Thriving in the Face of Adversity: How Moldova’s Vulnerable Populations Cope with Tuberculosis

By

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Class of 2018

A thesis submitted to the faculty of Wesleyan University in partial fulfillment of the requirements for the Degree of Bachelor of Arts with Departmental Honors in Psychology

Middletown, Connecticut April, 2018
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Acknowledgements

First and foremost, I would like to thank Jill Morawski for expressing interest in my research and being willing to advise my thesis, despite my initial setbacks and late start on it. Throughout my time in the psychology department, Jill has enriched my coursework and positively impacted my college experience with her wisdom, sincerity, and support.

I thank Mike Robinson for being a positive role model, as well as a source of support and guidance from the very first day of freshman year. I am eternally grateful for the opportunities to become a better writer, speaker, and scientist that his classes have provided me. His honest and frank advice has greatly shaped my academic and professional goals, as well as the way that I see the world.

I would also like to extend my gratitude to everyone at AFI in Moldova for providing me with hands-on experience in disease intervention and social work, as well as enthusiastically helping me conduct my research. I would not have been able to do it without Svetlana Doltu, Lilian Severin, Sergiu Cugut, and Ina Pușoi.

A big thank you to my housemates for encouraging both my writing and my procrastination, and for making my final year at Wesleyan warm and memorable. I am also grateful for my parents, who have endured so many difficulties in their lives in order to see my happiness and success. I am eternally grateful for their unwavering support in all of the things that I pursue in life, and I hope to continue making them proud of me as I continue my journey.
Abstract

Tuberculosis remains one of the top causes of death worldwide. Despite the fact that it is curable given a prompt diagnosis and proper treatment, its historical link to poverty significantly hinders elimination efforts in developing countries (World Health Organization, 2017). Moldova is a lower-income country that maintains one of the highest rates of tuberculosis and its drug-resistant forms. However, little is known about the personal experiences of Moldovan TB patients, and many Westerners are even quick to assume that they do not successfully manage everyday life given their low socioeconomic status. In this exploratory qualitative study, I aimed to uncover how marginalized tuberculosis patients in Moldova cope with the challenges of their conditions and treatments. Participants included prisoners, drug users, and rural villagers, and were recruited from a convenience sample provided by a nonprofit organization. Through interviews, these twelve participants provided verbal accounts of their diagnosis and treatment experiences on both a daily and long-term basis. Their accounts were supplemented with photographs in order to enhance the reader’s understanding of Eastern European culture and participants’ views of their illness. Standardized coping theories were applied and modified in order to reveal multifaceted details about cultural context, meaning-making, and the continuous coping process. The data revealed that certain elements characterized participants’ coping mechanisms and enabled them to better deal with TB, such as adaptive behavior and acceptance, self-centered approaches to problem-solving, guarded social behavior, and one’s identity within a specific community (such as prison).
Introduction

Tuberculosis control has improved significantly worldwide due to the introduction of successful vaccines and treatments in the late twentieth century. Despite these developments, Eastern Europe has maintained extremely high rates of this disease. As of 2014, 10 out of 25 high burden drug-resistant tuberculosis (MDR- and XDR-TB) countries fall into this region, indicating that there is an urgent crisis (Acosta et al., 2014). Located between Ukraine and Romania, Moldova has the highest burden of tuberculosis in Eastern Europe in terms of morbidity and mortality rates. New multidrug-resistant tuberculosis cases account for 26% of all new cases in the country, and the treatment success rate for these strains is less than 50% (World Health Organization, 2016). The modern tuberculosis epidemic is concentrated in underprivileged countries as opposed to affluent nations, and this poverty-specific context contributes to general indifference and ignorance of the disease. As a native Moldovan, I was ignorant of this pressing issue in my own country because from a young age I was encouraged to look away upon seeing or hearing anything related to drug users, the homeless, criminals, etc. During my childhood walks to the internet café across the street, it was not uncommon to see alcoholics passed out in the grass a few feet away from the monkey bars, or to come across piles of used syringes. I would often be woken up in the middle of the night due to intoxicated brawls and screams that could be heard from our fourth-floor apartment. Over time, I learned to push any sense of care or concern to the back of my brain in order to live a normal life. I lived in this state of blissful ignorance and thrived on my Moldovan pride instead of questioning the current affairs and structural problems that made my
country so troubled. It was this sense of pride that inspired me to conduct research on
the place that I know and care about, as well as to make an attempt to bring some of
its urgent problems to the surface. But I felt that my exploration of existing studies
and literature was missing a human link--I wanted to hear what the suffering
populations had to say about their health, their perceptions about the current state of
their country, and their thoughts about the future that they envisioned for themselves
in the midst of such chaos. It was clear that Moldova suffered from enormous social
and health problems, but I cared more about the experiences of these sick people, who
were being extensively studied, scrutinized, and ignored, all at the same time. Despite
the disorder and personal hardships, life was moving forward for these people,
regardless of what pace. In my work with TB patients, I was always greeted warmly
and accepted into their social circles; this openness allowed for honest conversations
not only about their problems but also their thoughtful plans for the future. Their
authentic accounts indicated that, in some way, these people were coping with the
hardships presented by their living conditions.

High rates of drug-resistant forms of tuberculosis in Moldova are largely due
to interrupted treatment regimens or default from treatment, and the low
socioeconomic status of individuals in vulnerable populations further exacerbates the
difficulty of treatment adherence. Soviet occupation after the Second World War
caused massive social disorganization, and this has led to the deterioration of not only
economic and political systems, but of the state of health care in Eastern Europe as
well (Vorkas and Horst, 2009, Piko, 2004). In terms of tuberculosis, diagnostic and
treatment technologies in particular have not been made universally available in
countries that were previously under Soviet rule. This is largely due to poorly
equipped medical facilities and incompetent health care professionals, if there are any
available to vulnerable communities at all, as well as gaps in funding for tuberculosis
action plans (Acosta et al., 2014). Adherence to full tuberculosis treatment is a
multifaceted issue that wholly consumes the lives of infected individuals, especially
those in vulnerable populations who are more likely to be living in the midst of pre-
existing social, economic, or medical problems (Vorkas and Horst, 2009). There is
little data on this complex issue, specifically regarding how these conditions are dealt
with by TB patients in Moldova on a daily basis. While efforts have been made by
governmental and health organizations to ameliorate the TB epidemic in the 21st
century, I believe that a more intimate and direct look into the lives of affected
individuals is necessary to understand their struggles and in turn, to be able to provide
more useful help to them. Specifically, it is essential to have an understanding of the
cultural and psychological mechanisms of ill populations in order to be better
equipped to improve their living conditions. As a native Moldovan, I am interested in
uncovering the ways in which these individuals, specifically drug users, prisoners,
and those from rural villages, perceive their health status as tuberculosis patients, and
how this informs their coping with the disease. Outsiders with little knowledge of
Eastern European culture as a whole may presume that populations that are more
difficult to reach physically and socially do not deal with their disadvantaged living
conditions and precarious health status in an effective, or even successful way, but I
aim to dispel this notion.
Patients’ perceptions of their illness and the stress associated with it are often grounded by cultural and personal characteristics. Moldova’s poor socioeconomic conditions and collectivistic culture set it apart from the affluent Western nations in which much of contemporary scientific research is conducted. Therefore, a place like Moldova does not fit into many of the behavioral models that are created by Western, Educated, Industrialized, Rich and Democratic, or WEIRD, nations (Henrich et al., 2010). By drawing upon coping theory and cross-cultural models of coping, my thesis situates Moldovan participants in a theoretical context that illuminates their unique process of dealing with tuberculosis. I address the complexity and shortcomings of coping theory through the use of qualitative methods in the form of interviews and photographs. Such methods are advantageous in that they better enable individuals to make meaning of their ideas and experiences through the use of their own words and methods of explanation. In turn, this open form of expression enables participants to create novel connections to their lived experiences and the environments associated with them. Interviews challenge the status of participants as victims—their structure avoids the disempowerment that arises from normative perceptions of marginalized participants and gives them the power to provide a more wholesome personal account, which is difficult to extract from quantitative data (Cosgrove and Flynn, 2005). Photographs convey facial expressions and body language, as well as spatial conditions and clothing choices, and provide an intimate look into people’s lives that goes past epidemiology and quantification. Thus, they effectively supplement the verbal accounts by providing concrete evidence of lived experiences, such as how participants live and survive with so few resources. This form of qualitative data
provides information about the context of individuals’ living conditions, specifically how they shape conceptualizations of coping or the coping strategies used. As such, my photographs serve two functions: a) to be a cultural primer for marginalized Eastern Europeans’ living conditions and personal histories and b) to supplement the interview data. Based on these functions, photographs are interspersed throughout this thesis. When so embedded, the photographs facilitate a deeper understanding of Moldovan TB patients’ views towards illness, their lives, and the culture as a whole. They enable the readers, most of whom have little knowledge of Eastern Europe and the marginalized populations within the region, to better understand the role that norms and customs of the culture, as well as social arrangements, living conditions, and general perspectives on life play in tuberculosis epidemiology and outcomes in Moldova.

In order to make sense of the photographic data and verbal accounts of coping given by Moldovan participants, it is imperative that readers are able to situate themselves within the relevant cultural context. To facilitate this, I provide an extensive three-part review of Moldova, tuberculosis epidemiology, and the psychological phenomena that are involved in stress management in the following chapter. In qualitative research, especially regarding vulnerable populations who may not have an established voice in expressing their lived experiences, reflexivity, epistemology, and ethical implications are important to consider. Upon framing the background of the participants, my research methods and their limitations are described in the second chapter. The following chapter of my thesis is dedicated to analyzing specific themes were deductively extracted from the literature and the
initial reading of the transcribed interviews. Participants’ verbal accounts are linked to photographs in a manner that supports and reinforces the analytic points. The final chapter is a discussion of the findings and future considerations in this field with regards to both research and care programs. My findings provide a nuanced and intimate understanding of these Moldovan populations that can be utilized in the development of future tuberculosis plans and care programs within the country.
Moldova, Tuberculosis, and Coping

Moldova: An Introduction

Many of those from affluent Western nations rarely come across the topic of Moldova in their daily lives, and therefore know little about the country, let alone that it exists somewhere in Eastern Europe. Moldova is the second-smallest of former Soviet states, and its 33,700 square kilometers of land make it approximately the same size as Maryland. Despite its small size and population of roughly 4 million, Moldova has a turbulent history that has significantly shaped its political and socioeconomic outcomes since the dissolution of the USSR and the country’s subsequent independence in 1991. These changes are evidenced by tremendous economic hardship that ensued following Moldova’s independence, especially in the scope of the deteriorating health care system and the failed attempts at social reform (Maclehose, 2002). It should be noted that the changes having significant cultural and social impact all occurred within a very short period. The challenge of managing urgent rearrangements in a small country resulted in the degradation of the government which in turn resulted in its inability to provide necessary resources for its citizens. What follows is a summary of these political and economic challenges and the ways in which they influenced societal structures and in some cases, disappearances of old institutions.

20th century USSR. The territory that comprises the contemporary Republic of Moldova overlaps with Bessarabia, a region that has experienced a vicious tug-of-war between Romania and Russia throughout history. After annexation by the Russian Empire in 1828, the Treaty of Paris returned the region to the Romanians in
1856, yet only two decades later the Russian Empire regained partial control (King, 2000). With such a turbulent history, Moldova was never truly independent, nor did it have the experience needed to govern its own people. The post-World War I unification of Romania and Bessarabia in 1918 powerfully affected the health care system and its organization. While some infectious diseases such as malaria were becoming increasingly widespread during this time, public health was a high, if not the top priority for the Romanian government (Plugaru, 2009). The 1940 establishment of the Moldovan Soviet Socialist Republic (MSSR) under the USSR prompted further government efforts in health care, which included increases in staffing and the number of health institutions, as well as the creation of two tuberculosis sanatoriums (King, 2000, Turcanu et al., 2012). However, these incremental improvements were disrupted by the onset of the Second World War, which, by its end, effectively destroyed 80% of existing health care institutions (Turcanu et al., 2012).

The USSR implemented a new health care system in the early stages of Soviet rule as a way to reduce the negative health consequences of war (Plugaru, 2009). This new system was created under socialist principles by the Soviet statesman, Nikolai Semashko, and eventually came to be known as the Semashko system. This period saw the majority of significant reforms in health care due largely to the prioritization of controlling communicable diseases and epidemics. In order to do so, the Semashko system built extensive infrastructure and increased medical staff. Hospitals were united with polyclinics and rural health care improved in the 1950s, both of which greatly expanded hospital capacity (Toungoussova, 2006). By the 1960s, the USSR
saw even greater improvements in the form of extended funding and provision of health care. Between 1950 and 1960, the number of hospital beds per 10,000 people increased from 27 to 44, and from 189 to 415 beds between 1970 and 1994 (Toungoussova, 2006). Many valued this health care system because the government genuinely listened to the Soviet citizens who demanded better care and, in turn, provided low-cost universal health care accessible to all.

**Independence and economic context.** Upon establishing itself as an independent country in 1991, Moldova was not prepared to maintain the standard of living that was promised under Soviet rule and the Semashko health care system. Plans were made immediately for implementation of economic liberalization and stabilization programs, privatization, and the establishment of a Moldovan currency, though the economy immediately began to crumble due to a combination of internal and external factors (Turcanu et al., 2012). The Soviet health care system that Moldova inherited in 1991 was one of the most significant structures adversely affected by the economic deterioration that followed the country’s independence (Vorkas and Horst, 2009, Piko, 2004). Within the country, economic decline was evidenced by decreasing wages, inflation, and near destruction of the social security system (Orlova and Ronnas, 1999). While the internal economy was crumbling, Moldova was forced to respond to the fact that they were no longer financially supported by the USSR. They now had to rely on imports for essential goods, such as energy, that could not be produced within the country. The resulting budget deficits and social made Moldova the most indebted country of the former USSR (Turcanu et al., 2012). All of these economic circumstances of Moldova’s independence resulted
in a declining GDP: between 1993 and 1999, it fell by 60% (World Bank, 2004). Moreover, domestic unemployment rose so steeply that by the turn of the century, labor emigration became a necessary solution for many Moldovans. Remittances provided by those working abroad greatly contributed to the Moldovan economy, so much that they made up 30% of the country’s GDP in 2008 (World Bank, 2011). These external forces have greatly shaped the economic and social landscape but most of the remittances were allotted for the building sector and private consumption, rather than for the provision of health care services (Atun et al., 2008). The trend towards external employment, with 40% of the population working and living abroad, has translated to “jobless” domestic economic growth (Maclehose, 2002). The ongoing trend to work abroad has provided the Moldovan government with enough resources to manage the cloud of cumulative debt, enough so that it is projected to decline (Shishkin and Jowett, 2012). Even with these minor economic improvements, Moldova still lacks sufficient financial capital that is required to assuage the poor living conditions and deteriorating care systems that make up the internal structure of the country. Employment abroad is considered better than total unemployment, but as of 2001, 90% of the population was living on less than $1.00 per day, indicating extreme rates of poverty throughout the country (European Commission, 2001). External factors aside, the current informal economy of Moldova maintains low levels of tax collection, which in turn reflects on inadequate funding for the provision of basic services, such as health care (Shishkin and Jowett, 2012).

**Implications for health care.** The declining health care budget translated to the decline of not only the inherited Soviet-era health system, but also to the
provision of the most basic health services within the country. Vaccination services across the country were nearly completely terminated between 1990 and 1993 due to the lack of financial resources (Maclehose, 2002). The loss of access to such services was a startling change for a population that previously benefitted from free and universal health care. Much of Soviet-era health funding was allocated to increasing health staff and available hospital beds; therefore, other necessary resources such as modern medical equipment, telephones, and running water in clinics were lacking (Toungoussova, 2006). Facilities and equipment were deteriorating due to old age, and basic provision of health services was in high demand, even fundamental drugs and contraceptive services (Plugaru, 2009). It soon became clear that the previously existing health care system could not survive in the increasingly disparate socioeconomic climate of Moldova. This harsh reality prompted the beginnings of slow reform in 1998, which saw a shift in focus from bed numbers and medical staff to accommodating the population per capita rather than by bed numbers (Atun et al., 2008).

**Beginnings of the tuberculosis epidemic.** The socioeconomic changes of the 1990s played an enormous role in the epidemiology of tuberculosis in Moldova, which, up until the demise of the USSR, had been controlled relatively well within the Soviet Republics. Patients had individualized treatment plans and were hospitalized for the entire duration of treatment, and both measures kept the disease contained within hospital walls, even if patients did not wholly adhere to treatment (Raviglione et al., 1994, Toungoussova, 2006). The greatest change within Moldovan society was the overall decrease in living standards, which in turn increased risk
factors for tuberculosis contraction in the late twentieth century. Unemployment drained any chance to gather and save financial resources, so most of the population was living in inadequate housing conditions and maintained poor nutrition habits for lack of other acceptable alternatives. Because the state owned all of the land and buildings during the Soviet era, many citizens found themselves waiting for over ten years to receive their own housing (Toungoussova, 2006). It was not uncommon to share one apartment with several other families in the 1990s; twenty per cent of Moldovan families did this, or simply lived in a very meager apartment (Toungoussova, 2006). As a result of these poor living conditions, tuberculosis was able to spread quite easily due to it being an airborne disease. Additionally, hospitals and medical centers experienced extreme shortages of anti-tuberculosis drugs, due to the disruption of drug distribution regimes under the Semashko system.

In addition to the increased risk of infection, the disruption of previous drug distribution regimes under the Soviet Semashko system affected tuberculosis treatment such that hospitals and medical centers were experiencing extreme shortages of anti-tuberculosis drugs. This was especially apparent outside of urban areas, as rural communities were already experiencing much more severe outcomes that resulted from insufficient government funding (Toungoussova, 2006). Lack of accessibility to anti-TB drugs greatly contributed to incomplete treatment regimens, which in turn increased the susceptibility for others to contract the disease and for the epidemic to spread within the tightly packed living conditions (Crudu et al., 2003, Raviglione et al., 1994). During this turbulent time in the 1990s, there was much criticism regarding the failing health system in post-Soviet countries (Toungoussova,
Mass media campaigns would frequently express the dangers of these drugs and their side effects, as well as the harmful effects of X-ray exposure, which was largely due to the 1986 Chernobyl nuclear accident in Ukraine (Takamura et al., 2000). As a result, many were dubious of the doctors who diagnosed and prescribed them drugs, denying that they were actually sick because of their lack of physical symptoms.

While there is a clear link between Moldova’s socioeconomic changes and negative health outcomes, there was another component to the crisis: the biological properties of tuberculosis had drastically changed within this region. These new TB strains were resistant to antibiotic drugs, which made the disease much harder to treat. Research conducted in Central Asia and Estonia found that many new cases of drug-resistant tuberculosis were linked to previously treated cases in the same individuals (Cox et al., 2004, Lockman et al., 2001, Toungoussova et al., 2002). These findings indicate that the initial treatment was unsuccessful for these patients, presumably due to interruption or default. Thus, inadequate access to essential drugs and general medical care contributed to poor patient compliance and in turn resulted in drug-resistant strains. Due to these conditions, Moldova now has one of the highest rates of MDR- and XDR-TB in the world (Acosta et al., 2014). As of 2016, drug-resistant forms make up 32% of all new TB cases, and 69% for those previously treated for TB (World Health Organization, 2016).

**History of Tuberculosis**

Tuberculosis is an infectious disease that is caused by Mycobacterium tuberculosis, or the tubercle bacillus. The bacillus spreads in the lungs and causes the
formation of hard nodules, referred to as tubercles (Pratt, 1979). Tubercles are a result of the body’s defense reaction to the bacilli, and in most healthy individuals, this defense will take care of the infection without causing symptoms and will also provide a lifelong immunity to the disease. In other cases, however, the defensive tubercles may fail to work properly and in turn break down through a process that releases bacilli into the bloodstream (Pratt, 1979). These bacilli stimulate infection in the lungs and sometimes in the other parts of the body, resulting in a highly contagious condition called pulmonary tuberculosis. This stage is the most concerning because once the tubercles enter the bloodstream, they have the ability to travel to any organ in the body and thus complicate the disease (Pratt, 1979). The chances for this to occur are higher in vulnerable individuals, such as children and the elderly, and those with an already-compromised immune system (Dubos and Dubos, 1952). The reality for immunocompromised individuals is far worse than any other group: the HIV/AIDS epidemic has been increasingly linked to tuberculosis, with one out of every four TB deaths involving HIV coinfection (Pawlowski et al., 2012).

Since Robert Koch’s 1882 discovery of the bacillus that causes tuberculosis, *M. tuberculosis*, the context of this disease has been deeply probed over the past century (Koch, 1932). According to microbiologists René and Jean Dubos, tuberculosis is a “social disease”. Their terminology links tuberculosis to poverty, indicating that contagiousness and conventional medical approaches aside, economic and social factors are critical in the transmission of the disease (Dubos and Dubos, 1952). While there is evidence of tuberculosis in early human history, the grand entrance of the disease was marked by the Industrial Revolution in the 19th century.
It was observed that tuberculosis affected vulnerable individuals more aggressively, and these trends in 19th-century epidemiology influenced the emergence of stereotypes and stigma (Dubos and Dubos, 1952). This stigma still exists today: infected individuals in impoverished settings are often held culpable for their diagnosis and spread of bacteria, forcefully screened and tested, and subject to denouncing language (e.g. “defaulters”) (Craig et al., 2017, Frick, Delft, and Kumar, 2015). Simply put, neither they nor their disease are approached in a humanistic manner.

**Tuberculosis in contemporary Moldova.** Tuberculosis’ historical link to poverty is the key to understanding the mechanisms that have propelled the TB epidemic in contemporary Moldova. The high rates of drug-resistant strains in this region are mainly due to interrupted or incomplete treatment regimens, a problem which in itself stems from inadequate access to resources for those who need them most (Jakubowiak et al., 2008). Those who lack the resources needed to obtain a diagnosis and commit to treatment, such as transportation, access to a health center, and financial capital, are often considered members of a vulnerable population. Vulnerable populations are largely comprised of socially and economically disadvantaged individuals, racial and ethnic minorities, and those with chronic health conditions, such as mental illness (“Vulnerable populations: Who are they?”, 2006). This population encompasses a wide range of groups, such as children and the elderly, prisoners, migrants, and the homeless. For those who have the resources to get diagnosed, tuberculosis treatment is an intense and highly involved process. After initial hospitalization that can extend up to a month, infected individuals are required
to consume upwards of twenty tablets containing powerful antibiotics each day, and for MDR- and XDR-TB cases, this treatment regimen can last for up to two years (Ingersoll and Cohen, 2008, Isaakidis et al., 2014). In addition to the diligence and mental fortitude required to adhere to the long treatment, the side effects of the pills can be excruciatingly painful and include, but are not limited to, joint pain, gastrointestinal and liver dysfunction, and psychological problems (Munro et al., 2007). If treatment is interrupted in any way, the risk of drug-resistant strains increases, and so does the necessity for longer and harsher approaches to eradicating the disease from the body.

**Stress and Coping**

The socioeconomic conditions and health status of marginalized individuals often inform the types and magnitudes of stressors that they have to deal with on a daily basis. The added diagnosis of illness or disease increases both physical and psychological pressures that are put on an individual. Not all stress has a negative effect, but regardless, the human body works to adapt to such pressures (Salleh, 2008). There is tremendous variability in stress responses across humans—this fact necessitates that we understand the various components of the coping process, and more specifically, what factors may influence individuals to assess their situation and subsequently cope with it in a certain manner. Therefore, it is crucial to consider individual differences in behavior resulting from stress under comparable external conditions and the cognitive processes that shape these behaviors.

**Cognitive appraisal.** An individual must first make sense of a particular situation or environmental change before responding to it. Lazarus and Folkman
(1984) term this process of categorizing a situation with respect to its significance for well-being as cognitive appraisal. Simply put, appraisal enables an individual to understand what is happening, and based on this decide whether or not it has implications for their well-being. Appraisal provides meaning and significance of an event through a continuous process of evaluation (Lazarus and Folkman, 1984).

Appraisal is divided into two stages: primary and secondary appraisal. The naming convention does not denote one as more significant than the other, but simply as separate functions of the same process. In primary appraisal, the individual evaluates the situation as irrelevant, benign-positive, or stressful. With secondary appraisal, the individual evaluates what can be done to manage the said situation (Lazarus and Folkman, 1984). In the case of inclement weather such as heavy snow, one’s primary appraisal may be that the snow has no importance because they did not have plans to go anywhere. The snow may be seen as positive because work was canceled today, or stressful because now arrangements must be made to plow the sidewalk and pick up the kids from school early.

According to Lazarus and Folkman (1984), the two main factors that influence appraisal are commitments and beliefs. Commitment can be people or things; it exemplifies what drives an individual. Beliefs are personally formed or culturally shared cognitive configurations (Wrubel et al., 1981). Both of these factors are important in appraisal because they not only shape an individual’s lived reality, but also the meaning that is extracted from a particular situation. Aside from general beliefs about control, there are appraisals that focus on situational control, or the extent to which a person believes that they can influence a stressful person-
environment relationship (Lazarus and Folkman, 1984). These appraisals are particularly difficult to evaluate because outside of experimental situations, the object of control is complex and difficult to put within clear parameters. For example, if suffering from an illness, there may be aversive factors such as financial or familial obligations that are not related to the illness itself. In addition to dealing with pain and treatment, an individual has to grapple with preserving social relationships and their internal state.

Coping. If a particular situation is appraised as stressful, an individual will then attempt to resolve it by either mastering, minimizing, or tolerating it (Snyder, 1999). This conscious effort is known as coping and is formally defined by Lazarus and Folkman (1984) as a dynamic process in which ongoing cognitive and behavioral efforts are made to manage specific external and/or internal demands. In coping, these demands are usually appraised as taxing or exceeding the resources of the individual, therefore limiting this process to what is thought or done about psychological stress. Lazarus and Folkman’s coping theory posits that there are at least two functions of coping: problem-focused and emotion-focused coping (Lazarus, 1993). With problem-focused coping, the individual attempts to change the environment that is causing distress, whereas emotion-focused coping changes either a) the method used to act upon the problematic environment or b) the meaning of or emotional response to what is happening. It is important to note that both can occur simultaneously and that one can shape the other within the coping process. The aforementioned construct of internally and externally targeted control fits into Lazarus and Folkman’s coping
framework in that they are extensions of emotion-focused and problem-focused coping, respectively.

Similar to the appraisal process, methods of coping are influenced by one’s personal and material resources, beliefs and commitments, problem-solving skills, social skills, social support (Lazarus and Folkman, 1984). As such, it is evident that both internal and external factors contribute to the coping process. What complicates coping is that there are factors that directly affect an individual’s resources and as a result, their behavior. An example of one factor is the presence of constraints, which weaken the effectiveness of one’s resources. Constraints can be personal, such as the influence of one’s culture, or they can be environmental, in that multiple individuals are competing for the same resources. This may be especially evident in vulnerable populations where resources are already limited to begin with, such as in rural areas or homeless populations.

**Role of culture in coping.** The social environment in which we live and build our lives around is one external force that greatly shapes our coping behaviors. For many, the social environment is synonymous with culture. Culture is defined as a dynamic system of meaning that governs the norms, beliefs, and values that prescribe behavior of a particular group of people (Triandis, 1995). Cultural contexts play a significant role in the coping process by prescribing thoughts and behaviors relating to appraisal and emotional expression (Triandis, 1989, Lazarus and Folkman, 1984). The complexity of culture is often overlooked in coping research and theories, especially since many point to the idea that the number of coping theories is potentially infinite (Aldwin, 1994, Sica et al., 1997).
**Individualism and collectivism.** The framework of individualism versus collectivism has been widely used as a theoretical basis to identify and differentiate cultures. This dimension enables cross-cultural comparisons to be made based on what behaviors, norms, and values are found to be meaningful in a particular culture (Triandis, Kashima, Shimada, & Villareal, 1986). On the most basic level, social goals priorities are what differentiate individualism from collectivism: individualism prioritizes the individual with the goal of self-sufficiency, and collectivism prioritizes the group and its interests through cooperation, interdependence, and conformity (Leung & Bond, 1984, Triandis, 1995). Because cultural values have been hypothesized to play a role in coping, various research has been conducted in order to reconcile differences in coping behavior across cultures (Hofstede, 1980, Ratzlaff et al., 2000). The individualism-collectivism framework suggests that depending on the cultural setting, certain coping behaviors may be more or less effective than others (Chun et al., 2006). In individualistic cultures, for example, control over the external environment, or problem-focused coping, appears to be more common. In contrast, those from collectivistic cultures employ an emotion-focused approach to coping by regulating their thoughts and perceptions regarding a stressful situation (Chun et al., 2006).

**Cross-cultural studies in coping.** Most of the research on coping has been conducted in individualistic Western countries, and as such, our knowledge of coping is mostly guided by Western concepts. However, some cross-cultural coping research has been conducted, much of which focuses on the aforementioned dimension of

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1 Moldova is considered a collectivistic society.
individualism-collectivism. Due to the complexity of culture and the consequent necessity for longitudinal research, a consensus has yet to be reached regarding culture-specific coping behaviors. Some research has found cross-cultural differences in coping behavior, with findings that those from collectivistic cultures utilize a more emotion-focused coping approach than those from individualistic cultures (Bardi and Guerra, 2010, Cortina and Wasti, 2005, Olah, 1995, Tweed, White, and Lehman, 2004). Alternatively, some studies show cross-cultural similarities in coping behavior, which indicates some universality, or invariance, in coping strategies and behaviors (Folkman, Munet-Vilaro, and Gregorich, 2002, Gibson-Cline, 1996, Jose et al., 1998).

**Case study of gypsies coping with Nazi persecution.** One of the minority groups that was heavily targeted during the Nazi regime was the gypsies. Gypsies migrated to central Europe from the East and West in the 19th and 20th centuries in massive waves in order to escape longstanding discrimination, poverty, and overall lack of resources. Predominantly known for their nomadic nature, gypsies are one of the most impoverished groups in Europe and the world (Zielke-Nadkarni, 2010). Their poor health outcomes are linked to their minority status, and are characterized by low immunization rates, limited access to health services and treatments, as well as having the lowest life expectancy in Europe (Zielke-Nadkarni, 2010). With such poor economic and health outcomes, gypsies can be categorized as a vulnerable population, and thus be considered as a case study for coping behaviors within vulnerable populations. The persecution that they were subjected to under Nazi rule called for coping strategies to effectively deal with, and ultimately survive such
strong discrimination during this time in history. Ethnographic research conducted by Andrea Zielke-Nadkarni found two ways to categorize their coping strategies: a) protecting against the gadje, or nongypsies, through language and the utility of familial ties and b) self-determination through control of their cultural norms, values, and codes. Gypsies communicate via the Romani language, which at the time had a tradition of orally sharing cultural norms, values, traditions, and histories (Schmidt, 2007). This orality allowed for gypsy secrecy by concealing the above information from questionable outsiders and dangerous situations, effectively serving as a form of protection. Additionally, gypsies have developed a strong system of moral codes, norms, and values, which, due to their specificity, reinforce the bonds between members of this culture. A breach of any rule or norm, such as the forbiddance of a man touching a menstruating woman’s clothes, would result in severe repercussions, even death in some cases; therefore, it deterred intruders from violating the culture and its people and enabled gypsies to maintain their identity.
Methods

Overview

Moldovans in vulnerable communities infected with tuberculosis reported their ways of coping with the disease and its treatment. In this study, vulnerability is defined by an individual’s social and economic disadvantages, minority status, and chronic health conditions. These data were collected through interviews conducted in four sites, each of which embodied the living conditions of the participants as vulnerable individuals in Moldova. Photographs were taken in each study site with the aim of supplementing the verbal accounts and providing a cultural basis for participants’ reports of coping. This combined qualitative method is particularly advantageous in depicting coping in a non-Western environment as it incorporates my own partiality as a native, knowledgeable member of this culture. While the photographs serve as a means of integrating my understanding of the research setting and intimate interactions with those in it, there are constraints to my unique position in this study in terms of access to participants and their willingness to provide honest accounts of their experiences. Therefore, in presenting my methods it is necessary to discuss reflexivity and epistemological concerns to data collection and analysis.

Participants

The participants were twelve Moldovan adults who are members of a vulnerable population by virtue of their drug use, present or previous incarceration experience, rural village living conditions, and/or their status as HIV positive patients. These participants were found through a nonprofit organization named Act for Involvement (AFI), which provides tuberculosis and HIV intervention, education, and
social support in marginalized communities throughout Moldova. I worked at AFI while conducting this research, which enabled me to gain access to vulnerable populations that would otherwise be difficult to reach and recruit for the present study. Specifically, I was assisted in locating the participants by local Moldovan medical staff and social workers at AFI.

**Procedure**

Informed consent was obtained in Russian from all study participants. Data collection took place in Moldova between June and July 2017 and occurred in four distinct settings: a medical prison in Chisinau, a community health center in Balti, and two rural villages, one in Anenii Noi and the other in Maximovca (Figure 1). The selection of participants from these particular environments aimed to represent individuals from vulnerable populations. Due to social limitations and government regulations, formal structured interviews could not be conducted in a prison environment. Furthermore, many village dwellers did not consent to the recording of any interview data despite agreeing to discuss their experiences. Therefore, the interviews that were conducted in the medical prison and the two villages were informal and not recorded.

Seven participants agreed to an informal interview, after which I manually wrote significant thoughts, quotes, or any other pertinent information that was shared during each correspondence. These data are largely subjective compared to the formal interview data due to the high probability that it was mainly distinctive and striking information that I remembered and recorded. Alternatively, one hour-long formal group interview was conducted at a community health center in Balti, in which five
participants coinfected with HIV and TB consented to an audial recording of the interview. The formal interview was recorded on an iPhone voice memo application and was transcribed and translated into English. Interviews were conducted in Russian and covered the participants’ experiences in coping with tuberculosis infection, diagnosis, and treatment, their support and/or belief systems, and thoughts regarding both the challenges and motivations behind choosing to seek or reject treatment. Due to the informal nature of most of the interviews, these topics were loosely presented in the more informal environments, such as villages. In the formal interview, these topics were guided by concrete questions such as, “How did your family and friends react to your diagnosis?” and “Do you have plans for the future?”

Figure 1. Data collection sites in Moldova

In addition to the collection of interview data, film photographs were taken at all four research sites. The photographic participants included but extended beyond
the recruited interview participants, therefore most of the photographic data are not a
direct depiction of those that were interviewed. All participants gave oral consent to
photographic documentation and presentation of the photographs as data. As residents
of the communities observed my photographic data collection over time, their interest
grew and the camera became an important medium to enter the setting and bridge
communication. Picture-taking enabled me to meet more people and gain their trust in
my process. While photographing the targeted settings, I noted my own observations
of the physical surroundings, individuals’ daily activities, body language, mood, and
facial expressions.

Photographs are precise records of reality that can be understood
interculturally and cross-culturally. They provide a detailed visual record of human
life through mechanic and repetitive documentation, supplementing field observations
to extend the scope of analysis. On a basic level, the photographic data inform the
reader about Eastern European, specifically Moldovan culture. This use of the data
borrows from realist theory, in which the photographs serve as informational, rather
than experiential evidence (Sontag, 1977). Based on my positionality, I instead argue
that my photographs act as both informational and experiential evidence. My
particular position of “belonging to” this research setting provides me with the ability
to capture moments in a more intuitive manner due to my longstanding immersion in
the culture itself. Because I already know and understand the setting, there is no
necessity to plan photographic images in order to fit them into the framework of the
study; at the same time, the photographs are created in a more controlled manner
based on my own unique partiality. This is because I do not aim to present a specific
reality, but rather my own reality as it is entangled in Moldovan culture. Therefore, my experiences converge with those of the participants and in turn provide information about an otherwise unexplored context. As such, my photographs serve as the predecessor for the content analysis of all collected qualitative data. This removes the viewer’s agency in creating their own meaning in the photograph upon first glance; instead, it provides a foundational base for my analysis by creating another means of dealing with my present experienced reality. Only then the viewer’s experience with the data becomes more intimate and engaging as they become able to refer to the photographs as a means of supplementing the interview data analyses. Furthermore, the photographs incorporate an anthropological approach that allows the tracing of social practices that are embedded within them. Because stress and coping are often exhibited through social means, those concepts may be better understood through more than one medium. Environmental elements that shape the lived experiences of participants, such as living conditions and family arrangements, are also difficult to express verbally. The visual data provide such information and supplements the verbal accounts.

**Ethics**

This study was approved by the Institutional Review Board of Wesleyan University in Middletown, CT. Information about the study was provided to the participants, and informed consent was obtained from them if they were willing to participate. Confidentiality and anonymity of interviews and photographic data was assured to all participants. Participants’ names and personal information were replaced with numbers before other individuals were given access to the transcripts.
Data analysis

Content analysis, as described by Rosengren (1981), was used to analyze both formal and informal interview data. This pragmatic method of data analysis produces content-related categories in order to organize and represent data, and therefore is a useful tool for analyzing text and interpreting meaning from data due to its flexible nature. The approach to content analysis can range from intuitive and impressionistic to structured and systematic, depending on the goals of the researcher (Rosengren, 1981). Given a researcher’s familiarity with their data, the categories follow a naturalistic paradigm in which both the interview questions and initial coding categories are based on existing knowledge or prior research (Hsieh and Shannon, 2005). The present study uses directed content analysis, which utilizes existing theory and research to identify key concepts as initial coding categories. This form of content analysis can provide both supporting and nonsupporting evidence for a theory, thus enabling the extension of existing knowledge. Any textual data that cannot be organized using these predetermined codes is given a new code, put into a subcategory, or left uncoded.

Interview transcripts and records were initially read multiple times in order to immerse and acclimate the researcher to the data in its translated form. The data was then coded for anticipated and predetermined themes of social support, perception of self, and perceptions of diagnosis and treatment, all of which were based on preliminary research on culture and coping, previous research studies on this topic, and my own knowledge of disease within Moldovan culture. This was initially done for a small sample of the data in order to ensure validity of the developed coding
scheme. The coding was highly consistent for this sample and therefore was used for the rest of the data. Because these initial coding categories were so broad, most of the accounts fell within a subcategory of each theme. Data that were uncategorized were identified and analyzed again to determine if they could be placed into a subcategory of the main themes, as there was insufficient uncategorized data to constitute the creation of an entirely new category. The data that were ultimately left un-coded consisted of answers that were not specific enough or pertained to a highly personal account that did not relate to the research topic. In order to ensure reliability and reduce bias, the interviews were re-coded by another individual with no knowledge of the research topic. As a result of this review, four major categories relating to participants’ coping with tuberculosis emerged: experience with treatment and the disease itself (psychological and physiological effects), the impact on social relations and support (family, friends, peers), practical coping (day-to-day motivation and drive), and emotional coping (managing emotions, religion).

**Photographic data analysis.** Photographs were selected based on their relevance to each of the four coding categories. For example, photographs of medical facilities were applied to the first category of participants’ experiences with treatment and the disease itself, photographs of social settings were applied to the social support category, and photographs with religious subject matter were applied to the emotional coping category. Most of the selected photographs applied to one subcategory in each of the four topics due to their specificity and the context in which they were taken. Once applied to a subcategory of one of the four topics, each photograph was provided with textual information based on the visual content that it represents, as
well as my own additional knowledge of the context beyond the limits of what the photograph shows.

**Reflexivity and Study Constraints**

Accurate human observation has historically been a concern in social science. There is little that can be seen without personal biases or projections, and this certainly applies to photographic records, in which the photographer controls the focal point of each observation. My positionality as a native Moldovan allows the photographic orientation of each encounter to be more controlled and authentic due to the entrenched sense of familiarity with this particular environment. This position garnered participants’ interest in my project and allowed me to establish a rapport, which gradually increased throughout the data collection process due to my adjunct professional duties to provide disease intervention and treatment assistance. Such intimate time spent with the participants is crucial to the collection of authentic and realistic data. The overt nature of the photographic process enables the participants to be able and willing to better grasp the goals of this work; in turn, they put themselves in a position to help achieve the project’s goals. This type of relationship helps constrain any expectations that the researcher may have prior to entering the photographic setting, since the photographer is not the only one with power to manipulate the environment. It also possibly contributes to the wholeness of my role as a researcher within this culture—my knowledge of the research setting and target population informs each component of this study, especially the initial questions and approaches to data collection and analysis.
However, awareness of my relationship with the research setting is critical. While my epistemological assumptions are grounded in my history and familiarity with Moldovan culture, this self-awareness limits other possible perspectives that may arise as a result of conducting research in this specific setting. It is also important to consider the role that this intimacy plays in the goal to be as neutral as possible in social science research; it is nearly impossible to set aside one’s political, economic, and cultural experiences and beliefs in any research setting. For example, I am likely to see certain behaviors within this cultural context as “normal” and overlook them in favor of others, thus omitting what could be crucial information from my data.

Researcher Donna Haraway (1988) deconstructs the idea of traditional objectivity and attempts to reconcile the perceived necessity of a pure and omniscient scientific gaze, specifically within observational research. The concept of situated knowledge moves away from the traditional scientist’s “view from above” and instead views subjects as complex and eternally variable being, thus rendering abject relativity impossible. Haraway posits that the act of seeing is active and, therefore, intrinsically linked to our own multifaceted experiences, perceptions, and positions in the world. This results in a contradictory and partial role of the observer which leverages the multidimensional nature of subjectivity; this embellishes the observational process rather than constraining it.

Given my knowledge of the language and culture, as well as my previous position as an active member in this particular setting, my partial vision provides me with a positive advantage rather than a limiting one. Readers are seeing through my partial vision, and while this view may help resolve ignorance of this topic and
cultural setting for readers bearing different perspectives of the world, it requires a more critical approach to the organization and analysis of the collected data on my behalf. My perspective here is particular and embodied, and extends to my vision within the photographic process. If placed in my research position, outsiders would likely have a differing vision of the setting, in that what environmental elements would draw and hold their attention likely contrast my own. This is especially relevant to the photographic data collection process, as I argue that photographs themselves pinpoint one’s field of vision in any environment in the same way that spoken words solidify the superfluity of our internal thoughts. The highly automatized and technological “eye” of the camera captures my perceptual framework and my own, active way of seeing the environment. As such, my partial vision extends to my photographs in this study based on this specific embodiment of the research context.

There are epistemological concerns that extend beyond positionality, namely those arising from the research setting itself. As indicated in the data collection section, interviews in villages and the medical prison were conducted informally and were not recorded in any way, aside from a film camera. Those who live in villages are wary of outsiders and those who do not identify with or fit into the long-standing framework of the small community, as the villages are often multi-generational\(^2\) and unrelated individuals are often considered to be a part of the large-scale family. This especially applies to medical staff and “professionals” of any sort due to the often-

\(^2\) In this context, multigenerational refers to multiple generations being born into the same community more so than multiple generations presently inhabiting one residence, although both are often true in a rural Moldovan setting.
invasive questioning process of these professions. Despite the fact that I was accompanied by social workers during my visits, many of the participants did not wish to be recorded because they feared that their accounts would be examined on a governmental level. Additionally, many of these individuals live a very primitive lifestyle, free of technology and other modern advancements, and therefore feel raise their guard at the mere sight of such unfamiliar tools. While they nonetheless agreed to answer my questions, and did so in a nonchalant manner which, to me, indicated honesty, their apprehension to being recorded may have skewed their responses to be less detailed for fear of scrutiny. Alternatively, these communal boundaries were present in a different manner in the prison research setting. Participants in the prison indicated their reasoning for rejecting to be recorded as having to do with the confidential nature of prison culture [in Eastern Europe]. Despite this sense of secrecy, many of the prisoners whom I spoke to were eager to answer my questions and divulged much more detailed information than the villagers. Their openness enabled me to be comfortable enough to share more personal information about myself, and in turn, they welcomed me into their community, even gifting me with fruit and a wooden carving.

These informal interviews required me to recall participants’ accounts after the fact; in this case, human memory is a significant limitation to this component of the data collection process. This limitation merits the recapitulation of Haraway’s theory of partial vision. My recollection of participants’ narratives was largely grounded in my existing knowledge of these individuals and their lifestyles, living conditions, and cultural context and therefore mainly consisted of information that
was novel and relevant to me, firstly as a member of this culture and secondly, as a researcher. More vibrant and intimate accounts were given in the prison setting, but despite this, my own memory limited my recollection of information; this resulted in my data for both settings being of equal length.
Results: Analysis of Stress and Coping

The participants employed various strategies to deal with their illness and overcome the challenges stemming from it, and this chapter analyzes their multifaceted approaches. Drawing from Lazarus and Folkman’s framework of coping, as well as Slomka et al.’s (2013) study on coping with HIV, four themes could be identified in the interviews: tuberculosis stressors, practical coping, emotional coping, and social support. Each of this chapter’s sections provides insight into participants’ daily lives in terms of the challenges that they face and the solutions they create to ameliorate them, given that they have the desire and sufficient resources to do so. Furthermore, these coding frameworks inform our understanding of participants’ visions for themselves and their futures based on their lived experiences with tuberculosis.

In looking to identify the ways in which marginalized Moldovans cope with their condition, it is essential to appreciate the challenges they face. The first section of this chapter explores various stressors and concerns that participants describe as having significant impact on their journey with tuberculosis, such as side effects of medication and their trust in the Moldovan medical system. These accounts inform the sections relating practical and emotional coping as methods used by participants to conquer their condition. Practical coping involves dealing with the demands of tuberculosis on a daily basis, whereas emotional coping covers cognitive frameworks that participants develop and modify to manage their emotional state as it relates to the extensive process of diagnosis and treatment. The final section on social support
examines resources that the external networks of friends, family, and medical professionals may offer throughout participants’ experiences with tuberculosis.

**Stress and Challenges of Tuberculosis**

“*Can you imagine what my stomach and intestines look like?*”

The prescribed course of treatment negatively affects the body and the mind, requiring patients to cope with the difficulties of the disease itself. Diseases differ in the amount and type of stress imposed on affected individuals, and for a particularly difficult disease like tuberculosis, it is also necessary to consider the physiological and psychological stress that arises from taking the medication in the analysis of the coping process. Tuberculosis treatment is particularly difficult for those who have a drug resistant form of the disease, and the newfound responsibility of having to take upwards of forty pills on a daily basis for a prolonged period of time comes with its own challenges. To a certain degree, these challenges relate to the trust that must be put into the medical system, ranging from the competency of healthcare professionals and the efficacy of the medicine, to the social obligations of the government to those who need the most assistance within Moldovan society. In addition to the insufferable treatment process, many marginalized Moldovans are further burdened by other health conditions, as well as their nescience, preventing them from being able to successfully take charge of their own health. These problems, many of which relate to the lack of sufficient social and medical resources, have significant impact on patients’ perceptions of the disease and in turn, adherence to treatment.
The Moldovans living with tuberculosis whom I interviewed gave voice to the stresses they experienced on both a daily and long-term basis and described how these stresses are due not only to their illness but also the inadequacies of the healthcare system. This section reports on participants’ thoughts and experiences pertaining to the medical effects of tuberculosis treatment, as well as the roles of incarceration and coinfection status in the treatment process. Participants discuss their perceptions of the Moldovan healthcare system as a whole, including the efficacy of the medication and credibility of medical staff, their experiences with negative psychological and physiological changes, and finally, their experiences with coinfection and incarceration. The accounts of these stressors serve as a primer for the following sections on coping by presenting the participants’ challenges throughout the treatment process.

**Trusting the medicine.** In describing their experiences with tuberculosis treatment, many participants first shared their disdain and distrust of the Moldovan healthcare system before sharing anything else. All of the participants in Balti reported being compliant with the treatment programs that were accessible, but throughout their treatment, they questioned the efficacy of the prescribed medication due to its harsh side effects and the sheer length of the treatment process. For them, it was often difficult to see the light at the end of the tunnel, as they were not provided with auxiliary support that is crucial for successfully undergoing treatment, such as nutritious food, financial assistance, and most importantly, additional medication to mitigate the side effects of the tuberculosis pills. Because efforts are primarily directed to eradicating the tuberculosis bacteria, these other resources are not seen as
‘medical’ and, therefore, are often not considered as treatment tools by medical professionals. When describing their experiences with treatment, participants emphasized that their poor social, economic, and/or health status was a precursor to the ways in which the treatment process unraveled for them.

Participants also indicated extreme variations in tuberculosis treatment, and attributed this to their significant vulnerability within the healthcare system and its offerings as a result of their low socioeconomic standing. Ivan and Artem made

Photograph 1. This is a room in a tuberculosis hospital in Chisinau. Each room holds 2-4 patients during the initial month-long hospitalization period upon diagnosis or in cases of extreme side effects and pain. Due to the small size of the room, there is little space for personal belongings; most patients keep a book or a pack of cigarettes. While basic accommodation is present, the rooms do not hold any medical equipment or means of sanitization. The large number of rooms and limited medical staff on each floor may indicate that medical delivery is often delayed.
multiple comparisons to tuberculosis treatment in the United States, indicating awareness that in other, more developed settings, treatment is approached in a significantly better way due to increased financial opportunities. They declared that Americans have their own personal hospital rooms and are prescribed more manageable treatment regimens. In an impoverished country like Moldova, these opportunities are severely limited. While treatment is available to all individuals, many believe that it is used as an experimental medium due to the marginalized status of many Moldovan patients. As Ivan stated, “We have absolutely no rights. That is, you become an experimental rabbit. That’s it. So here, they can try on you that which is still not allowed in other places.” Many participants expressed sufficient knowledge of the disease and believe that even in the worst circumstances, it should be treatable within a much shorter time frame. On the other hand, they have little information about the pills themselves, knowing only that they have serious side effects whilst treating the main problem. This incongruent understanding raises suspicion in patients of medical staff for prescribing a treatment that is so lengthy and involves so many pills.

Consequently, the medication is approached warily because some participants can tell its country of origin, meaning that pills from the United States are seen as superior to those from less developed, non-Western countries such as India. They often use this sole piece of information to compare their treatment regimen to that of other infected individuals, namely the same doctors who prescribe the treatment to them. In some cases of reinfection, participants expressed that their new tablets were visibly different from those taken previously. The differences in side effects between
pills from India and the United States were “obvious” to them: “you can see it yourself”. Pills from India are estimated to be cheaper, but in turn produce much more adverse side effects. Ivan was incredulous that there are such significant differences in treatment plans:

The same doctors that are in the risk group for TB, get treated for half a year.
We get treated for two years. See the difference? … They got TB open form, and resistant. You want to say that you can treat them with four pills a day? … I got the resistant form twice. The first time I took thirty-five pills. Can you imagine what my stomach and intestines look like? I would express it more clearly… but that would be uncultured.

The few Moldovans who do have financial resources were said to have better relations with medical staff and in turn, be given better care, such as quicker medical response time and attention. But most individuals do not have such opportunities, and are evidently treated worse. Artem explained that he could be speaking to a doctor in Russian, and the doctor would respond in Romanian. As a result of this barrier imposed by the doctor, Artem was unable to communicate that the side effects of the medication were becoming unbearable and that he needed assistance in alleviating them more effectively. Consequently, he did not receive any information from the doctor that would be useful in helping him better understand and manage the treatment. When he was admitted to the hospital, both he and a patient next to him waited two hours for an injection, despite the fact that the other patient was in so much pain that he could not walk. These patients want to get treated to feel better;
therefore, in similar situations, participants simply accept the inadequacies and get by on what little they can understand or are offered at medical facilities.

**Psychological effects.** Diagnosis and treatment interfere with many facets of life, yet all participants addressed the side effects of the medication as one of the, if not the most difficult, aspects of treatment. While psychological distress, such as hopelessness and fear, is a common effect of diagnosis and treatment, participants did not discuss this effect as much as their drug-induced psychosis as a side effect of treatment. All participants experienced drastic changes to their psyche quickly after initiating treatment, and all of them noted that many of these effects lasted for months. Ivan reported that the medication’s extreme psychological effects were the primary reason for the difficulty of undergoing treatment:

I finally felt it in the second week. When I started to walk… I can’t show you, but I couldn’t walk without holding on to the walls from taking the pills. I would walk, for example, from the kitchen to the hallway, like 50 steps… after 25 steps, I would ask myself: “Where am I going? Why am I walking? Will I even get there?” I would turn around and go back in the opposite direction to my ward. I would just sit down, and immediately remember, oh… I was going to the bathroom.

Can you imagine, to what extent this treatment blows your brains out? You think that with this I had the opportunity to think about other things? Only after two months it finally calmed down and I started to ponder how fatal this truly is, and what awaits me next.
The intensity of the medication’s psychological effects apparently is strong enough to drive some patients to commit suicide, as revealed through participants’ personal anecdotes of such events. There is little emphasis on mental health resources in Moldova, and because of this, many “go crazy” on the medicine and multiple participants even reported cases of patients jumping off of buildings because they weren’t caught or helped in time. While it was pointed out that one’s body gets used to the side effects, the impact extends long beyond this initial phase of treatment. The toll on mental health is severe because rather than rejoicing about the plateauing of psychosis, most participants recounted the slow but imminent onset of depression. Some further divulged that all they could think about was their condition, and worried what other side effects or problems could arise at any given point in time.

**Physiological effects.** The side effects of the medication are physiological as well; while the treatment is intended to kill the tuberculosis bacteria in the lungs, other internal organs suffer at the expense of this goal. Sabina described extreme and debilitating fatigue that persisted not only in the initial stage of her treatment, but intensified as soon as she took her daily dose of pills:

I laid in bed for around 6 months. For half the day, I was fine, then after I took the pills, right at 4 PM, I lost any energy I had. This was with the American pills, back when they were here for the first time. And it was like this for half a year.

Artem chimed in to include that this lethargy is often coupled with more targeted internal changes, such as “killing” the liver and intestines. These effects are so severe that participants were effortlessly able to tell me which specific organs were
affected, even in the absence of an additional medical diagnosis. The strain on internal organs is a slow process and intensifies over time; in contrast, this feeling of immobilization set in quickly and took the participants by surprise. The unexpected fatigue resonated with many because they initially felt fine and did not experience initial symptoms or indicators of any form of illness. Fatigue corresponds to the inability to begin and/or complete an activity, and for many participants, this stems from lower body pain, particularly in the legs. After briefly revealing her uncomplicated experiences of obtaining pills in Chisinau, Sabina pointed out that, unlike her, most patients have to walk to medical facilities on a regular basis to pick up their medication. She knows of others for whom this is especially challenging, as they live in areas in which these facilities are distant and therefore difficult to reach on foot. More populated cities, such as Chisinau and Balti, have more accessible medical centers due to the availability of public transport; the majority of Moldova is otherwise rural. Oleg, a Maximovca resident, ranted that his social and physical immobility threatens his capacity for health in addition to carrying out daily tasks, such as earning his livelihood as a construction worker. The participants from Balti had knowledge of certain government programs in place in which social workers bring the medication to the homes of significantly debilitated patients, such as the elderly, or those who live in a single rural household. However, such programs were believed to have sparse influence due to financial restraints and the ratio of available social workers to the number of patients who need these services. Therefore, most patients are required to take the initiative upon themselves; as Sabina shared:
Of course, it’s easier when someone brings them to you. I had to go every day to get my pills. On the way there you can barely walk, and on the way back you can’t even walk too because you feel so sick from the medicine. Your legs hurt, you’re so tired and you wonder how you’re going to make it home. Those poor people walk every day to get their pills.

Some participants indicated that they divide their 18-pill dose in half because the physical stress and pain on head and body is so strong. Despite these difficulties, it was unanimous among the Balti participants that the prescribed course of treatment must be endured and followed through to the end. Prior to moving on to the next topic, Vasily shrugged and said that you simply have to accept this because, “Medication affects every aspect of your life, so you have to get used to the effects of taking 18 pills a day for 2 years.”

**Coinfection.** The prevalence of HIV in Moldova is growing and in turn is causing tuberculosis and HIV coinfection rates to increase. In their reports of being coinfected with HIV, multiple participants expressed more expansive difficulties in treating their conditions and avoiding further immune breakdown than those who were only infected with tuberculosis. Many of the Balti participants were current or previous drug users and had become infected with HIV through their drug use. Although they did not go into detail about their own experiences with HIV treatment, they were in agreement that their already-compromised immune systems contributed greatly to becoming infected with tuberculosis, with Ivan asserting that “if you’re weak, you’re ready for it. Especially us who already have HIV, HIV and TB are like
brother and sister. They don’t go without each other.” Hepatitis was also revealed as a common secondary infection; Ivan admitted that “almost everyone has those too, especially those of us who have used any types of drugs.” In cases of coinfection, nearly all participants noted an increase in secretions coming from their body, particularly the nose and throat, which they attributed to their weakened immune systems. Their impaired immunity increased their susceptibility to less threatening, but nonetheless serious conditions as well, such as bronchitis. Ivan reported on his experience with this, sharing that:

Here it’s like, you get sick, and you get the secretions again. [coughs] The phlegm starts accumulating in your throat in the presence of being sick. For all of us who have been sick and in the hospital, most of us have severe issues with this bronchitis…it’s chronic. This… when you cough and spit it out, it’s genuinely scary, because it’s so green.

**Incarceration status.** Some of the participants were presently incarcerated; due to their tuberculosis infection, they were serving their time at a medical prison in Chisinau, the only one of its kind in the country. Shura revealed that the treatment process for tuberculosis occurs differently in prison, and further explained that the medicine is brought to the patients daily; all they have to do is take it. He maintained that it’s better to get treated for tuberculosis in prison than out of it because the difficult routine of acquiring the medicine is not required. He and his fellow prisoners do not have obligations to a job, nor do they have anything else that might get in the way of them getting their medicine on a daily basis, therefore, they feel that they are
less likely to interrupt treatment for a few weeks or a month. Ultimately, the prison participants agreed that there is no point in rejecting treatment, especially because they know that the disease is treatable and the daily medication routine is very accessible within the prison.

Photograph 2. A prisoner in the Chisinau medical prison is cooking himself a meal in the kitchen. Prisoner access to the kitchen is a privilege for few individuals, the others are given food cooked in bulk, such as soups and stews, through slots in their doors. When I asked the prisoner that was showing me around why this specific man had access, his response equated to something along the lines of, “he’s a gay.” Most prisoners have some form of free time, even those with highly contagious infections such as tuberculosis. I did not see any medical staff wearing face masks or other protective garments in the prison, nor was I offered any. Once the prisoners are successfully treated for their condition, they are sent to a regular prison, but one participant stated that in such cases, reinfection is likely.
Practical Coping

“You want to live: you have plans, a future.”

Practical coping is the ability to cope with the everyday demands of life that are associated with tuberculosis. This form of coping largely consists of active efforts to assuage the daily stressors and problems that stem from living with the disease. Here, practical coping closely resembles Lazarus and Folkman’s concept of problem-focused coping, defined as individual attempts to change the environment that is causing distress. However, their definition is broad and does not focus specifically on factors associated with disease management. Therefore, the term practical coping is used here as it is defined and explored by Slomka et al.’s (2013) study of coping with HIV. Their form of coping emphasizes adaptations to the immediate, day-to-day difficulties of tuberculosis. It warrants a note here that practical coping differs from emotional coping and social support in that it links cognitive reframing to action directed at the problem itself. Such efforts include behavioral and lifestyle changes, as well as long-term changes having to do with one’s plans and goals in life—both require acceptance of the problems at hand in order to actively begin resolving them. As discussed in the previous section, significant and challenging stress arises from tuberculosis infection; the magnitude of this stress raises questions on what gives incentive to individuals to overcome these challenges and be able to adhere to their treatment regimen.

This section relates the factors that motivate participants to undergo full treatment, as well as the cognitive and behavioral changes that they adopt to overcome the difficulties of this process. The following account, moreover, includes
the reflections of participants concerning their future plans and daily lifestyles as dictated by tuberculosis.

**Lifestyle changes.** When describing their initial diagnosis and initiation of tuberculosis treatment, participants expressed that they quickly acquired the responsibility to make significant lifestyle changes in order to successfully manage their condition. Artem shared that the first change that he experienced was the immediate awareness of the possibility of infecting those around him, namely friends and family who he interacted with on a daily basis. This was significantly felt when at home, where Artem took it upon himself to isolate himself as much as possible from the family in order to protect them. He took his contagiousness strictly by getting his own set of eating utensils, such as silverware and bowls, so that he wouldn’t touch anyone else’s and no one would touch his. Ivan echoed the idea of taking his condition into his own hands, because otherwise no one else would:

> Literally after one week, with open form [of TB], I walked freely in the city and only after a week laid [in the hospital]. There was no space! No police looked for me, no rights-protecting people were chasing me because I had the open form. No one ran after me or looked for me.

Numerous participants were highly aware of the high risk of infecting others, especially in their daily trolleybus commutes, and were extremely concerned that they could have infected anyone in their vicinity. Artem reported that “anyone could walk into a trolleybus, and there would be five people whose immune system is already compromised or weaker than the norm.” Others echoed the concern of the nonexistent
efforts at infection control within their cities, especially given their knowledge that
many citizens were living with weakened immune systems and, therefore, were
susceptible to tuberculosis. Given this knowledge, one major lifestyle change that
many chose to make was self-isolation. Gennadiy was living with his girlfriend when
he found out that he was sick, and chose not to disclose his condition. Instead, he
“threw everything away and just left her” and started drinking heavily in seclusion.
His reasoning for this decision was not based on shame or stigma surrounding the
disease, but rather on the fear of infecting loved ones: after his girlfriend’s multiple
attempts to obtain answers, he took her to the side, grabbed her, and sternly said, “I
don’t want you to get sick from me”. She expressed that it didn’t matter to her and
that she still wanted to live with him, and while ultimately they ended up living
together for ten years, Gennadiy maintained that he knew of many others who chose
to live in solitude in silence, stating that “there’s a lot like that”.

**Substance use.** Many participants also conveyed the role that substance use
plays in relation to lifestyle changes. For Sabina and Ivan, consuming less alcohol or
completely ending their relationship with substance use was a significant change that
they had to make in order to ensure a smooth course of treatment:

The most important thing is to not drink. It only makes the drug resistance
stronger—the vodka can wait. Just get better, then you can drink all you want.
But some start both taking the pills and drinking…. then they have drug
resistance, and nothing can help.
I mean, you get the information that you need to get rid of the disease, and you do it. You have to take the pills on time as the doctor prescribes. No consumption of alcohol, no drugs…lead a normal lifestyle in order to rid yourself of this sore. That’s it. The doctor tells you what, how, and why, so that you can get rid of it.

Sabina and Ivan indicated a strong desire to eradicate the disease and get better, and in order to do so, collected and assessed information on how to have the most successful treatment possible. Multiple participants echoed that they had a history of substance abuse, especially with alcohol, but they immediately changed this part of their lifestyle upon realization that their actions would likely lead to drug resistance, and even death. It quickly became apparent to them that it was not an issue simply regarding alcoholism, but a matter of life or death. However, Artem chimed in to say that “almost everyone drinks”, regardless of their knowledge that substance use is detrimental to one’s health, especially if combined with something as strenuous as tuberculosis treatment. He added that “those who drink are the ones who don’t want to live” and strongly emphasized that one must have a desire to be treated; otherwise, “he’ll drink and keep drinking”. In one of my social work-related within village populations, my group traveled to a village in order to locate a few diagnosed individuals and ensure that they were diligently taking their daily dose of tuberculosis medication. One man that took us some time to track down was found passed out on the grass nearby, clearly due to alcohol intoxication as indicated by the strong smell enveloping him. This man was living in a single household, and, having no one to
hold him accountable for his behaviors, was having difficulties regularly adhering to
treatment. In another related experience, my team provided support to an elderly man
who was in treatment for tuberculosis. He was also coinfected with hepatitis and
suffered from liver problems due to his heavy drinking. The resulting immobility
from these conditions and his old age required food to be brought to his home directly
by social workers. On these weekly visits, old food would be found sitting on the
windowsill: products would be barely touched, covered in mold, and infested with
ants. The patient barely ate and spent most of his time sitting in his bedroom and
consuming various substances. A week later, we were notified of his death, which
was due to liver failure. I discovered that those who live alone, either by choice or
due to personal circumstances, were most likely to find themselves in these situations,
and use substances as a negative coping mechanism.

Gennadiy reiterated his reliance on alcohol to get him through diagnosis and
the challenges surrounding it, and linked the hopelessness that resulted from these
initial difficulties to his fear that he would lose his loved ones through his own fault.
Maxim shared that at one point when he was out of prison, he was injecting and in
treatment for tuberculosis at the same time, indicating that drugs were the only thing
that powered him through the psychological and physiological effects of the
treatment. Both of these participants realized the detrimental effects of substance
abuse and ceased these behaviors early on, but their peers who continued consuming
substances throughout their treatment were not so fortunate. Sabina explained that for
some patients, the realization that substances would completely negate their treatment
came too late and ultimately resulted in death:
They ask, “why isn’t the treatment working, why aren’t I getting better?”

They soon realize the reality and drop the alcohol, but it’s too late and the medicine isn’t helping…only on the other side. That’s it.

Photograph 3. A patient coinfected with tuberculosis and hepatitis.
Motivation for treatment. Many participants repeatedly shared that motivation is a significant part of adherence to tuberculosis treatment with its harsh effects on the quality of life. Some motivations were internal, whereas other incentives were tied to the external world and other people. Sabina voiced that it is imperative to want to get better for your own sake and wellbeing, holding that it was the only way to get herself to make the difficult journey to the health clinic on a daily basis. She also shared that she “wanted to get treated, and wanted to feel better and escape it”; those who don’t want to “are not in this world.” Many realized that their condition brought them to an extreme crossroad in their lives: it was a matter of life or death. Based on this awareness, multiple participants’ internal motivations stemmed from the desire to survive. When prompted for further explanation on this
topic, Artem simply stated that he “wanted to live”, elaborating that this came before everything else in his life. Sabina was particularly proactive in this regard:

Yeah to be honest, in the beginning I was breaking the barriers by myself for myself…I knew that I needed, this and that and that. When I got sick I searched on the internet, I knew what medicine I needed, what bacteria I had. I acquired the information I needed. Where I worked, I knew people who were helping make calls to doctors. Their connections helped me a little…but it’s very hard, especially to get what you need for yourself when you’re in this condition.

Nearly all participants consistently linked their will to live to the idea of having future life plans. As Ivan stated, “how can you be without plans?” Gennadiy echoed this by adding that “as soon as you find out, your plans immediately start to change.” Marianna, presently incarcerated, had already created plans for her future prior to getting sick, confidently stating that they remain the same despite her condition and that she will accomplish them upon finishing treatment and being released. She attributed the optimism regarding her health to these firm plans, echoing the statement that plans serve as a motivator to get through treatment. In one case, my coworker tried to convince a village patient to start taking his medicine again by bringing up the fact that he was young, and therefore he must have plans for himself and his future. While the patient readily agreed that this was true, this statement, among others, did not persuade him to take his illness seriously.
Although the primary motivation for most participants was to get better for themselves, external motivators such as family and close ones also served as incentives to successfully complete treatment. Participants’ plans for the future often included family members, such as spouses or children, and the possibility of infecting them was a primary motivator in the early stages of treatment. For Ivan, this was a clear motivator because:

I have two boys, a brother, a wife. I could infect 4 people, of course it’s easy to do so. And this first week I didn’t live at home, you can even say that I lived on the street. So of course, you think to yourself to not infect others.

During a social work visit, my team was sent to check up on an infected man to ensure that he was adhering to the treatment regimen. It was discovered that despite being ill, he was actively taking care of his family by farming and doing construction work around the property, and maintained employment elsewhere. He expressed that the wellbeing of his loved ones and long-term family plans motivated him to maintain an active role as a provider for his household and be successfully treated. In contrast to the concerns about contagiousness, Efim was more optimistic, saying that “tuberculosis is treatable, so it should not stop any plans you have for your future.” The treatability of tuberculosis was linked to the knowledge that the condition and treatment is not a permanent part of one’s life. Efim also asserted that he would have to be in this horrible state for a few years at the most, so it was worth it to overcome treatment in order to live and see his family.
Photograph 5. An infected man who was successfully adhering to his treatment regimen. He kept himself busy by working to provide for his family, renovating his home, taking care of his chickens, and maintaining meaningful relationships with his neighbors.

For another prison participant, Andruha, motivation comes from the community within the medical prison. As an individual with significant power, he would get his mind off of the difficulty of treatment by carrying out a role as caretaker for other prisoners. Through this familial network of support, the prisoner community motivated each other to live normal lives despite the difficulty of treatment. However, this attitude did not extend to the older participants so much; as Constantin, a sixty-year-old prisoner, declared:

I’m old, I don’t have a future outside of my children and grandchildren. I’m doing it because I love my children, not because I love myself. There is not much of me.
These accounts depict how individuals cope with the stressors associated with treatment in order to function on a day-to-day basis. This practical coping involves modifications to lifestyles, motivations, and/or future plans that individuals take on to accommodate the significant life changes accompanying diagnosis and treatment. Although much of this section deals with changes in thoughts and behavior that focus on the problem of tuberculosis itself, it is important to consider the role of emotion regulation and the social environment in the coping process; the following two sections explore these matters respectively.

**Emotional Coping**

“Our type of people can adapt and get used to everything.”

Emotional coping entails resilience in dealing with distressing emotions caused by diagnosis and treatment. Rather than focusing on the stressful situation, this form of coping aims to manage negative emotions, feelings, and attitudes by modifying the perspectives from which the individual approaches their condition. The definition corresponds to Lazarus and Folkman’s second function of coping, emotion-focused coping, which involves changing meanings or emotional responses to the stressor. This strategy enables individuals to adjust the negative impact of stress by giving them the power to adapt to the stressors and subsequently accept their reality. By doing so, individuals become more apt to find strength and positivity in their lives and, in turn, avoid negative emotional responses to stress, such as hopelessness and frustration. Despite the usefulness of this definition, it is quite broad—I find it important to consider external elements that may contribute to the internal regulation
of emotions in the context of a collectivistic culture. Given the cultural specificity of this analysis, I extend this term similarly to that of Slomka et al. (2013) to include the use of religious faith as an approach to addressing negative emotions. The vast majority of Eastern Europeans believe in God; 95% of Moldovans express this belief (Mitchell, 2017). Therefore, I expect religious beliefs to influence participants’ emotional coping.

Emotional coping can also involve cognitive adjustment, in which the individual develops self-love by adopting an optimistic and positive view of themselves despite the problematic situation. In some cases, this form of coping can become maladaptive in individuals who have negative perceptions about themselves in terms of their self-esteem and their future. This section reports on participants’ reflections on their self-perceptions, their methods of managing negative emotions that arise when thinking about their illness, and the role of religion in their lives. Participant accounts are explored throughout various stages of their condition as they reveal how their emotions and perspectives have changed over time.

**Managing negative emotions.** As mentioned in the section on coping with stress, upon initial diagnosis, nearly all of the participants encountered severe physiological and psychological stressors. They explained that many of these stressors, such as malfunctioning of internal organs and psychosis, contributed greatly to a decline in their quality of life. However, they often emphasized that, in the midst of these challenges, the negative thoughts and emotions regarding diagnosis and treatment diminished over time. While this process was sometimes revealed as
conscious and deliberate, multiple participants greatly related to Ivan’s account of this occurring outside of his awareness:

In the TB ward, of course in the beginning you think that you have this one main problem, and you nearly spin yourself into a cycle thinking about it. After that passes in 2 or 3 weeks, a month, that’s it. It gets forgotten. That’s it, you live your life the way you lived it up until that point. It’s just that your own personal state is limited. That is, you get used to it, don’t dig yourself into a cycle or a hole, that is, how you lived before. It’s unavoidable, it’s not something you can take out of your pocket and throw away. You’re going to have to live with it. And life does go on. You come to your senses, don’t want to shoot yourself anymore. Nah. Even when they told me I had HIV too, I was like, well, maybe I don’t have it. No, you have it! Well, okay, we’ll live. But in the beginning, I wanted to hang myself.

After the initial loop of negative thinking that he adopted upon initiating treatment, Ivan’s self-described process of emotional adaptation largely rested on his ability to accept his present situation as unavoidable rather than simply terminal. For many, acceptance was entrenched in understanding that this part of their lives was an obligatory hurdle to pass, with no other way around it. Such reframing of negative emotions was a powerful step in the treatment process and enabled many participants to “move forward rather than backward.” One female participant asserted stark differences between men and women in managing emotions, voicing that “the male half of our population simply can’t handle it.” Another female participant echoed this
thought, adding that while “women are more hardy and hold themselves together somehow”, “the men are like children” because many of them decide to stop taking the pills once they experience negative emotions in addition to the physiological challenges.

Participants expressed fear as a pervasive emotion during the treatment process, evidenced by statements such as, “everything is falling apart for us, we see it and it scares us.” Those who were fearful of their condition and what it could potentially lead to for both themselves and their close ones were also the ones who mobilized their efforts to reduce their fear and negative emotions. On the other hand, some shared anecdotes of their peers who had no fear at all, with Sabina adding that “those who spread it are the ones who fear all of this the least, that they can infect others or even die. They simply don’t want to fear all of this.” During a conversation with a village patient who stopped taking his tuberculosis medication, my coworker explained that a patient who had abandoned his treatment died yesterday, saying that death is the only other alternative. The villager simply shrugged and said that “everyone has one end anyway”, marking his indifference to death, whichever way it would come. However, upon saying goodbye, his final words were that “everything will be fine.”

Mariana stated that while she initially spent most of her time alone, falling into a cycle of negative thoughts about herself and her life, she learned to deflect her negative thoughts by engaging in activities such as reading, painting, and spending time outside. By returning to doing things she previously enjoyed before her diagnosis, she was able to adopt a broader, more optimistic perspective on her
condition and health outcomes. Shura, another prisoner, emphasized the importance of humor in battling negative emotions, elaborating that it is the only way to “fight this”.

**Role of religion.** During interviews, I noticed that many participants had religious tattoos, and within the prison setting, nearly all of the prisoners’ rooms had multiple religious icons hanging on the walls. In discussing whether and how participants reframed their thoughts and emotions, I inquired about the role of religion in this process.

![Photograph 6. Many Eastern Europeans, especially prisoners, have tattoos of religious significance. The tattoos shown here have images of churches and saints, borrowing from icons and other culturally significant religious imagery. See the Russian Criminal Tattoo Encyclopedia Volumes I, II, and III (Dantsik Sergeevich Baldaev, 2009).](image)
While Andrey declared with confidence that he was religious, he did not see God playing a significant role in his treatment and general life, saying that “God is there, but he does not in any way help with getting through treatment.” He elaborated this thought by saying that it is more important to focus on that which you can see and experience in your everyday life, as opposed to someone or something you have not seen before. This emphasis on tangibility was echoed by Ivan, who distinctly separated his belief in God from the notion that God would be able to provide any help in regard to his health. He indicated that there was no intersection between the two by explaining that God was with him in “one place” and his illness was “in another.” He concluded his thoughts on the matter by stating “oh God, please help me… no, there’s none of that.” In contrast to those with some form of religious beliefs, a prisoner named Grisha expressed his religious views as atheistic, with religion playing no role in his life or treatment of tuberculosis and other health problems that he was suffering from. However, Sabina’s experiences with religion starkly differed those of her male counterparts:

The first time, it was in prison, it was the first time they told me that I’m dying from tuberculosis. I felt that I was dying, but I didn’t believe that I was dying. It came from inside of me. I said gospodi [oh God] ….and somehow it just came from my soul. In a week, I could walk. The doctors didn’t believe it, how I got better like that. After that, I started believing in God. Only then I started to believe, that there is some sort of…. spiritual strength, and it was given to me and it helped me to crawl out of it. And I am still living. That was 2002, 2003. *knocks on wood* From those years, that’s how it’s been. I
believe, because I directly felt that life was leaving me. They were ready to let me go, to sign me out so that I could die at home. When the doctors saw that I started to walk, I could even raise my voice and yell *laughs* …. mind that at the time I had angina as well, I wasn’t eating, and was internally bleeding. So much blood loss…plus HIV too. The doctors said it was surprising, they couldn’t compare it to anything else—they told me to thank god. And I did, I said thank you god. And to this day, I thank him.

She reported having been raised in a religious household; however, she was not influenced by religion whatsoever in her independent adult life. Yet her small prayer to God in this pivotal moment resulted in a complete religious awakening, as it helped her overcome her extreme near-death crisis both physically and emotionally. From that moment forward, faith became an integral part of her healing process and remains crucial to this day. Despite the religious awakening that occurred during treatment, she acknowledged that “some people believe in God, and it heals them or helps them deal with things in some way. Others, they simply get treated with medicine, or just drop it all together because they don’t know how to handle it.”

**Perception of self.** Participants’ abilities to manage their negative emotions often corresponded to their verbal accounts of how they saw and felt about themselves. Sabina was particularly adamant about her newfound love for herself during her treatment process, stating that this change in perspective came after realizing that she was the only one who could truly be good to herself. She practiced daily affirmations such as telling herself “Sabina, good job, mwah mwah [kissing
“noises].” When Ivan expressed the opposite—hating himself for being the way that he is—she faced him and explained that such a change does not come immediately, and one should not expect it to. She insisted that “starting little by little was hard but worth it”, adding that “everything changes, the whole picture changes and is put in an entirely different perspective.” Ivan retorted that although he is both “good and bad”, he just hates himself, and behaves toward himself “basically in no way at all.” Others echoed the importance of working on oneself, not simply for the sake of treatment, but in order to improve the overall quality of life and relationships.

The notion of having a meaningful relationship with oneself was tied to comments about optimism. Sabina shared that she is an optimist by nature, and uses this quality to “take small steps, tiny ones, quietly and calmly towards the goal, or where I need to be. That’s it.” As Gennadiy put it, taking even half a step if only forward, is helpful. Artem admitted that optimism would sometimes be lacking, indicating that for him, it was impossible to be constantly optimistic and positive. In such shortages, he would instead see things in a more practical way, but added that “practicality is not so optimistic, so you walk backward.” The idea of taking steps forward and backward was frequently brought up as a normal aspect of treatment, but as Artem put it, “you try not to walk backward, you want to at least stay in the same spot.”

The previous sections on coping have covered the use of inner strengths and internal motivations in dealing with tuberculosis diagnosis and treatment. However, coping efforts are also often reflective of a particular social environment; therefore, external components to coping are critical to consider. Some participants’ reports of
social support emerge in the practical and emotional coping sections through accounts of self-isolation and distrust of medical professionals, indicating a link between coping and external social resources. The final section of this chapter explores this relationship as it pertains to living with tuberculosis and getting treated.

Social Support

“The idea is to support yourself.”

The availability of support from friends, family, health professionals, and the community plays an integral role in shaping one’s coping mechanisms. In exploring the role of social support, it is important to note a distinction between coping resources and coping strategies. In this section, social support is discussed as a resource that is either available or absent. The ways in which individuals engage with these resources are their coping strategies. This distinction is integral to understanding the behaviors of participants who refuse available help and further exploring the effects of social support. According to Beehr and Glazer (2001), these resources can be physical actions provided by others, such as bringing medications to a patient’s home, or simply, “the mere presence of others in one’s life”. This may entail maintaining relationships with family members or those who are going through the same experiences. Whether patients seek social support is determined by cultural norms; in this case, the collectivistic culture of Eastern Europe may inform the degree to which social networks are useful in coping with tuberculosis within the context of this study.
Social resources help many patients to confront their illnesses and alleviate feelings of confusion, dissonance, and hopelessness, especially in the initial stages when there is a higher likelihood of stress. Social interactions are known to help individuals to cope with their conditions and the stressful thoughts and experiences that they may bring (Umberson et al., 2010). These positive forms of social support may be valuable in alleviating the stigma of a particular illness and providing knowledgeable advice to make the treatment process easier. On the other hand, due to certain factors, social resources are absent or insufficient in some environments. Cynicism of friends and family or the inattentiveness of doctors are all important circumstances. In such cases, individuals may not perceive any positive value in social interaction, and instead choose to rely solely on themselves. Although avoiding what is perceived as toxic interaction may benefit some and be a detriment to others, self-isolation is nonetheless considered a coping strategy.

Based on this framework, this section explores the perceived utility of social resources in participants’ coping with their diagnosis and treatment and the extent to which participants choose to interact with others. This is highlighted by participants’ relationships with family members who learn of their diagnosis, doctors who assess their condition and its treatment, and finally, other tuberculosis patients who are living through similar realities as them. In doing so, the availability of existing social resources and the experiences of those denying available help will be brought to light.

**Availability and impact of social support.** Many participants’ initial experiences with social support, or insufficiency of such, began at home, where family members were some of the first to learn of their tuberculosis diagnosis.
However, initial reactions of family members were fearful rather than supportive; being in such close proximity to an infectious individual caused them to be afraid of contracting the disease. As Ivan revealed, they said “here’s your plate, here’s your mug, here’s a fork and a spoon. That’s it. Don’t touch anything else.” This experience was emotionally difficult for him because he had already felt alienated upon receiving his diagnosis. Sabina added that his family members wanted to send her to the hospital immediately because they could become infected by simply talking to her. Based on these similar responses from his inner circle, Artem came to the conclusion that “the idea is to support yourself.” He felt that he had no support from his family at all, and explained that:

   Well, no one said anything out loud about fear, rather it was felt. The air even smelled. Just like a bad smell, their thoughts were hovering over me. Like, go away, go away. If you go somewhere or get admitted somewhere, where you won’t be seen or heard, they’ll be thrilled. It was all flying around me like a bad smell.

Others reported similar experiences within their families, summarizing with the idea that “no one supports, no one helps.” Lev, an MDR patient in the Maximovca, shared that although his father lives next door to him, he is not invested in making sure that his son gets treated. Lev’s father does not know much about his daily schedule or job, and even lies to medical staff about his son’s treatment and diagnosis history despite acknowledging that his family can get infected if Lev doesn’t get treated.
Photograph 7. A tuberculosis patient who lives alone with his dog in a small shack. When I noted the presence of various things, such as a radio, books, cups of warm tea, and a small garden, he expressed contentment with his solitary lifestyle and stated that everything he wants and needs is right here on his property. It was a well-maintained home, which indicated to me that he works hard to make it a comfortable place to live.

Participant accounts of social resources in the medical setting varied. Some believed that doctors and other patients were equipped with knowledge about what going through tuberculosis entailed. While in a tuberculosis hospital, Sabina received comfort from others who were getting treated. These individuals had been admitted to the hospital before her, and thus had already gone through the initial difficulties of the medication. They told her that her body would get used to it, and offered her support by sharing their own experiences; ultimately, her body did not get used to it. Later on, she got out of the hospital and started going to her local clinic in one town, where she said that the doctors were perceptive to her side effects and concerns. If she was
having problems with her psyche, they would work to alleviate her distress by listening to her problems and offering calming pills. However, the second time that she got infected, she was living in a different city, and subsequently switched doctors. In this new setting, she explained that “they give you nothing. They give everyone the same pills, regardless of individual symptoms or how it impacts your body. There, at least the doctors supported me well, somehow I lived for myself too.” Sabina emphasized the support of the doctors in her previous setting by reiterating the same phrase twice, again adding that this support “made me want to live for myself even more.” Other than the support of a few medical professionals, which she considered a rare case in itself, she echoed the thoughts of others by saying “other than that, no one else really cares.” Prison participants echoed Sabina’s experiences: when asked what her support system is, Mariana mentioned the nurses first, adding that they are helpful, knowledgeable, and help her get through the difficult treatment. However, not all participants chose to rely on medical professionals for social support. Lev, an MDR patient in Maximovca, expressed that the tuberculosis patients in his village do not trust the doctors and medical staff because many of them drink alcohol and are unreliable. Because of this lower quality of care, Maximovca patients don’t see a reason to depend on the medical professionals in the village. This was further revealed during a social work visit to a patient in the village; upon urging him to get tested and offering support, he replied that he supports himself just fine.
Photograph 8. People of all ages were admitted to this hospital. Despite differences in age, most appeared to be engaging in the same self-isolating behaviors. During my visit, I saw that many patients spent time outside. Even in close proximity to others who were doing the same thing, they chose to spend their free time in silence.
Experiences with social support were narrated differently in the prison setting than in other interviews. Multiple participants pointed out that there is a built-in community in the prison; most preferred to use this resource to their advantage. Andruha, who initially contracted tuberculosis in prison, said that he takes on the role as a caretaker and spends most of his time with others. He further elaborated on his caretaker role, adding that he focuses on others “because a lot of them need more help than I do.” Finally, he emphasized the importance of the company of others in the medical prison because they are all going through the same thing, so they understand the difficulties and what it’s like. Other prisoners had similar thoughts; as roommates, they support each other because they are all living the same experience. Although
Grisha stated that he enjoys the company of the other prisoners because he can relax and have a good time with them, he doesn’t trust anyone but himself.

Overall, most participants revealed that they limited their social interactions, even among existing friends. Sabina reasoned that many hide their condition because they don’t want people to know—“they’re afraid to lose their job, lose their friends”—admitting that although this mindset is wrong and emotionally difficult, the majority feel that way. Sabina also held that many of the people around her were simply toxic, pulling her to the bottom and charging her with negativity. She ended up cutting ties with them, admitting that before her second diagnosis she did not have the capacity to do so. During her first experience with tuberculosis, she indeed sank “to the bottom”, but managed to get out of it—not through reliance on her unhelpful friends, but by taking action herself. Sabina further explained that she had grappled physiological limitations that rooted out her desire to interact with others:

You don’t want to talk to anyone in this state, lady, I’m telling you. When you take these pills, they make you want to hide somewhere, you feel that bad. You want to fall and just lay on the ground. There is no desire to talk, you can’t. You’re nauseous, you’re throwing up, you can’t walk, let alone strike up a conversation with someone.

Although she acknowledged that there are helpful and supportive individuals, she did not have much energy to deal with people in general and thus chose them wisely. She revealed that she only has her mother left, earnestly thanking her for being understanding. Aside from her mother, she did not disclose her medical
problems or concerns in conversations with others. Instead, she would smile and say that “everything is good.”

Participant accounts of the social resources available to them bring insight into their perceptions of their immediate social networks and subsequently, their social practices. Many chose to not look for support from social interaction; instead, most relied on themselves throughout the course of their illness because they could not derive valuable help from others. Their experiences in various social situations subsequently shape their coping strategies, many of which share characteristics of practical and emotional coping.
Discussion

We live in an age of staggering scientific and medical advances, yet there are still millions of individuals whose marginalized status prevents them from receiving proper tuberculosis treatment. Many of those from Western nations are ignorant of the fact that tuberculosis is linked to impoverished settings which lack resources and power, and they frequently brush it off as an antiquated disease. However, I am constantly reminded of this: my home country of Moldova maintains one of the highest rates of drug-resistant TB and also holds the title of Europe’s poorest country. With the additional knowledge that few people have genuine concern and interest about contemporary issues in Moldova, I was motivated to investigate the lives of vulnerable Moldovans suffering from tuberculosis—a seemingly minor subpopulation, yet one that I was confident would be able to illuminate the ways in which the disease is dealt with (or not dealt with). This study aims to emphasize that, despite their low socioeconomic status, these individuals do indeed find successful ways to overcome their difficult health conditions and the experiences they bring. As such, the study analyzed photographs and interviews to uncover the coping strategies of rural villagers, drug users, and prisoners living with tuberculosis. Participants’ perceptions of their illness, as derived from their experiences with physiological, psychological, and social challenges, reveal insights into their methods of managing their condition on both a daily and a long-term basis. There were numerous findings in this study, but the following four must be emphasized—acceptance and adaptation are qualities useful to dealing with tuberculosis, a self-centered approach to problem-solving is often the most advantageous, patients’ roles and identities within specific
participants make a difference in their treatment outcomes, and finally, patients interact with others in various ways which are established by their perceptions and goals.

Participant reports of their perceptions and personal experiences with tuberculosis are strongly linked to their methods of managing their illness. As a whole, these accounts illuminate the participants’ process of accepting their condition as a necessary bridge to cross in their lives. Within this acceptance, they find ways to thrive by adapting their behaviors and cognitive processes to lessen the burden of various stressors that arise throughout diagnosis and treatment. They form new rituals and habits as a means to divert negative thoughts and to replace old, maladaptive behaviors. Some of these changes occur outside of one’s awareness while the body and mind adapt to the situation, whereas other changes are enacted deliberately—they may be a result of knowledge gained about the condition and others’ negative outcomes, or the simple desire to survive intact. The complexity of these experiences reveals a diverse approach to coping that fits into neither of the two components of the individualism-collectivism framework as explored by Hofstede (1980), Ratzlaff et al. (2000), and Chun et al. (2006).

Many participants employed problem-focused coping strategies in their day-to-day experiences by modifying the behaviors that they came to realize would impact their future health outcomes. Such behaviors included terminating substance use and isolating oneself socially. Medical professionals, friends, and family did not significantly contribute to the psychosocial and physical well-being of participants, and, as such, these relationships were weak throughout the treatment process.
Although prisoners displayed more reliance on their social environment than other participants, social resources as a whole were not instrumental for dealing with tuberculosis. Instead, most adopted an individualistic point of view in favor of self-preservation, with the belief that only they could help themselves overcome their condition. This view was established in tangent with long-term goals and the development of a more meaningful relationship with oneself. Interestingly enough, this was more evident among female participants as demonstrated by their greater efforts of self-awareness and care, as well as their observations that their male counterparts struggled with treatment to a greater extent due to their inability to adapt to the condition. Negative attitudes, such as disbelief that the medication is truly effective, were intensely present for most in the initial stages of diagnosis and treatment, but waned as familiarity with the disease increased. Emotion-focused coping was strongly linked to the management of these negative attitudes. Despite the surprise of initial hardships, an innate sense of optimism flourished; it enabled participants to deduce the best path of action for their condition and to eventually see an end to their adversity. Over time, fear was replaced with acceptance, and tuberculosis simply became a temporary experience that was necessary to overcome.

Incarcerated participants’ experiences with tuberculosis, as a whole, were more positive than those in different living situations. A built-in support network of medical staff and other infected inmates was always accessible, and while some prisoners adopted a solitary lifestyle despite the availability of these resources, most noted that it was beneficial to be surrounded by individuals who were going through the same experiences. Being admitted to the medical prison eased the burden of
deliberately enacting lifestyle changes; inmates had no other option than to adhere to prison routines as guided by the leading prisoner “caretaker”. By offering company, advice, and humor, this community supported living a “normal life” in the face of incarceration and illness. The formalities of prison environment oddly yet positively supplemented the role of the prisoner community, as they prevented individuals from using drugs and other detrimental behaviors to cope with their illness and treatment. Staff members further eased the treatment process by bringing the medication directly to the inmates and offering knowledgeable medical advice. These tangible resources were relied on more heavily than religious faith, which was not seen as an aid in treatment whatsoever.

The desire to survive in order to experience the future drove the marginalized individuals to adhere to treatment and take care of themselves despite barriers created by the medical system, social problems, and, most notably, the effects of the treatment itself. With the exception of some prisoners, nearly all participants did not trust the Moldovan medical system, their doctors, or their prescribed medicine. Some studies have demonstrated the importance of establishing positive relationships between patients and providers, as poor communication patterns lead to a higher possibility of treatment default (Comolet et al., 1998, Beach, Keruly, & Moore, 2006). However, this study did not find that distrust of medical providers hindered the completion of treatment. Interaction with doctors was minimal and only done when necessary; otherwise, patients themselves took on the role of the doctor by personally working to minimize their psychological and physical stressors. Self-isolation was beneficial as it provided participants with the power to remove themselves from
individuals who they deemed to be at risk of contagion, or unhelpful and ignorant of their challenges and experiences. In such situations, participants expended their social energy on themselves. With this individualistic focus, they were able to learn more about their condition and prescribed medication on their own terms, reframe their lifestyles, develop a more intimate relationship with themselves, and focus on their long-term goals in life. All of these helped them to adhere to treatment. These findings contrast those of Dimitrova et al. (2006), who, through interviews with Russian medical staff, found that providers believe that socially marginalized tuberculosis patients lack the discipline and sociability to take their health condition into their own hands and successfully adhere to treatment.

Although patients circumvent the inadequate Moldovan healthcare system through persevering self-reliance, they do not have the power, resources, or knowledge to remedy the unavoidable effects that the disease and its treatment produce; only medical assistance can alleviate pain and psychological changes. Unfortunately, the current state of healthcare is not equipped to deal with the offshoots of TB treatment, and Moldova’s present goals are to simply diagnose and treat people, and to prevent the spread of drug-resistant strains. Perhaps the problem lies in how they do this. I believe that the indifference of the medical system to the harsh realities of treatment prevents them from requesting less harmful pills to prescribe to patients, communicating and providing resolutions effectively, and ultimately being receptive to patient concerns. Treatment outcomes could possibly change for the better if the health care system’s utilitarian approach were to be replaced with a humanistic approach. I encourage such an approach by dispersing
photographs of patients and their lived environments, both home and medical, throughout my analysis, and incorporating to them my own remarks and anecdotes as an observer of these situations. The photographs provide a small glimpse into the daily lives of TB patients—from their household or hospital conditions to the activities they occupy themselves with, it is evident that they are still living normal lives that are full of both joys and sorrows. Images convey what text cannot: they give us visual information about facial expressions, nearby surroundings, as well as the objects that people carry and surround themselves with. They essentially let us visit the participants’ worlds by revealing what they see and experience on a regular basis, much of which cannot be expressed verbally. As such, the photographs help the reader craft a more authentic and substantial depiction of the participants’ lives and the complex experiences that color them. They also serve to dispel the notion that the participants do not successfully cope with both their condition and marginalized status.

The limitations of this study include sample size and the recruitment of individuals from a convenience sample, both of which do not allow for generalizability to other contexts, such as marginalized TB patients in another collectivistic country. Despite these limitations, the study has shed light on the complexity of marginalized tuberculosis patients’ experiences and coping strategies and revealed that they do not merely survive, many of them thrive. The study’s findings indicate that our understanding of stress and coping must be made more flexible in order to accommodate different contexts and experiences.
Furthermore, many of the uncovered themes are interrelated and affect each other, thereby not neatly fitting any one particular category or label. The creation and use of labels for coping strategies, such as problem- or emotion-focused, positive or negative, adaptive or maladaptive, does not effectively capture the dynamic and complex methods of managing a disease like tuberculosis, and therefore, hinders us from understanding what patients want or need in order to successfully undergo treatment; perhaps they don’t need anything at all, and can manage their illness on their own. Moreover, labeling another individual’s lived experiences or actions strips away the complexity of their being, and is highly subjective; I argue that it is more so a reflection of the labeler and their own perceptions and experiences. For example, social reclusion may be seen as an unconstructive coping strategy in certain contexts or cultures; for some participants, it was the chief strategy that enabled them to overcome their challenges.

My findings identify adaptability and resilience as qualities that allow marginalized Moldovan tuberculosis patients to thrive in the face of adverse physical, medical, and socioeconomic conditions. This has implications for the development of future tuberculosis care programs, as well as further research on the topic of coping in non-Western vulnerable populations. First, Moldovan health professionals, specifically doctors, social workers, and infection control teams, may become better able to achieve their respective goals by integrating patients’ narratives and experiences into their practice. Insight into their challenges and concerns would prompt providers to change their approaches to treatment and apply these changes in caring for other patients. Patient accounts may also be used to inform the goals,
methods, and target populations of health care grants that seek to improve the tuberculosis crisis in Moldova and other Eastern European countries. Second, patients who flourish despite an absent relationship with their healthcare providers would be a curious topic of research, as this form of resiliency is particularly interesting given the collectivistic cultural context of this study. In order to be able to ameliorate the contemporary tuberculosis epidemic, particularly in vulnerable populations, it is our responsibility to work to understand these individuals and their nuanced experiences. I believe that all of these considerations are viable strategies in getting us closer to decreased tuberculosis rates, as well as to becoming more cognizant of the fact that, regardless of culture, socioeconomic status, or health, all humans exhibit remarkable adaptability to life’s challenges.
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