

Stigma Engendering Biomedical Control

Why Ukrainian Healthcare Workers Favour an
Inpatient Treatment for Tuberculosis

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Abstract

This research article seeks to understand how the cultural context of tuberculosis (TB) care in Ukraine influences healthcare workers' perception of their patients and the choices they make in offering TB treatment. Specifically, we aim to explore healthcare workers' predilection towards inpatient treatment of TB in Ukraine in lieu of other, evidence-based treatment approaches. Based on qualitative research with TB care providers in Ukraine, we argue that a preference for inpatient treatment instead of the standard outpatient regimen is rooted in the care workers' assessment of the patient's desire to get well. In other words, the preferred treatment modality is not based on any biological characteristic of TB infection; instead, it is based on the perceived strengths and weaknesses of patients' psychology.

Keywords

Sick role, Stigma, Addiction, Imaginaries, Tuberculosis, Ukraine.

Introduction

Tuberculosis (TB) care often forces patients and providers to confront a classic tension in the medical sphere between the effectiveness of in-patient versus outpatient treatment. Frequently, the argument boils down to whether physically controlling a patient through inpatient care improves treatment compliance over outpatient care, which affords the patient more individual freedom (Albert et al. 2014; Ferreira et al. 2019). This tension is especially pronounced in the global standard for TB treatment, Directly Observed Treatment Short-course (DOTS), which is intended as a hybrid of inpatient and outpatient care, ostensibly maximising treatment adherence while reducing the chances a patient will refuse care—a real risk of mandating lengthy hospital stays. In Ukraine, social factors such as stigma and historically paternalistic medical practice in the former Soviet Union influence the execution of DOTS, often justifying healthcare workers' belief that inpatient care is categorically superior, as it maximises patient control.

DOTS is characterised by oral pharmacotherapy consumed by a patient in the presence of a trained individual who observes them take this TB medication (World Health Organization (WHO) 2020). The WHO states that this manner of treatment ensures patients are taking the correct combination of medication for the right amount of time while distributing the responsibility of treatment adherence between the patient and the treatment provider. In this way, DOTS has some of the benefits of inpatient treatment, such as close monitoring of the patient taking medicine. Despite the strict monitoring, DOTS is outpatient care, in which patients have more flexibility and control of their daily lives. The WHO stresses that this flexibility and self-determination is critical for effective TB treatment. However, the WHO states that hospitalisation during the initial, intensive phase of drug therapy (which lasts approximately two months) is an acceptable adaptation of DOTS. DOTS was first implemented as a pilot programme in Ukraine's southeastern city of Donetsk in 2001, and the implementation of DOTS has continued to scale up across the country since that time (ibid.).

Importantly, implementing DOTS countrywide requires significant political will to undertake the work of reforming and standardising diagnostic and laboratory systems, as well as patient care protocols. It has been estimated that 70% of the cost of TB control is provided via domestic state sources in 22 high burden TB countries but this varies greatly from country to country (WHO 2008). Ukraine has historically relied on support from international donors to implement meaningful TB control measures, especially laboratory-based testing and diagnostic procedures (WHO Regional Office for Europe 2013). This changed in 2018, when major healthcare reforms increased Ukraine's domestic financial investment in the control of TB and HIV (UNAIDS 2020). Today, Ukraine finances the purchase of

all TB medications from its domestic health budget but continues to rely on support from international donors for funding most other aspects of the country's TB control plan (Stop TB Partnership 2022).

Much international development aid directed at Ukraine's TB control systems in recent years has focused on strengthening laboratory standards for TB diagnosis but relaxing the strict inpatient treatment protocols that have defined TB care in Ukraine since the Soviet era (Chemonics International, Inc. 2017). Despite recent changes in national policy, TB care in Ukraine has long consisted—and largely continues to consist—of hospitalisation for months or years, followed by yet another lengthy outpatient phase (Gils et al. 2020). This lengthy hospitalisation negates the flexibility and self-determination that the WHO claims are integral for treatment success. This contradiction between the principals of DOTS and its execution raises the question not only of how but why DOTS implementation varies across regional and institutional contexts. TB is a 'social disease', which means that the spread of the disease as well as the experience of having it is influenced by political, economic, cultural, and historical context (Virchow 1958). Analysing these social factors can help explain why DOTS implementation takes its current form in contemporary Ukrainian medicine. Stigma is an especially critical social factor, as the way TB is treated can either exacerbate or ameliorate stigma, and vice versa.

In this Research Article, we will show how the distinction made by TB specialists between psychologically healthy and psychologically 'dangerous' patients who require inpatient care is a specific, medicalised manifestation of 'the addiction imaginary' (Carroll 2019). The addiction imaginary is the perception that an individual that displays anti-social behaviours (including drug use, regressive political behaviours, and more) is unable to connect their internal desire to their outward actions (ibid.). The addiction imaginary pertains to TB care in Ukraine, because patients who present anti-social behaviours are assumed to possess characteristics associated with addicted social identities.

The framework of 'intersectionality' as advanced by Kimberlé Crenshaw (1988), helps explain how the addiction imaginary relates to TB patients since it demonstrates the synergistic relationship of stigmatised attributes, such as being a TB patient and being drug dependent. Understanding this relationship is critical for understanding TB stigma and why the addiction imaginary is imposed on patients who are not themselves drug dependent. Talcott Parsons' theory of the 'sick role' is also useful for explaining how the addiction imaginary unfolds in Ukrainian TB clinics, because personal 'desire to recover', i.e., an expressed want to be healed, is a critical sick role obligation in Ukraine (Koch 2016). As a result,

the sick role provides a framework for the translation of the assumptions presupposed by the addiction imaginary to a biomedical setting.

Altogether, these social factors, stigma, the sick role, and the addiction imaginary shape how healthcare workers perceive their patients and determine the best treatment modality. Specifically, in Ukraine, we maintain that these factors work together such that treatment failure is not blamed on the structural challenges of care but on the psychology of patients. This results in a predilection by healthcare workers towards an in-patient treatment modality for TB that blocks the patient from fulfilling their personal responsibilities and impedes their daily life. To make this argument, we will first discuss the clinical and cultural contexts of TB in Ukraine. Then, we will explain how TB stigma in Ukraine has shifted away from morally implicating the patient in their TB infection, stereotyping them as poor, dirty, and immoral because of their TB diagnosis (Chang and Cataldo 2014), to morally implicating the patient in the recovery process. After analysing this shift, we will explain how the addiction imaginary and the sick role obligations in Ukraine have influenced this shift in TB stigma and consequently caused the perception among healthcare workers that an inpatient treatment modality is more effective at treating TB as it permits the healthcare workers to have more control over the patients and the treatment regimen those patients undertake.

Methods

The analysis presented here is based on remote, semi-structured interviews conducted with Ukrainian health care professionals from different tiers of the medical hierarchy. Participants were purposefully sampled to capture a diversity of experiences and situations among specialised professionals working in the sphere of TB. The final sample included a TB social worker who provides services for TB patients once they are in the outpatient phase of treatment, a paediatric TB nurse, a paediatric TB doctor, and an adult TB doctor who has, in the last two years, transitioned to a social work role. All but one identified as female, due largely to the fact that medicine is a heavily feminised profession in Ukraine. All participants were recruited from public healthcare facilities in urban areas of Ukraine, most, but not all, from Kyiv. The interviewees were recruited during September 2020 through referrals from US-based colleagues who maintain professional networks in Ukraine.

Semi-structured interviews were conducted [by MV] during October 2020. Participants were asked open-ended questions about different facets of TB care that were loosely based on Kleinman's explanatory model (Kleinman, Eisenberg, and Good 1978). Kleinman's theory of explanatory models uses a set of questions to reveal 'the beliefs the patient holds about his illness, the personal and social

meaning he attaches to his disorder, his expectations about what will happen to him and what the doctor will do, and his own therapeutic goals' (idem, 251). We used these questions to understand what healthcare workers believe is necessary for the successful treatment of TB. In this way, the questions were asked to help illustrate how the cultural context of TB in Ukraine influences healthcare workers' perception of TB and, in turn, how these perceptions are reflected in TB treatment.

The interviews were conducted remotely over Zoom, as international travel and in-person data collection were infeasible during the pandemic. In each interview, a Ukrainian-English translator was present and live interpreted between the interviewer and the interviewee. The audio of each interview was recorded and then transcribed. Transcripts were coded inductively to identify common themes and patterns. Once all the transcripts had undergone initial coding, patterns across all transcripts were categorised, and themes presented in this analysis were determined. These themes are: one, the shift of TB stigma from the disease itself to the recovery process; two, how TB stigma is currently manifested in clinics for TB and the implications of that form; and three, how the current stigma exacerbates the stigmatisation of already marginalised groups.

Past and present TB care in Ukraine

Multidrug-resistant tuberculosis (MDR-TB) is a threat to the global community and could render us defenceless against a disease that has been treatable for years. MDR-TB refers to the bacteria being resistant to the most potent antibiotic drugs, isoniazid, and rifampicin (US Centers for Disease Control and Prevention (CDC) 2016). MDR-TB infection can occur when an individual with TB does not complete their treatment regimen (Odone et al. 2016). It is also possible for someone to be newly infected with a strain of TB that is already resistant to antibiotics, a risk that previous studies have linked to socio-economic factors such as poverty (Souza et al. 2021). According to the WHO, Ukraine has one of the highest burdens of MDR-TB in the world (WHO 2022). Among previously treated TB cases in Ukraine, 58.1% are MDR-TB; further, 24.1% of newly identified TB cases are MDR-TB—a higher proportion than almost anywhere else in the world (Pavlenko et al. 2018). Additionally, the success rate of MDR-TB treatment in Ukraine is low, at 29% (Lytvynenko et al. 2014). For this reason, investigating how social dimensions influence the treatment modality of TB is crucial in high burden MDR-TB countries, such as Ukraine, as it can help explain treatment default.

Historically, a person diagnosed with TB in Ukraine was required, per national policy, to undergo at least two months of inpatient intensive phase therapy (Aibana et al. 2017). Today, according to the Ministry of Health of Ukraine (2020), hospital admission is not always necessary for TB treatment. However, from our

discussions with healthcare workers, many clinicians refuse to provide TB treatment on an outpatient basis; rather, inpatient treatment is *de facto* imposed, often spanning six to eight months or, in some cases, up to two years. One fifth of surveyed patients in Ukraine have described this inpatient phase of treatment as psychologically difficult (Aibana et al. 2017, 2020). After the intensive inpatient phase, patients must follow up with an outpatient treatment that also lasts for months. During the outpatient phase, the financial barrier to receiving treatment, created first by the unemployment during the inpatient phase, is intensified by additional costs for still more imaging tests, ancillary medications, and transportation to TB treatment facilities—all expenses which the state does not cover (ibid.). Additionally, as TB is severely stigmatised in Ukraine, many individuals prefer to spend more money to receive TB treatment from a facility in another town or *Oblast* [region] because they fear being identified as having TB, which could result in loss of social status and exclusion (Charyeva et al. 2019).

For the past few years, the Ukrainian healthcare system has been undergoing major reforms. The impact of these reforms has largely been limited to the realms of medical education and the provision of primary healthcare; TB diagnosis and treatment is considered tertiary (or specialty) care. In 2017, Ukraine's National Healthcare Service was created, effectively replacing the legacy Soviet system for primary care with a single payer system that finances healthcare through reimbursement for services rather than centralised budget allocations (Romaniuk and Semigina 2018). Plans were generated to expand these reforms into the secondary and tertiary healthcare systems by 2019 (ibid.). Public health advocates in Ukraine suggested that reforms to specialised healthcare would usher in major changes to TB treatment in Ukraine, including limiting the inpatient phase of treatment to a period of two weeks as studies have shown that after this length of TB treatment individuals are no longer infectious (Alliance for Public Health 2016). Reducing the time of inpatient care would help alleviate the burden imposed by inpatient care and ostensibly increase the proportion of patients who successfully receive treatment. However, as of the writing of this article (May 2022) this second wave of reforms affecting specialised healthcare delivery has still not been implemented. In addition to the enormous challenges posed by Russian military aggression in Ukraine, efforts by Ukraine's Ministry of Health to shift the general standard of TB care from inpatient to ambulatory treatment continues to be hindered by numerous systemic factors: insufficient healthcare staff and infrastructures for managing outpatient care; extremely low salaries for TB specialists that limit motivation for change; national TB plans that fail to elaborate financial or implementation strategies; and organised resistance from healthcare professionals against proposed reforms (Davtyan et al. 2019; Gils et al. 2020; Nading 2021).

Despite the recent (yet unfulfilled) promises for change, from our discussions with healthcare workers, it appears that the preferred treatment modality among clinicians remains the multi-month inpatient treatment. Many even voiced their disapproval for the current changes to TB treatment in Ukraine. Anthropologist Erin Koch's ethnography (2016) of TB care in the Republic of Georgia offers a framework for considering this disapproval of the proposed reforms to TB care as rooted in culturally informed values in healthcare: personalisation of care, moral duty, and stigma. These three critical social themes that Koch originally found surrounding TB care in Georgia, we argue, are also present in Ukraine due to the two nations shared historical context. For example, the value of personalisation of care helps explain the well-documented distrust many Ukrainians have toward biomedicine (Balabanova et al. 2012). In Kołodziejska-Degórska's analysis (2016) of the rural Ukrainian medicoscape, she noted that many Ukrainians believe each body reacts differently to clinically standardised biomedicines, and, therefore, they must 'check' if a medicine will work for their body. Importantly, this 'check' does not refer to laboratory assessments like drug susceptibility testing, which would determine whether and which antibiotics a particular TB strain is vulnerable to. Rather, this refers to a less scientific, more phenomenological assessment of whether a particular medication 'agrees' with the patient's body or is effective as a treatment given the unique characteristics a patient may believe their body to have. This sort of phenomenological 'checking' that patients seek could mandate various forms of personalisation in medical treatment, from deciding what kind and amount of medication is given to the duration of treatment that the individual believes best suits their body. However, DOTS is a global standard of TB treatment and, therefore, comes into conflict with the widespread perception of what care should look like in Ukraine. As a result, there are increased tensions in the relationship between patients and healthcare workers as patients are not generally afforded what most would consider sufficient opportunity to 'check' to their satisfaction whether the biomedicine used to treat TB works for them. These tensions can cause distrust among patients and doctors, which reinforces the belief among doctors that patients must be spatially controlled for TB treatment to be effective.

The perceived moral duty to act appropriately in healthcare interactions can espouse further tensions between patients and healthcare workers. In her research, Koch (2016) found that Georgians perceive doctors to be failing in their moral duty if they heal with any motive other than 'good faith'. Similarly, Kołodziejska-Degórska (2016) found that many Ukrainians believe doctors prescribe biomedicine to make money rather than for healing purposes, which they consider to be immoral. In this way, patient distrust of biomedicine results in the perception that doctors are failing their moral duty by prescribing something that is believed to benefit the doctor financially and not benefit the patient medically. Relatedly, medical anthropologists investigating treatment for substance use

disorders in the former Soviet Union have observed that healthcare workers believe patients fail their moral duty when they do not have the ‘desire’ (Rus: *zhelanie*; Ukr: *bazhannia*) to recover (Raikhel 2010; Carroll 2016). This is because the personal desire to recover is believed to be paramount for progress towards recovery for psychological and behavioural disorders—and, by extension, physical and infectious ailments in those living with psychological or behavioural disorders—in the eyes of Ukrainian medical professionals (Carroll 2016). As a result, healthcare workers are suspicious of their patients if they believe they do not have the desire to recover and fail in their moral duty to get better. Furthermore, Carroll noted it was common for healthcare workers in Ukraine to perceive people who use drugs as characterised by the absence of desire to recover. Analogously, we found that healthcare workers view TB patients, who display anti-social behaviour akin to those associated with people who use drugs, as having the same mentality as people who use drugs, because they supposedly lack the desire to recover. At times, this perspective meant that health workers assumed a TB patient also engaged in drug use.

This perception by healthcare workers further exacerbates stigma against patients who are not making progress in their treatment. Carroll (2019) coined the term ‘addiction imaginary’ to explain this phenomenon of stigma among people who use drugs in Ukraine. The addiction imaginary is a construct, ‘which explains how problematic substance use (or any other problematic, compulsive behaviour) arises in apparent contradiction to dominant theories of human will’ (idem, 185). In Ukraine, the dominant theory of human will dictates that biological recovery is only possible by having a healthy psychological state in which one can produce the desire to recover (Carroll 2016). Therefore, the patients who are not recovering are presumed to not be in a healthy psychological state and to suffer from a disconnect between what they desire and what they can do. In this article, the term addiction imaginary will be used in reference to TB patients who may not have any addiction because in Ukraine, the shared stigmatisation by medical professionals of drug users and people living with TB results in healthcare providers perceiving and treating these patients in a similar manner, as the addiction imaginary explains.

In this analysis, we view the concept of ‘desire’ as a moralised obligation. In this sense, we rely on the concepts of social stigma (Goffman 1963) and the sick role (Parsons 1951) to help explain why ‘desire’ manifests in a moralised manner that results in the preference of inpatient treatment by healthcare workers in Ukraine. Sociologist Erving Goffman defined stigma as ‘the situation of the individual who is disqualified from full social acceptance’ (1963, 9), because an individual has an ‘attribute that is deeply discrediting’ (idem, 3). Goffman discusses how stigma influences micro-level interactions such that those who bear the stigmatised

attribute are wary of interacting with those that do not share their stigmatised attribute. Conversely, those without the stigmatised attribute disparage the stigmatised individual. This dynamic between the stigmatised and non-stigmatised is essential as it influences how healthcare workers and TB patients interact.

Crucial to this analysis, too, is how desire is intertwined with stigma to become a personal and moralised duty of the patient. As Koch noted, moral duty is a key aspect that influences the preference of inpatient TB treatment. Moral duty during illness can be manifested through the obligations of the ‘sick role,’ which, as defined by Parsons (1951), gives an ill person certain rights, such as being exempted from carrying out regular social duties; however, these rights come at the cost of needing to fulfil certain obligations, such as trying to heal by seeking and submitting to appropriate medical care. Anthropologist Adriana Petryna (2013) argues that ‘the sick role ascribed moral efficacy to a social world in which the sick are not only managed in terms of disease but also have a chance to recover through good faith, unmotivated by secondary gains’. In this way, the sick role is moralised, such that those who are perceived to be neglecting their sick role obligations, especially by displaying no ‘desire’ to recover are seen as immoral. Without that desire to recover (or without actions to evidence such desire), people, specifically healthcare workers, perceive these individuals as failing their sick role obligation, which implies a moral failure.

Importantly, the ‘control’ that healthcare professionals seek to impose through inpatient treatment is not absolute. Patients are not incarcerated in TB hospitals and ostensibly maintain the right to leave. However, because many hospitals refuse to continue the intensive treatment phase on an ambulatory basis, choosing to end one’s hospitalisation *de facto* means ceasing care and defaulting from treatment—a significant risk factor for MDR-TB (Priedeman Skiles et al. 2018). As many as one in five people who begin TB treatment in Ukraine drop out of treatment early at some point (WHO 2022). Though the rate of treatment default that occurs specifically during the (typically inpatient) intensive phase in Ukraine is unknown, research conducted in Russia suggests that most people who drop out of treatment early do so during the intensive treatment phase (Jenkins et al. 2013). Ultimately, the control that providers seek to impose over patients is coercive, but not absolute. Indeed, the primary coercive element that providers have to leverage is their authority over treatment access: unless one conforms to providers’ inpatient demands, one will likely not be able to access TB treatment at all.

Yet, we argue that this control—namely, the ability to coerce patients to accept inpatient care so that hospital staff can directly manage all aspects of their treatment regimen—is deemed necessary by many providers to manage certain patient characteristics—namely, a pathological lack of desire to protect their health

and the health of others—that predict treatment failure. In other words, as they consider what constitutes appropriate TB care, providers take into account not only how they find it most appropriate to respond to the clinical manifestations of a patient's TB case but also how they might best manage a patient's psychological pathologies, which might hinder treatment and evoke consequences for not only the patient's health, but public health as well.

Stigma, illness, and recovery

In 1995 there were more situations where children with tuberculosis were from very poor families with really bad hygiene, and it was because of the poor condition in which they were living [that they got tuberculosis]. – Interview with a paediatric TB Doctor, 2020

During and for some time after the fall of the Soviet Union, there was a very particular image that was conjured when someone received a TB diagnosis in Ukraine. As the paediatric TB doctor quoted above shows, this image was closely associated with poor health and low socioeconomic status. Contracting TB, according to the stereotype, occurred only in this population, and, thus, TB diagnosis became symbolic of social, financial, and even moral failure (Jimenez 2003; P. Kelly 1999; S. Kelly 2011; Woith and Rappleyea 2016). For many years, the discrediting attribute that results in the stigmatisation of people living with TB, in accordance with Goffman's definition of stigma, was simply having TB (Rubel and Garro 1992).

Stigma towards TB remains to this day. However, this research suggests that the stigmatising attribute associated with TB has shifted away from simply having the disease and onto characteristics of the recovery process. This was expressed in the healthcare workers' responses when asked why patients contract TB. From the responses received, all the healthcare workers agreed that an individual cannot be blamed for acquiring this illness. Infection risk was widely viewed as part of everyday living. One social worker, for example, said, 'they can get TB in different places like public transport, night clubs, work, hospital.' The adult TB doctor described TB infection as, 'like accident. Sometimes it happens.' The paediatric TB doctor we interviewed further underscored this perceived universality of infection risk, saying: 'People and children that are from really nice families, from private schools, who have money to give their children, a nice life also, have tuberculosis ... you don't know if your neighbours have tuberculosis, you don't know if random people have tuberculosis'. The paediatric TB nurse we interviewed said she 'just feels very sorry for [children who contracted TB]. They are not to blame for anything or for getting the infection.' The paediatric nurse we spoke to corroborated the paediatric TB doctor's statement by saying she 'doesn't see any

similarities [among patients]. They come from very different backgrounds'. Interestingly, these informants do not reason that a TB patient became infected due to their social background nor because of a moral or socioeconomic failure. These responses dramatically deviate from the profound social stigmas observed in previous ethnographic research on TB in Eastern Europe (Woith and Larson 2008) Rather than framing TB as a social disease, these healthcare workers reflect the scientific explanation of TB contagion—that it is spread through the aerosolised droplets from one person to another through ordinary life activities—and do not attribute individual blame for contracting TB or discriminate between socioeconomic class or other labels. Interviewees stressed this by providing quotidian examples of social interactions that may have caused the contraction of TB.

Despite the lack of moral weight attributed to the contraction of TB, many Ukrainians still fear TB diagnosis for reasons beyond the purely biological. As the adult TB doctor said, 'They [patients] are really afraid to tell someone that they have TB, and they are afraid that someone won't accept them because they have TB.' In this quote, some of the fear associated with a TB diagnosis is rooted in the potential negative social reaction to the disease because of the stigma still associated with TB in broader Ukrainian society. However, interviews with these healthcare professionals suggest that, in the medical field, TB stigma is manifested in a different manner: namely, healthcare workers would stigmatise or discredit individuals with TB when a patient was not progressing in treatment and was therefore perceived as not fulfilling their sick role obligations.

One critical obligation of the sick role in Ukraine is having the desire to recover or being perceived as having the desire to recover by healthcare workers (Carroll 2016). As desire is perceived as essential for recovery, when a patient is perceived as failing their sick role obligation by 'lacking desire' to recover, the individual becomes stigmatised because of their moral failure. In this way, the TB recovery process is stigmatised. Similar ethnographic work carried out by Eugene Raikhel (2010) in Russia has found that a patient's desire, or motivation to recover, is considered essential for sustained recovery from alcohol use disorder. Raikhel (2013) also noted that the doctor's own will or desire for the patient to recover could be used a substitute for the patient's desire if the patient was perceived as lacking desire, which he calls the 'prostheses of the will', the doctor's desire being able to supplant the patient's lack of desire influences how therapeutic strategies are shaped.

Stories shared in interviews by healthcare workers illuminate the means by which individuals are discredited when perceived as lacking the desire to recover from TB. Through these narratives, the obligations and moralisation of the sick role

become apparent as well. In one anecdote, the paediatric TB doctor described with little emotion the death of a young woman whose failure to recover, by the doctor's estimation, was inevitable due to her poor psychological orientation to her own health:

She was 18 years old, and they were treating her with first generation drugs, and after she turned 18 years old she aged out of the children's hospitals and had to go to an adult hospital. But, unfortunately, she didn't care much about her health or anything, and she was just [interested in] living her life, and it was getting harder and harder [to treat] the disease, and she unfortunately died.

Likewise, the adult TB doctor mentioned that she had previously treated 'one young girl, and she [also] had AIDS, and because of her mental attitude, she didn't want to take treatment for AIDS or TB, and she said she didn't want any doctor to come to her house and no psychiatrist. Of course, she died.' In both examples, the patient infected with TB was determined by healthcare staff to have a poor attitude and to 'not care' about their health or TB diagnosis. As a result, these patients were presented by interviewees as failing in their sick obligation to have the desire to recover. Consequently, it did not shock either doctor that their patient ultimately succumbed to their illness and died, since the desire to recover, from the health worker's perspective, is critical for both treatment adherence and treatment efficacy—in other words, for the entire treatment effort to be successful.

Erin Koch (2016) previously noted the importance of moral duty and stigma in shaping the nature of TB treatment in the Republic of Georgia. In Ukraine, moral duty and stigma influence similarly matter, as it is understood to be the moral duty of patients to have the desire to recover. To be perceived as lacking this desire is, therefore, to be stigmatised. In this way, the patient's desire is the most pivotal aspect of recovery, and demonstrating it is the most vital sick role obligation, without which healing is perceived as practically impossible in the eyes of healthcare workers. The paediatric TB doctor we interviewed said this herself when she observed, 'in Ukraine, we have epidemic of TB, because people do not care about it.'

Intersectionality and psychology in TB care

In interviews, informants described the presence or absence of desire to be treated as a key factor in determining a patient's treatment outcomes. In the words of the TB social worker we interviewed:

There are more or less two groups of patients that [we] work with. One of them, they don't care about tuberculosis because they are usually drug or alcohol dependent [...] There is also another group of people which are approximately

middle class probably a little lower and are usually hard-working people who care about their health.

In this description, the social worker generalises TB patients into two groups characterised by their desire (or lack thereof) to recover. In Ukrainian clinics for medication for opioid use disorder (MOUD), Carroll (2011) found that healthcare workers made a similar distinction among patients. Additionally, there is an interplay of other stigmatised groups, namely drug and alcohol-dependent individuals, categorised as not caring about their health (Idem, 2016). Thus, the common characteristic attributed to both of these spoiled social identities—the wanton TB patient and the wanton addict—is the absence of desire to recover. This overlap bolsters the stigmatisation of each identity and increases a person's discreditation if they are considered to be both simultaneously. This phenomenon is in alignment with Kimberlé Crenshaw's (1988) concept of intersectionality that extrapolates how different aspects of an individual's identity combine to create various forms of discrimination and privilege.

The intersectionality between TB patients and substance use bolsters the assumptions created by the addiction imaginary (Carroll 2019). Put another way, even if a TB patient does not use drugs and is not experiencing a substance use disorder, non-compliance with TB treatment (believed to stem from the lack of desire to recover) can begin to shade into suspicions of drug use and stigmas associated with substance use disorders (also believed to stem from a lack of desire to recover). This lack of desire supposedly only happens to those who are not psychologically healthy, such as those in stigmatised groups. In the words of the social worker, 'They don't care about tuberculosis because they are usually drug or alcohol dependent.' In contrast, 'successful' TB patients—the 'hard-working people who care about their health'—are perceived to have the desire to fulfil their sick role obligation and get better as a result of their good psychological health.

This connection between a lack of desire to recover from TB and the palsy of will and wanting (Raikhel 2013) attributed to addiction imaginary was made explicit by the social worker: 'Their [people living with substance use disorder] mindset is completely different, and they look at it [diagnosis] like, "Ok, I have TB. What can I do. I'll drink more." They don't receive the diagnosis very emotionally.' Similarly, the adult TB doctor discussed how the 'brains' of people living with substance use disorder change as a result of their substance use. She mentioned, 'Some people, after a long period of taking drugs and everything, their mental activity is working different than our brain [mine and hers].' The paediatric TB nurse also gave a specific example to describe how substance use changes a person's mindset. When discussing how children contract TB, she told me that most children are

infected by their parents. She went on to say, ‘Lots of these parents are not social. They are, for example, alcoholic. They are drug dependent. That is why they don't have this feeling of guilt for giving their children TB.’ Here, she directly evokes the addiction imaginary, which casts those labelled *narkoman* [person who uses drugs or ‘addict’] as suffering a metaphysical disconnection between behaviour and emotions (Carroll 2016) in order to juxtapose what she saw as the emotionally stunted reaction of parents who use drugs to the emotional reactions of allegedly sober parents who ‘feel very guilty.’ She said, ‘They are different parents, the parents that are like this [who use drugs] don't feel guilt.’

In these statements, informants described people living with a substance use disorder as having an altered mental state, as incapable of feeling the desire to recover or other concerns about TB. These statements from healthcare workers insinuate that individuals who are part of a stigmatised group must be bad patients. This insinuation, we argue, is an example of the addiction imaginary (Carroll 2019), which assumes a disconnection between the patients' desires and actions, at work in shaping clinicians' assessments of their patients.

Alternatively, the addiction imaginary, then, is a way for healthcare workers to make sense of individuals who act in ways that do not appear to make sense. A patient may not even have a history of drug use, yet may still be labelled as an ‘addict’ by healthcare workers if they have TB and do not display this desire to recover or if the individual does not follow their healthcare provider's instructions in a satisfactory way. Indeed, most of the statements made by informants regarding substance use revolve around an individual not acting how healthcare workers expect the individual to react. In one instance, a patient was perceived to be indifferent to their TB diagnosis, and, due to this indifference, was labelled an alcoholic by the social worker. Put simply, the existing perception among healthcare workers in this study is that someone who does not have the desire to recover from TB is likely to be, or presumed to have the same mindset as, someone who uses drugs. Importantly, the logic of the addiction imaginary—specifically, the logic that addiction and lack of desire go hand in hand—reinforces the belief that health workers must impose control on these patients because they assume that the patients are incapable of meeting their sick role obligation. This imposition of control through inpatient care, then, can be considered a manifestation of stigma and an attempt to control a population who are deemed incapable of controlling themselves—are deemed incapable of even experiencing feelings of guilt if they pass their infection on to others. As we discuss below, the pathological lack of desire to recover attributed to problem patients, then, justifies the inclusion of psychiatric support in TB care, as fomenting desire is understood to be precisely the psychiatrists' skill and responsibility.

Psychological and spatial control of TB patients

In Ukraine, psychiatry has historically been a very paternalistic practice. As anthropologist Shelly Yankovsky has noted, 'Ukraine has inherited a psychiatric system overshadowed by particularly disturbing legacies from the Soviet Union, where psychiatric diagnoses and confinement were used as forms of political repression' (2016, 616). Furthermore, Yankovsky notes that 'the Soviet system was characterized by a highly paternalistic relationship between psychiatrists and their patients, with psychiatry enjoying almost unrestricted autonomy in its power to treat patients' (idem, 618). As a result of the historical context of Ukraine, psychiatry is deeply linked to political and mental control. For a medical professional in Ukraine, then, referring a patient to a psychiatrist is one method for increasing the degree of control maintained over a patient.

Many of the healthcare workers who we interviewed stressed the importance of TB patients seeing a psychiatrist. This insistence can be interpreted, in turn, as a defensive response to the addiction imaginary, which assumes that these patients lack desire, as adopted by TB care providers. Desire, as we have noted, is perceived as integral to recovery, the most crucial sick role obligation in Ukraine. Desire is also an emotion that cannot be physically coerced or controlled; however, a psychiatrist, our informants suggest, may be able to influence it or to compensate for its absence.

Among our informants, the perceived need for such psychiatric support in TB care was so great that it has essentially become part of the standard of care. The social worker said that finding psychiatrists is a service that he provides to TB patients. Informants also lamented the absence of this support when it was not available, often driving them to find other ways to insert psychological control into the patient-provider relationship. The paediatric nurse mentioned, 'It would be the best if there was a psychologist working with the children. Because since there is none all the medical staff, the nurses, doctors, everyone is also a psychologist.' The adult TB doctor who later transitioned to the role of a social worker appears to hold a similar opinion as the paediatric TB nurse. She observed that, 'Sometimes even strong people with TB cannot accept that they need psychiatric help.' She also described her own social work practice as 'helping [TB patients] with moral support, because it is very hard to treat and to push people to treat TB.' The idea of 'pushing' patients to be treated was reiterated by the paediatric TB doctor who said, 'In the hospital ... if the child needs moral support, they can call for a psychiatrist. Basically, they have persons in Ukraine that will help the child to overcome, and they will push these children to treat themselves.'

In all of these statements, the healthcare workers acknowledge that this psychological element is integral for physical recovery from TB. This makes sense

considering how central 'desire' is to recovery in Ukrainian clinics for this and other socially challenging chronic diseases (e.g., substance use disorder). The insistence by healthcare workers that TB patients should see psychiatrists further demonstrates the transition of TB stigma to the recovery process, because it cements within standard medical practice the notion that patients are capable of morally failing as patients within the treatment context, even as healthcare professionals insist that patients bear no blame for contracting the illness. Furthermore, the recommendation by healthcare workers that all TB patients should see a psychiatrist implies that they cannot count on all TB patients to have this desire on their own. Just as Raikhel (2013) observed in his own work on treatment for alcohol use disorder in Russia, the recommendation to see a psychiatrist can be seen as a 'prostheses of the will,' because an external force (the desire or will of a psychiatrist to 'push' a patient) is able to exert control in place of the desire of the patient, which is lacking.

Psychiatric treatment is not the only consequence of the addiction imaginary in TB clinics and the shift of TB stigma from infection to recovery. The many months-long inpatient treatment of TB that most TB patients endure in Ukraine is an even more substantial outcome. Psychologist Erik Erikson (1994) has argued physical containment is an indicator of social boundaries that uphold stigmatisation. In the context of TB care in Ukraine, inpatient treatment is not just about upholding stigma; it is also a direct result of the moral evaluation of patients' psychology, which is given shape by the addiction imaginary, and the determination of likely poor clinical outcomes when a patient's psychological strength is determined to be insufficient. As a result, healthcare workers appear to have a partiality for inpatient treatment because inpatient treatment allows the physical management of TB patients, who are perceived to lack the desire to recover.

Importantly, informants in this study indicated that establishing control over non-compliant patients was overwhelmingly accomplished for the safety of wider society, not the patient themselves. This sentiment was made clear by the paediatric nurse, who mentioned the need to control TB patients multiple times throughout our interview. At one point, she said, 'Patients need to be controlled in the hospital and afterwards, depending on his or her stay, they can go home if they are not dangerous to the society anymore.' Without inpatient treatment, the paediatric nurse insinuates that all of society would be in danger of TB infection as a result of patients who lack the desire to recover and remain capable of transmitting the disease. Later, the paediatric nurse described TB as 'a serious disease that needs to be treated seriously and has to be controlled properly, otherwise it [the treatment] will be ineffective.'

Appealing to this belief, she was very vocal about her opposition to planned healthcare reforms, which would limit the inpatient phase of treatment to only two weeks in most cases, with the remaining treatment provided outpatient. She insisted, ‘At home, it [TB treatment] can’t be properly controlled and done.’ The social worker and the adult TB doctor both made similar remarks about the reform. He said that ‘inpatient care should be provided for people who are addicted to alcohol or drugs to have better control over them.’ From this remark, we see the intersectionality of stigma against TB patients and people who use drugs, which results in the assumption that patients unable to sufficiently demonstrate a desire to recover to their providers must be physically controlled—through a psychologically (or in the case of inpatient care, physically) imposed ‘prosthesis of the will’ which the patient lacks (Raikhel 2013). Importantly, this motivation to ‘police’ TB patients by insisting on inpatient treatment is not echoed by Ukraine’s Ministry of Health, which has since Ukraine’s 2014 Revolution of Dignity, been attempting to reform TB care to promote outpatient treatment in accordance with WHO standards (Ministry of Health of Ukraine 2020). Rather, as has been documented elsewhere, inpatient TB care is largely perpetuated by the preferences of TB specialists (Aibana et al. 2017), resulting in extremely low rates of TB treatment and, consequently, one of the worst rates of MDR-TB in the world (WHO 2022).

The statements by the healthcare workers that patients and their treatment regimens need to be controlled via inpatient treatment are morally weighted as it assumes that these patients cannot fulfil their sick role obligation without this control. Assuming patients do not have the desire to recover, taking away an individual’s social freedoms by keeping them inpatient becomes socially permissible—even preferable—for healthcare professionals seeking to be diligent in their public service. In this way, the addiction imaginary, stigma, and the sick role interact synergistically to discredit patients struggling with their treatment for any reason and justify paternalistic forms of care. In sum, TB patients who are not getting better, or who are acting in a way that healthcare workers do not perceive to be appropriate, are discredited, stigmatised, and psychologically pathologised through the lens of the addiction imaginary. That pathology consists of lacking the desire to recover, which means that the patient is failing the most pivotal sick role obligation.

In plain terms, patients who are not recovering must lack desire, and if they lack desire, they are—or have the equivalent mindset of—‘addicts’ and should be treated as such. Due to this attitude, TB patients who are stigmatised during the recovery process are perceived as incapable of healing without the imposition of control to evoke desire or to ensure treatment success in its absence. The elicitation of desire, as seen by the remarks above, can only be done when there

is a prosthesis of the will via psychiatric intervention or physical control over the patient through inpatient treatment. This results in physical containment not just being permissible but advisable in order to keep society at large safe from the risk of contracting TB from those who are perceived as dangerous—a label that both emerges from and reifies their social marginalisation.

Conclusion

This analysis highlights a significant change in the manifestation of TB stigma in Ukraine: namely, the object of TB stigma has shifted away from the acquisition of infection, toward the patient's involvement in the recovery process of TB. This change has resulted in the rationalisation of an inpatient treatment modality for TB care in Ukraine that has been abandoned elsewhere. As Koch (2013) has previously noted, stigma, moral duty, and personalisation of care are among the main cultural components that shaped TB management in the former Soviet Union. The shift of TB stigma onto the recovery process underscores the utility of Koch's observation, because the change in how TB stigma is observed among healthcare workers hinges on patterns of social stigma and the perceptions of moral duties (for patients and providers), ultimately resulting in healthcare workers viewing the patients they perceive as problematic through the addiction imaginary (Carroll 2019). The addiction imaginary is a cultural construct that makes sense of substance use behaviours by theorising that the patient is unable to abstain from use because they lack the desire to recover. As desire is integral for recovery in both substance use and TB care in the eyes of Ukrainian healthcare workers, patients are failing their most integral sick role obligation when they lack desire and are therefore failing in their moral duty as a patient. As a result, healthcare workers prefer treatment modalities for TB that enable this kind of control. One way of controlling patients is to recommend a psychiatrist to the patient in the hope that this professional will be able to generate the patient's the desire to recover. Beyond this, inpatient treatment enables the physician control over patients and the implementation of the treatment regimens they receive. This is perceived as crucial for treating patients who are believed to lack desire and is considered an appropriate course of action for healthcare professionals insofar as it is framed as a form of protection to the rest of society.

Appreciating the way in which healthcare workers perceive the risks and benefits of outpatient care is integral for navigating further questions about healthcare delivery. How will the relationship between patients and providers change if healthcare reforms are finally implemented? And how is paternalism in medicine evolving in the context of an increasingly neoliberal and decentralised healthcare system? Here, we suggest that TB care is not only being shaped by Soviet legacies of state-paternalism, but that this paternalism is itself evolving into new types of

coercive practices in which healthcare providers feel they are protecting society from their patients, rather than protecting their patients from poor outcomes. This paper also provides a novel example of what can happen when patients and providers maintain incompatible explanatory models for illness. Further investigations should be conducted on how patient and provider explanatory models influence treatment of other socially-inflected illnesses and how those differences impact the achievement (or absence) of patient-centred outcomes. Moreover, the patient's perspective is vital to understanding the patient-providers relationship (Tabler et al. 2014), and future research should explore how individuals going through TB care navigate the challenges and pressures to conform to doctors' insistence that they take on preferred treatment regimes.

In sum, this paper demonstrates that TB management is as much a social as it is a biomedical problem, and that the challenges in TB management extend beyond the public into the healthcare system that is supposed to be working in service of TB control in the first place. In this way, we argue, as Jonathan Stillo (2020) has argued in his research on TB treatment in Romania, that the social nature of TB is not limited to the social and economic problems of people with TB but is intrinsically related to failures of health systems to provide locally adequate TB care. In this way, the sociality of TB is manifested in the policing of individuals with TB that occurs due to a shift in TB stigma.

In keeping with this observation, we urge other anthropologists to utilise a broader understanding of TB as a social disease, that extends beyond the individual's sociality and the lens of poverty, as it allows anthropologists to discover the vast array of other factors, such as political economy, colonial, and post-colonial histories, and local syndemics, that contribute to the present TB public health crisis. Other anthropologists have already done this in Romania, the Marshall Islands, and South Africa, to name a few examples (Stillo 2020; Yamada, Riklon, and Maskarinec 2016; Versfeld 2017). Consequently, understanding TB as a social disease in this broader sense allows for a reframing of the relationship between the social, economic, political, and biological factors that compose the TB experience.

The findings in this paper are of significance, because now—as MDR-TB strains are becoming increasingly resistant to available TB medications and extensively drug resistant TB strains (XDR-TB) are beginning to emerge—a global public health threat is developing that will be inequitably shaped, exacerbated or mitigated, through both social and biological factors. Unsuccessful TB treatment, especially when TB patients drop out of treatment or are otherwise lost to follow-up, remains a significant driver of MDR-TB infection (Stosic et al. 2018). Therefore, TB treatment needs to be accessible and low barrier to support patients in

completing an already burdensome treatment and to successfully clear their infection. Otherwise, we may soon be defenceless to a bacterium we have been treating for decades.

This investigation, conducted in a high MDR-TB burden country, illustrates some of the logic behind healthcare workers' belief that inpatient treatment modalities are more effective in treating individual patients. By taking their perspective into account, we can understand the various local arguments against low-barrier treatment modality, which may be more effective at controlling TB on a population level. Understanding the healthcare workers perspective in the context of Ukraine is especially critical now in the COVID-19 pandemic, during which TB care has been restricted almost entirely to outpatient treatment. Future investigations on how the COVID-19 have impacted TB care in Ukraine would be beneficial for understanding and mitigating potential backlash by healthcare workers to the proposed neoliberal health care reforms in tertiary care in Ukraine. Ultimately, investigating how various social factors interact and influence treatment is paramount for understanding the potential repercussions for certain treatment modalities and healthcare reforms.

Authorship statement

Mariana Villar conceived of this project, carried out data collection, analysed data, and was the primary author of this article. Dr Jennifer J. Carroll oversaw data analysis, contributed to data interpretation, and made critical revisions to the article.

Ethics statement

This project was also approved by the internal Institutional Review Board (IRB) at Brown University in Providence, Rhode Island, USA.

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