Vulnerability and tuberculosis in Rio de Janeiro'

Vulnerabilidade e tuberculose no Rio de Janeiro

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Abstract

This paper aims at understanding social causality of Tuberculosis in Rio de Ianeiro. This is one of the Brazilian states with the highest incidence of this disease. We follow the story of Paulo, a patient who received care at the outpatient clinic for multi-drug resistant Tuberculosis, in Rio de Janeiro. To make sense of his story, we will look at it through the concept of vulnerability in life conditions. Along with Sabroza (2006), we argue that this vulnerability is a collective expression of the economic insertion of a growing segment of Rio's population in the current technical-scientific-informational capitalism (Santos, 2002). Limitations in the health services add directly to vulnerability in life conditions of patients making treatment a hard endeavour. We propose to think and act on Tuberculosis at the collective level of reality, through intersectoral actions. We aim at contributing to the current debates on the social determination of Tuberculosis, to inform actions that can significantly reduce the suffering associated to this and other similarly caused diseases.

Keywords: Tuberculosis; Multi-Drug Resistant Tuberculosis; Vulnerability; Collective Health; Social Causality.

Resumo

Este artigo pretende compreender a causalidade social da tuberculose no Rio de Janeiro. Este é um dos Estados brasileiros com maior incidência da doença. Seguimos a história de Paulo, um paciente que recebeu cuidados no ambulatório de referência para a tuberculose multirresistente. Para fazer sentido da sua história, pensaremos nela por meio do conceito de vulnerabilidade das condições de vida. Junto com Sabroza (2006), argumentamos que essa vulnerabilidade é a expressão coletiva da inserção econômica de um segmento populacional crescente no Rio de Janeiro no atual sistema capitalista técnico-científico-informacional (Santos, 2002). Os limites dos serviços de saúde agravam a vulnerabilidade das condições de vida, tornando o tratamento difícil. Propomos pensar e agir sobre a tuberculose no nível coletivo, através de ações intersetoriais. Pretendemos, assim, contribuir para os debates atuais sobre a determinação social da tuberculose, e informar ações que possam reduzir significativamente o sofrimento associado a esta e outras doenças com causas semelhantes.

Palavras-chave: Tuberculose; Tuberculose multir-resistente; Vulnerabilidade; Saúde coletiva; Causalidade social.

Introduction

World Health Organization (WHO) has only recently recognized the fundamental role of social causes in the incidence of Tuberculosis, recommending they should be addressed by specific policies. We will be looking here at the specific context of Rio de Janeiro, Brazilian state with the highest incidence of Tuberculosis, with approximately 800 deaths a year, and also with the highest number of multi-drug resistant Tuberculosis (MDR-TB) cases (Rio de Janeiro, 2011). We will depart from one patient's story as a way to keep in mind the complexity and wholeness of Tuberculosis as expressed in people's lives. We will reflect firstly on the vulnerability of life conditions that most Tuberculosis patients face, and its role in disease transmission, activation and development of resistance. We will, then, look at the ways this vulnerability is generated in Rio de Janeiro, namely through Santos's (2002) concept of technical-scientific-informational capitalism and Sabroza's (2006) interpretation of it as applied to Tuberculosis in this city. A closer look at data from fieldwork in health services has shown important limitations that add to vulnerability in patients' life conditions, in a combination that makes treatment a difficult endeavour.

We hope to present a theoretical framework able to understand the social causes of Tuberculosis in Rio de Janeiro, and to point at levelled actions capable of influencing them, whilst avoiding simplistic links between poverty and this disease.

Methodology

The results draw upon data collected during qualitative fieldwork, namely participant observation and interviews, conducted in several contexts of Rio de Janeiro where intervention on Tuberculosis occurs: the outpatient clinic dedicated to MDR-TB, health services dedicated to Tuberculosis, the social movement for Tuberculosis control, communitarian associations, governmental programs of Tuberculosis control and HIV-Aids control, the Global Fund Project for Tuberculosis, and research settings. Fieldwork was conducted between June and December 2009, and between May and August 2010.

Tuberculosis and vulnerability of life conditions in Rio de Janeiro

Paulo² left home when he was 12. While he was away from home he worked shoe shining, begged for money, and slept in the street. He was arrested and lived in several institutes of juvenile detention. School?! They call it juvenile protection... to be in prison?! When he came of age he went to the adults' prison. He left when he was 21. He vomited blood when he was in prison and someone said it could have been of the beating he suffered. But, after that, health services in prison diagnosed Tuberculosis and he did his first treatment there. He said he didn't do it correctly because he kept drinking and smoking drugs. Before the treatment was over, he was already worse. He left prison in 2008 and between March and June 2009 he did a re-treatment regimen (according to the former recommendations in Brazil3) but his condition was serious, and, in April 2009, he was admitted in hospital. Culture and the sensitivity test revealed bacterial resistance to several drugs and motivated the change to the multi-drug resistant drug regimen. After some time he had trouble in the hospital and had to leave.

In July 2009, I met him the day of his first appointment at the outpatient clinic for MDR-TB in Rio de Janeiro. The pulmonologist received him with the comment that he had an abandonment history. He knew the treatments he had done. She went through his exams, which showed he was HIV negative, and had syphilis. This got him angry with his former doctor for not having told him about it. He asked the pulmonologist what was that and how to cure it. She said it is a sexually transmitted disease, and it takes an injection during 3 weeks to cure it. He complained of headache and asked her for a medicine to alleviate it, which she prescribed. He told her he was not taking his medicines correctly due to family problems at home. Besides, it was difficult to go to the outpatient clinic because it was too far. That day his mother cried when she gave him

the money for transport. Several times he asked the pulmonologist, with a sad voice, if he was going to be cured. The sweetness of this question contrasted with his hardness when talking to the pulmonologist about the treatments he had done and would do, very decided to proceed with the treatment, and quickly solve the situation. She answered he would be cured if he did his treatment correctly, but it would take time because the lesion in his lung was big. He missed his August appointment but came back two days later explaining to me that he hadn't come due to family issues. I asked how he was feeling and he said the headache continued, despite the medicines. He came the next day to take blood samples at the hospital nearby, and took a food donation from the outpatient clinic. In September he missed the appointment, and came four days later. He told the social worker he had gone back to drug dealing, because, unfortunately, he had no alternative. He was worried because he needed to smoke cannabis to relax and sleep. He had asked the hospital doctor about it, and he had answered it wasn't good. In October, he did not come to the appointment. In the end of November, he came to the outpatient clinic and told the social worker he had been arrested. He had only been released the day before, thanks to payment by the drug traffic. During that period he had missed eight days of treatment. He was very thin, complaining of extreme tiredness, pain and constant stress. He asked the social worker if he was left with only one lung. She showed him the drawings made by the doctor in the former appointment. He said he didn't want to take medicines that have no effect. To make it happen, the social worker said, he would have to come to every appointment so the doctors could check how the treatment was going. By that time, he had left his mother's house, with whom he had a very difficult relationship. He told us that his mother beat him as a child and also beat his sisters and brothers. She had told him she wanted him to die. When he was working in drug traffic he helped at home. He ate there. His mother did his laundry.

² Paulo is not the real name of this patient; it is used to preserve his anonymity.

³ In 2010, Brazil adopted new guidelines for Tuberculosis care, and re-treatment regimens were no longer applied. According to the new guidelines, patients who do not turn smear negative in the second month of treatment should perform culture and a sensitivity test and, if positive, start a MDR-TB regimen (Brasil, 2010).

Now, when he got home his mother asked if he was not dead yet. When he was feeling bad at home, he would go to the favela4, to buy some things, go home and cook for everyone. He had a course on cooking. Paulo had a good relationship with his older brother but he lived faraway and had his own life. It was the same with his sister, but they did not meet much. They had also left their mother's house in hostility with her. Paulo used to eat at his grandparents, with whom he had a good relationship, but his mother had been telling them bad things about him. He felt he had no peace. He told the social worker he would like to be able to pay a rent and live in the favela. But he didn't know what could he work on, everything got him tired, and everything made him cough. She told him of the possibility of staying in a municipal lodging for some time, but he did not want it because the location was dangerous and there were rules he did not agree with.

In mid 2010, I didn't meet Paulo. The social worker told me he had arrived very thin, telling her that in his community people saw him pass by and said Death is gonna get you! People of his group told him to get treatment. He told the social worker he was a powerful person in his group but he was going down, he had no strength to do anything. His mother had moved out and had left no address. Paulo's sister had come to the outpatient clinic, worried, to talk to the social worker. She spoke of him with tenderness, she tried to help him but it was hard, and they had lost contact several times. After that visit, the social worker phoned his sister and she told her she had given up. Paulo then wanted to be admitted to the hospital for a year. He was admitted and kept reducing the time he compromised to be there. He stayed for a month in which he gained some weight. In June 2010, he missed his appointment and I had no more news of him. In 2011, when I contacted the outpatient clinic team, I heard he had died in the street.

Paulo's story is disturbing. It conveys deep personal and social suffering, and his efforts, his family's, and the health services', to overcome it. His story is very similar to many other patients'. They tell us the expression of Tuberculosis in people's lives. How

can these stories help us understand Tuberculosis in Rio de Ianeiro?

Castellanos (2004) has proposed us to look at life conditions to understand health and disease processes in the collective level. According to him, "Life conditions are the expression, in daily life space, of the social reproduction of individuals and populations. Health situation is one of the particular expressions of these social reproduction processes" (Castellanos, 2004,p. 198). At the collective level, life conditions operate in different dimensions, according to dominant reproduction processes, which he groups into four:

- 1. predominantly biological processes, especially genetic and immunological potential;
- 2. predominantly ecological processes, expressed in residential and work environments;
- 3. processes predominantly related to forms of consciousness and conduct, expressed in habits, conducts, perspectives, and individual and collective lifestyles;
- 4. predominantly economic processes of production, distribution and consumption of goods and services (Castellanos, 2004).

How do these processes unfold in Rio de Janeiro when it comes to Tuberculosis?

Based in life stories that patients shared during fieldwork, I have built, in Table 1, a tentative systematization of the most important processes in each reproductive dimension of life conditions, in Rio de Janeiro, regarding MDR-TB.

These dimensions are not separated; we can well see their interplay in Paulo's story. Tuberculosis expressed in his body for the first time while he was in prison, living under violent relationships, and in an environment very favourable to bacterial transmission. He smoked and drank alcohol during his first treatment in prison. Already outside prison, he entered a re-treatment regimen, and later he would learn that the bacteria had developed resistance to first line medicines so he entered a MDR regimen. We see here the role of the biological and environmental dimensions as well as of forms of conduct

⁴ Favela is the denomination for urban communities in the city of Rio de Janeiro, most of them characterized by extreme concentration of population and precarious life conditions.

Chart I - Dimensions of the reproductive processes of life conditions, regarding multi-drug resistant Tuberculosis in Rio de Ianeiro

Dimensions of reproductive processes of life conditions	Multi-drug resistant Tuberculosis in Rio de Janeiro
Biological	Illness
	Comorbidities
	Side-effects
	Sequels
	Bacterial resistance to drugs
Ecological	Absence of sanitation
	Precarious housing
	Excessive population density
	Precarious and mobility-demanding work
	Bacterial transmission
Forms of consciousness and conduct	Abusive use of psychoactive substances like alcohol, cannabis, crack and
	others
	Breaking of family and communitarian networks
	Violence
Economical	Precarious work with no right to social security
	Low income
	Low access to first need goods
	Low access to public health services

and consciousness, reinforcing each other in a way that led to bacterial transmission, active disease, and the development of resistant bacteria. At the same time, these dimensions worked in ways that made treatment more difficult.

During his MDR treatment, he was facing the interplay of all the dimensions, again contributing to the worsening of his health condition. He also had syphilis, continuous headache and his lungs were weakening very fast. He lived with his mother, with whom the relationship was very conflictive. His close relations with his brother, sister and grandparents weakened, and so he lost social support. He continued working in drug trafficking, and there he got some support to go to health services. Yet, that involvement meant he was continuously in a context of violent relations and personal burnout. As his health got worse, the possibilities of getting another kind of job, and his access to income and basic goods, decreased. He wasn't going to the health services regularly. Meanwhile he lost the support of his family, and also of the drug traffic. Health services did not manage to reinforce support to him besides admitting him to the hospital when he first entered the MDR regimen, and, a year after, when he arrived in a very serious health condition. But he could not stay for long, and it was not enough to cure Tuberculosis.

Through Castellanos' categorization we discerned the different dimensions of life conditions involved in Tuberculosis in Rio de Janeiro. Paulo's story allowed us to see their concrete interplay. We see persistent efforts of him, his family and colleagues, as well as of the health professionals, to proceed with treatment and take care of his health. Yet we also see the extreme vulnerability characterizing his life conditions and the obstacles it raised.

Ayres et al. defined vulnerability in these terms:

It can be summarized as the movement of considering the chance of people's exposure to illness as the result of a set of aspects, not only individual, but also collective and contextual ones, which brings greater susceptibility to infection and illness, and greater or lesser availability of resources of all kinds to protect themselves from both (Ayres et al., 2003, p. 123).

The concept of vulnerability originated from dialogues between social movements of HIV-Aids and Human Rights, when the concepts of risk groups and risk behaviours proved insufficient to understand the continuous spread of the disease, and its increasing concentration among the poorest people (Ayres et al., 2003). Policies for HIV-Aids prevention, when going from risk groups to risk behaviours, no longer intended to establish barriers between infected and non-infected individuals. They sought changes in behaviours to reduce the probability of meeting the virus. But soon it became clear that the exposure to the virus, and the possibilities of changing behaviours, are not equal in the whole population. Researchers then proposed the concept of vulnerability. It can easily be confused with risk. However, vulnerability is especially based on synthesis, while risk is based on analysis. Risk analyses arrive at probabilistic relations between variables while studies on vulnerability are based in particular relations between the parts and the whole, and express illness potentialities of any person living in a particular set of conditions (Ayres et al., 2003).

This said, how is vulnerability generated in Rio de Janeiro? How does Tuberculosis reach people's bodies?

Sabroza (2006) argues that the high Tuberculosis incidence in Rio de Janeiro is connected to the insertion of urban social groups in the capitalist production process. Current capitalism is a technical-scientific-informational one (Santos, 2002), where:

The territorial de-concentration of population, and accelerated informational processes lead to job reduction, accompanying workers' qualification, associated to great development of media and new international division of work, directed by transnational corporations (Sabroza, 2006, p. 25).

In this context, states lost the central role they had in economical planning and infrastructure construction for transportation, energy and communications. One of the system's priorities is to increase productivity, and the resources transferred into it would, in other times, have been invested in consumption and population reproduction, while, now, they pass through the cribble of international finance. Another important priority of the system is the increase of urban consumption – despite unem-

ployment and cuts in social policies - while ensuring "the absence of revolt and sanitary crises, which can bring limits to economic restructuring" (Sabroza, 2006, p. 26). This new context created a spatial production circuit, a population segment which is dynamic, relatively autonomous, and requires a small expenditure to both capital and state, guaranteeing reproduction, increase of consumption, and resource transference to the main spatial circuit of economy. The "inferior urban circuit" denominates

a new poverty, very different from the rural poverty of conservative periods, and has been denominated radical poverty because people have school education and knowledge of their inequality situation. People in this situation do not see that it will change. And being urban and exposed to the contrast all the time by the media, they are angry (Sabroza, 2006, p. 26).

The inferior urban circuit is also characterized by a low incorporation of technical-scientific innovations, low income, and lack of social security. It is not a social class because it is composed by unemployed people, employed people and autonomous entrepreneurs (Sabroza, 2006).

According to Sabroza (2006), there are mainly three forms of insertion in productive processes in this period of capitalism: integration, vulnerability or exclusion. The first guarantees that people are part of the superior circuit of economy, they have a good life expectancy, health insurance and social security. Pressure for increase of productivity and stability in the job can increase their health problems, especially mediated by stress and inducing changes in lifestyle as a way of guaranteeing competitiveness. The second, vulnerability, is the insertion of people who are part of the inferior circuit of economy, which is dynamic and insecure. They are very vulnerable to socio-environmental risks. They are important as consumers, but the loss of their health does not compromise economy. When they fall ill, they run the serious risk of moving themselves, and their families, to the excluded group. They have high spatial mobility searching for better life conditions, and a high rate of social contact. They are subject to high burnout. The third, exclusion, describes the situation of the people outside the production process, they do not have a job or a predictable income. People in this situation are in serious danger of losing their citizenship condition (Sabroza, 2006).

Burnout is the mediator between these political/economical processes and the occurrence of Tuberculosis in peoples' bodies. It describes the incorporation of processes related to the inferior circuit of economy. Tuberculosis is one expression of burnout, and occurs disproportionately among people in vulnerable or excluded situations (Sabroza, 2001). Paulo's story reverberates here.

The intervention of health services in Rio de Janeiro

In Brazil the main political emphasis in MDR-TB care is on patients' adherence to treatment. However, the possibilities that services have to guarantee the success of treatment are still limited.

Despite of a growing and considerable political attention to Tuberculosis in the last decade, along with a restructuring of care in the health services, their coverage, especially primary care services, is very limited in Rio de Janeiro. Knowledge of the disease has also diminished due to its neglect in medical training. These two factors, added to the precarious socio-economical situation of many patients, determine a high number of wrong, and/or late diagnosis of Tuberculosis, as well as late detection of bacterial resistance, or even its creation by inadequate treatment. Since primary care services are not sufficient, a great percentage of Tuberculosis patients, 33%, get their diagnosis in hospitals (SBPT, 2008), where an appointment is guaranteed, but where transmission to other patients is favoured.

Treatment for MDR-TB is quite long and challenging both for patients and health professionals. Specialized services dedicated to MDR-TB face difficulties in dealing with the frequent comorbidities that patients suffer from, like hepatitis, diabetes, HIV-Aids, depression, and the considerable adverse side-effects of drugs such as nausea, joint pain, loss of audition and memory, neurological changes, and, importantly, pulmonary sequels. These conditions

force patients to a demanding pilgrimage through the public health services in the city, to obtain appointments, drugs and treatments, daily working for their health care. This is only mitigated by the presence of a public municipal hospital next to the outpatient clinic for MDR-TB, where patients can treat some comorbidities, and by the reference letters that the pulmonologists write to other services.

During fieldwork I could observe that in key moments of the treatment, services' actions were often inadequate or insufficient. This was the case at the moment when patients interrupt treatment.

Services use the term "abandonment" to refer to the interruption (temporary or definitive) of treatment by patients. It is a statistic category, one which social workers, community workers, some doctors, and some patients, question for attributing to the patient the whole responsibility for situations they consider to be more complex, and often also of services' responsibility. Farmer (1999) pointed out that frequently the patients' accused of abandoning treatment are the ones who have less conditions to keep it. Rocha and Adorno (2012) have argued for the use of the term "treatment discontinuity" because it opens up space to the perspective of the patient, and also avoids the judgement of the patient expressed in the term "abandonment". We also need to ask, after researchers Selig et al. (2012), who abandons who? These researchers have pointed to the boomerang effect of abandonment, calling our attention to successive relations and feelings of abandonment. Doctors feel abandoned by the patients who do not follow their instructions or refuse treatment, and also feel abandoned by the authorities who neglect the public health system. While health professionals say patients abandon treatment, patients also feel abandoned by the services, and often live abandonment situations in their social and/or family contexts (Selig et al., 2012).

In the outpatient clinic for MDR-TB, when a patient stops going to the appointments for more than 3 months (appointments are monthly for MDR-TB), health professionals tag him/her as an abandonment case⁵. Usually, during that time, services

⁵ According to the national guidelines, abandonment occurs when the patient does not attend the services for more than 30 days (Brasil, 2010). For the MDR-TB patients - whose appointments are monthly - the outpatient clinic for MDR-TB considered "abandonment" those situations where patients presented a successive absence to appointments for 3 months.

contact him/her and the family and try to know the motive of the absence and bring them back. However, there are no established procedures for these cases, and the outpatient clinic for MDR-TB team does not discuss them systematically. When we look at patients' stories, it becomes clear that the interruption of treatment occurs in very complex moments of their lives, when other issues take the front and somehow force the treatment to become secondary, or make it seem meaningless. As we have seen above, Paulo stopped taking his medicines when he had problems at home and for that reason did not go to the services; another time, he stopped taking his medicines when he was arrested. Other stories revealed that issues related to breakup of family and/ or social bonds, depression, disbelief in the success of treatment, as well as the feeling of already being cured, were among the motives for patients to want to, or to actually interrupt treatment. In Paulo's first MDR-TB appointment the pulmonologist told him he had "an abandonment history". Health professionals tend to quickly tag patients who interrupt treatment as "abandoners" turning a situation into an adjective, a general qualification of the person. This often occurred after professionals had already considered them as "difficult" patients, that is, the ones who do not follow doctor's prescriptions correctly. Thus, as much as they wish to avoid treatment interruption, they end up expecting it, or they feel, in advance, that their actions to bring the patient back are useless. In practice, services do not act precisely when patients most need them. There are several issues here. Patients and health professionals hardly base their relations on trust and knowledge exchange and so doctors do not know (and sometimes do not want to know) the deep implications of treatment in patients' lives, but often patients do not tell them (Rocha and Adorno, 2012). This occurs also because health professionals do not have the necessary means to deal with the "extra-clinical" situations that come up, be it for training and/or motivation limitations or because of the lack of a more interdisciplinary and intersectoral care provision. I heard several health professionals affirming they did not have the necessary skills and preparation to deal with complex situations. Health professionals can even neglect the importance of clinical issues like the extremely adverse side-effects of the treatment regimen, because of the distant relation to patients who do not reveal the extent to which they cause pain and interfere with their lives (Rocha and Adorno, 2012).

Another critical moment occurred when patients who had already been cured of MDR-TB came back to the services complaining of relapse. During fieldwork, I could record some cases that left doctors quite staggered, suspecting that patients were coming back to get some material support, because they thought it very unlikely that they had the disease again. Once more, situations falling out of the expected medical trajectory were revealing the complexity of the disease and its demands on the services. Tuberculosis, even when cured, can be a very incapacitating disease, for pulmonary sequels, according to their size, may compromise the vital function of breathing. Therefore, it is very common that patients have to radically change their professional and personal life in order to obtain income and maintain health. In many respects, MDR-TB - and sensitive Tuberculosis, when serious lesions are involved - can be considered a chronic disease. for it continues to be manifest for the rest of the patient's life. Thus, even when a patient comes back to the services and he/she does not have a positive exam for Tuberculosis bacteria, it is still that disease expressing itself in his/her life that motivates his/her return. Services are not ready for this, their eligibility definition leaves out patients who are in most need of their action.

The identification of specific conditions that make treatment and cure more difficult, or that services associate to an unsuccessful outcome, can easily turn into negative labelling processes which lead to negative expectations on the patients. This will stop professionals from knowing them as a person, and them, on their side, from fully sharing their experience of the disease and treatment. This happens with "labels" such as "drug users", "difficult" or "abandoners". Those conditions can easily become just one more feature noted in medical records, and an obstacle for the relationship between health professionals and patients, and for the treatment. It is important, therefore, to emphasise that we propose the concept of vulnerability as a collective feature,

mainly focusing on life conditions, which we think is the best way to see the mediations between levels of reality regarding tuberculosis. We intend to avoid using vulnerability as just another negative classification by the services upon individuals in precarious social-economic situations and/or whose conducts are not in conformity with social and moral patterns of the majority (Adorno, 2012). Conversely, we argue that we need to look at the stories of patients as integrated wholes, through sensitive theoretical frameworks, where both individual and collective issues become clear. This is essential to begin planning intervention on Tuberculosis as a biosocial phenomenon, that is, a specific embodiment of social relations.

Conclusions

The theoretical frameworks we have presented here offer an integrated multi-level portrait of Tuberculosis, in Rio de Janeiro. If we start to think on how to act, we may feel lost in complexity. However, we can take the effort further, and arrive at actions capable of addressing it. It is true we cannot change the world's socio-economic model in time to stop Tuberculosis now. But many other points of action are possible. Farmer (2010) has affirmed that the dilemma of having to choose between actions on the individual level and on the structural level is a false one. South American schools of public health propose the concept of collective health, underlining this level of organization of reality where action is wider, and earlier, than when we focus exclusively on the individual or the structural level:

Especially interesting for health surveillance are the problems defined in the dimension conceptualized as particular, because, at that level, problems emerge as characteristics of population groups, along with their social reproduction processes, configuring communities, or "particular social-spatial groups". [...] Actions and practices deriving from that particular approach allow us to work on more precocious moments of the determination process and, at the same time, to amplify the strategies of primary care with a set of social actions directed to those communities to promote life quality (Monken and Barcellos, 2005, p. 899).

Many patients' stories show that patients, health services, social services, and communitarian workers, can act on several dimensions of life conditions in order to reinforce their interplay towards cure. This is clearly an intersectoral framework, and our major challenge.

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