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

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TB TRUTHS

PATIENTS' EXPERIENCE WITH TUBERCULOSIS
AND HEALTHCARE IN SUB-SAHARAN AFRICA



LIANNE (A.L.) CREMERS

TB TRUTHS

This thesis was prepared at the Department of Tropical Medicine and Travel Medicine, Academic Medical Center and the University of Amsterdam, Amsterdam, the Netherlands.

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LAY OUT

Bas Reijnen, Nijmegen

FRONT COVER

Cercle d’Jill, Jill van der Vlugt (cercladjill.nl)
As Lianne, I would like to make a positive contribution to the world. My tool is visual art: to make a joke, to make a statement, or in this case to illustrate an important message.

PARANYMPHS

Emma Birnie & Saskia Janssen

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TB TRUTHS

*Patients' Experience with Tuberculosis and Healthcare
in sub-Saharan Africa*

ACADEMISCH PROEFSCHRIFT

Ter verkrijging van de graad van doctor
aan de Universiteit van Amsterdam
op gezag van de Rector Magnificus
prof. dr. ir. K.I.J. Maex
ten overstaan van een door het College van Promoties ingestelde commissie,
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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.¹ 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).¹

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.²

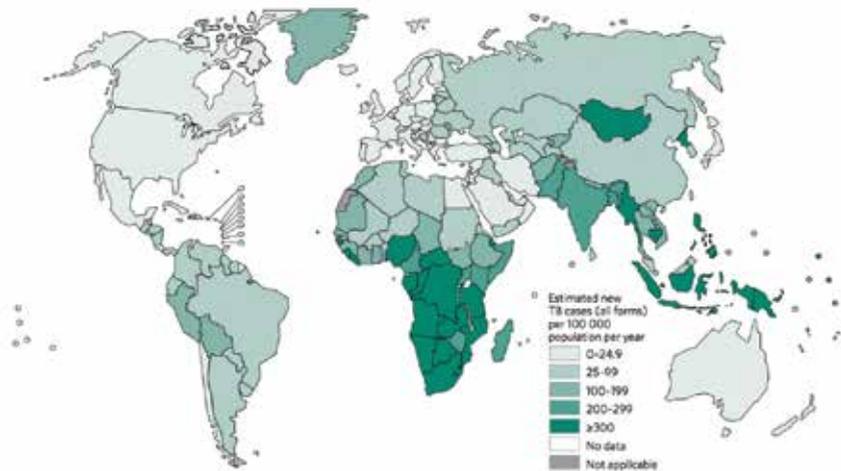


Figure 1 Estimated TB incidence rates, 2015

HISTORICAL PERSPECTIVES OF TUBERCULOSIS

Some authors hypothesize that TB accompanies humankind and its predecessors since its early days some 150 million years ago.³ Just like other infectious diseases, the disease has surged in huge epidemics around the world.⁴ 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.^{5,6} In 1882, scientific knowledge of TB changed drastically after the work of Robert Koch who identified *the tubercle bacillus* and established TB aetiology.⁴

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.^{4,7} 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.^{8,9}

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.¹⁰ 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.¹¹ 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 problematic¹² as it may overlook economic, social, or structural obstacles that influence health care seeking behaviour. In other words, DOT overestimates patients' agency,¹³ 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.² Farmer argues: *'Throughout the world, those least likely to comply are those least able to comply'*.² 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.¹⁴ 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.¹⁵ Nevertheless, DOT is in many countries still in place, but many variations of this approach have been developed since.¹⁶

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 2035.¹⁷

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.¹⁸ 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.¹⁸ 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.¹⁸

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.^{1,18}

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.¹⁹ 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.¹ 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.¹ 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.^{1,18} 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.^{17, 18, 20}

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.^{21–23} 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.²

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.² In general, vulnerable

populations have particular risk factors rendering them more exposed and susceptible to TB infection and development of active TB.²⁴ 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.^{25–27}

Moreover, TB patients are often stigmatized, leading to social exclusion or discrimination.²⁸ 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.²⁹

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.^{30,31} 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.³²

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.³³ Processes of globalization, i.e. flows of trade, migration, and tourism, speed up the mixing of people and the spread of infectious

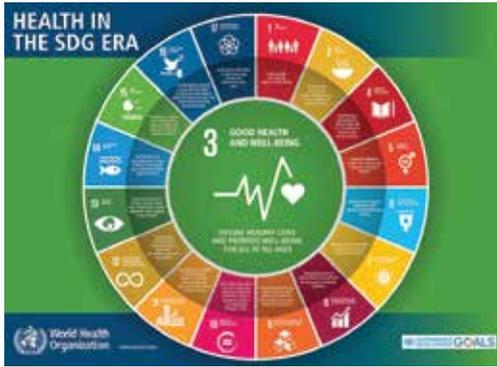


Figure 2 Health in the SDG era.³⁵

diseases.^{33,34} 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

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.³⁶ 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

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.³⁷ 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.³⁸ 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.^{39,40} *'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'*.⁴¹ 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.^{39,42,43} 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 ethnography⁴⁴ (yet a discussion exists whether ethnography is a method or the product of collecting and describing data, or both).⁴⁵ 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 In-depth interviews Focus group discussions Mapping healing landscapes
Zambia	Sept 2013 – Jan 2014	Ethnography In-depth interviews Focus group discussions Surveys
South Africa	Oct 2014 – March 2015	Ethnography In-depth interviews Focus group discussion 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 2012	Lusaka, Zambia 2013/14	Cape Town, South 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 (2 FGDs)	60 (6 FGDs)	10 (2 FGDs)
Traditional healers	10	10	10
Faith healers	8	10	10
Key respondents (visual methods)	0	0	7

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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.^{44,46} Consequently, it remains unclear what is going on beyond this world created with words by our respondents.⁴⁷ 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.^{16,48} 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.^{16,49,50}

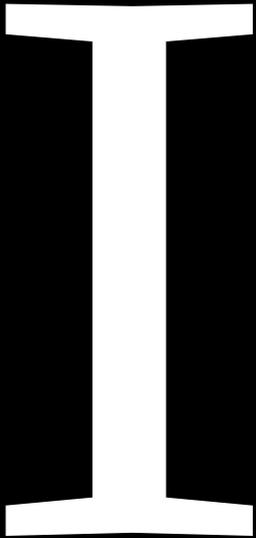
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Section



TB in countries of low or
medium TB incidence, a
systematic review



Barriers and facilitators for the uptake of tuberculosis diagnostic and treatment services by hard-to-reach populations in low and medium-incidence countries: A systematic review of qualitative literature

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ABSTRACT

Tuberculosis disproportionately affects hard-to-reach populations, such as people who are homeless, migrants, refugees, prisoners, or drug users. These people often face challenges in accessing quality healthcare services. We did a systematic review of the qualitative literature to identify barriers and facilitators to the uptake of tuberculosis diagnostic and treatment services by people from hard-to-reach populations in all EU, EEA, EU candidate, and OECD countries. The 12 studies included in this review mainly focused on migrants. Views on perceived susceptibility to and severity of TB varied widely and included many misconceptions. Stigma and challenges with accessing healthcare were identified as barriers for TB diagnosis and treatment uptake, whereas support from nurses, family, and friends was a facilitator for treatment adherence. Further studies are required to identify barriers and facilitators to the improved identification and management of tuberculosis cases in hard-to-reach populations to inform recommendations for more effective tuberculosis control programmes.

PROSPERO registration number: CRD42015019450

Worldwide, tuberculosis (TB) causes the largest loss of disability-adjusted life-years worldwide due to an infectious disease, after malaria and human immunodeficiency virus (HIV).¹ An estimated 9.6 million incident cases of TB occurred in 2014, of which 5.4 million were men, 3.2 million women and 1.0 million children.² In the European Union (EU) and European Economic Area (EEA), a third of 65 000 notified TB cases were in 18 low-TB incidence countries (i.e. a notification rate of less than ten cases per 100 000 population).³ In these countries, TB cases are disproportionately concentrated in big cities, associated with an over-representation of TB among various hard-to-reach and susceptible populations, such as people who are homeless, migrants, refugees, prisoners, drug users, sex workers, and people living with HIV.^{4,5} Although not all people living with HIV can be called 'hard-to-reach', many hard-to-reach populations are more likely to acquire or carry an HIV infection.⁶⁻¹²

Few surveillance and survey data are available for TB in hard-to-reach populations.^{13,14} In the EU and EEA, 28% of new TB cases occur in individuals of foreign origin, with thirteen countries reporting more than 50% of their TB cases occur in individuals of foreign origin.³ With the exception of information about TB in individuals of different origins, ages, and sexes, limited information is available about TB in hard-to-reach groups. Moreover, information on other risk factors or social determinants is not readily available, which hampers policy and guideline development required to optimize TB control efforts. The global End TB Strategy and Towards TB elimination (a guideline for low-incidence countries) highlighted this scarcity of information and identified the most vulnerable and hard-to-reach populations, which are often underserved, as a priority for action.^{5,15,16}

Hard-to-reach populations often have specific risk factors which render them more exposed and vulnerable to infection with *Mycobacterium tuberculosis* and development of active TB disease.¹⁷ These risk factors include living in crowded and poorly ventilated areas, co-morbidities, substance abuse, HIV infection, and malnutrition. Additionally, hard-to-reach populations face major challenges in accessing health care and in adhering to TB treatment, which include reduced awareness and knowledge of the signs and symptoms of TB, unstable accommodation, and difficulties in transportation and access to healthcare, such as the restricted opening hours of testing centres, the cost of testing, and the lengthy duration of treatment.¹⁸⁻²⁷

The European Centre for Disease Prevention and Control (ECDC) initiated guidance for controlling TB in hard-to-reach and vulnerable populations.²⁸ To provide an up-to-date evidence base, we did a systematic review of qualitative literature focusing on the barriers and facilitators to the uptake of TB diagnostic and treatment services in hard-to-reach populations, covering all EU, EEA, EU candidate, and Organisation for Economic Co-operation and Development

(OECD) countries. Information on barriers and facilitators is often best assessed with qualitative research of the perspectives of patients or health care workers. Additionally, qualitative methods facilitate a more in-depth understanding of barriers and facilitators, compared with, and in addition to, quantitative research methods.²⁹ Synthesized qualitative research findings thus aid the development of new theories, interventions, and policies.

The primary review question of our systematic review was What factors help or hinder the uptake of TB diagnostic and treatment services by people from hard-to-reach populations in EU, EEA, EU candidate, and OECD countries, and how can those barriers be overcome? Secondary review questions were: How do views vary between different hard-to-reach populations? and What are the views of service providers? The findings served as the evidence base for the development of guidance for control of TB in hard-to-reach and susceptible groups.

METHODS

Selection of studies and data management

In 2010, the National Institute for Health and Clinical Excellence (NICE) commissioned a systematic review of barriers and facilitators to the uptake of TB diagnostic and treatment services by people from hard-to-reach populations in OECD countries.³⁰ We updated and extended this review, following standards described by the Cochrane Collaboration³¹ and NICE.³² The results are reported according to the PRISMA guidelines for systematic reviews.³³ We deemed people who were homeless, migrants, travellers (including Roma), refugees, prisoners, drug users, sex workers, and people with HIV as belonging to hard-to-reach populations.

Search strategy and selection criteria

Using the same search strategies as in O'Mara and colleagues' 2010 National Institute for Health and Care Excellence (NICE) review (which covered the period 1990 up to September 2010), we searched MEDLINE, MEDLINE In-Process, Embase, PsycINFO, the Centre for Reviews and Dissemination database (for the Database of Abstracts of Reviews of Effects, the National Health Service Economic Evaluation Database, and the Health Technology Assessment database), The Cochrane Library, Cumulative Index to Nursing and Allied Health Literature. We searched for studies in all European Union (EU), European Economic Area, and EU candidate countries published between January, 1990, and April 10, 2015, and for studies in Organisation for Economic Co-operation and Development countries published between June 5, 2010, and April 10, 2015. In addition to the hard-to-reach popula-

tions covered by the NICE review (migrants, homeless people, people who abuse substances, prisoners, sex workers, and people with HIV), we included children in hard-to-reach populations. Definitions of hard-to-reach groups were those defined by the respective papers. We limited the search to active tuberculosis, excluding latent tuberculosis infection. We included qualitative studies related to either the views of hard-to-reach people regarding perceptions of or attitudes towards tuberculosis services, qualitative descriptions of the variations in views between different hard-to-reach populations, or the views of service providers (appendix). Additionally, we checked all included studies for relevant references; all identified systematic reviews were also checked for relevant references, although they were not included (appendix).

Citations identified by the search were imported to an EndNote database (Endnote X7.1) and duplicate records removed. Three authors (SdV, CCH, BJV) screened the titles and abstracts of records independently and in parallel using pre-specified criteria (Panel 1). One author (CCH) screened 100% of the records; the other two authors (SGdV and BJV) screened 50% each. Disagreements were resolved by discussion. We retrieved the full texts of all articles identified in the initial screening, and contacted authors in cases of incomplete data or irretrievable articles. If the article was irretrievable (i.e. not accessible from any source, or from authors), the study was excluded. The full text of selected articles was screened by three independent authors (SDV 100%, CCH and ALC 50% each) with a full text assessment inclusion checklist, derived from the previous NICE review.³⁰ Inter-reviewer agreement and reliability were calculated according to standard methods.³¹

Panel 1. In- and exclusion criteria for this review

Studies were included if they:

- had a focus on TB services of any kind (any study examining TB or a TB service delivered to a hard-to-reach population)
- had been done in any of the EU/EEA countries, the candidate countries (Albania, Montenegro, Serbia, the former Yugoslav Republic of Macedonia and Turkey) and the other OECD countries (Australia, Austria, Belgium, Canada, Chile, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Japan, Korea, Luxembourg, Mexico, the Netherlands, New Zealand, Norway, Poland, Portugal, Slovak Republic, Slovenia, Spain, Sweden, Switzerland, Turkey,

United Kingdom, United States)

- Had been published in 2010 or later for the OECD countries
- Had been published in 1990 or later for the EU/EEA countries and EU candidate countries
- Presented data on the views of hard-to-reach people regarding perceptions of or attitudes to TB services
- Presented original qualitative data (no systematic reviews)
- Included data from any hard-to-reach population, including homeless people, people with alcohol or other drug addictions, sex workers, prisoners or people with a history of imprisonment, susceptible migrant populations (e.g. asylum seekers and refugees), but also recent migrants and travellers (including the Roma population), children within susceptible and hard-to-reach populations, and people living with HIV

Respondents do not necessarily have to be diagnosed with TB, studies should not exclusively focus on latent TB infection (LTBI), and there were no language restrictions.

Data extraction, data items and synthesis

We extracted data by use of the same forms as in the previous NICE review.³⁰ For a random 10% of included studies, data extraction was performed by two independent reviewers. For the remaining studies, one reviewer conducted data extraction that was checked by a second reviewer; any disagreement was resolved by discussion.

To structure the data synthesis, we used the Health Belief Model (HBM),³⁴ which explains and predicts health-related behaviours. Two independent reviewers did thematic and content analysis.³⁵ Data were coded and categorized into potential determinants of health behaviours within five themes of the HBM framework: (i) perceived susceptibility (risk); (ii) perceived severity (consequences, such as mortality and morbidity); (iii) perceived facilitators (predisposing factors); (iv) perceived barriers (factors that hinder); (v) cues to action (motivating or precipitating forces, such as contact with someone else who has TB).

Risk of bias in individual studies and the overall strength of the evidence

Studies were assessed for quality and risk of bias with the modified NICE Quality Assessment Tools for qualitative research.³⁰ Two reviewers (SDgV and CCH) assessed ten percent of included studies independently; the remaining 90% were assessed by one reviewer (SGdV) and corroborated by a second reviewer (ALC). Any disagreement was resolved by discussion. We assigned each study

rating based on the quality assessment: high quality [++], medium quality [+] or low quality [-]. We did not investigate publication bias. The evidence was graded and reported as described previously (Panel 2).³⁰

Panel 2. Grading of evidence

No evidence

No evidence or clear conclusions from any studies

Weak evidence

No clear or strong evidence/conclusions from high quality studies and only tentative evidence/conclusions from moderate quality studies or clear evidence/conclusions from low quality studies

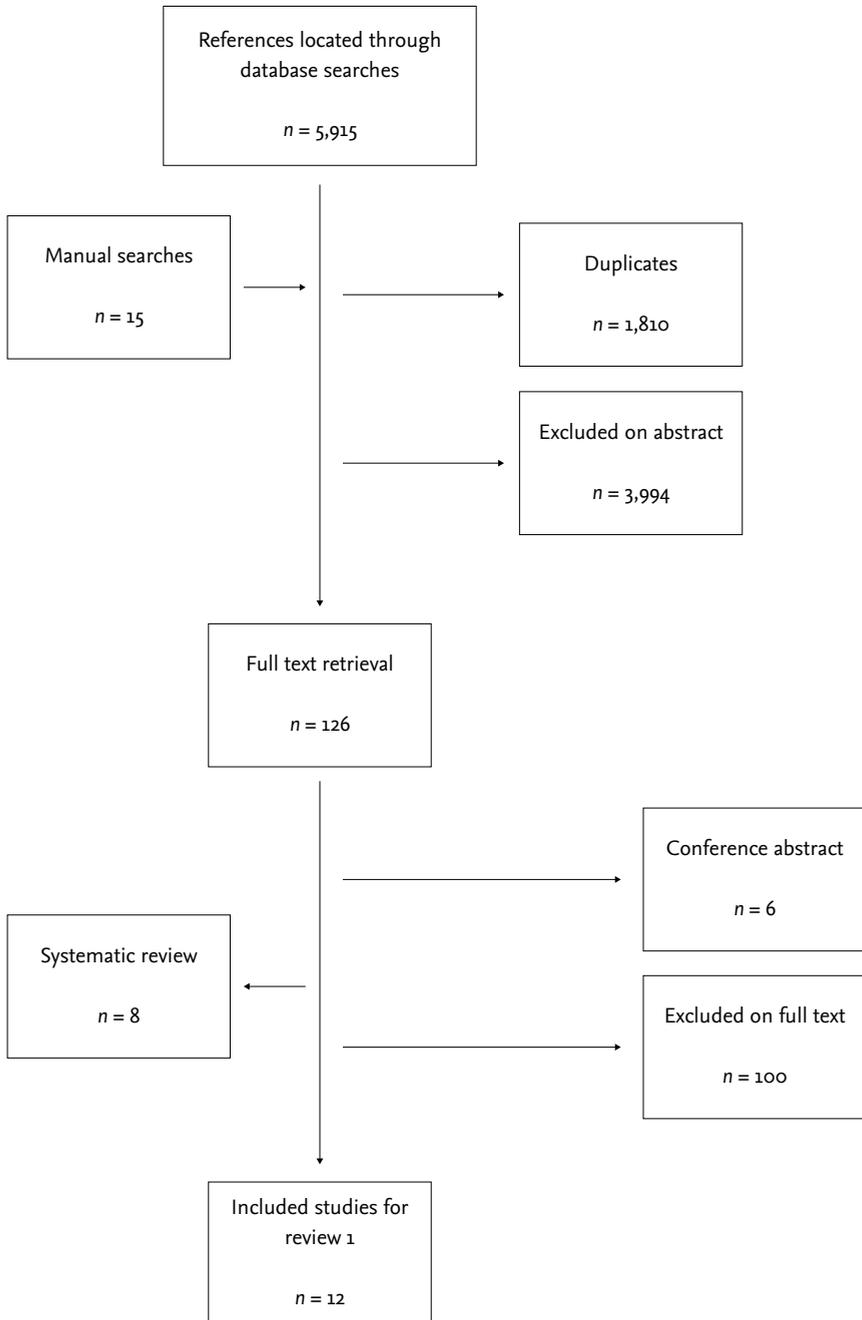
Moderate evidence

Tentative evidence/conclusions from multiple high quality studies, or clear evidence/conclusions from one high quality study or multiple medium quality studies, with minimal inconsistencies across all studies

Strong evidence

Clear conclusions from multiple high quality studies

Figure 1 Study selection process



RESULTS

The figure shows the study selection process. Database searches identified 5915 records. Citation searching of included studies and relevant (but excluded) reviews identified 15 records. Inter-reviewer agreement for the abstract screening was 98.1% before reconciliation; the inter-rater reliability (Cohen's k) was 0.627. Of the total 5930 abstracts, 1810 duplicate records were removed (Figure 1). In total, twelve studies were included in this review.^{19,36-46} The appendix and table 1 detail the characteristics of included studies. Of ten studies investigating the views of individuals belonging to hard-to-reach populations on TB and TB services, seven were of migrants,^{19,37,39,42,43,45,46} one of a mixed group of homeless people, migrants and drug users,³⁶ one was only of people who were homeless,⁴⁰ and one was of a Roma population.⁴⁴ We identified two studies focusing on views of healthcare providers on barriers or facilitators to the uptake of TB services by hard-to-reach populations.^{38,41} Studies were done in the United Kingdom (UK),^{36,38,39,42} the United States of America (USA),^{13,37,46} Sweden,⁴¹ Norway,⁴³ Serbia,⁴⁴ Canada⁴⁵ and Japan.⁴⁰ Table 2 shows the results of quality assessment. The appendix provides detailed evidence statements for all themes, combined with the findings of the previous NICE review.³⁰ Here, we present the findings of the update and extension of the NICE review.

Table 1 Characteristics of included studies

Year	First author	Aim(s)	Method
2010	Bender et al. ⁴⁵	To analyse how the experience of client displacement shapes the relational work of TB nurses.	Observations of the usual contacts between nurses and migrant clients. TB patients currently receiving direct observed treatment (DOT). Additionally, interviews with nurses and some of the observed clients were held.
2010	Coreil et al. ⁴⁶	To identify the components of stigma perceived as important within non-affected community samples in the two study populations (Haitians in Haiti and Haitian migrants in California); and second, to understand the contextual influences on these stigma components across sites (including affected members as well). For this review, only the views from participants in Florida are considered.	Interviews and observations at clinics with community members of Haitian origin.
2011	Vukovic and Nalgorni-Obradovic ⁴⁴	Exploring the knowledge and beliefs about TB transmission, symptoms and treatment, opinions on appropriate preventive measures, and attitudes towards people with TB among the Roma population.	Focus group discussions with the Roma population in Belgrade, living in selected Roma communities in different conditions (Living in the worst conditions (slums)/ living in conditions similar to the general population in Belgrade / living in conditions between the previous two).
2012	Gerrish et al. ⁴²	To ascertain the socio-cultural meaning and consequences of TB among people of Somalian origin living in the UK.	Interviews with community leaders from Somalian organizations and TB patients (in the Somalian community); interviews and focus groups with members of the wider Somalian community.
2012	Sagbakken et al. ⁴³	To explore experiences of being diagnosed with TB among migrants in Norway, with a view to identify factors associated with diagnostic delay.	Interviews with TB patients from Ethiopia and Somalia who had been diagnosed in a hospital and for whom TB treatment had been initiated.

Number of participants	Location	Study respondents	Quality score
N = 33 Nurses: 9 TB patients: 24	Toronto, Canada	Migrants and service providers	-
N = 81 CM: 24 HPs: 24 Patients: 33	Broward County and in Palm Beach County, California, USA	Migrants and service providers	+
N = 24	Belgrade, Serbia	Migrants	+
N = 104 CL: 10 CM: 80 Patients: 14	Sheffield, UK	Migrants	++
N = 42 Patients: 22 HPs: 20	Oslo, Norway	Migrants and service providers	++

Table 1 Characteristics of included studies

Year	First author	Aim(s)	Method
2012	Wieland et al. ³⁹	To understand the perceptions and misperceptions about TB among students and staff at an adult education centre. To understand how relationships and social structures influence the perceptions of TB. To understand what the perceived barriers and benefits to health seeking behaviour for TB are.	Separate focus groups at the adult education centre with students (from Somalia, Sudan, Vietnam, Cambodia, Laos, China, Pakistan, Ukraine, Russia, Turkey, Mexico, Colombia and Puerto Rico) and their teachers (from Somalia, Sudan, Asia, US).
2013	Croft et al. ³⁸	To understand the motivation and personal impact of being a peer educator on people with experience of anti-tuberculosis treatment, homelessness and addiction.	Interviews with peer educators who had had treatment for active TB and have experience with homelessness and/or drug/alcohol dependency, and have been a peer educator within the last 3 years of the project (Find & Treat)
2013	Gerrish et al. ³⁹	To explore experiences with the diagnosis and management of tuberculosis from the perspective of Somalian patients and healthcare professionals involved in their care.	Interviews with Somalian TB patients who had received treatment for TB in the UK and with healthcare practitioners with experience in caring for Somalian TB patients: general practitioners (GPs), TB specialists, nurses.
2013	Kawatsu et al. ⁴⁰	To explore the changes experienced by homeless TB patients, and to discuss the possible role of PHC-based DOT treatment in effecting these changes.	Interviews with homeless patients who had received and completed DOT at Shinjuku PHC.
2013	Wannheden et al. ⁴¹	To understand the challenges faced by nurses and physicians in the treatment of patients co-infected with the HIV and TB, with special focus on opportunities for information and communication technology.	Interviews with physicians and nurses of each speciality (HIV & TB), working with HIV/TB co-infected patients.
2014	Craig et al. ³⁶	To analyse patients' knowledge of TB, their experiences of symptoms, and their health care seeking behaviours.	Interviews with TB patients with health and social risk factors likely to complicate adherence to treatment (such as homelessness and drug use) attending a major TB centre.
2014	Zuñiga et al. ³⁷	Experiences of TB treatment among Mexican Americans living in the Lower Rio Grande Valley.	Interviews with Mexican American adults who were currently receiving DOT treatment.

Number of participants	Location	Study respondents	Quality score
N = 83 Students: 54 Teachers: 29	Rochester, USA	Migrants	++
N = 6	London, UK	Service care providers -Homeless and drug users	+
N= 32 Patients: 14 HPs: 18	Sheffield, UK	Migrants and service providers	+
N = 18	Shinjuku, Tokyo, Japan	Homeless	+
N = 9 Physicians: 4 Nurses: 5	Stockholm, Sweden	Service providers of HIV and TB co-infected patients, including migrants	+
N = 17	London, UK	Homeless, migrants, drug- and alcohol users, people living with HIV	++
N = 18	Lower Rio Grande Valley, Texas, USA	Migrants	+

Table 1 Characteristics of included studies

Year	First author	Aim(s)	Method
<i>Studies identified by the previous NICE review:³⁰</i>			
1994	Curtis et al. ⁴⁷	To examine the responses of injecting drug users to current TB management strategies and to explore the implications of these responses for the implementation of DOT.	Ethnographic interviews and observations in locations where drugs were sold and taken. Male and female injecting drug users were interviewed; Latino, black and white.
1995	Kitazawa ⁴⁸	To gather the knowledge and views of homeless people living in group shelters concerning tuberculosis, tuberculosis medical care and health education.	Interviews with men and women in homeless shelters who were English and/or Spanish speaking.
1996	Kelly-Rossini et al. ⁴⁹	To understand the experiences of respiratory isolation for HIV-infected patients with TB.	Interviews with males and females with a history of HIV infection or HIV risk behaviour, AFB positive sputum smears and confined to respiratory isolation; 30–51 years old.
1997	Jackson & Yuan ⁵⁰	To identify the non-clinical barriers family physicians may face in managing TB among patients and suggestions for overcoming these barriers.	Focus groups with primary care physicians, infectious disease specialists and respiratory physicians who work with TB patients.
1999	Ito ⁵¹	To investigate elements of ‘health culture’, which affect adherence with preventive treatment for inactive TB among Vietnamese refugees.	Individual interviews and observations with Vietnamese refugees; included individuals who were compliant with treatment and those who were non-compliant. Interviews conducted with clinic staff and various community members who were apparently not receiving TB services.
1999	Yamada et al. ⁵²	To understand what Filipino immigrants to the USA know about TB and examine their attitudes and practices concerning TB.	Focus groups with male and female Filipino immigrants in two locations.
2000	Fujiwara ⁵³	To explore the development of culturally appropriate marketing campaigns for TB awareness, testing and treatment for immigrants from China.	To explore the development of culturally appropriate marketing campaigns for TB awareness, testing and treatment for immigrants from China.

Number of participants	Location	Study respondents	Quality score
N = 68	Brooklyn, New York, USA	Drug users	-
N = 20	San Francisco, USA	Homeless	+
N = 18	New York, USA	People living with HIV	+
N = 15	Toronto, Canada	Service providers	+
N = 24 (individual who received treatment); others NR)	California, USA	Migrants	+
N = 36	Hawaii and California, USA	Migrants	++
N = 47	New York, USA	Chinese migrants	-

Table 1 Characteristics of included studies

Year	First author	Aim(s)	Method
2002	Houston et al. ⁵⁴	To identify the cultural health beliefs regarding TB and barriers to completion of TB prevention programmes among the Vietnamese population.	Individual interviews and observations with Vietnamese refugees; included individuals who were compliant with treatment and those who were non-compliant. Interviews conducted with clinic staff and various community members who were apparently not receiving TB services.
2003	Chemtob et al. ⁵⁵	To identify the barriers to diagnosis, prevention and treatment of TB among immigrants.	Interviews with immigrant Ethiopian families (ranging in size from 2 to 13 members); traditional healers and Israeli health and absorption professionals.
2004	Joseph et al. ⁵⁶	To identify the factors that influence healthcare workers' adherence to policies for routine tuberculin skin tests and treatment of latent TB infection.	Focus groups with healthcare workers from a range of occupations including clinical, janitorial, administrative, clerical and security staff; US and foreign-born.
2004	Swigart & Kolb ⁵⁷	To examine the factors that homeless people report as influencing their decisions to accept or reject TB screening.	Interviews with homeless men and women who either resided in or were visiting shelters.
2005	Gibson et al. ⁵⁸	To examine socio-cultural factors influencing behaviour related to TB prevention and treatment in high-risk cultural populations.	Interviews with immigrants from Hong Kong, China, Philippines, Vietnam, Punjab, Eastern Europe and Aboriginal populations; included those with active TB, those who had taken DOT, those who had been offered DOT and refused and those with past history of TB, or a relative with TB.
2005	Moro et al. ⁵⁹	To explore chest and infectious disease physicians' views of the barriers to effective tuberculosis control.	Focus groups with chest and infectious disease physicians offering TB care.
2005	Van der Oest et al. ⁶⁰	To explore the opinions of refugee and minority group representatives about the significance of TB for their community and perceptions of TB services.	Community representatives were interviewed from the largest community populations, including Maori and Pacific Island groups, as well as immigrants from China, The Philippines, Somalia, and Kampuchea (Cambodia).

Number of participants	Location	Study respondents	Quality score
N = 67 (53 in focus groups, 14 individual)	California, USA	Migrants	+
N = 36 (12 families, 3 traditional healers, 21 health professionals)	Israel	Ethiopian migrants and service providers	-
N = 106	USA	Service providers	+
N = 55	North-Western USA	Homeless	+
N = 133	Canada	Migrants	++
N = 49	Emilia Romagna region, Italy	Service providers	++
N = unclear ('several groups')	New Zealand	Migrants	-

Table 1 Characteristics of included studies

Year	First author	Aim(s)	Method
2006	Brewin et al. ⁶¹	To understand how acceptable tuberculosis screening is to immigrant populations and to explore immigrants' understandings of TB in relation to screening.	Interviews with adult immigrants from a variety of ethnicities who had been offered TB screening.
2006	Johnson ⁶²	To explore how specific cultural health beliefs regarding TB affect the awareness and understanding of the disease among at-risk communities.	Focus groups and interviews with members of the following at-risk populations: Chinese, Nigerian, women refugees, Vietnamese, substance misusers, HIV-positive people, homeless people and prisoners.
2006	Nnoaham et al. ⁶³	To describe the perceptions and experiences of African patients with TB, particularly relating to diagnosis, adherence and stigma.	Interviews with patients attending a TB clinic, either for preventive therapy or to receive a diagnosis; African-born; over 18 years.
2007	Brent Refugee Forum ⁶⁴	To examine the level of knowledge, attitudes and perceptions of TB among populations at high risk of social exclusion and deprivation. To identify barriers that different populations face in accessing treatment, and understand how the cultural context of TB affects their lives.	Focus groups with participants from different ethnicities including refugees and asylum seekers, people who are HIV positive, homeless, and prisoners; male and female. Focus groups with health-care professionals providing TB services to the same communities.
2007	Marais ⁶⁵	To identify the structural influences which operate across community and sector levels within the local context which may influence TB risk, healthcare access and outcome in migrant black African communities. To identify the resources to improve TB control which exist or could be strengthened within the sectors and within these migrant black African communities themselves.	Multi-method participatory research using questionnaires, in-depth interviews, community consultations and observations; migrant black Africans over 18 years old who had been in the UK for less than 10 years; key stakeholders including individuals and representatives of populations, organisations or institutions, which could significantly influence public health interventions for TB control.
2008	Belling et al. ⁶⁶	To conduct an audit of TB services in relation to the range of services and expertise required to control and treat TB in London.	Interviews with TB service users and TB service lead professionals. Focus groups with TB nurses and external respiratory physicians/epidemiology professionals.

Number of participants	Location	Study respondents	Quality score
N = 53	East London, UK	Migrants	+
N = 67	South East London, UK	Migrants, people living with-HIV, drug users, homeless, prisoners	
N = 16	London, UK	Migrants	++
N = 119 (104 migrants, 15 service providers)	Brent, UK	Migrants, PLHIV, homeless, ++ prisoners and healthcare professionals	
N = 329 (312 African migrants, 17 stakeholders)	London, UK	Migrants	++
N = 33	London, UK	Service providers	++

Table 1 Characteristics of included studies

Year	First author	Aim(s)	Method
2008	Craig et al. ⁶⁷	To explore how a social outreach model of care, including a TB link worker, can be best implemented for marginalised populations with TB.	To explore how a social outreach model of care, including a TB link worker, can be best implemented for marginalised populations with TB.
2008	West et al. ⁶⁸	To explore the knowledge, attitudes and beliefs about TB among homeless shelter residents and persons attending a drug/alcohol rehabilitation centre.	Focus groups of homeless participants at homeless shelters and people with drug/alcohol abuse problems attending a rehabilitation facility.
2008	Whoolery ⁶⁹	To explore what it means for homeless people to have TB and how this impacts their opportunities to complete treatment.	Semi-structured interviews with homeless persons, some of who were also drug users, commercial sex workers or HIV positive.
2010	Gerrish et al. ⁷⁰	To identify socio-cultural influences on the prevention, diagnosis, and treatment of TB within the Somalian community and to gain insight into healthcare practitioners' perceptions of and experiences with TB among the Somalian community. To identify ways in which culturally appropriate health promotion initiatives regarding TB can reach the Somalian community. To identify ways of supporting healthcare practitioners to provide culturally appropriate care in regard to the screening, diagnosis and management of TB within the Somalian community.	Interviews with Somalian community leaders. Interviews and focus groups with members of the Somalian community including those with personal experience of TB. Interviews with healthcare practitioners including GPs, consultants, TB nurses and Somalian nurses with experience of working with the Somalian community.
2010	Sagbakken et al. ⁷¹	To identify the factors associated with diagnostic delay for TB among immigrants in Norway	Interviews with male and female immigrants from Somalia and Ethiopia who had been diagnosed with TB.

- = low quality. + = medium quality. DOT = Directly observed therapy. GP = general practitioner. NICE = National Institute for Health and Care Excellence.

Number of participants	Location	Study respondents	Quality score
	UK	Service providers	-
11 focus groups of 52 participants	USA	Homeless and alcohol abusers	+
N = 16	UK	Homeless	++
N = 120 (N=56 for focus groups; N=64 for individual interview)	Sheffield, UK	Somalian Migrants	++
N = 22	Norway	Migrants	+

Seven studies analysed whether hard-to-reach groups viewed themselves as susceptible to TB and were therefore more inclined to undergo testing if they had symptoms of the disease. Five studies focused on migrant populations,^{19,37,39,42,46} one on a Roma population,⁴⁴ and one on a mixed population of homeless people, drug users and migrants.³⁶ Table 3 provides an overview of findings for views on susceptibility through reported concepts of causes and modes of transmission. The appendix provides an overview of illustrative quotations identified per theme.

A common misconception among migrant students and teachers at an adult education centre in the USA was that TB was not present in the USA.¹⁹ Mexican-American TB-patients living on the border between the USA and Mexico discussed being susceptible to TB because of the proximity to Mexico.³⁷ In a Somalian community in Sheffield, UK, community leaders generally showed accurate knowledge, but there was great variation among community members. Here, views were relatively accurate, with some people describing TB as '*an airborne disease whereby people became infected by "breathing in the germ" and once infected, they could pass it on to others*'.⁴² Conversely, in a mixed group of patients with TB who were homeless, drug users, or migrants in London, UK, knowledge of TB was generally poor and a wide variety of causes was mentioned.³⁶

The way in which communities perceive the severity of TB, including symptoms, health consequences, and treatability, affects people's health care seeking behaviour. Three studies on the views of migrant populations,^{19,37,42} one on a Roma population,⁴⁴ and one on a variety of urban risk populations in London³⁶ investigated the perceptions of TB severity.

Four studies reported on perceived TB severity in migrant and refugees in the USA,¹⁹ Mexican American migrants,³⁷ Somalian migrants in the UK.⁴² One was exclusively reporting on the views of TB patients,³⁷ one reported on views of non-TB patients,^{19,44} and one on both.⁴² Two studies reported good knowledge of the TB symptoms, persistent (bloody) cough, weight loss, fever and night sweats.^{37,42} Somalian TB patients had little knowledge of extra-pulmonary TB, but most were aware of the long duration of treatment with antibiotics and the prospect for good recovery. However, because of the belief that TB is hereditary, some thought that TB was incurable. Furthermore, people had various beliefs about the length of time a patient remained infectious.⁴² Similarly, a Roma population in Belgrade, Serbia, had accurate knowledge of symptoms, whereas their views on TB severity and the effectiveness of treatment varied, ranging from TB being a very serious and lethal disease to it being a long-lasting, but curable disease.⁴⁴ A mixed group of migrants in the USA reported fear of TB, which consisted mainly of fear of dying from an incurable disease.¹⁹

A mixed group of people who were mainly homeless, drug users, people living with HIV, and migrants, with (suspected) TB infection in London, UK, reported on common symptoms for TB; recognition of symptoms was not always accurate and miscellaneous explanations for common symptoms were

reported.³⁶ Symptoms were often attributed to other undiagnosed illnesses, poor diet, or to drug/alcohol abuse.

Eight studies elaborated on the barriers that affect the health care-seeking behaviour and treatment adherence of TB patients, which hinder effective implementation of TB prevention and control measures; seven studies reported on migrant populations,^{19,37,39,42,43,45,46} and one study reported on mixed urban risk groups in London, UK.³⁶

Various migrant populations in the USA reported difficulties with transport to the testing centre, the opening hours of testing centres, or the duration and cost of testing as barriers to the testing and treatment of TB.¹⁹ The challenges of TB symptoms combined with TB treatment side effects were described by Mexican American³⁷ and Somali¹⁹ migrants with TB in the USA. They experienced mental and physical conditions, which affected their treatment adherence. Two studies^{37,39} commented on stress and depression due to delay in diagnosis and treatment challenges. Somalian patients in the UK³⁹ reported feeling stressed, anxious, and powerless, especially if the diagnosis took a long time, and if they felt they were not being taken seriously. Moreover, these patients thought that the system had let them down and they did not trust their general practitioners (family doctors). Other patients felt relieved after TB was diagnosed.³⁹ Depression and feelings of sadness were described by Mexican Americans during TB treatment, often related to (self-chosen) social isolation at home and restricted daily activities to prevent transmission.³⁷

Two studies identified loss of privacy and breaches in confidentiality as important barriers to treatment adherence in two studies.^{43,46} The actions of TB health care services and outreach workers were perceived as revealing a patient's TB status to others, this was mentioned by Haitians in the USA⁴⁶ and by Ethiopian and Somalian migrants in Norway.⁴³ Patients were concerned that health workers in directly observed therapy (DOT) aggravated the stigma of TB and were unaware of the consequences of exposing their TB status to others. Three studies described negative attitudes or fear of DOT, which made people reluctant to undergo testing.^{37,43,46} Haitian Americans associated TB treatment with incarceration and feared loss of employment.⁴⁶ Some Somalian and Ethiopian patients in Norway questioned the necessity of DOT, feeling humiliated or discriminated by the frequent home visits. They felt unable to voice any criticism because of their migrant status, a scarcity of alternative TB services, and the threatening attitudes of nurses in cases of non-cooperation. Some patients did not understand why nurses suspected them of not being compliant with treatment; they argued that DOT should only be used where people needed assistance to be able to manage their treatment.⁴³ Furthermore, DOT was perceived as imprisoning, forcing the patient into a subservient and confined position hindering work responsibilities, and, consequently, complicating treatment adherence.^{37,43}

Somalian and Ethiopian migrants in Norway described the lack of continuity among health personnel as hindering the establishment of a secure and

trustful patient-nurse relationship during treatment. Some patients reported that some health workers tried to restrict patient contact as much as possible. Patients often did not know which health worker was attending and at what time, potentially causing feelings of stress and humiliation.⁴³

Economic hardship due to a TB diagnosis was mentioned by Somalian patients in the UK.^{39,42} A Somalian homeless patient described how inadequate accommodation, a lack of social support, and a poor diet complicated management of the disease.³⁹ Mexican American migrants reported economic hardship, losing their job or being unable to work as complicating factors.³⁷ Mixed migrant populations in the USA reported that knowledge about TB medication being free of charge reduced financial constraints to access of TB care.¹⁹

TB-related stigma was a barrier to seeking treatment and adhering to treatment.^{19,37,39,42,43,45,46} We identified five themes: face masks, stigma of association with HIV, self-stigma, consequences of stigma, and stigma due to poor knowledge. Mexican American TB patients associated wearing face masks with physical discomfort and stigma.³⁷ They were afraid the mask would reveal their TB status, and, therefore, most patients stayed at home or avoided crowded places out of fear of disclosing their TB status and experiencing discrimination. Similarly, migrants in Canada referred to the mask as an 'identifier of TB' and described the effect of face masks on losing friends, jobs, or being unable to find employment.⁴⁵

One study reported that many Haitian community members in Florida assumed that patients with TB were HIV positive, thus aggravating stigma.⁴⁶ In this study, the TB and HIV clinics were located together in one building, contributing to this assumption.

Four studies described TB self-stigmatisation.^{19,37,39,42} Mexican patients in the USA felt depressed and guilty about having TB; they were afraid of being a burden for family or friends. Negative feelings seemed to be intensified by non-disclosure and self-chosen social isolation. Five of 18 participants did not disclose their TB status, because of shame, not wanting to be a burden, protecting family from TB stigma, or protecting themselves from being stigmatized by family, friends or community members. Some patients only disclosed to their families and hid their TB status from friends, colleagues and community members.³⁷ Some Somalian patients in the UK disclosed their TB status, because they understood the importance of contact tracing, whereas others concealed their TB diagnosis to avoid distress and discrimination, and maintain isolation.⁴² Similarly, mixed migrant populations in the USA¹⁹ mentioned patients would shy away from their family members and other social contacts. Somalian migrants in the UK and Mexican American migrants perceived self-stigmatisation as a barrier to seeking TB care and support during treatment.^{37,39,42}

Four studies (on migrant populations in the USA,¹⁹ Somalian migrants in the UK,^{39,42} and Haitians in the USA⁴⁶) found that TB-related stigma was most likely to be caused by poor knowledge of the community. Haitians in the USA

reported being seen as a disadvantaged and socially marginalized group that brought TB and other diseases to the USA.⁴⁶ Many Mexican American patients felt they were stigmatized by family and friends who stayed away, did not want to share drinks or food, or slept separately. Consequently, most patients felt depressed, but accepted their situation; understanding that people wanted to protect themselves from TB.³⁷ Consequences of stigma in the Haitian community in Florida, USA, were discrimination, avoidance of TB patients by others, and negative effects on relationships with family members.⁴⁶ Many Somalian patients in Sheffield, UK, were supported by friends and family, but faced socio-cultural consequences in their wider social network.³⁹ In Somalia, TB is considered shameful for the whole family⁴² and, in some cases, the whole family is socially isolated and discriminated against. Some patients said community members still did not know that TB was curable. Moreover, the idea that TB is hereditary implies that the entire family will face stigma, which could affect employment and marriage prospects.⁴²

Perceived barriers to testing and treatment of TB were reported for other hard-to-reach populations. For drug using TB patients in the UK, the fear of opiate withdrawal symptoms resulted in most people seeking health care only when they had reached a crisis point.³⁶ Fear of hospital admission was also a barrier to seeking health care among drug users in the UK, especially if they were unaware of the availability of methadone to prevent withdrawal symptoms.³⁶

Seven studies reported on the facilitators that influence health care-seeking behaviour and treatment adherence of TB patients; five reported on migrant populations,^{37–39,43,45} one on homeless people in Japan⁴⁰ and one on mixed urban risk groups in London.³⁶

The importance of the nurse role in TB treatment was emphasised for mixed migrant and Somalian populations.^{39,45} For migrant TB patients in Canada nurses played an important role in supporting treatment adherence.^{37,39} Somalian patients in the UK appreciated support of Somalian health workers and TB specialist nurses.³⁹ Somalian TB patients in the UK were mostly supported by their family and friends.³⁹ Mexican American TB patients who disclosed their diagnosis of TB to their families received support and were accepted; however, those who did not disclose were not able to access this support.³⁷

A strong relationship of trust between care workers and patients, with care that goes beyond a single focus on drugs, was considered important by homeless patients in Tokyo, Japan. At the end of each successfully completed treatment course, the nurses organized a small ceremony, which was deemed important by patients.⁴⁰ These types of support, beyond normal TB care, made the patients generally feel more cared for and helped them adhere to treatment.

Two studies noted hospitalisation as a facilitator for health care seeking behaviour or adherence in migrants.^{37,43} Some female Somalian and Ethiopian TB patients in Norway described DO) as an expression of genuine care, which reduced their isolation.⁴³ In one study, most Mexican Americans with TB were

unable to work and limited other activities to prevent transmission of TB, making the hospital or nursing home visit *'the outing for the day'*.³⁷ Three studies noted hospital admission as a facilitator for health care seeking behaviour or adherence.^{36,38,40} A patient who was homeless and a drug user in the UK viewed hospital admission as *'a welcome break from the street'*. Some drug users turned to creative and strategic approaches to achieve hospital admission, thus avoiding opiate withdrawal symptoms.³⁶ Kawatsu and colleagues identified five subcategories of characteristics of homeless patients in Tokyo that improved after DOT: mental health, health behaviour, living environment, personal relationships, and attitudes towards society.⁴⁰ A peer educator in London with a history of TB noted the positive effects of DOT on treatment adherence.³⁸

Three studies mentioned cues to action for accessing TB care.^{36,39,44} Roma people in Belgrade, Serbia, indicated that Roma people often do not visit a doctor until the symptoms of the disease are so severe that they are unable to work.⁴⁴ Conversely, Somali TB patients in the UK were reported to have presented at the general practice shortly after initially feeling unwell.³⁹ Several participants in a mixed group (including homeless and migrants) in London, UK, delayed access to medical care, because they had been trying to self-manage and attributed symptoms to other factors, or sought help only after reaching a crisis point.³⁶

No studies directly comparing the views between hard-to-reach populations were identified. Five studies presented the views of TB health care/service providers, including those involved in the care of migrants in Canada,⁴⁵ Somali migrants in the UK,³⁹ Somali and Ethiopian migrants in Norway,⁴³ HIV infected patients in Sweden,⁴¹ and homeless and drug users in London.³⁸

As barriers to diagnosis and treatment adherence among migrant populations, service providers mentioned (fear of) stigma,^{39,45} the use of khat (resulting in late presentation of Somali migrant populations due to its escapist effects),³⁹ atypical presentation of the disease as a result of different cultural perspectives, language barriers (and the lack of professional translators), a paucity of TB cases seen each year,³⁹ negative psychological effects of wearing masks and experiencing isolation,⁴⁵ and an aversion to DOT.⁴³ Norwegian service providers acknowledged the existence of institutional barriers to treatment adherence.⁴³ Whilst DOT was generally seen as effective, most were aware of the implications of DOT on patients' lives, given their vulnerable socioeconomic position in society.⁴³ Service providers of Somali TB patients in the UK³⁹ and Norway⁴³ noted that most patients accepted and complied with treatment, non-adherence was sometimes due to the chaotic situation a patient was in, such as applying for asylum.

In Sweden, physicians and nurses specialised in HIV and TB were interviewed about the challenges in their work regarding TB-HIV co-infection,⁴¹ and reported a number of barriers to access to TB care and treatment adherence. These barriers included reduced continuity among physicians, staff shortages, difficulties in monitoring and managing the treatment process, insufficient networking between the HIV and TB specialties, a need for more collaboration,

uncertainty about division of tasks between HIV and TB clinics, and insufficient communication between team members.

Service providers additionally identified facilitators supporting treatment adherence, including the use of persuasion based on subtle threats,⁴³ assisting patients with needs beyond the administration of tablets,^{43,45} support by TB specialist nurses and Somalian service providers,³⁹ acknowledgement of the difficulties of being an immigrant,⁴⁵ and support from close family.³⁹

Peer educators in London, UK, who had received treatment for active TB and had been homeless or dependent on drugs or alcohol mentioned that their support could be motivational and have a personal effect on other TB patients in similar situations.³⁸

Table 2 Quality assessment of included studies

Year	Author	Quality score	1. Is a qualitative approach appropriate?	2. Is the study clear in what it seeks to do?	3. How defensible/rigorous is the research design / methodology?	4. How well was the data collection carried out?
2010	Bender et al. ⁴⁵	-	Y	Y	Y	NS
2010	Coreil et al. ⁴⁶	+	Y	Y	Y	Y
2011	Vukovic and Nagorni-Obradovic ⁴⁴	+	Y	Y	P	P
2012	Gerrish et al. ⁴²	++	Y	Y	Y	Y
2012	Sagbakken et al. ⁴³	++	Y	Y	Y	Y
2012	Wieland et al. ³⁹	++	Y	Y	Y	Y
2013	Croft et al. ³⁸	+	Y	Y	Y	Y
2013	Gerrish et al. ³⁹	+	Y	Y	Y	Y
2013	Kawatsu et al. ⁴⁰	+	Y	Y	Y	Y
2013	Wannheden et al. ⁴¹	+	Y	Y	Y	Y
2014	Craig et al. ³⁶	++	Y	Y	Y	Y
2014	Zuninga et al. ³⁷	+	Y	Y	Y	Y
1994	Curtis et al. ⁴⁷	-	Y	M	N	NS
1995	Kitazawa ⁴⁸	+	Y	Y	Y	Y
1996	Kelly-Rossini et al. ⁴⁹	+	Y	Y	Y	NS
1997	Jackson & Yuan ⁵⁰	+	Y	Y	Y	Y
1999	Ito ⁵¹	+	Y	Y	Y	Y
1999	Yamada et al. ⁵²	++	Y	Y	Y	Y
2000	Fujiwara ⁵³	-	Y	Y	Y	Y
2002	Houston et al. ⁵⁴	+	Y	Y	Y	Y
2003	Chemtob et al. ⁵⁵	-	Y	Y	N	N
2004	Joseph et al. ⁵⁶	+	Y	Y	Y	Y
2004	Swigart & Kolb ⁵⁷	+	Y	Y	Y	Y
2005	Gibson et al. ⁵⁸	++	Y	Y	Y	Y
2005	Moro et al. ⁵⁹	++	Y	Y	Y	Y
2005	Van der Oest et al. ⁶⁰	-	Y	Y	Y	Y
2006	Brewin et al. ⁶¹	+	Y	Y	Y	Y
2006	Johnson ⁶²	-	Y	N	N	N
2006	Nnoaham et al. ⁶³	++	Y	Y	Y	Y

5. Is the role of the researcher clearly described?	6. Is the context clearly described?	7. Were the methods reliable?	8. Is the data analysis sufficiently rigorous?	9. Is the data 'rich'?	10. Is the analysis reliable?	11. Are the findings convincing?	12. Are the findings relevant to the aims of the study?	13. Conclusions	14. How clear and coherent is the reporting of ethics?
NS	N	Y	Y	Y	NS	Y	Y	P	N
N	NS	Y	Y	Y	NS	Y	Y	Y	Y
Y	Y	N	Y	Y	Y	Y	Y	P	Y
Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Y	Y	N	Y	Y	Y	Y	Y	Y	Y
Y	P	Y	Y	Y	Y	Y	Y	Y	Y
NS	N	Y	Y	Y	Y	Y	Y	Y	Y
N	Y	N	Y	Y	Y	Y	Y	Y	Y
NS	NS	Y	Y	Y	NS	Y	Y	Y	Y
NS	NS	Y	Y	Y	Y	Y	Y	Y	Y
Y	Y	M	Y	Y	Y	Y	Y	Y	Y
N	Y	Y	Y	Y	NS	Y	Y	P	Y
N	NS	Y	N	NS	N	Y	Y	Y	N
N	Y	NS	N	N	N	Y	Y	Y	Y
N	NS	Y	Y	Y	Y	Y	Y	Y	Y
N	Y	Y	Y	N	Y	N	M	Y	Y
NS	Y	NS	NS	Y	NS	Y	Y	Y	NS
N	Y	Y	Y	Y	Y	Y	Y	Y	NS
N	N	N	N	N	N	N	P	N	N
Y	NS	Y	Y	N	NS	Y	M	Y	NS
N	N	N	N	N	N	N	N	N	N
NS	N	Y	Y	Y	Y	Y	Y	Y	Y
N	Y	Y	Y	NS	Y	Y	Y	Y	N
Y	Y	Y	Y	NS	Y	Y	Y	Y	Y
NS	Y	Y	Y	Y	Y	Y	Y	Y	NS
N	N	NS	N	Y	N	N	Y	Y	N
Y	Y	Y	Y	N	Y	Y	Y	Y	Y
N	Y	Y	N	N	N	N	Y	Y	NS
NS	NS	NS	Y	Y	NS	Y	Y	Y	Y

Table 2 Quality assessment of included studies

Year	Author	Quality score	1. Is a qualitative approach appropriate?	2. Is the study clear in what it seeks to do?	3. How defensible/rigorous is the research design / methodology?	4. How well was the data collection carried out?
2007	Brent Refugee Forum ⁶⁴	++	Y	Y	Y	Y
2007	Marais ⁶⁵	++	Y	Y	Y	Y
2008	Belling et al. ⁶⁶	++	Y	Y	Y	Y
2008	Craig et al. ⁶⁷	-	Y	Y	N	NS
2008	West et al. ⁶⁸	+	Y	Y	Y	NS
2008	Whoolery ⁶⁹	++	Y	Y	Y	Y
2010	Gerrish et al. ⁷⁰	++	Y	Y	Y	Y
2010	Sagbakken et al. ⁷¹	+	Y	Y	Y	Y

- = significant risk of bias. + = study might not have addressed all potential sources of bias.

++ = well-designed study, minimal risk of bias. N = no. Y = yes. NS = not sure (not reported or inadequately reported). M = mostly relevant. P = partially relevant. NICE = National Institute for Health and Care Excellence.

5. Is the role of the researcher clearly described?	6. Is the context clearly described?	7. Were the methods reliable?	8. Is the data analysis sufficiently rigorous?	9. Is the data 'rich'?	10. Is the analysis reliable?	11. Are the findings convincing?	12. Are the findings relevant to the aims of the study?	13. Conclusions	14. How clear and coherent is the reporting of ethics?
Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
N	Y	Y	Y	Y	Y	Y	Y	Y	Y
NS	Y	Y	NS	M	Y	Y	Y	Y	Y
N	N	Y	N	N	N	N	Y	Y	Y
N	Y	Y	Y	N	Y	Y	M	N	N
Y	Y	Y	Y	Y	NS	NS	Y	Y	Y
Y	Y	Y	Y	Y	NS	Y	Y	Y	Y
N	Y	Y	Y	N	Y	Y	Y	Y	Y

Table 3 Views on susceptibility: reported concepts of causes and modes of transmission across 20 studies (this update and the previous NICE review).³⁰

Cause	Total Mentions	Mixed populations*	Homeless	Migrants – mixed
Smoking	10	1 ⁶⁴	2 ^{48,68}	3 ^{19,58,61}
Food-related	9	1 ³⁶	2 ^{48,68}	2 ^{19,61}
Heredity	9	1 ⁶²	1 ⁶²	2 ^{58,60}
Other illnesses	8	1 ³⁶ (HIV)	1 ⁶⁸ (AIDS)	
Environment (typically 'dirty' or weather)	8	1 ⁶⁴	1 ⁶⁸	1 ⁵⁸
Poverty	8	1 ³⁶	1 ⁶⁸	1 ⁶¹
Lack of self-care, health imbalance	7	1 ⁶⁴	1 ⁶⁸	2 ^{58,61}
Sharing (e.g., cigarettes, cutlery)	6	1 ⁶²	2 ^{48,68}	1 ⁶¹
Sexual contact / Saliva	4	1 ⁶²		2 ^{19,61}
Stress	4			
God	3	1 ³⁶		
Lifestyle factors	2	1 ³⁶		1 ¹⁹
Blood (type)	2			1 ¹⁹
Touch	2			1 ¹⁹
Geographical localisation	2			1 ¹⁹ (not in USA)
Airborne	1			
Vectors (rats)	1			

*Mixed groups differed by study, but could include any of people who use drugs, migrants, prisoners, people with HIV, and homeless people in the same study. For this updated review and the previous National Institute of health and Care Excellence review.

Migrants – African: Somali & Ethiopian	Migrants – Asian incl. Chinese, Vietnamese & Filipino	Migrants – Roma	Migrants – Mexican, Haitian
2 ^{70,71}	2 ^{53,62}		
2 ^{62,71}	1 ⁶²	1 ⁴⁴	
4 ^{39,42,63,70}		1 ⁴⁴	
3 influenza & pneumonia ⁴² asthma ⁷⁰ pneumonia ⁶¹	1 ⁶² (low immunity)	1 ⁴⁴ (influenza, pneumonia)	1 ⁴⁶ (HIV)
2 ^{62,70}	3 ^{52,53,62}		
2 ^{42,70,71}	1 ⁵⁴	1 ⁴⁴	
2 ^{70,71}	1 ⁵²		
1 ^{42,63}			
		1 ⁴⁴	
1 ^{42,70}	1 ⁵⁴	1 ⁴⁴	
2 ^{39,42}			
1 ⁴²			
		1 ⁴⁴	
		1 ⁴⁴	
			1 ³⁷ (proximity Mexico)
1 ⁴²			
		1 ⁴⁴	

Our review provides evidence-based qualitative information about several important barriers and facilitators to the uptake of TB diagnostic and treatment services by people from hard-to-reach populations in EU, EEA, EU-candidate, and OECD countries of low and medium TB incidence. We identified 12 studies, in addition to 25 studies⁴⁷⁻⁷¹ included in the previous NICE review.³⁰ In this review,³⁰ 12 studies reported on migrants,^{51-55, 58, 60, 61, 63, 65, 70, 71} four on homeless people,^{48, 57, 68, 69} two on a mixture of hard-to-reach populations (migrant, homeless, and prisoners),^{62, 64} one on drug users,⁴⁷ one on people living with HIV,⁴⁹ and five on the views of health-care professionals.^{50, 56, 59, 66, 67} Combining the findings of the current review with those of the previous review³⁰ provides a body of evidence that shows important gaps in the provision of TB care in countries of low and medium TB incidence.

Low perceived susceptibility can be a barrier, because individuals who do not consider themselves susceptible to TB might not access health care when they develop symptoms. We found strong evidence that many misconceptions exist regarding susceptibility to TB among all investigated hard-to-reach populations in our review and the previous review.^{19, 36, 37, 39, 42, 44, 46, 48, 52, 53, 58, 60-64, 68, 70, 71} For TB severity, migrants, prisoners, drugs users, and homeless populations were generally aware of untreated TB being potentially fatal.^{19, 62, 65, 68, 70} Previous studies have shown the importance of awareness about the variety of perceptions on illness and health care,^{72, 73} and many have emphasised the importance of cultural-sensitive programmes.^{74, 75} Thus, in specific settings, introduction of awareness-raising programmes that acknowledge and appropriately address the variety of local perceptions is relevant, with the aim of enhancing early case-finding and reducing delay in health care seeking.

We identified numerous barriers to treatment seeking and adherence for migrant populations.^{19, 37, 39, 42, 46, 48, 51-53, 57, 58, 60, 62-65, 70, 71} We found strong evidence that TB-related stigmatisation was perceived as a major barrier in almost all migrant populations and some homeless people.^{37, 39, 43, 45, 46, 52, 58, 60, 63, 64, 69, 70} Stigma can be described as a discrediting attribute negatively affecting social status and position and often leading to rejection and/or exclusion.⁷⁶ Self-stigmatisation can be defined as '*a reduction of an individual's self-esteem or self-worth caused by the individual self-labelling herself or himself as someone who is socially unacceptable*,'⁷⁷ and can lead to denial of diagnosis, or hiding of TB status. Stigma and its social consequences is one of the major factors hindering TB diagnosis and treatment adherence.^{22, 78, 79} Various interventions exist to prevent stigma and its effects, including family and community sensitizations, treatment supporter programmes, and counselling. However, stigma is often embedded in a cultural context with deep-seated beliefs⁸⁰ and should therefore not solely be ascribed to a knowledge deficit as knowledgeable people might also stigmatize. Thus, it is necessary to organize interactive community sensitization programmes

that specifically target stigmatizing attitudes and actions. Notwithstanding the amount of literature on this topic,⁸¹ TB-related stigma remains prevalent and, therefore, a focus for international TB control efforts.^{79,82}

Institutional barriers, such as poor health infrastructure, unavailable diagnostic facilities, incorrect diagnosis, little health care provider training, and poor follow-up routines,²² were reported to delay TB diagnosis.^{19,36,43,62,63,65,70,71} Additionally, structural barriers were mentioned across studies.^{19,37,39,42,43,46,47,49,53,60,65,68,70} Hard-to-reach groups in countries of low and medium TB incidence often seek care or receive TB treatment under challenging circumstances, such as uncertain migrant status, undocumented immigration status, homelessness, addiction to alcohol or drugs, or vulnerable economic and social positions.^{78,83} Crucially, countries should reflect upon their immigration policies and how they might hamper TB control.⁸³ Evidence for the effect of incentives is conflicting.^{84–86}

We found no strong evidence for perceived facilitators of TB diagnosis or treatment adherence across hard-to-reach populations.^{36,37,40,43,45,46,49,51,63,65,69,70} Possible approaches to improve access to healthcare in general are support and social networks, multidisciplinary teams, care and transportation for free, use of outreach services, and trained care providers who are sensitive to gender and culture. A patient-centred approach plays a key role in improving treatment adherence.⁷⁸ For many migrants, interpreters and/or bilingual staff are needed.⁸⁷ In drug use and homelessness services, strong collaborations that integrate existing social services with TB care could be useful.⁸⁸ Furthermore, structural barriers need to be addressed.

No strong evidence for cues to action that motivate or precipitate health care seeking could be identified. Delay in health care seeking is often cited as a more complicated obstacle than treatment adherence among hard-to-reach populations, because people who delay care seeking are not yet in the health care system and, therefore, are difficult to reach. Discontinuity in primary care may also cause diagnostic delays.^{71,89–91} Such delays could be reduced by awareness training of health professionals about atypical TB symptoms, patients' history, and patients' interpretation of TB symptoms.⁷¹ Moreover, there is a need to improve the accessibility of TB services to hard-to-reach populations.⁹¹

The main challenges identified by service providers giving care to migrant TB patients were cultural and language barriers,^{39,41,43,45,59,65,70} and, with regard to TB care in general, a scarcity of specialist services and coordination of care,^{39,41,43,50,59,66,70} and complex social and clinical interactions.^{64,66,67} In settings with a low TB incidence, poor TB awareness and expertise among primary care providers is a problem, causing considerable treatment delays and distrust in the health system. Continuous training of health-care providers on TB and its diagnosis is needed; computer-based decision support has been suggested to improve clinical practice.^{41,92} Language and cultural barriers are considerable obstacles;^{87,93–98} care providers should have unlimited access to high-quality translation services, which are currently not readily available in many of the

studied countries.⁸⁷ Cross-cultural training of health care providers and the availability of bilingual, multidisciplinary teams have been associated with improved health outcomes.⁹⁶

Our systematic review highlights the small number of studies that have been of hard-to-reach populations in EU, EEA, EU-candidate), and OECD countries specifically, and in countries of medium and low TB incidence in general. A clear knowledge gap exists for drug- and alcohol users, homeless people, prisoners, and sex workers regarding the barriers and facilitators to TB services. Many studies focused on Somalian migrants; as such, most findings are specific to this migrant population and might not be transferrable to other hard-to-reach migrant populations. Children are not mentioned in the studies included in both our and the previous systematic review, and yet the World Health Organization (WHO) estimated 10% of the TB notifications worldwide to be in children.² Multidrug-resistant TB (MDR-TB) and HIV co-infection complicate TB care; HIV infection exacerbates mortality and facilitates the development of drug resistance.⁹⁹ MDR-TB was not cited in any of the identified studies, despite it being a growing problem in Europe.^{100,101} The lengthy duration of treatment with toxic drugs with potentially serious side effects complicates adherence to treatment.¹⁰² Only two studies about TB-HIV co-infection were identified; thus, more qualitative, large-scale, multi-country studies are needed to obtain evidence for operational factors that affect access and delivery of effective TB services, especially for MDR-TB and TB-HIV co-infected patients.

Our study had several limitations. One challenge was defining what groups are hard-to-reach;¹⁰³ this definition might vary between settings and in addition, not every individual within a so called hard-to-reach group is necessarily equally hard-to-reach. To be inclusive, we decided to include all people living with HIV and migrants in our analysis, because members of those groups are often hard-to-reach and face higher TB rates than other groups. Furthermore, we used wide inclusion criteria, which is common practice in qualitative literature synthesis,¹⁰⁴ but can affect reproducibility. Thematic analysis is, in view of its subjective nature, prone to bias; many views expressed in qualitative literature can be interpreted in different ways. We aimed to minimise this bias by following PRISMA guidelines, resulting in a critically appraised and structured analysis of the qualitative literature. The quality of the studies was generally moderate to high (for grading of qualitative research); there were shortcomings in the clarity of the role of the researcher, the description of the context, the reliability of the data collection methods, and reporting of the method of data-analysis. Our evidence is restricted because we identified relatively few studies, especially on non-migrant groups. Additionally, most studies focussed on Somalian migrant populations, hindering the formulation of generalized health care recommendations for other hard-to-reach populations.

Although countries of medium and low TB incidence might give lower priority to TB control and research activities than would high TB incidence

countries, TB has re-emerged as a significant problem.^{16,105} To ensure equitable access to TB care, increased investments are needed so that an evidence base for TB knowledge, stigma, DOT, and economic constraints is available to carefully tailor TB programmes to specific risk groups.¹⁰⁶ Such investment is of particular importance for progress towards TB elimination globally. The arrival of millions of refugees into Europe from high TB endemic regions of Asia, the Middle East, and Africa could increase the numbers of hard-to-reach populations with TB. The identified gaps in knowledge concerning drug- and alcohol users, homeless people, prisoners and sex-workers, and the new refugees, provide an opportunity to do future studies. A focus on patient autonomy, shared decision-making, and support systems, particularly for patients from hard-to-reach groups, might improve the uptake of diagnosis and adherence to treatment. The influence of poverty and gender on patients and their treatment adherence require further study.⁷⁸ Future research should cover the wide variety of hard-to-reach populations in EU, EEA, and OECD countries to make realistic recommendations to render TB control programmes maximally effective. Unfortunately, many countries, especially those where TB is concentrated in hard-to-reach populations, have limited resources at the national level and are not able to follow up such recommendations and take up the coordination.^{28,82}

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APPENDIX (AVAILABLE ONLINE)

Supplementary Material I: PICOS (Population-Intervention-ComparatorOutcome-Study design)

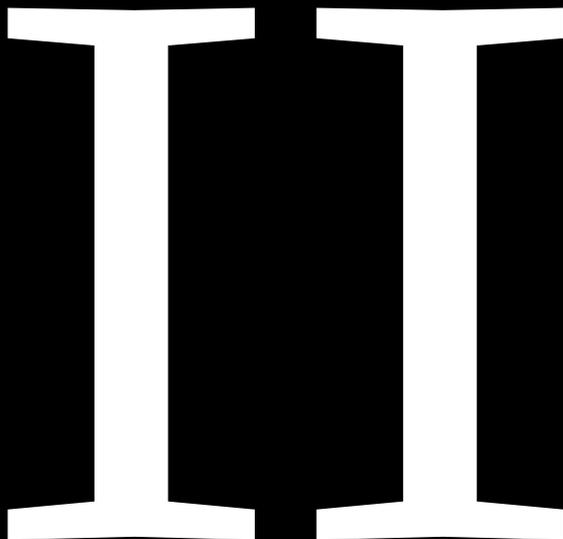
Supplementary Material II: Search strategy

Supplementary Material III: Evidence tables

Supplementary Material IV: Evidence statements

Supplementary Material V: Illustrative quotes per theme

Section



TB in South Africa, a visual ethnography



Visual ethnography: bridging anthropology and public health

Anne L. Cremers, René P.M. Gerrets, and Martin P. Grobusch

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The last scene of the film ends. The room remains dark and quiet. Someone switches on the light showing the audience of (public) health scientists digesting the story of six tuberculosis patients. One person remarks, 'Now I finally realize what your research is about.'

The ethnographic film presented in the scene above (*TB in Town 2*, the Academic Medical Center, Amsterdam, the Netherlands, 2015) was part of an interdisciplinary anthropological health study about patients' experience with tuberculosis (TB) in South Africa. Ethnography calls for immersion into the lives of research subjects by fostering in-depth interactions and relationships with them over an extensive period of time, aiming for a holistic understanding of the nuances and complexities of respondents' lives.¹ Through ethnographic health research, public health practitioners can be informed about patients' experiences of illnesses and health, potentially leading to improved health care programmes. Anthropologists have for many years played a significant role in public health as cultural brokers mediating between the variety of clinical realities and experiences of patients, clinicians, and policy makers.² However, anthropologists' actual contribution to the formation of health policies within the public health domain remains marginal.³

In the context of an interdisciplinary TB research at the Academic Medical Center (AMC) in Amsterdam, the anthropologist on the team (Cremers) aimed for a synergy of anthropology and public health while navigating differences between the disciplines. Scholars have discussed divergent scientific agendas: anthropological research often leads to context-bound specific findings and detailed, nuanced manuscripts, whereas public health research aims at generalizable extrapolation in the format of short, concise articles.⁴ Various scholars have written about the exploratory, question-driven character of anthropological research versus the formulation of hypotheses in public health research aimed at health recommendations.⁵ Another often-mentioned contrast is the use of qualitative versus quantitative methods.⁶ Public health researchers rely predominantly on quantitative techniques, and their limited use of qualitative techniques tend to depend heavily on researcher-defined categories. Consequently, the value of these methods has been criticized because it would yield data that may differ significantly from respondents' perspectives.⁷

Although the literature sufficiently mentions the disciplinary differences and contributions of anthropology and public health,⁸ there is a need to elaborate how these disciplines can benefit from each other, creating an effective synergy. We suggest that the use of visual ethnography can potentially bridge anthropology and public health, serving both disciplinary agendas while communicating ethnographic details to represent the voices and experiences of respondents within an academic and applied sphere. Potentially, this can contribute to theories on patients' experience with

illness and care, and hence, a deeper understanding of the functioning of care programmes.

VISUAL ETHNOGRAPHY

Over the past twenty years, visual anthropology was officially established as a sub-discipline of anthropology engaging in the making of ethnographic films (and photographs).⁴ Similar to ethnographic methods, these films are not directed by predetermined matrices but are gradually developed through discovery and collection of visuals of respondent's everyday lives over time.⁹ Ethnographic film captures the sensation of lived experiences evoking the idea of moving, seeing, and hearing.¹⁰ Visuals can additionally convey much deeper dimensions of experience: *'experience [...] is made up of ideas, emotions, sensory responses, and the pictures of our imagination'*.¹¹ Whereas the written word can inform the reader about 'thoughts' of respondents' experiences, visuals can additionally make someone empathetically understand patients' experiences.¹² The combination of space, gestures, emotions, attitudes, facial expressions, interactions, composition, and context communicates meaning and directly engages the audience in a complex representation of this experience. The boundaries between the audience, film subjects, and researcher become blurred, leading to a sense of shared experience.

SYNERGISTIC POTENTIAL OF VISUAL ETHNOGRAPHIC HEALTH RESEARCH

Visual methods can connect applied and academic anthropology to other disciplines, creating linkages and contributing to a wider interdisciplinary framework.⁴ Nevertheless, in medical sciences, scientific thoughts are generally confined to the printed and spoken word with the exception of some health campaigns and applied anthropological health research.¹³ Moreover, visual methods in health research have often been criticized for their limited use as illustrative materials for non-academic pursuits.¹⁴ A similar critique was mentioned in earlier debates on the value of visuals for academic anthropology, during which anthropologists advocated for a more significant role for ethnographic film.¹⁵ Film can generate forms of knowledge that are very different from written work and communicates messages that may be unsatisfactory to scientists who desire more clarification, contextualization, or more specific study results. The scientific value of ethnographic health films can be constructed through suggestion, reference, ambiguity, and implication without forming an explicit statement.¹⁰

Furthermore, ethnographic film can function as a platform on which various respondents can represent their ideas, experiences, and culture. All visual production is more or less created through collaborative and reflexive processes between the researcher and respondents, and herein, the filmmaker/researcher

and respondents can be considered active agents in the social construction of meaning.¹³ Tailored to issues of health and disease, patients may be empowered by this so-called communication competence¹⁴ in which they can express themselves while knowing that someone is paying attention to their words and experiences. Moreover, it can give voice, and a face, to those who are often under-represented in public discourse.¹⁶ Ethnographic film has the added value of communicating a message about larger structures of inequality or asymmetric power structures. Engaging policymakers in a process in which they are not only informed but also immersed in the patient's world, could enhance empathetic understanding, and consequently inform health strategies.¹⁴

INTERDISCIPLINARY STUDY ABOUT TUBERCULOSIS

With the ambition to draw from both the disciplines of public health and anthropology, we explored a variety of methods combining ethnography in three different sites with one or more other methods. In South Africa, we conducted visual ethnographic research and experienced its synergistic potential. The present article draws on the visual aspects used during this study.

Cremers served as director, camera operator, and researcher conducting visual ethnography about TB within the community of Town 2 in the township Khayelitsha, South Africa, in close collaboration with the University of Cape Town. South Africa faces one of the worst TB epidemic and highest HIV rates in the world with a TB incidence of 834/100 000, 61 percent TB-HIV co-infection, and 8.5 percent drug resistant TB (DR-TB).¹⁷ (DR-)TB treatment is available for free in Khayelitsha, but side effects are often aggressive (e.g., nausea, dizziness, psychosis) and especially severe on an empty stomach.

The aim of this sub-study was to enhance our understanding of how the complex relations between TB patients, community members, treatment, and the highly developed TB health programme in this township play out in everyday treatment compliance, that is, continuing TB treatment without interruption (Cremers et al. n.d.) For five months, Cremers worked with her local research assistant, Maqogi, a respected pastor and social activist of the community. They found respondents via the snowball technique. Six respondents, all TB patients, a pastor and community care worker were approached for the visual ethnographic part and consented with a long-term, intensive engagement during which they shared their experience of TB, care, and death embedded within the social structures of a South African township, characterized by high levels of poverty, unemployment, and crime.

AN ETHNOGRAPHIC HEALTH FILM

Cremers' request to film during interviews and participant observation and the presence of the camera seemed to work as a catalyst, as respondents reacted

positively and explained they hoped their struggles while being on TB treatment would reach beyond this research. They guided the visual data collection by explaining and showing intake of treatment, visits to the clinic, the way their family and community members supported or discriminated them, their living circumstances and neighborhood, and several funerals. After establishing a confidential relationship between researcher and researched, they shared not only the practicalities of having TB but also their TB-related difficulties, pains, fears, and hopes during interviews and informal conversations with Cremers, Maqogi, family, and friends.

The respondents' statements and the context in which they were filmed shows how treatment compliance is not exclusively the product of care programmes or patients' struggles but rather shows flexible and creative processes of survival, coping strategies, and the existence of social networks leading to supportive and stigmatizing actions. It gives the audience insight into social moments, the state of patients' bodies and minds, their emotions, the impact of extreme poverty and hunger, the mundaneness of death, and how this shapes the shifting agencies of TB patients navigating tuberculosis and treatment.

Cremers' position within this research field and her influence on what was being filmed became clear through the conversations she had with respondents (Photo 1). In a later stage of the filming process, many scenes happened unexpectedly, for example, as seen during an informal discussion with three tuberculosis patients about the consequences of taking TB medication: *'I just took my pills, I don't know what will happen. Maybe I will go mad. I think you [Lianne] should go now. Like now now.'* Or a patient who throws her medication in the bin explaining to Cremers: *'I am not going to take these pills, Lianne. The food is finished. I will go mad!'* illuminating the patient's fear of psychosis behind so-called 'non-compliant behavior'. The latter scene communicates how the relationship between Cremers and respondents did not necessarily trigger socially desired answers regarding treatment compliance or an ideal type representation of the 'good patient.' This could be linked to how respondents viewed Cremers: because of her long-term presence in the field, they may presupposed a certain degree of understanding that might give them the feeling of not being judged as irresponsible. The importance of this mutual respect was also visible during an interview with a respondent who had ceased TB treatment, amongst others because of side effects. She told Cremers that the camera gave her the feeling of being taken seriously and started crying because the attitudes of nurses made her 'not feeling human anymore'.

The film was co-produced by the key-informants who actively influenced the camera's orientation and the film's thematic content. The primary goal was to make TB patients' experience come to life for both a fundamental and applied research audience within the spheres of public health and anthropology.



Photo 1 Interaction between Cremers and her respondents in the township Khayelitsha, Cape Town, South Africa (written informed consent obtained from all visible respondents).

Consequently, the two-folded aim was to inform public health policies about patients' experience with TB and care and to reflect on theoretical debates on illness experience, treatment compliance, and care.

The preliminary study results of our South African sub-study were presented with the film *TB in Town 2* at a meeting for social scientists and public health practitioners in Cape Town (February 2015), the weekly scientific meeting for (public) health researchers at the Center of Tropical Medicine and Travel Medicine of the AMC in Amsterdam (April 2015), and at a meeting for anthropologists at the University of Amsterdam (April 2015). *TB in Town 2* embodied innovative means of communicating this study's ethnographically informed public health messages to different audiences. Various people were visibly touched by the audio-visual stories and reported to have gained better understanding of the complex decision making processes in which TB patients engage while being on treatment. One public health practitioner explained, '*I now realize that even for myself, I might choose to stop TB treatment in this situation.*'

We argue that visual ethnographic film can be a powerful source of detailed data, a quick and efficient way of conveying and evoking deeper understanding of patients' experience, and engaging diverse audiences, while sharing interdisciplinary knowledge.

ETHICS IN VISUAL ETHNOGRAPHIC HEALTH RESEARCH

During this collaborative visual ethnographic research process, it is important to consider various ethical implications. The most visible one is that respondents cannot participate anonymously in this kind of research; otherwise important data would be lost. This foregrounds a particular informed consent process in

which ethics of filmic representation and the loss of personal privacy should be discussed. Moreover, film is a medium that in modern technology is easily spread over the Internet, reaching different audiences. Respondents cannot always foresee different interpretations by audiences. Audience reactions are seldom discussed within visual anthropology,¹⁸ let alone the related task of the anthropologist to deal with this adequately. We argue that visual anthropologists should facilitate full information about the ethics and practices of filmmaking to respondents,⁴ both at the beginning and end of fieldwork, and discuss potential audiences and their reactions. This was extensively discussed with respondents of our visual ethnographic study.

Another often-voiced dilemma in the field of visual anthropology is the fear of reinforcing ethnocentric notions and stereotypes. Since the sixties, visual anthropologists have debated the effects that film can have on different audiences related to the idea of different ways of seeing.¹⁴ To some extent, we see literally, but we also look conceptually, linguistically, and metaphorically as informed by our cultural conditioning.¹¹ A tension can exist between different forms of seeing, but additional interaction occurs during which ‘meaning shapes perception, but in the end, perception can refigure meaning, so that at the next stage this may alter perception once again’.¹¹

Visual anthropology must confront how ethnographic films can misleadingly communicate the idea of an objective representation of reality.¹⁹ Visual anthropologists have a great impact on the message and meaning through the assembling of the film; selective emphasis, camera position, secretiveness, and the order in which scenes are presented all create meaning.¹⁰ Preventing the audience from thinking they are watching an unmediated reality, the researcher should share throughout the film how the visuals are collected, what the relationship was with respondents, and what influence the researcher had on events. This approach was used in the ethnographic film *TB in Town 2*. If the positionality of the researcher is integrated into the story, the viewer gets a clearer idea how this ‘reality’ is produced.

CONCLUSION

Our study elaborated how public health and anthropology may benefit from each other. After exploring a wide variety of data collection methods in three different study sites, we argue that visual ethnography has enormous synergistic potential. An intensive visual ethnographic collaboration between researcher, local research assistant, and key respondents was aimed at creating an in-depth, nuanced view of TB patients’ everyday experiences with TB and care in Khayelitsha, the largest and fastest growing township of Cape Town, South Africa. Visual methods fostered the interdisciplinary process by communicating ethnographic knowledge and engaging various public health and anthropological stakeholders of both fundamental and applied research fields.

The impact of previously made ethnographic health films²⁰ suggests that this method is likely to synergize these two disciplines and enhance interdisciplinary research. Further research is needed to address methodological questions such as informed consent and the avoidance of perpetuating stereotypes that may arise from this approach.

There are various approaches in which visual ethnography can be embedded, such as the multimedia approach – a combination of new media, printed words, photographs, and film in an integrated, relational structure.^{19,21} The variety of media gives the viewer extra sensorial layers of sound and sight to immerse themselves in a mediated reality produced by researchers and participants. A non-sequential organization of study results enables the viewer to independently make links between ideas and explore the subject. Another approach is the creation of an interactive platform in which the researcher, patients, medical practitioners, public health scientists, and the general audience can communicate with each other.

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Resilience and survival: a visual ethnographic health study of patients with tuberculosis in Cape Town

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Under review

ABSTRACT

South Africa faces one of the worst tuberculosis (TB) epidemics in the world. Khayelitsha, one of the biggest and poorest townships of this country, has a well-resourced TB programme with an extensive interdisciplinary approach addressing medical, social, and economic barriers of TB care. Nevertheless, the township has one of the highest TB burdens in the world. Our (visual) ethnographic study looks into patients' experiences to explore socio-economic and structural factors that might enhance understanding why this well-resourced TB programme has been unable to quell the epidemic. Between October 2014 and March 2015, we approached 30 TB-patients, ten health-care workers, ten pastors, and ten traditional healers, using participant observation, in-depth interviews, and focus group discussions. Seven key-informants were additionally followed day-to-day with a camera. The work reported here (both text and videos) illustrates the complexities of TB patients' everyday life in Khayelitsha. Treatment was challenging for most TB-patients, because of severe side-effects. More attention is needed for the bodily experience of the highly toxic TB-treatments. TB was often experienced as shameful and associated with HIV and being 'irresponsible'. Many DR-TB-patients faced the extra stigma of being blamed for their drug-resistance and seen as crazy and dangerous. All TB-patients struggled with poverty and hunger, at times hindering treatment intake. Alcohol use often caused pre-hospital-delay. In conclusion, many TB patients were constrained, but also empowered, by processes of survival and resilience. A survival and resilience framework, may shed light on potential facilitators and barriers to a well-resourced TB programme. Our use of a short films gave patients a voice and triggered the question as to whether there is a need to create synergies between patients, researchers, and policy-makers for improved TB programmes.

South Africa faces one of the worst tuberculosis (TB) epidemics and highest human immunodeficiency virus (HIV) rates in the world.¹ Khayelitsha, a township in Cape Town, is a focal point in this TB epidemic. The public healthcare system is actively supported by the international non-governmental organization Médecins Sans Frontières (MSF). Together, they have launched a more advanced interdisciplinary TB control programme as compared to other South African regions or other countries globally. Despite these services that focus on the medical, cultural, social, and economic components of TB care, however, Khayelitsha has one of the highest drug susceptible (DS) TB and drug resistant (DR) TB burdens in the world.²

In South Africa, quantitative studies have given insights on the factors influencing the functioning of an NTP.³ For example, barriers include the high rates of TB infection,⁴ DR-TB development, and HIV co-infection,⁵ socio-economic determinants,^{6,7} alcohol misuse,^{8–12} and structural obstacles leading to provider delays.¹³ Facilitators constitute an integrated HIV/TB policy^{14–16} and collaborations between traditional healers and TB health facilities.^{13,17} However, these studies do not afford an in-depth understanding of how these factors are intertwined with the everyday lives of patients. Published qualitative research on patients' day-to-day experiences of TB in urban South Africa remains scarce and have addressed TB treatment adherence,^{18–22} TB-related stigma,²³ HIV/TB treatment,²⁴ and MDR-TB treatment adherence.^{25,25,26} Most of these South African qualitative studies were conducted at the clinic and few used ethnography.

Our ethnographic study looks into patients' experiences to explore socio-economic and structural factors that might enhance understanding why such a well-resourced TB programme in Khayelitsha has been unable to quell the epidemic. Ethnography provides a layer of context as researchers immerse themselves into the lives of research subjects by fostering in-depth relationships over an extended period of time. This approach enables researchers to differentiate between discourse and practice; between what people say they do and what people actually do in everyday life.²⁷ Practices may reveal what lies beyond a world created by our respondents with words.^{28,29} Comprehension of patients' complex realities and their movements within these realities, may enhance a richer understanding of how TB policies play out in the day-to-day lives of the people it serves, and in turn shape patients' responses to treatment. Globally, various ethnographies have been conducted to analyze TB programmes and patients' treatment adherence.^{30–33} However, there remains a need for more ethnographic research to understand context-specific barriers to treatment and tailor TB services to people's realities.^{30,34,35}

Health ethnographies can be lengthy, may contain difficult anthropological jargon, and are often published in journals that are not Pubmed indexed. As a result, ethnographic knowledge may not reach a more applied audience in

order to inform interventions, public debates, and political processes. Therefore, within this overall study, we have made short films informed by our ethnographic research to more effectively communicate our results to researchers and policy makers and immerse them in the patient's world. We aim at enhancing empathetic understanding of the complexities of TB patients' everyday life in Khayelitsha, and to potentially inform health strategies.³⁶

The interdisciplinary TB programme in Khayelitsha may serve as an example for other settings with a high TB burden, yet it is important that TB patients' processes of survival and resilience are addressed. By survival, we refer to the context and practices of the majority of Khayelitsha's population, people who are confronted with death on a daily basis, whether from disease, violence, traffic accidents, or hunger. Nancy Scheper-Hughes has described how people in a Brazilian township daily faced death, taking it for granted.³⁷ The demands of survival and the frequency of death have become normalised making life feel less valuable. By resilience, we mean *'the ability of an individual or group to bounce back from a blow'*.³⁸ A survival and resilience approach may highlight strategies for TB control and prevention, as these processes may either impair or support patients' treatment compliance and health seeking practices.

CONTEXT AND RESEARCH SETTING

South Africa is facing a TB-incidence of 1 003/100 000, 65% TB-HIV co-infections, and 8.5% drug-resistant (DR-)TB. In 2012, only 6 494 of the 15 419 multidrug resistant (MDR-)TB-patients started treatment, 1/3 of patients ceased treatment prematurely,³⁹ and overall TB-mortality rate was about 228/100 000.¹

Our research took place in the South African township Khayelitsha, the largest township in Cape Town with nearly 1 000 000 inhabitants. Half of its inhabitants are not officially registered and the majority live in informal dwellings (shacks). As a result of the segregationist politics of the Apartheid regime, the inhabitants continue to be predominantly from the Xhosa ethnic group.⁴⁰ Crime rates are very high in Cape Town,⁴¹ especially in Khayelitsha, the most violent urban area in South Africa.⁴²⁻⁴⁴ Major contributors to high crime rates are poverty and high unemployment rates.⁴¹ South Africa is an upper middle income country,⁴⁵ but has high levels of economic inequality, meaning that many communities are very poor. Black Africans were strongly marginalised and discriminated against during Apartheid regime, and this still impacts on their socio-economic status in post-Apartheid South Africa.⁴¹ Consequently, this part of Cape Town is known as 'Cape Town's poverty trap'.^{40,46}

TB care (integrated with HIV care) is available in, amongst others, the Khayelitsha SiteB Ubuntu Community Health Clinic (CHC) and a smaller primary health care clinic in Town 2. Here, TB patients on Direct Observed Therapy (DOT) collect their anti-TB drugs at the clinic on a daily basis from Monday to Friday during a treatment course of 6 months. A community-based Direct

Observed Therapy (DOT) programme was piloted (after two weeks of DOT, patients may continue treatment at home instead of at the clinic, if a community care worker (CCW) considers them sufficiently responsible).⁴⁷

Moreover, it is one of the few places worldwide where new DR-TB drugs are both highly needed and available.⁴⁸ MDR-TB stands for resistance to the first-line anti-TB drugs isoniazid and rifampicin, and extensively drug resistant TB (XDR-TB) means resistance to isoniazid and rifampicin, to any fluoroquinolone, and to any of the injectable anti-TB drugs.⁴⁹ MDR-TB patients follow a treatment of 21 pills daily for two years and one injection daily for eight months (this has recently been adjusted to 9–12 months).¹ The first project for treatment of DR-TB-patients at primary health care level was introduced.

Additionally, the programme addresses social and economic barriers via counselling, sensitization programmes, community care workers, social grants, and food supplement programmes.^{50,51}

METHODS

One researcher (ALC) and a local research assistant (MM) conducted a five-month ethnographic research project in Khayelitsha, with local support from CC, between October 2014 and March 2015. Through chain-referral sampling-techniques, 30 DS-TB and DR-TB-patients were approached for between one and three in-depth interviews at their homes. Included respondents consisted of patients with active (extra-)pulmonary DS-TB or DR-TB-infection who had just started, were receiving, had previously received anti-tuberculosis treatment, or had recurrent TB (i.e. had TB for the second/third time through relapse of previous TB infection or infection with a new strain).⁵² Patients were above the age of eighteen, and attended or had attended one of the ambulatory TB-clinics at Site B Ubuntu or Town 2. Additionally, ten patients were invited to two focus group discussions (FGDs) that took place in the church of MM. We interviewed ten health workers / staff members of clinics, Treatment Action Campaign (TAC), and MSF, ten traditional healers, and ten pastors to gain more insight into the context for patients' perceptions and practices. Participant observation took place from morning until evening, during weekdays and on weekends, at respondents' homes, neighbourhoods, churches, and funerals.

Of the 60 respondents, six patients, one pastor and one CCW were additionally asked to participate as key informants for the visual component of the project and were followed on a daily basis with a video camera (Table 1). Selection occurred after one month of ethnographic research and was based upon their open-mindedness to discuss TB-related matters, their ability to speak fluently and coherently, and their passion to change the marginalized situation that most people living in Town 2 were facing. The camera was not taken on all occasions and even if the camera was present, this did not hinder interaction with participants as the camera was either in a corner on a tripod or hand held.

Table 1 Methodological approach for study in Khayelitsha, Cape Town

Method	Participants	Timing/frequency/place	Research topic
Participant observation	TB-patients and their families Health-workers Community-members	For 5 months on a daily basis on various places in the community; Patients' homes, visits to the clinics and hospitals, churches, houses of traditional healers, pharmacies, shopping, market, organizing TB-grants, meetings and presentations of NGOs, (preparation for) funerals, celebrations, social events, barbeques	Relation between patients and health care services, medication, stigma, poverty, death, hope, position in society, social support, group dynamics
In-depth interviews	30 TB-patients	1–3 interviews with each respondent of 1–2 hours at patients' homes or at MM's home	TB-perceptions, medical knowledge, poverty, social support, TB-grant, stigma, structural obstacles to TB-treatment
	10 health-workers 10 traditional healers 10 pastors	1–2 interviews with each respondent of 1 hour at respondents' homes or at MM's home	TB-policy, TB-treatment, patient contact, TB-perceptions, poverty, stigma, structural obstacles to TB-treatment, work relation with other healers in the area
Focus group discussions	10 TB-patients	2 meetings of 2–3 hours in MM's church	Interaction and discussion between participants regarding concerns, struggles, ideas, wishes, norms and values
Visual methods, e.g. in-depth interviews, participant observation	5 TB-patients 1 pastor 1 community-care worker	Daily visits during the 5 months study period in various places in the community	Life, community, social support, stigma, poverty, treatment, experience with TB, funerals

Due to the unstructured character of the interviews and participant observation, respondents were able to guide the visual data collection telling the researcher what to film. They explained they had the feeling that they were given a platform

to speak their minds. During our fieldwork, we sometimes looked back at the filmed materials together with our key respondents to illustrate what kind of data we collected and how they were presented. They all agreed with the lack of anonymity that is associated with interviews captured on film. We did agree that respondents would always be informed if the visuals were used anywhere.

The in-depth interviews contained semi-structured, open-ended questions in English or translated in isiXhosa by MM (isiXhosa-speaking). Questions covered TB perceptions, medical knowledge, social support, structural obstacles to TB treatment, poverty, and sensitive topics such as stigma. This was supplemented by Focus Group Discussions (FGDs), which elaborated on these topics and stimulated interaction and discussion regarding conflicting perceptions, opinions, and experiences of participants. To enhance group dynamics, we used various research techniques, such as word clouds, theme selection, ranking, and poster presentations. Participant observation generated rich data regarding the social and cultural context and patients' everyday-life experiences with tuberculosis. This information partially overlapped with visual data collection for which we followed up seven respondents leading to intense researcher-respondent relationship, generating a high level of trust and valuable informal conversations. To foster informal interview settings, we used photo-elicitation techniques⁵³ and asked respondents to keep a diary.⁵⁴ The additional value of these alternative methods was to gain a deeper understanding of the richness and complexity of people's experiences and to collect data regarding emotions and non-verbal behaviour and interactions.

During and after data collection, we used an inductive approach to analysis.⁵⁵ In-depth interviews and FGDs were audio- and sometimes video-recorded, transcribed verbatim and screened multiple times by ALC. Field notes of participant observations, videos, and transcripts were first coded into meaning units and then divided into categories and subcategories in order to identify patterns. This was checked by MM. Open data collection techniques lead to the emergence of themes formulated by respondents in order to avoid researcher-defined categories. With Qualitative Data Analysis and Research Software (ATLAS.ti, 7th edition), we identified recurring themes, analysed structures, meaning and context. We used short videos of respondents for case illustration.

Ethical clearance for the study was obtained from the University of Cape Town (HREC REF 726/2014). Verbal informed consent was obtained from each participant before recruitment, interviews, and observation. We presented ourselves as researchers who wanted to gain more understanding about TB and how TB may affect people's life in Town 2. We explained that the goals of our research was to write a paper in the hope that people's experiences could possibly inform health policies. Because of the relations build with patients and community members and the fact that we attended almost every event in the course of five months, we were able to attend churches (services) and funerals

inn integrative fashion. We used pseudonyms and unidentifiable descriptions of respondents throughout this article to ensure anonymity and confidentiality. The key-respondents participating in the visual ethnographic part of this study signed special consent forms, because they will not remain anonymous.

RESULTS

The average age of the TB patients in our study (N=30) was 37 [range 19–89 years]. Thirteen were male, 14 were in a relationship, and nine were employed. Twelve patients had DS-TB, seven MDR-TB, and one XDR-TB. Ten patients had recurrent TB (Table 2). Through our long-term visual ethnographic approach, we collected data regarding patients' experience with TB and care. We have synthesized the themes found into the following inter-related themes: *the embodied experience of TB treatment; alternative healing methods and TB aetiologies; non-biomedical healing methods and TB aetiologies; support and stigma; financial constraints, and alcoholism*. We will present our findings with text and short films to engage the senses of our readers and create a more empathetic understanding about experiences of patients with TB and care.

Table 2 Socio-demographic characteristics and tuberculosis-related parameters of 30 TB-patients, Cape Town, South Africa

Variable	Study group N=30 N(%)
Age	
Median (IQR)	39.0 [19–89]
Sex	
Male	13 (43.3)
Female	17 (56.7)
Marital status	
Married/relation	14 (46.7)
Single	16 (53.3)
Occupation	
Employed	9 (30.0)
Unemployed	19 (63.3)
Student	1 (3.3)
Retired	1 (3.3)
TB-patients	
TB	12 (40.0)
MDR-TB	7 (23.3)
XDR-TB	1 (3.3)
Recurrent TB	
Yes	10 (33.3)
No	20 (66.7)

The embodied experience of TB-treatment

The harsh side-effects of MDR-TB treatment were a central theme for health-workers and made many patients discontinue treatment. However, DS-TB-patients referred to very similar bodily experiences, especially in the case of comorbidities. They intensely described how the high load of toxic medications seemed to destroy their bodies. They described how the TB-pills made them throw up, feel nausea, dizzy, weak, and hungry. Moreover, both DS-TB and DR-TB-patients described psychotic incidences due to the medication.

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CHAPTER 4



Video 1 <https://vimeo.com/229094551/fcfaef89f2>

George (DS-TB patient): *It doesn't stop. Every day tablets. Tonight I was sleeping I saw a snake coming down from the ceiling. It's not a joke, I tell you the truth.*

Chumisa (MDR-TB patient): *He was screaming.*

George: *They [pills] make you, like you... I don't know what I can say. Sometimes I open the door and I run outside, it is not a joke! They make you, like you are crazy. You are mad. It [the medication] is strong too much. You must be stronger. Otherwise you'll be mad. It's not a joke. It is strong too much.*

ALC: *Is that because of the TB pills?*

George: *This is the drugs. It is not a joke, this is the drugs.*

ALC: *You had that too, right, Chumisa?*

Chumisa: *Yes.*

George: *You must be strong, otherwise you'll be mad. The TB tablets I have used now. My head is not right now. I can't talk too much [with you]. Now, I use these tablets now. You see after that I don't know what is going to happen. Maybe I am going to be like mad.*

During participant observation, respondents at times warned the researcher that they had just taken drugs what potentially could trigger unpredictable behaviour. Various DS-TB and DR-TB-patients explained they feared to become crazy because of the drugs and potentially harm themselves or people around them. Some respondents mentioned they particularly feared DR-TB-patients for their dangerous behaviour.



Video 2 <https://vimeo.com/229095082/a2432a822e>

There is another TB, I am scared of that. MDR, the people they say it's too dangerous. Because the people who have that TB, they pass away. Because most of the people that got MDR. While I am talking with you, I am not talking the way we talk. They just talk nonsense. So they've got... That TB. So they are dangerous.

(Tamtam, DS-TB-patient)

In this study, every MDR-TB-patient described the daily MDR-TB-injections as a horror. Side-effects were into detail described during FGDs and informal conversations and consisted of haematomas on the buttocks, painful legs hindering walking, and some mentioned hearing-loss. One patient explained to be relieved that his MDR-TB turned into XDR-TB, because that meant no more injections. Few patients continued with injections. Some decided to only continue with pills. Others totally stopped with treatment, because they feared dying of side-effects.



Video 3 <https://vimeo.com/247461491/d7bf42725>

When I told the nurse of my problem, she didn't listen to me. And she threatened me that she would stop my government grant, because she knows I get a grant. After that, I tell myself, this is not right. Because I will end up dead. I know what I was doing, it was wrong. To leave my treatment. To nog finish. [...] But I can't do it anymore. I can't.

(Nokuzola, MDR-TB-patient).

Nokuzola continued injections for months despite reporting severe side-effects at the clinic. Nokuzola said that health-workers accused her of non-compliance in order to receive a governmental grant. This resonated with some respondents who argued that people were purposely getting infected with TB in order to get a grant. Nokuzola, however, worried about losing her hearing, and additionally explained being afraid of losing her mind and sight, as her complaints remained unheard. This was the reason why she decided to stop treatment and rely on prayers only.

Non-biomedical healing methods and TB aetiologies

Many patients used prayers to enhance TB-treatment. Few patients mentioned they had visited faith or traditional healers to cure their TB. Most traditional healers and all faith healers explained they were not able to cure TB (alone) and referred people (additionally) to the clinic. Some added that it was too risky to treat these 'big diseases', because they would be blamed if someone would die. During observations and informal conversations, it became clear the police hardly ever came in the township and at times community members took justice in own hands, resulting in violent community assaults.

The majority of respondents stressed the fact that everyone could obtain TB. Yet, various respondents cautiously explained that TB was more often found in poor and dirty households. Health-workers often stressed that HIV, smoking, and drinking were risk factors for TB. During FGDs and interviews, respondents often mixed up risk-factors with TB-aetiologies. Other TB-aetiologies mentioned were cold, wetness, sleeping around, hereditary (referred to as *family-TB*), and sharing glasses or cutlery with TB-infected people.



Video 4 <https://vimeo.com/229099207/4db25c4942>

I was so shocked before, that one. The first TB. I never get sick. And I asked myself where does it come from, this TB? Even in my family, no one has TB, where does this TB come from? I was thinking that maybe I was infected by my friend. Maybe I shared the glass with my friend. Or we share the same cigarette.
(George, DS-TB patient)

Only one respondent described TB as an evil spirit. Some health-workers said TB used to be explained with the myth *Impundulu*; *the big bird that kicks you in the chest so you start coughing blood*, or referred to *edliso*; *black poison caused by witchcraft with similar symptoms as TB*.

Support and stigma

The gigantic township was divided into different quarters with close communities and social structures of support. During FGDs, interviews, and participant observation, respondents often referred to '*the spirit of ubuntu*' to explain how neighbours took care and cooked for each other, and accompanied patients to the hospital.



Video 5 <https://vimeo.com/247458395/b143f6832e>

Chumisa: *Friend!*

ALC: *Hey George, how is it?*

George: *Good, how are you? Can I take this, for me?*

Chumisa: *Yes*

ALC: *Did she cook for you?*

George: *Yes. Do you know what it is?*

ALC: *No what is it?*

George: *Spinach and millimille [mais porridge] to make someone strong who is sick. Just all, you eat and that will make you strong.*

ALC: *How are your legs?*

George: *You can see me walking. That is why I said, day after day it is coming. It is coming day after day.*

Some people explained DS-TB-patients were no longer stigmatised, e.g. kicked out of the house, beaten up, or socially isolated. During this study, these examples of stigmatisation were indeed not observed or heard of, but some respondents (also former TB-patients) did talk in a stigmatising way about TB-patients.



Video 6 <https://vimeo.com/263827752/a9547d34ff>

They [TB-patients] shrink. Because they don't want to eat, they don't want to do anything, they don't want to talk. They are smelly. They don't want to drink. If like now you smell, I smell poopoo in this house, somebody has got a TB. [...] That one is not going to survive.

(Tamtam, DS-TB-patient)

Tamtam made a difference between herself and 'those patients who carried a lot of diseases'. TB-patients were often suspected of carrying a wide range of diseases, amongst others HIV. Many respondents said that only HIV-patients were stigmatised, because it was 'a personal problem', referring to behaviour such as sleeping around. On the contrary, TB could be obtained by anyone through the air. However, various respondents explained that social consequences for HIV and TB were often intermingled.



Video 7 <https://vimeo.com/263509566/e6c1a9256c>

They [TB-patients] are not open. They don't want to share. Anything with TB, it's just that they don't accept the TB. [...] I think they're having a problem with thinking that TB is only for HIV people. But a person that has a normal TB with no HIV, a normal person, just gets TB with no HIV. She doesn't accept that. It means you are a whore. That's what they say.

(Vuyelwa, CCW).

Respondents explained there is an assumption that only HIV-patients are susceptible for TB. Various respondents described that TB was by many considered a disgrace and some additionally explained that your position in society was in danger of being degraded.



Video 8 <https://vimeo.com/229096551/94fa9ea298>

So I didn't hang myself. [...] Not expecting that they could get TB. They must do something, as if it is a disgrace. [...] We are not all the same. Some people don't like to get sick, and that they can get lower than you. And some of them can't stand that knock. That if you are suffering of something, you can't take it. Some people can't take that. Some of them hang themselves, shoot themselves, go into a car, burn themselves. Doing funny things, because they are too weak. They can't stand that punch.

(Khulish, DS-TB-patient)

Khulish described how many people already have a vulnerable position and are not able to cope with unexpected events, such as TB.

One respondent had obtained TB *on the mountain*, indicating his initiation rite; a ritual marking his passage into manhood. For him, and for men in general, TB was additionally complicated and shameful as men are expected to be strong and healthy. Many respondents stated men only seek care when they are bed-ridden. Various respondents explained their concern for a (male) coughing family-member who refused to seek care.

Some health-workers and patients labelled DR-TB-patients as irresponsible and endangering their social environment. Sensitization programmes warned against incorrect drug-intake as this might lead to drug-resistance; yet various respondents remained unaware of direct transmission of DR-TB. DR-TB-patients described they additionally had difficulties with wearing a mask as it signalled TB and sometimes triggered fear and rudeness of bystanders. The danger of MDR-TB-infection was often equalled with Ebola.

Another problem mentioned by participants was stigmatizing attitudes of nurses at the clinic.



Video 9 <https://vimeo.com/247461786/1d64f26034>

But the way she [the nurse] was treating me, I didn't like it. She puts the injection in that lump. But she can see, that lump is bleeding. But she carries on to put that injection in that lump. So that is why I didn't want to go there, to the clinic of Town 2. I hate them. I don't want to go there. I talk the truth, now I hate the clinic. [...] I feel like I am not a person. The nurse shouting at me like that.

(Nokuzola, MDR-TB-patient)

Some patients described feelings of frustration and dehumanization because of nurses' treatment. Several health-workers explained feeling threatened by TB-patients who complained about treatment as this potentially signalled patients being non-compliant, increasing the risk of infection. Clinics were often understaffed, resulting in excessive workloads, long waiting queues, and at times rude attitudes of both health-workers and patients towards each other.

Financial constraints and social grants

Patients with a low-economic status received a social grant from the government and patients weighing under 40kg received food supplements. During participant observation, the grant and extra food was often shared with the whole family, for some turning the patient into a bread-winner. Few respondents mentioned that relapse or MDR-TB-patients were often non-compliant TB-patients who wanted a grant from the government.



Video 10 <https://vimeo.com/247458785/c76aa8ac9c>

[If] you take your treatment regularly, you can't die. And if you tell yourself, I'm not going to die, [then] you are not going to die. Other people, they say, I want a grant. A grant from the government. So I am not going to take treatment really. I'm going to take treatment some of the days. Me, I regularly said, that money is not going to give my life back. If I've passed away, I've passed away already. And I know there are a lot of people, who are healthy and then, they see they are getting healthy now, the government takes the grant away. They are sick again! Because they want the grant from government.

(Tamtam, DS-TB-patient)

Most TB-patients had financial problems, mostly due to unemployment, consequently interfering with treatment-intake. During participant observation, TB-patients did not always take all their pills, because lack of food worsened side-effects.



Video 11 <https://vimeo.com/229097663/566bd3feda>

No, I can't take those pills. The food is finished, Lianne. I'm going to throw it in the bin. Now. I don't want, I am not going to take these. These pills make me mad. I'm going to drink this, only this.

(Chumisa, MDR-TB patient)

Alcoholism

Many patients were aware of the devastating effects of alcohol on their TB and the potential development of drug-resistance. Nevertheless, about one third consumed alcohol, and at times, a couple of our male and female patients seemed too drunk for interviews and CCWs and pastors explained these patients had been drunk for days. Some older respondents who had been politically engaged in the fight against the Apartheid-regime described feeling disillusioned, because persisting economic constraints hindered them to live life reaching its fullest potential. They explained how alcohol consumption helped to reduce feelings of vulnerability.



Video 12 <https://vimeo.com/229098126/2f5a263247>

Something is wrong. I just want to drink. You understand? Even in the morning, during the day. [I am] unemployed. With him [son] in the school. There is no income. I can't sleep. I'm just restless and vulnerable. I'm just telling myself, I go to the clinic, I go, I go, I go, I go... Up until I was taken to the hospital.

(Khulish, DS-TB-patient)

Alcohol gave some of them a feeling of being in control again, to forget problems, and free their minds. Some respondents explained that alcohol-consumption made them ignore their health-status up until they had to be carried to the hospital.

Various health-workers and researchers had a pessimistic attitude about the functioning of the TB programme in Khayelitsha, a frustration amplified by huge health inequalities within South Africa. They often blamed mismanaged TB interventions, limited political will and resources, and patients' irresponsible behaviour for the expanding number of TB-patients.

DISCUSSION

Our visual ethnographic study allows for sharing of knowledge and interpretations that reside beyond medical and scientific rationales, offering alternative ways of understanding and explaining TB.³⁶ (A trailer of the longer ethnographic health film 'TB in Town 2' can be found at: vimeo.com/227797348). The use of visual ethnography raises the question of what platforms can be given to TB patients and what roles patients could play within the field of TB research,

knowledge construction, and policy making. TB-related activism in South Africa remains limited, with the exception of the TAC and a few other small NGOs, and networks.⁵⁶ Considering lessons learned from the fields of HIV,⁵⁷ Ebola,⁵⁸ and Lyme disease,⁵⁹ we call for more research on how synergies can be created between communities, researchers, and policy-makers and the role of visual ethnography herein.

To stimulate community synergies, we argue that TB research needs to focus on barriers and vulnerabilities, but additionally on strengths and facilitators within communities.⁶⁰ Therefore, we will briefly discuss our findings using a lens on survival and resilience. Most of our patients were deeply struck by poverty and seemed to be shaped and shaken by processes of survival and resilience informed by post-Apartheid-related injustice. The situation of TB patients can be explained by theories of structural violence referring to longstanding oppressive structures of social and economic inequality deteriorating health.⁶¹ Such processes of survival and resilience fuelled by structural violence seemed to neutralise beneficial impacts of Khayelitsha's interdisciplinary TB program,⁶² hindering positive changes in TB control or prevention. Below, we will discuss several processes of survival and resilience shaped by the contingencies of respondents' daily experiences.

While our patients were well informed about the importance of treatment compliance, they had to balance treatment demands with food shortage and severe side effects. At times, they made calculated decisions to pause treatment in order to avoid becoming psychotic and to live a dignified life. Various authors refer to poverty and malnourishment as one of the main obstacles of TB care.⁶³⁻⁶⁷ The side effects for both DS-TB and DR-TB patients and its effect on treatment adherence have been reported.⁶⁸⁻⁷⁰ However, the embodied experiences of DS-TB and DR-TB patients need more attention. Challenges related to DS-TB sometimes got downplayed by health workers and are less frequently mentioned in the latest TB studies that often focus on the devastating impact of resistant forms of TB.

Many patients used alcohol, despite knowing alcohol's disastrous effects on health and potential drug resistance. Drinking alcohol was often a strategy to enhance their own well-being, but at times caused delay or interruption of TB care. A South African study showed that poverty-alleviation lowered TB patients' substance abuse, consequently improving TB outcomes.⁷¹ Interestingly, this study focused merely on men, while our study showed that about one third of our female respondents similarly used alcohol.

Since 1999, social grants have reduced poverty in South Africa,⁷² yet unanticipated consequences need consideration.^{73,74} Several patients, health workers and pastors believed that some patients got infected with TB on purpose or did not take treatment correctly, in order to pursue a social TB grant. Various TB patients indeed became breadwinners thanks to their grant; their illness and lives at risk fuelled financial income to provide for their family. Social grants

are intended to support effective treatment of TB patients by alleviating poverty-related barriers. However, in some cases grants may feed into the circle of poverty when patients continue to be ill or face recurrent TB, remain unemployed, and stay dependent on these external financial resources. Ferguson⁷⁵ argues that every person has the right to equally share in its countries wealth, and should therefore be able to receive a cash grant (thus, regardless TB status). Moving away from Western ideologies of capitalism and fear of dependency structures, he argues that we should consider African values of sharing wealth and making direct payments. Consequently, we may be able to stimulate activity among every citizen and deal with settings characterized by structural unemployment. The discussion of social grants remains complex as questions arise who will be responsible for such payments and how this would be translated to an every-day context. TB programmes could, instead of grants for individual patients, rather invest in the wider community (including patients who are no longer infectious) by creating jobs, fostering education, and promoting rights to stimulate sustainable economic development. Moreover, the TB programme could be mandated to pressure employers to provide fair compensation for employees who develop active TB. If deep-seated structures of economic and health inequality may be overcome, and problems related to survival and resilience solved, this potentially leads to more patient-centred and successful TB programme outcomes.

Narratives of patients pursuing TB grants may, however, be produced by social processes of stigmatization. Some respondents described TB patients in a stigmatizing way (e.g. that TB patients smelled like faeces) and various patients mentioned that they themselves felt ashamed of having TB. Especially for men, who were supposed to be strong and healthy, shame often hindered TB disclosure and health seeking. TB was often linked to HIV, leading to double stigma.^{23,76} DR-TB patients faced another dimension of stigma, as they were by many considered dangerous, highly infectious, and irresponsible (assuming they had been previously non-compliant with treatment). This discourse of responsibility is strengthened by the TB programme that allows *responsible patients* home-based care and warns that non-adherence to treatment leads to drug resistance. The lack of studies reporting on DR-TB-related stigma might be explained by South Africa being one of the few countries where second- and third-line TB-drugs are available.

In conclusion, there is a need to respond to processes of survival and resilience that shape barriers, such as extreme poverty, hunger, alcoholism, and stigma. A chain of TB policy impacts is required to cause a fundamental change⁶² in Khayelitsha that better supports TB patients in their treatment process. Khayelitsha's interdisciplinary TB interventions may not impact patients' situations immediately in the face of adversity, yet may do so overtime and may continue as an example for other settings with a high TB burden. However, we additionally need to explore the facilitators shaped by processes of survival and

resilience within communities. Our study illustrated strong social structures of support, nuancing the statement of a South African study that in slum areas, the majority of people live in similar poverty unable to substantially support each other.⁷⁷ Close connections between people of a community play an important role in accelerating economic change⁷⁷ and may additionally play an important role in interventions to sustain well-being and health of TB patients.^{78,79}

Limitations and strengths

Our study participants (N=60) were recruited in one township characterized by high crime rates, social and racial tensions, intense levels of poverty and marginalization, and extended TB programmes launched by M S F. This may complicate translation to other settings in South Africa and beyond. However, this information sheds light on the challenges of a TB programme that may be considered as exemplary in other settings. This study focused on adults and included only one XDR-TB patient, consequently experiences of children and XDR-TB patients remained underexposed and future ethnographic research is needed.

The strengths of this study constitute a variety of data collection techniques, such as FGDs, (video recorded) in-depth interviews and participant observation, enabling triangulation of study findings.⁸⁰ Our ethnographic approach forming long-term relationships with respondents revealed the complexities of TB-patients' experience with TB and care. The camera functioned as a catalyst as respondents reacted positively and explained that they hoped their struggles related to TB treatment would reach beyond this research. Moreover, patients' narratives captured on film may provide insights on the subjectivities attributed to tuberculosis.

CONCLUSION

Our ethnographic study looks into patients' experiences to explore socio-economic and structural factors that might enhance understanding why a well-resourced TB programme in Khayelitsha, Cape Town, has been unable to quell the epidemic. We found that treatment was challenging for most DS-TB and DR-TB patients, because of devastating side-effects. Attention to DR-TB seemed to overshadow challenges regarding DS-TB that is laden with similar issues. Moving beyond a focus on drug-availability, more attention should be paid to the bodily experience of the highly toxic TB-treatments. Prevailing discourses of '*the responsible patient*' or MDR-TB patients as crazy and dangerous lead to stigmatizing attitudes. Many TB patients were both constrained and empowered by processes of survival and resilience. A survival and resilience framework, may shed light on potential facilitators and barriers to a well-resourced TB programme. Our use of short films gave patients a voice and triggered the question as to whether there is a need to create synergies between patients,

researchers, and policy-makers for improved TB programmes and the role of visual ethnography herein.

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TB in Town 2: an ethnographic film

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49th Union World Conference on Lung Health 2018, The Hague.

What is there to worry if you have a disease that is curable? How much hope do you have to get better in a country with a very well-run health programme? A country where the medication is for free and you can receive financial and psychological support in case needed? How would you feel if this whole system seems out of your reach? This ethnographic film zooms in on Town 2. Town 2 is situated in one of the biggest and most violent townships of South Africa, Khayelitsha. This film tells the story of patients with tuberculosis (TB). A curable disease you see everywhere in the South African townships and spreads so easily through the air. A disease of which so many people have died already. This film is about patients' experience with TB, the medication, and the clinic. How they deal with friends and family. How they cope with side-effects of the medication that are so strong that some are afraid to become crazy. It's about their hunger in combination with treatment that seems to crush them.

The aim of this visual ethnography is to enhance understanding of how complex relations between TB patients, treatment, and a highly developed TB health programme play out in everyday treatment-adherence – that is, continuing TB treatment without interruption. For five months, Cremers conducted research in Town 2, Khayelitsha with her local research assistant, Mr. Maqogi. This film shows how treatment adherence is not exclusively the product of care programmes, providers, or patients' struggles. Rather, treatment adherence is intertwined with patients' flexible and creative processes of survival, coping strategies, and the existence of social networks leading to supportive or stigmatizing actions. This film gives insight into social moments, the state of patients' bodies and minds, their emotions, the impact of extreme poverty and hunger, the mundaneness of death, and how this shapes shifting agencies of TB patients navigating tuberculosis and treatment.

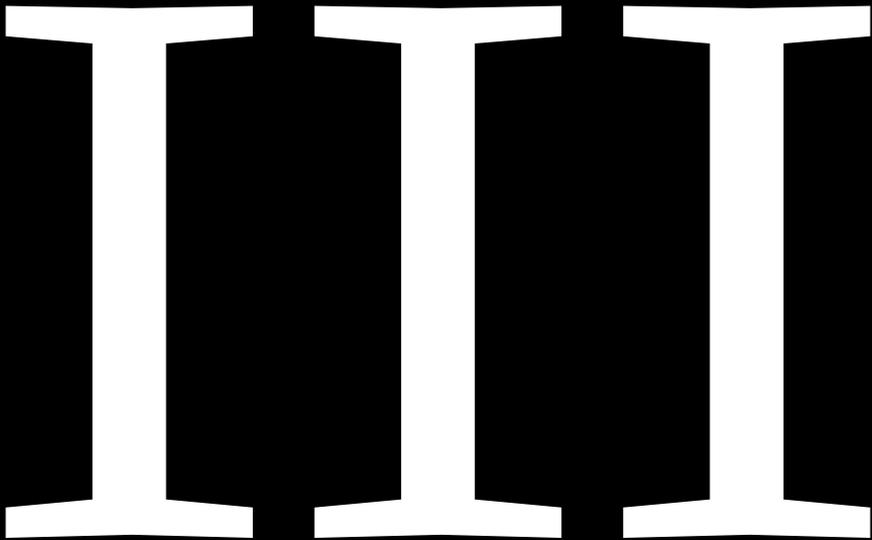
The red thread of this film is death. It begins and ends with a funeral. Throughout the film, the themes death, survival, dying, and struggle are interwoven with the rest of the information and simmer just below the surface. Another important story line is the close social ties within the community. All filmed subjects seem to know each other and take care of each other. Slowly you get to know the different respondents. It appears they additionally have an intimate relationship with the director. The viewer gets the idea of a warm, small community, and may at times forget this story is situated in a township with over one million inhabitants that is called the most violent area of South Africa. The film tries to show different important sides of the patients: as patients taking good care of their health, but also as people fighting for a dignified life.

Link: <https://vimeo.com/259898896>

Password: Tuberculosis

In loving memory of Nokubonga Maqogi (1976–2014) and George Lungile (1963–2015)

Section



TB and stigma in Zambia, a mixed methods study



Tuberculosis patients' pre-hospital delay and non-compliance with a longstanding DOT programme: a mixed methods study in urban Zambia

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CHAPTER 6

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ABSTRACT

Background: Tuberculosis (TB) remains a major health problem in Zambia, despite considerable efforts to control and prevent it. With this study, we aim to understand how perceptions and cultural, social, economic, and organizational factors influence TB patients' pre-hospital delay and non-compliance with care provided by the National Tuberculosis Programme (NTP).

Methods: A mixed methods study was conducted with 300 TB patients recruited at Kanyama clinic for structured interviews. Thirty were followed-up for multiple in-depth interviews. Six focus group discussions were organised and participant observation was conducted. Ten biomedical care providers, 10 traditional healers, and 10 faith healers were interviewed. Factors associated with non-compliance (disruption of treatment > one week) were assessed by applying logistic regression analyses; qualitative analysis was used to additionally assess factors influencing pre-hospital delay and for triangulation of study findings.

Results: TB treatment non-compliance was low (10%), no association of outcome with cultural or socio-economic factors was found. Only patients' time constraints and long distance to the clinic indicated a possible association with a higher risk of non-compliance (OR 0.52; 95% CI 0.25, 1.10, $p=0.086$). Qualitative data showed that most TB patients combined understandings of biomedical and traditional TB knowledge, used herbal, traditional and/or faith healing, suffered from stigmatizing attitudes, experienced poverty and food shortages, and faced several organizational obstacles while being on treatment. This led to pre-hospital delay or treatment non-compliance in some cases.

Conclusions: Mixed methods analysis demonstrated the importance of in-depth information ascertained by qualitative approaches to understand how cultural, socio-economic and organizational factors are influencing patients' pre-hospital delay and treatment compliance. To strengthen the Zambian NTP, combating stigma is of utmost priority coupled with programmes addressing poverty. Organizational barriers and co-operation between (private) clinics, traditional, and faith healers should be considered.

Tuberculosis (TB) is one of the major global health problems causing morbidity and mortality worldwide,¹ with the highest death rates in sub-Saharan Africa.² In Zambia, the estimated incidence of tuberculosis is 427/100,000; 61% of TB patients are co-infected with the human immunodeficiency virus (HIV), and multi-drug resistant TB (MDR-TB) is found in 0.3% of new cases and in 8.1% of retreatment cases.¹

In 1993, the World Health Organization (WHO) responded to this severe public health threat by promoting the Directly Observed Therapy (DOT) policy to ensure patients' compliance with their treatment.³ However, DOT is often criticized for its paternalistic nature, and its implementation by National TB Programmes (NTPs) is often complicated by socio-economic factors.⁴ Current public health approaches to control TB infection often take into account the co-prevalence of MDR-TB and HIV infections, pill burden, long treatment intervals, overburdened TB control programmes, and generally also consider cultural and socio-economic factors influencing health care seeking behaviour of TB patients.⁴⁻⁹ Often, vulnerable populations are afflicted as TB is closely related to issues of stigma, (economic) inequality, and poverty.⁵ Stigma often leads to the discrimination or social exclusion of TB patients, negatively influencing their health care seeking behaviour.¹⁰ Poverty complicates access to health care as people are unable to stop working or to pay for public transport; and hunger aggravates side effects of TB treatment. Moreover, children with TB are difficult to diagnose and are often under-represented in NTPs.¹¹⁻¹⁴

The worrisome situation in Zambia has triggered the development of various TB strategies and public health efforts.^{15,16} Despite a longstanding DOT and sensitization programmes, Zambia still struggles with optimizing its NTP to avoid pre-hospital delay and treatment non-compliance of TB patients. Most studies reporting on the TB policy and care provision in Zambia use quantitative methods,¹⁷⁻²² focus on HIV-TB co-infection,^{19,20,23,24} are located in rural Zambia,^{19-21,23-25} or do not take children with TB into account.^{17-21,24} To the best of our knowledge no study has been published focussing specifically on pre-hospital delay and treatment non-compliance of TB patients (including children) in urban Zambia using a combination of qualitative and quantitative methods. The first analysis of our TB patients' Adherence and Compliance (TBAC) study focused on TB-related stigma in Lusaka, Zambia;¹⁰ the current analysis aims to investigate the influence of perceptions and cultural, social, economic, and organizational factors on TB patients' pre-hospital delay and compliance with care provided by the Zambian NTP.

METHODS

Setting

The study took place at Kanyama clinic in the urban township Kanyama in Lusaka, Zambia, from September 2013 to January 2014. Details on Kanyama (clinic) and the tuberculosis programme have been reported elsewhere in detail.¹⁰

Mixed methods

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We used a mixed methods approach and a sequential explanatory model in which quantitative and qualitative research techniques were given equal priority; highlighting different aspects of the study. The mixed methods approach allowed for triangulation of study findings.

TB TRUTHS

Study population and collection of data

During four months, we conducted researcher-administered structured interviews (each approximately 30 min) with 300 TB patients attending Kanyama clinic for TB treatment. The sample size allowed us to estimate nine parameters of treatment compliance in a multivariate logistic regression, based on a prevalence of patients lost-to-follow-up (LTFU) of 30% in a Zambian study²² and the sample size recommendations for a logistic regression analysis to investigate predictors with a 95% confidence interval.²⁶ Patients who paused their treatment for one or more weeks were considered non-compliant and those who had abandoned treatment for two weeks or more were additionally considered LTFU.

Subsequently, of those 300 patients, we randomly followed-up on 30 patients for one to three in-depth semi-structured interviews (one to two hours each) at their homes. To enhance our understanding of the TB programme and the social and cultural context, we conducted in-depth interviews with ten TB health workers, ten faith healers, and ten traditional healers located in Kanyama using a convenience sample.

Additionally, we organised six focus group discussions (FGDs). Through convenience sampling, we recruited 10 treatment supporters for the first FGD and for the other five FGDs eight patients and two treatment supporters each. We conducted participant observation at the clinic, the TB department, patients' homes/neighbourhoods, clinics/homes of traditional healers, and during faith healing sessions in various Christian churches in Kanyama district.

We designed a structured questionnaire to discuss demographics, biomedical knowledge, treatment history, treatment compliance, and TB-related difficulties. The in-depth interviews elaborated on the questionnaire and discussed sensitive or complex topics, such as stigma and pre-hospital delay. Patients who had waited over four weeks since the onset of symptoms prior to their

initial hospital visit were considered to have a pre-hospital delay.²⁷ The FGDs covered the topics (1) challenges in the work of TB lay health workers; (2) childhood TB-related difficulties; (3) TB-related struggles; (4) stigma; (5) health care seeking; and (6) biomedical knowledge about TB. We used techniques to evoke discussions and make respondents comfortable to speak their minds; such as word association games, ranking of themes, and poster presentations. The semi-structured in-depth interviews with TB health workers, traditional and faith healers elaborated on TB care and their work-related challenges.

Statistical outcomes, variables and analysis

We compared demographics and TB treatment-related parameters of the in-depth study sample (N=30) with the larger study group of TB patients (N=270). We used the Fisher's exact test for categorical data and the Student t-tests for normally distributed continuous data. To identify factors that could be associated with TB patients' treatment non-compliance, we conducted logistic regression analyses. We conducted analysis with IBM SPSS statistics version 21.0 (IBM Corp, Armonk, NY).

Qualitative outcomes, thematic, and content analysis

Qualitative data was analysed to explain, contextualize and interpret quantitative findings. For the in-depth interviews and FGDs, we conducted thematic and content analysis assisted by Qualitative Data Analysis and Research Software (ATLAS.ti, 7th edition; Scientific Software Development GmbH, Berlin, Germany). Transcripts were screened multiple times, coded into meaning units and categorized into broad themes.²⁸ Additionally, we analysed context, meaning, and structures of identified codes and themes.²⁹ Some quotes of respondents were used to illustrate the most important themes.

Ethics

We obtained ethical approval and consent (HSSREC 02-08-13) from the University of Zambia Biomedical Research Ethics Committee (UNZAREC). All informants provided written informed consent using UNZAREC forms before inclusion in the study. For respondents under the age of eighteen, we additionally asked their parent/guardian for written informed consent. We guaranteed anonymity and confidentiality of given information by using pseudonyms and unidentifiable descriptions of patients throughout this article.

RESULTS

Study group

Mean age of the study population (N=300) was 33 years (range 1–70 years), including 25 children and teenagers under the age of 20. In total, 193 patients were male (64%); 179 (59.7%) were in a relationship; 126 (42%) had attended seven years of state-funded primary school; and 205 (68%) were (self-)employed. Patients were on average 11 weeks on treatment [range 1–52]; 86 (29%) relapsed, i.e. were diagnosed again with active TB after TB treatment completion (some repeatedly); 274 (94%) had done Voluntary Counselling and Testing (VCT) for HIV; and 147 (54%) had a positive HIV status of which 101 (69%) were on antiretroviral therapy (ART). For the qualitative sample, six children/adolescents and 24 adults were in-depth interviewed with a mean age of 31 years [range 2–54]; of which 17 (57%) were male. Demographics and tuberculosis-related parameters of the in-depth sample were similar between the in-depth and quantitative sample (Table 1).

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TB TRUTHS

Table 1 Patient characteristics (300 TB patients), comparison quantitative sample N=270 with in-depth sample N=30, Lusaka, Zambia

Variable	Overall study group N=300 N(%)***	Quantitative sample N=270 N(%)	In-depth sample N=30 N(%)	P-value*	OR (95%CI) **
Age (years)					
Mean [SD]	33.3 [11.3]	33.6 [11.1]	31.0 [13.3]	0.240	(-6.85, 1.72)
Sex					
Male	193 (64.3)	176 (65.2)	17 (56.7)	0.422	1.43 (0.67, 3.08)
Female	107 (35.7)	94 (34.8)	13 (43.3)		
Marital status					
Married/relation	179 (59.7)	165 (61.1)	14 (46.7)	0.169	1.80 (0.84, 3.83)
Single	121 (40.3)	105 (38.9)	16 (53.3)		
Education					
Low (none-7 yrs)	148 (49.3)	136 (50.4)	12 (40.0)	0.337	1.52 (0.71, 3.28)
High (7 yrs-higher)	152 (50.7)	134 (49.5)	18 (60.0)		
Profession					
Employed	205 (68.3)	187 (69.3)	18 (60.0)	0.307	1.50 (0.69, 3.26)

Table 1 Patient characteristics (300 TB patients), comparison quantitative sample N=270 with in-depth sample N=30, Lusaka, Zambia

Variable	Overall study group N=300	Quantitative sample N=270	In-depth sample N=30	P-value*	OR (95%CI) **
Unemployed	95 (31.7)	83 (30.7)	12 (40.0)		
Treatment duration (wks)					
Mean [SD]	10.8 [8.3]	10.9 [8.3]	9.5 [9.0]	0.368	(-4.60, 1.71)
TB Relapse					
Yes	86 (29.0)	77 (28.8)	9 (30.0)	1.000	1.06 (0.46, 2.41)
No	211 (71.0)	190 (71.2)	21 (70.0)		
Unknown	3 (1.0)	3 (1.1)	0 (0.0)		
VCT					
VCT	274 (94.2)	247 (94.3)	27 (93.1)	0.681	1.22 (0.27, 5.62)
No VCT	17 (5.8)	15 (5.7)	2 (6.9)		
Unknown	9 (3.0)	8 (3.0)	1 (3.3)		
HIV					
HIV positive	147 (53.8)	130 (52.8)	17 (63.0)	0.417	0.66 (0.29, 1.50)
HIV negative	126 (46.2)	116 (47.2)	10 (37.0)		
Unknown	27 (9.0)	24 (8.9)	3 (10.0)		
HIV patients on ART					
ART	101 (68.7)	86 (66.2)	15 (88.2)	0.094	0.26 (0.06, 1.19)
No ART	46 (31.3)	44 (33.8)	2 (11.8)		
Unknown/not applicable	153 (51.0)	140 (51.9)	13 (43.3)		

* Fisher's Exact Test for categorical variables, t-test for continuous variables comparing quantitative and in-depth sample

** OR (95%CI) Odds Ratio and 95% Confidence Interval

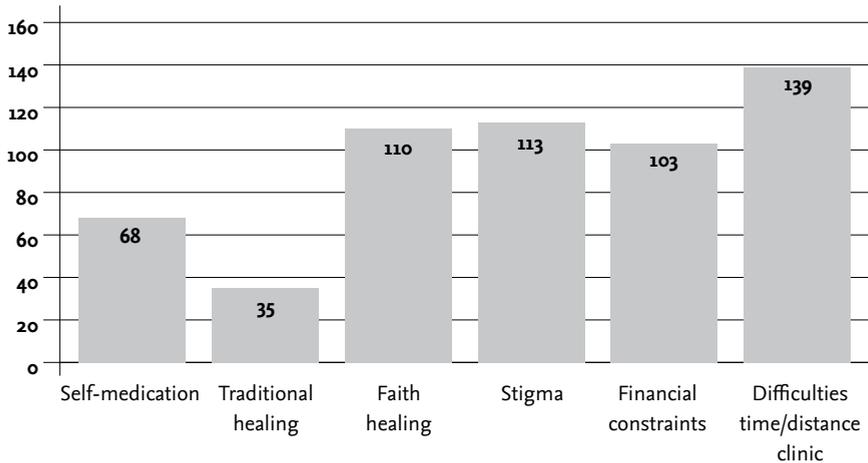
*** Valid percent

Statistics and TB treatment non-compliance

In total, 31 patients (10%) had previously been non-compliant, ranging from pausing treatment for a week to completely abandoning treatment (LTFU). Patients mentioned one or more of the following reasons: feeling better (4%), side effects (2%), being physically and financially unable to come to the clinic (2%), inability to buy food (1%), drinking beer (1%), or having switched to faith healing in a Christian church or herbal healing (1%). Overall, patients mentioned the use of alternative health care, such as faith healing (36.6%), self-medication

(22.7%), and traditional healing (11.7%), and struggles with TB care, such as stigma (37.7%), financial constraints and hunger (34.3%), and/or difficulties with time constraints and/or long distances to be covered to reach the clinic (46.3%) (Figure 1).

Figure 1 TB-related struggles and alternatives for biomedical TB care of 300 TB patients, Lusaka, Zambia. Numbers do not add up to 300, because the questions allowed for multiple responses.



There was no evidence of an association between non-compliance and sex, age, education, profession, HIV, seeking alternative health care, stigma, or financial constraints (Table 2). Patients' difficulties with time/distance to be at/reach the clinic indicated a possible association with a higher risk of non-compliance (OR 0.52; 95% CI 0.25, 1.10, $p=0.086$). The majority (76%) came on foot to the clinic (time ranged from five minutes up to two hours depending on distance and ability to walk). Many patients declared drug collection constraints with time and distance to the clinic due to work, travel, domestic responsibilities, financial hurdles, or physical inability to walk.

TB perceptions

In total, 175 TB patients (58%) explained they had no previous biomedical knowledge before coming to the clinic; and 198 (66%) did not associate their symptoms with TB beforehand. Forty-five patients got biomedical TB information at school (15%), 180 from friends or family (60%), and/or 201 at the clinic (67%). In total, 99 patients (33%) said they had not received any information at the clinic. Some explained that they had been too tired for the sensitization talks of the TB health workers or that the information was too difficult to comprehend.

Table 2 Univariate logistic regression analyses of factors associated with treatment non-compliance of 300 TB patients, Lusaka, Zambia

Variable	Compliant	Non-compliant	P-value	OR (95%CI) ²
	N=269	N=31		
	N(%) ³	N(%) ³		
Sex (male)	169 (63.3)	24 (72.7)	0.230	0.60 (0.26, 1.39)
Age (>31 years ⁴)	151 (56.1)	16 (51.6)	0.632	1.20 (0.57, 2.52)
Level of education (none - primary school)	133 (49.8)	15 (45.5)	0.624	0.83 (0.39, 1.75)
Profession (employed)	179 (67.0)	26 (78.8)	0.255	0.60 (0.25, 1.45)
HIV (HIV +)	129 (53.3)	18 (58.1)	0.586	1.24 (0.57, 2.71)
Seeking alternative health care (yes)	138 (51.7)	16 (48.5)	0.729	1.14 (0.54, 2.40)
Stigma (yes)	101 (82.1)	12 (80.0)	0.841	0.87 (0.23, 3.35)
Financial constraints (yes)	89 (33.3)	14 (42.4)	0.348	0.70 (0.33, 1.48)
Difficulties with time/distance to be at/reach the clinic (yes)	104 (39.0)	17 (51.5)	0.086	0.52 (0.25, 1.10)

¹ Patients who had previously paused their treatment for one or more weeks or had abandoned treatment were considered non-compliant.

² OR (95%CI): Odds Ratio and 95% Confidence Interval.

³ Valid percent

⁴ In both age groups same percentage of non-compliant patients

A majority of 293 patients (98%) was able to mention one or more of the four main TB symptoms highlighted in the clinic's sensitization brochure: coughing, night sweats, loss of appetite/weight, and chest pain. When asked about the consequences of interrupted or incorrect drug intake, 51 patients (17%) had no idea; 79 (26%) mentioned resistance to TB drugs, and 170 (57%) referred to death, injections, restart of treatment, and/or falling ill, but were generally unsure about the reason why this would happen. The biomedical aetiology of TB was known by 286 patients (95%) who mentioned its airborne nature and/or coughing. Some patients used biomedical terms, but after probing they did not fully comprehend the meaning. Moreover, 270 patients (90%) combined biomedical explanations (cough/airborne) with one or more alternative aetiological principles. A considerable group of patients stated that TB could be contracted by sharing a cup or plate with a TB patient (52%) or that TB could (also) be caused by evil spirits or witchcraft (28%). Some respondents claimed that TB was a genetic disease (*family TB*), a disease caused by God or fallen angels, or by immoral behaviour, such as drinking beer, smoking, promiscuity and prostitution (Table 3).

During in-depth interviews and FGDs, various respondents explained that coughs in general, and TB more specifically, could be explained with the local

Table 3 Biomedical TB knowledge reported by 300 TB patients during researcher-administered structured interviews at Kanyama clinic, Lusaka, Zambia

		N(%) ¹
Symptoms		
Respondents who knew TB symptoms: coughing, night sweats, loss of appetite, chest pain	no symptoms of TB	7 (2.3)
	two or three symptoms of TB	207 (69.0)
	four symptoms of TB	86 (28.7)
Treatment compliance and multi-drug resistant TB		
Respondents who	did not know the importance of treatment compliance	51 (17.0)
	knew the importance of treatment compliance	170 (56.7)
	knew the importance of treatment compliance and understood the meaning of DR-TB	79 (26.3)
TB aetiologies		
Respondents who mentioned	airborne	257 (85.7)
	cough	233 (77.7)
	sharing cups, utensils	155 (51.7)
	evil spirits/witchcraft	85 (28.3)
	traditional myths	58 (19.3)
	smoking	50 (16.7)
	drinking beer	39 (13.0)
	promiscuous behaviour	38 (12.7)
	prostitution	32 (10.7)
	god	28 (9.3)
genetic disease (Family TB)	11 (3.7)	

¹ Numbers do not add up to 300, because the questions allowed for multiple responses

term *traditional myths*. According to such myths, a cough was caused by eating food that had been salted by a menstruating woman or a woman who had just aborted; or when having sexual intercourse with a menstruating woman or a woman who had just aborted. In the latter case, the spirit of an aborted embryo (*Kapopo*) caused the cough. Some respondents also mentioned that babies with a cough are suspected to have been *tyoled* – a locally used term indicating that their father had been unfaithful and touched the baby in the first week after birth.

When asking about the links between *traditional coughs* and TB, responses varied. Some patients denied any linkage:

'I don't believe you can get TB according to this myth about abortion or menses, but you can get Chantanda wanga [a cough] if you do that. The

kapopo [aborted embryo] comes to you, just like that, but it is not TB.
 (in-depth interview 52-year old male TB patient)

Most traditional healers and several TB patients made a distinction between heavy, deep coughs that can be explained by a traditional myth, versus normal coughs caused by TB. Health workers said that some patients didn't believe their cough was related to TB. This disbelief was even more prevalent in case of children, because many people explained that children were unable to get TB and that their cough had to be caused by witchcraft or by being *tyoled*. Some patients attributed both myths and biomedical aetiologies to TB infection combining the information of clinical staff with the local knowledge about traditional myths. Some patients explained that any cough, and therefore also the traditional coughs could indicate TB infection. Health workers shared this message during community sensitization programmes. Various patients were uncertain about the relation between traditional coughs and TB.

Cultural factors

In total, 154 patients (51.3%) reported concurrent use of biomedical health care provision, such as traditional, faith, and self-healing (Tables 2 and 4). During FGDs, respondents explained that many community members did not start with a clinic visit, but rather used locally available herbal treatments in Kanyama to treat their cough. Generally, the second step was going to a market or *Kantemba*, a cheap unlicensed pharmacy.

Table 4 Alternative healing methods for tuberculosis in Urban Zambia assessed both during researcher-administered structured interviews, in-depth interviews with TB patients, traditional and faith healers, and FGDs at Kanyama clinic.

Healing methods	Medication or practices
Self-medication – herbal	Lemons, ginger, garlic, beetroot, leaves of: the banana plant, the Moringa, Nim, Blue Gum eucalyptus, guava, or mango tree, aloe Vera
Self-medication – Katemba / markets	Panadol, cough syrup, Chinese medicine, Back-to-Eden-herbs
Faith healing	Prayer, deliverance (exorcism of evil spirit), fasting and praying on a sacred mountain, holy water and/or anointed oil, Back-to-Eden-herbs, faith
Traditional healing – herbal	Traditional herbs, such as Nkonka, Muleza (also named Kankalamba or Munsokansoka), Mutato (herbal energy booster)
Traditional healing – spiritual	Witchcraft (mfuiti), consulting the spirits/ancestors, sacrificing small animals

During FGDs, participants explained that the majority of Zambians generally used traditional healing for treating illness, yet seldom for TB. This idea was slightly nuanced during in-depth interviews where often a difference was made between traditional healers in the city and in the village, making some of them travel to rural areas for TB care:

'For TB I don't like African herbs or pastors. Many people have died. [...] Traditional healers steal your money. Only some will know everything, if you are bewitched and by whom. But nowadays many doctors just make it up. The real traditional healers from the village can heal TB, but they're few.'
(in-depth interview, 28-year old male TB patient)

Some respondents had initially started with faith healing. Respondents favouring faith healing often said that TB resulting from evil spirits could only be healed by faith healing and not in the clinic.

'At church, people say spirits bring disease. A demon for TB, a demon for HIV. If you pray, you get healed. I also believe in that. But for my daughter it is not a demon, because deliverance [exorcism of disease-bringing spirit] didn't help. Then we went to the clinic.'
(in-depth interview 33-year old mother of nine year-old TB patient)

During in-depth interviews and one FGD, patients mentioned reasons for not first attending Kanyama clinic when falling ill, such as the idea they had a general cough; that TB was caused by non-biomedical causes; advice of their pastor or family member; or advantages from attending alternative care providers such as absence of long queues, quick patient service, guaranteed anonymity, and easier accessibility. Some patients and biomedical staff explained that traditional healers and faith healers could cause substantial pre-hospital delays.

Social factors

During structured interviews, 113 TB patients (35%) mentioned they suffered from loss of self-esteem, shame, insulting remarks, ridicule, discrimination, divorce, dismissal at work, and/or social isolation. Yet during in-depths interviews at home, more than half of the patients (60%) elaborated on the consequences of stigmatizing neighbours and friends.

'I had TB before, and my neighbours said to their children: don't go in that house! They never come near me, only greet me from far away. They are afraid of getting TB. They will say: that is not a normal cough. That is TB. He has Kanayaka.'
(in-depth interview 24-year female TB patient)

During the FGD on TB-related stigma, both patients and TB health workers explained to me that the local derogatory term for people with HIV, *kanayaka* – literally, ‘the red light that does not switch off’ – is often used to label TB patients. The label *kanayaka* signalled to others that TB patients were infectious and therefore dangerous, and that their lives would soon come to an end. Because of the label many TB patients explained that they additionally dealt with HIV-associated negative stereotyping, being accused of immoral behaviour, promiscuity, alcoholism, chain-smoking, and prostitution.

The FGDs also provided insight in the relation between stigmatization and a denial of a positive TB diagnosis, non-disclosure, and/or difficulties with initial hospital visit and treatment compliance. Fearful of a positive diagnosis and associated stigmatizing reactions, some people rejected testing:

‘One of my cousins [a household member] died of TB, because she didn’t want to go to the clinic and didn’t want treatment. I have tested myself and my grandson. The rest of the household doesn’t want to do a test for TB or HIV, because they are afraid for the test results. They say they can’t have TB.’
(interview 65-year old grandmother of 1-year old child on preventive TB treatment)

Respondents explained that women were sometimes forcibly expelled to the village to hide their TB diagnosis and treatment from neighbours. (No answer was given to why this did not happen for men.) During one in-depth interview, a TB patient described that she was sent away and that in rural areas TB treatment was not easily accessible or available. This contributed to her treatment disruption and aggravation of TB. She had almost died and came back to the city to attend Kanyama clinic and retake TB treatment.

Economic factors

Quantitative data showed that 103 patients (34%) faced serious food shortages.

‘In Zambia the problem is mostly food. You eat once a day, it is not even good. Especially with TB drugs, it is hard, every day we have to take drugs. It makes you hungry, dizzy, shaky, but I have no food, no money.’
(interview 37-year old male TB patient)

The in-depth interviews provided insight into the intersection of poverty and treatment compliance. Patients explained that the ‘strong medication’ made them feel hungry and weak. Hunger complicated coping with side effects and treatment compliance. Some patients filled their stomach with cheap maize opaque beer (*Chibuku*), generally not realising that alcohol can render TB medications less effective. Patients explained that alcohol was also a way to free their minds of (financial) problems.

During in-depth interviews, health care workers and various patients indicated delays in search for TB care at the clinic, because poverty forced many patients to continue working and the majority had no health insurance. 136 patients (45.3%) were in a severe health condition on first arrival at the clinic. Few patients were financially supported by their family-members, employers, or landlords.

Organizational factors

Participant observation and informal conversations with both the TB health workers and the patients provided insight into the efforts of the understaffed TB team regarding provision of patient service, medication distribution, and record-keeping at the TB department of Kanyama clinic. The voluntary treatment supporters seemed an indispensable asset enhancing contact between TB patients and the clinic and sensitizing the community about TB infection. Moreover, the nurses explained that in the past the clinic had contacted several faith healers and three private clinics in Kanyama district in order to enhance hospital referral of TB patients, and to supply the latter with correct TB drugs. The Kanyama clinic worked with a strict TB drug collection schedule based on the stage of treatment patients were involved in. Consequently, family members in different treatment stages were required to individually collect medication on different days.

Participant observation showed that patients simultaneously diagnosed with TB and HIV received additional care at the clinic (different medication, support groups); however, three HIV patients who started TB treatment at a later stage went unnoticed by health workers, leading to a mismatch of TB and HIV drugs. Other organizational problems regarding administration of TB patients occurred when patients moved to the rural area and were transferred to a local clinic. These patients were invariably LTFU.

DISCUSSION

In this study, we examined perceptions and cultural, social, economic, and organizational factors influencing TB patients' pre-hospital delay and compliance to care provided by the NTP using a mixed methods research approach. Quantitative data analysis showed no association between treatment compliance and demographic characteristics, patients' TB-related struggles, or alternative health care seeking. In contrast, qualitative data identified how TB perceptions, stigma, poverty, and organizational obstacles influenced TB patients' pre-hospital delay and treatment non-compliance undermining an effective TB control programme.

Quantitative findings illustrated that most TB patients used both biomedical and traditional understandings of TB knowledge. Qualitative findings provided insight that many patients were unsure how to combine the variety of TB perceptions available. Previous studies have shown the importance of perceptions on health care seeking behaviour³⁰⁻³⁴ and have stressed the importance of cultural-sensitive sensitization programmes.^{7,8,35} We propose interactive awareness programmes that acknowledge and appropriately address the variety of local perceptions to enhance early case-finding and reduce hospital delay. Furthermore, patients' usage of traditional healers, faith healers, and private clinics calls for a collaborative strategy between clinics and these alternative healers, as promoted by the WHO³⁶ and proven effective according to various studies in sub-Saharan Africa.³⁷⁻⁴⁰

Stigma

Quantitative analysis showed a high prevalence of stigmatising attitudes and actions by patients' community and family members, as we have previously reported in detail¹⁰. Stigmatizing perceptions were amongst others represented by the locally-used derogatory term *Kanayaka*, to label both TB and HIV patients. This linkage seemed to aggravate TB patients' experience of stigma, targeting them additionally with HIV-related accusations. This is in line with previous reports from Zambia.^{3,25} Children were as vulnerable to stigma as adults calling for more research focused on this age group.¹⁰ A high number of the stigmatised patients in this study consisted of women, whose vulnerable position in society was exacerbated by the use of local traditional myths blaming women for the spread of TB and HIV.^{3,10} TB programmes targeting stigma-related perceptions and attitudes need further improvement,¹⁰ specifically regarding patient support and family sensitization, which could be achieved through organisation of support groups for TB patients irrespective of HIV status. Moreover, the collaborative TB/HIV programme should address the extra dimension of TB-related stigma linked to HIV with renewed TB/HIV sensitization programmes and pay particular attention to the vulnerable position of children and women herein.

Poverty

Patients' low socio-economic status was related to often cited struggles of regular food shortages, resonating with World Bank statistics⁴¹ that 61% of the Zambian population lives below the poverty line. A case study from Lusaka described poverty levels to be specifically high in slum areas such as Kanyama.⁴² In-depth interviews with health care staff and patients clarified that almost none of the respondents had a private health insurance. Consequently, patients

often postponed an initial clinic visit or (temporarily) discontinued treatment to avoid loss of income. When falling seriously ill, many patients faced (financial or physical) difficulties attending the clinic, taking treatment, and/or deal with adverse medication effects. TB often disrupted livelihoods as cash income declined, especially when breadwinners fell ill.

Participant observation showed that TB patients lived in conditions with a high risk of TB infection due to overcrowded housing and poor ventilation. The majority of people in the community were too poor to reduce these risks, and given high local crime rates, many patients preferred closed doors and windows. Because the TB programme is mainly focused on physical health and not on improving living conditions, cured patients can acquire TB again and again. Poverty is well known to fuel tuberculosis and remains a major challenge to TB control programmes worldwide, undermining the effectiveness of (free) TB drugs.^{5,43-46} Several Zambian studies have described low socio-economic status to be an obstacle to TB care referring to the necessity of food aid and payment of transport costs for both TB and HIV patients.^{21,23,47,48} About a decade ago, two Zambian studies described successful Home Based Care (HBC) organisations^{49,50} providing food aid, but due to financial constraints these organisations ceased their programmes. Based on our qualitative findings and the literature, we advocate to not only diminish symptoms of poverty with renewed HBC programmes, but to also make an end to what may be considered structural violence embedded within longstanding social and economic structures of inequality.⁵¹ The position of TB patients and associated TB prevalence and incidence, can only be improved if poverty is substantially alleviated.

Alcohol consumption was often mentioned by respondents in relation to poverty. Sensitization programmes about alcohol's destructive effects on TB treatment fall short, ignoring the socio-economic context in which TB patients in our study sometimes depended on alcohol to deal with hunger, (financial) problems, and to numb themselves. Data from South Africa showed that poverty alleviation reduced substance abuse among South African TB patients and improved TB care.⁵²

Organizational obstacles

Difficulties with TB patients' long time/distance to the clinic' indicated a trend with 'treatment non-compliance', which could potentially relate to patients' work-related commitments making it difficult to (timely) collect medication. The clinic should take time and distance constraints into consideration permitting patients to collect medication for a longer period of time and/or for the whole household, eliminating long queues and enhancing a direct flow to the TB department possibly preventing unnecessary deaths and in-hospital transmission.

Furthermore, full integration of TB and HIV services fell short in certain instances and is of utmost importance; as recommended by the national TB

control programme; and as implemented in other sub-Saharan African countries.^{53–55} Moreover, inadequate communication between Kanyama clinic and rural clinics hindered record keeping of transferred patients and an accurate administration and are in need of improvement.

Limitations and strengths

A limitation of this study was that pre-hospital delay was only qualitatively and not quantitatively assessed, because related structured interview questions triggered vague or contradictory responses due to lack of time, and inability of interviewees to remember in detail their pre-hospital illness experience. In-depth interviews did generate insights regarding pre-hospital delay, suggesting future qualitative research on the topic. Furthermore, it was impossible to add TB knowledge as a risk factor for treatment compliance in the univariate analysis, because of the time gap between previous non-compliant behaviour and current knowledge. Prospective studies are needed assessing the impact of baseline TB knowledge on treatment non-compliance.

The strengths of this study was the mixed method design and sequential explanatory model. Triangulation of research findings enabled iterative analysis. The combination of methods was specifically valuable when quantitative methods fell short and qualitative methods could fill these information gaps.

CONCLUSIONS

Mixed methods analysis clearly demonstrated the importance of qualitative approaches to understand how cultural, social, economic and organizational factors are influencing pre-hospital delay and treatment non-compliance with regards to the Zambian NTP. Patients' concurrent use of local TB understandings and health care calls for cultural sensitive TB education and co-operation between (private) clinics and traditional/faith healers. To strengthen the Kanyama clinic's existing programmes, combating stigma is of utmost priority coupled with programmes addressing poverty. Organizational barriers regarding drug collection schedules, patient transfers, and integrated HIV-TB programme should be addressed.

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Assessing the consequences of stigma for tuberculosis patients in urban Zambia

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ABSTRACT

Background: Stigma is one of the many factors hindering tuberculosis (TB) control by negatively affecting hospital delay and treatment compliance. In Zambia, the morbidity and mortality due to TB remains high, despite extended public health attempts to control the epidemic and to diminish stigma.

Study aim: To enhance understanding of TB-related stigmatizing perceptions and to describe TB patients' experiences of stigma in order to point out recommendations to improve TB policy.

Methods: We conducted a mixed method study at Kanyama clinic and surrounding areas, in Lusaka, Zambia; structured interviews with 300 TB patients, multiple in-depth interviews with 30 TB patients and 10 biomedical health workers, 3 focus group discussions with TB patients and treatment supporters, complemented by participant observation and policy analysis of the TB control programme. Predictors of stigma were identified by use of multivariate regression analyses; qualitative analysis of the in-depth interviews, focus group discussions and participant observation was used for triangulation of the study findings.

Results: We focused on the 138/300 patients that described TB-related perceptions and attitudes, of whom 113 (82%) reported stigma. Stigma provoking TB conceptions were associated with human immunodeficiency virus (HIV)-infection, alleged immoral behaviour, (perceived) incurability, and (traditional) myths about TB aetiology. Consequences of stigma prevailed both among children and adults and included low self-esteem, insults, ridicule, discrimination, social exclusion, and isolation leading to a decreased quality of life and social status, non-disclosure, and/or difficulties with treatment compliance and adherence. Women had significantly more stigma-related problems than men.

Conclusions: The findings illustrate that many TB patients faced stigma-related issues, often hindering effective TB control and suggesting that current efforts to reduce stigma are not yet optimal. The content and implementation of sensitization programmes should be improved and more emphasis needs to be placed on women and children.

Alongside biological, economic, and cultural barriers to effective tuberculosis (TB) control, stigma constitutes one of the major social factors causing hospital delay and hindering compliance among TB patients.^{1,2} Various studies conducted in different African settings have exposed negative attitudes towards TB patients and/or described the subsequent consequences. Oftentimes attitudes can be explained by local beliefs and knowledge of TB transmission, such as shared use of eating utensils,³ hereditary factors,³⁻⁵ sexual intercourse,⁶⁻⁸ bewitchment,^{3,5,9} smoking,^{3,4,7,8} heavy labour,^{3-5,7} human immunodeficiency virus (HIV)-infection,⁹⁻¹² and poverty.¹³ These perceptions lead to shame,^{12,14} fear of physical contact among community members,¹⁰ affected marriage prospects,¹⁵ social isolation,^{9,10,14} and discrimination.¹⁶ The extensive systematic review of Chang et al. describe that consequences of stigma hinder, or even adversely influence, efforts to stimulate treatment compliance and reduce delays in diagnosis and treatment worldwide.¹⁷ Moreover, stigma impedes the application of preventive measures such as coughing-hygiene and good ventilation at home resulting in increased transmission risk, severe morbidity and mortality and increased development of multi-drug resistance (MDR-TB), thus undermining successful TB control.^{12,18,19}

Stigma is often explained as a discrediting attribute leading to an impairment of social status and position, rejection and/or exclusion.²⁰ In addition, stigma is seen as a key factor in the production and reproduction of power structures, causing devaluation of certain social groups or individuals, thus aiding social inequality.²⁰⁻²² Stigma can be differentiated into three main sub-categories: *experienced stigma* (the experience of exclusion and/or discrimination), *anticipated stigma* (the perception, expectation and/or fear of stigma), and *internalized stigma* (a loss of self-esteem, dignity, fear and/or shame).^{1,18} Since these sub-categories elicit the diversely layered struggles associated with stigma, we have applied those in this study. Taking into consideration that stigma varies from culture to culture,^{22,23} we will address the context of stigmatizing actors, local values and ideology, political organization and economic system of the society from which stigma arises.^{21,23} Moreover, we will critically evaluate how the Zambian National TB Programme (NTP) addresses TB-related stigma and whether the programme plays a role in the (re)production of stigma.

The importance of addressing stigma related to TB is illustrated by the fact that this disease is one of the major causes of death worldwide. Zambia ranks 29th among the world's top TB countries identified by the World Health Organisation (WHO) having 427/100 000 incident TB cases in the year 2012. HIV co-infection rate is 61% and MDR-TB prevails in 0.3% of new TB-cases and 8.1% of retreatment TB-cases. Males are more often affected by TB than females (Zambian male-to-female ratio: 1.7:1).²⁴ Besides epidemiological factors, the NTP faces a wide variety of clinical, operational, and social challenges.

Stigma is still a low-priority issue in international TB control efforts,¹ notwithstanding the numerous papers written on this topic.^{2,4,19,25-27} However, in Zambia, little research has been performed on HIV/TB-related stigma¹² and an assessment of the scope, nature, and social consequences of specifically TB-related stigma in Zambia has not been published.

Therefore, we combined both qualitative and quantitative research methods²⁸ to investigate TB-related stigma in an urban health care setting in Lusaka, Zambia. The research aim is to enhance understanding of stigma and its effects on TB patients' lives and the NTP to offer suggestions for improving health interventions. Secondly, our study may serve as a baseline for monitoring and evaluating potential future interventions and prevalence of stigma over time.

METHODS

This research is part of the broader TB patients' Adherence and Compliance (TBAC)-study that took place from September 2013 until January 2014 in Kanyama (Lusaka, Zambia), an urban squatter settlement characterised by poverty and a high TB prevalence. In the Kanyama clinic, a modified version of WHO Direct Observed Therapy (DOT) policy to address tuberculosis is applied. The first two months, smear-positive and DR-TB patients receive medication daily at the clinic, and smear-negative patients once a week. After this period, patients collect TB-drugs every two weeks. Treatment takes several months and on average a patient is no longer infectious after two weeks of continuous drug-intake. Isoniazide Preventive Therapy (IPT) is offered for HIV-infected children who have close contact with TB patients.

Various (education) programmes address TB-related stigma: treatment starts with a one-on-one talk to educate patients about TB. A treatment supporter is assigned to each patient for answering questions, family-sensitization, treatment encouragement, or finding patients who are lost to follow up (LTFU). A household member of the patient gets involved in supervising treatment intake. In addition, a counsellor is available for TB patients and support groups are organised for people with TB-HIV co-infection. Treatment supporters organise twice a week sensitization programmes in the community. They go from door to door to discuss TB and to hand out information brochures. Occasionally, they give a music and theatre show about TB. Additionally, the clinic allocates long-term TB nurses with expertise in TB, putative aetiologies, fear of transmission, and stigma-related struggles.

We used a mixed method design in a sequential explanatory model for which we first collected quantitative data and subsequently qualitative data to gain an in-depth understanding of statistical relationships and its context.¹⁶ The four-month study period enabled us to conduct structured interviews with 300 (extra-) pulmonary TB patients undergoing Direct Observed Therapy at Kanyama clinic willing to participate in the study. Respondents under age

eighteen were either interviewed with permission of their parent/guardian or their parent/guardian was interviewed. All 300 patients completed the structured interview. The sample size was considered to be sufficient to investigate the nine predictors of compliance for the TBAC study, considering a prevalence of defaulting patients of 30% of the overall study group²⁹ and the sample size recommendations for a logistic regression analysis³⁰ to investigate predictors with a 95% confidence interval. For this sub-study on stigma, we focused on the 138 patients, who were identified to have experienced stigma, defined as having experienced negative or positive attitudes or perceptions regarding TB patients.

Additionally, we conducted qualitative research for which we randomly selected 30 patients of the study group (N= 300) for in-depth interviews of which six patients were younger than 20 years. Respondents under age eighteen were either interviewed with permission of their parent/guardian or their parent/guardian was interviewed.

Moreover, we approached ten biomedical health care providers (both nurses and treatment supporters of the TB department) for in-depth semi-structured interviews in the clinic. In addition, we organised three focus group discussions (FGD) in a secluded area of the clinic in order to enhance confidentiality. We randomly recruited ten treatment supporters for the first FGD and eight patients and two treatment supporters for both the second and third FGD. Participant observation was conducted at the clinic, during sensitization programmes in the community, and in patients' homes/neighbourhoods.

The structured interview contained questions regarding demographics, treatment history, bio-medical knowledge, and TB-related difficulties. Three questions were stigma-related: Do you feel shy/shame coming to the clinic? What do people in the place you live/in your neighbourhood think about TB? How do they compare HIV and TB? The questions were based on the literature,^{1,18} screened by a Zambian medical doctor and the nurses of the TB corner in Kanyama clinic, and tested in a two-week pilot study. Subsequently some questions were adjusted, added or deleted to optimise the questionnaire for use in the current study. The interviewer fitted the responses to response-options using verbal and numeric labels. We allowed space for respondents to elaborate on their answers or to provide additional comments.

We visited 30 patients 1-3 times at their homes for in-depth, semi-structured interviews (1-2 hours each) extensively assessing stigma-related topics. The in-depth interviews with health workers focused on the functioning of the TB programme and the challenges in their work. The FGDs addressed (1) childhood TB & parents, (2) problems of TB patients encountered in daily life, and (3) TB-related stigma. We used various techniques to foster an informal setting in which respondents felt free to talk, such as forming word clouds, theme ranking, making posters, and group presentations. All interviews and FGDs were conducted by a medical anthropologist and local research assistant

in the local Zambian languages (English, Nyanja, Lhosi, Tonga, or Bemba) and transcribed into English.

We divided the 138 included patients in two groups: one comprising patients describing negative attitudes/perceptions (*stigma*), and another with patients describing supportive or positive responses from their social environment (*no stigma*). Furthermore, the group of stigmatized TB patients was subdivided into the above-mentioned subcategories experienced, anticipated and/or internalized stigma.^{1,18}

In order to identify factors that rendered a TB patient more vulnerable for stigma, we conducted univariate logistic regression analyses. Variables that had an association with stigma with a significance of $p < 0.1$ were subsequently included in a multivariate regression model predicting stigma. We compared the sample ($N=30$) undergoing multiple in-depth interviews with the overall study group ($N=300$) regarding demographics (sex, age, education, marital status), treatment-related parameters (HIV co-infection, TB relapse, treatment duration, TB knowledge), and the percentage of people suffering from stigma applying Chi Square and T-tests. All analytic tests were performed using IBM SPSS statistics version 21.0 (IBM Corp, Armonk, NY).

Qualitative data analysis was conducted to explain, contextualize, and interpret quantitative outcomes. Using Qualitative Data Analysis and Research Software (ATLAS.ti, 7th edition; Scientific Software Development GmbH, Berlin, Germany), we conducted thematic and content analysis for the in-depth interviews and FGDS. Transcripts were screened multiple times, coded into meaning units and categorized into broad themes.³¹ Additionally, we analysed context, meaning and structures of identified codes and themes and explained statistical relationships found in quantitative analysis.³² Some quotes of respondents were used to illustrate most important themes.

Ethical approval (HSSREC 02-08-13) for the study was obtained from the University of Zambia Biomedical Research Ethics Committee (UNZAREC). Written informed consent was obtained from all informants using UNZAREC-forms prior to inclusion in the study. For respondents under age eighteen we asked additional written informed consent from their parent/guardian. We guaranteed anonymity and confidentiality of given information by safe storage of data, usage of pseudonyms, and unidentifiable descriptions of patients throughout this article. Data were stored safely under lock and key. Only the main investigator had access to these data.

RESULTS

Mean age of TB patients participating in the study ($N=300$) was 33 years, ranging from 1 to 70 years and including 25 children and teenagers aged 1 to 19 years. Almost two thirds (64.3%) were male; 148 patients (49.3%) had a low education level (0-7 school years), and about half (49.0%) were co-infected with

Table 1 Socio-demographic characteristics and tuberculosis-related parameters of TBAC study participants, Lusaka, Zambia

Variable	All TB patients N=300 (%)	Patients report- ing TB-related perceptions & attitudes N=138 (%)	Patients not reporting TB-re- lated perceptions & attitudes N=162 (%)	P-value
Sex				0.850
Male	193 (64.3%)	88 (63.8%)	105 (64.8%)	
Female	107 (35.7%)	50 (36.2%)	57 (35.2%)	
Age (yrs)				0.030
Mean (SD*)	33.3 (11.33)	31.8 (11.15)	34.6 (11.35)	
Level of education				0.061
Low (<8 yrs)	148 (49.3%)	60 (43.5%)	88 (54.3%)	
High (≥8 yrs)	152 (50.7%)	78 (56.5%)	74 (45.7%)	
Marital Status				0.207
Relationship	121 (40.3%)	1 (44.2%)	60 (37.0%)	
Single	179 (59.7%)	77 (55.8%)	102 (63.0%)	
HIV co-infection				0.451
Yes	147 (49.0%)	73 (52.9%)	74 (45.7%)	
No	126 (42.0%)	54 (39.1%)	72 (44.4%)	
Unknown	27 (9.0%)	11 (8.0%)	16 (9.9%)	
TB-relapse				0.310
Yes	86 (29.0%)	36 (26.1%)	50 (31.4%)	
No	211 (71.0%)	102 (73.9%)	109 (68.6%)	
Duration treatment (weeks)				0.135
Mean (SD)	10.8 (8.33)	10.0 (7.95)	11.5 (8.60)	
Knowledge of TB				0.724
None	175 (58.3%)	82 (59.4%)	93 (57.4%)	
Some	125 (41.7%)	56 (40.6%)	69 (42.6%)	

* Standard Deviation

HIV (Table 1). The sample of 30 TB patients that was followed up for in-depth interviews did not significantly differ from the overall study group (N=300) concerning study population characteristics (Table 2).

Table 2 Socio-demographic characteristics and tuberculosis-related parameters of in-depth sample of TBAC study, Lusaka, Zambia

Variable	All N=30 (%)	Stigma N=18 (%)	No Stigma N=12 (%)	P-value
Sex				0.024
Male	17 (56.7%)	7 (38.9%)	10 (83.3%)	
Female	13 (43.3%)	11 (61.1%)	2 (16.7%)	
Age (yrs)				0.442
Mean (SD)	31.0 (13.29)	29.5 (12.67)	33.3 (14.42)	
Level of education				0.879
Low (<8 yrs)	12 (40.0%)	7 (38.9%)	5 (41.7%)	
High (≥8 yrs)	18 (60.0%)	11 (61.1%)	7 (58.3%)	
Marital Status				0.060
Single	14 (46.7%)	11 (61.1%)	3 (25.0%)	
Relationship	16 (53.3%)	7 (38.9%)	9 (75%)	
HIV co-infection				0.807
Yes	17 (56.7%)	11 (61.1%)	6 (50.0%)	
No	10 (33.3%)	6 (33.3%)	4 (33.3%)	
Unknown	3 (10.0%)	1 (5.6%)	2 (16.7%)	
TB relapse				0.261
Yes	21 (70.0%)	14 (77.8%)	7 (58.3%)	
No	9 (30.0%)	4 (22.2%)	5 (41.7%)	
Duration treatment (weeks)				0.402
Mean (SD)	9.5 (8.97)	8.4 (8.39)	11.2 (9.92)	
Knowledge of TB				0.757
None	19 (63.3%)	11 (61.1%)	8 (66.7%)	
Some	11 (36.7%)	7 (38.9%)	4 (33.3%)	

Responding to the three stigma-related interview questions and/or elaborating in free text answers, 138 TB patients reported positive or negative perceptions or attitudes regarding TB whereas 162 did not. Socio-demographic characteristics and tuberculosis-related parameters were similar in both populations with the exception of age and educational attainment that was observed to be higher in the first group (with a minor difference of one school year and age difference of three years). Of those, 16/138 patients (12.0%) were younger than 20 years of age. We focused on the group reporting perceptions or attitudes regarding TB (N=138).

In total, 113/138 TB patients (81.9%) reported that they personally encountered consequences of stigma of which 47/113 patients (41.6%) were female and 13/113 patients (11.5%) were aged under 20 years (Table 3). Using the above-mentioned

subcategories, 22/113 stigmatised TB patients (19.5%) reported *experienced stigma*, 61/113 (54.0%) faced *anticipated stigma* and 57/113 (50.4%) had *internalised stigma* (Table 3). The study sample (N=30) included more women suffering from stigma.

Table 3 Socio-demographic characteristics and tuberculosis-related parameters of TBAC study participants who reported TB-related perceptions/attitudes, Lusaka, Zambia

Variable	All N=138 (%)	Stigma N=113 (%)	
		All stigma N=113	Experienced stigma N=22
Sex			
Male	88 (63.8%)	66 (58.4%)	10 (45.5%)
Female	50 (36.2%)	47 (41.6%)	12 (54.5%)
Age (yrs)			
Mean (SD)	31.8 (11.15)	31.1 (10.27)	33.0 (9.50)
Level of education			
Low (<8 yrs)	60 (43.5%)	51 (45.1%)	8 (36.4%)
High (≥8 yrs)	78 (56.5%)	62 (54.9%)	14 (63.6%)
Marital Status			
Single	61 (44.2%)	46 (40.7%)	12 (54.5%)
Relationship	77 (55.8%)	67 (59.3%)	10 (45.5%)
HIV co-infection			
Yes	73 (52.9%)	60 (53.1%)	13 (59.1%)
No	54 (39.1%)	45 (39.8%)	8 (36.4%)
Unknown	11 (8.0%)	8 (7.1%)	1 (4.5%)
TB-relapse			
Yes	36 (26.1%)	26 (23.0%)	5 (22.1%)
No	102 (73.9%)	87 (77.0%)	17 (77.3%)
Duration of treatment (weeks)			
Mean (SD)	10.0 (7.949)	9.7 (7.480)	12.9 (7.383)
Knowledge of TB			
None	82 (59.4%)	69 (61.1%)	11 (50.0%)
Some	56 (40.6%)	44 (38.9%)	11 (50.0%)

			No Stigma N=25 (%)	P-value Stigma - No stigma
	Anticipated stigma N=61	Internalised stigma N=57		
				0.010
	36 (59.0%)	37 (64.9%)	22 (88.0%)	
	25 (41.0%)	20 (35.1%)	3 (12%)	
				0.156
	30.6 (9.87)	30.2 (9.96)	34.6 (14.36)	
				0.406
	30 (49.2%)	24 (42.1%)	9 (36.0%)	
	31 (50.8%)	33 (57.9%)	16 (64.0%)	
				0.083
	19 (31.1%)	20 (35.1%)	15 (60.0%)	
	42 (68.9%)	37 (64.9%)	10 (40.0%)	
				0.867
	33 (54.1%)	24 (42.1%)	13 (52.0%)	
	22 (36.1%)	31 (54.4%)	9 (36.0%)	
	6 (9.8%)	2 (3.5%)	3 (21.0%)	
				0.085
	13 (21.3%)	13 (22.8%)	10 (40.0%)	
	48 (78.7%)	44 (77.2%)	15 (60.0%)	
				0.312
	9.0 (7.216)	8.5 (6.625)	11.5 (9.845)	
				0.405
	42 (68.9%)	36 (63.2%)	13 (52.0%)	
	19 (31.1%)	21 (36.8%)	12 (48.0%)	

Univariate analyses identified an important difference in sex between stigmatized and non-stigmatized patients. Moreover, relapse cases and married persons were less stigmatized (Table 3). In a multivariate logistic regression model, the variable sex (female) was found to be a significant predictor for stigma (Table 4), and being single or a relapse case were further, albeit non-significant, predictors for stigma. In the sample (N=30), the variables sex and marital status were also found to have an association with stigma ($p < 0.1$) (Table 2).

Table 4 Multivariate logistic regression analyses predicting stigma in 138 TB patients, TBAC study, Lusaka, Zambia

Variable	B (SE)	OR	95% CI	P-value
Sex (female)	1.701 (0.658)	5.479	1.51 – 19.88	0.010
Marital status (single)	-0.848 (0.472)	0.428	0.17 – 1.08	0.073
TB relapse (yes)	-0.77 (0.488)	0.462	0.18 – 1.20	0.113

Patients' experience of the TB programme

At Kanyama clinic, most patients were satisfied with the TB department (*the 'TB corner'*) and its staff. However, TB patients described more uncomfortable situations at the general clinic:

'I came to the clinic, because I was not feeling well. [...] The nurse did not respond well, because they suspected TB. When I came I was coughing and she was very rude. She shouted: "If you are coughing, this is not the right place to come. Go to the TB corner!" I felt stigmatized at that first day.'

(TB patient during FGD)

Several patients were critical about the stigma-reducing measures at the TB corner. They described being too ill to comprehend the one-on-one introduction talk about TB. Other patients explained their treatment supporter was unmotivated, because he/she was not always present at the clinic, did not visit them at home for support or family sensitization, or did not properly answer their questions. Some patients had not known that there was a counsellor present at the clinic. More than a quarter of all patients (28.3%) declared they had not received any sensitization at the clinic.

TB perceptions

Most patients (94.9%) used biomedical explanations for contracting TB referring to coughing or the airborne nature of TB. However, 112/138 (81.2%) combined this with alternative aetiological explanations such as: sharing cups; familial

inheritance; drinking spirits; smoking cigarettes; promiscuous behaviour; abortion; sleeping with a menstruating woman or a woman who had just aborted; a woman adding salt to food while menstruating or after an abortion; or evil spirits. Patients' aetiological reasoning often blended different supposed causes:

'It feels so bad to have TB. And I don't understand, because I am so young. I am not drinking, not smoking, I don't have a relationship. I am just a student. Why do I have TB?'

(In-depth interview Claire, 14 year old TB patient).

Claire's answer illustrates existing negative perceptions regarding TB aetiology and demonstrates her struggle as a TB patient. Additionally, Claire explained that TB-affected children faced a lack of understanding and uneasiness in their social environment, because people generally believed children were unable to contract TB. For this reason, being young was an extra burden for her aggravating TB-related stigma.

The fear for TB was also reflected in frequent use of the term '*Kanayaka*' meaning '*the red light that never switches off*'. This stigmatising term was initially used in the community for HIV patients and a warning to avoid contact. However, we found that this label was also used for TB patients. Some patients and many of their relatives/neighbours believed that HIV and TB were the same disease or that TB patients were always co-infected with HIV. Accordingly, negative attributes associated with HIV, such as (presumed) immorality and promiscuous behaviour, were also attributed to TB patients. Moreover, the term *kanayaka* foreshadowed the alleged upcoming death of a HIV and/or TB patient. Indeed, various TB patients (28/138, 20.3%) reported encountering these negative attitudes and were consequently approached as if they were 'doomed to die'. Overall, this linking with HIV and community-based fear and aversion aggravated TB stigma and often prompted patients not to disclose their TB status.

Experienced stigma

We assigned TB patients to the sub-category *experienced stigma* if they declared being treated differently by relatives/neighbours/friends after disclosure of TB, for instance by facing ridicule, insulting remarks, discrimination, social exclusion, and/or isolation. Social exclusion was often triggered by the idea that TB is highly infectious, manifesting in dining and sleeping separately; avoidance of sexual intercourse; exclusion from activities in school and/or at work. The story of a child with open-TB exemplified such social exclusion prompted by fear of presumed contagiousness:

'After disclosure they tried to avoid her [Helen], run away, not even greet. Children in school were not allowed to play with Helen because their parents

would tell them Helen had TB and they should keep their distance.'

(In-depth interview Rosemary, mother of 9 year old TB patient Helen).

With the term social isolation, we refer to more drastic social consequences caused by stigmatizing actors, such as divorce, permanent dismissal at work, or ostracism. Various respondents mentioned that some TB patients were banished to a village to live with relatives. The main explanation given for this banishment was to prevent infection of household members and/or to hide patients from neighbours and relatives. This theme recurred during FGDs during which various respondents indicated that women were more often expelled to the countryside than men.

Anticipated stigma

We assigned the label *anticipated stigma* to respondents who mentioned difficulties disclosing their TB status due to the fear of negative reactions by others.

'I did not tell anybody [...] Because there is too much stigma. I mean there is too much fear. That is why I used to hide. They think if someone is infected with TB, he can have any disease, he is stupid, he is not thinking. They spread it to other people, and people just add some diseases on top of that. Instead of praying, they make it worse.'

(In-depth interview Bo, TB patient)

As this quote illustrates, the social standing of TB patients is negatively affected because people consider them irresponsible and likely to spread TB or other diseases (such as HIV). Faced with prejudices, these patients often concealed their TB in order to avoid insulting remarks, misunderstandings, and a disrupted social status. This is shown by the following quote:

'When you have TB, you are degrading yourself if you tell others [that you have TB]. You get a problem. They will use it against you. [...] I did not tell anyone in church, because I don't want to destroy my [social] position there.'

(In-depth interview Alex, TB patient)

Internalised stigma

Half of the stigmatised TB patients (50.4%) had internalized the stigmatizing ideas and, consequently, they believed that they were less worthy than others. This belief was expressed by either fear, shame, hopelessness, guilt and/or a loss of self-esteem. Moreover, internalization of devaluating beliefs altered TB patients' expectations of life.

'I don't want people to know I have TB. To find a husband is difficult. Who wants to have us [herself and her sister]? We have TB, no one will be interested.'

(In-depth interview Virginia, TB patient)

Virginia and her divorced sister both suffered from TB and had lost hope to ever get (re)married. As they explained elsewhere in the interview, the inability to find a marriage partner severely constrained their social and economic prospects and, thereby, the hope of escaping the severe poverty in which she, her sister and her three children were living.

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CHAPTER 7

Impact of stigma on the TB programme

Processes of stigmatization can lead to denying a positive TB diagnosis, non-disclosure, fear, and poor quality of life. Some patients did not want to be seen in the TB corner, were reluctant to openly take tablets, and avoided to be associated with the clinic. As a result, stigma led to patients' hospital delay and poor treatment compliance and undermined efforts to screen for TB in the households of TB patients. An example hereof was raised during an FGD:

'The nephew of my neighbour got the diagnosis TB at the clinic, this means they will do a household screening, but the family refused. The aunt said: "no one can have TB, because I believe in God", even though the nephew is smear-positive. Instead of testing, they do nothing. The nephew now has to sleep alone, eat alone and no one talks to him. He is taking treatment on his own.'

(TB patient during FGD)

The aunt's religiously framed argument as to why her nephew could not have a positive TB diagnosis shows how stigma can adversely affect a TB control programme. Increasingly deprived of social support, the nephew was socially excluded, hindering his compliance with treatment guidelines. Moreover, since household members believed that God protected them against TB, their rejection of TB screening could possibly delay diagnosis and fuel the spread of TB. This link between stigmatization and the TB control programme is also present when TB patients were banished to their relatives' village:

'I did not finish my treatment, because after the hospital my mother and grandmother took me to the farm [in the village]. It was a long distance to the hospital. I ran out of TB drugs and I didn't have transport. I couldn't walk and my mother got tired of it. Four years later I came from the farm here [at the clinic].'

(In-depth interview Sarah, TB patient)

Sarah's social position was not only adversely influenced, she was also sent far away by her family. This banishment and the inadequate availability or accessibility of TB treatment in the villages led to poor treatment compliance and, in Sarah's case, a sharp decline of her health.

Shortcomings of sensitization programmes

During the (structured) interviews and FGDs, the majority of respondents emphasised that inadequate biomedical knowledge and existing misconceptions of TB among community-members were key factors in negative attitudes and behaviour toward TB patients. Some respondents educated relatives/neighbours, such as the earlier mentioned Rosemary:

'When I figured out that children in school were told by their parents to keep [their] distance from Helen [her daughter], I got mad. I explained all the parents that Helen had been on treatment since more than two weeks and that she was not infectious anymore. Then the mothers and children apologized. That helped. Now the situation is fine.'

(In-depth interview Rosemary, mother of TB patient)

In this case, providing biomedical knowledge reduced fear and stigma. However, not all respondents were aware of those misconceptions and/or able to (successfully) confront their stigmatizing environment with biomedical information in order to change these attitudes. Despite existing sensitization programmes, various health care providers and TB patients described difficulties in reaching all TB patients and community members, and in making the TB-information understandable to patients.

'Stigma can kill a lot of people. [...] They are not encouraged to seek health care. [...] Sensitization is working, but it's a matter of listening. People will hear, but not listen or understand. There should be more active sensitization, get them involved, so they listen and understand.'

(In-depth interview Alex, TB patient)

DISCUSSION

Based on a mixed methods design, this study aimed at assessing stigma for TB patients in Lusaka, Zambia. We focused on TB-related stigmatizing perceptions and attitudes mentioned by the TB health care workers and 138 TB patients of the TBAC study including their influence on patients' lives and the TB control programme. In total, 82% of these patients were affected by consequences of stigma.

Some of the stigma-related TB perceptions found in this study were likewise mentioned in studies in other parts of the world: the assumption that TB

patients are careless and responsible for their own infection;¹⁹ the association of TB with HIV¹² and with immoral behaviour;¹⁹ and perceptions that TB is incurable⁴ and very infectious throughout the treatment trajectory.¹⁷ These perceptions were often associated with patients' fear of disclosure, discrimination, social exclusion, and/or isolation.^{12,17,19,27}

Within community-level discourses, perceptions of TB were often linked to HIV, a finding that coincides with a Zambian study on HIV-TB related stigma.¹² We found that the derogatory term *Kanayaka*, used to warn against contacting with HIV patients,³³ was also used for TB patients. One Zambian HIV-study briefly referred to the usage of this term for contagious disease in general³⁴ explaining that HIV patients faced an extra dimension of stigma as the term additionally symbolised their upcoming and inevitable death. However, we found that *Kanayaka* for TB patients was used in a similar stigmatizing manner, labelling them both as a source of infection and as doomed to death. Additionally, TB patients experienced the negative attributes of HIV, such as allegations of immoral behaviour. The linking with HIV seriously aggravated TB stigma and illustrates that research on TB should not ignore HIV.

In contrast to findings in a Nepalese and a Zambian study,^{27,35} respondents did not associate TB with poverty or low class. A plausible explanation is the relatively limited socio-economic variation in the studied population. This resonates with World Bank statistics³⁶ that 60.5% of the Zambian population lives under the poverty line and a socio-economic case study of Lusaka describing that poverty levels are specifically high in slum areas such as Kanyama.³⁷

Two groups that have proven extra vulnerable were children and women with TB. First of all, childhood TB is a recognised, yet under-researched problem³⁸⁻⁴⁰ and studies on children and TB-related stigma are scarce.^{41,42} Our quantitative data demonstrated that children were as vulnerable as adults to suffer from the social consequences of stigma. During qualitative data collection, several patients explained that community members generally thought children were unable to contract TB. A paradoxical finding was that as a result, TB infected children faced an extra dimension of stigma being confronted with misunderstanding and uneasiness.

Secondly, quantitative analysis showed that women were significantly more vulnerable to stigma than men. Additionally, qualitative analysis showed more women faced stigma, despite the higher number of men interviewed. This finding resonates with previous research worldwide.^{17,43-45} Another study conducted in Lusaka describes the vulnerable position of female TB patients explaining that this group has more often diagnostic delays because of stigma.⁴⁶ Moreover, we found that women are often blamed in the local understandings of TB transmission, a finding that parallels a study on HIV-related stigma in Zambia³³ in which women are blamed for the spread of HIV and more impacted by stigma. Gender inequality enhances the vulnerability for stigma and, additionally, leads to different consequences of stigma among women and men.^{33,35,43-45} Following

this argument, the differences in stigma between male and female patients reflect gender inequalities in Zambian society where, historically, women often have more limited rights and power than men.⁴⁷⁻⁵⁰ In this context, TB-related stigma can be perceived as being rooted in cultural patterns of gender inequality. Therefore, we postulate that there is an important link between stigma, gender, and TB perceptions, a connection insufficiently recognised in the literature on TB-related stigma as in TB policies.

It is important to fight stigma as its social consequences hinder effective TB control causing delayed diagnosis and poor treatment compliance. Consequently, this leads to poor treatment outcomes and treatment failure, fuels ongoing transmission, and facilitates the emergence of TB drug resistance. Kanyama clinic has acknowledged the importance of fighting stigma, and developed several interventions such as a treatment supporter programme, family and community sensitization, and counselling. However, based on the findings of this study these programmes are not (yet) functioning optimally.

Many patients reported experienced and/or anticipated stigma. Anticipated stigma should be taken as seriously as experienced stigma as it reflects the prevalence of stigmatising understandings and practices in the community. Accordingly, respondents mentioned repeatedly that community members possessed insufficient (biomedical) knowledge and hold TB misconceptions. However, ascribing stigma solely to a knowledge deficit and assuming that knowledgeable people will not stigmatize ignores the cultural context with deep-seated beliefs.⁵¹ Therefore, instead of simply relaying biomedical knowledge, we advocate interactive sensitisation programmes at schools and in the community that stimulate discussion and raise awareness regarding stigma. In addition, stigma-reducing measures should not only be implemented at the TB corner, but across the clinic.

Strikingly, almost one third of patients reported that they never received TB-information, notwithstanding the available sensitization programmes at the clinic and the skilful, experienced staff. This gap was only partially explained by patients who mentioned that they had been too ill to pay attention; that educational sessions did not sufficiently capture patients' attention; and that information was often too complicated for patients to comprehend.

Patients' ignorance regarding TB can be associated with the fact that about half of the stigmatized patients had internalized stigmatizing beliefs. They reported shame or self-exclusion indicating that, notwithstanding education and supervision, they blamed themselves for contracting TB and lacked sufficient ability to ignore or resist stigmatizing cultural ideas. To diminish internalised stigma, more empowerment of patients with regards to their TB status is needed, either through sensitization, counselling, or support groups. For instance, the clinic's current running and successful support groups for TB-HIV co-infected patients should extend to all TB patients regardless of their HIV status.

Lastly, within these programmes more attention is needed for the vulnerable position of women and children. Since women disproportionately bear the burden of TB stigma in Zambia, they urgently need better care. Although gender inequality is influenced by structural patterns that cannot be changed easily, it is important to take these factors into consideration. Interventions aimed at combating TB and TB-stigma need to acknowledge that women often have a lower social status, insecure economic position, and receive less education. Furthermore, children may be even more affected by stigma than adults that calls for interventions specifically targeted at this vulnerable group.

Limitations and strengths

The study was embedded into the larger TBAC-study allowing identifying those 138 patients who described positive or negative TB-related perceptions and attitudes for detailed assessment. However, it may be that we underestimated the extent of stigma: the structured interview questions might have been inadequate to provoke associated answers or shame resulting from stigma could have made respondents reluctant to discuss the topics. As we did not find major differences in characteristics between the two groups, we consider risk of selection bias to be minor. In future research, we suggest that the quantitative component of the study should contain more stigma-related questions to allow a focus on the overall study group. Additionally, during qualitative research, we found that children and adolescents faced an extra dimension of stigma, yet their low representation within the study group impeded extensive analysis. Further research is required to study TB-related stigma for this group in more detail. Furthermore, the fact that patients referred to rural areas were lost to follow up, reflects the poor administration systems in rural clinics. In addition, some patients referred to rural clinics' difficult accessibility and availability, calling for a similar research in a rural area. Unfortunately, we did not document patients' non-response rate.

The major strength of this study was the mixed methods design enabling triangulation of study findings. Quantitative research illustrated how many patients struggled with TB-related stigma and identified sex to be significantly associated with stigma. Subsequently, qualitative data analysis was conducted to contradict or confirm quantitative outcomes, to explain the statistical relationship, and to provide in-depth case illustrations for a comprehensive understanding of TB-related stigma.

CONCLUSION

Despite the existence of various programmes fighting TB-related stigma in urban Zambia, TB patients continue to experience stigma extensively. Prominent findings are the high vulnerability of women to stigma, the prevalence of stigma

among children, the influence of stigma-related issues on the TB control programme, and the stigma-provoking misconceptions in the community regarding TB transmission, the relation between TB and HIV, and the perceived upcoming death of TB patients. We therefore recommend a revision of both the content and the implementation of interventions aimed at reducing stigma.

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Section

IV

TB and medical pluralism in Gabon



Perceptions, health care seeking behaviour and the implementation of a tuberculosis control programme in Lambaréné, Gabon

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ABSTRACT

Setting: Lambaréné, Gabon.

Objectives: To describe patients' perceptions of tuberculosis (TB) and to determine factors that influence their health care seeking behaviour in order to gain insight in the management of TB.

Design: Participant observation, in-depth semi-structured interviews and focus group discussions were conducted with 30 TB patients, 36 relatives, 11 health care providers and 18 traditional and spiritual healers. Recruitment of patients was linked to the PanEpi study and took place at the Albert Schweitzer Hospital, the General Hospital and the human immunodeficiency virus (HIV)-TB clinic.

Results: Patients generally described TB as a natural and/or magical disease. The majority of the patients combined treatment at the hospital with (herbal) self-treatment, traditional, and spiritual healing. Despite the free availability of TB treatment in principle, patient adherence was problematic, hindering effective TB control. Most patients delayed or abandoned TB treatment due to financial constraints, stigmatisation, ignorance about treatment, change of health care service, or use of non-prescribed antibiotics. The situation was occasionally complicated by drug stock-outs.

Conclusion: There is an urgent need to bridge the gap between patients and the hospital by avoiding drug shortages, intensifying cultural-sensitive TB health education, embedding TB care into the cultural context and enhancing cooperation between hospitals, patients, traditional healers and communities.

With an estimated worldwide incidence of 9.4 million cases in 2009, tuberculosis (TB) remains a major public health problem and the epidemic is increasing, despite efforts to contain it.¹ Eighty per cent of all TB patients live in sub-Saharan Africa,² where the disease is putting enormous pressure on many health care systems.

In Gabon, the estimated incidence of TB is 450 per 100 000 population: 46% of all TB patients are co-infected with human immunodeficiency virus (HIV), and 10% have multi-drug resistant (MDR)-TB³ posing a severe Global Public Health threat. The Gabonese National TB programme (NTP) is responsible for (passive) case detection and provides antituberculous treatment without cost, however stock-outs occur repeatedly, there is no countrywide infrastructure for sputum culture and drug susceptibility testing, and the World Health Organization (WHO) promoted TB control strategy is not implemented. As in other settings,⁴⁻⁷ adherence and compliance problems contribute to a low (34%) TB treatment completion rate, with 45% patients abandoning treatment.⁸

In general, cultural, economic, and social considerations play a significant role in treatment adherence. Traditional and spiritual healing services, which are commonly used by Gabonese TB patients, constitute an important alternative to hospital services. Economic factors are significant as TB, classified as disease of the poor and facilitated by inadequate nutrition or overcrowded living conditions, places a financial burden on most patients.^{6,7,9} Gabonese patients often face financial problems regarding transport or in accessing treatment during the frequent temporary national drug stock-outs. Social constraints exist as TB often generates stigma, a discrediting social label.^{7,10,11}

In Gabon, little research has been conducted so far on TB.^{8,12,13} No medical socio-anthropological TB research has been published, whilst previously published studies from other areas have proven important for health care improvement.^{4-7,11} Considering the major issues surrounding TB in Gabon, such research is highly relevant as it provides knowledge about the health care seeking behaviour of patients, which may guide the development of interventions for the prevention and control of TB.

METHODS

The study population consisted of patients (aged >18 and diagnosed with TB) recruited into an ongoing TB epidemiology study in Lambaréné, Gabon. Families of patients, health care providers, traditional healers registered with the Gabonese National Traditional Healer Association, and spiritual healers (Catholic, Protestant, Pentecostal, Celeste, and Reveil churches) were approached. In 2012, a four-month case study was conducted using a mixed-methods approach that consisted of document analysis, participant observation, in-depth

semi-structured interviews, and focus group discussions. Participant observation was conducted at the Albert Schweitzer Hospital, the general regional hospital, the governmental ambulatory health care centre for HIV and TB, patients' homes, traditional healing sessions, spiritual healing sessions, and l'Institut de Pharmacopée et de Médecine Traditionnelles (governmental institute for herbal treatment). Respondents were interviewed repeatedly using a questionnaire on socio-demographics, treatment, perceptions about TB, health care services, and stigma. The latter three topics were also discussed during two focus group discussions with TB patients, acquaintances, and health care providers. Ethical approval was obtained from the institutional review board of the Centre de Recherches Médicales de Lambaréné (CEI-MRU number: 011/2012). Informed consent was provided by respondents before recruitment, interviews, and observation.

RESULTS

Thirty TB patients, 36 relatives, 11 health care providers, and 18 traditional/spiritual healers were included. Patients attended the hospital to see a doctor and for sputum analysis after a period of coughing and/or being ill [range two weeks - two years] and were generally unaware of having TB (27/30, 90%). At arrival, the majority of the patients (18/30, 60%) had already developed signs and symptoms that had profoundly compromised their activities of daily living. Almost half of the patients (14/30, 47%) were so ill that they were convinced they would not survive. Four patients (13%) died due to TB during the four-month study period. Eight patients (27%) abandoned the treatment provided by the hospital.

Perceptions of tuberculosis

An examination of local terms for TB revealed five aetiological principles: 1) *vampires* or *fusils nocturnes* (night rifles), i.e. evil spirits launched with sorcery, 2) *poisons*, 3) *demons*, Gabonese nature spirit, 4) *germs*, and 5) *God*. TB caused by the first three principles was called *magical TB* (*disease from the Blacks*) in contrast to the latter two principles which caused *natural TB* (*disease from the Whites*). Sometimes TB was considered both magical and natural referring to at least two of the aetiological principles. Twenty-four patients (80%) believed evil spirits could make you ill. The remaining six patients and all of the spiritual healers acknowledged the existence of spirits, but said not to believe in them, as this could aggravate illness.

Respondents described different ways of diagnosing the cause of TB. Although hospital tests were seen as the best method, only seven patients (23%) initially made use of these. Positive test results were explained as patients having natural TB, while negative results suggested magical origins. However, sometimes

diagnostic difficulties (sputum negative or extra-pulmonary TB) or inadequate diagnostics (e.g. only taking a blood sample) could at times be interpreted as magical TB (interviews with health care providers, focus group discussions). Moreover, if TB was diagnosed magically by spiritual or traditional healers, the patients did not attend the hospital, believing that the *Treatment from the Whites* would not be effective.

Anti-tuberculosis treatment

Twenty-two patients (73%) agreed that magical TB could only be treated by a traditional or spiritual healer, in contrast to natural TB, which could additionally be cured in the hospital. Six patients (20%) reported TB did not have magical causes and thought that it could only be cured in the hospital.

The majority of the patients had turned to various forms of health care, such as (medicinal) plants, pharmacy, *fokoro* (antibiotics without prescription), the hospital, traditional healing, and spiritual healing (prayer or exorcism) (Table 1). Twenty-two patients (73%) combined western and spiritual or traditional health care, mostly successively (20/30, 67) when TB perceptions changed or different healing services were viewed as effective yet too powerful to be used simultaneously.

Table 1 Health care services for TB patients in Gabon

Patients' Choice for Health Care Service				
Nr.	First	Second	Third	Fourth
1	Plants	Traditional healer	Hospital	
2	Plants	Hospital	Traditional healer	
3	Plants	Exorcism & prayer	Fokoro	Hospital
4	Plants	Exorcism & prayer	Fokoro	Hospital
5	Plants	Traditional healer	Hospital & prayer	
6	Plants	Hospital		
7	Plants	Exorcism & prayer	Hospital	
8	Plants	Hospital		
9	Plants	Hospital & prayer		
10	Plants	Pharmacy	4 traditional healers	Hospital
11	Plants	Pharmacy	Hospital & prayer	Traditional healer*
12	Plants	Traditional healer	Hospital	
13	Plants & traditional healer	Hospital	Traditional healer	
14	Plants & Fokoro	Hospital & prayer		
15	Plants & pharmacy	Hospital & prayer	Exorcism	

Table 1 Health care services for TB patients in Gabon

Patients' Choice for Health Care Service				
Nr.	First	Second	Third	Fourth
16	Hospital			
17	Hospital			
18	Hospital & prayer			
19	Hospital & prayer			
20	Hospital	Traditional healer		
21	Hospital & exorcism & prayer			
22	Hospital & plants	Traditional healer**		
23	Pharmacy	Plants	Hospital	
24	Pharmacy	Hospital		
25	Pharmacy	Traditional healer	Hospital	
26	Pharmacy	Hospital & traditional healer		
27	Pharmacy	Hospital & prayer	Traditional healer*	
28	Pharmacy	Hospital		
29	Pharmacy & prayer	Hospital		
30	Fokoro	Hospital & prayer		

* Option for the future, in case hospital treatment would not work

** Patient died before going to traditional healer

Fifteen patients (50%) initially used (medicinal) plants. All respondents said that in almost every Gabonese family someone had traditional knowledge about herbal treatments, making this healing method common and easily accessible.

'When I fell ill, my mother started of course with the trick of the village. She used wood, leaves, medication to get me back, to get me better.'

(Patient interview)

One third of the patients (9/30, 30%) first went to the pharmacy or bought fokoro, believing their TB to be an ordinary fever or cough. A third group began with a hospital visit (7/30, 23%).

For many of the patients, the hospital was not the first choice of health care, and even considered problematic or unacceptable by some. Long treatment and correct use of anti-tuberculosis medication were difficult since they explained that *'many Gabonese patients have "another concept of time", being less punctual or future-oriented'* (interviews with health care providers, participant observation). Moreover, many Gabonese people did not believe that diseases could be chronic or prolonged; rather diseases were considered as instantly

curable. Some patients felt that the Whites and their hospitals were a threat to traditional health care services (interviews with health care providers, three patients, focus group discussions, participant observation).

Almost a quarter of the respondents (7/30, 23%) explained the importance of traditional health care, which is deeply anchored in local religion. Use of traditional health care requires an initiation ritual, a ceremony to become part of the ethnic group, as illustrated by the following quote:

'I was initiated. That is obligatory here in the village. You have to secure yourself against sorcery and vampires. I was 12 and wanted my initiation so badly. All my friends had done it already.'

(Patient interview)

Informants explained that without initiation there was a risk of becoming marginalised: *'Because you are not protected against evil spirits and more important, you are not part of the group'* (Patient interview).

Almost half of the patients made use of spiritual healing, through prayer (13/30, 43%) and exorcism (4/30, 13%). According to these patients and spiritual healers, this gave strong (psychological) support. Two patients and two spiritual healers described how certain spiritual healers prevented patients from going to the hospital as they claimed this was unnecessary.

Socio-economic factors

Most patients (28/30, 93%) had a low socio-economic status, as determined from their housing, education, and stories (interviews, participant observation). They lived in wooden houses with few windows and no running water. Patients lived with on average six other household members [range 0-30]. Nineteen patients (63%) were financially responsible for their family, their disease therefore placed a significant economic burden on the household. Two patients (7%) had postponed a hospital visit, because they were unable to leave work for financial reasons or children, or pay for transport.

In principle, the NTP covered anti-tuberculosis medications, but patients occasionally had to buy their drugs from local pharmacies (maximum €70-110 per month) due to drug shortages, resulting in three patients (9%) abandoning treatment. Traditional healers charged around €200 for treating TB, which was sometimes cheaper and more accessible being located in the villages.

Generally, the educational level of patients was low; they (had) attended primary school (67%) secondary school (37%), or an occupational training courses (9%). None of the patients nor their families knew in advance that anti-tuberculosis treatment was provided free of charge. Health care providers, two spiritual healers, and three traditional healers were aware of this. Two patients (7%) abandoned treatment, because they felt cured, not realising that they could

relapse. TB was only briefly discussed in primary school. One non-governmental organisation for TB was located in Libreville, but no campaigns had been conducted in Lambaréné.

The majority of the patients felt stigmatised describing their disease as socially problematic (20/30, 67%). They understood people's fear of becoming infected and therefore occasionally concealed from others the fact that they had TB (Table 2). Two patients (7%) denied having TB and three patients (9%) had an acquaintance who denied having TB. Going to a traditional healer guaranteed greater privacy, as they were located nearby and visits could be arranged quickly. As a consequence some patients felt less stigmatised (focus group discussions, participant observation, interviews patients & health care providers).

Table 2 Stigma and TB patients in Gabon

Experience with stigma	Number (percentage)	
Not problematic	10/30	(33%)
Not (or less) problematic, because TB is curable	15/30	(50%)
Problematic	20/30	(67%)
Difficulties at social level	17/30	(57%)
Trouble at work	2/30	(7%)
Only informing some people about their TB	8/30	(27%)
Hiding/refusing their TB	2/30	(7%)
Knowing someone who hides/refuses TB	3/30	(10%)
Double stigma: TB & HIV	4/30	(13%)
No TB stigma, only HIV stigma	2/30	(7%)

DISCUSSION

In Gabon, TB remains a major issue despite the free access to anti-tuberculosis drugs. Based on an analysis of TB perceptions and the health care seeking behaviour of TB patients, this case study demonstrates how cultural, social and economic factors influencing patient adherence prevent successful implementation of the TB control programme.

Illness perceptions are an important focus of medical research as these generally affect health care seeking behaviour.¹⁴⁻¹⁹ In Gabon, the respondents explained TB in a biomedical (*natural*) or a traditional or religious (*magical*) way. This dichotomy is often described in African settings,^{11,16,20,21} having *natural* TB explained *how* a patient got infected with TB bacteria, but did not explain *why* the person got ill. Having *magical* TB meant jealous people had performed sorcery on the patient. In contrast to a Tanzanian study on malaria,²¹ traditional explanations were used not only when medical knowledge met its limits, such

as in the case of negative test results or treatment failure: inadequate diagnostics additionally evoked at times suspicions of magical TB, which called for traditional or spiritual healing. Moreover, when traditional or spiritual healers diagnosed *magical* TB, patients were encouraged to avoid the hospital or to abandon treatment as the *Treatment from the Whites* was considered ineffective.

It thus becomes clear why patient and care giver perceptions of TB are an essential factor in health care seeking behaviour. There may have been a selection bias in the study, as all patients were recruited from recognised health care services. Nevertheless, valuable insights were gained, as most respondents did not present first to the hospital, a finding that is in contrast with a Kenyan study⁷. Data were gathered regarding patients' *pluralistic health treatment*,^{4,11,19,22,23} i.e. combining various formal and informal health care services, such as hospitals, pharmacies, traditional or spiritual healers, and herbal treatment.

Hospital delays and treatment abandonment led in approximately half of the cases to such a poor state of health that the patients were convinced that they would not survive. This was related to patients' poor financial situation or the patients' impression of being healthy, a finding supported by previous work on TB in Gabon.⁸ However, drug shortages, the availability of *fokoro*, usage of alternative health care services, and stigma were other important determinants. As previous research suggests, the degree of TB-related stigma was not as great as HIV-related stigma,¹¹ yet TB-HIV co-infected patients were often double stigmatised. Felt or feared stigma occasionally led to fear of disclosure and self-exclusion from health care services.²⁵ One study described how the chronic nature of TB aggravated stigma.⁷ Interestingly, during focus group discussions and interviews, TB stigma was often denied because of the curable nature of the disease. In fact, it was said that many Gabonese people denied the concept of chronic or long-term diseases, and preferred traditional healers, who supposedly provided immediate cure.

Structural factors, such as poverty, poor infrastructure, or NTP drug shortages negatively impacted the patient's ability to adhere to treatment. The majority of the TB patients had a low socio-economic status and faced financial difficulties with transport or drugs. In Gabon, the distance to the health centre is the most important determinant of survival for malaria patients.^{20,26,27} Traditional healing was occasionally considered by patients to be cheaper and more convenient, in line with reports from other studies.^{6,7} However, traditional healing sessions were also oftentimes expensive. Furthermore, none of the patients knew that anti-tuberculosis medication at the hospital was provided free of charge in principle.

TB is an under-addressed topic in Gabonese health education and the early symptoms are often initially believed to be an ordinary cough, hence a preference for herbal treatment. People should be made more aware of TB symptoms and the danger of prolonged self-treatment. In addition, an understanding of adequate anti-tuberculosis treatment is necessary to avoid the development

of drug resistance. Furthermore, the consequences of fokoro use should be researched in Gabon, where the prevalence of MDR-TB among TB cases is 10%³ and a second-line drug repository is lacking,¹³ this is highly urgent.

The usual theories on poverty and low level of education do not adequately explain the spread of TB however. Important too, especially in rural areas, were deep-seated traditional beliefs and the fear of being marginalised if TB patients did not use traditional healing. Protection against witchcraft and magical diseases provided by a traditional healer was often socially mandatory. However, these social expectations and associated power structures have not been reported by previous socio-anthropological TB studies.^{5,6,11,25} This finding highlights the need for culturally sensitive TB health education in which traditional and religious perceptions and practices are not neglected, but identified as part of the cultural context. Similarly, embedding the medical perspective into the socio-cultural context could advance communication between health care providers and patients.^{6,7,25}

Interaction between hospitals and traditional and spiritual healers is advocated by the WHO.²⁸ In the light of the fact that that 30% of the TB patients presented to traditional healers, such calls for integration of traditional healers into national health systems should receive continued support. This collaboration is important to soften patients' defensive attitude to hospitals and encourage patient adherence.

Previous work has elaborated on the substantial influence of family and community members on health care seeking behaviour resulting in shorter hospital delay⁶. Their influence and possible cooperation should be further explored.

CONCLUSION

Attention should be given to the influence of structural, cultural, and socio-economic factors on the health care seeking behaviour of TB patients, as this has a major impact on infection and the emergence of MDR-TB. In addition to structural improvements in hospital diagnostics, availability of drugs, and reduction of transport costs, it is important to provide culturally sensitive TB education, embed medical perspectives into the cultural context, and involve traditional and spiritual healers and communities in bridging the gap between patients and caregivers to improve TB control.

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Exploring processes of boundary-making and the concept of medical pluralism in Lambaréné, Gabon

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Submitted

ABSTRACT

The topic medical pluralism fuels interesting discussions about how healers position themselves and their healing practices within a therapeutic landscape, and how patients navigate between a vast array of therapeutic traditions. Based on fieldwork in Lambaréné, Gabon, this paper examines discursive practices of tuberculosis patients and healers indicating that therapeutic traditions were kept separate. Attention is given to a national programme of the Gabonese government which fosters traditional medicine and potentially informs boundary-making processes between therapeutic traditions. They reinforce traditional healers' position within the Gabonese therapeutic landscape and additionally aim for collaboration between traditional medicine and biomedical medicine. This paper confirms popular paradigms of boundary-making within the medical pluralism debate wherein boundaries are produced and crossed to contrast, strengthen, purify, and divide the therapeutic landscape. Additionally, I differentiate between formal, state-sponsored and local discursive practices. I introduce the concept *conventional boundary-making* describing the reluctance reflected in patients' and healers' discursive practices regarding the notion of fluid or adaptive boundary-making processes within the therapeutic landscape.

Jadougou had brought his wife, Adeline, to a hospital in Lambaréné, Gabon, because she had felt very ill for months. Here, she was diagnosed with extrapulmonary tuberculosis (TB). Adeline was hospitalized for several weeks and put on first-line antituberculous drugs, but did not seem to recover. During my visits at the hospital, Adeline was too ill to converse, so I mostly talked to Jadougou. He continuously expressed his troubles regarding the care of his wife. He feared that her TB was magical; that someone had bewitched her, but struggled with the taboo of using different therapeutic traditions simultaneously. Their church leader had approved this hospital visit, yet condemned consulting a traditional healer as such healing practices were associated with work of the devil. However, in case of bewitchment, treatment from the hospital could not cure his wife. During several visits he admitted that he was planning on visiting a traditional healer:

'If my wife is still ill after some time, we might go to the traditional healer. We, Protestants, are not supposed to go there. [...] The church doesn't like it if two different religions are combined. But you have to do something to get healed'

(Informal conversation, husband of TB patient Adeline, Jadougou).

Jadougou carefully expressed that he could only justify a switch to another therapeutic tradition if it was certain that the biomedical treatment would provide no cure. Unfortunately, Adeline died after four weeks leaving Jadougou devastated and with mixed feelings about his own care-taking behaviour. On the one hand He regretted that he had not done everything to save Adeline's life. However, on the other hand he described feeling relieved at not having engaged in different therapeutic traditions at the same time.

Jadougou's carefully plotted care seeking behaviour and his changing decision points over time, raises the question how medical pluralism is shaped and organized in Lambaréné, Gabon. In this article, I focus on TB patients and their healers in Lambaréné, Gabon who resort to discursive practices to explain how they navigate a plural medical field while acting on TB. With discursive practices, I refer to discourse that not merely reflects the existence of a reality, but additionally defines the social rules that construct this reality.¹ Moving away from literal actions or behaviour, this study analyses the idea of conceptual boundary-making processes that are principally constructed within speech. Within the field of medical anthropology, encounters with different therapeutic traditions have often been discussed in the light of notions of boundary-making processes.

The idea of fixed, static boundaries between different therapeutic traditions has shifted to theories of how the variety of illness perceptions and therapeutic traditions intermingle and interact in people's practices while searching for a cure.^{2,3} The reproduction and the crossing of boundaries are mutually constitutive acts, as no boundaries are to be crossed if there are none produced and the other way around.⁴ Boundary-making practices between therapeutic traditions are often presented as being fluid and continually reconfigured.^{4,5}

Whilst explaining the functioning of medical pluralist societies and associated practices of boundary-making, various authors have referred to the role of the state, predominantly in Eastern^{6,7} or Western countries.^{8,9} States may impose a discourse that purposely excludes biomedical explanations and practices to professionalise and strengthen the position of traditional medicine within society. Their campaigns may prompt processes of negotiation and redefinition of both traditional and modern medicines.⁷ Luedke and West⁴ describe how boundaries are created to define and delineate traditional healing, but at the same time can be crossed, challenged, and shifted.

Likewise, in Gabon, boundary-making practices within the Gabonese therapeutic landscape have changed and shifted through colonialism and nationalistic political programmes. TB patients negotiate treatment decisions in a context where the national political programme fosters the traditional cult and same-named religion *Bwiti* and associated traditional therapeutic practices. *Bwiti* has been given a lot of emphasis, because the Gabonese government claims that it represents Gabonese tradition. Scholars describe *Bwiti* as a political project to reunify the various ethnic groups of Gabon defining what is 'authentically' Gabonese.^{10,11} Traditional medicine is one of the important elements embedded within this politicised traditional *Bwiti* culture. A state-imposed campaign fosters traditional healing and may produce processes of boundary-making by acknowledging the position of traditional healers in the therapeutic landscape. Moreover, their campaign breaks boundaries down by encouraging collaboration between healers. Such a therapeutic discourse of boundary-making and -breaking can achieve local and national relevance informing the medical plural landscape and the position of its actors.

Within this debate about medical pluralism and boundary-making, I would like to add an additional concept, *conventional boundary-making*. This concept is derived from my respondents' discursive practices which portrayed a separateness between therapeutic traditions. Both healers and patients explained that boundaries were crossed at times, a practice that is extensively discussed in the literature. However, boundaries were not shifted or reconfigured. Similarly, Orr¹² briefly notes that in contrast to contemporary theories, he had hardly encountered a blurring of boundaries between therapeutic traditions in southern Peru. One of the examples in which discursive practices reflected notions of conventional boundary-making was the case of Jadoungou who explained a preference to engage in therapeutic traditions subsequently and not simultaneously.

To elucidate notions of conventional boundary-making, I draw on five months of fieldwork in Lambaréné, Gabon. This study has been part of a larger health study on TB in Lambaréné, hence this explains why the focus of fieldwork has been narrowed down to TB patients and their healers. Nevertheless, study results go beyond the theme of TB, as patients and healers often discussed healing practices and navigation of the therapeutic landscape in general. In this article, I discuss some of the vast array of literature concerning medical pluralism with a focus on conceptualisations of therapeutic traditions. After, I will introduce this study and the main therapeutic traditions encountered in the field. I draw on notions of conventional boundary-making to present TB patients' and healers' discursive practices in response to their experiences of navigating the therapeutic landscape. I do not claim that the notion of boundary-making is new, neither that medical pluralism does not occur. Instead, I aim to describe a variant of boundary-making processes that manifests in discursive practices and in which a reluctance towards boundary-reconfiguration is embedded. In other words, boundaries are said to be crossed but not challenged and shifted. Finally, I will speculate why discursive practices of such boundary-making practices occur and how these could be related to theories of state power^{13,14} and Gabonese therapeutic identity politics.^{10,11,15}

MEDICAL PLURALISM AND PROCESSES OF BOUNDARY-MAKING

In the seventies, Leslie¹⁶ represented the variety of biomedical, traditional, and alternative health care in India and China as *medical systems* acknowledging their well-developed and sophisticated nature. This idea formed a sharp contrast with previous studies that described traditional medicine merely as part of traditional religions. The representation of medical pluralism as equal to medical systems strengthened traditional healers' positions and recognized their ability to compete with biomedical systems.^{5,17} Kleinman¹⁸ further questioned the ubiquity of biomedical interpretations by introducing a differentiation between the social construction of *disease* and *illness*. He advocated recognition of both biomedical diagnoses and of patients' experience of illness. Within the idea of an individualised illness experience, scholarly attention was increasingly given to the influence of specific sociocultural, political, and economic contexts, leading to a wide range of models to explain illnesses and health care.⁵

The notion of *multiple explanatory models*¹⁸ evoked discussion about patients' responses to an environment in which a variety of therapeutic traditions were present. Theories started off with the idea of fixed, parallel systems with sharp boundaries, used by patients either sequentially or simultaneously.^{18,19} This paralleled the popular multiculturalism theories of the nineties in which minority groups maintained their identities and practices and were not expected to assimilate into a dominant cultural group.²⁰ Yet, the representation of closed medical systems with their own internal logic, homogeneous group of practitioners

and patients, and structured treatment regime became criticized. Last³ referred to a spectrum of de-systemized and scattered medical practices from which patients would choose when it was considered appropriate. He presented patients as pragmatic, i.e. patients who would engage in pluralist health strategies in order to get healed as soon as possible. Several anthropologists described trial and error practices as a common part of decision-making processes regarding therapeutic traditions. Failed treatment in one tradition would trigger the patient to seek health care from another therapeutic tradition.^{2,21} The associated taxonomy of therapeutic traditions often applied by anthropologists became widely rejected.²³ Rejection of a certain hierarchy should be seen in the context of the modernization debate in which the superior position of modern culture and the presumption of a linear evolutionary development into modernity was replaced by processes of cultural maintenance and interplay between *modern medicine* and *traditional medicine*.²² African therapeutic traditions did not seem to be destroyed through colonialism or replaced by biomedicine, but appeared adaptive and resilient.²³ Conversely, Europeans likewise adopted and internalised elements of African therapeutic traditions, such as herbal remedies.²⁴ Following these ideas, later approaches presented biomedical and traditional therapeutic traditions in a more symmetrical fashion leading to a reconsideration of the latter and its importance for patients. Moving beyond the idea of systems within certain hierarchies, various authors have offered looser frameworks, such as the term *therapeutic traditions*.²⁵

Nowadays, anthropologists have repeatedly demonstrated the problematic conceptualization of processes of entanglement between different therapeutic traditions and explanatory models. A variety of processes have since been described, including *bricolage*, *hybridism*, *syncretism*, *assemblage*, *eclecticism*, *selection*, and *adaptation*.⁵ In addition, various concepts came into use, such as *circulation*²³ and *indigenization*²⁶ to describe how actors in the therapeutic landscape crossed, shifted, and reproduced boundaries by adopting each other's therapeutic elements. In the last decade, yet another perspective which emphasises the fluid and continually changing nature of boundaries between therapeutic traditions, has gained popularity.^{4,5}

The notions of multiple explanatory models and *boundary-making* are closely related to debates of power strategies, as boundaries are generally considered arbitrary yet always powerful.²⁷ The maintenance and crossing of boundaries within the medical landscape are described by many as a tool to empower therapeutic traditions.⁴ For example, biomedical professionals may aim to maintain sharp boundaries with alternative therapeutic traditions in order to prevent competition and to confirm their superiority.²⁸ Similarly, faith healers have been observed to create a boundary by stressing how divergent their healing approaches are compared to other approaches.²⁹ Nevertheless, many contemporary ethnographers discuss how actors (mainly from the traditional or religious therapeutic traditions) transgress imposed boundaries, using this

action as a tool of resistance against taken-for-granted hierarchies in the therapeutic realm.³⁰ Studies have described how traditional and faith healer categories seem to mix and entangle leading to healers representing a variety of healing traditions and combining healing techniques.²⁸ Some traditional healers transgress boundaries by incorporating biomedical practices³¹ or creating institutions.²⁸ Boundary transgression fuels reinforcement of their medical expertise, authority, and legitimacy to heal.

Boundary-making processes can similarly be imposed by states generating powerful realities. The state can have an important influence on the development of a medical pluralist society and the maintenance or crossing of symbolic boundaries between therapeutic traditions. Most plural medical studies that focus on the role of the state, explore co-existence and processes of intertwinement between therapeutic traditions. Consequently, the literature often describes an integration of traditional medicine into national health systems.^{6,8,9} Zhan⁷ describes how the state aimed to scientificize Chinese medicine to enable competition with biomedical science. As a consequence of traditional medicine success, biomedicine and traditional therapeutic traditions were woven together, intermingling, interchanging and adapting. Zhan analysed-Chinese state-imposed discourses regarding traditional medicine and its relationship with national identity politics, but argued that the position of traditional Chinese medicine within the therapeutic landscape remained marginal.

This brief overview of medical pluralism with a focus on processes of boundary-making and the role of the state therein, scratches only the surface of the enormous plethora of available literature. However, it provides a framework for exploring and understanding the findings of my study.

METHODS AND SETTING

In 2012, I conducted four months ethnographic fieldwork in and around Lambaréné, Gabon with assistance from Grace Bikene, a local researcher. Aiming to explore how TB patients navigated a medical plural landscape, I approached thirty patients who were following TB treatment at the Albert Schweitzer Hospital (ASH), the governmental regional hospital, or the governmental ambulatory health care centre for HIV and TB (GAHC). Recruitment took place with the help of researchers from a TB epidemiology cohort study (PanEpi) at the ASH in Lambaréné. We visited patients multiple times at their homes and interviewed them and their family members in French about their experiences with TB and the associated (medical plural) care they engaged in. All interviews lasted one to two hours, were in-depth and semi-structured, and were complemented with various informal conversations. Additionally, we approached faith healers (N=8), biomedical healers (N=10), and traditional healers (N=5) to understand how they positioned themselves within the medical plural landscape of Lambaréné and its surroundings. I intentionally approached one

traditional healer outside of the research area, in the capital Libreville, because he was well-known to most respondents as a healer who combined both biomedical and traditional healing practices. Two focus group discussions were organized with around eight TB patients each, one at the ASH and one at the GAHC to discuss perceptions about TB and health care seeking behaviour. I conducted extensive participant observations at patients' homes and villages, the biomedical hospitals, during nocturnal traditional healing practices, and during exorcist sessions conducted by faith healers in various churches (Pentecost, Protestant, Catholic, Christiansme Celeste, Christianisme du Réveil).

In order to understand the position of the state regarding the therapeutic landscape and traditional healing, I visited the governmental Institute of Pharmacology and Traditional Medicine (IPHAMETRA) in Libreville, Gabon's capital. I conducted participant observation, and several in-depth interviews with its director and traditional healers (N=5) to discuss the role of traditional healing in Gabon. As stated earlier, *Gabonese traditional identity* is officially represented by the political construction of the Bwiti,³⁰ yet there are many other traditional societies and healing practices such as the *Ndokwe*, *Mekum*, and *Ndjembe*. These have received less political attention compared to Bwiti.³⁵ The website of IPHAMETRA merely referred to the broad term *traditional healing* and did not particularly specify Bwiti as the bringing together of a wide variety of traditional healers regardless of their cult or religion.

For analysis of ethnographic data I used a grounded theory approach leading to the emergence of five main themes of conventional boundary-making: dichotomy between medicine from the *Blacks* and *Whites*, a taboo of combining therapeutic traditions, justifying a change of therapeutic tradition, the danger of combining two therapeutic traditions, and therapeutic traditions in their essence being the same. Some themes may be familiar as they confirm older literature discussing the classical natural-supernatural dichotomy presented in African literature on health care³² and the secrecy surrounding traditional healing.³³ In the context of increased interest in shifting and reconfiguration of boundary-making between therapeutic traditions, these themes may take on a new meaning. Moreover, the latter three themes may shed some alternative light on how and why patients navigate between therapeutic traditions and may provide additional perspectives for the medical plural debate.

MEDICAL PLURALISM IN LAMBARÉNÉ

In Lambaréné, medical pluralism manifested in the vast array of therapeutic traditions available. I will, for the sake of convenience, loosely divide this medical plural landscape into three distinct categories: traditional healers, faith healers, and biomedical healers. In order to present a more symmetrical conceptualisation of these therapeutic traditions, I will refer to each of them as *healers* in this section. However, in the results section these terms will be

used interchangeably with the terms used by my respondents. Interestingly, respondents often referred to biomedical healers as doctors or medical doctors. However, one could argue that all categories can be considered as medical and all healers as doctors. Therefore, I have chosen to nuance this category with the term *biomedical*. The three categories of healers are based on a combination of the literature from Gabon, my observations during this ethnographic fieldwork, and the framing of healers and patients.

In order to understand the construction of *the traditional healer* in Gabon and the socio-political processes involved, traditional healing needs to be situated within the history of Bwiti. Around 1890, the ethnic group Fang incorporated the masculine initiation cult Bwiti and its similarly named religion Bwiti from the ethnic groups Mitsogo and Apindji in their own culture. With the arrival of colonist- and missionary influences in the same episode, Bwiti developed into a syncretic religion in which God, ancestors, and nature spirits were equally recognised. Many subcategories of Bwiti arose for different functional specialisations (*le Bwiti Disumba*, *le Misoko*, *le Ngonde*, *le Myobe*), varying rituals (*le Ndea*), or schismatic innovation (*le Sengedy*).³⁴ Samorini³¹ refers to inter-ethnic marriages, travel and local migration in order to explain how a wide variety of Bwiti interpretations was spread and practiced by a majority of ethnic groups. In addition, Ngolet³⁵ stresses that variety occurred because of different responses to economic and social problems encountered in Gabon.

Christians generally perceived the Bwiti religion and its followers as diabolic, because of their rich history of human sacrifices, anthropophagy, sorcery, and communication with the deceased. With support of the French colonial government, they aimed to eradicate this religion by killing Bwiti leaders and destroying their temples. This persecution and weakening of traditional knowledge invoked Bwiti to become a collective tool of resistance against colonial rulers meanwhile enhancing social cohesion among the Gabonese. In 1948, several important spiritual Bwiti leaders started a popular movement to reunify the different (Bwiti) cults and to strive for recognition by the Gabonese government.^{30,35} In 1960, Gabon became independent with its first president Léon Mba being a Bwiti initiate. After years of persecution, Bwiti came to symbolise a national and anti-colonial sentiment and '*the birth of the new Gabon Republic*'.³⁵ Nowadays, Bwiti is a fully recognised religion in Gabon and an important aspect of national identity, which secures traditional values. The therapeutic traditional values are promoted by IPHAMETRA. Interestingly, IPHAMETRA only represents herbal traditional healing and excludes traditional healing on a spiritual level.

Faith healers are not part of IPHAMETRA's assortment of traditional specialists despite the fact they have a prominent role in Gabonese society. In the literature, faith healers are often classified as the third type of traditional healer (alongside herbal and spiritual traditional healers), because of their similarities in therapeutic beliefs and practices. Both faith and traditional healers included

in this study explained TB as the involvement of evil spirits and were seen as authorities on witchcraft and sorcery. Whilst traditional healers were oftentimes additionally Christians, faith healers responded defensively after pointing out these similarities. They often stressed the fact that no linkages existed between them and traditional healers, because they condemned their work as practices of the devil. I will elaborate on faith healing practices in the context of Gabon's rich history, because they were presented as inseparable positioned within the Gabonese therapeutic landscape.

Processes of religious diversification in Gabon were not only apparent in traditional societies, but also within Christianity. New religious sects raised social and political issues and advocated an Africanization of the church. Their approach criticized the existing church policy for their sole focus on moralistic and religious issues, because of their state sponsorship. The proliferation of different churches, such as *Christianisme Celeste*, paralleled the emergence of new healing practices.³⁵

Biomedical medicine was introduced in Gabon during the colonial era and the arrival of missionaries. In 1913, Albert Schweitzer founded the first hospital in Lambaréné.³⁶ Nowadays, the hospital's colonial image with foreign sponsorship and foreign biomedical healers and nurses has progressed into a partially state-sponsored biomedical service with almost all the staff being Gabonese. It has developed into one of the three main biomedical facilities in this area. Biomedical healing has become more acceptable and accessible in the area, but is not universally trusted nor considered appropriate for all illnesses or conditions.

MEDICAL PLURALISM AND TUBERCULOSIS

The number of TB patients is alarmingly high in Gabon and many pass away because of this disease.³⁷ Despite my use of the term tuberculosis throughout this article, I do recognise the existence of a variety of diagnostic labels for this disease.

The traditional healers approached for this study used different names for TB but recognised its biomedical synonym. They treated TB patients with herbs, and some additionally used spiritual healing. Traditional healers formed a scattered, disconnected group, because of the variety of sources for their traditional healer knowledge and skills (e.g. through a dream, training of a spiritual father). Yet, there were some similarities as all healers were initiated in a traditional cult (three were Bwiti initiates), carried the name *nganga* (meaning healer in Bantu languages), and used the hallucinogen plant *iboga* as a central element in their (TB) healing practices. *Iboga*, by respondents referred to as *le Bois Sacré* (holy wood), was firstly used by the Pygmies who are seen as the original inhabitants of Gabon^{34,35} and is a symbol for Bwiti healing practices.³⁵ Moreover, these traditional healers were connected by a state-imposed campaign that professionalised traditional healing and each obtained a IPHAMETRA issued certificate to confirm their expertise in traditional healing.

Of the numerous Christian churches in Lambaréné, many engaged in faith healing of patients, using a power derived from the Holy Spirit. TB was often described as an illness bringing spirit and healing was represented in many different forms ranging from prayers to individual or communal exorcism sessions during which patients were released of evil spirits. Some faith healers additionally made use of herbal medication, holy water, or advised fasting. Various faith healers informed their patients of the option to additionally follow treatment at the hospital, but most condemned attending traditional healers.

Biomedical tuberculosis treatment at the included hospitals consisted of a first-line four-drug therapy to cure patients in six months. The Gabonese National Tuberculosis Programme (NTP) provided treatment without costs, but hospitals faced repeated drug stock-outs,^{38,39} which sometimes persisted for several months up to a year. At the time of this study, there were no diagnostic facilities to diagnose resistance against first-line TB drugs, and second-line drugs were not available.

Gabon's rich history of medical pluralism with its wide spectrum of traditional, faith, and biomedical therapeutic traditions, raises the question about what discursive practices are used by TB patients and healers regarding their own position while navigating this plural therapeutic landscape in search for a cure? In Lambaréné, notions of conventional boundary-making between therapeutic traditions were reflected in my respondents' descriptions of navigating the medical plural landscape of Gabon indicating how therapeutic traditions were kept separated.

DICHOTOMY BETWEEN MEDICINE FROM 'THE BLACKS' AND 'THE WHITES'

My research assistant's mother, Joessabe, was a traditional healer in one of the villages in the surrounding area of Lambaréné. On a daily basis, patients visited her house, often accompanied by their family members. Joessabe's important position as traditional healer within this village and the importance of traditional healing for the people living in the area was emphasised during various discussions and also observed during my many visits. While discussing traditional healing practices, they placed emphasis on terms, such as *tradition* and *real Gabonese*. Most framed it as '*this is what we have done for generations*' or '*what we have, is the medicine from the Blacks*'. Joessabe and the other traditional healers explained how their practices did not contain any Western elements, and illustrated their sole reliance upon traditional Gabonese resources, such as herbs, fetishes, and connection with their ancestors. These discursive practices reflected processes of boundary-making in which a distinction was made between *the medicine from the Blacks* as opposed to *the medicine from the Whites*.



Photo 1 Traditional healers during healing ritual using amongst others iboga and fetishes.

The hospital, described as a facility of the Whites, was considered *un-African* referring to the anonymous policy in the hospital whereby doctors did not know their patients and family members could only visit during strict visiting hours. Moreover, they explained that the traditional way of healing was considered *normal* for this country and its people; for *the Blacks*. This di-

chotomy between the hospital and traditional healers, between *the Whites* and *the Blacks*, seemed to play a central role in most of my conversations with both T B patients and traditional healers. Sometimes this topic was closely intertwined with stories of distrust towards doctors in which accusations of stealing blood for witchcraft and keeping Black people dependent on medication by not instantly curing their T B (and HIV) were voiced despite the availability of medication. Moreover, the hospital was perceived by many as a place where people died and therefore some people were reluctant to seek care in this place.

In general, traditional healers were the first point of care when falling ill for many Gabonese people. The majority of Gabonese people were initiated in a traditional cult, marking the transition into woman- or manhood, and additionally protecting you against evil spirits that might bring diseases. Udagudu, one of Joessabe's T B patients, explained what the consequences would be if someone was not initiated in a cult, '*Because [if you are not initiated] you are not protected against evil spirits and more importantly, you are not part of the group.*' Members of this group were expected to seek help from their traditional healer first and foremost. For many the hospital was not an accepted choice to seek healing, or at least not considered as an adequate first point of care.

At the governmental institute IPHAMETRA, the presentation of traditional medicine formed a sharp contrast with those accounts described above. Instead of a *Black* and *White* dichotomy, discursive practices reflected a merging of therapeutic traditions. Biomedical terms, such as *consult*, *prescription of medication*, and *written instructions* were combined with traditional terms. This mixing was also visible when I went to visit the IPHAMETRA centre in what appeared to be a big, sterile, white building with traditional healers wearing white coats, and the presence of both a laboratory and a pharmacy with herbal medications. This collection of biomedical elements gave the traditional healing institute the impression of a hospital. Additionally, the employees of IPHAMETRA underlined the need for traditional healers to professionalize and to collaborate with medical doctors.

The state's Bwiti campaign and IPHAMETRA's efforts to professionalize or enhance corporation between traditional and medical healers seemed to have little impact in Lambaréné. On hospital territory biomedical traditions dominated formal discourse from which traditional healing was excluded. Various biomedical doctors explained that for many Gabonese people the first point of care were traditional healers or faith healers. As a consequence, many patients attended the hospital when they had developed a very advanced stage of TB and were therefore seriously ill. At times patients were close to dying. In general, patients were very reluctant to discuss previous visits to faith healers or traditional healers with their medical doctors. Doctor Jean explained that this was problematic:

*'It is so important to know what healing they have done before coming to us. So I say: tell me, because I can see you are traditional.'*¹ *But even then patients will deny they have done any traditional healing practices.'*

(Interview biomedical doctor Jean)

Some doctors and nurses explained that the choice of healer often depended on a person's religion. Camilla, one of the nurses, expressed firmly, *'You can't combine different sides. That is not good. That is a taboo. You can go to the hospital or to the traditional healer.'*

During an in-depth interview at the home of TB patient Omelia, we discussed the topic of secrecy regarding traditional healing in hospitals. Bikene and Omelia explained that TB patients and health workers in the hospital were reluctant to straightforwardly admit usage of other therapeutic traditions, as doctors would scold or ridicule them. The corrections or jokes made people often feel ashamed. Moreover, patients were aware that doctors wield considerable power and were afraid that this might negatively influence their TB treatment. These boundary-making processes between biomedical healing and traditional or faith healing were enforced by biomedical healers because they often viewed the latter as problematic, due to the number of TB patients who delayed seeking urgently-required medical health care. Patients additionally engaged in boundary-making processes induced by attitudes of secrecy as they were aware that usage of traditional and faith healing was not considered appropriate at the hospital. Many patients did however engage in various therapeutic traditions. The way they navigated this medical plural landscape and boundary-making processes that arose from these practices, will be discussed below.

1 Being 'traditional' or part of a traditional cult, could be observed in initiation scars or certain clothes or accessories.

Patients regularly mentioned the need to put faith into one therapeutic tradition at a time. The case of Cedric is a good example of turning to different sorts of health care subsequently. I met him at the Albert Schweitzer hospital where he had received his first package for TB treatment and I offered him a ride home. We needed to drive for two and a half hours by car, take a canoe to cross a river, and walk for half an hour. In contrast to Cedric's initial claim that everyone in his village goes straight to the hospital when falling ill, he later elaborated about the role of different therapeutic traditions within his village:

'When I fell ill my uncle tried to heal me with medical herbs from the jungle. In every family there is someone with herbal knowledge, so that is the first thing to do. When this didn't work, I went to the pharmacy. I kept coughing and then I turned to four different traditional healers. [...] If a traditional healer can't heal you, you try another one, and so forth.'

(Interview TB patient Cedric)

Cedric explained that when a traditional healer had given up on him, he was advised to go to the hospital, *'[The traditional healers I attended] gave me the diagnosis "Tuberculosis of the Hospital". That meant they could not do anything for me anymore.'* Cedric subsequently visited four traditional healers and only decided to go to the hospital when he was assured that none of them was able to heal him. Cedric explained that he had lost confidence in the effectiveness of traditional treatment, which triggered him to try out *the medicine from the Whites*. By not engaging in multiple therapeutic traditions simultaneously, this boundary between the therapeutic traditions seemed to be maintained.

The choice of following only one healing practice at a time can be linked back to the often-heard phrase that it was very important to have faith in a treatment. TB patients Fussala, emphasised the power of having confidence or faith in a singular treatment:

'If you believe it [your treatment], you will get cured, but if you don't believe in it, it won't work. That's how it is. For the traditional healer and for the hospital too. For all different healing methods.'

(Interview TB patient Fussala)

She explained that a patient turning to different explanations for TB at the same time would hinder his own healing. Various patients and healers highlighted that believing in one singular treatment not only stimulated treatment compliance, but additionally enhanced the healing process on a spiritual level.

Besides faith or spiritual considerations, there were also physical reasons mentioned for engaging in a singular treatment at a time. I was introduced to Jack, a nurse from the hospital, whose sister was following TB treatment at his hospital. His sister lived next door with her husband who was a traditional healer. Jack, and with him many other biomedical health workers, had to navigate a pluralistic therapeutic landscape manifesting within their own family. Jack talked with respect about the work of his brother-in-law and described how his sister followed traditional treatment for eight months using herbs and plants from the jungle, but was not getting better. Her decision to attend the hospital, made her stop taking traditional treatment. Jack explained that the two treatments should not be combined, because the body was not strong enough to deal with two strong treatments at the same time. Similarly, most biomedical doctors described how they always advised patients to not combine treatments as they feared negative drug interactions.

There appeared to be a fine line between traditional and biomedical therapeutic traditions in the case of a biomedical doctor in Libreville, who was at the same time a traditional healer. However, instead of an ostensible intertwining of therapeutic traditions, the doctor stated that healing traditions were strictly separated, *'You should not combine the different healing practices. So we have different consults for them.'* The therapeutic traditions he engaged in were carefully separated in space, practice, and in speech. It was not considered *'good'* to combine two powerful healing traditions. Yet, it was accepted to first attend his biomedical consult at his biomedical consulting room and after treatment continue with a traditional approach in his traditional consulting room. The healing traditions were considered too powerful to be used simultaneously. A time restriction was maintained resulting in the use of different therapeutic traditions subsequently and requirement of having a biomedical consult first.

This boundary-making processes within time and the connection to the danger of combining powerful traditions were similarly presented during interviews with faith healers. Despite the fact that the church's doctrine condemned traditional healing and prohibited communication with the deceased (ancestors), most faith healers accepted the position of traditional healers within the therapeutic landscape. Aruna explained that even though it was *'wrong'* to



Photo 2 faith healer exorcizing TB-bringing spirit.

combine faith and traditional healing, everyone in Gabon would follow 'his roots' and additionally make use of traditional healing. He explained:

'We are in Gabon, in Africa. It is part of where we are and who we are.' [...] Everyone attends the traditional healer, you can never stop that. And some are able to heal TB. [...] But you should never combine two big forces, then it is better to choose [between traditional or faith healing].'

(Interview faith healer Aruna, church Christianity de Reveil)

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They made a clear distinction between themselves and traditional healers stating that, *'We don't use herbs from the jungle. We leave that to the traditional healers. They do healing on another spiritual level.'*

THE THERAPEUTIC TRADITIONS IN THEIR ESSENCE THE SAME

An often mentioned statement was that that healing from the Whites and from the Blacks was in their essence the same. It depended on the choice of the patient where s/he preferred to go, either to the traditional healer or to the hospital. Dala explained how therapeutic traditions were seen as in their essence, the same:

'The Africans, [...] the plants they use from the jungle, those are used by the whites as well. The Whites are in a way using the knowledge of the Blacks. [...] They only compress it in tiny, balanced pills. In contrast, the Blacks cook a big pot full of medication and tell you that you should drink everything. But in fact, it is the same thing, exactly the same medication. [...] So it wouldn't make sense to use both. [...] Patients choose one healing.'

(Informal conversation, TB patient Dala)

The idea that traditional and biomedical healing is in their essence the same, was in some way mentioned by biomedical doctors who explained that their pills consisted of plants from the jungle. Yet, they did stress the importance of laboratory-made pills and the careful balancing of ingredients. This idea reflects a blurring of boundaries between therapeutic traditions, but triggers boundary-making processes when patients ought to make a choice between therapeutic traditions. Joessabe emphasised, *'You either go to the hospital or you go to the traditional healer. It is your own choice.'*

DISCUSSION

Describing accounts of my fieldwork in Gabon, I illustrate how TB patients' and healers' discursive practices regarding their navigation of therapeutic traditions reflect processes of *conventional boundary-making*. This is distinct to the

concept of *boundary-work* in which boundaries are often framed as arbitrary, permeable, and flexible. In recent anthropological literature in general,^{40,41} and in medical pluralism literature specifically,^{4,5,23,26} boundaries are often described as being maintained, crossed, changed, shifted, and reproduced. Rather, with the notion of conventional



Photo 3 Albert Schweitzer Hospital

boundary-making, I do refer to the maintaining and crossing of boundaries, but additionally describe a reluctance towards the reconfiguration of boundaries and the protection of the purity of therapeutic traditions. This notion of boundary-making processes resonates with theories on multiculturalism. According to various authors, many people resist the dissolution or shifting of old boundaries in order to protect the purity of their cultural identity.⁴² Along the same lines, many anthropologists have been concerned with the notion of boundaries to describe how ethnic groups mobilize typification systems to define who they are and who they are not.⁴³

Conventional boundary-making processes are created through an interplay of personal choices of health care, relational processes between therapeutic traditions and healers, and are intertwined with notions of purification, distinction, credibility, and authority. The way these processes influence connections, separations, and alignments within the therapeutic landscape, affects how therapeutic traditions are defined and positioned in Gabonese society. The findings of this study suggest that boundary-making processes exists in various forms and carry disparate values and meanings. Respondents intentionally stress the difference between therapeutic traditions and associated medication with the prominent and often-mentioned dichotomy Medicine from the Blacks versus Medicine from the White. (Synonyms for this dichotomy mentioned by respondents were: disease of Blacks vs. disease of Whites, disease of God vs. disease of witchcraft, and disease of the hospital vs spiritual disease. The terms resonate with the classical natural-supernatural dichotomy presented in African literature on health care.)³² Consequently, this dichotomy roughly divides the therapeutic landscape and its actors, notwithstanding each bounded ascriptions representing a wide variety of therapeutic traditions.

This boundary-making process has spatial and discursive dimensions as it influences what topics can be discussed in which areas. For instance, it is a taboo to discuss matters of traditional healing on hospital territory, and for patients who are initiated into a specific cult it is not considered appropriate

to (first) consult a biomedical doctor. The latter was sometimes enforced by discursive practices about conspiracy theories in which the Whites try to suppress the Blacks by not providing them with an instant cure for their TB and by the belief that they potentially steal their blood for witchcraft. These stories reflect and negotiate certain concerns and anxieties regarding biomedical health workers and hospitals, places that are often conceived as a place where people die. Likewise, Saethre and Stadler⁴⁴ describe various tales of white malice in the field of public health that exist throughout sub-Saharan Africa. Beyond this Black-versus-White dichotomy, faith healers' discursive practices similarly reflected taboos informing boundary-making processes, as they condemned patients who went to traditional healers accusing them of working with the devil.

Exploring the idea of taboo, this boundary-making can be linked to underlying power strategies. Both healers and patients' discursive practices reflect clear distinctions between the pure therapeutic traditions, leaving no space for processes of syncretism, bricolage or eclecticism. The various healers mostly present themselves as being purely biomedical, traditional/Gabonese, or Christian to pursue a pure and authentic position within Gabonese society. (This purification can be slightly nuanced as all traditional healers identified themselves as Christians, hence this may indicate some form of shifting or blurring of boundaries. However, traditional healers did explain their healing practices differed completely from those of faith healers.) Besides boundary-making processes on a discursive and spatial level, there are additionally discursive practices illuminating boundary-making processes that seem to influence how patients navigate the therapeutic landscape over time. Temporal boundaries compel patients to negotiate the variety of therapeutic traditions in a certain way: patients are not supposed to engage in different therapeutic traditions simultaneously, but can make use of a variety of traditions subsequently. These boundaries are constructed on individual levels, as it is deemed necessary for patients to fully commit to a therapeutic tradition in order to achieve cure. If patients have exhausted all means of one therapeutic tradition and consequently have lost faith, it is socially acceptable to move to another therapeutic tradition. The choice of therapeutic tradition depends heavily on the patient's religion and associated faith, but is not a static preference as patients are allowed to change and adapt their faith in a therapeutic tradition overtime. Another form of a temporal boundary that is closely related, derives from discursive practices about '*the danger of combining two different therapeutic traditions at once*'. Using therapeutic traditions simultaneously would accumulate excessive power and could have damaging (physical or spiritual) consequences for patients. Crossing this boundary by mixing therapeutic traditions would not cure patients, yet choosing one after the other would avoid premature death. Through this boundary-making process, each therapeutic tradition is considered very powerful, thus, claiming its own space and legitimization within the therapeutic landscape.

Discursive practices about '*all healing being in their essence the same*' seems at first to contrast boundary-making processes described above. Because therapeutic traditions that are *the same* and obtain a similar level of credibility, would indicate that boundaries become blurred and consequently lose their value. In contrast to the literature, this blurring of boundaries is not caused by a transgression of boundaries by traditional healers who are copying biomedical aspects.³⁰ Respondents simply explained how biomedicine is rooted in traditional medicine, as both their medications originates from the same plants in the jungle. (It is interesting to note that faith healers are not mentioned within this argument, amongst others because most faith healers practice healing methods on a spiritual level and do not use plants or biomedical medication). However, this blurring of boundaries does trigger boundary-making processes on an individual level for patients navigating therapeutic traditions. Their choice depends on a personal preference for a certain therapeutic tradition, because it does not make sense to try different therapeutic traditions if they are essentially the same thing. According to this reasoning, individual health care decisions and thus boundaries between therapeutic traditions, determine how patients should navigate the therapeutic landscape. This can be related to the often-mentioned idea of '*having faith in one therapeutic tradition at a time*'. However, individual boundary-making processes informed by the idea that therapeutic traditions are the same, omit a temporal division as a change of therapeutic tradition even later in time is difficult to justify. Therefore, a change of therapeutic tradition is often explained with a change of TB aetiology and consequently the need for a new therapeutic approach.

On the governmental level, discursive practices reflect processes of negotiation, interchange, and redefinition of traditional medicine shifting and recreating boundaries. The aim of IPHAMETRA's to professionalise traditional healing is reflected in their presentation of laboratories, biomedical devices, and distribution of certificates to professional traditional healers. They do not only transgress boundaries between traditional and biomedical therapeutic traditions, but additionally create new boundaries by presenting traditional healing as merely an herbal and not a spiritual practice. Meanwhile, they strive for collaboration between traditional and biomedical healers, which breaks down boundaries between therapeutic traditions (again faith healers are not mentioned within this discourse despite the fact that faith healers behold a prominent position within Gabonese therapeutic landscape).

Comparing discursive practices of boundary-making of IPHAMETRA's employees with those discursive practices of patients and healers shows various differences. Despite the potential of a state to influence boundary-making processes between therapeutic traditions, IPHAMETRA's reconfiguration and reproduction of boundaries is not reflected in the discursive practices of healers and patients in this study. In contrast, as described above, discursive practices show processes of boundary-making in which intertwining of medical practices

and the recreation of therapeutic traditions not only does not occur, but is even considered a taboo. Both patients and healers deploy discursive practices that clearly separate the various therapeutic traditions and stress in multiple ways that mixing and combining therapeutic traditions is not considered appropriate. Similarly, Herzfeld⁴⁵ describes the often found incongruence between formal, state-sponsored versus local discourse about identity and boundaries.

In sum, this study confirms several components of the debate surrounding medical pluralism, such as patients' and healers' boundary-making processes and the transgression of boundaries. However, I would like to introduce the concept of *conventional boundary-making* to additionally illustrate how my respondents' discursive practices reflected the need to keep different therapeutic traditions separate. This neither entailed rethinking of local illness explanatory models nor the creation of a new syncretic model wherein different therapeutic practices were combined. Boundary-making processes were intentionally enforced to contrast, strengthen, purify, and to divide the therapeutic landscape in time, space, and speech. Meanwhile, these processes may guide patients in their navigation of this space and their search for cure and may additionally confirm healers' place and authority in the therapeutic landscape.

Whilst creating conceptual parameters for the medical pluralism debate with the notion of conventional boundary-making processes, I underline that this research focused on discursive practices as opposed to actual behaviour. Following this argument, discursive practices reflecting boundary-making do not necessarily reflect practices. Indeed, given that my research merely focuses on discursive practices, no conclusions regarding respondents' daily activities can be drawn. However, respondents did give the impression that they literally kept therapeutic traditions separate while navigating the therapeutic landscape and that therapeutic healers aimed to maintain and practice a pure therapeutic tradition. Therefore, it would be interesting to further explore patients and healers daily practices and how and why they are compelled to navigate the disparate therapeutic traditions in Gabon during future ethnographic research. Moreover, as respondents of this study tended to discuss the medical plural landscape and their navigation in more general terms, future research could narrow its focus down on the particularities of TB within the context of medical pluralism.

EPILOGUE

Lastly, I would like to speculate why discursive practices of conventional boundary-making are deployed. Looking at literature about Gabon's therapeutic landscape, the state-imposed discourse regarding therapeutic traditions provides an extra layer of context while analysing boundary-making processes. In Gabon, state-imposed identity politics could play a role in the formation of power division within the therapeutic landscape.^{10,11,15} This is particularly interesting

within a post-colonial timeframe where social orders often get contested.¹³ For example, the state's amplification and maintenance of '*the traditional*' can create a strong and authentic position within a country augmenting political power as a contra-movement to colonial rule.¹¹ Diving into political literature about Gabon, these processes of boundary-making may be read as being part of a larger political process.

Explaining the underlying reasons for national identity politics and the focus on 'Bwiti' in Gabon, scholars have referred to contrasting arguments. Samorini¹¹ and Swiderski¹⁰ describe how imagined ecumenism of a Bwiti society is supported by the Gabonese state and functions as an empowerment of the Gabonese people and traditional medicine against colonial powers. Ngolet describes that the state proclaims the purpose of unification of the Gabonese people with an emphasis on their tradition or 'Bwiti', and pre-eminence (*Gabon d'abord*, translation: Gabon first, one of Omar Bongo principles written in his famous Little Green Book). However, according to Ngolet, the main reason for this state's identity politics is to convince the Gabonese of perfect leadership and to stay in power. Meanwhile, most of Gabonese society remains poor and obtains a marginalised position in society. Ngolet explains that this political strategy to enhance false thinking elicited a counter-reaction of the disillusioned Gabonese people against the state transforming Bwiti (and other emerging traditional societies and religious sects) into their own instrument to reject this post-colonial hegemony. Consequently, this provided a new space for a wide variety of therapeutic traditions.

Following Ngolet's line of reasoning, the question arises whether patients' and healers' discursive practices reflecting boundary-making can be seen as part of this strategy to rebel against the powerful position of the post-colonial government. Resorting to the purity of therapeutic traditions might be considered a remedy to deal with 'associated societal problems like political and economic marginalization, disturbed social order, and an associated sentiment of frustration'.¹⁵ This is specifically interesting while looking at tuberculosis, one of Gabon's major health concerns^{37,46} and described as a 'disease of the poor'.⁴⁷ Social scientists focused on tuberculosis often refer to theories of structural violence⁴⁸ as this disease mainly hits the most marginalized and vulnerable people with a low socio-economic position in society due to social structures of inequality and poverty. More research is needed to explore this extra dimension of why boundary-making processes may occur within discursive practices of both TB patients and their healers in Gabon.

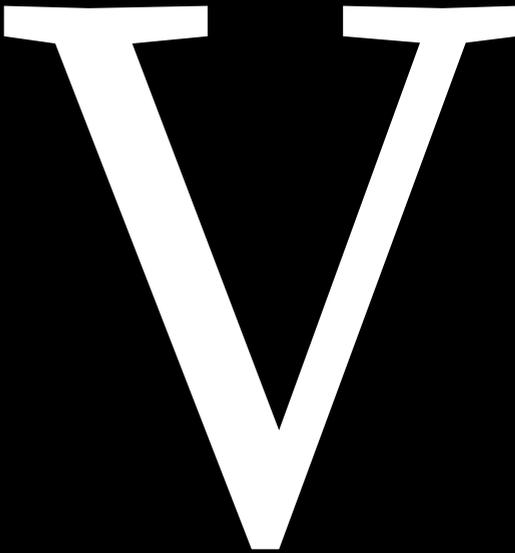
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Section



Epilogue



Summary, Future Perspectives & Reflection

In this thesis, we investigated different national and individual approaches to one of the most alarming global health threats of this age: tuberculosis (TB). The TB burden in the world is globally slowly decreasing, but remains highly problematic with around 1.7 million deaths in the year 2016.¹ TB rates are not being significantly reduced and in some areas rates are even going up.² Epidemiological patterns of TB have been changing and becoming more complex, due to the HIV epidemic since the nineties and the development of drug-resistant forms of TB. Drawing on anthropological and public health approaches, this thesis provides insights in patients' individual and social experiences of TB and treatment, their bodily state, their feelings and interpretations of getting cured and cared for. Moreover, we aim at generating a more holistic understanding of the challenges of National TB Programmes (NTPs) and how NTPs impact on TB control and prevention is not always what governments, policy-makers, and health workers had envisioned. We explore the dynamics between such patients' experiences and structures of care. The aim of this thesis is to inform NTPs and improve TB care. This thesis starts with a systematic review giving insight into the paucity of qualitative TB research available from countries with low and medium TB incidence. Subsequently, this thesis focuses on sub-Saharan Africa, an area that is dramatically hit by the TB epidemic. Out of many, we chose countries with divergent epidemiologic characteristics and NTPs, yet where TB remains a significant threat to the public health situation: South Africa, Zambia, and Gabon.

Countries of low and medium TB incidence

In **Chapter 2**, we systematically reviewed the qualitative literature on barriers and facilitators for the uptake of TB diagnostic and treatment services by hard-to-reach (HTR) populations in low- and medium TB incidence countries. In total, we found twelve studies published between the years 1990-2015. Most studies covered barriers and facilitators regarding migrants, leaving other HTR groups underexposed (homeless, drug users, refugees, people with HIV, prisoners, health workers) or even un-discussed (sex workers). Views of HTR groups on the severity of TB or the perceived susceptibility to TB varied greatly and many misconceptions existed. Important barriers to TB diagnosis and treatment uptake included stigma and health care accessibility. Support from family, friends, and nurses was by many studies deemed important to foster treatment adherence. Our findings point out a need for future research regarding TB knowledge, stigma, directly observed therapy (DOT), and economic factors in low and medium TB incidence countries.

Visual ethnography and health research

Regarding our original studies, we aimed at converging public health and

anthropological information to form one interdisciplinary body of information. **Chapter 3** elaborates on how visual methods may synergize the disciplines public health and anthropology. It shows the possibility to translate a vast body of ethnographic information into film. Consequently, with film we could overcome the fact that public health researchers and anthropologists often seem to speak a different 'language', differences that can hinder effective communication. Disparities between the two disciplines seemed to be bridged, because visuals could serve as an interdisciplinary product of science that was received and appreciated by both audiences. Moreover, film appeared to be a strong medium to blur boundaries between film subjects, the audience, and researcher, constituting a sense of shared experience. In **Chapter 4**, we interchanged the writing of ethnographic results with short videos of our data collection in a multimedia article. A longer visual ethnographic paper (film) was introduced in **Chapter 5** that intends to transcend explicit scientific interpretations or arguments in words, but brings the viewer back to an empathetic understanding of what is happening to some of the TB patients included in our study. This interdisciplinary knowledge may be shared widely, to be later translated into one's own discipline's jargon, or to a more applied field.

Patients' experience with NTPs and TB: South Africa, Zambia, and Gabon

Chapter 4 and 5 focusses on TB in Khayelitsha, South Africa. South Africa obtains a well-organised TB programme with a clear interdisciplinary approach. The NTP constitutes the availability of advanced TB diagnostic tools for drug susceptible (DS-) and drug resistant (DR-)TB, medication for DS-TB and DR-TB, a combination of DOT and home-based care, TB counsellors, community care workers, and social programmes for the neediest patients. However, the available social TB programmes in South Africa, consisting of social grants and food supplements, are unable to overcome social and economic inequalities deeply rooted in society due to national history. Poverty is not alleviated; rather, the symptoms of poverty are targeted in an unsustainable manner. Poverty alleviation is particularly complicated in this country that is still recovering from the devastating effects of the racist Apartheid regime that officially repealed its laws in 1991. During post-apartheid, wealth and health inequalities have shifted and social situations have changed for some, but still many people face severe poverty.³ As a result of former segregation politics, the majority of people in Khayelitsha are Xhosa⁴ and most are deeply marked by marginalization. Up to today, this has resulted in high unemployment rates, severe poverty, and lots of violence and crimes.^{4-8,9} Most people live in overcrowded shacks and are more susceptible to infectious diseases, such as TB. Moreover, they are much more likely to develop active TB and face many difficulties in accessing care.

The availability of social TB programmes in Khayelitsha seemed to fuel prevailing conspiracy theories amongst health workers and patients about

other people getting TB on purpose in order to get social grants. Additionally, patients described how health workers threatened to stop their TB grants if they voiced any complaints about the treatment's side effects. The high unemployment rates are a possible explanation for considering the financial benefits of TB infection. It sounds plausible that people sacrifice themselves in order to feed their family and live a dignified life. Coping strategies of survival often interfered with health care seeking behaviour and treatment adherence of TB patients.

We found that one of the biggest struggles for most patients was dealing with TB treatment in combination with a lack of food. Patients often described severe adverse effects and voiced the fear to become crazy. DS-TB patients faced similar embodied experiences in which they were terrified that the drugs would not only destroy their body, but foremost their mind and sanity. This formed a contrast with many health workers arguing that DS-TB was currently very well understood and managed. Because of the plenitude of TB services and TB health education in Khayelitsha and the unlikely option that patients remained ignorant regarding the need to continuous treatment-intake, health workers often pointed at irresponsibility and substance abuse for reasons of non-compliance. However, according to patients, they had to choose between taking pills and potentially becoming crazy or not taking pills and risking the chance of dying at some point from TB. Seeing it from this perspective, it is rather a choice of dignity and survival than of responsibility. Moreover, TB was often associated with HIV and experienced as shameful. Many DR-TB-patients faced additional stigmatizing attitudes as they were blamed for their own drug-resistance status and by many seen as irresponsible, crazy, and dangerous. Stigmatization not only deteriorated respect and social status, but may also harm social structures of support. In our study however, patients were generally supported by family and/or friends.

Chapter 6 looked into pre-hospital delay and treatment compliance of TB patients in Lusaka, Zambia. Using quantitative methods (questionnaires), we found a low level of non-compliance amongst TB patients (10 %), no association with socio-economic or cultural factors, and a possible association with long distance and time constraints to the clinic. The combination with qualitative methods ascertained in-depth information about the existence of varying and sometimes contradicting TB perceptions and aetiologies. Half of the patients attended a wide variety of healing methods for TB alongside or before following biomedical anti-TB treatment. Health educators did recognize the wide variety of explanations for a cough and had adjusted their TB sensitization message accordingly. They did not simply relay biomedical knowledge, but respected local perceptions meanwhile assuring that all people with a cough were checked for TB at the clinic. They pronounced that any cough could be TB. In a way, this helped many people making sense of the many, often contradicting, explanations for TB. However, one third of respondents reported to have not received

any information about TB indicating that the mode of information-transmission calls for revision and more creative approaches.

Many inhabitants lived below the poverty line and TB patients' problems often comprised struggles with food and hunger. The majority of respondents introduced themselves as self-employed, having small businesses in selling popcorn or fruits on the streets, but explained they could hardly make ends meet. To address this grinding poverty, several non-governmental organizations (NGOs) in collaboration with the Kanyama clinic had launched social TB programmes. Unfortunately, NGOs' private funding had become sparse and consequently, the organizations ceased their programmes. The volunteers once recruited by these NGOs were no longer receiving any allowance and many stopped working. With the reduction in numbers of community care workers, the social programme that had run for a decade staggered, but did not seem sustainable without the influx of cash flows of private donations. Few elements remained, such as food supplements for children under one-year old, but it remained unclear for how long. The lack of sustainability is a well-known pitfall of foreign aid.

The impact of TB-related stigmatizing attitudes on our patients in Lusaka, Zambia is discussed in **Chapter 6**, and further elaborated on in **Chapter 7**. The vulnerable position of TB patients was affected by (patients' fear of) stigmatizing attitudes, such as insulting remarks, ridicule, discrimination, isolation, and/or social exclusion. Children with TB were equally or even more vulnerable to stigmatizing attitudes than grown-ups, because they faced controversial perceptions as community members generally believed children were unable to contract TB. More female than male respondents described experience with stigmatization and their position seemed to be exacerbated by narratives of stigma in the form of traditional myths that blamed women for spreading TB and HIV. Many people linked TB to HIV and referred to the existence of a double-stigma for TB patients confronted with both devaluing characteristics of HIV (immoral behaviour, chain-smoking, being a prostitute, promiscuity) and TB (careless, irresponsible, having aborted, chain smoker). Half of our respondents who felt stigmatized, additionally mentioned loss of self-esteem and shame, because they had contracted TB, also referred to as *internal stigma*.¹⁰⁻¹²

In **Chapter 8**, we focus on the NTP and experience of TB patients in Lambaréné, Gabon. Gabon is a sparsely populated country with a middle-high incidence of TB. The care for TB and HIV was more limited compared to the above mentioned countries. The main focus of the NTP was the availability of drugs for DS-TB. No social programmes or TB grants were in place to address TB as a problem of poverty, neither were community care workers, DOT, or educational programmes. So now and then, the NTP faced drug shortages and then TB drugs could only be bought via private pharmacies. For the majority of patients this was not affordable, because of the high costs. There were no diagnostic tools or medication for resistant TB. TB was often explained as an illness derived from a germ, evil spirit, poison, or God. For most patients, the first step to healthcare

was self-medication with use of plants of the jungle or going to a traditional healer. The traditional healer was by most considered as part of their initiation cult and society, easily accessible, and in case of a visit the patient could remain anonym. Most patients had a low socio-economic status and more than half were breadwinners. TB posed an enormous pressure on patients' household incomes, due to job absenteeism and travel costs to the hospital. Moreover, many patients postponed a hospital visit due to poor infrastructure or inability to pay for transport. Other obstacles of TB care were stigmatizing attitudes and behaviour within TB patients' social environment. Most respondents explained that TB disclosure lead to social isolation and some chose to hide their TB status, only informed some family members, or postponed health care seeking behaviour. Few respondents explained only people with HIV were stigmatized and others stated that HIV-TB co-infection exacerbated stigmatizing attitudes.

The wide variety of TB aetiologies was not addressed in the Gabonese NTP (amongst others because of a lack of TB sensitization in general) and different therapeutic traditions appeared to co-exist. In **Chapter 8**, and more extensively in **Chapter 9**, we explored local TB perceptions and how TB patients navigated this plural medical landscape. Patients' discursive practices revealed processes of invariable boundary-making. Respondents explained how they generally attended healers subsequently and not simultaneously for a number of reasons. In general, most respondents differentiated between medicine from the Whites versus medicine from the Blacks; many described that combining more than one medical tradition was a taboo; a combination of medical traditions was by many considered too powerful; a treatment was often believed to only be effective if you put all your faith into it; or a combination of medical traditions was explained to not have any additional value. Likewise, healers' discursive practices reflected processes of boundary-making between therapeutic traditions and did not engage in renegotiating their therapeutic tradition. We tied our findings into contemporary debates of boundary-making and medical pluralism and aimed at nuancing popular paradigms of bricolage and syncretism wherein boundaries seem to be recreated and shifted. Attention is given to a national programme fostering traditional medicine potentially informing boundary making processes. We introduced the concept *conventional boundary-making* referring to processes of boundary making on a local level that were used to purify, strengthen, contrast, and divide the therapeutic landscape, meanwhile guiding patients in navigating this space.

FUTURE PERSPECTIVES

Will it be possible to free this world from TB in 2035, as formulated in the Sustainable Development Goals? South Africa, Zambia, and Gabon have made many improvements over the last decades regarding TB care, control, and prevention. Nevertheless, there are still many issues to be addressed within

each of the NTFS. This is important for remote areas such as Gabon, but also in countries such as South Africa, where TB care is of relatively high standard, yet TB incidence remains alarmingly high. With this dissertation, we strive at making a contribution to the ultimate goal of eliminating TB by exploring TB patients' experience with care and the challenges of NTFS in these three sub-Saharan African countries. We have organized various identified discussion points according to five topics: patients' embodied experience of TB treatment, treatment adherence and socio-economic inequalities, TB-related stigma, and perceptions and therapeutic traditions. We will describe similarities in data we have found across study sites and attempt to avoid oversimplifications as we do recognize how fundamentally different the three sites are. The reader should additionally keep in mind that in each country only a small population was selected to conduct research and that the cultural, social, economic, and political contexts of study sites vary greatly.

Patients' embodied experience of TB treatment

Over the past decades, the pillars of TB control have been the availability of diagnostics and treatment, correct treatment intake by patients, the implementation of observed therapy, and more recently the development of effective treatment for MDR-TB and XDR-TB. During our research in South Africa, Zambia, and Gabon, one important finding was respondents' emphasis on the harsh adverse effects of anti-TB drugs. Adverse effects such as anorexia, nausea, vomiting, or abdominal pain of both DS-TB and DR-TB drugs and their effect on treatment adherence is known,¹³⁻¹⁵ but in the literature is sparsely commented on a patient perspective. We call for more attention to both DS-TB and DR-TB patients' embodied experience, physical and mental, aggravated by grinding poverty and hunger.

Health professionals often use a biomedically oriented definition of *treatment*, referring to the use of drugs or therapy to cure *disease*, referring to a bodily and/or psychologically dysfunction, versus *illness*, the patient experience and meaning of disease.¹⁶ The former may be presented as single truths, whilst the latter implies that a range of views could be simultaneously considered valid.¹⁷ Such an opposition can also be applied to the concept *treatment*, for example with the concept *care*.¹⁸ Whilst the concept *treatment* is simple and operative, a concept such as *care* may inform health care policies to look more broadly at how TB treatment and adverse effects are exacerbated, interpreted, experienced, and managed by patients. For example, Patient Centred Care (PCC) refers to care that is respectful and responsive to the situation and preferences of individual patients. PCC roots go back to the International Human Rights Declaration in 1948 and its right to health.¹⁹ Likewise, the global End TB strategy advocates the use of PCC,²⁰ yet in practice, the concept is often considered vague and therefore complex to implement. Film may be used as a tool to facilitate translation of the concept to the local context and inform TB policies.

Additionally, our finding regarding the embodied experience of TB patients calls for a critical look at the available TB regimens. Scholars have shown that the effectiveness of standardized short-course chemotherapy is compromised by the long duration of the treatment.²¹ Adverse effects and drug-drug interactions influence patients' treatment adherence. For MDR-TB and XDR-TB treatment regimens are even more complex, due to huge number of pills, high toxicity, and high rates of mortality in HIV-TB co-infected patients.²¹ Pharmacovigilance (PV) is a science that aims at the detection, monitoring and prevention of adverse effects of medication to improve the safety of patients. In 2015, the World Health Organization (WHO) published a PV framework to implement active TB drug-safety monitoring and management.²² Unfortunately, national PV authorities and NTPs are usually insufficiently linked and guidelines are often not systematically followed.²³ It is of utmost importance to pay more attention to PV, but additionally to strengthen the global anti-TB drug pipeline and to develop simple and short regimens that are effective and safe for both DS-TB and DR-TB.

Moreover, accessibility of diagnostics and treatment for DR-TB should be improved in many endemic settings. In Gabon, there were no diagnostic facilities to test drug-resistance nor was there second-line drugs available. Patients who did not adequately respond to treatment had no prospect to getting cured. In Zambia, every patient was first put on a standard regimen for DS-TB. After months, when anti-DS-TB treatment did not seem to be effective, patients got tested for drug-resistance and were referred to a tertiary health facility. In Khayelitsha (South Africa) MDR-TB diagnostic facilities and treatment were available. However, other obstacles were found in this setting. Most concerns of health workers and research focused on MDR-TB patients, yet many DS-TB patients similarly continued to struggle with treatment. We argue that in this high resource setting DS-TB policies should not be forgotten. More qualitative research is needed to tailor both DS-TB and DR-TB policies to vulnerable groups to ensure timely health care seeking behaviour and treatment adherence.

Treatment adherence and socio-economic inequalities

One of the burning questions in TB research and policy-making is why TB patients would not adhere to treatment if diagnostic facilities and medication are available and financially supported by an NTP. Not adhering to treatment could possibly lead to premature death, transmission of the disease to others, and moreover, to the development of drug resistance. These risks put an enormous pressure on health systems²⁴ and have led to a search of means to assure treatment-adherence. A solution that changed the history of global TB control was the introduction of DOT as part of the larger DOT Short-course Chemotherapy (DOTS). This policy was actively promoted by the WHO in 1993.²⁵ Since then, DOTS has rapidly expanded to NTPs almost anywhere in the world.

DOT has been widely questioned regarding its universal, rigid, and paternalistic approach^{26,27} and in practice has been subjected to numerous variations.²⁷ The ideas informing DOT are rooted in the assumption that patients are able to attend the clinic and take treatment, overestimating patients' agency. It ignores a perspective on deep-seated structures of poverty, stigma, racism, political violence, sexism, and associated constraints to seek care. Farmer coined the term *structural violence* to describe such structured inequalities conditioned by historical contingencies. Most of our TB patients had been marginalized for generations unable to escape severe poverty. TB can be viewed as the tip of the iceberg, one of the numerous challenges in their lives. On top of this iceberg, the mandatory character of DOT was often not in our patients' best interest and for many rather counterproductive. Clinic visits would often take hours due to poor health infrastructure or lack of transport and would interfere with patients' job or household responsibilities. Especially for those patients who were breadwinners, a missed day of work because of a clinic visit for some equalled one day of not eating. Additionally, DOT and the obligation to daily attend the clinic complicated for many respondents stigmatizing attitudes in their social environment. The approach of DOT forms a sharp contrast with HIV programmes that are generally focused on the emancipation of patients. As many areas face high HIV-TB co-infection rates, a full service integration regarding HIV and TB prevention and care is considered desirable.²⁸ In still too few areas in the world, such as in Khayelitsha, TB and HIV programmes are integrated. Integration of TB and HIV services calls for a reconsideration of the role of patients in such care programmes.

Most NTPs are aware of harsh global health inequalities and the marginalized position of most of its TB patients. How this is addressed varies across countries. Poverty alleviation is often a common rhetoric within NTPs and global health organizations. In Zambia and South Africa, community care workers supported their TB patients with counselling, contact tracing, and encouragement of treatment adherence. In South Africa, a more advanced interdisciplinary approach tried to meet patients' needs in the form of social grants and food supplements. Gabon formed a contrast with the policies in South Africa and Zambia, lacking any social programme for TB patients.

Social programmes of NTPs that are in place do often not adequately reach out as they only target symptoms of poverty. Moreover, socio-economic inequalities often complicate social, economic, and political efforts of global health delivery. Patients living under extreme poverty are constantly fighting for survival, hoping they will be able to provide food for their family, and dealing with sentiments of frustration. The combination with a TB programme that is principally focused on biomedical cure and alongside touches upon social support during treatment, may lead to unanticipated consequences of purposive social action.²⁹ An example was found in the narratives of various respondents in Khayelitsha about patients being infected with TB on purpose in order to

receive a social TB grant and support their family. In this light, TB grants may serve as a way to escape extreme poverty. It raises the question whether the modest social component of this TB programme may unwittingly fuel the spread of TB infection instead of helping patients adhere to treatment. More research should be conducted to see how these narratives of such unintended and gruesome consequences of NTPs play out in TB patients' realities and how these can be avoided.

In all three countries, the NTPs had the tendency to focus on biomedical health interventions and to get patients cured as efficiently as possible (**Chapter 4, 6, 8**). Social programmes, if available, tended to be pushed to the side-line and were merely targeted to financially support patients while dealing with TB. However, after successful treatment, patients were predisposed to TB relapse as they continued living in areas with overcrowded living conditions, poor ventilation, malnutrition, immunosuppression, and poor access to health care. Especially in the slum areas Khayelitsha (South Africa) and Kanyama (Zambia), most of our respondents lived under circumstances in which they could acquire TB again and again. In order to adequately prevent TB, we propose a paradigm shift towards a holistic TB approach in which much greater emphasis is posed on the circumstances that make diseases such as TB flourish. There is a need to directly engage in creative means aiming for sustainable economic development, e.g. job and education opportunities targeted at the overall community and not merely at TB patients. Such programmes require collaboration across other sectors and ministries as the problematic situation of TB exceeds the limits of the ministry of health. Moreover, this requires political efforts.

TB-related stigma

One important element of TB elimination strategies globally constitutes the reduction of TB-related stigma.³⁰ The importance of gaining a deeper understanding of TB-related stigma is reflected in the fact that it hinders amongst others patients' care seeking,^{31,32} treatment initiation,³³ and treatment adherence.³⁴ Moreover, it negatively impacts patients' social networks, degrades social status,³⁵ and deprives patients of their rights and respect.^{36,37} In all three study sites, respondents described stigmatizing attitudes in their social environment. Our comparison across countries informed us about similarities and variation in manifestations and motivations of TB-related stigma.³⁸

Across study sites, respondents generally explained TB patients were seen as people who would soon die and may spread the disease to others. In South Africa and Zambia many patients explained feelings of worthlessness, shame, and self-blame, in the literature also referred to as self-stigma.¹² This may be linked to certain perceptions about TB aetiology. In Zambia, our respondents referred to stigmatizing narratives blaming women for the spread of HIV and TB. In South Africa, many respondents associated TB with poverty and dirtiness.

In Gabon, few patients mentioned feelings of self-stigma. Here, TB aetiologies roughly differed between *natural* and *magical* explanations, but we did not encounter narratives about blame or dirtiness. Many respondents, especially in Zambia and South Africa, only few in Gabon, considered TB and HIV the same disease. Consequently, TB patients were often confronted with HIV-related judgements, such as prostitution, promiscuity, and immoral behaviour.

Moreover, in South Africa, we found that prevailing discourses of biomedical staff of 'responsible patients' fed into perceptions of relapse and MDR-TB patients as irresponsible and dangerous. Such discourses require more nuance to overcome stigmatizing attitudes. In Zambia, stigmatizing attitudes of health workers were mentioned in the general clinic, but most respondents stressed that TB health workers in the TB department did not stigmatize patients. This can be related to the fact that most health workers had a lot of experience in TB care and felt well prepared to confront (infectious) TB patients. In Gabon, respondents did not mention stigmatizing attitudes of health care staff, but maybe this can be explained by the absence of DOT and the limited amount of visits patients had to attend the hospital.

Combating stigma is a complicated target, especially as stigmatizing behaviours are often complex, multi-layered, and deeply embedded in societal norms and values. Most anti-stigma policies are aiming at education, however, simply relaying biomedical knowledge overlooks the idea of multiple explanatory models.¹⁶ In Gabon and Zambia (**Chapter 7, 8, 9**), biomedical TB aetiologies existed alongside traditional or spiritual TB aetiologies. Moreover, presumptions that knowledgeable people do not stigmatize, do not take into account deep-seated beliefs and the cultural context.³⁹ Additionally, we should keep in mind that TB sensitization may have the potential to aggravate stigma due to fear caused by knowledge about TB being transmitted by air.⁴⁰

In **Chapter 7**, we advocate more counselling and empowerment of TB patients to avoid perceptions of guilt and internalization of stigmatizing beliefs. However, this may additionally oversimplify the impact of stigmatizing cultural ideas on the individual and overestimate the ability of someone to ignore or resist those. Nevertheless, perceptions are not a static condition, nor are motives to stigmatize. Therefore, it is important that sensitization programmes do not have a pedantic and one-direction character. Instead these programmes need to be interactive, enabling a space wherein peoples' current and ever-changing perceptions can directly feed into the programme leading to discussion in which stigmatizing thoughts can be challenged. Recently, a systematic review⁴¹ has been published about TB-related stigma reducing interventions additionally advocated the use of support groups with a focus on improving community attitudes.⁴²⁻⁴⁴ The authors suggest stigma-reduction interventions may engage a variety of populations simultaneously, e.g. TB patients, families, and health workers.^{15,43} We additionally argue more research should be conducted regarding the variations of stigma across treatment sites (e.g. complementary and

alternative medical healers, private hospitals, pharmacies), and urban spaces (e.g. patients' homes, bars, social gatherings, work) to gain more insight into processes of stigma, and informing stigma-reducing interventions. Moreover, research is needed to explore the potential role of film herein. Does film have the potential to alter stigmatizing narratives, to create an empathetic understanding of having TB, or even to trigger a shared experience between the audience and the filmed subjects? To not only inform, but additionally to inspire, and imagine the possible? Could film constitute a platform for TB patients to raise their voice or for Civil Society Organizations (CSOs) to represent those groups that are most vulnerable?

TB perceptions and therapeutic traditions

In **Chapter 4**, we described that most of our respondents explained that local TB perceptions were used in the past or solely prevailed in rural areas. Therefore, many said that associated healing traditions seemed no longer having influence on TB patients' health care seeking behaviour in this area. In Khayelitsha, there was a considerable amount of biomedical TB education that seemed to reach most people living in the study area. Only the differentiation between TB aetiologies and risk factors at times caused confusion among respondents. Consequently, many respondents were insecure about how to prevent TB, because risk factors included practices many respondents engaged in, such as smoking or drinking alcohol. In **Chapters 6 and 8**, we describe that in Gabon and Zambia, the majority of respondents shared a variety of local TB perceptions. Often they explained how perceptions were intrinsically linked to their choice of healthcare provider. Many scholars describe how illness perceptions and health care seeking behaviour are closely intertwined and interconnected. We suggest there is a need for cultural-sensitive TB sensitization programmes in these areas that address both biomedical and the variety of local TB perceptions in order to enhance early case-finding. However, some counterarguments elicit too much emphasis is placed on cultural barriers to TB treatment ignoring or downplaying socio-economic barriers.⁴⁵ In this thesis, we argue that all cultural, social, economic, and organizational barriers to TB treatment adherence need to be taken into account to understand patients' experience with TB and care.

Similar to our findings in **Chapter 8 and 9** exploring the medical plural landscape in Gabon, we describe in **Chapter 6** how TB patients in Zambia attended a wide range of care providers, such as traditional healers, faith healers, private clinics, and public clinics. We advocate a collaborative strategy between these non-biomedical care providers and clinics linking our recommendation to a statement of the WHO regarding collaboration with traditional healers back in 1979.⁴⁶ Several studies highlight the success achieved by such programmes.⁴⁷⁻⁵⁰ In Khayelitsha, traditional healers and faith healers were present, but were mostly attended for minor diseases. For this reason, we did not recommend

collaboration with traditional and faith healers in **Chapter 4**. However, many traditional healers do treat coughs. This shows how the recommendation of the WHO may also be applicable in this context. In 2013, the WHO presented the Traditional Medicine Strategy which recognized that the role of and demand for traditional and complementary medicine in health care is underestimated anywhere in the world.⁵¹ We agree that there is a need to consider a cohesive, integrative, and regulated health care approach.

Low TB incidence countries

Last but not least, we recommend future research that covers above-mentioned themes in low TB incidence countries and additionally addresses the variety of hard to reach groups in order to tailor TB control programmes to specific risk groups. Unfortunately, we have to keep in mind that many of these countries lack an NTP, thus complicating uptake of TB control.

In conclusion, this thesis shows that despite internationally recognised guidelines for TB care formulated by the WHO, there are many differences between countries regarding NTPs. The discussed NTPs in South Africa, Zambia, and Gabon have developed over the years, yet many improvements are still needed. This does not only account for more deserted areas, such as Gabon, but also in countries such as South Africa where care is of relatively high standard, yet TB incidence remains alarmingly high. This thesis addresses the severe side effects TB patients deal with and the importance to improve PCC, PV, and drug development. We suggest to critically look at DOT and the role HIV-TB integrated services can play herein. Moreover, we pay attention to the problematic interaction between poverty and TB, and the need to collaboration across sectors. Furthermore, we illustrate the complexity and context-specific manifestations of stigmas and the need for new interventions. It would be of interest to explore the potential role film could play in TB research, interventions, and advocacy. Lastly, we advocate a universal TB approach, including a focus on TB in middle- and high-income countries.

REFLECTION

Notwithstanding the fact that this research has been conducted with many collaborators, in this section I will reflect only on my own position during this research and discuss how this may have influenced the collected data. Whilst being in the field, I faced numerous methodological challenges. I was daily confronted with the gruesome unequal division of the worlds' resources, getting acquainted with respondents who mostly lived in severe poverty and struggled with having enough food for the day, both for themselves and for their families. This contrasted my position as a white, relatively rich, educated

woman. This disparity may have influenced my research, making some respondents reluctant or shy to speak their minds. However, my sincere interest, my partnership with my local research assistants, my gathered knowledge of the local culture, and additionally my young age (I do not have children yet, so I was by many defined as young without sharing my age) may have positively influenced this relationship. This shifting of my position fuelled many open, intimate, and in-depth conversations with my respondents. We discussed the complexities of having TB and care, the secretiveness surrounding traditional healing (most prominent during my field site in Gabon), and the shame regarding topics such as poverty and TB-related stigma.

Moreover, I conducted most interviews at patients' homes' to actively try to dissociate myself from the clinic and related hierarchy between patients and medical staff. This was only a challenge in Gabon and Zambia, as my research in South Africa was not tied to a clinic. The community-based research setting in South Africa triggered more intimate relationships with my respondents than in Zambia and South Africa and therefore, this setting seemed very convenient for this type of research. However, the South African study fuelled other challenges, as the area was very poor and violent because of petty crime and gangs restricting me in entering certain areas on certain times. Additionally, recruiting respondents with TB was more time-consuming compared to the research projects in Zambia where dozens of patients were lined up at the clinic every day or in Gabon where medical doctors linked me to patients.

The fact that all my respondents were ill, sometimes made it impossible to continue interviews, either because they did not feel well enough or I feared risk of infection with TB. This disruption in data collection could be resolved, as the extended amount of time I was in each field site often allowed me to return to my respondents' houses. In the case of fearing infection, there is a fine line between participant observation and interfering with the lives of my respondents. For example, one day I was confronted with a patient who had prematurely stopped MDR-TB treatment and was coughing. It was an ethical consideration to offer her a ride to the clinic in order to get tested and to avoid further spreading of the disease to her family members amongst which were many children. This action did, however, influence the data I collected as I changed my respondent's situation.

My most vulnerable experience in the field was when one of my closest key-respondents, passed away during one of our long conversations. We were sitting on the sofa when she suddenly gasped and collapsed. My research assistant and I took her immediately in my car to the hospital, but when we arrived she had already passed away. I was extremely shocked and sad. I realized once again that for many TB patients, death was not that far away. A couple of months later, another of my dear respondents passed away. This greatly influenced my writing about TB and the urge I felt and still feel to explain more people about the devastating effects TB can have on someone's life, notwithstanding availability of treatment for free. I have been very motivated in making a longer

ethnographic film about their story and that of many other TB patients in South Africa. I hope this will have its impact, reaching out to a broader audience, and potentially contribute in some way to improve their situation.

What I highly appreciated about my research was the ability to collaborate with physicians and to better understand their perspective and practices of TB care. During my first research project in Gabon, I discussed with my fellow PhD student and medical doctor which of her patients I could include in my research and who was lost to follow up. It was of value to supply her with information about the reasons why patients had stopped going to the clinic. However, I realized that most of the 'cultural' explanations for not attending the clinic led to frustrations among physicians. This attitude contrasted with one of the core elements of anthropology: aspects in live that are considered 'normal' or 'rational' in a society can be seen as socially constructed and valid in the specific cultural context.⁵² In this biomedical environment, it was a challenge to present the wide variety of local TB knowledge and practices in a symmetrical fashion with biomedical TB knowledge and practices and to avoid phrasing the latter as being universal or normative. During the process of writing this thesis, I often found myself being influenced by this dominating biomedical orthodoxy. Being self-aware of this pitfall, I aimed at nuancing my formulations and statements throughout this thesis.

Another challenge was to present my ethnographic data to a biomedical audience. The weekly research meeting at the Academic Medical Center (AMC) often allowed me to discuss detailed ethnographic research findings in the short amount of fifteen minutes. I found that the audience, mostly physicians, were often focused on tables, figures, and statistics. For my fieldwork in South Africa, I decided to use visual methods enabling me to communicate study results via film. I got trained as a visual anthropologist at the School of Media in Manchester and brought a camera with me to Khayelitsha. The camera formed an important part of my research as it often functioned as a catalyst making respondents more motivated to speak up. With support of the Documentary Institute Amsterdam, I edited my material into a visual ethnography. The responses from both public health, anthropology, and medical audiences were very positive and some physicians admitted they could finally grasp what kind of research I was conducting. Further research is necessary to address methodological challenges that arise from such a method.

Concluding remarks

Throughout my PhD trajectory, my identity as a researcher was at times questioned, being trained as a social and cultural anthropologist, but conducting interdisciplinary research that was rooted in a global health research project. Receiving feedback from my (co-)promotors from the disciplines medicine and anthropology was both highly useful and valid and at times integration of

information was complex and challenging. I regularly needed to position my research within the intricate field of interdisciplinary research. To find a nuanced answer to my more global health oriented research question of how TB patients' experience of care was related to NTPs in South Africa, Zambia, and Gabon, I resorted to anthropological methods, such as ethnography. Whilst collecting data, the anthropological methods enabled me to pay attention to cultural frames,^{53,54} and to historical, social and political fields in which I embedded and substantiated my arguments.⁵⁵ For my colleagues in the medical field, this approach made me undoubtedly a medical anthropologist. However, some anthropologists may argue that this research diverges from conventional anthropology of single-site participant observation and rather place this research within the discipline of global health. The question whether multi-sited ethnography can do justice to the local context is broadly debated in anthropology.⁵⁵ Moreover, my articles are mostly global health-oriented and published within global health journals, where little space is left for anthropological theory. Some anthropologists describe this separation of method from theory in anthropological health research as a problematic tendency.⁵⁴ However, others argue that this type of research about barriers to TB prevention and control with a policy-relevant aim (**Chapters 2, 4, 6, 7, 8**) can be considered as one of the many strains of medical anthropology.²⁷ Some authors claim anthropology has more to offer to the field of global health.^{27,54} Therefore, this thesis additionally aims at a reconfiguration of the boundaries of TB research by offering new conceptual frameworks about resilience and survival (**Chapter 4**) and medical pluralism (**Chapter 9**) and methodological insights regarding the use of visual ethnography in interdisciplinary health research (**Chapter 3, 5**). Based on the above, I would like to conclude that this thesis draws on both global health and anthropological approaches.

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Nederlandse Samenvatting

Tuberculose (tbc) is een ziekte die onder eindeloos veel namen bekend staat. Over de wereld worden de oorzaken van tbc op tal van manieren uitgelegd en verschillend aangepakt. Volgens de biomedische wereld is tbc een infectieziekte die wordt veroorzaakt door een bacterie (*Mycobacterium tuberculosis*). Iedereen kan tbc krijgen, ongeacht sekse, etniciteit of leeftijd. Tbc wordt vrijwel altijd door de lucht verspreid. Wanneer een patiënt met besmettelijke longtuberculose hoest, kunnen de bacteriën uit de longen in de lucht komen. Als een ander deze bacteriën inademt, is er een kans op besmetting. Tbc kan overal in het lichaam voorkomen, zoals de botten, het bloed, lymfeklieren, maar uit zich vaak als een longziekte. Tbc patiënten kunnen last hebben van hoesten, gewichtsverlies, nachtzweeten, koorts en algeheel ziek-zijn. Mensen met hiv hebben een veel hoger risico om tbc te krijgen als gevolg van hun verzwakt immuunsysteem. Tbc is voor hen doodsoorzaak nummer één. Tbc patiënten kunnen volledig genezen, mits tijdig ontdekt en behandeld met anti-tbc medicatie. Desondanks is deze ziekte wereldwijd nog steeds een groot probleem met ongeveer 1,7 miljoen doden in het jaar 2016. Het aantal patiënten daalt nog onvoldoende en in sommige gebieden stijgt het zelfs. Co-infectie met hiv en de toenemende resistentie voor tbc medicijnen maken de behandeling aanzienlijk gecompliceerder en vormen een dreiging voor veel nationale tbc programma's (ntp's).

Sub-Sahara Afrika is een regio die dramatisch is geraakt door de tbc epidemie, onder andere door de hiv epidemie. Dit proefschrift richt zich op Zuid-Afrika, Zambia en Gabon; landen met uiteenlopende ntp's wat betreft middelen en epidemiologie. Alle drie de landen hebben te maken met een problematische tbc situatie. We hebben in deze landen interdisciplinair onderzoek verricht, waarin we gebruik hebben gemaakt van zowel een public health aanpak als een antropologische visie. Een etnografische methode vormde in elk land de basis en werd gecombineerd met een kwantitatieve, kwalitatieve of visuele methode. Het doel van dit proefschrift is om meer inzicht te krijgen in de ervaring van patiënten met tbc, hun lichamelijk welbevinden, emoties en percepties van de ziekte en zorg. We laten zo zien dat er nog steeds belangrijke uitdagingen zijn voor ntp's ondanks adequate tbc medicatie en diagnostiek. Onderstaande samenvatting geeft kort weer wat de belangrijkste onderzoeksresultaten zijn van dit proefschrift. Tevens wordt er een beeld geschetst van de mogelijke implicaties voor zowel het onderzoeksveld als voor ntp's. Dit zou vervolgens tot verbeterde tbc zorg kunnen leiden.

DEEL I

Het eerste gedeelte van dit proefschrift richt zich op de landen met een lage of middelhoge tbc incidentie. **Hoofdstuk 2** is een systematisch overzichtsartikel van kwalitatieve wetenschappelijke literatuur over mogelijke obstakels en ondersteunende factoren bij tbc diagnostiek en behandeling voor moeilijk te bereiken en kwetsbare populaties. De meeste kwalitatieve studies richten zich

op migranten in landen met een lage of middelhoge tbc incidentie. Andere kwetsbare groepen (daklozen, drugsgebruikers, vluchtelingen, mensen met hiv, gevangenen, gezondheidsmedewerkers) blijven onderbelicht of worden zelfs geheel niet besproken (zoals bijvoorbeeld prostituees). Onder deze groepen bestaan veel misvattingen over de zwaarte van en de vatbaarheid om tbc te krijgen. Belangrijke obstakels voor diagnose en behandeling zijn stigmatisering en problemen met het verkrijgen van toegang tot gezondheidszorg. Steun van familie, vrienden en verpleegkundigen worden vaak als belangrijke ondersteunende factoren genoemd voor patiënten om tbc behandeling te blijven volgen. Ons overzichtsartikel laat zien dat er echter maar weinig bekend is over de kennis van tbc onder deze kwetsbare groepen, stigmatisering, de rol van direct geobserveerde drugs-inname in de kliniek (dot) en economische obstakels van patiënten. Daarom suggereren wij dat er meer vervolgonderzoek nodig is op dit gebied.

DEEL II

Het tweede gedeelte gaat in op de situatie in een van de meest gewelddadige sloppenwijken van Zuid-Afrika, Khayelitsha (Kaapstad), met één van de hoogste tbc gevallen wereldwijd. Tijdens het etnografische veldwerk is gebruik gemaakt van een visuele methode waarvoor acht respondenten intensief zijn gevolgd met een videocamera. In **hoofdstuk 3** wordt dieper ingegaan over de toegevoegde waarde van visuele methode, in het bijzonder voor interdisciplinair (gezondheids-)onderzoek. We beschrijven dat de aanwezigheid van de camera werkt als een katalysator, waardoor respondenten nog gedrevenner zijn om hun boodschap over te dragen. De vertaling van ons onderzoek naar een etnografische documentaire zorgt ervoor dat gedetailleerde etnografische informatie sneller gedeeld kan worden en er een groot en diverse publiek wordt bereikt. Film is een krachtig medium waardoor de kijker meegenomen kan worden in de wereld van tbc patiënten en een gevoel krijgt van een gedeelde ervaring. **Hoofdstuk 4** is een multimedia artikel waarin tekst wordt afgewisseld met videobeelden. **Hoofdstuk 5** bestaat uit een langere etnografische documentaire genaamd 'TB in Town 2' (link trailer: <https://vimeo.com/227797348>, link film: <https://vimeo.com/259898896>, wachtwoord: Tuberculosis).

In **hoofdstuk 4 en 5** wordt beschreven dat Khayelitsha één van de best functionerende gezondheidszorgsystemen in Zuid-Afrika heeft. Er is onder invloed van internationale donoren een goed functionerend hiv en tbc programma opgezet. Er zijn veel nieuwe interventies ingevoerd of getest, zoals geavanceerde diagnostische apparatuur, gratis medicatie voor zowel tbc als resistente tbc, en een combinatie van dot en thuiszorg. Ook is er duidelijke tbc voorlichting, psychologische hulp, vrijwilligers uit de gemeenschap die zich inzetten voor tbc patiënten, en sociaaleconomische support programma's. Na de afschaffing van het apartheidssysteem in 1991, is de extreme ongelijke verdeling in rijkdom,

gezondheid en de marginalisering van etnische groepen voor een enkeling iets veranderd. Toch leven er nog steeds vele mensen in extreme armoede. Werkloosheid is hoog wat vaak resulteert in geweld en misdaad. De sociale programma's waarbij de armste tbc patiënten een beurs kunnen krijgen, veranderen hier weinig aan. De symptomen van armoede worden op deze manier bestreden, maar de diepe structuren van ongelijkheid niet. Mensen die in armoede leven, zijn kwetsbaarder om tbc op te lopen en te ontwikkelen, omdat onder andere voedseltekort het immuunsysteem verzwakt. Ook zoeken patiënten vaak pas laat zorg, omdat ze dit niet kunnen betalen. Bovendien verergert honger voor vele patiënten de bijwerkingen van hun tbc behandeling waardoor sommigen deze tijdelijk stoppen of voortijdig afbreken.

Verschillende patiënten en zorgverleners vertellen dat andere tbc patiënten expres ziek worden of ziek blijven om zo een tbc beurs te kunnen ontvangen. Vanwege de hoge werkloosheidscijfers en armoede, lijkt het aannemelijk dat sommige personen ervoor kiezen zichzelf op te offeren. Dat wil zeggen dat zij besmet raken met tbc om op deze manier zichzelf en hun familie te kunnen onderhouden en een waardig leven te kunnen leiden. Ook vertellen een paar patiënten dat er negatief op hun klachten over bijwerkingen is gereageerd door zorgverleners, die dan dreigen met het stopzetten van hun tbc beurs als ze niet hun medicatie blijven innemen. Meerdere patiënten geven aan last te hebben van bijwerkingen van de medicijnen: van een allesoverheersende misselijkheid tot doofheid en psychose. Patiënten beschrijven dat ze zich klem gezet voelen om te kiezen tussen het afronden van hun tbc behandeling in combinatie met bovengenoemde bijwerkingen en het staken van de tbc behandeling met de mogelijkheid in de toekomst te overlijden aan tbc. Dit laatste wordt door sommigen beschouwd als een waardigere manier. Overlevingsstrategieën en alcoholconsumptie kunnen een negatieve invloed hebben op zorg zoekend gedrag en therapietrouw. Ook stigmatiserende houdingen in de sociale omgeving hebben hier een negatieve invloed op. Ondanks de hoeveelheid aan tbc voorlichting in dit gebied, zijn er vele ideeën dat tbc wordt verkregen door viezigheid en armoede of door het hebben van hiv. Hiv wordt vaak beschouwd als een gevolg van immoreel gedrag, prostitutie, of promiscuïteit, kenmerken die regelmatig ook aan tbc patiënten worden toegekend. Patiënten met resistente tbc krijgen te maken met een extra dimensie van stigmatisering, omdat hun resistentie wordt verweten aan onverantwoordelijk medicijngebruik. Dit stigma wordt versterkt door de manier van praten onder gezondheidsmedewerkers, die patiënten als verantwoordelijk of onverantwoordelijk categoriseren. Op basis hiervan bepalen zij of de patiënt thuiszorg of dot krijgt. Tevens omschrijven verschillende respondenten patiënten met resistente tbc als gek en gevaarlijk. Door stigmatisering wordt respect en sociale status, maar ook ondersteuning vanuit het sociale netwerk van een patiënt aangetast.

Het derde gedeelte van dit proefschrift kijkt naar de situatie van tbc patiënten in Lusaka, de hoofdstad van Zambia. De aanwezige ntp heeft een vrij uitgebreid programma, maar er zijn minder beschikbare middelen vergeleken met de Zuid-Afrikaanse ntp. Een team van vrijwilligers zet zich in door voorlichting aan tbc patiënten te geven. Dit team wordt steeds kleiner door het ontbreken van financiën voor onkostenvergoeding. In **hoofdstuk 6** tonen we aan de hand van vragenlijsten aan dat een klein gedeelte van de tbc patiënten in onze studiegroep niet therapietrouw is (10%). Er is geen associatie gevonden met culturele of sociaaleconomische factoren. Wel is er een mogelijk verband met tijdsbeperking en afstand tot de kliniek. Aan de hand van het kwalitatieve onderzoek zijn er wel verscheidene obstakels voor therapietrouw gevonden. Ook blijkt dat het te laat zoeken van biomedische zorg, pas wanneer iemand in een vergevorderd stadium van tbc is, veel voorkomt. De grote verscheidenheid aan (vaak tegenstrijdige) tbc percepties, oorzaak van besmetting, en scala aan traditionele, kerkelijke en biomedische zorgverleners, kunnen zorgen voor onduidelijkheid over tbc bij patiënten. Gezondheidsmedewerkers spelen hierop in door toe te lichten dat elke hoest tbc zou kunnen zijn en dat het goed is om voor de zekerheid naar het ziekenhuis te gaan. Ook wanneer een hoest wellicht veroorzaakt lijkt te zijn door hekserij. Er zijn echter ook patiënten die aangeven geen voorlichting over tbc te hebben gekregen. De voorlichting kan weinig creatief zijn of niet interactief. Patiënten voelen zich soms te ziek om goed te kunnen luisteren. Een ander belangrijk obstakel is de grote armoede van het merendeel van de tbc patiënten. Honger compliceert ook hier de inname van tbc medicatie en geeft verergering van bijwerkingen. De aanwezige dot structuur, waardoor patiënten veelvuldig aanwezig moeten zijn in de kliniek, hindert werkverplichtingen. Verschillende buitenlandse hulporganisaties hadden een tijdelijk sociaal programma opgezet om tbc patiënten met laag sociaaleconomische status te ondersteunen. Maar door bezuinigingen en het tijdelijke karakter van deze projecten bleek dit geen duurzame oplossing.

Stigmatiserend gedrag uit de sociale omgeving is ook een belangrijk thema en wordt uitgebreid besproken in **hoofdstuk 7**. Patiënten worden geconfronteerd met uitschelden, ridiculiseren, discrimineren, isoleren of buitensluiten. Dit heeft een grote invloed op de al kwetsbare positie van tbc patiënten en sommigen worden hierdoor gehinderd in hun therapietrouw of zorg zoekend gedrag (o.a. omdat sommigen hun diagnose niet accepteren). Er zijn meer vrouwen dan mannen met tbc die met stigmatisering te maken hebben. De kwetsbare positie van vrouwen wordt verergerd door traditionele mythes die vrouwen beschuldigen van het verspreiden van tbc en hiv. Bijvoorbeeld doordat vrouwen koken of gemeenschap hebben na het uitvoeren van een abortus of tijdens de menstruatie. Tbc patiënten worden ook gezien als onachtzaam, onverantwoordelijk, of kettingrokers. Tbc en hiv wordt regelmatig met elkaar

geassocieerd of gezien als dezelfde ziekte wat leidt tot dubbele stigmatisering. Net als in Zuid-Afrika, wordt in Zambia hiv gezien als een gevolg van prostitutie, promiscuïteit, maar ook van kettingroken. Veel patiënten geven aan dat zij een minderwaardigheidsgevoel overhouden aan tbc gepaard gaande met gevoelens van schaamte.

DEEL IV

In het laatste deel van dit proefschrift richten we ons op de situatie in Lambaréné, Gabon. Gabon is een dunbevolkt land, met een middelhoge incidentie van tbc. De zorg voor tbc en hiv is beperkter dan in de voorgenoemde landen. In **hoofdstuk 8** beschrijven we dat de ntp zich voornamelijk richt op de aanwezigheid van gratis tbc medicatie. Dot, tbc voorlichting programma's of een sociaal zorgprogramma, in de vorm van vrijwilligers of tbc beurzen, zijn niet aanwezig. De medicijnen zijn niet altijd voorradig en kunnen dan alleen aangeschaft worden via private wegen. Vanwege hoge kosten is dit niet toegankelijk voor de gemiddelde patiënt. Verder zijn er geen diagnostische middelen of medicatie voor resistente vormen van tbc. Tbc wordt vaak aangeduid als een ziekte afkomstig van een bacterie, vergif, demonen of hekserij. Voor de meeste patiënten is zelfmedicatie met planten uit de jungle of de traditionele genezer de eerste stap naar zorg voor (tbc) klachten. De traditionele genezer wordt gezien als onderdeel van de gemeenschap en cultuur, makkelijker te bereiken, zeer toegankelijk en bij een bezoek kan de patiënt anoniemer blijven dan bij een bezoek aan het ziekenhuis. Het hebben van tbc en de tbc behandeling van het ziekenhuis zorgt voor veel druk op de inkomens van patiënten, aangezien velen door hun ziekte niet meer kunnen werken. Voor de patiënten die ver van het ziekenhuis wonen, is het ziekenhuis moeilijk toegankelijk, onder andere doordat het merendeel geen geld heeft voor transport. Een bezoek aan het ziekenhuis wordt dan ook regelmatig tot op het laatste moment uitgesteld. Andere obstakels van tbc zorg zijn de stigmatiserende houdingen en gedrag van de sociale omgeving, vooral veroorzaakt door de angst om besmet te worden met tbc. Hierdoor houden vele patiënten hun tbc status geheim. De associatie met hiv wordt slechts door een enkeling gemaakt.

In **hoofdstuk 9** wordt verder ingegaan op het brede scala aan biomedische, traditionele en kerkelijke tbc genezers en de verschillende manieren om het verkrijgen van tbc uit te leggen. De vraag was hoe zowel genezers als tbc patiënten navigeren in een medisch landschap dat zo divers is, ook wel medisch pluralisme genoemd. Recente literatuur beschrijft hoe de grenzen tussen medische tradities vervagen, worden verlegd of overschreden door zowel genezers en patiënten. In plaats van afgebakende werelden, zouden deze tradities op een pragmatische wijze worden samengenomen in de zoektocht naar de meeste efficiënte en effectieve tbc zorg. Genezers zouden grensverleggend werken om meer autoriteit te verkrijgen. Om deze tendens in de literatuur aan te vullen,

introduceren wij het idee van conventionele grensvorming. Onze respondenten geven aan dat je de verschillende geneeswijzen niet gelijktijdig kan combineren om verschillende redenen. Zo wordt er een sterk onderscheid gemaakt tussen de geneeswijze van de zwarten versus de witten. Ook is het een taboe om meerdere geneeswijzen te combineren. Een combinatie wordt door velen als te krachtig beschouwd en daarom gevaarlijk voor de gezondheid. Verder werkt een behandeling pas goed als je er volledig in gelooft en heeft een combinatie gewoonweg weinig nut. Tevens hebben we aandacht besteed aan de politieke context. De Gabonese overheid heeft een nationaal programma gelanceerd, waarbij traditionele geneeswijze meer aandacht en autoriteit krijgt en zo grenzen worden bevestigd. Gelijktijdig zijn zij voorstander van een verlevting tussen traditionele en biomedische geneeswijzen, wat weer duidt op een vervaging van grenzen. Dit vervagen van grenzen tussen geneeswijzen op nationaal niveau werd echter niet genoemd op lokaal niveau. Met het concept conventionele grensvorming geven we aan hoe het therapeutische landschap door onze respondenten wordt gecontrasteerd, versterkt, gezuiverd en verdeeld. Deze processen zullen indirect patiënten beïnvloeden bij het navigeren in het therapeutische landschap op zoek naar tbc zorg.

TOT SLOT

Dit proefschrift geeft aan dat ondanks internationale richtlijnen voor nationale tbc zorg, er grote verschillen zijn tussen landen wat betreft ntp in sub-Sahara Afrika. Ook zijn de obstakels voor ntp's van de drie landen in dit proefschrift in grote lijnen vergelijkbaar, maar in detail toch zeer context-specifiek. De ntp's in Zuid-Afrika, Zambia en Gabon zijn sterk ontwikkeld vergeleken met een aantal jaren geleden. Desondanks kan er veel verbeterd worden op het gebied van tbc zorg. Dit geldt niet alleen voor afgelegen gebieden in Gabon. Ook in een sloppenwijk met een miljoen inwoners in Zuid-Afrika, waar zorg van relatief hoge standaard is, maar tbc aantallen nog steeds alarmerend hoog, is verbetering van de ntp een noodzaak. De vraag is of het mogelijk is om de wereld te verlossen van de tbc epidemie in 2035, één van de Sustainable Development Goals. Ondanks de decennia aan wetenschappelijk onderzoek naar tbc en de beschikbare diagnostische middelen en medicijnen, blijft de sterfte aan deze geneesbare ziekte onacceptabel hoog.

In de algemene discussie van dit proefschrift (**hoofdstuk 10**) worden de inzichten van dit onderzoek verbonden aan nieuwe mogelijkheden om tbc zorg te verbeteren, die ingezet zouden kunnen worden in de strijd tegen tbc. Daarnaast zijn er vele essentiële vragen voor toekomstig wetenschappelijk onderzoek op het gebied van tbc. Zo wordt de noodzaak duidelijk dat tbc onderzoek overal in de wereld onder de aandacht moet komen, ook onder de kwetsbare groepen in landen met een lage tbc incidentie. Een tweede belangrijk thema dat in alle drie de landen naar voren komt, is dat veel tbc patiënten te laat biomedische

zorg zoeken of vroegtijdig hun tbc behandeling staken. Hierdoor overlijden onnodig veel patiënten aan tbc. Zo is er meer aandacht nodig voor de ervaringen van patiënten met hun tbc behandeling en de bijwerkingen. Ook al pleit de wereldwijde End TB strategie voor patiëntgerichte zorg, zorg waarbij de situatie en voorkeuren van individuele patiënten met respect worden bejegend en tegemoet gekomen, toch blijkt de vertaalslag naar de praktijk ingewikkeld. Mogelijk is film een goed medium om concreter voor ogen te krijgen wat de ervaringen van tbc patiënten zijn. Het idee van patiëntgerichtheid binnen tbc beleid kan op deze manier naar de lokale context worden vertaald. Op welke manier film als instrument kan worden ingezet, wat de voordelen en valkuilen zijn, zou verder onderzocht moeten worden. Verder is er sinds de jaren zeventig bijna geen nieuwe tbc medicatie ontwikkeld. Er is wel nieuwe medicatie voor resistente tbc op de markt gekomen, maar deze behandeling is nog niet voor iedereen beschikbaar en geeft nog meer bijwerkingen. Met welke medicijnen kan tbc veilig worden behandeld zonder zware bijwerkingen en gedurende een korter tijdsbestek?

Er bestaat in alle drie de landen een enorme wrijving tussen therapietrouw en armoede. Een extra dimensie op het armoede vraagstuk zijn de sociaaleconomische programma's voor tbc patiënten die beschikbaar zijn in Khayelitsha. Belangrijk is dat deze programma's onvoorziene consequenties kunnen hebben en zo infectie van tbc in de hand kunnen werken. Meer onderzoek zou gedaan moeten worden naar de effecten van zulke beurzen op gemarginaliseerde mensen die hierdoor mogelijk extreme armoede kunnen vermijden. Daarnaast blijft de vraag op welke manier armoede en honger onder tbc patiënten het best kan worden aangepakt. Is het wellicht zinvoller dat sociaaleconomische programma's zich richten op de gehele gemeenschap waar tbc incidentie hoog is? Moet armoede worden bestreden met tbc beurzen of met het verbeteren van onderwijs en het creëren van werkgelegenheid? Het dilemma van tbc en armoede verdient de hoogste prioriteit binnen ntp's, maar vraagt ook om een verruiming van de blik over de grenzen van de gezondheidssector. Dit vereist onder andere politieke inspanning.

Een ander veel besproken punt is de rol van dot om therapietrouw van patiënten te stimuleren. Dot is voor vele ntp's een centraal element ook al is er veel kritiek op geuit. Deze aanpak zou te paternalistisch of te simplistisch zou zijn. Patiënten worden geacht in staat te zijn elke dag naar de kliniek te kunnen komen, daarmee fysieke, financiële, sociale of culturele factoren die toegang tot de kliniek mogelijk verhinderen negerend. Waarom zien we in veel landen geen thuiszorg voor tbc patiënten en al helemaal zelden voor diegene met resistente vormen van tbc? In hoeverre is het effectiever om tbc patiënten thuiszorg te geven? Als patiënten thuiszorg kunnen ontvangen, komen ze minder met hun werk in het gedrang. Gezien hun kwetsbare sociaaleconomische positie, zou dit een enorme invloed hebben op hun financiële situatie. Met het oog op hiv-tbc co-infectie, is het interessant dat hiv patiënten op een tegenovergestelde manier

worden benaderd. Bij hiv programma's staat voornamelijk emancipatie van de patiënt centraal. Steeds vaker worden hiv en tbc programma's gecombineerd, zoals in Khayelitsha, Zuid Afrika. Hoe kunnen hiv en tbc zorgprogramma's van elkaar leren en op welke manier kunnen programma's het best worden geïntegreerd?

Stigmatisering van tbc patiënten is een ander belangrijk punt. Wat stigma precies inhoudt, op welke manier het zich manifesteert en wat de achterliggende motivaties zijn, is voor elk van de drie landen verschillend. De variaties in tbc stigma's in de wereld is nog onvoldoende onderzocht. Waarom zijn stigmatiserende houdingen in de ene context problematischer dan in de andere? Welke interventies kunnen worden ingezet om dit tegen te gaan? Waarom leidt tbc voorlichting niet noodzakelijk tot een vermindering van stigmatisering? Hoe belangrijk is het om te kijken naar de lokale cultuur en geschiedenis? Welke rol is er mogelijk weggelegd voor film in de strijd tegen tbc stigmatiseringen? Zou de kracht van verhalen en een gedeelde ervaring van film kunnen worden ingezet om stigmatiserende verhalen om te buigen?

Een volgende vraag is hoe we kunnen inspelen op samenlevingen met andere vormen van tbc zorg. In tegenstelling tot Khayelitsha waar lokale verklaringen van tbc, zoals hekserij, over het algemeen wordt gezien als iets van het verleden, wordt in Zambia en Gabon de behoefte aan cultuur sensitieve tbc voorlichting duidelijk. In Gabon geven artsen biomedische kennis aan hun patiënten, maar gaan zij niet in op lokale percepties van tbc en zijn alternatieve geneeswijzen zelfs een taboe. Hierdoor ontstaan er meerdere percepties voor tbc naast elkaar. Dit leidt in sommige gevallen tot onduidelijkheid en vertraging van biomedische zorg. In Zambia wordt de verscheidenheid aan percepties verweven en een plek gegeven, met als doel om een zo groot mogelijk aantal patiënten tijdig te diagnosticeren en behandelen in het ziekenhuis.

Maar de belangrijkste vraag is: hoe kan deze eeuwenoude ziekte het best worden aangepakt? Een ziekte waarvan al decennia lang bekend is dat deze mede wordt veroorzaakt en in stand gehouden door armoede en ongelijkheid. Een ziekte die in principe te genezen is, maar waar ontzettend veel mensen aan overlijden. Welke combinatie van nieuwe behandelingen tezamen met een sociaaleconomische, culturele, politieke en creatieve aanpak zal het beste zijn om de sterftcijfers van tbc patiënten omlaag te brengen?



Abbreviations, Contributing
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ABBREVIATIONS

ACF	Active case finding
AIDS	Acquired immunodeficiency syndrome
AMC	Academic Medical Center, Amsterdam
ART	Antiretroviral Therapy
ARV	Antiretroviral Drugs
ASH	Albert Schweitzer Hospital
CCW	Community Care Worker
CERMEL	Centre de Recherches Médicales de Lambaréné
CHC	Community Health Clinic
CSO	Civil Society Organization
DOT	Directly observed treatment
DOTS	Directly observed treatment, short-course
DS	Drug Susceptibility
DR	Drug Resistant
ECDC	European Centre of Disease Prevention and Control
EEA	European Economic Area
EU	European Union
FGD	Focus Group Discussion
GAHC	the governmental ambulatory health care centre for HIV and TB
HBC	Home Based Care
HBM	Health Belief Model
HIV	Human Immunodeficiency Virus
HTR	Hard To Reach
IPHAMETRA	l'Institut de Pharmacopée et de Médecine Traditionnelles
IPT	Isoniazide Preventive Therapy
KAP	Knowledge, Attitudes, and Practices
LMIC	Low and middle income countries
LTBI	Latent TB Infection
LTFU	Lost To Follow Up
MDR TB	Multi-Drug Resistant Tuberculosis
MSF	Médecins Sans Frontières
MTB	Mycobacterium tuberculosis
NICE	National Institute for Health and Clinical Excellence
NTP	National Tuberculosis Program
OECD	Organisation for Economic Co-operation and Development
PCC	Patient Centered Care
PH	Public Health
PLHIV	People living with HIV
PV	Pharmacovigilance

TAC	Treatment Action Campaign
TB	Tuberculosis
TBAC	TB Patients Adherence and Compliance
UK	United Kingdom
UNZAREC	the University of Zambia Biomedical Research Ethics Committee
UNZA-UCL	University of Zambia – University College London
USA	United States of America
UvA	University of Amsterdam
VCT	Voluntary Counselling and Testing
WHO	World Health Organization
XDR TB	Extensively Drug Resistant TB

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Visual Methods, Manchester School of Media	2014
Xhosa language course, Cape Town	2014
Creative Writing, University of Cambridge	2015
Final Cut Pro edit course, UvA	2015

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Perceptions, health care seeking behaviour and implementation of a tuberculosis control programme in Lambaréné, Gabon. 16th International Congress on Infectious Disease, Cape Town, South Africa (poster)	2014
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Traditional Healers, Medical Doctors, and E-health. Dutch Albert Schweitzer Foundation (oral)	2014
Visual Methods in Health Research. University of Cape Town, Cape Town, South Africa (oral and visual)	2015
Panel Debate: the pros and cons of stories, images, personal narratives and messaging for reducing TB stigma at the community-level. Getting to Zero TB stigma, The Hague, the Netherlands (oral)	2017

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CURRICULUM VITAE

Lianne Cremers was born in Leiden on Sunday 23rd of March, 1986. After secondary school at the Stedelijk Gymnasium Leiden, she lived in Oxford for one year and worked as an au pair. Inspired by the multicultural student environment, she returned to the Netherlands to study social and cultural anthropology at the VU University Amsterdam. She studied half a year in La Paz, Bolivia. In between her bachelor and master she worked in Pokhara, Nepal at a local NGO that aimed at improving education in rural areas. She decided to follow a second master in Governance at the VU University. Fascinated about medical anthropology, she started working as an anthropologist for a clinical study on TB in Lambaréné, Gabon. In this little village in the jungle, she met the love of her life. Additionally, she was offered to continue her research in the form of a PhD at the Academic Medical Center with a focus on patients' experience of tuberculosis and National TB Programmes in sub-Saharan Africa. She involved the anthropological department of the University of Amsterdam to give her research an interdisciplinary character. During her PhD, she conducted research in Zambia and South Africa using a variety of methods, such as ethnographic, qualitative, and quantitative methods. Fascinated by documentary as a medium for research, she got trained as a visual anthropologist in Manchester. She made an ethnographic documentary for her PhD thesis to not only write, but to additionally show what TB means for patients who are living in South Africa. In 2015, she started her own business and worked as a freelance anthropologist. She lectured the course Global Health, Care & Society at the University of Amsterdam and the course Medical Anthropology at the Amsterdam University College. Moreover, she conducted various research projects in the field of tuberculosis, hypertension, e-health, community preparedness, and HIV for a variety of organizations, such as the KNCV Tuberculosis foundation, the AIGHD, ECDC, and the AIDS foundation. Additionally, she works as a documentary maker. She lives with her fiancée Emma Birnie in Amsterdam.





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