



Doing with, not doing to or doing for: the continuing challenge of transforming the institutions and practices of the South African health system

Introduction

Historically, South Africa's health system was, in part, a site of injustice. After its hearing into the apartheid health sector (1960-1994), the Truth and Reconciliation Commission (TRC) found "millions of South Africans were denied access to appropriate, affordable healthcare...Healthcare workers, through acts of commission and omission, ignorance, fear and failure to exercise clinical independence, subjected many... to further abuse".

Across this time, healthcare was broadly delivered in authoritarian (*doing to* patients) and paternalistic (*doing for* patients) ways, especially for black South Africans. Since the advent of democracy in 1994, laws and policies have sought to protect human rights, address disparities in health and wealth, and encourage the delivery of care in more restorative, participatory (*doing with* patients) ways. Alongside the TRC, itself a vehicle for restorative justice, we find the Constitution's Bill of Rights, Batho Pele (People First) Principles, Patients' Rights Charter, and proposed National Health Insurance system.

However, those who suffered most under apartheid still struggle most to access care and continue to experience the poorest health outcomes. Mistrustful provider-patient relationships and provider hostility, neglect, sometimes even abuse, remain part of the health system.

This brief shows how authoritarian and paternalistic practices persist in the new democratic context.

These undermine efforts to steer the health system towards a more restorative ethos, as intended by policy and required by past injustices.

Conclusions and policy implications


- Restorative practices that *do with* patients accord with South Africa's democratic social contract, but older authoritarian and paternalistic practices persist. The unjust past remains embedded in the health system's geography, architecture and relationships.
- Such practices reflect the health system's lack of transformation and undermine democracy: they disempower and dehumanize people rather than supporting them to be active, knowledgeable and responsible citizens. They perpetuate out-dated paternalistic ideas that providers know best and patient input is unimportant.
- Providers' negative exercise of power deleteriously impacts on patient satisfaction and adherence to treatment, which is encouraged when providers respectfully *do with* patients.
- Current health reforms around National Health Insurance, District Clinical Specialist Teams and Community Health Workers provide a window of opportunity for strengthening new ways of *doing care with* patients, thereby reflecting democracy and reducing the injustice experienced in the health system.
- This requires changes to provider behaviour and better systems of accountability, but these reforms are largely silent on how to improve accountability to patients and communities.
- It also requires engagement with the lived reality of providers. While not the focus of this brief, providers themselves often feel acted upon. Many are acutely aware of the pressure to change, but have to do so with inadequate resources, skills and training and while feeling ill-equipped to deal with daily realities such as onerous paperwork, multiple meetings and trainings. This may see them falling back on hierarchy and paternalism in an attempt to cope with the pressure and maintain a sense of control.
- The hierarchical health system focuses providers' accountability upwards towards their superiors, not downwards to patients and the community. Also, how providers are *done to*, *done for* or *done with* by colleagues and managers will influence their interactions with patients. Restorative health system practice thus requires *doing with* providers and patients.

Methods

This research (2009-2010) investigated access and barriers to anti-retroviral treatment (ART), tuberculosis (TB) care and maternal delivery services. We observed 12 facilities and interviewed 45 patients and 63 healthcare providers in rural Bushbuckridge (Mpumalanga) and the cities of Cape Town (Western Cape) and Johannesburg (Gauteng).

In doing this work, we met Gugulethu Ngwenya (26), an expectant mother in Johannesburg. Her story is emblematic of broader problems in the organisation of health services.

Gugulethu Ngwenya*

- 
- She fell pregnant 2 years after being diagnosed with HIV/AIDS.
 - Excited but anxious, she became an "expert" patient who read pregnancy books, attended antenatal classes and enrolled in the (restorative) prevention-of-mother-to-child-transmission programme.
 - Towards the end of a smooth pregnancy, she experienced intense pain and was admitted to a community health centre (CHC).
 - She was discharged the next day and told to go to the hospital next time she thought she was in labour.
 - When her pain returned that evening, she phoned an **ambulance, which did not arrive** due to striking staff.
 - Hours later, **a neighbour drove her** back to the CHC, where **staff refused to admit her** because they had already referred her to the hospital.
 - After claiming that she had walked to the CHC and had no transport, the nurses let her in, but continued *doing to her* by **being uncaring, offering limited assistance and ordering her about** in an authoritarian way.
 - She was eventually put on a drip and transferred to a hospital, one centimetre dilated and bleeding.
 - 12 hours after arriving at the hospital from the CHC, Gugulethu was sent to the delivery ward, initially **moving between wooden benches and beds**.
 - She waited 2 more days while **doctors examined her intermittently and told her that she needed a caesarean section, without explaining why or when** the procedure will take place.
 - 5 days after she went to the CHC, she attempted to give birth in full view of **5 students (present without her consent)**, before she was taken to the theatre for a caesarean section, only to be returned to the ward to "try again" because she was fully dilated.
 - In front of yet more students, she eventually required 4 vacuums for her vacuum-assisted delivery.
 - Her baby died shortly after.
 - Gugulethu endured this tortuous process and the **petty power and ridicule of nurses** for bringing a birth bag with ART, blankets and snacks ("going to a picnic"), as well as their ire for screaming out in pain and banging against the wall while struggling to endure the pain ("you are here to bother us").

*Pseudonym

Gugulethu Ngwenya endured a disempowering, dehumanizing chain of events, tragically magnified by the death of her baby. In a post-apartheid context, her experience stands out as nondemocratic and shocking – the opposite of a restorative, *do with* approach. While extreme, hers was not an isolated experience. Our study unearthed other examples of providers negatively exercising their power to deny patients care, withhold their treatment, deride, scold or ignore them.

“The counsellor got mad and started shouting to all the patients, telling them they are not honest, they lie about taking their treatment, and they also miss their appointment dates, and create a mess at the same time.”

(Facility observation notes, ART, Bushbuckridge)

“[In the labour ward, the cleaners shout], ‘Who has made this mess? Bring the mop and clean up your mess. You are dirty, your husband or boyfriend is going to leave you. How will they love you when you mess like this?’ The mothers just keep quiet. The cleaners then bring the mop and clean up being angry.”

(Facility observation notes, maternity, Johannesburg)

Organising care on punitive and paternalistic foundations: further examples	
ART	TB - Directly Observed Treatment (DOT)
<ul style="list-style-type: none"> • If patients lose their ART or it is stolen, they need to make a sworn statement at a police station to account for the loss before their treatment will be replaced. • Underpinning this policy is an assumption that patients are irresponsible or deceitful, and capable of lying to providers and abusing resources. • Ostensibly a response to an illicit market for ART drugs, the policy affects all patients and requires people with a highly stigmatized illness to submit to police surveillance. 	<ul style="list-style-type: none"> • TB DOT requires patients, paternalistically so, to swallow their tablets daily while under the surveillance of “reliable” witnesses such as nurses or community health workers. • Such surveillance practices are often implemented rigidly and become ends in themselves, neglecting objectives such as whole-person care. • One TB patient’s observer was oblivious to how, for a month, he vomited after swallowing his treatment. • He did not tell her and she simply observed him taking the pills and left.

Gugulethu Ngwenya’s experience also highlights structural contextual factors that influence access to healthcare and the very spaces in which providers work and patients receive care, which encourage *doing to* and *doing for* patients, not *doing with* them:

Access to health facilities

For some patients, the “legitimacy” of their claim to care was questioned. Despite her emergency, Gugulethu Ngwenya struggled to access the CHC because of the argument that she had already been referred to hospital.

In a further example of *doing to* that limited

service availability, some facilities opened late or closed early. In many, patient care was informally scheduled for mornings only, with afternoons reserved for administration. This caught some patients unaware, while others were aware of, but unable to influence the practice.

Divergence from official opening hours caused frustration, inconvenience and added expense for patients. While some were turned away, most patients who presented during “unacceptable” times were reluctantly seen, but with orders to ensure their next visit was within the “acceptable” hours.

Unfriendly spaces

Having gained access to facilities, patients often found themselves in forbidding spaces where they were liable to be *done to* and *done for* in various ways.

First, without clear, respectful communication, which would have represented *doing with*, patients occasionally struggled to grasp the spatial and temporal logic of facilities.

Spatially, not all facilities had helpdesks or clear signage, leaving patients unsure of where to go. Temporally, patients saw providers moving around – for anything from having to work across different treatment rooms, doing administrative tasks, attending meetings or taking breaks (sometimes perceived as too long by patients) – and also standing around and talking, leaving them feeling overlooked and uncertain of who would see them and when this would happen.

Second, patients often had to wait for care in uncomfortable spaces. In a few facilities, the waiting area was outside or under a temporary structure such as a tent, leaving patients exposed, at the time of the research, to cold, wind and dust. Even inside, patients sometimes waited in cold, overcrowded rooms with uncomfortable seating.

Third, space constraints in facilities, high patient loads and staff shortages meant that often care activities were undertaken in groups, when they should have been individualised, or occurred in (semi) public view, when they should have been private. This included counselling, weighing, pill counting, dispensing and swallowing, and sometimes even birthing. This *doing to* compromised patient privacy and confidentiality.

Gugulethu Ngwenya also experienced an unclear temporal logic (intermittently examined

by different doctors; receiving no explanation for when her procedure would happen), coped in uncomfortable spaces (she felt mostly invisible while waiting on hard wooden benches or moving between beds) and struggled for privacy (the students' unwanted gaze objectified her).

Structural factors

Finally, the non-arrival of Gugulethu Ngwenya's ambulance and her reliance on private transport show how interconnected factors such as poverty, long distances, expensive private transport and unreliable ambulances can *do to* patients to constrain their access to care; challenging policy assumptions about the availability of emergency services and the absence of transport barriers.

In an emergency, shifting the transport burden from the state to the citizen can impose financial costs that many will find hard to bear.

For patients in need of chronic care, difficulties included having to use costly private transport for regular visits to health facilities, walking to facilities while feeling unwell, and having to make multiple visits (sometimes to different facilities) to receive the needed care. Some patients borrowed transport money, which caused anxiety about financial commitments and sometimes led to interruptions in treatment. In the absence of money, the sheer effort of reaching the facility was overwhelming for some patients:

"I just told [the nurses] straight, 'I can't come tomorrow. I can't make it. I can't walk every day so far [an hour] and the same distance back'...Every time I have to sit on the pavement to catch my breath and pain in the chest." (TB patient, treatment temporarily interrupted, Cape Town)

Source: Harris B, Eyles J, Goudge J. (2016). Ways of doing: restorative practices, governmentality, and provider conduct in post-apartheid health care. *Medical Anthropology*, <http://dx.doi.org/10.1080/01459740.2016.1173691>. **Funding:** This study is part of the Researching Equity and Access to Health Care (REACH) project. It was carried out with support from the Global Health Research Initiative, a funding partnership of the Canadian Institutes of Health Research, the Canadian International Development Agency, Health Canada, the International Development Research Centre, and the Public Health Agency of Canada. JE acknowledges the support of the South African Research Chairs Initiative (SARChI) programme (Department of Science and Technology, National Research Foundation). **CHP Policy Briefs:** The briefs aim to make CHP's research accessible to key stakeholders by summarising the work and presenting key policy implications and recommendations. This policy brief is produced and distributed under the terms of the Creative Commons Attribution-NonCommercial-No Derivative Works 3.0 Unported licence.