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Fear of drug-resistant tuberculosis as social contagion

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Abstract

This article explores the spread of tuberculosis, the fear of infection as well as rejection and care across family ties and doctor-patient relationships based on a case study in Odisha, India. Social contagion is seen as the communication of the phenomenal in ways that reproduce perceptions, feelings or the faculty of will in another person, involving modifications of intensity, meaning and context. This paper discusses the impact of the social contagion of fear in relation to drug-resistant tuberculosis. It shows how such contagion can be stimulated by medical doctors and severely disrupt kinship ties with a serious negative impact on the course of treatment. The paper argues that in such cases, social contagion and biological infection become mutually reinforcing through a vicious cycle: the former may undermine necessary social support embedded in family relations, thereby allowing the latter to thrive and in turn cause more fear in the patient and her family.

Keywords: phenomenology, India, fear, antimicrobial resistance (AMR), tuberculosis (TB), kinship.
Drug-resistant tuberculosis and phenomenology

What is there to say about drug-resistant tuberculosis? It is deadly, it prefers the disadvantaged, it spreads like the common cold, its treatment is potentially as dangerous as the disease, it is slowly replacing the classical tuberculosis that we have been able to treat for a few decades now, and it is manmade.

Kona Kar, 46 years old, looked at me. Her big eyes sunken into her emaciated face, she looked at least 20 years older. Kona lived in a small two-room house on what I came to think of as ‘TB Lane’, a straight line of small similar houses where most inhabitants had suffered from tuberculosis. Covering her mouth with her sari, Kona said:

‘This disease has happened to all of my friends. Like the total lane. Means that in this lane I was the last to have it. First, my friend got TB then another and another but I got TB last. First, my mother got TB and she died, then it happened to my younger sister, and she also died. Then it happened to my neighbour. She got medicines from Dr A. and she got cured. After her, it happened to her son and daughter. Then it happened to me. Then my daughter got infected. And then again, it happened to her elder daughter. They all took the medicine from the beginning. But from the beginning I couldn’t know about the disease so I didn’t take it. So I got it more… They took it from the beginning, that’s why they were cured. But it happened to me badly.’

‘It happened badly’ for Kona meant that her disease had become resistant to standard medical treatment, known as DOTS, which since 2006 had been available in
Bhubaneswar, the capital city of the Indian state of Odisha. Bhubaneswar had witnessed a dramatic growth since India’s independence (Seeberg 2014). ‘TB Lane’ was just one of many small, poor neighbourhoods scattered all over the city, in between middle-class houses, shops and small-scale industries. Labelled by the TB control programme as ‘urban slums’ and ‘floating populations’, respectively, such areas and their inhabitants had been identified as an Achilles heel for DOTS, with high incidence rates and low treatment success rates. Kona witnessed the weakness of the government health system, as she was labelled as a ‘defaulter’, a person who fails to adhere to the six months’ standard TB drug regimen.¹ When I met Kona, she nevertheless tried to follow through with the much more toxic regimen for multi-drug resistant TB (MDR-TB), at the time usually lasting around two years. This treatment often causes severe adverse effects in patients, such as vomiting, joint pain, fatigue, burning sensations, head reeling and, in some cases, severe mental illness such as psychosis and depression. So, let me rephrase my initial question and ask instead: What did Kona have to say about drug-resistant tuberculosis? How did the disease and its treatment influence her perception of the self and others and the social world she used to know?

This paper explores social contagion as a phenomenon that is contiguous to bacterial infection. It looks at the transmission of social and emotional responses to TB among people engaging in significant relations, whether kinship ties, friendship bonds or other relations of dependency, such as consultations between patients with long-term illness and their doctors. Tuberculosis – and especially its drug-resistant strains – casts

¹ Realising the stigmatising consequences of victim-blaming, in recent years leading global health actors in the TB field have pushed for a move away from using terms such as ‘defaulter’ and ‘non-compliance’.
haunting shadows of potential transmission of a deadly infection over such relations. This paper explores how the exchange of emotions spurred by the risk of infection and the signs of disease are interpreted in ways that in turn influence the course of the infection. With reference to the introduction of this special issue on kinship and contagious connections (Meinert and Grøn, this issue), it explores how the social life of a patient infected with drug-resistant tuberculosis (DR-TB) becomes haunted by the fear of infection by placing intimate kinship relations in broader configurations of relatedness: to medical doctors, TB programmes and structural conditions of poverty.

For a period of almost three years, beginning in late 2015, I have been following 20 people with drug-resistant tuberculosis (DR-TB) in urban and rural areas of Odisha, India. Five have died during this period. Over the course of eight fieldwork episodes, each of two to four weeks’ duration, I visited patients in their homes and talked with them about their disease, its treatment, and how both have affected their lives. Six patients were closely related (siblings in two cases, in-law relations in the third), indicating that intra-family transmission of DR-TB occurred. But rather than bacterial transmission, this paper focuses on the ever-present possibility of such transmission and its disruption of social interaction linked to feelings of fear, rejection and isolation. In what follows, I shall first provide some theoretical underpinnings of social contagion as an instantiation of the communication of the phenomenal and then discuss the role of the social contagion of fear in Kona’s case in the light of this theoretical framework.

‘What is the relation between the phenomenal and the discursive—between, that is, experience, being, and sensate perception, on the one hand, and language, aesthetic and rhetorical forms, and communicative practices more generally on the other hand?’, ask Robert Desjarlais and C. Jason Throop (2011). In this paper, I argue that social contagion constitutes one such relation between communicative practice and ‘the
phenomenal’. This point will help explore what is at stake for Kona, as I analyse the interplay between three registers that in a phenomenological context correspond ‘to three basic faculties. These include the faculty of perception (cognition, intellection, memory), the faculty of feeling (emotion, affect, sensation), and the faculty of will (volition, conation, intention’) (Throop 2010, 28). The three registers constitute analytical orientations across these basic faculties pointing to vital dimensions of human experience, even if one or the other may be privileged in a given situation. Yet, while we approach an understanding of the multiple ways the subject perceives the world and the self through phenomenological analysis, linking phenomenology to an analytics of communication is necessary to reach an understanding of social contagion, seen as the (direct or mediated) intersubjective spread of particular kinds of responses to a perceived phenomenon. In other words, social contagion is the communication of the phenomenal in a way that reproduces perceptions, feelings or the faculty of will in another person, always involving modifications of intensity, meaning and context. Since kinship often (but clearly not always) constitutes a set of social relations of major social and emotional significance, such social contagion can play out in particularly important ways across kin-based networks.

In what follows, I shall focus on these three registers as an analytic frame to understand the dynamics of social contagion, biological infection and biosocial resistance in a context of DR-TB infection, as I return to my initial question in a slightly modified version: How did Kona Kar’s drug-resistant tuberculosis become a phenomenon to be dealt with through faculties of perception, emotion and will, and how were these subjective transformations communicated in ways that changed her family ties and broader social life?

**The phenomenology of drug-resistant tuberculosis**
Making our way through the congested traffic of Bhubaneswar, we stopped at one of the main crossings. I watched the home guard heroically trying to control the flows of cars and motorbikes coming from all sides, scolding and threatening undisciplined drivers with an angry face. Ranjan, the driver of our small team,² told us that he had a clash with Kona not very long ago. He said that Kona was particularly eager in service and feared if not detested by professional drivers like himself. I tried to imagine Kona directing the traffic amidst dust and pollution in a khaki coloured uniform and hoped she had been given a mask. The salary for home guard traffic controllers in Odisha was 240 Indian Rupees (€ 3) per day. But she had already been too sick to work for a while when I first met her in her home. Kona lived in a small house on ‘TB Lane’ with her husband and her second daughter, Laxmi. Practicing cross-cousin marriage, the older daughter, Romini, had already been married and subsequently given birth to a child, and now, Laxmi’s impending marriage was constantly on Kona’s mind, as it would be an important parental achievement as well as a substantial financial burden.

**What is there to communicate about MDR-TB?**

When Kona was diagnosed with drug-resistant TB, Laxmi had also started coughing. Unsurprisingly, she was diagnosed with TB and placed on standard treatment. Kona being the most likely source of infection, the time of transmission would make all the difference between drug-susceptible and drug-resistant TB for Laxmi. However, Kona

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² I am indebted to Bijaylaxmi Rautray, Shyama Mohapatra and Biswa Ranjan Choudhury for their invaluable assistance in the field, and to Animesh Mohapatra and Bigyan Ranjan Das for their tireless transcription work.
was confident about the ‘ordinary’ nature of her daughter’s disease, and she had informed the groom’s parents about Laxmi's condition. Kona said:

‘She was taking medicine and if she would have married at that time, the course of treatment would have been disturbed… so we told them [the groom’s parents]. They said that “TB is a minor disease – now it’s happening to everyone. If you take the complete treatment, you’ll be fine.” […] Anyone can have TB.’

It seemed that Kona was right in assuming that she had not infected her daughter. The local area Accredited Social Health Activist (ASHA Didi), whose primary task is to act as an interface between the community and the public health system, sometimes including supervision of swallowing oral medicines in standard TB treatment, happened to be involved in a field trial of a new molecular diagnostic technology. She told me that she committed ‘forgery’ by running a test on Laxmi (who was not enrolled as a patient in the project and therefore not entitled to a test) to confirm that she did not suffer from a drug-resistant strain of TB. Such ‘forgery’, she felt, was necessary and justified by the negligence of the hospital to do this in the case of a TB positive patient living in the same house as a known case of MDR-TB. Laxmi had already completed her treatment when I met her, and she looked strong and healthy as she stood next to her emaciated mother, and the wedding preparations were underway.

Not only did the ASHA Didi help with the test, she also complained about Dr K., one of the main physicians in charge of Kona’s treatment, based on her own experience:

‘Dr K. makes a lot of problems. He had killed my father…He wrote one injection costing 2,500 Rupees. We are poor people… If you are thinking that… that man...
yeah he was old. […] You say: today, I give a 2,500 Rupees injection, tomorrow he is dead.’

Leaving the outrageous (whether justified or not) accusation aside, we may safely assume that Dr K. managed to effectively communicate neither the medical intentions with this treatment nor its chances of success or failure. Kona was equally harsh when assessing the communicative skills of Dr K. When she was first diagnosed with TB and put on standard treatment, she came to Dr K. to discuss the adverse effects of the treatment.

‘For two months, I had the medicine. Then, when in the third month my hair and all became like this [thin, falling] […], I went to Dr K. He didn’t listen to me but said: “You stay outside. Send your husband inside”. My husband – what he said or not, I don’t know – like this it happened that I stopped the medicine because I was angry. They did not listen to what was happening to me so I left it. I didn’t eat the next three months. Totally, I didn’t go to him’.

While this central role of relatives as mediators between medical doctors and patients is not uncommon in India, the emotional response this may generate in the patient is rarely acknowledged. In Kona’s case, her feeling of being humiliated merged with a strong sense that her medical condition was neither taken seriously nor addressed appropriately.

It was one year later, during the time following the birth of her grandson, when Kona had come to help take care of her oldest daughter, Romini, and her baby that Kona’s TB disease returned in a dramatic way. She started coughing up blood and had to return to the hospital by car. It was a drive of around six hours, but her relatives had to make several roadside stops to allow her to spit out blood. When they finally reached the hospital, Dr K. refused to see her as a punishment, she felt, for not having completed the
treatment. She was left with the family, unattended by Dr K., on the veranda of the TB ward all through the night, as she continued coughing up blood. In the morning, the family managed to take her to the TB ward in the city of Cuttack, another one-two hours’ drive, where she was diagnosed with drug-resistant TB and was started on the much stronger, highly toxic two-year treatment regimen for MDR-TB. Following admission there, she was referred back to Dr K. for ongoing follow-up.

For the patient under treatment, the daily interpretation of signs and symptoms of the disease – e.g. cough, breathlessness, chest pain, night sweats in the case of pulmonary TB – involves all three registers of perception, feeling and will, as the medicines send bodily messages that seem to make the patient weaker and sicker, because the adverse reactions are much more prompt than the potential long-term curative effect. This makes it difficult to sustain motivation for treatment.

‘I brought the medicine and ate it. After eating it, I felt like vomiting and my head started spinning. When I called them, they didn’t say anything. I felt uneasy and didn’t say anything. They said: “You eat this and you will be fine.” They wrote some medicine for vomiting. I took that medicine but it didn’t help. Like that it happened. My head became like this [ache], my hands became like this [stiff]… hands and legs are becoming like this…stomach started to pain. […] When I didn’t eat the medicine and left it, I vomited blood.’

The inability for patients to live through this toxic treatment regimen without substantial support is a well-established problem in the history of tuberculosis, even if it has often been constructed as victim-blaming in the form of non-compliance, a term that has recently been replaced by non-adherence in TB public health discourse (Harper 2010).
This supposedly ‘softer’ term still regards a perceived reluctance in the patient as being the essence of the problem. Dr K. used none of these terms when I visited him in his office at the government hospital where he worked. I was waiting for him to talk with me, while he was seeing one TB patient after another. As he sat at his desk, a patient walking behind a relative would enter his room, and one or both would answer his questions for one or two minutes. He would write a prescription, and they would follow the TB treatment coordinator behind a glass wall, where TB medicines were stored and distributed. After a few minutes of dialogue, they would leave the consultation room. Neither health staff nor patients were wearing masks, and patients were not told to, indicating that in some cases Dr K. did assume that TB drugs prevent infection; however, he did not conduct any routine physical examinations of patients and was never close to them. His view on his duties seemed rather narrow, as he saw himself fulfilling a very limited and specific role in the government TB control programme: to write medicines:

Dr K.: ‘Here we just do the medication. And side effects, only if they develop, they come to us. It is those symptoms and the side effects.’

Common side effects, he said, included vomiting, psychosis, and jaundice.

Dr K.: ‘[There are a] lot of side effects in those patients. Some patients are not taking drugs…’

Jens: ‘Because of the side effects?’

Dr K.: ‘No, not due to the side effects, means, I don’t know. They don’t tell this, why they are not taking medicines.’

Jens: ‘You don’t know?’

Dr K.: ‘We are….we are just taking care of those patients. Why they are not taking [I don’t know].’
Jens: ‘What in your perspective are the reasons for that, I mean, why are they not taking their drugs regularly?’

Dr K.: ‘Some people are alcoholic. Or they are simply, they are not taking.’

Jens: ‘What do you do when a patient is irregular with the medicine – if it’s a drug resistant case?’

Dr K.: ‘We will sensitise [them so] that they take the drugs...’

Jens: ‘But if they still don’t do?’

Dr K.: ‘We will explain to take the drugs.’

There is a friction between such generalised mistrust in TB patients’ ability to follow the treatment regimen and domiciliary treatment of patients with DR-TB. Domiciliary treatment serves to avoid unnecessary isolation of TB patients, and for DR-TB in India, it is based on the assumption that after an initial phase of hospital treatment for two to three weeks, the patient is no longer infectious and can safely return to her family and continue partially supervised outpatient treatment.

While Dr K. insisted on excluding her from the dialogue in the clinic, he also penetrated the intimacy of the family by instructing Kona’s husband to use a mask inside the house, sleep separately from his wife and throw her sputum outside.

According to Kona, Dr K. had said:

“‘Keep at a distance from her. You may get infected by the bacteria while you are breathing.” He also told my son-in-law, and he even didn’t bring my grandson near me. I cried a lot at that time and thought of committing suicide. […] If by chance I hold my grandson and if he coughs due to cold or something like that, then he [son-in-law] will tell her [daughter]: “He got infected due to your mother. If anything happens to my son, then I will leave you.”’
Kona could not talk to Dr K. about the impact of his actions, nor could she convince her family herself about changing the ways of action. But there was another doctor at the hospital, Dr A. His approach was different. Even if Dr A., according to Kona, also did not check the patients properly at the hospital, he would behave nicely towards the patients. They knew that if they came to Dr A.’s private clinic, they would receive much better treatment. Dr A.’s clinic was located in a tiny construction adjacent to his big residence in a quiet residential area of the city, next to a cyber café. The large sign on top of the construction announced the presence of a specialist in pulmonary medicine, and its faded colour indicated that he had been there for a long time. A sign next to the wooden door informed that samples, their exact nature unspecified, could be handed in during morning hours, when a pathologist would be present. ‘There he take fees’, Kona said.

‘So then I went to Dr A. and told him all those thing that had happened to me. That time it was 200 Rupees, so I told him. Then, he saw me properly and then he measured my weight and saw all that, and wrote medicines for five days and told me to come back again. […] There, Dr A. checks us properly and sits closely and checks properly like putting a stethoscope and using a light to see the eyes properly and measures the weight and also measures blood pressure.’

With Dr A., Kona felt she could be properly and regularly checked and communicate about side effects in ways that reassured her that the treatment could become bearable and perhaps even be successfully completed.

**TB as environment**

‘TB Lane’ was no more than seven small houses in one row, each house around 20 m² divided into a large and a small room with no toilet. The row of entrances faced a tall wall, but even if the lane itself was only about one meter wide, it was bright in the
sunlight and neat and clean. In front of Kona’s house was the shared water tap, sometimes with a long orange tube leading the water to a particular house, and close by, a colourful stand carried an orange flower. This poor but neat lane was where TB had spread to all households. Many inhabitants were related, and the combination of poor housing, insufficient diet and exposure to pollutants and contagion provided a conducive environment for *Mycobacterium tuberculosis*. For Kona to have TB in this environment was nothing special; after all, TB is TB, and whether the disease responds to one kind of treatment or another, the symptoms that emerge as indexical signs of its bodily existence are the same: invalidating weight loss, coughing up or vomiting blood, breathlessness and fatigue as well as fever. But on TB Lane, only Kona knew how much worse the side effects from the DR-TB treatment were compared to the standard treatment. The adverse effects of tablets and injections during early treatment came on top of the impact of the disease. Kona suffered from joint pain, incessant vomiting of all food, hair loss, nausea, dizziness and the inability to walk, work, cook and eat. She detailed how she tried to adhere to the treatment by experimenting with ways to eat the drugs in the evening, carefully spacing the different medicines over several hours before she would try to escape the worst side effects while sleeping. For a while, she seemed to get better. During this time, she still managed to go to work and make enough money to pay for Dr A.’s services. Over the three-year period I have known Kona, the consultation fee doubled from 150 to 300 Rupees. But Dr A. also had an income from the common practice of overprescribing drugs and receiving rewards through small networks that link practitioners with particular chemical and pharmaceutical companies (Seeberg 2012). Kona showed me some of the transcriptions written by Dr A. In addition to the 11 drugs she had to take for MDR, which she received directly from the hospital for free, she had to take six other drugs, and prescriptions were stamped with
Dynamics of hope, despair, fear and betrayal

In what follows, I shall return to some of the events described above in an attempt to better understand their emotional impact on Kona as they played out in her changing relations with her family and her doctors. The fear of infection is an understandable concern regarding this disease, and even more so is the fear of one’s small child being infected. Concerning Dr K., what seems striking is Kona’s perception of the way this fear was managed. From her perspective, Dr K. undermined possible ways in which such fear could have been controlled by reducing her to a feared object rather than a person in need of support during a very difficult treatment period. She was to be avoided and contained within her family, not cared for and supported in order to reach a non-infectious stage of illness. Rosenberg (1992, 295) has described ‘contagion’ as part of the general concept of ‘contamination’ to cover not only contagion and infection but also pollution, i.e. ‘an event or agent that might subvert a health-maintaining configuration’ (Rosenberg 1992, 295). Rather than simply fear of contagion or infection, this is fear as contamination, a ‘pollutant’ deliberately spread by Dr K. This resembles the fear described by Lisa Stevenson (this volume). Developing 'scenes of instruction through which what there is to fear is transmitted', we see how fear is shared as a sociality in which there is a degree of communal protection against whatever or whoever is feared. ‘Fear is communicated, (or not), to someone who is from somewhere else, someone who doesn’t belong to this particular world of fear’ (Stevenson, this volume). Dr K. includes Kona’s relatives in his world of fear. By so doing, the world of the sane is expanded: ‘Sanity, in both its clinical and everyday existential sense has to do with living in a shared world. Insanity, then, is also about
being excluded from a shared world’ (Stevenson, this volume). Whereas Stevenson’s primary focus is on fear among the sane, mine is on the source of fear itself, the person who is excluded from the world of the sane, both in the existential aspect of no longer being part of a shared universe and in the clinical aspect of misery created by profound social alienation.

Even if Kona kept alluding in passing to the theme of death on other occasions, she only disclosed what was at stake much later, and again Dr K. was a key figure. His seemingly unacceptable behaviour towards his patients aside, it seemed clear that he was afraid of infection. The mask is not only a protective device, but it also constitutes an indexical sign that reveals to the patient and his or her family that the knowledgeable person insisting on wearing the mask is not convinced that the patient is no longer infectious. I asked Kona why she thought Dr K. kept patients at a distance. Full of anger and despair, she exclaimed:

‘They hate us!’ ‘They are telling: “She is ill; if we stand near her, we may fall ill.” […] They tell me: “Stand wearing the mask... [over] there. Send the person who has come with you [to see the doctor instead of you].”’

The index of the mask is seen by Kona as revealing Dr K.’s true feelings. But it was not only that Kona was rejected and left with a feeling of despair. She was also cut off from communicating about the self, the disease and others.

Haemoptysis, or coughing up blood, is one of the signs of advanced pulmonary tuberculosis that, to many people, would immediately create fear; but as Kona spoke about it, it had become common. Having seen both her mother and her sister die from TB, and now living on ‘TB Lane’ where her neighbours’ TB had preceded that of her two children, followed by Kona’s infection, coughing blood was hardly unusual. The
angst caused by reading her own body seemed subsumed under the anger caused by reading Dr K.’s continued rejection.

Being reduced to a feared object, a reader of others’ bodily signs of rejection, a receiver of others’ communication about her impurity and dangerousness, Kona was excluded from ‘the world of the sane’ (Stevenson, this volume). Alone with her feelings of fear and betrayal, she decided to commit suicide and bought rat poison. ‘I thought of sleeping after taking it and everything will be finished.’ But her youngest daughter, Laxmi, found it near the bed.

‘My daughter held me crying and told me, “[…] will you look after me or do you want to die?” Then, because of my daughter’s face, I stayed. Had there been no one near me I would have finished the job [suicide] long ago. Dr K. told everyone! Even […] my son-in-law and daughter over phone.’

Laxmi’s accidental discovery of the rat poison re-opened a pathway for Kona’s negative feelings to become more manageable as they became reflected in a sociality where care was possible and suicide no longer necessary. What ran in the family at this moment, perhaps along the lines of genealogy and inheritance (Meinert and Grøn, this volume), was a regenerative relation of affection between mother and child. Later, Kona described this relationship between her daughter’s wedding and hoped-for subsequent childbirth and her will to stay alive as a matter of postponing death for a little while: ‘I will make my daughter marry and then I will see a grandson […] after that, if I die, then no problem.’

Making sense of domiciliary treatment

Looking at Kona’s experience as a process of sense-making across the three phenomenal registers helps us localise significant moments in each mode and makes it
possible to see how they connect to one another as they change over time. These registers are analytical distinctions, and they should not be seen as mutually exclusive. On the contrary, interpretive processes may run back and forth, simultaneously occupying registers and, as we have seen, along profoundly relational lines, change and re-shape, in the process, both intrasubjectivity and intersubjectivity. This happened in so many ways between Kona and her family, as everybody was trying to read her words, her body and her disease under the influence of Dr K.’s interventions, and as she was reading those of the self and others. To the person interpreting the world, this, of course, not only applies to relations to the self and others, but to any object that is interpreted as meaningful in some way, including medicines for MDR-TB. The regimen varies with different degrees of drug resistance, and during this period of MDR-TB, treatment in India consisted of a combination of around ten drugs to be injected or taken orally for a period of approximately 24 months, with varying periods for different medicines. This treatment involved high levels of toxicity and high risks of both non-serious but uncomfortable side effects and serious adverse reactions such as deafness, psychosis as well as liver and renal failure. As we have seen, such adverse reactions set off additional prescriptions for even more medicines.

The friction between adherence and domiciliary treatment increases with the severity of side effects. The experience of Dr K.’s rejection, along with his intervention into her family relations, told Kona that her attempts to adhere to the treatment were not working to the satisfaction of Dr K. Whereas the medicines are toxic for the body, Dr K.’s intervention constituted a toxic form of social contagion. Assuming non-compliance and fearing infection resulted in an inability to align the domiciliary treatment policy in India with his own practice. In combination with a regime of exclusion, this came to shatter all intrasubjective modes of reality in Kona’s attempt to
understand her situation and started waves of contagious fear and rejection that in her vulnerable condition disrupted her basis for domestic support and entailed no less risk of death as the disease itself. To Kona, the rejection reflected the perceived efficacy of the treatment. She said:

‘I think this, perhaps, to be a big [i.e. severe] disease; and hence, they disdain us. This disease generally doesn’t occur to most of the people, but it has affected me. Hence, he [Dr K.] loathes me – if it may infect him or if he or I may die. In this way, I feel bad.’

The answer to Dr K.’s treatment was resignation and despair. Dr K. undermined the logic of domiciliary treatment in Kona’s eyes, because Dr K.’s rejection pointed to the potential incurability of her disease, further undermining her motivation to take the medicines and tolerate the side effects. Yet, she was barred from entering the room and addressing the problem openly.

**Dr K.’s perspective**

Dr K. declared that he only prescribed medicines. He did not understand why patients did not adhere to treatment, and he routinely limited his intervention to ‘sensitising’ and ‘explaining’ – what Kona experienced as ‘scolding’. How are we to understand that he deviated from these routines in the case of Kona and decided to intervene directly in her intimate family relations? For ethical reasons, I did not ask him about her case directly, but here I suggest two potentially interconnected interpretations, one dominated by perceptual judgement (Bernstein 1964) and the other by feelings.

Perceptual judgement would cover a medically informed justification to take such action. Suffering from DR-TB, treatment interruptions could make Kona potentially infectious with this dangerous form of TB. In a domiciliary treatment system, this would place her close relations at a serious risk of contracting the disease.
In this situation, the standard medical action would be hospitalisation in the DR-TB ward, but given the overcrowding and very difficult conditions for patients in this ward, where the high-risk co-hospitalisation of close relatives was a precondition for patients’ admission, it was not surprising that patients with potentially infectious DR-TB were routinely treated at home. Informing close relatives of the risk of living together with a DR-TB patient is a responsible action in order to contain infection. As a consequence, Kona and her husband stopped eating and sleeping together, and she no longer saw her grandchild.

To become a medical doctor, medical students undergo difficult training to dissociate emotionally from patients in order to provide equal treatment and treat their bodies in painful ways that would be unacceptable outside the medical context. Whereas training of medical students has been a subject of study for medical anthropology and sociology (e.g. Good 1994, Hafferty 1988), physicians’ ability to actively disregard emotional responses to individual patients remains an understudied area. In the case of Dr K., it is perhaps likely that the seemingly extraordinary act of informing the relatives of a patient who to him represented a particularly difficult doctor-patient relationship was emotionally laden. From the perspective of Dr K., she was repeatedly interrupting treatment, but neither did he not know why, nor did he feel that it was his responsibility to pursue such insights. So he did not know about the side effects that – together with her illness – made it increasingly difficult for her to work while undergoing treatment. Originally, she was a traffic controller in the home guard, but after she fell ill, she was taken in as a maid in the senior police officer’s private home. When this was no longer possible, she was allowed to appear as an ‘errand boy’ at the local police station, where she struggled to cover even the small distances involved in delivering letters. Kona was caught in a dilemma. Side effects made it very difficult for her to manage the work; and
avoiding side effects by not taking the medicines would allow her to work but involved a high risk of relapse and becoming infectious, which would bar her from working. Living in poverty and having been the main breadwinner and in control not only of traffic but of the household and family matters, her inability to work created a feeling of loss of control. But all this could not be explained to Dr K., ‘who did not listen’. From his experience, she would have been the one who did not listen, and whose unsuccessful treatment signified non-compliance. Feeling ‘hated’ on Kona’s part could well reflect emotional reactions of powerlessness, anger and frustration on the part of Dr K. A threat to inform her family members, and taking action on the threat, could perhaps re-establish power relations.

‘We assert our kinship in spite of our difference, in spite of the fact that such an assertion requires a radical uncertainty about what kind of world we live in,’ says Stevenson (this volume). As a way to maintain her sense of humanity and find comfort in this situation, Kona informally ‘adopted’ her sister’s daughter. The practice of informal temporary or permanent quasi-adoption within extended family relations in India sometimes works, as in this case, to rearrange relations of care across generations. The girl, around 10 years of age, had been given to another family by her mother, who could not take care of another child, but whom Kona had now brought back so they could take care of each other. When I visited them together, Kona’s face was relaxed and smiling. Challenging the infectiousness of her condition, she said:

‘As I didn’t feel good, I brought her back. Since that day onward, that girl is with me. She is staying with me, sharing food and bed with me; she is doing everything. Why doesn’t she get infected then? As she is with me…’
When Dr K. saw Kona, he saw an infectious person with a deadly disease, and he wanted to keep her away from himself as well as her relatives, attempting to isolate her in her house. When Kona looked at her face in the tiny mirror over her cot – the only piece of furniture in her house – she saw a non-infectious person who was being unfairly stigmatised by the physician at the government hospital, whose verdict was contradicted by the health of her ‘adopted’ daughter.

**XDR-TB as a biosocial outcome of social contagion**

Perhaps it was no wonder that the category of drug resistance in Kona’s case went from ‘multi-drug resistant’ (MDR) to ‘extensively drug resistant’ (XDR) – a level of drug resistance where the still more toxic treatment offered an even more hopeless prognosis with little chances of survival. In this way, Dr K.’s interpretation of Kona as an unreliable patient seemed to become a self-fulfilling prophecy. To Kona, it was the final betrayal. XDR-TB was diagnosed upon completion of 24 months of MDR-TB treatment, but it should have been detected much sooner as an outcome of routine tests showing that MDR-TB treatment was not effective. Kona knew this and blamed the doctors:

‘I will not take the medicines anymore; I will leave them. I will rather die and leave them. Tell me! Who will bear such pain? Tell me, I took medicines for two years and now you decide it. I took for two years. If I got MDR… XDR, wouldn’t it be right that they should have sent me [for drug sensitivity test] after one year? I, with much difficulty, took that medicine for two years; I also took the injections; all these portions [of the body] ached a lot. […] Now consider it a little! Now, I will have to take more powerful medicines than before, for two and a half years more. It is better to die than to suffer like this. So everything will be
settled. Otherwise, I will take something and sleep. What will I do then? Who will bear such pain? Tell me!’

Kona looked at me from her cot, her mouth covered behind a handkerchief. From a weight of 45 kg when I first met her, she was now visibly thinner. Neither of us knew that another eight months would pass before she would be offered Delamanid, one of two new drugs that had recently been introduced to XDR patients, resulting in better treatment outcomes. Subsequently, I learned that this may have been too late for Kuna. She had left the hospital without medicines, at a body weight of 25 kg.

So what runs in the family? The fact that TB does has been known for years due to the heightened risk of infection among people living intimately together. For people on ‘TB Lane’, this observation could be expanded to include the entire neighbourhood. Importantly, care and support run in the family too, as illustrated by Kona’s daughter’s response to Kona’s suicide plans and the temporary ‘adoption’ of another daughter. But care and support seem less socially contagious than the fear of infection. As the disease progressed, this arrangement was interrupted due to fear of infection. The fear worsened along with the accelerating drug resistance. The iatrogenic disruption of family relations due to fear of disease transmission stimulated by DR K. translated into feelings of worthlessness in Kona. I started out by arguing that social contagion is the communication of the phenomenal in a way that reproduces perceptions, feelings or the faculty of will in another person. The communication of fear of infection in Kona’s case is an illustration of this point. However, her story enables me to push this point further. Social contagion not only resulted in a vicious cycle of withdrawal of caring but undermined medical treatment as well. This cycle links fear (the phenomenal) with withdrawal of care (the social) and increased bacterial resistance to treatment (the biological) in a causal chain of communication, where the boundaries between these
three domains become blurred as they incessantly interact to the extent that they become part of each other. In the case discussed in this paper, this inseperability expresses itself in the dynamic interplay between (on the one hand) social contagion that moves along kinship ties and is stimulated by communication with medical doctors, and (on the other hand) the course of infection playing out in the body of the patient. Social contagion involves bacteria as well as humans and significantly overlaps with biological infection in the case of drug-resistant TB.

References


