

A close-up photograph of a person's hand holding several pills of various colors (orange, white, yellow, red) over a person's lap. The person's hand is open, and the pills are scattered across the palm. The background is dark, and the person's lap is visible, wearing a dark blue or black garment. The overall scene suggests a medical or healthcare setting.

# Human Rights, Ethics, and DOT

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I have no conflicts of interest to  
declare.

# In this presentation, I will:

- Discuss DOT from a person-centered care and human rights perspective using original ethnographic and other published data. Topics covered include:
  - Whether DOT happens in real life as it is described on paper and variation in how DOT is provided
  - The right to health
  - The availability, accessibility, acceptability, and quality (AAAQ) framework.
  - Nondiscrimination and privacy
  - The right to participation
- I argue that DOT, as it is commonly practiced is not in keeping with human rights and that it is time to move beyond one-size-fits-all approaches and to adopt rights-based, person-centered models of care which allow for individually differentiated models of treatment **support** based on the values and preferences of the person being treated.

# Research and Policy Work

- 20 years researching TB. More than 5 years of research and policy work while living in Romania including hundreds of interviews and surveys, accompanying medical staff on rounds, observing facilities-based and (rarely) in-home DOT and living at a TB sanatorium for 6 months. Because of the length of my research, I was often able to follow people from diagnosis through either cure (and subsequent challenges with sequelae and reintegration) or all too often, their eventual deaths.
- Since then, I have done additional research on TB and mental health, research and policy work on hearing loss, XDR-TB and compassionate use, and person-centered care and human rights.
- I have worked in Romania, Moldova, Hungary, Italy, Switzerland and consulted for the WHO, ECDC, Global Fund, and US Embassy in Romania.
- I have worked a lot with TB survivors and am one of the people who started Romania's STOP TB Partnership.
- In recent years, I have stopped working only in Eastern Europe and done more work in the USA and around global TB policies.



# A Harm Reduction Approach

“Harm reduction refers to policies, programmes and practices that aim to **minimise the negative health, social and legal impacts** associated with drug use, drug policies and drug laws.

Harm reduction is grounded in justice and human rights. It focuses on positive change and on working with people without judgement, coercion, discrimination, or requiring that people stop using drugs as a precondition of support.” (Harm Reduction International <https://hri.global/what-is-harm-reduction/>)

- Most simply, harm reduction **meets people where they are at**

# DOT: a touchy subject? An article of faith? The third rail in TB?

- In 2013, the head of Romania's National TB Program announced at a press conference that DOT was not happening in rural areas and had not been for years. It was not possible to organize it.
- We know that DOT is not happening as intended in many places, as I describe in Romania, as others such as Benbaba et al (2015) have described in India, as Hu et al (2008) describe in China, as Rainho Bras et al (2020) describe in Brazil, then is it an indictment of the system? Or further evidence that DOT as it exists in the world is not living up to its promise?
- This is not a criticism of the medical personnel. They are placed in an impossible position.

RESEARCH ARTICLE


## Direct Observation (DO) for Drug-Resistant Tuberculosis: Do We Really DO?

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# DOT is not in keeping with human rights

## Connecting the DOTS: Should we still be doing directly observed therapy?

Jonathan Stillo 

### ABSTRACT

Since the 1960s, the primary approach to treating tuberculosis (TB) worldwide has been directly observed therapy (DOT) (taking medication under supervision). Drawing on ethnographic data from Romania, literature on DOT globally and a human rights-based analysis, I argue that in many places DOT is not occurring as intended, and that it is ineffective, onerous to the people being treated and in conflict with their human rights. Instead, DOT should be one of several types of adherence supports from which people can choose within a rights-based and person-centered treatment that serves their varied needs through their long and difficult TB treatment.

## DISMANTLING THE DOGMA OF DOT: A HUMAN RIGHTS-BASED REVIEW OF DIRECTLY OBSERVED THERAPY FOR TUBERCULOSIS

*Brian Citro, Dr. Jennifer Furin, Rhea Lobo, Ingrid Schoeman, Timur Abdullaev, and James Malar*

**ABSTRACT**—The global tuberculosis (TB) response is at a crossroads. In recent years, new ideas, technologies, and political commitments have reinvigorated the fight against this age-old disease that kills more people each year than HIV and malaria combined. But with key indicators just beginning to recover after moving in the wrong direction during the COVID-19 pandemic, hard-earned gains are at stake. In this rejuvenated yet challenging context, we critically review an idea and practice at the heart of the TB response—directly observed therapy or DOT. First, we explore DOT’s controversial method and history as a component of the World Health Organization’s recommended TB strategy. Second, we outline a rights-based disease response and examine DOT through the lens of human rights and related principles. Third, we review the evidence for DOT’s effectiveness. Fourth, we highlight DOT’s most salient and enduring problems. Finally, we propose two essential principles for the way forward to protect and promote the rights of people affected by TB.

Even the WHO’s Ethical Guidance for the Implementation of the END TB Strategy states that due to its burdens, **“DOT is ethically justifiable only when done as a patient-centered approach to care.”** (2017)

# The right to health

- Availability, Accessibility, Acceptability, Quality
- The right to health requires that goods and services have these characteristics.
- Accessibility- is especially difficult both in economic and physical terms
- Acceptability- is the way that DOT is organized acceptable to the people being treated?
- Quality- Can we say that DOT (especially facilities based) is of quality with such a weak base of evidence supporting its use? Multiple meta analyses suggest DOT provides no benefit over self administration.

# Mariana

- “I had to hurry so that it [the drugs] wouldn’t start working on the way, because I would have walked down my street leaning from one side to another, the neighbors would look at me funny, seeing me leaving fine and coming back like that all dizzy.” (Mariana, DR-TB survivor)
- While Mariana was undergoing treatment, she struggled to work and take care of her young son. DOT was a burden for her both in terms of time, physical and economic costs. She could not work and walking to the clinic (she could not afford public transit) exhausted her.

# Gilda

- “He [her husband] is alone, with two children. To wash, cook, find a job, let them by themselves, come back and cook for the next day, like a woman. You need someone, it does not matter if it is a woman or a man. You need help.” (Gilda 34, died of DR-TB).
- Gilda and her family were poor and TB as well as the facilities-based DOT kept her in poverty. She endured 9 years of treatment with many interruptions. She needed support and was unable to adhere to DOT.

# Nicolae and Alexandru

- “I can’t go back and forth to the clinic. I need to be at work. There you can’t say ‘I have to go take my medicine’ and then come back after.” (Nicolae)
- Alexandru worked in forestry and was entitled to 100% of his salary and eventually being able to return to his job. However, because his employer found out he had TB, during the course of his treatment he said “Oh, no you had TB; I can’t hire you.” (Alexandru)
- In these examples, we see challenges with the right to participation, nondiscrimination, and privacy as well as in Nicolae’s case, a lack of economic accessibility of treatment as it would have prevented him from working.

# What did people tell me they needed?

- Support- economic support not just transportation reimbursement, but to replace lost wages, to enable them to hire someone to watch children or elders. Support to keep their homes heated and electric on
- Social support, especially peer-support.
- Psychological support
- Flexible Options! which might include DOT, in community, Digital assisted tech such as VOT, self-administered treatment with a mechanism for check-ins about adverse reactions, the ability for continuity of care even when traveling to different cities and countries as a migrant or for work.

# Would we create DOT today?

- “The tradition of all dead generations weighs like a nightmare on the brains of the living.” (Karl Marx, 1852)
- Some medical personnel have expressed fear that if they lose DOT, they will lose funding and their ability to keep a connection to their patients who have adherence challenges.
- **If the tradition of DOT was not weighing on our brains, and we brought the best and brightest from the TB community together, would they offer us DOT today? And would the TB community accept it?**

# What might the future look like?

- **Rights-based, person-centered**
- **Developed *with* TB survivors and affected communities**
- **Individually differentiated care that is based on the values and preferences of the person being treated.**
- **Adherence support broadly understood**
- **Moving beyond DOT for most people does NOT mean dismantling it entirely. Rather, it means accepting that it does not serve *most* people with TB well and that they not just deserve, but **have a *right* to better options.****
- **It does NOT mean simply replacing DOT with digital technologies such as DAT or VOT**
- **Instead, it should mean that resources that focused on surveillance are shifted to **supportive services that make people feel respected and cared for.****

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with any questions!

