Cancer and secrecy in contemporary India

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Dr. Nigam was the department head of the palliative care program at the cancer center at the All India Institute for Medical Science (AIIMS)—North India’s largest and most well-reputed public hospital. Her afternoons were usually spent at the inpatient units of the cancer ward. Here she could take her time with each patient, freed from the compulsive speed of the outpatient clinic where physicians like her saw about forty cancer patients a day. Accompanying her on one such inpatient round, I met a twenty-two-year-old man with an advanced malignancy that left him only a few months to live. He had been admitted to the inpatient ward for palliative analgesia. His face revealed little expression, and he remained silent until the end of Dr. Nigam’s examination. As she was about to move to the next patient, he quickly called out a question: “Doctor, why am I in this hospital?” I took it as an expression of existential anger I had heard many times before: why was he in the hospital, why not someone else? Dr. Nigam answered, “Why do you think?” This struck me as insensitive until I heard his response: “There must be some misunderstanding (galatphemi).” I had misheard the emphasis of his demand: he had not asked why he was in the hospital, but rather, why he was in this hospital. In other words, why was he in a cancer ward? He looked away, and after a moment’s hesitation and silence, Dr. Nigam turned to the next bed.

Later that day the meaning of this cryptic exchange would become clearer. I was sitting in the doctors’ common space when Dr. Nigam gestured me to her office. She had asked the young man’s mother and sister to come in to talk with her. After telling them about how he was responding to palliative pain treatment, she asked directly: “How long do you expect him to go
on like this? I think he really wants and needs to know; he’s asking again and again—why are the doctors not telling me?” His sister’s face clouded as she responded: “We don’t have the courage (himmah nahin hain).” The young patient had been so far shielded from the word cancer. From the time of his diagnosis a year ago, his family had hidden his disease and its bleak prognosis from him. Dr. Nigam asked in reply: “Do you want me to tell him?” Visibly distraught, the mother responded: “No, he won’t be able to take it. We cannot let him lose hope, he will just give up if he knows.” Dr. Nigam nodded, but pressed: “I think we should, he will be angry in the future, when the pain gets worse, and he finds out that you knew all along.” Still hesitant, the mother replied: “But don’t tell him it’s over, that there’s no treatment. Tell him we’ll still be trying.”

In my brief interactions with this family, this was the closest I had found them to speaking the word cancer. Yet, even without the patient present, they had refused to say the word aloud. I would later find out that for months they had decided to not come to AIIMS because a sign with the words “Institute Rotary Cancer Hospital” marked the entrance of the cancer ward building. Instead, they had been to two private hospitals where the thicker concentration of departments—often more than one on the same floor—allowed them to avoid explicit signage about the disease. They had, however, been dissatisfied with the pain care at these hospitals and finally came to the palliative ward at AIIMS. Here, the patient could not have missed the large board that marked the space as a hospital for cancer treatment when he was wheeled in through the door of the cancer ward building. At the same time, it was unlikely that this was the first time he would have encountered his diagnosis. He was literate, had undergone several rounds of chemotherapy, and had been alone with several other patients with the same disease.

This tricky relationship between speech, secrecy, and cancer would continue to haunt the
rest of my fieldwork, never quite resolving itself. Looking through over six hundred patient records at AIIMS, I found that over 80% of the patients had been recorded as “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 that the motivations for concealment as varied and unpredictable as the practices through which secrets were sustained.

In introducing an important volume on practices of medical disclosure, Davis and Manderson suggest that “There has been surprisingly little critical attention on how and what people disclose, question and expose, for what purposes, and in what ways” (2014). They find this lack surprising, since they understand disclosure as fundamental to clinical practice—always entangled with research, diagnosis, discussions of treatment choices, and prognosis. By focusing attention on cancer in this article, I expand the discussion of medical non-disclosure outside its dominant association in the social sciences with infectious diseases—particularly HIV-AIDS—the context in which it has received the most analysis. When scholars examine medical non-disclosure in relation to HIV-AIDS, they most often focus on the stigma that accrues to the disease because of its negative cultural associations with non-normative sexual practice. Here, I join other recent work that brings cancer into this literature on the ethics of non-disclosure. I argue that centering cancer in these discussions reveals how non-disclosures grow out of the give and take of everyday life and as a response to prior social vulnerabilities, rather than only as a
defense against stigmas born out of cultural beliefs about disease.

What one told, how, when and to whom were crucial ways through which the burden of cancer was distributed across social networks, falling more heavily on some than others. In this distribution of speech, awareness of diagnosis and prognosis were never a matter of all or nothing, but a dynamically negotiated site of social transaction. In what follows, I argue that speech (or non-speech) about cancer were experiments in social relations. They were strategies through which my interlocutors tested the strength or vulnerability of ties with neighbors and kin, relations whose edges had frayed over time.

Further, a major limitation of public debates about medical non-disclosure—including that of cancer—takes its lack or presence as indicative of cultural backwardness or advancement. These framings take non-disclosure as evidence of a culture-bound reluctance in ‘Asian’ countries to measure up to biomedical realities. To the contrary, medical anthropologists Good and colleagues explain how the norm of disclosure is of recent vintage in the United States, only institutionalized around 1971 with the passage of the National Cancer Act, which shifted the bioethical and cultural consensus from the question of whether to tell, to how to tell. And, as Cecilia Van Hollen shows, medical bioethicists began to posit telling as normative only after this relatively recent institutionalization of the ideal of cancer disclosure. Van Hollen goes on to argue that with the rise of professional bioethics in the last few decades, the right to autonomy has come to be pitted against "other" cultures where non-disclosure might be contextually appropriate. Rejecting this dichotomy, through her ethnography of cancer amongst women in Tamil Nadu, Van Hollen describes how her interlocutors were less interested in what information was conveyed or withheld, and more interested in how the act of non-disclosure revealed the care or neglect of those around them. Similarly, in her ethnography of cancer in Botswana, Julie
Livingston explains how non-disclosure did not indicate a failure of prognostication, but rather revealed the ethical practice of patients and relatives who took on the burden of discretion as a sign of care. I join this rejection of framing cancer non-disclosure as a sign of cultural lack or medical failure. Rather than take concealment as evidence of biomedical non-compliance, I show that it was a mode through which social relations around cancer were tested, mediated and reshaped. Specifically, I show that weaving between concealment and speech allowed my interlocutors to inhabit the space of the ‘as-if,’ opening the possibility of living in a subjunctive mood. For some, not speaking of cancer opened possibilities of hope. For others, it opened means of persisting in circumstances in which revelation carried danger. I argue then that to inhabit this space of the subjunctive was not to escape biomedical realities, but rather, an attempt to make space for the disease within already tense social worlds that were further tested by the new pressures and doubts of a life-threatening diagnosis.

I conducted my fieldwork about cancer in Delhi at two primary sites: AIIMS and Delhi’s largest cancer NGO—CanSupport. While secrecy was an ever-present concern at AIIMS, I was able engage the problem more substantially alongside the staff of CanSupport with whom I spent time in the homes of patients. This paper develops insights garnered through visits with the NGO to the homes of about 120 cancer patients between 2011 and 2012. Entering the tricky world of diagnostic secrecy required me to take on a somewhat circumspect role as an ethnographer. In giving me permission to work alongside CanSupport teams, the only condition that the NGO put to me was that I be careful about what I said about the disease, to whom, and when. Without already knowing how patients and families were managing their knowledge, asking questions about disclosure risked impoliteness at the very least, and a disruption of familial dynamics at worst. The condition put to me by CanSupport taught me to pay attention to the dexterity with
which my informants would 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 pre-formulated questions. While this approach had the limitation of not easily offering systematic answers, it also had the advantage of helping me reframe my attention onto the question of secrecy, which had not been the initial focus of my investigation. In this paper, I discuss only two of the many cases I followed. They are not representative of the many varied forms and functions of concealment that I encountered. Rather, I focus on them here as indicative of precisely this variability. Concealment appears in the first case within a context of relatively strong familial and neighborly support. In the second, the appearance of the disease deepens already existing fault lines in my interlocutor’s social world. Concealment was never a stable and uniform practice, but constantly shifted in relation to response to different people and at different times of the illness trajectory at the same time, even as the forms and function of non-disclosure were irreducibly multiple, in each case I tracked, they revealed something about the social worlds within which their practice unfolded. That is, as concealment opened up a space of the subjunctive, it sharpened my sense of the actual to which the world of the as-if was inextricably bound.

Cansupport was founded in 1996 by Harmala Gupta. She had been successfully treated for Hodgkin’s Lymphoma as a graduate student in Canada in 1986. The first person to use the word cancer to her was a visitor; her doctor had only told her she had “Hodgkin’s disease.” Gupta remembers not being prepared for the insensitivity with which this visitor named the disease; This incident convinced her of the importance of not “whether you should tell [the diagnosis] but rather how you should tell” (Harmala Gupta 2004). From that moment on, the
importance of the relation between words and illness remained impressed upon her. She returned to India after her treatment and gathered a small group of women to start her work. As the group grew, they began collaborating with AIIMS to offer support to their patients. This informal project concretized into a collaboration with the pain clinic at AIIMS which continues to the present. By the time of my fieldwork in 2011, Cansupport was operating out of 13 centers in and around Delhi. Its staff included 24 teams—each comprising a physician, nurse and counselor, each covering a radius of about 15-20 miles. Within this radius, every team was responsible for about 50 families and patients. About half of these patients had heard of the organization from friends or family and called their helpline while another fourth was referred to them by doctors at the AIIMS pain clinic. By the organization’s own estimates, they had provided care to 746 patients over the year before my fieldwork, and roughly equally to men and women. According to the same estimates, most of these patients were ‘lower-class’ (54%), while most others were ‘middle-class’ (38%).

Living in the Subjunctive

On one home-care visit with Cansupport, I accompanied a team to the city’s eastern border. Rohini—the wife of the patient we were visiting—greeted us on the path leading to her home. She then took us inside where her husband Shambu lay in apparent discomfort in a double bed placed in the center of a small room. Their teenage son was away at school. Shambu had been a door-to-door life-insurance salesman who now presented an advanced stage of prostate cancer. He was the family’s sole earner and two years of treatment had depleted their financial resources. He did still own the plot of land on which his two-room house was constructed. The Cansupport doctor I was with administered to his pain and enlisted the help of a nurse he knew who lived a few houses away in the neighborhood.
Here, as in most others, who knew what was a sensitive matter. We walked outside the house under the pretext of seeing a new provision store in the neighborhood. The counselor’s tactful conversation in that time with Rohini elicited that she had an accurate picture of both Shambu's diagnosis and prognosis. However, Rohini was certain that while Shambu knew his diagnosis, he was unaware of its prognosis. That is, while he probably knew he had cancer, she believed he did not know how far advanced his malignancy was. She had colluded with the doctor to protect him from the psychic impact of the knowledge of his imminent death. But maintaining this secrecy had been difficult for her and she was open to the counselor's suggestion they talk to Shambu about how much he knew and whether he was prepared for the months ahead of them. Soon we returned to their house and Rohini left us alone with Shambu. Talking to Shambu revealed that he was not as much in the dark as Rohini imagined. He had spoken to other patients at AIIMS and had learned to read between the lines of clinical conversations. While we spoke to him, no one said the word cancer out aloud. We spoke instead of the side effects of his bimari (illness) and treatment. Talking with him also revealed that the couple had gravitated toward a new “alternative” cancer hospital in a nearby neighborhood. They had been visiting this hospital over the past few weeks hoping for a better outcome. The staff there had complied and claimed they could completely cure the disease if Shambu and Rohini paid with all their savings and the proceeds from selling their house. The hospital’s promise did not surprise the counselor. She had heard of several such private cancer clinics cropping up around the city, at least some of which crushed steroids and painkillers into small paper pouches and charged high fees. Oncologists at AIIMS also knew of these clinics and told me how they often lost patients to the promise of a quick and complete cure. Treatment at AIIMS required long travels across the city and hours, if not days, of queuing on the pathways around the hospital.
Encouraged by the rejuvenating effects of the steroid cocktail, many would sometimes abandon curative and palliative treatment at the hospital. Cecilia Van Hollen has written of a similar world of “alternative” and “complementary” therapies that emerged in response to the HIV-AIDS crisis at the turn of the century where promises of quick complete cures by some alternative medicine practitioners not only discouraged patients from pursuing available biomedical treatments but also dangerously led them to believe that they would no longer transmit their disease (2005).

A few days before visiting Shambu, I had spoken with another family facing a similar conundrum. The aging father of that large joint-residence family had been diagnosed with cancer. Hearing of alternative treatments at new cancer clinics, his two sons had paused his chemotherapy; the alternative clinic the sons found discouraged them from continuing biomedical treatment. After the short-term benefits of the painkiller and steroidal cocktail had worn off, the effects of the disease returned redoubled. With curative or life-extending treatment no longer an option, the two sons now lived with deep regret for having switched treatment modalities. The counselor I was visiting with knew of the potentially devastating effect of promises of cure, but she did not tear down Shambu and Rohini’s last hopes for treatment. Later, she told me that directly criticizing such clinics might have risked their trust in her; they might read professional jealousy into her effort to discourage them from seeking treatment elsewhere. As the family talked, it became clear that they were considering risking their savings for their son’s school education to avail of this therapy and selling their small home. Remaining non-committal on the viability of a cure, the counselor urged Shambu and Rohini to talk through the potential implications of their decision.

Later in this conversation, Shambu and Rohini complained about the treatment they had
received at this alternative clinic. The physician there had refused to come into physical contact with Shambu. Instead, their conversation had revolved around the staff determining where the family lived, whether they rented or owned their home, and how much they had saved over the years. The counselor urged them to think about what kind of trust such an interaction could build. Shambu and Rohini first demurred, but then revealed their skepticism about the clinic’s eagerness to dispense medicine conducting no tests. The counselor took this opening to tell stories of other patients who had lost their life-savings seduced by the promise of cures. Soon afterwards, Shambu again changed the course of the conversation and told the story of his life. As an insurance salesman, he had planned his own life policies based on an astrological prediction he would contract a life-threatening disease. but that prediction had fallen short by two years and derailed his plans. His guilt at leaving his wife and son without financial means weighed heavily on the rest of our talk.

How might we understand the stakes of the secrecy between Shambu and Rohini? Why did it remain so important to not speak directly of cancer, even as both the diagnosis and prognosis lay in plain sight? Shambu, Rohini, and the nurse from the NGO all knew Shambu had cancer and that his prognosis was not hopeful. But while they knew, they shared the vital knowledge of knowing what not to say. Knowing what not to say allowed for them to continue to live in the present, without compromising all hope of the future. In their work on illness narratives, Byron and Mary-Jo Good call our attention "subjunctivizing tactics"—stories through which patients, families and physicians maintain multiple perspectives on the disease and the possibility of hope and healing, even when healing would be miraculous. In Shambu and Rohini’s life, I suggest that secrecy evidenced a similar desire to live in the subjunctive, to not foreclose possibilities of hope and life even in the face of likely death. Living in the subjunctive
allowed Shambu and Rohini to continue their life in the present as if the future was not already pre-ordained. They staked their concealments on their judgement of how much knowledge the other could absorb and how they could disclose when they knew knowledge could put their relation at risk. In Good and Good’s description, living with illness often “embodies contradictions and multiplicity” and so its narrative “cannot be represented all at once or from a vantage. It is constituted, rather, as a ‘network of perspectives’”. For Shambu and Rohini, secrecy was precisely such a subjunctivizing strategy, a grappling with the incoherence and disruption of cancer by maintaining multiple and even somewhat contradictory points of view, simultaneously knowing and keeping at bay their knowledge of what their futures held. To be clear, this space of hope was not the space of denial or an imaginative transcendence of the messy facts of the disease. The as-if was always bound tightly to the real. Both knew the bleak prognosis, both experimented with other possible therapeutic options, but at the same time, both understood the limits of such possibilities. The "as-if" of the subjunctive mood as it unfolded here was not an escapist fantasy, but a mode of coping with the ever-present stakes of the actual.

Thinking beyond stigma

In Shambu’s case, the network of social relations around him afforded support within which Cansupport could work. Despite his difficult financial circumstances, Rohini was a constant presence, they could rely on their son on to run errands, and the nurse in their neighborhood would be a consistent resource. However, for many other patients, neighbors and kin often exacerbated their vulnerabilities. In one of my first home visits with Cansupport, I met Rajesh, a twenty-nine-year-old man who had been battling leukemia since his teenage years. Rajesh rented a small makeshift room on the roof of the house of his paternal relatives. To arrive at his room, we had to walk up a narrow, snaking staircase that took us through the lower floors.
His family’s greetings to us were perfunctory; they were not keen on Rajesh having visitors. Reaching Rajesh’s room, I saw how its walls were bare but for two pictures—one of a Hindu deity (Vishnu) and another of his parents, who had died in a road accident when he was a teenager. Rajesh had contracted cancer soon after his parents’ death while he was working at a chemical factory on the outskirts of the city. The little money they had left him and the wages he had saved were spent in the early months of his treatment. His paternal kin had taken him in but refused to extend any care. In the early days after his diagnosis, his family’s resentments saw to Rajesh’s isolation in a small, barely covered verandah of the house. Yet, his will to live was strong: He would undertake a difficult journey to AIIMS in the early morning and make himself available for consultations and treatment. Hospital policies at AIIMS dictated that given the debilitating effects of cancer therapies, patients must always be accompanied by a family member or attendant. To circumvent this requirement, Rajesh would sign his patient forms twice—once under his own name and once again after leaving the ward and returning in disguise to sign as his own attendee.

Rajesh’s family had hidden his diagnosis from their kin and neighbors, ensuring their protection from accusations of neglect. Even if it were not their intent, this arrangement benefited Rajesh. He believed if their neighbors found out he had cancer, they would ostracize him. This would not only result in further social isolation but would exacerbate his financial duress. At the time, Rajesh was earning the supplementary money he needed for his treatment by running errands for many families in his neighborhood. Rajesh was convinced that they found out about his cancer diagnosis, they would shun him, and he would lose the only income he had. I asked whether it might help if his neighbors found out that his family was neglecting to care for him; perhaps that would shame his kin into extending him some support? Rajesh was not sure
that this would be the outcome of his diagnosis becoming public; he suspected that his neighbors might side with the family rather than with him, sympathizing with the family’s misfortune in having to take care of an unwelcome invalid.

One way to understand and examine Rajesh’s insistence on concealment would be to look for its cause, asking after the cultural beliefs that lead to its practice. Indeed, public health writings about cancer non-disclosures in India focus on the stigma associated with the disease, offering up a typology of cultural misunderstandings about the disease they believe to contribute to this stigma. For example, many physicians and health experts identify beliefs that cancer is contagious, that it is a punishment for a past sin, that it is necessarily a death sentence, and so on, as explanations for why patients are stigmatized and feel the need to conceal their diagnosis.

Yet, while these beliefs might well contribute to stigma, this explanation leave out an important aspect of concealments that primarily interests me here: the prior social worlds within which concealments and disclosures unfold. That is, while practices of concealment might certainly have something to do with cultural beliefs about the disease’s etiologies, its intensity and distribution take shape in relation to present social vulnerabilities, giving concealment its practical consequence and force. Put differently, even as public health articles are preoccupied with beliefs about contagion and moral disorder leading to the disease’s concealment, neither Rajesh nor his family members ever offered such causal explanations for their desire to conceal. When I asked him in general terms why he thought cancer evinced such strong and negative reactions, Rajesh shrugged inconclusively. But when we talked about another cancer patient in the same neighborhood who also kept the disease secret, Rajesh remarked that he did not think disclosure would have the same devastating effect it would for him. The other person he talked about was the head of his household, had a secure source of income and had access to officials.
who could help him access state financial aid. The consequences of a forced or unintentional
disclosure to the wrong person or at the wrong time would mean quite different things for the
two. For the other patient, Rajesh suggested, this might mean only unwanted concern. For
himself, it would mean the loss of livelihood, or an isolation even more limiting than what he
already experienced. Drawing from my experience in talking to Rajesh and others like him who
felt it necessary to keep the disease secret, I suggest that the least understood and most important
dimensions of disease non-disclosure are not the cultural stigmas associated with the disease, but
the shifting, local relational worlds within which the disease appears. In other words, one
possible why of cancer stigma (for example, a typology of cultural beliefs) does not help reckon
with how non-disclosures gathers force within a person’s world and illness experience. How the
disease folds into local worlds depends on the singularity of biographies and the social relations
through which a person comes to matter. For Rajesh, his isolation and abandonment had begun
long before his diagnosis. If the fear of contagion or an attribution of the disease to his moral
failing mattered at all, it was only in how they joined with his already vulnerable place in his
world. Cultural understandings of the disease only sharpened the consequences of these long-
existing vulnerabilities, whose roots ran deeper than the fact of his illness.

Remaining attentive to these relational stakes of non-disclosure—when and to whom
practices of speech and concealment are dynamically directed—helps focus our understanding of
its consequences. As the costs of his treatment escalated, Rajesh’s long history of familial
isolation and financial vulnerability became increasingly significant. For many patients in the
world with financial resources or comprehensive cancer insurance, the first-line treatment for
CML is a pill taken once a day: Gleevec. At the time, the drug was the focus of a legal battle
between Novartis and the Indian government and not easily available in Delhi’s public hospitals.
And as Stefan Ecks has explained, the philanthropic patient-access programs developed by Novartis—the pharmaceutical corporation behind Gleevec—does more to foster a fiction of corporate responsibility than it does to actually enlarge possibilities of care (Ecks 2008). At AIIMS, unable to prescribe Gleevec, Rajesh’s doctor recommended a bone marrow transplant (BMT). When Gleevec is available, transplants—which often carry a risk of fatality and are associated with far worse outcomes—are now only a last option. However, without Gleevec, Rajesh’s only choice was to risk the infections, organ damage, and graft failure associated with BMTs. Since it is a public hospital, treatments at AIIMS cost a fraction of what they would in private hospitals. For example, subsidized surgical tumor excisions range from around 3000-13000 rupees ($50–$200). To offset this cost, showing that one’s family income falls under the poverty line makes one eligible for a further fee remission of up to 6000 rupees ($100). However, the bone marrow transplant that Rajesh needed fell within a range of interventions (along with others such cardiac defibrillation, carotid stenting, and hip replacements) that incur prohibitive costs even at AIIMS. While the cost of a BMT in a private clinic can exceed a million rupees ($15,000), AIIMS offered this treatment to Rajesh for about 260,000 rupees ($4000), a third of the private care price.

For more expensive cancer treatments, the only financial respite are a few government grants redeemable only at the 27 National Cancer Control Program accredited hospitals in the country. AIIMS is the accredited center for much of North India. With Cansupport's help, Rajesh had sought these government cancer funds. However, there were only three he was eligible to apply for. The first was the “Prime Minister’s National Relief Fund.” This grant is funded by public contributions and gets no budgetary support. Consequently, Even though it has the least complicated application procedure, its disbursements are too small to cover the cost of more
expensive cancer treatments. The second and third funds—the “State Illness Assistance Fund” and the “Health Minister’s Cancer Fund” under the Rashtriya Arogya Nidhi (National Health Fund)—were administered by the Ministry of Health and Family Welfare directly to AIIMS. The first allocates about 50 million rupees for “life-threatening” illness, with a maximum of 150,000 rupees for every patient. The second—designated for cancer patients—allocates about 5 million rupees to each of the 27 national centers, with a maximum of 100,000 rupees per patient. These discretionary funds allowed AIIMS to subsidize patient costs. But like many others, Rajesh’s treatment exceeded the per-patient allocation. To circumvent this, he would have to apply to the Ministry of Health and Welfare for an individual dispensation. To do this, he had to work with both his treating physician and the head of department at AIIMS to prove to the Ministry of Health and Welfare that his disease was immediately life threatening. This would require several visits to the hospital, all while his disease continued to progress. Then, he had to demonstrate an income below the poverty line for his entire family, proof of which would need to be attested to by two local political authorities responsible for his neighborhood. For those that lived outside Delhi and had traveled for treatment, this itself would often be an almost insurmountable obstacle. Rajesh’s problem was different. If the income of the extended family he lived with was added on to his own earnings from running errands, he would no longer qualify for government assistance. But since no financial assistance was forthcoming from his family, he would have to approach the district officer as an individual and convince him of his situation. To do this, he drew up a document that proved he paid a small rent to his family members. With no income of his own to show, Rajesh visited district offices, seeking the help of a broker who helped him negotiate the tricky process. At this stage, district clerks and officials could easily hold up his application. This provided opportunities to demand bribes, and Rajesh had to convince them he
had no money at hand to give. It took several months before he could submit his application to the Ministry of Health, holding up his treatment because the assistance programs stipulate that they do not reimburse costs incurred before the final receipt of the application. Fortunately, after all this, Rajesh's transplant surgery and adjuvant therapies proved successful.

That Rajesh could negotiate these transactions and successfully prove his eligible vulnerability was almost miraculous. During our conversations, he would speak knowledgeably about the intricacies of every bureaucratic procedure he had encountered and the ways he had devised to circumvent the process. Much of this story was of strategic disclosures, of knowing what to say to whom to remain on track for his treatment. In negotiating this process, Rajesh had been aided by the type of his cancer, one that did not require debilitating surgical amputations. He had also relied on the strength of his young age, and his ability to learn the language and subterfuges of the bureaucratic process. Signing under two different guises to access treatment was only one of the many kinds of skills that Rajesh had mastered. He also spoke about which doctor at AIIMS was the most pliant and empathetic, about which clerk at the Ministry of Health had been the least corrupt or most likely to help, and about which forms were most vital, and which forms could be filled out with less attention to procedural detail. Through his negotiations of this array of governmental processes, Rajesh himself has become a source of expertise. The team I was visiting with deferred to Rajesh’s experiential knowledge as they asked for his help in guiding another recently diagnosed young cancer patient. Thus, Rajesh’s appearance in the legal and bureaucratic process as an eligible recipient of aid was a hard-earned status. Unsurprisingly, few others could construct their own vulnerability with the proficiency and speed that the disease demanded. At the same time, the long course of his illness had exhausted him. He continued to run errands for his family and neighbors, earning his keep from those who had either not
acknowledged nor known of his disease. When I met him, Cansupport had been urging its philanthropic funders to buy a food-vending cart for Rajesh, to help him secure the monetary independence he needed. Meanwhile, he had learned to swallow his resentment, strategically disclosing his diagnosis to some and not to others. At the end of our last conversation, his usually upbeat demeanor collapsed, and he stated bluntly that if the disease returned, he would not fight it again.

In Rajesh’s world, cancer was a different kind of secret than for Shambu and Rohini. It did not evidence care more complicated than a simple equation of non-disclosure with non-compliance; concealments do not indicate the absence of a desire to find and seek treatments (2015). Similarly, in her work on birth and death in rural India, Sarah Pinto writes that biomedical doctors and NGO workers committed to full disclosures misrecognized practices of concealment as a sign of women’s ignorance or disinterest in better health. Pinto’s ethnography shows instead how acts of disclosure and concealment became crucial to the bodily and moral praxes of her interlocutors, situated as they were within complex social relations of caste and gender. Crucially, Pinto suggests that such acts of concealment were part of a complex push and pull towards and away from authority, a simultaneous evasion of and a longing for institutional attention. My approach towards concealment here thus mirrors Pinto’s in resisting explanations that assume Indian patients are somehow incapable of fully grasping the significance of their disease, or that acts of concealment necessarily evidence the absence of health-seeking behavior. Such acts are not "ignorant" of reality, nor do they "normalize" or "deny" difficult circumstances. Instead, non-disclosures reveal how encounters with life-threatening illness are never far away from the experience and durable vulnerabilities of everyday life within the disease appears.

The many lives of concealment
In this article, I hope to have responded to calls for an ethnographic attention to illness disclosure (2014). The two cases I described in this article do not exhaust the many forms and functions of concealments in the lives of cancer patients I encountered during my fieldwork. But in each instance, managing illness knowledge played an important role in shaping the possibilities and trajectories of treatment and care. For Shambu and Rohini, secrecy helped sustain the possibility of living in the subjunctive—in the mode of the ‘as if’—performing the hope of survival even with the knowledge of likely death. For Rajesh, too, inhabiting the possibilities of the concealment was a crucial coping strategy: his ability to move between different narrative positions, between disclosure and non-disclosure, aided his survival. Thus, even if practices of concealment varied in motivation, purpose and consequence, they were always a way for my interlocutors to negotiate proximate others and the textures of support or harm they promised. Concealing helped many to weave the disease into broader concerns of their lives, allowing them to live within social relations within which they found varying degrees of abandonment and support. It became one more way, among others, through which patients, families and caregivers tested the durability of already frayed social relations put under further pressure by cancer.

It is worth nothing here that cancer is not the only disease whose knowledge requires circumspect experiments with speech and disclosure. For example, anthropologists and other scholars of public health have documented the concealment of HIV-AIDS in many parts of the world. For example, drawing from his work with an HIV-AIDS non-profit organization in Indonesia, Tom Boelstorff describes the disease’s association with non-normative sexuality as contributing to a reluctance to name the disease. Similarly, Kate Wood and Helen Lambert illustrate the disease’s non-disclosure in South Africa as a response to its stigma, suggesting that
concealment evidenced a desire to avoid the disease’s association with sexual promiscuity. My work here joins such writings about non-disclosure as a coping strategy, but also departs from them in one important respect. That is, the focus of the literature on HIV-AIDS emphasizes how negative cultural beliefs stigmatize the sufferers of this disease, sharpening the presence and consequences of its non-disclosure. For example, Wood and Lambert describe how their ethnographic interlocutors diagnosed with HIV-AIDS preferred to say they have cancer, as a ruse to escape this stigma. Here, I argue that bringing cancer (a disease not often associated with non-normative sexual practice) into discussions of non-disclosure pushes us to look beyond the role of cultural beliefs as determinant of stigma. Speaking with interlocutors such as Rajesh helped me to see that non-disclosures were as much a result of fears that disclosures might exacerbate prior vulnerabilities that preceded the illness, as it might be about negotiating cultural beliefs associated with cancer. In other words, paying attention to the embeddedness of non-disclosure in everyday life helps reveal how familial dynamics, personal biographies and situated social vulnerabilities shape the distributions of speech about cancer, while also pointing to the differential consequences of non-disclosure.

At the same time as I push against the emphasis on cultural beliefs in the HIV-AIDS literature on non-disclosure, I draw crucial insights from that literature. For instance, Lambert and Wood argue that practices of non-disclosure maintain hope and keep alive imagined possibilities of recovery (2008). Similarly, Steven Black focuses on the performative practices of an HIV-AIDS group to show how alternating between disclosure and concealment opens up the possibility of living with multiple, even contradictory narratives about HIV-AIDS. Closer to the context of this paper, George and Lambert show how the concealment of the HIV-AIDS diagnosis. Closer to the context of my work here, Lambert and George show how the
concealment of HIV-AIDS diagnoses helped patients and families in South India re-assert and maintain a sense of normality in their lives (2015). My work here rests on such insights that concealment is often a coping strategy for living with a life-threatening disease. I have argued that. Similarly, in the fraught and unsteady arrangements of my ethnographic contexts within which cancer appeared, concealment allowed for the possibility of thinking and living in the subjunctive, in the mode of the ‘as if’—performing the hope even with the knowledge of a likely death.

To live in the subjunctive involves “expressing wish, emotion and possibilities rather than actualities” (Das 2015, p. 141). Developing the work of Seligman (2008), Vaibhav Saria argues that living in the subjunctive in times of social failure allows for a temporary respite from broken worlds of experience, producing ways to manage the fractures of everyday life (Saria 2015). But in the end, Saria suggests, this escape is ultimately doomed, as the actual returns to make demands upon the ‘as-if.’ Similarly, I argue that strategic non-disclosures make space of living in the subjunctive, the space of ‘as-if’ nonetheless remains anchored to the actuality of the disease and the durability of long-standing prior vulnerabilities. Even as Shambu and Rohini made space for contradictory narratives and partial hopes, they remained caught in the uncertain space between the diagnosis and the disease’s outcome. I think of concealment here then as a strategy that seeks to multiply possibilities of living with the disease, while at the same time remaining aware of and mired in its consequences. Living in the subjunctive, made possible brief respites from the real, even as such respite often turns out to be temporary, and the as-if never really escapes the grasp of the actual.

Further, I argue that non-disclosure cannot be taken as evidence of denial or as a failure to comply with biomedical norms. The scholarship on HIV-AIDS disclosure describes a
biomedical and public health valorization of disclosure as an ethical ideal. For example, Steven Black explores how a medical imperative to disclose conflicts with social duties to conceal (2015). Betsey Brada joins Black in finding a “disclosure-catechism” among US physicians practicing pediatric HIV treatment in Botswana (2013). Writing about medical non-disclosure of pregnancy in rural India, Sarah Pinto describes the biomedical imperative to transparency that casts social worlds into distinct domains of compliance and non-compliance, rationality and irrationality (2008). Similarly, many cancer physicians in India understood non-disclosure of the disease as indicative of ignorance, even as they participated and colluded in the act. In an important study of Indian oncology clinicians, Alex Broom and Assa Doron find that most viewed non-disclosure as hindering their desire for ethical and informed decision making, highlighting the particularly ‘Indian’ quality of this ‘backward’ practice (2012). My approach toward concealment here mirrors Pinto’s in resisting these explanations that assume that Indian patients are somehow incapable of fully grasping the significance of their disease. I argue that such acts are not ‘ignorant’ of reality, neither do they ‘normalize’ nor ‘deny’ difficult circumstances. Instead, I have argued that non-disclosures reveal how encounters with life-threatening illness are never far away from the experience and durable vulnerabilities of everyday life within which the disease appears. Non-disclosure almost never meant that patients and families were unaware of their illness. Patients like Shambu and Rajesh were often very knowledgeable about their diagnosis and prognosis; they chose not to speak about it to some and at certain times. These strategies played out over time in the shifting space between disclosure and non-disclosure, between concealment and revelation. As Holly Donahue Singh writes in her analysis of fertility treatment in North India, strategies of disclosure and non-disclosure are never straightforward evidence of either liberation or autonomy, but rather, enmeshed with the
structures of everyday life and kinship (2017). With Rajesh, for example, cancer appeared in his life at a time when it was already fractured by the death of his parents and the fraught kinship world within which he found himself caught. Non-disclosure was a way through which he reconciled the entanglement of his life before and after the disease.

Finally, my understanding of biomedical non-disclosure aims to push against its representation as the opposite of disclosure. The practices of concealment I tracked shifted dynamically between disclosure and non-disclosure. Through them, my interlocutors negotiated proximate others and the textures of support or harm they promised. All this while, they made themselves available for care without always needing to risk the transparent and open naming of their condition. Strategic concealments helped many to weave the disease into broader concerns of their lives, allowing them to live within social relations within which they found varying degrees of abandonment and support. Concealment became one more way, among others, through which patients, families, and caregivers tested the durability of already frayed social relations put under further pressure by cancer.

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