought experimental fetal cell transplantation surgery at this clinic and at other urban tertiary-care sites along China’s eastern seaboard. The photographs, lining the hallways at West Hill, are set out in alphabetical order by country: Mohamed

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from Bangladesh, Jan from Belgium, João from Brazil, Gwen from Canada, Francisco from Chile, Ivan from Croatia, Beatrice from Cuba, Emilios from Cyprus, Claes from Denmark, Mario from Ecuador, Sharif from Egypt, etc. With diagnoses of incurable neurodegenerative conditions ranging from amyotrophic lateral sclerosis (ALS) to spinal cord injury, these patients are part of a growing movement of people seeking medical treatment beyond the borders of their home countries.

Although medical anthropologists have long explored the diversity of health-seeking practices (cf. Kleinman 1978; Janzen 1982; Inhorn 1994), the way people now embark on medical quests and the scope of their journeys have changed with the advent of rapidly evolving technologies. The conjunction of Internet-based communication tools, popular hype surrounding stem cell research advances, and the commodification of health care has fueled a global search for biomedical cures stretching from computer screens in New Jersey to hospital wards in Beijing. In urban China, increasingly profit-driven hospitals and restructured government priorities have encouraged former state-employed health care professionals to experiment with radically new and potentially dangerous therapeutic interventions such as fetal cell transplantation surgeries (Song 2008). The proliferation of experimental therapies in China has also opened up new possibilities for families from other countries who may not be willing or able to wait for the conventional course of biomedical research to wind its way through years of animal testing and multi-stage clinical trials. Frustrated by hospitals and health insurance companies, people suffering from conditions regarded as incurable in their home countries are looking to China for alternatives with the help of Internet search engines and online discussion forums.

In this article, I investigate these transnational encounters unfolding in the realm of “cutting-edge” medicine. I draw on 24 months of ethnographic fieldwork conducted at Beijing’s West Hill Hospital, including observations of clinical ward experiences and interviews with patients, family members, neurosurgeons, nurses, and other hospital staff members. I have complemented this research with content analysis of patients’ and caregivers’ online contributions on Internet health forums and personal blogs. I develop the concept of “biotech pilgrimage” to explore how faith intertwines with technology, travel, and the political economies of health care and medical research in a global era.

BIOTECH PILGRIMS: AN ALTERNATIVE PARADIGM FOR TRANSNATIONAL MEDICAL TRAVEL

Over the past several years, stories have multiplied in the mass media on the phenomenon of medical tourism. Journalists have raised alarms with
headline-grabbing news declaring “thousands of medical tourists are traveling abroad to save money” (Davidow 2006). Meanwhile, publicists in receiving countries have heralded the boon to local economies. The Tourism Authority of Thailand (2004), for example, promotes the country as the “health tourism hub of Asia,” while the Hindustan Times has proclaimed medical tourism as a multi-billion dollar business opportunity in India (2007). “How-to” books have also flourished, providing readers with step-by-step guides to obtain “affordable” yet “world-class” medical care abroad (Woodman 2008). These news reports and guidebooks emphasize the cheaper costs of health care abroad as the primary factor driving border crossings while touting recreational opportunities available on the side (cf. Price 2006; Konrad 2009).

While tourism may be an apt description for package deals combining elective procedures with sightseeing and beachside lounging, it falls short in accounting for the diverse types of medical journeys people undertake. The foreign patients I encountered at West Hill Hospital rejected this popular framing of their health-seeking activities. Medical tourism implies a frivolity that runs counter to the lived experiences of those suffering from paralysis and fails to capture the significance that experimental therapies hold for them. Although studies of tourism have emphasized the transformative power of renewal embedded in the concept of “re-creation” (Graburn 1983:10), the fundamental association of tourism with leisure renders it a problematic term to describe the experiences of patients who often feel forced to travel in order to seek the medical care they desire or need. Unlike those searching for more affordable surgeries or attempting to circumvent waiting lines, the people seeking stem cell treatment in China are spending tens of thousands of dollars in pursuit of a therapeutic breakthrough—a process that one paraplegic writer has described as “scouring the globe for a cure” (Vgrafen 2007). Marketing their experience as “medical tourism” misconstrues both the purpose and the significance of their journeys. Far from being a vacation on the cheap, these quests for a cure involve significant expense and hardship. The patients and families I studied did not come to China on holiday excursions to climb the Great Wall or visit the Forbidden City, and some of them never ventured beyond the hospital grounds during their month-long treatment course in Beijing. They made their arduous trips for a very specific objective: to obtain an experimental treatment unavailable elsewhere in the world.

These border-crossing patients grappled with the limitations of language in trying to find adequate terms to describe their novel experiences. In an online forum discussing patients’ experiences undergoing experimental treatment in Beijing, therapy seekers described each other with labels ranging from “pioneers” and “heroes” to “guinea pigs” and even “martyrs”
(CareCure Community 2003). The first US recipient of the Beijing fetal cell transplant chose to refer to himself and his fellow patients as “pilgrims” (Tim C. 2004). Although only a few of my interviewees explicitly used this term to describe themselves, many recognized the sense of hope and transformation embedded in the metaphor of pilgrimage. The promise of salvation evoked by the sacrosanct idiom of pilgrimage captures their attempts to cure what conventional medicine has deemed incurable in ways overlooked by a focus on the touristic aspects of their travels.

In this article, I articulate an anthropological framework of pilgrimage as an alternative model for thinking about transnational journeys for experimental medicine. The Oxford English Dictionary (2009) defines pilgrimage foremost as “an act of religious devotion,” but notes its more extended use as “a journey undertaken to a place of particular significance or interest” as well as its figurative meaning of “mortal life as a spiritual journey leading to heaven.” I will show how these three aspects of pilgrimage—faith, travel, and a sense of higher purpose—have become embedded in patients’ hopes for regenerative medicine. Victor Turner’s foundational work on pilgrimage as a social process provides a helpful model for understanding how patients’ quests for a cure acquire symbolic meaning and transformative power that go far beyond media portrayals of medical tourism. Drawing on Arnold van Gennep’s (1960) work on the three stages of separation, transition, and reincorporation involved in rites of passage, Turner noted that pilgrimages entailed “beginning in a familiar place, going to a Far Place, and returning to a Familiar Place, theoretically changed” (1974:195). This change hinged on the spatiotemporal experience of liminality or the transitional threshold of being “betwixt and between,” which separated pilgrims from the familiar and habitual in order to effect a transformation in social status (Turner 1967:93–94). In addition to personal transformation for the pilgrim, Turner argued that the shared process of making an arduous journey to an unfamiliar place outside the routines of daily life created a new mode of social relatedness. Benedict Anderson (1991) has also highlighted the role of pilgrimage in community-building in his definitive study of nationalism. As collective journeys of the imagination, pilgrimages create shared meaning among travelers from “remote and otherwise unrelated localities” whose encounters would otherwise have been an “inexplicable juxtaposition” (Anderson:54). Instead of framing patients as individualized tourist-consumers hunting globally for the cheapest deal, I thus argue that the language of pilgrimage more powerfully represents these travelers as participants in a shared quest of greater significance.

While I seek to dislodge the prevailing idiom of tourism in transnational medical travel by emphasizing the analytical advantages of pilgrimage, these concepts can be understood as varying points along a continuum of travel.
experiences ranging from the sacred to the secular (Smith 1992). Indeed, anthropologists who study tourism have drawn on pilgrimage theory to legitimize their subject of inquiry (MacCannell 1976; Graburn 1983, 1989). Demonstrating that pilgrims are not necessarily more authentic than tourists, religious scholars have also questioned “any radical phenomenological difference” between the two forms of travel (Pfaffenberger 1983:72; Badone and Roseman 2004). My work contributes to this blurring of the boundaries in emerging forms of travel by considering transnational quests for medical treatment as “biotech pilgrimages.” The secular pursuit of health is often an important component in sacred journeys (cf. Dubisch and Winkelman 2005), as Catholic pilgrimages to Lourdes in the French Pyrenees and the Our Lady of Fatima shrine in Portugal illustrate. The transnational quest for regenerative medicine likewise involves an intertwining of material rationality and spiritual faith in the healing of the sick, albeit with a very different set of assumptions about the efficacy of science and religion. Unlike supplicants seeking a miraculous recovery by bathing in the waters of a holy spring, patients at West Hill Hospital grounded their quest for a cure in biological processes. Most patients fortified themselves with results of the latest studies published in medical journals rather than relying on Biblical verses. Yet their decision to subject their bodies to an experimental procedure involved an essential act of faith in the advances of biomedical science.

The concept of pilgrimage enables us to explore the symbolic and material significance of travel in shaping secular health-seeking experiences. The journeys of patients and caregivers to unfamiliar terrain in China to seek out risky therapies have enabled both personal and social transformation. In the next section, I consider how the border-crossing experiences of Tim C., the first US recipient of the Beijing fetal cell surgery, inspired him to frame his journey in terms of a distinctly American narrative of pilgrimage.3

AMERICAN PILGRIMS IN A NEW WORLD

Tim became paralyzed from the chest down in 2002 at the age 42, when a collision with a tree during his first ride in an all-terrain vehicle injured the cervical vertebrae of his spinal column. His doctors told him that he would never regain functional control of his hands, legs, bowel, or bladder. Refusing to accept a life sentence of complete tetraplegia, Tim turned to the Internet to search for alternatives and discovered the CareCure Community, an online discussion forum for people with spinal cord injury (SCI) and their family members, caregivers, researchers, and clinicians. Consisting of
more than 30,000 registered members who have collectively posted over one million messages online, CareCure featured a signature “Cure” forum in which members discussed the latest scientific advances in SCI research and treatment.

Through the Cure forum, Tim learned that Chinese SCI patients had experienced some recovery of motor function and sensation after undergoing a fetal cell transplantation procedure developed by a Beijing neurosurgeon named Huang Hongyun. Huang’s experimental treatment involved injecting a suspension of olfactory bulb cells extracted from aborted fetuses into the spinal cord. As one of only two areas of the central nervous system known to continually regenerate new neurons in adults, the olfactory bulb held particular promise for repairing damaged spinal cords (Doucette 1990; Ramon-Cueto et al. 2000; Raisman 2001; Marshall et al. 2006). Huang and colleagues (2001) studied the role of olfactory ensheathing glial (OEG) cells in restoring function to spinal-injured rats at the Keck Center for Collaborative Neuroscience at Rutgers, the State University of New Jersey. Upon returning to Beijing after his postdoctoral fellowship, Huang adapted his laboratory technique for clinical use and began transplanting fetal OEG cells into the damaged spinal cords of patients at the end of 2001. Huang’s timing was astute: US President George W. Bush had issued a statement on August 9, 2001 curtailing federal funding of research conducted on human embryonic stem cell (hESC) lines. Widely proclaimed to be the future of regenerative medicine, hESC research suddenly faced significant obstacles in the United States. Not surprisingly, attention shifted to promising developments elsewhere in the world, including Huang’s clinical work with fetal cells. Wise Young (2002b), a Rutgers neuroscientist who established the CareCure website and supervised Huang’s research on rats, described the Chinese neurosurgeon’s preliminary clinical results on the message boards as “a credible phase 1 trial” that demonstrated the feasibility and safety of the fetal cell transplants. The journal Nature Biotechnology noted that the “Bush doctrine” created “leaders and laggards in the stem cell enterprise,” enabling scientists in other countries such as China to “seize the moment and [get] an early run at [embryonic stem] cell research” (Herrera 2005:775).

After contacting Huang through the CareCure forum, Tim became the first American to undergo the Chinese fetal cell transplantation procedure in September 2003. He provided frequent updates of his experiences in China for his fellow CareCure members, describing everything from minor frustrations and bodily symptoms to encounters with hospital personnel and surgical procedures. As one of the first foreign patients treated by Huang and his staff, Tim bore the brunt of cross-cultural miscommunications, conflicting expectations about caregiving, and mundane practicalities such
as voltage incompatibilities. His online postings detailed grimy hospital conditions that “would not win any awards for cleanliness by our standards” (Tim C. 2003a), outdated equipment such as hand-crank operated hospital beds and old transformers which “appeared U-boat vintage” (2003b), and the difficulties he faced in trying to fit his bulky power wheelchair through the narrow bathroom door frames.

CareCure members like Tim embodied the collective hopes of the SCI community by personally undergoing experimental treatments and sharing their results online. The updates Tim posted on the Cure forum about his experiences garnered a cult following that hung onto every byte of information coming from China (to date, his Beijing surgery report has received 31,000 views and more than 250 replies). His report was an example of one of the most popular discussion genres on CareCure:

These discussions of the actual experience and recovery of individuals who have gone for experimental and alternative therapies are unique. The community can share vicariously with the experience and judge for themselves the merits and risks of such therapies. There is a strong sense of altruism in the sharing of these experiences, so that others can benefit. (Young 2002a)

Tim’s postings on CareCure can also be understood as a public transcript of his illness narrative—an attempt to make sense of his experiences of suffering and treatment. While Kleinman (1988) discussed the construction of illness narratives in the context of patient-physician interactions, Tim’s online narrative unfolded in the context of a community of people grappling with spinal cord injuries. Transcending an individualized search to heal his own damaged body, Tim’s publicly documented “blow-by-blow diary” enacted a collective testament for rejuvenating an entire community.

Laurence Kirmayer (1992) highlighted the role of metaphor in giving meaning to illness experience that is grounded simultaneously in bodily experience and social interaction. By describing himself as an “OEG pilgrim,” Tim articulated a purposeful trajectory to his illness narrative steeped in an American idiom of self-reliance in the face of hardship. The pilgrimage metaphor gave meaningful shape to the suffering he endured in seeking treatment in an unfamiliar hospital in a foreign land. He lamented the hostile political climate in the United States under the Bush administration, blaming “the few ‘righteous’ decision makers in our government” for restricting stem cell research and driving him abroad to search for potential treatments (2003a). His use of pilgrimage evoked a metaphorical kinship with the early settlers of Plymouth Colony, who left behind the familiarity of home to escape religious persecution and search out better opportunities in a new world.
Tim’s special status as “OEG pilgrim” imbued him with a sense of purpose that extended beyond his own bodily concerns. He saw himself not only as an individual patient seeking to heal his own body but also a contributor to the scientific enterprise:

This therapy is in its model-T stage and the Rolls Royce is down the road a piece. I have to believe that by allowing US citizens to participate in his work, Dr. Huang hopes that we...help plant the seed...within other countries who have the resources to build upon the technology (not just criticize it).

(Tim C. 2003c)

His industrial and agricultural metaphors enacted a distinctly American tale of hard work and innovation in which his suffering played a leading role. As a self-declared pilgrim in the brave new world of experimental medicine, he interpreted the significance of his journey not just in terms of his own personal benefit but for the future of the entire SCI community and scientific enterprise.

THE POLITICAL AND MORAL ECONOMY
OF CORPOREAL SALVATION

Tim’s quest for regenerative medicine promised the possibility of bodily transformation for himself and others suffering from paralysis. As his experience suggests, the concept of pilgrimage imparted a transcendental significance to these medical journeys that many used to justify the costs—both financial and moral—of undergoing the controversial procedure in Beijing. While Huang’s Chinese patients paid 30,000 yuan (approximately US $3600 at the time of Tim’s surgery in 2003) for the basic fetal cell transplant, the neurosurgeon charged his foreign patients US $20,000 for the experimental procedure and month-long stay in the hospital’s VIP ward. How did patients and their caregivers justify spending tens of thousands of dollars on a potentially risky therapy? For some, cost posed no barrier to treatment: Huang’s wealthiest patients, including a member of the Kuwaiti royal family suffering from ALS and the paralyzed heir of a canned goods magnate from Mexico, arrived in Beijing on chartered jets. Many generated support from their communities, including a terminally ill firefighter from Colorado whose colleagues auctioned off a Harley Davidson motorcycle to help pay for his treatment and a Louisiana schoolteacher who organized fundraisers for her spinal-injured son. Still others cashed out their life savings, refinancing their homes or tapping their retirement funds to finance their medical quests. Gary, an electrician from
Wisconsin who had become paralyzed from the waist down after an abdominal aortic aneurysm, compared the expense of the fetal cell transplant with the price tag of a new car: “It costs no more than a new set of wheels, and everyone needs a new set of wheels once in a while.”

Some “biotech pilgrims” grappled not only with financial concerns but also ethical questions about the Chinese therapy. A couple I met from Kentucky actively drew on their faith as Southern Baptists to reconcile their church’s stance against abortion with their choice to pursue a procedure that utilized cells from aborted fetuses. Describing their trip to China as part of “God’s plan for us,” Roberta, whose husband Sam suffered from ALS, recounted how their pastor had come across a story in the Baptist Record about a paper mill worker in Alabama who had undergone the experimental treatment in China. With the spiritual and financial support of their congregation back home—including daily prayers and $30,000 in donations—Sam and Roberta traveled to the Chinese clinic in an effort to halt the rapid deterioration of his motor neurons. By the time he arrived in Beijing, Sam had already lost control of his lower facial muscles and even his wife had difficulty understanding his garbled speech. Caressing the corner of an embroidered prayer cloth, Roberta explained their decision to undergo the fetal cell transplantation surgery as a way of redeeming the immoral practice of abortion in China: “It’s like making lemonade out of lemons. We feel like this is a way God has of taking something bad and making something good out of it.” Roberta resolved their uneasiness about benefiting from abortion by placing the exchange firmly within a Christian narrative of sacrifice. Her husband’s use of the cells ensured that the death of the fetus was not in vain, effectively transforming an otherwise unholy act into a meaningful sacrifice.

Many foreign journalists have also seized on the religious connotations of these patients’ quests for treatment. As a journalist for the London-based Guardian newspaper 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. (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. While Roberta and Sam drew on their religious faith to make sense of their
experiences in China, they—like most other patients and caregivers in Beijing—avoided sensational terms such as “miracle.” Most 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.

The pilgrimage metaphor underscores the transformative potential of the journeys in both symbolical and material terms. Although most patients and caregivers I interviewed in Beijing did not invoke religious belief to explain their journeys to China, their hopes for a life-saving intervention were often just as palpable as Sam and Roberta’s faith in a divine plan. Describing their transnational journeys as biotech pilgrimages highlights the intertwining of faith with technology and travel in these patients’ encounters with experimental medicine. Drawing on Weber’s insight that civilizations are organized around a “soteriological vision” that provides an understanding of the nature of suffering and a means of deliverance from it, Byron Good (1994) suggested that biomedicine offers its material vision of good health as the ultimate form of modern salvation. The concept of biotech pilgrimage thus provides a useful analytical framework for highlighting the salvation-oriented nature of transnational health-seeking and travelers’ beliefs in a biotechnological solution to their troubles.

In particular, the merging of the transcendental and technological registers in biotech pilgrimages highlights the power of hope in motivating people to travel to great lengths and spend significant resources to find a high-tech means of deliverance from their bodily suffering. Medical anthropologists and sociologists have articulated a “political economy of hope” structuring high-tech therapeutic practices in American oncology (M. D. Good et al. 1990; M. D. Good 2001) and patient activism in genetic research (Novas 2006). This framing emphasizes both the financial and affective dimensions of biotechnology by showing how hope in the possibility of a cure is linked to the funding of research, the professional ambitions of scientist-clinicians, the business dreams of entrepreneurs, and the subjective experiences of patients and their families.

In his analysis of India’s efforts to develop a biotech industry and become a global player in genomic research, Kaushik Sunder Rajan (2006) has likewise articulated the “promissory horizon” of biotechnology as both a “therapeutic realization” on the level of personalized medicine and a “commercial realization” for corporate, state, and even academic actors.
The quests to China for regenerative medicine arguably embody this mode of speculative capitalism even more starkly. For the biotech pilgrims in China, the promise of corporeal salvation is embedded in the distinct political and moral economies of transnational stem cell research. Their border-crossing journeys have been enabled by the ethical dilemmas, political calculations, and financial motivations structuring medical care and research, including the former Bush administration’s restrictions on federal funding and the politics of abortion in the United States as well as the privatization of health care and the pursuit of lucrative high-tech interventions in China.

INVERTING CENTER AND PERIPHERY: THE GEOPOLITICS OF BIOMEDICAL RESEARCH

Although China has become an increasingly dominant world power in terms of political influence, financial sway, military might, and technological prowess, its health care system is still characterized in the global imagination more by the iconic barefoot doctors of the Cultural Revolution than the “cutting-edge” neurosurgeons of the new millennium. The journeys of Dr. Huang’s US, Japanese, and European patients—from supposedly technologically superior countries to China for medical treatment—thus disrupt conventional assumptions about the centers and peripheries of the biomedical world. This interplay between a familiar center and distant periphery plays a crucial role in biotech pilgrims’ transnational quests for stem cell therapies. In addition to creating new modes of sociality, the pilgrimage also transforms conceptions of social space by creating an alternative imagined geography of power that at least temporarily trumps the dominant secular order. In Mexican and European pilgrimages, for example, pilgrimage shrines tend to be located in remote locations, which underscore their distance from the main administrative centers of state and church (Turner 1974:193–198). The journey from the familiar to the peripheral effectively separates the pilgrim from the established sociopolitical structures of his or her everyday life and inserts him or her into a new space marked as meaningfully different.

Frustrated with what they considered the slow pace of clinical research in their home countries, patients were electrified by the possibility of a cure on the horizon in China. A CareCure member from Chicago contrasted what he saw as the overly cautious mentality paralyzing American researchers with China’s “anything goes” environment:

I am just glad that they are doing what they are doing in China, they seem to be on the wild and wooly side when it comes to research/experimental therapies.
on people, and they don’t have any religious nay-sayers badmouthing research either, which is great for us. With the safety conscious and generally restricted research in the Western world I suspect that China will be the first to come up with a cure if it is possible. Thumbs up for what they are doing there. (Andy 2003)

The distinctive moral and political economies of countries such as the United States and China produced differential regulatory environments, shaped research agendas, and ultimately enabled the flow of patients, scientists, and resources across borders.

Drawing on his patients’ often vituperative critiques of their own medical systems, Dr. Huang took obvious pride in treating those whom his American and European colleagues had declared incurable. Western patients were coming to China because of the failures of their own governments and doctors to care for their own, despite these countries’ claims to superior medicine. In nearly all of the dozens of interviews I conducted with him over the course of two years, Huang enjoyed pointing out how his fetal cell transplantations demonstrated that China had surpassed the West in advancing cutting-edge medical treatment: “The West hasn’t been able to do it… They think that China is a backwards place, that it can’t possibly be ahead in science. [But] I’m using Western medical methods to treat foreign patients. This proves that China is superior.”

Huang recognized the geopolitical significance of focusing on foreign patients, noting that a Chinese doctor treating Chinese patients would never be able to command an international stage: “If I don’t treat foreigners, people won’t pay attention, they won’t know what’s happening in China. If I were just treating Chinese patients, do you think the editor of the New England Journal of Medicine would visit West Hill? Would Nature send a reporter here?” In an ironic twist, Huang justified his decision to treat foreigners over Chinese patients as a way to assert China’s new dominance in the field of regenerative medicine.

Huang’s transnational patients have played a central role in catapulting him from the fringes of biomedicine to the center of attention. Intrigued and apprehensive about the steady flow of foreign patients coming to Beijing for treatment, leading scientific experts and journalists from around the world have toured Huang’s clinic and interviewed his patients. A subsidiary of the prestigious scientific journal Nature even featured Huang as one of China’s top three “people to watch” (Cyranoski and Mandavilli 2006).

Huang’s delight in treating American and European patients tapped into a broader nationalist sentiment shared among many Chinese citizens. Instead of viewing China as the “sick man of East Asia,” he interpreted his efforts as part of a patriotic plan to establish his country as an innovative world leader
in regenerative medicine: “This pioneering research fills an international gap and brings our country to the forefront of this field” (Huang 2006).

As Huang’s nationalist rhetoric illustrates, these biotech pilgrimages draw on an alternative imagined geography of power that inverts conventional assumptions about the West’s technological superiority and China’s supposed inferiority. Complementing global-scale events such as China’s hosting of the 2008 Olympic Games, individual patients’ transnational quests for stem cell cures in Beijing contribute to larger narratives about China’s rising prominence in world affairs.

CONCLUSION

In the face of overused terms such as “medical tourism” circulated by journalists, medical anthropologists can explore the contexts and stakes of deploying travel metaphors to make sense of illness experiences. Inspired by an American patient’s use of pilgrimage to give meaning to his illness narrative, I have sought to emphasize the analytical advantages of drawing on pilgrimage theory to understand the experiential dimensions and political economies of transnational health-seeking. These novel configurations take us far beyond the assumed linkage between travel and leisure embedded in uncritical notions of medical tourism. The concept of biotech pilgrimage highlights the ways in which faith intersects with technology and travel to inspire both corporeal salvation and collective transformation. John Eade and Michael Sallnow (1991:16–17) noted the significance of the suffering body in uniting near strangers on a pilgrimage into a coherent social group through the physical care of sick members and discourses around the meaning and value of the suffering body. Nearly all biotech pilgrims were accompanied by at least one family member or caregiver, and these lay helpers spent much of their time in Beijing discussing various treatments they tried and challenges they encountered over the course of caring for their loved ones. Surrounded by family and friends, patients at West Hill Hospital embodied an economy and ethics of care that pushed them and their caregivers to travel to the ends of the world for a cure. These biotech pilgrims challenge established wisdom about the incurability of paralysis by going online to search for alternative possibilities and by undergoing innovative but potentially dangerous therapeutic interventions far from home. In the process of traversing these new liminal spaces at the “cutting edge” of medicine, they have ended up reconfiguring ideas about personal salvation and modes of social relatedness in ways far beyond what Turner imagined.

As patients and their caregivers search online for emerging treatments around the world, they are “re-creating” new biopolitical practices that extend
across the borders of the nation-state. Reframing their quests as collective journeys of the imagination (Anderson 1991) provides an important transnational illustration of "biosociality": Paul Rabinow’s (1996) term for how individuals in an era of genomics form new group identities and practices based on developments in the life sciences. While the distinctively modern form of biopower that Michel Foucault (1990) articulated focused on disciplining bodies and regulating populations, biosociality draws on a "post-disciplinary rationality" that emphasizes the management of risk rather than the direct domination of individuals or groups (Rabinow 1996:91–111). Medical anthropologists and sociologists have taken up this project in the context of national “citizenship projects” (Rose and Novas 2005), such as Adriana Petryna’s poignant study (2002) of how Chernobyl victims in the Ukraine claimed state welfare benefits on the basis of their radiation-damaged bodies. Foreign patients traveling to China to seek experimental therapies are also finding common cause for solidarity based on their injuries and illnesses. However, they have largely given up finding treatment in their home countries. For these border-crossing patients, the promise of corporeal salvation is embedded in the distinct moral and political economies of global stem cell research. Instead of biological citizens seeking entitlements from the state, they have become biotech pilgrims embarking on transnational quests for a cure.

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NOTES

1. I use the actual names of the neurosurgery clinic and its director Dr. Huang Hongyun since they have received extensive public attention in the domestic and foreign media. This decision also reflects Dr. Huang’s request to be named in my work. To protect the privacy of patients and their family members, I have used pseudonyms for others mentioned in this article, except where I cite statements made on publicly accessible websites.
2. I first learned about this neurosurgery clinic in 2004 through media reports while conducting research for a broader study on postsocialist health care practices in urban China (Song 2008). An American caregiver whose son had undergone the experimental treatment introduced me to the hospital staff, and the clinic’s director subsequently accepted my proposal to study the experiences and motivations of the patients and medical personnel. As ethnographers who have worked in hospitals have noted, fieldwork in these settings poses special challenges of access and interaction (Van der Geest and Finkler 2004; Inhorn 2004; Long, Hunter, and van der Geest 2008; Zaman 2008). My work largely entailed observation of everyday activities in the ward, clinical interactions, staff meetings, and social gatherings. I also participated by facilitating communication between the Chinese staff and English-speaking patients, helping out with patient care, taking caregivers on shopping trips, and living with staff members in the hospital dormitory.

3. My analysis of Tim’s experiences is based on his public account on the CareCure website.

4. Unlike basic neuroscience programs, the Keck Center focuses specifically on developing treatments for spinal cord injuries. Neurosurgeons and molecular biologists collaborate to bring discoveries in the laboratory to clinical use.

5. As a report on the state of Chinese stem cell research in the New England Journal of Medicine has noted, Chinese researchers have had greater latitude in transforming laboratory innovations into clinical treatments (Murray and Spar 2006). Fetal and stem cell transplants received little regulatory oversight in China until 2009, when the Ministry of Health issued national guidelines on the clinical application of medical technologies. These regulations outlined a comprehensive review and approval process for medical technologies deemed “high risk” or involving “major ethical problems” (People’s Republic of China Ministry of Health 2009).

6. While fetal olfactory cells technically are not hESC (which are derived from early stage embryos), the hype surrounding the more (in)famous variety of cells has led patients, reporters, and even other scientists and clinicians to conflate the two. Subsequent testing conducted by an independent American laboratory suggests that the cell suspension Huang uses may also contain neuroectodermally derived stem cells (Guest, Herrera, and Qian 2006). Given the ambiguities, I have characterized the cells in question as fetal cells and recognize that patients’ quests for a cure were often predicated on hopes and misunderstandings generated by stem cell research.

7. While patient experiences can be easily faked on blogs and other online forums, websites such as CareCure provide participants with many methods of verification including endorsement by trusted members, careful scrutiny over time, corroboration by external experts and reporters, and multimedia evidence such as MRI scans and video footage.

8. Pilgrimage may be a distinctively American or Judeo-Christian metaphor for making sense of medical journeys. None of the Chinese patients I interviewed used the term to describe their health-seeking activities, even though their quests for treatment were often as arduous as those undertaken by patients from other countries. The specific material referents of Chinese pilgrimage terms may partly explain this difference in illness narratives. Chao shan literally refers to “paying obeisance to a mountain,” the most common destination for a sacred journey in both Buddhist and Daoist traditions (cf. Naquin and Yü 1992; Wu 1992; Lagerwey 1992). The other term for pilgrimage, jin xiang, refers to the presentation of incense to make contact with a deity (cf. Naquin and Yü; Sangren 1988, 1993). Chinese forms of pilgrimage thus invoke concrete material activities that may leave little room for the figurative notions of personal transcendence and salvation enabled by the more generalized English term.

9. This flat rate covered the fetal cell transplantation and all associated medical and living costs during a patient’s month-long treatment course, including laboratory tests, 24-hour nursing care, rehabilitation therapy, medicine, acupuncture, meals, transportation, and a private room with attached bathroom and accommodation for an accompanying caregiver. To put
Huang’s fees in perspective, the American Academy of Orthopedic Surgeons (2007) reported that the average cost per hospitalization for patients undergoing a spinal fusion procedure in the United States in 2003 was US $50,000 for an average stay of 4.3 days (approximately US $11,630 per day compared with US $650 per day for Huang’s patients).

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