

Living in Prognosis: Cancer and Pain in Contemporary India

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Book Prospectus

"If my cancer returns, I do not have the will to fight again." - Rajesh

Rajesh was one of the few urban poor cancer patients who had succeeded in outliving the months long wait times for treatment in Delhi's public hospitals. He was one amongst even fewer who had garnered financial assistance from the Indian state. Orphaned at a young age, Rajesh had worked at a chemical factory through his teenage years. When I met him early in the course of his illness, he had recently lost his job and lived with his extended family. While they allowed him a makeshift space on their balcony to sleep, they had withdrawn care and support as soon as they learned about the seriousness of his prognosis. Yet, Rajesh fought desperately to live, and quickly learned to maneuver the intricate public health system and bureaucracy that were the gatekeepers to state care. He spoke with authority about which doctors at the public hospitals had been willing to waive certain fees and about the clerks at the Ministry of Health who demanded the smallest bribes to process his appeals for financial support. Unreliable and difficult to procure, these limited state funds were often the only option for the urban poor seeking life-saving cancer treatment. Rajesh also received assistance through a private cancer NGO. This constellation of care that Rajesh cobbled together fortunately led to successful treatment and remission. However, cancer continued to mark him even after he had survived its biological onslaught. In its wake, Rajesh trusted neither his vulnerable body nor the precarious infrastructure of care that protected his life. He had lost his savings as well as crucial years of work and training that might have allowed a stable future. Instead, he had become an errand boy, earning his rent by doing chores for family and neighbors. In my final conversations with Rajesh before the end of my research, it became clear that survival in such conditions of abandonment had spent him, draining him of his will to outlive the disease's likely recurrence.

Most of the urban poor in Delhi are not as able as Rajesh to construct such a journey to even temporary survival. For him and many others, a cancer prognosis does more than foretell the likelihood of death or survival. Rather, it inaugurates a condition of living where the sufferer learns to doubt the social relations that constitute a person and protect life. Through their struggles with cancer, Rajesh and others like him were forced to confront not only their bodily vulnerability, but also the precarity of the social and political structures within which they lived. *Living in Prognosis* tells the stories of these urban poor cancer patients and their caregivers, as they confront the vulnerability of their marginalized lives in the shadow of a cancer prognosis.

Cancer has become the leading cause of mortality worldwide (International Agency for Research on Cancer, 2014). As the rising incidence rates of the disease provoke fears about how all humans are equally at risk for the disease, this book

argues that in fact both cancer risk and survival are unevenly distributed. The same WHO statistics show how the burden of cancer mortality falls disproportionately upon the global south, defying a longstanding public health imagination that has historically linked such regions with infectious diseases. In India, as elsewhere in the world, cancer is shaped by the social and political conditions in which the disease appears. At less than 1.5 percent of the GDP, the Indian state's public spending on healthcare has been amongst the lowest in the world. The decolonized Indian state's promise of universal healthcare never materialized in comprehensive infrastructural commitments in the four decades following independence. However, since the 1990s, this historic state neglect of healthcare has been further exacerbated by a new set of neoliberal economic policies. These new policies aim to subsidize new luxury private hospitals while reducing support to the public health system. Despite the storied rise of India's economy in the last two decades, healthcare costs have risen exponentially at the same time as such large corporations have begun to dominate the urban healthcare landscape (Selvaraj & Karan, 2009). At present, healthcare costs push more than 39 million patients into poverty every year. Through the lens of cancer, *Living in Prognosis* explores the urgent stakes of the intensifying withdrawal of the Indian state from public healthcare. The book describes how doctors improvise practices to alleviate the pain of patients unable to access curative interventions, how bioethical debates struggle to address the vulnerabilities of the urban poor, and how domestic drug makers and patient groups fight global corporations to lower the prices of cancer drugs. Thus, *Living in Prognosis* draws attention to the ethical challenges faced by a transforming health system ill equipped to bear the burden of cancer, and by extension, many other chronic diseases that have begun to concern global public health. It tells the stories of doctors, families, caregivers and patients who struggle to care for cancer-marked bodies as they appear in conditions of healthcare precarity and structured marginalization.

Framing the Research

My first academic engagement with healthcare in Delhi dates back to my years as a graduate student in Delhi University from 2004-2007. While formulating a project to study end of life care at the time, I was struck by the proliferation of many new cancer care NGOs whose vans, buildings and posters had begun to appear across the urban sprawl. After leaving the city for graduate coursework at NYU, I returned in 2011 and began fieldwork within this emerging world of cancer care. First, I joined the largest of the new cancer care NGOs in the city – *Cansupport* – following its teams of doctors, nurses and counselors to the homes of over a hundred urban poor patients. While cancer care NGOs have become a global phenomena, given the scarce availability of curative treatments in India, mobilizations around the disease were not characterized by the corporatized, life-affirming pink-ribbon campaigns of the global north (cf. Jain, 2013). In the absence of accessible treatment, the diagnosis of cancer almost certainly meant an imminent death. Unable to promise curative intervention, both family members and doctors systematically hid the prognosis from patients and isolated them from neighbors and kin. Already marginalized, this further isolation provoked feelings of anger, betrayal and mistrust amongst many of my diagnosed

interlocutors. Working at *Cansupport* revealed to how under such circumstances, the primary institutional focus of cancer NGOs in India was to help cancer patients die with dignity and without pain. Thus, the moral complexities of such practices of helping the poor die with dignity under circumstances of financial and psychological duress became a central concern that guided my research.

While *Cansupport* gave me access to the domestic and non-governmental spaces of care for the urban poor, I also sought to track how state hospitals were responding to cancer as a new public health problem. Nearly all the patients I worked with were being treated at the cancer center of the country's largest public health hospital: the All India Institute for the Medical Sciences in New Delhi. When I approached the director of palliative cancer care here for permission to conduct ethnographic work, she saw an opportunity for an interdisciplinary collaboration and welcomed me into the center's research team. My staff position at the hospital provided me unprecedented access to one of the largest cancer facility in the global south. Most importantly, it allowed me an entry into the private lives of cancer physicians, as we talked in backrooms, meetings and dining halls about the struggles of providing empathetic care within an under-resourced healthcare system. In telling the stories of these physicians, I describe their tireless empathy, as they struggled to treat the thousands of patients under their care. Yet, I show the limits of this empathy as physicians turned towards inculcating spiritual self-care in their patients, rather than towards addressing the problem of infrastructural failure.

The limits of Delhi's public health system pushed me to investigate the parallel rise of private luxury hospitals. To this end, I joined the staff of *Artemis*, one such hospital at the outskirts of the city. *Artemis* largely catered to local and global elites who traveled there from all over the world for treatment. Yet, given the lack of space at public hospitals, the families of lower-income patients would rush here for critical end of life care. Once at *Artemis*, they would often have to make the difficult decision of continuing care at the risk of financial ruin, or discontinuing hospitalization with nowhere else to go. I began a collaborative project at *Artemis* with the country's leading intensive care specialist to formulate medical guidelines for appropriate end of life care. In the book, I examine how many medical and legal actors including my interlocutor sought to formulate ethical norms through which they hoped to protect the dignity of the poor. Yet, telling the stories of patients themselves, I reveal how such bioethical norms framed out the structural and financial vulnerability of the poor at the end of life.

The final site of my fieldwork was in the Indian courts focusing on a legal dispute contesting the global poor's access to cancer drugs. Here, global pharmaceutical corporations vied with the Indian state, patient organizations and local drug manufacturers over the legal status of generic cancer therapies. The implications of these ongoing battles have consequences not only for equitable access to cancer therapies, but also for the global availability of new generic drugs for the treatment of HIV-AIDS, TB and a range of other diseases. Thus, this legal controversy has attracted the attention of global coalitions of both activist groups and pharmaceutical lobbies. I tracked this battle in the courtroom, in the archives and through interviews with

lawyers involved in these cases. If in my broader fieldwork I found that a humane medical orientation provided only a limited vision of the vulnerabilities of the poor, here I discovered a similar myopia in legal debates. As the state and patient associations allied with generic drug companies and battled global corporations, both sides framed the question of cancer rights as primarily a matter of drug pricing rather than about access to public care. Thus, both sides produced a vision of healthcare rights that, however humane, ignored the structural conditions that prevented the poor from accessing treatment leading to the possibility of more timely drug prescriptions in the first place.

In summary, across these sites of public, private and legal healthcare work, I tracked the form and orientation of the response to cancer as a growing health concern. At each of these sites, I followed how doctors, lawyers, caregivers and cancer patients themselves framed the vulnerability of lives in prognosis, and in response formulated appropriate and urgent modalities of care. Yet, in telling the stories of the urban poor cancer patients consigned to death by a failing public health system, I show the ethical limits entailed in present modalities of care, even as they make possible many kinds of humane intervention.

Target Audience and Relevance

In mainstream global health work, a strong association between the global south and infectious diseases has led to a structured invisibility of chronic and non-communicable conditions such as cancer. As one of the only ethnographic efforts to track cancer in the global south, *Living in Prognosis* tracks the exponentially growing presence of cancer-marked bodies and the structured absence of biomedical care. It describes a terrain in which vocabularies, practices and institutions are only recently emerging, creating points of friction between the demands of care and the modes of triage through which this care is extended or denied. In drawing attention to such emergent and improvised cancer care in the developing world, I extend Julie Livingston's pioneering ethnography of public health oncology in Botswana (cf. Livingston, 2012). However, in contrast with Livingston's description of the Botswanan commitment to expanding public health capacity, the appearance of cancer in India coincides with policies designed to diminish the Indian state's role in providing public healthcare. Thus, my work examines a different critical conjuncture in global health: the rapid privatization of healthcare infrastructure in many parts of the world, coinciding with the rise of cancer as an urgent public health concern. In this, *Living in Prognosis* will be of interest to an interdisciplinary readership of faculty and students in anthropology, public health, development and allied social sciences that are tracking the rise of the cancer epidemic. It will also be of interest to scholars and students in these fields examining transformations in the global political economy of health.

The book will also engage students and researchers across the social sciences that study the ethics and practices of humanitarian care. In writing *Living in Prognosis*, I join recent efforts by anthropologists to point to the limits of empathetic humanitarian interventions in periods of healthcare crisis. Amongst others, Peter Redfield and Didier Fassin have pointed to the overwhelming urge in humanitarian intervention to preserve life only at moments of its extreme vulnerability (Fassin,

2012; Redfield, 2013). They describe how such efforts, however heroic and humane, fail to address the underlying political and economic structures that produce crises in the first place. In my work, I extend this understanding of humanitarianism to describe the work of public health in India, as it shifts away from its promise of universal care for all, and towards humane care for a few. As both governmental and non governmental public health physicians in India struggle to alleviate the pain of patients left to die under their care, they respond with individualized empathy and concern. Increasingly constrained from preserving life, here humanitarian empathy extends into the fraught ethical domain of providing dignified deaths for a few amongst the poor that seek out such support. Thus, *Living in Prognosis* seeks to extend the analysis of humanitarian medicine beyond the work of global NGOs and into descriptions of state institutions in conditions of infrastructural crisis. In so doing, this book will contribute to an interdisciplinary conversation about the limits of humanitarian empathy, and the troubling consequences when such limits bound the work of state-led public health.

This book will also be of interest to undergraduate, graduate and postgraduate scholars of South Asia. While much literature exists on medical systems in colonial India, there are few sustained investigations of public health as it has taken shape after decolonization. This book is an inaugural effort to tell the story of the contemporary public health failures in India, in the context of previous transformations in the post-Independence political economy of health. Thus, *Living in Prognosis* will trace the history of post-Independence public health in India, while bringing to light recent systematic exclusions of the poor from the storied rise of the Indian economy.

The teams of doctors and caregivers across my field sites welcomed me into their work because they too sought to understand the lives, struggles and vulnerabilities of the patients under their care. This book is responsive to their work and deeply informed by our collaboration. Some of this collaborative research has been published, while others of my co-authored texts circulate as policy documents within these institutions. In light of these partnerships, *Living in Prognosis* should contribute to an interdisciplinary and public conversation between the medical and social sciences, pointing to the possibilities and limitations of specific grounded collaborations in which I was fortunate to participate. To this end, written with minimal disciplinary jargon, this book will hope to draw in medical practitioners, public health researchers, and policy makers that are concerned about the global response to the cancer epidemic.

Chapter Précis

Chapter 1: Producing Empathy, Constructing Pain

Producing Empathy, Constructing Pain explores the emotional labor of caregivers in India's largest public oncology ward at the All India Institute of the Medical Sciences. At the Institute, I trace the ongoing failure of India's public health system by focusing on the burden the growing cancer epidemic places on its scant resources. In a context where the speed of cancer progression often outstrips the long wait for treatment at public hospitals, highly trained doctors encounter a patient

population usually beyond curative intervention. In this chapter, I describe how the rapid rise of palliative cancer care as a public health priority reveals the pressing failure of the state health system. As physicians respond to the urgent ethical demands of treating end-of-life pain, they produce a picture of empathy that acknowledges the individual suffering of the patients under their care. Yet, I trace the limits of their empathetic vision, as these physicians seek to inculcate self-care in their patients through the putatively 'Indian' practices of spiritual belief, yoga, meditation and ascetic resilience. I follow how the medical treatment for their suffering is thus routed through colonial and postcolonial tropes about native minds and bodies, and diverted away from their political etiologies in infrastructural failure. As the sheer numbers of patients overwhelm these public health practitioners, their humane and empathetic response is to pursue, study and scientifically validate the efficacy of such cultural practices as a partial panacea to the problem of cancer.

Chapter 2: Transactions in Pain and Silence

If the first chapter describes the limits of a vision of empathy and suffering amongst beleaguered cancer care doctors in Delhi, *Transactions in Pain and Silence* examines the overwhelming silence around cancer in the region. In a survey of 600 patients I conducted alongside the doctors at the All India Institute, we found that less than a fifth of the patients were aware of their diagnosis. In many cases family members had hoped to protect patients from the terminal prognosis. In others, overburdened treating physicians had failed to communicate their diagnosis in clear terms. I describe this enforced, collaborative silence between doctors and families as both a form of care that softens the blow of the prognosis, as well as a form of violence that disguises the scant possibilities of treatment afforded to the poor. I go on to describe how cancer care NGOs such as *Cansupport* sustain the fragile networks of support around these patients without disrupting the silence around the disease. Yet, I point to the difficult ethical dilemmas and risks of sustaining such practices of care and silence. A refusal to acknowledge the prognosis often led to new forms of health risk, as patients took recourse in new alternative healthcare providers that exploited their financial vulnerability and promised easy cures. While imagined as a form of care, the silence around cancer often exacerbated economic and social marginalization.

Chapter 3: Guilt and Accusation at the End of Life

Chapter 1 and 2 focus on the struggle to achieve dignified deaths, while *Guilt and Accusation at the End of Life* highlights how the specter of bad deaths insistently disrupts such efforts. Here, I show a tussle between medical and legal end-of-life bioethics in the region as they vie for authority to determine the boundary between life and death. Yet, through my fieldwork with patients, I reveal how their anger and accusations against an unresponsive health system disrupt all bioethical attempts to produce dignified deaths. Thus, in this chapter, I foreground the sentiments of accusations, anger and guilt that simmer below the surface of the humanitarian hope of dignified deaths. I also track the recent bioethical guidelines that have been recently put into place to protect the poor from malpractice at the end of life. I demonstrate how these new protective guidelines stand to further marginalize the region's poor by making the criteria of death even murkier than before, further lengthening hospital

stays and increasing hospitalization costs. In effect, end of life legal and medical guidelines in India that aim to protect the vulnerable poor at the end of life now threaten to place even higher financial burdens upon families. This chapter then further reveals the limits of a “death with dignity” orientation as it is enacted under the conditions of daily life for Delhi’s urban poor.

Chapter 4: Kinship Trouble

Kinship Trouble describes buried histories of gender violence that characterize marriages in the region, and how these histories erupt in the aftermath of cancer prognoses. As the past comes to surface, it complicates and limits the care that marital couples extend to each other at the end of life. In this chapter, I place my analysis within a long tradition of feminist scholarship about the particular vulnerability of women and the invisibility of gendered violence within North Indian kinship arrangements. Always cognizant of the intense ethical questions that surrounded my own role as participant observer, I enter the intimate realm of the households of the dying poor. Here, poignant, painful, and occasionally healing stories gleaned from patients, their caretaking kin, and neighbors illuminate my analysis of on-the-ground structural violence (Farmer, 1996) as it plays out in the inability to confront, control or transcend the pain of cancer suffers and their intimate others. As cancer prognoses disrupt the lives of those without recourse to institutional care, women bear the brunt of the labor of care within household arrangements. I argue that the conduct of this labor allows for subtle shifts in the relations of power within marital arrangements, allowing women possibilities of speech as well as the hope for redressals of past wrongs. Yet, I demonstrate that an overwhelming public health emphasis on producing peace and dignity in the process of death emphasizes marital reconciliation, re-establishing the vulnerability and silence of marginalized women.

Chapter 5: Lively Rights

Lively Rights traces legal battles in the Indian courts over the availability of cancer drugs for the global poor. When the Indian state signed the WTO agreement in 1995, it capitulated to trade regulations that bar the domestic production of generic drugs discovered after 2005. In providing generic alternatives to expensive drugs, Indian drug companies have been central to global public health interventions around HIV-AIDS and other life-threatening diseases. The WTO agreement jeopardizes the future of all such interventions, raising urgent concerns amongst the global public health community. In this chapter, I show how cancer drugs have become a new legal battleground for health sovereignty in the global south. By declaring cancer an epidemic, Indian state actors, patient associations and generic manufacturers hope to circumvent WTO stipulations and reopen the trade of essential drugs in the global south. I suggest that much of the future of low-cost public health interventions depends on the outcome of these promising legal battles. At the same time, I demonstrate that the framing of healthcare rights as only a matter of drug access fails to acknowledge that the urban poor are unable to access life-saving treatment in the first place. Thus, along with anthropologists Joao Biehl and Adriana Petryna, I examine both the possibilities and limits of such a judicialization and pharmaceuticalization of public health. In the spirit of their work, I ask whether such judicial processes can

possibly produce a space where social rights might come to be executed (Biehl & Petryna, 2011, 2013).

Chapter 6: Conclusion

In the conclusion I draw together a picture of cancer care in Delhi where doctors, lawyers, public health workers and family members struggle to produce conditions of humane care for the urban poor. I describe how across the multiple sites of my work – public and private hospitals, NGO interventions and legal battles – my interlocutors mobilize humanitarian sentiments of empathy, rights, and a concern for dignity at the end of life. I suggest that even such powerful and empathetic humanitarian mobilizations remain unable to acknowledge the forms of marginalization that mark the urban poor in India as they live in the shadow of cancer prognoses.

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