**Title: A Disease Beyond Reach: Nurse Perspectives on the Past and Present of TB Control in South Africa**

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**Abstract**

Although access to healthcare has improved since South Africa’s democratic transition, neoliberal reforms have had detrimental effects on clinic-community and nurse-patient relationships, undermining efforts to control TB. This article focuses upon the work of nurses in three public health clinics in the Western Cape. We explore how they experienced, made sense of and grappled with the challenges of TB control, especially patients ‘defaulting’ on medication. Paying particular attention to confrontations between nurses and patients, we build upon previous qualitative studies that have contested popular constructions of nurses as ‘rude’ and ‘uncaring’. We argue that patient blaming and scolding need to be understood in light of nurses having to tread a fine line between compassion and assertiveness, individual and public good against the backdrop of a dissonance between the theory and reality of TB control. Nurses’ confrontational approaches are responses to the messy reality of TB control on the ground, solutions to which require attention to the socio-economic and historical context of nursing and primary healthcare. In the absence of such attention, animosities between clinics and communities could continue being cyclically reproduced.

**Key words:** Tuberculosis, nursing, South Africa, care, adherence, scolding

Dear residents of Worcester,

TB is a big problem. It’s a highly infectious disease and the main cause of deaths worldwide. Disobedient patients who refuse TB treatment are around in town and they infect the healthy, especially children and the elderly people. Currently TB is spreading like wildfire through Worcester. This means everyone can be infected with TB or die from TB. Our children and grandchildren might never have the opportunity to reach adulthood. Thus, all residents must immediately stand together to fight this evil and prevent Worcester becoming a ghost town.

(TB nurse, Worcester Community Health Centre)

The above extract is from a flyer composed by a TB nurse at Worcester Community Health Centre (CHC), a large public clinic in Worcester, a provincial town in the Breede Valley sub-district of the Western Cape. From the moment that Worcester CHC opened at 8am each morning, a long queue of health seekers promptly formed outside, from which they either underwent triage by a uniformed nurse or waited to be called inside for appointments. As patients were called into the building, an iron gate opened and shut behind them, with metal detectors and security searches ensuing just beyond – a stark reminder of the neighbourhood of clinic and its proximity to gang territories (Muller 2004). Down a back corridor of the clinic, somewhat out of view, lay the clinic’s TB department. One of the permanent fixtures of the TB department was Sister du Plessis[[1]](#endnote-1), a world-weary but highly-experienced nurse who, as the author of the flyer, was driven to appealing to the residents of Worcester about a TB epidemic spiralling out of control.

This article is about how public clinic staff, primarily TB nurses, made sense of one of the most severe TB epidemics in the world and strove to deliver care in precarious circumstances. We show, firstly, that one of the most pressing challenges of TB control was a ‘gap’ between clinic and home, a challenge that incorporates both late diagnoses and patients ‘defaulting’ on medication. We then home in upon the ways in which ‘defaulting’ was managed as well as when tensions boiled over into confrontations. Two bodies of literature converge in our analysis: anthropological critiques of TB discourse (e.g. Farmer 2000, 2004, Harper 2006, 2010) and qualitative studies contesting popular constructions of nurses in post-apartheid South Africa (e.g. Walker and Gilson 2004; Hull 2009; Joyner, Shefer, and Smit 2014). We argue that patient blaming and scolding do not simply evidence ‘uncaring’ but rather nurses having to tread a fine and at times impossible line between compassion and assertiveness, individual and public good against the backdrop of a fundamental dissonance between the discursive framing of healthcare relations (premised upon patient rights and responsibilities) and the material circumstances in which nurses must actually deliver care. Yet at the same time, it is through the work of these agents of the state that structures of domination which have endured through the democratic transition are reproduced, reinforcing constructions of ‘irresponsible’, ‘disobedient’ bodies while deflecting attention away from the structural determinants of TB. Solutions, therefore, require close attention to the socioeconomic and historical context of nursing and primary healthcare in South Africa, lest animosities between nurses and patients, clinics and communities continue being cyclically reproduced.

The fieldwork upon which this article is based took place between August 2014 and August 2015 as part of a project exploring the effects of a large TB vaccine trial site on primary healthcare in the Breede Valley (Dixon 2017). The Breede Valley has one of the most severe burdens of TB in the world, with an annual incidence of 1200 / 100 000 persons (Western Cape Government 2015) compared to the national average of 781 / 100 000 persons (WHO 2017). Although the main focus of the project was on the workings of medical research in the midst of this epidemic, the project involved ethnographic work in three public clinics. The largest, Worcester CHC, is located in the centre of Worcester, serving around 70,000 primarily Coloured[[2]](#endnote-2), Afrikaans-speaking people living in the town’s low-income suburbs. The second, Empilisweni clinic, is located on the town’s outskirts in Zwelethemba, a primarily Black African, Xhosa-speaking township of around 32,000. The third and furthest afield, De Doorns clinic, is nestled between a host of farms approximately 10km outside of Worcester, servicing a population of around 22,000. Between them, these clinics cover approximately 70% of the Breede Valley’s 167,000 inhabitants.

Across the three clinics, participant-observation and interviews were conducted by the first author (Justin) with 20 clinic staff members, primarily nurses in the TB departments, or ‘TB rooms’ as they were known colloquially, but also nurses in other departments, facility managers, and sub-district managers. Participant-observation involved Justin sitting with the nurses during their day-to-day routines, such as patient consultations, paperwork, preparing medication, and tea breaks. Interviews were conducted opportunistically when there was time in and between their busy schedules. Interviews were often multiple and were responsive to findings that emerged in the course of participant-observation. Ethical approval was obtained from the University of Cape Town’s Health Sciences Faculty Human Research Ethics Committee. We begin with a brief exploration of the historical context of primary healthcare provision in South Africa, which sets the backdrop for recent qualitative studies of nursing and anthropological critiques of TB discourse.

**A Shifting Primary Healthcare Landscape**

Access to basic healthcare in South Africa has improved since the democratic transition. In 1992, with the end of apartheid imminent, the National Party ended the racial segregation of healthcare facilities, which was followed soon after by a radical restructuring of the health system in order to make healthcare more accessible to the country’s poor. The Mandela government vowed to make primary healthcare “the cornerstone of health policy” (Coovadia et al. 2009:828), following which 1,345 clinics were built and a further 263 were upgraded nationwide (Coovadia et al. 2009). State-employed clinic nurses, who previously delivered mainly preventative services, were trained in primary healthcare, with the intention that more curative services could be offered at the clinic level and decrease the reliance on the (very limited number of) doctors. This included treatment for (uncomplicated) TB, in which doctors had an increasingly peripheral role through the 1990s and early 2000s. User fees were scaled back and eventually eliminated (Foster 2005). Moreover, the Patient Rights Charter (1996) was introduced, which included the right to a comprehensive range of healthcare services, privacy and confidentiality, participation in decision-making and to refuse treatment. It also includes the right to a “positive disposition” on the part of health workers, one that “demonstrates courtesy, human dignity, patience, empathy and tolerance”.

The corollary of greater rights for patients, however, was a set of assumptions that patients would hold up their end of the bargain, as it were, which took the form of patient ‘responsibilities’. Such responsibilities are written into the Charter and include the responsibility to: take care of one’s own health; know the health services and what they offer; not abuse the health services; and comply with treatment regimens. It might be noted that this increasing emphasis on patient responsibility was happening at the same time that the health sector faced a new wave of challenges through the 1990s and 2000s. The clinics, despite being more in number and better resourced, were quickly over-stretched, due to a number of factors including the removal of user fees, increased migration into and within South Africa, the rapid escalation of HIV and AIDS, which in turn amplified TB, as well as increasing alcoholism, substance abuse and violent crime (Walker and Gilson 2004; Compion 2008; Coovadia et al. 2009). Moreover, whilst taking a welfarist stance in relation to healthcare and social services, the Mandela administration bowed to international pressure to implement neoliberal macroeconomic policies that greatly limited government expenditure on healthcare and social services through the 1990s (Foster 2005).

Against this backdrop, the increasing emphasis on patient responsibilities can be situated within a broader shift in responsibility away from the state and towards individuals and communities. As the HIV and TB epidemics surged and outstripped the capacity of many developing countries’ health systems to handle the volume of patients, the WHO and Stop TB Alliance advocated “the building of ‘partnerships' with the private sector and civil society to aid in the development of so-called ‘community-centred’ care” (Compion 2008:96). One of the most significant developments in South Africa was the institution of home-based carers in the late 1990s: community workers without formal biomedical training who, supported by NGOs, took on a key role in the treatment of HIV and TB. Their work included the direct observation of TB treatment (discussed below), ‘defaulter’ tracing, palliative care for HIV, and health education. While home-based carers were – and continue to be – an important complement to clinics, as Compion (2008:96) argues, “community-based care has the latent result of allowing the state to withdraw from certain core obligations and functions”. Thus, just as the nation’s epidemilogical profile was deteriorating, the state deferred core healthcare responsibilities onto a largely unskilled commmunity-based workforce.

An expanding body of anthropological literature has shown how responsibility and blame is cast within the domain of TB control. Since TB was labelled a ‘global emergency’ in 1993, the WHO’s primary response was to advocate the worldwide implementation of directly observed therapy, short-course (DOTS)[[3]](#endnote-3) through country-level National Treatment Programmes. Motivated by poor patient adherence and substandard public health interventions, DOTS remains a central component of global efforts to control TB. Anthropologists have argued that DOTS and attendant biomedical discourse narrowly frame TB treatment as a matter of individual ‘adherence’, obscuring structural determinants of the disease and placing blame upon impoverished individuals for their own treatment ‘failures’ (Farmer 2000, 2004; Das and Das 2007; Compion 2008; Harper 2006, 2010). These critiques importantly call for greater attention to the connections between TB and structural violence. However, as Ecks and Harper (2013:256) point out, “anthropologists have hardly looked beyond TB *patients*”, and where healthcare workers are mentioned, they tend to be construed as passive purveyors of TB discourse. Although anthropologists have begun to respond to this challenge (e.g. Abney forthcoming), there remains a paucity of studies applying the sort of critical gaze used to vindicate TB patients to healthcare workers, especially nurses, to understand the pressures to which they are subjected.

Addressing this gap in knowledge, this article draws upon qualitative studies on nursing in South Africa. South Africa’s nurses have a poor media reputation, and numerous studies document patient perceptions of them being ‘rude’ and ‘uncaring’ (e.g. Gilson, Palmer, and Schneider 2005; Jewkes et al. 1998; Sokhela et al. 2013). Yet, such observations often fail to consider the drastic and detrimental changes that the nursing profession underwent through the democratic transition. Nurses bore the brunt of the increased workload that came from the influx of patients, exacerbated by many nurses heading to the private sector or ‘overseas’ (Foster 2005; Joyner et al. 2014). Moreover, as nurses’ skills increased to meet the demand for more services at clinic level, the resulting “facility focus” (Daire & Gilson 2014:ii87) meant that nurses lost much of the connection to communities that they had while performing preventative services. Workloads were increased further with a growing emphasis on patient data collection, which “becomes a source of intense anxiety [for nurses] and serves to exacerbate [their] workload” (Hull 2012:629; see also Strathern 1996). Finally, just as patient rights were improving, nurses felt less respected by both communities and their superiors, leading many to feel a profound sense of lost professional status (Walker & Gilson 2004; Foster 2005; Hull 2009; Joyner et al. 2014).

The high-stress, facility-focused nature of primary healthcare documented above is very much the reality that Justin encountered when he started spending time in the clinics in 2014. In this article, we show how factors such as heightened facility focus, heavy workloads, patient data, and declining respect were experienced and made sense of by nurses working in TB care, one of the most stressful domains of primary care nursing. In doing so, we expand both expand the emerging anthropological interest in TB and add disease-specificity to existing social science literature on nursing in South Africa.

**“It’s the Ones that are Out There”**

Located towards the back of the clinics, the TB rooms were large, well-ventilated spaces that contained a couple of desks, a treatment table, a sink, shelves full of medication, and filing cabinets. The corridors outside were lined with chairs or benches for patients to sit on while they waited, and the back doors led to the clinics’ backyards, which is where patients were sent to produce sputum samples. Far from sombre and clinical, the TB rooms all bore the signs of familiarity and domestication, scattered with stationery, post-it notes, bags of pills bearing patients’ names, and often the radio playing. Working from their desks, two or three nurses worked side-by-side throughout working hours. Doctors from the regional TB hospital visited on a biweekly basis to handle more complex cases; but as the sub-district primary healthcare manager Dr Van Zyl said, TB is a “nurse-driven, doctor-supported service”. Most of the nurses were warm, friendly characters and allowed Justin to pull up a chair at the side of one of the desks from which to observe and ask questions.

From the second the clinics opened, the TB rooms were busy. Most patients were referred to the TB rooms after experiencing symptoms, attending the clinic and undergoing a process of triage. In the language of public health, this is referred to as passive case finding, which involves waiting for patients to come to the clinic rather than vice versa (active case finding) and is premised upon patients recognising symptoms and attending their clinic for treatment (Golub et al. 2005; Uplekar et al. 2013; WHO 2013). Other paths to the TB rooms included: children being sent from the paediatric department; HIV-positive patients being sent for TB screening; patients being referred from the regional TB hospital; and referrals from a nearby TB vaccine trial site (Author 1 2018). For adults, the first thing the nurses did was ask patients to produce two sputum samples in the backyard and instruct them to return 48 hours later for results. The process was more complex for infants, because TB bacteria can only be detected in their sputum in 40% of cases (Moyo et al. 2012). As a result, they were tested for latentTB using a TST skin test and then, if found positive, they were sent to the TB hospital for a chest X-Ray, which was examined by a doctor to determine whether or not they had active TB.

For patients who had positive results upon their next visit, a six-month regimen of antibiotics was started immediately. To give a sense of the volume of patients, at the end of 2014 there were 741 TB patients at Worcester CHC, 393 at Empilisweni and 389 at De Doorns. Throughout their regimens, patients had multiple appointments in the TB room. For the first two months (intensive phase), many would come to the TB room every day to be observed taking their medication (i.e. DOTS). Aside from this, patients had a sputum check at the two-month, four-month and at six-month mark. For many, this concluded their relationship with the TB nurses, and they could either stop attending the clinic or, if they needed ARVs, they would be referred to the Infectious Disease room.

While the volume of TB patients moving through the TB rooms day after day, month after month seemed staggering, when Justin related this sentiment to Sister du Plessis, she looked at him with an ‘oh please’ sort of expression and said: “the ones that come here aren’t the problem; it’s the ones that are out *there*” (her emphasis). This she said while pointing emphatically in a southerly direction, towards Worcester’s low-income suburbs. Her words and gesturing conjured images of uncontrollability, the wild, and territories without grip. While most of the suburbs to which she referred were geographically close, her sentiment captures the distance and impenetrability of these areas felt by many of the nurses, exacerbated by the gangs and violent crime that made accessing them very dangerous. Somewhat more matter-of-factly, Dr Van Zyl identified “the gap between the clinic and the home” as one of the main challenges of TB control.

TB cases “out there” included, firstly, those who had developed disease but remained undiagnosed. This meant they were highly infectious and, because of the overcrowded and impoverished living conditions in much of Worcester, likely to spread the disease (Naidoo et al. 2017). The second and far more persistent source of frustration were patients who were diagnosed, commenced treatment but stopped prematurely. This is widely referred to as ‘defaulting’, with people who default labelled ‘defaulters’. Closely connected to the notion of ‘adherence’, the appropriateness of this term has been hotly contested (Farmer 1998; Ditiu and Kumar 2012), a point to which we will return. Whatever it is named, the premature discontinuation of treatment is highly dangerous both for the individual and from a public health perspective. Missing even a few weeks of treatment runs the risk of developing multi-drug resistant TB (MDR-TB), which includes resistance to at least rifampicin and isoniazid, the two most powerful first-line drugs. Moreover, unless adherence to second-line drugs is scrupulous, MDR-TB can easily become extensively drug-resistant TB (XDR-TB) (resistance to all second-line drugs). The public health concern for both MDR and XDR-TB is that these strains can be passed onto others, meaning that even without being non-adherent themselves, some people have to bear the consequences of those that have.

**Balancing Acts and Confrontations**

Patients who ‘defaulted’ on their medication were engaged with in a number of ways. For the purposes of locating patients who had stopped treatment, home-based carers were valuable resources to the clinics. Funded by a local NGO, each clinic had about ten carers assigned to them who performed the majority of community-based healthcare tasks, including: taking TB medication to those who were unable to attend the clinic, ‘contact tracing’ (identifying individuals in patients’ houses who needed to be screened for TB) and, most significantly here, ‘defaulter tracing’ (finding non-adherent patients). As one of the nurses aptly put it, the home-based carers are “the length of the nurse’s arm”. Each morning, the carers came to the TB rooms to collect names, addresses and treatment – and sometimes assisted with other tasks like counting pills – before heading out into residential settings. Along with their other duties, the carers attempted to locate non-adherent patients and, if they were successful, requested that they return to the clinic to resume treatment.

While spending time in the clinics, Justin frequently saw patients who had ‘defaulted’ slinking into the TB rooms before sitting in front of a stern-looking nurse. As part of their return to treatment, patients were referred to one of the clinic counsellors, whose job it was to communicate the importance of adhering to medication, both at the time that they originally started treatment and in the instances that they ‘defaulted’. But the nurses, too, took an active role in managing non-adherence and, while attending to patients, spoke to them at length. In this regard, the nurses stressed the importance being strict and firm, on the one hand, but at the same time respectful and compassionate, on the other: “Sometimes you have to be strict with them, but with that compassion” (Nurse Botha, De Doorns); “It’s a very fine line. You can’t let them walk over you, they have to take their tablets…But it’s not like you force them to do it” (Nurse Jacobs, Empilisweni). Sister Harmse of Worcester CHC expressed that there was a difference between addressing younger and older patients:

I will speak to them nicely and not in a rude manner – but in a strict manner. If it’s an older person I would not speak like that. If I’m talking to a younger one I will be stricter than with the older person. But I really try hard not to be rude. So patients can feel welcome to come to the clinic, because if you are rude they are not going to come.

The picture that emerged was that the nurses felt they had to tread a fine line with non-adherent patients. If they came across as rude and disrespectful, patients would not return to the clinic again, to the detriment of their own health and that of others. But at the same time, being too ‘soft’ could have a similar outcome.

In spite of these practices, the rates of non-adherence had only been getting worse in recent years. As Sister du Plessis said: “the defaulter rate, it keeps getting higher and higher”. The ‘defaulter rate’ at all three clinics was about 20% and, at the time of fieldwork, there were six MDR patients at De Doorns, 14 MDR and one XDR patient at Empilisweni, and over 30 MDR patients and 3 XDR patients at Worcester CHC. It is against the backdrop of a frustration about the patients “out there”, whose presence was experienced primarily as an absence, that tensions regularly boiled over.

One morning when Nurse Jacobs was working in Empilisweni’s TB room, a young woman entered the room holding a baby who was coughing profusely. Nurse Jacobs was aware of this particular baby and was immediately cross with the woman, who was not the baby’s mother but rather someone sent in her stead. She was cross because the baby had recently been brought to the clinic and, after a scan, had been found so sick that they needed to be hospitalised. The mother was supposed to have brought the baby to the clinic to be transported to the hospital, but had not attended. Now, having sent the baby with someone else several days late (the mother’s presence was required), Nurse Jacobs lost her cool. She said to the woman – who was sitting defensively and not saying a word – that if the mother does not bring the baby in personally tomorrow she is going to send her to the clinic social worker. In fact, at that moment the social worker walked into the room (for other reasons), and Nurse Jacobs pointed and exclaimed, “look here’s the social worker! The baby is sick, she’s coughing all the time and she [the mother] knows it”. Nurse Jacobs said “thank you” to the woman and then looked down at her desk as if to say, “you are dismissed”.

Similar events occurred in Worcester CHC almost every day Justin was there. He arrived one day to find Sister du Plessis on the phone to a patient with XDR-TB who had been released from hospital to attend the funeral of his wife but was supposed to return to the hospital soon afterwards. However, he had now been out of the hospital for a month and had decided to stay out. At the time Sister du Plessis reached him, he was busy setting up for his son’s birthday party. For obvious reasons, this deeply upset Sister du Plessis; the possibility of a large group of children being infected with XDR-TB did not bear thinking about. But this was a real possibility and, as a result, Sister du Plessis chastised the man and threatened to call the police.[[4]](#endnote-4) This episode was followed shortly after by an incident where the clinic had found an MDR patient who had been off medication for several weeks. Upon arriving at the clinic, however, he promptly changed his mind, excused himself use the toilet, and disappeared. It was in one such moment of frustration that Sister du Plessis said:

You can’t be nice to them. If you give them the pinky [little finger] then they will take the whole hand. Some of the sisters try to be nice to them but it is only me that will give them *skel* [to scold, or have strong words with]. Nobody likes me here. Only God loves me [she points upwards to the heavens]! But I don’t worry, I’m not here to be nice I’m here to do my work.

The above vignettes give a sense of why, from the perspective of patients and residents, the nurses might be perceived as ‘rude’ and ‘uncaring’ proponents of harmful patient-blaming TB discourse (Farmer 1998, 2000). In the following, we show that, while nurses are certainly implicated in the reproduction of harmful discourses, patient blaming and scolding need to be understood in light of a fundamental dissonance between the theory and reality of TB control as well as detrimental changes to the nursing profession that constrain the practice of caregiving. We divide the remainder of our findings into two sections: isolation and accountability; and responsibility, blame and nostalgia for the past.

**Isolation and Accountability**

One of the most frustrating parts of life as a TB nurse was not only that they were working on the frontline of one of the most challenging diseases to manage. It was that few seemed to appreciate the pressures and challenges to which they were subjected. As mentioned above, the TB rooms were around the back of the clinics at one remove from most of the other departments. Sister du Plessis quipped one morning that “we are like Sewende Laan [Seventh Avenue] – on our own – that’s how we feel”. Referring to a popular South Africa soap opera, her meaning was that the TB room was like a little world of its own, full of drama yet cut off from the rest of the clinic. The feeling among the TB room nurses was that none of the other nurses wanted to learn how to treat TB. As a result, once assigned to the TB rooms they were stuck there and denied the rotation around the clinic that the other nurses enjoyed. Reflecting on this, Sister du Plessis suggested that it was the infectious nature of TB and the poverty of patients that underlay the resistance of other nurses:

It’s an infectious area…They are afraid that they’ll get TB…And I think it’s because there is not enough information. Look, the staff say they can’t help us because they don’t want to know what’s going on here. Then I told Sister Kruger, if they don’t come and see what’s going on here or come and work here, they will never know what is going on here, right? Look, for the people who come here it’s a social problem: they’re not so clean, they smell, you understand? It’s not everyone who will work with that type of patient.

Sister du Plessis here reveals an honest and uncomfortable truth about TB: that it is highly stigmatised and has heavy associations with ‘dirt’ and the poverty it symbolises. Kate Abney (2011), in an insightful thesis entitled *Whoever Said a Little ‘Dirt’ Doesn’t Hurt?* has written at length about this symbolism and how it contributes to the stigmatisation of TB patients (see also Dixon & Tameris 2018). For Sister du Plessis, the ‘dirtiness’ of TB patients was one reason other nurses did not want to care for them. Moreover, almost none of the nurses wore masks, who expressed a concern that, if they did, this would only contribute further to the stigma and alienation felt by the patients (see Abney this issue).

One of the managers, Sister Pienaar, explained the logic behind the differential staffing of the TB rooms:

Currently, there is a big, big issue with the staffing at TB. They are very frustrated there. At the end of the day we want every sister to do everything. We want to rotate them. At first, we rotate them on a quarterly basis, but we found out it’s better to put a person in the TB or chronic department for at least one year so that they can build a kind of relationship. But at the end of the day we said to each other, we mustn’t change the staff in the TB room. We must rather let them stay stable, the same people doing the job all the time. But…we are trying to get sisters, one at a time, to learn also about TB.

There was, in other words, a tension between wanting to rotate nurses to ensure they had a comprehensive skill-set, on the one hand, and needing continuity in the staffing of the TB rooms, on the other. This understandably came across as a lack of fairness on those who were assigned to the TB room and unable to leave.

Worse than a feeling of being isolated in the TB rooms was the belief that that managers, both in the clinic and at district level, paid much attention to the statistics without actually coming and seeing how things were in the TB rooms. This reflects the increasing incursion of ‘audit culture’ into healthcare in South Africa (Hull 2012; Strathern 1992). The result was that the nurses felt they were being unjustly held accountable for the high ‘defaulter’ rates and poor treatment outcomes despite doing everything they could to ensure patients adhered to treatment. Sister du Plessis related the journey of self-doubt that she went through when the ‘defaulter’ rates began to skyrocket when she began working in TB in 2009:

Sister du Plessis (dP): I don’t know really, but it was very good. And when I started here there were also statistics on the wall, and most of the time, a hundred percent. When I came here it fell, and I think oh, me the problem, right?

A1: I’m sure.

dP: But I do it right. I also say that is the real thing. And that’s what I told Dr [Van Zyl] when he phoned last year in November about a patient, and he was very angry. So I said, doctor, TB is a bad problem in Worcester at this clinic. The default rate, it’s going higher and higher. And I don’t think they realise what a big problem it is, because you talk and talk…

A1: The doctors.

dP: Ja, and also the operational manager, because they don’t come here so often, and now they realise when we talk. I asked Dr [Van Zyl] that he must come and have a look here. Then he was here last week, but now I think they realise how many patients are here.

As fieldwork went on, there was a growing feeling among the TB nurses, as alluded to above, that the clinic managers were becoming aware of how out of control the TB situation was. This was, in large part, what prompted the district health authorities to place renewed emphasis on TB during the year of fieldwork, which we discuss in the conclusion. However, the issue of staff rotation was never fully resolved during the time of fieldwork. Moreover, that there is a history of nurses being blamed when their patients ‘defaulted’ is important to consider when we describe below how nurses in turn held patients responsible for their own treatment and to blame when they ‘failed’.

**Responsibility, Blame and Nostalgia for the Past**

All of the nurses were well aware of the relationship between TB and poverty. This was not only in relation to the mechanisms by which the disease is spread (e.g. overcrowded living conditions and poor sanitation) but also how it can be a barrier to attending the clinic for diagnosis and treatment (e.g. Farmer 2000; Compion 2008; Harper 2006, 2010; Das & Das 2007). To give one notable example, Sister Kotze of De Doorns clinic said:

A1: What would you describe as the major challenge at the moment, especially with TB?

R: You know, as soon as we diagnose, number one, it’s poverty. Poverty plays a huge role in this community, and alcohol abuse as well. But as soon as the patients are diagnosed with TB, they start a few months or maybe a few weeks on TB treatment, but I think due to the poverty they need income [the implication being that they stop medication because of work].

However, with the daily frustrations of trying (often in vain) to steer several-hundred patients through long and arduous treatment regimens, and the pressures placed on them from management, it is unsurprising that it was hard for them to always see the patients themselves as victims. Blaming was indeed fostered by the discursive environment within which the nurses worked: that patients must “take responsibility for their own health” was an omnipresent saying in the clinics and invoked far more often than the corollary notion of patient rights. The fact that so many patients were stopping their medication was often enough to conclude that they were not taking responsibility for their health.

The nurses expressed this in a variety of ways, drawing upon notions of responsibility to shed light on patient behaviour. Nurse Kriel of Empilisweni TB room, for instance, said: “At the end of the day the responsibility of your health is your own. You can’t put the responsibility of being healed on someone else. You must stick to your appointments and the dates”. Sister Pienaar of Worcester CHC expressed with great regret that people in the Breede Valley did not seem to care about health:

We do whatever we can, but at the end of the day it’s your decision and your health, and you must come to the clinic…But they don’t want to…It’s very difficult for the staff because they are trying and they’re doing their best, but at the end of the day if you are my patient, I can’t just open your mouth and put tablets into your mouth. You know, it must come from yourself as well. And you know, the kind of community that we are serving, they are very…it seems as if they don’t care. They really don’t care.

What sticks out here is not only the way in which blame is placed on individuals, but perhaps more significantly the way generalisations were easily made. While it was the minority of patients that were visibly not ‘taking responsibility’, this was a stereotype which easily applied to everyone, resulting in an entire community being constructed as ‘uncaring’.

Discourses of patient responsibility also intersected with other sources of thinking about responsibility. Struggling to make sense of the epidemic, Sister du Plessis’ explanation featured a large overlap between biomedicine and Christianity, an association with a long history in South Africa because of the missionary origins of biomedicine in the country (Vaughan 1991; Marks 1994; Hull 2009). This she drew upon to explain why it was that people often did not comply with the clinics’ prescriptions:

If you look, the end of the world is near, and there are so many people whose heart is not right…Most of the people here, if you don’t drink your pills, you haven’t got responsibility. Because the Bible says that your body is the body of god, so you must look after your body. And illness is part of this, right? TB can be cured, you must only drink your pills and then you can be cured…If the patient can change his whole attitude, it changes his heart. He starts taking responsibility for his illness. He will take his pills and complete it…So, if the heart is right and it started at home, in each home, in each street…

Here we get a sense that, for Sister du Plessis, the TB epidemic is not only a highly moral condition but also one of Biblical proportions. The reason for the magnitude of the disease is a wide-scale failing of people’s “hearts” which worried her given that the end of the world and the Day of Judgement is near. Vaughan (1991:74) argues that “healing, for medical missionaries, was part of a programme of social and moral engineering though which Africa would be ‘saved’”. For Sister du Plessis, ridding Worcester of TB meant a combined emphasis on medical and moral healing, a sustained community-wide endeavour to change people’s hearts. This, for her, legitimised governmental intervention, the object of which was a particular imagining of immoral, irresponsible bodies needing to be changed.

Yet reaching people with this message was precisely the problem. The clinics were disconnected from the communities that they serve, and those who most needed to attend the clinics seemed the least willing to go. Thus it was that she composed the flyer with which this article opened, to be delivered to as many houses as possible via the home-based carers: “That is why the flyers must get out, right? The flyer must get to the home…The [home-based carers] who are in the field can go and give it out at the homes, you understand?” That flyer was never actually put to print. The managers deemed it too full of religious rhetoric and harmful language to be appropriate for distribution. One can certainly see why this was the case, given the kinds of words and phrases used: “disobedient patients who refuse treatment”, “evil” and “ghost town”. However, we suggest that it ought to be read as an attempt – a desperate one, for sure – to get some kind of grip on what was happening “out there” and over which she and the other TB nurses seemed to have little control, compounded by their feeling of isolation. On one level, Sister du Plessis’ efforts showed how much she cared.

The nurses drew heavily on the language of responsibility in order to explain the epidemic and attribute blame. However, the ‘gap’ between the clinic and home was so wide that it seemed often to outstrip the capacity of this language to offer tangible solutions to the problem. As a result, a number of the nurses, especially those who had practiced nursing during apartheid, reflected back to a time when things seemed somewhat simpler. This is not to suggest that the nurses wished for a return to apartheid. It was just that certain forms of healthcare seemed to offer more effective means of controlling TB than the current prevailing paradigm revolving around the rights-bearing, responsible patient.

One aspect of healthcare during apartheid that was invoked repeatedly among the nurses was the active presence that they had in community settings. One manager, Nurse Kriel, suggested the benefits of this community presence: “There was great interaction with your patients. It was nice because people who didn’t want to go to the clinic got seen”. Further to this, Sister Pienaar of Worcester CHC said that clinics had greater control over patients: “We used to take the service to the community. We used to do home visits. There was more control over the patients, because the sister in the TB room can go out herself – that time the patients listened to us more”. Finally, Sister Harmse of Worcester CHC said: “Ja. You can ask Terence (another nurse). They’ve got a scooter and then they go out to call on the patients to come in. And they did come in, you understand, but now they don’t. They come once and never again...The problem is that they don’t care”. In the intervening time since the nurses stopped being an active community presence, the home-based carers have, taken on much of the work outside of the clinics. However, despite being valued, there was a feeling that this was not the same as having trained nurses being able to go to people’s homes, not only because of the greater expertise of the nurses, but because people seemed to respect them more.

Part of the reason for this, however, was that patients had few rights, and thus what seemed like respect was more likely subservience and obedience for fear of the consequences. Sister du Plessis, however, felt that such was the scale of the epidemic that patients should not have the rights that they do now when it comes to TB:

In the beginning, [TB] wasn’t such a big problem, but now it is, because of the defaulters. Now the patients have rights, but that time we didn’t have rights like after 1994. You know, I think that is a big problem.

Few other nurses put the matter quite so bluntly as Sister du Plessis. Nonetheless, patients being seen to ‘abuse’ their rights was present in many nurses’ narratives. Moreover, nostalgia for apartheid healthcare has been similarly observed by Walker and Gilson (2004:1257). Like Walker and Gilson, we stress that the nurses did not express a desire to return to apartheid. Rather, these backward-looking perspectives just show how much of a disconnect there is between the theory and reality of TB control. Therefore, it is perhaps unsurprising that tried and tested methods that were acceptable in the old regime – for instance scolding, disciplining, and threatening to call the police – were re-activated in instances where the prevailing logic of patient responsibility reached its limits. Whether these techniques are justifiable is another matter. Sister du Plessis, certainly, could cite many instances where patients had resisted treatment but had later thanked her for being tough.

**Conclusion**

In this article, we highlighted the challenges of TB control from the perspective of those working on the frontline of the epidemic. We pointed towards a dissonance between the imagining of how healthcare ought to function in post-apartheid South Africa – rights-bearing individuals taking responsibility for their health – and the reality in which people were not attending the clinics and ‘defaulting’ on treatment regimens. We noted that the ‘gap’ between clinic and the home is a product of a series of historical changes, including the restructuring of the health system, a lack of funding to support such changes and worsening socioeconomic and epidemiological conditions. Yet it was the nurses who shouldered the burden of negotiating this dissonance on the ground. By showing how they balanced compassion and assertiveness, individual and public good, responsibility and blame, we argued that scolding did not simply evidence ‘uncaring’ but rather their desperation to gain traction on a disease that was often experienced by its absence and seemingly beyond reach.

Because of the increasing numbers of TB patients and ‘defaulters’, the district health authorities made TB their number one priority during the period of fieldwork, resulting in a number of initiatives that were beginning to be implemented. Some involved efforts to bridge the clinic-home ‘gap’, including projects to identify TB ‘hotspots’, systematically locate TB contacts and ‘defaulters’ and screen all clinic attendees for TB symptoms (regardless of presenting complaint). Others, meanwhile, fell within the prevailing paradigm of ‘patient responsibility’, including projects to increase awareness among residents of rights and responsibilities and to (re)train nurses in the ‘softer skills’ of patient management (i.e. deterring negative attitudes). Anthropological work on TB has highlighted from a patient perspective the harms inherent in placing responsibility (and thus blame) on the sick (e.g. Farmer 1998, 2000). Our contribution here has been to balance these patient-centred insights with an understanding of the social and historical processes that underlie and reinforce constructions of ‘rude’ and ‘uncaring’ nurses. Given that TB treatment (still) involves long and arduous drug regimens, its success is heavily dependent upon positive nurse-patient relationships. But unless the broader structures informing fraught nurse-patient and clinic-community relations are addressed, mutual animosities and blame could continue to be cyclically reproduced. This only further deflects attention away from the socio-economic and historical conditions that produce both uncaring, irresponsible patients and rude, irritable TB nurses.

**Acknowledgements**

We would like to thank all of the public clinic staff who were a part of this study. We also thank two anonymous reviewers for their insightful comments. This study was funded by a Collaborative PhD Studentship from the Economic and Social Research Council, United Kingdom [﻿1332788].

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1. **Notes**

   All participants in this article have been assigned pseudonyms. [↑](#endnote-ref-1)
2. The denotations of racial groups in South Africa have shifted over time and been hotly contested. Here we use the racial categories deployed in the 2011 South African census: ‘White’, ‘Coloured’, ‘Black African’, and ‘Indian’. [↑](#endnote-ref-2)
3. The central component of DOTS is health workers, volunteers or relatives directly observing patients taking each dose of medication. [↑](#endnote-ref-3)
4. Since the democratic transition, threats to call the police on TB patients are largely rhetorical. However, there is precedent from a 2008 court case for the forced containment of XDR patients in hospital for the first months of treatment: www.saflii.org/za/cases/ZAWCHC/2008/41.rtf [↑](#endnote-ref-4)