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TB truths

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

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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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