The making of a public health problem: multi-drug resistant tuberculosis in India

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This paper examines how actors construct the public problem of multi-drug resistant tuberculosis (MDR-TB) in India. MDR-TB has been framed by the World Health Organization as a pressing, global public health problem. The responses to MDR-TB are complicated as treatment takes longer and is more expensive than routine TB treatment. This is particularly problematic in countries, such as India, with high patient loads, a large and unregulated private sector, weak health systems and potentially high numbers of MDR-TB cases. This paper analyses how actors struggle for control over ownership, causal theories and political responsibility of the public problem of MDR-TB in India. It combines Gusfield’s theory on the construction of public problems with insights from literature on the social construction of diseases and on medical social control. It highlights that there are flexible definitions of public problems, which are negotiated among actor groups and which shift over time. The Indian government has shifted its policy in recent years and acknowledged that MDR-TB needs to be dealt with within the TB programme. The study results reveal how the policy shift happened, why debates on the construction of MDR-TB as a public problem in India continue, and why actors with alternative theories than the government do not succeed in their lobbying efforts. Two main arguments are put forward. First, the construction of the public problem of MDR-TB in India is a social and political process. The need for representative data, international influence and politics define what is controllable. Second, the government seems to be anxious to control the definition of India’s MDR-TB problem. This impedes an open, critical and transparent discussion on the definition of the public problem of MDR-TB, which is important in responding flexibly to emerging public health challenges.

Keywords Policy change, public problems, multi-drug resistant tuberculosis, India

KEY MESSAGES

- Despite a policy shift towards a response to MDR-TB, the Indian TB community has not reached agreement on the magnitude and causes of the public problem of MDR-TB, what solutions should look like and who should be responsible for them.

- The making of MDR-TB as a public problem in India is a social and political process wherein dominant actors can exert medical social control by actively framing causal theories and placing political responsibility onto other actors.

- Alternative causal theories of actors fail to be heard because of mismatches of problem definitions and dominant causal theories, and unco-ordinated practices in defining alternative causal theories.

- In order to cope with changing challenges and opportunities, TB control in India needs the capacity to respond flexibly, which requires an open and critical discussion with all the actors involved on emerging challenges such as MDR-TB.
Introduction

Multi-drug resistant tuberculosis (MDR-TB) has been framed by the World Health Organization as a pressing, global public health problem (WHO 2008a). Tuberculosis (TB) is an infectious disease caused by the Mycobacterium tuberculosis which is commonly transmitted through inhalation of bacteria into the lungs. In its most common form of pulmonary TB, the disease, if untreated, will lead to gradual destruction of the lungs, increasing incapacity of bodily functions and death. The disease is curable with a cocktail of anti-TB drugs that have to be taken for at least 6 months. Patients who suffer from TB that is resistant to at least rifampicin and isoniazid, two of the most important standard anti-TB drugs, are defined as MDR-TB patients. They have only a 60% chance of cure. XDR-TB, or extensive drug resistant TB, is MDR-TB that is resistant to three or more of the six classes of second-line drugs.

MDR-TB develops due to an infection with a resistant strain or due to poor treatment with inadequate drugs or irregular drug intake (CTD 2007a). Most of the steps involved, such as diagnosis, treatment set-up, follow-up test schedules, reporting and recording activities, are longer and more extensive and complicated than in routine TB treatment. MDR-TB treatment takes 24 to 29 months and involves a daily injection and drugs intake of 10–13 different drugs. It is toxic, painful, frustrating, more expensive and more difficult to bear for patients than the routine TB treatment. In countries like India, with high numbers of TB patients, a large and unregulated private sector and weak health systems, the fear is that MDR-TB might eliminate the successes of TB control achieved so far and render TB practically uncontrollable (Udwadia 2008). This article examines how MDR-TB is being constructed as a public problem in India.

The Central TB Division, the department of the Government of India responsible for TB control, used to argue that the public TB programme [the Revised National Tuberculosis Control Programme (RNTCP)] is not able to also care for patients who suffer from MDR-TB, since diagnosis and treatment are very costly and not operationally feasible for the TB programme. MDR-TB patients had to search for their treatment elsewhere at their own cost (Udwadia 2001). By 2009, the Central TB Division had changed its strategy and regarded MDR-TB to be part of the TB problem that the programme should address. This article shows that despite the shift in strategy, debates and disputes continue about the magnitude and causes of the problem of MDR-TB, what solutions should look like and who should be responsible for them. What is more, the government seems to be anxious to control how India’s problem of MDR-TB is defined. This hinders an open, critical and transparent discussion on the threat that MDR-TB poses.

The current public TB programme has contributed immensely to TB control in India. Since its inception in 1997, the programme has treated more than 12.6 million patients and averted 2.2 million deaths. For 2012–2017, the TB programme has set the ambitious plan to provide universal access to quality TB diagnosis and treatment for the entire Indian population (CTD 2011). This will require, among other things, much more financial resources allocated to TB, a strong involvement of the private sector and improved diagnostics (Pai 2011). However, if Indian TB control is to strengthen its capacity to respond to changing challenges and opportunities, it is crucial to openly negotiate emerging challenges. Public debate and experimentation and a process of consultation, research and learning have been identified as important to respond flexibly to changing public health challenges (Porter et al. 1999; Peters et al. 2003). The emergence of MDR-TB in India requires innovations in new tools, financing and service delivery approaches by a range of actors. These actors should be included in the process of defining the problem in order to avoid unnecessary acts of blaming and to encourage all actors available to the country to join forces. The results presented here have implications for the governance of emerging public health threats beyond India and TB control.

Analysing the construction of a public problem

This article examines the construction of MDR-TB in India as a public problem in the making. Different actors struggle for control over defining the public problem of MDR-TB. These processes are social and political. They shape the construction of knowledge about the disease and the strategies to control it. The article makes use of Gusfield’s public problem theory to analyse the struggles over ownership, causal theories and political responsibility for the public problem of MDR-TB in India (Gusfield 1981). This conceptualization builds on two theoretical points identified in the literature, namely that problem definitions matter for health care practices and that problem definitions are crucial in understanding policy change and processes.

Social scientists concerned with health and medicine have emphasized, under different terms and viewpoints, that definitions influence clinical practice and guidelines. Some examples of such theoretical perspectives include the social construction of diseases (Lloyd 2000; Nicholson-Crotty and Nicholson-Crotty 2004; Kreimer and Zabala 2007), explanatory models of disease and illness (Rodlach 2006), framing (Leach and Fairhead 2007; Aronowitz 2008), social representation (Flick 2000; Mosquera et al. 2001) and the role of metaphors, such as war and plague (Sontag 1978; Wallis and Nerlich 2005). In general this literature highlights that perspectives on illness, health care and the politics of responsibility often differ and conflict among different groups, such as local populations, public health practitioners, health planners and policy makers (Nichter 2008). Concepts of diseases (frames or metaphors) are, furthermore, used strategically in the public arena to gain attention, political and medical interest and, ultimately, funding and support (Glass 2004; Wallis and Nerlich 2005).

In line with the cognitive turn in the vast literature on policy processes (Hajer 1993; Hall 1993; Rein and Schön 1993; Grindle 1999; Collins et al. 2000; Surel 2000; Kingdon 2002), studies on policy-making in TB control have also revealed a struggle over policy formulations and definition of problems and solutions (Narayan 1999; Porter and Ogden 2001). Porter and Kielmann (2003), for example, argue that policy-making in TB control is based on a structure with a technical perspective—a rational, biomedical approach—at its core, whereby it ignores the political, social and historical context of policy-making. Likewise, policy changes require changes in problem
definitions. Several studies show how the strategy to control routine TB (DOTS) emerged as a key international health policy and how DOTS was transferred from international to local levels (Narayan 1998; Porter and Ogden 2001; Ogden et al. 2003; Porter and Kielmann 2003). Yet, implementation of policy changes is likely to fail if the policy development at international level does not link with national and local levels (Porter and Ogden 2001). It is thus essential to examine the construction of problem definitions alongside policy changes.

This article adds to literature on policy processes and social construction of diseases by examining the construction of MDR-TB as a public problem in the making. According to Gusfield (1981), public problems differ from individual problems in two main aspects. Individuals cannot experience the aggregate level of the public problem and public problems result in public action for their resolution. The central agency that ensures public action is likely to be the government, but does not need to be. MDR-TB in India has become a public problem because a central agency, the Central TB Division, is dealing with its solution and because individuals need experts, advocates, pressure groups, lobbyists or the government to be able to experience the aggregate level, beyond its immediate impact on an individual.

According to Gusfield (1981), public problems are characterized by conflicts and struggles over ownership (the ability to influence the public definition of a problem), the acceptance of causal theories and the fixing of political responsibility on certain actors charged to find a solution. Those owning a problem might try to convince another group to take over political responsibility. Certain actors, such as the Central TB Division, have more power in defining the problem of MDR-TB and can therefore exert medical social control (see Conrad 1992 and Conrad 2005 for an overview). The literature on medicalization (see Conrad 1992 and Conrad 2005) argues that medical language exerts social control by excluding the social context from medical attention.

This paper uses Gusfield’s (1981) public problem theory to analyse the struggles over policy shifts (shifts in ownership), over magnitude and causes of MDR-TB in India (clashes of different causal theories) and over responsibilities of different actors (political responsibility). These definitional processes are decisive in what counts as a problem and a solution. The notions of ownership (Gusfield 1981) and medical social control (Conrad 1992; Conrad 2005) help to make sense of the political and strategic aspects of constructing a public problem.

The analysis is based on qualitative fieldwork which was undertaken as part of a larger project on innovation dynamics in TB control in India (Engel 2011). The research approach was exploratory and ethnographical, as practiced in science and technology studies (Collins 1985; Latour 1987), and followed actors and action across different social worlds engaged with TB control in India. These range from the worlds of global health policy, the national TB programme, patients and practitioners, to the world of the laboratory. A network of informants across the country was built up using snowballing and following actors and actions (Latour 1987). The fieldwork took place between December 2007–April 2008 and November 2008–April 2009 in Hyderabad, Krishna and Warangal District (Andhra Pradesh), Ahmedabad, Pune, Mumbai, Delhi, Chennai and Bangalore. More than 100 semi-structured interviews were conducted with public health experts, policy makers, scientists, physicians, medical staff, private practitioners, consultants and members of the civil society, community volunteers, patients and the international donor community. Visits to hospitals, health centres, research institutes, community projects, patient homes and treatment sites, and document research (government documents, conference proceedings, research articles, news items and the Internet) completed the fieldwork.

The topics explored across different social worlds included origins of policy shifts, key actors and their interactions, critical events and crucial factors influencing policy, decision-making and evaluation processes, controversies, construction of evidence, expectations and ideals. The analysis is based on writing thick descriptions and examining patterns and linkages between themes and codes (Eisenhardt 1989; Kelle and Kluge 1999; Rubin and Rubin 2005; Eisenhardt and Graebner 2007).

In accordance with the conceptual framework, the shift in ownership was examined by analysing how actors handle policy and by assessing the factors and conditions which led to the policy change (Mooij 2007). Problem definitions were analysed by examining different causal theories, including views and perspectives on problems, causes and solutions, and practices of defining problems. This also shed light on who actors thought should take over political responsibility for the problem and why. Different data sources were referred to in order to validate findings, cross-check and triangulate data.

Results: the construction of MDR-TB as a public problem

In the following, and in line with the conceptual framework outlined above, the shift in ownership, the struggles for control over causal theories of MDR-TB and over fixing of political responsibility are examined. The analysis follows two contrary positions in the debates: the argumentation of the Central TB Division (Government of India) and of vocal actors outside the government, such as private practitioners, non-governmental organizations (NGOs) and engaged researchers.

Accepting MDR-TB as a public problem: a shift in ownership

Prior to 2005, the Central TB Division regarded MDR-TB treatment as not cost-effective and not operationally feasible to treat within the TB programme—this was an accepted public health trade-off (interview, chest physician, Delhi, 21 February 2008). This was in line with the initial international opinion that had viewed MDR-TB as a non-alterable problem in resource-poor settings (Kim et al. 2005).

The TB programme has since changed its strategy with regard to MDR-TB. In 2005 MDR-TB was for the first time mentioned as a standard of TB care in a strategy document (CTD 2005). Around the same time, the WHO published revised global guidelines for programmatic management of MDR-TB (WHO 2006). In 2007, the Central TB Division officially launched the first treatment site for MDR-TB patients in Gujarat and published an official consensus statement on the threat of MDR-TB (CTD 2007a). Since then, the TB programme has been
upgrading its laboratory and diagnostic facilities across the country, has been providing the DOTS Plus treatment guidelines (CTD 2010) and is providing free treatment for MDR-TB patients in the emerging DOTS Plus treatment sites (Stop TB Partnership 2005; CTD 2007a; CTD 2008; CTD 2009b). By 2009, MDR-TB was commonly mentioned as one of the biggest challenges for TB control in India among almost all the interviewees of this study (for example, interview, TB consultant, WHO – I,4 Delhi, 14 January 2009). The Indian TB community, notably the Central TB Division and its programme officers, have accepted ownership of the problem of MDR-TB. They agreed with actors who had been advocating for a response to the threat of drug-resistance that MDR-TB needs to be treated within the TB programme.

According to Gusfield (1981), a phenomenon needs to include a moral judgement of its character and a cognitive belief in its alterability in order to be perceived as a problem.5 Both can be observed in the shift in ownership of MDR-TB in India.

International and local voices made moral judgements about MDR-TB, namely that ignoring the problem any longer is unethical and unacceptable (Udwadia 2001; Farmer 2003). A profound change in policy discourse at the international policy level was decisive in the making of MDR-TB as a global public health problem. Within several years (from 1995 to 2002) it evolved from a position of non-treatment of MDR-TB in resource-poor settings (no data, no drugs, no policy) to a position where pilot programmes for MDR-TB treatment in resource-poor settings are on-going and new treatment programmes have been approved for funding by the Global Fund to fight AIDS, Tuberculosis and Malaria (GFATM) (Kim et al. 2003). By 2002, media attention increased and vocal international actors emphasized that not treating MDR-TB patients was immoral. Every TB patient should have a right to treatment (Farmer 2003; Kim et al. 2003); untreated MDR-TB patients who are left to die are likely to infect others; and lastly, not treating MDR-TB will lead to higher costs than treating it—you either pay now or later (Farmer 2003; Kim et al. 2003).

Actors in India were also voicing moral arguments. A public health consultant argued that MDR-TB cannot be wished away because it is potentially disturbing existing control efforts of the TB programme (interview, Pune, 16 December 2008). A private physician published data on MDR-TB patients and argued that a large and ever-expanding MDR-TB population exists in India that was given the status of untreatable, undesirable (in the sense of being wished away in order to not have to deal with it) and untouchable (Udwadia 2001). Such critical voices also emphasized that the emergence of MDR-TB is politically sensitive, since MDR-TB should not increase when a DOTS strategy is working successfully (China Tuberculosis Control Collaboration 1996). Accepting MDR-TB as a problem would imply the acknowledgment that the TB programme is not as successful as claimed by programme officers (interviews: chest physician, Delhi, 21 February 2008; director, research centre, Hyderabad, 10 March 2008).

The cognitive belief about the alterability of MDR-TB was formed with new actors and funds in reach and through a feeling of accomplishment by the TB programme. International advocacy, global media attention to MDR-TB and XDR-TB (Stop TB Partnership 2005) and changes in global TB strategies (WHO and the Stop TB Partnership 2006) led to new funding opportunities from international donors and new actors pushing for action [mainly the Global Fund to fight AIDS, Tuberculosis and Malaria (GFATM), the Bill and Melinda Gates Foundation and the Foundation for Innovative New Diagnostics (FINDI)]. Development of new diagnostics and the availability of international funds for second-line drugs (provided through the Green Light Committee6) helped to pave the way for a response to MDR-TB. The director of the TB programme, the Central TB officer, made clear that the TB programme needs external funds to take MDR-TB treatment forward and to avoid budget cuts in existing TB control efforts (interview, Delhi, 15 January 2009). According to an NGO programme manager with government experience, international pressure is in general not enough to convince the Central TB Division (interview, –3, Hyderabad, 27 November 2008). What further strengthened the belief about the alterability of MDR-TB was the feeling of accomplishment that arose from the TB programme expanding to cover the entire country in 2006. This allowed more focused attention to emerging issues such as MDR-TB (interview, consultant, WHO India, Delhi, 22 February 2008).

Although the shift in ownership led to new policy and guidelines (CTD 2007a; CTD 2010) and the widely accepted acknowledgement that MDR-TB was a problem for India, actors have different theories about the problem and envision its solutions differently.

Debating causal theories: normalizing magnitude and externalizing reasons

Causal theories concerning a public problem (Gusfield 1981) indicate who is responsible and what solutions should look like.

Normalizing the magnitude of MDR-TB

Defining the magnitude is an important aspect of the causal theories on MDR-TB. The prevalence and the potential impact of MDR-TB on TB control in India are uncertain and debated (CTD 2007b) (interviews: chest physician, Delhi, 21 February 2008; public health consultant, national NGO, Hyderabad, 16 February 2008). Data on the epidemic situation of TB in India are generally weak (interview, senior researcher, research centre, Chennai 13 March 2008) (Udwadia 2001). This situation is related to differences in health system capacities across the country for diagnosing, collecting and reporting data, and a lack of data for the large, unregulated and diversified private sector.

As a consequence, figures reported on MDR-TB in India vary. Official data from government sources based on Drug Resistance Surveillance surveys in Gujarat and Chennai7 show 1–3% MDR among new sputum-positive cases (patients whose sputum contains TB bacilli) and 13–17% MDR among previously treated8 cases (CTD 2007b; CTD 2008). The figures of 3% native MDR-TB and 17% among the previously treated TB cases are readily cited by all the government officials and programme officers interviewed and are being reported to the WHO (WHO 2009). The opinion among programme officials is that no more resources should be spent on further Drug Resistance Surveys in additional areas in India, since the surveys and former studies reveal similar incidence rates (CTD 2008; CTD 2010) (interviews: TB consultant, WHO India, Delhi, 22 February 2008).
Conducting MDR-TB as a Public Problem in India

Doubts remain as to whether the two study areas for MDR-TB in Gujarat and Chennai are representative of the whole country. There is a feeling that the additional drug resistance survey was mainly conducted to silence critics of the data from Chennai. According to an NGO consultant, proper mapping of the MDR-TB problem in India is not missing because it would be impossible to do, but because the Central TB Division fears that it might reveal much higher rates of MDR-TB (interview, NGO consultant, Pune, 16 December 2008). Another microbiologist argued that the Central TB Division does not like data on high MDR-TB rates: “They make you feel as if you are a traitor if you present your results!” (interview, microbiologist, Mumbai, 19 December 2008).

Critics of the government’s theory about the magnitude of MDR-TB thus try to frame the magnitude as uncertain, non-average and potentially very high. Their theory represents not just public health data but also individual suffering. They argue that defining magnitude is a matter of politics, whereby potentially uncontrollable high numbers of MDR-TB are hidden.

Shaping evidence through data becomes an important control tool in defining causal theories. In the calls for evidence-based medicine the inherent politics involved in the making of evidence are rarely mentioned (Rodwin 2001). Rather, evidence-based medicine has been introduced as a tool to “...introduce rationality into the innovation process and improve the quality of innovations being adopted in healthcare settings” (Lemieux-Charles et al. 2002). The construction of evidence of MDR-TB’s magnitude shows that these are not only inherently political but also strategic processes.

Externalizing the reasons for MDR-TB

Another important aspect in defining the causal theories about MDR-TB is attributing the causes of the problem. It is generally acknowledged that MDR-TB is increasing due to mismanagement and repeated mistreatment of TB cases (Raviglione et al. 2001; Paramasivan and Venkataraman 2004; Sharma and Mohan 2004; WHO 2008a). However, actors define the factors responsible for poor treatment in the Indian context differently and tend to blame each other.

In the eyes of programme officers, MDR-TB is created by others: by the former National TB Programme (NTP), where the lack of regulation and mistreatment was common (diagnosis was based on X-rays and treatment was not supervised); by the private practitioners who are unregulated, diverse, often unqualified and tend to provide inadequate or non-standardized treatment; and by non-adhering patients who shop around, seek advice from many different health care providers, stop and restart often non-standardized treatment regimens according to what they can afford and depending on how severe their symptoms are (interview, physician RNTCP, 2, Ahmedabad, 2 December 2008).

2008; international NGO programme manager –1, Delhi, 17 January 2009; RNTCP consultant –1, 15 January 2009). According to the Central TB Division, other data available on MDR-TB from private, tertiary care centres, which report higher numbers of MDR-TB, are not representative of the general population because these are often well-known referral centres for failure cases and therefore biased (CTD 2009b). Rather, 3% native MDR-TB and 17% acquired MDR-TB have stabilized into accepted facts among government officials and TB programme staff.

In defining the problem of MDR-TB with the figure of 3%, it is framed as manageable in relation to other countries and it is seen as normal, being on a level with the global average. In this way, the sense of threat and disaster is lost. International and national statistics and policy documents, guidelines and statements, news and conferences are used to convey the message. TB programme officers at the state and district level and WHO consultants include these figures in their PowerPoint presentations throughout the country. This is part of their practice in defining the public problem of MDR-TB. It furthermore represents a public health understanding of TB control which Harper (2005) calls ‘statisticos-tuberculosis’ and which concentrates on global and national prevalence rates and aims to decrease those by targeting infectious patients.

Critics of the Central TB Division’s position deconstruct the belief in the figure of 3% native MDR-TB as overly confident and argue that defining the magnitude of MDR-TB is rather a matter of politics. Several actors I spoke to argue that the TB programme ignores figures that deviate from the 3% figure (interview, microbiologist, medical college, Delhi, 21 January 2009). Other studies from within the country show prevalence rates of native MDR-TB ranging from 0.9% to 36.6% and acquired resistance rates varying from 6.3 to 56.6% (Udwadia 2001). In 1996, the private, not-for-profit Hinduja Hospital in South Mumbai published data on its TB patients, of which 32% had MDR-TB and 8% were XDR-TB cases. This created quite a debate among public health experts in India (Udwadia et al. 1996; Udwadia 2001). The mycobacterial laboratory serves as a reference laboratory for Mumbai and reported in 2001 that around 60% of all isolates it receives are MDR-TB (Udwadia 2001). In 2007, these numbers rose again (interview, microbiologist, Mumbai, 17 December 2008). Interviewees at Hinduja argued that, despite their status as a referral centre, their increasing numbers of MDR-TB and XDR-TB patients are very high for a particular urban area and cannot be ignored as exceptional anymore (interviews: Mumbai, 17 December 2008). These actors had been lobbying for a response to MDR-TB for several years with the help of research studies published in national and international academic journals, newspaper articles and at conferences.

According to several actors interviewed, the government is not facing up to the real size of the problem. According to a private practitioner who interacts with patients and is concerned with the disease in the individual body, MDR-TB is the most pathetic situation, since there is insufficient provision for MDR-TB patients within the TB programme. He suspected the government’s data to be overly optimistic. He argued that unless the shortage in laboratories able to reliably diagnose MDR-TB is corrected, India will not be able to adequately estimate its MDR-TB problem. “Those are government data, the data you’d like to believe” (interview, –1, Mumbai, 17 December 2008). A microbiologist in a medical college argued that 3% native MDR-TB is providing a false sense of security, since it depicts the threat of MDR-TB for India as not too bad: “You just have the feel good factor, because 3% is not bad” (interview, Delhi, 21 January 2009).
This causal theory attributes causes for MDR-TB to exterior system failures (‘the previous TB programme’ or ‘the private sector’ or ‘the patients’). A study on TB in the UK shows that through the construction of risk groups or ideal deviant others in public health discourses, the risk of TB is attached to certain social categories and is thereby rendered manageable (Craig 2007). From the perspective of the Central TB Division, the ideal ‘deviant others’ are ‘the patient’, ‘the private sector’ or ‘the former national TB programme’. However, these factors are not entirely under the control of the TB programme. Rather, according to critics of this position, the ideal deviant other is used to protect the image of the TB programme and the potential shortcomings of control efforts.

Actors outside the TB programme are attributing causes of MDR-TB not only to patients or private practitioners. They propose alternative causes of MDR-TB, such as a microbiological problem, a problem of the DOTS strategy, the TB programme (poor quality of DOTS implementation) or a problem of the biomedical perspective (neglecting socio-cultural factors).

A microbiologist argued that certain mutations in drug resistant genes can promote the acquisition of additional resistance (Jerrold 2009). This biological phenomenon, called drug pressure, can cause drug resistance also during properly taken treatment courses. Furthermore, with each infection, the TB bacterium grows stronger (Basu and Galvani 2008). According to the microbiologist, the conventional wisdom that the drug resistant germ is weaker than the non-resistant one is not true: “With every infection the germ grows stronger (…) The germ goes through a training ground, particularly if it is trained in countries with high stress, malnutrition, etc.” (interview, microbiologist, Mumbai, 19 December 2008). According to the microbiologist, the government has failed to recognize these new paradigms in biological medicine. Instead, research in health and biomedical sciences is not considered valuable enough.

Other actors argued that the TB programme itself, particularly the DOTS strategy, is breeding drug resistance due to the continuing neglect of socio-cultural factors, the authoritative nature of direct supervision (Ogden 1999; Porter and Ogden 1999) and the lack of cooperation with the private sector (interview, chest physician, Delhi, 21 February 2008). The poorly treated failure cases within the TB programme are a further concern for MDR-TB emergence (Gupta et al. 2001; Udwadia 2008). Since only one drug is added to the drug regimen of patients who failed previous treatment, many of the practitioners interviewed are convinced that this is amplifying drug resistance.11 “You already ask for MDR to occur!” as one physician put it (Delhi, 21 February 2008). Furthermore, the uncritical application of standard DOTS drug regimens in areas where levels of MDR-TB are not known will amplify drug resistance further (Farmer 2003). These actors acknowledged the high expectations and pressure put on the TB programme to make DOTS work and that it is difficult to admit that certain aspects of the control strategy might be breeding drug resistance. A physician argued “…you are very committed to a programme and there is lot of pressure to show that it works” (Delhi, 21 February 2008). This might also explain the strong focus put on treating as many routine patients as possible.

In my discussions with actors in the private medical sector on the causes of MDR-TB, underlying tensions surfaced between different levels of specialization and qualification, such as TB and chest physicians, different systems of medicine, non-qualified practitioners and local healers. In general, less-qualified practitioners see more TB patients since they tend to be closer to the communities where TB patients live and also have more affordable rates. However, less-qualified practitioners are often accused by highly specialized practitioners of providing inadequate treatment to patients—which indeed continues to be widespread as studies on different TB treatment practices among private practitioners in a Mumbai slum show (Uplekar and Rangan 1993; Udwadia et al. 2010). Furthermore, they are unable to voice their own causal theories of MDR-TB because they lack capacity, access and resources to collect data and evidence. These tensions hinder a co-ordinated alternative causal theory in response to the Central TB Division’s theory of externalizing causes.

**Envisioning political responsibility: solutions for MDR-TB**

Causal theories and ownership of MDR-TB for TB control are decisive in defining what solutions should look like and who should be responsible for it (political responsibility).

If the government figures are correct, India is dealing with a huge amount of MDR-TB patients in absolute numbers—more than 100,000 per year, who can potentially transmit the resistant strains. The absolute numbers of MDR-TB patients worried the Central TB Officer as they were only beginning to set up treatment sites (interview, TB consultant, WHO –1, Delhi, 14 January 2009). In line with the strategy of externalizing causes, the programme officers at the Central TB Division tended to emphasize existing challenges in the health system, such as the scaling up of laboratories, funds, the complexity of clinical care or the lack of infrastructure, which challenge the TB programme in its first treatment sites for MDR-TB patients (interviews: TB consultant, WHO –1, Delhi, 14 January 2009; Central TB officer, Delhi, 15 January 2009). The Central TB officer argued that MDR-TB cannot be prevented entirely, but can be at least reduced by implementing quality DOTS, reducing the number of failure cases and making sure the private sector is following a standardized treatment regimen (interview, Central TB officer, Delhi, 15 January 2009). He was convinced that MDR-TB does not increase once DOTS is implemented (Delhi, 15 January 2009).

The causal theory is that MDR-TB is being created by factors other than DOTS. The solution is to provide DOTS Plus to treat MDR-TB (which is hampered by external factors such as the health system) and quality DOTS to prevent MDR-TB. The political responsibility for preventing MDR-TB is therefore shifted to TB programme staff, to health workers and to patients. The biomedical and de-contextualized view on TB, which has been criticized in relation to the DOTS strategy (Ogden 1999; Porter and Ogden 1999), is thereby continued. The TB programme applies established ways of attributing political responsibility. These solutions include only part of the causes voiced by other actors.

Actors outside the government challenged this perspective and called for clear political responsibility for MDR-TB by the TB programme (interview, microbiologist, private lab, Mumbai, 17 December 2008). These actors argued that MDR-TB is a
social, as much as a biomedical, problem and thus different solutions are needed which address root causes. These could be: test and treat everyone for MDR-TB no matter what it costs; tailor treatments to different patient groups; and allow for going beyond DOTS in order to understand the causes and be able to respond adequately (interview, NGO consultant, Pune, 16 December 2008). Several actors outside the government emphasized that, to control MDR-TB, more is needed than DOTS, which can only serve as a foundation (Sharma and Liu 2006). Additional aspects include the development of new drugs, diagnostics and vaccines (Sharma and Liu 2006), increased government and donor funding, integration of TB and HIV programmes, legislation of drug prescription, identification of ways to involve private practitioners and the testing of non-DOTS options (Udwadia 2001). These aspects are also encouraged by the Stop TB partnership of the WHO in order to strengthen health system aspects of TB (Stop TB Partnership 2010). The partnership has called for ways to make the routine TB treatment more acceptable to patients (WHO 2002). It is increasingly understood that the core of routine TB treatment, direct observation, alone is not sufficient to control TB (Raviglione and Uplekar 2006).

Discussion: mismatches between causal theories and control practices

This analysis reveals that the public problem of MDR-TB as propagated by the TB programme is in the process of being stabilized by defining it as normal, by attributing causes of MDR-TB to factors external to the TB programme and by applying established ways of attributing political responsibility. The TB programme thereby exerts medical social control on the aggregate level of a public health programme, rather than on the level of individual, private practitioners as the literature on medicalization would suggest.

Some actors challenge these stabilization processes and argue against particular causal theories and political responsibility. However, these alternative causal theories fail to be heard or to become dominant causal theories. This is partially because they do not match the dominant causal theory of the owners who are more powerful in defining the problem. Alternative causal theories are focused on the individual dimensions of suffering and costs of MDR-TB and absolute numbers of MDR-TB patients, which are uncertain and potentially uncontrollable. This focus clashes with the public health focus of the TB programme on aggregate numbers.

Furthermore, the various alternative causal theories are not able to influence dominant causal theories, because the practices of actors are too fragmented, unco-ordinated and hampered by underlying tensions. Experts of different kinds, such as bureaucrats, academics, journalists, NGOs and lobbyists, need to organize and dramatize public problems for individuals (Gusfield 1981; Bijsterveld 2008). Among the many voices raised around MDR-TB in India, the voices of patients, field-level workers and less qualified practitioners are suspiciously absent. The experts that are able to voice concerns and causal theories about MDR-TB are only a few, vocal, often highly specialized, private practitioners and a handful of research centres with access to decision-makers, the international research community and the necessary resources to undertake research. They are often unco-ordinated and work in isolation from each other. Underlying tensions between professionals inhibit closer co-operation in dramatizing MDR-TB as potentially uncontrollable and as caused by other factors besides patients and malpractice in the private sector. The practices in defining those alternative theories are not co-ordinated towards one clear alternative. They do not match with the task at hand: gaining access to the policy agenda and partaking in the definition of the public problem of MDR-TB. There is thus a mismatch between different causal theories and between different practices influencing them.

Conclusion

This paper highlights that meanings and definitions of public problems are flexible, are negotiated among actor groups and shift over time. The discussions around the magnitude and causes of MDR-TB show that, despite a policy shift towards a response to MDR-TB, the Indian TB community has not reached agreement on the causal theories about MDR-TB. The politics of evidence and medical social control feature in the struggles over defining the problem of MDR-TB. Alternative causal theories of actors fail to be heard because of mismatches of problem definitions to dominant causal theories, and unco-ordinated practices in defining alternative causal theories. The ability to match causal theories and co-ordinate control practices, to generate representative data, mobilize international influence and political relationships, and co-ordinate alternative causal theories define what is controllable.

In conclusion, two main arguments are put forward. First, the making of MDR-TB as a public problem in India is a social and political process and is shaped by politics of evidence. Dominant actors can exert medical social control. As the owner of the problem, the Central TB Division can dominate the public definition of the problem of MDR-TB. It is clear that accepting ownership of a public problem does not imply also accepting political responsibility. Rather, ownership can be used to actively frame causal theories and direct political responsibility to other actors.

Second, the Central TB Division seems to be caught in dilemma-thinking that shifts in strategy may come at the expense of controlling the public problem. They are framing the problem as average and manageable. The requirement to provide representative data and the attempts to protect its image hinder an open, critical and transparent discussion among actors with different theories on the causes and magnitude. Actors propagating alternative theories argue for more openness and transparency in debating data and changing strategy. Such a discussion might result in re-defining the public problem of MDR-TB.

TB control is often viewed as a role model for strengthening the rigour of health care services in India. In particular, the strong reporting and recording focus of the TB programme has been a major achievement for the health system in general (for example, interview, international NGO programme manager –1, Delhi, 17 January 2009). These insights have therefore implications for the health sector in general and for the governance of emerging public health threats beyond India and TB control. In order to cope with changing challenges and opportunities, TB control in India needs the capacity to respond flexibly in terms of strategy,
but also in terms of innovating technological, organizational and service delivery aspects of its control efforts. In order to encourage innovation in the health sector in India, the government needs to support public debate and encourage experimentation (Peters et al. 2003). Similarly, Porter et al. (1999) argue for a more process-oriented approach to infectious disease policy—rather than the current biomedical approach—for which a process of consultation, research and learning is required. Yet, such approaches require openness by the government to actors’ different problem definitions without fearing the loss of control over public opinion or the public image.

The case of constructing the public problem of MDR-TB in India reveals that while the shift towards responding to MDR-TB has been welcomed by all actors engaged, there is a need for open and critical discussion on the magnitude and causes of MDR-TB in India. This became evident again in recent debates on 12 patients in Mumbai that were identified with, what the physicians called, totally-drug-resistant TB (TDR-TB) (Loewenberg 2012). The Indian Ministry of Health argues that this labelling is misleading and not endorsed by the WHO instead speaks about a specific form of extreme drug-resistant TB. This again is decried by part of the Indian medical community as an attempt to underplay the extent of the TB. This again is decried by part of the Indian medical community as an attempt to underplay the extent of the MDR-TB problem in India (Mudur 2012). An open and critical discussion is crucial to avoid unnecessary acts of blaming between the different actors involved and to ensure maximum support and engagement of all actors in devising a co-ordinated response to MDR-TB in India.

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Conflict of interest
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Endnotes
1 DOTS, directly observed treatment, short course, is the WHO’s strategy for routine TB treatment that is being applied worldwide in slightly varied national adaptations. The DOTS strategy consists of five elements: government commitment, case detection by sputum microscopy, standardized treatment regimens of 6 to 8 months with direct observation (DOT) for at least the initial 2 months, regular supply of anti-TB drugs, and a standardized recording and reporting system (WHO 2010b).

2 Medicalization is generally criticized as a process of de-contextualization of collective social problems, which are put under medical control and are thereby individualized (Wailzkin 1989; Conrad 1992). Medical social control needs a particular set of (medical) definitions realized, both in spirit and in practice (Conrad 1992). Medicalization originates in the class and origin of medical professionals, in the focus of attention in medical curricula on individual factors and the lack of attention to issues of medical social control. As a result, social factors seem to be beyond the influence of medical professionals. Medical practitioners end up responding to social problems in limited ways and thereby shift attention from societal issues on a more aggregate level to individual problems (Wailzkin 1989).

3 India expected 450 cases to be treated in 2008 and 1420 cases to be treated in 2009 (WHO 2009). These numbers show how inadequate the relation is between reported incidences of MDR-TB and the expected number of people put on treatment. In addition, these cases of MDR-TB are only the ones detected and reported in the public sector.

4 Interviews are numbered if more than one person with the same function was interviewed at the same location.

5 Public problems have moral and cognitive dimensions. The cognitive side consists of beliefs about facts and events that compromise the problem. The moral side allows the situation to be viewed as painful, immoral or unjust and makes alteration desirable (Gusfield 1981).

6 Established in 2000, the Green Light Committee (GLC) Initiative is the mechanism that enables access to affordable, high-quality second-line anti-TB drugs for MDR-TB treatment for countries treating MDR-TB in line with the WHO guidelines. Arrangements with the pharmaceutical industry have been made to provide concessional-priced second-line anti-TB drugs. As a result, prices have been reduced up to 99% compared with the prices in the open market (WHO 2010a).

7 The first Drug Resistance Surveillance (DRS) survey by the government took place in Gujarat and Maharashtra. The data from Maharashtra, however, could not be used because it reached the National TB Institute (NTI) in Bangalore—where samples were to be analyzed—contaminated and thus the whole study failed (Interview, international NGO programme manager –1, Delhi, 17 January 2009).

8 Patients who failed the first treatment course and started retreatment (Cat II). The proportion of MDR-TB is higher in patients who have previously received anti-TB treatment. Host genetic factors may contribute, but incomplete and inadequate treatment is the most important factor leading to the development of MDR-TB (Sharma and Mohan 2004).

9 MDR-TB among new sputum-positive TB patients ranges worldwide from 0% in two Western European countries to 22.3% in Baku, Azerbaijan (WHO 2008b).

10 The area in Chennai has been the research and pilot site of the Tuberculosis Research Centre in Chennai for a number of years and MDR-TB is likely to be lower there (Interview, microbiologist, medical college, Delhi, 21 January 2009).

11 Patients under category II (retreatment, failure/relapse cases) are treated with only one additional drug, in contrast to other countries where two to three additional new drugs are added, which is much more costly. In addition, these patients are not immediately tested for MDR-TB, but only if they fail the category II treatment. Many practitioners interviewed think that this category is breeding resistance and there is anecdotal evidence confirming these concerns. Furthermore, it violates one of the basic tenets of TB chemotherapy, namely that one should never add a single drug to a failing regimen. Besides the toxic side-effects and the frustration that come with an ineffective treatment, it amplifies resistance even further (Farmer 2001; Bhargava et al. 2011).

References


