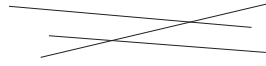


3



RESEARCHING PAIN, PRACTICING EMPATHY

The word “cancer” hides more than it reveals. Scientists and doctors often correct its unqualified usage, pointing out that cancer is not just one disease, and that contemporary fears about its ubiquity are based on this misunderstanding. Rather, cancer is really an ensemble of specializations, modes of diagnosis, and kinds of treatments. So, when I naively began fieldwork at the All India Institute of Medical Science (AIIMS) hoping to study cancer, it quickly became clear I would have to focus my inquiries much more narrowly and concretely. What were the specific practices I would examine within this constellation of specialties, practitioners, and patients that constituted cancer care in this specific hospital? For example, studying the medical physics or radiology units would direct me toward practices of imaging and testing. Working in the medical or surgical oncology divisions would focus my attention on diagnostic and therapeutic interventions. Or following the cancer registry would turn my attention to the relation between demographics and health policy. Such units and departments make up most cancer hospitals worldwide, and each would have made for its own research site.

However, my attention was drawn to a corner of the cancer hospital that is not globally ubiquitous—a unit staffed by anesthesiologists specializing in cancer pain and dedicated to palliative care. The presence of this unit surprised me partly because palliative care is globally still quite a nascent biomedical field. The first hospital-based palliative care units emerged in

the late 1980s and 1990s in Europe and the United States. But even as the field has continued to grow in the twenty-first century, the specialization remains peripheral to supposedly more urgent oncological modalities—radiation, chemotherapy, and surgery. For example, at the time of my fieldwork, less than a fourth of the major cancer hospitals in the United States reserved beds for palliative care as was done at AIIMS.¹ And if palliative care is uneven in places like the United States, it is almost absent in most of the global south. A 234-country survey conducted during the time of my fieldwork found that about a third had no palliative care services of any kind.²

The presence of an advanced palliative care unit at the cancer ward at AIIMS—staffed with experts and allocating beds to palliative care—reflects how, as the country’s leading hospital, AIIMS can claim an exceptional amount of government resources. Its annual budget of about \$226 million is around 4 percent of the national health budget.³ At the same time, the cancer hospital was dedicating expertise to palliative care in ways that far surpassed what was being done at many of its peer institutions elsewhere in the world. Even in the most well-resourced hospitals in the global north, the field of palliative care still draws its practitioners from undervalued, low-prestige specializations such as social work, counseling, nursing, and mental health. At AIIMS, the core staff of the palliative care ward were practitioners at the opposite end of the biomedical hierarchy: anesthesiology.⁴ Further, as Sarah Pinto and Cecilia Van Hollen describe, anesthesiologists are a rare commodity in Indian public health.⁵ Instead, they remain caught within a conventional ordering of public health priorities—urgent and life-saving treatments first, care and concern for “symptoms” such as cancer pain later. At the cancer hospital, my interest was thus drawn to this puzzling presence of a team of dedicated anesthesiologists, all transacting palliative care in a hospital struggling to provide timely conventional therapies.

In this chapter, then, I track the emergence of cancer pain as a central preoccupation at the cancer hospital at AIIMS. Usually considered by public health and biomedicine as a symptom and not an urgent subject for intervention, how did pain become such a central concern here? I found that palliative care specialists understood that to treat pain, they had to treat the social worlds within which pain takes shape. In conversations, medical journals, and practice, they defined “total” cancer pain—a condition that was simultaneously social, spiritual, psychological, and physical. Here, tracking cancer pain as a subject of research and intervention, I come to understand the pathways through which these specialists translated social, spiritual, and psychological distress into physical pain, and vice versa. Further, I find that

the possibilities of treating pain understood in this way were staked on specialists' understandings of "culturally appropriate" modes of empathy and humane practice. While tracking cancer pain, then, I also trace these responsive visions of empathy. Thus, two questions guide this chapter: What does cancer pain, in its intensifications and obfuscations, teach us about the infrastructures of care within which it ebbs and flows? And what have been the felicities and failures of the modes of empathy that have emerged in response?

Total Cancer Pain

The AIIMS campus sprawls under one of the busiest traffic intersections in New Delhi—a crisscrossing layer of overpasses referred to as the AIIMS flyovers. A few high-profile patients, ministers, and bureaucrats reach the institute by driving along these overpasses; others take buses or autorickshaws or use the subway system. Some have traveled from the edges of the ever-expanding metropolis, while others have made their way from more distant parts of the country on the subsidized national railway system. At the main gate, hawkers sell food and illicit brokers peddle hospital forms to patients and their attendants. Many of their customers have camped outside the walls of the institute for weeks. The well-guarded entrance gate bottlenecks a steady stream of ambulances, cars, pedestrians, and staff. Beyond the entrance, in contrast to this crowded space, the 233-acre hospital campus is lined with trees and dotted with open gardens. This contrast reflects the founding vision of the institute, whose first buildings were constructed in the heady first decade after Indian independence as part of Jawaharlal Nehru's plan for the new nation-state. Nehru's dream was that along with the nearby Indian Institute of Technology, AIIMS would produce a class of Indians insulated within elite centers of excellence.⁶ These scientists and researchers would be free from government interference and the uncertainties of social change. Thus unencumbered, they would work on the native Indian subject as a resource to educate and cultivate. Srirupa Roy describes these spaces as nation-statist heterotopias, imagined as unmarked by identities and interests.⁷ Others shared Nehru's vision. Brought to India as a scientific consultant in 1943, the British Nobel laureate Archibald Hill recommended that "a great All India Medical center should be established, an 'Indian Johns Hopkins' staffed in all departments by the ablest people everywhere."⁸ In 1946, a committee led by the Indian civil servant Sir Joseph Bhore took Hill's advice and gave AIIMS its name and institutional structure.⁹



FIGURE 3.1 The All India Institute of Medical Sciences (AIIMS). Photo by Javed Sultan.



FIGURE 3.2 Patients queued outside the gates at AIIMS. Photo by Sushil Kumar / *Hindustan Times*.

In the present, the heterotopic fantasy of a space insulated from social chaos falls away as soon as one enters its gate.¹⁰ The institute estimates it treats more than 3.5 million outpatients every year. Patients with meager economic resources are drawn here by the promise of the highest quality of medical services at a cost subsidized by the government. The paths to the superspecialty buildings evidence relationships of care under conditions of duress: a child, no older than ten, guiding his father by the hand from the subway to the entrance; a young man carrying another on his back with a practiced effortlessness. The most debilitated lie on makeshift stretchers outside buildings. Before they encounter medical staff, they will have to negotiate the fixers who surround the building. The wait time for tests performed within AIIMS can be a few months; these fixers arrange to have patients' tests done at nearby diagnostic centers, charging them a higher fee. Some will help patients jump the queue or, for a larger fee, even secure hospital beds. Security guards with whistles patrol the buildings and manage crowds. Mostly, their whistles warn errant visitors away from restricted spaces. Sometimes, they deliver warnings, clearing a space for emergency patients rolled on stretchers along potholed roads. AIIMS is more the debris and ruin of a heterotopic historical vision than its practical realization.¹¹

During my fieldwork in 2012, I found the cancer hospital exemplary of the paradoxical juxtaposition of care and duress at AIIMS. Called the B. R. Ambedkar Institute Rotary Cancer Hospital, it is one of twenty-seven state-accredited regional cancer centers for all of India. Many patients travel here over long distances across North India for treatment. In part, they are drawn to the center by the reputation of the country's flagship public hospital within which it is situated. To meet with a specialist, patients and their families queued inside and then outside the building in the early hours of the morning. The first queue led to rooms that housed patient records. New patients had a new file recorded, and returning patients registered their arrival; then, both sets of patients joined longer queues that led to three outpatient rooms. The process of queuing took several hours, culminating in a short ten- to fifteen-minute consultation with a specialist. The most debilitated lay on stretchers along the passageways; others stood, to not lose their place. The outpatient meeting rooms were some of the busiest and most chaotic spaces at AIIMS. During prearranged clinic hours, teams of doctors would arrive, jostling past patients to make their way into the rooms. Once past the crowds, they would seat themselves around two or three small tables while a staff member brought them the day's patient files. During each scheduled four-hour outpatient time, three or four doctors would meet with



FIGURE 3.3 The B. R. Ambedkar Institute Rotary Cancer Hospital at AIIMS.
Photo by Javed Sultan.



FIGURE 3.4 Patients waiting on cots outside the emergency ward at AIIMS.
Photo by Saumya Khandelwal / *Hindustan Times*.

more than one hundred patients. This included glancing over patient records, recording new data, conducting diagnoses, prescribing medicines, scheduling tests, and communicating prognoses. Here, as Julie Livingston observed in Botswana, the form of triage was multilayered.¹² An independent journalistic investigation into AIIMS in 2011 revealed that getting an appointment for an MRI could take anywhere from a month to a year and that a CAT scan has a waiting period of more than four months.¹³ As for curative interventions, surgeries for malignant tumors could take up to six months, while patients with benign tumors waited nearly two years.

Under these conditions of infrastructural pressure, pain often accompanies cancer. To elaborate, for patients diagnosed with certain types of cancer, pain is inescapable. Tumors may compress the spinal cord, damage nerves, press upon organs, or spread to bones. At times, pain is also an outcome of cancer's highly debilitating treatments—surgery, chemotherapy, and radiation. But for all its variations, one predictor of the presence of cancer pain is the stage to which the disease has progressed: it is twice as likely that a patient will experience moderate to severe pain if their cancer is advanced.¹⁴ It is no surprise, then, that in India, where patients are almost always diagnosed at late stages of disease progression, pain is an overwhelming part of cancer. Such a strong association of pain with cancer is inevitable in other parts of the world too, where infrastructural conditions do not support timely diagnosis. For example, global health researchers describe a “pain gap” between the global north and global south, captured succinctly by a Lancet Commission report which indicated that in 2015, 80 percent of the 25.5 million people who died with need of and without access to palliative care were from lower- and middle-income countries.¹⁵ It also found that only twenty countries in the world had integrated pain specializations into their public health systems.¹⁶

While global health experts have only recently described a global “cancer pain epidemic,” palliative care practitioners in Delhi have been actively responding to the condition for more than two decades. My first clues to the practices that have cohered at AIIMS appeared in a conversation with Dr. Abha, an anesthesiology resident in the palliative care unit: “When I was fresh out of medical school, I used to look at a patient and say if you have lung cancer, you should have pain in the chest, and nowhere else.”¹⁷ The complex pathways, etiologies, and somatosensory frameworks of cancer pain require specialized medical training; these concerns were not part of the traditional training of an Indian anesthesiologist. Dr. Abha laughed and added something that every resident told me during my fieldwork: “You

know, practicing palliative care, you really shift in your orientation. You begin, or at least try, to think of pain from the patient's perspective, or even the family's. You begin to see *through the patient's eyes*" (emphasis added). This orientation that Dr. Abha pointed to—of seeing "through the patient's eyes"—was the mantra of pain therapeutics at AIIMS; I would hear it again and again in conversations with other residents, at training sessions for doctors in different parts of the city, and in weekly staff group meetings. Of course, the encouragement to cultivate an empathetic orientation in medicine extended beyond the specificity of palliative care at AIIMS. I could find similar exhortations—"to adopt the patient's perspective," "to share the patient's pain"—in palliative care textbooks published in North America and Europe. However, hearing it repeatedly, I wondered about the specificity of empathy in this pain clinic, and the distinct orientation that residents were urged and able to cultivate *here*.

Dr. Abha and I were talking in the room in the anesthesiology unit that housed the old research computers I was working on. The room doubled as the residents' makeshift office space, where they took breaks for meals, conducted impromptu meetings, and discussed difficult cases. It was just a few feet wide and long and contained a small sofa and dusty piles of old, discarded patient files. While I queried an institute database for a project I was collaborating on with the residents, Dr. Abha described a battle between the head of the palliative care unit—Dr. Nigam—and the hospital bureaucracy. "It took Dr. Nigam ten years to even get us this small room and the six-bed inpatient unit. Earlier, we just had an OPD [an outpatient department], and soon realized that if we were to do any meaningful work, we needed to admit patients! She fought for years, and they finally gave us the six-bed ward. It's not much, but it is at least a start." The struggle for space and resources reflected a broader disciplinary struggle to have cancer pain recognized as a syndrome in its own right, and for palliative cancer care to be recognized as a specialty with its own standing. Finishing her lunch, Dr. Abha good-humoredly pointed around and told me, "Imagine, at first we didn't even have any space to show our families around when they would come to visit us at work."

The emergence of palliative care both at AIIMS and in Delhi has much to do with the charismatic head of the anesthesiology department. Dr. Nigam began her career in 1991 at a small municipal hospital in Bombay. In 1999, she was hired as an assistant professor at AIIMS, and by the time of my fieldwork in 2011–12, she had risen through the ranks to a full professorship. She was also a founding member and editor of the *Indian Journal of Pal-*

liative Care and served on several governmental committees on regulating pain management. She has been responsible for introducing the specialty to this flagship government institution's teaching curricula and therapeutic practice. AIIMS remains one of the few medical teaching institutions in the country that recognize palliative care as a specialty. At the time of writing, it offers both a doctoral program that allows students to specialize in palliative medicine and a postdoctoral fellowship leading to a further subspecialization in onco-anesthesia. Dr. Nigam had also campaigned for renaming and upgrading the palliative care unit as the Department of Onco-Anesthesia. "Onco-anesthesia" was a hyphenated neologism I had never heard before I worked at the ward. It was only a year later, while scouring medical publications, that I found the word in the title of an article in an international anesthesiology journal that prospectively called for such a future subspecialty.¹⁸ At AIIMS, Dr. Nigam was anticipating this future, and her pioneering work had not gone unnoticed. Her office desk was lined with several international awards, including a prestigious one from the International Association for the Study of Pain. She was involved with World Health Organization (WHO) initiatives to develop shared pain management expertise across developing countries in Africa, South Asia, and Southeast Asia.

But for all her international recognition, the achievements she took the most pride in were the young residents she trained to specialize in the emerging discipline. Given the specialization's relative lack of prestige, this had been no easy task. At the time she entered the field, government funding for cancer care was already plagued with problems. A senior oncologist recalled how the visit of a foreign dignitary in 1998 occasioned a paint job worth 400,000 rupees, while his request for the sterilization of the unit's toilets was dismissed as too expensive. At the time, he went on, one of the CAT scanners at the institute had been in need of repair since 1991, the inpatient units lacked air conditioners, and the outpatient waiting rooms did not even have fans for relief from the heat of the Delhi summer. It was within these infrastructural challenges that Dr. Nigam had started a new palliative care ward, secured a space for outpatient meetings, and set up the residents' office.

Within these infrastructural limits, Dr. Nigam and her teams of residents worked tirelessly to sketch out the contours of cancer pain as a research and therapeutic object. She was an exacting mentor, demanding that the residents not only keep up with an exhausting patient load but also complete a monthly quota of publishable research. During my time there, I would design and execute two collaborative clinical research projects with the residents, one of which was published, and the other used as the starting point

for new projects.¹⁹ The published article was a clinical audit of the pain ward. The second aimed to redesign the clinic's pain assessment procedures, paying special attention to factors understood as nonbiological or "psychosocial" indicators of distress. Both projects immersed me in the complex world of clinical research and diagnostic questionnaires concerning pain.

While similar questionnaires used elsewhere in the world have been standardized to ensure quick quantification and comparison, an examination of the institute's questionnaire revealed a different story. First, I found that given the constraints of time, questions understood as "psychological" and "social" were often left unanswered by examining doctors. Second, even for those that were filled in, the overall design hindered standardized quantification contributing to an overall score. Third, a study conducted at the pain clinic seven years earlier by clinical psychology researchers had discovered high incidences of "depression" and "anxiety" among cancer patients.²⁰ However, in the outpatient questionnaires I surveyed, such conditions were rarely reported. The recommendations we made at the conclusion of the study demanded more attention to depression and anxiety during interviews. I also suggested in the paper that we adopt a research instrument validated in Kerala.²¹ This instrument—called the Distress Inventory of Cancer—was the only one I found in India that related socioeconomic conditions to psychological distress. Its authors highlighted the importance of socioeconomic standing, educational background, and the quality of medical infrastructure in easing or increasing psychological pain. In our collaborative paper, I wrote that given the vulnerabilities of the institute's patient population, this diagnostic instrument would be more sensitive to psychosocial distress.

While our collaborative work was well received, I soon realized that research had a more complicated role to play in the institute's setting. In a meeting about future collaborations, I asked the residents if they knew when our recently completed research would be translated into practice. The residents met my question with equivocation. Finally, one of the more senior residents, Dr. Arjun, demurred by asking me to help him administer the existing pain questionnaire during the next outpatient clinic. As I helped him do so, it quickly became clear that the heavy patient load made the administration of most global instruments exceedingly difficult, if not impossible. We were scheduled to spend four hours in the outpatient clinic. Administering the pain questionnaire to the first patient, I watched the clock run up to fifteen minutes before I finished. Looking at the queue, I saw at least forty patients impatiently waiting in line for Dr. Arjun. Meanwhile, his lesson

taught, Dr. Arjun had abandoned the questionnaire for his usual mode of outpatient examination. While I had been administering the questionnaire, he was talking to an elderly woman, who was flanked on either side by her two sons. She had her medical records with her, which showed she had advanced chondrosarcoma—a type of bone cancer. When Dr. Arjun asked for the X-rays, one of her sons replied that they were with another doctor. This response was not uncommon at the pain clinic. It usually meant one of three things—the tests were lost; the tests were indeed held by a private physician who did not want the patient to seek treatment elsewhere; or the patient and/or family mistrusted the tests or else were withholding the results, hoping to get a favorable second opinion. Dr. Arjun asked the woman directly to describe her pain. She said it throbbed like a gas flame and was becoming more constant. A month ago, it was worse at night, keeping her husband and daughter-in-law awake. Now, she could not really tell much of a difference between night and day. Dr. Arjun nodded in response and turned his attention to a lump close to the woman's left knee. The sons interrupted, never once mentioning the word “cancer,” calling the lump a *soojan* (swelling). Dr. Arjun quietened them with a look and began to feel his way around the lump. With just two fingers, he pushed and probed, asking at short intervals: “Does it hurt here? And now? And here?” He nodded and gently felt around the edges of the growth. When the woman tensed up, Dr. Arjun reminded her to relax and trust him. While continuing to sense his way, he asked her to stretch her knee and to stop where it was uncomfortable. He also asked which position she found the most restful. He then returned to the focal point of the lump, this time pressing more firmly and judging the woman's discomfort. Satisfied with his examination, he looked back once again at the sheet of paper they had brought, as if to confirm what he had just felt. Dr. Arjun asked the sons where they lived and worked; I knew from prior exams that this was his way of ascertaining what drugs they could afford. Determining from their responses that they were neither wealthy nor extremely poor, he prescribed a cocktail of generic morphine, an antidepressant, an anti-inflammatory painkiller, and an anticonvulsant. As the woman left, I asked Dr. Arjun why he had not asked for further tests. He replied that asking for further tests would lessen the chances of their returning to the pain clinic, and that his touch examination had helped him confirm that the tumor had metastasized rapidly. He guessed, too, that the oncologist had understood that curative treatment would be futile. Finally, he recognized that the sons had kept the diagnosis from their mother, but that she too knew all about her condition. How Dr. Arjun would gather all this from the conversa-

tion and exam remains somewhat of a mystery to me; pressing him further did not yield new insight. Instead, he shrugged and said it was “experience” that had taught him pain diagnosis, not just textbooks. Mercifully, he did not mention the pain questionnaire.

Administering even the shortest versions of global cancer pain questionnaires, let alone finding the time to score and record them, had been a lost cause. Instead, Dr. Arjun’s lesson was an education in tacit knowledge—a familiar anthropological preoccupation I had almost lost sight of. In his canonical work, Michael Polanyi made the simple assertion that we can know more than we can tell.²² He deepened this insight by suggesting that processes of scientific formalization often threatened to destroy tacit knowledge gained through proximal, personal, and bodily encounters. One might think of testing and quantifying as precisely such moments of formalization. The tactility of the knowledge that Dr. Arjun possessed was not easily amenable to quantification—either as a research model or as a questionnaire. In itself, this resistance of the practical to abstraction is not surprising. I want to point out here the particularity of the relation of the tacit and the explicit. Pain practice took place in conditions of infrastructural pressure where even the conduct of research itself is a luxury. It relied on habit, experience, and tactility. It engaged the sensory and experiential in ways that opened therapeutic conversations, relationships, and possibilities. Pain questionnaires, in contrast, engaged the body more distally. Rather than play a significant role in guiding practice, they often helped gather data for research. In what follows, I delve deeper into this tension between practice and research and between the proximal and the distal. On the one hand, practice engaged the somatosensory in ways that allowed for certain modes of empathy to cohere. On the other, pain research helped establish the grounds on which palliative care could grow as a biomedical field. Cancer pain—as both a therapeutic and an epistemological subject—cohered in this push and pull between research and practice.

The Metaphysics of Research

The possibilities and limits of cancer pain research in India first presented themselves to me during the annual conference of the Indian Association for Pain and Palliative Care at Kolkata in 2012. Dr. Nigam and the residents at AIIMS were among the event’s headliners. I had traveled to the conference to present some of my early ethnographic work while also hoping to speak with leading cancer pain specialists from regions outside Delhi. It

quickly became clear at the conference that cancer pain research in India was at a stage where some of its most basic vocabularies were still uncertain. Unsatisfied with the applicability of pain research developed in the United States, several participants spoke about the need to develop indigenous cancer pain questionnaires. One presentation included an anecdote that described the difficulty of indigenizing an American pain questionnaire that asked whether the patient ever experienced the sensation of “butterflies in the stomach.” For a while, the discomfort of several patients when asked that question perplexed the doctors who were administering this questionnaire. Only after several weeks did they realize that the phrase “butterflies in the stomach” had elicited concerns about meat eating among vegetarian patients. Interrupting the laughter that followed this anecdote, a senior doctor from South India raised a question about a specific American diagnostic instrument he had been considering for use at his hospital. In responding to this question from the floor, one panelist wondered in passing about how that doctor could afford the high copyright pricing on that instrument. The uncomfortable conversations that followed soon revealed that the doctor had not known that such tools were under copyright in the first place. The murmurs that went around the conference hall revealed that he was not alone. Already, it seemed that there was a gap between the pervasiveness of pain questionnaires as diagnostic tools in the global north and their relatively recent and uneven arrival in Indian pain practice.

Misgivings about copyright aside, a more fundamental concern exercised these participants against global pain diagnostic questionnaires. The point of friction they identified in the translation of such instruments formulated elsewhere was that the instruments were not attuned to the spiritual orientation of Indian patients. At first, I was not surprised by this insistence on the importance of spirituality in Indian emotional life. Through the British colonial period, the region was associated with an otherworldly ascetic ethic. Its inhabitants were imagined by Europeans as predisposed to a transcendental negation of this-worldly sensations and experiences, and death and pain were understood as exemplary of detachment and equanimity.²³ Anthropologists and historians working in the region have demonstrated how this characterization of the subcontinent lent itself to the colonial project. If native subjects were understood to be more concerned with otherworldly matters, then it was the task of the colonizer to provide them with a grounded political orientation—that is, the colonial government.²⁴ Similarly, contemporary American medical ethics textbooks, journals, and monographs look to India to teach the “West” to be more accepting of death

and to resist Euro-American trends toward overmedicalization.²⁵ Thus, it seemed plausible to me that contemporary Indian research would echo these past constructions of pain. The conference evidenced many such reverberations. In a panel on palliative care ethics, the backgrounds of several slide-shows were composed of faded-out tableaux of Hindu gods and goddesses. Ethical guidelines about “dying well” from Hindu scriptural texts were laid over these tableaux, intended to urge doctors to pay attention to particularly Indian spiritual needs. Later, at a training session on how to communicate a terminal prognosis, participants were urged to look for signs of religious orientations and to temper their communication using the vocabularies of resilience and forbearance found in “Hindu” religious belief.

To take a longer view, research into the relation between ascetic transcendence and culturally “Indian” practices at AIIMS is as old as the institute itself. In 1952, a French cardiologist, Therese Brosse, traveled to Delhi to conduct experiments on yogis to explore their ability to control their heart and respiration. She had already visited in 1936 on a French medical mission and had tested the famous yogi Tirumalai Krishnamacharya, with positive results for her claim.²⁶ During her 1952 visit, she could not conduct her experiments because an electroencephalograph that she had sought to import from America did not arrive in time. The machine finally arrived in 1957 and was installed at AIIMS. In 1961, a team of three researchers—from UCLA, the University of Michigan, and AIIMS—sought to confirm Brosse’s finding, even retesting her original subject.²⁷ Their conclusions prevaricated on Brosse’s claim. They suggested that the machine Brosse had used was not sensitive enough to record what they found: that some of the yogis could significantly slow their hearts, but none could stop it. Another example of research with the electroencephalograph at the institute was conducted on Shri Ramanand Yogi, who was studied in an airtight sealed box for ten hours (figure 3.5).²⁸ The study concluded that by controlling basic involuntary biological mechanisms, the yogi could significantly reduce his oxygen intake and carbon dioxide output.

As William Broad describes it, experiments such as these sought to move asceticism from a science of the spectacular and mystical to one that was measurable, biological, and observable.²⁹ Drawing on Projit Mukharji’s analysis of Ayurveda in a different time period, the reconceptualization of asceticism might be described as a shift from a pataphysics to metaphysics: from a science of the singular, the unrepeatable, and the inexplicable, to a science of explicability and representability.³⁰ In other words, if pataphysics acknowledged limits of generalizability and understanding, the new mod-

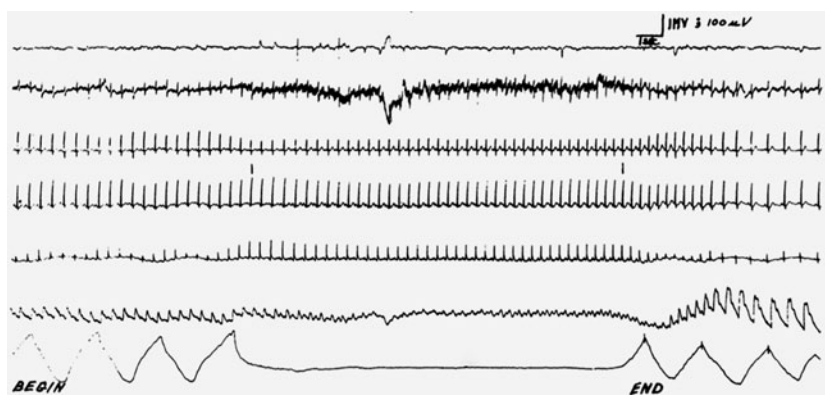


FIGURE 3.5 EEG report from an AIIMS study on Shri Ramanand Yogi's ability to voluntarily "stop" his metabolism and respiration. From B. K. Anand, G. S. Chinna, and B. Singh, "Studies on Shri Ramanand Yogi during His Stay in an Air-Tight Box," *Indian Journal of Medical Research* 49, no. 1 (1961): 88.

ern postcolonial metaphysics was amenable to representations in machines such as the electroencephalograph. This early work at AIIMS was crucial in opening the domain of the mystical and spiritual to measurable biomedical research. The collaborator on the Brosse confirmation research—Dr. Bal K. Anand—would continue research on yogic practices over the next two decades at AIIMS. By 1969, Dr. Anand's collaborator, Dr. Chinna, claimed that more than five hundred yogis had been tested in the first two decades of the institute, and that the team at AIIMS were close to putting yoga on a "rational basis."³¹ Even as studies such as these continued through the postcolonial decades, the turn of the twenty-first century saw an exponential increase in the scale of such research. Whereas somewhere between 10 and 30 studies were published in five-year periods from 1967 to 2003, the number tripled to 76 for the period between 2004 and 2008, and then tripled again to 243 between 2009 and 2013.³² It was also around the turn of the century that I found the relation between spirituality and cancer pain emerging as a biomedical research concern in India.

One of the first articulations of cancer pain as a problematic appeared in 1998, in a clinical psychology study that sought to understand culture as a factor in how patients dealt with terminal cancer diagnoses (figure 3.6).³³ This early study set a precedent for foregrounding spirituality and a theory of karma as strongly determining a patient's ability to cope with cancer. Positing that metaphysical beliefs strongly influenced psychological well-being,

Table 2
Correlations of Causal Beliefs with Perceived Controllability and Measures of Psychological Recovery (N = 132)

<i>Causal Beliefs</i>	<i>Perceived Controllability</i>	<i>Perceived Recovery (Measure 1)</i>	<i>Reactions to Crisis (Measure 2)</i>	<i>Psychological Recovery (Measures 1 + 2)</i>
Fate	-.22*	.07	-.06	-.03
God's Will	-.22*	.20*	.11	.15
Karmaphala	-.12	-.04	-.12	-.10
Own Carelessness	.04	-.14	-.08	-.10
Bodily Weakness	-.04	-.16	-.25**	-.24**
Mental Stress	-.05	-.30**	-.36**	-.36**
Family Circumstances	-.03	-.26**	-.31**	-.31**
Other's Negligence	.23**	-.12	-.13	-.14

Notes: * $p < .05$. ** $p < .01$.

FIGURE 3.6 Table from a study that measured the relation between beliefs about illness and psychological recovery. From Neena Kohli and Ajit K. Dalal, "Culture as a Factor in Causal Understanding of Illness: A Study of Cancer Patients," *Psychology and Developing Societies* 10, no. 2 (1998): 123.

the authors concluded that patients who attributed illness to God's will and karma (rather than physical etiology) were better equipped to deal with cancer-related psychiatric distress. A study published two years later developed this hypothesis by studying the correlation between spiritual belief and recovery across a range of life-threatening diagnoses, including tuberculosis, heart disease, and cancer (figure 3.7).³⁴ In this second study, the results confounded researchers. It appeared that in some diseases, a Hindu attribution of disease to a transcendent religious will helped in coping and recovery, while in others it hindered psychological well-being. These conflicting results pushed subsequent researchers in opposite directions. Some researchers wondered whether the effect of religious beliefs was too varied for statistical quantification; others hoped that they could resolve these anomalies through an accounting for a broader range of variables. As transcendent Indian spirituality became a central theme, it led to practical suggestions for therapeutic management. Several studies suggested that "spirituality" did indeed offer a powerful coping mechanism and that Indian practitioners should incorporate it into therapy.³⁵ Others suggested that research questionnaires needed to be modified to account for the role of Indian spirituality in psychiatric well-being.³⁶ At present, one of the leading researchers on this theme

Table 4
**Correlation of Health Beliefs with Psychological Recovery/
Adjustment Measures**

	<i>TB</i>	<i>MI</i>	<i>Cancer</i>	<i>Orthopaedic</i>	
				<i>Temp</i>	<i>Perm</i>
<i>n =</i>	70	70	114	20	21
Causal Beliefs					
Own Carelessness	.22	.30**	-.10	.30	.01
Other's Carelessness	-.24**	.01	-.14	.11	.25
Family Conditions	.26**	.02	-.31***	-.06	-.14
Fate/Chance	-.15	—	-.03	—	—
God's will	-.09	-.37***	.15	-.05	.29
Karma	-.06	-.19	-.10	.39*	.29
Recovery Beliefs					
Self	.05	.24*	.28***	—	—
Family	-.03	-.06	.16	—	—
Money	.08	—	—	—	—
Fate/chance	-.28**	—	.11	—	—
God	-.29**	.29**	.09	—	—
Karma	.18	.29**	.02	—	—
Doctor	-.12	-.18	.00	—	—
Control Beliefs					
Self	.40***	.21	.04	—	—
Disease	.18	.33**	.29**	—	—

Notes: * $p < .10$, ** $p < .05$, *** $p < .01$.

Temp = Temporary; Perm = Permanent.

FIGURE 3.7 Table from a study that measured the relation between beliefs about illness and psychological adjustment across different illness groups. From Ajit K. Dalal, "Living with a Chronic Disease: Healing and Psychological Adjustment in Indian Society," *Psychology and Developing Societies* 12, no. 1 (2000): 76.

is Dr. Santosh Chaturvedi, professor of psychiatry at the National Institute of Mental Health and Neurosciences. One of India's leading psychiatrists, he has published a range of clinical studies suggesting that particular forms of spiritual satisfaction correlate with "Indian" psychiatric well-being.³⁷ The broader implication of his work and the work of others on the theme was that if the "materialistic West" understood happiness materially and functionally, spiritual welfare might be an important dimension of well-being in India.

In 2016, Dr. Chaturvedi and a team of authors including Dr. Nigam (as well as researchers from the United States and Europe) collaborated on a research project at AIIMS to produce a spiritual questionnaire for Indian cancer patients.³⁸ This study was the most sophisticated attempt yet to co-

alesce the decades of interest in spirituality and pain into a concrete diagnostic tool. Much like my collaborative attempt to produce an appropriate “psychosocial” questionnaire, it aimed to assess the “spiritual” dimension of cancer pain. In consonance with the literature they drew upon, the researchers found a connection between spirituality and transcendence, understanding spiritual belief to be a belief in a power, force, or entity that transcended human life. Operationalizing this conception of spirituality, they set out to validate their initial questionnaire, enlisting three hundred patients at AIIMS as research subjects. Based on this questionnaire, this prospective study argued that most Indian cancer patients derived support from their relationship with the divine. The researchers also reported that older patients were more likely to bear the burden of an “existential blame”—attributing their disease to their own bad karma, sin, or wrongdoing. As for a correlation between spirituality and the intensity of pain, the study found that higher degrees of pain correlated with patients questioning their religious views and their belief in God. At the same time, the study recognized that earlier work had not found clear correlations between spirituality and the intensity of pain, and that the phenomenon of “spirituality” might be too complex to serve up clear, unambiguous correlations with pain scores. A year later, a follow-up study that included the original authors sought to find out the most common signs of spiritual distress from the same data, and to explore gender differences in these results. In this follow-up, the authors conceded that patients might exaggerate their belief in God in such interviews, conforming to wider Indian societal expectations to express religiosity. Yet, the authors contended, this did not invalidate what they believed to be the patients’ genuine longing for spiritual peace and divine support.

The emphasis on spiritual transcendence in studies such as these bears some traces of historical constructions of Indian spirituality. It is impossible to disentangle two centuries of European and native interest in ascetic resilience from the contemporary biomedical discourse about a particularly “Indian” capacity to invoke spirituality as a response to cancer pain. Yet, these long historical imprints are, at best, just traces; it is difficult to draw direct lines of influence from a colonial past to the contemporary future. The more proximate and explicit referents of such research are “new religious movements” that have become immensely popular among the Indian middle classes. Gurus of such movements seductively blend the languages of self-help, business-speak, and science, claiming to reinvent “old” traditions for the challenges of the contemporary world. Tulasi Srinivas describes the leaders of these movements as “hyper-gurus” who can build a global co-

alition of devotees and transnational infrastructures of support.³⁹ Further, Joanne Waghorne pinpoints their special popularity among technological professionals in global Asian cities, who are drawn to their guru's seamless mixing of business, scientific, and putatively "Hindu" vocabularies.⁴⁰ While working at AIIMS, I saw how in an interdepartmental project between the cancer institute and the department of neurology, one such new religious movement found its way into the research on cancer pain. This project sought to determine the effect of yogic practices on easing cancer-related distress. The practices identified for testing were Sudarshan Kriya, a set of exercises codified by the influential guru Sri Sri Ravi Shankar as the core component of the Art of Living. The goals of the Art of Living movement are seductively simple and nondoctrinal—to relieve stress, resolve conflict, and improve health. According to the movement's own estimate, it has more than 350 million followers worldwide. Ravi Shankar began his career working with Maharishi Mahesh Yogi in Switzerland, returning to India in 1981 to start the movement in Bangalore. The growth of the movement coincided with the explosion of IT firms in the city; middle-class entrepreneurs and businesses would become its chief followers. Nandini Gooptu argues that the movement articulates well with a middle-class politics of personal growth and responsibility; for example, she quotes Ravi Shankar as stating that those who demand rights from the state are weak.⁴¹

Ravi Shankar's influence has been significant at AIIMS, where some doctors at the cancer institute sign off research papers acknowledging his inspirational teaching. Much like the engineers described by Waghorne, the predominantly middle-class doctors at the cancer hospital were particularly open to his adept blending of scientific, religious, and self-help vocabularies. In part, his influence was routed through Dr. Panikkar, who joined AIIMS in 1975. She became the head of medical oncology in 1986, then rose to the highest position in the cancer institute as its chief director in 1992, a post she held until 2008. Having published more than a hundred research papers, she is one of the most prolific authors at the hospital. Through her time at AIIMS, Dr. Panikkar has been a strong proponent of the Art of Living movement. During her time as department head, she organized several international workshops and conferences on the benefits of Kriya for cancer patients, bringing in psychiatrists and oncologists from all over the world. She also worked alongside the Department of Physiology to set up a yoga space called the Integral Health Clinic. Although she was no longer the chief at the cancer hospital when I conducted my fieldwork, I was able to sit in on a presentation she conducted for the staff on the benefits of Kriya. The talk

began with an informal poll that asked, “Are you happy with your life?” When most members of the audience halfheartedly raised their hands, her reveal was that this poll was contrary to studies that show a high prevalence of depression and anxiety in India. She went on to talk about the mind-body connection and about neuropeptides as the “molecules of emotion.” This then led to her describing a perfect match between a map of chakras and of neuropeptides arranged along the spine. Having thus laid the ground for a relation between mind, body, and indigenous systems of knowledge, she introduced the Art of Living movement. Aware of her biomedical audience, she stressed the relation between Kriya, peptides, the frontal cortex, and endorphins. To demonstrate her point, she displayed electroencephalography (EEG) charts that showed a marked difference between those who practiced Kriya and those who did not. Her broader claim was that practicing Kriya increased “natural killer cells” and the body’s “antioxidant defense,” slowing down cancer progression. The presentation ended with a quote from Sri Sri Ravi Shankar: “The systematic understanding of reality is called science and systematic understanding of one who is understanding is called spirituality.”

In consonance with this blending of medicine and Art of Living, a series of recent clinical trials at the cancer hospital have sought to show the positive effects of Kriya and other forms of yoga on immune function, tobacco addictions, antioxidant status, and blood lactose levels. In 2004, Dr. Panikkar assisted an EEG-based study conducted on two groups of policemen. After six months, the experimental group was found to exhibit far lower levels of stress than the control group. A major pilot study between the cancer hospital and the Department of Biochemistry at AIIMS in 2008 identified positive effects of Kriya at the level of gene expression. During my fieldwork, I was able to follow a project that was the newest iteration of the theme of cancer and yogic practice. The team of doctors I worked with at AIIMS included a resident physiotherapist intern, Shilpa. A young woman in her twenties, Shilpa was placed in charge of a clinical research project to study the effects of yogic practice on cancer patients. The study was undertaken and funded in collaboration with the Ministry of Ayurveda, Yoga and Naturopathy, Unani, Siddha and Homoeopathy (AYUSH), a government body set up in 1995 under the National Ministry of Health and Family Welfare to encourage research into alternative health systems. The researchers at the cancer hospital focused on two forms of yogic practice: Kriya and Pranayama (exercises focused on the breath). This 2012 study sought to find out the influence of the combined practices on pain and stress among advanced-stage breast cancer patients. Shilpa would recruit eligible patients from the

outpatient and inpatient clinics of the institute and then train them for individual practice. This preliminary training took place over eighteen hours, spanning three days. Acknowledging the inability of poorer patients to repeatedly make their way to AIIMS, Shilpa taught them basic techniques they could practice at home. The team also developed a simple version of a self-monitoring chart that patients would be responsible for over two to three months. At the end of this period, they would report to the institute for tests, including the measurement of their serotonin levels (a neurotransmitter associated with feelings of well-being and happiness).

Shilpa's task was not an easy one. Human subjects research on vulnerable cancer patients has had a difficult history in India, as in many other parts of the world. For example, in 1997, the *British Medical Journal* threatened to blacklist all research published by biomedical researchers in India. This was after it was revealed that the Indian Council for Medical Research had sanctioned cervical cancer research that did not inform 1,100 patients about the existence of precancerous lesions, leading to 62 of these women developing cancer. While AIIMS was later absolved of participation in this trial, the cloud never lifted from its inclusion in the accusation.⁴² As rumors of clinical research malpractice abound, lower-income patients justifiably feel anxious about becoming unwitting research subjects in trials they do not fully understand, and might never benefit from.⁴³ To ensure the compliance of advanced-stage patients, Shilpa had to follow up with nearly every one of her recruits, grapple with high dropout rates, and fight for the resource-constrained testing facilities at the biochemistry department. She managed to enroll 147 patients in the trial and, miraculously, was able to convince them to come back for three-day workshops when large enough groups had been assembled.⁴⁴

Conducting the trial involved Shilpa spending long hours at work well beyond the normal clinic schedule. She was already vital to the pain and palliative care team, which called on her to help negotiate the large influx of patients in the outpatient wards. The clinical trial made a heavy demand on the time of both the patients and the staff of the cancer institute. Yet, as its current flagship research project, conducting the trial was a priority that neither its administrators nor its participants could ignore. When the study was concluded, its authors reported that 78 percent of the intervention group regularly practiced what they were taught in the workshop.⁴⁵ The authors admitted that it had been difficult to determine whether subjects were able to follow the strict practice schedule when they were at home. Finally, the authors concluded that they had found a statistically significant

difference between the cortisol levels of those who had received standard biomedical treatment and those who received the standard treatment supplemented with Kriya and Pranayama. Celebrating the positive result, the authors suggested that this kind of therapeutic intervention was wonderful, since it could be universally applied: yoga could be “uniformly followed across the countries, irrespective of cast [*sic*] creed.” Bolstered by two decades of such research across the cancer institute as well as at other departments at AIIMS, a new Center for Integrative Medicine and Research was inaugurated in the hospital in 2016. The four-thousand-square-foot facility houses a massive yoga studio and an Ayurveda and naturopathy center. In inaugurating the facility, the Indian health minister J. P. Nadda identified its cost-effectiveness benefits for the poor and stated that it was another step in the government’s goal of continuing to shift focus away from treatment and toward well-being and prevention.⁴⁶ Because noncommunicable diseases were primarily caused by lifestyles, he added, they could be “easily cured by practicing yoga,” even in “malignant” cases.⁴⁷ As I discussed in the introduction, the context of Nadda’s statements is a long shift in government policy away from treatment and toward behavioral modification. They reveal the continuing implications of framing noncommunicable diseases as “lifestyle” problems. In this instance, a proposed “Eastern” practice is operationalized to treat cancer, a disease associated with “Western” lifestyles.

In tracking this orientation in biomedical research on cancer pain in India, and particularly at AIIMS, I thus found sincere efforts to conceptualize cancer pain as more than its physical etiologies and biological damage. Through measurable and evidence-based research, palliative cancer care researchers and physicians sought to expand the definition of pain to encapsulate further dimensions and etiologies, variously understood—the “social,” “psychological,” and “spiritual.” At the same time, in enacting this desire to expand the etiological boundaries of cancer pain, they often took recourse to old and new vocabularies of resilience and transcendence. The “psychosocial” that came into being was a manifestation of these contextual conjunctures, diffusing pain through the capacities of the putative “Indian” mind.

To my mind, even as this research promises novel therapeutic approaches to dealing with the distress of cancer patients, it frames the extrabiological in ways that might need some rethinking. Its explicit focus on “transcendence” reveals in sharp relief the absence of research on the more this-worldly socioeconomic forms of affliction. To think of this in another way, palliative care research frames existential concerns (the waxing and waning of faith, of divine support, of the cause and blame for misfortune) as

separate and distinct from the difficulties of everyday life. This, despite Dr. Nigam's perceptive claim in one published piece that poverty was perhaps the most crucial factor contributing to the suffering of Indian cancer patients. My intention here is not to call into question the growing interest in the spiritual dimensions of pain. More recent work (particularly the collaborative research at AIIMS that involves health care researchers across the United States and Europe) has taken seriously the multidimensionality of what a concept like spirituality might mean and acknowledged the difficulty in finding correspondences between its many dimensions and intensities. However, I suggest that thickening this research, framing the "spiritual" as growing out of everyday life and not emerging as above and apart from it, will reveal new directions for understanding the existential dimensions of cancer pain. As I have described in prior chapters, feelings of anger, blame, hope, and helplessness are rooted in the everyday worlds in which cancer appears, and not primarily dependent on religious and cultural beliefs that stand apart from social life. If palliative cancer care research aims to identify the transcendental and the otherworldly as sites of both distress and support, my aim here is to continue to put the otherworldly in conversation with more immanent concerns.

Acknowledging Limits

In my first few days of working at this palliative care unit, I encountered Hardeep Singh, a patient whose name I had heard mentioned in several conversations. He was the stuff of lore among pain professionals in Delhi. In conferences, talks, and meetings, discussions of his case would bring together practitioners who might never have met before. Hardeep was a sixty-four-year-old man who first came to the hospital in 2001 with a rare, fast-growing malignant mesenchymal tumor lodged in the bones of his right leg. Following the treatment protocol for this cancer, his leg was amputated above the knee. Hardeep returned to the hospital after ten days, showing telltale signs of phantom limb pain. He had already been prescribed oral morphine, and then Dr. Nigam increased the dosage. This was the first of many visits that continued until the time of my research. He would present with only partial pain relief, sometimes resulting in a further escalation of his morphine dosage. At other times, he would be admitted to the inpatient unit for more serious interventions. His relationship with Dr. Nigam had grown over this time. She had tried every available therapeutic option, delving deep into the biomedical literature on phantom limb pain. These

had included intravenous opioids, ketamine, electrical nerve stimulations, and a range of semi-invasive surgeries placing spinal cord stimulators, neuromodulators, and nerve blocks within his body. Hardeep's pain resisted each of these interventions. Through Dr. Nigam, Hardeep availed himself of therapies as advanced as any offered by the best pain clinics anywhere in the world. Yet, the only thing that provided him any measure of relief was oral morphine. And so, over the next decade, Dr. Nigam slowly raised his dose. By the time I met Hardeep, he was prescribed more than 1,200 mg of morphine a day, along with other pain-relieving medications.

Given his decade-long pain biography, only Dr. Nigam and a few other veteran oncologists had been at the cancer hospital as long as Hardeep. New junior residents often worried about the possibility of his addiction to his high morphine dosage and the "truth" of his mysterious pain. One junior resident went as far as to doubt even the existence of a baseline pain and attributed all Hardeep's actions to drug-seeking behavior, asking, "We've titrated his dose for over ten years, we've tried every block, every experimental procedure, nothing has worked. His pain is not physical. Should we not try psychiatric de-addiction therapies?" This was a familiar question for Dr. Nigam, one that many cohorts of residents had asked her before. As she had with his predecessors, she urged this new resident to think beyond the "easy" answer of addiction: "It is difficult to call him an addict. Yes, we should try it [de-addiction], and I will recommend an appointment with a psychiatrist. But pay attention to how he talks about his pain, how he always describes it in the same way, and how its intensity matches the dose. They are all classic symptoms of phantom limb. Go do your research, see if there are newer pain therapies we could try." In fact, they had already sent Hardeep to the hospital's de-addiction specialists to guard against this line of questioning. I never met the psychiatrist, but I was told that Hardeep had been cleared of the charge of "drug-seeking behavior."

Dr. Nigam's haste to clear Hardeep of the charge of addiction was crucial to maintaining their long-standing therapeutic relationship. As Helena Hansen and Mary Skinner have shown in their work on analgesic politics in the United States, long histories of politically stratified assumptions about patients and their psychiatric states lie behind the marketing and prescription of opioid painkillers.⁴⁸ Medical morphine is heavily controlled by the Indian state. In 1985, the Narcotics Drugs and Psychotropic Substances Act criminalized morphine, with a ten-year minimum mandatory sentence for prescription-related abuse. It also put in place bureaucratic hurdles for hospitals and pharmacies seeking to stock the drug. Thus, while the act might

have aimed to curtail addiction, palliative care specialists like Dr. Nigam argue that one consequence of its implementation has been the virtual disappearance of morphine from institutional medical practice in India. It took five years for the cancer care NGO that I describe in chapters 4 and 5 to negotiate a license to prescribe the drug to its terminally ill patients. At the same time, India remained the largest licit producer of raw opium in the world market, accounting for nearly 90 percent of global production. In 1998, two physicians filed a public interest litigation suit in the Delhi High Court, demanding the drug for cancer patients. Their mother had died of the disease a year earlier, and despite their connections with the pharmaceutical industry, they claimed they had been unable to procure any licit morphine. Their litigation led to the relaxation of licensing rules in eight out of India's twenty-nine states, including Delhi. Cansupport and Dr. Nigam's lobbying of the Delhi Drug Control Department had particularly eased restrictions in the region in 2007. Yet, through the course of my fieldwork in Delhi in 2011–2012, I found that doctors (apart for those at AIIMS) would often prescribe acetaminophen (Tylenol) or ibuprofen (Advil) for many instances of cancer pain.

However, most doctors campaigning for the availability of morphine—including Dr. Nigam—contend that the Narcotics Act did far more damage than just restrict legal sales. They suggest that it produced a climate of fear among pharmacists and doctors, even in places like Delhi that have seen the most legal reform. I encountered this fear of prescription when I sat in on one of Dr. Nigam's many training sessions in hospitals across the city. I sat in the audience as Dr. Nigam cited several studies that showed the relative absence of opioid addiction among terminally ill cancer patients. She went further to claim there was not a single documented case of opioid addiction among the cancer patients she had treated at AIIMS. While I was unfamiliar with the research she cited, I wondered at the strong concern about addiction among terminally ill patients who had little time to live in the first place. I was sitting in the audience with a general physician I had struck up a conversation with, and I asked him what he thought. He responded that he respected Dr. Nigam's expertise and thought she perhaps was right about morphine being the most effective therapy. But, he continued, the patients he saw would not understand the strict rules about how, when, and how much of it to take. He had enough on his hands, without the added hassle of dealing with a police case, if something were to go wrong. Throughout my fieldwork, I found echoes of his assumptions among

middle-and upper-class doctors about poorer patients' propensity toward addiction and illicit use.

To be clear, this is not to say that opioid abuse is not a problem in India and that the doctors' assumptions of a prevalence of addiction were necessarily wrong.⁴⁹ However, my aim here is not to evaluate the claims of morphine addiction in Delhi; rather, I am interested in how claims about the absence or presence of addiction guided palliative cancer care. In this regard, the difficulty of procuring licit morphine was the most cited concern expressed by the physicians I worked with. They published on, lectured on, and campaigned for public recognition that cancer patients did not abuse prescription analgesics, and they simultaneously produced and drew upon the discourse of an epidemic of untreated cancer pain. A statistic that recurred in their claims was that only 0.4 percent of cancer patients in India who needed morphine had licit access to the drug.⁵⁰ It is within this discursive context of an epidemic of cancer pain that Dr. Nigam sought to treat and rehabilitate Hardeep. Her aversion toward the quick label of addiction was a careful and strategic act, designed to keep at bay accusations of abuse and unregulated drug use. To call Hardeep an addict would place him in de-addiction interventions and could remove him from Dr. Nigam's direct care. In the severely controlled world of opiate regulation in India, she believed it could also lead to his decisive, long-term severance from future licit prescription. Further, cases such as these would compromise her continuing efforts to lobby the Delhi government and would dilute her argument that there had not been a documented case of opioid addiction among her cancer patients.

Toward the end of my time at AIIMS, Dr. Nigam threw a party at her home for past and current residents of the pain clinic. The conversation at the party drifted to Hardeep's condition, with one of the older residents narrating the following story. When the resident had joined the clinic, he had asked Hardeep in a tone of incredulity about his lack of relief from his high morphine dosage. He had even asked Hardeep if he had tried counseling and meditation. Hardeep had shot back, "You're new here, aren't you?" The memory of this quip evoked laughter all around. The conversation turned then to the "truth" of Hardeep's condition. A senior resident said elliptically, "With pain, you never know." Most nodded in agreement. Thus, while residents would continue to try every possible therapeutic option, Hardeep's phantom pain would meanwhile serve as a disciplinary reminder of the limits of what the pain specialists could do. While newer residents responded to Hardeep

with suspicion, older residents allowed the recalcitrance of Hardeep's pain to teach them lessons in humility. Both shared an openness to the idea that Hardeep's pain was "real," and that, in any case, if morphine helped ease his complaints, then so be it.

This theme of Hardeep's recalcitrant pain as a point of learning continued when I visited him in his home with Cansupport. After a treacherous car ride through the narrow by-lanes of a West Delhi housing community, we abandoned our car some distance from Hardeep's house. In collaboration with Dr. Nigam, the Cansupport team I was visiting him with had recently tried the well-known mirror box therapy devised by the Indian American neuroscientist V. Ramachandran. The mirror box is designed to trick the mind into seeing the amputated limb in a reflection of the existing physical limb. The phantom limb is thus made to appear real, allowing the patient to work through the virtual pain through physical exercises. The mirror box exercise perfectly illustrates the neuroscientific consensus on locating conditions of pain primarily in the brain. That is, if pain exists only as a virtual neuronal image, the malleability of the brain can be engaged by tricking it into believing a virtual limb exists, and then training it to release the limb's phantom pain. In Hardeep's case, however, the therapy had met with repeated failure. Instead, Hardeep continued to describe his pain through his own metaphors. The metaphors he drew upon were those that were most real to him from before his illness, when he had worked as a furniture maker. Pointing to his real limb, he described the pain in his absent limb as being like the hammering of nails and the cutting of a saw. Most of our visits consisted of the home-care team patiently listening to Hardeep narrate the events of his week, followed sometimes by adjustments to his morphine dosage that were punctuated by his descriptions of his recalcitrant pain. Sometime later, I visited Hardeep with a counselor who was new to the profession. This counselor tried to distract Hardeep with conversation about his family and his grandchildren, urging him to think of the time that had passed since his amputation and of the comfort that his familial life must provide. In response, all he received was Hardeep's famous condescension. The more experienced doctor who had been collaborating with Dr. Nigam for several years winced at the counselor's intervention. Later, she would privately tell me that perhaps this failure was for the best; it was a way for the counselor to learn the limits of what they could do.

Phantom limb pain is not the only type of cancer-related pain, nor is it even necessarily the most common. Like most kinds of cancer pain, it is related to the type of cancer, its correspondent damage, the nature of treat-

ments, and the stage of the cancer's progression. I focus on it here primarily because of the particular problem it raises for pain physicians. As a kind of pain, it is without a specifiable location. It epitomizes the inherent and much-discussed difficulty of empathizing with pain: to relate to the pain of another is often to relate to something invisible, to take as fact a feeling one does not feel or cannot even see.⁵¹ The repetitive mantra of palliative care—of seeing through the patient's eyes—was then both a recognition of this problem of empathy and a wager that empathy in such conditions of doubt was still possible. To treat Hardeep's pain, the pain physicians had to take him at his word, moving past the cloud of his possible addiction. Dr. Nigam's pedagogical impulse was to introduce this problem of recognition and to communicate the necessity of staking their pain practice on trust. To see through the patient's eyes was *not* to directly feel the experience of the patient. Rather, it was to take the pain as real, attuned to the possibility of its intractability.

This orientation at AIIMS becomes clearer when put in relief against other biomedical approaches to phantom limb pain. In almost every work of contemporary pain science, a paper coauthored in 1965 by the neuroscientist Patrick Wall and the psychologist Ronald Melzack is cited as having laid the foundations for pain research.⁵² As Melzack has written since, in that paper they sought to correct a three-century-old biological model of pain therapeutics inherited from Descartes. For Melzack and Wall, prior pain theories presented an all-too-simple relationship between bodily damage and the nature and extent of pain as the body's response. They argued that this led to the devaluation of the psychological etiologies of chronic pain, since chronic patients often could not present signs of obvious organic damage. Instead, the "gate-control theory" proposed by Melzack and Wall emphasized the central nervous system and the brain as constituting an active system that filters and modulates sensory stimuli. Thus, the "psychological" factors of chronic pain (previously devalued as not real, since they had no biological basis) could now be understood as dynamically modulating the perception of pain. Through an appeal to the malleability of the central nervous system, pain physicians learned to understand psychological experience as central to pain. Because pain experience was no longer equated with physical damage, psychological factors such as past experience became legitimate therapeutic concerns.

However, in 1990, Melzack revised his earlier position and proposed a new refined hypothesis: the "neuromatrix" theory of pain.⁵³ The explanatory power of the neuromatrix theory lay in its claim of having solved the problem of phantom limb pain. The condition had resisted the gate-control the-

ory, which still rested on the presence of some form of physical damage or sensory input. The new theory proposed that a matrix of neurons produces characteristic nerve impulse patterns for the body and its somatosensory apparatus. The neuromatrix theory purported to explain not only how physiological damage produced unanticipated patterns of dispersed pain (often found in cancer pain) but also, and more ambitiously, how pain could exist in the absence of any sensory input at all (such as with phantom limb pain). Thus, as Melzack writes, “Phantoms become comprehensible once we recognize the brain generates the experience of the body.”⁵⁴ It is only by considering this neuronal theory of pain that the mirror box intervention to relieve phantom limb pain makes sense. If phantom pain can be found and localized in the brain, it can be alleviated by briefly tricking the brain into believing that the absent limb—evidenced by the mirror—is not absent after all.

The pain physicians at AIIMS were both part of this biomedical tradition and departed from it. In one study, Dr. Nigam described phantom pain thus: “The mechanisms for phantom phenomenon are complex and involve various elements in the somatic pain generators, peripheral nervous system, spinal cord, and brain.” Following the broader biomedical consensus on research into phantom limb pain, she too located it biologically—dispersing it across parts of the body—especially in the nervous system and the brain. Following from this, she attempted several interventionist pain therapies. At the same time, she remained open to the possibility of the ongoing intractability of Hardeep’s pain, even if it could not be precisely located in biological damage. Taking Hardeep as a paradigmatic case, she taught newer specialists to attend to pain while remaining attuned to the possibility of therapeutic failure. At the margins of the heroic interventions of curative oncology, these physicians worked within and through the uncertainties and long temporality of pain that could not easily be localized and removed. Allowing Hardeep’s phantom limb pain to rest somewhere between the possibility of addiction and truth, Dr. Nigam took this pain as a lesson about limits. The virtual excess of phantom limb pain—its unclear etiologies and resistance to imaging and treatment—was the point at which she turned her spade.

A Shared Death

At the palliative care ward, this pedagogy of limits was confined not only to pain but also to the ever-present possibility of death. If witnessing intractable pain taught practitioners to acknowledge the limits of their interven-

tion and to acknowledge and trust the voice of the patient, the reminders of mortality in a cancer ward demanded similar efforts at recognition and empathy. But, as I describe here, if phantom limb pain resisted easy translation from patient to physician, the fact of mortality was something that physicians could claim to share.

At the time of my fieldwork, Dr. Arjun was the most senior resident in the cancer pain and palliative care unit at AIIMS. Many other residents echoed the narrative of his turn to palliative care. Like Dr. Abha, his first serious introduction to palliative care and chronic cancer pain was not through his training as an anesthesiologist but under Dr. Nigam's tutelage at AIIMS. While many of his friends had left for the lucrative prospects of the United States after medical school, he had instead joined AIIMS. Then, three years ago (he cited the exact date as if it to underline its significance), his chest X-ray had showed the possibility of tumorous growth. He explained his reaction to this discovery in the following way:

I can't explain to you what that did to me. I spent the entire day thinking, knowing, I was going to die a painful death within the next six months, that's the prognosis with that kind of carcinoma. I didn't tell my wife or my parents. The next day I had a CT scan, where I reacted badly to the dye. Anyway, it turned out to be nonmalignant, and not even a cancer-related growth. I could only tell my wife after finding out that it wasn't malignant, and she's also a doctor! I couldn't tell my parents over the phone, I had to wait to physically see them. Every time I look at a patient, and I tend to lose my temper sometimes, but as soon as I think of this, I can't help but see the world *through their eyes* [italics added]. Trust me when I say this, anyone can get cancer, anyone. I don't drink, I don't smoke, but it nearly happened to me. Every time I have to get an X-ray now— there's a 20 percent chance of recurrence, so I have to get an X-ray every year—I have to really work up the courage to go.

A few weeks later, Dr. Arjun walked into the residents' office looking visibly distraught. He sat down at the computer next to me, clicking distractedly. Before long, unable to maintain his usual studied reserve, he sought a conversation. "I'm glad you're here, I don't really want to be alone right now." A patient the residents had all been close to, Kamini, was nearing the end of her life. Kamini was the wife of a member of the department's cleaning staff, twenty-nine years old and the mother of a four-month-old child. She had been battling the quick progression of her disease for the last year.

In that year, Dr. Arjun and Dr. Nigam had been particularly attentive to her care, in part because they were the ones closest to her husband. In the past few days, Kamini's condition had quickly deteriorated. While talking, Dr. Arjun added, "You've never been married. You can't know what this feels like." I remembered that his own daughter was just a few months older than the patient's child. Gathering himself, he returned to the inpatient ward where Kamini was admitted. A few minutes later, he returned and said, fighting through his tears, "She just passed." A little while later, Dr. Mohit—another senior resident—walked into the office. He had sensed that Dr. Arjun needed consolation. Over the next hour, they talked about how it was not the fact of death that scared patients but the desolation of the family members they left behind. Dr. Arjun and Dr. Mohit filled out the death certificate and paused over whether it was a "natural" or "unnatural" death, mulling over whether those categories really meant anything. There was some indecision about whether the cause of death was to be attributed to coronary failure, to the advanced progression of the malignancy, or to both. Dr. Mohit presented a stoic demeanor, saying, "I have got used to all this." Moments later, however, he turned to me to rhetorically ask, "How can anyone believe in God at a time like this?"

After a while, Dr. Mohit left the room to attend to the business of the inpatient ward. It was only then that Dr. Arjun told me that Dr. Mohit's father was in critical care at that moment, having struggled with multiple myeloma (a cancer of the plasma cells) for almost ten years. Dr. Mohit had first come to AIIMS not as a doctor but as a son accompanying his elderly father, queuing at the same outpatient lines he now administered. A few days later, I would find out that over the past ten years, his father had been in and out of critical care, and with each admission attending oncologists had told Dr. Mohit to give up and prepare for the end. Dr. Arjun said, quietly and with admiration, "He has single-handedly brought his father back to life, not once, but four times." He then described how his own cancer scare had changed his outlook on his work: "I used to have a bad temper before the diagnosis, and like many other oncologists here, I could not help but shout at patients when I thought they did not understand what I was saying. You know, we Indian doctors have a bad reputation for being angry. But after that incident, I have learned to become more of a palliative specialist. I try to wonder what it must feel like for them. You know, cancer is a disease that anyone can get. *There's no difference between them and me* [italics added]." When Dr. Mohit came back in, they talked first about a friend's wife who had been diagnosed with cervical cancer a few months after marriage. I

asked both doctors about how they felt about the choice to specialize in palliative care at times like this. Smiling, Dr. Mohit said other kinds of specialists talk about life, but all palliative care specialists think about is death.

The conversation shifted back to Dr. Nigam, as it often did in the pain ward. Dr. Arjun marveled at how she survived death after death among her patients: “She’s a very emotional person, and yet she has been doing this for twelve years now!” Often, they would describe her as a *bhavishyavan* (a divinator). Kamini (the patient who had just passed away) had come into the outpatient clinic a few days earlier. No other specialist at AIIMS had prognosticated how quickly her condition would decline; others had told her she still had time to live. At the outpatient clinic, I was told, Dr. Nigam had looked at Kamini and, after a brief examination, whispered to the residents that she had about three days to live and that they should immediately admit her to the inpatient ward to manage her pain. I had not been present when Dr. Nigam had prognosticated Kamini’s death in the way that had struck the residents, but I had seen many times before how she and other more experienced palliative care residents quickly took in the condition of patients even in the most fleeting of outpatient clinic encounters.

These prognostic moments resisted formalization and verbalization in much the same way I described Dr. Arjun’s tactile diagnosis of pain. Acutely ill palliative care patients presented with innumerable symptoms such as pain, anorexia, constipation, numbness, anxiety, difficulty swallowing, weakness, labored breathing, nausea, and insomnia. To complicate matters further, their etiologies and prognostic implications were as numerous as the symptoms themselves. The weakened bodies of cancer patients manifested pain and discomfort in unpredictable sites and ways, sometimes unrelated to the original tumors and malignancies and reflecting systemic bodily breakdowns. Dr. Nigam’s ability to separate out the immediately life-threatening from the chronic was a skill she had developed through years of experience. In acute cases like Kamini’s, she looked for subtle shifts in heart rate and pulse, the color and clamminess of the skin, shifts in the quality of breath, the manifestations of fatigue in the eyes and body language, the sites of pain and weakness, sensory amplification and numbness, and, always, the distribution of pain. She also would look for signs of delirium or visible distress. Because psychological distress is an inevitable consequence of a cancer diagnosis, she would have to distinguish the kinds of disturbance (dysphoria, hypomania, hallucinations, somnolence) and determine whether they were the side effects of drugs or instead indications of temporary bodily imbalance or significant organ failure. The expertise of prognostication rested on

the reading of such subtle and constantly shifting signs, and a practiced ability to interpret them as a side effect of debilitating treatments or as a sign of permanent bodily breakdown.

On this last day of Kamini's life, the residents had tried to reach Dr. Nigam on the phone; she had been giving a lecture elsewhere in the city. Soon, Dr. Nigam arrived in visible distress at the residents' office. She was troubled not only because she had not been present at the time of death but also because the patient had not been sent home to be with her family. The residents apologetically explained that it had all happened quickly, and that the patient did not have an oxygen cylinder at home. Instead, they had brought the family to the ward to be with her in her last moments. I witnessed then how the inpatient ward had been turned into a space of grief, with curtains drawn, doors closed, and the family at the side of the patient. As silence fell upon this conversation, we could hear Kamini's husband weeping in the corridor between the office and the inpatient ward. Dr. Nigam tidied herself up and walked out to him. Through the doorway, I watched her standing with her arm on his shoulder, letting him cry. In a sight that was rare elsewhere in the hospital, I saw a doctor and patient grieving together in a space that for a moment felt less like a hospital and more like a place of mourning.

If relating to pain produced demands of empathy and recognition, witnessing death produced resonant claims. If pain attuned physicians to the limits of their interventions to ease suffering, witnessing death dramatized a similar helplessness in the face of human mortality. This reminder shook Dr. Arjun, even after his tumor turned out to be benign. The same reminder hung over Dr. Mohit, even as he struggled against all odds to save his father's life. The possibility of death was an ever-present haunting at the palliative care ward. In a hospital space designed to save or at least maintain life, the palliative care ward marked a zone where life could be allowed to ebb away. In 2013, Dr. Nigam wrote a powerful piece that captures this paradox. The piece began with her consoling a senior resident drained by her repetitive confrontation with death. This encounter pushed Dr. Nigam to ask: "All through as a medical student, we were preparing her to fight death, the enemy. We never prepared her to face the inevitable truth that death is a part of life. I pondered who really is afraid of death, the patient or us?" Growing out of this question, her hope for the medical profession was that it "accept death as an essential friend of all life forms, not a foe." If confronting pain demanded an acknowledgment of biomedicine's limits, confronting death demanded similar humility.



FIGURE 3.8
The palliative care
unit at AIIMS, with
its door closed.
Photo by author.

The Bounds of Empathy

The exceptionality of the space of the palliative care ward and the practices of empathy that were produced in its midst cannot be exaggerated. The perception in India that Dr. Arjun referred to—of doctors as uncaring and rude to patients from lower socioeconomic strata—is an enduring accusation, and not without some truth. Toward the end of my fieldwork, an investigative television show dramatically reenacted countless horrors perpetrated on patients by greedy doctors. At the same time, a study was being conducted at a nearby tertiary care hospital in Delhi. The study concluded that about 40 percent of doctors reported experiencing violence in the previous year, because of patients who were furious and frustrated by what they imagined to be medical negligence.⁵⁵ By the time of my last follow-up visits to AIIMS, I found that the institute had begun to offer self-defense martial arts lessons

to its medical staff, to guard against patients who turned against them. The careful practices of empathy I have described here contrast with these accusations of malpractice and neglect and a perception of unfeeling doctors pushing patients to their death.

A few years after my fieldwork, I found such accusations recur in a different register in a piece written by Sumegha Gulati, a journalist for *The Caravan* magazine. This was her “last dispatch” written for the magazine as she struggled with cancer.⁵⁶ In these writings, Gulati described the suffocating crowds within the cancer hospital at AIIMS. She recalled how her father would have to join the registration queue before dawn for every chemotherapy session, since only patients who registered by eight o’clock in the morning would receive treatment. While inside, she witnessed several confrontations between guards and the patients’ attendants seeking a word with their doctors. Each day, at least ten patients would be turned away at night, as time ran out for accommodating even those who had been able to register in the morning. When Gulati’s cancer recurred, her experience at AIIMS motivated her to move to Bombay for treatment.

If Gulati—an upper-class journalist with a network of social support in the city—described her experience as “harrowing,” it is no surprise that poorer patients who often travel long distances to reach the hospital might be at an even further end of their tether. Talking to patients queued outside the hospital, I heard endless angry accounts of prior neglect and present duress. One patient I spoke to stated that he was only visiting the cancer pain clinic because he was leaving for his home in Bihar the next day. The oncologist had told him his tumor needed to be surgically excised. He had heard too many stories of unnecessary surgeries in government hospitals, and he had no interest in being experimented on. He hoped that the clinic might give him enough morphine to afford him a couple of pain-free weeks back at his village. When I cautiously suggested this might be the wrong course of action, he shot back that people lost limbs and body parts at hospitals all the time against their will. Accusations of such medical malpractice are pervasive in India, and AIIMS has not been exempt. In 2007, a consumer court found AIIMS liable for the unnecessary mastectomy of a woman wrongly diagnosed with cancer. The next year the hospital was forced to set up an internal committee to review the death of a thirty-five-year-old man who had died when his oxygen mask was removed while he was being wheeled into the cancer institute. Rumors, investigations, and charges such as these have done little to bolster the credibility of public cancer care.

Palliative care unfolds in Delhi in the shadow of these widespread per-

ceptions of medical neglect, corruption, and malpractice. If I found that oncologists in the cancer hospital often withdrew from engaging with patients after terminal prognoses, I saw how it fell upon pain and palliative care specialists to deal with the last weeks of a patient's life. Thus, the pain clinic came to stand in as the space of hope for dying well, the provisional rubrics of a compassionate response to those who had been denied timely treatment. Yet, this is not to say that the care Kamini and Hardeep received was representative of treatment at the pain clinic. Dr. Arjun was not being overly self-critical when he said he could not help but shout at many patients under his care. Nor were all patients as demanding of their right to care as Hardeep. But while he would sometimes lose his temper, Dr. Arjun worked well over the institute's mandated forty-hour workweek, as did his colleagues. His eight-hour workday inevitably stretched to twelve, and sometimes longer if there was a patient in particular distress. It was within these conditions of infrastructural pressure that the palliative care team sought to treat and alleviate cancer pain.

How might we best understand the contours and limits of empathy in these conditions of both care and disregard at the cancer hospital? Throughout this chapter, I have described the trajectories and orientations of empathy that came to be improvised in this space that demanded the recognition of pain and the inevitability of death. Palliative care research—in its quest for transcendence—sought to respond and ease the existential distress that was partly an outcome of a debilitating disease, and partly a consequence of these infrastructural pressures and lacks. In so doing, it looked to available vocabularies to formulate pathways through which pain could be dispersed and diffused. An appeal to transcendence offered one way out, a way to look past the dispiriting conditions of everyday failures and toward the resilient capacities of a mind strengthened by the development of its spiritual capacities. In practice, however, palliative care physicians took another tack. The rubrics of empathy that were taught and transacted in the work of recognizing pain emphasized an acknowledgment of limits. If pain remained intractable, empathy involved an attunement to intractability, while maintaining therapeutic relations as far into the illness as possible. Thus, on the one hand, the recognition of suffering entailed transcendence; on the other, it required a grappling with limits.

At the same time, while research and practice diverged on the forms of recognition and practices of empathy, the two forms of palliative care work shared an underlying limit. Both research and practice enlarged what cancer pain encapsulated, mobilizing the biomedical specialty's imaginations of the

“psychosocial.” Both research and practice produced responsive modes of feeling, empathy, and recognition that allowed for interventions into easing and ameliorating this pain. But in these same gestures, biomedical palliative care practitioners stopped short of an even more expansive vision, one that could include the structural preconditions of pain that were a result of long-standing public health failures. For all the provisional possibilities of empathy and recognition, palliative care remained trapped within the institutional failures that characterize public health care in India.

Even after decades of pioneering work, Dr. Nigam too expressed dissatisfaction with the pace at which her field was developing. In a reflective piece on the discipline published in 2015, she wrote that a “lack of acknowledgment of people’s suffering, lack of acceptance of a separate medical specialty and apathy are largely responsible for the unheard agony and preventable suffering thriving even five decades after the big bang origin of the modern hospice and palliative care movement.” She urged “sensitizing” the Indian medical and social worlds to the suffering of cancer patients. But, despite her frustrations, Dr. Nigam’s mission to alleviate cancer pain continues unabated. Both before and after my fieldwork, in 2009 and then in 2018, newspapers covered her declaration that AIIMS would soon be transformed into a “pain-free” zone. In gestures such as these, Dr. Nigam displaced public health failures in treating cancer onto a more manageable project of at least relieving the institute’s cancer patients from pain. The forms of recognition and empathy I have described throughout this chapter remain caught within this bind. The gestures that strive to recognize pain and suffering have little to say about the structural conditions that produce pain and suffering in the first place. Luc Boltanski describes the contemporary politics of empathy as that which “is not put into action in wholly general terms but is inscribed in particular relationships between particular individuals . . . an unfortunate whose suffering manifests itself locally.”⁵⁷ The palliative care practice of seeing through the patients’ eyes instantiated precisely such a model of empathy and recognition. In highlighting the immediacy and urgency of pain, practitioners were forced to push aside questions of health care justice and structural failures. These are, then, both the limits and the possibilities of the ethical commitment of palliative cancer care to “see through the patient’s eyes,” and the complexities of its mission to help the poor die free of pain.