

ENDURING CANCER

LIFE, DEATH, AND
DWAIPAYAN BANERJEE
DIAGNOSIS IN DELHI



ENDURING CANCER

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DUKE

UNIVERSITY
PRESS

ACKNOWLEDGMENTS vii

CONTENTS

INTRODUCTION 1

1

CONCEALING CANCER 35

2

CANCER CONJUGALITY 64

3

RESEARCHING PAIN,
PRACTICING EMPATHY 84

4

CANCER MEMOIRS 121

5

CANCER FILMS 142

6

ENDURANCE 171

NOTES 183

BIBLIOGRAPHY 205

INDEX 219

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PRESS**

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INTRODUCTION

I

I am at a messy table, full of government forms, medical instruments, and diagnostic charts. Across me, Sameera, a young medical resident, has just finished attending to about eighty patients in less than three hours. We are at the cancer ward of one of India's largest, busiest, and best-regarded public hospitals—the All India Institute of the Medical Sciences (AIIMS). Cancer patients flock here by the thousands from all over the country. Many know that if the long journey here does not push their disease past the possibility of treatment, the months-long wait times once they reach AIIMS will. At this moment, in the early days of my fieldwork, I am confused about how the word “cancer” is never spoken. I have already seen how many patients are not told their diagnosis even until their death, and how families often react with anger upon hearing the word. In India's largest cancer ward, nobody seems to have cancer.

I know about a reticence in speaking about the disease in many parts of the world, but I am interested in finding out why it is particularly pronounced here. If patients do not know they have cancer, I ask Sameera, what brings them to an oncology ward for treatment? Exhausted, she looks up and says elliptically: *shak*. The Hindi word *shak* is translatable as “doubt,” “skepticism,” or “suspicion.” Unsure of what she means, I continue to push her. If *shak* first brings patients to the clinic, why is it not dealt with, why do you not tell them what they have, how long they will live? Putting her pen down, she elaborates. “You see, *shak* does not just mean they are unsure about what disease they have. It also means they do not know whether they will be able to afford treatment, whether their family or neighbors will stand by them. Later, *shak* will stand between us doctors and them, whether they trust us when we advise a lengthy treatment, or when we tell them that there is nothing more to do.”

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II

I have just traveled with a Delhi cancer care nongovernmental organization (NGO) during their home visit to a patient who lives in the outskirts of the city. Our car had broken down earlier, and we traveled the last miles in the official NGO van with its logo “Caring for Cancer” printed on the door. The patient—Amarjit—was a man in his seventies. Amarjit seemed visibly discomfited by the logo: he absolutely did not have cancer, he asserted. In his refusal to name his diagnosis, he was exemplary of many others who resisted the enclosure of his disease within an already fixed script. The nurse expertly played along, hoping to transact care on his terms rather than her own. She asked, “Aapke khyala mein aapko kya hua hain?” (What do you think has happened to you?). The Hindi word *khyala* translates to “thought” as well as “care.” His careful reply was that he had “oncology,” a dexterous negotiation of the word “cancer” and all that the diagnosis entailed.

III

Accompanying a different team from the same NGO a few weeks later, I visited a young couple, Malika and Madanlal. Malika had recently been diagnosed with breast cancer. As I walked in, I was struck by how different their one-room home was from others I had seen in the neighborhood: it was beautifully painted, and ornate new moldings lined the walls and window. Later, the NGO workers told me that Malika had been in pain and depressed after her diagnosis. While she was hospitalized, Madanlal, a construction worker, had borrowed money and materials from his employer and remade their room. He had crafted it with Malika’s favorite designs and colors and covered the walls with framed photos from when they had vacationed as newlyweds. To ameliorate her pain, Madanlal had taken it upon himself to literally rebuild Malika’s collapsing world.

These fragments offer a glimpse into the concern of this book: the efforts of patients, families, physicians, and cancer care workers in Delhi to manage the unsettling force of a cancer diagnosis. With a word, *shak*, Sameera described the power of the disease and the disrupted social relations it left in its wake. With a word, she synopsized a feeling that recurs in the narra-

tives of cancer patients all over the world—a sense of being unmoored from prior certainties about oneself and one’s place in the world. When cancer appears, it distributes itself across networks of social relations, testing them for strength and vulnerability. In Madanlal and Malika’s case the ties between them proved resilient, helping mitigate the shock and force of the diagnosis. In time Malika would recover, bolstered in part by the efforts of her kin to sustain the world in which she lived. But often, the diagnosis put pressure on already fragile social bonds, pushing capacities of endurance to the point of their exhaustion. Many, like Amarjit, chose to conceal their cancer because they did not trust the worlds in which they lived to welcome them.

To live with cancer in Delhi, then, was to navigate the many doubts, suspicions, and skepticisms that spread through social relations in the wake of a cancer diagnosis. Those who lived with or alongside the disease had to account for which medical institutions and practitioners were affordable and dependable, which neighbors and kin they could trust and who might wish them harm, and whether old histories of violence and resentment within marriages would resurface in this time of vulnerability. In these and many other ways, to live with cancer, my interlocutors had to figure out more than the capacity of bodies to withstand and respond to therapies. They also had to learn the strengths and vulnerabilities of the social worlds within which the disease unfolded, the kinds of speech and action that would be conducive to their well-being, and the infrastructures of care and neglect that would shape the trajectory of their treatments. In this book, I present the efforts of my interlocutors to live within these shifting tensilities of social relations in the wake of cancer. I argue that living with and alongside the disease was to be newly awakened to the fragility of social ties, some already made brittle by past histories, and others that would be retested for their capacity to support.

Such an attunement to the fragility of social relations around cancer helps me explain how the disease is experienced in a specific place and time. While investigating the force and impact of a cancer diagnosis upon social relations, I found older cracks and fault lines: long-standing failures in Indian medical care, prior betrayals in marriages, and personal histories that made some more vulnerable to the consequences of the disease. For example, this ethnography unfolds in Delhi, where for most of the urban poor a cancer diagnosis came too late for curative intervention. That is, long wait times in public health facilities ensured that the disease would have progressed beyond the time of cancer’s traditional treatment modalities: chemotherapy, surgery, and radiation. Often, then, when cancer appeared in con-

ditions of long-standing precarity, the disease articulated with past vulnerabilities, inflecting their points of stress in new and urgent ways. A cancer diagnosis was the latest and most serious in a long series of infrastructural, domestic, and familial episodes of failure and violence. My effort in this book is to present a picture of how cancer settled into these longer histories of vulnerability, and how these forces of the past shaped the contours of life around and after diagnosis.

Thinking about such an accretive impact of a cancer diagnosis—as it articulates past vulnerabilities with new pressures—goes against the grain of how it is often represented: as a cataclysmic breakdown of a person’s social world, inaugurating a new life in the “kingdom of the sick” (to paraphrase Susan Sontag).¹ Without discounting the dramatic impact of the disease’s diagnosis, my aim is to supplement such accounts of rupture with one of continuities, tracing how a person’s past reverberated into his or her present and future. To understand the continuities between a pre- and post-diagnosed self is to understand how the disease sedimented into the give-and-take of everyday life, rather than marking a departure from it. It is to understand, for example, how the disease nestled into or tore apart already fragile kinship ties, why my interlocutors spoke indirectly or not at all about the disease to those closest to them, and why some within the same neighborhoods could access treatment while others could not. Thinking of the impact of cancer in such an accretive way helps uncover the long durability of social doubts in everyday life within which the disease took shape, not rupturing prior certainties, but inflecting long-standing vulnerabilities in new and subtle ways.

The chapters that follow build on this underlying insight: when cancer appeared in conditions of precarity, it put further pressure on already frayed social relations; living with cancer entailed living with a pervasive doubt about the viability of such relations. In this space, my interlocutors experimented with strategies to negotiate this doubt, never entirely dispelling it, but keeping its capacity to overwhelm at bay. In such circumstances, the diagnosis of cancer cannot be described as a critical breakdown in an otherwise stable life, because in conditions of precarity, such certainties about one’s health and well-being were never easily at hand. The concern of this book, then, is to describe such experiments to live with or alongside cancer, managing doubts about social relations in *already* fragile worlds. In the book’s concluding chapter, I understand these experiments in relations as demonstrative of an ethics of endurance. Suspicions and deficits of trust never came to be entirely dispelled or absorbed by the strategies invented

to manage them. This was not only because treatments were often scarce or because remission was always a risk, but also because efforts to maintain brittle social ties around a patient required continuous work. The analytic of endurance aims to explain this durability of doubt—in bodies, social relations, and institutions—that remained ever-present, guiding what it meant to live with or alongside cancer.

More specifically, I thematize these experiments with doubt and social relations across three fields: a circumspection of speech about the disease, the problem of cancer pain, and the dangers and possibilities of its aesthetic representation. Across each of these fields, I describe strategies to manage doubts about social relations awakened by cancer diagnoses. For example, concealing diagnoses was often a strategy through which my interlocutors anticipated how their pasts would reverberate into the future: telling some and not others helped them maintain a sense of continuity in their lives, as well as guard against those whom they already mistrusted. The problem of cancer pain similarly required a testing of fragile social ties. In a context where diagnosis often came too late, the physical pain that accompanied cancer became more than a “side effect,” pushing public health workers to take it on as a central concern. In investigating this prominence of pain in Indian cancer care, I show how its meaning (as a research subject) and amelioration (as a therapeutic practice) depended on apprehending the fragility of a patient’s social world. Finally, in exploring aesthetic accounts of cancer in India (primarily in films and memoirs), I examine attempts parallel to my own to investigate the disease’s social reverberations. Many of these aesthetic accounts are pedagogical, offering moral lessons about how to correctly respond to the disease and, in the process, establish a proper national, gendered, and psychological state. Other accounts reject such transformative visions, exploring the durable consequences of the disease that could not be so easily transcended. In describing these contrasting moral visions, I explain the dangers of aesthetic abstractions that erase cancer’s everyday stakes while also exploring the felicity of those that do not. In the process, I sharpen my own ethnographic sense of the fraught socialities that cohere around the disease.

Concealing Cancer

Amarjit’s response—that he really had “oncology” and not cancer—was one way, among others, through which my fieldwork interlocutors evaded directly naming the diagnosis. This tricky relationship between language

D U K E

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PRESS

INTRODUCTION 5

and cancer continuously haunted my fieldwork, never quite resolving itself. Looking through more than six hundred patient records at AIIMS, I found that more than 80 percent of the patients had been recorded as being “unaware” of their diagnosis when they came to the clinic. But, through the course of my research, I came to understand the limits of the word “unaware.” Patients and families often came to the ward and hid prognoses they had received from other doctors or oncologists. At other times, they colluded to conceal their diagnosis from neighbors and kin. And most frequently, family members colluded with each other to protect patients from the perceived psychic impact of the word. In these cases, patients were almost always more “aware” of their disease than family members imagined them to be. Throughout my fieldwork, I would find their motivations for concealment as varied as the practices through which secrets were sustained.

Yet, despite this variance in motivations and practice, I understand concealment as part of a broader repertoire of strategies to apprehend and mitigate fragile social relations put under pressure by cancer. For example, by hiding prior diagnoses from new doctors, some patients and families evidenced their skepticism about biomedical practitioners and institutions. Many believed that revealing a bleak prognosis to a new physician would hurt their chances of accessing care. In such instances, concealment was indicative not of a hope of recovery but of a deep deficit of trust between poorer patients and medical institutions. However, while I describe a few moments of diagnostic nondisclosure, the forms of concealment I pay most attention to are those that unfolded *after* diagnosis, in the homes of patients and among kin, neighbors, and NGO caregivers. I do this in keeping with my effort throughout the book to pay attention to the slow reverberations of cancer, shifting attention away from the life-altering moment of diagnosis that preoccupies the sociomedical literature concerned with the disease. In these homes, intimate and neighborly relations were often already undermined by past histories of violence or neglect. When cancer care NGO workers entered these fraught worlds to offer care, they understood that they would need to work on reknitting these frayed relational threads. Often, this meant maintaining fictions of concealment. Working alongside these cancer care workers, who were ethnographers in their own right, I came to understand how negotiating the vulnerabilities around cancer involved deciding whether, when, and how much to reveal about diagnoses. Over time, patients, families, and palliative care workers would experiment with these relations, testing what could be said without incurring harm. For example, for one young cancer patient, concealment became a way of safeguard-

ing his livelihood. He earned his small income by running errands for his neighbors and believed that revealing his diagnosis would isolate him, taking away the money he required for treatment. For many others, concealing became a way to avoid the psychic damage caused by well-meaning kin and neighbors who would often begin mourning living patients as if they were already dead. And for still others, concealing became a way to maintain the hope of a future together, even while knowing full well that such optimism was unwarranted.

More broadly, I argue that such practices of concealment evidence a pervasive subjunctive mood in the experience of cancer in Delhi. As anthropologists understand it, the subjunctive mood is a world ordered through narrative or rituals *as if* it were real, but separate from lived reality.² They are illusions that are not intended as lies, but rather as a play with another possible reality, a mutual entry into the worlds of “could be,” when the “is” might have become too difficult to bear. While judgments based on sincerity and authenticity might find such illusory plays difficult to accept, they are crucial to all kinds of social rituals, expressing possibilities rather than actualities.³ Often, the conjuring up of the subjunctive reflects that ordinary life has become so overwhelming that the subjunctive mood allows for another, incongruous world. I present this explanation of the subjunctive because it captures the relation between the lived experience of cancer and the active concealments of its diagnosis. Social rituals of concealment opened the possibility of another world in which cancer did not shape and deform every moment of social life. Thinking about the subjunctive mood in contexts of illness, Byron and Mary-Jo DelVecchio Good and Veena Das separately describe it as allowing for traffic in human possibilities rather than certainties, keeping alive multiple perspectives, emotions, and moods as a way to cope with the harms of disease.⁴ Developing this insight, I describe concealment as a practice of inhabiting the subjunctive mood, as patients, kin, caregivers, and physicians helped sustain possibilities of relations that disclosures might foreclose.

Importantly, in anthropological description of rituals as worlds of the subjunctive, the “other worlds” that rituals create are not escapist fantasies, but rather a realist assessment that this world cannot always be bent to one’s will.⁵ In consonance, I stress that in concealing their diagnosis, my interlocutors were not escaping or denying the truth and consequences of cancer. They did not misunderstand its force or believe that by simply not speaking about their disease, it would go away. I argue to the contrary that by concealing, they opened a range of reflections on the actual circumstances of their

lives. To not name the disease was often a tacit expression of a knowledge of infrastructural failure: What use was speech when treatments were not easily at hand, or had not been at the appropriate time? At other times, concealment could indicate the presence of untrustworthy kin or neighbors. And in yet other instances, it was often a sign of care and thoughtfulness. Taken together, these practices of concealment shared one feature: they reflected on the intransigent social circumstances within which the disease appeared.

Pointing out that practices of concealment are not escapist is important because, as Cecilia Van Hollen describes in her work, biomedical ethicists and public health researchers have made them out to be so.⁶ Such bioethical discourses, committed to autonomy and transparency, understand any prevarication about revealing diagnoses as evidence of medical noncompliance or as a contravention of the patient's right to know. But as Byron and Mary-Jo DelVecchio Good as well as Van Hollen show, even when cancer bioethics seem universal and ahistorical, the norm that diagnoses must always be disclosed is one of fairly recent vintage.⁷ Further, in practice, such norms are often a red herring, when ethical decision making in the real world has little to do with the abstract principles that are supposed to guide them.⁸ The practices of concealment I describe reveal biomedical ethics in practice, from the point of view of those who experience their disease and navigate its consequences in their everyday lives.

Further, writing about medical nondisclosure in the context of pregnancy in rural India, Sarah Pinto describes the biomedical imperative of transparency as casting social worlds into distinct domains of compliance and noncompliance, rationality and irrationality.⁹ Within this context, Pinto explains how the near-silences of pregnant women are often misrecognized by doctors and NGOs as perversely normalizing the pathological fact of infant death, as evidence of a putatively Indian propensity toward fatalism, or as plain rural ignorance about health. Similarly, I describe how the medical literature on cancer in India consistently misreads practices of concealment as evidence of an "Indian" capacity to accept and reconcile with the inevitability of loss. Some describe this acceptance as fatalism, while others call it denial; some encourage its mobilization in the clinical encounter to bolster coping, while others castigate it as ignorance of the truth of cancer. Resisting such readings of acts of concealment as evidence of lack, I show instead that they reveal ethical negotiations with already fraught circumstances. As Pinto too recognized in her work, acts of concealment did not "normalize" difficult circumstances, but rather revealed how encounters with life-threatening suffering haunted already fragile worlds.

As such, my understanding of the stakes of concealment departs from bioethics and comes closest to Anne-Lise François's description of an ethics of "recessive action."¹⁰ François thinks of concealment as more than just the absence of knowledge and transparency. Instead, she understands concealment as a release from the imperative of actions that knowledge often demands. I share François's refusal of the equation of action with agency and concealment with passivity. Rather, I argue that concealment reveals an ethical way of being, not circumscribed to the meaning of ethics as acting upon the world to better oneself. It reveals the capacity to *not* act in the face of knowledge and of the potentially destructive consequences of action. In the following, I show that concealment sometimes evidences an ethics of responsiveness to conditions where revelation holds danger. These are acts of ordinary ethics, grown from within preexisting economies of speech and silence.¹¹ I argue, then, that describing concealment as denial or escapism is exactly the wrong way to understand its practice in the lives of the urban poor in Delhi. Instead, "escapist" better describes the hubris of public health dogma that believes disclosure and transparency are necessary preconditions for better health.

Cancer Becomes Pain

Pain has long been theorized as a condition so ensconced in doubt that it poses a biological limit to sociality. For example, Elaine Scarry's canonical description of pain stresses its capacity to destroy language, causing a reversion to "the pre-language of cries."¹² Scarry reserves for pain a unique ontological status, thinking it capable of producing a doubt in relations so intense that it creates an unbridgeable chasm between the person who witnesses and the one who suffers. Taking cancer pain as central to my analysis here, I move past such characterizations of pain as so mired in doubt that it disables relations. To the contrary, the ethnographic work of this book is premised for the most part on socialities that have cohered around cancer pain in Delhi.

To elaborate, in beginning to study socialities of cancer in Delhi, I had to make decisions about which of its constituent practices I would focus on: detection, diagnosis, its various treatment modalities of surgery, chemotherapy, and radiation—these were all possibilities. However, the set of practices I found most striking was the emerging specialization of palliative cancer care and its object of intervention—cancer pain. Palliative care is a biomedical specialization founded on the possibility of understanding, in-

tervening in, and easing pain. In Delhi, where wait times in public hospitals for chemotherapy, surgery, and radiation are often months long, doctors in those hospitals and cancer care NGOs have taken it upon themselves to at least ease the pain that accompanies the disease. By examining this work of palliative cancer care, I describe the many ways pain *is* brought into language, both by those who experience it and those who seek to mitigate it. Explaining the practices that have cohered around pain helps reveal the texture of practices through which cancer is experienced and treated in Delhi.

My focus on cancer pain raises an important conceptual question: Is this a book about cancer or about one of its peripheral symptoms? Is there something missing in an ethnography about cancer that does not focus on the “core” biomedical practices responsive to the disease—screening, chemotherapy, radiotherapy, surgery, and so on? To the contrary, a central concern of this book is to disrupt this distinction between what makes up cancer’s center and periphery. Lochlann Jain describes the pink-ribbonization of cancer in the United States and how private corporations have come to dominate its public representations. Their campaigns ask patients to hope and take responsibility for their disease, without questioning the systems that have consistently failed them.¹³ Developing Jain’s work, Juliet McMullin wonders about the global limits of hope as an imaginary associated with cancer.¹⁴ She hypothesizes that in places where treatments are even more inaccessible than they are in the global north, a concern for pain rather than an embrace of hope might make up the disease’s dominant trope.¹⁵ In centering pain, I explore precisely an imaginary and experience of cancer that depart from those associated with cancer in the global north. I center pain because in parts of the world where treatments remain inaccessible, the condition is often an inescapable companion to the disease. Thus, much in the same way that oncologists stress that the category “cancer” suggests a false uniformity when in fact it is a collection of disorders, I argue that taking apart what cancer means unravels the boundaries between the “core” of the disease and its “peripheral” symptoms.¹⁶

Writing about dialysis in Belize, Amy Moran-Thomas describes how while in many parts of the world the practice is considered a holding measure until transplant treatment, in Belize, a country where no renal transplant has yet been performed, dialysis was reconfigured as a holding measure against death. She describes her ethnographic work, then, as an effort to “remain with these long-term maintenance projects.”¹⁷ Similarly, for many patients I spoke to, cancer pain was not a side effect to be treated while curative treatments were enacted. Because of structural difficulties in accessing ther-

opies, pain treatments were often the only form of cancer care they would receive. My effort here to examine pain thus resembles Moran-Thomas's focus on the durability of chronic conditions when treatments remain inaccessible, demanding efforts to endure without the promise of recovery.

Such an approach, focusing on the collections of meaning that have cohered around cancer in one part of the global south, pushes us to rethink its tropes in the global north. That is, even as some public health experts foreground an "epidemic" of cancer pain in lower- and middle-income countries, others point to a simultaneous undertreatment of cancer pain in the United States and Europe.¹⁸ I argue that the underanalysis of cancer pain in places in the global north is a consequence of the overwhelming discourse of hope and survival that envelops the disease. Thus, I show how centering cancer pain forces an acknowledgment of messy realities otherwise obscured by campaigns that "pink-wash" the many inequalities that contribute to its etiologies, prevalence, and consequences. In this way, centering pain in an analysis of cancer is demonstrative of what Jean and John Comaroff call "theory from the south."¹⁹ Thinking through cancer pain offers an opportunity to clarify the *collective* stakes of this condition not only in Delhi but also in other parts of the world where, as Jain and others have shown, its realities have been obscured by tendencies to proselytize its eclipse through individual willpower.²⁰

In the same way I do not claim cancer pain is a problem only for the global south, I also do not claim that imaginaries of hope and survivorship are absent in India. The boundaries between the global north and south are hardly ever so clear. The NGO I worked with, Cansupport, organized "Walk for Life" events in the city that resembled similar gatherings of support for survivors elsewhere in the world. However, I found that even such events, oriented toward survival, always highlighted the centrality of cancer pain. For example, in advertising the walks, Cansupport was always careful to emphasize that its primary mandate was "adding life to days, *not* days to life." That is, rather than offer patients the false hope of survivorship, Cansupport workers aimed to make patients' last days meaningful and pain-free. If most cancer patients in Delhi present for treatment past the stage of therapeutic intervention, NGOs orient their work toward helping patients live out their last days without pain. During the time of my fieldwork in 2011, Cansupport's founder, Harmala Gupta, described this orientation as a realist response to the context of cancer care in India: "Is there any point in investing our limited resources in more and more expensive and futile treatments when the majority of our cancer population is unlikely to bene-

fit from them?”²¹ Citing studies by the *Lancet* and the *Economist*, she critiqued the blinkered search for an elusive cure as “a path strewn with broken promises, dashed hopes, crushed lives and public health systems that can no longer cope.”²²

Echoing Gupta, a palliative care professor at another leading regional cancer care center in South India described his mission against cancer as a second “freedom struggle.” If the first freedom struggle secured India’s independence from colonial rule, this second would win freedom from cancer pain.²³ The nationalist metaphor of a freedom struggle reveals a pervasive belief among palliative care specialists that India lags behind the rest of the world in cancer pain treatment. They are not alone in this belief; public health experts echo this concern about an untreated pain epidemic in lower- and middle-income countries. A report commissioned by the *Lancet* and authored by some of the most prominent names in global public health begins with the testimony of an Indian palliative cancer care physician and is followed by this editorial comment: “Poor people in all parts of the world live and die with little or no palliative cancer care or pain relief. Staring into this access abyss, one sees the depth of extreme suffering in the cruel face of poverty and inequity.”²⁴ The same study found that in 2015 alone, about twenty million people in lower- and middle-income countries died with serious pain and most of them without access to pain relief. A similar report commissioned by the American Cancer Society in 2013 put the number of global HIV and cancer deaths with end-of-life pain at 2.3 million.²⁵ Such reports find India at the center of the global pain epidemic. For example, the American Cancer Society report claimed that about 24 percent of these deaths happened in India alone, singling the country out as having the highest incidence of untreated cancer pain. Likewise, journalistic accounts that report on the global pain epidemic focus on cancer in India. Reports in the *New Yorker* and by the BBC restate a statistic that is ubiquitous in such writings: that while India produces most of the world’s licit opium, restrictive drug laws deny opioid analgesia to all but about 2 to 4 percent of its cancer patients.²⁶

I share this public concern for the undertreatment of cancer pain in India. Much of my work in this book focuses on the experience and treatment of the condition. But I also argue that much like the preoccupation with hope and survival in the United States, there is nothing obvious about the centrality of pain in the biomedical imaginary about cancer in the region. Instead, along with other historians and anthropologists of pain, I show how

examining the condition reveals broader assumptions about human vulnerability and social hierarchy.²⁷ For example, while studying the research literature produced by the growing number of palliative cancer care specialists in the country, I found them preoccupied with the heightened capability of the Indian body to withstand pain. This literature presumed that spirituality and religion were particularly salient in Indian cultural life and hypothesized that they could be instrumentalized as coping mechanisms. Further, experts concurred that any biomedical research on pain among cancer patients needed to account for the role of Indian spirituality. To understand this research orientation, I trace its resonance and roots in several directions. These include the interest of doctors at AIIMS in the new age Art of Living movement and a history of research as old as the institute on spiritual practices to transcend pain. In examining this orientation, I was struck by how much this research resonated with British colonial ideas about Indian bodily dispositions. Historians of colonial India describe the obsession of European writers and colonial officials with the ability of mystics, ascetics, and the *sati* (widows who immolated themselves on their husband's funeral pyre) to withstand pain.²⁸ These colonial accounts constructed the Indian native as radically different, oriented to a religious transcendence of this world. I do not suggest that there is an unbroken line of continuity from the eighteenth century to the present in social understandings of pain. But I compare these historical and contemporary discourses about pain to explore how cancer research risks depoliticizing the disease. That is, I ask whether this pervasive desire to find ascetic pathways to transcend pain obscures the socioeconomic distributions of the condition in Delhi.

However, despite the limitations of this research paradigm, I found that *in practice*, palliative cancer care practitioners inquired with sophistication into the biological, psychological, and familial etiologies of pain. The multimodality of pain—its varied etiologies and treatment possibilities—offered pain practitioners a productive site for blurring the line between symptom and disease, the critical and the chronic, and the biological and extra-biological etiologies of suffering. In outpatient clinics, home-care visits, and hospitalized care, pain physicians demonstrated expert knowledge of how neighborhood and kin relations exacerbated or eased cancer's distress. Take, for example, a condition I describe later in the book—phantom limb pain (pain in amputated limbs). The experience of phantom limb pain has been a critical concern in global biomedical pain research. Its intractability has mystified pain physicians for more than a century. One ascendant biomed-

cal pain theory, the neuromatrix model, stakes its validity on its claim to offering the first solution to the problem. Its proponents argue that pain exists as an image in the brain as a neuronal matrix, thus living on in the body even after the amputation of its prior site in the physical limb. Based on this theory, the model offers the device of the mirror box as a treatment. The mirror box reflects a present limb where the absent one should be, tricking the brain into exercising and releasing the pain through this virtual proxy. Yet, as seductive as the neuromatrix theory is in abstraction, ethnographically following a cancer patient with phantom limb pain led me in a quite different direction. This patient's pain biography was more than a decade long. Pain specialists across the city were well acquainted with the intractability of his pain and the failure of a range of treatments. Physicians I worked with had tried the mirror box and many other anesthetic interventions. The thing that had provided the patient in question with the most relief, however, had been high doses of morphine. But rather than dismiss his pain as a lie masking the cravings of an addict, the more experienced specialists maintained their relationship with him, treating him while acknowledging the limits of what they could do. In stark contrast to the imagination of the mirror box that promised a miraculous cure by relocating pain in the brain, these pain physicians understood pain as part of a social relation between themselves and their patient.

Across several sites, then, I came to see that to communicate cancer pain required staking a capacity for belief, even in the presence of suspicions and doubt. It was no surprise, therefore, that pain physicians at AIIMS took a keen interest in its "psychosocial" dimensions, hoping to track down its extrabiological etiologies. At the same time, these expert interventions into the social etiologies of cancer pain hardly solved the problem of pain's unequal distribution. Empathy, in all its forms, could not address the problem that the pain many patients experienced could have been mitigated with timely access to treatment. Further, the small number of trained pain specialists and workers meant that only a small fraction of those needing analgesia received it. Thus, in their capacity for empathy, cancer pain physicians showed both the possibilities and limits of medicine at its most humane.²⁹ Even as they expressed their capacity for empathy for many individual patients, they could do little to fix the collective inequalities that produced more pain in some rather than others, or the structural limits that put analgesia beyond the grasp of most.

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A Disease of Civilization

In discussions about the rise of cancer in India, journalists and scholars often conflate the uncontrolled growth of cancer cells with the recent, rapid growth of the Indian economy. Articles in scientific journals such as *Nature* have claimed that cancer is “a disease of growth” linked to increased affluence.³⁰ Similarly, newspapers have found that “most cancers in India are caused by lifestyles gone awry” and an outcome of the country putting “economic growth above all else.”³¹ Medical journals also link a new exposure to international markets with an increased exposure to cancer, while reports from the World Health Organization (WHO) find that cancer is now no longer a “Western” disease but has for the first time entered the developing world on an epidemic scale.³² The agenda-setting American Cancer Society urges policy makers to look beyond aging and population growth for an explanation of the exploding cancer epidemic in low- and middle-income countries. Specifically, it asks for research on “behaviors and lifestyles associated with economic development and urbanization.”³³ Here, I examine this trope of cancer as a new epidemic in India, brought on by lifestyles and behaviors after rapid socioeconomic change. I discuss this trope to demonstrate how it misrepresents the history of cancer in the region and obscures the disease’s stakes in the present.

The most recent iteration of the narrative of cancer as a Western epidemic spreading to the non-Western world took shape around the end of the twentieth century, when several global health organizations and experts announced a collective mea culpa. Specifically, they regretted that their long-standing focus on infectious diseases had blinded them to the rise of non-communicable diseases (NCDs) as global health problems. A few scholars took a long view, understanding that NCDs and infectious diseases had always been a simultaneous problem, and that the recurrent panics around infectious epidemics had created a myopia about diseases like cancer.³⁴ In other words, these scholars recognized the mistake of creating an artificial divide between diseases of the rich (NCDs such as cancer and heart disease) and diseases of the poor (infectious diseases such as HIV-AIDS, tuberculosis, and malaria).³⁵ However, most public health experts and organizations did not adopt this more measured response; instead, they described NCDs as another *new* precipitous epidemic, much like the ones that had come before. Rather than take the lesson that seeing through frames of crises had narrowed their vision, they replaced an old catastrophe narrative with a new one.

David Jones and Jeremy Greene place this contemporary panic about NCDs within a long history of what they call “public health catastrophism.”³⁶ They describe how such catastrophic narratives project messy contemporary data into the past and future, shaping health policies around pronouncements of ever-repeating crises. Similarly, Carlo Caduff’s ethnography of the influenza pandemic shows how such pronouncements concentrate prestige and authority in the hands of experts.³⁷ The contemporary panic about cancer takes its place within this long history of catastrophic pronouncements of health crises. To locate the starting point of this particular catastrophe, experts mark 2010 as a turning point—the year cancer is said to have outstripped heart disease as the leading cause of death worldwide.³⁸ Echoing the discourse around NCDs more broadly, cancer catastrophists project a global asymmetry in disease burden; that is, they find mortality rates for cancer rising in lower- and middle-income countries, while rates are in decline in high-income countries.³⁹ They also find that most cancer cases and deaths have begun to occur in the less-developed world, with Asia accounting for half of the world’s new cancer cases and deaths.⁴⁰ As Julie Livingston writes in the context of Botswana, these patterns of global visibility and invisibility about cancer frame possibilities of treatment and exposure.⁴¹ Several organizations have emerged in the wake of this alarm, with most large cancer institutions working in the United States and Europe expanding their operations to include lower- and middle-income countries. The global cancer epidemic is now a key target of intervention in the UN Sustainable Development Goals, the World Bank’s Disease Control Priorities, and the 2013 WHO Global Non-Communicable Disease Action Plan.

Within India, journalistic and scientific accounts echo this global alarm about a new cancer epidemic in the global south. International epidemiologists estimate that about 1.1 million people in India were diagnosed with cancer in 2018, accounting for about 6.4 percent of the worldwide cases.⁴² The Indian government’s own disease surveillance data project even more alarming figures. For example, whereas the International Agency for Research on Cancer (IARC) estimates about 1.21 million new cases of cancer in India in 2020, the Indian Council for Medical Research (ICMR) estimates a dramatically higher figure of 1.73 million, which would constitute over 9 percent of worldwide cases.⁴³ Of course, the same statistics can be made to tell different stories. When adjusted for India’s large population, the high numbers of cancer cases in India do not seem as alarming.⁴⁴ There is also no consensus on whether the rise in numbers is in or out of step with demographic changes and population growth. That is, researchers disagree

on whether there is indeed a dramatic rise in incidence that cannot be explained by considering an aging and growing population. In fact, two persuasive studies demonstrate that if these factors are taken into account, there really has not been a dramatic rise in the rate of cancer in the last decades.⁴⁵ Thus, those wary of the narrative of cancer as a “new” epidemic in India contend that cancer incidence has been relatively steady for decades. This is not to say that they do not believe cancer to be a serious public health problem. They more specifically reject claims of a recent surge in the disease’s incidence. At the same time, despite this counterevidence, the deceptively self-evident assumption—that the rates of cancer in India have accelerated dramatically in recent years—has become an unshakable trope in journalistic and scholarly accounts.

I draw attention to this trope because it demonstrates a long-standing historical paradox in discussions of cancer. Throughout the twentieth century and into the present, experts have consistently demonstrated cancer’s pervasive presence in India.⁴⁶ But despite all the evidence to the contrary, writings about the disease continue to associate it with an imagined West and its so-called modern lifestyles. To elaborate, as early as the late nineteenth century, physicians and public health experts demonstrated that cancer was *not* a “Western” disease, and that its lack or presence could not be taken for granted as evidence of a radical difference between the East and West.⁴⁷ For example, in 1888, the resident British surgeon-major in Jaipur contested claims in British medical journals that cancer was a disease of the meat-eating West that did not affect predominantly vegetarian Indians.⁴⁸ With his experience of the previous eight years in Jaipur, where he had conducted 102 cancer operations, he claimed not only that cancer was highly prevalent among Indians but also that its presentation in advanced stages was a serious and underappreciated problem in the colonies. In 1904, colonial surgeons presented further evidence of the widespread prevalence of cancer in the British colonies, leading the Prince of Wales to declare that “cancer was not a scourge of civilization” as had been previously thought. Rather, he now understood that the disease was prevalent throughout the empire, even where the “civilizing” colonial mission had not yet succeeded.⁴⁹ This realization led in 1904 to the addition of the word “Imperial” to the name of the recently founded British Cancer Research Fund (ICRF). For decades after, ICRF researchers continued to reject the framing of cancer as a disease restricted to the colonial metropole. Even as they contended that the disease in India took on particular traits thanks to “barbaric” native customs, they claimed that susceptibility to the disease was not culturally

bound.⁵⁰ The ICRF's findings were echoed by the British Indian Medical Service, whose epidemiological studies also found that the incidence of cancer in India was similar to that in Western countries.⁵¹ Similarly, Indian epidemiologists too produced research pointing out the relative equality of cancer incidence across the "East" and "West." For example, two Indian doctors at the King Edward Medical College in Lahore published a persuasive study in 1935 showing that the incidence of cancer in India was about the same as elsewhere in the world.⁵² At the same time, despite such studies, many contemporaneous researchers obstinately held on to the idea that cancer incidences were and had always been low in India. For example, after surveying the extant epidemiological data, the famous American statistician Frederick Hoffman found that despite the evidence, he could not bring himself to "escape the conviction that cancer in its different forms is unquestionably relatively very rare throughout India."⁵³

At the same time, a few voices insisting on the importance of cancer as a health problem in India proved persuasive enough to lead to the foundation of the Tata Memorial Hospital in Bombay in 1940. Founded by the Tatas (one of India's first and most successful capitalist families), the sixty-bed facility was one of the earliest anywhere in the world to combine treatment and research. By 1951, V. R. Khanolkar—president of the International Cancer Research Commission from 1950 to 1954 and a senior oncologist at the hospital—would call it the premier cancer institute in the East. Kavita Sivaramakrishnan describes how Khanolkar pushed against the persisting assumption of the relative unimportance of cancer in India.⁵⁴ Instead, establishing a network of support with colleagues worldwide, he argued for a "sameness" in cancer disease rates across the world.⁵⁵ India's first health minister, Rajkumari Amrit Kaur, was a prominent supporter of the India Cancer Society.⁵⁶ In a 1952 speech inaugurating a session of the International Cancer Research Commission, she claimed that data gathered by Tata Memorial researchers showed that "Indians are as susceptible to cancer as the inhabitants of Western countries and that its incidence is as frequent here as elsewhere."⁵⁷ Soon after, she called a press conference to draw attention to the alarming rise in cancer cases in the country.⁵⁸ In this "emergency" address, she estimated 200,000 annual deaths to the disease, and its incidence as high as one in every six Indians. In her last two years of her decade-long tenure as the national health minister, she convinced the central government to take control of Tata Memorial Hospital, with the aim of extending its capacity.⁵⁹

The history of cancer in India is thus driven by this curious paradox. On

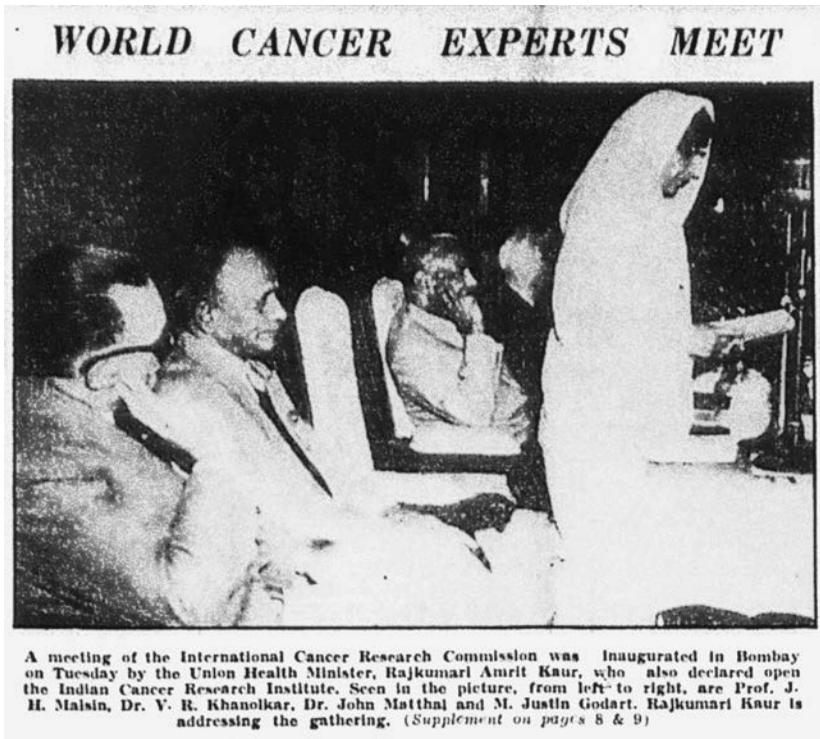


FIGURE 1.1 Health minister Amrit Kaur speaking at a meeting of the International Cancer Research Commission in 1952. Image from the British Library Board Asia, Pacific and Africa SM 77 *Times of India* (Bombay).

the one hand, studies and reports throughout the postcolonial period continued to raise alarms about the disease's critical explosion in India. In 1969, for example, the *Times of India* claimed without evidence that the disease claimed 425,000 lives annually, an estimate that suggested that cancer was more prevalent at that time in India than it is in the present.⁶⁰ Even after decolonization, international health agencies continued to warn the Indian government that the incidence of cancer in the country was steadily on the rise.⁶¹ On the other hand, despite these alarms, the myth of cancer as a disease of the civilized West has been difficult to dislodge.⁶² Sivaramakrishnan describes the pervasiveness and persistence of the belief among experts and policy makers in the postcolonial period that cancer was a disease of the "West."⁶³ She also describes how, much to the disappointment of those like Khanolkar who had advocated for a comprehensive cancer program in India, the postcolonial government was instead drawn to developmental-

ist goals such as population control.⁶⁴ Thus, despite the many studies and pronouncements of a cancer crisis throughout twentieth-century India, the myth of cancer as a disease of the West proved an unshakable trope. As a result, infrastructural efforts to treat the disease have remained piecemeal and provisional, limited to a few hospitals in the country's urban centers.

This persisting trope continues to shape contemporary framings of the disease. If cancer is a disease of the West, the story now goes, then its rising incidence must have something to do with the region's increasing westernization. And if this is indeed the case, the disease must disproportionately concern a newly prosperous, westernizing elite. Take, for example, a leading contemporary public health account of cancer in the developing world. This account takes as self-evident the notion that in India "a new middle class has embraced a 'Western' lifestyle characterized by western habits such as high-fat diets, reduced physical activity, increased alcohol consumption and tobacco smoking. Not surprisingly, there has been a surge in the incidence and prevalence of 'Western' diseases such as cardiovascular disease, hypertension, cancer."⁶⁵ Or take, for example, a journalistic account of the disease in 2015 that began with the headline "In an Ominous Sign, India Transits Speedily from Infectious to Lifestyle Diseases."⁶⁶ Reports such as these identify post-1980s economic growth as the chief culprit for the supposed acceleration in cancer rates, assuming that new "modern" lifestyles adopted by a recently prosperous middle class are responsible for the rise in incidence. In identifying a "speedy transition" to lifestyle diseases such as cancer, this journalistic account looked to public health theories to substantiate her claim. Specifically, she turned to American epidemiologist Abdel Omran's theory of a global "epidemiological transition."⁶⁷ In its simplest terms, this theory maps diseases onto progressive civilizational stages. It argues that each society goes through three ages—the age of pestilence and famine, the age of receding pandemics, and the age of degenerative and man-made diseases.⁶⁸ As it appears in this journalistic account, the idea perfectly explains the rising rates of cancer in India; cancer is part of the third civilizational age, and westernization is its "man-made" catalyst. In other words, the article presents what is now almost public health dogma: that recent socio-economic change is a key causative agent in an explosion in cancer rates in places like India. Such accounts present a picture of cancer as a disease of a prosperous Indian middle class that cannot absorb the shock of new social transformations. Their bodies, unable to assimilate rapid modernization, become particularly susceptible to chronic diseases such as cancer. This article's final sentence succinctly captures the troubling implications of such

arguments: in the fight against cancer, “there is a lot that is up to one person—you.” That is, if a turn to Western lifestyles among an elite few is at the heart of the cancer epidemic, then it follows that correctible behaviors must be at fault, and that the response to cancer must be one of individuals taking responsibility for their self-harming decisions.

Cancer is not the only disease that is framed in such a way in India. Lawrence Cohen writes about how the supposed abjection of old people in postcolonial India became a sign of the decay of an authentic Indian society and the seductions of a putative Western modernity.⁶⁹ Cohen describes how experts and policy makers concerned with aging assumed that the traditional Indian joint family had been in decline since the 1980s, and that with the advent of “Westernization, modernization, industrialization and urbanization,” aging had suddenly become an alarming problem threatening the country’s future.⁷⁰ More recently, Harris Solomon has shown how diabetes is similarly configured in popular Indian and scientific accounts as a disease of economic prosperity and modernity, as obese bodies become signs of a failure to metabolize a fast-changing world.⁷¹ I argue here that much in the same way as aging and diabetes, cancer has become a new subject of discussion and intervention, with journalists and experts taking for granted that “westernized” lifestyles are behind the disease’s rise. Much like those other NCDs, cancer appears in journalistic and scientific accounts as a marker of the new and a paradigm of an unassimilable modernity. Framed as such, it generates presumptions about the inability of Indian bodies to adapt to social and relational change.

This book has emerged in response to the consequences of framing cancer through such developmentalist tropes. Specifically, I find that these tropes have two dangerous outcomes. First, framing cancer as a disease of a prosperous urban elite legitimizes the absence of cancer care for India’s rural and urban poor, when in fact the disease does not respect regional or class lines. A comprehensive study of the distribution of cancer based on 2014 data showed that even though there was a higher prevalence of cancer in urban India, it was also widespread in rural areas that had little access to treatment.⁷² Within urban areas, the disease spanned income groups, affecting the city’s rich and poor. Further, cancer not only affected both the rural and the urban, the rich and the poor, but also had the ability to *make* poor.⁷³ In my fieldwork primarily (but not only) among the urban poor, I found several patients driven to distressed financing, incurring financial debts and selling assets to afford treatments or hospitalization. In its ability to make poor, cancer outstrips every other disease; a recent study found that 79 percent of

Indian cancer patients had been driven to catastrophic health expenditures, a number far higher than for any other disease.⁷⁴ Thus, framing cancer as collateral damage for postliberalization economic prosperity obscures the prevalence of the disease among the already economically marginalized as well as those driven to poverty after diagnosis.

The second reason that the trope linking cancer to behaviors and lifestyles is troubling is because it places blame on patients rather than on failed health care systems. Khanolkar's postindependence suspicion that the government would not focus its infrastructural energies on cancer proved well-founded. In 1975, the Indian government inaugurated the National Cancer Control Program (NCCP) to build treatment infrastructures and expand access to care. However, the program was soon plagued by charges of corruption. For example, a significant portion of the funds allocated to the program were diverted; out of a budgetary provision of 142 crores in 1984, only 82 crores were used and accounted for.⁷⁵ National grants were diverted to other programs, while state governments delayed the release of the funds that were available. In a testament to low expectations, an erudite piece on the state of cancer treatment in 1980 *celebrated* the fact that there were six major hospitals in the country equipped to provide surgery, radiation, and chemotherapy.⁷⁶ Soon after, Darab Jussawala (Khanolkar's colleague and his successor as director of Tata Memorial) pointed out the insufficiency of having just ten cancer treatment centers in the country, criticizing the NCCP for having failed in its mandate to build treatment infrastructure.⁷⁷ By 1985, only ten years after its founding, the NCCP announced a shift in priorities away from expanding access and toward awareness programs directed at early detection and prevention. While early detection and prevention are laudable aims, they also achieve the effect of diverting attention away from systemic infrastructural lack and toward individual behaviors. As Lochlann Jain suggests, the fetish of early detection obscures the cost and accessibility of treatment, erasing the underlying politics of the disease.⁷⁸ Rather than scrutinizing the failures of public health, the NCCP's move distracts from its long-standing failures in bolstering hospital infrastructures.

Further, pinpointing behaviors and lifestyles as causes and promoting early detection as the answer shift the burden of responding to the disease onto already vulnerable patients. For example, the current National Institute of Cancer Prevention and Research guidelines emphasize how new lifestyle choices such as alcohol consumption, overwork, meat eating, and sexual promiscuity are primary risk factors for cancer. In response, this apex governmental body promotes abstinence from such harmful practices to

prevent the disease, in the process urging early detection and screening as secondary measures if the first line of defense fails.⁷⁹ For another example, the most comprehensive government report on cancer care in postcolonial India begins with messages from the prime minister and health minister urging behavioral correction as an answer to this new “lifestyle” epidemic brought about the “plagues of modernity.” The report rehearses old tropes that cancer is a consequence of “Western” practices of drinking alcohol and eating meat.⁸⁰ This report then approvingly cites the government’s historical shift away from treatment and toward prevention as the correct response to the disease and its thus-identified etiologies. This thrust of governmental cancer policy appears most succinctly in a 2005 *Lancet* article coauthored by officials at AIIMS, the Indian Council for Medical Research, the WHO, and the contemporaneous national minister of health: “As chronic disease epidemics gather pace in India . . . [h]ealth systems need to be reoriented to accommodate the needs of chronic disease prevention and control, by enhancing the skills of health-care providers and equipping health-care facilities to provide services related to health promotion, risk detection, and risk reduction.”⁸¹

Further, the overwhelming focus on early detection and prevention not only places the burden of responsibility for seeking scarce treatments on already vulnerable patients, but also sets patients up for disappointment. As one prominent cancer researcher put it: “Early detection and awareness initiatives of the NCCP may give rise to a rather piquant situation wherein the demands on cancer departments and hospitals may increase exponentially. . . . If the cancer diagnosis and treatment facilities are unable to keep pace, the unmet demands may lead to disillusionment among patients, physicians as well as health planners.”⁸² In sum, the focus on cancer as “a disease of civilization” and behaviors distracts from infrastructural lack, at the same time as it places responsibility and blame on already vulnerable patients. In a chapter on cancer memoirs, I describe how the callousness of this discourse enters patient memoirs, as writers internalize accusations flung at them by physicians, family members, and neighbors about their cancers being their own fault. Many write about being accused of bad lifestyles and negligence right from the moment of diagnosis, regardless of the type of their cancer and whether it was detectable or treatable in the first place. Such accusations recur most frequently in the accounts of women patients who were often told that their “modern lifestyles” and the stress of entering the workforce had brought on their disease.

Further, in the ethnographic chapters of this book, my descriptions of

cancer in India aim to counteract this trope that attaches the disease to a newly prosperous elite, picturing it as a problem of lifestyle and behavior and a by-product of modernity.⁸³ Instead, I show the effects of the disease on the urban poor and the lower middle class, focusing particularly on how they found ways to manage the duress it placed upon their lives. I find that the pervasiveness of cancer has little to do with lifestyle and behavioral faults, and everything to do with a health care system that fails to provide adequate treatment and care. Thus, rather than fault patients for their inability to absorb socioeconomic change, I demonstrate their inventive strategies to seek treatments and maintain networks of social support, so that they might endure in circumstances hostile to their survival. I track their efforts to negotiate kin, manage pain, and strategize speech, all the while demonstrating capacities for endurance that directly contradict assumptions about their class, lifestyles, and behavioral inflexibilities. Thus, moving away from a paradigm of representing cancer patients as marked by behavioral failure, I present the many ways my interlocutors strove, with varying degrees of success, to absorb the diagnosis into their everyday lives.

Aesthetic Flights

If in my face-to-face ethnography I found a reticence to speak about cancer, in films and memoirs from the region I found instead a profusion of speech about the disease. These aesthetic accounts took the fragility of social worlds around cancer as their theme, staking their own narrative claims about the effects of the disease on social life. My method in engaging these aesthetic efforts is not exactly ethnographic, in that I do not track people's engagement in producing and receiving them.⁸⁴ Instead, I am interested in their narratives as complex texts that themselves externalized, critiqued, and reflected social patterns and processes.⁸⁵ In exploring films and memoirs, then, I think of them as active attempts alongside my own to imagine and dramatize the ethical stakes of living with cancer.

At the same time, the efforts of many of these aesthetic accounts differ from my ethnographic work in one important respect. If during my ethnography I found no easy answers to the ethical dilemmas provoked by a cancer diagnosis, films and memoirs were much more forthcoming about the lessons that might be learned from an encounter with the disease. For example, in films about cancer, dying patients left behind lessons for other characters and the audience on how to die with dignity, giving their death meaning. For their part, patients in memoirs proselytized the power of in-

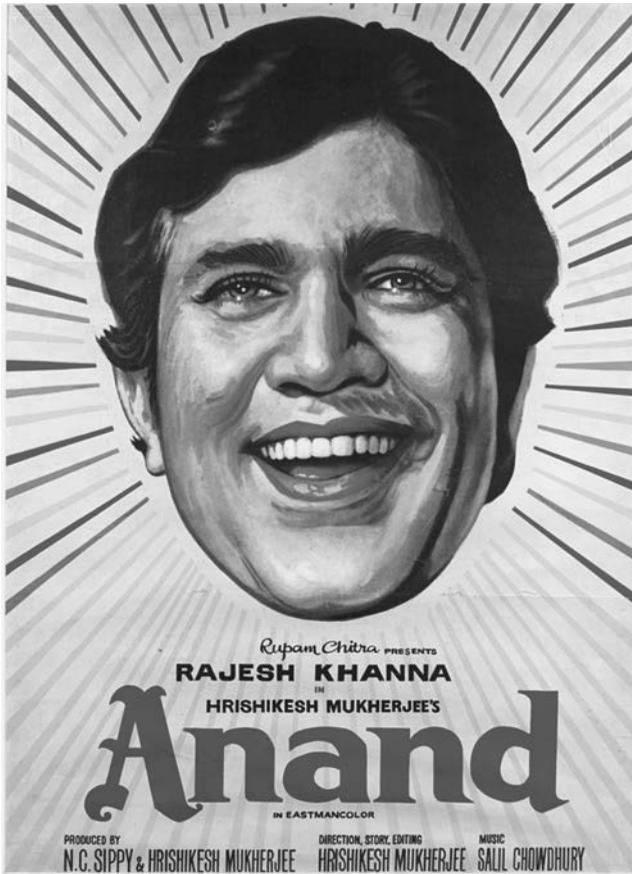


FIGURE 1.2 Film poster for *Anand* (1971), arguably cancer's most famous aesthetic account in India. Image from the Osianama Research Centre Archive, Library and Sanctuary, India.

dividual willpower to transcend the disease's suffering, promising survival and joy as rewards for personal resilience. Thus, films and memoirs tended to neatly resolve the fragmentation and crises the disease catalyzed, offering lessons and resolutions that did not come so easily in my ethnographic narratives. Juxtaposing these lessons about resolutions against my ethnographic work helps me to clarify, in relief, the many irresolvable breakdowns in the lives of my interlocutors. In exploring these accounts, then, I ask, what is lost in this aesthetic will to pedagogy and resolution? In answering this question, I sharpen my understanding of the fragmentation erased by such aestheticization.

I share this concern about cancer's aestheticizations with many scholars who study the disease elsewhere in the world. Take, for example, the canonical work of Susan Sontag on the problem of abstracting the messy realities of

the disease. As Sontag writes in the opening lines of her own cancer memoir, *Illness as Metaphor* (1978), “Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick.”⁸⁶ *Illness as Metaphor* remains the disease’s most famous literary formulation. In the period since the book’s publication, the metaphor of the “kingdom of the sick” has inspired two generations of doctors, patients, and kin to produce memoirs and films about their experience with cancer. However, Sontag herself expressed displeasure that her words had inspired writings about the disease. She wrote later of this opening as “a brief, hectic flourish of metaphor, in mock exorcism of the seductiveness of metaphorical thinking,” and of the book itself as an attempt “to calm the imagination, not incite it.”⁸⁷ She summed up her book’s purpose just a few sentences after the opening: illness was *not* a metaphor, and the most truthful way of regarding illness was one purified of metaphoric thinking.⁸⁸

For Sontag, damaging cultural tropes associated with cancer—depressive personalities, military warfare, terrorism—had already hurt cancer patients for too long. Her aim in writing her memoir had been to persuade readers to escape such metaphors and confront the biological consequences of the disease. Ironically, however, despite Sontag’s warnings, metaphors and aesthetic productions about cancer have flourished, drawing upon her formulation for inspiration. This flourishing afterlife of Sontag’s metaphor, despite her warning against its use, reveals a fundamental tension in representations of disease. Literary scholars criticize the genre for metaphors that abstract away from the suffering caused by the disease.⁸⁹ But such critical disapproval has not thwarted the genre’s popular success. In the early twentieth century, illness memoirs had a marginal place in literary production.⁹⁰ Contemporary memoirs, in contrast, have become one of the most reliably successful commercial genres.⁹¹

My work draws upon Sontag’s impulse to remain wary of cancer’s aestheticizations, at the same time as it departs from her normative goal to cleanse representations of illness of all cultural metaphors. Instead, my work here joins other anthropological efforts to delve into such metaphors for what they reveal about the disease’s social and cultural life. For example, in her ethnographic memoir, Lochlann Jain examines contemporary representations of cancer in the United States across a range of media.⁹² As an anthropologist, she understands her task not as one of “freeing” illness from these cultural metaphors—as Sontag would have it—but of examining them for what they reveal about the worlds in which the disease appears. Simi-

larly, my aim here is to explore the many “cognitive dissonances” (to borrow Jain’s phrase) produced by cultural representations of cancer. That is, I describe the vast fissure between the aesthetic abstractions of the disease and the messy experiences of living with cancer. For example, despite the pedagogy of transcendence proffered by many aesthetic representations, the ethnographic stories I tell show how such escapes were only available to very few. In the simplest terms, diagnosis for most of my interlocutors came too late for treatment, giving the lie to aesthetic accounts that proselytized individual willpower and personal strength as the primary preconditions for survival.

At the same time, I also find that a blanket scholarly suspicion toward illness narratives misses the point.⁹³ Living with the everyday stakes of caring for her ill husband, the literary scholar Ann Jurecic found herself dissatisfied with the all-too-easy critical dismissal of cancer representations. Instead, her experience led her to wonder whether it was possible to define critical practices that were at the same time critical and compassionate.⁹⁴ In other words, Jurecic argues that a suspicion toward such narratives risks a disengagement with what aesthetic genres might offer to those who live with critical illness. Here, my way of remaining open to the promise of aesthetic accounts of the disease is to foreground those that hesitate in their search for narrative resolution and restitution. Certainly, some cancer representations I describe here reproduce the same, unsatisfying narratives of personal growth and willed transcendence that have drawn justifiable scholarly ire elsewhere in the world. At the same time, some depart from this trope, describing practices of endurance that rarely resolve in easy recovery and restitution. These accounts offer multiple, fragmented, and even contradictory accounts of everyday life with the disease. In remaining partial and incomplete, they offer a picture of the irresolvable contradictions involved in living and dying with the disease. The main felicity of such accounts is that they do not resolve whether the tragedy they describe is cancer, or the fraught social worlds in which the disease appears. That is, they do not separate out life after diagnosis (the kingdom of the sick) from the life lived before (the kingdom of the well). Rather, they entangle already damaged personal biographies and familial histories with the violence of a new life-threatening diagnosis. Because of this entanglement of past, present, and future vulnerabilities, resolutions in these accounts are never easily at hand. I take these specific genre-resistant films and memoirs as intertextual to my own, offering a set of adjacent entry points with which to understand the lived experience of my interlocutors.

Juliet McMullin examines graphic novels about cancer in the United

States in a similar way.⁹⁵ The ubiquity of cancer narratives in popular culture leads her to ask: What can we learn from the narrative work of others about the social relations of cancer? What do these works add to our understandings of stigma, hope, difference, and inequality? Like McMullin and other anthropologists, I find my analysis sharpened in the movement between my own ethnographic text and those aesthetic accounts of disease that stay with the fragmentation in social relations awakened by the disease.

Hesitant Methods

The pervasive reluctance to talk directly and transparently about cancer posed productive challenges to conducting ethnography. These challenges are worth nothing here because they inform the texture and shape of the chapters that follow. In giving me permission to work alongside Cansupport teams, the only condition that the home-care workers put before me was that I be careful about what I said about the disease, to whom, and when. This warning taught me to pay attention to the dexterity with which my informants would both talk and not talk of cancer, describe and deny pain, produce and deny empathy, sometimes all within the same few moments. Guided by the Cansupport teams, I took the methodological tack of witnessing conversations unfold slowly, only rarely intervening with my preformulated questions. While this approach had the limitation of not easily offering systematic answers, it also had the advantage of helping me reframe my attention on subtle practices of care and violence I would have otherwise missed.

To elaborate, in her work on studying performances of mania, Emily Martin draws upon Roman Jakobson's writing about aphasia.⁹⁶ Confronted with losing an aspect of linguistic ability, Jakobson saw aphasics as improvising a variety of stylistic maneuvers that were idiosyncratic and yet drew upon the fluidity of language as a social system. In Martin's work, "style" captures both the patterning of social actions and its many indeterminate idiosyncrasies. Styles are personal and particular at the same time as they are social, drawing upon available repertoires of action and behavior. This analytic of style helps me to understand the work of improvisation around cancer as specific to families and patients while at the same time drawing upon the social and political conditions in which the disease emerged. I had to learn through my ethnography to apprehend these many patterned and performative solutions to the problem of language in living with cancer.

Take, for example, the anecdote with which I began this introduction, when our mistake in not hiding the logo “Caring for Cancer” upset a patient. In his naming of his disease as “oncology,” this patient was exemplary of many others who preferred to live within a space of ambiguity, rather than inhabit the strict closures that the naming of the disease put into place. Yet, there was no fixed formula on the metaphoric elision of the word “cancer”; such dexterity and concealments took specific forms in every conversation, revealing varied types of context for each negotiation over language. Each ethnographic encounter demanded my pedagogical immersion in this communicative game.

Paying attention to this elision between what was sayable, what could not be said, and what was understood without saying formed the messy site of my ethnographic work. To describe these transactions of words as styles is not to undermine their stakes. The wrong word or gesture could unravel days and weeks of careful work through which my interlocutors sustained their worlds. Mindful of this, if there was one lesson I took away from my interlocutors, it was a lesson in the importance of recognizing my ethnographic limits.

This was never clearer than when I returned to a house where a Cansupport home-care team had visited many times before. This time, they had been called by the family to sit by the bedside of a father who was minutes from passing away. The doctor turned to the family for some holy water from the sacred river Ganga that he pressed to the lips of the patient in his last moments—a gesture toward ritualizing a good death. The son and his wife took part in this shared act. In these last seconds, however, the patient’s daughter walked in and, in her grief mistaking the water for morphine, accused the doctor of trying to end her father’s life. The team had established a deep rapport with this family, as they had with many others, and they could quickly tap into this reservoir of trust. But while doing so, they quietly sent me away, protecting me as much as protecting the family from the gaze of a relative stranger. The ethnographic lesson I took away from this day was a lesson about witnessing in silence and knowing when to turn away. It is a lesson I hope is reflected in the texture of the work that follows. If I am sometimes reluctant to offer certainty or closure in my analysis, it is because in certain moments, that hesitancy is more faithful to the uncertainties that characterize the experience of critical illness, at a time during which words and gestures sometimes mean more than we know or intend.

Mapping the Book

When I returned home to Delhi in 2011 for fieldwork after spending three years away for graduate school in New York, I noticed signs for several new cancer care NGOs across the city. These included ROKO Cancer, Global Cancer Concern, Indian Cancer Society, CanKids, Cancer Sahyog, Cancer Patient Aid Association, Cancer Aid Society, and the largest and most prominent among them: Cansupport. While some of these NGOs were founded before I had left the city, the number of organizations had multiplied in the years I had been away. Curious about this, I approached the founder-director of Cansupport, exploring the possibility of conducting ethnographic fieldwork alongside the institution's home-care teams. She agreed to my participation, and I was able to follow about ten of the NGO's teams as they provided home-based palliative cancer care to patients. Each team comprised a physician, nurse, and counselor and covered a radius of about fifteen to twenty miles. Over my time with Cansupport, I was able to visit the homes of about a hundred patients who lived across the city. More than half of these patients were among the urban poor who lived in formal and informal settlements. Cansupport staff also introduced me to the director of the palliative cancer care program at the All India Institute of Medical Sciences, which then became the second site of my fieldwork.

The cancer hospital at AIIMS has several teams of specialized cancer experts, an innovative nuclear medicine center, and the latest diagnostic machines and technologies. Its annual budget of about \$230 million matched the budgets of many of the best-funded hospitals in the world.⁹⁷ With a two-thousand-bed capacity and treating five million patients every year, it is also one of the world's largest hospitals.⁹⁸ Writing about ethnographic research at AIIMS thus posed a challenge. As the country's leading hospital, it draws immense budgetary resources from the government and for this reason is hardly representative of many other underresourced public hospitals. At the same time, its reputation attracts patients in numbers beyond its capacity to treat. In this, it resembles many other public hospitals in the country whose infrastructural capacities do not come close to meeting the needs of patients. As will become clear in the following chapter, my description of AIIMS negotiates this combination of its specificity and generality within the Indian biomedical landscape. Rather than taking it as exemplary of Indian health care, I think of this hospital as one entryway into understanding public cancer care in the city.

The chapters that follow are divided by the geography of these sites: the first two come out of my work with Cansupport, and the third is situated at



FIGURE 1.3 The All India Institute of Medical Sciences (AIIMS). Photo by Javed Sultan.



FIGURE 1.4 Relatives of patients sleeping on the pavement outside AIIMS. Photo by Virendra Singh Gosain / *Hindustan Times*.

DUKE

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AIMS. But they are also divided by thematic and methodological orientations: the first three chapters are based on ethnographic research, while the fourth and fifth chapters depend on the analysis of cultural texts. Consequently, readers with different expectations might choose to focus on different sections of this book. The anthropologically and sociologically inclined might choose to focus on the next three chapters, while those with an interest in the medical humanities might find chapters 4 and 5 closer to their interests. I would urge all readers to end with the concluding chapter, which extends and completes this introduction.

Chapter 1, “Concealing Cancer,” focuses on the concealment of cancer diagnoses and its irreducibly multiple textures and implications. For example, concealment for some evidenced care within families. For others, it was a way to safeguard themselves from the harms of revelation, when kin and neighbors hurt rather than aided recovery. I trace the implications of these many motivations and consequences of concealment for palliative care policy, as competing groups of practitioners offered contrasting political models in response to the problems concealment posed for public health work. I also describe an event organized by Cansupport in which family members came together to remember their deceased kin, revealing the importance of concealment in the very moment of overturning its norms. Across these scenes of concealment, I describe it as a strategy to manage the stress that the disease put on social relations. By speaking of cancer only indirectly or not at all, patients and families kept alive a world of an “as-if” in which the disease would not take on the overwhelming force it would gain once named. Through strategic and partial disclosures, they kept alive other ways of relating to family, kin, patients, and neighbors.

Chapter 2, “Cancer Conjuality,” tracks the entanglement of palliative care, conjuality, and cancer. I describe how the disease puts pressure on already fraught marital biographies, revealing durable fissures in household relations. As cancer appeared in already broken worlds, it shifted the capacity of husbands and wives to inflict and absorb violence. The debilitating experience of cancer often confined husbands within their homes, making explicit their dependence on the care of their wives. Often, these shifts in the distribution of conjugal vulnerability opened cracks that allowed for long histories of domestic violence and betrayal to seep through. In subtle ways, women could express pasts they had kept hidden and accrue a delicate agency through their practices of care. But at the same time, they continued to inhabit the vulnerable space of affinal homes. I describe, then, how in these

conjugal arrangements, empathy, and misrecognition followed each other closely in their tracks, braiding together care and violence to the point of their indistinguishability. I also describe how cancer NGO workers—aiming to treat the social and physical world of their patients—intervened into these broken social relational worlds. In doing so, they found themselves drawn into difficult decisions about how to manage past histories of violence alongside present vulnerabilities.

Chapter 3, “Researching Pain, Practicing Empathy,” is based in AIIMS and examines how its doctors produce, treat, and research cancer pain. Physicians at AIIMS who treated pain took an interest in its “psychosocial” dimensions, aiming to track down its social and cultural etiologies. Through these speculative models, they revealed their understanding of how the disease and its social world mutually shaped each other. Their conditional hypotheses about these social worlds demonstrated their efforts at offering a response, however partial, to the constant flow of patients they found themselves responsible for treating. In their responsive capacity for empathy, they expressed a desire to practice a form of humane and humanistic medicine. But even as they showed their capacity for empathy for each individual patient, they could do little to address broader structural inequities that conditioned how pain was socially distributed. Cancer pain, I argue, comes into being in the process of doctors, families, and patients reaching an agreement on how the social and biological etiologies of pain intersect. But I also show how such forms of agreement are hard to reach in conditions of longstanding infrastructural duress that breed doubt about the possibility of pain’s amelioration.

Chapters 4 and 5 take cultural representations of cancer in India as their subject. Chapter 4, “Cancer Memoirs,” explores how Hindi and English cancer memoirs offer identification and consolation to a new, growing readership in the region. Yet, I describe how such comfort comes at a cost, as many memoirs ask readers to accept responsibility and blame for the disease. These memoirs make the troubling promise of restitution, asking patients to learn to “love their cancer” and relinquish the pessimism that might have contributed to their bodily failure. I describe how I find these generic conventions troubling for laying blame and responsibility on patients rather than on the structural inadequacies in health care that failed them. I then shift focus to memoirs that go against the grain of these generic conventions. Unlike the promise of transcendence offered by accounts of personal responsibility, these explore the durable, and often irresolvable, doubts about

social relations that accompany a cancer diagnosis. In doing so, they refuse to draw lines between the precarity of life before and after cancer, showing how the disease folds into already fragile social arrangements.

In chapter 5, “Cancer Films,” I describe how, unlike in memoirs, in which cancer patients are urged to live happier lives, patients in Hindi films tend to die. If the dominant affect in memoirs is optimism, cancer films are marked by an overwhelming pathos. Yet, I caution against elite criticisms of cancer films that claim that such portrayals of pathos hinder the happiness of real patients. To the contrary, I find pathos an appropriate mode of representation of a context in which, often, a cancer diagnosis portends death. I find in these films an impulse like my own to investigate the breakdown of social worlds in the wake of a cancer diagnosis. At the same time, if my face-to-face ethnography is concerned with the fragility of everyday life, in these films, cancer becomes a narrative shorthand for a range of imaginations of social crisis—the failure of decolonization, the inability of physicians to live up to their vocational calling, the decline of the modern family, the importance of traditional gender roles, and so on. After identifying these narrative crises, these films tend to resolve them through the death of the patient, leaving other protagonists and the audience with a lesson about the duties of citizenship and personal responsibility. I show, then, how these films—in their will to displacement and resolution—contrast with my ethnographic description, at whose scale ethical resolutions often remained an impossible ideal.

Finally, in the concluding section of the book, “Endurance,” I offer some concluding thoughts on the mode of ethics I find characteristic of the practices of my interlocutors. I describe the ethical weight of the effort to carve out a livable life in response to circumstances that do not offer hope. I argue that such a picture of ethical life takes livability rather than flourishing as its potential and horizon. In situations and times that do not readily offer pathways to collectivization and rights, I argue that anthropologists would do well to explore the terrain of everyday ethics committed to enduring in the present. At the same time, in thinking of endurance as ethical, I do not mean that its practices offer a way out of the many impasses of inequality. Instead, I draw attention to the challenging work of maintenance, of folding and absorbing critical illness into everyday life, even in the face of life-threatening duress that continuously invites exhaustion.

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NOTES

INTRODUCTION

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 - 15 As one instance, Julie Livingston describes how pain runs through the experience of cancer in Botswana. Even as it is often unvocalized and hidden, it is crucial in bringing patients to the cancer ward, where it creates demands for care and responsiveness. Julie Livingston, *Improvising Medicine: An African Oncology Ward in an Emerging Cancer Epidemic* (Durham, NC: Duke University Press, 2012), 142–43.
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1. CONCEALING CANCER

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