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Cremers, A.L.

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

Anne L. Cremers, René P.M. Gerrets, Christopher J. Colvin, Monwabisi Maqogi, Martin P. Grobusch

*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.<sup>1</sup> 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.<sup>2</sup>

In South Africa, quantitative studies have given insights on the factors influencing the functioning of an NTP.<sup>3</sup> For example, barriers include the high rates of TB infection,<sup>4</sup> DR-TB development, and HIV co-infection,<sup>5</sup> socio-economic determinants,<sup>6,7</sup> alcohol misuse,<sup>8–12</sup> and structural obstacles leading to provider delays.<sup>13</sup> Facilitators constitute an integrated HIV/TB policy<sup>14–16</sup> and collaborations between traditional healers and TB health facilities.<sup>13,17</sup> 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,<sup>18–22</sup> TB-related stigma,<sup>23</sup> HIV/TB treatment,<sup>24</sup> and MDR-TB treatment adherence.<sup>25,25,26</sup> 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.<sup>27</sup> Practices may reveal what lies beyond a world created by our respondents with words.<sup>28,29</sup> 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.<sup>30–33</sup> However, there remains a need for more ethnographic research to understand context-specific barriers to treatment and tailor TB services to people's realities.<sup>30,34,35</sup>

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.<sup>36</sup>

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.<sup>37</sup> 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'*.<sup>38</sup> 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,<sup>39</sup> and overall TB-mortality rate was about 228/100 000.<sup>1</sup>

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.<sup>40</sup> Crime rates are very high in Cape Town,<sup>41</sup> especially in Khayelitsha, the most violent urban area in South Africa.<sup>42-44</sup> Major contributors to high crime rates are poverty and high unemployment rates.<sup>41</sup> South Africa is an upper middle income country,<sup>45</sup> 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.<sup>41</sup> Consequently, this part of Cape Town is known as 'Cape Town's poverty trap'.<sup>40,46</sup>

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).<sup>47</sup>

Moreover, it is one of the few places worldwide where new DR-TB drugs are both highly needed and available.<sup>48</sup> 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.<sup>49</sup> 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).<sup>1</sup> 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.<sup>50,51</sup>

#### 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).<sup>52</sup> 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 techniques<sup>53</sup> and asked respondents to keep a diary.<sup>54</sup> 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.<sup>55</sup> 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, 7<sup>th</sup> 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(%)
<b>Age</b>	
Median (IQR)	39.0 [19–89]
<b>Sex</b>	
Male	13 (43.3)
Female	17 (56.7)
<b>Marital status</b>	
Married/relation	14 (46.7)
Single	16 (53.3)
<b>Occupation</b>	
Employed	9 (30.0)
Unemployed	19 (63.3)
Student	1 (3.3)
Retired	1 (3.3)
<b>TB-patients</b>	
TB	12 (40.0)
MDR-TB	7 (23.3)
XDR-TB	1 (3.3)
<b>Recurrent TB</b>	
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.<sup>36</sup> (A trailer of the longer ethnographic health film 'TB in Town 2' can be found at: [vimeo.com/227797348](https://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.<sup>56</sup> Considering lessons learned from the fields of HIV,<sup>57</sup> Ebola,<sup>58</sup> and Lyme disease,<sup>59</sup> 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.<sup>60</sup> 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.<sup>61</sup> Such processes of survival and resilience fuelled by structural violence seemed to neutralise beneficial impacts of Khayelitsha's interdisciplinary TB program,<sup>62</sup> 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.<sup>63-67</sup> The side effects for both DS-TB and DR-TB patients and its effect on treatment adherence have been reported.<sup>68-70</sup> 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.<sup>71</sup> 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,<sup>72</sup> yet unanticipated consequences need consideration.<sup>73,74</sup> 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. Ferguson<sup>75</sup> 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.<sup>23,76</sup> 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 change<sup>62</sup> 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.<sup>77</sup> Close connections between people of a community play an important role in accelerating economic change<sup>77</sup> and may additionally play an important role in interventions to sustain well-being and health of TB patients.<sup>78,79</sup>

### *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.<sup>80</sup> 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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