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# Behind the mask

A Qualitative Study of the Impact of Tuberculosis on Food Security  
in Migrant's Households in Tajikistan

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## **Abstract**

By using Tajikistan as a case, this study adopted a qualitative approach to understand the different dimensions which make households of migrants with tuberculosis vulnerable to food insecurity. A vulnerability framework was used to identify the risks that tuberculosis poses on households' availability, accessibility and utilization of food. Then, these risks were analysed in relation to the coping strategies that households employ in order to reduce harm. Data were collected through semi-structured interviews, and observations. Findings highlighted that TB negatively impacts food accessibility, by affecting income-generating activities, labour productivity, and overall expenditure. On the other hand, it affects food utilization, by decreasing patients' capacity to absorb nourishment and increasing their nutritional requirements. As a result, the gap between nutritional intake required, and household's ability to access food becomes wider. Households manage the risks posed by tuberculosis by selecting different coping strategies such as borrowing from relatives in migration, taking loans, reducing their expenditures and food consumption, start working, diversify their income, and selling productive assets. As the treatment prolongs, the coping mechanisms employed become more detrimental, compromising their resources. In the long term, the combined effect of being continuously exposed to TB risks, and the negative consequences of the coping mechanisms employed endangers both household's livelihoods and their food security.

**Key Words:** *Tuberculosis, Food Security, Vulnerability, Labour Migrants, Coping Strategies, Tajikistan.*

Word Count: 14585

## List of abbreviations

|        |   |
|--------|---|
| DOTS   | Directly Observed Therapy Short-Course    |
| MDR-TB | Multi Drugs Resistant - Tuberculosis      |
| MP     | Medical Personnel                         |
| MWTB   | Migrants with tuberculosis                |
| TB     | Tuberculosis                              |
| USDA   | United States Department of Agriculture   |
| WHO    | World Health Organization                 |
| XDR-TB | Extensively Drug Resistant - Tuberculosis |

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## 1. Introduction

The negative effects produced by shocks are gradually going to increase, as new threats emerge, such as global warming and climate change, world population growth, communicable as well as non-communicable diseases, just to name a few (Geleta *et al.*, 2012: 1). Those among the population that are particularly exposed to external unexpected shocks are considered vulnerable, because less capable to insure themselves from the effects of shocks, and to cope with their consequences (Von Braun, 2009: 3). With regard to food, shocks seriously deplete vulnerable individuals and households' resources, compromising their availability, accessibility, and utilization of food (Geleta *et al.*, 2012: 1). In a more broader term, they affect food security, which is usually defined as the situation when “all people at all times, have physical and economic access to sufficient, safe and nutritious food to meet their dietary needs and food preferences for an active and healthy life” (World Food Summit, 1996: 4).

Health shocks such as communicable diseases are extremely linked to food security. Their converging impact represents one of the main threats to global public health, since it largely increases mortality and morbidity associated with them. Food insecurity and malnutrition weaken the immune system, increasing the likelihood of contracting the infection and the frequency in which severe episodes of the illness occur. Similarly, infection can lead to acute malnutrition and undernourishment by decreasing appetite and food intake, but also through malabsorption, nutrient loss or metabolic changes (WHO, 2010a: 5; Katona & Katona-Apte, 2008: 1). Understanding how the specific shocks affect vulnerable groups, and how these groups cope with the shocks and manage the risks that threaten their livelihoods and health, is crucial to effectively protecting them.

Tuberculosis (TB) is a particular example of communicable disease tightly linked with food security. TB is an infectious disease related to poverty, undernutrition and malnourishment, and poor immune factors (WHO, 2013: 8). The association between TB and social and economic deterioration has been known for long time (Barr and Menzies, 1994; Pocter and MC Adam, 1994; Hargreaves *et al.* 2011). However, recently the attention given to the social determinants of tuberculosis has been increasing, especially due to the re-emerging of tuberculosis in several

countries and the inequitable distribution of the cases (Hargreaves et al. 2011: 654).<sup>1</sup> Crowded housing condition, poor ventilation, indoor pollution, as well as malnutrition and poverty are all factors which increase the risk of uninfected individuals to be contaminated (Idem: 655).

TB is most prevalent in regions of the world characterized by poverty and food insecurity, affecting populations with limited access to a healthy diet. TB and food insecurity interact as in a vicious circle, since undernutrition increases the risk of tuberculosis, and in turn TB can lead to undernutrition (WHO, 2013: 1). In fact, tuberculosis lowers patients' appetite, affecting their nutritional intake. Moreover, it modifies their metabolic processes making them less able to absorb micronutrients, consequently worsening their nutritional status (Gupta *et al.*, 2009: 11-13). On the other hand, undernutrition and malnutrition have a detrimental effect on the immune response to the bacteria, consequently enhancing the likelihood that latent TB infection will progress into active TB disease (WHO, 2013: 1). By increasing the risk of progression to active TB disease, food insecurity and poor nutritional status in the population become crucial contributors to the global burden of tuberculosis (WHO, 2013: 7). Additionally, food insecurity is one of the barriers that affects individuals adherence to TB treatment (Pee *et al.*, 2014: 531).

Tuberculosis is often defined as a social and economic diseases and a major cause of poverty aggravation. The economic impact of TB comes from the magnitude of the problem and from the fact that it especially affects the most economically productive age group of the population (WHO, 2014: Ch.1; Ahlburg, 2000: Ch.1). People affected by TB are often too sick to work and their household have to face catastrophic expenses connected with their treatment and care, which threatens individual and household's food security throughout the course of the illness (WHO, 2013: 10). By affecting their ability to earn a living, TB has an immediate impact also on households' capacity to access food and it increases food insecurity, especially if the patient is the main source of income. On the other hand, when people living with TB are food insecure, the risk of mortality and morbidity increases significantly. This converging burden of reduced incomes and increased expenses leads every year to an estimated one million people falling behind the poverty line (Tanimura *et al.*, 2014: 1764). Indeed, there is a potentially destructive cyclical relationship between food insecurity, poverty, and tuberculosis: “[p]overty and food insecurity are both causes and consequences of TB” (WHO, 2013: 21). However, while the

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<sup>1</sup> Recent esteems indicated 9 million of new TB cases only in 2013, while 1.5 million people every year die despite most death being preventable, if access to diagnosis and treatment is provided (WHO, 2014:1).



effects on poverty have been largely discussed, the role played by TB in moving households and individuals from a food secure status to a food insecure status has not been properly researched yet.

By using a vulnerability framework, this study aims to identify the threats that tuberculosis, and in particular its multi-drugs resistant (MDR-TB) and extensively drug-resistant (XDR-TB) forms, poses to household's availability, access and utilization of food. These threats (or risks) are then analysed in relation to the available risk management mechanisms. For this purpose, tuberculosis is considered as an external (health) shock and food insecurity as the negative outcome which follows this harmful event (Lovendal & Knowles, 2006: 2).

The study was conducted in Tajikistan, which ranks high-priority country for prevalence rates and annual incidence of TB in the WHO European region (ECDC *et al.*, 2015: 10). Furthermore, it is also among the 27 high burden countries in the world for MDR-TB (WHO, 2010b:37). The emerging of tuberculosis in Tajikistan as a major threat to public health was caused by the exacerbation of the socio-economic conditions of the population, together with the fall of its healthcare system, which followed the collapse of the Soviet Union (Toungoussova *et al.*, 2006: 2; Cegielski *et al.*, 2007: 35). In 2002 the government adopted the Directly Observed Therapy, Short-course (DOTS) control strategy, and thanks to a widespread network of TB hospitals and other medical institutions was able to cover large part of the population, which led to a decrease of the mortality and morbidity rates during the last years (Korobitsyn *et al.*, 2013: n.a.; WHO, 2014: 59; WHO, 2014: 12, 17; UN & GoT, 2010: 87). Characterized by being a low income and food deficit country, Tajikistan presents the ideal conditions for the purpose of this study (FAO, 2014).

The focus is on a particularly affected group of the Tajik population, labour migrants (Gilpin *et al.*, 2011: 1-2). Labour migrants consist of an interesting case because they usually are the main source of income in the household, therefore the burden associated with tuberculosis should be higher for their household than for others. Labour migration is also one of the main socio-economic characteristics of modern Tajikistan, with more than 60% of the households with family members in labour migration (Khakimov & Mahmadbekov, 2009: 19). Furthermore, due to their high level of mobility, Tajik labour migrants are exposed to the risk of contracting TB both in Tajikistan and in their hosting countries (Hargreaves *et al.*, 2011: 655). Lastly, they often

live and work in substandard conditions, which increase the likelihood of contracting TB, or reactivating a previous infection (WHO & IOM, 2014: 1-2; WHO ROE, 2014: 72).

## **1.2 Purpose and Research Question**

This study seeks to understand the different dimensions which make households of individuals with tuberculosis at risk to fall, or stay, below the food security threshold. The focus is on a particularly group of population at risk of infection, labour migrants in Tajikistan. Therefore the research question is formulated as follow:

*How does tuberculosis affect vulnerability to food insecurity of labour migrants' households in the urban areas of Tajikistan?*

In order to facilitate the analysis the research question has been operationalized into two sub-questions, which reflect the main components of vulnerability: sensitivity to external shocks and the ability to cope with related risks and stressors.

1) *How does tuberculosis threat the availability, accessibility, and utilization of food in labour migrants' households in the urban areas of Tajikistan?*

2) *How do households of labour migrants with tuberculosis in the urban areas of Tajikistan organize their resources and activities in order to cope with the risks posed by tuberculosis to their availability, accessibility, and utilization of food?*

## **1.3 Outline of the Thesis**

The second chapter presents the research design and methodology. The literature related to vulnerability in the food security context, as well as literature focusing on the connection between tuberculosis and food security is reviewed in chapter three. The fourth chapter is dedicated to the theoretical model which drives the analysis in chapter five. Finally, the sixth chapter concludes the thesis summarizing the findings and placing them in the development debate.

## **2. Methodology**

In this chapter the research designed is presented, followed by a description of the sample strategies used, the data collection procedures, and on how data were analysed and validated. Finally, in the last two parts the ethical consideration related to the study, and the limitations are discussed.

### **2.1 Research design**

This study adopts a qualitative approach to explore vulnerability to food insecurity in a specific subgroup of the population (Creswell, 2007: 39-40). Qualitative methods strengthen the study capacity to investigate underlying mechanisms, and allow a greater insight on complex and multifaceted issues than the quantitative ones (Ibid.). Moreover, employing participant's narratives helped better understanding not only the economic burden, but above all the social consequences connected with a poverty disease such as tuberculosis (Creswell, 2007: 40; Flyvbjerg, 2006: 238).

### **2.2 Data sampling**

Information rich cases were purposefully selected in order to better answer the research questions. In this study two levels of sampling were employed, one for the selection of the context and one for the selection of participants (Bryman, 2012: 417). Initially, research sites were designated according to their relevancy to the research questions, as indicated in Creswell's "data collection circle" (2007: 146-147). In Dushanbe there are 14 clinics specialized in the treatment of TB and one National TB Control Centre: data collection started from this latter, the institution responsible for the screening of sputum samples. Then, after gaining access to the medical personnel responsible for the registration of TB patients in this centre, a snowball sampling was adopted to broaden out the selection process. The application of two sampling approaches adds to the study the advantage of having elements of both purposiveness and representativeness (Bryman, 2012: 427). As a result, gatekeepers working as doctors in some of the remaining clinics were also identified (Idem: 424, 427).

The selection of participants was facilitated by the above mentioned gatekeepers using a purposive sampling technique. Two different selection criteria were applied. Firstly, key

informants were selected based on relevant working experience in the treatment of pulmonary diseases, specifically TB. Secondly, main respondents were identified based on their age, health status, and history of migration. Participants needed to be older than 16 years of age, represent both sexes, have lived and worked abroad at least once between 2012 and 2014, and being under or have recently completed TB treatment.

### 2.3 Data collection procedures

In order to identify the different aspects of vulnerability data were collected on few in-depth cases: Silverman describe this type of study as “collective case study” since “a number of cases are studied in order to investigate some general phenomenon” (2013: 164). Multiple sources of data were employed for data collection, such as semi-structured interviews, documentary analysis, and direct observations. Interviews were conducted face to face with the help of a female interpreter, with the exception of one which was by telephone since the participant could not attend the meeting (although this inhibited the observation of participant’s informal communication) (Creswell, 2007: 164). Data collection was carried out between December 2014 and January 2015 in Dushanbe, capital of Tajikistan, and in the city of Qurghonteppa. These are the two main urban centres of the regions of Khatlon and Republican Subordination. A basic map of Tajikistan is given below for geographical reference (Figure 1)

**Figure 1.** Map of Tajikistan



**Source:** U.N. (n.d).

All in all 16 semi-structured interviews were conducted, two with medical personnel (MP), and 14 with migrants with tuberculosis (MWTB). Firstly, key informants were interviewed in order to gather background information on the healthcare system, as well as on the epidemiology of tuberculosis in Tajikistan. Then, MWTB were interviewed as representative of the main unit of analysis. A record of the participants is given in Appendix I. Interviews lasted between 45 minutes and one hour, with questions covering topics such as employment, migration history, household's income and expenditure, and health status of migrants. Additionally, in order to have a better insight on the level of food security in the household, the Household Food Security Measurement survey developed by the United States Department of Agriculture (USDA) was adapted to be used in semi-structured interviews, and integrated with questions addressing the status of food security after the diagnosis of TB (USDA, 2012). The interview guides can be found in Appendix II.

Interviews were conducted either in Tajik or Russian, according to respondents' preference, and translated simultaneously into English. Two protocols were specifically created to record MWTB and MP's responses, as suggested in Creswell (2007: 133): the first interviews helped to test the design of the questions, then these were revised and reframed with the assistance of the interpreter (Creswell, 2007: 165).

Interviews took place in different TB clinics of Dushanbe and Qurghonteppa. The medical personnel in the clinics allocated a consultation room for this specific purpose. Participants were acquainted with the locale; however the setting seemed to recreate the doctor-patients power dynamics (Creswell, 2007: 133-134). The interpreter was asked to sit close to participants, in order to put them at ease and minimize any possible negative impact of the location. The interviewer sat in front of them so as to establish eye contact during the interview. Having a local interpreter helped approaching the subject of this study in a culturally sensitive manner, by gaining the trust of the respondents or using ice-breakers to relax the conversation (Creswell, 2007: 140).

Observations through the form of field notes on the status of the healthcare system in Tajikistan, and on the conditions of TB patients, were also gathered during the several visits to hospitals, diagnosis centres, and other facilities.

## 2.4 Data Analysis and validation

The analysis was conducted by using a qualitative data management software (NVIVO) for the coding process. Data were coded using prefigured codes identifiable with the key elements of the theory, and hierarchically classified into different categories and subcategories (Bryman, 2012: 578). Additional categories were added when new and unexpected codes arose (Creswell, 2007: 185). The recurring motifs emerged were then placed in a framework, and compared in order to develop generalizations on the phenomenon studied (Creswell, 2007: 200)

As it regards the questions adapted from the Household Food Security Measurement survey, the responses were coded following the directions given by USDA. Responses “yes”, “often”, “sometimes”, “almost every month”, and “some month but not every” were coded as affirmative. The sum of the affirmative responses was used to determine the overall food security level of the household as indicated in the table below (Table 1):

**Table 1.** USDA food security scale

| Level of Food Security | Households with one or more children | Households with no children |
|------------------------|--------------------------------------|-----------------------------|
| High food security     | 0                                    | 0                           |
| Marginal food security | 1-2                                  | 1-2                         |
| Low food security      | 3-7                                  | 3-5                         |
| Very low food security | 8-18                                 | 6-10                        |

**Source:** USDA (2012:10-12)

The following strategies were adopted in order to verify the trustworthiness of the findings (Creswell, 2009: Ch.9). Firstly, primary data were triangulated with secondary sources of information, such as observations, interviews with key informants, publicly available documentation, and previous research. Secondly the study was peer reviewed throughout all its stages. Thirdly, the use of NVIVO ensure the transparency of the coding process, and the record of the code can be made available for sharing (Gibbs, 2007 cited in Creswell, 2009: 198).

## **2.5 Positionality and Ethical Dilemmas**

The observations collected during the stay in the country, and the extensive literature review conducted beforehand, were used to identify power asymmetries which potentially could have influenced data collection and shape its results. Above all, the most significant barrier was the mask which separated the healthy from the non-healthy. This separation was both psychological and physical. It was psychological because despite taking all the necessary precautions, the hazard of contracting tuberculosis was constantly present. This inevitably affected the position of the researcher in the field, and how participants' identity was constructed. It was physical because the decision of asking participants to wear protective masks in order to avoid the exposure to the slightest threat of contamination emphasized even more said distinction, reinforcing the existing power asymmetries between researcher and those who were researched, between the healthy and those who were on the other side of the mask.

In this specific context the problematization of the role and identity of the researcher was extremely important given the sensitive nature of this study. Reflecting also on the identity of those who were researched, and how they constructed the researcher's identity helped determine what could, and could not have been done to minimize the impact of the small but nevertheless present hazards for health, while maintaining the ethical commitments towards the participants (Sultana, 2007: 376-375, 382). Some of the limitations presented in the following part are the direct result of the several ethical dilemmas faced during the data collection process.

## **2.6 Limitations**

Having labour migrants representing the entire household involves possible biases that need to be taken into consideration. Firstly, participants might have omitted or underreported information on their level of food security due to lack of trust in an external researcher, or feelings of shame connected with admitting food deprivation. Secondly, participants might have overlooked aspects related to intra-household distribution of food that other members could have better highlighted. Thirdly, during data collection was very difficult to access female participants, and this affected the gender balance of the sample.<sup>2</sup> The prevalence of males among

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<sup>2</sup> In fact, the percentage of female migrants in Tajikistan is very limited (only 13.4%), which made particularly difficult to identify female respondents (Danzer *et al.*, 2013: 12).

respondents might have led to an underestimation of the weight of the financial and caregiving burden on female members of the households, as well as other gender biases.

Including different members of the household among the respondents would have helped address these limitations. However, living with an ill person implies being continuously exposed to TB, which involves the risk of other members of the households being infected without yet knowing. Therefore, while interviewing them it would have been necessary to wear a mask, consequently treating them as sick in order to avoid any risk of contagion. However this option was discarded so as to avoid reproducing forms of stigma.

Another important limitation concerns the government restrictions on the use of tape-recording procedures during interviews, which could have affected the accuracy of the data. Essentially, key informants and local researchers claimed tape-recording to be illegal in Tajikistan. Previous cases of restriction of freedom of speech seemed to confirm these rumours, although no clear legal evidence was provided.<sup>3</sup> Besides, Tajikistan is also characterized by a very low level of trust, and tape-recording participants could have potentially spoiled the whole interview process. Due to the before mentioned reasons, it was decided to note-taking the information during interviews, using an interview protocol to facilitate the process. Notes were then double checked with the interpreter and transcribed immediately after the interview.

The poor weather conditions which characterized winter in Tajikistan, and the dangerous status of the road, limited the choice of sites for the collection of data to the two largest urban centres easily accessible. In order to reduce the impact of this limitation the study was specifically designed to focus on food security in urban areas.

Finally, the mediation of an interpreter could have affected the trustworthiness of the data collected. Researcher and translator discussed beforehand the meaning of the questions so as to increase their comprehensiveness and reduce the impact of language and cultural barriers.

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<sup>3</sup> Few months before starting data collection PhD student Alexander Sodiqov was charged with high treason while conducting research in Tajikistan (CBC, 2014).



### **3. Literature Review**

#### **3.1 Vulnerability in the food security literature**

In the 1970s the physical unavailability of food on the market was commonly considered as the major cause of food deprivation (Davies *et al.*, 1991). This belief was challenged in 1981, when Amartya Sen published his seminar works on poverty and famines (Sen, 1981). Sen's new approach gradually led to a shift of focus from natural to societal causes in the global debate on food security (Frankenberger & McCaston, 1998: 30). The operationalization of Sen's entitlements theory into practical methods for the assessment and prevention of famines brought different authors to encompass the complex socio-economic determinants outlined by Sen in the concept of "vulnerability" (Dilley&Boudreau, 2001: 233).

In 1989 the Institute for Development Studies bulletin became the stage where the discussion on vulnerability took place (Chambers, 2006; Swift, 2006).<sup>4</sup> In the opening article Chambers defined vulnerability as the condition of "exposure to contingencies and stress, and difficulty in coping with them." (Chambers, 2006: 33). Although this definition is the most commonly accepted, vulnerability has also been adopted in a wide range of disciplines, and each time defined differently. In 1990, Downing moved the focus from causal stochastic events (shocks, hazards, risks), to the consequences or outcomes of those events (Dilley & Boudreau, 2001: 234). All in all, there is a large series of outcomes that people can be vulnerable to, such as income shocks, illnesses and other communicable diseases, climate change and environmental hazards along with others (Ellis, 2003: 3).

The popular definition given by Chambers identified two main aspects related to vulnerability: "an external side of risks, shocks, and stress to which an individual or household is subject", and an internal one of defencelessness, that is to say the "lack of means to cope without damaging loss" (Chambers, 2006: 33). The external face of the concept involves shocks and the different type of risks and stress that determine household's sensitivity: this is in fact shaped by reciprocal actions of socio-economic, political and biophysical factors (Hart, 2009: 368). For instance, Drimie and Casale (2009) studied the connection between children vulnerability, HIV-AIDS, poverty and food security using the approach theorized by Chambers and Conway in 1991.

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<sup>4</sup> The Institute for Development Studies republished the Chambers and Swift article of 1989 in 2006. The most recent version is the one referenced in the text.

Another example specifically related to tuberculosis, is the research of Huffman *et al.* on migrant workers vulnerability to TB and the mechanisms which prevent them to access healthcare (2012). Similar studies have been conducted to confirm the association between socio-economic deprivation, tuberculosis, vulnerability and nutrition (Moustafa & Elamin, 2014; Burke *et al.*, 2014).

On the other hand, the internal face reflects the ability to withstand different type of shocks or risky events, and to cope with the subsequent risks or stressors (Hart, 2009: 368). Far from being just victims of negative events, individuals and households are actors that can respond to, or manage those risks in ways that allow them to reduce their exposure to adverse effects (Lovendal & Knowels, 2006: 12). Formal and informal risk management instruments can be used for coping in times of crisis or stress, depending on the assets or resources available, and their effectiveness against the risks (Alwang *et al.*, 2001: 2). Furthermore, the ability to cope is deeply context bound, and it depends on individual and households perceptions of the risks (Hart, 2009: 369).

Drawing from previous research on food security and environmental sustainability, in 1991 Chambers and Conway were able to put livelihoods at the centre of the debate by defining them as a system “comprising the capabilities, assets (stores, resources, claims and access), and activities required for a means of living” (1991: 6). The household’s decisions on how to mobilize these resources and allocate them, and the activities that result from these decisions constitute their livelihood strategies (Maxwell *et al.* 2000: 8). The interaction between household’s personal goals, the available assets, and finally their understanding of the option available determines which livelihood strategies a household will pursue (Maxwell & Smith, 1991: 27). In 2000, Maxwell *et al.* adopted the sustainable livelihood approach to better understand the complex interactions between these internal and external dimensions, and the system in which households’ livelihoods are embedded (Idem.: 7-9).

In 2001 Alwang *et al.* presented an overview of the different meaning and concepts of vulnerability, from economics, sociology, disaster risk management, and food security (2001). In order to simplify the literature he decomposed vulnerability into three main components that form a “risk chain”: a) the risks or risky events which follows a shock b) the options for managing risk, or the risk responses, and c) the outcome in terms of welfare loss (Alwang *et al.*, 2001: 2). Individuals or households are said to be vulnerable to suffer an undesirable outcome,

and this vulnerability comes from the combination between their exposure to the risks and the responses given (Idem.: 3). Similarly, Ellis reviewed the concept of vulnerability and he related it to the factors implicated in the 2001 food security crisis in southern Africa (2003: 1)

Holzmann and Jorgensen (2000) have developed a framework for analysing vulnerability to negative social welfare outcomes in general, which helps identifying people whose income falls below a certain threshold. Similarly, Dercon has been working specifically with income and consumption poverty (2001). Tesliuc and Lindert used vulnerability to understand the poverty context in Guatemala (2002). By linking risks and shocks to the households affected they identified the characteristics of those households.

In the field of food security these frameworks help to analyse the dimension of access to food, but do not consider availability and utilization. Lovendal and Knowles tried to fill this gap by providing a specific framework where vulnerability is the result of a recursive process (2006): here, household's socio-economic characteristics and exposure to risks determine their future characteristics, and their risk management capacity (Capaldo *et al.*, 2010). Babatunde *et al.* (2008) and Capaldo *et al.* (2010) applied this framework to empirical cases, the first one in Nigeria and the second one in Nicaragua.

### **3.2 Tuberculosis and Tajikistan**

Several authors have investigated the relationship between the collapse of the Soviet Union, and the significant increase in the epidemiological indicators of tuberculosis registered in all post-soviet states (Toungousova *et al.*, 2006: 2; Cegielski *et al.*, 2007: 35). Generally, the fall of the subsidized healthcare system in the early 1990s is indicated as one of the main reasons of the re-emerging of TB in these countries: due to lack of funding, drugs stopped being regularly supplied to hospitals, causing TB patients to receive inadequate and irregular treatment (Toungousova *et al.*, 2006: 2; Keshavjee & Becerra 2000: 1201). Cox *et al.* particularly stressed how this decline of the healthcare services led to a misuse of the already sporadic TB drugs, which consequently increased the likelihood of patients developing MDR-TB (2004: 5-6). As a result, former Soviet Union countries became a large basin for drug-resistant forms of TB (Cox *et al.*, 2004: 5-6). According to Zaleski *et al.* among the factors that contributed to increase the risk of exposure to TB there were the surge of numerous ethnic conflicts, together with a

substantial decrease in the employment rates, living standard, and nutritional intake (1999: 394-395).

Tajikistan healthcare system and its relation with the high TB prevalence and incidence rates have been largely discussed, from the initial transition period to the effectiveness of the modern TB treatment. Keshavjee and Becerra defined the reorganization of health services in Tajikistan, from the soviet model to a fee-for-service system, a soft form of structural violence since it caused an increase in the morbidity and mortality rates (2000: 1201). Similarly, in a following contribution Keshavjee focused specifically on health policies in Tajikistan, describing the damages that revolving drug funds have produced in this specific context (2004)

Regarding the TB treatment in Tajikistan, Thierfelder *et al.* investigated in a cross-sectional study the factors that determine hospitalization, identifying positive sputum smear, supply of hospital beds, and gender as the main predictors for hospitalization in Tajikistan (2008: 1369). Interestingly, the study found that inpatients have fewer chances than outpatients to complete the therapy successfully (Idem: 1370). Recently, Aye *et al.* approach the problem of treatment from the access dimension, focusing on the role of medical and non-medical cost as barrier to access treatment (2010b). Similarly, Korobitsyn *et al.* analysed the barriers which hinder the detection and diagnose of TB (2013).

Several studies focused on the economic burden of illnesses in developing countries, especially malaria, TB, and HIV-AIDS (Russell, 2004; Bond *et al.*, 2009; Ahlburg, 2000). However an accurate review related to this specific aspect exclusively in tuberculosis, and its effects in low and middle income countries can be found in Tanimura *et al.* (2010). This study showed that TB related costs in average account for 58% of the annual individual income, and 39% of the household's income, which qualified them as "catastrophic" since they surpass the 40% threshold established by WHO (2014: 1766). In 2010 Aye *et al.* extensively examined the different costs that households in Tajikistan face when diagnosed with TB. They analysed the medical and non-medical health expenditure that patients usually undergo during the phases of the treatment. These were then added to the perceived loss of income. As a result Aye *et al.* were able to estimate the overall economic burden associated with TB in Tajikistan (2010a). On the same line, a specific analysis of the factors which influence the expenditure rate in Tajikistan was given in the following year (2011). In this last study the different coping mechanisms adopted by households were used to complement the analysis of the costs.

Finally, few study specifically research the relationship between TB and at risk groups in Tajikistan, such as migrants and prisoners. Gilpin *et al.* studied the misbeliefs associated with TB among the migrant population (2011): their findings revealed that sufficient knowledge of TB is very low and limited to those migrants with higher level of education, while misconceptions and stigma are largely diffused (2011: 9). This study also indicated TB as a major issue for migrants, and called for an improvement of the access to TB treatment both in Tajikistan and Russia (2011: 10). A similar study but on Uzbek migrants was conducted in Kazakhstan (Huffman, 2012). Winetsky *et al.* instead investigate the social and biological factors which expose prisoners in Tajikistan to a high risk of contracting TB, especially MDR-TB which in this context is prevalent (2014).

## **4. Theoretical Framework**

In this section the theoretical model that guides the analysis of households' vulnerability to food insecurity is given. Drawing from the concepts presented in chapter three, the model studies how the internal and external faces of vulnerability intertwines in relation to the outcome of food insecurity. The first paragraph introduces the model and its basis assumptions, explaining also the role played by household's assets, social context, and food security status in determining how the risks are managed. The second part explains how tuberculosis threatens food security, and it represents the external dimension of vulnerability. The last part focuses on the internal dimension, and specifically on how households organize and manage their resources to cope with different risks, and their potentially detrimental impact.

### **4.1 Households vulnerability to food insecurity**

As seen previously, vulnerability is a function of two different elements: the exposure to risks factors and the ability "to cope with those risks and to recover from a shock and deterioration of [individual or household's] current status". (Maxwell *et al.*, 2000: 9). This model uses these concepts to build a framework where both the risks to food security and the behaviours that households adopt when facing said risks are considered (Barret, 2002: 4). The interaction between these two aspects is used as an analytical tool to understand the reasons behind certain

individuals, households, or group of population “being more vulnerable than others to stochastic economic, environmental, and social variables” (Barret, 2002: 18).

In this particular context vulnerability is defined in relation to the negative outcome of food insecurity, hunger and famine. Therefore “vulnerable” here refers unambiguously to individuals or households whom are susceptible to fall below the food security threshold during the period of time which follows a specific shock, i.e. the contagion of tuberculosis (Lovendal & Knowles, 2006: 2). Consequently, the likelihood of becoming food insecure is determined on one hand by the risks occurring after the TB infection, and their potential threats to food security. On the other hand by individuals or households’ ability to manage said risks. Key component to understand their degree of vulnerability and its overarching causes is the identification of the available coping instruments and their relevance vis-a-vis the specific risks (Idem, 2006: 12).

To these two aspects are dedicated the following sections. However, before moving on there are three elements mentioned by Lovendal and Knowles that need to be taken into consideration throughout the phases of the vulnerability analysis: namely asset portfolio, context, and food security status (2006: 6).

According to Lovendal and Knowles, the resources on which individuals or households can draw to in order to meet their needs, are a key element to define risks and threats to food security, and how these are managed (2006: 6). These resources are important risk management tools in general, and are used by households to ensure their livelihoods (Maxwell, 2000: 8). In fact, being able to choose among a wide range of strategies requires having diverse resources, and consequently different ability to draw from them, both in normal condition as in time of need. Regarding food security, the characteristics or channels that allow households to access food are normally mediated by the resources available (Maxwell & Smith, 1992: 14). In fact, households with fewer resources do not have choice but to bear the effects of the shock by reducing their nutritional intake (Ibid.). Said resources are generally called capitals or assets, and include human capabilities, natural resources, savings and financial resources, physical possessions, political capital, and social nets (WFP, 2009: 25). It is worth noting that these resources should not be considered as mere means for survival, but are the bases of people’s capability to “act and to reproduce”, and “challenge or change the rules that govern the control, use and transformation of resources” (Bebbington, 1999: 2022). Consequently, in order to secure their livelihoods households need first to secure the ownership and access to “[the] resources and income earning

activities, including reserves and assets, to offset risks, ease shocks and meet contingencies” (WCED, 1987: 2-3 in Chamber & Conway, 1991: 5).

The second element, which potentially influences access to assets, includes the institutional and organizational frameworks within people are embedded. Social actions play also a role in reducing risks; therefore, they need to be taken into account when investigating the relationship between risks and risk management instruments. For instance, the presence of safety-net programmes impacts the decisions on how to manage the risks by lowering the need for other coping mechanisms, and therefore need to be included in the analysis (Lovendal & Knowles, 2006: 5).

Collecting information on the food security status of households helps determining how much their status needs to diminish or increase in order to change. In fact, the status of food insecurity does not imply the concept of vulnerability per se, since this latter is more related to the probability for a food secure individual or household to move from a food secure status to a food insecure status as a result of an unexpected shock (Maxwell *et al.*, 2000:9). Individuals or households frequently move in and out of a state of undernutrition, suggesting that the notion of food security at any given point in time is best to be thought of in a dynamic sense (Capaldo *et al.*, 2010: 3). Consequently, being food insecure does not necessary imply vulnerability because the food situation could improve, while vulnerability refers more to people propensity to fall below or to stay behind a predetermined food security line within a certain timeframe (Babatunde *et al.*, 2008: 117-118). For instance, chronically food insecure people are already living below the food security line and a shock would not change their situation.

Lastly, the analysis of vulnerability requires a clear identification of the unit of analysis. In fact, a vulnerability assessment can be both at micro, meso, macro level and even super-macro level (Lovendal & Knowles, 2006: 13). On the other hand, food security and related concepts tend to be applied to individuals, and consider households only as aggregation of individuals. This study is designed so as to conduct the analysis at household level, therefore the following assumption on household’s behaviour are required (Maxwell & Smith, 1992: 19; Corbett, 1989: 1001). Firstly, strategies on how to allocate resources are studied as they are commonly shared by all the household’s members. Secondly, household’s income and assets are thought as pooled, and used for the welfare of all the members of the household. Lastly, households with similar assets and characteristic respond similarly but independently to external changes.

### 4.3 Tuberculosis as shock and threats to Food Security

Risks are known or unknown distribution of events, trends, or structural factors following a shock.<sup>5</sup> They can have several forms, and are able to hit individual/household as well as entire communities. Therefore, understand their characteristics (magnitude, timing, history, and response), and how they affect household's resources is important to determine vulnerability, especially because their impact is not limited only to the level of occurrence, but can be relevant to other levels as well (Alwang *et al.*, 2001: 3-4; Lovendal & Knowles, 2006:9; Campbell, 1991: 408).

Lovendal and Knowles' framework identifies four main threats to food security posed by tuberculosis at household level: economic, social, health, and lifecycle-related risks (Table 2). Risks connected with tuberculosis in many ways cut across the above mentioned ones. TB as a shock generates risks impacting the productive capacity of households as well as the resources available to them. It has spill over effects on income and employment, because when people become sick with TB their earnings are reduced from loss of working days, due to the sickness. This directly and indirectly contributes to deplete household's assets, consequently leading to further impoverishment (Ahlburg, 2000). Moreover caretaker's productivity and livelihoods are also disrupted, further reducing household's income. The negative effects on family structures caused by tuberculosis increase the chances of food insecurity and malnutrition. Additionally, TB drugs cause hunger and boost the demand of food intake, leading to food insecurity and intra-household tensions (Bond *et al.*, 2009: ix). Lifecycle related risks have also an economic impact on households, given the costs often associated with funerals (Bond *et al.*, 2009: xi). Households therefore need to muster their resources and assets to face treatment's costs and provide adequate care for the patient (Bond *et al.*, 2009: ix).

All these risks have the potential to damage food security by directly threatening the availability, access, and utilization of food (Alwang *et al.*, 2001: 2). These are the four faces or dimensions that are encompassed in the concept of food security.

Risks to availability threatens the supply side of food security, which is the necessary condition of ensuring that households have adequate access to food supplies (provided through domestic

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<sup>5</sup> In the food security literature the term "risk" is used to refer to external events or hazards, rather than to the likelihood of a singular outcome (Dilley&Boudreau, 2001: 234).



production, existing stocks, commercial imports or food programs) (Bashir *et al.*, 2010:403; FAO, 2013:18).

Tuberculosis threatens household’s access to food by directly and indirectly depleting their human, social and financial assets. In fact, access reflects the demand side of food security, encompassing dynamics of intra-household food distribution and socio-cultural limits. More to the point, accessibility concerns the ability to economically and physically access sustainable sources of food for a healthy diet. It focuses specifically on household’s income, distribution of incomes within the households, and price of food. This aspect particularly strengthens the relationship between food security and poverty, casting a light on the social, economic, and political determinant of food insecurity (Bashir *et al.*, 2010: 403; FAO, 2013: 20).

The impact of TB on food utilization is mainly related to the nutrient value of diets their connection the health and well-being of individuals or households. Utilization concerns dietary quality, especially micronutrient deficiencies associated with inadequate intake of essential minerals and vitamins (Bashir *et al.*, 2010: 404; FAO, 2013: 21).

**Table 2.** Potential risks related to tuberculosis and impact on household food security

| TUBERCULOSIS   | Household Level   |   |   |   |
|----------------|---|---|---|---|
|                | Risks   | Availability  | Access  | Utilization   |
|                | Health Risks  | <ul style="list-style-type: none"> <li>• Lower own production</li> </ul>  | <ul style="list-style-type: none"> <li>• Reduced income</li> <li>• Increased health costs</li> <li>• Reduced asset holding (selling off)</li> <li>• Increase indebtedness</li> </ul>                                | <ul style="list-style-type: none"> <li>• Reduced uptake of macro and micronutrients</li> <li>• Poor food utilization</li> </ul> |
|                | Lifecycle related Risks   | <ul style="list-style-type: none"> <li>• Lower own production</li> </ul>  | <ul style="list-style-type: none"> <li>• Reduced income</li> <li>• Increased health costs</li> <li>• Increased non-food expenditures</li> <li>• Reduced asset holdings</li> <li>• Increased indebtedness</li> </ul> |   |
|                | Social Risks<br>(inequitable intra-household food distribution)         |   | <ul style="list-style-type: none"> <li>• Discriminatory access to food by certain household members (women or children)</li> </ul>  | <ul style="list-style-type: none"> <li>• Transfer of malnourishment to children</li> </ul>                                      |
| Economic Risks | <ul style="list-style-type: none"> <li>• Less own production</li> </ul> | <ul style="list-style-type: none"> <li>• Reduced income earned</li> <li>• Reduced asset holdings</li> <li>• Increased indebtedness</li> </ul> |   |   |

**Source:** Adapted from Lovendal & Knowles (2006: 11)

#### 4.4 Coping with threats to food security

By accurately managing their resources household's decision-makers can undertake activities which ensure them to be able to meet their basic needs (Chambers, 2000: 7).<sup>6</sup> When facing uncertainty and substantial risks individuals or households enact a series of behavioural modifications or short-term responses to cope with the immediate situation. Those that are unable to cope, or to adapt their livelihoods in order to face the change posed by risks, are inevitably vulnerable (Davies, 1996: 55).

Food security is deeply connected to the strategies that households select to negotiate their survival. For instance, household's ability to purchase food in the market plays a paramount role in determining access to food, and it is deeply linked to the income generating ability (LIFT, n.d.: 8). Considering that many food insecure people in developing country are net purchaser of food, income generation activities acquire even more relevance in determining food access. Studies indicate that the quantity and quality of food purchased is positively associated with household's income and food production (Ibid.).

Households that on regular bases face episodes of food insecurity triggered by risky events tend to develop a set of strategies for coping with them (Maxwell & Smith, 1992: 26). These take place after the event itself, and depend on the specific context and local conditions (Barrett, 2002: 21). Since households differ from each other, their response to stress and repeated shocks will be different as well (Payne & Lipton, 1994: 15). Typically, coping strategies include a wide range of activities to deal with risks, such as selling assets, removing children from school, migration of selected family members, seeking temporary employment, etc. (Alwang *et al.*, 2001: 3). Barrett identifies seven classes to which the coping mechanisms can be referred: (1) transfers and loans, (2) foraging for wild foods, (3) sale of unproductive assets, (4) reduced food, energy and other type of consumption, (5) sale of productive assets, (6) theft or refusal to comply with social obligations, (7) seasonal or temporal migration (Barret, 2002: 21).

These have been classified from relatively nonthreatening approaches, which are centred on protecting economic assets and livelihoods, to potentially detrimental ones (Barrett, 2002: 21;

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<sup>6</sup> Basic needs include a series of factors such as adequate food, health, shelter, and so on (Frankenberger & McCaston, 1998: 31).

Corbett, 1988: 1100). Individuals that face food insecurity tend to adopt coping strategies to secure their livelihoods that are gradually less flexible and potentially more injurious (Barrett, 2002: 22). That is to say that some coping strategies might enable households to get by the risks which threatens them in the short term, but at the cost of potentially compromising their long term adaptability (Hadley & Crooks, 2012: 77). Usually households employ strategies that they do not consider costly, or with low reversibility: for instance, eating less preferred food has a low degree of severity, and its frequently adopted (Maxwell *et al.*, 2008: 536). However, the last four classes especially are able to negative affect future production capability and physical well-being much more than the former three (Barret, 2002: 21). Despite these might improve food security on the short run, they also tend to have a detrimental effect in the future (Hadley *et al.* 2012: 77). Additionally, as their level of food security decrease, households tend to employ these strategies more and more often. Consequently those who regularly rely on these types of coping strategies are more vulnerable to suffer chronic food insecurity (Maxwell *et al.*, 2008: 534).

According to Barret, borrowing money from family members or through community networks help mitigate the risks (2002: 22). However these transfers are usually limited, and offer incomplete restitution in the wake of an adverse shock to the recipient's food security. Short term consumption credit and state-dependent credit contracts are likewise important to food consumption smoothing, but most households but his opting tend to be constrained in most households. When loans or transfers are not enough, households generally move to the next class and start disposing of their non-productive assets. Generally, to all assets can be associated a value, and therefore can be used as a form of insurance. However, not all individuals or households are able to negotiate the value of the assets on fare basis. In fact, those with higher income receive more for the same assets than those with lower income. Having a solid economic base works as self-insurance mechanism, since give the possibility to wait more favourable market conditions (Ibid). Similarly, productive assets (agricultural land, livestock, etc.) carry out an insurance function especially if financial market or social safety nets do not provide significant opportunity to smooth the consumption (Barret, 2002: 22-23). However, households might be reluctant to dispose of the main means of their livelihoods, and therefore decide to adopt different option. For instance, households can decide to temporarily immolate their nutrient intake in order to "preserve productive assets (e.g. land, livestock) or to make other current expenditures (e.g., on medicine, shelter, or education) necessary to secure future

livelihoods, and thereby future food security” (Barret, 2002: 21). Food is in fact only one among the wide range of factors that determine how households spread the risks and balance their interests during a crisis (Maxwell & Smith, 1992: 28). A good example was given by De Waal, who found that during the 1984/85 famine in Darfur people were prepared to reduce their food intake in order to preserve assets that were important for securing their livelihoods in the long term, such as seeds for planting and livestock (De Waal, 1989: 68). Similar conclusions can be found both in Turton (1977) and Corbett (1988)(Cited in Maxwell & Smith, 1992: 29). Undertaking small changes in the diet pattern is a strategy that does not involve long term consequences, such as selling productive assets. Additionally it can easily be reversed (Maxwell *et al.* 2008: 534). However, in its more severe forms, reducing food intake can lead to extreme consequences for the health of individuals and households who employed it, and can even cause health crises (Maxwell & Smith, 1992: 27).

## **5. Analysis**

The analysis is divided into three parts. Firstly, the impact of tuberculosis on households is analysed. Then, the second part investigates how households cope with TB related risks. Lastly, the link between risks and coping mechanisms is discussed. To better understand the initial situation of the respondents a table with their main demographic and socio-economic characteristics is given in Appendix III.

### **6.1 The impact of TB on households**

This part aims to analyse the impact of tuberculosis on availability, accessibility, and utilization of food. Here, the risks reported during the interviews are compared with those identified in the theoretical model. It specifically addresses the first sub-question of this study:

1) *How does tuberculosis threat the availability, accessibility, and utilization of food in labour migrants' households in the urban areas of Tajikistan?*

### 6.2.1 Availability

According to the theoretical framework, TB threatens household's food production. By physically incapacitating patients to do extended efforts, TB prevents them to work in agriculture, or taking care of livestock which are important sources of food for Tajik families. During the interviews none of the respondents mentioned a reduction of their own food production following the TB infection. Although, only two out of the 14 respondents owned food-productive assets, such as land or cattle. Besides this, migrants cannot be the main caretakers of this type of assets since they mainly live and work abroad.

### 6.2.2 Accessibility

TB related risks to accessibility in Tajikistan are mainly due to loss of working hours and productivity, caused by poor health conditions. These consequently lower household's income and affect their capacity to purchase food. At the same time, poor health conditions require medical treatment which enhances household's expenditure, once again affecting their income. A study at household level on TB related expenditure in Tajikistan has estimated these costs to be approximately \$4900 PPP per TB patient, in comparison with a GDP per capita of \$1600 PPP (2007 estimates) (Aye *et al.*, 2010a: 7). However, these may be even higher in MWTB's households, given the low income diversification which characterizes them.

This part is divided into five sections: four follow the possible risks identified by the theoretical framework, namely reduced income, health costs, lifecycle related costs, and intra-households distribution. To these, it was added a fifth risk which emerged during data collection, that is to say stigma. This last one particularly reflects the general characteristic of TB in Central Asia. For this study purpose health costs have been disaggregated into direct and indirect medical costs, and non-medical costs.

#### *Reduced income*

The long period of treatment associated with TB involve either a complete withdrawal from the labour market, or a significant reduction in hours of work. Usually patients with active TB are hospitalized until the disease becomes non-infectious, then a certificate is released and they are allowed to leave the hospital. This certificate is required in order to find a job, however according to the medical personnel (n.2) interviewed migrants usually do unqualified jobs where

the certificate is not asked. Patients with non-infectious TB are often in the physical conditions to work. Seven out of 14 stated to feel physically fine. However, only three of them were employed in the informal sector. For instance, respondent n.1 after being five months in the hospital was eventually able to work in his family business. The large majority of the respondents (11 out of 14) were unemployed when interviewed. In this regard, it is worth noting that doctors in Tajikistan tend to recommend to not work during the treatment, and up to two years afterwards (Ayé *et al.*, 2010a: 6). This tendency seems to be inherited from the former Soviet TB care system, where patients used to be treated frequently and for long period in specialized TB sanatoriums, often isolated from the main urban centres (Thierfelder *et al.*, 2008:1364).

The loss in terms of working hours and productivity is significantly larger for MDR-TB patients, since their period of treatment is longer and their symptoms more severe. The average length of the treatment period among respondents was around nine months, with the shorter being one month and half and the longer 27 months.

Caregiver's lives and productivity are also disrupted because of tuberculosis. For instance, several respondents have reported frequent visits of family members, which not only deplete economic resources due to the transportation costs, but also it diverts time from productive activities to caring for the ill. Respondent n.2 (construction worker, 24 years old) who lives in Dushanbe but with family in Farogh, stated that his family members cover the 220 km distance between Farogh and the capital three times per week to visit him, with repercussions on his father's job. Similarly, respondent n.10 (driver, 40 years old) stated that his mother came from Badakhshan and spent the summer taking care of him.

### *Health related costs*

Findings show that diagnosis and hospitalization, as well as first and second line TB drugs are provided free of charge to patients in Tajikistan (Landeck & Peck, 2011: 7, 12, 15). As a result, direct medical costs seem to have small or no impact on household's expenditure. This statement was reinforced by the opinion of medical personnel interviewed, and by the large majority of the respondents confirming of receiving free medications and treatment. Only a small minority, two out of the 14 TB patients interviewed were asked to pay for medicines they were entitled to. Respondent n.5 (taxi driver, 24 years old) claimed to have received only one pill during the three months period of hospitalization, due to collusion among the care providers.

Indirect medical costs play a more significant role, and seem to be the main key drivers for the health expenditure of MWTB and their households. In fact, ancillary treatments such as generics medicines, vitamins, and radiography are charged, consequently enhancing the economic burden associated with the disease (Aye *et al.*, 2010b: 4). As the mother of respondent n.9 clearly explained: “now that there is a sick person in the house the money is mainly spent on medicines and vitamins”. Additionally, respondents frequently mentioned chest X-ray being used as diagnostic instrument, both for themselves and for their families, which also involves high costs (Idem: 4).

Food and family members’ transportation to health facilities are non-medical costs with a major weight on health expenditure (Tanimura *et al.* 2014: 1770). These factors were often mentioned during the interview process. For instance, respondent n.3 (construction worker, 30 years old) indicated transportation and money among the main challenges faced by his household’s members during the TB treatment. Similarly, respondent n.4 (construction worker, 36 years old) highlighted the economic burden posed by the cost of transportation and food on his household’s income since he was diagnosed with TB. In fact, patients require nutrient-rich supplementary food to counter the weight-loss, and macro and micro nutritional deficiencies caused by their medical conditions.

Noticeably, although hospitalization does not involve costs *per se*, it also weighs on the expenditure for food and transportation (Aye *et al.*, 2010b:4). The quality of the health care services in Tajikistan is generally poor, and the amount of food which is provided in hospitals is often does not adequate for the treatment requirements (Thierfelder *et al.*, 2008: 1365; Forster *et al.* 2009: 80-81 ). Therefore, caregivers tend to bring food when visiting hospitalized patients, consequently leading to higher food-related expenditure during hospitalization. For instance, respondent n.1 (economic programmer, 25 years old) said that his mother had been visiting him twice a day, bringing food and medicines. Additionally, Gilpin *et al.* found that TB patients are discouraged by the poor conditions of hospitals, and prefer to be treated at home with further costs for the households (2011: 10).

Finally, it is worth discussing the health costs related to the period before diagnosis, and the long and frequent treatment delays. Previous studies showed that half of the total TB related costs occurred before the beginning of the treatment (Tanimura *et al.*, 2014: 1770). Labour migrants often realize to have TB in their host country, when their conditions have already worsened

significantly. Here access to medical services is expensive and often limited, especially for unregistered migrants who might fear legal consequences or deportation if they are found infected (Cook, 2014: 4). When diagnosed with TB, ill migrants need to return to Tajikistan for seeking treatment, which involves high cost for transportation: often they are deported by the host country, however in some cases they have to wait until they collect the money or receive it from home. This delay in diagnosis and treatment of TB cases contribute to the rising rates of MDR-TB. (Landeck & Peck, 2011: 7). The story of respondent n.11 (sport teacher, 33 years old) illustrates quite well the general trend:

when I was working at the service car I had a very bad heart pain. The ambulance came to pick me up and linked my lungs to a machine and brought me to the hospital. Then I did an X-ray, and they found that I had tuberculosis. The first time, the doctor in Russia asked for \$ 2000 for the treatment: this was too much money and I could not afford it. I lost a lot of weight: at the beginning I was 89 and I became 54. I felt really tired when they brought me back to Tajikistan.

His family had to send him medicines to Russia, but was only when he went back to Tajikistan that he started to seek proper treatment. By that time the disease was worsened to MDR-TB stage, which involves even higher medical and non-medical costs, besides the loss in productivity and income.

#### *Lifecycle related Costs*

Previous studies indicate funerals as an extreme cost for households, both in term of loss of income and additional expenses related to the ceremony (Bond *et al.*, 2008:63-65). During data collection respondents often confirmed deaths among their inner circle of friends and relatives, which is also in line with the high mortality rates for TB in Tajikistan. However none of the interviewees had a TB related death in their household, therefore it was not possible to estimate the impact of the funeral costs on household's expenditure.

#### *Unequal Intra-household Distribution of food*

Tuberculosis can lead to unequal intra-household access and distribution of food, which can result in access to food being reduced for certain groups (especially women and children) due to discrimination factors. Tajikistan is indeed characterized by high gender inequality, however



during the interviews process direct elements of intra household's discrimination did not emerged. Nonetheless, the type of sample chosen did not allow an in-depth analysis of this issue, and further research is required.

As it regards children, in Tajikistan malnutrition and underweight among this group is generally increasing. Few progress have been made in reducing stunting rates, nonetheless these are still high (27%) (UNICEF, 2014: 46; FAO *et al.*, 2013: 37). Given this particularly severe situation, special attention was given to ask MWTB living in households with children under age 18 specific questions designed to asses if, and how TB has affected them. Noticeably, food security was recorded among children. Furthermore, respondents often replied almost offended by this very idea: in fact, in the dominant idea of masculinity men are sees as the breadwinners, which have to provide food and income for their family. There are also reasons to believe children being a prioritized group within the household, however no sufficient data are available on this specific issue. Nonetheless, it needs to be said that undernutrition in adults can affect mothers' capacity of breastfeeding, consequently lowering infants and young children level of food security.

### *Stigmatization*

Among the risks connected with TB, there is stigmatization. One of the doctors interviewed claimed that TB patients in Tajikistan very rarely face stigma, however interviews with MWTB, as well as the existing literature contradict this statement. Respondents revealed to be afraid of people reaction, to the point to indicate managing relationships, as the most difficult thing of having tuberculosis. Respondent n.7 (nanny, 35 years old) said: "I feel sorry for myself" and "I feel that everybody looks at me with different eyes". Similarly, respondent n.5 (taxi driver, 24 years old) stated: "friends and people start to think you are not human anymore when you have tuberculosis".

### 6.2.3 Utilization

#### *Macro and Micro nutrients Deficiency*

As seen before, TB make undernutrition worse, and in return undernutrition and malnourishment weakens body immunity response, consequently increasing the probability of latent TB

developing into active disease (WHO, 2013:8; USAID, 2008: 1). Studies found nutritional status to be significantly lower in patients with active pulmonary tuberculosis compared to those with latent one (Gupta *et al.*, 2009: 11; Shetty *et al.*, 2006: 84). Consequently, these are more likely to be wasted or have a lower body mass index which is associated with increased mortality in TB patients (USAID, 2008: 1). Generally, tuberculosis threatens the utilization of food in the two following ways.

Firstly it reduces appetite and the ability to take food. As a consequence of the disease respondents experienced abdominal pain, lack of appetite, and vomit. A construction worker (21 years old) described his health conditions as follows: “I feel like throwing up, and that everything in my body is broken, kidneys and all the other organs. These medicines are breaking my organism”. Another construction worker (30 years old) said: “Every time I eat I also throw up, because of the medicines”. All these symptoms have an impact on individual food intake and result in severe weight and in some cases vitamin and mineral deficiencies (WHO, 2013:8)

Secondly it affects protein metabolism and reduce the ability of the body to absorb macro and micro nutrients (Gupta *et al.*, 2009: 11). Deficiency in vitamins and minerals (such as A, E, and C, zinc, and selenium) has been associated with secondary immunodeficiency and infection related morbidity including tuberculosis (Gupta *et al.*, 2009: 11-15). As a consequence TB patients need to assume vitamin injections and rehydrating infusion as complementary treatment, adding costs to the overall medical expenditure as previously seen (Aye *et al.*, 2010b:4; Gilpin, *et al.*, 2011:10).

According to WHO the most effective TB therapy is assuming sufficient food. By improving the nutritional status and reducing energy/nutrient demands the risk of death or TB relapsed can significantly decrease (WHO, 2013:8, 9). As one of the doctors (n.1) clearly stated: “TB patients need to eat all kind of food. A lot of milk/ yogurt, steaks, rice, fruits. They usually receive meals 5 times per day [when hospitalized]. They need little food but often otherwise they will throw up”.

## **6.2 Coping with TB related risks**

In order to face the risky events caused by tuberculosis and their related burden, MWTB's households need to re-organize their resources in a way which allows them to secure their future

livelihoods, and so their survival. The second sub-question of the study is therefore the focus of this part:

*2) How do households of labour migrants with tuberculosis in the urban areas of Tajikistan organize their resources and activities in order to cope with the risks posed by tuberculosis to their availability, accessibility, and utilization of food?*

### 6.3.1 Household's coping strategies

Interviews had shown that usually the most economically active members of the household support the sick. The more diversified the household's income is, the more the household is able to cope with the risks without adopting particularly detrimental strategies. In fact, households with a large number of members contributing to the overall income are less dependent on the breadwinner, and more able to cope with the income loss by rearranging labour time within the household itself (Wagstaff, 2005: Ch.1). This also entails having as part of the household individuals in age or condition to work.

#### *Borrowing*

According to Tanimura *et al.* the most common coping strategies adopted by TB patients include taking a loan, receive transfers from relatives, selling household items, using savings (2015: 1769). Interviews show that borrowing is the most common strategy also in Tajikistan, adopted by the large majority of the respondents. Moreover, evidence from previous studies indicates that having permanent migrants as household's member creates a sort of informal insurance mechanism that helps their origin household facing income shocks (Millan, 2014: 2). Understandably the effectiveness of this mechanism depends on the type of relation that exists between the parties (Idem: 2). Similarly, in Tajikistan households with close family members into labour migration (usually the father, or brothers of the patient) tend to temporarily rely on their economic assistance. On the other hand, those that do not receive any remittances resort to borrow money from financial institutions. It is worth mentioning that borrowing from other members of the community or just receiving support from them does not seem a common option in Tajikistan. Indeed, some respondents stated they have not received any help from other relatives and friends. The lack of support from households' social nets may be due the stigma associated with TB, which isolates the household's affected from the rest of the community.

According to Hargreaves *et al.* individuals with TB symptoms might fear stigmatization, which prevent them to seek assistance from the rest of the community when they become sick (2011: 655).

#### *Reduced Household's Expenditure*

Borrowing and taking loans are usually associated with other coping behaviours that are reducing household's expenditure. Firstly, households start from less important items. For instance, respondent n.4 (construction worker, 36 years old) mentioned that before the illness they used to spend on technology, and after the shock they decided to cut on that. Energy and cloths are also elements on which households tend to save money on. However these are only secondary components of the overall household's expenditure, which consist mainly of food in Tajikistan. Aliments typically accounts for over two third of an average household's expenditure (Asadov, 2013:10). However MWTB's households need to face additional costs, since TB patients are required to change their eating habits for a more balanced diet, in order to assume the nutrients-rich food they need. Usually, food consumption in Tajikistan is based on bread, or other aliments, such as oil and fat which give cheap calories, but not meat, fish, or dairy products (Asadov, 2013: 12; UN & GoT, 2010:18). These latter belongs to the type of aliments that doctors suggest TB patients to eat, and are considerably more expensive.

#### *Redistribution of food*

There also a series of coping mechanisms which are based on the redistribution of food within the household. For instance, respondents stated that sometimes their household's members had to cut the size, or to skip food in order to provide TB patients with a full meal. While this solution decrease the level of food security of the household in short term, it helps avoiding more extreme measures, such as going twenty-four hours without eating. This is a less frequent option, which only one household with a low food security level adopted (respondent n.4). Another coping mechanism is to buy food on credit. In general household's members tend to cut the food expenses but not those related to TB patients. It is worth noting that households which borrow from family member into migration tend to not adopt strategies that impact household's members food consumption.

### *Selling Productive Assets*

Aye *et al.*, indicated selling productive assets as the most common strategy among the coping mechanisms adopted in Tajikistan, especially cattle, goats, and sheep. (2011:311). This tendency was not confirmed by the respondents. In fact, only three respondents owned physical assets able to produce an actual revenue. Of these, only respondent n.5 (taxi driver, 24 years old) sold his car in order to pay down his loan, depriving himself of the means to sustain his livelihoods in the future. This difference might be due to the fact that in Aye *et al.* study the sample chosen represented the whole population with tuberculosis in Tajikistan, and not the subgroup of migrants.

### *Return to Migration*

Return to migration is also an element which needs to be taken into consideration. One of the reasons why migrants are considered a particular at risk group of the population is their low adherence to DOTS. As doctor n.2 reported: “patients start taking medicines and when they begin to feel better they leave the country, interrupting the cure”. Some of the migrants interviewed have expressed the intention to return to labour migration as soon as they will feel better. In the short term this decision might sooth household’s expenditure, and increase the household’s income. However the potential risk of relapse, which might lead to drug resistance forms of tuberculosis, poses a serious threat to future sustainability of the household, making this strategy extremely hazardous.

A summary of the coping strategies adopted in relation to the security status of the respondents can be found below in Table 3.

**Table 3:** Main coping strategies employed by respondents

| ID | Family Support | Use of assets | Migrants Support | Taking Loans | Cut/skip meals | 24h without eating | MWTB starts working | Family starts working | Selling assets | Food security Status   |
|----|----------------|---------------|------------------|--------------|----------------|--------------------|---------------------|-----------------------|----------------|------------------------|
| 1  | X              |               |                  | X            | X              |                    | X                   |                       |                | Marginal Food Security |
| 2  | XX             | X             | X                |              |                |                    |                     |                       |                | Food secure            |
| 3  | X              |               | X                |              |                |                    |                     |                       |                | Low Food Security      |
| 4  | X              |               |                  |              |                |                    | X                   |                       |                | Low Food Security      |
| 5  | X              |               |                  | X            |                |                    |                     |                       | X              | Low Food Security      |
| 6  | X              |               |                  |              |                |                    |                     | X                     |                | Marginal Food Security |
| 7  | X              |               |                  | X            | X              |                    |                     |                       |                | Very Low Food Security |
| 8  | XX             | X             |                  |              | X              |                    |                     |                       |                | Marginal Food Security |
| 9  | X              |               |                  | X            | X              | X                  |                     |                       |                | Low Food Security      |
| 10 | X              |               | X                |              |                |                    |                     |                       |                | Marginal Food Security |
| 11 | X              |               | X                |              |                |                    |                     |                       |                | Marginal Food Security |
| 12 | XX             |               |                  |              | X              |                    |                     |                       |                | Marginal Food Security |
| 13 |                | X             | X                |              |                |                    | X                   |                       |                | Marginal Food Security |
| 14 | X              |               | X                |              |                |                    |                     |                       |                | Marginal Food Security |

**Source:** Compiled by the Author

### 6.3.1 Potentially Detrimental Strategies

According to Aye *et al.* households affected by TB in Tajikistan tend to cope with the economic burden of tuberculosis by adopting potentially detrimental coping strategies, consequently enhancing their risk of impoverishment (2011: 3010). Moreover, their findings showed a statistical tendency for patients who were into migration to rely more on detrimental strategies than other patients (Ibid.). This tendency can be attributed to the role of breadwinner played by migrants in their households: in fact, as migrants become sick suddenly the overall income of the household drastically drop, leaving household's members to deal with devastating loss in term of hours of work and earnings. The economic loss which households of MWTB face derives mainly from this lack of diversification of source of income.

In order to cope with this issue households tend to draw resources from the assets they have available, however those with more limited resource have also a more limited set of coping strategies on which they can rely on. Often these households can draw only on their human capital, by increasing the hours of work of other household's members. As a result, family

members that were not employed before are forced by the necessity of the moment to seek employment. This is the case for instance of respondent n.6 (42 years old), whose wife started working when he became sick, so as to provide the household with an additional source of income. Generally, from the interviews appear clear that female members, especially mothers and wives of migrants, are those bear the major part of the economic and social burden of tuberculosis. Firstly, in form of increased caregiving duties, especially considering that in Tajikistan unpaid work within the household is unequally distributed and deeply weighs on women (Falkingham, 2000: 50). Secondly, in terms of increased paid working hours, since often they become the main source of income in the household.

Several respondents reported to cut the size of their meal or to reduce the money spent on food in order to cope with the increased overall expenditure. These strategies might temporally help MWTB' households to cope with their present needs. Nonetheless, in the long run they have a potential negative impact on the level of food security. By adopting this type of coping strategies they increase their level of malnourishment and undernutrition, which in turn weakens immunity to TB, thereby increasing their exposure to the disease. It is worth remembering that household's member of TB patients are a particular at risks group of the population since they have frequent contacts with people with TB.

The strategies adopted for coping with body loss of nutrients also present some detrimental aspects that necessitate to be commented upon. There are several misbeliefs which influence household's food expenditure, and might lead to diets that do not effectively address the nutritional requirement of TB patients and increase the food expenditure. Firstly, what is perceived as healthy and nutritious food varies largely from person to person. For instance, one respondent indicated eating often at the restaurant as example of good diet, a second respondent specified eating at home, and another salad and dairy products as nutritious meals. Additionally misbeliefs on food preparation seem to be quite diffuse: a study from Forster *et al.* highlighted that "hot-nature" food is considered to be more suitable for TB patients compared to "cold-nature food" which instead is avoided (2009: 80-81).

Finally, in order to guarantee the safety of the food households often separate the plates and utensils used by TB patients from the others, and in some case the sick consume their meal alone. This attitude is based on the misbelief on how TB is spread. Since traditionally Tajik

people eat from a share plate this coping strategy contribute to intensify patient's isolation and the misperception of the disease.

### **6.3 Discussion**

This part analyses how the TB related risks to availability, accessibility, and utilization of food interact with the coping strategy adopted by households.

#### *6.3.1 The impact of coping with the risks to food availability*

The dimension of food availability which was presented in the theoretical framework it revealed to be irrelevant for the analysis. As seen, before tuberculosis did not affect the availability of food. Consequently the strategies that households employed did not specifically address this aspect of food security. It can be argued that being related to the supply dimension of food security, availability concerns more the meso, macro, and super macro level of analysis rather than household level. Nevertheless, home production plays an important role in the food status of households in Tajikistan. The fact that it did not in this study could depend both by the urban setting, as well as the type of sample, and it requires further investigation.

#### *6.3.2 The impact of coping with the risks to food accessibility*

When asked about the main challenge that TB posed to their households, many respondents mentioned factors ascribable to economic costs. These represent the most serious threat to household's capacity to access food. Indeed, the economic burden associated with continuous TB treatment was demonstrated to be extremely high, especially in terms of income loss and non-medical expenditure (Tanimura *et al.*, 2014:1770). The implementation of the DOTS strategy in Tajikistan has significantly reduced the impact of direct medical costs, which often have been reported as not relevant. All in all, the costs that households face vary largely according to factors such as socioeconomic status, type of treatment, distance to health services, capacity to work, and existence of social protection nets.

Generally, respondents who did not have a close relative into migration were not able to smooth the health related expenditure, or insure themselves effectively against the TB related economic risks. As a result, these income changes passed through the household's consumption pattern, which consequently changed accordingly (Wagstaff, 2005: 1). From comparing interviews



emerged also that households that borrow from institutions tend to adopt other complementary strategies, in order to either increase income, or to reduce consumption. Regarding this latter, among the mechanisms that households employ more frequently there are those moderately reversible in the short term, such as eating non-favourite or low cost type of food, or cut the size of their portion (Maxwell *et al.* 2008: 535-536). Strategies that are perceived as more severe, such as skipping a meal or not eating for the entire day are less common, and can be associated with a higher level of food insecurity.

The impact of TB on accessibility to food becomes extremely severe mainly for two types of households of MWTB: those which include MDR-TB patients, and households characterized by limited income diversification. The extreme incapacitating effects of this strain of tuberculosis, together with its long treatment period, lead to an higher and prolonged income loss which might become catastrophic, making them more and more vulnerable to food insecurity in the long term (Tanimura *et al.*, 2014: 1772). Additionally, the trend of coping strategies employed clearly shows that most of the migrants face the risks posed by tuberculosis by temporarily sacrificing their food consumption. As previously seen, these strategies allow a certain degree of flexibility. Households start adopting the less detrimental coping mechanisms first, which decrease the overall level of food security in the short term. However, by doing so they have the opportunity to reorganize their economic assets, so as to ensure the access to the necessary food and health related needs for the patients recovery. In fact, generally households tend to secure their livelihoods in the long term through restoring the patient's income. As time passes, strategies become less and less flexible, and households are bound to adopt more detrimental options, which significantly increase their vulnerability. In the case of MDR-TB, households might exhaust their resources before the recovering of the TB patients, consequently becoming food insecure.

For the second group, low income diversification means that the TB related costs, as well as income loss, in many cases may exacerbate already serious economic vulnerability leading households to face catastrophic costs (Tanimura, 2014: 1772). In this case more severe coping strategies can be adopted from the beginning, such as taking a loan, or selling productive assets. Some households, address the root of the problem directly, drawing from the human capital available in order to diversify their income. In these cases the members that are not formally employed seek to join the formal and informal labour market. As we have seen before this was

the case of respondent n.6. However, there are more severe forms possible, such as sending children to beg, which were not identified among the respondents (Maxwell *et al.*, 2008: 536). Sometimes, patients who feel in the right physical conditions might start working, notwithstanding the negative effect that can have on the treatment.

While there is no evidence of direct discrimination regarding the intra-household distribution of food, it appears clear that the coping mechanisms adopted indirectly increase vulnerability to food insecurity of the non-sick members of the households. Among these, the burden associated with TB becomes especially high for female members, who not only support the households economically, but become also the main caregivers. Studies show that the excessive burden that fall on women is connected with high level of stress (Falkingham, 2000: xvii). Stress, together with depression are among the approximate risks factors which can have a negative effect on the immune system, consequently increasing the risk of TB (Lonroth *et al.*, 2009: 2243)

### 6.3.3 The impact of coping with the risks to food utilization

The coping strategies usually employed to face the TB related risks to utilization have the double effect of increasing the food and nutritional security of the TB patients from one side, and of decreasing those of their household's members from the other side. Generally, households lean towards two different coping strategies which seem to contradict each other. At first, in order to cope with the loss of income and the higher expenditures, households tend to reduce their expenses, which in Tajikistan are especially related to food. At the same time, they need to provide TB patients with five meals per day of nutritious food, in order to counterbalance the combined effects of the medicines and of the metabolic changes produced by the disease. They need therefore to balance out these two directions of their expenditure. Respondent n.3 (construction worker, 30 years old) situation was particularly explicative of this phenomenon. After the beginning of the treatment, his household's food-related expenses were reduced to one third of what they used to be in the past. "Before everything was fine and all problems could have been easily solved", he said, and then he added: "before we spent around \$200 for food, now is around 60/70". Such a severe reduction translates into practice in cutbacks on the most consumed items. "We used to buy 50kg of rice, now only two or three", he said. It needs to be mentioned that this respondent confirmed receiving food transfers by international organizations, which might have positively complemented this major reduction. Nonetheless, this large cut on

the food related expenditure had a significant impact on the overall household's level of food security. It happened that members of his household had to eat less, or skipped a meal when hungry, because there were not enough resources/ money to buy food. However this does not include the very respondent, who also stated to be eating too much. As previously seen, one of the risks that patients incur when they contract TB is a drop in their nutritional intake. Consequently they require additional nourishment, which increase the food expenditure of the entire households, and in return lead other household's members to reduce their own consumption. For instance, respondent n.13 (nurse, 31 years old) reported that sometimes his family does not have enough food for themselves, nonetheless they force him to eat.

#### 6.3.4 The crosscutting impact of safety nets on accessibility and utilization

The role played by conditional food transfer interventions, implemented by different international organizations in Tajikistan need also to be taken into account. These interventions aim to increase patient's adherence to DOTS through conditional food transfers (WFP, 2010: 1). After two months from the beginning of the treatment TB patients receive food supplies, mainly flour, peas, vegetable oil and iodized salt. All in all, patients and their family members receive three parcels during the course of full treatment period (UNDP, 2012: 13). As doctor n.2 said: "these [food parcels] help especially because Tajik people eat a lot of bread". When asked, only three respondents who were eligible for the transfers reported they did not receive any. Although there is no clear evidence on impact of these transfers on the adherence to TB treatment, they did provide an important support for nutritional recovery and mitigate part of the financial and social consequences of TB. Food interventions have proved to be very effective in alleviating food expenditure. They allowed large size households to better cover the costs associated with TB treatment, without having to extensively reduce their food expenditure.

## **6. Conclusions**

This study aimed to contribute to the theoretical discussion on vulnerability to external shocks, and more specifically on the link between communicable disease and food security. This work focused on tuberculosis, given its importance for development and its well-known link with nutrition. As seen before, there are several studies that investigate the relation between TB and undernourishment, and even more that explore the links between TB and poverty (Gupta *et al.*,

2009; Shetty *et al.*, 2006; Katona & Katona-Apte, 2008; Ahlburg, 2000). Although very important, studying TB only from an economic or nutritional point of view partly limits the understanding of its effects on vulnerable groups. Using the concept of food security helps to encompass these aspects, by including them in a broader framework. However, only few researchers have studied the impact of TB on food security, and usually in correlation with disease such HIV-AIDS and malaria, or other shocks (Bond *et al.* 2009; Burke *et al.*, 2014; Moustafa & Elamin, 2014; Russel, 2004). Therefore this study tried to fill this gap by focusing on how tuberculosis impact vulnerability to food insecurity in a group of the population especially at risk, labour migrants.

Findings highlighted the negative impact of TB on accessibility and utilization of food, while the availability dimension seems to not being affected, probably due to the characteristics of the subgroup studied. Through chronic illness, social stigma, and eventually death TB negatively impacts household's income generating activities and labour productivity, while increasing the indirect and non-medical costs. On the other hand, it affects TB patients' absorption mechanisms and nutritional intake. As a result, specific and more expensive food requirements become necessary for recovering. Hence, the gap between nutritional intake required by the TB patients, and household's ability to access food becomes wider. Households manage the risks posed by tuberculosis by selecting different coping strategies such as borrowing from relatives in migration, taking loans, reducing their expenditures, start working, diversify the income, and selling productive assets. As the treatment prolongs, the coping mechanisms employed become more and more detrimental and less flexible. This involves not only economic implications, but compromises the all set of human, financial, natural, social, and physical assets that households own. In the long term, the combined effect of being continuously exposed to TB risks, and the detrimental effects of the coping mechanisms employed begins to endanger household's very livelihoods and food security.

As mentioned at the beginning, tuberculosis and food insecurity negatively influence each other. Low food security and undernourishment weaken the immune system, consequently increasing the degree of exposure to tuberculosis. In return, tuberculosis reduces individual's capacity to absorb nutrients, and consequently enhances their likelihood of becoming food insecure. However, the situation is way more complex, because the effects of this vicious cycle do not concern TB patients only, but are extended to the members of the household as well. The

increased household's food insecurity considerably escalates the degree of exposure to TB contagion of other household's members, posing a major threat to their future health and wellbeing. Time is a decisive element to break this circle. Households that employ the most detrimental coping strategies are those that do not rely on family members' economic assistance. Deprived of an appropriate ensure mechanisms, they tend to cope by temporally sacrificing their food security status. But this strategy can be effective only in the short term. This also involves that households with patients affected with MDR-TB, and those with less resources to draw on, are the most vulnerable. The first ones because for them the period of treatment is generally really long, the second ones because are less flexible and can cope only for a short period before exhausting their assets and beginning to adopt detrimental measures. As a consequence, social interventions which specifically address the time factor, can both decrease vulnerability to food insecurity and reduce the risk of tuberculosis spreading to other family members.

By using Tajikistan as a case, this study helped to achieve a more holistic understanding of the relationship between tuberculosis and household food insecurity. The vulnerability framework employed allowed to interconnect TB risks threatening food insecurity, with the strategies that households adopt to cope with them, and to refer them to the outcome of their combination, that is to say food insecurity. Moreover, this approach allowed to identify several issues that require further investigation. These were outside the design of the study; nevertheless they are extremely relevant for understanding other dimensions of tuberculosis. In fact, during the interview process became clear that female members of the household were the main caregivers, and those who were more involved in the TB treatment of the patients. Moreover they were also the one shouldering the burden of tuberculosis. The existing literature tends to consider this burden only in economic terms, as productivity lost or increased expenditure. However the psychological aspects also play a very important role in the spread of TB. Close contact with TB affected people, stress, and depression all determinants of Tuberculosis since they weaken the immune system (Lonnroth *et al.*, 2009: 2243). Being the main caregivers, women are continuously exposed to the risk of infection, which already involves a certain degree of stress. Additionally, TB is often associated with intra-household tension, since the prolonged period of treatment often causes frustration and anger in patients (Bond *et al.* 2009: 54). The combination of these two aspects, together with the economic elements increase the vulnerability to TB of female

members. Studying the emotional impact of TB in relation to gender roles would considerably enrich the understanding of this shock with a new point of view, moving the research forward.

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## Appendix

### Appendix I – Sample Record

| Medical Personnel |            |        |          |          |
|-------------------|------------|--------|----------|----------|
| ID                | Date       | Gender | Position | Comments |
| <b>Dushanbe</b>   |            |        |          |          |
| 1_MP              | 22/12/2014 | Female | Doctor   |          |
| 2_MP              | 22/12/2014 | Female | Doctor   |          |

| Migrants with Tuberculosis |            |        |     |                |                |   |
|----------------------------|------------|--------|-----|----------------|----------------|---|
| ID                         | Date       | Gender | Age | Marital Status | Household Size | Comments  |
| <b>Dushanbe</b>            |            |        |     |                |                |   |
| 1_MWTB                     | 24/12/2014 | Male   | 25  | Married        | 7              |   |
| 2_MWTB                     | 24/12/2014 | Male   | 24  | Single         | 2              |   |
| 3_MWTB                     | 07/01/2015 | Male   | 30  | Married        | 7              |   |
| 4_MWTB                     | 07/01/2015 | Male   | 36  | Married        | 5              |   |
| 5_MWTB                     | 08/01/2015 | Male   | 24  | Single         | 5              |   |
| 6_MWTB                     | 08/01/2015 | Male   | 42  | Married        | 15             |   |
| 7_MWTB                     | 08/01/2015 | Female | 35  | Married        | 4              |   |
| 8_MWTB                     | 12/01/2015 | Male   | 21  | Married        | 9              |   |
| 9_MWTB                     | 12/01/2015 | Male   | 34  | Separated      | 4              | The mother of the respondent was answering for him because medicines made him deaf        |
| 10_MWTB                    | 12/01/2015 | Male   | 40  | Divorced       | 2              |   |
| <b>Qurghonteppa</b>        |            |        |     |                |                |   |
| 11_MWTB                    | 22/01/2015 | Male   | 33  | Married        | 8              |   |
| 12_MWTB                    | 22/01/2015 | Male   | 19  | Single         | 5              |   |
| 13_MWTB                    | 22/01/2015 | Male   | 31  | Married        | 20             |   |
| 14_MWTB                    | 22/01/2015 | Male   | 29  | Single         | 11             | The participants decided to withdraw from the interview before questions on food security |

## Appendix II – Interview guides

### Interview Protocol Medical Personnel

|    |  |
|----|--|
| 1. | <i>How long have you been working with Tb patients and what are your most significant experiences?</i>   |
| 2. | <i>How many are the patients with tuberculosis who seek assistance in this structure every year (how many of them are women)? How many of them are migrants? How many migrants are currently here? (How many of them are women)?</i> |
| 3. | <i>In your opinion what are the main challenges that migrants with TB face? Can you give some examples?</i>  |
| 4. | <i>In your opinion what are the main expenses that households of migrants with TB face? Can you think of any other challenge?</i>  |
| 5. | <i>How does tuberculosis affect the patients' diet</i>   |
| 6. | <i>In your opinion does tuberculosis make migrants' households more vulnerable to the lack of food?<br/>If yes, can you please describe how?</i>   |

### Interview Protocol Migrants With Tuberculosis

|           |   |
|-----------|---|
| <b>1.</b> | <b>Household</b>  |
| 1.1       | <i>Who is the head of the households?</i>   |
| 1.2       | <i>What is the age and gender of the household's members?</i>   |
| 1.3       | <i>Where do you live (urban or rural area)?</i>   |
| 1.4       | <i>Are parts of your family living elsewhere? If so, where do they live and what is their age and gender?</i>   |
| <b>2.</b> | <b>Occupation</b>   |
| 2.1       | <i>Can you please describe your current occupational status?</i>  |
| 2.2       | <i>Has your occupational status changed because of the disease? If so can you please describe how and what was your previous job?</i>   |
| 2.3       | <i>Do you have any other job/source of income aside your main occupation?</i>   |
| 2.4       | <i>What is your professional background, if any?</i>  |
| 2.5       | <i>What is your level of education?</i>   |
| <b>3.</b> | <b>Migration</b>  |
| 3.1       | <i>What were your main reasons for migrating?</i>   |
| 3.2       | <i>What was your job and type of labour migration?</i>  |
| 3.3       | <i>Which countries did you go to work to? And for how many years?</i>   |
| 3.4       | <i>Can you please describe the working and living conditions (ex. how many people in the same room, how many toilets, was the place well ventilated, did you have access to water, how was the level of hygiene)? Can you please compare them with your working</i> |



|           |   |
|-----------|---|
|           | <i>and living conditions in Tajikistan?</i>   |
| 3.5       | <i>Did you earn enough to send money or other commodities home? If so, how much/what type of commodities usually? Can you describe how the money/commodities were used (giving a percentage if it is possible)?</i>   |
| <b>4.</b> | <b>Income and expenditure</b>   |
| 4.1       | <i>Before being diagnosed with TB, how much was the income of your household per month and how much is it today</i>   |
| 4.2       | <i>Has your contribution to the household's income changed after you contracted tuberculosis? If so, how is your household coping with this lack of income? How much is your contribution nowadays?</i>   |
| 4.3       | <i>Is any other member of the household contributing to the household's income? Does your household have other sources of income, entrances or assets apart from jobs (ex. livestock, grants, borrowing, etc.)? Before being diagnosed with TB, which source of income was the most important for your household and which one is today</i> |
| 4.4       | <i>Do you receive any assistance from the state or international organizations?</i>   |
| 4.5       | <i>Before being diagnosed with TB, what were your household main expenses and what are today? How much of your household's income was spent on food before and how much is spent today?</i>   |
| <b>5.</b> | <b>Health</b>   |
| 5.1       | <i>Can you please describe your health conditions and symptoms?</i>   |
| 5.2       | <i>When did you realize to have Tuberculosis and how do you think you got this disease?</i>   |
| 5.3       | <i>What did you think when the doctors told you that you have tuberculosis? What were your main fears?</i>  |
| 5.4       | <i>Can you please describe the duration and type of treatment you are undergoing? What is the most difficult thing for someone with TB?</i>   |
| 5.5       | <i>What are the main difficulties your family had to face in relation to your treatment?</i>  |
| 5.6       | <i>Has tuberculosis brought any change in your diet? If so, can you please describe how it changed?</i>   |
| 5.7       | <i>Has Tuberculosis brought any change in your household's eating habits?</i>   |

### Household Food Security Module

The Households Food Security Module is a survey developed by USDA to measure the status of food security of households. It is divided in five different parts with screeners, but only the first one is asked to all households. For the purpose of the study the survey has been adapted to two temporal spaces: participants were asked to answers questions related to their food security level from the diagnosis of tuberculosis up to the present.

| <b>HH Household Stage 1: Questions HH1-HH4</b> |   |
|--|---|
| HH1  | <i>Which of these statements best describes the food eaten in your household: —enough of the kinds of food (I/we) want to eat; —enough, but not always the kinds of food (I/we) want; —sometimes not enough to eat; —often not enough to eat?</i> |
| HH2  | <i>(I/We) worried whether (my/our) food would run out before (I/we) got money to buy more, or other resources”. Was that often true, sometimes true, or never true?</i>   |
| HH3  | <i>The food that (I/we) bought just didn’t last, and (I/we) didn’t have money or other resources to get more”. Was that often true, sometimes true, or never true for you?</i>  |
| HH4  | <i>(I/we) couldn’t eat healthy and nutritious meals because of a lack of money or other resources”. Was that often true, sometimes true, or never true for you?</i>   |

If participants give a negative response to question HH1, or an affirmative response to one or more of questions HH2-HH4, then the interview will move on to Adult Stage 2. Otherwise, if there are children under age 18 in the household, the interview will move directly to Child Stage 1. If there are no children the interview ends here.

| <b>Adult Stage 2: Questions AD1-AD4</b> |  |
|---|--|
| AD1                                     | <i>Did (you/you or other adults in your household) ever cut the size of your meals or skip meals because there wasn't enough money for food?</i> |
| AD1a                                    | <b>[IF YES ABOVE]</b> <i>How often did this happen—almost every month, some months but not every month, or in only 1 or 2 months?</i>            |
| AD2                                     | <i>Did you ever eat less than you felt you should because there wasn't enough money for food?</i>  |
| AD3                                     | <i>Since the beginning of TB treatment, were you ever hungry but didn't eat because there wasn't enough money for food or other resources?</i>   |

If participants give an affirmative response to one or more of questions AD1-AD3, then the interview continues to Adult Stage 3; otherwise, if children under age 18 are present in the household, the interview moves to Child Stage 1. If there are no children the interview ends here.

| <b>Adult Stage 3: Questions AD4-AD4a</b> |   |
|--|---|
| AD4                                      | <i>Did (you/you or other adults in your household) ever not eat for a whole day because there wasn't enough money for food?</i>       |
| AD4a                                     | <b>[IF YES ABOVE]</b> <i>How often did this happen—almost every month, some months but not every month, or in only 1 or 2 months?</i> |

If there are no children the interview ends here.

| <b>Child Stage 1: Questions CH1-CH3</b> |   |
|---|---|
| CH1                                     | <i>“(I/we) relied on only a few kinds of low-cost food to feed (my/our) child/the children)</i> |

|      |  |
|------|--|
|      | <i>because (I was/we were) running out of money to buy food or didn't have other resources." Was that often, sometimes, or never true for (you/your household) in the last 6 months?</i>   |
| CH2  | <i>"(I/We) couldn't feed (my/our) child/the children) healthy and nutritious meals, because (I/we) couldn't afford it due to lack of money or other resources." Was that often, sometimes, or never true for (you/your household)?</i> |
| CH3. | <i>"(My/Our child was/The children were) not eating enough because (I/we) just couldn't afford enough food." Was that often, sometimes, or never true for (you/your household)?</i>  |

If participants give an affirmative response to one, or more questions CH1-CH3, then the interview continues to Child Stage 2; or otherwise it ends here.

| <b>Child Stage 2: Questions CH4-CH7</b> |  |
|---|--|
| CH4                                     | <i>Since the beginning of the TB treatment, did you ever cut the size of any of the children's meals because there wasn't enough money for food?</i> |
| CH5                                     | <i>Since the beginning of the TB treatment, did any of the children ever skip meals because there wasn't enough money for food?</i>                  |
| CH5a                                    | <b>[IF YES ABOVE]</b> <i>How often did this happen—almost every month, some months but not every month, or in only 1 or 2 months?</i>                |
| CH6                                     | <i>Since the beginning of the TB treatment, were any of the children ever hungry but you just couldn't afford more food?</i>                         |

## Appendix III

| ID     | TB Patient Profile               | HH Size | HH Composition   | HH Socio-economic Status before TB   |
|--------|----------------------------------|---------|--|--|
| 1_MWTB | 25-year-old<br>Male<br>Married   | 7       | TB Patient (25) (HoH)<br>Wife (?)<br>Father (49)<br>Mother (49)<br>Four Brothers (22) (17) (12) (10)   | - The father works<br>- TB patient used to send remittances for around USD 1300 per month. The money was used for food and financing brother's education   |
| 2_MWTB | 24-year-old<br>Male<br>Single    | 2       | Brother (26)<br>TB Patient (24)  | - They have a cotton field<br>- Father works as gardener for the UN.<br>- Mother works in the bazar.<br>- TB patient used to send remittances for around USD 600 per month. The money was used for food and the rest was saved for his marriage  |
| 3_MWTB | 30-year-old<br>Male<br>Married   | 7       | TB Patient (30) (HoH)<br>Wife (20)<br>Mother (51)<br>Brother (28)<br>Sister in law (24)<br>Two Children (2 months) (3)   | - one brother is a migrant in Russia<br>- His mother works in a theatre.<br>- TB patient used to send remittances for around USD 400/500<br>- Before everything was fine and all problems could have been easily solved.   |
| 4_MWTB | 36-year-old<br>Male<br>Married   | 5       | Tb Patient (36) (HoH)<br>Wife (31),<br>Three Children (11) (9) (18 months)   | - The wife is a teacher and she gets around 1000 Somoni per month<br>- TB patient used to send remittances for around USD 500, which were used for the children (school, food, clothes)  |
| 5_MWTB | 24-year-old<br>Male<br>Single    | 5       | Father (56)<br>Mother (48)<br>TB Patient (24)<br>Sister (19)<br>Brother (16)   | - He was the main source of income, and used to send home around USD500. Most of this money was used to build a family's house.<br>- The mother works<br>- A brother is studying in China and he does not work<br>- They own a car   |
| 6_MWTB | 42-year-old<br>Male<br>Married   | 15      | TB Patient (42)(HoH)<br>Mother (?)<br>Brother<br>Sister in law<br>Two of his kids (3, 18 months)<br>Two Brothers (40, 39)<br>Two sisters (36, 31)<br>Two kids (10, 13) | - The wife and mother works.<br>- The mother receives a pension from the state.<br>- HH receives around USD 600 of remittances , which was used mainly to buy food<br>- Before he contracted TB the household's income was described as "good"   |
| 7_MWTB | 35-year-old<br>Female<br>Married | 4       | Husband (42) (HoH)<br>TB Patient (35)<br>Two Daughters (25) (20)   | - The husband works as truck driver and is the main contributor to the household's income<br>He gets up to 2000 somoni for a long day drive.<br>- She used to send back around USD 400 to his father, mother, and her daughters. The money was used to funds their daughters studies, and buying cloths, and food<br>- Before she contracted TB the HH's income was good |
| 8_MWTB | 21-year-old<br>Male<br>Married   | 9       | TB Patient (21)<br>His wife (18),<br>Brother (24)<br>Brother's Wife (23)<br>Brother (18),  | - HH's income is around 1000 USD.<br>- His brother and his father are the main source of income in the household. His father is an engineer and his brother works in the construction sector.<br>- They receive rent from a house they own. They also own another house but they are not renting it.<br>- He did not send remittances home.                              |

|         |                                  |    |  |   |
|---------|----------------------------------|----|--|---|
|         |                                  |    | Four Children (10) (7) (2) (7 months)  |   |
| 9_MWTB  | 34-year-old<br>Male<br>Separated | 4  | Mother (59) (HoH)<br>TB Patient (34)<br>Two Sisters (31) (30)  | - The mother is the only source of income. She works in a kindergarten.<br>- He did not send remittances home   |
| 10_MWTB | 40-year-old<br>Male<br>Divorced  | 2  | TB Patient (40)(HoH)<br>Sister (54)  | - Sister works as a teacher at the university.<br>- He used to send home around USD 150 to the mother   |
| 11_MWTB | 33-year-old<br>Male<br>Married   | 8  | TB Patient (33) (HoH)<br>Mother (50)<br>Wife (32)<br>Sister (20)<br>Four Brothers (29) (20) (14) (13).                     | - HH received around USD 800 during last year<br>- The mother works as a tailor<br>- One brother is a migrant in Russia   |
| 12_MWTB | 19-year-old<br>Male<br>Single    | 5  | Mother (HoH)<br>Brother (?)<br>Sister in law (?)<br>Brother (?)  | - The mother and one brother work<br>- During the 5 months of migration the TB patient used to send remittance for around USD 300/400 per months to his mother. The money was used mainly for food and clothes  |
| 13_MWTB | 31-year-old<br>Male<br>Married   | 20 | TB Patient (31) (HoH)<br>Four brothers<br>4 sister in law<br>11 Children   | - They own a small farm and grow some vegetables<br>- They also have livestock which sell and buy during summer<br>- TB patient used to send remittances between USD 700-2000 per month, depending on the period/job. The money was used mainly for food. |
| 14_MWTB | 29-year-old<br>Male<br>Single    | 11 | Father and Mother (HoH)<br>TB Patient (29)<br>Six Brother and Sisters<br>His sister in law<br>Her two kids (2) (18 months) | - The father and one brother are migrant in Russia<br>- The mother works in the Bazar, and receives some money from the government<br>- No assets<br>- During the first 4/5 years he did not send anything home   |

