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### TB truths

*Patients' experience with tuberculosis and healthcare in sub-Saharan Africa*

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CHAPTER 1

# General introduction

9

CHAPTER 1



*I look at Buhle's face, her cheekbones sticking out and her eyes sunken in her once beautiful face. Her tight, colourful shirt and skinny jeans give her a childish look while she is bending over and sorting out the pills on her lap. Her sinewy graceful hands, her height, and slightness would actually make her a beautiful model. We sit on her bed in her 'hokkie', one of the many corrugated sheet shacks that characterize this violent township of South Africa. In the summer too hot, in the winter too cold, in spring... 'Can't sit on this part of the bed, Lianne' she warns me with a grin, 'the water came pouring down last night.'*

*We've just been to the hospital to collect Buhle's medication. She also got an – in her words – nasty and painful injection that makes her bum bloody and her legs sore. After that, we slowly walked home, sometimes taking the tarmac road and sometimes venturing in the maze of little alleys between the shacks of which new ones seem to pop up every day. 'I made my hokkie myself', she proudly said. 'It was done in a day.' She unlocked the big chain that is bluntly threaded through rough holes in the wall and the wooden door.*

*Her hokkie is dark with the only light coming through the half open door. The bare bulb hanging from the ceiling doesn't seem to work. The only furniture is a double bed with a lot of brown, woolen blankets, a white cupboard with glass doors, and a gigantic empty fridge that makes a zooming sound. It smells damp with a hint of her perfume. Buhle and her daughter, who has curled up behind her on the bed, are wearing matching green nail polish. I lean back and watch her medication ritual. As if trying to brighten up the situation, her colourful pills stand out: fishbowl blue, banana yellow, strawberry pink. She takes them one by one with the juice I had brought for her, interrupted at times by a shudder of disgust.*

*'But these pills I am not gonna drink today, Lianne' Buhle says tapping on the box of the remaining pills and subsequently putting them away. 'What do you mean?' I ask confused. She is one of the patients who said that she always takes treatment. 'The food is finished today, I think I ate too much the days before and my grant is finished as well.' I give her a puzzled look. If Buhle wants to survive her TB, she has to take every pill of this treatment every day for two years. 'These pills make me too hungry, Lianne, and there is no food.' I remain silent and don't know what to do. 'There is no food.' She sits there with a straight back giving me a fierce look. I realize I have an apple in my bag and give it to her. She accepts it with a smile and turns to her daughter. Her daughter jumps up, grabs the apple with two hands and eagerly bites into it. I look from her child back to her. Her skin seems stretched over her skull. Too skinny for a model. She responds to my worried look with a dismissive gesture of her hand and continues talking about what happened to her neighbour the other day.*

This vignette is synthesized from our various encounters with Buhle, a young woman living in the township Khayelitsha, Cape Town, South Africa. Just as many of our respondents, she struggled every day to obtain enough food for herself and her family. Her situation was even more complex, because she was having tuberculosis (TB) and tried to adhere to the prescribed daily treatment. Conducting ethnographic research enabled us to stay for months in one location giving us the chance to build warm and in-depth relationships with our respondents. Our key respondents, such as Buhle, welcomed us in their world and enabled us to become temporary part of their lives. The vignette gives a hint of what our interdisciplinary research on TB involved in three African countries, South Africa, Zambia, and Gabon. Using an anthropological approach, we zoomed in on personal experiences of TB patients and the complexities and tensions faced whilst dealing with TB and treatment. Looking from a public health perspective, we focused on the available TB treatment and implementation of TB health policies. The objective of this thesis in its broadest sense is to compare different implementations of National Tuberculosis Programmes (NTPs) and associated experiences of TB patients in South Africa, Zambia, and Gabon, and to ultimately explore ways for optimizing TB elimination and prevention strategies, and improving TB care for patients.

#### TUBERCULOSIS EPIDEMIOLOGY

TB is one of the deadliest infectious diseases in the world and additionally ranks in the top ten of causes of death globally. In 2014, it was estimated that 9.6 million people were newly infected with TB, of whom 1.5 million people passed away.<sup>1</sup> TB prevalence is unequally distributed over the world, with over 95% of TB cases and deaths in low- and middle-income countries and over 25% of the TB burden in Africa (Figure 1).<sup>1</sup>

The TB epidemic is internationally recognized as an alarming global health threat that needs to be urgently and adequately addressed. The global TB incidence is slightly declining, but in areas such as sub-Saharan Africa still highly problematic. Notwithstanding guidelines of the World Health Organization (WHO) to prevent and control TB, there is a great variety amongst the approaches, contents, and impacts of NTPs in the world. Where some programmes appear to be highly successful, in other areas TB seems out of control. The shaping of an NTP is not a uniform process, but is influenced by and manifests particular to its context. Big influences are the incidence rate of TB, emergence of multidrug resistant (MDR) TB, co-infection with HIV, drug shortages, overburdened health systems, poverty rates, local perceptions and attitudes towards health care and disease in general and TB specifically, and patient treatment adherence.<sup>2</sup>

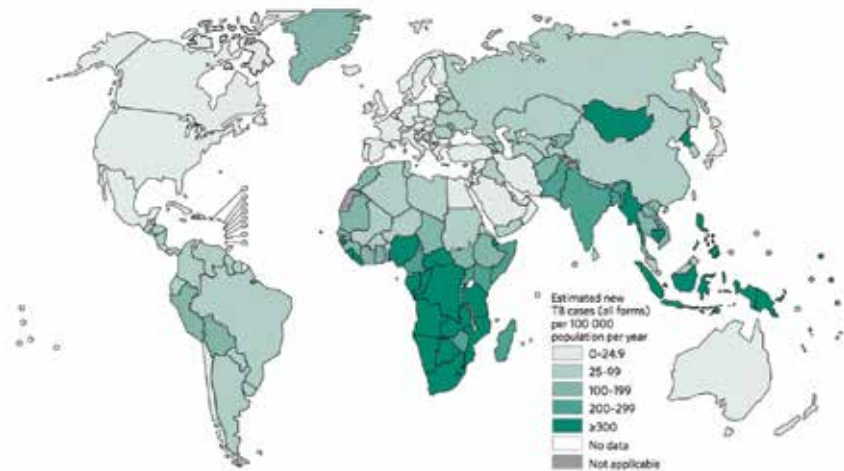


Figure 1 Estimated TB incidence rates, 2015

#### HISTORICAL PERSPECTIVES OF TUBERCULOSIS

Some authors hypothesize that TB accompanies humankind and its predecessors since its early days some 150 million years ago.<sup>3</sup> Just like other infectious diseases, the disease has surged in huge epidemics around the world.<sup>4</sup> During the industrial revolution, the 18th and 19th centuries, TB was the leading cause of death in North America and Europe. Around 800–1,000 deaths per 100,000 people per year occurred in cities such as London, Hamburg, and Stockholm.<sup>5,6</sup> In 1882, scientific knowledge of TB changed drastically after the work of Robert Koch who identified *the tubercle bacillus* and established TB aetiology.<sup>4</sup>

In the early 19th century, TB rates started to decline. Hypotheses why this occurred range from improved social and living conditions, improved nutrition, or strengthened immunity because of natural selection.<sup>4,7</sup> In 1859, the first of many sanatoria was opened by Brehmer who advocated a TB treatment of sunlight, fresh air, rich diet, rest, and regular exercise.<sup>8,9</sup>

After the invention of effective chemotherapy to cure TB in the 20th century, TB health programmes changed tremendously. In the 1950s, the drug isoniazid was introduced, soon followed by rifampicin. Suddenly, the global health approach was re-directed towards cure instead of symptomatic treatment. However, with the rise of HIV and acquired immune deficiency syndrome (AIDS) fuelling TB in sub-Saharan Africa and the development of drug resistant TB strains, the epidemic continued to be highly problematic on a global scale.

In 1993, the WHO declared TB as a global health threat and promoted the use of Direct Observed Therapy – Short course (DOTS) policy.<sup>10</sup> This policy constitutes five elements: the availability of resources, identification of TB through good sputum microscopy services, constant availability of drugs, an accurate

administration and report system, and direct observed TB treatment.<sup>11</sup> The direct observation of patients taking treatment formed for many the central element of DOTs and was a response to high numbers of patients being non-compliant with treatment or lost to follow up. However, this approach was by many considered ethically and operationally problematic<sup>12</sup> as it may overlook economic, social, or structural obstacles that influence health care seeking behaviour. In other words, DOT overestimates patients' agency,<sup>13</sup> suggesting that all patients have the capacity to act independently and are therefore able to comply with antituberculous (anti-TB) treatment and daily visit the clinic.<sup>2</sup> Farmer argues: *'Throughout the world, those least likely to comply are those least able to comply'*.<sup>2</sup> In contrast, DOTs policy is additionally criticized for underestimating patients' agency and being too paternalistic, as patients are observed whilst taking treatment and are not allowed to self-administer treatment in their homes. The rationale of this policy may hint at the assumption that non-compliant patients may be either irresponsible or ignorant.<sup>14</sup> Moreover, the term compliant has the unfortunate connotation of patients being subservient and docile and some authors argue adherence is a better word reflecting the importance of patient and provider interaction.<sup>15</sup> Nevertheless, DOT is in many countries still in place, but many variations of this approach have been developed since.<sup>16</sup>

In 2006, the Stop TB Strategy was launched building upon DOTs covering the period 2006–2015. New objectives included universal access to patient-centred treatment and protection of populations from TB/HIV and multidrug-resistant TB (MDR-TB). The post-2015 End TB strategy aims at ending the TB epidemic in the world by 2035.<sup>17</sup>

#### CLINICAL CHARACTERISTICS OF TUBERCULOSIS – A BIOMEDICAL EXPLANATION

Worldwide, TB is named and explained in multiple ways and additionally anti-TB treatments vary, but here, we will briefly share some biomedical information regarding the clinical characteristics of TB.

TB is an infectious disease that is caused by the bacterium *Mycobacterium tuberculosis* and related organisms, affecting the lungs in more than 80% of the cases (also referred to as pulmonary TB), but potentially affecting all organs (extra-pulmonary TB). The latter is seen particularly in HIV-positive individuals. Symptoms of TB may be persistent cough, loss of appetite, weight loss, night sweats, and general weakness. A pulmonary TB patient who is sputum positive and coughs, may spread the disease to others through aerosol droplets and can, if untreated, infect around 10 to 15 people yearly.<sup>18</sup> Drug susceptible TB is preventable and curable if patients are timely diagnosed and follow a biomedical treatment with anti-TB drugs.

Infected people do not always develop active TB. It is estimated that about one third of the world population has latent TB. In general, the lifetime risk for

people with latent TB to develop TB in a later stage is about 10%. HIV increases the risk of developing active TB.<sup>18</sup> Co-infections with HIV and TB are a lethal combination, as TB is the leading infectious killer of HIV patients. In total, about 70% of HIV-TB co-infected patients worldwide live in African countries.<sup>18</sup>

TB is either diagnosed by light microscopy of sputum smears, following culture, or via molecular methods. Isolate sensitivity is either evaluated by culture sensitivity testing or with molecular methods. Diagnosing TB in HIV-positive patients, children, and extra-pulmonary TB is often complex. Treatment of drug-sensitive pulmonary TB consists of daily intake of anti-TB drugs for six months: isoniazid, rifampin, ethambutol, and pyrazinamide during the two-month initiation phase and then the first two backbone drugs for another four months of continuation therapy.<sup>1,18</sup>

There has been an increase of drug-resistant TB, such as multidrug resistant TB (MDR-TB), meaning resistance to the first-line anti-TB drugs isoniazid and rifampicin, and extensively drug resistant TB (XDR-TB), meaning resistance to isoniazid and rifampicin, to any fluoroquinolone, and to any of the injectable drugs capreomycin, amikacin, or kanamycin.<sup>19</sup> Drug resistance is in many settings only detected months after the diagnosis of TB. Treating MDR-TB patients with a standard regimen may lead to additional resistance, limiting further treatment options. During the past decade, the rapid molecular diagnostic tool, GeneXpert, has been introduced to test for drug-susceptible and rifampicin-resistant TB.<sup>1</sup> On a global scale, it is estimated that only half of the MDR-TB patients and one third of the XDR-TB patients who are correctly diagnosed are successfully treated.<sup>1</sup> Until recently, MDR-TB treatment consisted of a plethora of pills for about two years and one injectable over many months in addition. In 2016, this has changed to a regimen of 9–12 months.<sup>1,18</sup> However, if patients are additionally resistant to second-line anti-TB drugs or have full-blown XDR-TB, a longer, more complex individualized treatment regimen is required, possibly involving novel, very costly drugs, such as bedaquiline or delamanid.<sup>17, 18, 20</sup>

#### LOCAL PERCEPTIONS, POVERTY, STIGMATIZATION

Various authors mention how local perceptions of disease and treatment may influence or delay patients' health care seeking behaviour at biomedical facilities and emphasise the importance to address such perceptions in sensitization programmes.<sup>21–23</sup> However, some authors claim that 'culture' is not the reason why TB (and additionally the current TB epidemic fuelled by drug resistance and the advent of HIV) is not yet eliminated. They argue that the main problem of TB is rooted in structural violence, i.e. forces that structure the marginal position of many, but not all, TB patients.<sup>2</sup>

TB, known as a disease of poverty, is closely related to forces of economic inequity, gender inequality, racism and/or poverty and often strikes those people that already have a vulnerable position in society.<sup>2</sup> In general, vulnerable



populations have particular risk factors rendering them more exposed and susceptible to TB infection and development of active TB.<sup>24</sup> Risk factors include HIV infection, poverty, malnutrition, living in poorly ventilated and crowded areas, co-morbidities, and substance abuse. Moreover, these vulnerable groups often face challenges that negatively influence care-seeking behaviour and adherence to TB treatment. Challenges may consist of low awareness of TB symptoms, difficulties in accessing care (because of lack of transport, money, or job responsibilities), long duration of treatment, severe side effects, lack of food aggravating adverse effects, and/or lack of social support during the lengthy treatment period.<sup>25–27</sup>

Moreover, TB patients are often stigmatized, leading to social exclusion or discrimination.<sup>28</sup> In 1963, Goffman's work on stigma was ground-breaking and still influences many researchers in the field of global health, sociology, and psychology today. The term stigma originates from a Greek method to mark slaves physically by burning or cutting them. Consequently, such marks indicated which people were slaves, who were generally identified as immoral and to be avoided. Nowadays, the notion of stigma has foremost shifted to a label or attribute to discredit someone's social status leading to social disapproval. Goffman frames this as 'a spoiled social identity'. In the case of TB, stigma is often shaped by various beliefs that TB patients are immoral, promiscuous, prostitutes, and/or unhygienic. Instead of using the concept stigma, it seems more accurate to talk about stigmatizing attitudes or actions as stigma does not exist on its own, but resides within people and social interactions. The social context shapes what people consider as immoral and what or who consequently will be stigmatized. In this way, particular attributes may be stigmatized in one community, but not in the other.<sup>29</sup>

#### RATIONALE OF THIS THESIS

This thesis comprises eight papers: one review paper, one methods paper, and six papers based on original studies. Our review paper focuses on TB in developed countries of medium and low TB incidence where new TB burden trends amount to a re-emerging public health problem.<sup>30,31</sup> This coincides the transition of the Millennium Development Goals (MDGs) 2000–2015 of the United Nations (UN) into the Sustainable Development Goals (SDGs) in the year 2015, representing a shift in the global health focus. Not only the poorest countries are considered for their health care targets, but emphasis is placed upon a universal and equitable approach in which anyone's health is recognized, including marginalized social groups in middle- and high-income countries.<sup>32</sup>

TB is a global health threat that needs to be addressed in every country in order to achieve, or at least get close to, TB elimination. Yearly, 700 million people cross national borders.<sup>33</sup> Processes of globalization, i.e. flows of trade, migration, and tourism, speed up the mixing of people and the spread of infectious



Figure 2 Health in the SDG era.<sup>35</sup>

this recent shift in global health focus, we decided to systematically review qualitative literature on barriers and facilitators for the uptake of tuberculosis diagnostic and treatment services by hard-to-reach (HTR) populations in low- and medium TB incidence countries. HTR populations included migrants, travellers (including Roma), refugees, people with HIV, homeless, prisoners, drug users, and sex workers. With this review we try to highlight the paucity in qualitative TB research in these areas and the need to additionally address TB in the developing world in order to eliminate TB globally.

The original work of this thesis comprises comparative, cross-sectional (visual) ethnographic health research about the functioning of NTPs and the experience of TB patients conducted in three sub-Saharan African countries. In these countries, South Africa, Zambia, and Gabon, TB rates are high, yet NTPs and local contexts vary greatly. Moreover, the thesis contributes to the knowledge of using ethnography in a larger comparative health study and the role this method plays in understanding why some NTPs are not adequately lowering TB rates or fully addressing TB patients' needs.

Our research is part of a larger body of clinical research on TB and HIV, one of the first research activities to improve local health care for TB and HIV in Gabon. This Central African country, located on the equator, has a population of around two million people and is for over 80% covered by tropical rain forest. Gabon is a former French colony and politically stable. Given its plentiful natural resources and small population, the country is additionally wealthy, yet many of Gabonese population live below the poverty line (that is to say they are very poor) and life expectancy is low.<sup>36</sup> Gabon is one of the areas in the world where little is known about TB epidemiology and there is a scarcity of facilities to diagnosis and treat TB. An NTP is in place, but the WHO-recommended Direct Observed Therapy–Short Course (DOTS) is absent, drugs or diagnostic facilities for MDR-TB do not exist, drug stock-outs are a national and frequent problem, and there is no TB health sensitization. At the time of writing this

diseases.<sup>33,34</sup> In areas where TB was considered a disease of the past, national health systems become challenged by people originating or traveling from countries where TB is still highly endemic. Due to high disparities in TB prevalence levels coupled with high disparities in socio-economic wealth in the world, TB control or elimination seems almost impossible. In line with

introduction, second line drugs in a research setting became recently available. To add to the collected clinical data on TB leading to potential improvement of TB care, we aimed at providing insight into cultural, social, and economic factors influencing the Gabonese NTP's outcomes. Therefore, we conducted an ethnographic health research in the town Lambaréné and surroundings. We collaborated with the Centre de Recherches Médicales de Lambaréné (CERMEL) of the Albert Schweitzer Hospital (HAS), a worldwide well-known and respectable center in tropical medicine and infectious diseases.

Whilst being in Gabon, a proposal for a larger study was getting shape to compare different implementations of NTPs in sub-Saharan African countries and the experiences of TB patients with the program. We selected South Africa, one of the leading countries regarding TB prevention and control and specialized in targeting resistant forms of TB and HIV-TB co-infection. The country has one of the highest TB rates worldwide and alarmingly high rates of HIV co-infection and TB drug resistance. Gross national product rankings indicate that South Africa has one of the largest sub-Saharan African economies.<sup>37</sup> Yet, the country is scarred by its history of racist Apartheid regime and political violence of which the consequences remain visible in the current unequal division of wealth and health. TB is highly present in townships populated by Black populations, such as the Xhosa. We collaborated with the University of Cape Town, School of Public health and Family Medicine and located our study in one of the poorest and most violent townships of South Africa, Khayelitsha where TB rates are highly problematic.

The landlocked country Zambia was chosen as the third research site. The country is a former British colony and politically stable. It's economy has historically been based on the production of copper increasing GDP, but there is a substantial income inequality and the majority of people live in poverty.<sup>38</sup> The country was chosen for comparison, because of its high TB prevalence and differing socio-cultural and economic contexts shaping the implementation of its NTP. Zambia's NTP was more developed than the NTP in Gabon and had especially improved in the past decade, but had fewer financial means compared to the South African NTP. Working together with the director of the National Leprosy and Tuberculosis Control programme of Zambia and the University of Zambia – University College London (UNZA-UCL) programme, we conducted our research in one of Lusaka's townships, Kanyama, and collaborated with Kanyama clinic.

While being in the field, the following questions arose: How can practices of TB patients whilst seeking care or following treatment be understood and explained? In what way is health care seeking behaviour of patients shaped by experiences of TB, TB perceptions, the availability or unavailability of TB medication, and the way TB care is delivered? How are the international guidelines regarding TB elimination of the WHO reflected in NTPs? In what way does



Field site 1 Cape Town, South Africa.



Field site 2 Lusaka, Zambia.



Field site 3 Lambaréné, Gabon.



the NTP incorporate the by the WHO recommended Direct Observed Therapy (DOT)? What are facilitators and barriers that may influence the successfulness of NTPs? Why may a well-run NTP not necessarily indicate a decline of TB rates?

Additionally, the field work in Gabon raised questions about how TB patients navigate the medical plural landscape in Lambaréné and surroundings wherein biomedical approaches exist alongside traditional and faith healing. This often-mentioned question amongst medical anthropologist has fuelled a contemporary anthropological debate that is mostly dominated by theories on how healers and patients are mixing and combining all sorts of health care.<sup>39,40</sup> *'They [patients] are less concerned with whether therapy is indigenous or foreign, traditional or modern, than with how much it will cost, whether or not it will work, how long it will take, and whether the physician will treat them in a sympathetic manner'*.<sup>41</sup> In a similar way, various scholars describe how healers transgress boundaries exploring healing methods of different therapeutic traditions. Boundaries between therapeutic traditions are often described as fluid and continually changing.<sup>39,42,43</sup> We explored healers' and patients' discursive practices regarding navigation of the therapeutic landscape and whether or in what way processes of interchange, negotiation, and redefinition of therapeutic traditions and its boundaries were reflected.

#### FIELD WORK

With the ambition to draw from both the disciplines anthropology and public health, we turned to a variety of methods. This combination allows for triangulation of study findings and increases the validity of the research. One of the central research methods used within anthropology is ethnography<sup>44</sup> (yet a discussion exists whether ethnography is a method or the product of collecting and describing data, or both).<sup>45</sup> This method formed the basis of our data collection techniques in each site. It is challenging to explain this complex method in a few sentences, but simply said, ethnography can be understood as conducting participant observation over an extended period of time to enhance understanding of the respondents' point of view. We engaged in TB patients' daily activities of visiting the clinic, collecting pills, taking treatment, traveling, taking care of themselves and their families. Moreover, we were present during emotional times during which participants experienced sadness, fear, happiness, insecurity, pain, or worries. We experienced various tensions or unexpected events. Moments during which patients were caught in surprise or when everything was too much for them to handle. By exploring these everyday activities and embodied experiences of our respondents, we try to grasp the complexities of their realities. For more information on ethnography and health research, see Box 1.

Ethnographic data consists of a large body of field notes and long detailed descriptions of (participant) observations and informal conversations. Exploring

**Table 1** Research methods of interdisciplinary ethnographic health study on Tuberculosis in Gabon, Zambia, and South Africa 2012–2015.

| Study site   | Time                  | Methods   |
|--------------|-----------------------|---|
| Gabon        | Jul 2012 – Dec 2012   | Ethnography<br>In-depth interviews<br>Focus group discussions<br>Mapping healing landscapes |
| Zambia       | Sept 2013 – Jan 2014  | Ethnography<br>In-depth interviews<br>Focus group discussions<br>Surveys                    |
| South Africa | Oct 2014 – March 2015 | Ethnography<br>In-depth interviews<br>Focus group discussion<br>Visual methods              |

ways to merge and communicate ethnographic knowledge into a medical environment, we used mixed methods (ethnography and quantitative data collection techniques) during our research in Zambia. Realizing that quantitative results received much more attention in our work area than our ethnographic results, we decided to look at new, innovative ways. Therefore, we conducted visual methods during our research in South Africa enabling us to communicate ethnographic results via film. For a detailed description of visual methods, see **Chapter 3**. For more information on the methods in general, see the methods section in each of the articles presented in this thesis (Table 1).



Research assistants: Grace Bikene (Gabon), Austin Kabika (Zambia), and Monwabisi Maqogi (South Africa).

Together with our local research assistants (Grace Bikene in Gabon, Austin Kabika in Zambia, and Monwabisi Maqogi in South Africa), we recruited TB patients, health workers, traditional healers, and faith healers in each site (Table 2). In **Chapter 10**, a reflection can be found regarding the data collection methods and the interaction shaped between our research assistants, respondents and the researchers.

**Table 2** Fieldwork sites & respondents

| Respondents   | Lambaréné, Gabon<br>2012 | Lusaka, Zambia<br>2013/14 | Cape Town, South<br>Africa 2014/15 |
|---|--------------------------|---------------------------|------------------------------------|
| TB patients (qualitative methods)   | 30                       | 30                        | 30                                 |
| TB patients (quantitative methods)  | 0                        | 300                       | 0                                  |
| Health care workers (e.g. medical doctors, nurses, community care workers, NGO employees) | 10                       | 10                        | 10                                 |
| Key respondents (focus group discussions)   | 20<br>(2 FGDs)           | 60<br>(6 FGDs)            | 10<br>(2 FGDs)                     |
| Traditional healers   | 10                       | 10                        | 10                                 |
| Faith healers   | 8                        | 10                        | 10                                 |
| Key respondents (visual methods)  | 0                        | 0                         | 7                                  |

22

TB TRUTHS

#### OUTLINE OF THIS THESIS

In Section I, **Chapter 2** of this thesis, we present a systematic literature review of qualitative research on hard-to-reach (HTR) populations with TB in low- and medium-incidence countries. We aimed at identifying barriers and facilitators to the uptake of TB diagnostic and treatment services by HTR populations in European Union (EU), EU candidate, Organization for Economic Co-operation and Development, and European Economic Area countries.

Section II elaborates on our visual ethnographic study in South Africa. In **Chapter 3**, we advocate the use of visual methods to synergize the disciplines anthropology and public health and enhance interdisciplinary research. **Chapter 4 and 5** discusses one of the worst TB epidemics in the world, namely in South Africa, Khayelitsha. **Chapter 4** is based on visual ethnographic research resulting in a multimedia paper. Through a combination of text and short videos, we describe socio-economic and cultural determinants of both drug susceptible (DS-)TB and drug resistant (DR-)TB on patients every-day life in-depth. **Chapter 5** is a visual ethnography paper, or in other words, a documentary based upon ethnographic fieldwork. Following up on eight key-respondents with a camera during five months has resulted in a 45-minute documentary on patients' struggle with TB and treatment on a daily basis. It captures unexpected confrontations, everyday life situations, and the mundane presence of death.

In Section III, **Chapter 6 and 7**, we examine the NTP in Zambia, Lusaka and health care seeking behaviour of TB patients using a mixed methods study. **Chapter 6** focuses on influence factors on pre-hospital delay and non-compliance with care of TB patients in general and in **Chapter 7** we explore in-depth the role stigma played herein.

In Section IV, **Chapter 8 and 9**, we shift our focus to Gabon, Lambaréné, looking at TB patients' experience with TB, the NTP, and a wide variety of traditional

and faith healers. Where **Chapter 8** is written with a public health motive of formulating health care recommendations, **Chapter 9** embodies an anthropological approach and analyses the way TB patients and the variety of healers in Lambaréné engage in a medical plural landscape. The concept *conventional boundary-making* is introduced to complement the current medical pluralism debate and popular paradigms of fluid and ever-changing boundaries between therapeutic traditions. Finally, **Chapter 10** constitutes a discussion of the main results, comparing NTPs and patients' experience with TB and care, to ultimately define barriers to NTP outcomes in respectively South Africa, Zambia, and Gabon. Moreover, we discuss future perspectives and reflection.

### Box 1 Ethnography and health research

Most of social science research focusing on health and care relies on qualitative research that constitutes of in-depth interviews and/or focus group discussions. Research merely turning to language and discourse, however, has a problematic tendency as it equates discourse with practice, or in other words, making no distinction between what people say they do and what people actually do in everyday life.<sup>44,46</sup> Consequently, it remains unclear what is going on beyond this world created with words by our respondents.<sup>47</sup> Research drawing mainly on discursive explanations of actions are essentially investigations of respondents' commentaries on social reality. But what is actually happening, is not studied. That does not mean respondents are prone to tell lies, but accepting their descriptions of reality as simple truths provides the researcher with a limited and biased form of knowledge. Following this line of reasoning, qualitative research confined to interviews on hospital territory is a valuable method to gain insights of a TB programme evaluation, but to fully grasp the complexities of everyday life with TB, researchers may combine qualitative methods with ethnography. An ethnographic approach enables the researcher to explore every-day activities and embodied experiences by going into the field and focus on both practices and speech. Comprehension of complex realities can be enhanced by not only observing for a longer period of time, but also by getting close to their respondents, building relationships, and engaging in their activities.

Various authors argue that ethnographic information is needed for a holistic understanding of why NTPs fail in a world where TB medication is supposed to be distributed for free.<sup>16,48</sup> Through ethnography, we can learn about such ostensible contradictions and why associated social programmes and the implementation of direct observed therapy (DOT) are not always as successful as intended. We argue that the in-depth experience of TB patients



should be taken into account to fully comprehend the impact of NTPs on their lives. Unfortunately, there have been few ethnographic studies that analyse TB patients' experience with taking treatment and NTPs.<sup>16,49,50</sup>

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