Tuberculosis patients and resilience: A visual ethnographic health study in Khayelitsha, Cape Town

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ABSTRACT

Khayelitsha, one of the biggest and poorest townships in South Africa, has a well-resourced tuberculosis (TB) programme with an interdisciplinary approach addressing the medical, social, and economic forces impacting TB care. Nevertheless, the area remains burdened with one of the highest TB rates in the world. Using a resilience-based approach, we conducted a critical ethnographic study to develop deeper insights into the complexities of patients’ experiences with TB and care. Between October 2014 and March 2015, we approached 30 TB patients, 10 health-care workers, 10 pastors, and 10 traditional healers, using participant observation, in-depth interviews, and focus group discussions. In addition, seven key informants were filmed on a daily basis by the lead researcher. The work reported here (both text and short videos) illustrates the various manifestations of resilience that patients demonstrated and how these impacted on decisions involving treatment seeking and adherence. We have synthesized the data into the following inter-related themes: TB aetiologies and treatment; the embodied experience of TB treatment; alcohol consumption; financial constraints; and support and stigma. The findings from this research highlight patients’ strategies for adapting to adversities, such as pausing TB treatment when lacking food to avoid becoming psychotic, consuming alcohol to better cope, obtaining social grants, and avoiding stigmatizing attitudes. Some manifestations of resilience may interact and, inadvertently, undermine TB patients’ health. Other aspects of resilience, such as strong community ties, elicited long-term health benefits.

TB programs would benefit from a resilience-building approach that builds on pre-existing strengths and vulnerabilities of TB patients and their communities. With the use of short videos, we provided patients with an alternative path for expressing their experiences, which we hope will support synergies between patients, researchers, and policy-makers for improved TB programmes.

1. Introduction

South Africa faces one of the worst tuberculosis (TB) epidemics and highest human immunodeficiency virus (HIV) rates in the world (WHO, 2013). Khayelitsha, a township in Cape Town, is a focal point in this TB epidemic. The public healthcare system in Khayelitsha—and especially its TB services—is actively supported by the international non-governmental organization Médecins Sans Frontières (MSF). Together, they have launched a comprehensive interdisciplinary TB control programme (the Khayelitsha programme) that addresses the medical, cultural, social, and economic aspects of TB care. Despite this comprehensive programme, this area still has one of the highest drug-susceptible (DS) TB and drug-resistant (DR) TB burdens in the world (MSF, 2011a,b).

Quantitative studies have provided insights into what factors influence the functioning of South African TB Programmes, such as TB rates (Wood et al., 2011), DR-TB development, HIV co-infection (SANAC, 2012), socio-economic determinants (Harling et al., 2008; Pronyk et al., 2001), alcohol misuse (Otwombe et al., 2013), organizational obstacles (Colvin et al., 2003), an integrated HIV/TB policy (Uyei et al., 2014), and collaboration between traditional healers and TB health facilities (Colvin et al., 2003). However, these studies generally do not afford an in-depth understanding of how these factors play out in the everyday lives of TB patients. In contrast, published
qualitative research on patients’ experiences with TB and TB care in urban South Africa offers insights into patient’s MDR-TB and TB treatment adherence (Birch et al., 2016; Daftary et al., 2014), the combination of TB and HIV treatment (Daftary and Padayachy, 2013), and TB-related stigma (Daftary, 2012). However, most of these qualitative studies in South Africa were conducted at clinics and few used more in-depth ethnographic methods.

This ethnographic study examined patients’ experiences with TB and TB treatment and aimed to enhance our understanding of why the Khayelitsha programme is still struggling to quell the TB epidemic. Ethnography provides context-specific insights as researchers immerse themselves into the lives of research subjects by fostering in-depth relationships over an extended period of time. This approach enabled us to examine gaps between policy and practice, the slippage between what people say they do and what people actually do in everyday life (Lambert and McKevitt, 2002). Practices may reveal what lies beyond our respondents’ words (Panter-Brick and Eggerman, 2017). Understanding patients’ complex realities and their practices and perspectives within these realities enables a richer understanding of how TB policies play out in the day-to-day lives of those with TB, and, in turn, of how these policies shape patients’ responses to treatment. Globally, various ethnographies have examined TB programs and patients’ treatment adherence (Gerrish et al., 2013; Koch, 2013; Harper, 2006; Greene, 2004). However, there remains a need for more ethnographic research to understand context-specific factors and dynamics in order to better tailor TB services to people’s realities (Mason, 2014; Harper, 2006; Farmer, 2000).

TB is one of many adversities people in Khayelitsha face, as they are confronted daily with disease, pervasive poverty, hunger, unemployment, traffic accidents, and violence. Such adversities are often associated with poor health outcomes (Wexler et al., 2009). The public health literature on the social determinants of health has put a great deal of effort into examining the pathways between social injustices and poor health (Farmer, 2000). In contrast, resilience-based approaches to health provide an alternate emphasis: while acknowledging the health consequences of suffering, vulnerability, victimization, and risk, these approaches also highlight strengths, capabilities, and capacities for well-being (Panter-Brick, 2014). Thus resilience-based approaches seek to examine these experiences within a broader context that highlights agency as people deal with adversity. Individuals, families, and communities often find creative ways to support and sustain themselves and others. They seek to counter, transform or mitigate challenges they encounter in life. Our TB patients’ narrations of suffering and hardship likewise offered compelling accounts of resilience. In this article, the concept of resilience refers to how individuals are able to socially function and emotionally adapt themselves despite living in a context of severe adversities (Masten, 2006).

The concept of resilience has been widely applied in the global health literature to describe people’s diverse attempts to overcome adversities, for example, through resource negotiation (Woodward et al., 2017), psychological coping strategies (Waugh and Koster, 2015), and the strengthening of social structures, community functioning, and social relationships (Perez-Brumer et al., 2017; Zraly and Nyirazinyo, 2010; Wexler et al., 2009). Resilience is often linked to better-than-expected social, psychological, and physical outcomes given the significant challenges individuals and communities often face (Vanderbilt-Adriance and Shaw, 2008).

Our findings confirm that the link between resilience and health benefits is complex, as many TB patients struggle to survive in a context with multiple and varying adversities. A person may show resilience in one domain (family life), but not in another (employment) (Southwick et al., 2015). Moreover, resilience is not static and uniform but arises through processes and may change over time (Fergus and Zimmerman, 2005). In this article, we would like to add that the various manifestations of resilience may interact with each other, i.e. resilience in one domain can influence vulnerability in another domain. Consequently, such multiple manifestations of resilience may have divergent impacts on TB patients’ well-being.

A resilience-based approach may inform TB programmes about the importance and complexities of pre-existing strengths and vulnerabilities of TB patients and their communities. With the use of visual ethnography and short videos, we offered patients a voice and hopefully contributed to the creation of new synergies between patients, researchers, and policy-makers for improved TB programmes. Moreover, visual methods may strengthen the impact of ethnographic health research on policies and discourse (Cremers et al., 2016).

1.1. Context and research setting

South Africa is facing a TB incidence of 1003/100,000, 8.5% drug-resistant (DR-) TB, and a 65% TB-HIV co-infection rate. The overall TB mortality rate is about 228/100,000 (WHO, 2013). In 2012, only 6494 of the 15,419 multidrug resistant (MDR)-TB-patients started treatment (WHO, 2013). About 1/3 of MDR-TB patients ceased treatment prematurely (Shean et al., 2008).

Our research took place in the South African township of 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. As a result of the segregationist policies of the Apartheid regime, the inhabitants continue to be predominantly from the Xhosa ethnic group (GoCT, 2006). Crime rates are very high in Cape Town (Jean-Claude, 2014), and especially in Khayelitsha (Nleya and Thompson, 2009). Major contributors to high crime rates are poverty and high unemployment rates (Jean-Claude, 2014). South Africa is an upper middle-income country (World Bank, 2016), but has high levels of economic inequality, resulting in pervasive poverty. Black Africans were strongly marginalised and discriminated against during the Apartheid regime, and this still impacts on their socio-economic and health status in post-Apartheid South Africa (Jean-Claude, 2014; Packard, 1989). Consequently, this part of Cape Town is known as “Cape Town’s poverty trap” (GoCT, 2006).

TB care (integrated with HIV care) is available in, amongst others, the Khayelitsha Site B Ubuntu Community Health Clinic 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 six 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, provided that a community care worker (CCW) considers them sufficiently responsible to manage their own care (Atkins et al., 2011).

Moreover, Khayelitsha is one of the few places worldwide where new DR-TB drugs are both highly needed and available (MSF, 2016). MDR-TB signals TB infection that is resistant to the first-line anti-TB drugs isoniazid and rifampicin, and extensively drug resistant TB (XDR-TB) indicates resistance to isoniazid and rifampicin, to any fluoroquinolone, and to any of the injectable anti-TB drugs (WHO, 2010). At the time of this research, MDR-TB patients followed a treatment of 21 pills daily for two years and one injection daily for eight months. MSF has launched the first project for treatment of DR-TB-patients at primary health care level. Additionally, the Khayelitsha programme addresses social and economic risk factors via counselling, sensitization programmes, community care workers, social grants, and food supplement programmes (MSF, 2005; MSF, 2011a,b).

2. Methods

One researcher (ALC) and a local research assistant (MM) conducted a five-month ethnographic research project in Khayelitsha, with support from a local researcher (CC), between October 2014 and March 2015. Through chain-referral sampling-techniques, 30 DS-TB and DR-TB-patients were recruited for various 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) (Chaisson and Churchyard, 2010). 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, two focus group discussions (FGDs) (10 patients per group) took place in the Town 2 community. We also interviewed 10 employees of clinics (nurses and CCWs), Treatment Action Campaign (TAC), and MSF, 10 traditional healers, and 10 pastors to gain more insight into the social context. Participant observation took place from morning until evening, during weekdays and on weekends, at respondents’ homes, neighbourhoods, churches, and funerals.

Of the 60 respondents, five patients, one pastor and one CCW were additionally asked to participate as key informants for the visual component of the project and were filmed on a daily basis by ALC (Table 1). Selection occurred after one month of ethnographic research and was based upon respondents’ willingness 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 video camera was not taken on all occasions and even if the camera was present, this did not seem to hinder interaction with participants as the camera was either in a corner on a tripod or held. 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 to 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.

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 the FGDs, which elaborated on these topics and initiated 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 TB. This information partially overlapped with visual data collection, which led to intense researcher-respondent engagement, generating a high level of trust and valuable informal conversations. To foster informal interview settings, we used photo-elicitation techniques (Harper, 2002) and asked respondents to keep a diary (Elliott, 1997). 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 (Glaser and Strauss, 2009). In-depth interviews and FGDs were audio- and sometimes video-recorded, transcribed verbatim, and screened multiple times by ALC. Field notes of participant observations, films, and transcripts were first coded into meaning units and then divided into categories and subcategories. This was checked by MM. Open data collection techniques led 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.

Ethical clearance for the study was obtained from the University of Cape Town (HREC REF 726/2014). Verbal informed consent was received from each participant before recruitment, interviews, and observation. We presented ourselves as researchers who wanted to gain a better understanding about TB and how TB may affect people’s life in Town 2. We explained our goals to write an article and make a film with the hope that people’s experiences might help inform health policies. Because of the relations built with patients and community members and the fact that we attended many events in the course of five months, we were able to attend churches (services) and funerals in an integrated 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 separate consent forms, because they will not remain anonymous.

3. 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. We have synthesized the data into the following inter-related themes: TB treatment and aetiologies; the embodied experience with TB treatment; alcohol consumption; financial constraints; and support and stigma. We present our findings with text and short videos to engage the senses of our readers and create a more empathetic understanding about experiences of patients with TB and care.

3.1. TB aetiologies and treatment

The majority of respondents explained they had received a lot of health education about TB. Most patients 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. Health workers explained that the *Impundulu* myth (about a big bird that kicks you in the chest so you start coughing blood), and the idea of *edliso* (a black poison caused by witchcraft) were TB aetiologies used in the past, but rarely mentioned nowadays. More current TB aetiologies mentioned were cold weather, wetness, sleeping around, heredity (referred to as family-TB), and sharing glasses or cutlery with TB-infected people (S0277953618302776).

Supplementary video related to this article can be found at http://dx.doi.org/10.1016/j.socscimed.2018.05.034.

I was so shocked before, that one. The first TB. I never get sick. And I am 52 now. 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).

All patients attended or had attended a clinic for biomedical TB treatment. A few patients mentioned they additionally had visited faith or traditional healers to cure their TB. Most traditional healers and all faith healers we spoke with explained they were not able to cure TB (alone) and referred people to the clinic.

3.2. The embodied experience of TB-treatment

The harsh side-effects of MDR-TB treatment were a central theme for both patients and health workers and led to difficulties with treatment adherence. DS-TB patients also referred to very similar bodily experiences, especially in the case of comorbidities. Patients intensely described how the high load of toxic medications seemed to destroy their bodies. They mentioned how the TB pills made them throw up and feel nausea, dizziness, weakness, and hunger. Moreover, both DS-TB and DR-TB patients described psychiatric incidences due to the medication (Video 2).

Supplementary video related to this article can be found at http://dx.doi.org/10.1016/j.socscimed.2018.05.034.

During participant observation, respondents sometimes warned the researcher that they had just taken drugs that could potentially trigger unpredictable behaviour. Various DS-TB and DR-TB patients explained they feared becoming crazy because of the drugs and potentially harming themselves or people around them. Some respondents mentioned they particularly feared DR-TB patients for their dangerous behaviour (Video 3).

Supplementary video related to this article can be found at http://dx.doi.org/10.1016/j.socscimed.2018.05.034.

There is another TB, I am scared of that. MDR. The people they say it’s too dangerous. Because the people who have MDR-TB, they pass away. Because most of the people that got MDR, they just loose their minds. 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 described in detail during FGDS and informal conversations and consisted of haematomas on the buttocks, painful legs hindering walking, and hearing loss. One patient said he was relieved his MDR-TB turned into XDR-TB, because that meant no more injections. Few patients continued with injections. Some decided to only continue with oral medication. Yet others discontinued all treatment, because they feared dying of side-effects (Video 4).

Supplementary video related to this article can be found at http://dx.doi.org/10.1016/j.socscimed.2018.05.034.

When I tell my side effects to the nurses, no one seems to listen to listen to me. She shouts at me all the time. And she threatened me that she would stop my government 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 not 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. She explained that health workers accused her of non-adherence with treatment 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.

3.3. Alcohol consumption

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. Pastors explained some 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 from living life to its fullest potential. They explained how alcohol consumption helped to reduce feelings of vulnerability (Video 5).

Supplementary video related to this article can be found at http://dx.doi.org/10.1016/j.socscimed.2018.05.034.

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 … Up until I was taken to the hospital (Khulish, DS-TB-patient).

Alcohol gave some patients a feeling of being in control again, to forget problems, and free their minds. Some respondents explained that alcohol consumption allowed them the chance to ignore their health status up until they developed a severe manifestation of TB.

3.4. Financial constraints and social grants

Patients with a low socio-economic status received a social grant from the government and patients weighing under 40 kg 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. A few respondents mentioned that relapse or MDR-TB-patients were often non-compliant TB patients who wanted a grant from the government (Video 6).

Supplementary video related to this article can be found at http://dx.doi.org/10.1016/j.socscimed.2018.05.034.

Most TB patients had financial problems, mostly due to unemployment, that interfered with treatment. During participant observation, TB patients did not always take all their pills because lack of food worsened side-effects (Video 7).

Supplementary video related to this article can be found at http://dx.doi.org/10.1016/j.socscimed.2018.05.034.
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).

3.5. Support and stigma

Khayelitsha is divided into different quarters that are characterised by 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 8).

Supplementary video related to this article can be found at http://dx.doi.org/10.1016/j.socscimed.2018.05.034.

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 (themselves sometimes former TB patients) did talk in a stigmatising way about TB patients (Video 9).

Supplementary video related to this article can be found at http://dx.doi.org/10.1016/j.socscimed.2018.05.034.

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. 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 distinction between herself and ‘those patients who carried a lot of diseases’. TB patients were often suspected of carrying a wide range of diseases, including 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 10).

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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 considered by many a disgrace and some also explained that one’s position in society was in danger of being degraded (Video 11).

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Kulish 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, referring to the site of his initiation ritual 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 a danger to 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 said 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 12).

Supplementary video related to this article can be found at http://dx.doi.org/10.1016/j.socscimed.2018.05.034.

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.

Various health workers and researchers had a pessimistic attitude about the functioning of the Khayelitsha programme, 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.

4. Discussion

Our resilience-based approach may provide a deeper understanding of how TB patients in Khayelitsha negotiate adversities while dealing with TB and TB care. Most of these adversities - poverty, hunger, stigma - were related to tenacious social, political, and economic inequalities. However, we want to complement our investigation of vulnerability and victimization with a perspective that better integrates patients’ strengths and competencies. We focus here on patients’ manifestations of resilience that may influence their wellbeing and more indirectly, the outcomes of the Khayelitsha programme. We argue that TB patients in this study were strong-willed, proud, and showed substantial agency in making informed decisions despite difficult circumstances. Below, we will explain how decision-making was shaped by the contingencies of respondents’ daily experiences and discuss under what conditions we might consider these as manifestations of resilience.

All patients included in this study were living in dire poverty. Numerous authors have argued that poverty and malnourishment are two principle obstacles to TB care (Ndewa et al., 2007; Waaler, 2002). The side effects of treatments for both DS-TB and DR-TB patients, worsened by a lack of food, and their negative impact on treatment adherence have been reported (Chalco et al., 2006; Törün et al., 2005; Yee et al., 2003). Nevertheless, many of our patients stated that they were not being heard about this aspect of TB treatment. While our patients were generally well-informed about TB and the importance of adherence have been reported (Chalco et al., 2006; Törün et al., 2005; Yee et al., 2003). Nevertheless, many of our patients stated that they were not being heard about this aspect of TB treatment. While our patients were generally well-informed about TB and the importance of treatment adherence, issues such as medications’ side-effects sometimes forced them to deviate from treatment guidelines, especially when food was scarce. At times, some patients decided to pause or stop treatment in order to avoid becoming psychotic. In these moments, patients’ resilience manifested as protecting their psychological health. While this enabled them to live a more dignified life in the short run, they worried that TB might kill them in the long term. In this context, patients weighed alternatives. However, this decision-making did not necessarily translate into long-term health benefits. This resonates with the idea that individuals may be resilient in one domain or phase of their lives, but not in others (Southwick et al., 2015; Vanderbilt-Adriance and Shaw, 2008). Resilience may manifest variably in different contexts and additionally, these different manifestations of resilience potentially interact with each other.

Many patients used alcohol, countering treatment guidelines and despite knowing its disastrous effects on health and potential drug resistance. Nevertheless, drinking alcohol appeared to be an important coping strategy to promote a sense of well-being. At the same time, however, this coping strategy often caused delay or interruption of TB
care. TB patients’ alcohol use may be lowered by poverty alleviation and consequently improve TB outcomes, as a South African study illustrated (Louwagie et al., 2014). Interestingly, this study focused on men, while our study showed that women also used alcohol.

Since 1999, social grants have reduced poverty in South Africa (Armstrong et al., 2008). Yet, as Merton already noted in 1936 (Merton, 1936), social interventions can exert both intended and unanticipated consequences. TB social grants are supposed to financially support recipients and improve their adherence to treatment. Those who complete TB treatment eventually lose access to such grants. Several patients, health workers, and pastors said that some patients prolonged access to such a grant by avoiding or delaying getting cured, or by getting reinfected. Various TB patients did indeed become breadwinners thanks to their grant; their illness and lives at risk assured financial income for their family. Paradoxically, grants may feed into the poverty cycle whereby patients continue to be ill or face recurrent TB, remain unemployed, and stay dependent on these external financial resources. The use of social grant resources to address socio-economic adversity could be considered as enhancing economic resilience, while negatively impacting other domains of resilience, undermining health.

Some authors have argued that unconditional cash transfers to the poor are the way forward (Ferguson, 2015). If most people in Khayelitsha would be able to receive money regardless of TB status, challenges with TB grants as described above may potentially be avoided. The discussion of social grants remains complex as questions arise around whether the structural aspects of this problem are properly addressed, who would be responsible for such payments, and how this would be applied to an everyday context. Instead of grants for individual patients, governments could invest in the wider community (including patients who are no longer infectious) by creating jobs, fostering education, and promoting rights in order to stimulate sustainable economic development. Moreover, TB programmes could be mandated to pressure employers to provide fair compensation for employees who develop active TB.

Narratives of patients deliberately pursuing TB grants may, however, be fuelled by social processes of stigmatization. Some respondents described TB patients in a stigmatizing way and various patients (especially men) mentioned that they felt ashamed of having TB, often hindering TB disclosure and seeking of care. TB was linked by many to HIV, leading to a double stigma (Cremers et al., 2015; Daftary, 2012). DR-TB patients faced another dimension of stigma, as they were often considered dangerous and irresponsible (assuming they had previously been non-adherent with treatment). This discourse of responsibility is strengthened by the Khayelitsha programme that allows ‘responsible patients’ home-based care and warns that non-adherence to treatment leads to drug resistance. South Africa is one of the few countries where second- and third-line TB-drugs are available, explaining the lack of studies reporting on DR-TB-related stigma.

The persistence of strong community ties may heighten vulnerability to TB stigma. At the same time, this kind of intense social interconnection can also serve as a critical resource for enhancing resilience among people living in Khayelitsha and a source of support for their TB treatment. Close connections between people of a community may play an important role in interventions to sustain well-being and health of patients (Hawe and Shill, 2000; Seeman, 1996).

In sum, TB patients’ responses to the Khayelitsha programme must be examined in relation to the manifold adversities they encounter and negotiate in their daily lives. Within this context, resilience among people with TB may differ from time to time and across various domains of life. Moreover, these various manifestations of resilience may interact with each other. Resilience in one life domain may, paradoxically, lead to vulnerability in others. The Khayelitsha programme may currently have limited impact on patients’ situations in the face of dire circumstances. However, a resilience-focused approach could make a unique contribution to this effort by identifying the complex and varying ways resilience manifests itself. TB programmes would benefit from a resilience-building approach that considers pre-existing strengths and vulnerabilities of TB patients and their communities.

Our visual ethnographic study allows for the sharing of knowledge and interpretations that reside beyond medical and scientific rationales, offering alternative ways of understanding and explaining TB (Cremers et al., 2016). A trailer of the longer ethnographic health film “TB in Town 2” can be found at: https://vimeo.com/244487053. 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 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 (TAC, 2017). In considering lessons learned from the fields of HIV (Epstein, 1995), Ebola (Abramowitz et al., 2015), and Lyme disease (Zavestoski et al., 2004), we call for more research on how synergies can be created between communities, researchers, and policy-makers and the role of visual ethnography herein.

4.1. Limitations and strengths

Our study participants (N = 72) were recruited in one township characterized by high crime rates, social and racial tensions, intense levels of poverty and marginalization, and advanced TB programmes. This may complicate translation to other settings in South Africa and beyond. However, this information sheds light on the vulnerabilities and the capabilities within communities with high TB risk 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 remains unknown and future ethnographic research is needed.

The strengths of this ethnographic study include a critical inquiry into the functioning of the Khayelitsha programme and how this impacts the lives of its patients. Our approach to 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. Patients’ narratives captured on film may provide insights on the subjectivities attributed to TB. Finally, the need to broaden the impact of ethnographic health research on policy agendas and public discourse (Panter-Brick and Eggerman, 2017; Hansen et al., 2013) may be addressed by the use of video recordings.

5. Conclusion

Our ethnographic study assessed patients’ experiences with TB and TB care using a resilience-based approach. The findings may enhance understanding of why the Khayelitsha programme is still struggling to quell the epidemic. We aimed to identify and understand the complex and varying manifestations of resilience in contexts profoundly shaped by economic and health inequalities. TB programmes can benefit from this approach by understanding and drawing on pre-existing strengths and vulnerabilities among TB patients and their communities. By using visual ethnography and short videos, we aimed to present patient perspectives and hope to contribute to improving TB programmes by creating novel synergies between patients, researchers, and policy-makers.

Conflicts of interest

None.

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