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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

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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 Padayatchi, 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 Nyirazinyoye, 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 (CoCT, 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” (CoCT, 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