
The subtitle of this essay on the theme of tuberculosis and urban poverty is taken from Gilles Deleuze (1997) who thought of literary works as implying a way of living, a form of life that must be evaluated not only critically but also clinically. The critical (in the literary sense) and the clinical (in the medial sense) he proclaimed in an earlier essay, may be destined to enter into a new relationship of mutual learning (Deleuze 1989). In the literary works he takes up for analysis, Deleuze traces a rigorous symptomatology that can bring to light, the conditions under which certain disorders are produced. Such a symptomatology is not limited to chains of causation alone. Thus the etiological work of the clinician begins to resemble the associational chains of an artist - a table is produced in his work “where a particular symptom is dissociated from another, juxtaposed to a third, and forms the new figure of a disorder or illness.” (p. xvii) In this process the term “critical” takes on the added valence of an infirmity, possibly terminal, to which the “clinical” responds with its own valences, therapeutic suggestion or incision.

In this paper we propose to perform a simple task in the spirit of Deleuze – to present some stories of people residing in urban slums in Delhi, who suffered from TB and to describe what kind of possibility of life exists in the face of this devastating disease. Our narrations bear some relation to the genre of “illness narratives” but there are important ways in which these depart from the classical way in which narratives have

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1 We are grateful to the team of researchers at ISERDD, Delhi and especially to Rajan Singh for conducting interviews with such sympathy and to Purhottam, Gita, Simi, Charu, Poonam, Harpreet, Ranjit, for their contributions to data collection and data entry. We thank Jishnu Das and Ranendra Das for continued support. We offer our grateful thanks to the families in our study. We dedicate this paper to the memory of the woman we call Meena.
been used to elicit explanatory models from the patient.\(^2\) The public health literature on TB and AIDS is dominated by the notion that dangerous infections persist among the poor because ordinary people are “superstitious”, “non-compliant” and try to hide their illness and its associated stigma\(^3\). The curative task of policy makers and of medicine, then, is seen to find ways of delivering health care that will overcome these obstacles – DOTS, or the directly observed therapy (short term) was devised precisely as a way of dealing with these set of recalcitrant patients in low income areas, especially in low-income countries. The illness narratives we present here are of low income families who live with TB and of patients who die of it. While these lives and deaths do not directly contest the dominant claims of international organizations or of biomedical understanding of problems of non-compliance or therapeutic infidelity, they point to a series of problems - each problem in itself might be regarded as “minor”- nut they lead us to think of a different way in which “symptoms” in the larger sense can be grouped and thus a different figure of disorder produced. In providing such a reading of signs and symptoms, these accounts might provide a very different diagnosis of the situation.

**The Context**

The national TB control program (NTP) was implemented in India in 1962 and for many years was hailed as an example of a program that was particularly suitable for resource constrained countries such as India. The program was based on the assumption that instead of massive investment in TB eradication that would mean taking away

\(^2\) There is a rich literature on this genre of writing. The classical model was developed by Kleinman (1988) and has been used to great effect by Good 1994; Mattingly and Garro (2000) and many others. For a recent review of the methodological issues and types of illness narratives, see Bury (2001).

\(^3\) The most powerful critique of this position still remains Paul Farmer’s classic paper on immodest claims of causality. See Farmer (1999) and also Briggs and Briggs-Mantini (2003)
resources from other priorities; a limited investment in a suitably oriented TB program could accelerate the decline of the disease. One of the achievements of this program was that it showed that a domiciliary program could be more effective than a hospital based program. However, in 1992, there was a sense of a global crisis in TB management, precipitated on the emergence of HIV infection as a major global health problem. A review by WHO in 1992 identified some major problems ranging from undue reliance on x-rays for purposes of diagnosis to problems of adherence and incomplete treatment by patients. The dangers of multi-drug resistant TB were also recognized in this period, leading to the Revised National Tuberculosis Program that was a result of a joint initiative between GOI, state governments, World Bank and some bilateral donors. The major innovation that was introduced was based on WHO’s DOTS or Direct Observation Therapy short treatment program. This program was introduced in 1993 and despite initial criticisms, has been generally regarded as constituting an important breakthrough in TB treatment in India.

For the conceptual plane of our analysis the importance of DOTS as an administrative mechanism for health delivery lies precisely in the specific way that Deleuze conceptualized control society in terms of micro-political proliferation in which in relation to the crisis of hospitals or asylums as institutions of closure, neighborhood clinics, hospices, day care centers could at first express new freedoms but then within each of them new mechanisms of control begin to assert themselves. One of our concerns

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5 The success is claimed for both high rates of case detection and rates of cure. For example see Khatri and Frieden (2000) report that 81% of new smear positive cases and 70% of retreatment cases in DOTS centers were cured. Others have expressed far greater caution in claiming success. See especially Blower and Daley (2003) and Singh, Jaishwal et al (2002).
here is to show ethnographically how mechanisms of control have appeared within DOTS centers that lead to a cut being made between those whose lives are to be saved and those who will be allowed to die.

We are mindful of the fact that it might be possible to defend the claims of success of DOTS program if we take population as the object of intervention and treatment and recount success in terms of number of patients treated, case detection rates as well as rates of cure. We submit, however, that such a construction of the problem simultaneously serves to eclipse a different way of grouping symptoms and thus being attentive to the way that the illness and, even cure, might point to a new set of questions about tuberculosis as a disease of this particular moment in these specific milieus. We present some case material from a longitudinal study on health and urban poverty conducted at ISERDD, Delhi, to show how TB might be configured as a new kind of disorder, as much a symptom of the possibilities of life available to the urban poor as a disease that affects them. From a strictly biomedical perspective, TB is an ancient disease – yet, how it is now experienced bears the imprint of new imaginaries of regulation, new ways of making a cut between patients who are to receive attention and those who are left to deal with the disease through their own devices as well as the devices, however singular that are available across various strata and milieu.

For the last four years we have been part of a longitudinal study on urban health in a collaborative research project building panel data on 300 households located in seven

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6 This particular mode of telling a success story is often based upon willful ignoring of the manner in which numbers have been arrived at. For instance, at least one study points to the fact that health workers screen patients for their ability to confirm to the direct observation therapy and thus those patients who are in absolute poverty, do not have proof of residence or are otherwise seen as not fully integrated into the city are screened out of the program. The high rates of case detection and of cure are a result of the fact that it is easily identifiable patients and easily treatable patients who form the population on whom figures are produced. See Singh, Jaiswal et al (2002). For the implications of the present strategy of targeting this set of patients for modeling the epidemic, see Blower and Daley (2002) and Dye, Wall, Bleed (2002).
localities in Delhi. Three of the neighborhoods were poor, two middle income and two were relatively wealthy. The localities were chosen on the basis on initial contacts; once a contact had been established, the sample of households was drawn randomly by asking every alternate household to participate. There was less than 4% rate of rejection. The sample characteristics are similar to representative samples of Delhi residents in the National sample Survey and National Family Heath Survey (see Das and Sanchez 2002 for sample details). Within the larger study we have also followed 46 cases of patients, 22 male and 24 female, who received a diagnosis of TB (of different kinds) at some time. Although there are enormous differences among low income neighborhoods in terms of basic facilities such as running water or sewage disposal, it is striking that with one exception, cases of TB are confined to such localities alone. There have been seven deaths among the cases we followed in the last four years. These were of four women and three men – of these, three women and two men were over sixty years of age, while one woman and one man were in their thirties. Eight of the patients in our list report themselves unambiguously cured after having been treated at the DOTS centers or in private medical facilities while the rest are either under treatment or have reported reappearance of symptoms after taking treatment. Deleuze constructed his picture of the critical and the clinical through an analysis of literary figures. We take narratives from

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7 Every patient was interviewed at least once and there were close interactions with family members through repeat visits to the household. Interviews were conducted in Hindi by Rajan Singh, Charu Kumar and Veena Das. Rajan Singh and Charu Kumar were trained in the field on amplificatory techniques of interviewing by Veena Das. These interviews built upon data gathered through weekly and monthly visits to the households for a health survey. In all the data on the 300 households comes to 35 weekly surveys and 42 monthly surveys. During visits fieldworkers kept a diary in which they recorded their observations on events in the household and in the neighborhood.

8 We use the phrase “unambiguously cured” to refer to the fact that what counts as a cure is not only the clinical definition as smear negative but the patient’s own experience. As we shall see later we have cases in which a patient who is declared to be cured because she is smear negative might still feel that the disease persists. In some cases the persistent of symptoms is indicative of the fact that while the patient is not contagious any more, she might still be suffering from residual effects such as weakness or, indeed might not be cured. We discuss this further in the conclusion.
these low income localities to describe the conditions under which patients live and die with and of TB. Let us keep in mind that these conditions of life and death that we plot belong(ed) to Delhi, fully and “successfully” covered by the DOTS program unlike some other remote parts of the country. We present two case studies of one woman and one man who died in the survey period. Despite the fact that the research team has maintained close contact with the families over the last four and a half years through weekly and monthly surveys and ethnographic interviews, the stories patients and their families relate are not clear cut in terms of plot, narrative coherence or delineation of characters. The suffering produced by the illness, as well as what we call institutional incoherence (at least from the perspective of the poor), produce stories that achieve coherence only retrospectively in the telling\(^9\). This lack of a coherent plot or narrative structure is also related to the methodological device by which researchers not only asked people to relate what happened but also observed relations within the family and made notes in their diaries through naturalistic observations and conversations in the course of regular visits to the neighborhoods. Thus our methods in their requirement of repeated, long-term engagement result in some disturbance in the pressure towards coherence that the act of storytelling often produces when patients are invited to offer their explanatory models especially in a single interview. While plot in the context of fiction, often refers to the series of events consisting of an outline of the action of a narrative, there are other meanings of a plot, such as the ground, that might be more appropriate here. In the sense of ground, plot may be taken to refer to a setting or the soil on which stories grow. Thus a

\(^9\) The incoherence we refer to is not a result of some kind of culture of poverty but can be described in precise terms as produced through the functioning of institutions put in place by the state and global programming to contain the threats of disease and disorder as they are seen to emanate from such local settings.
singular body which inhabits this plot is a function, firstly, of substances and forces which compose it and which pass through it and secondly, of the events and trajectories in which it participates, which we might refer to as its life; as well as those events it perpetuates, its residual effects which constitute the after life of that singular body. These wide ranging and relatively distinct conceptual valences must be kept in mind even if we group them together under the supposedly self-evident term “individual”.

*Meena: the mother*

Meena was a resident of a cluster of *jhuggis* (shanties) in the industrial area of Noida that lies on the border of Delhi and U.P. Noida has grown to be one of the most affluent residential and commercial areas but the sector in which the *jhuggis* in which Meena lived, is located primarily in an industrial area dominated by factories with clusters of *jhuggis* where migrant families from U.P and Bihar have settled and who provide semi-skilled or unskilled labor. The residents of the jhuggi settlement in our sample had arrived in waves – the earliest settlement can be traced to forty five years ago. Subsequent movements have followed networks of kinship and village affiliations. The settlement is an unrecognized colony which means that the residents do not have a legal right to the land but complicated customary norms have evolved here as in many other slums of this kind, so that people have “bought” land and built *jhuggis* on this land. New migrants usually rent *jhuggis* from the older residents till they can earn enough money to buy one themselves. The residents have also registered themselves as a scheduled caste association under the Societies Act of U.P. This has enabled them to obtain a stay

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10 See Das (2004).
11 Scheduled castes refer to previously untouchable castes recognized by the Constitution as entitled to protective legislation and administrative action. In many parts of the country such castes refer to themselves as Dalits and it has become common for scholars to use this vocabulary. However, in these areas residents
order from the Allahbad High Court which forbids the government to take over their land unless alternate housing is provided to them. The government policy on this issue has vacillated over time but with each election, as residents are courted by candidates, they become hopeful of getting rights to *pakka* (i.e. built with bricks and cement) housing in a “recognized” colony.

Meena lived in this colony in a jhuggi with her husband, two young sons and the husband’s father. Her two sisters were married to the two brothers of her husband but relations between them were fraught with conflict. Meena’s husband and his father were both employed by a contractor in the U.P Water supply department as cleaners. Thus they had a stable but meager income throughout the period of our study which meant that small amounts of cash were available to the family, though this cash was never adequate for the many demands ranging from food, providing school supplies for the children, as well as money spent on alcohol and tobacco by Meena’s husband. In addition, there were regular expenditures incurred on medications, especially as the younger son suffered from a respiratory ailment.

At the initiation of our survey in this area (August 2000) Meena had reported that her first episode of TB occurred three to four years ago. At that time she said that she took medications for a long time – perhaps seven months, perhaps one year. However, in a later interview she said to one of the fieldworkers that she had TB for the last eight years which had “never been cured”. She described a complicated story in which first, she talked about a breast abscess after her child’s birth, a minor surgery as well as fever, cough and weakness. This was when she was living in the village with her conjugal refer to themselves as SC (short for scheduled caste). As we follow these households over time, it will be interesting to see the shifts that occur in linguistic practices and their relation to political practices.
relatives while her husband had come to the city in search of a job. Following is an extract from an interview done by our co-researcher Rajan.

Rajan: So, in your conjugal family did you know that you had TB?
Meena: In the beginning I did not and the doctor also did not say that.
Rajan: then you were having cough, and fever and weakness.
Meena: Yes, they gave me lots to eat but still the weakness did not go.
Then I became okay when they took me to Vrindavan.
Rajan: Government hospital or private?
Meena: Government hospital - but there check up and everything is free but you had to buy medicines from outside.
Rajan: How long ago was this?
Meena: Eight years ago. I took medicines for three months. Then I became healthy.
Rajan: So did the doctor ask you to stop the medicine?
Meena: No, but thee was no money. For three months my husband’s father bought medicines but then the money got over and no one helped. (original text in Hind, translated by Bhrigupati Singh)

From the village Meena moved to Noida to join her husband. In the city she said she was healthy for a little while but then her symptoms recurred after her one year old daughter died. When we began our survey, she reported that she had completed another course of TB medication recently but was still feeling very sick and weak. In the initial weekly survey period of four months in 2000, Meena reported ill with various symptoms ranging from cough to fever during eight weeks out of the total of 16 weeks. Since she had
already completed a six months course of TB medications recently from a government dispensary and had been reported cured after a sputum test, she did not return to this dispensary for treatment of her symptoms in these eight weeks. Instead, she intermittently accessed a private practitioner in the area who had a BAMS (Bachelor of Ayurvedic Medicine and Surgery) degree, for relief of symptoms. He gave her a range of medicines from analgesics to antibiotics. Her mode of accessing medical care was typical of many in the area – that is to say, a mode in which symptoms are treated by practitioners by dispensing medications for a day or two for a consolidated fee of Rs. 20 to 30.12 This was also a very difficult period for her because she suspected that her husband was having an affair with a married woman in the neighborhood. During conversations Meena said she feared that her husband would send her to the village where his mother lived, on the pretext that her illness made it difficult for him to look after her and might even marry the other woman. She wanted desperately to recover her strength so that she could attend to household chores effectively in order to keep her place within the family.

One of the diary entries made in the fourth week of the survey recorded by Lathika, the fieldworker, reads as follows:

Meena cried today. She had a small gash on the head. On probing she said it is because her husband hit her. She is very weak and sad and told me with tears in her eyes that her husband was having an affair. The lady, Meena told me, lives opposite the house… Mukesh (her son) has seen them walking hand in hand in Harola market. She was hit yesterday because she asked her

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12 For a detailed discussion of the medical environment in this area see Das and Hammers (2004, 200.) and Das and Das (in press). Other researchers have reported that practitioners in private clinics tend to use a range of treatments for patients reporting with symptoms of TB. Thus, Uplekar and Juvekar et al (1998) reported that there were 79 different treatment regimes prescribed by 105 reporting private practitioners for treatment of TB in a study based in Maharashtra.
husband where are you going so early in the morning and he said, I give you
and your children food and shelter and it is none of your business to talk
more. (Original entries in English)

Towards the end of the first year of our survey in 2000, Meena’s condition
seemed to have worsened to the point of an emergency. She was beginning to cough
blood stained mucus and was constantly coughing. The neighbors reported to us that her
husband had tried first to get her admitted to a private hospital in the neighborhood but
did not have the requisite money to make the advance payment demanded by the hospital.
The solution was found through a relative, who was employed as a Ward Boy in a
government hospital in South Delhi and who managed to get Meena admitted under
another name in that hospital on the pretext that she was his dependant relative. Meena
stayed in the hospital for six months. Here is the description of the event in the words of
her son Mukesh in a conversation with Veena. The conversation took place in Hindi.

V. Mukesh, why are you not going to school these days? You have lots of
work at home?

M: No, it is not the work. But I feel very scared. I think mummy is no more
and Papa is not telling us.

V. But why should you think that?

M. Because that night when she had blood in the vomit, everyone had given
up hope - the neighbors came and they were preparing to lay her on the
ground (i.e. in anticipation of imminent death). So then someone said, take

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13 The relative advised them to admit Meena under the name of his wife as otherwise she would have to
wait for a bed – as an employee of the hospital, however, the Ward Boy could get a preference over others.
This, at least, was the reason given by her husband. We discovered this quite accidentally when one of us
went to visit her and could not find her name among the registered patients.
her to Kailash hospital but Papa said that he did not have money for Kailash hospital. So where did they take her? (Translation by Veena Das).

Frightened by this conversation we found out the name of the TB hospital and one of the members of our research team visited her in hospital. The entire story about the altered name and the help given by the relative came out because her husband told us that she was admitted on a different name when on an initial visit the field researcher could not find her name among registered patients.

By the time Meena was discharged from the hospital after a six months stay and came back home, the Pradhan (headman) of this cluster of jhuggis had acted decisively against the woman with whom her husband was having an affair as a result of various other complaints from the neighborhood. Consequently, the woman’s husband was persuaded to send her back to the village to live with the husband’s extended conjugal family. Meena had now taken another course of TB medication and the hospital discharged her with instructions to complete the course of medications. She was required to go the hospital OPD to receive medication but her husband managed to get her name transferred to another DOTS center nearer their home. Meena completed the remaining course of medications from the DOTS center. For the next three months she was free of symptoms and had begun to put on weight. One can detect the altered affect even in the small entries in the diary of Purshottam who was then covering these households.

Today looking at Meena ji’s (ji is an honorific in Hindi used for all elders) face one felt that she was a little better. I asked Meena ji, how are you. She smiled and said, “Now I am better. I went to get medicine for Rahul (younger son).” She showed me (i.e. Purshottam) the medicine – Ampicilin
with Cloxacin. On the label it was printed MCD - Not for Sale\textsuperscript{14}. I said but this medicine is not for sale. She said, “Brother, I don’t know – this is the medicine Titu (name of practitioner) gave me and with this Rahul is absolutely fine.” (Original entries in Hindi, translation by Veena Das)

A few days later Pursottam recorded in the diary that while he was visiting the household, Meena’s husband came from the market with a bag of pomegranates which he had bought from the market and he handed these to Meena for her to eat. (In parenthesis we note that pomegranates and grapes are among the most expensive fruits and often denote the extra care being showered on a sick person.)

In the third year of our survey, Meena’s symptoms reappeared. The diary entries record that she was lying in the bed all the time and coughing. At one point she said to the field researcher, Pursottam – brother, I feel broken from inside. On her husband’s request two members of ISERDD (the research organization) took her for consultation to a referral hospital in Kingsway Camp where the attending physician was prepared to admit her as an in-patient though no one was willing to address the question as to why her symptoms were repeatedly reoccurring. Off the record, one of the physicians told one of us (Veena) that it would not be of much use to conduct any diagnostic test for multi drug resistant TB as the hospital did not have the resources to provide treatment. Meena’s husband did not want her to be admitted to a hospital so far away from home so they went to another DOTS center by providing a false address. Here again she was dispensed the anti TB regimen under the DOTS protocol but reported serious side effects such as continuous nausea. Her condition continued to worsen, so she stopped taking

\textsuperscript{14} MCD refers to Municipal Corporation of Delhi. It is often alleged that medicines in government dispensaries are illegally sold off by the attendant physicians or pharmacists. This would be one instance of this kind of corruption in the area.
medications. She died in a private nursing home in December 2003 where she was rushed in the last two days of her life. The family at the end of her life was in debt to the order of several thousand rupees.

Given the weight of the literature on TB and stigma one might have expected that stigma would play a major role in this illness trajectory. What seems to emerge from the story, instead, is consistent institutional neglect and incoherence. This neglect exists in conjunction with the care and neglect built into Meena’s domestic relations. In the course of three and a half years, Meena took three rounds of TB medication, all under the protocols of TB management in DOTS centers. There was no consistent record of her illness with any of the practitioners. When she was admitted to hospital, she took an assumed name and did not show her previous medical records but even when she used her own name there was no attempt on the part of the DOTS center to ascertain her medical history. In each episode of the disease she completed the course of medications, and was declared to be sputum negative and thus “cured”. In addition to the prescribed first order drugs in the TB regime, she also consulted a private practitioner in the area between treatments and was given specific medicines to address symptoms such as fever, pain, and cough. She did not conceal her illness from anyone. The private practitioner she consulted in the locality was well aware that she had accessed various practitioners for her disease and that had been on medication for TB. Though she had the treatment

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15 For instance, Rajeswari, Balasubramaniam et al (1999) reported that 15% of women in their sample were rejected by their families. One of the difficulties of interpreting these results is that a woman who is sent to her natal family is often reported by researchers as “abandoned” or “rejected” by the family. However, in our field sites we found that women interpret the move to the natal family for treatment as part of their entitlements in the natal home and interpret the fact of being received in the natal family as an opportunity to be free of domestic responsibilities as wives in the conjugal families. Sometimes, if the woman is not allowed to come back to the conjugal home or if the husband takes on another wife it might, indeed a case of abandonment but the fact of being sent to the natal home cannot, in itself, be interpreted as rejection. On the impact of tuberculosis on women, see also Connoly and Nunn (1996) Some of the literature completely confuses material and efficient causes in the analysis of factors that are cited as causing TB.
cards that she had collected from the DOTS centers as well as the hospital, she did not carry her medical records from one government institution to another. Nor did any practitioner try to get a detailed medical history from her. This is consistent with the common practice in the area for practitioners trained in all streams (i.e. in biomedicine, ayurveda, homeopathy, unani) to assert that “residual” effects of TB include weakened respiratory functions and to treat coughs and fevers with analgesics and inappropriate antibiotics, even after the patient has been declared cured by the DOTS center. This is despite the fact that at the level of knowledge, practitioners from all streams recognize the symptoms of TB. For instance, when asked to respond to a hypothetical case of respiratory TB, most practitioners immediately suggest that the patient should have a sputum test, an x-ray and should take TB medication for six to eight months\textsuperscript{16}. Yet in actual practice they do not hesitate to use such terms as “residual effects of TB” and prescribe antibiotics for one or two days to make the symptoms “better”. This understanding of the course of the disease is shared by many families. From a strict biomedical perspective we could say that patients do not have any clear understanding of when their disease began and when it is that they can say that they were cured. However, the disease scenario of repeated re-infections and the way practitioners in the area themselves deploy categories such as “residual TB” or “old Koch” in explaining symptoms to patients might also contribute to local understanding of the severity and course of the disease.

I hope it is clear that Meena’s death cannot be attributed to any simple notion of stigma that prevented her from going to a DOTS center for treatment. There was no effort

\textsuperscript{16} For a detailed analysis of practitioner competence in these localities see Das and Hammer (2004).
on her family’s part to conceal her disease\textsuperscript{17}. Paradoxically, the notion of stigma operates more in alliance with the medical system for what made it necessary for her family to move her from one DOTS center to another was the fear that she would be held responsible for her failure to be cured (cf. Das forthcoming\textsuperscript{17}). The result of these treatment strategies on the part of the patients and their families is that there is no way of knowing whether someone like Meena was repeatedly re-infected because of compromised immunity, environmental factors, concomitant HIV infection, or whether she was infected by an acquired or transmitted drug resistant strain. Meanwhile the records of each DOTS center classify her as a cured case. It should be noted that if HIV were to become endemic in such areas it will become even more difficult to know how to classify such cases of repeat infections.\textsuperscript{18}

Meena was completely bewildered as to why her symptoms kept recurring when she was pronounced cured at the end of each treatment cycle. Throughout her treatment, she plunged between despair and hope. If her symptoms improved, she became active in making little improvements in the house such as paving a little space in front of her \textit{jhuggi} with cement so that she could wash it and keep the entrance clean. When the symptoms recurred, she would lie inside the \textit{jhuggi} and say – now I must prepare for going to Jamna ji (the river near the cremation ground). Yet she hoped to survive and even in the last month of her life, her husband tried to take her back to the DOTS center from which she had received the last course of her treatment. The nurse in attendance

\textsuperscript{17} We are not arguing that the notion of stigma is never evoked – however, in the kinds of shanty clusters under consideration here, life is lived more in the street than in the house. The material conditions for concealment are simply not available. It should also be kept in mind that in an arms length one shot survey in which researchers have one point of contact with subjects, it is more probable that people will try to conceal certain illnesses. We have other cases in localities with built houses in which families conceal the illness, especially of unmarried daughters, for fear that it would affect the prospects of their marriage.

\textsuperscript{18} Some studies have estimated that 21\% to 40\% cases among smear positive patients in Maharashtra and Gujarat are re-treatment cases.(Lambregts-van Weezenbeek 2004).
there was not willing to register her case again – she told her that they had done all they could and that their records showed that had been cured of her TB. In the last week of her life when she was coughing incessantly, her husband took her again to a private nursing home which admitted her but at enormous cost, and she finally died there.

We are not trying to put here a picture of heroic patients versus heartless doctors but struggling to find a way to tell the story so that we can understand how the “letting die” happens even as international agencies and the government are engaged in the global “Stop TB” program. In Foucault’s rendering this ‘letting die’ is an aspect of biopower in which a cut is made as to whose life is to be enhanced and whose life is not worth preserving (Foucault 1997). We hope to show that the way in which the letting die of the family happens does not have the same texture of feeling than that of the state. Thus terms such as abandonment or triage cannot be deployed in a seamless manner as we traverse the milieu of the family and the state even as we track the manner in which the state’s signature can be read in the lives of families and local communities.

At the conceptual plane of the micro politics of families and communities, there are qualitative differences and variations that are internal to the family. Thus we are not holding up a picture of the “care” provided by families that can be held up against the “neglect” of the state. In Meena’s life there were periods of neglect, when her husband probably just wanted to get rid of her – there were also periods of care when he would make the long journey to the hospital whenever he could get leave from his work or come home in the afternoon during his lunch break and cook food for the children and her. The family tried to devise strategies of treatment within the institutions that formed part of their local ecology. The inability to acknowledge treatment failures seems to be an
unintended consequence of the planning to equip DOTS centers for treating easily identifiable and easily treatable patients in the first phase of the Stop TB program (see Blower and Daly 2002). This strategy leads to the practices in which it is assumed that patients are non-compliant while treatments are always efficacious. While there might be many conditions in which patients are unable to comply - treatment failures, repeated re-infections or multi drug resistant TB also provide the conditions under which “therapeutic fidelity” becomes impossible to maintain.

In the literature on the economic consequences of diseases such as TB and AIDS, one sometimes finds calculations about the impact of deaths of particular kinds of populations (e.g. the young versus the old; heads of households versus dependants). The consequences of the death of a young mother for the life of the family, however, cannot be computed in strictly economic terms. Meena had ceased being an earning member of the family and her illness had further put her husband in debt. In that sense she was more of an economic liability and thus deaths of unproductive members of the family might be seen as less grievous for the family from a strictly economic point of view. Yet, however much her illness drained out the resources of the family, her husband and children mourned for her. There are less tangible effects of her death on the family that will become manifest only over a longer period of time. Her elder son, for instance, who had passed his sixth grade with excellent marks because, as he told one of us, he had wanted to please his mother, is now studying in middle school. Will he lose his motivation for studying hard? Will his father continue to give him money for school books and school uniform or will the absence of the mother affect relations between them? These are questions that require long term observation. Meena’s younger son already refuses to go
to school regularly and since the father is away at work, there is no one to see to it that he goes to school in a timely manner. In fact the child refused to acknowledge that his mother is dead, insisting that she had gone to the village and would return later. Meena’s two sisters live in the neighborhood but relations between the families are full of conflicts – so it falls on the neighbors and on the elder son to provide some supervision to the younger son. The impact of the mother’s death on the children and thus the social and emotional costs of institutional incoherence in the treatment of TB cannot be computed in strict economic terms but we can at least point to the manner in which it has already begun to affect the children’s attendance in school and thus formation of skills to improve their prospects. But more importantly, we should ask what the experience of the loss of a mother might mean to the children – how do they learn to read their social environment or trust institutions which seem to have failed them so dismally?

*Ahmad: the patriarch*

The second death we describe is of an elderly Muslim man whom we shall call Ahmad Mian from B.Kheda who reported that he was suffering from TB in the initial survey period in 2000. Our weekly survey records show him to have accessed the DOTS center at the government hospital once and then to have switched to local practitioners whom he accessed on an intermittent basis. An interview with his wife revealed that he had quarreled with the attending doctor at the government center who told him that due to a change in the jurisdiction of DOTS centers, he was being transferred to another DOTS center. Ahmad Mian did not want to go to another doctor and insisted that he had a right to continue to receive treatment from the initial DOTS center. After this quarrel he refused to go to a government hospital for about twelve weeks but consulted local
practitioners twice in this period for relief of symptoms. Towards the last two weeks of the survey period of sixteen weeks he went for some medications to the Delhi Administrative Health Center where he was dispensed Belargen for stomach ache. Till he died in December 2003, this was the pattern of his medical treatment. He refused to go to the DOTS center to which he was assigned, because he maintained that the attending doctor there was rude and insulting. He consulted local practitioners sporadically when his fever or stomach ache from incessant coughing became hard to bear. In addition to medicines dispensed from the two local practitioners whom he sporadically consulted, his family sometimes gave him Crocin or Ballargen bought from the pharmacist for symptomatic relief. His widow informed us that the local practitioners had told them that Ahmad Mian’s TB was not curable. She also said that before our survey started Ahmad Mian had been on medication for about six months from the hospital where he had quarreled with the doctor\textsuperscript{19}. Paradoxically, the very requirement of taking medicines in the presence of a doctor or a nurse as envisaged in the DOTS protocol generated quarrels with the care givers both at home and in the clinical setting. In this as in other cases where elderly patients are concerned, it might appear that the family simply abandons the elderly members once they become economically unproductive because of old age or disease. In fact the situation is much more complicated since care might mean very different stances towards life. In the case of Ahmed it seemed that the family strove to maintain certain fictions of patriarchal honor that preserved normativity at the expense of his health and even of his biological life.

\textsuperscript{19} We expect that the medicines he was dispensed were first line anti TB medicines but the family did not have prescriptions or empty foils from which we could have definitively discerned the names of the medicines.
When one of us (Veena) went to Ahmad’s house some months after his death, his widow began to relate the entire story of their life again. She said that she got married at a very young age and that she and her natal family only discovered that Ahmad Mian had TB after her marriage. It is, as we have said, not uncommon for patients to project TB backwards and forwards in time. In this case it was perhaps because Ahmad Mian had never been able to hold a steady job even in his youth and his wife had to steadily serve the other members of the extended household to justify the expenses they were incurring on his frequent illnesses that perhaps made her project the TB back to more than thirty years. In this case there is no way to know whether, like Meena, he too suffered from repeated infections or whether TB that was definitely diagnosed in the last five years was projected back to account for his general ill health.

His widow, Chano described his illness and her predicament in the early years of their marriage thus:

My heart knows how difficult it was to bring up my four children. Everyone used to say her husband is always ill; we (the conjugal extended family) have to feed her family – yet she goes on producing children. Who will feed them, who will get them married? No one gave any money to me. My husband’s mother owned a buffalo – I would feed the buffalo, pick up the droppings, make fuel cakes out of them, get grass from the grazing land – many, many, bundles of grass to feed them – I did all that because my husband was ill and they gave food for my children.

In any case, since the time our survey began in 2000, it was clear that no one in the family felt that they had the authority to compel Ahmad Mian to go regularly to the
DOTS center to receive his medication under the supervision of the attending doctor or nurse. His widow said that she knew that her husband could not bear to be insulted and also that the people at the government hospital were very rude.

Chano: the medicine was free at the General hospital but they refused it (mana kar di). They said thus, he does not have TB. So they said, go home. He (her husband) said can you write it down that I don’t have TB. I will go straight to Camp hospital (referring to the largest referral hospital in Delhi). So a fight erupted between him and the doctors, the TB ones, but that doctor refused to put it in writing. (Translated from Hindi by Veena Das).

We wondered how much this sensitivity stemmed from his being a Muslim and whether the medical personnel at the DOTS center felt authorized to be arrogant and rude because of embedded institutional attitudes towards Muslims as a minority. Two points would lead us to approach this question with caution. First, there are similar stories from two other elderly men – both of whom are Hindus living in similar localities. Second, Ahmad’s Mian’s two nieces who were also infected, received treatment from the same DOTS center and were cured. Thus while it is clear that care and neglect in the family are not simple matters in which the logic of the market and the state would be simply mapped on to the practices of the family, it is also evident that kinship norms are being profoundly changed in relation to the experience of intractable infections and the chronic character diseases such as TB acquire because of treatment failures. Ahmad Mian’s widow used the ambiguous term seva, to refer to her relation with her husband in the last phase of his life. It appears that on her pleading, her elder son Mushtaq, had gone to the DOTS center to find out from the attending physician whether he could come and collect
the medicines on his father’s behalf and the physician had told him – there is no more cure, you should go home and offer seva (service, care) to your father. The terms seva is derived from the devotional Hindu practice of offering service to the deity but moves between the domains of religion, kinship and healing practices. In the specific context of clinical encounters it may also be used euphemistically to convey to the relatives of a patient that he or she is beyond cure and thus all that remains is to show one’s piety to the ill person by offering seva to him or her. Ahmad’s Mian’s wife, in relating this story concluded by saying – bahut seva kari -Seva to din raat kari hamne, which roughly translates as – we did lot of service – day and night we offered our service/care. At the moment, we will not comment on the interesting way that Hindu devotional religious vocabulary is secularized through the site of the clinical and circulates to signify piety in the kinship domain in a Muslim family. What is important is to note that the term seva becomes a composite term to signify both, that one has given up on a patient and that one has not abandoned one’s piety towards him or her. The material practices of offering seva raise a host of questions on what it is to let die; whether the state’s letting die which consists of the policies and practices that include the resource constraint settings of public hospitals in low income areas, and the family’s practices of letting die, are the same.

Family, State, Social Suffering

The two narratives of dying we relate here are not about the family or the state as distinct institutions but rather about how we might track the movements of each in the other through the social suffering produced by the tuberculosis epidemic and the global imaginaries of management. We do not see the family as either the agent of the state or as the moral community in which market and state are kept at bay. Rather the thrust of our
argument is that the institutions evolve, mutate, and change in singular ways: they are in constant motion bearing the tracks of each other. Thus our understanding of these processes is similar in some ways to the powerful work of Joao Biehl on kinship and abandonment in Brazil, and yet there is an important difference. Biehl sees the matter in the following way:

…the family is increasingly the medical agent of the state, providing and at times triaging care, and that medication has become a key instrument for such deliberate action …In engaging with these new regimes of public health, families learn to act as proxy psychiatrists, illness becomes the ground on which experiment with changes and breaks with intimate household relations can occur…Families can dispose off their unwanted and unproductive members, sometimes without sanction, on the basis of individuals’ noncompliance with their treatment regimes. Thus, psychopharmaceuticals become central to the story of how personal lives can be made or unmade in this moment of socioeconomic transformation and how people create life chances vis-à-vis what is bureaucratically and medically available to them. (Biehl 2004: 475-76).

In the case of tuberculosis within the context of urban poverty, the global programming of the epidemic and the state’s management of it, create specific local environments within which the poor create life chances. Within this environment we do not see the family as the agent of the state – rather, it generates its own internal variance in which we can read a whole spectrum of moods, colors, hopes, despair. The cases we
present here show how difficult it is to nail down such concepts as care or neglect in this environment. The critical reading of the “disorder” produced by a regrouping of symptoms tends to show that the issue is not simply that the family will replicate the logic of the state in letting its unproductive members die but rather that the extreme difficulty of managing the disease in cases of repeated infections creates a kaleidoscope of emotions, strategies, struggles and resignations in which neglect and care come to be woven into a single fabric of relations. How can the clinical respond to this scene of local affects?

We are struck by the specificity of this epidemic and the way its treatment and management fold into the processes of the family. At present DOTS centers work with the assumption that they are treating easily identifiable and easily treatable patients – hence there is no room for attending to treatment failures in their protocols. This means that when patients who get repeatedly re-infected present themselves, the staff feels authorized to assume that the treatment failure is due to the patients’ behavior and not because the treatment is not efficacious. Within this medical environment, patients then simply move from one treatment facility to another, changing their names, procuring false documents and ending up with the picture of government institutions as incoherent, unable to provide treatment that is widely publicized, and concluding that the representatives of both medicine and state are unpredictable. This is consistent with other ways in which government institutions function in their lives. In this case, though, the state does not have any power outside the clinical context to compel treatment or incarceration in institutions20.

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20 The specificity of the interventions must never be lost sight of. In the late seventies the power of the state was experienced as much more coercive as in the small pox eradication campaign and the sterilization
The proliferation of unregulated practitioner markets and pharmaceutical markets in low income localities makes other alternatives available which, in general, complicate the treatment protocols. Patients can access these practitioners easily and get sporadic medicines, including anti TB medication, but in inappropriate doses. However, disastrous this might be for the actual course of the disease, patients and their families feel that they are “doing something” about the suffering produced by the disease.

It seems to us that the logic through which the epidemic is sought to be modeled assumes that logic of control would work because patients would be treated directly under the supervision of medical personnel located in DOTS centers. And in many cases where the DOTS centers are well equipped and patients are able to access them regularly, the logic of control works. Yet, as our case studies demonstrate, the juxtaposition of local practitioner markets and unregulated movement of pharmaceuticals along with an assumption of therapeutic efficacy of the first line drugs leaves patients extremely vulnerable in those cases which are not easily treatable. An attention to their predicament would suggest that a public health strategy for such patients needs to be urgently devised. At the minimum, we need to see that such patients do not simply drop out of the records. Perhaps a strategy complementary to the DOTS strategy in which individual case workers are trained to do follow up of cases of patients who are repeatedly infected and a move to second order drugs for that section of the population within the DOTS plus program along with greater regulation of practitioner markets would be the first step in this direction.

campaign. The first was implemented in the period 1973 to 1976 and the latter during the national Emergency of 1976. See Basu, Jezek and Ward (1979); Greenough1(995) and Tarlo (2004).
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