The ethics of compulsory notification of tuberculosis

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The government of India recently passed a notification making the non-reporting of tuberculosis (T.B) cases by the clinical establishment, including private practitioners and pharmacists, a punishable offence. Under sections 269 and 270 of the Indian Penal Code, this may now be deemed either a – “Negligent act likely to spread infection of disease dangerous to life” or a “Malignant act likely to spread infection of disease dangerous to life.” This will be punishable with either a fine or a period of imprisonment of up to 6 months/2 years depending upon the section invoked.(1)

It is entirely reasonable for a government which takes the responsibility to ensure treatment of everyone with a disease to collect data from all care providers about the said disease in order to establish its true burden and plan policy. And this is even more so in the case of a communicable disease where prevention is closely intertwined with early diagnosis and treatment and there is, in addition, the dimension of drug resistance to be dealt with.(2)

And to be clear, despite the furor that this notification has caused, mandatory reporting of tuberculosis is not new.  It had already been made compulsory by a gazette notification back in 2012.(3)

However making such notification a punishable offence is cause for serious concern and pathognomonic of the lack of foresight and tokenism that ails Indian health policy-making today. The concerns with this move can be discussed under the following broad categories – violation of patient privacy, poor cost-benefit ratio in terms of actionable data obtained, unintended harmful consequences of mandatory reporting, possible widening of the private vs. Government divide and lastly distraction away from the more urgent issues with the tuberculosis program today.

The second principle of the Code of Ethics for Public Health states that community health should be achieved in a way that respects the rights of individuals in the community.(4) Without doubt, mandatory reporting infringes on the right of patients to confidentiality.(5) This is especially concerning in a society where there is a lot stigma surrounding a diagnosis of tuberculosis.(6) There is also the question of a balance of the fiduciary duty of the doctor to the patient versus that to the government. While there might be situations where the benefit caused by a setting aside of these principles is justified in terms of public benefit accrued, our article takes the position that this new policy is not one of them.

The public health goals that this notification seeks to achieve are unclear, which is unacceptable when one considers that (aside from ethical concerns) a significant amount of time, energy and money will be spent in pursuing of prosecutorial processes. If the goal is to have a more complete database on disease trends, it should be noted that for the purposes of planning a program, meta-data is of little use. Representative sample surveys provide high quality data with significantly less input required for data collection not to mention the fact that the confidentiality of patient data is maintained. If the purpose is to ensure that all patients receive care as per Standards of T.B care then the pathway from notification to this care is unclear. There appears to be no established pathway to provide feedback on the quality of their care both regarding diagnosis and treatment to the private providers of care. (1) Nor indeed is there any safety mechanism for intervention in case of a patient who is being provided grossly inappropriate care, for example, with an inadequate drug regimen.  Will the government intervene in such a situation? And if not - what are the ethics of collecting information that is not being acted on for the patient’s immediate benefit?

We envision the enforcement may go one of two ways- the first possibility is that it will be ignored by the clinical establishment, like its predecessor.(7)  And while this may not adversely affect the existing care of TB patients, laws that are not enforceable on account of their conceptual framework are counterproductive as they normalize a disregard for the law. If it is ever actually enforced (if only by means of a few high profile convictions) it may well cause harm to the status quo.  The private medical sector when faced with the option of “mandatory reporting” with its inevitable burden of red tape and privacy concerns  vs. the option of “no treatment and referral” may opt (as it often does ,for example, in medico-legal cases ) for “no treatment”.(8) Where does that leave about half of all TB patients who currently seek care in the private sector?(9) Lessons from other programs around the world that employ strictly enforced mandatory reporting like child abuse programs (where early interventions are far more critical) suggest that mandatory reporting is often a deterrent to patients accessing care.(10)

This coercion may further alienate a private sector that already has a fair amount of distrust of the RNTCP (Revised National Tuberculosis Control Program) and the quality of care provided therein.  Distrust that is not entirely misplaced when one considers that the RNTCP stuck to policies like alternate day drug treatment until recently when it was clear for long before that this is inappropriate and most private practitioners had switched over to daily treatment.(11)

But perhaps the biggest problem with this notification is that it turns away the conversation from the real and burning challenges that face the national tuberculosis program today.  Like - how do we standardize extra-pulmonary TB diagnosis in both public and private sector? How do we upscale our DST (Drug and sensitivity testing) so it is available to all newly diagnosed patients when this is clearly the need of the hour? While the upscale is awaited how do we screen for INH (Isoniazid) mono-resistance? How do we work on nutrition in the face of overwhelming evidence that this is critical in successful treatment?

Perhaps the only critical piece of data that needs analysis for policy planning is - why are 50 % of TB patients seeking care in the private sector? (9) For a program that provides (or claims to provide) not only completely free treatment but also transport and nutrition allowances as well as  financial incentives ; why does one need any sort of notification at all? Why is there no queue outside the door? While the concerns about the private sector in health being unethical, substandard and responsible for gross errors in TB diagnosis and treatment may be justified, it is chilling to realize that 2.2 million TB patients still prefer to seek this care ( and pay for it) rather than access public health services.(12)

TB care in India, more than that of any other disease makes evident the fallacy of a policy trend that increasingly outsources the most critical job of the state i.e. health care to the private sector.  Examples of this outsourcing trend include insurance packages that incentivize private inpatient care under RSBY or the recent disturbing privatization of the Chhattisgarh community health centers.(13)(14) In the absence of a robust general primary and secondary care systems, a health program (even a vertical one) cannot sustainably survive; especially one where early diagnosis and appropriate treatment is key.

It is time for all stakeholders in tuberculosis care to come together and take decisions that can have an actual impact on the state of affairs that exists.  With the spectre of drug resistant TB looming large over us, failure to do so even now would most certainly constitute a “negligent act likely to spread infection of disease dangerous to life”. Can the state be booked for being negligent and allowing spread of drug resistance and endangering other people?

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