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SCHOLAR RESEARCH BRIEF:
“ALL MY PROBLEMS STARTED WITH TUBERCULOSIS:” AN
ETHNOGRAPHIC ANALYSIS OF TREATMENT FAILURE IN ROMANIA

Romania is the site of one of Europe and Central Asia’s worst tuberculosis (TB) epidemics. Cure rates for sensitive as well as M/XDR-TB (Multidrug and Extensively Drug-Resistant TB) are poor. TB is a social disease that is influenced by one’s overall quality of life. While patients of all economic classes are becoming infected, those without social and economic support face great difficulty getting cured. Patients in the second (outpatient) phase of treatment frequently abandon treatment and there is no system of casework and follow-up to help them complete treatment. This especially affects poor and working-class patients who must return to work. Romanian TB control is poorly funded and the problem lacks public awareness. Medication shortages are frequent and patients with TB face the stigma of having a disease still considered incurable and shameful (*ruşinos*) by many. This report is based on over two years of ethnographic research in Romania including surveys, interviews and visits to multiple hospitals, sanatoria and clinics.

RESEARCH IN CONTEXT

Romania is the site of one of Europe's worst tuberculosis (TB) epidemics. In 2003, the incidence rate peaked at 146 cases per 100,000 people, the second-highest rate in all of Europe and Central Asia (WHO 2009). The rate has declined since then, but remains by far the highest in the European Union with a 2011 rate of 90.5 per 100,000, more than five times the European Union average and twenty times the U.S. rate (WHO 2011). Despite recent drops in incidence rate, **TB is not under control in Romania.** The cure rate for new cases is only 81.4% falling below the World Health Organization's (WHO) minimum threshold of 85%. **The cure rate for patients with MDR-TB (Multidrug-Resistant TB) is less than 50% and for XDR-TB (Extensively Drug-Resistant TB) only 23%** (WHO 2011).¹ These rates are far below the WHO 2015 target of 75% for M/XDR-TB.

TB is an airborne, bacterial disease that usually affects the lungs. It is generally caught indoors as sunlight and good ventilation deter its spread. There is no effective vaccine, but it is curable in most cases using a powerful combination of antibiotics. Treatment lasts six months for sensitive TB and two years for M/XDR-TB. There are about 20,000 cases of TB in Romania every year and over 5,000 of these are retreatments—patients who were unsuccessfully treated previously or who have relapsed. The low treatment success rates and high retreatment rates in Romania are major problems as they may lead to increased rates of M/XDR-TB.

TB exacerbates and is exacerbated by poverty. It takes people out of the workforce and puts them into a state of poverty. As they become sicker, they become more contagious and infect others with this deadly disease. Having a family member with TB in a household can mean losing the only breadwinner, a situation which pulls the entire family into poverty. Many patients lose their jobs, spouses, even homes. My 2006-11 research in Romania, examines the lives of TB patients and medical staff.

“All my problems started with tuberculosis. I can say that tuberculosis destroyed my family, since my father became ill ... He was sick in the hospital a lot, my mom was by herself with no money ... My family struggled, got in a lot of debt, which in a few years led to their not having a home ... They were left on the street because of tuberculosis.”

Mariana, 30 year-old XDR-TB patient

I focus on the conditions that prevent patients from completing treatment.

The Romanian TB epidemic exists within the broken, underfunded and inefficient health care and social welfare systems. Health outcomes are among the worst in the entire region. This is true of TB, but also of infant and maternal mortality, cervical and uterine cancer and male life expectancy. The system faces challenges including lack of investment, crumbling infrastructure, lack of quality management, efficiency issues, rising drug costs, corruption, and an aging population whose long term care needs are not being met. These are not simply issues of poor management or residual socialist mindsets but systemic problems (Weber 2008, Vlădescu et al 2008, Popa 2010, Mihăescu-Piñtia 2011, Pop 2011, Stillo 2011).

TB is widely recognized as a social disease, meaning that social and economic conditions such as quality of life and social support greatly influence one's chances of both becoming ill and being cured. TB does not stop at the patient; it is passed on to their family, including children who live in the house. The disease is particularly stigmatized in Romania and patients are often ostracized for having a disease still viewed as “shameful” (*rușinos*) (Stillo 2012). This makes people less likely to seek treatment and to support those who are infected. A holistic approach combining medical interventions, social supports and public education is necessary to ensure patients, especially poor and working class ones, are cured and do not relapse.

RESEARCH PROCESS AND RESULTS

My Individual Advanced Research Opportunities (IARO) grant funded the final three months of a two-year study of TB in Romania. During this time, I conducted ethnographic investigation at hospitals and clinics, as well as extensive research at one large TB sanatorium where I lived for part of the research period. I surveyed 230 patients and 100 non patients, conducted 150 semi-structured interviews with patients, NGO representatives and medical staff. I accompanied doctors and nurses on rounds, and also utilized archival sources.

The long term nature of this research allows me to report on the trajectories of patients' lives rather than simply provide a snapshot specific to one period of time as other methodologies would do. The most valuable data I gathered came from relationships I developed with patients over a period of years. I spent hours interviewing them, visited them in their homes, celebrated with them when they were getting better and, more often than not, watched them deteriorate, sometimes holding their hands as they died.

Inefficiency in the Romanian health system is often blamed for its problems. However, this is only part of the problem. Romania has one of the lowest health expenditures as a percentage of Gross Domestic in the world. The rate has hovered between 3 and 4% since the 1989 revolution, falling far short of virtually every country in the region and well below the global average of 6.1% (WHO 2010:138). In the case of TB, there is a documented gap of funding that has led to shortages in medication, a failure to adopt modern, rapid diagnostic methods (especially DNA based tests which can provide results in hours rather than months), and an absence of patient support programs that are common even in much poorer countries. Romanian public spending on TB was only six million US dollars in 2010 for more than 20,000 patients. This is less than half of what Bulgaria spent on its 2,649 patients, and less than a

third of what much smaller and poorer Moldova invested in 5,434 patients. It is estimated that a budget of at least \$22 million per year is necessary for Romania to reach the WHO M/XDR-TB goals by 2015 (Romanian National TB Control Program 2012).

My research reveals that in Romania, medical institutions such as hospitals and sanatoria are filling a social welfare role. A lack of adequate social welfare services has made these institutions one of the last sources of care for those without economic and social support. Doctors admit to extending the stays of patients who they feel do not have the means to care for themselves. These "social cases" are present in most Romanian medical institutions. Jack Friedman documents a similar situation in Romanian psychiatric hospitals (2009), and the 2008 Presidential Commission on Report also acknowledges this issue (Vladescu et al 2008). **The weakness in the social welfare sector is actually driving people to seek shelter in the medical system** (Stillo 2011). Many of these patients are elderly and would be better served in nursing homes, but are unable to gain admission due to a severe shortage of public beds, long waiting lists and the expectation of bribes. This lack of support predisposes people to TB infection and also increases the chances of relapse in the future as poverty, stress and difficult living conditions weaken the immune

Romania spends far less on TB control than its neighbors (both absolute and per capita)

Country	Number of new TB cases diagnosed in 2010	Number of re-treated TB patients diagnosed in 2010	National TB Control Program budget from public funds in 2010 (US Dollars)
Romania	15,963	5,115	\$6,000,000
Bulgaria	2,301	348	\$12,600,000
Moldova	3,745	1,689	\$18,460,000
Ukraine	31,295	5,114	\$148,800,000

system, thus increasing one's susceptibility to TB.

It is well known that TB is a disease of poverty, but in Romania, the disease is now affecting every social class. Members of the middle and upper classes come into contact with TB sufferers in a variety of settings including public transportation, markets and offices. I surveyed and interviewed numerous members of the middle and working class as well as lawyers, office workers, and **even a Romanian Olympic athlete** who were suffering from TB. Interestingly, the vast majority of middle and upper class patients told me that **they had never met anyone with TB before; the source of their illness was a mystery.** In countries like the U.S., U.K., and Germany TB is limited to "risk groups" such as the homeless, incarcerated or recent immigrants. In Romania, the TB rate is high enough for people of all backgrounds to unwittingly be exposed to this disease in the course of everyday life. This has been a problem for U.S. volunteers, international business people and students who have been infected with TB in Romania.

There are several factors responsible for Romania's high TB rates and poor treatment success rates. General poverty and systemic weakness in the health sector lead to TB and complicate its treatment. These are daunting problems. My research supports the consensus of Romanian TB experts who point to **a lack of casework and follow-up as the most important factors responsible for treatment failures.** After the inpatient treatment phase, no one is responsible for ensuring that the patient continues with outpatient treatment. When patients stop coming for treatment there are no protocols to locate them and compel them to continue taking their pills. This would require additional staff, monitoring of patient treatment completion (which is recorded by hand on paper charts rather than in electronic databases.) Presently, there are no regulations compelling patients to continue treatment and most districts lack the personnel and resources (for example a

vehicle and fuel to make home visits to non-adherent patients) to ensure outpatient treatment. Thus, when patients stop coming, it is rare that someone tries to convince them to continue their treatment.

My patient survey and interview data suggest that while people of all social classes get infected with TB in Romania, poorer people face far greater difficulties, especially during the outpatient phase of treatment when they must travel to a doctor or clinic three times a week to take their pills under supervision. During this time they are instructed to eat lots of healthy food, to rest and not to return to work. However, once discharged from the hospital, they are another mouth their family must feed. This places a great strain on the family's finances, especially if the primary breadwinner is the TB patient. Iulian, a 40-year-old MDR-TB patient from a village, told me, **"Here in Romania, if you don't work, you starve to death. There are two options: you take the TB pills and get better but starve, or you work and have to come back to the sanatorium. So it's a lose-lose situation."** He is not exaggerating. When I first met Iulian he was rugged and strong. He successfully completed his inpatient treatment but when he returned home to his wife and children he was forced to choose between going back to work (doing off the books construction and agricultural work) or watch his

"We are losers in society. And when you see yourself, the way you are now, and you know what you used to be, when you mattered, and worked... it's hard for you. This is why we say we are embarrassed, because you don't matter anymore, to anybody."

Mircea, A 50 year-old former coal-miner, now a "social case" dying of XDR-TB.
Dâmbovița

family starve. Six months later, he returned to the sanatorium a shadow of his former self and having developed additional antibiotic resistance. Now his TB is almost XDR. Iulian's story is a common one. Worse still, every time he returns home and relapses, he becomes contagious again and places his wife and six-year-old daughter at risk of contracting his drug resistant TB.

Iulian's case demonstrates why TB prevention and treatment are considered among the most economically efficient health interventions (World Bank 1993, 2009, Sachs 2001). His illness means his family lives in poverty, they can no longer contribute to the economy, or consume. For Iulian, getting cured means returning to work and being able to provide for his family.

DOTS (directly observed treatment short-course), the global standard TB treatment, requires that patients take their medication under supervision. **In Romania, DOTS coverage varies widely. Many general practitioners have refused to supervise TB treatment when financial incentives were recently removed.** The TB program lacks the resources (vehicles and staff) to have trained DOTS supporters supervise treatment in the homes of patients in much of the country. Without the cooperation of local physicians, many TB patients are not being supervised. This will likely increase default rates and may lead to more drug resistance.

Another one of the cornerstones of DOTS, is an uninterrupted supply of TB medications. Romania has yet to achieve this as shortages of critical drugs are rampant, especially for the more expensive second line drugs used to fight M/XDR-TB. **When treatment is disrupted due to drug unavailability, patients lose confidence in the system and worse still, develop additional antibiotic resistance.** Some of these shortages result from an ill-conceived plan which decentralized drug procurement in 2008. This increased costs and led to shortages of cancer, diabetes, TB and HIV drugs.² Romania had an inadequate supply of many TB drugs in 2011 including: capreomycin, PAS,

amikacin, kanamycin, moxyfloxacin, ofloxacin, ciprofloxacin, and protionamide.³ The complexities of drug shortages are of no interest to TB patients, they simply need to know that their medications are on hand so they can finish their treatment without interruption.

There is little interest in TB in Romania on the part of the public and in the government.

Few in Romania see TB as a serious problem, and the disease is stigmatized. Patients often keep their disease a secret and those who are cured rarely become advocates. People tend to see it as an issue that does not affect them. In fact, 75% of respondents in Bucharest, when asked whether it is possible for them to catch TB, responded "no" (n=100). Because of this, there is little political will to increase funding and to draw attention to the disease.

Frequently I am asked who is to blame for Romania's TB problem. The answer is a complicated one and beyond the scope of this brief. However, I can say that **Romanian hospitals are full of well-meaning doctors and nurses whose best efforts are limited by a lack of funding, shortage of medication, and lack of social support for patients who are discharged.** There are few NGOs focused on TB (only two weak patients' groups) and virtually no TB-related charity activity in the private sector or by the Romanian Orthodox Church. In short, this deadly disease is neglected in Romania. The public is not aware of its danger and patients have few resources to support themselves and their families during and after treatment.

Every day, M/XDR-TB patients often take a dozen pills.



CONTINUING RESEARCH

I will return to Romania in June of 2012 to conduct additional research on TB and thus further determine how to improve treatment for patients who are poor or without family support. I am also working on a survey of the general public to gain additional information on knowledge and perceptions about TB that will build upon the small survey I conducted in 2010. I will work with Romanian students on this project later this year.

There is virtually no social science research on TB in Romania and even epidemiological research is extremely limited. The last survey of first line drug resistance took place in 2003. A new study would provide valuable data about the spread of drug resistant TB in Romania and should be a priority. There are opportunities for additional research related to TB prevalence in risk groups such as the homeless, and injection drug users. However, Romania can be a difficult place to research because positions from local hospital managers to the Minister of Health are politically appointed. With every Romanian election (and often more frequently), health care is “under new management.” This lack of continuity creates chaos and prevents progress in the health system.

RELEVANCE TO POLICY COMMUNITY

Health reform in Romania is once again under serious consideration and even served as the spark which ignited the 2012 protests that led to the Prime Minister’s resignation. The place of TB within any health reform is of great importance as TB control is already in a precarious position. Reforms must recognize TB’s special status of TB as a public health danger and implement the WHO’s guidelines that require standardized, supervised treatment with an uninterrupted drug supply.

Rapid drug sensitivity testing (DST) should be introduced to locate and treat M/XDR cases and an investment in casework and patient support should be made to ensure that all cases of TB are treated correctly and patients are cured the first time—before they develop antibiotic resistance, before their lungs are permanently damaged and before

they lose faith in their ability to be cured.

Addressing lack of diagnostic capacity and shortages of anti-TB drugs, while crucial, are only the beginning. **20% of Romania’s TB patients are unsuccessfully treated every year.** Some of these patients have undiagnosed M/XDR and others find the medication’s side-effects too difficult to bear. Many are discharged from the hospital to the same poor living conditions that placed them at risk for TB in the first place. Romania’s underfunded and overstressed social services sector is unable to meet these patient’s needs.

Since 2004, there have been two successful pilot projects which provided incentives such as food vouchers and bus tickets to Romanian TB patients. Both significantly increased treatment adherence. However, present funding levels prevent the expansion of this program. At \$17 per patient per month, this is a cost-effective way to ensure that working-class and poor patients complete treatment and do not relapse.

Unsuccessful treatment leads to drug resistance and patients without any social supports have worse treatment outcomes and relapse more frequently. Some of these patients become social cases with no homes to return to and some are virtually incurable and need end of life care. However, these contagious patients are unwelcome in Romania’s nascent hospice system or its overburdened nursing homes. One solution would be constructing a specialized unit to treat and care for patients with such extensive social problems as well as for those requiring compassionate care in a hospice-like setting.

Romania’s TB epidemic is a major public health threat and if not controlled, poses a danger to other European Union nations where so many Romanians are now working. TB is not only a health problem, but also an economic, social and political issue that will require political commitment, additional funding, and public education to address.

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ENDNOTES

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1. MDR-TB is resistant to rifampicin and isoniazid, the two most powerful anti-TB drugs. XDR-TB is resistant to those two plus at least one second line injectable drug and a drug in the fluoroquinolone class of antibiotics. XDR-TB is very difficult to treat; in Romania, it is virtually impossible to cure.

2. This decision was reversed, but not before funds for 2011 drugs were disbursed to individual units.

3. Drugs like capreomycin, PAS, moxyfloxacin and amikacin were available to only a limited cohort of patients enrolled in the Green Light Committee project at Romania's two special MDR centers which together only have 120 beds). These drugs are generally unavailable otherwise. Ciprofloxacin is still in use in Romania despite WHO guidelines stating it should be immediately replaced with more effective ofloxacin.



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