Surveillance, Discipline and Care Technologies of Compliance in a South African Tuberculosis Clinic

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Abstract: Concerns about medical non-compliance have generated interest in the potential of remote, digital reminder and surveillance technologies. Amidst a devastating HIV/AIDS epidemic and outbreaks of drug-resistant tuberculosis (TB), compliance technologies are touted by developers and medical researchers as a solution to the ‘problem of non-compliance’. The appeal lies in the prospect of fashioning disciplined bodies, but at the cost of sacrificing the intimacy of care for technical expediency. Despite the growing popularity in global medicine to account for disease in terms of the ‘social determinants of health’, digital medical technologies reproduce discourses of health as an individual responsibility. I conducted research in a TB clinic in South Africa that experimented with an electronic reminder and monitoring device that sought to improve compliance to a new regimen of drugs for TB prevention. I found that patients embraced the apparatus through local framings of TB, and deployed it in their everyday struggles for care.

Keywords: care, non-/compliance, South Africa, surveillance, technology, tuberculosis

Over the past few years that I have been observing and interviewing patients and medical researchers in a variety of clinical settings,¹ patient non-compliance with medical treatment has increasingly been regarded as a hindrance to improving public health and medical progress. Seeking to discover novel pharmaceuticals and drug regimens to prevent and manage HIV and tuberculosis (TB), medical narratives frame non-compliance as a barrier to a hopeful future free from infections and disease. In the context of the devastating South African HIV/AIDS and TB syndemic, adherence to medical prevention and treatment is regarded as a critical public health concern.

The widespread failure to effectively manage the TB epidemic in South Africa² is evinced by the emergence of drug-resistant strains of the disease, often attributed to treatment ‘defaulters’. Despite attempts to manage the spread of TB using direct observed treatment, the disease has spread widely, particularly amongst those who are co-infected with HIV. Likewise, the success of national programmes to ‘test and treat’ HIV has been uneven, with widespread resistance to testing and suspension of treatment (Niehaus 2014). Similarly, clinical trial research is dogged by non-compliance. Following a series of HIV prevention studies with disappointing results, allegations surfaced that accused trial volunteers of being, at best, unreliable and, at worst, intentionally dishonest about adherence (Saethre and Stadler 2017; Stadler et al. 2016). Accounts of non-compliance to medication often echo long-enduring medical narratives that portray patients as ‘ignorant, vicious, [and] recalcitrant’ (Jones 2001: 280).

Reflecting discourses of ‘therapeutic infidelity’, medical authorities have pathologized non-compliance (Applbaum and Oldani 2010; Greene 2004) to account for the failure of medicines. Seeking objective measurements of compliance and tools to regulate medication consumption, clinical researchers have begun to rely on sophisticated digital surveillance technologies. These technologies produce adherence as an objective fact that can be monitored, measured and modified. Compliance is narrowly defined in terms of ‘professional expectations’ while ignoring behaviour that ‘contradicts the profession’s view of its own centrality to healthcare’ (Trostle 1988: 1300).

The use of digital applications to measure adherence purports to remove intersubjective bias and produce more honest responses, for instance, by eschewing traditional medical interviews for computer-administered questionnaires (Stadler et al. 2016). It is assumed that people are less likely to lie to a computer simulation of an interview than to a person. Bodily fluids and hair cuttings can be harvested and analysed in laboratories to detect drug levels as objective biomarkers of compliance (A. Liu et al. 2011). In a HIV prevention clinical trial, pharmacokinetic evidence of the presence and movement of drugs within the body was presented as the absolute truth against which patient self-reported adherence was scrutinised; patients were categorised as poor/good adherers, or honest/dishonest, and confronted with their results (Montgomery et al. 2016). As a proxy of compliance, medical devices such as digital ‘smart’ pill boxes or medication event monitoring systems (MEMS) can be programmed to remind patients to take their pills and to detect whether and when they did, sending data to

computer servers to be downloaded and analysed, to provide the 'care-giver with an instant record of usage patterns, and allow swift action in case of non-adherence' (WHO 2017: 15).

In this process, consuming a pill is transformed into a medication 'event' and expressed as statistical evidence of non-/compliance. Patients' actions, thoughts and experiences are converted, through these technologies, into objective, data-driven truths that are unquestionable. The enthusiasm by which these technologies have been embraced suggests that establishing the truth about compliance, and promoting better compliance, is contingent on creating distance and reducing the intimacy in relationships between patient and medical professional. This has significant implications for the relationships of care and trust between patients and health-care providers (Jones 2001).

Technologies of compliance potentially sacrifice care, and transform suffering from 'a moral experience into a mere technical expediency' (Kleinman and Kleinman 1997: 15). For instance, antiretroviral therapy (ART) clinics introduced electronic pill boxes to monitor patient behaviours, supplanting the need for patients to have more regular clinic visits or undergo regular viral load testing (Lyimo et al. 2011). Replacing regular contact between patients and health-care professionals with remote technologies is marketed as being especially appropriate in rural and impoverished areas, where health resources are scarce. It is also being done as an alternative to investing in health-care infrastructure. In state-funded hospitals, patients often struggle to make their bodies known and visible due to a scarcity of personnel and finances (see Gibson 2004; Le Marcis and Grard 2015; Street 2014). While remote technologies are believed to fill in the gaps in the health-care system, their use can further alienate patient populations from sources of health care.

The growth in recent years of remote surveillance technologies to track compliance ties into a broader global trend described as the 'datafication of medicine', epitomised by a multitude of applications that fall under 'M-Health', 'e-Health', or 'Health 2.0'. The Internet and an array of mobile self-care and personal fitness monitoring devices and accessories have become ubiquitous, particularly amongst consumers in the Global North (Ruckenstein and Schüll 2017). These technologies have also been applied to tracking and collecting data on infectious disease outbreaks and their spread, with limited success. For example, during the 2014–2016 Ebola outbreak in West Africa, mobile phones were tracked to detect the flows of people, producing vast datasets ('big data') to predict epidemic spread. However, the assumption that cell phones

represented individual persons meant that this data was intrinsically flawed (Erikson 2018). More recently, phone apps have been developed to map COVID-19 contacts, and they rely on similar assumptions of the correlation between things and persons (Engelmann 2020).

A key feature of the datafication of health is the dramatic shift in the sites of care from the hospital and clinic, to the arena of self-care by patients. Echoing neoliberal health policies, individual patients are believed to be sufficiently empowered through diagnostic and monitoring technologies to deal with their own health requirements (Ruckenstein and Schüll 2017). This potentially distracts attention away from the everyday struggles that patients experience in managing illness, obfuscating their unique circumstances. The datafication of health and the use of 'big data' are believed to increase efficiency and reduce the costs of health care. However, in the United States the widespread adoption of electronic health records effectively redefines clinicians as administrators, diminishing their role as carers, while patients become 'digital entities', forgoing their personal narratives of illness (Hunt et al. 2017). Ultimately, the datafication of health behaviours converts the qualitative life of people into statistical indicators, exemplifying the digitisation of biopower (Lupton 2016).

The appeal of technologies for monitoring and promoting medical compliance can be compared to the rapid rise in popularity in the twentieth century of magnetic resonance imaging (MRI) as a diagnostic tool. The MRI quickly became the 'gold standard' for medical diagnoses. As a cultural icon, the MRI is celebrated as an objective technology that reveals the truth about the body and identity (Joyce 2008). Along these lines, monitoring and surveillance technologies render the body observable to the clinical gaze 'by converting everyday activities into data flows that can be monitored continually and at a distance' (Ruckenstein and Schüll 2017: 264). Previously invisible, private areas of peoples' lives are exposed remotely by technologies of sight.

While the datafication of health transforms individual subjectivities and encourages 'performances of healthy citizenship' or the 'digitally engaged patient', this does not exclude the possibilities of non-compliance and the adaptation of these technologies for uses that may be contrary to their design (Ruckenstein and Schüll 2017). Medical technologies are designed to monitor and regulate compliance to produce disciplined patients. However, patients may also refashion technologies in ways that are unanticipated by developers, creating new meanings and uses. Moreover, assumptions that compliance technologies produce data that represent autonomous individuals ignore the social and

cultural contexts in which they are deployed. Decisions about compliance to medication may be shared amongst numerous other actors, including household members, neighbours and work colleagues, thereby distributing individual agency.

Questions of how the digitisation of health through electronic and mobile devices impacts on and transforms the meanings of illness, health and medication compliance surfaced during a South African clinical study of preventive medicine for patients with latent TB – people infected with *Mycobacterium tuberculosis* without TB disease. The clinic, located in a township on Johannesburg's East Rand, enrolled HIV-positive patients with latent TB. A pilot study sought to demonstrate the acceptability of a monitoring and reminder device to encourage, and produce data on, compliance with preventive treatments for TB. The medical researchers presented this technology as an efficient and apparently simple solution to remind patients and monitor their pill consumption.

The medical researchers and the producers of the technology imagined that the device would promote autonomous decision-making, and that the data it generated would reflect individual acts of non-/compliance. While the clinical researchers highlighted the need for accurate and truthful surveillance data, patients appropriated the device as an object through which their vulnerability, suffering and everyday struggles to adhere to the medication were performed. Rather than objecting to being reminded to take their pills or having the device monitor their behaviour, patients embraced the apparatus of the clinical surveillance system as a form of care. The discussion that follows situates compliance technologies in the historical context of drug discovery and development, which promoted patient independence but simultaneously undermined physicians' authority to discipline patients and make medicines work.

Potent drugs and undisciplined patients

Concerns about medical compliance have a lengthy history. First recorded in the fifth and fourth centuries BCE, Hippocratic writings observed that non-compliant patients lied about their behaviours (Sokol 2006: 632). Yet, the development of effective treatments for infectious diseases in the mid-twentieth century represented a turning point in the production of compliance as an objective category. It was at this point that the emphasis shifted from the belief in the potency of healers

to alleviate suffering, to faith in the potency of pharmaceuticals to heal, cure and prevent disease.

New and potent drugs were found to cure streptococcus infections (strep throat), the polio vaccine was discovered and antibiotics were developed that effectively cured TB (Greene 2004; Jones 2001; Trostle 1988). Also at this time, statistical analysis became integral to the study of experimental pharmaceuticals, heralding the birth of the modern randomised clinical trial (RCT) (Saethre and Stadler 2017: 48). These transformations in the production of biomedical knowledge simultaneously created new concerns about compliance, and resulted in the popularisation of the term 'non-compliance' in the medical literature (Greene 2004). In RCTs, compliance is critical to demonstrate experimental drug efficacy, while non-compliance to highly effective drugs raises the threat of antibiotic resistance. The latter was especially critical for TB control and management.

In the 1940s, new antibiotics to treat TB had miraculous effects. The sick no longer had to spend lengthy periods in TB sanatoria or undergo invasive surgeries that usually had low rates of success. Yet, hospitalisation was still required for treatment: streptomycin, which was given intravenously, and para-aminosalicylic acid (PAS), which had severe side effects, required in-patient care. In 1951, this changed with the discovery of isoniazid, an oral antibiotic that could be self-administered as an outpatient under limited medical supervision. However, this also introduced new dilemmas about the possible emergence of drug-resistant strains of the disease. Facilitating patient independence, the new drugs were administered by the patient at home, thereby minimising physician power and influence. As a result, researchers and clinicians started to focus attention on developing new approaches and technologies to promote adherence. David Jones sums the situation up as follows: 'Just as they sought to deploy the technology of antibiotics against the social disease of tuberculosis, physicians responded by deploying the technology of surveillance against the social problem of non-compliance (2001: 280).

Innovations such as fluorescent tracers, urine tests, pill calendars and radioactive pill clocks were developed by physicians dealing with populations that were deemed as non-compliant. Jones (2001) documents the experiences of US doctors who treated Navajo communities in the 1950s, and experimented with a variety of technologies to inculcate discipline and create adherent patients. However, reliance on these surveillance instruments undermined the trust established between patients and doctors, and was seen by physicians as a threat to 'medicine

at its core' (Jones 2001: 281). These conclusions are echoed in a more recent study of TB medication electronic monitoring devices in India. Here, digital adherence data collection potentially transformed the role of health-care providers from 'counsellors to surveyors' (Papineni 2020: 25).

While 'problematic patients' were commonly regarded as irrational, careless and irresponsible, devious and rebellious (Jones 2001: 280), by the 1960s and 1970s non-compliance was pathologized as a 'real disease' (Greene 2004). Redefining compliance as a medical problem rather than a social one spurred the development of a new field of compliance research. Nurses, pharmacists and medical sociologists secured a stake in this emergent field, striving to create novel methods of monitoring patient compliance (Greene 2004). An industry emerged that sought to promote compliance as well as offer reliable and objective measures thereof.

By the early 1990s, the comorbidities of HIV/AIDS and TB had become a syndemic of significant proportions in South Africa (Singer and Clair 2003). While TB drugs had been available since the 1950s and ART has been distributed in public health clinics since the mid-2000s, South Africa has struggled to control rates of TB infection and its spread. TB in South Africa represents a significant public health crisis, exacerbated by HIV co-infection and the recent emergence of multi-drug- and extreme-drug-resistant strains (Abdool Karim et al. 2009). This was highlighted in 2006, when a rural hospital in KwaZulu-Natal Province reported 39 per cent of HIV co-infected patients with multi-drug-resistant TB, with almost all of those infected dying (Abdool Karim et al. 2009; Gandhi et al. 2006). In the years that followed, resistant strains of TB were reported throughout South Africa and neighbouring countries. The medical literature observes that patients often present at clinics with advanced TB symptoms, that TB testing is often inaccurate and inadequate, and that adherence to the lengthy six- and nine-month treatment courses is sub-optimal. Patients are labelled 'defaulters' and are hard to trace and therefore difficult to treat (Abdool Karim et al. 2009).

The current crisis in treatment and management can be traced back to the 1940s, when social reforms such as improved housing and social medicine were being proposed to alleviate the spread of TB. In his address to the National Tuberculosis Conference in 1947, then South African health minister Dr Henry Gluckman endorsed the call for improvements to the living conditions of all South Africans to curb the spread of TB (Gluckman 1947). Yet, in the years that followed the pro-

posed social reforms were steadily squashed by the newly established Nationalist government (1948–1994).³ Moreover, the discovery of highly effective drugs in the 1950s presented public health authorities with a cheaper and simpler biomedical solution than social reform, which was no longer regarded as a priority for managing the TB epidemic, effectively ‘turning back the clock’ on addressing the social and economic circumstances of TB spread (Packard 1989: 18). The social and economic causes of the spread of TB continued unhindered to the point that extreme under-reporting of the disease in the 1970s rendered it almost invisible (Packard 1989). Reflecting the growing concern amongst medical professionals that medical treatment alone was insufficient to manage the TB epidemic, a report from this era declared: ‘Unsupervised treatment is not treatment, and it is no longer acceptable to dish out tablets at weekly or monthly intervals’ (qtd in Griffiths et al. 1981: 16).

Between the 1980s and early 1990s, the introduction of new antibiotics (rifampicin), delivered through direct observed treatment therapy (DOTS) was used to treat a far broader population and directly supervise patient compliance. However, these services were hindered by being inaccessible to many and too costly to maintain (Dixon and Macdonald 2018), and in certain contexts they could even amplify the emergence of drug-resistant forms of TB (Harper 2006). By the early 1990s, the rapid increase in HIV prevalence undermined any gains that had been made in managing the TB epidemic (Abdool Karim et al. 2009). Moreover, despite acknowledgement of the social determinants of TB spread, morbidity and mortality, the narrow focus on biomedical treatment alone had implications for containing and managing the TB epidemic (Dixon and Macdonald 2018). It is in this context that we see the emergence of technologies of compliance as a solution for medication adherence.

A ‘digital solution for medication adherence’

In 2017, I was approached by a medical research organisation to assess the feasibility and usability of an electronic medication memory and monitoring device in a TB research clinic.⁴ Located in Johannesburg’s East Rand township of Tembisa, the population served by the clinic was drawn primarily from the Winnie Mandela informal settlement in the north-eastern corner of the township. Located in Ekurhuleni, Tembisa has a population of over half a million inhabitants, representing a wide range of economic classes, which is apparent in the stark differences in

residences. The bank-financed ‘bond’ houses of the more affluent and established Tembisa neighbourhoods such as Hospital View contrast dramatically with the sprawl of corrugated iron shacks that spill into the streets, and the clusters of so-called ‘RDP houses’ in the Winnie Mandela informal settlement.⁵

Like many Black townships in South Africa, Tembisa was a product of forced removals from old locations and peri-urban areas, designed to separate people based on racial and ethnic categories. The township was established in 1957, following the resettlement of ‘squatters’ from urban areas such as Alexandra Township, which was designated for migrant hostels and the exclusively white towns on the East Rand. Tembisa, meaning ‘promise’ in Xhosa, was so named to conjure the hopefulness of finding a home (Bonner and Nieftagodien 2012).

Population growth was rapid between the 1960s and 1970s as the East Rand rapidly emerged as a significant industrial hub. Manufacturing firms in the area increased from a mere eight in the 1940s to 374 in the 1970s, creating possibilities of employment. Following the relaxation of laws governing the movement of Black South Africans into urban areas, large numbers of the rural poor migrated to the area in search of jobs. However, hope turned to despair, and by the 1990s many large employers had shed hundreds of thousands of jobs, resulting in mass unemployment (Bonner and Nieftagodien 2012: 117–121). Moreover, the township continued to have a disappointing shortfall in housing. In 1994, Tembisa was incorporated into the Ekurhuleni municipality, which had become the site of both unplanned and planned housing developments. By 2008, the urban areas east of Johannesburg had the highest concentration of informal settlements in South Africa, owing to government neglect, rapid urbanisation and non-delivery of housing in the 1990s (Bonner and Nieftagodien 2012: 216).

The TB project, located on the grounds of the Department of Health’s Winnie Mandela Clinic, consisted of a row of mobile offices erected on a concrete platform. The project staff recruited HIV-positive patients who were receiving ART from the Winnie Mandela Clinic. After being screened for HIV and latent TB, and following informed consent, patients were offered a combination of rifapentine and isoniazid, or isoniazid alone—the same drugs that are usually used to treat TB. The aim was to compare the effectiveness of a daily dose of isoniazid plus pyridoxine with a weekly dose of rifapentine and isoniazid plus pyridoxine. Pyridoxine contains vitamin B6 to alleviate the side effects of the antibiotics, which included weakness, nausea, stomach pain, dark-coloured urine and jaundiced yellowing of the eyes.

Based at the TB clinic, with a few opportunities to visit patients at home, and permitted to observe clinical consultations, I interviewed 46 patients, 24 of them on two separate occasions. Most of those interviewed were female (60 per cent), and on average were 41 years of age, ranging from 23 to 69 years of age.

The medical researchers were keenly aware of the potential difficulties facing adherence to these medications. The sheer pill burden, especially of the weekly dose of ten pills, seemed unimaginably hard to swallow. Indeed, treatment for TB is usually a daily dose of isoniazid over six to nine months during which time patients often struggle to remain compliant (Lobue and Menzies 2010). While in previous studies the same regimen was successful in preventing TB illness amongst HIV-positive patients with latent TB, these results were obtained by directly observing patients taking their pills in a clinic setting (Sterling et al. 2011). The current study sought to see whether patients would be able to self-administer the drugs in their homes without direct support from a clinician. Other options such as conducting home visits and surprise pill counts were discounted as far too invasive and ineffectual. Having seen the success of digital compliance-monitoring devices elsewhere, a decision was made to try this out in a pilot study.

By August 2017, several months into the study, a small sample of patients was given Memory Event Reminder Monitoring (MERM) devices programmed to remind them to take their pills and monitor when and how often they did so. The MERM device was essentially a white plastic pill box that reminded patients to take their pills by flashing a light and sounding an alarm. It also monitored a proxy of compliance by recording on a computer chip each time the box was opened, assuming that this represented pill-taking (see Figure 1). Data from the chip was downloaded at the clinic when patients returned for their monthly visits. Real-time data could also be transmitted via short message systems (SMS) to the clinic computers, although this feature was not activated during the pilot study.

It was envisaged that if the study demonstrated acceptability, then the MERM device could be distributed in large numbers in similar 'resource-limited' settings in Southern Africa. This would do away with the need for direct medical supervision as in-patients or through a DOTS system (see, for example, Moulding and Caymites 2002). Funded by grants from the Bill and Melinda Gates Foundation, clinical researchers and developers of the MERM device reported success with its application in China (El Alili et al. 2016; X. Liu et al. 2017), India (Thomas et al. 2021) and Vietnam (Drabarek et al. 2019), and they were keen to

Figure 1. The components of the Medication Event Reminder Monitoring (MERM) device.

test it out in an African context, hoping to attract donor investment in a roll-out.⁶ Evaluations of the MERM devices enthusiastically pointed out that they could replace the problematic, labour-intensive, expensive and disruptive DOTs system. In conclusion, the authors of a Chinese study wrote: ‘The patients themselves reported that the MERM was easy to use and improved their adherence and their experience of taking their medications, thereby enhancing their quality of life and that of their families. The medical staff also reported that it reduced the workload and increased their job satisfaction’ (X. Liu et al. 2015: 9). Chinese news reports on the Bill and Melinda Gates Foundation’s investment in TB control stressed the scientific advancements that the new diagnostic technologies represented as a solution to non-compliance and the ‘reckless attitude(s)’ of patients (Xiaoyu 2019).

The MERM device was closely modelled on the Wisepill that possessed the same functions but was noticeably sleeker-looking. Developed by a South African couple in Cape Town, Wisepill Technologies began in 2007 ‘to tackle the challenging problem of medication non-adherence, in both developed and developing countries’. Wisepill marketing applauds its ease of use, real-time monitoring capabilities, capacity to manage large patient populations and a range of chronic diseases, and applicability in low-resource settings, particularly in combatting drug-resistant TB.⁷ A South African evaluation compared the Wisepill to patient recall and pill counts. The authors concluded:

'Real-time monitoring of adherence using a next-generation electronic pillbox (Wisepill) has important potential to identify early adherence lapses prior to TB treatment failure and may have a role to play in the prevention of drug resistance' (Bionghi et al. 2018: 2).

These monitoring devices promised simple technological fixes to problems of forgetful patients and overstretched clinical services. However, these common sense practical solutions had social implications. James Trostle (1988) observed that compliance as an ideology legitimises the authority of physicians. The development of compliance technologies can be seen as an attempt to maintain this authority and discipline bodies, particularly by shaping their personal experiences of time. Devices such as the MERM presented opportunities to address not only compliance failures, but to combat tradition and 'modernise' African culture by regulating time and ultimately mediating 'the rhythms of everyday life' (Comaroff and Comaroff 1992: 189).

The regulation of time coincided with medical discourses of irresponsible Black bodies and African cultural practices that were unsuited to biomedicine. In the early 2000s, the United States Agency for International Development (USAID) was deliberating on whether to provide antiretroviral drugs to Africa. Andrew Natsios, the USAID administrator, justified why his agency should not sponsor ART for Africa. He stated: '[Africans] do not know what watches and clocks are. They do not use western means for telling time. They use the sun. These drugs have to be administered during a certain sequence of time during the day and when you say take it at 10:00, people will say what do you mean by 10:00?' (qtd in Attaran 2007: e83). Invoking popular stereotypes of 'African time' and professional narratives that award explanatory power to 'traditional practices' and culture for the spread of infectious diseases (see Briggs and Mantini-Briggs 2004; Gausset 2001), these ideas legitimised denying life-saving drugs to people in need.

Re-socialising compliance: Patients' narratives of illness, care and compliance

I have argued that the MERM device embodied prevailing ideas that Black, African bodies were inherently undisciplined. It follows that compliance technologies represent a means to exert control, remotely, over behaviours and bodies. Drawing from Susan Erikson's (2018) observations regarding epidemiological big data and the complex social life of things (Appadurai 1986), these assumptions are based on an

inherently flawed notion that as a ‘thing’ the MERM device was interchangeable with persons as consumers of medicine, and that the data it produced was a true and objective representation of individual adherence, divorced from context. Below, I explore patients’ narratives of TB and treatment medication that highlight the historical, environmental and economic framing of vulnerabilities to TB.

‘TB is in the air we breathe’

TB illness was conceptualised by patients of the TB clinic as a shared experience of Black South Africans’ vulnerabilities to social and economic conditions that have created toxic environments in which illnesses flourish. This was evident from the ways patients perceived TB as pollution and the accumulation of ‘dirt’ in the individual and ‘social body’ (Scheper-Hughes and Lock 1987).

The perpetual presence of ‘dust’, ‘chemicals’ and smoke that emanated from coal-burning stoves, fumes from roadside cookers, the close proximity of residential areas to public rubbish dumps, and the noxious fumes from petrochemical and other industries contributed to anxieties about the ‘dirty air’ in Tembisa Township. Tembisa is located within a vast industrial complex that dates back to the discovery of gold, the rapid development of manufacturing industries in the 1970s, as well as to being situated next to ORT International, the biggest airport in South Africa. Environmental reports identify air pollution from airborne particles blown from disused mine dumps, vehicle emissions and coal fires (Shirinde et al. 2014).

Anxieties about dirty air and infected bodies emerged in the narratives of patients who had been diagnosed with HIV and latent TB. Joe Ngomane,⁸ a 32-year-old unemployed man, explained how the ‘lack of hygiene’ contributed to the spread of TB:

If you are sick and you just sleep there for days without waking up and letting those sheets and blankets get some oxygen, there is a high chance that your blankets carry all the germs that are making you sick. So, look, we come into your house and you’ve been in that situation for a while, we can contract TB. It’s sleeping there with you, the moment we shake you up and say ‘*hao bathong! Chomi*’ [hey buddy! wake up], the TB also grins and shakes our hands [infects us].

TB was viewed as a ubiquitous and inevitable part of life in South Africa’s townships. Joe continued: ‘TB is not this complicated thing that people make it to be. You can get it anywhere. You don’t have to sleep

with anyone before you contract it. You can get it in the air. You can get it when you live in shacks with no proper sanitation. You can get it when you work at a factory. It is just everywhere. Anyone has a chance of contracting it, as I've mentioned'. Mr Ngubane, a former plastics factory worker, a resident of the Winnie Mandela settlement, agreed: 'No one wants to think it is their environment that is making them sick or that all these unhygienic people who spit everywhere are making us sick'. He felt that HIV-positive people were discriminated against and blamed for spreading TB: 'They choose HIV-infected people as their scapegoat'.

Patients' commentaries made reference to the long history of TB in South Africa and especially its intimate association with the mining industry. Forty-year-old Sarah Dumuzulu remarked:

Do you know that TB is an old disease and has always been here? We grew up witnessing miners dying from TB, and we always said they were killed by the dust. We knew TB to be the result of dust and smoking. Smoking, yes. Because old people back then got so excited at the sight of tobacco. It was a new trend and they were dying from it. They coughed for a long time, and some doctor will come and say they damaged their lungs. We will know it was that infection that killed you, if you had inhaled a dangerous amount of dust or smoked.

Statements such as these link TB to being Black and living in informal settlements, exposed to pollutants at home and at work. Sarah, who was now in her mid-forties, contracted TB as a child along with her sister and her grandfather; she recalled accompanying her grandfather to the clinic for medical check-ups when he was sick. Now, as an HIV-positive woman with latent TB, she was at risk of acquiring the disease for the second time in her life.

Responding to the environmental threats posed by pollution and the fears associated with dirt, residents attempted to sanitise their homes to protect themselves against TB. Mrs Olifant, an unemployed mother of three, was constantly cleaning her house: 'I try to clean up, open the windows and have everything in the house washed because I live with children but then I still can't say I am avoiding TB because my children and I can still contract it from anywhere'. Mr Ngubane, pointed out the lack of water-borne sewerage. He used chemicals to clean the plastic toilet in his yard, fearing that the fumes from decaying faecal matter would weaken his lungs. The local council was supposed to have removed and replaced the plastic toilets that were installed in informal settlements in the 1990s. Residents compared them to the old

'bucket system' and complained that they were 'unclean, unsanitary and smell especially in summer' (qtd in Bonner and Nieftagodien 2012: 222). They remarked: 'We have no proper toilets. This place is filthy because there is no rubbish removal' (qtd in Bonner and Nieftagodien 2012: 218).

The drugs prescribed by the TB clinic were seen by patients as an antidote to the polluted environment and dangers posed by the dirty air. Agnes Mathebula, 52, complained that she was constantly exposed to 'dirt' because 'people do not look after the environment. They throw their dirt anywhere and also do not wash their animals. So, I still stand a chance [of catching TB], because I come from an unclean environment'. She was happy she had been given TB medication, and felt that it had reduced her chances of falling ill.

The environmental model of TB resonated with broader conceptualisations of diseases that are caused by the accumulation of 'dirty' blood that blocks the healthy flow of fluids in the body (see, for example, Stadler and Saethre 2011; Wood and Jewkes 2006). The embodied experience of cleansing and purification is an often reported attribute of traditional medicines that resounds with pollution beliefs and practices in Southern Africa (Berglund 1976; Hammond-Tooke 1981; Ngubane 1977). The same effects are also often attributed to biomedicines.

The patients I spoke to talked about the effects of the pills as stimulating a healthy flow and expulsion of 'dirt' from the body and as 'cleaning' their blood, sputum and urine. For example, Anna Mathonsi noted that her sputum changed colour from green to translucent, indicating that the drugs were cleaning her body. Others noted that their urine became yellow and brown (listed as a side-effect of the TB drugs), and saw this as evidence of the cleansing of their liver. Ronald Mambo, a 54-year-old factory employee, compared the effects of the pills to taking emetics: 'I always take my pills with lots of water so they melt into my body and clean me. It's like a laxative. It shows in the colour of my urine that it cleans. It's like a laxative getting rid of the dirt'. Dudu Mackenzie, a single woman of thirty-two, thought that the pills cleansed the 'dust that lives in the body'. She coughed up 'black specks', which she took as a sign that her body was ridding itself of what she called 'the parasites'. Mrs Nhlapo, a widowed pensioner, described feeling her 'joints tense up', and believed that this was a sign that 'the pills are working. I know they are travelling all around the body searching for what could make me sick, killing every little virus of TB that wants to grow. I wait for that feeling every week because it is a sign that these pills are working'.

While the pills for preventing TB acquired meanings that resonated with local ideas of contagion and cleansing, they were also heavily invested with hope. For Mrs Nhlapo and many other patients in similar situations, taking the pills represented an investment in a hopeful and healthy future. Mrs Nhlapo remarked: 'The thing that makes me take my pills is because I know that if I stop taking the pills my children will be left alone and suffer'. Like Mrs Nhlapo, Magodi was separated from her husband several years prior, and, at 45 years of age, was solely responsible for caring for her three children: 'My health is very important to me now', she remarked. Others found inspiration from their families, such as young and single Gladys Sekgopela, whose family lived in rural Limpopo Province, a day's journey north of Johannesburg: 'They have been very comforting to me since they discovered that I am sick [HIV positive]. I am inspired to live for longer because they have held me together'. In a slightly different vein, for Cornelius Ndlovu, a young unemployed man, taking the medication was a matter of daily survival: 'I still take my pills so that I can have strength to hustle the next day. If I don't take my pills, then that means I am trying to kill myself'.

Compliance was also motivated by the acts of kindness and the respect displayed by the TB clinic staff. Unlike the crowded and somewhat harsh conditions of the Winnie Mandela Clinic, the TB clinic staff were friendly and supportive, offering patients cups of tea and sandwiches while they waited and spending time explaining the clinical procedures to them. Mrs Nhlapo had good things to say about the TB clinic: 'I feel accepted, unlike the clinic [Winnie Mandela Clinic] where people like me [HIV positive] are treated unkindly. Here [the TB clinic] I have found a home. I feel encouraged to return just because of the services'.

While from a medical point of view preventing TB disease depended on objective individual acts of adherence to the course of medication, patient narratives drew attention to a shared social and economic context that created vulnerabilities to disease and compliance to medication as an investment in social relationships. The pills not only cleansed the individual body, but were effective in combatting the effects of a disordered environment. Moreover, the act of taking pills was experienced as a social act, a way of extending support to one's children and securing their futures. Maintaining the healthy self was imbricated in the livelihoods of others; this reflected the mutual constitution of persons and bodies, or what Hayder Al-Mohammad (2010) describes as 'ethical intercorporeality'.

The “box” is like my child’: Performing vulnerabilities and soliciting care

In discourses and practices of the digitisation of health, the risk of disease is individualised, conceived of as being manageable and controllable, but contingent on people adhering to technologies that offer self-management and care (Lupton 2016). In this fashion, the MERM device was designed to embody an ideology of health as autonomous responsibility and behaviour, promoting individual decisions. In contrast, TB patients’ narratives highlighted the socialisation of the MERM by drawing attention to its incorporation into everyday strategies of seeking care and support. Referring to the device as ‘like a child’, they evoked a relationship of mutual interdependence between parent and offspring. This was first brought to my attention through conversations with Mrs Khumalo, a 40-year-old woman who lived alone in an RDP house in the Winnie Mandela settlement.

I first met Mrs Khumalo when she arrived at the TB clinic for a monthly visit. She was in the second month of the study and was taking the weekly dose of a combination of isoniazid (six tablets) and rifampentine (three tablets) as well as a single dose of pyridoxine or vitamin B6. Mrs Khumalo was supposed to swallow all ten tablets at once on a specific day each week. On the day that I met up with her, she had come to the clinic for a medical exam and to refill her medication for the second time. I had noticed her earlier when she was queuing with other patients in the waiting area; she was lively and interacting with the clinic staff and fellow patients as the staff handed out mugs of tea, cheese and tomato sandwiches, donuts (*vetkoek*: Afrikaans unsweetened deep-fried dough cakes) and orange juice.

Later, having finished her clinical exam, we met up in the pharmacy and she greeted me, Rahima (the pharmacist) and Thulani (the research nurse), and asked us why we appeared ‘troubled’. Rahima replied that she was not troubled, but was a little bit busy. Mrs Khumalo advised us all to catch a break, and everyone laughed. Thulani, who was in charge of patient adherence, asked Mrs Khumalo to tell him how she felt since taking the medication. Mrs Khumalo said she had no reason to complain because ‘it helped me to avoid a painful death’. Thulani smiled and nodded, happy with her response. Rahima then informed Mrs Khumalo that she would refill her medication and observe her while she took her pills. She fetched a bottle of water and watched as Mrs Khumalo swallowed all ten pills. Satisfied, Thulani scribbled in Mrs Khumalo’s file. Rahima returned and handed Mrs Khumalo the pills for the remainder

of the month and explained that she would need to continue taking her medication each Wednesday like she had on that day.

After her visit was over, I accompanied Mrs Khumalo to the room we used for interviews. Although she had not said anything to Rahima and Thulani, Mrs Khumalo told me that she often took her medication on an empty stomach. This worried her because she had been told that she ought to eat fatty, nutritious foods. The informational pamphlet that was distributed to patients advised: 'Take your medication with meals. Try to eat healthy foods such as eggs, avocado, full fat yogurt, and cheese'. Reliant on the occasional donation from a church and on money from her mother who received a state pension, Mrs Khumalo considered these to be luxury foods. Yogurt and cheese were usually reserved for young children to build healthy bodies. Eggs, like meat and vegetables, were eaten as relish with the staple maize porridge (pap). Avocados were only available in season, when trucks arrived from the north of the country loaded with produce, and were sold by street-sellers.

Mrs Khumalo's story of her struggle to eat nutritious 'protective foods' resonated with historical experiences of TB sufferers in South Africa (Packard 1989: 148, 154) and, more recently, those of HIV-infected patients receiving ART (Hardon et al. 2007). Potent drugs often stimulate hunger, as the body starts to heal. New-found appetites can exacerbate pre-existing social divisions between those who can afford food and those who lack the material and social resources (Kalofonos 2010). These were the unspoken and hidden costs and requirements for being compliant and acquiring 'pharmaceutical citizenship' (Ecks 2005).⁹

While the TB clinic guidelines recommended that patients include nutritious foods in their diets, there was a failure to acknowledge that for some patients this was almost impossible. Isiah Zulu, an unemployed man in his forties, frequently purchased food on credit from 'the Pakistani Shop', a neighbourhood *spaza* ('tuck shop') that sold small quantities of basic essentials, tinned food, cold drinks and cigarettes. He had lost a great deal of weight. Of medium build and height, he had dropped from 65 to 58 kilogrammes since starting the medication. Isiah told me: 'The pills make me feel dizzy, they make me eat too much and when you start taking them they will make you feel hungry the whole time'. During Isiah's clinic visit, the doctor prescribed appetite stimulants to encourage him to eat and made an appointment for him to see an optometrist. The problem of Isiah's food insecurity remained unaddressed. Likewise, Abel Mathegka, who lived with his mother and siblings, found that the servings at meal time were insufficient for

his new-found appetite. This occasionally sparked squabbling between Abel and his siblings over portion sizes and his special needs.

Under these circumstances of food insecurity and hunger, patients like Mrs Khumalo struggled to raise awareness about their condition. In her consultations with the clinic staff, Mrs Khumalo did not talk openly about her impoverished state, only revealing this to me in our confidential interview. The social stigma associated with being HIV positive meant that the disclosure of an illness such as TB risked alienation (see, for example, Reid and Walker 2003). However, Mrs Khumalo had found a source of support and care in her next-door neighbour, an older single woman.

After receiving the MERM device, Mrs Khumalo displayed it in a prominent position in her home. A common feature in small government-built homes (the 'RDPs') like Mrs Khumalo's was the room-divider, a large, laminated chipboard unit with shelves and built-in cupboards. Designed to separate the lounge from the kitchen, the room-divider housed television sets and music systems, framed photos of family members, porcelain animals and ornate drinking glasses. I noticed that in several of the homes I visited, such as Mrs Khumalo's, the MERM device had been placed amongst these objects, signifying its importance. When her friend from next door visited her, Mrs Khumalo pointed out the MERM device, and showed her how it worked. In the weeks that followed, Mrs Khumalo's neighbour would call out over the fence separating the two houses, and ask if the alarm had rung. Later, she would arrive with a plate of cooked food from her home for Mrs Khumalo to eat with her pills. For Mrs Khumalo, the MERM alarm reminded her neighbour to prepare a meal and to help her friend to take her medicine. Incorporated into her narrative and performance of illness and vulnerability, it helped to make Mrs Khumalo's need for support and care visible.

For those who shared their households with their spouses and children, the MERM device supported pill-taking as a shared responsibility. Mr Gumede, who lived with his younger siblings, remarked 'I have my family' when he did not respond to the alarm. He pointed out that the volume of the alarm was too low. Siphamandla Khosa lived with his girlfriend, and when the alarm rang, 'she reminds me. Even when I am taking a shower she comes and reminds me when it is time for medication'. Doris Makhubela similarly remarked: 'My family and also the boyfriend helps because he calls just to remind me'.

Demonstrating the shared responsibility for compliance was Gugu Sithole, who often travelled to see her children, who lived in a rural area

of KwaZulu-Natal. Worried that she might lose or damage the MERM device when travelling, before she left on a trip she removed her pills from the box and packed them in her handbag. Each day that she was away, she phoned her mother to open and close the pill box at a specific time, ensuring that it recorded her 'medication events' accurately.

As an apt illustration of its incorporation into the field of domestic relations, some patients referred to the MERM device using affectionate nicknames. While most patients simply referred to the MERM device as 'the box', Mrs Mangozi, for example, nicknamed hers 'my child', because, she said, 'I love the box like it is my child'. Elaborating, she said: 'I am over-protective when it comes to my box, because it contains the pills that give me life'. She elaborated, saying 'Yeah, yeah . . . I look after the box the way I look after my child. This box is very important – it has something inside it that is important for me'. Mrs Mangozi had recently lost her youngest child to an undisclosed disease. Her affection towards a plastic box containing a microchip and a blister pack of pills represented the hope of a healthy life so that she could support and care for her remaining children. She continued, saying that taking her pills 'makes me feel at peace. I take my pills because I want to live a long life, so I can be around for my three children'. Like her, Mr Dlamini commented: 'I treat the box like one of my children'; he made sure that when he was out he stored the box in a safe space in the wardrobe in his bedroom out of harm's way. Phumela displayed a similarly affectionate attitude, saying: 'I love the box – even the colour. As you can see, I am also wearing all white today which matches the colour of the box'. In this fashion, it was as if the MERM device was transformed from an adherence-monitoring and memory device into a person-like entity that represented hope. Looking after the box ensured that it would look after you.

The MERM device not only communicated individual needs for care and support to neighbours and household members, but was regarded as an honest and reliable monitor of a patient's progress for the clinic staff. Rather than regarding monitoring as an intrusion into private life, being placed under surveillance meant being made visible to the medical staff. In contexts where patients were so often invisible in health-care settings, the 'box' placed them in clear sight. The digital records that were produced by the device contained important information and indicated that the clinic cared about their patients' progress. Mr Sithole remarked that 'the box [MERM device] is something that is honest because it reports when I did not take the pills. It is like a human'. He called it 'the messenger'. Even though the 'box' was 'like

a human', its very non-humanness meant that it could be trusted to support patient compliance by sounding an alarm when it was time to take the pills, and by reporting this accurately to the clinic. Rather than alienating and eroding trust and care, the MERM device had become a trustworthy and reliable link in the relationship between patient and health-care provider.

Conclusion

Technologies of compliance potentially alienate patients from care, transform physicians from care-givers to administrators and thereby threaten to undermine the relations of care. Furthermore, by reducing compliance to digital 'medical events', these technologies obfuscate or actively 'unknow' the social and economic circumstances of patients' lives. As Paul Geissler points out, ignorance is a 'condition of scientific knowledge production' that shapes 'scientific work and sustains and exacerbates some of its inherent political-economic contradictions' (2013: 13). Moreover, the design and deployment of digital technologies to monitor and shape adherence behaviour relies on the fundamental assumption that people think and act as autonomous individuals.

In the TB prevention study described in this article, patients' narratives about TB illness, medicine and compliance drew attention to the integration of the MERM device into local understandings of illness, medical treatment and relations of care and support. Embracing the MERM device in performing their vulnerability, patients highlighted their needs for the care and support of others. The 'box' encouraged sharing the responsibility for taking the pills at the correct intervals, as well as drawing attention to the nutritional requirements that the drugs demanded. The device came to represent the hope for good health and the future, not only of the individual patient, but for those who depended on them. Like parent and child, the box and the patient were tied into a reciprocal relationship of care, support and, as some said, love.

These responses cast light on how decisions about taking pills are distributed amongst people, rather than reflecting independently made choices, echoing the notion of 'distributed agency'. Writing in a similar vein about reproductive health decisions amongst pregnant women in Brazil during the 2016 Zika virus outbreak in Brazil, K. Eliza Williamson notes that 'agency is not necessarily the realm of autonomous subjects'; she demonstrates how 'distributive agency manifests

as care' (2021: 280) as family members and health-care professionals interceded to ensure surgical births.

In the context of extreme uncertainty about the future, the persistent threat of drug-resistant disease and feelings of vulnerability, compliance technologies are transformed from embodying autonomous decision-making individuals to symbols of care.

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Notes

1. I worked on clinical trials that tested microbicides and antiretroviral drugs to prevent HIV acquisition amongst women.

2. South Africa has one of the highest burdens of TB, contributing 4 per cent globally. It also has one of the highest incidences of drug-resistant TB (Abdool Karim et al. 2009).

3. In the late 1940s, the Nationalist government also set back the development of a primary health-care system in South Africa (Phillips 2014).

4. The phrase in the header is taken from a WHO handbook on medical adherence technologies (WHO 2017: 23).

5. In 1994, the economic Reconstruction and Development Plan (RDP) for the new African National Congress (ANC)-led government included the mass construction of cheaply built two-roomed houses to address South Africa's housing crisis. These are known as 'RDPs'.

6. The Bill and Melinda Gates Foundation funded the development and piloting of the MERM device in China and South Africa.

7. Please visit <https://www.wisepill.com> for more information.

8. All patient and clinic staff names have been replaced with pseudonyms.

9. The term 'pharmaceutical citizenship' is used here to denote the promise of belonging through complying with pharmaceutical treatment. Citizenship thus conceived is achieved not solely on the relationship between the state and the individual, but occurs through multiple and overlapping spheres including the biological and biomedical (Ecks 2005: 241).

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