Not just health:

Narrating access to post-apartheid health care as a matter of restorative justice

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Thesis submitted for the degree: Doctor of Philosophy

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18 January 2016

Candidate declaration

I BRONWYN HARRIS do solemnly declare, in accordance with Rule G27 that this thesis is my own work. This thesis is being submitted for the degree of Doctor of Philosophy at the University of the Witwatersrand, Johannesburg, and has not been used as a submission for any other degree or submitted at any other university.

Signature:

Date: 18 JANUARY 2016

Acknowledgements

I extend the warmest of thanks to:

- My supervisors, Jane Goudge, John Eyles, and Liz Thomas: in the kindest, funniest and most insightful of ways you have scripted this story *with* me.
- Graeme Simpson for sparking the idea for this doctorate and providing mentorship in the difficulties of unscrambling unjust and violent omelettes.
- The patients, providers and REACH team-members for so generously sharing the stories that have warmed and broken my heart.
- My intellectual home during this study - the REACH team, including Helen Schneider, Diane McIntyre, Stephen Birch, Duane Blaauw, Pascalia Munyewende, Lehlohonolo Senoko, Mosa Moshabela, Realise Mhlongo, Phumzile Qhibi, Susan Cleary, Vanessa Daries, Sheetal Silal, Veloshnee Govender, Jana Fried, and Till Bärnighausen; and the South African Research Chairs Initiative (SARChI) programme of the Department of Science and Technology, administered by the National Research Foundation.
- The three anonymous examiners, Gillian Eagle, Jo Veary, Courtenay Sprague, and Marlise Richter who engaged so thoughtfully and constructively with my ideas.
- Jackie Roseleur, Ann Luusah, Zwelakhe Khumalo, Greer van Zyl, and Susan Benvenuti for administrative, editorial and coaching support.
- Laetitia Rispel, Kathleen Khan, Alicia Wade, Paul Bohloko, Busi Ngoyi, Aimee Stewart, Jude Igumbor, and the community that is the Wits School of Public Health PhD Programme.
- Prudence Ditlopo, Nonhlanhla Nxumalo, Kafayat Oboirien, Marsha Orgill, and Natsayi Chimbindi for the daily encouragement and support.
- Piers Pigou, Brandon Hamber, and the VTP team at the Centre for the Study of Violence and Reconciliation, for all the change and continuity.
- Sasha Gear, Ceasar Pirs, Betty Tshehla, Loveday Penn-Kekana, Polly Dewhirst, Nahla Valji, David Bruce, Ruth Prince, and Ann Stellenberg (gone too soon) for teaching me about compassion, courage, endurance and the joyful art of silliness.
- Joan, Terry, and Nicky Harris for always opening new windows for me.

- Louis, Sam, and Adam Greenberg for sailing me straight through all windows to a small island of pirate dogs, bartering bandits, and other treasured misfits.

This study is part of the *Researching Equity in Access to Health Care* (REACH) project and was carried out with support from the Global Health Research Initiative (GHRI), a collaborative research 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 (103460-054). It was also supported in part by the National Research Foundation (NRF) of South Africa (86472), Carnegie Corporation of New York, the Wits SPARC fund, the Wits School of Public Health Thanda Ukubhala writing retreat (which received financial support from the Faculty of Health Sciences Research Office), and the CLTD Coaching Programme at the University of the Witwatersrand. Thank you to the Centre for Health Policy, Waheeda Bala, Zoe Boutilier, Ibrahim Diabes, Hugo Canham, Robin Drennan, Khaled Fourati, Beverley Kramer, Laetitia Rispel, and the many others who have provided funding support. I acknowledge that the views expressed, findings and conclusions are solely my responsibility and that the funders accept no liability whatsoever in this regard.

For Harrison Eugene Nyathela (14 July 1974 - 23 March 2014)

Abstract

Rationale

Historically, South Africa's health system perpetuated – in complex and multiple ways – the oppression, neglect, and violations of colonialism and apartheid. The South African Truth and Reconciliation Commission (SATRC) established that "millions of South Africans were denied access to appropriate, affordable health care" and that the system itself was complicit in sustaining the structural and physical violence of the past. Key recommendations were made for reforming the health system. Yet, due to structural and political reasons, these reforms have not been as far-reaching as was envisaged. Twenty one years into the country's democracy, although the right to access health care is constitutionally guaranteed, inequitable access barriers persist. These disproportionately affect many who experienced the dispossession and structural violence of apartheid - black, poor, rural and informal-urban communities- as well as newer marginalized groups, including internal and cross-border migrants, and legal and undocumented refugees with little access to health services and other state care. The social contract has formally changed from apartheid to democracy but exclusion, including from health care, continues.

Transitional justice (TJ) processes are designed to support societies as they move from authoritarianism towards democracy, using strategies of truth-telling, institutional transformation, reparations, criminal prosecutions, and memorialisation. Most popularly associated with the SATRC in South Africa, this approach seeks to restore justice to victims through making individuals accountable, and with social and institutional reforms to 'make good'. Persistent barriers to health care (structural, institutional, and interpersonal) can thus be seen to reveal the 'unfinished work', or perhaps more condemningly, the 'disappointment' of TJ

as much as they testify to unfulfilled human rights in a post-apartheid context. Yet there has been limited engagement and 'sensemaking' between those seeking to reform health systems and those designing TJ reforms.

Aim and methods

The aim of this thesis is to situate access to post-apartheid health care as a matter of restorative justice, *as part of* South Africa's broader transitional justice agenda to restore, or 'bring', justice in the aftermath of apartheid. Conceptually, access is understood as a *negotiation* between patients (households) and providers (health system) around the availability, affordability and acceptability of care. It is seen as a political process, constantly conferred and translated by those implementing and practising policies, often with consequences unintended by policy makers.

This research is nested in the *Researching Equity in Access to Health Care* (REACH) project, a five year, multi-method study of equity in access to tuberculosis (TB) treatment, antiretroviral therapy (ART), and maternal deliveries in several South African provinces, including one rural (Bushbuckridge) and two urban health sub-districts (Cities of Johannesburg and Cape Town). Between 2009 and 2010, access stories were collected from in-depth interviews with 45 patients and 67 providers, and observations were carried out at 12 health facilities. These stories have been analysed using a narrative approach for 'making sense' of personal experience (stories) in relation to broader socio-political and cultural discourses (narratives). In this approach, different theoretical lenses are drawn on as part of such 'sensemaking' - restorative practices and governmentality; critical social contract theory; and street-level bureaucracy. These narratives have been theorized for continuities and changes with South Africa's past, and examples of 'restorative practices' (as more equitable and inclusive

ways of doing health care) have been sought. Additionally, theories of violence and trauma have been introduced as a tentative step towards 'making sense' of the tragic murder of Harry Nyathela (narrated in the Epilogue) – a haunting, seemingly 'senseless' death that fundamentally undermines restorative justice.

Findings

While restorative provider engagements are expected in health policy, older authoritarian and paternalistic norms persist in practice, undermining active, engaged citizenship and exacerbating affordability and availability barriers to care (largely located in unaddressed structural violence and poverty). Furthermore, institutional 'logjams' and outdated modes and infrastructures, coupled with new epidemiological stresses, have created additional challenges for health system transformation and those practicing care. Provider accountability remains 'upward' (to managers), rather than 'horizontal' (to other providers) or 'downward' (to individual patients and communities). Within this context of change and continuity, new identities, inclusions, and exclusions from health care are produced, and the contradictions and disappointments of a restorative TJ project are revealed.

Conclusions

Despite the SATRCs vision "to promote national unity and reconciliation in a spirit of understanding that transcends the conflicts and divisions of the past," *this* post-apartheid project is incomplete and disappointing. Strengthening street-level accountability and engendering respectful, empathetic provider practices - a restorative shift from older authoritarian modes - is vital to improving access to services and contributing more generally to the restoration of justice

and health in society. A restorative approach to health care requires a health system that does *with* providers as much as providers who do *with* patients. Yet, as with any regime of power, vigilance is needed: what has changed and how? What has stayed the same and why? In complex, subtle ways, power, violence, trauma, and suffering continue to find expression overtime and in the everyday practices of health care, as well as daily life. Accountability requires a collective 'repairing' of human relationships and a problematisation of power at the interface of both patients and providers, *and* communities and the health system. For health policies (including the proposed National Health Insurance system) to restoratively shift South Africa's story of 'lack of access to health services' towards one of 'universal health coverage', it is important to conceptualise restorative justice and health system accountability as a matter for collectives. A 'sensemaking conversation' that draws on lessons from both TJ, and health policy and systems research is recommended to further locate and problematize access to health care as a matter of restorative justice. And with this, an invitation to 'haunting', to seeking out and listening to that which cannot be said yet cannot be forgotten.

Thesis overview and structure

This PhD is written 'by publication' and is structured around four broad sections: I. Introductory contextualising overview; II. Three research articles; III. Brief conclusion; and IV. Epilogue.

I. 'The time is out of joint': Contextualising access to post-apartheid health care as restorative justice

This section establishes the aim of this study, which is to situate access to post-apartheid health care as a matter of restorative justice, *as part of* South Africa's broader transitional justice (TJ) agenda to restore, or 'bring', justice in the aftermath of apartheid. Grounded in the legacy of apartheid medicine *and* subsequent efforts to 'make good' in a post-apartheid context, this section is an updating, a re-telling, of the country's 'lack of health services' story in order to create a new narrative, one that conceptualizes access to health care as a matter of restorative justice. A restorative approach seeks to bring justice to victims and communities by holding perpetrators accountable, repairing relationships, and rebuilding institutions. Persistent barriers to health care (structural, institutional and interpersonal) are therefore presented as part of the 'incompleteness' and 'disappointment' of a TJ project, as well as impediments to the right to access health care in a post-apartheid context.

This section introduces the methods and data of the study – located in the *Researching Equity in Access to Health Care* (REACH) project in three health sub-districts: one rural (Bushbuckridge, Mpumalanga) and two urban (Cities of Johannesburg, Gauteng, and Cape Town, Western Cape). Using autobiographical snapshots, historical events, theory, ethnographic observations from 12 facilities, and accounts from 45 patients and 67 providers, this introduction seeks to initiate a 'sensemaking' conversation between those seeking to reform health systems and those designing transitional justice reforms, in this way foreshadowing key themes and

issues (Research Articles – Section II), which are drawn together (using the lens of accountability) in Section III and the Epilogue (Section IV).

II. Research Articles: Theorizing access as justice

This section is structured around three research articles, each introducing a different theoretical slant to framing and analyzing access to post-apartheid health care as form of restorative justice: governmentality, critical social contract theory; and street-level bureaucracy.

1. Harris B, Eyles J and Goudge J. (accepted for publication). Ways of doing: Restorative practices, governmentality and surveillance in post-apartheid health care. Manuscript submitted to *Medical Anthropology*.

In this article, we consider the conduct of post-apartheid health care in a policy context directed towards entrenching democracy, ensuring treatment adherent patients, and creating a healthy populace actively responsible for their own health. We ask how tuberculosis treatment, antiretroviral therapy, and maternal services are delivered within South Africa's health system, an institutional site of colonial and apartheid injustice, and democratic reform. Using Foucauldian and post-Foucauldian notions of governmentality, we explore provider ways of doing *to, for,* and *with* patients in three health sub-districts. Although restorative provider engagements are expected in policy, older authoritarian and paternalistic norms persist in practice. These challenge and reshape, even 'undo', democratic assertions of citizenship, while producing compliant, self-responsible patients. Alongside the need to address pervasive structural barriers to health care, a restorative approach requires community participation,

provider accountability, and a health system that does *with* providers as much as providers who do *with* patients.

2. Harris B, Eyles J, Penn-Kekana L, Thomas L, and Goudge J. (2014). Adverse or acceptable: negotiating access to a post-apartheid health care contract. *Globalization and Health,* 10(1):35.

Critical social contract theory provides an opportunity to explicitly acknowledge health in the relationship between citizens and the state, and to critically examine the nature of this relationship in South Africa's health system. Although the right to access to health care is constitutionally guaranteed, in practice we find that a post-apartheid health care contract is not automatically or unconditionally inclusive. Access barriers, including poverty, an under-resourced, hierarchical health system, the nature of illness and treatment, and negative attitudes and actions, create conditions for insecure or adverse incorporation into this contract, or even exclusion (sometimes temporary) from health care services. Such barriers are exacerbated by differences in the expectations that patients and providers have of each other and the contract, leading to differing, potentially conflicting, identities of inclusion and exclusion: defaulting versus suffering patients, uncaring versus overstretched providers. Conversely, caring, respectful communication, individual acts of kindness, and institutional flexibility and leadership may mitigate key access barriers and limit threats to the contract, fostering more positive forms of inclusion and facilitating easier access to health care.

3. Harris B, Eyles J, Penn-Kekana L, Fried J, Nyathela H, Thomas L, and Goudge, J. (2014). Bringing Justice to Unacceptable Health Care Services? Street-Level Reflections from Urban South Africa. *International Journal of Transitional Justice*, 8(1):141-61.

In this article, we argue that street-level bureaucrats – the healthcare workers tasked with delivering services - are a gauge of both individual and institutional transformation, situated 'somewhere in the middle' of the structures, institutions and relationships that mediate and produce society. Through eight cases, we explore a set of individual and institutional responses to 'typical' access barriers. We consider ways in which these responses either ameliorate or compound access barriers, and explore some conditions for bringing justice to patient-provider interactions. We note that street-level bureaucrats, as both state representatives and individual citizens, are well positioned to support a transitional justice agenda and bring justice to health care delivery. However, they are also potentially agents of resistance, capable of frustrating efforts at social reconstruction. Strengthening street-level accountability and engendering respectful, empathetic provider practices is consequently vital to improving access to services and contributing more generally to the restoration of justice and health in society.

We give particular profile to the case of Harry Nyathela, who was denied access to ART while in police custody but served justice through a form of victim-offender mediation at the police station. This case is a reminder that individual actions can make a difference, that there is an important role for civil society in a post-apartheid context, and that there is a need to develop and nurture active, engaged and empowered citizens.

III. Accounting for access to health care as a form of restorative justice

This section draws together the different theoretical framings of access as restorative justice (governmentality, critical social contract theory, and street-level bureaucracy) (Research Articles - Section II). Using the notion of accountability, it locates community approaches and (health) systems in a discussion of restorative justice that seeks to move beyond the individual victim-perpetrator relationship. This section argues that to change the story from 'lack of health services' to 'Universal Health Coverage', a conversation is needed to explicitly draw together notions of accountability, justice and health; to express and learn from efforts (including the South African Truth and Reconciliation Commission) that have looked back in order to move forward *in* the health system; and to situate the country's proposed National Health Insurance system as part of the restorative trajectory undertaken by the country's variant of transitional justice. Building on the research in Section II, this section argues that such a shift might be facilitated by expanding the ways in which access to health care is conceptualised in Health Policy and Systems Research - as a negotiation between patients/households and providers/the health system along dimensions of availability, affordability, acceptability (Thiede et al. 2007) AND accountability. Such accountability needs to include communities (as well as individuals) and the health system itself. This requires a shift away from individualized governmentality, towards the social solidarity of ubuntu, made all the more urgent in a context where 'violent democracy' continues to fragment relationships and silence 'sensemaking' efforts.

IV. Reckoning with violent limits: An Epilogue

This PhD closes with an account of Harry Nyathela's shocking, and seemingly 'senseless', murder in March 2014: beaten to death for trying to secure access to health care (ambulance) and justice (police) for another man, who had himself been badly beaten, for reasons that are yet to emerge. In complex, subtle ways, power, violence, trauma, and suffering continue to find expression overtime and in the everyday practices of life, including health care. Despite the SATRC's vision "to promote national unity and reconciliation in a spirit of understanding that transcends the conflicts and divisions of the past," *this* post-apartheid project is incomplete and disappointing. This epilogue offers no neat or hopeful resolution but rather serves as an invitation to 'haunting', to seeking out and listening to that which cannot be said yet cannot be forgotten.

List of Acronyms

ANC	African National Congress
ART	Antiretroviral Therapy/Treatment
CBO	Community-based Organisation
CHC	Community Health Centre
CTS	Continuous Traumatic Stress
DA	Democratic Alliance
GBV	Gender-based Violence
HIV	Human Immunodeficiency Virus
HPCSA	Health Professions Council of South Africa
HPSR	Health Policy and Systems Research
ICC	International Criminal Court
IMR	Infant Mortality Rate
MDR	Multiple-Drug Resistant (Tuberculosis)
MK	Umkhonto we Sizwe
MMR	Maternal Mortality Ratio
NGO	Non-governmental Organisation
NHI	National Health Insurance
NIMART	Nurse Initiated Management of Antiretroviral Treatment
NMR	Neonatal Mortality Rate
NSVS	National School Violence Study
PHC	Primary Health Care
PTSD	Posttraumatic Stress Disorder
RJ	Restorative Justice

SATRC	South African Truth and Reconciliation Commission
TAC	Treatment Action Campaign
TB	Tuberculosis (*tubercle bacillus*)
TJ	Transitional Justice
U5MR	Under-5 Mortality Rate
UHC	Universal Health Coverage
VOM	Victim-offender Mediation

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No act of kindness, no matter how small, is ever wasted.

- Aesop

Section I

‘The time is out of joint: Contextualizing access to post-apartheid health care as a matter of restorative justice

Let us go in together,
And still your fingers on your lips, I pray.
The time is out of joint—O cursèd spite,
That ever I was born to set it right!
Nay, come, let's go together.

-William Shakespeare, Hamlet

Watching for the ambulance

One hot afternoon, when I was five or six, a man was stabbed in his face near our house. We did not witness the attack but my younger sister and I watched through the lounge window as events unfolded on a vacant plot of land outside. My mother remembers:

> I went outside to see what had happened after we saw the man through the window, lying on the ground in the veld next door. There was blood pumping out of the cut in his face - so as far as I remember, I went inside, phoned Bara [Hospital] for the ambulance (no cell phones in those days) and took a towel out and pressed it on the cut to stop the bleeding, which it did as long as I kept pressing hard. I also put some sort of pillow under his head. You kids stayed inside and watched out of the window. When the ambulance didn’t come after some time, I asked one of the people who had gathered around to keep holding the cloth while I phoned again, and then I took out the beach umbrella to give him some shade, and continued pressing on the cut. We probably gave him a sip or two of water, and washed his face to cool him down. There was a lot of blood if we relaxed our pressure, it just kept pumping out, and he

> was in a panic and kept saying he thought he would die. The ambulance only came much later, maybe an hour or so. The ambulance men got out in their spotless white uniforms, and they were quite condescending, didn't seem to want to get blood on their uniforms. They said something disapproving like, "Next time, don't wash his face" – something completely irrelevant, and then off they went to the hospital (email correspondence, May 2015).

Our house was a mere 11 kilometres from Baragwanath Hospital, no more than 15 minutes' drive away. Today, 15 minutes is South Africa's "national yardstick" for urban ambulance response time (MacFarlane, van Loggerenberg, and Kloek 2005:147). But this was apartheid South Africa in the late 1970s, a few years after the Soweto Youth Uprisings, a few years before the infiltration of Wouter Basson's "hideous trinkets" of biochemical warfare into the clothing, muscles, and blood of state enemies around the world (Beresford 1998). It was three or four years into the government's free family planning programme, designed to "increase the white population and decrease the black" (Baldwin-Ragaven, de Gruchy, and London 1999:31), the time of the brutal torture and death in police custody of Steve Biko, leader of the Black Consciousness Movement and former medical student. By 1990, an estimated 80,000 people, some just 10 or 11 years old, would have been detained without trial, many tortured, one in every thousand left dead (Baldwin-Ragaven et al.; South African Truth and Reconciliation Commission 2003). White boys just ten years older than me were being armed and conscripted into two years of compulsory military service (End Conscription Campaign). Over 3.5 million black people were being forcibly removed to under-resourced, repressive 'homelands', where 81 percent of households were relegated to illness, starvation and "dire poverty" (Savage 1990:24), and a growing number of young men were being forced away from their families into the tightly regulated, exploitative migrant labour system (Baldwin-

Ragaven et al; Gilson and McIntyre 2001; Savage 1990; Susser and Cherry 1982). A few years later, probably with the same beach umbrella in tow, we would drive to the 'independent' Transkei for a family holiday. None of us would need passports. The stabbed man, because he was black, would have needed a pass to legally navigate the humiliations, harassments, and hazards of everyday urban life for black Africans.

At the time of his attack, my sister and I, together with 98.4 percent of all white children, had lived to celebrate our first birthdays (white infant mortality rate 16 per 1000)[1] (Savage 1990), while an estimated 10 (Savage 1990) to 20 (Susser and Cherry 1982) percent of black children had not.[2] We would soon be starting at a school where state expenditure was five to six times more than in the schools of nearby Soweto (Gilson and McIntrye 2001). There, we would learn in English, a bit of Afrikaans and even some isiZulu from white teachers with Dallas-inspired[3] hairstyles, some mostly kind, a few occasionally cruel. We would learn to hide under our desks when the alarm bell rang once. Or evacuate to the field when it rang twice. A decade later, our high school in Botswana would receive a bomb threat.

[1] Our brother, Michael, my sister's breached twin, would have been counted amongst the 16/1000, suffocated during a birth badly managed by an arrogant junior doctor.

[2] In contrast to the intense state surveillance and scrutiny of certain individuals, population level data were not nearly as well recorded for black people as for white, reflecting the state's interest in keeping to a minimum knowledge about the social determinants of life and death within this group (Baldwin-Ragaven et al. 1999; Gilson and McIntyre 2001). During the life of the South African Truth and Reconciliation Commission, "[s]wathes of official documentary memory, particularly around the inner workings of the apartheid state's security apparatus, [were] obliterated […] Ultimately, of course, all South Africans have suffered the consequences – all are victims of the apartheid state's attempted imposition of a selective amnesia" (SATRC (1,8) 2003:104 and 106). Data collection, interpretation and management remain challenges for the post-apartheid (health) system.

[3] Television arrived in South Africa in 1975 and the American soap opera, Dallas, hit the airwaves in 1978, enduring across my entire school career.

We would both walk home against the school's orders, newly aware of the apartheid state's proclivity for crossing borders and blowing up people. We would get afternoon detention for a month.

In the late 1970s, Baragwanath was our nearest hospital, or rather, was the hospital nearest to our house. Designated as an 'African' facility, it was under-resourced and overstretched, running on R37.24 per patient day, "compared with 107.47 Rands for the exclusively white Johannesburg General" (Susser and Cherry 1982:470), our nearest hospital as a white family. A few years later, in 1987, 101 doctors from Baragwanath would sign a letter, protesting its "appalling conditions":

> the facilities are completely inadequate. Many patients have no beds and sleep on the floor at night and sit on chairs during the day. The overcrowding is horrendous. Nurses are allocated according to the number of beds, and not to the number of patients (South African Truth and Reconciliation Commission vol. 4 (5, 136) 2003:153).

Access to health care was racially determined. So were health care resources, health outcomes and the broader determinants of health.

A few months after the stabbing, the man and his wife knocked on our door. He was growing a beard but it didn't quite cover his healing scar. Their visit was short but they left behind a floral tea set and a touching handwritten note that my mother still remembers thirty five years later: "May God bless you forever and ever." We would never sit together over a shared pot of tea. But theirs was a gesture as kind and hauntingly "out of joint" (Shakespeare/Derrida cited in Decoteau 2008) as my mother's efforts to staunch the blood under the shared shade of an umbrella that could not be shared at the beach; all of us watching patiently, with hope, for an ambulance to arrive.

The 'story of lack of health services'

On 17 and 18 June 1997, the South African Truth and Reconciliation Commission (SATRC) held a special hearing into the apartheid health sector and found that:

> Millions of South Africans were denied access to appropriate, affordable health care during the period under review [1 March 1960-10 May 1994]. Health care workers, through acts of commission and omission, ignorance, fear and failure to exercise clinical independence, subjected many individuals and groups to further abuse. Fundamental reforms in the health care delivery system, legislative controls, monitoring and accountability mechanisms, and the training of health professionals are required (vol. 5 (8, 79) 2003:337).

In essence, the SATRC established that "the story of apartheid medicine is a story of lack of health services" (van der Merwe 2000:19).

The SATRC hearing into the apartheid health sector has been remembered as "one of the success stories of the TRC […] significantly better planned, more participative, and more practical in its contribution to further transformation and self-reflection [… than] many of the TRC's other interventions" (van der Merwe 2000:1). Yet, for political and structural reasons, these recommendations have not been as far reaching as was envisaged, and major gaps continue in the capacity of health workers and the health system to provide equitable care (Coovadia et al. 2009; Mayosi et al. 2012). Twenty one years into democracy, although the right to access health care is constitutionally protected (Statutes of the Republic of South Africa 1996), the "story of lack of health services" continues through variants of unaffordable, unavailable, and unacceptable care (see Coovadia et al. 2009; Harris et al. 2011; Mayosi et al. 2012; and Research Articles 1-3 in Section II).

This doctoral study is grounded in the legacy of apartheid medicine *and* subsequent efforts to 'make good', to restore justice in a post-apartheid context. It is an updating, a re-telling, of the "lack of health services" story using autobiographical snapshots, historical events, theory, ethnographic observations, and accounts from patients and providers, in order to create a new narrative, one that conceptualizes access to health care as a matter of restorative justice (RJ). RJ seeks to bring justice to victims and communities by holding perpetrators accountable, repairing relationships, and rebuilding institutions (SATRC 2003). Explored in the research articles presented as part of this thesis (Section II), RJ is understood as:

> a victim-centred approach in which 'the parties with a stake in a particular offence come together to resolve collectively how to deal with the aftermath of the offence and its implications for the future'(Marshall 1996 quoted in Llewellyn and Howse 1999). A restorative approach typically seeks to resolve such offences through [victim-offender mediation] VOM (Llewellyn and Howse 1999). VOM entails a carefully facilitated process with victims, offenders and their respective communities and is an applied method for resolving certain types of interpersonal conflict. Furthermore, restorative justice is a philosophy of justice, providing a theoretical framework for conceptualizing fractured social relationships and efforts to 'right wrongs' (Llewellyn and Howse) (Harris et al. 2014:157 - Research Article 3).

As a philosophy and method of justice, with an "emphasis on 'establishing or re-establishing social equality in relationships' (Llewellyn and Howse 1999:1), and prioritizing victims' needs [RJ] has recently found application in education, law, transitional justice, and social work (Wachtel and McCold 2004)" (Harris, Eyles, and Goudge draft - Research Article 1). In the South African context, RJ can be located beyond individualized VOM, as part of a wider

justice effort to move South Africa from authoritarianism to democracy. Known as transitional justice (TJ) (see Hamber 2015; Peacebuilding Support Office 2008; de Greiff 2013; Mutua 2015), these efforts have run alongside similar attempts to reform the post-apartheid health system. Both TJ and health system reforms are infused with a restorative ethos directed at redressing past injustice and bringing equity to the present. By narrating access to health care as a matter of restorative justice, I seek to weave together these largely-parallel efforts, and to initiate a "sensemaking" conversation (Weick 1995) between the fields of TJ, and Health Policy and Systems Research (HPSR), about how and why barriers continue to obstruct access to health care.

'Making good': Restoring justice and recommending change

In 1995, the *Promotion of National Unity and Reconciliation Act, No. 34 of 1995* established the South African Truth and Reconciliation Commission (SATRC) "to promote national unity and reconciliation in a spirit of understanding that transcends the conflicts and divisions of the past" (Republic of South Africa 1995). Truth commissions are typically viewed as instruments, or "macro strategies" (Hamber 2015:6), of a wider transitional justice approach to managing the "often unique conditions of societies undergoing transformation away from a time when human rights abuse may have been a normal state of affairs" (Peacebuilding Support Office 2008:1). Originating at the end of the Cold War as dictatorships gave way to democracy, first in Latin America and Eastern Europe, then Africa and Asia, transitional justice reforms traditionally look 'back' in order to move a society 'forward'. Ideally, this process is facilitated through a comprehensive, context-specific programme designed around truth-telling, institutional transformation, reparations, criminal prosecutions, and memorialisation (Hamber 2015; Peacebuilding Support Office 2008; de Greiff 2013; Mutua 2015).

The SATRC, famously chaired by Archbishop Desmond Tutu, quickly came to symbolise the 'miracle' of South Africa's transition to democracy (in much the same vein as a newly freed Nelson Mandela shaking hands with both former president FW de Klerk (1992) and Springbok Rugby captain, Franscois Pienaar (1995) after the team's world cup victory). The Commission promised a new way of "dealing with" past political conflict: amnesty for truth, forgiveness without forgetting, carrots and sticks offered through "a fusion of an amnesty process with a truth recovery and reparative process" (Simpson 1998:4). The model would prove catalytic for a number of truth and reconciliation processes that followed around the world. By 2011, 40 official truth commissions had been established (International Centre for Transitional Justice 2015).

The SATRC strategy was founded on the idea of a "'healing' truth, the kind of truth that places facts and what they mean within the context of human relationships - both amongst citizens and between the state and its citizens" (SATRC vol. 1 (5, 43) 2003:114). Rather than seeking vengeance or punitive justice, the SATRC chose a path of restorative justice, "broadly defined as a process that":

> a. seeks to redefine crime: it shifts the primary focus of crime from the breaking of laws or offences against a faceless state to a perception of crime as violations against human beings, as injury or wrong done to another person;
>
> b. is based on reparation: it aims at the healing and the restoration of all concerned – of victims in the first place, but also of offenders, their families and the larger community;
>
> c. encourages victims, offenders and the community to be directly involved in resolving conflict, with the state and legal professionals acting as facilitators;

> d. supports a criminal justice system that aims at offender accountability, full participation of both the victims and offenders and making good or putting right what is wrong (vol.1 (5,82) 2003:126).

A restorative approach prioritises the healing of victims through the accountability of perpetrators or offenders. It is a participative effort at restitution, to 'make good'.

Reconciling victims and perpetrators

One late night in February 1993, a friend was viciously assaulted as we walked from a campus concert to our university residence. We were making our way through the crowd when two assailants simply walked up to him and, without a word, silently punched and kicked him to the ground. Then they continued, almost casually, up the hill. We drove him to the Johannesburg General Hospital (no longer "exclusively white") for stitches. Two other people, similarly attacked at the concert, were also in casualty that night; one was in a coma. We heard nothing further but knew, *felt*, this had been a racist hate crime, provoked by a multiracial group of friends laughing on our way home. As they walked away from my friend's crumpled body, I noticed that those smug white boys, no older than 18 or 19, had guns in the back pockets of their jeans. Six weeks later, Chris Hani, the eminent communist leader, was assassinated.

In 1996, the SATRC held its first hearings, with a mandate focused on narrowly defined politically-motivated violence:

> There were cases in which people were victims of racist attack by individuals who were not involved with a publicly known political organisation and where the incident did not form part of a specific political conflict. Although racism was at the heart of the South African political order, and although such cases were clearly a violation of

> the victim's rights, such violations did not fall within the Commission's mandate (vol. 1 (4, 128) 2003:84).

A decontextualized narrative

Many have criticized the SATRC for too narrowly focusing on *individual* perpetrators and victims of too narrowly defined political violence while neglecting the racism, structural violence, and everyday injustice of the apartheid *system* – the pass laws, forced removals, cheap migrant labour system, and differentially-funded health and education systems that entrenched and racialized benefits and deprivations (Brankovic 2013; Feldman 2002; Fullard and Rousseau 2008; Gready 2011; Harris 2014; Hamber and Kibble 1998; Madlingozi 2015; Mamdani 2002; 2015;Mbembe 2008; Miller 2008; Posel and Simpson 2002; Powell 2010; Simpson 1998; van der Merwe 2000). As Brandon Hamber and Steve Kibble (1998) note:

> The danger in constructing the 'truth' solely from the testimony of individual human rights victims and abusers is that the larger picture - centuries of systematic subjugation, enslavement, oppression and exploitation - can be obscured.

Of course, the SATRC did attempt some kind of reflection on systemic issues that gave rise to the gross human rights violations it sought to investigate. Moreover, it held (limited) institutional hearings, including into the Health Sector, and asked, "How did so many people, working within so many influential sectors and institutions, react to what was happening around them?" (vol. 4 (1, 3) 2003:1). It also made recommendations for institutional reform and social transformation. However, by largely omitting the broad story of "colonialism and capitalism" (Miller 2008:281), it failed to explicitly link past abuses to the need for both socioeconomic redress, and a critical examination of the role of (mostly white) beneficiaries in the system (Feldman 2002; Mamdani 2002; 2015; Miller 2008; Posel and Simpson 2002).

Consistent with a decontextualized, individualized focus on gross human rights violations, the SATRC's mode of reparation (restorative justice) was heavily influenced by Christian traditions - individual forgiveness and redemption through individual apology and disclosure, a model that has attracted widespread criticism (Brankovic 2013; Fullard and Rousseau 2008; Gready 2011; Harris 2014; Hamber and Kibble 1998; Madlingozi 2015; Mamdani 2002; 2015; Mbembe 2008; Miller 2008; Posel and Simpson 2002; Powell 2010; Simpson 1998; van der Merwe 2000).

This thesis seeks to move restorative justice to a more collective conceptualization, to open up a discussion about restorative justice as a matter for collectives, and to think about RJ as a systems issue by focusing on access and barriers in the public health system in a post-apartheid context. The articles presented in Section II chart how certain practices of colonialism and apartheid have continued in multiple and adaptive ways in this system: in the persistence of health worker paternalism and authoritarianism; through poverty, violence, and other structural barriers to health care; and in the "interconnected and rising 'syndemics' of HIV and tuberculosis (TB), maternal and perinatal deaths, non-communicable diseases, and violence and injury-related problems (Coovadia et al. 2009)" (Harris et al., draft - Research Article 1). These syndemics:

> underscore the inequitable ways in which 'social encumbrances "get under the skin" and have direct impact not only on disease development and progression, but on deleterious disease interaction as well' (Singer 2013:2). Access to health care, health outcomes, and the broader determinants of health remain racially and spatially determined – etched *on* the skin as much as under it. There is an urgent ethical and public health need to ensure the accessibility of health services and to align the practices of health care workers with a restorative framework (Harris et al. draft:3-4 - Research Article 1).

At the same time, these research articles also document new ways of governing and controlling individuals and populations: through an individualising "regime" of governmental power (Research Article 1), in the promised inclusions of a democratic health care "contract" (Research Article 2), and with the discursive, individualizing shift from "patients" to "clients" (Research Article 3). The highly inequitable public-*private* split in health care, while beyond the scope of this study, also illustrates this complex legacy - a reminder that "promoting national reconciliation in health care [may still be] about reconciling those who did not have adequate health services with those who had" (van der Merwe 2000:19); a point poignantly expressed in a recent update on the health of Archbishop Emeritus Desmond Tutu. While hospitalised in August 2015 for a persistent infection, he met with the Minister of Health:

> He shared with Dr Motsoaledi his concern that, while he had enjoyed first-class treatment and the attention of the finest doctors, most South Africans did not have access to decent health care. Archbishop Tutu pronounced himself 100% behind the proposed introduction of Universal Health Care in South Africa, to be known as National Health Insurance [NHI] (The Desmond & Leah Tutu Legacy Foundation 2015).

The proposed NHI reform (presently being piloted in 11 health districts), recognises that this public-private "two-tiered system" is "neither rational nor fair", and aims to achieve better integration towards a unified, singular health system (Republic of South Africa 2011; 2015). In essence, NHI seeks to shift the "story of lack of health services" to one of "Universal Health Coverage" (UHC).

A (neo)colonised narrative

Enabled through South Africa's negotiated settlement, the SATRC was intrinsically constrained by the political compromise of its origins (Hamber and Kibble 1998; Simpson 1998). This compromise was codified in a set of "sunset clauses" that (i) established a power-sharing model of quasi-federalism;[4] (ii) guaranteed amnesty-for-truth to perpetrators of past political conflict; and (iii) traded political democracy for the "retention of all other structures of the apartheid state" (Mamdani 2015:69). As political economy, these constraints (facilitated through the Commission), have been criticised as simply effecting the transfer of power between elites (Bond 2005; Harris 2014). As (Foucauldian) genealogy, the SATRC – in its role as a commission of enquiry and through the indemnity it ultimately conferred – has been recast as a mechanism consistent with "colonial and imperial jurisprudence", less a novel break with South Africa's past than "more of the same" (Sitze 2013:253). Similar critiques have recently emerged about transitional justice as a whole - its ideological basis in free market liberalism (Mutua 2015); its uncritical and wholesale application to post-conflict contexts (de Greiff 2013); a lack of political will enabling "old habits and cultures of repression and corruption [to] reemerge" (Mutua 2015:2); and a global power imbalance that remains "geared towards the maintenance of the perpetual teacher status of the North […so that] 'democratizing' or 'emerging' countries are re-captured and re-inserted back into the global matrix of coloniality" (Madlingozi 2015:3).

As the field of transitional justice comes under the disapproving gaze of disciplinary knowledge, including from its own experts and self-critics (many who have personally lived

[4] Today, South Africa's federalism is consolidated through one national, nine provincial, and various local-level, and metropolitan governments, with implications for how (health) budgets are allocated, managed and accounted for, especially in a context where the decentralisation of health services to district-level is once again on the policy agenda to reengineer primary health care (Republic of South Africa 2011; 2015).

through the hopeful highs and disappointing lows of trying to 'do' transitional justice in fragile societies), so there is renewed interest in "repairing human relationships" (Mutua 2015:5), and problematizing power (Hamber 2015). These new directions in transitional justice offer an important springboard for locating and problematizing health care in a post-apartheid context – in the structural, institutional, *and* interpersonal factors that may impede or enable accessible care.

The 'unfinished business' of transitional justice

In 1998, five volumes of the SATRC's *Final Report* were presented to President Nelson Mandela. In 2003, a sixth volume was added from the work of the Amnesty Committee. During the course of the Commission, more than 21,000 people testified as victims of gross human rights violations, and over 7 000 applications were made for amnesty. Amnesty was granted in approximately 12 percent of these cases, and the Commission recommended prosecution for those whose applications had been unsuccessful (where evidence was available): 350 such individuals were identified for prosecution, yet "not one […] has been brought to court" (Khulumani Support Group 2014:3). The SATRC also identified 477 people who were forcibly 'disappeared' during apartheid (a much lower estimate than the 6 800 cases recorded by Khulumani Support Group).[5] The Reparation and Rehabilitation Committee made recommendations for the reform of state institutions and for individual, community, and symbolic reparations, including the renaming of "streets and community facilities […] to reflect, remember and honour individuals or events in particular communities" (vol. 5 (8, 87) 2003:189).

[5] The tireless and ongoing work of the Missing Persons Task Team in the National Prosecuting Authority is noteworthy here.

In 1997, Baragwanath Hospital, which started as the Imperial Military Hospital, Baragwanath during the Second World War, was renamed Chris Hani Baragwanath Hospital in honour of the communist leader assassinated by right-white extremists just before the country's first democratic elections (Chris Hani Baragwanath Hospital 2015). In 2008, the Johannesburg General was renamed after Charlotte Maxeke, founder of the Bantu Women's League (forerunner of the African National Congress (ANC) Women's League) and anti-pass activist (Ginwala 2015). Also in 2008, the Pretoria Academic Hospital (previously known as HF Verwoed Hospital (1967-1997) after the psychologist, architect of apartheid, and prime minister), was renamed in honour of Steve Biko (Steve Biko Academic Hospital 2015).

And yet… In March 2015, a national social movement #rhodesmustfall was "sparked" when students mobilized against a statue of the British imperialist, Cecil John Rhodes, situated at the University of Cape Town (UCT). The "fall of 'Rhodes'" (statue removed in April 2015) has come to symbolise a stand against "white supremacy and privilege" in higher education (Rhodes Must Fall 2015), part of a growing call to "decolonise" post-apartheid society (Mbembe 2015). In October 2015, riot police used stun grenades and tazers on unarmed students and workers on campuses across the country, and outside Parliament and the Union Buildings (formal sites of state power), as they protested against fees (#feesmustfall) and the outsourcing of university labour (#endoutsourcing) (Furlong, Washinyira and Heard 2015; Support the Student Struggle in South Africa 2015). These protests are deeply connected to a wider set of social worries and discontents, themselves intimately tied to the intractable determinants of health: the poverty, illness, racism, and massive inequalities that continue to divide South African society, and shape medicine and health (student leaders engaging with the Dean of the Faculty of Health Sciences, October 2015, personal memory; see also Doherty and McIntyre 2015). They testify to pervasive "structural violence" (Farmer 2004) and "structural vulnerability" (Quesada, Hart, and

Bourgois 2011) in the society. Also, they speak of what many have termed the "unfinished business" of South Africa's transition to democracy (see, for example, the Askiaqedi Campaign – let's finish what we started, Khulumani Support Group 2014; Brankovic 2013; Gready 2011; Powell 2010). Or, more condemningly, they express a bitter "disappointment"[6] in the post-apartheid project (Field 2011), characterised by a fundamental questioning of "race and property, class and inequality, identity, sexuality, justice and what many now call 'lived experience' […accompanied by] an explicit decentering of whiteness" (Mbembe 2015). Within this disappointment resides a critique of the failure of transitional justice to address the trauma and pain of the past:

> In a country where empty gestures such as the Truth and Reconciliation Commission (TRC), which solicited forgiveness from the victims of Apartheid and those they left behind, predominate; where static symbols like the Apartheid Museum and the like abound; and exclusive spaces like Robben Island function as tourist destinations rather than as sites of public memory, it comes as no surprise that articulating black pain is still taboo (Njovane 2015).

Amnesty or impunity?

Where are they all now? In 1993, Clive Derby-Lewis and Janus Walus were sentenced to death for the murder of Chris Hani. Their sentences were commuted to life imprisonment after South Africa abolished the death penalty in 1995 (Munusamy 2013). In 1999, the SATRC denied the pair amnesty, a decision imbued with irony given that "the decidedly political nature of their crime - to derail transitional negotiations – [was] sidelined in the official account, which focuse[d] on issues surrounding [their lack of] full disclosure and orders" (Nagy 2004:18). In May 2015, Clive Derby-Lewis was released on medical parole

[6] I am grateful to the anonymous examiner (2) for directing me to this "disappointment" literature.

after serving nearly twenty two years in prison (Mail and Guardian Reporter 2015). Janus Walus continues to serve his life sentence.

In 1997, the SATRC held a special hearing into prisons at the Hillbrow Fort,[7] a space that had seen the incarceration of "common criminals" alongside "political prisoners" and "hundreds of thousands of ordinary men and women who contravened colonial and apartheid legislation" (Constitution Hill 2015), a space where district surgeons had needed to manage "dual obligations" and split "allegiances" towards detainees (as patients) and employer (as state) (Baldwin-Ragaven et al. 1999:81). Not long after the SATRC hearings, the Fort was host to a rave, the Voortrekker Monument was a venue for a rock concert (Britten 2006; personal memory). International entertainers jetted in and kwaito – a distinctly "township post-1994" genre of music - flourished (McGregor 2005:86). "Streets once colonised by Casspirs and police vans became giant dance floors. Spirits for so long cramped by fear and despair now exploded in collective celebration" (McGregor 2005:85). In the 1990s, rumours would surface of "Basson's Brownies" circulating through the clubbing scene (Kemp 2015); 95 percent pure ecstasy (MDMA) allegedly manufactured in the biochemical laboratories headed by Wouter Basson. Urban myth or not, in 1997, Dr Wouter Basson, a trained cardiologist who headed the secret chemical and biological warfare programme of the South African Defence Force (Project Coast) from 1981-1992, was arrested for the illegal possession of ecstasy (People's Health Movement-South Africa 2015).[8]

In 1999, 67 criminal charges were brought against him, "relating to murder, conspiracy to murder, drug offences and fraud" but in 2002, the case was dropped because of the State's failure to prove the charges "beyond reasonable doubt" (People's Health

[7] Home to the Constitutional Court since 2004.

[8] Wouter Basson never applied for amnesty and "refused to cooperate" with the SATRC's investigation into Operation Coast (People's Health Movement - South Africa, 2015).

Movement – South Africa 2015). In 2013, after a protracted 13 year hearing, the Health Professions Council of South Africa (HPCSA) found Wouter Basson guilty of professional misconduct. However, in mid-2015, sentencing by the HPCSA was postponed (again) due to "Dr Basson […] exercising his legal rights by exhausting all avenues available to him in law" (eNCA Reporter 2015).

In June 2015, the South African state contravened international and domestic law by granting free passage to Sudanese President Al-Bashir, who is wanted by the International Criminal Court (ICC) on charges of crimes against humanity, genocide and war crimes (Southern Africa Litigation Project 2015). South Africa is a signatory to the Rome Statute (under which the ICC is established). The ICC is seen by many as a mechanism of transitional justice. It is also seen by many as an instrument of neo-colonialism (Times Live Reporter 2015).[9]

Inequitable access to health care: A 'disappointment' of transitional justice?

The SATRC recommended "fundamental reforms in the health care delivery system, legislative controls, monitoring and accountability mechanisms, and the training of health professionals" (vol.5 (8, 79) 2003:337). These recommendations have been taken forward in multiple ways – some deliberately in response to the SATRC, which was seen as "a catalyst in engaging parties in a process of accounting, dialogue and public education" (van der

[9] A danger of presenting the ICC as an instrument of neo-colonial power is that this discourse may lead to the selective application (or non-application) of the law to perpetrators of gross human rights violations, and with this, a lack of state accountability, as the Al-Bashir case has shown. The tireless and courageous efforts of the Southern Africa Litigation Centre to hold the South African State accountable for contravening international and domestic law are noteworthy here.

Merwe 2000: 21); others as part of a wider post-apartheid activism for health system transformation, *viz*:

- The advocacy, litigation and training work of a wide range of health movements for justice, including the Health and Human Rights Project (Baldwin-Ragaven et al. 1999), the Treatment Action Campaign, Section 27, the Rural Health Advocacy Programme, Khulumani Support Group, Southern African Litigation Project, and the People's Health Movement-South Africa;
- The work of the Health Professions Council of South Africa, including the "institutionalization of human rights training for health professionals" (London and Baldwin-Ragaven 2008:15), and the pursuit of the Wouter Basson case (see below);
- A 2007 Public Inquiry into Access to Health Care Services by the South African Human Rights Commission, which acknowledged the "severe constraints" on access to health care services, "especially for the poor" (2007:6);
- A Market Inquiry into the Private Healthcare Sector by the Competition Commission (presently underway, 2015); and
- Policy reforms to reengineer primary health care and implement a National Health Insurance (NHI) system (Republic of South Africa 2011; 2015).

Yet, access barriers to health care persist, and "the story of lack of health services" continues, inequitably affecting black, poor, rural and informal-urban communities (Coovadia et al. 2009; Harris et al. 2011), alongside newer marginalized groups, including internal and cross-border migrants, and legal and undocumented refugees with little access to health services and other state care (Vearey 2011). A founding motivation for this study is to reflect on the country's transitional justice agenda for transforming access to health care as a way for restoring or bringing justice.

An access framework: negotiating affordable, available, and acceptable health care

Access to health care is complex and multifaceted; and, despite a long history of debate, there is no commonly shared definition or singular 'access' approach (Dixon-Woods et al. 2006; Thiede et al. 2007). However, recent mid-level theories seeking to guide equity-related policy and research have returned to the notion of access as relational and dynamic, as first proposed in the 1970s by Donabedien and Penchansky (Dixon-Woods et al. 2006; Thiede et al. 2007). In this perspective, access is defined as a "degree of fit" (p.106) between users and the health system: the closer aligned an individual/household's circumstances, health beliefs and expectations with the type, style and location of care provided, the better the access or "freedom" of patients to utilise services (Thiede et al. 2007:105). Conversely, the greater the social, cultural, financial and/or physical distance between patients and the health system, the more "unfitted" and inaccessible such care. In this understanding, access is considered a *negotiation* between patients (households) and providers (health system).

Framing access as "the freedom to use health services, whereby individuals should have the right 'to do' rather than 'to be done to' in terms of their engagement with the health system" (Thiede et al. 2007:106-107) resonates with Amartya Sen's (2009) capabilities approach to social justice. In this approach, access barriers to health care are also obstacles to justice because they diminish the "capability" (or "genuine opportunity") of individuals to achieve health, and with this, the capability to live a "good life" built around "valued functionings" such as health, education, food security etc. (Entwistle and Watt 2013: 33). Inaccessible health care in this understanding is therefore a matter of justice denied.

Michael Thiede and colleagues (2007) consider three interconnected "dimensions" along which access may be negotiated, or ultimately denied: the availability, affordability and

acceptability of care.[10] *Affordability* denotes financial access, including the direct and indirect costs of seeking and delivering care. For individual users and their households, this involves their ability to pay - for transport costs, user fees, and the opportunity costs of accessing services. For the health system, affordability resides in its financing, including the staffing, drug, and operational costs of running a health service, alongside the country's macro-economic policies and related 'popularity costs' associated with agenda setting and policy prioritization. *Availability* of health care describes the physical and geographical accessibility of services, including distance, location, infrastructure, opening hours, staff numbers and skills, and the functionality of the system's supply-chain. It describes the extent to which the "appropriate services are available in the right place and at the time that they are needed" (Thiede et al. 2007:108). *Acceptability* involves the expectations that providers and patients have of each other and how closely these are aligned (Gilson 2007; Thiede et al. 2007). The closer the fit between "lay and professional health beliefs, provider-patient engagement and dialogue, and the ways in which health care organizational arrangements frame patient responses to services" (p.142), the more equal these relationships and therefore the more accessible this dimension of health care (Gilson 2007). Acceptability encompasses the "software" of the health system – the values, beliefs and trust that patients and providers have in each other and the system to deliver quality care (Gilson). Although less tangible than the affordability and availability dimensions (and consequently not as well researched), acceptability is acknowledged to play a key role in both the quality of care received (real and perceived) and whether services are accessed at all (Gilson; Thiede et al.). Acceptability is important for understanding who is able, who *feels* able, to claim the right to health care and how their eligibility is negotiated (Dixon-Woods et al. 2006).

[10] The REACH project was designed around this access framework.

Mary Dixon-Woods and colleagues (2006) introduce the idea of "candidacy" to explain *how* eligibility for health care is "jointly negotiated between individuals and services". They caution that the "social patterning of perceptions of health and health services, and a lack of alignment between the priorities and competencies of disadvantaged people and the organization of health services, conspire to create vulnerabilities". Vulnerabilities may diminish the claim to candidacy for marginalized social groups, ultimately reducing their access to such care. Strengthening candidacy is consequently an important part of making health care more inclusive and equitable. In the South African context, where apartheid denied whole populations the right to access health care, and the health system itself was complicit in structuring vulnerability and disadvantage, it seems necessary to conceptualize candidacy (or eligibility for health care) beyond an individual level, to include that of the collective. Surely any efforts to strengthen candidacy must involve a broader programme to transform and strengthen the health system itself? Furthermore, improving access by closing the social, cultural, financial and/or physical distance between patients (individually *and* collectively) and the health system must also count as an act of justice too?

Study aim, objectives and methods

The aim of this thesis is to situate access to post-apartheid health care as a matter of restorative justice, *as part of* South Africa's broader transitional justice agenda to restore, or 'bring', justice in the aftermath of apartheid. This research is nested in the *Researching Equity in Access to Health Care* (REACH) project, a five-year, multi-method study of equity in access to tuberculosis (TB) treatment, antiretroviral therapy (ART) and maternal deliveries in several South African health districts (Cleary et al. 2013; Fried, Harris, and Eyles 2012;

Moshabela et al. 2011; Schneider et al. 2012). As such, it is guided by the broad purpose of REACH, which is to:

> enhance the management, planning and delivery of public sector health care services in ways that ensure access to services reflects the levels and distribution of need for care, and responds to changes in levels and distribution of needs in the South African population as a means of reducing systematic inequalities in health (Schneider et al. 2006:4).

As part of the REACH project, the first objective of this thesis is,

1) To document key access barriers to TB treatment, ART and maternal deliveries in one rural (Bushbuckridge, Mpumalanga Province) and two urban health sub-districts (in the Cities of Johannesburg, Gauteng; and Cape Town, Western Cape) (study setting and data described below).

Guided by an understanding of access as a *negotiation* between patients and health care workers (as per Thiede et al. 2007 access framework), key access barriers are documented in the research articles presented in this thesis (Section II), and contextualized in the tragedy of Harry Nyathela's murder (Epilogue - Section IV). Broadly, the issues that impact on health access and outcomes are the same across these sections; in each case, the (familiar) social determinants of poor health are enumerated. The differences in the articles relate primarily to the theoretical take adopted for making sense of these barriers, in order to tease apart how inequalities persist (as expressed in objectives 2-4 below).

Three additional objectives expand this study beyond the main focus of REACH:

2) To develop an analytical approach for framing and analysing access as justice in a post-apartheid context.

Critical narrative analysis is used for converting the stories of those seeking and delivering – negotiating – health care into narratives of health care access. This approach is underpinned by a Foucauldian framing of power and positionality, seeking out the 'hows' and 'whys' of governing and including/excluding individuals and populations from health care (Research Articles 1 and 2). Narrative analysis is complemented by case reporting, designed to show a range of street-level responses to access barriers, including victim-offender mediation (Research Article 3), as well as the violence and trauma that pervade everyday relationships (Epilogue – Section IV).

3) To theorize access to health care as a matter of post-apartheid restorative justice.

In each research article in Section II, a different theoretical lens is introduced for conceptualizing patient and provider access narratives: restorative practices and governmentality (Research Article 1); critical social contract theory (Research Article 2); and street-level bureaucracy (Research Article 3). Empirically grounded, the practices and conduct of health care are explored for continuities with South Africa's past; changes brought through democratization; and illustrations of more equitable ways of 'doing' health care as a condition for bringing justice to unacceptable practices. Violence and trauma are theorized in the Epilogue as a tentative step towards making sense of Harry Nyathela's seemingly 'senseless' death, in itself a fundamental undermining of restorative justice.

4) To initiate conversation as "sensemaking" between two largely-parallel fields, namely, Transitional Justice (TJ), and Health Policy and Systems Research (HPSR).[11]

[11] HPSR, in which the access framework and REACH approach originate, "seeks to understand and improve how societies organize themselves in achieving collective health goals, and how different actors interact in the policy and implementation processes to contribute to policy outcomes. By nature, it is interdisciplinary, a blend

Institutional learning requires "sensemaking", a collective understanding and making sense of why things happen in order to bring about positive change (Weick 1995). Both TJ and HPSR are rooted in principles of social justice and human rights, and both contain lessons for transforming institutions and relationships, yet there has been limited sustained engagement between the two.[12] Drawing together health care access and restorative justice provides an opportunity for jointly making sense with both fields (Section III).

This thesis is an introductory conversation, threading - as stories, facts and emotions - through each of the articles (Section II), into the terrible death of Harry Nyathela (Section IV). Storytelling is an "essential feature of the way we organize the array of passing events and make meaning in our lives as human beings" (Gockel, 2013:190). *This* "story of lack of health services" is a re-telling of history, "a construct, fused from selected documentation and living memory" (Manderson 2008:19). As a "story of lack of health services *in post-apartheid South Africa*" it is also a 'looking forward', a call to action:

> We need new narratives that connect with peoples' deepest motivations and promote more radical action. Stories engage people at every level – not just their minds but in

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of economics, sociology, anthropology, political science, public health and epidemiology that together draw a comprehensive picture of how health systems respond and adapt to health policies, and how health policies can shape − and be shaped by − health systems and the broader determinants of health" (Alliance for Health Policy and Systems Research 2011, quoted in Gilson 2012:21).

[12] This is not to suggest that there is no conversation – the work of the Health and Human Rights project in South Africa opened an important dialogue in response to the SATRC; internationally, there have been various special journal editions seeking to draw together themes of conflict, trauma, peacebuilding and TJ – see for example Social Science & Medicine, 70 (2010). Also, the work of Lisa Laplante and colleagues through the FriEnt-supported (2011) collective, as well as the Health Systems Global Thematic Working Group on Health Systems in Fragile and Conflict Affected States, are important interlocutors. Additionally, there is a growing body of literature focused on mental health, trauma and recovery in transitional contexts (see for example, Hamber 2015).

their emotions, values and imaginations, which are the drivers of real change (Hodges, 2015:1).

Study setting and data collection

The REACH study followed a mixed methods design, with an initial quantitative Phase 1 of data collection in four health sub-districts (2008-2009), followed by an in-depth qualitative Phase 2 in three of the four sites (2009-2010). This thesis is located in the sites and data collected as part of Phase 2 (Map 1).[13] In consultation with policy makers and research users, these sites were selected in order to to examine access issues across provinces, and in urban and rural contexts:

- *An urban sub-district in Cape Town in the Western Cape Province*. At the time of the study, this sub-district, located in the only province to be administered by the Democratic Alliance (DA) (rather than the African National Congress - ANC),[14] was home to approximately 290,000 people (Cleary, Birch et al. 2013). In 2010, HIV/AIDS (15.9 percent), interpersonal violence (10 percent) and TB (8.1 percent) were among the leading causes of premature mortality in the sub-district (Groenewald et al. 2013). Safety concerns and anxieties about high levels of violence in the area were expressed by some participants, as well as fieldworkers who were collecting data for REACH. At the time of the study, it was estimated that 4 843 people had been initiated onto ART: "high" coverage of those in need of the treatment (Cleary, Birch et al. 2013:142). Patients collected ART on a monthly basis through a doctor-delivered service available from three

[13] In REACH Phase 1, a fourth site was included, Hlabisa - a rural sub-district in Northern KwaZulu-Natal. However, due to time and financial constraints, Hlabisa was excluded from Phase 2 and is not part of this thesis.

[14] The DA took over provincial leadership from the ANC in 2009 in the country's fourth national election.

Community Health Centres (CHCs). During the course of REACH, an "extremely high" number of TB cases were reported in Cape Town (28,658 in 2011), and the TB incidence was 752 per 100,000 (compared to 500 per 100,000 nationally), with "high case loads and high dual [HIV] infection rates" noted in parts of the REACH sub-district (City of Cape Town 2011). TB services were clinic-based and patients were generally required to collect their treatment daily, as was the norm in the City of Johannesburg at the time too. This model of delivery had negative implications for the retention of sick and poor patients who were not always able to access clinics every day (Research Articles 1-3; see also Birch et al. 2015).

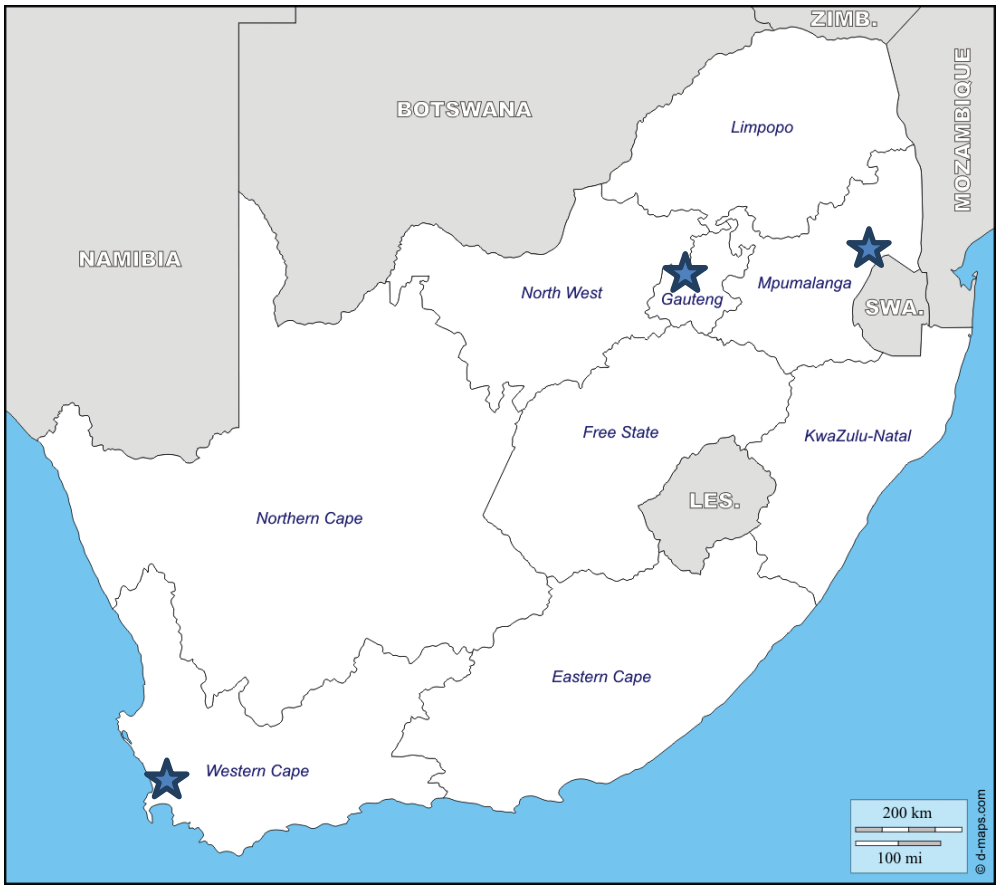
- *An urban sub-district in Johannesburg in the Gauteng province.* With a population size of over one million people, this sub-district was the most populous in the study. At the time of the fieldwork, the sub-district had the highest rate of unemployment (42.7%) in the City (City of Johannesburg 2011), and spatially concentrated poverty was visible in the informal settlements and hostels that surrounded many of the facilities where we were working. An estimated one in three pregnant women in the district was living with HIV, compared to 17.9 percent in the City of Cape Town, and 34.9 percent Ehlanzeni District (where Bushbuckridge is located) (Cleary, Birch et al. 2013). Between 2002 and 2010, the total number of births rose from 26,000 to 32,000 in this sub-district plus one other – both served by a large central hospital, and the caesarean section rate increased from 17 to 25 (Buchmann et al. 2015). At the time of the study, the maternal mortality ratio was starting to declining from a high of 139 per 100,000 live births in 2004, to 119 (2008), 105 (2009), and 93 (2010) (Buchmann et al.), largely due to available HIV treatment (see also Methodological musings below). By December 2009, approximately 28,500 people had been initiated onto ART at a well-established HIV clinic run from the large central

hospital in the sub-district, as well as four Community Health Centres and one primary health clinic (Cleary, Birch et al. 2013). Serving more than seven times the number of ART clients in the other two sites, this coverage was classified as "medium" relative to population need (Cleary, Birch et al. 2013:142).

- *Bushbuckridge – a rural sub-district in Mpumulanga Province.* During apartheid, Bushbuckridge was divided into three ethnically-differentiated 'homelands' – Lebowa, Gazankulu, and KaNgwane (Mayher and Raab 2009). With democracy in 1994, these were reunified and integrated into Limpopo Province. But, after a contentious political struggle about administrative boundaries, the area was absorbed as part of Ehlanzeni District in Mpumalanga Province in 2005 (Mayher and Raab 2009). Home to approximately 523,00 people, the sub-district is characterised by high levels of unemployment and poverty, with many households subsisting on financial remittances received from migrant labour, social grants, and borrowing (Moshabela et al. 2011). In a REACH Phase 1 study of users of ART services, 45 percent of respondents in Bushbuckridge had disability grants, while 27 percent had needed to borrow money to pay for healthcare in the last month, compared to almost 2 percent in the City of Johannesburg, and 11 percent in Cape Town (Cleary, Birch et al. 2013). Geographical barriers were greater in Bushbuckridge than in the two urban sites, due to greater distances between fewer health care services. Furthermore, at the time of the study, the sub-district was still using a largely centralized, doctor-based model to deliver ART to 3 900 patients: "low" coverage of those in need (Cleary, Birch et al. 2013: 142). Geographical barriers and this centralized model of care (seen for maternal patients too, who had to deliver at one of two hospitals in the sub-district) also affected the affordability of services (Research Articles 1-3). For example, in REACH Phase 1, the

mean cost of travel for maternal services was R148.83 in Bushbuckridge, compared to R36.44 in the City of Johannesburg, and R51.72 in Cape Town (Rural Health Advocacy Project 2013). For TB, mean travel costs were R23.14 (Bushbuckridge), versus R2.11 (City of Johannesburg) and R3.77 (Cape Town) (Rural Health Advocacy Project 2013).

Map 1: Location of thesis/REACH 2 study sites



Map source: http://d-maps.com/carte.php?num_car=4414&lang=en

Shows the study sites

In-depth access stories

This thesis/REACH Phase 2 sought to explore the 'hows' and 'whys' of access and barriers faced by patients and health care workers in TB, HIV (ART) and maternal services. These were selected as health tracers because they are closely associated "syndemics" (Singer

2013), embedded in the country's history and policies (especially HIV policy – see Methodological musings below), and they account for a large proportion of the country's burden of disease (Coovadia et al. 2009). Furthermore, their treatment requires sustained engagement with the health system, which may present complex access challenges.

Between June 2009 and July 2010, access stories were collected through in-depth interviews with 45 patients and 67 health care providers and facility/sub-district managers: those at the frontline of health care in the three sites.[15] Participants were guided to explore the availability, affordability, and acceptability of services in the context of their own lives and experiences (see interview guides in Appendix 1). These interviews were complemented by ethnographic observations in four facilities per sub-district (total=12) (Table 1). The observed facilities were drawn from the 50 health care institutions sampled in REACH Phase 1 (Appendix 2), with the aim of including different facility sizes, management styles, and geographical and community characteristics (see also Cleary, Birch et al. 2013; Silal et al. 2012). In each facility, observers were guided to watch 'place', 'space' and 'relationships', using an observation grid (Appendix 1) and weekly team debriefings. We also shared our insights and experiences:

> on the drive home, waiting for team debriefings, in response to a newspaper headline or someone else's experience- thereby generating our own set of small stories nested in the bigger narrative of access to health care (Harris et al. 2014: 4 - Research Article 2).

[15] Please note that Research Article 3 in this thesis, *Bringing justice to unacceptable health care services? Street-level reflections from urban South Africa,* involves urban cases only, drawn from interviews with 29 patients and 49 providers in the two urban sites.

Table 1: Facility observations carried out across the three sites (2009-2010)

	BBR	CoJ	CoCT
ART	2 hospitals observed over 3 intense periods: June, October, and February	1 Community Health Centre observed over a 2 month period, at different times of the day and week.	1 Community Health Centre observed over a 3 week period, at different times of the day and week.
Maternal deliveries*	1 hospital observed in June and February	1 hospital observed over a 3 month period, at different times of the day/night and week/weekend	1 hospital observed over a 6 week period, at different times of the day/night and week/weekend
TB	2 clinics observed over 3 intense periods: June, October and February. 1 geographically more peripheral with a very small patient load; other more central with a larger patient load. In both, small numbers of staff available to interview.	2 clinics observed over a 6 week period at different times of the day and week. 2 chosen to complement strategy undertaken in BBR, taking into account smaller staff and patient numbers.	2 clinics observed over a 2 month period at different times of the day and week. 2 chosen to reflect different geographical/racial communities.

* Hospitals were chosen for maternal delivery observations because they offer the full spectrum of comprehensive essential obstetric care (unlike the more basic midwife obstetric units).

'Sensemaking' in context

The collected access stories were analysed using a narrative approach for 'making sense' of personal experience (stories) in relation to broader sociopolitical and cultural discourses (narratives) (Chase 2011). While the focus of this thesis is on the micro-practices of those seeking and delivering care, the embeddedness of people and facilities in 'place' is also an important contextual feature (Stuttaford, Harrington, and Lewando-Hunt 2012). In particular, the challenges of geographical access and affordability of care stand out as differences in the rural and urban stories (Research Articles 1 and 2). Similarly, Harry Nyathela's murder (Epilogue – Section IV) is located in time and place as part of reckoning with the violence of

his death. Different theoretical lenses have been drawn on as part of such "sensemaking" - restorative practices and governmentality, critical social contract theory, and street-level bureaucracy. These narratives have been theorized for continuities and changes with South Africa's past, and examples of 'restorative practices' (as more equitable and inclusive ways of 'doing' health care), have been sought. They are set within the 'haunting' of the country's HIV policy (see below). Theories of violence and trauma have been introduced in the Epilogue to introduce the "violent democracy" of a post-apartheid context (von Holdt 2013): itself a 'haunting' of apartheid and transitional justice policies.

Ethical clearance and research permissions

Ethical clearance for this thesis was granted by the University of the Witwatersrand (M090951) (see Appendix 3). The study was guided by the ethics and research practices established by the REACH project, which received Phase 2 ethical clearance from the Universities of Cape Town (Health Sciences Faculty Research Ethics Committee: 460/2008) and Witwatersrand (Human Research Ethics Committee (Medical): R14/49/2008); and the Western Cape Health District Health Services and Programme (19/18/RP11/2008), Gauteng Directorate of Policy, Planning and Research (06/06/2008), and Mpumalanga Health Research and Ethics Committee (MP/09/08). Study permission was also received from the Cities of Johannesburg (23/07/2008) and Cape Town (13/12/2008), and verbal approval was granted by district managers in each study site, as well as heads of the health facilities involved. Informed, written consent was obtained from all individuals interviewed. For the facility observations health care workers were invited to participate at a staff meeting, and signed consent was obtained from managers in observed areas. Written consent was obtained from patients before any consultations were observed. Posters in local languages informed patients and visitors that the facility was being observed for research purposes; a message

often reinforced by staff announcing us in waiting areas of facilities. All interviews and facilities were anonymized and stored on a secure server available only to the research team. Pseudonyms were assigned to people and facilities to protect confidentiality.

Methodological musings: The 'haunting' of HIV policy and its remaining salience

> We emerge from the meeting, all sombre, some weepy. A few people gather in the reception area. She takes a long sip of her soft drink, clearly drained but also relieved for having disclosed her status to us. A colleague picks up the same can with deliberate casualness and takes a long sip of solidarity. It is the year 2000 (personal memory).

In 1990 (the year Nelson Mandela was released from prison), South Africa's HIV prevalence rate was estimated at 0.8 percent (Simelela and Venter 2014). In 1992, a few months before my friend was racially assaulted, I had my first HIV test, which was carried out for free at a clinic in Hillbrow, Johannesburg. When I went to collect my results a number of days later (no rapid testing then), a white doctor told me, with genuine concern, to "be careful. I'm not saying your boyfriend himself but maybe he's slept with someone who has slept with someone who is black". By 1994 (the year of the country's first democratic elections), HIV prevalence had risen to 4.3 percent (Simelela and Venter) and the new government, supported by a progressive health movement, adopted an AIDS Plan that "set the stage" for effectively tackling the epidemic (Natrass 2008:158). However, in the immediate post-apartheid era, policy implementation – in all sectors - was mired by the *nature* of the country's negotiated political settlement; through the "sunset clauses" that saw the retention of an expensive,

dysfunctional and authoritarian civil service (Mamdani 2015; Schneider and Stein 2001). Into this context, new, inexperienced cadres were appointed to reengineer the public sector away from entrenched discrimination and corruption towards equitable, accessible service delivery (Schneider and Stein). The ensuing ”institutional logjam” in public institutions (Pieterse, 1997, quoted in Schneider and Stein 2001:726) was further cemented by growing conflict and mistrust between the government and civil society, as a series of imposed political actions (and related scandals) unfolded to reveal inappropriate “centralist and authoritarian styles of leadership in facilitating the response to AIDS” (Schneider and Stein 2001:728), alongside an expensive military “arms deal” and concerns about the state’s macro-economic policy shift away from “reconstruction and development” to “growth, employment and redistribution” (Coovadia et al. 2009; Doherty and McIntyre 2015).

This political struggle intensified during Thabo Mbeki’s presidential term (1999-2008); a “testing period for the country as the full extent of the epidemic’s health impact became apparent in the face of [his] increasingly apparent denialism” (Simelela and Venter 2014:249). Flying in the face of scientific evidence, life-saving antiretrovirals (ARTs) were labelled as “toxic” and “poison” and their introduction into the public health system was resisted and delayed at the highest political level, causing an estimated 171,000 new infections and 343,000 deaths between 1999 and 2007 (Natrass 2008). HIV-related stigma, confusion, and fear grew within the society. A positive diagnosis without access to ARTs was viewed by many as a death sentence and “medical charlatans and self-styled ‘traditional’ healers” flourished in the treatment gap (Natrass 2008:167). In 1998, Gugu Dlamini, an AIDS activist and educator, was beaten and stoned to death by a crowd for “degrading” her community by living openly with HIV (Kortjass 1999). In this bleak context, acts of public disclosure, whether on an international stage, at a work meeting, or to family and friends, were truly acts of courage and activism.

During this dark denialist period, the Treatment Action Campaign (TAC), which was founded in 1998 as a campaign for access to AIDS treatment, galvanized into a world-renowned political movement for health. By situating the issues firmly within South Africa's constitutional framework, the movement

> framed its demands not simply as 'better pro-poor policy' but as policy alternatives based on legal entitlement – and therefore as positive duties that rest with national governments and, where relevant, the multi-national corporations and multi-lateral institutions (Heywood 2009:22).

Between 2001 and 2008, TAC successfully litigated "on at least five occasions", securing *viz.* the introduction of the prevention of mother to child transmission (PMTCT) programme (2003) and access to the implementation plan for the national roll-out of ART (2004) (Heywood 2009:22). Yet, even once the Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa was approved by "Cabinet revolt"(Natrass 2008:166) and effected in 2004, it fell far short of the set targets (Natrass; Simelela and Venter 2014). It was only when Thabo Mbeki and his health minister, Dr Manto Tshabablala-Msimang resigned in 2008 that the country's HIV Programme came into full force, supported by the new leadership of the interim government (2008-2009), and from 2009 onwards, President Jacob Zuma and Minister of Health, Dr Aaron Motsoaledi.

Today, in 2015, the country runs the largest ART programme in the world, coordinated through a grant of R8.7 billion (2013/14 financial year) (Simelela and Venter 2014), serving 3.1 million of the estimated 6.3 million people living with HIV (National Department of Health 2015). This programme is a haunting legacy of previous HIV policy, which was completely "out of joint" (Shakespeare/Derrida cited in Decoteau 2008) with the country's health and justice needs. It is impossible to consider the accessibility of health care

in contemporary South Africa without acknowledging this history or the challenges that have emerged/intensified with the restorative ART programme. These challenges – which include drug stock-outs, low levels of health worker motivation, weak information, monitoring, and evaluation systems, adherence fatigue, a growing TB epidemic, and entrenched social inequities - reside in, and reflect on, the functionality of the health system as a whole (Simelela and Venter 2014). South Africa is estimated to have "the third highest TB incidence rate and the second highest Multiple-Drug Resistant or MDR-TB incidence globally" (WHO Global TB Control Report (2012) cited in Republic of South Africa 2015:19). Health system strengthening (at the core of Health Policy and Systems Research) must be seen as a prerequisite for the equitable delivery of available, affordable and acceptable health care.

Research during a period of rapid policy change

The data used in this thesis were collected between 2009 and 2010, at the point when the ART roll-out was slowly gaining momentum and a few stable patients were being down-referred from ART initiation centres to nearby clinics for monthly treatment collection. However, ART services were not decentralised as they are today (through 3 591 fixed public health facilities) (National Department of Health 2015). Nurse Initiated Management of Antiretroviral Treatment (NIMART), still in its infancy in 2015 (Evans 2013), was but a whisper on the lips of nurses then, many of whom were feeling stressed and anxious at the thought of having to absorb additional tasks without additional resources. Some patients were feeling worried about having to leave their initiating treatment centre, unsure of the quality of care they might find in their 'new' clinic. A few were also fearful of possible stigmatization from attending services in communities closer to home. Yet, many were hopeful that more and closer services would reduce access costs and improve waiting times. And hope has

continued to endure (see Fried et al. 2013), even alongside the 'disappointment' (Field 2011; Mbembe 2015; Njovane 2015).

In the five years since the study data were collected, ART coverage has been extended to all patients with a CD4 count of <500 cells/μl (2015), from <350 (2012) and <200 (the initiation threshold during REACH) (Joint HIV, TB and PMTCT Review Steering Committee 2014; Simelela and Venter 2014). The TAC has recently called for ART to be made freely available for anyone living with HIV, regardless of CD4 count, in light of growing scientific evidence for the individual and public health benefits of early treatment initiation (Malan 2015). There has been a steady decline in the Mother-to-Child-(HIV)Transmission rate from 3.5 percent in 2010 (the end of the fieldwork for this study) to 2.7 percent in 2011 (Bhardwaj, Barron, Pillay, Treger-Slavin, Robinson et al. 2014). It is estimated that between 2008 and 2011, the Maternal Mortality Ratio (MMR) fell from 281 to 197 per 100,000 live births, while, between 2009 and 2011, the Neonatal Mortality Rate (NMR) reduced from 14 to 11 deaths per 1 000 live births; and the Under-5 Mortality Rate (U5MR) declined from 56 to 41 deaths per 1 000 live births (Rapid Mortality Survey of the Medical Research Council (2014), cited in Republic of South Africa 2015:19). Similarly, the Infant Mortality Rate (IMR) has also fallen between 2009 and 2013 from 39 to 29 deaths per 1 000 live births (Republic of South Africa 2015:19). Overall, it is anticipated that by 2016, 2.2 million deaths will have been averted through access to ART (Joint HIV, TB and PMTCT Review Steering Committee 2014).

When hearing of these successes, I often think of the anxiety, stress and sense of dislocation experienced by both patients and providers in health services under previous HIV policy. Consider the following 'diagnosis experience' suffered by a woman who, at the time of her interview in 2009, was successfully using ART and TB services:

> I was diagnosed in 1995 at the antenatal clinic. They did a blood test and they never did pre-counselling. I am saying this now because I know how the process *should go*, the procedure as a whole. I never got the counselling, they took the blood test without my consent [...] then from the queue they called me [and another pregnant woman...] I thought the nurse was going to ask this funny question like, 'At your age, you're pregnant?' But then she asked us to tell her if we know HIV. The other girl kept quiet and I responded and said, 'yes I know HIV, it is a virus' [...] Then the sister said, 'as you both are here, I will like to tell both of you that you're HIV positive'. Heeey that other girl started crying and I was just puzzled […] that girl kept on crying. Then the sister asked me to help that girl not to cry because she thought that I was strong and brave. […] I told that girl that the thing that we need to do now is to know how to take care of ourselves with this illness, we must take some lectures if we get them somehow. It was just like that, understand? Then I got the child and there was no AZT by those times. Nothing. That was in 1995 […] so it was that thing, 'Now that I am HIV+, now what?' Then I was asking myself 'What about the baby is she going to be infected?'

In many ways, the narratives presented in this study reference an earlier era. They contribute to an archive that is 'then' not 'now'. Yet, they also reveal residual challenges, many deep-seated and stubborn; a sober reminder that the past itself is an intractable determinant of health. Left unresolved, these narratives are "out of joint" with a new vision in a new time (Shakespeare/Derrida cited in Decoteau 2008). Like Hamlet's ghost in Derrida's hauntology, they confront and haunt us 'here', demanding justice for both the past and the future. It is in this haunting that they reveal directions for future research and policy engagement, as well as

the changes, continuities, and contradictions that shape a time of political and health transition.

Watching the ambulance: A circle in a spiral, a wheel within a wheel?[16]

> Memory is not at the level of representation, but at the level of a particular gesture with which you inhabit the world (Das 2010:144).

Today, twenty one years into South Africa's democracy, I sit in the beautiful new School of Public Health Building at Wits looking directly at the grey monolith that is Charlotte Maxeke Johannesburg Academic Hospital. Every now and then, a helicopter whirls up or down directly outside my window. A pinnacle of access to needed, quality health care. I know that access is much more than an ambulance in the air or on the ground. And that, "national yardsticks" or not, emergency medical services still often take an hour or so, if they come at all. Yet, as I read the newly-released White Paper on National Health Insurance, noting that

> all medical emergency vehicles will be of a standard colour regardless of whether they are publicly or privately operated and there will be a single national emergency number to serve both public and private operators to improve services and effective response to the needs of the population (Republic of South Africa 2015:45),

I wave to my five or six year old self, watching through a different window, with hope, for an ambulance to arrive.

[16] Bergman, A. and M. Bergman (1968). English lyrics for "The Windmills of Your Mind" (music by Michel Legrand).

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Research Articles 1-3 in this thesis:

Research Article 1

Harris, B., J. Eyles, and J. Goudge

Draft Ways of doing: restorative practices, governmentality and provider conduct in post-apartheid health care. Medical Anthropology (accepted for publication).

Research Article 2

Harris, B., J. Eyles, L. Penn-Kekana, L. Thomas, and J. Goudge

2014 Adverse or acceptable: Negotiating access to a post-apartheid health care contract. Globalization and Health 10(1): 35.

Research Article 3

Harris, B., J. Eyles, L. Penn-Kekana, J. Fried, H. Nyathela, L. Thomas, and J. Goudge

2014 Bringing justice to unacceptable health care services? Street-level reflections from urban South Africa. International Journal of Transitional Justice 8(1):141-61.

Section II

Research Articles 1-3: Theorizing access as justice

Research Article 1

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Research Article 1: Ways of doing: Restorative practices, governmentality and surveillance in post-apartheid health care

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WAYS OF DOING: RESTORATIVE PRACTICES, GOVERNMENTALITY, AND PROVIDER CONDUCT IN POST-APARTHEID HEALTH CARE

Journal:	*Medical Anthropology*
Manuscript ID	GMEA-2015-086
Manuscript Type:	Original Article
Keywords:	Restorative Practices, Governmentality, Post-apartheid health care, Provider conduct, Patient experiences, Narratives

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WAYS OF DOING: RESTORATIVE PRACTICES, GOVERNMENTALITY, AND PROVIDER CONDUCT IN POST-APARTHEID HEALTH CARE

ABSTRACT

In this article, we consider the conduct of post-apartheid health care in a policy context directed towards entrenching democracy, ensuring treatment adherent patients, and creating a healthy populace actively responsible for their own health. We ask how tuberculosis treatment, antiretroviral therapy, and maternal services are delivered within South Africa's health system, an institutional site of colonial and apartheid injustice, and democratic reform. Using Foucauldian and post-Foucauldian notions of governmentality, we explore provider ways of doing *to, for,* and *with* patients in three health sub-districts. Although restorative provider engagements are expected in policy, older authoritarian and paternalistic norms persist in practice. These challenge and reshape, even 'undo', democratic assertions of citizenship, while producing compliant, self-responsible patients. Alongside the need to address pervasive structural barriers to health care, a restorative approach requires community participation, provider accountability, and a health system that does *with* providers as much as providers who do *with* patients.

Key words: governmentality; narratives; patient experiences; post-apartheid health care; provider conduct; restorative practices

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Following a special hearing into the apartheid health sector in 1997, South Africa's Truth and Reconciliation Commission (SATRC) found that:

> Millions of South Africans were denied access to appropriate, affordable health care during the period under review [1 March 1960 – 10 May 1994]. Health care workers, through acts of commission and omission, ignorance, fear and failure to exercise clinical independence, subjected many individuals and groups to further abuse (2003:337).

As a state institution, the South African health sector was implicated in normalizing and perpetuating the apartheid system, a racist "crime against humanity" built on legislated discrimination, racial and spatial segregation, insidious violence, and social prejudice (South African Truth and Reconciliation Commission). The SATRC made key recommendations for reforming the health sector, and preventing future abuses by health care workers, including the establishment of "accountability mechanisms", and ongoing human rights training of health professionals (2003:337). Additionally, since the country's first democratic elections in 1994, a number of progressive laws and policies have been developed to protect human rights, and redress the massive health and wealth disparities that persist between races and geographical areas, and continue to make South Africa one of the most unequal societies in the world (Inchauste et al. 2014). In health, these reforms include the Bill of Rights, *Batho Pele* (People First) Principles, the National Health Act (2003), the Patients' Rights' Charter (Hassim, Heywood, and Berger 2007), and, more recently, a proposed National Health Insurance System (NHI) to deliver affordable, quality care to all in need (Republic of South Africa 2011).

Yet, due to structural and political reasons, these reforms have not been as far-reaching as was envisaged. Twenty one years into the country's democracy, although the right to access

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health care is constitutionally guaranteed, access barriers persist. Poverty, large distances to clinics (especially in rural areas), stigma, and shortages of financial and human resources for health disproportionately affect many who experienced the dispossession and violence of apartheid - black, poor, rural, and informal-urban communities- as well as newer marginalized groups, *viz.* undocumented migrants and refugees (Cleary, Birch et al 2013; Silal, et al. 2012; Treatment Action Campaign 2014; Veary 2011). The social contract has formally changed from one of racist authoritarianism to democracy but exclusion, including from health care, continues. Furthermore, hostile, neglectful, sometimes abusive, provider actions continue to be documented (Harris et al 2014; Jewkes, Abrahams, and Mvo 1998; Wood and Jewkes 2006), alongside patient-provider relations of mistrust, suspicion and blame (Eyles et al 2015). Mismatched patient and provider expectations of service delivery may negatively affect health-seeking decisions and behaviors, while shared expectations built on respectful, dignified clinical engagement may facilitate patient retention within services and encourage their sustained access to care (Gilson 2007).

In the post-apartheid context, interconnected and rising "syndemics" of HIV and tuberculosis (TB), maternal and perinatal deaths, non-communicable diseases, and violence and injury-related problems (Coovadia et al. 2009) underscore the inequitable ways in which "social encumbrances 'get under the skin' and have direct impact not only on disease development and progression, but on deleterious disease interaction as well." (Singer 2013:2). Access to health care, health outcomes, and the broader determinants of health remain racially and spatially determined – etched *on* the skin as much as under it. There is an urgent ethical and public health need to ensure the accessibility of health services and to align the practices of health care

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workers with a restorative framework. We introduce the idea of "restorative practices" to frame ways in which health care is practiced in this context.

RESTORATIVE PRACTICES

> The fundamental unifying hypothesis of restorative practices is disarmingly simple: that human beings [patients] are happier, more cooperative and productive, and more likely to make positive changes in their behavior when those in positions of authority [health care providers] do things *with* them, rather than *to* them or *for* them. This hypothesis maintains that the punitive and authoritarian *to* mode and the permissive and paternalistic *for* mode are not as effective as the restorative, participatory, engaging *with* mode (Wachtel and McCold 2004:1-2, original italics).

The notion of "restorative practices" originates out of a restorative justice approach to addressing wrongdoings. Restorative justice is most commonly associated with victim-offender mediation in criminal cases but its emphasis on "establishing or re-establishing social equality in relationships" (Llewellyn and Howse 1999:1), and prioritizing victims' needs has recently found application in education, law, transitional justice, and social work (Wachtel and McCold). In this article, we extend the idea of restorative practices to service delivery in South Africa's public health system. Broadly, the authoritarianism of health care workers doing *to* patients and the paternalism of doing *for* them resonate with the overall mode of health care delivery in the country's repressive past. In contrast, the doing *with* mode communicates a form of democratic engagement in line with post-apartheid discourse. This suggests an opportunity for empowering patients, encouraging equitable clinical relationships, and contributing towards the institutional

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transformation required for consolidating democracy. In the post-apartheid policy ideal, provider practices *should* have changed in line with the county's transformative political agenda, and yet, remnants of past ways of doing continue alongside newer modes (Coovadia et al. 2009; Eyles et al 2015; Harris et al 2014; Jewkes et al 1998; Wood and Jewkes 2006). In this article, we chart some of these modes and their repercussions for patients and providers in three health sub-districts. To achieve this, we locate our study in Foucauldian (1980; 2007) and post-Foucauldian analyses of power and governmentality: the ways and practices by which individuals and populations are shaped, controlled, and governed (Death 2013; Mbembe 1992; 2005; Mckee 2009).

POWER, REGIME CHANGE, AND THE ART OF GOVERNANCE

The post-apartheid health system is firmly rooted in earlier regimes of colonial power and apartheid capitalism (Butchard 1997; Burns 2004; Coovadia et al. 2009). Since the permanent settlement of Europeans in the Cape in 1652, health determinants and outcomes have been tied to the brutal conquest of indigenous people for the benefit of a white minority (Comaroff 1998; Coovadia et al.; Zwi 1984). First under the political control of the Dutch East India Company, then under various forms of British administration (1806-1910; 1910-1960), the country's colonial trajectory, as elsewhere in Africa, followed a "fourfold mandate…discovery, pacification, commerce, and rational administration" (Comaroff 1998:324). This was accompanied by the spread of Christianity, and from the early-nineteenth century, mission medicine became a vehicle for promoting western ideology and serving racial domination (Zwi).

Through ministering to bodies in the interests of their souls (doing *for*), by "tracing [a patient's illness] trajectory on the history of salvation", mission services assigned a certain

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autonomy and self-responsibility to patients that was not present in the (gradually emerging) biomedical approach (Kistner 2003:148). Mission medicine also created a certain type of provider, trained to "carry the torch of Christian-inspired civilization", while harnessing the "benefits of Western biomedicine" (Burns 2004:193). This pastoral mode was further replicated in the organization and delivery of mission services; different from the modern secular norms that evolved into and through the apartheid-era, although similarly working for racialized power (Burns).

In parallel to mission services, and with the rise of the social sciences and biomedicine in the early twentieth century, a wide range of strategies, technologies, and techniques developed to subjugate individual bodies ('disciplinary power'), and manage populations in life ('biopower') and death ("necropower") (Mbembe 2003). State-led public health, concerned with infectious disease and "differences in social and moral hygiene" assisted in consolidating racial segregation and controlling space, as well as bodies (Butchart 1997: 411). For example, an outbreak of bubonic plague in 1900 in Cape Town created an impetus for formal urban segregation (Swanson 1977). The legislated racism of the apartheid state (1948-1994) extended and deepened colonial practices of land dispossession, industrialization, cheap labour, and socio-spatial segregation. Between the 1960s and 1980s, more than 3.5 million black people were forcibly removed from their homes to become 'citizens' of under-resourced, repressive 'homelands', where 81 percent of households were relegated to illness, starvation and deep poverty (Baldwin-Ragaven, de Gruchy, and London 1999; Coovadia et al. 2009; Gilson and McIntyre 2001; Susser and Cherry 1982; Zwi 1984). Young men were forced away from their families into the tightly regulated, exploitative migrant labour system that sustained South Africa's mines and industry, a system that remains a major determinant of disease within Southern Africa (Coovadia et al). Justified

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through ideologies of racial domination, the "burdens" of apartheid economic expansion, including preventable ill-health related to malnutrition and poverty, were "transferred to the black population, and the rewards reaped by whites, although not all whites equally" (Marks 1997:215). As with all apartheid public institutions, state expenditure on white facilities was five to six times more than on black African care (Gilson and McIntyre; Susser and Cherry). The state apparatus, including the health system, was employed differently towards different populations, nurturing white citizens and controlling black subjects.

Up until the late 1960s, mission hospitals, which flourished after the second world war, were perceived as complementary to the state health system, and were often the only mode of available care in rural and underserved areas, especially in the 'homelands' (Zwi 1984). However, in the 1960s and 1970s, 126 mission hospitals were nationalized, partly because of their growing potential to resist apartheid but also to cement the state's policy of "separate development" by subsuming them under 'homeland' administration (Zwi). This process allowed the (white) state to further abdicate from its duties to a (black) populace formally excluded from South African citizenship (Zwi). By the end of apartheid in 1994, there were 14 separately administered health departments - one of many challenges for creating a single, unified post-apartheid system (Coovadia et al 2009).

As resistance to state power started to consolidate through formal liberation movements - for example, the African National Congress was established in 1912 – so state surveillance, record-keeping, queuing systems, clinical procedures, and patient-provider etiquette shifted to bring *into being,* to make knowable, and controllable, the "African Patient":

> an individual who through appropriate training in health and disease could be recruited as an active relay in a synaptic network of discipline, exercising hygienic surveillance over,

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> and against, himself, both in the preventive domain of public health, and within the curative domain of the clinic (Butchart 1997: 412).

Drawing on Foucault's (1980; 2007) formulation of power as adaptive and creative, Alexander Butchart charts the mutation of this objectified, passive African Patient across the apartheid period into a suffering, emotional Whole Person by the 1990s. Unsurprisingly, this shift took place on the eve of democracy, when the crass repressions and explicitly racist identities of the apartheid state were largely untenable due to internal and international pressures. It signals a discursive re-membering of a whole patient within the clinical relationship, a re-assembling of individual and collective bodies previously disembodied, compartmentalized, and racialized. This humanist shift is closely aligned with the rights, responsibilities, and expectations of democracy: doing *with* bodies. But, these are bodies located within wider communities, and the idea of restorative practices in *this* context resonates closely with a discourse of *ubuntu* (humanness) and *umuntu ngumuntu ngabantu* (a person is a person because of people):

> Metaphorically, [ubuntu] expresses itself in *umuntu ngumuntu ngabantu*, describing the significance of group solidarity on survival issues so central to the survival of communities. While it envelops the key values of group solidarity, compassion, respect, human dignity, conformity to basic norms and collective unity, in its fundamental sense it denotes humanity and morality. Its spirit emphasizes respect for human dignity, marking a shift from confrontation to conciliation (Justice Mokgoro, *State v Makwanyane* 1995, quoted in Bennett 2011:34, original italics).

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Constitutionally embedded, ubuntu conveys social solidarity, dignity and belonging (Bennet). It is a fundamental recognition of Self (identity) in the Other, including the relationships and community through which human kindness is constructed.

The right to access health care in post-apartheid South Africa forms part of a broader agenda to democratically transform the country from its colonial and apartheid past. Yet, it is often very difficult to remove the past with its inculcated values, modes of operation, and mentalities of rule (Foucault, 1980; 2007; James 2013; Mbembe 1992; 2005). That the old continues to operate alongside the new is critical to understanding how power manifests in postcolonial Africa (Mbembe). With limited resources it is difficult to develop new modes and infrastructures necessary to operate complex systems such as health care. The past remains embedded in geography, architecture, and professional and personal relations. It haunts interactions between providers and patients, shaping their practices and identities. Simultaneously, however, the pressures of needing to change, to implement new policies often without adequate resources, skills or training, have seen managers and providers reverting to a hierarchical status quo, even as part of a policy emphasis on patient-centred care and improved accountability (Cleary, Molyneux, and Gilson 2013; Gibson 2004; Hull 2012; Penn-Kekana et al. 2004). The past is an important determinant of both health and transformation, setting parameters on what can be changed and how. At the same time, the present reshapes and molds older ways of doing and being. We situate South Africa's health system in this context of change and continuity - transition - between old and new modes of governance, with the new emphasizing citizen engagement and working with populations for shared goals (i.e. healthy, productive lives).

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CONTROLLING FREE INDIVIDUALS: GOVERNMENTALITY AND DEMOCRACY

Manufacturing consent by acting "upon *individuals' very subjectivities*, so that it is their own will that guides their actions" (Martin et al. 2013:81, original italics) is symptomatic, for Foucault (2007), of governmental power working through individuals in neoliberal (Lemke 2001), and postcolonial contexts (Death 2013; Mbembe 2005), including South Africa (Hull 2012; James 2013). Governmentality describes the ways in which a society functions to create, manage, and control "(at least partially) free" individuals and populations (Death 2013:764). Premised on a degree of freedom, governmentality is contiguous with democracy and therefore a springboard for thinking about restorative practices and doing *with* each other in the post-apartheid context.

Globally, technologies of public audit have emerged as increasingly important ways for controlling and shaping the conduct of public officials (health care providers and managers included), while simultaneously deepening population surveillance through the keeping of population registers, files, and records (Ferlie and McGivern 2014; Ferlie et al. 2012). Public audit technology emphasizes accurate record-keeping, routinized data collection, and financial prudence in the interests of transparent, accountable service delivery. As in many postcolonial societies, the post-apartheid health system has seen the introduction of new administrative and financial controls, such as the Public Finance Management Act (1999). However, in a context of persistent staff shortages and limited resources, rather than addressing past inefficiencies and lack of accountability, financial management has become increasingly separated from clinical practice, often taking precedence over quality patient care (Hull 2012; Penn-Kekana et al. 2004), leaving patients dissatisfied and providers anxious and overstretched – done *to* – in the name of accountability. Additionally, Diana Gibson (2004) notes that resource constraints, coupled with

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pressures on providers to account, have fueled fragmentation and inconsistencies in post-apartheid surveillance, resulting in "unseen areas" (p.2015) and "invisible patients", alongside those with "value in the medical economy" (p.2020).

Governmental regimes work through and encourage self-managed individuals and their associated rights, responsibilities, and freedoms. In this way, post-apartheid democracy, as a formal political system, can be sharply differentiated from its oppressive ancestors. Yet, a shift towards governmentality does not mean a total replacement of sovereign or disciplinary regimes; rather, these forms of power overlap and coalesce in complex ways to create taken for granted ways of doing and being in society (Martin et al. 2013; Mbembe 1992; 2005; Mckee 2009).

For example, vestiges of mission medicine continue to find expression in the post-apartheid clinic, where the notion of being called into service remains a commonly expressed raison d'etre for health care workers, lending a moral, as well as scientific, authority to provider identities and practices. Additionally, by doing *for* patients, by serving them, this discourse allows providers to do *for* their own souls too. Remnants of mission medicine also persist in certain clinic rituals, for example, morning prayers facilitated by health care workers for staff and patients. Largely dismissed as symbolic and consequently ignored by post-apartheid health policy, these rituals have been shown to "reinforce asymmetrical relations of power...and strengthen conventional modes of provider-patient interaction", rather than equalize or challenge them (Lewin and Green 2009:1464).

Furthermore, Ulrike Kistner (2003) argues that even as South Africa was moving away from apartheid-era repression, the country's catastrophic HIV/AIDS policies in the early 2000s signified a strengthening, not diminishing, of sovereign power over individuals and populations. During this period, the state, under Thabo Mbeki's leadership, actively withheld antiretroviral

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therapy from the public health system, causing an estimated 171,000 new infections and 343,000 deaths between 1999 and 2007 (Natrass 2008). More recently, state actions of physical violence against civil, industrial, and student 'protest' signal the persistent workings of repressive power in a post-apartheid context. Examples include the internationally condemned police massacre of 34 striking platinum miners at Marikana in 2012 (Breckenridge 2014), the forceful arrest of 129 community healthcare workers staging a peaceful night vigil against the Free State Department of Health in 2014 (Gontsana 2015), and the use of stun grenades and tazers by riot police on unarmed students protesting against unrealized promises of free education outside the country's parliament in 2015 (Furlong, Washinyira, and Heard 2015). The state should not be forgotten as a "site at which power condenses" (Cowan and Mcdermont 2006, quoted in Mckee 2009:476). This seems particularly pertinent given South Africa's long history of state engineering and entrenched relations of authoritarianism and paternalism between those in positions of formalized power and those without. In this article, through examining modes of health care delivery - doing *to, for,* and *with* patients - we engage with the exercise of power in narratives of post-apartheid South African health care provision. We ask how health care is 'done' in a post-apartheid setting, and examine whether and how such modes might facilitate, or restrict, access to health care for those who need it.

METHODOLOGY: NARRATING PRACTICES

This research is part of the Researching Equity in Access to Health Care (REACH) project, a five year study of access and barriers to ART, TB, and maternal delivery services in several South African provinces (Cleary, Birch et al. 2013; Eyles et al. 2015; Harris et al. 2014; Silal et al. 2012). These health 'tracers' were selected because they account for a large proportion of the

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country's burden of disease (Coovadia et al 2009), and require sustained engagement with the health system, which may present complex access challenges. Between June 2009 and July 2010, we carried out in-depth interviews with 45 patients and 63 health care providers and facility/sub-district managers, seeking and delivering health care in one rural health district (Bushbuckridge, Mpumalanga Province), and two urban sub-districts located in the Cities of Cape Town (Western Cape Province) and Johannesburg (Gauteng Province). These sub-districts were selected to illuminate access issues across three provinces, and in urban and rural contexts. Furthermore, 12 facilities (4 in each sub-district) were selected for detailed observations. They were drawn from 50 health care institutions sampled as part of the broader REACH project with the aim to include different facility sizes, management styles, and geographical and community characteristics (Cleary, Birch et al; Silal et al).

Patients were recruited at the observed facilities, and via community health workers, and support groups to reflect a diversity of access experiences. Fourteen men and fifteen women were interviewed about TB and/or ART services; half were accessing services, while half had interrupted their treatment, even if only temporarily. Sixteen women were interviewed about their pregnancies and deliveries; eight gave birth in facilities and eight delivered at home or en route to a facility. Four of the babies (25%) died during birth (Silal et al. 2012). Interviews were carried out in patients' home languages by trained fieldworkers at a patient-selected venue (coffee shop, home, health facility). Patients narrated their 'access stories' within the context of everyday life: illness, relationships, support networks, employment, education, and politics. Interviews were audio-recorded and lasted between 45 minutes to 1.5 hours of 'recorded time' although there were often delays and interruptions - small stories of daily life – that prolonged each engagement. These provided important insights that were discussed in weekly team debriefing meetings. Interviews

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were translated into English and transcribed. Transcripts then underwent a first analysis by several team members to prepare a follow-up interview aimed to explore treatment progress and clarify patients' narratives. However, not all patients could be traced and we carried out follow-up interviews with 21 patients, almost half of the participants.

Health care workers, including frontline providers (nurses, doctors, cleaners, pharmacists, data capturers/clerks, counsellors, social workers), and facility and sub-district managers (20 TB services, 21 ART, and 22 maternal deliveries), were selected from the 12 observed facilities (approximately 5 staff members per facility), and interviewed about their career paths and understandings of patients and access issues. Additionally, one focus group took place with twelve community health workers in Bushbuckridge, covering similar issues. Participants were selected to reflect diversity in age, seniority, and length of service. Audio-recorded, interviews took place in health facilities (the working environment) for approximately an hour, although this varied according to provider availability. As with patients, delays and interruptions extended our engagement beyond the transcribed product, richly illustrating the daily context of health care provision.

We also observed services in each sub-district over the course of the fieldwork. Formally, these observations were non-participatory but we were often 'drawn in' to the daily routines, for example, locating and filing records, finding information for patients, preparing and drinking tea with staff, chatting to patients in queues. We shared these experiences in often fragmented ways: as field notes, in discussions on the drive home, at team debriefings, or on hearing of someone else's experience– thereby generating our own set of small stories nested in the bigger narratives of access to health care.

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Framed by themes of governmentality and restorative practices, we analyzed the access stories using a narrative approach, which strives to make sense of personal experience in relation to broader cultural and socio-political discourses (Chase 2011). In selecting the narratives below, we have tried to give voice to as many participants as possible, while simultaneously acknowledging that access is an individual journey experienced over time, in geographical and social communities, between facilities, and with different providers. Many voices are heard, but we begin our account with the story of Gugulethu Ngwenya as her experience illustrates so well ongoing authoritarian practices and norms. All participants were offered anonymity, and therefore pseudonyms are used. To further minimize any risk of identification (of staff or patients), we have not named the sub-districts or facilities. We have also categorized quoted participants broadly as patients, providers, or managers.

DOING *TO* AND *FOR* PATIENTS: AUTHORITARIAN AND PATERNALISTIC NORMS

Gugulethu Ngwenya (26) fell pregnant – unexpectedly - with her first child two years after receiving an HIV-positive diagnosis. She was excited, although anxious about her HIV status: "what if the baby gets infected or I die?" So she became an expert: "read a lot of pregnancy books", attended antenatal classes, enrolled in the prevention-of-mother-to-child-transmission (PMTCT) program, and pre-packed an overnight hospital bag with antiretrovirals, "sweets, blankets, and snacks, so I was really prepared, you know?" In Foucauldian terms, she was a disciplined, self-managing, and responsible subject, participating enthusiastically in the health of both baby and self.

One Sunday night, in intense pain, Gugulethu was admitted to her nearest community health centre (CHC) but was discharged on Monday with "false labor" and told to go to the

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hospital “next time”. Her pain returned that evening and her mother phoned for an ambulance (20h00), which did not arrive due to striking emergency personnel. Four hours later, feeling she “would not make it”, a neighbor agreed to drive her back to the CHC. There, Gugulethu was initially refused entry because of the hospital referral. To gain admission, she claimed she had “walked” and was without transport, constructing herself as a responsible patient limited only by factors completely out of her control. The nurses let her in but rudely, “shouting ‘do that, don’t do that’, you know, and I’m in so much pain, they won’t assist you with anything”: doing *to* her through authoritarian communication and uncaring care. One centimeter dilated and bleeding, she was put on a drip and transferred to the hospital (by one of the two available ambulances serving the city’s major hospitals that night).

Arriving at the hospital after 01h15 (Tuesday), Gugulethu was told she needed a caesarean because the baby was “too big”. Twelve hours later, she was moved to the delivery ward where nurses started “making fun of me going to the picnic” – directly mocking her pre-packed bag (a proud symbol of her expertise) - a petty assertion of power *over* her. There, with limited information, Gugulethu found herself waiting for two more days, feeling mostly invisible on hard wooden benches or moving between beds to make space while “at least twenty” births took place around her: women “screaming, and moaning, and swearing, bleeding…not a very comforting or nice-looking place,…the toilets…smelly and dirty, actually the facility is not up to standard.”

Gugulethu was examined intermittently by different doctors, who re-confirmed that she needed a caesarean but no one would tell her why she was waiting or when she would go for the surgery. Time wore on. “I so needed to pee but they didn’t allow me to go to the loo…I was so thirsty, asked for water, and I was told that I can’t drink water because I’m in labor”. Physical

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control was exerted at a micro, bodily level, with no medical reason offered other than that of being in labor (not contraindicated). "I remember this one nurse, as I was screaming in pain, she just walked out and the other one was sitting on the corner with her phone and her feet on top of a table, laughing and chatting.…I started banging the wall because I couldn't bear the pain. She just said to me I shouldn't do that because I will break down the hospital. The other one said to me 'you are here to bother us'…I was so tired and needed to stretch a bit. I got off [the bed] and reached for [the water in] my bag and they started shouting at me…I had to lie and say I was just gagging": a poignant example of a subject "refusing", in the smallest of ways, "to know her place" (Mckee 2009:479) and provoking the sovereign 'might' of the ward.

On Thursday, the nurses called a doctor and suggested a vacuum to assist the birth, but the doctor said "'caesarean.'…And what's embarrassing is that they have students there and they don't ask for your permission for those people to work on you. I remember my legs were stretched, and I don't know which position to call that, and there were five girls standing right in front of me, and two nurses, and I was like pushing, and everything there was just exposed"; diminished to a birthing 'object' under a curious medical gaze.

Later that morning, Gugulethu was finally taken to the theatre, where she was found to be "fully dilated". She was sent back to the delivery ward to "try again." Here, in front of more students and nurses, she had a vacuum-assisted delivery, using four vacuums because the first "jammed", the second "didn't work", and the third was "too small." During her labor, she had heard the baby's heartbeat on a monitor but once delivered, "they did not show me the baby.… He did not cry. …I even asked if they have given him the [PMTCT] baby-drops because they were supposed to give him Neviropine for seven days" - an expert patient and now, a responsible mother. "Well, they said the baby is fine and I should not worry… [but] I saw a nurse coming

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with a doctor and for some reason I felt that something was wrong." She was informed that her baby had died. The nurse "showed me the file and I realized that it wasn't my file so for a moment I thought they made a mistake." But they had not; the baby was dead.

The hospital contacted her relatives and they were taken to a counselling room. "It was not a proper room…they don't have a proper room for mothers who just lost their babies." Staff expressed sympathy and brought the baby, "wrapped up in a sheet and I held the baby." A seemingly gentle, kind, and respectful engagement – doing *with* her - despite the lack of proper grieving space (and contrasted to another patient we interviewed in the same facility whose stillborn baby was placed next to her bed in a plastic bag, in a ward experiencing a shortage of baby-sized body bags). She was kept for observation overnight but, due to space constraints, was placed in a post-delivery ward with live babies: "I could have been better off if they took me to a room for mentally ill people rather than in a room where there were women carrying their babies, and I stayed there, and I was crying because babies were crying, and I could not take it you know.…I even thought of taking a drip just to hang myself with it."

POWER "CONDENSES": INSULATED PRACTICES AND PROVIDER DISCRETION *OVER* PATIENTS

Gugulethu Ngwenya's story highlights one doing *to* after another, a disempowering, dehumanizing chain of events and interactions tragically magnified by the death of her baby. Her confinement in the ward was poorly communicated yet invasive. Failing equipment, a filing error, 'gazing' students, and space shortages (most distressingly in the post-natal ward) were underscored by individual acts of provider cruelty and casual neglect. Similar forms of individual misconduct have been documented in both apartheid and post-apartheid health systems

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(Coovadia et al 2009; Jewkes et al 1998; South African Truth and Reconciliation Commission 2003; Wood and Jewkes 2006), and in our study, we found various other incidents of providers negatively exerting their discretionary power *over* patients (see also Harris et al. 2014). In some extremes, providers acted with obvious impunity, denying patients care, withholding their treatment or taunting them. More often though, providers wielded power by ignoring or silencing patients, treating them as docile recipients meant to follow instructions.

> If I try to say something, the nurses don't listen; they are just right every time…I must just listen to them. (Mark Kriel, TB treatment temporarily interrupted, Cape Town)

> The other nurse pricked the mother [blood test], and didn't say a word, and left the room. The patients complained that the nurses would do things and say nothing to them. (Facility observation notes, maternity, Cape Town)

These practices were often infused with paternalism, rendering patients child-like under the provider's disapproving *moral* gaze:

> Did patients stop to think about how they would afford a baby when they were making it? It's like we are spreading measles instead of immunizing, allowing poor, unemployed people to have babies…this is a form of child abuse all in the talk of 'parents' and their 'rights'. (Sam Dickson, provider, maternity, Johannesburg)

> The patients' rights; it's the 'ugliest'. You know, patients are like children. A child does not know a thing. You as an adult, you teach the child. (Nhlanhla Dube, manager, TB, Johannesburg)

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Approaching patients as passive objects, as medical curiosities to be done *to* (recall Gugulethu surrounded unceremoniously by students) or as children to be done *for*, allows providers to simultaneously assert their own expertise, to reinforce a relational distance from patients consistent with disciplinary power imbued with a culture of authoritarianism. In our study, punitive and paternalistic norms carried through and beyond individuals into many of the "taken for granted rationalities" of the clinic – communication, infrastructure, layout, opening hours, tea breaks, surveillance – arrangements that shaped how care was 'normally' delivered and experienced.

DOING IN SITU: THE CLINICAL SPACE

> I: I noticed there is a little A4 sign there saying the clinic is open Monday to Friday from seven to four. R: Maybe it's other departments. Here we don't open seven till four on Fridays. On Fridays, it's seven till one o'clock. I: Is it? It's just there [pointing to the sign on the wall clearly within the ART clinic] R: Maybe it's, it's other departments. (Zodwa Mbeki, provider, ART, Johannesburg)

Mandated operating hours govern public sector services, setting parameters around their availability and guiding users on when to seek care. However, in many of the study facilities, we observed that actual opening hours and patient 'contact-time' diverged from publicized times, often creating frustration, inconvenience, and added expense for patients. Some clinics simply opened late or closed early:

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> The clinic is meant to open at 07h00. I probe and ask a woman who is waiting outside: "so what time do they normally come." She says, "Ah it depends they can come at 07h45, or at 08h00 or at 08h30. It depends on their mood really." (Facility observation notes, ART, Johannesburg)

In many facilities, services were loosely arranged around patient clinical care (mornings) and administration (afternoons), thereby contracting the availability of services for patients and confirming to them the need to come early and queue; a long-established clinic ritual throughout South Africa. In one of the urban districts, no ART-related bookings were made on Fridays to allow staff time for meetings, stock-taking, data entry, and file preparation. These clinics closed at 13h00 (see quote above) unbeknownst to many patients when they first entered the system. Although some were turned away and denied care (see also Harris et al. 2014), most patients who transgressed de facto opening hours (provided they went within official opening times) were given limited care, such as a few 'emergency' tablets to prevent defaulting, under orders to return again during 'acceptable' hours.

Once within facilities, patients were not always sure of where to go or what to do. Not all clinics had staffed helpdesks or clear signage, although this was sometimes deliberate - out of sensitivity to the stigma surrounding HIV and TB (treated in areas separate from other chronic conditions at the time of the project). Once in the (hopefully) right queue, unpredictable staffing arrangements kept patients uncertain – who would see them and when? In short-staffed facilities, providers often needed to work simultaneously across different services (for example, chronic treatment and maternal/child heath), travelling between different rooms, while also fitting in breaks, meetings, and administration. But, without communication, it was difficult for patients to

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follow the spatial and temporal logic of the clinic. Many felt particularly marginalized when providers took tea breaks, partly because some providers did not seem accountable with their time:

> The nurse went in for tea at 10h00, came out at 12h30, then went back in around 1 and came out at 2, then stood there with other nurse, chatting, laughing. (Facility observation notes, ART, Johannesburg)

'FIELDS OF VISIBILITY' AND FLAWED SURVEILLANCE

'The wait' itself could be uncomfortable, physically doing *to* sick, frail or laboring bodies on hard benches (as Gugulethu experienced), in 'packed', often very cold waiting areas where windows were generally left open out of medical necessity (to improve ventilation and reduce the risk of TB transmission); and, at a few facilities, in temporary structures or even outside:

> We went to the tented waiting area and about 30 patients were sitting there in the freezing, cold weather.…it was very windy with sand blowing into our faces. Windy, cold or rainy, patients have to sit outside waiting for the doctor or the counsellor. (Facility observation notes, ART, Cape Town)

Additionally, space limitations, staff shortages, and high patient volumes – common across the three sites – compromised privacy, with counselling, weighing, pill counting, swallowing, dispensing, even, in the rare case, birthing (as Gugulethu witnessed) sometimes occurring in (semi) 'public' view, or undertaken as a collective exercise:

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> The nurse called them all, one female and three males, into the room at the same time. The pricking [blood test] was done in front of everybody [who had been called] into the room. (Facility observation notes, TB, Cape Town)

Like patients, providers had to work in the same cramped, cold, uncomfortable 'public' environment, themselves subject to patient scrutiny (albeit averted and non-medical). While some expressed concern that patients might "abuse" their rights and complain (do *to* health care workers), in practice, providers rarely seemed to 'see' waiting patients as active witnesses rather than passive audiences for educating, disciplining, praying with, and preaching to, in ways reminiscent of missionary medicine. This working mode was often replicated in complex ways throughout the hierarchy of the facility, carried into different spaces and relationships by nurses and doctors, but also security guards, cleaners, data clerks, counsellors, and pharmacists:

> The counsellor got mad, and started shouting to all the patients telling them that 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 labor 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.…There was a male clerk who also shouted at the women. He shouted at a woman who was bleeding and touched the desk. He shouted at everyone, "How dirty they all are, these mothers they need to be taught. You

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> are dirty and careless". The nurses said: "it's better if you listen from a male, maybe you'll understand and stop being dirty." The mothers just keep quiet. Just waiting to be released. (Facility observation notes, maternity, Johannesburg)

Punitive, patronizing, and silencing actions of this nature assume an irresponsible, even deceitful patient capable of lying to providers and abusing state resources; a construct inherent in certain policies. For example, in one clinic we were told that if a patient's antiretroviral therapy was lost or stolen, they needed a police affidavit to access replacement treatment. While designed in response to an illicit ART-recreational drug market (which does implicate *some* patients), the policy onus here falls on *all* patients, individuals with a still-highly stigmatized illness, to submit to police surveillance. Similarly paternalistic, the prevalent mode of TB care at the time of the study was Directly Observed Treatment (DOTs). This policy involves a patient swallowing tablets daily under the surveillance of a reliable witness (a healthcare professional, community health worker, or responsible community member), and has been shown to be cost-inefficient and ineffective (Volmink and Garner 2006).

In all three sites, patient and population surveillance was practiced with some rigidity (according to the rules), yet there were flaws. Often applied in isolation from whole-person care, these rules did not always serve their intended policy outcomes, becoming instead Kafkaesque ends in themselves: for a month, Peter Isaacs, a TB DOTs patient in Cape Town vomited after swallowing his treatment but did not tell anyone: "My TB supporter saw that I drank the pills then she left."

Most facilities were battling with outdated systems for completing and storing registers, files, and records: unwieldy paper-based systems largely unable to "keep up with" high volumes

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of patients, multiple indicators, and shortages of skilled data-clerks/capturers, and consequently often unrecorded. In one ART clinic with a large backlog of un-filed test results, data clerks pretended that results were "lost" and told patients to re-test, imposing unnecessary, expensive medical procedures on patients and the health system as a whole. As part of the broader REACH project, we reviewed patient records, and found many to be missing or incomplete. This was regularly confirmed in our facility observations, leading to wasted or duplicated effort on the part of facility staff:

> [After looking for the missing file a few times], the administrator then went to the computer and created a new file for the patient with the baby. And then went [again] to look for the correct file for the other woman. (Facility observation notes, ART, Bushbuckridge)

For many providers, the need to manage, record, and administer patients, to make them "knowable, calculable and administrative object[s]" (Miller and Rose 1990:5 quoted in Ferlie and McGivern 2014:67) was an ordeal, a doing *to*, especially because many felt ill-prepared or unqualified to manage the required paperwork, multiple meetings, and related trainings that took them away from their clinical practice. As much as these flawed practices of surveillance affected patients, populations, and their health, they also governed provider practices, with implications for individuals and facilities whose performance they measured:

> A lot of patients are poorly managed, mismanaged, not managed according to protocols and we do have the coordinators visiting clinics at least minimum once a week or twice a week and even more so at the problem clinics…one of the key areas [is] to do audits: 'you know you incorrectly coded this patient, you understand what code you've given

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that it's wrong'…so on a monthly basis they submit the audit reports to me and I expect a change. (Maria Klokker, manager, TB, Cape Town)

Under the 'gaze' of their managers, many providers, like patients, felt done *to*, overstretched and exhausted:

I am just a stent, you know, that thing in a drip that tries to stop all the fluid from pouring through at the same time. (Shammi Naidu, manager, TB, Johannesburg)

BORROWED ACCESS: THE IMPOSITIONS OF STRUCTURAL VIOLENCE

South Africa's maternal referral system assumes available emergency services and an absence of transport barriers. However, in practice, delayed or unavailable ambulances, long distances, and expensive private transport often impede patient access, contributing to provider frustration and poor maternal outcomes (National Committee on Confidential Enquiries into Maternal Deaths 2012). For six of the eight women in the REACH study who gave birth before arriving at a facility, emergency services were delayed or did not arrive at all (Silal, et al. 2012). As Gugulethu Ngwenya found, needing to use private transport during an emergency shifts the transport burden of accessing care from state to citizen; a social, often economic, imposition that other maternity patients spoke of too. In rural Bushbuckridge where distances were greatest and transport costs consequently the highest, Charlotte Sediba paid US$50 and Zandile Lituli paid US$10 for private transport after waiting for ambulances that did not arrive. Both delivered en route to the hospital.

For patients requiring chronic care, the transport costs associated with regularly attending services caused stress and anxiety, sometimes leading to interruptions in ART and TB treatment,

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or delayed, irregular antenatal visits. Some patients, especially in the rural district, spoke of having to borrow transport money from relatives, neighbors or money lenders (see also Cleary, Birch et al 2013). Upset and worried about how to pay back these loans, their access to health care was precarious and borrowed. In the urban sites, where clinics mostly fell within a walkable five kilometer radius (theoretically eliminating the need to incur transport costs), the walk itself was sometimes the 'last straw' for patients in poor health:

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

Additionally, overloaded, closed or fragmented services may require patients to make multiple visits, sometimes to different facilities, to receive the full spectrum of required care, compounding transport costs and patient anxiety. These costs must be located in a complex context of poverty, inequality, persistent racism, patriarchy, and other health determinants (Coovadia et al. 2009; Inchauste et al. 2014) that structure privilege, deprivation, and social ways of 'doing':

> Sometimes he would beat me up for no reason (crying)…this went on until my family came with a car to get me …they were scared that he might beat me to a point where I don't wake up anymore, and die, and leave my kids to suffer. (Nozipho Nzima, ART interrupted, Bushbuckridge)

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> I didn't really care about me but my worry was, what am I going to feed the baby [and my little sisters]? I am used to not eating [but] what was I going to feed them and what were they going to wear? (Sthembiso Nene, 20 year old scholar and household head, supporting two younger siblings, speaking of her stress when she discovered she was pregnant, Johannesburg)

DOING *WITH* PATIENTS: A RESTORATIVE, PARTICIPATORY MODE

In policy and aspiration, the post-apartheid health system visualizes providers engaging *with* patients as equals, treating them as individuals and families with health issues requiring skilled attention (Hassim et al. 2007; Republic of South Africa 2011). When providers do *with* patients in mutually respectful relationships they are likely to positively impact on patient satisfaction, and improve long-term treatment adherence rates. This is an assumption of restorative practices, as noted in other jurisdictions (Cropley 2012). In our study, many patients echoed this vision, expressing a wistful desire to be treated holistically, with ubuntu, as people first rather than anatomical objects of medical curiosity or provider scorn.

> I would like to see nurses being patient and kind to their patients during labor because they know that…pain. I wish that they could be gentle to their patients and do their work with passion because they studied for what they are doing. And I don't think they studied this because they wanted to have money but they did it because they love what they are doing. (Victoria Ditlopo, second delivery, Johannesburg)

A minority of patients described compassionate, respectful interactions with providers, in which they felt recognized as people with lives beyond the clinical space:

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> [Nurses here are] always nice. They greet, they call me by my name, they smile or laugh and make jokes…asked every day if I was alright, and they gave me bread. (Lorraine Geld, adherent to TB treatment, Cape Town)

Some providers and managers also sought to address aspects of patient poverty and malnutrition through establishing 'feeding-scheme' partnerships with non-governmental organizations, cultivating community vegetable gardens on clinic grounds, or making personal donations. Although resonant with the kindness of missionary-era paternalism (doing *for* patients), such charitable acts, when situated as part of the wider need to redress insidious health determinants and social inequities, are restorative in *intention*, even if they are not adequate or sustainable 'solutions'. It is in the recognition of structural violence and vulnerability in patients' lives and the effort to act against it, that these acts transcend simple paternalism and invite ubuntuism.

However, respectful, participatory engagements with providers and a few slices of daily bread were not always enough to retain patients within the health system when poverty, distance, and transport costs were "too much". These availability and affordability barriers resulted in some patients dropping out of care, even if only temporarily (see also Harris 2014). Conversely, many patients showed resilience and determination to access services and adhere to their treatment, even when individual providers were punitive or patronizing. But, this was *despite* being done *to* or *for*. In contrast, when done *with*, *because* of such doing, patients indeed seemed to be active and engaged participants in their own care, as anticipated in Wachtel and McCold's (2004) "hypothesis" of restorative practices.

UNDOING CITIZENS, REMAKING PATIENTS

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Yet, while advocating for a shift from authoritarian to restorative health care delivery, the doing *with* mode should not be uncritically embraced. As with all strategies of power, restorative practices are "particular responses, to particular problems, at particular times" (Rose 1999, quoted in McKee 2009:468). If applied in isolation without structural reforms, restorative practices may simply emulate the same neoliberal mode of governance that advocates individual agency and self-regulation, instead of direct governance from above. Such internalized power is itself a form of control even although it is based normatively on values of democracy and freedom (Foucault 1980; 2007). As Gugulethu Ngwenya's experience shows, this mode of power may be directed towards the production and control of compliant, responsible, and disciplined patients, *instead of* actively engaged citizens and communities with lived rights and potential to challenge the status quo.

Gugulethu approached her pregnancy from an empowered, knowledgeable position: a patient embracing and doing *with* the system. The importance of South Africa's PMTCT program in enabling such participation must be recognized as a restorative shift away from the country's earlier repressive HIV/AIDS policies. And yet, in the insulated sovereignty of the ward, her attempts to perform a variant of 'full' citizenship consistent with post-apartheid ideals, were challenged and reshaped by an older, authoritarian mode of 'doing'. In the ensuing 'clash' between old modes of practice and her expectations of how healthcare *should* be done, Gugulethu was converted from an active, responsible citizen to a humiliated, ultimately suicidal, object: not only done *to*, she was, in some ways, *undone*, stripped of both dignity and citizenship.

Individualized governmental power may also facilitate the contraction of a welfare state (Lemke 2001). Welfarism is often conservatively viewed as unwanted 'nannysm', paternalism at its worst (Carter, Entwistle and Little 2015; Cody 2003). Yet, state-driven interventions

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(including the establishment of a vibrant, trustworthy, and well-funded public health system) are particularly important for fragile and post-conflict nations seeking to 'undo' the legacy of state-created injustice. In this regard, the post-apartheid state has remained interventionist in important, intentionally "transformative" ways (Sabates-Wheeler and Devereux 2008, quoted in Devereux and Solomon 2011:13). Necessarily, there remains "a much greater impetus towards social welfare, towards trying to rethink what it might mean under current conditions, than in much of the rest of the world" (Jean Comaroff, in Bangstad et al. 2012: 23). For example, since the country's social protection system was first introduced in the 1920s as an instrument of white minority rule, it has grown into a strongly pro-poor "tool for reducing poverty and redressing historical inequities" (Devereux and Solomon 2011:10). By 2015, an estimated 16.9 million people were accessing social grants, compared to 4 million people in 1994, signaling sustained post-apartheid commitment to social justice (Ferreira 2015). In health, social grants enable access to services and provide protection for those most vulnerable to poverty and illness (Inchauste et al 2014). However, in the context of the country's macroeconomic policies, social protection, while necessary, may not be sufficient for radical transformation. Rather, it may simply "underwrite the social costs of South Africa's neoliberal growth strategy" (Devereux and Solomon 2011:2), becoming a band aid as disparities in wealth widen. In this complex political economy, overlapping temporalities of power emerge. Elements of the old continue alongside the new, and the new mutates and responds to the old (Foucault 1980; 2007; Mbembe 1992; 2005).

ACCOUNTABILITY IN SOVEREIGN SPACES

Crass manifestations of provider authoritarianism (violently doing *to* patients, as Gugulethu Ngwenya repeatedly experienced), stand out as non-democratic and shocking not least because

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they remain integrated into normal ways of delivering care. Visible exertions of power *over* and *on* bodies (doing *to*) testify to the failure of the health system to absorb a set of democratic practices. Similarly, the paternalism of doing *for* patients reflects an insistence that patient input is not important (MacIntosh and McCormack 2001). This 'we know best' approach has also been observed beyond the clinic in practices of community health workers (CHWs) (Dewing et al. 2013). In South Africa's 2011 policy vision for a National Health Insurance (NHI) System, CHWs are conceptualized as promoters of health *and* agents of surveillance (Republic of South Africa 2011). This dual role enables a "para-medical gaze…which operates in an increasingly complex network, extending through and linking institutions and communities, in formal and informal circuits of surveillance" (Heaton 1999:774).

Higher up in the hierarchy, NHI reforms have seen the introduction of new District-based Clinical Specialist Teams (DCSTs) to strengthen clinical governance (Republic of South Africa 2011). Comprised of doctor and nurse experts in maternal, child and primary health care, DCSTs have been met with some suspicion by their intended beneficiaries - frontline providers and managers in clinics, hospitals, and sub-districts – unsure of whether they are district "spies" or empowering "mentors" (Oboirien et al. 2015:50). Whether and how they transform clinical governance and clinical practice remains to be seen. But the formation, roles and practices of DCSTs, as well as the (anxious, hopeful) responses of others, point to new forms of power 'condensing' around older, established ways of both delivering and managing health care.

In South Africa, NHI reforms, including DCSTs and CHWs, present an opportunity to strengthen institutional and provider accountability towards a new way of doing care (Republic of South Africa 2011). But, accountability cannot be done in isolation from whole system transformation. As long as the health system remains hierarchical and authoritarian, provider

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accountability directed myopically 'upward' may continue to threaten, rather than complement, 'downward' accountability to patients and communities (Cleary, Molyneux et al 2013; Penn-Kekana et al 2004). If the health system is to become a vehicle for restoring justice, then strengthening accountability towards patients and communities is critical. Yet, other than to promote the idea of communities sharing responsibility for improving their health, the NHI policy proposal (Republic of South Africa 2011) is largely silent about community participation. Moreover, in the sovereign space of the ward and clinic, mechanisms to engender accountability between providers (horizontal accountability) are also vital for managing the necessary discretion required for effective service delivery (Hupe and Hill 2007). How different might Gugulethu's experience of care have been had individual providers felt accountable to her and each other?

PROVIDER CONDUCT: REFUSING POWER OR MANUFACTURING CONSENT?

The notion of restorative practices assumes that those in authority have scope to shape the social world, to manufacture the conduct of those they do *to, for* or *with*, simply by virtue of how they practice their authority (Wachtel and McCold 2004). In post-apartheid health care, providers-as-authority continue to do *to* and *for* patients, replicating older authoritarian and paternalistic practices, even alongside a more participatory (yet still marginal) doing *with* mode. Democratically transforming these outdated practices consequently requires a change in the conduct of *providers* as much as of patients; and with this, a better understanding of why and how providers themselves are done *to, for* or *with*.

In Foucauldian (1980; 2007) and post-Foucauldian (Mbembe 1992; 2005; McKee 2009) theory, relations of domination and subjugation are not one directional or simply imposed: ever

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productive, power automatically generates the potential for resistance. As Kim McKee notes, "subjects may refuse to know their place" (2009:479). Resistance, like power, is also productive, taking on different expressions and working through bodies to disrupt, subvert or challenge prevailing norms and ways of doing (Foucault). While patients resist 'normal' provider practices in small and big ways (often becoming the 'deceitful' or 'defaulting' stereotypes expected by the system), providers, hierarchically sandwiched between patients and their managers, may also be resisting power even as they exert it. Indeed, while on one hand, doing *to* and *for* patients is a clear perpetuation of older power modes, on the other, these acts simultaneously resist new norms and challenge policy expectations of participatory, restorative health care delivery. The co-existence of old and new power modes in this way may thus culminate in "the mutual 'zombification' of both the dominant [providers] and those whom they apparently dominate [patients]…[meaning] that each [has] robbed the other of their vitality and has left them both impotent" (Mbembe 1992:5). Consequently, alongside engaging communities, and transforming systems of accountability, attention must also be given to modes of power (and resistance) between staff and within the institution itself. In other words, a restorative approach also requires a health system that does *with* managers and providers as much as providers who do *with* patients.

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Research Article 2: Adverse or acceptable: Negotiating access to a post-apartheid health care contract

Harris, B., J. Eyles, L. Penn-Kekana, L. Thomas, and J. Goudge

2014 Adverse or acceptable: Negotiating access to a post-apartheid health care contract. Globalization and Health 10(1): 35.

Harris et al. Globalization and Health 2014, 10:35
http://www.globalizationandhealth.com/content/10/1/35

GLOBALIZATION AND HEALTH

RESEARCH Open Access

Adverse or acceptable: negotiating access to a post-apartheid health care contract

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Abstract

Background: As in many fragile and post-conflict countries, South Africa's social contract has formally changed from authoritarianism to democracy, yet access to services, including health care, remains inequitable and contested. We examine access barriers to quality health services and draw on social contract theory to explore ways in which a post-apartheid health care contract is narrated, practiced and negotiated by patients and providers. We consider implications for conceptualizing and promoting more inclusive, equitable health services in a post-conflict setting.

Methods: Using in-depth interviews with 45 patients and 67 providers, and field observations from twelve health facilities in one rural and two urban sub-districts, we explore access narratives of those seeking and delivering – negotiating - maternal health, tuberculosis and antiretroviral services in South Africa.

Results: Although South Africa's right to access to health care is constitutionally guaranteed, in practice, a post-apartheid health care contract is not automatically or unconditionally inclusive. Access barriers, including poverty, an under-resourced, hierarchical health system, the nature of illness and treatment, and negative attitudes and actions, create conditions for insecure or adverse incorporation into this contract, or even exclusion (sometimes temporary) from health care services. Such barriers are exacerbated by differences in the expectations that patients and providers have of each other and the contract, leading to differing, potentially conflicting, identities of inclusion and exclusion: defaulting versus suffering patients, uncaring versus overstretched providers. Conversely, caring, respectful communication, individual acts of kindness, and institutional flexibility and leadership may mitigate key access barriers and limit threats to the contract, fostering more positive forms of inclusion and facilitating easier access to health care.

Conclusions: Building health in fragile and post-conflict societies requires the negotiation of a new social contract. Surfacing and engaging with differences in patient and provider expectations of this contract may contribute to more acceptable, accessible health care services. Additionally, the health system is well positioned to highlight and connect the political economy, institutions and social relationships that create and sustain identities of exclusion and inclusion – (re)politicise suffering - and co-ordinate and lead intersectoral action for overcoming affordability and availability barriers to inclusive and equitable health care services.

Keywords: Social contract theory, Health care access, Suffering, Defaulting, Post-apartheid South Africa

Background

With universal health coverage firmly on the global policy agenda, there is renewed interest in finding ways to alleviate inequities in health care, address access barriers, and make services more inclusive for marginalized groups [1]. Accessible care requires the provision of affordable, available and acceptable services, responsive to patients' needs and expectations [2,3]. However, health system priorities, values and arrangements are often not well aligned with patient circumstances (especially those from marginalized groups), diminishing their ability to negotiate quality care and fueling inequities in access [2,3]. Closing the social, cultural, financial and/or physical distance between patients and the health system is consequently an important part of making health care more inclusive and equitable [2,3]. Yet this is not easy, even with legal provisions, equity-oriented policies and political will. Additionally,

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fragile and post-conflict countries also face challenges of rebuilding weak, fragmented or decimated health systems, overcoming historically-entrenched inequities, transforming relationships and changing authoritarian institutions [4]. Twenty years into South Africa's democracy, the right to access health care is constitutionally guaranteed but access barriers continue to inequitably affect many who experienced the dispossession and structural violence of apartheid - poor, black, rural and informal-urban communities [5,6]- as well as newer marginalized groups, including refugees and migrants [7]. The social contract has formally changed from apartheid to democracy but exclusion, including from health care, continues. A social contract describes institutions, principles and practices that structure and legitimate relationships between citizens and with the state [8]. In this article, we draw on social contract theory to examine how post-apartheid health care is envisaged and practiced by patients (citizens) and providers (state) in the public sector. We consider ways in which identities of inclusion and exclusion are generated through this contract and related implications for conceptualizing and promoting inclusive health care in a post-conflict setting.

A post-apartheid health care contract

We situate South Africa's right to access health care as part of a new social contract – initiated in 1994 with the country's first racially-inclusive elections - to "build a democratic state founded on the values of human dignity, the achievement of equality and the advancement of human rights and freedoms" [9]. This social contract represents a break from the country's apartheid past of legislated oppression and structured racism. It conveys a Rawlsian "moral vision" in which rights and responsibilities are fairly balanced and justice is served through mutual agreement between citizen and state [10]. In health, this democratic goal is formally communicated through laws, policies and codes of conduct, including the Bill of Rights, Batho Pele Principles (People First), the National Health Act (2003) and the Patients' Rights' Charter (PRC). These instruments define rights and responsibilities for providers and patients, and contextualize the health system – with its aspiration to provide equitable, quality care for all - within a wider context of redress [11-13].

However, while a democratic social contract portrays itself as a product of mutual agreement in which rights and responsibilities are fairly balanced, a critical perspective warns that this is not necessarily a "magic formula" [14] equitably serving all members of society [8,10,15-17]. Instead, the democratic ideal may depoliticize and hide structural issues, such as the "political economy, class, income inequity, education, and the bureaucratic compulsion to meet targets" [10], excluding certain people and groups (often those most in need of social assistance) as much as it includes [10,18,19]. In South Africa, two decades after apartheid, an inclusive, equitable society remains elusive. High levels of poverty, inequality, unemployment and "everyday suffering" [20-22] persist [5,22,23]. Barriers to inclusive health care include high transport costs, large distances to services [24], and a public sector that services 85% of the population with just 56% of health expenditure [25]. Rude, dismissive, sometimes abusive, provider actions have also been documented [26,27] and the health system remains fragmented and "dysfunctional" [5] characterized by weak stewardship, a human resource crisis, and limited financial, technical and administrative capacity [5,28]. Furthermore, transformation efforts have been undermined by the country's crippling, complex disease burden of HIV/AIDS, TB, non-communicable disease (NCD) and violence [5]. Efforts to improve the country's poor maternal and child health outcomes have also been frustrated by "avoidable" health system and patient-related factors, including a lack of appropriately trained staff, inadequate monitoring of patients, poor teamwork and leadership in facilities, blood shortages, patient delays in seeking care, and limited or poor antenatal attendance [23,29,30]. Looking at the impact of sub-optimal care on maternal deaths between 2008 and 2010, the National Committee on Confidential Enquiries into Maternal Deaths (2012) found that: "In 23.2% of cases the death was thought to have been probably avoidable and in a further 30.2% the death was considered possibly avoidable" [30].

Yet, there are also signs of progress. South Africa's ART programme - now the largest in the world – is making strides: since 2009, new HIV infections have declined by 63% and the mother-to-child transmission rate has fallen below 5% [31]. There are also efforts to better integrate HIV and TB services, and develop a national NCD plan [23]. Other policy reforms, including reengineering of primary health care and piloting of a National Health Insurance system, similarly signal renewed state commitment to expanding welfarism and implementing an inclusive and equitable health care contract. In this article, we use narratives of those seeking and delivering – negotiating – health care, to explore this contract in practice. In particular, we focus on access to maternal health, tuberculosis (TB) and antiretroviral (ART) services, given that mortality and morbidity in these areas account for a large proportion of the country's burden of disease [5]. Additionally, HIV, TB and maternal health require sustained engagement with the health system. As they are often closely associated, simultaneous access to more than one service may be required. This may present additional access challenges for patients and providers.

Methods

Big and small stories

Narrative research involves listening attentively to voices within stories to interpret the meanings that emerge

around events, people and actions; as well as the identities that are produced and reproduced through storytelling [32]. Often intensely personal, narratives are seen as a medium through which social realities speak, hide, contest, order and disrupt, whether as "big" or "small" stories. Big stories, commonly drawn from in-depth interviews and clinical encounters, "entail a significant measure of *reflection* on either an event or experience, a significant portion of a life, or the whole of it…*making meaning*" [33]. They are usually past-oriented and linked to important life events and rites of passage [32,34], such as the onset of illness, initiation of chronic treatment, or the birth of a baby. By contrast, small stories are more immediate and shared, found in everyday talk and local "sites of engagement" [34,35]. Expressed in snippets of interaction, rather than as coherent grand narratives, they are conducive to analyses of contemporary social media, corridor chat and conversations in social settings [33,34]. Without reflexive distance, they are often about very recent, or even upcoming, events, becoming "rehearsals for later action more than reconstructions of the past" [34].

Although big and small stories suggest different levels and entry-points to narrative research, they are not dichotomous and recently, there have been calls to consider the synergies between them [34]. In this article, we draw on both, using in-depth interviews with 45 patients and 67 providers, and field observations from twelve health facilities in one rural and two urban health subdistricts in South Africa. This study was carried out as part of the *Researching Equity in Access to Health Care* (REACH) project, a five-year, multi-method study of equity in access to TB treatment, ART and maternal deliveries in four South African provinces [24,36,37].

Ethical approval and consent

Ethical clearance was granted by the South African Universities of Cape Town (460/2006) and Witwatersrand (R14/49), and permissions were also obtained from relevant provincial and local health research committees and district- and facility-managers. Informed, written consent was obtained from all individuals interviewed. At a staff meeting, health care workers were invited to participate in facility observations, and signed consent was obtained from managers in observed areas. Written consent was obtained from patients before any consultations were observed. Posters in local languages informed patients and visitors that the facility was being observed for research purposes; a message often reinforced by staff announcing us in waiting areas.

Telling and documenting stories

Interviews and observations took place between June 2009 and July 2010. We were particularly interested in the challenges faced by both men and women living in rural and urban contexts, who were successfully or unsuccessfully accessing TB, ART and maternal delivery services. Successful service users were patients who were adherent to treatment or who had delivered in an appropriate facility, while unsuccessful users included patients whose treatment had been interrupted or who had delivered at home or before arrival (BBA) at a facility. Therefore, participants were purposively sampled according to these criteria and recruitment followed multiple means, including at facilities (for example, using admissions registers to identify BBAs, approaching patients queuing to see doctors, pharmacists, social workers); via community health workers (often tasked with tracing non-adherent ART and TB patients); and from local HIV/AIDS support groups (attended by a variety of patients – adherent and non-adherent, new and experienced). Providers were similarly selected purposively to reflect different age groups, levels of seniority, and length of service. Patients were interviewed in their home languages by trained fieldworkers, at/outside health facilities, in their homes, or other "sites of engagement" (for example, a coffee shop), where they felt comfortable to talk. We used an interview guide to encourage the telling of illness/pregnancy trajectories and treatment/delivery experiences within the context of everyday life: relationships, support networks, employment, education, and political transition. Providers were interviewed in health facilities about their career paths and understandings of access challenges, as well as their own health-seeking behaviours. Additionally, one focus group took place with twelve community health workers in the rural district, covering similar issues.

Interviews were audio-recorded and lasted between 45 minutes to 1.5 hours of recorded time although there were often delays and interruptions - small stories of daily life – that prolonged each engagement providing important insights that were discussed in weekly team debriefings. Interviews were translated into English, transcribed and reviewed by the research team for questions of clarification and further exploration, and we conducted follow-up interviews with patients we were able to trace (n = 21). All interviews were anonymized and stored on a secure server available only to the research team.

Team members also observed the services in each sub-district, across a few weeks, on different days and at different times. Formally, these observations were non-participatory, recorded as field notes and structured through an observation grid that drew attention to physical space, patient flow, interactions among and between patients and providers, daily tasks, and responses to unusual or problematic situations [38]. Less formally, we were often drawn in to the daily routines - locating and filing records, finding grant-related information for patients, preparing and drinking tea with

staff, chatting to patients in queues. Not always written down, we shared these experiences in various, often fragmented, ways - on the drive home, waiting for team debriefings, in response to a newspaper headline or someone else's experience- thereby generating our own set of small stories nested in the bigger narrative of access to health care.

From stories to narratives

Data were analyzed by members of the team using Atlas.TI. The analytical task of narrative research is to convert stories into narratives through actively listening to, and interpreting, textual voices. While interpretation starts within each story, it is not devoid of context but rather strives to "make sense of personal experience in relation to cultural discourses […] a window to the contradictory and shifting nature of hegemonic discourses, which we tend to take for granted as stable, monolithic forces" [32]. Stories are thus interpreted *in situ* and are often compared to similarly-located stories to gain a richer understanding of the situation, as well as the identities generated in specific contexts [32]. Our interviews and observations were situated in and around local clinics and hospitals – literal manifestations of the right to access health care and the democratic social contract. Our resultant narratives of inclusion and exclusion from the contract represent but one interpretation. However, while allowing for alternatives, narrative research is not a relativist exercise devoid of methodological rigour or "trustworthiness" [32]. Interpretation needs to be grounded in the texts analysed and tested against other explanations and a-typical cases, to show its feasibility. In our analysis, we embarked on an iterative process of interpretation by collectively sharing and debating our understanding of the stories with reference to social contract theory, and refining them into the narratives presented below. In selecting these narratives, we have tried to give voice to as many participants as possible. However, we recognise that these voices are limited in number and that other notions of inclusion/exclusion might be present - amongst those accessing services, as well as those who are partially- or fully-excluded from the health system as a whole. In recognition of the constraints of second-language translation and for clarity reasons, we have made minor stylistic and grammatical changes.

Results

Social contracts are clearly symbolic rather than conventional, legal contracts involving reciprocity, mutual consent, terms and conditions [10]. However, contractual rhetoric provides a way of organizing and revealing the moral vision, inclusions and exclusions of social contracts and our results are therefore loosely arranged to explore the terms, expectations, threats and assertions of the post-apartheid health care contract.

Entering and maintaining the post-apartheid health care contract

In this section, we explore the expectations that patients and providers have of themselves and each other, and their reasons for seeking or delivering health care services: why they enter and remain in the post-apartheid health care contract and what they expect from it.

Patients

In need of care

To become a patient and thereby enter the post-apartheid health care contract, individuals must need care. To establish need, the health system produces indicators, measures and clinical benchmarks that guide diagnosis and treatment. These include guidelines for interpreting physical symptoms, testing blood, urine and sputum, weighing patients, and analyzing their medical histories. In our study, most patients indeed sought care when they felt they were sick, pregnant or 'in labour' - in need - presenting with physical symptoms that providers then measured and assessed to determine a treatment course:

> I just started feeling my legs were painful, swollen and they were very sore, [I was coughing badly] so I decided to come to the clinic so that they can check it out […] and they ran some tests, they tested me for HIV and found that I was infected and […] have TB. So I had to go to classes where they taught me about the treatment of HIV, after that they referred me to [the ART clinic] they checked me, actually they took my blood, and then they gave me the HIV tablets […] TB tablets as well (female patient, 23, TB/ART services, rural site).

However, needing care from the patient perspective was not always enough to secure patient admission to the health care contract. Some patients *felt* very much in need of medical attention but did not always receive it, even if they expressed their need to providers. This could result in their exclusion, sometimes just temporarily, from the contract, with providers overlooking patient histories, patients confusing (often unexplained) treatment side-effects with ill health, lack of equipment, lost or unfiled records, or false test results.

> The clerks would tell people that their results were lost and advise them to have their tests re-done, instead of ever managing to get on top of the unfiled results' backlog (observation notes, ART services, urban site 2).

> My period was gone, I was two months when I found out that I was pregnant […] I went to the [Midwife Obstetric Unit] and they told me that they don't do pregnancy tests there and they told me to go to a private doctor, and the private doctor did the test (female patient, 29, maternal services (homebirth), urban site 1).

With his second case of TB, a casual construction worker (unable to work at the time of the interview due to his ill health) was told that his sputum tests were negative and to retest in eight weeks:

> I said to the sister, "but I can feel that I am [too] sick to wait for eight weeks" so sister said, "you want to have TB?" but I said, "sister, it is not that I want TB but I can feel my heart is sore and I am short of breath" (male patient, 35, TB services, urban site 1).

Conversely, some patients did not realise or acknowledge that they needed (specialized) care until the system 'told' them (particularly women diagnosed with HIV during pregnancy and patients who tested HIV positive through the TB service). Sometimes, individuals only entered the health system when they were extremely sick or during/after the birth of a baby; more than simply in need but in crisis.

> You still get patients who are very sick, being initiated very, very late in their stages of the illness (female social worker, aged between 30–34, ART services, urban site 2).

> The pains started around two […] Then at around three that's when I woke my baby's father and when he tried to find transport from our neighbours, we found that their cars do not have petrol. Then we called an ambulance and they were not cooperative […]. Then at around four he called them again and told them that I am ready to give birth now. Fortunately this time the [emergency services] lady answered the phone and she listened. He then explained to her that the baby is coming out now. Then the lady asked if there was an older woman in the house but he told her that there is just the two of us there. Then on the other hand they heard the baby crying. Then the lady asked if everything has come out and he said no […] (female patient, 27, maternal services (homebirth), urban site 2).

Complex, varied reasons were offered for such delays, including stigma and fear of being diagnosed with HIV or TB, high costs of seeking care (see also [24]) and, for six of the eight babies born before arrival, unavailable or delayed ambulances (see also [27]).

In keeping with the narrative of (extreme) need, once admitted as patients to the health care contract, many chronic care participants were motivated to stay by the alleviation of physical symptoms and improved health:

> The hospital visits are good for me because I get my treatment and that will help me stay alive for a long time (female patient, 23, TB/ART services, rural site).

> […] reason that made me to continue with the treatment is that I feel comfortable with the treatment and you cannot see it that I am ill. I am no longer coughing or suffering from headaches. I am always feeling well and I have no complaints with my health (female patient, 32, ART services, rural site).

Complying with the terms of the health care contract: the docile patient

However, from the perspective of the health system, needing care and feeling better with treatment, while important, are not sufficient, for ongoing patient inclusion. Ideally, patients must also take on a medical discourse and internalize their responsibilities:

> [Before being initiated onto ART, patients] have to attend three classes. The day they have to initiate, they come to us and there is a form they have to sign that states they do understand that they have to take the medication for the rest of their life. Because sometimes they might come back and say that they didn't want to take the treatment so by signing the form they are actually binding themselves and showing responsibility (female enrolled nurse, aged between 45–54, ART services, urban site 2).

Pregnant women must similarly show responsibility by following an ideal care pathway: early and regular attendance of antenatal care, pre-booked deliveries, postnatal care, and re-entry into family planning services. In this narrative, to be successfully admitted to the health care contract, patients themselves must become authorities, "experts" [39], about treatment adherence, weight, blood pressure, good nutrition, medication, CD4 counts, viral loads, and other medical touchstones important for their physical recovery or safe pregnancy: "they have to know them by heart" (female enrolled nurse, aged between 45–54, ART services, urban site 2). They have to become self-disciplined [40].

Additionally, patients have to show that they can be trusted to maintain this contract, usually by expressing willingness, commitment and adherence to chronic treatment or natal care (measured by pill counts, improved physical symptoms, blood results). Being compliant, deferring to the provider's opinion and accepting their

diagnosis, treatment path and rules, are also important for ongoing patient inclusion. For many patients in our study, this meant being quiet and passive – becoming "docile bodies"[40] – rather than risking humiliation, ridicule or ostracism:

> It's like the nurse that was helping us [with our antenatal care] had an attitude; when we asked her something, she treated us like children or comics. She was so impatient […] shouting all the time, when we asked for help she would get irritated and you could see that she is irritated. Especially there was another lady here […] who did not understand English, meaning these medical terms they use […] they made her a joke […] All the nurses were laughing at her […] You do understand that this lady didn't know anything, that is why she was asking because she doesn't know anything like that […] once when I was trying to ask something as well and this nurse just looked at me as if I was crazy and never responded, so I just kept quiet (female patient, 25, maternal services (stillbirth), urban site 2).

Here, belittlement and public shaming of "ignorant" or "troublesome" patients by providers – a commonly reported practice in this study and previously [26,41,42]– serves as a form of contractual maintenance, keeping docile those who witness the public spectacle, while simultaneously reprimanding transgressors [40]. In Foucauldian fashion, successfully included patients were often also rewarded with greater autonomy and independence *viz.* fewer clinic visits, self-management of larger volumes of treatment drugs, and other incentives to maintain their contractual commitment:

> you have to come to the clinic every time to take the pills but if you [show that you] know how to take the pills […] they give you more pills to take on your own […] when they see that you are committed into taking your treatment (male patient, 36, TB/ART services, urban site 2).

Providers

Moral guardians of the post-apartheid health care contract

As an expression of the right to access health care for all, the post-apartheid health care contract has to be inclusive of everyone; no one in need of care should be excluded by having their treatment or care denied. This rhetoric was often repeated by providers in our study:

> Remember that you don't require an ID or passport. Everybody gets treatment, no matter their creed, race, nationality (female programme manager, 50, ART services, urban site 2).

> So we know we have been told to treat [patients] equally irrespective of their social standing or whatever (female assistant manager, 61, maternal services, urban site 2).

However, with the onus falling on patients to prove their worthiness for inclusion, this all-inclusive ideal was rendered conditional in practice. Not everyone in our study was automatically or un-problematically included. Simultaneously, the creation of conditions for patient inclusion in the health care contract conferred a form of moral guardianship on providers: contractual caretakers who ultimately determine which patients to include in what ways. For many providers in our study, this guardian role was expressed as one of paternalism, reminiscent of an era before patients had the rights they do now [41]:

> You know, patients are like children. A child does not know a thing. You as an adult, you teach the child. The patient knows nothing about TB. He knows nothing about what he is suffering from. We've got all the knowledge and the facts about TB (female operational manager, aged between 50–54, TB services, urban site 2).

Often, steering patients on the "right" path, teaching them to do the "right" thing, was tied to an identity of working altruistically, "in service" of patients.

Altruistic professional versus uncaring mercenary

With their job descriptions and place in the system, health care workers are - by definition – included in the health care contract. In our study, many spoke about becoming providers and thereby entering the contract in response to a "calling" or willingness "to serve"; a vocation. For some, this was an active political decision to uplift their communities and support the country's transformation agenda. However, others admitted more pragmatic reasons for initially joining their profession, mostly linked to limited career opportunities, either when apartheid policies restricted career paths (especially for black women) [43], or post-1994, where training is state-subsidized. Yet, most followed with: *but*, "I have learnt to love nursing and think it is a calling in a way" (female programme manager, 50, ART services, urban site 2), deferring to the dominance of an in-service narrative:

> Currently, I am in public service because it's part of the training and I am specialising in obstetrics, so […] I am forced to be part of the service. [But] I intend to stay longer even after qualifying as a specialist because it's eh, I think the public sector has more people who need us than private: people who are not cared for, people who have less resources who cannot

> afford the private doctor, so they have got nowhere to go. And they need us most. So I believe it will be the right thing to be where l am needed actually […] where people, the poorest of the poor, are needing a doctor (male registrar: obstetrics, aged between 35–44, maternal services, urban site 2).

This envisaged ideal was given further definition by providers who spoke about expected ways of being and interacting once in the provider role - caring medical experts and *more*: professionals, conducting themselves "properly", maintaining confidentiality and establishing boundaries with their patients:

> [My] problems are left behind, put them aside because […] the patients […] too have their own challenges in life and part of those challenges are the reason why they are here and they want us to help them, so it won't be professional for me to offload to them as a service provider (female VCT counselor, 28, TB/ART services, urban site 2).

"Being professional" was also linked for providers to punctuality, neatness, institutional loyalty, supporting and respecting colleagues, and showing willingness to go the extra mile; a reminder that providers operate and are accountable within a complex organisation, governed by formal employment contracts and codes of conduct. This requires that providers respond to a set of expectations from within the health system (alongside acting in the service of patients and communities) in order to maintain their own inclusion in the health care contract. They too must become "docile bodies" [40].

Some patients in our study similarly imagined an ideal provider motivated by altruism and professionalism. But, this expectation was often revealed only in contrast to a disappointing or negative experience:

> […] the staff here is useless because *they don't do their work like they love what they do* (patient comment, observation notes, ART services, urban site 2, emphasis added).

> And even the way they were treating us it was *not a proper way* of treating other people. We don't deny that we are there to get help but that is *not the way they should* offer us their help […] they don't respect us at all, it's like we are there to bother them, some of them it seems like they bring their problems from home to work, you can't wait to be out of the clinic sometimes because of the way they treat people (female patient, 25, maternal services (stillbirth), urban site 2, emphasis added).

Other patients had lower expectations of health care workers, repeating a popular public stereotype of providers as uncaring and mercenary, acting in their own interests, rather than in support of patients or communities [44]. Many providers, especially nurses who had been working in the system for a long time, were also aware of, and reacted to, this stereotype:

> [When community members see you are a nurse] they suddenly forget that you are one of them […] I usually take off my epaulets the minute I reach home. I go back into my ordinary clothes and be just like the basic person that is accessible to them (female assistant manager, aged between 55–64, maternal services, urban site 2).

> […] after work, I've got a spare jacket in my car. I take off this [gestures to jacket with epaulets] and wear my spare jacket because people no longer respect nurses like before. They say nurses are not nice, they are very bad. I don't know why (female professional nurse, 60, maternal services, urban site 2).

Such representations of providers (particularly nurses) as "not nice" or "very bad" contradict and threaten their stated raison d'etre of altruism and professionalism, and many nurses in our study expressed hurt, anger, demotivation, and even withdrawal from the contract as a consequence. While most providers identified positive changes with democracy, some (mostly older nurses) also mourned a lost identity; on one hand nostalgically evoking a sense of belonging to an earlier social contract which had been configured - in a highly complex way around race, class and gender - to accord nurses a certain social status within their communities [43], and on the other, conveying a sense of displacement, of not quite belonging to the present social contract and feeling marginal in the changed context.

Threatening the post-apartheid health care contract

Veitch (2011) argues that those within the margins of society are not marginal in the discourse of the social contract but rather generate anxiety and attention because they have *potential* to affirm (if they can be re-included) or derail (if they refuse to participate) the moral vision of an inclusive and equitable contract, and the structural, systemic divisions that this ideal may gloss over [10]. In Foucauldian terms, the social contract produces "deviant categories" of people – hazardous, useless or worthless – who simultaneously threaten and entrench the status quo and the docile bodies it safely includes [10]. In this section, we consider patient and provider accounts of access barriers to health care and ways in which these threaten the post-apartheid health care contract.

Defaulting or delayed: the dangerous patient

Drug resistance caused by patients interrupting their ART or TB treatment (defaulting) has undermined the TB cure rate and compromised the efficacy of ART, creating enormous frustrations for providers, patients and the South African health system as a whole [45]. Similarly, the delayed presentation of pregnant women to antenatal care is a major challenge for improving the country's poor maternal health outcomes [29]. For providers in our study, defaulting or delayed patients were generally represented as dangerous because of their risk to patient- and community-health but also, because they were perceived to threaten provider professionalism: "when they have defaulted it comes back on you" (female student nurse, aged between 25–30, TB services, urban site 2). Defaulters draw unwanted attention to clinical services (and a related "bureaucratic compulsion to meet targets" [10]) and thereby challenge the quiet inclusion of providers in the healthcare contract:

> Now remember that if your TB cure rate goes down, [the authorities] will phone the manager of the clinic to say, "hey there is something wrong with your services?" Now if you don't go in and pick up the areas of concern and address them you are not going to be able to account for your low cure rate, you know (female operational manager, 54, TB services, urban site 2).

> I get affected when I have defaulters because they put a drawback on me and I can't push [up] my cure rate […] I look like I am not taking my job seriously, you see, something like that. And it looks like I don't give health education but you know that you do give them health education (female auxiliary nurse, 53, TB services, urban site 2).

Staff in maternal services similarly expressed anxiety and frustration about having to manage complications (and associated high mortality and morbidity rates) that might have been avoided if women entered the health care contract earlier in their pregnancies.

Various explanations were offered for defaulting and delayed attendance of antenatal care services, including HIV-related stigma, lack of social support for patients, and patient beliefs and pressures:

> When a patient is sick, this is now culturally speaking, they will first try other things, you see, before they come to hospital. As a result of that, the greater majority of the patients who die usually come late to hospital, very late. And now with HIV around, it's even worse. And sometimes, while patients are still in hospital the relatives will come and say "look, we would like to have our patient because we have established what the problems are, we need to take the patient home" (male doctor, age unknown, TB services, rural site).

Treatment side effects, health improvements with treatment or simply wanting a break from the chronic routine were also presented as reasons for defaulting:

> When they start to feel better they will give you trouble (female auxiliary nurse, 53, TB services, urban site 2).

> This lady was on treatment since 2004, then she just said, "I just wanted to take a break and um I mean I've been taking this medication far too long now and I felt that I was better […] so I just wanted to take a break" and actually when she came back [six to eight months later], she was very sick (female social worker, aged between 30–34, ART services, urban site 2).

Some defaulters were portrayed as "stupid" or "ignorant":

> Patients are so ignorant because honestly and truly they are educated on this and all the information is all around them but because of blind ignorance […] they end up saying, "I'd rather die than go to the clinic to take treatment" (female student nurse, aged between 25–30, TB services, urban site 2).

Others were presented as defaulting out of entitlement, wilfully abusing their contractual rights without living up to their responsibilities "because if one feels that they want to stop treatment they do so":

> Before people had rights, patients used to do the right things and you wouldn't fight or argue with them, everything was nice (female auxiliary nurse, 53, TB services, urban site 2).

> I hate the patients' rights with all my heart. Because they have got rights and they ignore the responsibilities […] And you can't do a thing, your hands are tied (female operational manager, aged between 50–54, TB services, urban site 2).

Poverty: the suffering patient

Poverty was identified by both patients and providers as a significant barrier to uninterrupted patient inclusion in the health care contract, impacting especially on transport affordability, particularly difficult for those in the rural area, where distances to health facilities are large – see also [24]) and the availability of food for patients (essential for the efficacy of ART and TB treatment):

> [Defaulters] don't have money to go to [the clinic], nê? At the same time they don't have food at home,

> they don't have money to buy soap to wash (female staff nurse, 28, TB services, urban site 1).

Most patients in our study wanted to be adherent, often making large sacrifices in an effort to remain included in the health care contract - walking long distances daily (often in bad weather while in frail health), waiting for a number of hours in long queues, borrowing medication or money, sometimes even selling assets (see also [24]) - and consequently feeling that if they had to break the contract, this was not done by choice:

> I stopped in the middle because these tablets you cannot take them without eating. And I was not working and these tablets are eating your stomach and [you vomit] when you have not eaten. I tried to borrow some money from someone to sell some cheap stuff at home so that I can eat because even my children were not working - they were looking to me [to put food on the table]. That is why *I look like someone who is taking treatment wrongly* [i.e. defaulting]. Then after I sold those things, then I saw the profit; there was food in the house then I always came in here […] So when I started having some money I always came to the clinic always (male patient, 53, TB services, urban site 1, emphasis added).

Many providers were sympathetic to such "everyday suffering" [20-22] and did not allocate blame: "at the end of the day, you know that [patients] can't take medication on an empty stomach" (female pharmacy assistant, 26, ART services, rural site). Rather, this suffering was largely viewed as beyond the control of patients, providers and the health system; a social determinant of health requiring upstream and long-term solutions:

> Maybe to get them a job so that they can get something to eat, because most of them, they are not working, there's no pay. If maybe, the government can do the pay [grants] for them […] (female acting TB assistant, 27, TB services, urban site 1).

In addition, however, many patients in our study *included unacceptable provider actions and attitudes* as exacerbating their suffering.

Unacceptable care: the dangerous provider

In our study, patient inclusion in the health care contract (mostly from the patient perspective) was threatened by unacceptable provider behaviour and the delivery of uncaring care. In some extreme cases, negative interactions with providers resulted in patients withdrawing (even if temporarily) from the contract by dropping out of services:

> […] the nurse was standing in front of many people talking to me loudly saying that my CD4 count now is very low and I have to start the treatment afresh. And that hurt me a lot because *she should have been* polite, maybe call me to her office because she's got one, and talk to me nicely, explain that because I have defaulted and my CD4 count is low, then I have to start the treatment afresh, *unlike what she did* shouting at me in front of many people. Then I went home but I was not ok with that. Then after two or three days I came back here and told her how I feel about what she did. And she only shouted back asking me why am I there at that time to collect the pills and that's when I decided to give up the pills [for eight months until I developed sores. Then I forgave the nurse and went back to the clinic] (male patient, 35, TB/ART services, urban site 2, emphasis added).

More typically, chronic patients continued (or attempted) to access services but were left feeling disrespected, dehumanised and devalued in these interactions. Some maternal patients similarly narrated negative experiences with health care workers during antenatal care and labour:

> I remember this one nurse as I was screaming in pain she just walked out and the other one was sitting on the corner with her phone and her feet on top of a table, laughing and chatting […] I started banging the wall because I couldn't bear the pain. She just said to me I shouldn't do that because I will break down the hospital. The other one said to me "you are here to bother us" and I responded that the only thing I'm asking for is water - they still said I'm not supposed to drink water (female patient, 26, maternal services (stillbirth), urban site 2).

While never questioning their own commitment or intention to serve patients, certain providers in our study did reflect on the behaviour of a few "difficult" colleagues:

> [She is] somebody who is difficult […] She does not see the perspective [of the mothers or the hospital's efforts to entrench a new baby friendly, kangaroo care policy]. We are struggling [to manage her] (female assistant manager, 61, maternal services, urban site 2).

Dismissive, overly-technical or limited communication with patients was also identified by providers as a challenge for sustaining patient inclusion:

> [Ongoing access] depends on the way we as providers treat them [patients] and how well you communicate with them (female VCT counselor, age unknown, TB services, urban site 2).

Under-resourced: the overstretched provider

For providers in our study, unacceptable care was largely narrated around the negative actions and attitudes of *individuals*. In contrast, resource constraints and staff shortages emerged as more systemic threats to the quality of care delivered and, ultimately, their own inclusion in the contract:

> I would like to see the clinic being well staffed so that we can give quality nursing. What we are doing now is not quality nursing. We are just trying to cover everybody; nobody must go home having not met the nurse. And we don't feel good about it. We are not practising what we are trained to do but it's beyond our powers. […] When I see a crisis there, I turn that way, another crisis there, I turn that way. There is no planning (female operational manager, aged between 50–54, TB services, urban site 2).

> […] the clinic is growing, it's not frozen [unlike staff posts] and the work must go on, you know because you don't want the patients to be unhappy so […] we try to make the best of you know the few resources but of course, I mean I woke up today I was sick but [came to work nonetheless because …] we see over 120 patients in the clinic and then [I am the only] doctor, it's crazy (male doctor, 36, ART services, urban site 1).

Feeling overstretched and under pressure, yet also beholden to "keep patients happy", was a common complaint for providers, often causing conflict, rather than complementarity, between being an accountable employee responsible for "getting the work done" on one hand, and acting "in service of patients", on the other: "at the end of the day it's not the best quality of care that you are supposed to [deliver]" (female professional nurse, age unknown, TB services, rural site). Through this narrative, providers perceived themselves as "doing their best" under difficult circumstances (much like "suffering" patients). Any compromised patient care was presented as beyond their control and despite their best intentions as guardians of the contract. Many providers felt highly anxious and frustrated by having to manage competing and intense pressures within the constraints of limited resources, further fueling a sense of marginalisation from the present context:

> I lie awake at night, worrying that I will be sued, my house and car repossessed, my family compromised by these challenges. And I think, "why don't I just emigrate or leave the public sector?" (manager comment, observation notes, maternal services, urban site 2).

Demotivation, burnout, and withdrawal from the system are ever-present threats on the provider-side of the health care contract. Patients in our study were not unaware of these challenges but felt they should not have to bear the negative consequences thereof:

> I felt that I was not treated the way I wished I would have been treated. I know it is not a private hospital and I understand [providers] are overworked and underpaid but it is not my problem. It should not affect my health (female patient, 26, maternal services (stillbirth), urban site 2).

Reasserting the post-apartheid health care contract: ways of including

From a Foucauldian perspective, the social contract seeks to reward and re-integrate those on its margins (defaulting or suffering patients, overstretched or difficult providers) when they comply with contractual norms and return to the mainstream, while denying access to those who stay out of the contractual reach [10,46]. In this section, we consider some ways in which the post-apartheid health care contract strives to reassert itself when threatened by access barriers, including poverty, resource constraints and unacceptable service delivery.

Trusted, docile patients and quietly productive providers – the successfully included – are, in many ways, invisible in the health care contract, while defaulters from chronic care and late-comers to maternal services, along with the providers responsible for them, solicit much more attention. For ART and TB services, the health system has developed extensive procedures and protocols for trying to re-include defaulters: follow-up telephone calls, home-based visits, making use of treatment buddies, volunteers and community health workers, sometimes even nurses themselves, to trace people:

> [Our TB nurse] was so dedicated, she would go out to look for a patient that hasn't attended to for a number of days […] personally she would go out and find the patient ask, tell the patient that she didn't see her in the clinic […] beyond the call of duty (female student nurse, aged between 25–30, TB services, urban site 2).

The caring provider

Within the South African health system, untraceable patients are usually categorised as "lost to follow up" and excluded, with little further effort to find them. However, for those on the margins in our study (traced defaulters or those who seem about to default), a number of strategies were deployed to retain or return them to care. At an individual provider level, these included positive rewards such as offering encouragement, friendship, food and financial assistance:

> We've had to give money […] privately […] to patients, which we don't encourage but sometimes you hear their stories, you just cannot hold back (male doctor, 36, ART services, urban site 1).

Providers also sometimes mediated health beliefs and cultural practices for patients at risk of compromising the efficacy of their ART or TB treatment or defaulting in favour of traditional medicine:

> I also tell them that, "people you can do your traditional things but please ask them not to make you vomit […] They can steam you or do anything but they should not make you vomit or give you a laxative because when they do, all that they are getting rid of is tablets in your blood system, you see" (female auxiliary nurse, 53, TB services, urban site 2).

> I just tell them that, "if that is what you believe in then its fine" because I can't stop them from believing in what they want to […]. I just explain to them that sometimes HIV can become latent and undetectable and the person will start believing that they are cured whereas they are not, that person can still infect the other, without forcing them to believe in what you say, they have to make their own choices (female VCT counselor, age unknown, TB/ART services, urban site 2).

Respectful communication

The value of "good communication" was acknowledged by providers in both chronic and maternal services; important for retaining patients in the health care contract, reasserting the terms of engagement, and even expanding the scope of such inclusion to additional or future services:

> I think communicating with the clients is very, very good. You know talking to them even for a short while means you are part of them: "remember that we are part of the community" […]. It's a matter of marketing our services that we are rendering at our catchment area so that they know […]. One day you want to talk about cleanliness, one day you want to talk about children, you know, you want to talk about the road to health (immunization) card. You know, just to remind them that these are the things *we expect you to do at the clinic* (female operational manager, 54, TB services, urban site 2, emphasis added).

For patients, respectful, attentive communication, humour and kindness positively enhanced their access experience (in contrast to the alienating and disempowering effects of adverse engagements). Often this alleviated their suffering and became a reason to regularly return to services:

> I started to know the sisters that helped me and I started to talk with them. They would ask you, "how do you feel? […] what can I tell them about the illness?" […] They helped me a lot. Sister [name] was my pillar here. She was making me happy, she always smiled and she encouraged me to say that it was worth it to live. It was a pleasure to come to this clinic (male patient, 49, TB services, urban site 1).

Facility-level leadership, flexibility and initiative

Beyond individual provider actions of kindness, facility-level initiatives, driven or supported by managers, were also in place to overcome access barriers and threats to the health care contract. Some of these were consistent with national policies and approaches, such as the ongoing education and training of patients (always potential defaulters) and the implementation of policies aimed at improving quality of care and acceptable service delivery, for example improving the baby-friendliness of hospitals. Other strategies of patient retention were more directly reliant on the initiative and flexibility of senior staff and managers. For example, at one ART clinic where transport "used to be a problem" for many unemployed patients living in an impoverished area eight kilometres from the service, the facility manager arranged for use of an inter-clinic bus previously reserved for x-ray patients, as a way to cut out transport fees. Additional efforts to tackle obstacles included managers seeking donations of food parcels, growing vegetables for patients on site, hosting or partnering with non-governmental and community-based organisations, facilitating patient applications for disability grants, and using referral systems, social workers and counsellors to strengthen available social infrastructure and support.

Individual and institutional efforts were similarly described to manage and contain hostile or uncaring providers and an under-resourced working environment. These included the provision of regular in-service training aimed at imparting "professional values" to providers; constantly reallocating resources, such as linen, medical supplies and staff, between zones of crisis in a facility "we rob Peter to pay Paul" (female assistant manager, 61, maternal services, urban site 2); and encouraging formal and informal support between colleagues and across facilities:

> This is a very stressful department. We don't have formal debriefing [anymore because we ran out of funds]. If a staff member gets to a point with a patient where they just can't take it, they go to the kitchen so that they can rest […] none of the staff should feel imprisoned. [We run our own debriefing sessions]. The doctor is a priest, so if the staff need to, they can

talk to him on site (female programme manager, 50, ART services, urban site 2).

Providers also partook in small rituals, such as a daily morning prayer - typical at most facilities in the country – which seemed to encourage their sense of belonging and reinforce the vocational nature of their work (see also [47]). Provider inclusion was similarly nurtured through informal but institutionalised involvement of staff in personal networks and lives of colleagues: gossip, baby showers, funerals, weddings, birthdays:

Observer 1: [The facility manager] calls for a meeting [to discuss three things outstanding from yesterday's agenda]: birthdays, farewells and baby showers. They start with deciding what would be the right amount [for staff to contribute financially] R50 or R30 (US $5-3)? A heated debate ensues with some arguing that R50 is a lot of money […] put the matter to a vote again and then after a long time decide that R50 is the right amount. A question is asked about what to do on birthdays […] one staff member presents an example to say that what they did for Valentine's Day was everyone contributed R5 for cakes.

Observer 2: This meeting is the most animated and involved I've seen the staff all day! (observation notes, ART services, urban site 2).

Discussion

Although access to health care is a right guaranteed for all in South Africa, access barriers continue to undermine this right. In our study, the constitutional ideal of automatic and positive access for everyone, i.e. unconditional inclusion in a post-apartheid health care contract, was contested by everyday patient and provider stories of seeking and delivering health care. Through these stories, we identified a number of barriers to TB treatment, ART and maternal services, including poverty, the nature of illness and treatment, difficult or uncaring providers, an under-resourced health system, negative provider stereotypes, and a "compulsion to meet bureaucratic targets" [10], with related pressures for providers to be accountable employees. In narrating these barriers, participants revealed differing insights and expectations of the health care contract, and with this, differing, potentially conflicting, identities of inclusion and exclusion: defaulting versus suffering patients; uncaring versus overstretched providers.

To be successfully included in the post-apartheid health care contract, patients had to earn and maintain their position by demonstrating that they were sick, responsible and docile, adopting a specific form of patient identity that was often rewarded with autonomy and independence, as well as improved health. Without this identity (which for many patients, was closely connected to whether they had financial means to regularly attend services or afford food with which to take their treatment), patients risked being humiliated or even excluded from services. With a narrative of defaulting, providers described excluded and dangerous patients, dangerous to the population and their own quiet inclusion in the health care contract. Providers also described their efforts – as guardians of the contract - to re-include defaulters. These efforts were linked to institutional pressures to improve cure or retention rates and be accountable employees, as well as to serve patients. Yet, in the resource-constrained environment of the health system, many felt overstretched, unappreciated and unable to consistently deliver good patient care (see also [48]) not excluded but also not safely or positively included – "adversely incorporated" [49] - in the health care contract, and for some, marginalised from the broader social contract through a perceived fall in the social status of nurses.

With a counter-narrative of patient suffering, the financial struggles, competing responsibilities and daily hazards of living emerged as barriers to access [21,50]; social determinants that generate similarly insecure forms of inclusion or even (temporary) exclusion from the health care contract. Although many providers were sympathetic to patient barriers of poverty and difficult life circumstances, for patients, suffering was more than adverse socio-economic conditions. It was exacerbated by uncaring, hostile or dismissive providers and certain health system arrangements, which were often intended to curb defaulting, yet added to the risk of patients dropping out of the system. Conversely, caring, respectful providers and facility-level efforts to alleviate affordability and availability barriers assisted positive patient inclusion in services.

Conclusions

Establishing individual, population and social health in fragile and post-conflict societies requires not only overcoming past and present barriers to care, but negotiating and implementing a new social contract. Conceptualising access to health care as a social contract, a negotiation between two parties, helps to reveal the relational, constructed nature of patient and provider identities: *created*, as well as reflected, in the social exchanges of health care delivery [51]. Closing the distance between patients and providers, while not an easy policy task [52], may potentially transform these relationships and shift identities of exclusion and insecure inclusion to more positive forms. Because the expectations, threats and terms of the health care contract differ depending on 'where' an individual is positioned and 'who' they are, jointly engaging citizens and state representatives (including health care providers, managers and policy

makers) to re-examine this contract may contribute to narrowing gaps in access. Such engagements could potentially be facilitated through existing legislated advisory and consultative bodies, *viz.* Clinic Committees and Hospital Boards, which formally bring together community representatives, civil society structures and service providers [13,53,54]. While these bodies presently face a number of challenges, including inadequate resourcing and lack of capacity [53,54], the current emphasis on NHI policy reform has seen renewed interest (including from donors) in community participation and governance [53,55] and thus presents an opportunity for reinvigorating such sites of engagement and piloting of patient-provider dialogues at a local level. Additionally, renewed policy interest in management strengthening and health worker training offers an opportunity to advocate for an expanded curriculum that engages with these different perspectives and access challenges [55]. Materials could be designed to explore – through a facilitated process - the differing expectations and identities attached to the health care contract: debating and problematising stereotypes of "defaulting" patients and "uncaring" providers, promoting examples of "caring" providers and "responsible" patients, exploring ways for providers to account to patients, communities and each other, encouraging patient agency, and better-rewarding providers who deliver patient-centred care.

Alongside surfacing challenges of (un)acceptable care, social contract theory also allows for a re-examination of cost and physical barriers to accessing and delivering health care services. Many of these barriers – poverty, suffering, resource-constraints – extend beyond the scope of the health system, excluding people not only from health care but from a wider democratic social contract. Yet, the health system is well-positioned to coordinate and lead intersectoral action for social reconstruction (nationally and locally) and should be better integrated with transitional justice processes in fragile and post-conflict states [56]. Additionally, critical social contract theory warns against a retreat or weakening of civil society with a contractual shift from authoritarianism to democracy. Holding the state accountable and making health matter requires coordinated, robust social activism [13], alongside academic inquiry and evidence-based research. Furthermore, rendering visible and connecting the political economy, institutions and social relationships that create and sustain identities of exclusion and inclusion - a (re)politicization of suffering – may offer new policy insights and opportunities for better "rehearsing" [34] a future that is more equitable and inclusive than the stories in our study currently anticipate.

Competing interests
The authors declare that they have no competing interests.

Authors' contributions
BH conceptualised and wrote the first draft of the manuscript, which was critically reviewed by JE, JG, LPK and LT. All authors contributed to subsequent drafting and editing of the manuscript. BH, JE and LPK contributed to the study design and data collection. All authors read and approved the final manuscript.

Acknowledgements
This study is part of the *Researching Equity and Access to Health Care* (REACH) project. We thank all of our REACH colleagues who contributed in so many ways to the overall project and express our sincere gratitude to all those who took part in the study and generously shared their stories. We also thank the editors and two anonymous reviewers for their constructive comments and insights. This work was carried out with support from the Global Health Research Initiative (GHRI), a collaborative research 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 (103460–054). BH's research is also supported in part by the National Research Foundation (NRF) of South Africa (86472) and Carnegie Corporation of New York. As the South African Chair for Health Policy and Systems Research, JE acknowledges the support of the South African Research Chairs Initiative (SARChI) programme of the Department of Science and Technology (DST), administered by the NRF. Funding for this publication was supported by the SPARC fund, University of the Witwatersrand, South Africa. We acknowledge that the views expressed, findings and conclusions are solely the responsibility of the authors and that the funders accept no liability whatsoever in this regard.

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Received: 29 October 2013 Accepted: 6 February 2014
Published: 15 May 2014

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doi:10.1186/1744-8603-10-35
Cite this article as: Harris *et al.*: **Adverse or acceptable: negotiating access to a post-apartheid health care contract.** *Globalization and Health* 2014 **10**:35.

Research Article 3: Bringing justice to unacceptable health care services? Street-level reflections from urban South Africa

Harris, B., J. Eyles, L. Penn-Kekana, J. Fried, H. Nyathela, L. Thomas, and J. Goudge

2014 Bringing justice to unacceptable health care services? Street-level reflections from urban South Africa. International Journal of Transitional Justice 8(1):141-61.

The International Journal of Transitional Justice, Vol. 8, 2014, 141–161,
doi:10.1093/ijtj/ijt028
Advance Access publication: 30 December 2013

Bringing Justice to Unacceptable Health Care Services? Street-Level Reflections from Urban South Africa

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Abstract[1]

Transforming repressive institutions into respected instruments of justice is necessary for the social reconstruction of fragile and postconflict states. Yet, little attention has been given to the role of health systems in facilitating such change. We situate South Africa's right to access health care as part of a broader sociopolitical endeavour to 'bring justice' in the aftermath of apartheid and argue that street-level bureaucrats tasked with

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[1] This study is part of the Researching Equity and Access to Health Care (REACH) project. We thank all of our REACH colleagues who contributed in so many ways to the overall project and express our sincere gratitude to all who took part in the study and generously shared their stories. We are deeply grateful to the editors and three anonymous reviewers for their thoughtful and constructive comments on the article. This work was carried out with support from the Global Health Research Initiative, a collaborative research 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 (103460-054). It is also supported in part by the National Research Foundation of South Africa (86472) and the Carnegie Corporation of New York. We acknowledge that the views expressed, findings and conclusions are solely the responsibility of the authors and that the funders accept no liability whatsoever in this regard.

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delivering health services are a gauge of both individual and institutional transformation. Using cases from two urban areas, we consider responses to inaccessible antiretroviral therapy, tuberculosis treatment and maternal deliveries and ask whether these ameliorate or compound access barriers. We also explore some conditions for bringing justice to street-level interactions. Our cases suggest that, if left unchallenged, negative street-level bureaucracy may compound inaccessible care for patients and perpetuate a wider culture of disempowerment, deprivation and poverty – ongoing structural violence – for citizens, while positive provider practices may be ameliorative. Strengthening street-level accountability and engendering respectful, empathetic provider practices is consequently vital to improving access to services and contributing more generally to the restoration of justice and health in society.

Keywords: South Africa, health, institutional reform, restorative justice, social reconstruction

Introduction

One Friday evening in 2009, I, Harry Nyathela, an AIDS activist and then-fieldworker in this team, was arrested. The charges were later dropped but I spent the weekend in the holding cells of a police station in Soweto, South Africa. Here, my sister delivered my antiretroviral therapy (ART) and the police committed to giving me treatment twice daily as prescribed. This happened each morning but, on the two evenings, the night officer refused me my pills, effectively denying my right to access health care during incarceration; a right that is constitutionally guaranteed.

Assisted by members of our team, I took this case to an NGO, Lawyers for Human Rights and, with their support, laid a charge. The night officer was subjected to an internal disciplinary process and found guilty of withholding my medication, at which point the station commander asked me, 'What would make you happy in resolving this?' Rather than a fine or suspension, I proposed that I be personally involved in training all members of the station on human rights, imprisonment and HIV, including ART and treatment literacy. Within this wider intervention, and to show him that he was not above the law, I requested that on each day of the training, the night officer:

1. Collect and deliver me from my house in a courteous manner; no hooting, he was to come up to my gate;
2. Bring me lunch supplied by the police station; and
3. Sit in the front row of the training.

The training took place over a week and involved all members of the station. The night officer sat in the front row, drove me to and from home and delivered my lunch. At the end of the week, he offered an apology – he really seemed genuine and remorseful – and has since remained in touch, phoning on a regular basis to check that I am okay. Subsequently, I have facilitated similar trainings at two other police stations in the area, and am often invited to deliver motivational talks to police and prison officials. It was a bad experience but, for me, justice has been served – personally and also, I hope, by avoiding similar victimization for future arrestees through the education and training I helped to deliver.

–Harry Nyathela

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Harry's story is one of access denied and justice restored. It took place 15 years into South Africa's democracy, where the right to access health care is constitutionally enshrined and legally protected. Yet, it evokes the country's apartheid past, in which human rights violations were entrenched in multiple ways, including through petty abuses by state bureaucrats as well as the broader dispossession, structural violence and institutionalized racism of an unjust system.[2] As access denied, Harry's story illustrates the difficulty of implementing a human rights culture and transforming institutional and interpersonal relationships, despite fundamental policy and legislative change. As justice restored, however, Harry's experience suggests a break from South Africa's past – an empowering and transformative response to the abuse of power by a state bureaucrat.

For fragile and postconflict states, transforming repressive institutions and those who work in them into respected instruments and agents of justice is a crucial part of the transition away from authoritarianism.[3] In the immediate aftermath of war and mass violation, priority is usually given to rebuilding state security forces due to their role in past violence and importance for keeping (often fragile) peace.[4] Little attention has been given to the health system as a potential facilitator of social reconstruction and peacebuilding, 'to the detriment of the whole peacebuilding enterprise.'[5] Additionally, Pham et al. argue that a public health perspective is urgently needed to assess and shape transitional justice policies 'designed to address the effects of war on traumatized communities and bring justice.'[6] In this article, we situate South Africa's right to access health care as part of a broader sociopolitical endeavour to 'bring justice' in the aftermath of apartheid and argue that frontline providers tasked with delivering health services and enabling this right (e.g., nurses, doctors and, as in Harry's case, police officers) represent a gauge of both individual and institutional transformation. Using cases from patients and providers – those at street level – we reflect on barriers to health care and responses to inaccessible ART, tuberculosis (TB) treatment and maternal deliveries in urban postapartheid South Africa. We consider whether these responses ameliorate or compound access barriers and explore some conditions that may bring justice to street-level interactions.

[2] Mahmood Mamdani, 'Amnesty or Impunity? A Preliminary Critique of the Report of the Truth and Reconciliation Commission of South Africa (TRC),' *Diacritics* 32(3) (2002): 33–59; South African Truth and Reconciliation Commission (TRC), *Truth and Reconciliation Commission of South Africa Final Report*, vol. 5 (Cape Town: Juta, 2003).

[3] Laura Davis, *Transitional Justice and Security System Reform* (London: Initiative for Peacebuilding, 2009).

[4] Ibid.

[5] Joel Negin, 'The Central Role of Health in Building Peaceful Post-Conflict Societies,' *Journal of Peace Conflict and Development* 10 (2007): 3.

[6] Phuong N. Pham, Patrick Vinck and Harvey M. Weinstein, 'Human Rights, Transitional Justice, Public Health and Social Reconstruction,' *Social Science and Medicine* 70(1) (2010): 98.

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Discretionary Power, Abuse and Street-Level Bureaucracy

Entrusted to implement and protect citizen rights, state bureaucrats should be well positioned to promote democracy. Yet, they are not passive instruments of the state but rather can be considered 'agents of social control' who mediate a complex space between state and citizen, policy and practice.[7] Termed 'street-level bureaucrats' by Michael Lipsky, such frontline providers are characterized by the discretionary power they exert in their day-to-day dealings with clients (e.g., patients or prisoners). Having flexibility and discretion in their work allows street-level bureaucrats to shape and practice policy, rather than robotically implement it.[8] This is inevitable and necessary in a pressurizing, resource-constrained environment where decisions are needed to '[translate] clients into bureaucratically defined categories in order to provide services, treatment and other forms of assistance.'[9] However, such power can be exerted negatively, or even actively abused,[10] as has been shown in the South African health system.[11] While not unique to either health care[12] or South Africa,[13] negatively practiced street-level bureaucracy and unacceptable provider attitudes in this sector may present a major barrier to the right to access health care[14] and can be located in the country's colonial and apartheid past, as well as more recent processes of democratization.

An Unjust System

Historically, South Africa's health system perpetuated – in complex and multiple ways – the oppression, neglect and violations of colonialism and apartheid.[15] Services were planned and unequally delivered along racial lines to 'deprive a

[7] Michael Lipsky, *Street-Level Bureaucracy: Dilemmas of the Individual in Public Services* (New York: Russell Sage Foundation, 1980), 4.

[8] Ibid.

[9] Patrick G. Scott, 'Assessing Determinants of Bureaucratic Discretion: An Experiment in Street-Level Decision Making,' *Journal of Public Administration Research and Theory* 7(1) (1997): 37.

[10] Lipsky, supra n 7 at 140.

[11] Rachel Jewkes, Naeemah Abrahams and Zodumo Mvo, 'Why Do Nurses Abuse Patients? Reflections from South African Obstetric Services,' *Social Science and Medicine* 47(11) (1998): 1781–1795; Julia Kim and Mmatshilo Motsei, '"Women Enjoy Punishment": Attitudes and Experiences of Gender-Based Violence among PHC Nurses in Rural South Africa,' *Social Science and Medicine* 54(8) (2002): 1243–1254; Loveday Penn-Kekana, Duane Blaauw and Helen Schneider, '"It Makes Me Want to Run Away to Saudi Arabia": Management and Implementation Challenges for Public Financing Reforms from a Maternity Ward Perspective,' *Health Policy and Planning* 19(suppl. 1) (2004): i71–i77.

[12] For an overview of police corruption and abuse in the South African criminal justice system, see, for example, Gareth Newham and Andrew Faull, *Protector or Predator? Tackling Police Corruption in South Africa* (Pretoria: Institute for Security Studies, 2011).

[13] Ana F. d'Oliveira, Simone G. Diniz and Lilia B. Schraiber, 'Violence against Women in Health-Care Institutions: An Emerging Problem,' *Lancet* 359(9318) (2002): 1681–1685.

[14] Lucy Gilson, 'Acceptability, Trust and Equity,' in *The Economics of Health Equity*, ed. Di McIntyre and Gavin Mooney (Cambridge: Cambridge University Press, 2007).

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whole population of its right to access health care.'[16] Budgets and resources were disproportionately allocated in favour of white citizens, and the health of black 'groups' was underfunded, underdeveloped and largely relegated to geographically defined, peripheral and impoverished spaces – bantustans and townships.[17] The South African Truth and Reconciliation Commission (TRC) found that

> the health sector, through apathy, acceptance of the *status quo* and acts of omission, allowed the creation of an environment in which the health of millions of South Africans was neglected, even at times actively compromised, and in which violations of moral and ethical codes of practice were frequent, facilitating violations of human rights.[18]

In conjunction with other institutions and state policies, the health system fed the 'structural violence'[19] of apartheid, that is, systematized and entrenched injustice 'often embedded in longstanding "ubiquitous social structures, normalized by stable institutions and regular experience."'[20] Apartheid structural violence translated into massive and avoidable inequalities and power differentials between communities and population groups, reflected in highly inequitable health outcomes between races and places.[21] For example, in 1971, 'deaths from diarrhoea were 100 times more common among black children than among white children,' and in 1990, 'the number of doctors to patients in urban areas was 1:900, while in rural areas, it was 1:4 100.'[22]

The public health system was itself governed in hierarchical, authoritarian style.[23] Race, class and gender permeated and complicated relations among health care providers, while clinical interactions with patients were often paternalistic, reinforced by these same social divisions and identities.[24] Unethical,

[15] Alexander Butchart, 'The "Bantu Clinic": A Genealogy of the African Patient as Object and Effect of South African Clinical Medicine, 1930–1990,' *Culture, Medicine and Psychiatry* 21(4) (1997); Hoosen Coovadia, Rachel Jewkes, Peter Barron, David Sanders and Diane McIntyre, 'The Health and Health System of South Africa: Historical Roots of Current Public Health Challenges,' *Lancet* 374(9692) (2009): 817–834; Leslie London, 'Health and Human Rights: What Can Ten Years of Democracy in South Africa Tell Us?' *Health and Human Rights* 8(1) (2004): 1–25; Max Price, 'Health Care as an Instrument of Apartheid in South Africa,' *Health Policy and Planning* 1(2) (1986): 158–170.

[16] London, supra n 15 at 3.

[17] Coovadia et al., supra n 15; London, supra n 15; Price, supra n 15.

[18] TRC, supra n 2 at 250–251.

[19] Johan Galtung, 'Violence, Peace, and Peace Research,' *Journal of Peace Research* 6(3) (1969): 167–191; Paul E. Farmer, Bruce Nizeye, Sara Stulac and Salmaan Keshavjee, 'Structural Violence and Clinical Medicine,' *PLOS Medicine* 3(10) (2006): e449.

[20] James Gilligan, *Violence: Reflections on a National Epidemic* (New York: Vintage, 1997), quoted in Farmer et al., supra n 19 at 1686.

[21] See, Mamdani, supra n 2; TRC, supra n 2; Coovadia et al., supra n 15.

[22] Adila Hassim, Mark Heywood and Jonathan Berger, eds., *Health and Democracy: A Guide to Human Rights, Health Law and Policy in Post-Apartheid South Africa* (Cape Town: Siber Ink, 2007), 12.

[23] Shula Marks, *Divided Sisterhood: Race, Class and Gender in the South African Nursing Profession* (Basingstoke: St Martin's Press, 1994). See also, Jewkes et al., supra n 11.

[24] Marks, supra n 23. See also, Butchart, supra n 15.

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authoritarian and abusive provider practices were documented,[25] and despite many acts of individual resistance and humanely delivered health care, the overall system was bureaucratically administered in support of an 'apartheid vision.'[26]

A Health System in Transition

With democracy, the postapartheid state immediately developed and implemented a set of progressive, human rights-oriented policies aimed at improving health outcomes, equity and efficiency.[27] Since the early 1990s, however, many health outcomes have remained stagnant and certain indicators have worsened. For example, life expectancy has fallen by nearly 20 years while maternal mortality has doubled.[28] This 'paradox,'[29] or 'counter transition,'[30] is largely due to the complex intersection of HIV/AIDS, TB, noncommunicable disease and violence, a health transition that has imposed a large, complex burden on the health system. Additionally, the health system is struggling to transform managerial and staffing practices, attract and retain staff and overcome resource constraints.[31] Access to health care remains inequitable, with barriers disproportionately affecting groups that are poor, black, rural or resident in informal settlements.[32] Such barriers include high costs of transport, large distances to services, facility-level variations in quality of care and a fragmented health system, with the private sector absorbing 44 percent of health care expenditure to service 15 percent of the population.[33] Mismatched 'lay and professional health beliefs, provider–patient engagement and dialogue, and the ways in which health care organizational arrangements frame patient responses to services' also impede access and undermine patient trust in the system.[34] Yet, building trust and transforming patient–provider relationships is important for creating an acceptable, accountable health system *and* a broader transitional justice agenda aimed at nurturing reconciliation and equality.

[25] TRC, supra n 2; Jewkes et al., supra n 11; London, supra n 15.

[26] London, supra n 15 at 5.

[27] Mickey Chopra, Joy E. Lawn, David Sanders, Peter Barron, Salim S. Abdool Karim, Debbie Bradshaw, Rachel Jewkes, Quarraisha Abdool Karim, Alan J. Flisher, Bongani M. Mayosi, Stephen M. Tollman, Gavin J. Churchyard and Hoosen Coovadia, 'Achieving the Health Millennium Development Goals for South Africa: Challenges and Priorities,' *Lancet* 374(9694) (2009): 1023–1031; Coovadia et al., supra n 15.

[28] Chopra et al., supra n 27.

[29] Ibid., 1025.

[30] Kathleen Kahn, 'Population Health in South Africa: Dynamics over the Past Two Decades,' *Journal of Public Health Policy* 32(suppl. 1) (2011): S30.

[31] Ibid. See also, Coovadia et al., supra n 15; Chopra et al., supra n 27.

[32] Coovadia et al., supra n 15; Bronwyn Harris, Jane Goudge, John E. Ataguba, Diane McIntyre, Nonhlanhla Nxumalo, Siyabonga Jikwana and Matthew Chersich, 'Inequities in Access to Health Care in South Africa,' *Journal of Public Health Policy* 32 (2011): S102–S123.

[33] Diane McIntyre, *Private Sector Involvement in Funding and Providing Health Services in South Africa: Implications for Equity and Access to Health Care* (Harare: Health Economics Unit, Institute for Social and Economic Research and Equity in Health in East and Southern Africa, 2010).

[34] Gilson, supra n 14 at 142.

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In the postapartheid health system, the persistence of negative provider attitudes and hostile or abusive actions towards patients has been linked to rapid changes in the policy environment after the country's first democratic elections in 1994, a high volume of new policies and their 'top-down' imposition, as well as new demands, fears and perceived threats to the work of frontline providers.[35] In this context, patient 'needs and desires almost invariably [have] not [been] prioritized in comparison with the demands of managers further up the health system.'[36] Additionally, a failed district health system (visualized in the early 1990s as a necessary foundation for promoting health equity)[37] and the related recentralization of power, resources and control have contributed to sustaining negative street-level practices,[38] which are sometimes understood as ways of 'coping' with the pressures and demands of the working environment.[39] Furthermore, in organizations with a history of impunity or authoritarianism, where managers and colleagues 'turn a blind eye' or local accountability is generally lacking,[40] abusive or corrupt street-level actions may become the norm, instead of the work of a 'few rotten apples.'[41] Finding ways to transform institutional norms characterized by abuse and corruption into norms based on accountability and empathy is important for democratically reforming institutions and positively shifting interpersonal and individual practices.

Methods

Case reports and studies are common in law, medicine and the social sciences and involve the intensive analysis of an individual unit (e.g., a person, group or event) with respect to context. Here, we present eight cases that are responses to inaccessible health care within the postapartheid context. When carefully chosen and described, cases can be used to illustrate problems, extract lessons, identify opportunities for change and find underlying principles for interpreting and responding to 'real life.'[42] Case reporting methodology has also been used in the field of restorative justice to illuminate the process and impact of victim–offender mediation (VOM).[43] We report Harry's case in this tradition. More generally, we

[35] Penn-Kekana et al., supra n 11.

[36] Ibid., i76.

[37] The district health system has recently been revitalized in policies to reengineer primary health care and establish a national health insurance system.

[38] H. Schneider, L. Gilson, J. Ogden, L. Lush and G. Walt, 'Health Systems and the Implementation of Disease Programmes: Case Studies from South Africa,' *Global Public Health* 1(1) (2006): 49–64.

[39] Lipsky, supra n 7.

[40] Peter Hupe and Michael Hill, 'Street-Level Bureaucracy and Public Accountability,' *Public Administration* 85(2) (2007): 279–299.

[41] Jewkes et al., supra n 11 at 1791; Newham and Faull, supra n 12 at 8.

[42] Jan P. Vandenbroucke, 'In Defense of Case Reports and Case Series,' *Annals of Internal Medicine* 134(4) (2001): 330–334; Robert K. Yin, *Case Study Research: Design and Methods*, 4th ed. (Los Angeles: SAGE, 2008).

[43] For example, Restorative Justice Council of the UK, http://www.restorativejustice.org.uk/rj-in-action/ (accessed 10 November 2013).

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argue that the possibility of detecting linkages between individuals, their context and their desire for wrongs to be righted – here the injustice of inaccessible health care – is well illustrated through particular cases.

Harry's story unfolded alongside the Researching Equity in Access to Health Care (REACH) project, a five-year, multimethod study of equity in access to TB treatment, ART and maternal deliveries in four South African provinces.[44] As one component of REACH, we interviewed 29 patients and 49 providers about access barriers in urban Cape Town (Western Cape Province) and Johannesburg (Gauteng Province). Interview guides were semistructured, focusing on access to health care in the context of patients' illness trajectories and providers' work-life experiences, but leaving ample room for interviewees' own narrative direction and emphasis. Choosing a narrative approach allowed participants to use their own narration – their telling of stories – to select events, give them coherence, meaning and direction and, in this, provide their own perspective and moral theory to justify and/or critique events around access to health care.[45] It is from these interviews that we have developed six of the cases reported here. A seventh case emerged from our research feedback and engagement with facility managers, providers and student midwives working in urban maternal health services as part of our efforts to build consensus and translate knowledge into action. Harry Nyathela's story is included as an eighth case.

The interviews were conducted between June 2009 and July 2010 and stakeholder feedback took place across February 2011 through April 2012. Ethical clearance was granted by the Universities of Cape Town[46] and the Witwatersrand,[47] and interviews were conducted in the spirit of the Helsinki Declaration of 1975, as revised in 2000. Study permission was also received from provincial and local government, as well as district managers and the heads of the health facilities involved. Informed, written consent was obtained from all interviewees. Interviews were conducted by researchers and trained fieldworkers in English or the respondent's home language, audio-recorded, translated and transcribed, then anonymized and stored on a secure server available only to the research team. Research feedback involved engaging key stakeholders formally (meetings, conferences and workshops) and informally (social and academic networks). Pseudonyms have been assigned to people and facilities to protect confidentiality (although Harry Nyathela chose to be named as part of his activism).

[44] S.M. Cleary, S. Birch, M. Moshabela and H. Schneider, 'Unequal Access to Art: Exploratory Results from Rural and Urban Case Studies of Art Use,' *Sexually Transmitted Infections* 88(2) (2012): 141–146; J. Fried, B. Harris and J. Eyles, 'Hopes Interrupted: Accessing and Experiences of Antiretroviral Therapy in South Africa,' *Sexually Transmitted Infections* 88(2) (2012): 147–151.

[45] Donald E. Polkinghorne, 'Narrative and Self-Concept,' *Journal of Narrative and Life History* 1(2–3) (1991): 135–153.

[46] University of Cape Town Human Science Faculty Research Ethics Committee, REF: 460/2006 (7 November 2007).

[47] University of the Witwatersrand Human Research Ethics Committee (Medical), REF: R14/49 (14 January 2008).

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Our analysis followed Alfred Schutz's sociological phenomenology, which emphasizes 'commonsense' knowledge in the practice and interpretation of everyday life and the intersubjective and constructed nature of such knowledge production.[48] We selected a number of information-rich narratives, constructed around access barriers to health care and responses to these barriers. As 'first order subject typifications,' these narratives were then coded, interpreted and developed into 'second order researcher typifications' – the eight cases presented in this article.[49] The cases were validated by several members of the team and through some engagement with respondents, including Harry Nyathela as subject, researcher and author. The resulting 'constructs of the constructs'[50] have been designed to show different 'everyday' responses to fairly typical access barriers identified by patients and providers. They are presented in three parts: patient cases where street-level bureaucrats cause or exacerbate the injustice of inaccessible health care; reflections from providers about access barriers; and cases where street-level bureaucracy seeks to 'bring' or restore justice.

Part 1: Injustice Intensified for Patients

Naledi Tso: Adding Insult to Injury

Naledi Tso (33) was unemployed and living with her supportive grandmother, her two teenage children and her two younger siblings when we interviewed her. She was diagnosed with HIV in 2004, contracted from a physically abusive boyfriend (who was in jail at the time of her diagnosis and 'did not want to listen' to her test result, 'because he was still busy with his other girlfriends'). Feeling deeply betrayed – 'I felt like he had a purpose to kill me' – she ended the relationship only to discover that she was pregnant. However, the baby died from pneumonia aged four months; an extremely painful experience for Naledi. After three bouts of TB and almost dying herself, Naledi was initiated onto antiretrovirals in 2007 as part of the state's publicly financed ART programme (an important step in redressing past inequalities), and her health improved immediately. Seeing the benefits and supported by her family and friends, she did not miss taking her medication, 'not even once,' until a treatment-collection day in March 2009 when she overslept and arrived at the clinic at 11h45, finding it already empty of patients:

> This nurse said to me without even looking at me 'we have already packed the files come back on Wednesday' and at that moment [the nurse] was shouting and acting out.

Taken aback – 'but I thought clinics operate until 4pm' – and feeling 'very hurt' and shamed in front of the other staff, Naledi left the clinic. On her way out, two providers asked what was wrong. She explained, saying: 'I am not going to come back on Wednesday because this nurse is going to be the one [dispensing] these pills ... [so] if anything wrong happens to me she is going to be responsible.' A few months later at

[48] Kwang-ki Kim and Tim Berard, 'Typification in Society and Social Science: The Continuing Relevance of Schutz's Social Phenomenology,' *Human Studies* 32(3) (2009): 263–289.

[49] Ibid.

[50] Alfred Schutz, *Collected Papers: The Problem of Social Reality*, vol. 1 (The Hague: Martinus Nijhoff, 1962), quoted in Kim and Berard, supra n 48 at 272.

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the time of our interview, Naledi was coughing and short of breath and awaiting results from another TB test. She was desperate to restart her antiretroviral treatment but could not bring herself to return to the ART clinic (physically separate from the TB service), angry and anxious that she might encounter the same nurse again. When asked if she had 'ever thought about another way' of accessing treatment, she replied: 'No, I usually think about it but I haven't come across any solution.'

As access denied, Naledi Tso's case is very similar to Harry Nyathela's in that both had their right to access health care aggressively refused by a street-level bureaucrat. However, in stark contrast to the justice sought and achieved by Harry, Naledi's response was to completely withdraw from the double injustice of being denied ART despite having an appointment and arriving during working hours and of feeling publicly humiliated by the nurse's dismissive, dehumanizing behaviour. Beyond the two provider bystanders asking what had happened, no one seemed to take any interest in her case. There were no apparent consequences for the nurse, who seemed to operate with impunity. We were told in other interviews that several patients had 'quit' the facility as a result of similarly bad experiences. A few months later, Naledi had not been contacted by anyone to find out where she was, although patient tracing is part of the ART protocol, rendering her further invisible in the system – a silent response that left her without resolution.

Lesedi Ledwaba: Forgive . . . But Keep Your Options Open

Lesedi Ledwaba (38) was 16 when she fell pregnant in Grade 6. After the baby was born, her grandmother, who had raised and financially supported her, died and she couldn't afford to return to school. She went to live with her violent, alcoholic mother who beat her regularly and, in 1995, left home for an 'unfaithful' man who would 'bring his girlfriends to our room and sleep with them in front of me.' A year later, after finding a vaginal rash, she tested positive for HIV and was stigmatized by her boyfriend, who told her not to use his soap or cook for him. 'He said to me that he won't be affected by HIV; it means that I came with it from wherever I was.' However, at a follow-up clinic visit, 'the nurse said to me just look for your boyfriend's file here' and Lesedi was 'shocked' to find he was HIV positive. Yet, she persisted in the relationship, experiencing ongoing emotional and physical abuse until 'we had a fight that led to him wanting to cut my throat with a knife.' She opened a case against him, resulting in his arrest and imprisonment. When we interviewed her, she was living with a kindly neighbour – 'my adopted mother' – who gave her emotional support and money for doing housework. She was ART-adherent but had stopped TB treatment because it made her vomit. However, there was no communication about these side-effects with her or between the ART and TB health workers. The TB team sent community health workers (CHWs) to her house in an effort to trace her but she lied, saying that 'Lesedi is no longer staying here, she went home to Natal.' However, a CHW recognized and reported her. When she went for her routine ART appointment, the nurse asked, '"Why are you infecting me with TB?" shouting at me as if I am a child,' and threatening to 'even stop my ART.' The nurse then marched her to the TB-side to open a new card and re-test, loudly emphasizing that she would withhold Lesedi's ART if she did not adhere to the TB treatment.

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> I felt so numb . . . you can be harsh on me but not that harsh because I am not supposed to be stressed because of my health . . . it was hurtful. I even told my adopted mother that, 'this nurse did not treat me right and I am going to report her to her superiors' . . . [but] she reminded me that I am a Christian; that I should let go. Then I said: 'It's fine I will forgive her for that' . . . but it took a while for me to be fine again, because even [at the clinic today . . .] I was just thinking to myself, 'How am I going to look at this nurse?' . . . I got scared . . . I am no longer angry towards her. It doesn't matter whether she apologised or not . . . she can stop giving me treatment but what I know is that the clinic is not hers and . . . is not the only clinic around here; we have lots of clinics around. I can [go elsewhere].

Lesedi Ledwaba's experience of unacceptable health care was ironically not treatment denied but rather (TB) treatment enforced. The ART nurse's actions suggest the frustrations and worries we heard from providers about being personally exposed to TB and their inability to control a curable condition (partly due to increased drug resistance from defaulting) (see also Nonhlanhla Dube's case below). Yet, her bullying, threatening manner compromised Lesedi's right to participate in decision making about her health, experience respectful, dignified care and even refuse treatment as set out in the Patients' Rights Charter. In contrast to Naledi Tso, Lesedi's response was not to withdraw from the health system but to consider turning to the complaints' channel for remedy. Even when pressured to rather 'forgive' and let go, she continued to access her treatment. But this was tenuous, insecure access, compromised by the injustice of feeling wronged, a lack of apology and the nurse's ongoing threat to withhold her ART.

Mark Kriel: Catch-22

Mark Kriel (30), a TB patient on directly observed treatment, short course (DOTS), was unemployed and sleeping in a car outside his mother's house. As a former methamphetamine (tik) user who still smoked marijuana, he was largely ostracized by his family and neighbours. He lived on a hand-to-mouth basis, often going without food, which made it difficult for him to tolerate his TB medication. Unable to afford transport to the clinic (approximately US$1 return per trip) and initially too weak to walk up to two hours daily, he 'stayed away for two weeks.' When he returned to the clinic, he was 'scolded' by the nurses and unsympathetically told to come daily 'or die':

> It is as if they don't listen when I talk to them. If I tell them I can't make it then they will just say, 'You must make a way to come [daily].' Uhmmm, then I asked them, 'Is there no way to get something [a grant, weekly treatment] to make it better for me?' because they know my circumstances. I am sleeping in a car and my mother doesn't care about me. There is no way that I can get transport to here. It is like I talk but they don't listen to me, they don't hear me. I just get negative answers.

Mark Kriel defaulted from his TB treatment out of poverty. Yet, this act of defaulting elicited a health system response that overlooked his circumstances and consequently worsened them. DOTS is intended to minimize defaulting by placing those most at risk firmly under surveillance, but here, it simply realized the

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risk.[51] Although extremely marginalized, Mark Kriel was not without any agency, actively identifying distance and cost barriers and appealing for ways to alleviate these (weekly visits, a grant application). However, the nurses' indifference and lack of sympathy intensified the injustice of unaffordable health care and further entrenched his marginalization and sense of being unheard.

Part 2: Provider Responses to Access Barriers

Nonhlanhla Dube: Patients' Rights, It's the Ugliest!

Nonhlanhla Dube (early 50s) was the operational manager of a busy clinic located in an impoverished community where, for many patients, there 'is no food at home, there is no place to stay.' While sympathetic to the health and life challenges imposed by poverty and unemployment, her response to patients defaulting from TB treatment was one of frustration, anger and blame directed at democracy and patients' rights:

> Before [democracy], we could do our work properly. Our patients were like school children: we could teach them, we could train them, we could do everything we wanted to do with them. They would comply with their TB treatment . . . And they got cured . . . Now patients have rights, the person can refuse to take treatment, and what if he refuses to take treatment? It complicates to MDR [multidrug-resistant TB]. It complicates to XDR [extensively drug-resistant TB]. The person with MDR needs to be admitted so that he doesn't infect other people with MDR. The patient has a right to refuse to be admitted. One told us that, 'no, I am working for my children, I am not going to that hospital of yours' and he is giving MDR to the neighbourhood, wherever he goes. And it's, it's uncontrollable since these patients' rights. You would stand there and try and educate them [but they say]: 'We have not come here to be educated, give us treatment we want to go' [says in aggressive mimicry]. These rights they have disrupted a lot of things. I blame all this mess with TB on patients' rights.

By way of contrast, she recalled that early in her career (which started in 1977), she, a tiny nurse, had physically slapped a big, strapping patient into submissively taking his daily medication, and that '30 years later, he still shakes my hand and thanks me for saving his life whenever he sees me at the mall.'

Along with feeling disempowered by patients' rights, Nonhlanhla Dube conveyed a broader sense of lost identity and a fall in her professional status that was shared by many other providers we interviewed:

> When you get out the room, you want to take your epaulets and hide them because being a nurse is being nobody, is being a doormat where . . . even the patients, they don't take us seriously.

She felt that democracy had brought additional challenges to the health system, including staff shortages because 'people are leaving for greener pastures,' resulting in an increased workload for those left behind: 'I've got to take work home and I'll

[51] For the impoverishing effects of seeking chronic care, see, Jane Goudge, Steven Russell, Lucy Gilson, Tebogo Gumede, Steve Tollman and Anne Mills, 'Illness-Related Impoverishment in Rural South Africa: Why Does Social Protection Work for Some Households but Not Others?' *Journal of International Development* 21(2009): 231–251.

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knock off maybe 10, 11pm.' She also identified a lack of financial resources/skills and task shifting as obstacles to effectively running the clinic, where she felt she had to rely on 'community health workers who are not qualified, they are just volunteers.' Overall, hers was a story of feeling silenced and belittled in the new dispensation, unsupported by politicians and treated with disdain by patients and communities: 'Poor staff and they have no one to talk for them. The client is always right.'

As our research findings emerged from the REACH project, we engaged with facility-level providers and managers in maternal services so that they could take practical ownership of the research and make a difference in their own environments. In many ways, our results confirmed already-held knowledge, including about poor quality of clinical care and unacceptable treatment in services, but providers and managers felt they and others had been grappling with these issues for many years, often under immense pressure from senior officials and the media, and without obvious solutions. Many seemed to feel powerless to change the situation or make a difference. One particular facility had also had some bad press coverage at the time, and most providers seemed burnt-out, defensive and sometimes very emotional.

Asked to reflect on their own birth experiences, student midwives described how as 'patients' they had experienced exactly the same problems as the patients we had interviewed in REACH, including rude, hostile provider attitudes. Yet, almost schizophrenically, as 'midwives,' the same individuals made no links to their own negative delivery experiences. Instead, along with other providers, they fell back on dominant discourses (that have validity) of staff shortages, poverty in the community and, in the case of a higher-tiered hospital, overloading because there was no nearby district hospital and women were bypassing clinics. When we presented that many women would have liked a birth companion, staff said wards were too crowded, there was no privacy and companions would just create more work for already overworked providers. When we mentioned the poor quality of medical records, they said, 'Shortages of staff.' When we suggested that services are confusing and not well organized, often inconveniencing impoverished women and incurring additional transport costs, we were told that it was impossible to change services as they were already overloaded. At the start of our project, a triage system had been implemented in the hospital to stop normal deliveries from clogging up beds by sending women to nearby clinics. Two years later, there was a general feeling that this system had failed and hope was instead resting on a new district hospital that was being built.

Although limited, there was some self-reflection about negative communication with patients, which staff explained as the work of a 'few bad apples' or good providers 'having a bad day.' Nurses mentioned that problems at home or work tended to make them harsh with patients – a reminder that while street-level bureaucrats are state agents, they are also individuals with their own stresses, values and expectations, just like other citizens. Doctors and unit managers reflected that while the head of department was always deliberately polite and

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interactive with staff and patients, this bedside manner was not necessarily practiced by everyone, and providers were often rude to each other as well as patients. Consequently, they agreed to be more considerate of each other, in the hope that this would rub off on how staff treated patients, a small, yet important, response to our findings, particularly in light of the ways that hostile or dismissive providers had intensified the injustice of inaccessible care for Naledi Tso, Lesedi Ledwaba and Mark Kriel.

Part 3: Bringing Justice

Peter Isaacs: She Was My Pillar Here

Peter Isaacs (49), HIV positive and a diabetic, was diagnosed with TB after feeling his body was 'not right' while living in a place where 'poverty is the problem and the coldness of the place.'

> Houses that are not nice to live in . . . the cold in the lungs it is a lot in the area where we live. The houses are not properly built and it is council houses . . . there are a lot of families living in one house: 20 to 25 families.

With the TB, he 'felt like somebody that is going to die' and lost 20 kilograms in one month. He was fired from his job because he was ill and told that he could not access a social grant due to a technicality of not having divorce papers. He moved in with his sister and niece, who supported and nursed him. As he was initially too weak to attend the clinic, a community health worker visited him daily:

> She encouraged me to go on with life. She said it is just a disease that can be cured and she encouraged me to drink my pills, eat right and eat healthy and she told me about the rice water and to drink it, that was when I could not keep [down] the food, it was a month and a half that I could not eat because why? I was just nauseous and I was apathetic. I gave up I did not want to live. If I took a bath then I looked like a skeleton and then she encouraged me . . . the second month I started to get an appetite and from that time I started to eat and gained weight and felt to live.

Once stronger, he successfully completed his treatment at a clinic that provided bread daily for TB patients (however, he said he usually gave away his half loaf as he did not feel hungry). He looked forward to going, mostly to engage with the staff:

> They will ask you how do you feel . . . what can I tell them about the illness? . . . They were very helpful, they helped me a lot. [The TB coordinator] was my pillar here, she was making me happy. She always smiled and she encouraged me to say that it was worth it to live. It was a pleasure to come to this clinic.

As with Naledi Tso, Lesedi Ledwaba and Mark Kriel, Peter Isaacs' case touches on the complex interconnectedness of health determinants (e.g., poverty, unemployment and housing insecurity) and access to health care. However, unlike the patient cases presented in Part 1, he received a positive, supportive response from the health system and those providing his care. Although unemployed and unable to access a social grant, his treatment was made more accessible through home visits, the provision of bread at the clinic and, mostly, provider encouragement and engagement.

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Precious Khomo: The Role Model

Precious Khomo was an occupational nurse in South Africa's private sector until she retired at 60. Seven months later, to 'give back' to her community, she responded to a call for retired nurses to work in the public sector. She was placed in the maternity unit of a busy academic hospital, one of two nurses responsible for making the facility 'baby friendly' for accreditation under a UN Children's Fund/World Health Organization 'baby friendly hospital initiative.' Here, she encouraged mothers to breastfeed and trained colleagues about the importance of kangaroo care, exclusive breastfeeding and communication with patients. 'Changing attitudes and ways of working is not easy,' she noted. She identified a culture of antagonism towards patients, with nurses expecting women to be 'difficult' and treating them accordingly, shouting and issuing commands, often without even realizing it. This, she felt, demotivated mothers who were already struggling with other barriers to exclusive breastfeeding, including health complications, high costs of travelling to feed hospitalized infants and cultural norms around mixed feeding. Staff shortages and resource constraints, such as limited bed space, coupled with fears of litigation around babies falling, also led to babies being separated from their mothers at birth and being formula-fed by nurses instead. She noted how entrenched routines were obstructing the new baby-friendly approach:

> And the way things are done, because at present, the nurses who do them, who bring the [formula] milk to the patients, sometimes they just give everybody . . . They won't say, 'Are you breastfeeding? . . . How about trying first?' Sometimes, routine, you know, in the hospital, if it's too busy, routine, you just do what you are supposed to do, you know, give . . . even those with full breasts, give the babies formula. That's a big challenge.

Consequently, she felt it important to explain the reasons for the baby-friendly initiative to staff instead of forcing a new way of doing things:

> They [nurses] think it's difficult, only to see that after attending a course like this, they can see the reasons and the importance of this programme, then they cooperate better.

Additionally, she introduced a new style of engagement, reconceptualizing patients as 'customers' deserving of a holistic 'service,' rather than simply being told how to breastfeed:

> It's customer service because we don't just talk breastfeeding . . . [patients] come to us and say, 'Sister, I want to talk to you about something' . . . Then you talk to them, then you show them, you allay their fears . . . We do counselling, a lot of counselling in between.

She emphasized the value of modelling this new behaviour for the other nurses:

> If I behave the right way and you keep on seeing me behave the right way towards the patients: being customer friendly, the patients talking to me, being happy, greeting me, I greeting them. Then you'll also think, 'Is this not nice?' It won't be everybody changing but most of the nurses will think, 'Hey, this is good,' and they'll also change.

While she had only been working on the programme for four months when we interviewed her, she felt that there were small, positive changes:

> This particular nurse that we observed that was very loud, she's slowly improving, we can see that . . . she's changing. People don't change immediately but I think she's seeing the way we talk to the mothers and they also change . . . As I keep on going to

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> the wards, I see the nurses' attitudes changing towards me because, you know, I'm like a foreigner coming into their territory . . . Their attitude is no longer like when I started. They are now open and welcoming.
>
> Beyond the immediate benefits for patients (and providers) of positive staff attitudes, she felt that modelling respectful, polite and friendly behaviour was important for the next generation of nurses – 'those little ones' – to learn from older staff members. Additionally, through improving the hospital's reputation and creating a pleasant working environment, such an attitude shift, she hoped, would pay off in the long term by attracting privately based nurses to the public sector.

Precious Khomo's case highlights the efforts of, and challenges for, an institutionally mandated individual to implement reform within a busy, understaffed hospital. Specifically employed to change practices, her post reflects a justice-oriented institutional response to 'unfriendly' baby and mother care. Her individual response of 'changing through doing' was based on modelling an alternative, respectful style of interaction. Although she observed small changes, she was constantly managing (without much authority) a culture of unfriendly care, partly because staff perceived themselves to be overworked in an underresourced unit and felt that the new approach would add to, rather than alleviate, their pressures. Senior managers, often struggling to provide clear direction and leadership, also felt hamstrung by the staff shortages: 'We strive not to [give final written warnings] because we still need them [the staff], isn't it? The worst that I've seen is a verbal warning.' In this sense, Precious Khomo's case cautions about the efficacy of individuals with limited resources and authority (despite her age and experience) to institutionalize change as much as it shows institutional commitment and a positive individual effort to bring justice.

Discussion: Conditions for Bringing Justice to Street-Level Interactions

The cases reported in this article highlight certain structural, institutional and interpersonal barriers to the right to access health care in postapartheid South Africa, and various justice-denying or justice-bringing responses from patients, providers and the health system itself. Barriers identified by patients and staff include: poverty, unemployment, food and housing insecurity and sometimes physical violence and abuse in people's everyday lives; staff and resource shortages within the health system; a perceived loss of provider status and authority; lack of facility-level accountability; recalcitrant patients; and negative provider attitudes and (in)actions. Responses to these barriers ranged from provider indifference or hostility, patient blaming and even flagrant power abuse to acts of provider kindness and encouragement, as well as institutional efforts to ease access difficulties through, for example, providing home visits and food to patients, creating a new 'baby-friendly' post, acknowledging the need to change communication practices and, in Harry Nyathela's case, engaging in VOM.

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Restoring Equity to Interpersonal Relationships

Harry's story stands out for the justice it brings to him as the victim and institutionally. In its resolution, it is textbook restorative justice, a victim-centred approach in which 'the parties with a stake in a particular offence come together to resolve collectively how to deal with the aftermath of the offence and its implications for the future.'[52] A restorative approach typically seeks to resolve such offences through VOM.[53] VOM entails a carefully facilitated process with victims, offenders and their respective communities and is an applied method for resolving certain types of interpersonal conflict. Furthermore, restorative justice is a philosophy of justice, providing a theoretical framework for conceptualizing fractured social relationships and efforts to 'right wrongs.'[54]

The restorative VOM approach followed in Harry's case was made possible by the nature of the incident – a straightforward contained case involving one perpetrator violating the rights of one victim – which clearly lent itself to identifying the relevant parties, articulating the experience of injustice and ultimately mediating a successful outcome. This process was initiated with support and intervention from civil society through Lawyers for Human Rights, a long-established nongovernmental organization that provides free legal support to vulnerable individuals and communities. While the other patient cases presented in this article were confined to the clinic, the organization's involvement confirms in a small, everyday sense the role for nonstate actors in consolidating 'democratic norms, institutions and practices' and holding the state accountable, long after the attainment of formal democracy.[55]

Additionally, the leadership and authority of the station commander contributed to a restorative approach, through sensitive arbitration, victim-centred consultation ('What would make you happy in resolving this?') and proper implementation of Harry's proposal. Harry's response was similarly important – he did not seek revenge, prosecution or retreat (unlike Naledi Tso, who withdrew from the system completely) but rather opted to set the perpetrator on a personal path of redemption, as well as tackle attitudes at a station level. This suggests a degree of individual empowerment, confidence and ability to claim rights, a form of citizenship resilient to the 'wounding,' powerlessness and

[52] Tony Marshall, 'Criminal Mediation in Great Britain 1980-1996,' *European Journal on Criminal Policy and Research* 4(4) (1996): 21–43, quoted in Jennifer J. Llewellyn and Robert L. Howse, *Restorative Justice: A Conceptual Framework* (Ottowa: Law Commission of Canada, 1999), 10.

[53] Llewellyn and Howse, supra n 52. Restorative justice contrasts to retributive approaches, which are often articulated around the principle of the 'punishment must fit the crime.' Summary justice and vigilantism represent extreme forms of retributive justice, but a formal criminal justice system that deals with perpetrators at the level of the state (as in South Africa), rather than directly with the victim, and metes out punishment through sentencing could also be considered retributive.

[54] Ibid.

[55] David Backer, 'Civil Society and Transitional Justice: Possibilities, Patterns and Prospects,' *Journal of Human Rights* 2(3) (2003): 297–313.

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subjugation[56] experienced by Naledi Tso, Lesedi Ledwaba and Mark Kriel. Creating engaged, empowered and active citizens and communities is an important transitional justice goal,[57] institutionally conveyed in South Africa through the principle of *Batho Pele* (People First). Patient empowerment, rights and responsibilities are also stated objectives of health system reform in South Africa, found in instruments such as the Patients' Rights Charter and Clinic Committees, and most recently expressed in policies to reengineer primary health care and to develop a national health insurance system.

The perpetrator's compliance, genuine apology and ongoing engagement with Harry also rebalanced their relationship. Bringing equality to social relationships is a core tenet of restorative justice.[58] This seems particularly important in fragile and transitioning countries where past conflict was premised on, sustained by and reproduced in unequal relationships. It is also crucial in a context where, historically, street-level bureaucrats (including health care providers) have contributed to reproducing unequal relationships, both as individuals and on behalf of the state.

Creating 'Webs' of Institutional Accountability

Because street-level bureaucracy is practiced at the discretion of providers, 'managing providers better' will not automatically produce patient-centred services. A top-down management approach, for example, is more likely to (further) alienate providers and transfer new challenges to patients.[59] Street-level bureaucracy involves a 'multi-dimensional "web" of relationships' and therefore accountability cannot just be vertical (to managers), although this is necessary and important. It must also be bottom-up (to patients and communities) and 'sideways' (to colleagues).[60] Creating a 'web' of accountability requires making political choices – driven by practicality as much as ideology – that are designed for the local context.[61] For transitional societies, there is a need to address explicitly the legacy of authoritarianism within state institutions and the historical role of street-level bureaucrats in sustaining and promoting injustice, not only to restore justice for past victims but also, looking forward, to disentangle old threads of impunity from emerging accountability webs.[62] At the same time, it is important to consider that democratization itself may present new conditions, such as anxiety-provoking policy changes, new managerial pressures and

[56] Mamphela Ramphele, 'Unleashing the Power of Communities to Confront Health Inequity,' Public Health Association of South Africa, 2012, http://www.phasa.org.za/unleashing-the-power-of-communities-to-confront-health-inequity/ (accessed 10 November 2013).

[57] Wendy Lambourne, 'Transitional Justice and Peacebuilding after Mass Violence,' *International Journal of Transitional Justice* 3(1) (2009): 28–48.

[58] Llewellyn and Howse, supra n 52.

[59] Penn-Kekana et al., supra n 11.

[60] Hupe and Hill, supra n 40 at 285.

[61] Ibid.

[62] See, Lambourne, supra n 57, for a discussion of the retrospective and prospective purposes of a transitional justice framework.

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demands[63] and the 'ugly threat' of patients' rights (as expressed by Nonhlanhla Dube), which ironically enable negative street-level bureaucracy instead of dismantling it.

Restoring Health as a Form of Justice

A large body of literature seeks to identify and understand the determinants of discretionary decision making at street level.[64] Context-bound and complex, street-level bureaucracy cannot be reduced to a singular factor, process or theory.[65] Important determinants include organizational factors (e.g., institutional culture, values, control and management style) and individual characteristics (e.g., patient background, expertise/knowledge and need, as well as provider altruism, rule orientation and professionalism). Broader extraorganizational factors (e.g., social context, law and wider community) are also important,[66] especially in South Africa, which remains one of the most inequitable societies in the world. Structural violence – *the* injustice of the apartheid state[67] – continues to constrain the right to access health care. Tackling this legacy requires state-level interventions to restore a 'fundamental level of health care and health resources' to all – what Angela Henderson and Margaret Jackson term 'restorative health':

> The idea that those who, particularly as young children [and, we argue in the South African case, historically and intergenerationally], have had their rights of access to the social determinants of health systematically denied to them have the right to restoration.[68]

Restorative health extends far beyond redressing relationships and institutional reform to linking a much wider set of (denied) social determinants of health, such as access to clean water, food security and personal safety, with (barriers to) health care and justice. Clearly, the health system alone, and those working in it, cannot be expected to remedy a complex set of inequities that affect the upstream determinants of health and access to health care. 'Structural interventions' to dismantle the social, political and economic processes that create and sustain these inequalities are also required.[69] Yet, South Africa,[70] like many other postconflict states, has been criticized for

[63] Penn-Kekana et al., supra n 11.

[64] Kim Loyens and Jeroen Maesschalck, 'Toward a Theoretical Framework for Ethical Decision Making of Street-Level Bureaucracy,' *Administration and Society* 42(1) (2010): 66–100.

[65] Ibid.

[66] Scott, supra n 9; Loyens and Maesschalck, supra n 64.

[67] Mamdani, supra n 2.

[68] Angela Henderson and Margaret Jackson, 'Restorative Health: Lessening the Impact of Previous Abuse and Violence in the Lives of Vulnerable Girls,' *Health Care for Women International* 25(9) (2004): 794–795.

[69] Farmer et al., supra n 19.

[70] Mamdani, supra n 2.

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> fostering a notion that transitional justice can contribute to stabilizing the future by resolving the past while ignoring deep and abiding inequalities or socioeconomic relations that may well contribute to ongoing violence.[71]

We would add that it may sustain inaccessible services and poor health outcomes.

Structural barriers constrain and set limits on the right to access health care. While it is beyond the scope of this article to engage with the conditions necessary for bringing about structural justice, it is important to note that provider practices and the arrangement of health services can, even if only in small or temporary ways, respond to and potentially ameliorate some of these structural challenges, as shown, for example, by the provision of home-based care or giving of bread to TB patients at clinics. Conversely, as our cases suggest, poorly organized health services, limited human and financial resources, disempowering management systems and unsympathetic, at times hostile, providers may perpetuate broader structural problems. Therefore, alongside the need for structural programmes, policies and interventions, creating the discretionary space and flexibility for street-level bureaucrats to identify and respond to structural barriers may be as important for a transitional justice agenda as encouraging respectful provider–patient relationships.

Conclusion

In the postapartheid context, profound 'extraorganizational'[72] factors condition the lives of both patients and providers and ultimately set limits on the accessibility of health care for all. Restoring 'rights of access to the social determinants of health'[73] and systematically 'undoing' structural violence may thus be important conditions for fully realizing the right to access health care. In fragile and post-conflict states, locating a restorative health[74] approach as part of a transitional justice agenda may also create new opportunities for engaging with often-ignored 'deep and abiding inequalities or socioeconomic relations.'[75] Because structural violence is often sustained and reproduced in institutions and by 'regular experience,'[76] disrupting convention and destabilizing institutional norms of abuse and corruption – through structural interventions *and* street-level practices – may similarly begin to challenge these limiting extraorganizational factors.

Therefore, within the constraints of ongoing structural inequalities, there is a need to examine critically institutional culture and power relations between providers and with patients. This is particularly important given South Africa's history of providers abusing patients and the complex ways in which such practices

[71] Zinaida Miller, 'Effects of Invisibility: In Search of the "Economic" in Transitional Justice,' *International Journal of Transitional Justice* 2(3) (2008): 288.

[72] Scott, supra n 9; Loyens and Maesschalck, supra n 64.

[73] Henderson and Jackson, supra n 68 at 794–795.

[74] Ibid.

[75] Miller, supra n 71 at 288.

[76] Gilligan, quoted in Farmer et al., supra n 19 at 1686.

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have continued into democracy. Restorative justice focuses on identifying and repairing 'broken relationships and communities' through dialogue, community participation and finding locally relevant 'solutions.'[77] A philosophy as well as a practical set of tools for remedying wrongs, restorative justice offers an avenue into assessing the feasibility and scope of interpersonal transformation at street level. As state-appointed 'agents of social control'[78] and individual citizens, street-level bureaucrats embody the challenges of implementing democratic reforms, changing attitudes and transforming authoritarian and 'wounding'[79] practices, both past and present. Along with ethical, accountable decision making and conduct by health care providers, resources, leadership, active civil society, progressive policies, patient agency and individual 'champions' are important factors for improving access to health care and normalizing equitable, empathetic relationships between providers and patients.

Restorative justice and restorative health are not interchangeable; they respond to different expressions of injustice, at interpersonal and structural levels. However, they are closely interconnected. If left unchallenged, negative street-level bureaucracy (interpersonal injustice) may compound inaccessible health care for patients and perpetuate a wider culture of disempowerment, deprivation and poverty for citizens (structural injustice). In contrast, positive interpersonal practices may be ameliorative of individual and structural conditions of injustice. Indeed, when achieved, restorative justice may partially restore health, while restorative health has the potential to improve interpersonal practices and bring justice to relationships. Yet, for a society seeking to realize the right to access health care, transform state organs and achieve genuine social reconstruction,[80] one form of restoration cannot be fully substituted for the other. There are limitations to each. Instead, taken together, both approaches may contribute to democratic transformation.[81] As state representatives in a 'web' of multidimensional relationships,[82] street-level bureaucrats are located 'somewhere in the middle' of the structures, institutions and relationships that mediate society. They are therefore well positioned to be agents of change in support of a transitional justice agenda. However, for these same reasons, they are also potentially agents of resistance, capable of frustrating efforts at social reconstruction. Finding ways to strengthen street-level accountability and engender respectful, empathetic provider practices is consequently vital to improving access to services and contributing more generally to the restoration of justice and health in society.

[77] Christine Bell and Catherine O'Rourke, 'Does Feminism Need a Theory of Transitional Justice? An Introductory Essay,' *International Journal of Transitional Justice* 1(1) (2007): 40.

[78] Lipsky, supra n 7 at 4.

[79] Ramphele, supra n 56.

[80] Negin, supra n 5; Pham et al., supra n 6.

[81] See, Lambourne, supra 57.

[82] Hupe and Hill, supra n 40.

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Section III

Accounting for access to health care as a matter of restorative justice

On the 11 December 2015, South Africa's Minister of Health, Dr Aaron Motsoaledi, released the country's much anticipated White Paper on National Health Insurance (NHI) (Republic of South Africa 2015). Framed as a vehicle for achieving universal health coverage (UHC), the White Paper seeks to guide the financing of NHI, while rolling out reforms to strengthen the health system and improve the quality of public sector care. Implementation of NHI is seen as a way to realise the constitutionally protected "right to have access to health care services":

> Progressively realising this right will contribute to a healthy population that benefits the entire nation. NHI is a policy shift that will contribute towards poverty reduction and addressing the inequalities inherited from the past. Implementation of NHI is a reflection of the kind of society we wish to live in: one based on the values of justice, fairness and social solidarity. Implementation of NHI is consistent with the global vision that health care should be seen as a social investment and therefore should not be subjected to market forces where it is treated as a normal commodity of trade (Republic of South Africa 2015, Para 3-4:1).

In aspiration, NHI seeks to remedy past inequalities so that "the population has access to needed quality health services at affordable cost" (para 49:8), in other words it seeks to shift the "story of lack of services" to one of "UHC". The policy (as intent) thus remains consistent with the country's transitional justice agenda to restore justice while promoting a forward-looking human rights paradigm.

A restorative approach requires accountability, restitution, and recognition of suffering. It is an effort to humanize or "re-humanize" all involved and thereby offers an

alternative to the impunity that still "condenses" in the clinic, hospital ward, police cell, and elements of everyday life (Research Articles 1-3; Epilogue). It is itself a new way of practicing health care. Yet, restorative justice is also a strategy of disciplinary power. It turns on individualization by making perpetrators take responsibility for their own actions and giving victims their own voices.[17] As with any power regime, it requires vigilant attention: what new expectations, identities, and practices are produced? Who is included and excluded? How can policies such as NHI restoratively shift the "story of lack of health services" to one of "UHC", in which the right to access health care becomes a human right lived by all?

Available, affordable, acceptable, AND accountable health care

A human rights approach to health requires a particular type of *accountability*, "which reframes a claim away from the domain of charity or largess to that of an entitlement, structured in ways that are intended to preference the most vulnerable in society" (London and Schneider 2012: 8): a doing *with*, rather than *to* or *for* (Research Article 1). This paradigm draws attention to agency - both by individuals but also (and more importantly in the context of this thesis) by collectives in redressing human rights violations or preventing conditions which give rise to violations. Yet, the NHI policy, currently framed in the language of public health (efficiency, effectiveness and equity), is largely silent on rights holders, duty bearers and accountability.[18] Although the White Paper makes provision for an oversight role for clinic committees and hospital boards (structures that include community representatives), "these bodies presently face a number of challenges, including inadequate resourcing and lack of capacity" (Harris et al. 2014:13 – Research Article 2). Moreover, the

[17] I am grateful to Gillian Eagle for pointing this out.

[18] I am grateful to the anonymous examiner (3) for making this valuable point.

genuine participation of communities in such structures is precarious, as illustrated by a proposed Western Cape Health Facilities Board and Committees Bill, which would enable the Provincial Government to appoint these committees "without due community involvement in their election [leading] to decision-making outside of community control" (Stinson 2015).

> Furthermore, the proposed clustering of the health committees at a level higher than that of the community will undermine the unique representation that each committee currently has, and this approach will ultimately work against strengthening the health system through community participation. This threatens the very essence of and rationale for community participation in the right to health (Stinson 2015).

If NHI is to facilitate restorative justice, then an inclusive, engaged public conversation is needed to ensure individual and collective accountability through:

> 'external' or community accountability mechanisms which may be used by non-state actors to hold public sector power-holders to account, and 'internal' or bureaucratic mechanisms that are comprised of the institutional oversights, checks and balances internal to the public sector (Cleary, Molyneux, and Gilson 2013:2).

This accountability conversation is needed to shift the right to health from "simply an entitlement applied to collectives [..to] an entitlement that is fundamentally social in nature" (London et al. 2015:940); and with this, to shift away from individualising governmentality to a collective form of solidarity and ubuntu (London et al. 2015; Research Article 1). A similar shift is needed to locate community (population) approaches and health systems in the discussion of restorative justice, which is traditionally focused in its primordial conception on the individual victim-perpetrator relationship with only sometimes a minor detour through

structural antecedents (Research Article 3). Building on the research in this thesis, such a shift might be facilitated by expanding the ways in which access to health care is conceptualised in Health Policy and Systems Research (HPSR) literature - as a negotiation between patients/households and providers/the health system along dimensions of availability, affordability, acceptability (Thiede et al. 2007), AND accountability. In the South African context, where past "ways of doing" (Research Article 1) continue as part of a new democratic social contract (Research Article 2), ensuring accountable access needs a strengthening of health worker "candidacy" (Dixon-Woods et al. 2006) and the health system itself to provide services, while also building the resilience of vulnerable patients and communities, and protecting the right to access health care (Quesada, Hart, and Bourgois 2011). Enacting accountability within the health system thus requires "repairing human relationships" (Mutua 2015:5), and problematizing power (Hamber 2015), as well as ensuring structural change (Research Article 3).

Repairing human relationships and the problem of power

Human relationships and power are central themes of this thesis, explored in the micro-practices of health care between patients and providers. Questions asked include: What relationships and identities are produced in the ways in which health care is done (Research Articles 1 and 2)? How do power and resistance operate to either damage, or repair and restore, these relationships (Research Article 3)? Power expressed through street-level bureaucracy (Research Article 3) is neither unique to the health system (Hupe and Hill 2007; Lipsky 1980; World Bank 2011), nor South Africa (see for example d'Oliveira, Diniz, and Schraiber 2002; Hupe and Hill 2007; Lipsky 1980; Mbembe 1992). Rather, (often unacceptable) ways of "coping" (Lipsky 1980) extend across civil services in the actions of magistrates, police (Newham and Faull 2011), home affairs officials (Hoag 2010), those

providing social services and social welfare (Donavan 2013), and anyone on a helpline or at a counter in a government office (Hupe and Hill 2007; Lipsky 1980). Yet, the application of street-level bureaucracy to a health system in *transition* – both politically and epidemiologically (Research Article 3) - where old ways of "doing" persist alongside new forms of power (Research Article 1) in a democratic health care contract (Research Article 2), opens a conceptual space for collectively making sense, "sensemaking" (Weick 1995), of institutional transformation across public services in fragile and post-conflict contexts.

Cemented between the demands of their managers and the public they serve, during a regime change marked by institutional crisis[19] and individual loss of social status (especially for nurses in South Africa – Research Article 2), relatively powerful-yet-powerless frontline staff may exercise power in petty and sometimes terrible ways. This is forcefully brought to the fore in the neglect and cruelty experienced by Gugulethu Ngwenya during her labour and the tragic death of her baby (Research Article 1), and in the case of Harry Nyathela, denied access to ART by a policeman (Research Article 3).

It is worth noting that these cases took place just 15 years into the country's democracy, at the time of the "failed stewardship of ex-President Thabo Mbeki and the disastrous policies of his health minister Mantombazana Tshabalala-Msimang" (Mayosi et al. 2012: 2029). Yet, even now, twenty one years into South Africa's democracy, under new and proactive stewardship in the National Department of Health, is it still too early to expect the radical transformation of service delivery and modes of governance? Is part of the failure to provide equitable and quality health care linked to a crisis in the capacity to lead, not only from the top, but throughout the bureaucracy, where there is growing recognition that all managers "should go beyond routine implementation of rules and instructions from their

[19] In South Africa, this crisis was particularly exacerbated by the politics of AIDS during the first decade of democracy (as explored in Methodological musings, Section I).

superiors, and instead use local information to guide and lead change in their areas of responsibility" (Mayosi et al. 2012: 2030; see also Republic of South Africa 2011; 2015)? Has there been enough investment in strengthening the management capacity of civil servants (of all kinds)? And if this 'crisis' is not exclusively about the capacity of public sector employees, then how are relationships of inequality and abuses in power replicated elsewhere – in the private sector, within non-governmental organisations (NGOs) and community-based organisations (CBOs), and between CBO/NGO staff and community members? Is the issue specifically one of bureaucratic failings, or more generally about the playing out of power in everyday life?[20]

Beyond the institutional walls of the clinic/ward and the police cell, terrible expressions of power as everyday violence and abuse speak through some of the patient stories documented in Research Articles 1 and 3. And, perhaps most terribly of all, in the shocking murder of Harry Nyathela (Epilogue), beaten to death for trying to secure access to health care (ambulance) and justice (police) for another man, who had himself been badly beaten. High levels of violence directly undermine restorative justice and efforts to repair relationships in fragile and post-conflict states (Mutua 2015). Violence is the antithesis of ubuntu, a shared sense of solidarity and common humaity that comes with the "fundamental recognition of Self (identity) in the Other, including the relationships and community through which human kindness is constructed" (Harris et al. draft - Research Article 1). Dehumanised and fractured relationships thread through the everyday violence (Epilogue), individualized governmentality (Research Article 1), and negative street-level bureaucracy (Research Article 3) documented in this thesis. Such ways of relating confirm the violence of South Africa's democracy (von Holdt 2013), and prohibit any satisfactory closure of the country's transitional justice project.

[20] I am grateful to the anonymous examiner (2) for provoking these questions.

Making sense of access to health care as a matter of restorative justice

For a thesis that aims to narrate access to health care as a matter of restorative justice, it is deeply symbolic that South Africa's NHI White Paper was launched on the day before World Universal Health Coverage Day (12 December) and in the same week as the country's Day of Reconciliation (16 December). Universal Health Coverage Day is:

> the anniversary of the first unanimous United Nations resolution calling for countries to provide affordable, quality health care to every person, everywhere. Universal health coverage [UHC] has been included in the new Sustainable Development Goals adopted by the United Nations (Global Coalition for Universal Health Coverage 2015).

The Day of Reconciliation is "a day of great significance in South Africa because of two historical events that took place on that date" (South African Government 2014): the apartheid "Day of the Vow" imbued with "enormous ideological significance" (Girshick 2004:25) as a day commemorating the (gun-powered) "victory" by Afrikaans Voortrekkers over King Dingane's amaZulu at the "Battle of Blood River" in 1838 (Girshick; South African Government); and the formation of Umkhonto we Sizwe (MK), the military wing of the African National Congress (ANC), on the 16 December 1961 (South African Government).

> With the advent of democracy in South Africa 16 December retained its status as a public holiday. South Africa's first non-racial and democratic government was tasked with promoting reconciliation and national unity. One way in which it aimed to do this symbolically was to acknowledge the significance of the 16 December in both the Afrikaner and liberation struggle traditions and to rename this day as the Day of Reconciliation (South African Government 2014).

The NHI White Paper was also launched in a week of heightened economic and political turmoil in South Africa, as the position of finance minister "controversially passed through three pairs of hands over the space of four days" (Areff 2015). Sparked by President Jacob Zuma's "redeployment" of the Minister of Finance, Nhlanhla Nene in favour of little-known ANC backbencher, David van Rooyen (09 December 2015), this move had a dramatic effect on financial markets and cost the country billions of rands during van Rooyen's brief tenure. On 12 December, the president replaced van Rooyen with Pravin Gordhan, former Minister of Finance (2009-2014) (Areff 2015), which partially restored market confidence but left the credibility of the country's senior leadership under question:

> President Jacob Zuma has attacked the independence of the treasury, and by failing to give legitimate reasons for his attack, has given the country no choice but to believe that he is anxious to cover up corruption, in particular the South African Airways Airbus deal and the trillion-rand secret nuclear deal (Corruption Watch 2015).

On the 16 December 2015, a number of protest marches were held around the country - #zumamustfall, no reconciliation with corruption - part of a growing civil movement against corruption and lack of state accountability; and directly connected to the #rhodesmustfall, #feesmustfall, #endoutsourcing movement (discussed in Section I) as yet another expression of post-apartheid discontent and 'disappointment' (Field 2011; Mbembe 2015; Njovane 2015). The Minister of Health has expressed "hope" that the current political climate will not adversely affect progress with NHI (702 Talk Radio 2015). But, *this* climate is not simply a backdrop to NHI. Rather, these social worries and disappointments are critically intertwined with NHI policy and its future. To change the story from "lack of health services" to "UHC", a conversation is needed to explicitly draw together notions of accountability, justice and

health; to express and learn from efforts (including the South African Truth and Reconciliation Commission) that have looked back in order to move forward *in* the health system; and to situate NHI as part of the restorative trajectory undertaken by the country's variant of transitional justice.

> It is easy to say, 'the issue is communication,' and it is easy to say 'we have to talk to each other.' But it is hard to collaborate, make meaning, and improvise. It is difficult to create conversation that facilitates sensemaking and learning, and avoid the barriers to conversation that facilitates sensemaking and learning. Even though conversation is hard, we really have to do it if we want to deliver good health care (Jordan et al. 2009:11)

In light of the brutal murder of Harry Nyathela (Epilogue), we really do have to have this "hard" conversation, to reckon with the limits of language itself, if we also want to deliver justice.

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Research Articles 1-3 in this thesis:

Research Article 1

Harris, B., J. Eyles, and J. Goudge

Draft Ways of doing: restorative practices, governmentality and provider conduct in post-apartheid health care. Medical Anthropology (accepted for publication).

Research Article 2

Harris, B., J. Eyles, L. Penn-Kekana, L. Thomas, and J. Goudge

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Research Article 3

Harris, B., J. Eyles, L. Penn-Kekana, J. Fried, H. Nyathela, L. Thomas, and J. Goudge

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Section IV

Reckoning with violent limits: An Epilogue

> South Africa, a country not at war, faces an unprecedented burden of morbidity and mortality arising from violence and injury (Seedat et al. 2009:1011).

> Our inability to analyse the violence of the present does not mean that the violence is 'senseless' but rather that we do not know how to explain it (Thomas 2012:8).

Street-level Injustice: Harry's story continued

On the afternoon of Sunday 23 March 2014, Harry Nyathela said goodbye to his wife and travelled from Soweto to Tembisa on the East Rand of Johannesburg, his home for the working week. In the early evening, he strolled to a nearby spaza shop and purchased a soft drink and some bread for his dinner. On the way back to his rented room, he encountered a badly hurt man lying unassisted on the street. It would later unfold that this man had been severely and publicly beaten by a group of at least four men, described by some as a 'mob'. Details of why are yet to emerge.

Vigilante actions (popular justice, mob justice)

South Africa has a long and complex history of vigilantism, or "extralegal forms of violent punishment that are perceived as a means of attaining justice" (Thomas 2012:4). Vigilante punishment often involves visible and symbolic corporal punishment (theatrically intended to send a 'message' to potential transgressors, the state and society at large), as much as directly 'punish' its immediate victims (Feldman 2003; Thomas; von Holdt 2013). Prior to 1994, vigilante actions were largely associated with conservative, politically-motivated violence

endorsed by the apartheid state (South African Truth and Reconciliation Commission 2003) although a number of non-political actions also took place beneath this mantle and across the political spectrum (Harris 2001a). This was a time of "death by unofficial state execution and mutilation and execution by vigilante acts [that had] supplanted judicial processes, the common rules of law, and human rights" (Feldman 2003:59).[21] Such acts, many of which occurred in the early 1990s (on the eve of South Africa's political transition) were performed on the streets, in single-sex migrant hostels, townships, and between neighbouring villages – racialized apartheid geographies that were the "staging ground of political violence" (Nordstrom 1998:103). Post-1994, such actions have been largely depoliticised, portrayed as "crime-fighting" in public discourse (Harris 2001a) and rendered "senseless" by the state (Thomas). However, their persistence in form and function - as terror, control, and "sacrifice" (Feldman 2003:68) - reflects historical and political continuities, while also revealing new meanings, actors and spaces of struggle; a new politics (Thomas; von Holdt). Such acts of violent justice are a reminder that "there is no singular conception of law post-apartheid and that the law of the state is by no means the only law that rules" (Thomas 2012:4).

Harry stopped to help the injured man and phoned the police and an ambulance. But two of the man's assailants returned to warn Harry off.[22] *When he persisted with assisting the victim, the men beat Harry to death.*

[21] Feldman (2003) is writing here particularly of Northern Ireland in the mid-1980s but his conceptualisation of extralegal violence, infused with political terror and symbolism, applies neatly "beyond" (p.68), including to an apartheid context.

[22] Perhaps not wanting Harry to interrupt the instrumental (punish the victim) or symbolic (send a message) suffering of the man?

Murder

Murder is "an important crime to monitor because unlike other crimes, the number of reported murders is likely to be very close to the actual number of murders committed" (Institute for Security Studies and Africa Check 2014). Between April 2013 and March 2014, an average of 47 murders was committed daily in South Africa. In that period, Harry was one of 89 people murdered in Tembisa, 3 333 in Gauteng Province, and 17,068 nationally (South African Police Service 2014) (see Table 2).

Although murder statistics have fallen over the course of South Africa's democracy – from 66.9 per 100,000 in 1994/5 to 42.7 in 2003/4 (Altbeker 2008), and 32.2 in 2013/14 (South African Police Service 2014) – the present murder rate is still extremely high: five times the 2013 global average of 6 per 100,000 (Institute for Security Studies and Africa Check 2014). Furthermore, there has been a recent upward turn: "for the first time in 20 years the number of murders and the murder rate has increased for a second consecutive year" (Institute for Security Studies and Africa Check). Additionally, other serious and violent crimes continue at high levels, for example, in 2013/14, the following cases were reported (South African Police Service 2014):

- 17 110 - attempted murder;
- 183 173 - assault with the intent to inflict grievous bodily harm;
- 119 351 - robbery with aggravating circumstances (weapons involved); and
- 46 253 – rape.[23]

[23] It is estimated that only 1 in 9 cases of rape is reported to the police (Jewkes and Abrahams 2002).

Table 2. Reported murders: April-March 2004/2005-2013/2014 (South African Police Service 2014).

Apr-Mar	04-05	05-06	06-07	07-08	08-09	09-10	10-11	11-12	12-13	13-14
Tembisa	106	116	131	148	122	111	76	78	78	89
Gauteng	3818	3621	3884	3766	3963	3444	3257	3012	2997	3333
National	18793	18545	19202	18487	18148	16834	15940	15609	16259	17068

Witnesses identified the perpetrators of Harry's death as Mozambican citizens. At his funeral, a few people expressed hostile, 'anti-foreigner' sentiments, prompting a colleague to note she was "glad" the funeral was not in Tembisa where Harry was killed as "the anger" might have been physically directed at foreigners living in the area.

Xenophobia

Between 11 and 26 May 2008, at least 62 people were killed and over 100,000 displaced during xenophobic attacks which started in Alexandra Township in Johannesburg and spread to over 135 locations (Misago et al. 2010). Globally, these particular events were met with shock and disbelief, and "2008" has become a popular benchmark against which to measure newer incidents of "anti-foreigner" violence and conflict. Seven years later, in April and May 2015, at least seven people were killed and thousands displaced during another "wave of xenophobic attacks" (Haffejee 2015). Yet, xenophobia - with collective violence occupying one end of a much wider spectrum of everyday harassment, discrimination and hostility - is not new in South Africa (Dobson 2010; Harris 2001b; Polzer 2010). Its roots can be found in "the racism, nationalism, violence, and isolation of the apartheid era" (Dobson 2010:12) which shaped ways of seeing, defining and doing to Others. Furthermore, processes of democratisation, including an exclusionary form of nationalism (Harris 2001b) and "differentiated" and "insurgent" citizenship (von Holdt et al. 2011:6-7) linked to rapid,

unstable class formation, have also generated conditions for xenophobia, marginalization and social exclusion.

Xenophobic attitudes remain pervasive throughout the society, transcending race, class and gender (Dobson 2010). In a 2014 survey of over 27,000 people living in Gauteng (the province where Harry was killed), more than a third (38 percent) agreed with the statement: "Send all foreigners home", while 69 percent felt that "foreigners were taking benefits meant for South Africans" (Gauteng City-Region Observatory 2014), causing political leaders to express concern about an "escalation in xenophobia" (Eye Witness News 2014).

Yet, negative attitudes, as widespread as they are, do not automatically transfer into violent action (Dobson 2010; Harris 2001b; Polzer 2010). Instead, spatial mapping and local-level case studies reveal the situated nature of such attacks, often triggered through "localised competition for political […] and economic power" and symptomatic of "broader challenges of legitimate and accountable local governance" (Polzer 2010:2). Here, the role of individuals and local leaders in either inciting or curbing xenophobic and other forms of collective violence, is critical (Polzer). In this context, it is worth noting that at Harry's funeral, the calls were mostly for calm and patience, and to allow the law to follow its course.

A few days after Harry's funeral, the police traced and arrested a man in Mozambique and a bail hearing was set. However, this has been postponed at least twice. A year on and the wheels of justice are turning. The law is taking its course. But slowly for a family who has lost a loved one and a primary breadwinner. And slowly for a detained man awaiting a decision on whether he qualifies for bail and when to expect a trial.

Remand detention

Remand detention describes the detention of unsentenced persons "awaiting further action by the court" (Republic of South Africa 2014:10). As of the end-March 2014, nearly one in three (44,236 of 154,648) inmates was in remand (Masuta 2014). By June 2014, largely enabled through new legislation for improved management of remand detention, this number had fallen to 41,690, a step closer to the "ideal international target of 25%" (Masuta). Of those in remand, five percent (1 922) had been held in custody for at least two years (Masuta) and many more (including the man arrested for Harry's murder) had been detained for at least six months (the figure was 33 percent in 2012) (Centre for Legal Studies 2013). Given that "approximately 2 in 5 of these people will eventually be acquitted […] a staggering number of innocent people are being deprived of their freedom" (Wits Justice Project 2014).

While waiting in unsentenced limbo, Harry's alleged killer faces a concentrated set of public health challenges, including exposure to high levels of violence, TB and HIV (Judicial Inspectorate for Correctional Services 2014; Vanleeuw 2014). These risks are further intensified by "unacceptable" overcrowding (Judicial Inspectorate for Correctional Services) (28.65 percent in 2012) (Republic of South Africa 2014), poor ventilation, and severe shortages of medical staff. At the time of Harry's death, 40 out of 48 doctor posts were vacant in the prison service (Vanleeuw; Section 27 2014). In December 2012, a landmark ruling by the Constitutional Court found the Department of Correctional Services to have "negligently caused" a remand detainee, Dudley Lee, to become infected with tuberculosis sometime between 1999 (the time of his arrest) and 2004 (when he was acquitted and released) (Treatment Action Campaign 2012). This ruling prompted a national roll-out of TB testing in prisons, a small yet important first step towards "reasonably" managing the disease behind bars; however much remains to be done to improve health-related conditions in detention overall (GroundUP 2014).

Violent limits

It is poignant that Harry – so successful in negotiating his own access to health services - lost his life while securing access to health care (ambulance) and justice (police) for someone else in need.[24] In times of peace, violent obstruction is not usually expected as a barrier to health care.[25] Yet, in post-conflict settings, violence (past and present) may well shape geographical barriers, transport and infrastructural obstacles to health care (Bornemisza et al. 2010; Laplante 2011). It may also influence the (un)availability of qualified staff and funds for health system reform (Bornemisza et al.; Laplante), and persist through authoritarian attitudes, identities and institutionalised 'ways of doing' health care (von Holdt 2010; Research Article 1). Violence creates a need for health care, while simultaneously limiting the "freedom" (Thiede, Akweongo, and McIntyre 2007:106) or "capability" (Sen 2009) of individuals and communities to use services. It may also impede emergency services – directly and by creating insecure 'no-go' areas for paramedics and police alike.[26] In the REACH project, two unattended women gave birth at home because they were unable to walk to pre-arranged ambulance 'collection points' during labour (a clinic near an informal

[24] I am grateful to Greer van Zyl for making this point explicit.

[25] This is not to suggest an absence of violence (with implications for health care) in a democratic context but rather, that access-related literature does not typically present violence as obstructing (or peace as aiding) the availability, affordability, acceptability, AND accountability of services.

[26] In established democracies, violence may well present similar barriers to health care in certain locales. The formality of past conflict (itself a determinant of health) and the scale of enduring violence in fragile and post-conflict states may, however, have more wide-spread implications for access to services and the health system as a whole.

settlement; and the gate of a hostel). Both only received emergency attention when their male partners met, and accompanied the ambulances to them[27] (see also Silal et al. 2012).

It is conservatively estimated that at least a third of South Africans will be exposed to physical violence at some point in their lives (Kaminer et al. 2008) and this may be much higher in specific communities facing widespread violence underpinned by "structural issues of historical oppression and socioeconomic marginalization" (Kaminer, du Plessis, Hardy, and Benjamin 2013:121). Recent research with young South Africans aged 12-15 years (a 'born-free', post-apartheid generation) living in a low-income, urban community with high homicide rates and pervasive gang-related activity, found that 93 percent had experienced more than one form of violence (poly-victimization), while nearly half had seen dead bodies in their neighbourhood, and 31.9 percent had directly witnessed a murder (Kaminer et al. 2013:117). Over three quarters of this group had also witnessed domestic violence and 52.1 percent reported being directly beaten with an implement at home (p.118). Furthermore, for the majority, school was a space of danger, rather than safety (Kaminer et al. 2013). In a 2012 National School Violence Study (NSVS), one in five secondary school learners - an estimated 1,020,597 school children - reported violent victimisation at school in the past year (Burton and Leoschut 2013:11). Half of these learners reported that they had experienced corporal punishment at school (this is illegal), while 36 percent reported corporal punishment at home. One in three educators admitted to "ever having felt unsafe while on school premises" (Burton and Leoschut 2013:24). Learners also reported repeat- and poly-victimization; and the NSVS established a close link between school safety and community safety. Poly-victimization is thought to bring a greater risk for depression, anxiety and aggression than exposure to a singular form of violence, although further research is required into resilience,

[27] In 2010, at the time of the REACH project, two female paramedics were raped when responding to a call-out, bringing the safety of emergency staff under the public spotlight (personal memory; see also COSATU 2014).

coping strategies, and possible interventions in contexts where multiple exposure is the norm (Kaminer et al. 2013).

The normalisation of violence through and across South Africa's institutions of everyday life - communities, homes and schools – alongside high levels of criminality and growing political contestation, points to the complex, subtle ways that violence finds expression overtime, effectively cutting across political regimes, and ultimately challenging the notion of "peaceful democracy" (Barolsky 2005; Graham, Bruce, and Perold 2010; von Holdt 2013). Indeed, Karl von Holdt (2013) concludes that violence is part of, not antithetical to, the country's democracy: a "violent democracy".

> South Africa is torn between the persistence of an exclusionary socio-economic structure marked by deep poverty and extreme inequality on the one hand, and on the other the symbolic and institutional rupture presented by the transition to democracy. This relationship produces a highly unstable order in which intra-elite conflict and violence are growing, characterised by new forms of violence and the reproduction of older patterns of violence, a social order that can be characterised as *violent democracy* (p.591, emphasis original).

Here, violence is understood to be productive as much as it is destructive, generating and reinforcing social relationships, identities, institutions, even the nature of democracy itself. Moreover, in a post-conflict context, it is important to take "cognisance of the lineaments of war in peace and the ways in which peace is configured by war" (Barolsky 2005:2). Violence, normalized through conflict, continues in post-conflict settings. Violence begets violence. Violence also generates trauma and with this, a complex set of health needs, for communities and individuals (Barolsky; Eagle and Kaminer 2013; Stevens et al. 2013; Straker 2013) including the frontline health workers who suffer from occupation-related

traumatic stress (see Martin 2006 for an account of high levels of vicarious trauma among South African nurses). Like violence, trauma and suffering thread, in complex, non-linear yet interconnected, ways across time and socio-political order (Barolsky, see also additional work of the Centre for the Study of Violence and Reconciliation, including the Violence and Transition; and Trauma and Transition Projects)

Continuous trauma

Nearly thirty years ago, anti-apartheid health practitioners coined the term "continuous traumatic stress" (CTS) to describe the psychological impact of living with protracted political violence and state oppression (Eagle and Kaminer 2013; Stevens et al. 2013; Straker 2013). Subsequently applied in other contexts, including *post*-apartheid South Africa, the definition of CTS has expanded beyond its roots in overtly political violence to describe the precariousness of "living in conditions in which there is a realistic threat of present and future danger" (Stevens et al. 2013:76): community violence, gangsterism and xenophobia, as well as civil war and armed conflict. Unlike posttraumatic stress, which may develop as a response to *past* traumatic event(s), CTS is produced through *ongoing exposure* to life-threatening incidents, leading to anticipatory anxiety, hypervigilance and a constant preoccupation with safety (Eagle and Kaminer 2013; Stevens et al. 2013; Straker 2013). Because CTS is contextually generated, the state is implicated in its production; highlighting what Gillian Eagle and Deborah Kaminer (2013) term a "fundamentally broken" social contract, in which,

> [s]ystems designed to create a sense of accountability and to minimize harm to citizens are ineffectual or overstretched, at best, or corrupt and collusive with informal systems of power, at worst (p.94).

To properly alleviate CTS, therefore, the conditions under which it is produced - institutional, political and structural – must be transformed; a new social contract must be built (Eagle and Kaminer 2013; Straker 2013). In the absence of fundamental sociopolitical change, the ongoing production of trauma at psychological, interactional, institutional, and structural levels persists, and the therapeutic bandaid is simply, chillingly, to "prepare for future traumatization" (Eagle and Kaminer 2013:91).

(Re)politicised suffering

Because CTS is ongoing and unresolvable without contextual change, it can be seen as both a response to, and a *symptom of,* the ways in which violence and suffering are embedded and institutionalized in everyday life. Here, the past alone does not disrupt and distort the present (as it does with posttraumatic stress). Rather, the present itself is continually shaped by complex cycles of violence and the threat thereof. While not the only expression of trauma (or suffering) in post-apartheid South Africa, the notion of CTS elicits a clear conceptual link between individual suffering (manifest in trauma) and the broader state and its "systems of protection" (Eagle and Kaminer 2013:94), revealing – even if in the extreme - the political heritage of such suffering; and reinforcing "the need for interventions to change contexts as well as to treat individuals" (Straker 2013:215).

At the same time, in fragile and post-conflict contexts, many of these systems, including health and justice, are implicated in past atrocities and violence (South African Truth and Reconciliation Commission 2003) and are often directly connected to the production of *post*traumatic stress for many ex-combatants (Gear 2002), former political prisoners, activists, their families, and other victims of state torture and political detention (Kaminer et al. 2008; Langa 2013). Recent research in the South African context, suggests that for men, lifelong posttraumatic stress disorder (PTSD) may remain "most strongly

associated" with political torture and detention (Kaminer et al. 2008:1589) - most of the reported state sanctioned violence reported in the Kaminer et al. (2008) study was perpetrated during the apartheid era, although there is evidence of similar practices continuing in contemporary South Africa (Independent Complaints Directorate 2010; Langa 2013). For women in the same study, rape (often a weapon of war – see Sigsworth 2008) had the strongest association with lifelong PTSD (Kaminer et al.). That an estimated one in nine rapes is formally reported to the police in a post-apartheid context (Jewkes and Abrahams 2002) additionally testifies to deep levels of public mistrust in these systems.

Imbued with high levels of physical violence and trauma, the South African health system also continues to reap a "harvest" of structural violence (Farmer 2004:315), germinated through taken-for-granted "social arrangements that put individuals and populations in harm's way" (Farmer et al. 2006:1686). The country remains one of the world's most inequitable (Inchauste et al. 2014) and relative deprivation, poverty, racism, and patriarchy continue to shape health outcomes and the accessibility of health care (Coovadia et al. 2009). Power and "positionality" (the 'place' of an individual in sociopolitical hierarchies viz. socioeconomic, gender, race, and cultural orders) (Quesada, Hart and Bourgois 2011:2) are particularly relevant in light of South Africa's racist history, produced in the interstices of structural *and* "transacted or performed violence of the apartheid regime - two levels of political domination that the TRC was often accused of artificially separating" (Feldman 2002:238). At the same time, the country's current "growth path" has also been implicated in renewing "institutionalisation of previous forms of historical exclusion" (Brankovic 2012:41), resulting, for many, in a tenuous inclusion, an "adverse incorporation", into the democratic social contract (du Toit 2008; Quesada et al. 2011; see also Research Article 2).

Because structural violence is institutionally normalized, socially engrained, and embedded in policies and systems, it is usually more hidden and diffuse than physical force:

"an invisible norm, a fact of life" (Brankovic 2012:35). However, both can be seen to originate in the same political economy and both occupy the same violence "continuum" (Brankovic 2012; Feldman 2002; Scheper-Hughes and Bourgois 2003). In this vein, a growing body of literature identifies South Africa's 'macho culture' as integral to perpetuating high levels of physical violence (Brankovic 2012; Chagutah 2013; Hamber 2007; Jewkes, Abrahams et al. 2009; Sigsworth 2008; Seedat et al. 2009) where

> the dominant ideals of masculinity, across racial groups, are predicated on a striking gender hierarchy, with demonstrations of toughness, bravery, and defence of honour, which readily translate into risk-taking behaviours and the high status gained by fighting rather than to resolve differences peacefully. Men tend to be highly competitive about power, respect, and status (Seedat et al. 2009:1015).

Gendered suffering

It is perhaps unsurprising that all of the actors involved in Harry's murder were men: the perpetrators, their first victim, and Harry himself. Continuous with apartheid-era patterns of violence, men (especially young men) in the post-apartheid context are disproportionately at risk of being *both* victims and perpetrators of violence (Kynoch 2008; Seedat et al. 2009). At the same time, patterns of gender-based violence (GBV), including intimate partner violence, show that men and women experience violence differently, with women bearing the brunt of a GBV epidemic that ranks amongst the world's highest for a nation not at war (Abrahams et al. 2012; Mankazana 2015; Seedat et al. 2009).

> The normalisation of violence often affects women more than men. Norms are related to power dynamics and in patriarchal societies, norms are therefore often shaped more predominantly by men (Graham et al. 2010:96)

It is estimated that in South Africa, a woman is killed by her intimate partner "every eight hours"[28] (Abrahams et al. 2012:2), and rape remains highly prevalent. In recent studies, between 21 percent (Jewkes et al. 2006) and 28 percent (Jewkes, Sikweyiya et al. 2009) of men interviewed admitted to having ever raped, three quarters of whom first raped as teenagers (Jewkes, Sikweyiya et al. 2009). Rachel Jewkes, Yandisa Sikweyiya, and colleagues (2009) also found that perpetrators of intimate partner violence were more likely to be HIV positive than their non-violent counterparts. They estimate that "16% of all HIV infections in women could be prevented if women did not experience domestic violence from their partners" (p.1). In the interviews collected for this thesis/the REACH study, many of the women we interviewed spoke of physically and emotionally abusive partners, often when describing how they became HIV infected (while in a relationship with an abusive man) and/or when disclosing their HIV status to a partner (who responded abusively). Some of the men also described a close proximity to violence and crime – a brother raping women at home, friends carrying out armed robberies, abusive fathers, even a few themselves directly involved in past political violence, or more recently, hijacking and theft.

Researching the limits

Harry's murder can be located, with some precision, on South Africa's "continuum" of violence (Brankovic 2012; Scheper-Hughes and Bourgois 2003); a micro-incident of physical

[28] This 2009 figure is lower than in 1999, when one woman was killed by her partner "every six hours" - in keeping with the overall reduction in homicide across the ten year period – but Abrahams et al. (2012) note that during this time, gender-based homicides were "disproportionately resistant to the change" and that rape homicides "proportionately increased" (p.1). Additionally, given the upturn in the country's homicide rate between 2012 and 2014, a concurrent rise in intimate femicide might be expected, unless prevention efforts start to make some headway.

force structured by a changing-but-not context of extreme inequality and unsettled identities of masculinity, citizenship, race and class (Brankovic 2012; Chagutah 2013; Dodson 2010; Kynoch 2008; Seedat et al. 2009; Thomas 2012; von Holdt 2013). His murder can be placed in space, located in time, referenced through history, politics and economics (Brankovic 2012; Thomas 2012). It can be represented statistically. Told dramatically. Theorized as power and resistance, and conceptualized as suffering and trauma (Barolsky 2005; Eagle and Kaminer 2013; Stevens et al. 2013; Straker 2013). It shows a 'way of doing' (Harris et al. draft – Research Article 1), of producing, South Africa's "violent democracy".[29]And, at the same time, reveals profound limits: to individual and community agency, to justice and accountability, and to language itself. Harry's murder is not quite senseless, but it is difficult to fully explain. It *feels* difficult to explain.

Recognising this difficulty requires a theoretical shift towards the "experiential aspects of violence" (Whitehead 2004, quoted in Accomazzo 2012:548); a recognition that violence is physical and non-verbal, as well as symbolic and ritualised.[30] On this level, Harry's murder *is* shocking beyond words; it is unspeakable. The experiential quality of

[29] Harry's murder could, of course, also be approached from a much wider range of perspectives, frameworks, disciplinary angles not explored here. It is probably safe to say that every discipline has, in some or many ways, tried to make sense of violence. This, of course, begs the question of whether language itself can ever escape violence. As Zizek (2008) concludes, "There *is* a "language" which is outside violence […] It is not the language of peaceful communication among subjects, but the language of pure mathematics, this joyful study of multiplicities. Should we still call it language? Lacan's choice was a no […]" (p.11, emphasis original).

[30] Although Whitehead's (2004) appeal is for a new anthropology of violence, there is a long-standing psychodynamic concern with the ways that violence subverts, displaces and re-creates the once-ordinary and everyday bodies of individuals and society. Whether as Freud's uncanny, Kristeva's abject, or Lacan's real, this theoretical trajectory draws attention to how violence ghoulishly recasts the familiar in ways that elude symbolic expression and language itself.

violence[31] complicates efforts to 'make sense' of it, to bring it into language; a common therapeutic challenge to regaining mastery after a traumatic experience (Eagle and Kaminer 2013; Scarry 1985; Stevens et al. 2013). More broadly, it may account for some of the difficulties of negotiating peace and "ending" armed conflict, as well as developing and implementing effective violence prevention policies. Furthermore, the "unspeakable" property of violence potentially complicates a research agenda, raising questions about how to remember, tell, challenge and exorcise traumatic and violent experiences that go beyond language. Twenty one years into South Africa's democracy, it remains important to reflect on ways of researching violence, to draw in multiple perspectives, including (as argued throughout this thesis) from a human rights paradigm, the field of transitional justice, and health policy and systems research. There may also be merit in exploring the health system as itself a possible site of memorialization, thinking too of whether and how to admit 'newer' post-apartheid ghosts to older archives.

This epilogue narrates Harry's murder as a "small story" of violence within a much "bigger" South African history. In one way, it is a story that begins with a clear and final ending – his death – but, the narrative of what happened and why only picks up somewhere in the middle, with no obvious start or finish. It is based on fragments, snippets, differently told perspectives: a few emails between colleagues, some statements made at Harry's funeral, the occasional phone call with relatives; not quite corridor-chat or overheard gossip, but without the coherence, closure or "grandness" of a "big story" (Georgakopoulou 2006). The absence of a trial, a formal storytelling platform (for both the alleged perpetrator and the criminal

[31] This "unspeakable" quality can be extended – in some ways - to illness, birth, dying, the "bodily" of health, or, perhaps more particularly, "The Body in Pain", as explored by Elaine Scarry (1985) in her examination of the role of pain in torture, the role of terror, and the ways that physical pain is beyond language. This complements recent scholarship around the Kleinian notion that "harm inflicted can never be completely 'made good'" (Hamber 2015:7).

justice system), simply generates further fragmentation.[32] Harry's story is still unfolding; it is future-oriented as much as it is about a past event.

The methodological value in understanding small stories as "rehearsals for the future" (Georgakopoulou 2006:126) takes on an added gravitas in South Africa's context of continuous stress, ongoing violence and future-oriented trauma. The language of trauma offers one way of bridging the past and present and bringing to the fore the continuities as well as changes in the everyday experience of suffering. Although individualized (and contiguous with the deepening of governmental power – much like restorative justice) (see Harris et al. draft – Research Article 1), trauma is also a political and socially embedded issue. Harry's story is a narrative of trauma as much as it is a testimonial of violence and injustice. But whose trauma? Researcher reflexivity requires an awareness of self in the text, a contextualization of self in the research. It is an ongoing effort to grapple not only with the limits of language but the boundaries, the *limits*, of research in society.

Reckoning with the limits

This epilogue ends with the horror and shock of Harry's murder. It offers no neat or hopeful resolution. Harry's death is haunting. It *should* be haunting. Both because of the brutal, yet almost incidental, way in which he died and because of the hopeful way in which he lived: seeking justice, easing access to health care, and pioneering new 'ways of doing' between people. Without a change in context, without institutional and individual transformation, there can be no easy conclusion to Harry's story. Instead, this epilogue is an introduction to Harry's ghost. It is an invitation to haunting.

[32] Not that the creation of a judicial platform for the alleged perpetrator will necessarily enable more coherence or allow for a 'deeper' or 'truer' understanding of what happened and why (whether expressed through his 'confession' or the formal judgement).

“Haunting is an active presencing of that which is disavowed—making cultural repression and social othering manifest” (Decoteau 2008:232). It is seeking out and listening to that which cannot be said yet cannot be forgotten. Haunting is a “reckoning;” it transfers responsibility to the audience and beckons us to justice (Decoteau 2008:251). The South African health system is steeped in dying, in death, and in ghosts. It is haunted by illness and violence. Harry died brutally but he also died courageously, showing kindness to someone who needed his help. Perhaps it is this kindness – itself not easy to “speak” – that should be the most haunting for us all, a small way to reckon with the ghosts and challenge the unspeakable limits.

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Research Articles 1-3 in this thesis:

Research Article 1

Harris, B., J. Eyles, and J. Goudge

Draft Ways of doing: restorative practices, governmentality and provider conduct in post-apartheid health care. Medical Anthropology (accepted for publication).

Research Article 2

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Research Article 3

Harris, B., J. Eyles, L. Penn-Kekana, J. Fried, H. Nyathela, L. Thomas, and J. Goudge

2014 Bringing justice to unacceptable health care services? Street-level reflections from urban South Africa. International Journal of Transitional Justice 8(1):141-61.

Appendix 1: REACH Phase 1 methods for site selection and sampling[33]

The sites and facilities sampled in REACH Phase 1 provided the basis for sub-district/facility selection in REACH Phase 2, including this thesis.

Study sites: sub-district setting

Four health sub-districts were selected as the study sites, based on the following criteria:

- Geographic location: two of the study sites are in urban areas while two are in rural areas.
- Each site is in a different province to allow for insights from different governance contexts (this is particularly important given the 'federal' structure of South Africa, where the provinces have considerable decision-making autonomy).
- User partners should be involved in site selection and the sub-district should be identified by them as a priority area for utilisation evaluation.[34]
- The sub-district must have at least 1 hospital providing maternity services, including caesarean sections, 2 ART delivery sites and 2 TB service sites.
- The availability of data on the socio-economic status of those with TB and AIDS in the sub-district would be an advantage.[35]

[33] This document was developed by members of the REACH Phase 1 team, as presented in the REACH Project Final Report to the IDRC (2012). With special thanks to Duane Blaauw, Susan Cleary, Helen Schneider, and Sheetal Silal.

[34] For example, in both Johannesburg and Cape Town, meetings were held with government about the most appropriate sub-district to select. In both instances, government officials suggested sub-districts that were not "over-researched" and did not have relatively high levels of NGO input or donor funding in the health system. Sub-districts were therefore chosen if they could contribute to an understanding of a 'normal' or 'average' public sector use or access experience.

Based on the above criteria, sites chosen were:

i. An urban sub-district in Cape Town in the Western Cape province.

ii. An urban sub-district in Johannesburg in the Gauteng province.

iii. Bushbuckridge – a rural sub-district in Mpumulanga; part of Bushbuckridge is included in the Agincourt Demographic Surveillance Site.

iv. Hlabisa – a rural sub-district in Northern KwaZulu-Natal; part of Hlabisa is included in the Africa Centre Demographic Surveillance Site.

The location of these sites is presented in the map in Figure 1.

Figure 1: Geographic location of REACH sites

[35] This consideration particularly influenced the choice of the rural sub-districts, both of which have the benefit of detailed surveillance on a part of the sub-district population including demographic and socioeconomic data as well as information on births, deaths and HIV status.

While it was not intended that the findings would be generalisable to the whole country, the selection of sites ensures that urban-urban, rural-rural and urban-rural comparisons was feasible.

Sampling of tracer service users and health facilities

A sampling procedure was established to allow for the creation of a representative sample of users of the three tracer services in each sub-district. Because the most efficient way of sampling users is to conduct surveys at the point of use in health facilities, we first selected a representative sample of health facilities, then within these facilities, a representative sample of users. With this type of two-step process we have sampled 'clusters' of patients in the sub-district, which introduces a 'cluster design effect'.

The sample size was calculated using a chi-squared 'goodness of fit' test, comparing socio-economic distribution of need with a hypothetical pattern of unequal use based on Bushbuckridge as the example, and taking into account the effects of clustering for TB services. From this we settled on a sample size for each tracer of 300 (or a total of 900 per site). We therefore maintained the planned sample size for interviews / record reviews in TB and ART but doubled the sample size for CEOC (maternal deliveries).

Given variations in models of service provision, the sampling of health care facilities was tailored to the specific circumstances of each sub-district. In order to obtain a representative sample of facilities we generated several options, as outlined in Table 1.

Table 1: Options for sampling of health facilities across tracers

	Option 1	Option 2	Option 3
ART	Where there are three or less facilities providing ART, then recruit patients from all the facilities, proportional to the numbers of patients enrolled onto ART in each facility.	If there are more than three facilities and if patient numbers vary considerably between facilities, consider a probability proportional to size (PPS) approach to sampling. The cluster size and number of units sampled will depend on the degree of variation in numbers and types of patients being seen in facilities. If, for example, there is one very large ART service at the hospital and smaller services in many PHC clinics facilities, the cluster size will need to be small enough and the facilities sampled sufficient in number to ensure that the final sample adequately represents both the "concentrated" and the more peripheral user populations.	If there are more than three facilities and patient numbers are even across facilities then a simple random procedure may be adequate, with the proportion of the patient sample allocated evenly between them. The number of facilities to be sampled will have to be judged separately in each sub-district, depending on the total.
TB	TB care is provided in most facilities in each sub-district. Numbers of patients being followed up tends to vary by size of facility. A PPS facility sampling method appears to be the best way to select TB facilities (see below). As with ART, the number and size of clusters sampled will depend on the degree of variation in numbers and types of patients being seen in facilities. The minimum proposed is 5 facilities.		
CEOC	Select the facility providing CEOC in or for the sub-district.	If there are two facilities, divide the sample between them proportional to the number of deliveries conducted at the two facilities. If one facility providing CEOC is outside the district, only those patients from the sub-district must be selected for interview at that facility.	

If a proportional sampling technique is chosen, this means that the 300 exit interviews are allocated to each facility according to the percentage of overall users in each facility. For example, if there are 1000 users in the sub-district, 300 of whom are at Facility A and the remainder at Facility B, then 30% of the user exit interviews should be conducted at the first facility and the remainder at the second. On the other hand, probability proportional to size (PPS) is a sampling technique in which the probability of selecting a sampling unit (e.g. health centre) is proportional to the size of its user population. It gives a probability (i.e., random, representative) sample. A summary of facilities, planned sample sizes and final realized sample sizes is presented in the tables below.

Table 2: Sample of facilities and patients for exit interviews – urban areas

City of Johannesburg	Planned N	Final N	City of Cape Town	Planned N	Final N
TB facilities (PPS sampling) – total	**300**	**301**	**TB facilities (PPS sampling) – total**	**300**	**335**
Facility 1	30	30	Facility 11	60	57
Facility 2	30	30	Facility 12	60	58
Facility 3	30	32	Facility 13	60	76
Facility 4	30	28	Facility 14	60	82
Facility 5	30	30	Facility 15	60	62
Facility 6	30	30			
Facility 7	30	30			
Facility 8	30	30			
Facility 9	30	31			
Facility 10	30	30			
ART facilities (proportional sampling) – total	**300**	**331**	**ART facilities (proportional sampling) – total**	**300**	**322**
Facility 16	75	91	Facility 19	138	106
Facility 17	85	108	Facility 20	25	79
Facility 18	140	132	Facility 21	137	137
CEOC facilities (proportional sampling) – total	**300**	**358**	**CEOC facilities (proportional sampling)**	**300**	**350**
Facility 22	22	40	Facility 25	180	156
Facility 23	25	45	Facility 26	120	194
Facility 24	253	273			

Table 3: Sample of facilities and patients for exit interviews – rural areas

Hlabisa	Planned N	Final N	Bushbuckridge	Planned N	Final N
TB facilities (PPS sampling) – total	**300**	**296**	**TB facilities (PPS sampling) – total**	**300**	**349**
Facility 27	60	60	Facility 32	30	18
Facility 28	60	56	Facility 33	30	30
Facility 29	60	61	Facility 34	30	32
Facility 30	60	59	Facility 35	30	18
Facility 31	60	60	Facility 36	30	31
			Facility 37	30	44
			Facility 38	30	17
			Facility 39	30	19
			Facility 40	30	30
			Facility 41	30	63
ART facilities (proportional sampling)	**300**	**300**	**ART facilities (proportional sampling)**	**300**	**312**
Facility 42	120	120	Facility 46	155	157
Facility 43	60	60	Facility 47	145	155
Facility 44	60	60			
Facility 45	60	60			
CEOC facilities (proportional sampling)	**300**	**300**	**CEOC facilities (proportional sampling)**	**300**	**308**
Facility 48	300	300	Facility 49	168	171
			Facility 50	132	137

Appendix 2: Research Instruments

Facility Observation Grid

RESEARCHING EQUITY AND ACCESS TO HEALTH CARE
OBSERVATION FRAMEWORK

Name of Facility			
Type of Facility	Fixed Clinic	CHC	Hospital
Date of Observation			
Person conducting the Observation			

NOTES TO OBSERVERS

Detailed field notes must be kept for each visit. These must include date and location, the name of the observer, number of patients and providers observed, a basic description of the facility.

During the observation, detailed attention should be paid to the who, what, where and when of the different processes taking place at the facility. However, in order to 'set the scene', one of the first steps should be a very detailed description of the physical infrastructure of the facility (see below for some guidance), which then will be followed by a shift of attention to the processes at the facility. Here, a detailed description of the steps an average patient goes through from arrival at to leaving the health facility. The what, with whom, where and when should be derived from observing several individual patients and should be summarized, e.g. in tabular form.

After these more general observations, the focus of the observation should shift to the interactions between people in the facility (providers and patients, providers and each other, patients and each other). We are particularly interested in whether providers treat different

patients differently and if so, 'which' patients these are and how are they treated and if your presence has in any way contributed to what you observe.

This is not a checklist, i.e. we are not "looking for" specific items or standardised information. Rather, it is a set of categories/themes to guide the observation process, i.e. what to "look at" in terms of relationships, interactions and dynamics between people (Taylor-Powell and Steele 1996:3).

OBSERVE WHAT?

PHYSICAL SPACE

Physical layout of the facility (here, it can be useful to draw a sketch of the layout of the facility):

Exterior:

- Accessibility of clinic
- parking area, public transport, taxies, walking distance from closest taxi drop-off point;
- opening hours, gated access, presence of security guards
- physical barriers for people with disabilities
- Outdoor environment:
- cleanliness, lighting, specific waiting/ seating area
- Are there amenities nearby (toilets, drinking water, public telephones, place to buy food?)

Interior:

Description of the layout of the facility

- How is the interior space structured? What is the overall impression (e.g. dirty/clean; bright colours/dark, gloomy; patient-friendly or intimidating; etc.)?
- Is it easy to find the relevant treatment area?
- Is there a designated waiting area? Does it have sufficient seating?
- Are the reception and information desks arranged so the patient has privacy?
- Is there clear sign-posting?
- Where do the consultations take place? Are they private or public?
- Objects related to hospital policies and health-related information

Are there any posters, signs, directions, mission statements etc.?

- What topics do they address?
- Are these displayed visibly?
- Is the Patients' Rights Charter displayed?

Are there Complaints Boxes and are they accessible to patients?

- What languages are they in? Do they use clear graphics?

THE 'AVERAGE PATIENT' FLOW

Detailed description of the steps a patient goes through from arrival at the facility until s/he leaves the facility again (queuing, reception/information, waiting area, consultants, etc.)

For each step, the what (e.g. registration), who (e.g. with the receptionist), where (e.g. at the reception desk) and when (chronologically, and also how long it approximately takes to reach each next step; e.g. after one hour waiting time).

What	Who	Where	When/how long	Comments

THE NATURE OF THE INTERACTION: Between patient and provider a) in general

- How do staff members treat patients in general?
- How do they speak to patients (friendly, rude, dismissive, attentive, flirtatious, respectful, courteous)?
- Do they use the patients' language?
- What is their tone of voice?
- What body language do they use (open, closed, facial expressions, eye contact, physical distance between patient and provider)?
- Is the patient the primary focus of the interaction or are they neglected or objectified?
- Do staff members discuss patients with other patients?
- Is there privacy in the interactions?

THE NATURE OF THE INTERACTION: Between patient and provider b) in particular

- Do staff members treat all patients the same or are they treated differently?

If differently, who is more/less likely to get service and what is the quality care?

- Do some patients seem to have a special rapport with providers?

On what basis? (use the checklist below to assist if necessary)

- Are any patients marginalized or overlooked by the staff?

What seems to be the basis for this (use the checklist below to assist if necessary)

CHECKLIST: How do staff members (including clerks, cleaners, etc.) treat/respond to:

- Men and Women (the same, differently, how)
- Poorer and Better off Patients
- People wearing old, worn clothing vs those in new, smart clothes
- Literate vs illiterate patients
- Different ethnic/race groups
- Different language groups
- People with different accents
- South Africans and Foreigners
- Different religious groups
- Teenagers, Adults and the Elderly
- Gay patients
- Very sick patients
- Patients they know or relatives of other staff members
- Patients who know a lot about their condition
- Patients who don't know much about their condition
- Patients who do as expected by staff
- Patients who do not do what is expected of them by the staff.
- Women who are delivering "precious babies"? (i.e. women who have had previous miscarriages)
- Are there any patients who manage to develop a special rapport with health care providers. Explore what is the basis of this rapport.

CHECKLIST: How do patients treat/respond to:

- Male and Female staff members
- Providers from different ethnic/race groups
- Providers from different language groups
- Senior and junior staff
- Older and younger staff
- Clerks/bureaucrats and clinicians
- Staff they know and those they don't
- Staff who seem to know about their condition and staff who seem to have less knowledge?

THE NATURE OF THE INTERACTION: Amongst providers in relation to the patient

- Do staff members speak about the patient(s) to each other in a particular way (with respect, quietly, loudly, mockingly, dismissively)?
- Do staff members use the same amount of time on all the patients?
- Do staff members ignore patients/prioritise other tasks when they are together?

THE NATURE OF THE INTERACTION: Amongst providers in general

- What is the overall mood amongst the staff?
- Do they interact as part of a team or in a disconnected way?
- Do staff members support and cooperate with each other?
- How do junior staff members engage with their seniors (relaxed, confident, afraid)?
- How do senior staff/managers engage with their juniors/subordinates (punitive, encouraging, confidentially, professionally)?
- How are Community Health Workers treated by other staff members?
- How are agency nurses treated by other staff members?
- How do providers address each other? Are some people called "sister", "doctor" while others are called by their first names?

THE NATURE OF THE INTERACTION: Between patients

- Do patients engage with each other or is there a climate of silence?
- At what points do patients interact the most and the least?
- Do patients seem comfortable, uncomfortable, relaxed, stressed, interested in their surroundings, hostile towards each other?
- Do patients treat different patients differently?

DAILY TASKS

- How do people go about their jobs on a day-to-day basis (with diligence, calmly, carelessly, distractedly?)
- Do staff members seem happy, willing, resentful, disinterested, afraid?
- How often do staff members take breaks? How long are these breaks? Do they take them at the same/different times?
- How busy do providers seem to be? Are they all equally busy? Are they busy at certain times, or the whole day?
- Who directs activity? Is there anyone who can disrupt others at any time, but not the other way around?
- Are staff members given 'freedom' to conduct their duties in an uninterrupted way or do supervisors interrupt arbitrarily?
- Are all patients actually examined by providers or are some simply 'diagnosed'/'treated' without examination?
- On average, how long does each interaction between provider and patient take? Is there significant variation? What do you think explains that variation?

RESPONSES TO PROBLEMS/UNUSUAL SITUATIONS

- How do providers tackle problems/unusual situations? (panic, calm, confusion, with focus?)

OTHER OBSERVATIONS

- About the context
- About the time taken to do some processes
- About the processes and interactions
- About the actors involved
- Other issues?

Note these down.

Qualitative Interview Guide: Health Care Workers

This interview schedule serves as a guide for the areas that we will explore with health care workers in in-depth interviews. The order of the areas explored will depend on the flow of the interview, and areas that the interviewee brings up.

This is a schedule for health care workers specifically dealing with ART (adapt for TB and maternal deliveries) services

Before we start each interview:
Begin with an opening statement to introduce the interviewer, the topic and purpose of the interview and the research.

Our team of researchers is conducting a project that aims to develop a better understanding of the barriers to obtaining health care faced by people living in South Africa. We would like to talk with you about your views on issues related to access to health care, with a specific focus on access to ART services.

Outline interviewees' rights (right not to answer specific questions, withdraw at any point, confidentiality, further questions at this stage?). Get the participant to sign the consent forms. Hand out the info sheet.

Moving to the interview:

1) Before we start discussing access-issues, I would like to learn more about you and how you came to be a 'nurse'/'doctor'/'clerk' [designation] within this [facility].

2) To start with, can you tell me how and why you came to be working in the public health sector?

- Explore professional trajectory.
- Use timeline and plot key events, including schooling, training, previous facilities worked at, key people/influences.

- Probe reasons for going into the health sector.

When reach present facility:

3) Can I confirm your job title? How long have you worked here for?
4) Are you from the community where the facility is located?
5) Do you live in the community?
6) Can we move onto your role as a 'nurse'/'doctor'/'clerk' etc here: Can you please describe your average working shift? What do you do on an average day?

- Explore workload and complexity, decisions around which tasks to tackle first and why, relationships with management and patients.
- Map this – break down into a daily timeline and mark key daily events.

7) How is your actual working shift different to your official job description? Can you give me an example of this?

- Explore norms and realities and gaps between.

8) How do you prioritise/juggle your daily tasks and patients and resources in any given shift?
9) What would you like to see being done differently?
10) As I've explained, we are interested in exploring patients' access to ART services. Can you tell me what problems your patients face in accessing these services? Get a general list then specific prompts/examples:

- Can you tell us about any financial barriers?
- Can you tell us about any physical barriers?
- Can you tell us about any cultural barriers?

11) Do patients face different problems at the beginning of their treatment to the end/at a later stage? If so, what are these and why?
12) Other barriers?

13) How do these problems/barriers impact on your work?

14) Once a patient gets to your facility, what happens? Can you give me an example of a problem/challenge that a patient might have experienced with actually getting their treatment once they are at your facility?

- Explore: Are different socio-economic and race groups?

15) How do you help your patients to overcome these problems/barriers?

16) Also explore ARV policy.

17) If there is a defaulter/complication, how is this communicated and how is this handled?

18) Can you tell us about the different types of patients you deal with?

- Who are the difficult patients and why?
- Explore whether these patients share a typical profile ito race, SES, language, ethnicity etc
- How do you deal with them?
- Who are the easy patients and why?
- Ditto
- How do you deal with them?

19) [If not covered above] Can you tell us about defaulting?

- Who are the defaulters and why do you think they default?
- What do you think can be done to minimise defaulting?

20) How do you feel the health system has changed with democracy since 1994?

- Have there been changes in the care that people accessing ARTs need and the care that they are getting? Are these changes for the better or worse?
- How have these changes impacted on your job?
- How do you feel about the health system today?
- How do you feel about being a [insert position/professional identity] today?
- Are you seeing different types of patients today compared to those you used to see when you first started working with ARTs?
- Do they face different access problems today compared to previously? What are these?

21) How does your work affect you?

- What aspects of your work do you enjoy? Can you give me an example of something that you like in your job?
    i. What aspects do you like less? Can you give me an example of a difficult experience that you have had? [could be inter-personal issues, administrative tasks, organisation of tasks, patient-provider interactions etc]

Thank you very much for all of your insightful comments. Could I ask you a more personal question at this point?

22) Can you tell me what you would do if a family member/close friend needed ARTs?

- Explore what it means for them to be users of the system

23) Have you got any suggestions for how to improve the situation so that patients are able to successfully access good quality ARTs?
24) Before we say good bye, please can I get/confirm some basic details from you, like your: **Age** (perhaps ask them to tick a sliding scale so it doesn't seem too personal),

Sliding scale age:

18-24 □
25-34 □
35-44 □
45-54 □
55-64 □
65 and above □

- home language,
- marital status, and
- who else lives in your household.

If these details have already emerged through the story, ‘answer’ them to show that you have listened to the respondent.

25) Have you got any further questions? If there are, provide answers to those and offer information contacts/ leaflets.

Thank participant for their time and input. Explain that we may approach them for follow up informal discussions when we are conducting our facility observations. Remind them that talking about their jobs can be difficult and point out contact details for nearby/telephonic counselling services in case they would like to talk about any feelings that the interview or topic has raised for them.

Qualitative Interview Guide: Successful users TB/ART services

Before we start each interview:

Begin with an opening statement to introduce the interviewer, the topic and purpose of the interview and the research. Outline interviewees' rights (right not to answer specific questions, withdraw at any point, confidentiality, further questions at this stage?). Get the participant to sign the consent forms.

Moving to the interview:

1) Before we start talking about living with HIV/TB, I would like to get to know a bit about you. Can you tell me about the major events in your life? Perhaps we can start with when and where you were born?

Introduce the timeline.

2) Let's now talk about living with HIV/TB. When did it start and what happened?
[prompts: What happened next? And then? Tell me more about…].

Timeline cont.

2a) How are you coping with living with HIV/TB?
[or, for successfully completed TB treatment]:
2c) How have you coped with living with TB?

3a) For TB and HIV: Is this the first time that you have been sick in this way? [If not], please will you tell me about the other time(s) you had these symptoms. When did it start and what happened?

3b) *Also ask for HIV:* How long have you been unwell/were you unwell for? When did you first get sick and what happened?

Timeline cont.

For each care-seeking event:

4) Can you describe a 'typical' visit (to the clinic/TH etc), including your journey of getting there and back?

5a) Can you tell me about a visit that stands out for you/that you remember?

5b) Can you tell me about a time that you had a good visit? What made it good?

5c) Can you tell me about a time that you had a visit that was less good? What made it so?

6) In accessing this treatment, do you feel that you were/are treated fairly? Please tell me more.

7a) Are you currently attending a clinic/hospital for any other services or treatments?

<u>If so</u>

7b) Are you able to get everything you need at the same clinic/during the same visit? Please can you tell me more?

8) How is your life now different to how it was before you got ill?

9) Do you think your illness has changed how other people behave towards you? If so, please can you tell me more about these changes?

10) How has your (current) treatment changed your life?

11) Do you think that getting treatment has changed the way that other people behave towards you? If so, please can you tell me more about these changes?

12) Is there anything you would like to add, which can help us to understand your experience?

13) Before we say good bye, please can I get/confirm some basic details from you, like your:

- age,
- home language,
- employment status,
- marital status, and
- who else lives in your household.

If these details have already emerged through the story, ‘answer’ them to show that you have listened to the respondent.

14) Have you got any further questions? If there are, provide answers to those and offer information contacts/ leaflets.

Thank participant for their time, input and willingness to talk. Ask if they would be willing for us to contact them again. If so, what would be the best way to agree on a meeting (get cell number). If they are willing to be contacted again, explain that we may follow up with them in a few weeks if we have any further questions. Leave an updated referral list with relevant service provider contact details, including counselling services.

Qualitative Interview Guide: Unsuccessful users TB/ART

Before we start each interview:

Begin with an opening statement to introduce the interviewer, the topic and purpose of the interview and the research. Outline interviewees' rights (right not to answer specific questions, withdraw at any point, confidentiality, further questions at this stage?). Get the participant to sign the consent forms.

Moving to the interview:

1) Before we start talking about your illness, I would like to get to know a bit about you. Can you tell me about the major events in your life? Perhaps we can start with when and where you were born?

Introduce the timeline.

2a) Let's now talk about your illness. When did it start and what happened?
[prompts: What happened next? And then? Tell me more about…get a sense of symptoms].

Timeline cont.

2b) How are you coping with this illness?

3a**)** *For TB and HIV:* Is this the first time that you have been sick in this way? [If not], please will you tell me about the other time(s) you had these symptoms. When did it start and what happened?

3b) *Also ask for HIV:* How long have you been unwell for? When did you first get sick and what happened?

Timeline cont.

For each care-seeking event (i.e. related to each time the person had these symptoms):

4) Can you describe a 'typical' visit (to the clinic/traditional healer/GP/church etc), including your journey of getting there and back?

5a) Can you tell me about a visit that stands out for you/that you remember?

5b) Can you tell me about a time that you had a good visit? What made it good?

5c) Can you tell me about a time that you had a visit that was less good? What made it so?

6) In accessing this service, do you feel that you were/are treated fairly? Please tell me more.

IF the person previously went to a clinic and was treated for their TB [and it's not apparent from their story already], explore:

7) Can you tell me why you have decided to follow your current course of treatment [e.g. seeing a traditional healer] instead of going to a clinic like you did previously?

IF the person is currently defaulting [and it's not clear from their story already], explore:

8c) Can you tell me why you are no longer getting your treatment from the clinic?

8b) Are there any circumstances under which you would consider going back to the clinic?

9) How is your life now different to how it was before you got ill?

10) Do you think your illness has changed how other people behave towards you? If so, please can you tell me more about these changes?

IF the person is following some remedial course (as opposed to simply living with illness)

11) How has your current treatment (in whatever form) changed your life?

12) Do you think that getting treatment (whatever form) has changed the way that other people behave towards you? If so, please can you tell me more about these changes?

13) Is there anything you would like to add, which can help us to understand your experience?

14) Before we say good bye, please can I get/confirm some basic details from you, like your:

- age,
- home language,
- employment status,
- marital status, and
- who else lives in your household.

If these details have already emerged through the story, 'answer' them to show that you have listened to the respondent.

15) Have you got any further questions? If there are, provide answers to those and offer information contacts/ leaflets.

Thank participant for their time, input and willingness to talk. Ask if they would be willing for us to contact them again. If so, what would be the best way to agree on a meeting (get cell number). If they are willing to be contacted again, explain that we may follow up with them in a few weeks if we have any further questions. Leave an updated referral list with relevant service provider contact details, including counselling services.

Qualitative Interview Guide: Maternal Deliveries

Before we start each interview:

Begin with an opening statement to introduce the interviewer, the topic and purpose of the interview and the research. Outline interviewees' rights (right not to answer specific questions, withdraw at any point, confidentiality, further questions at this stage?). Get the participant to sign the consent forms.

Moving to the interview:

1. Before we start talking about your pregnancy and delivery, I would like to get to know a bit about you. Can you tell me about the major events in your life? Perhaps we can start with when and where you were born.

Introduce the timeline:

Draw a line: If this line is your life over the years, starting with your birth over here (draw in), what other events and relationships would you say have been important to you?

2a) Let's now talk about your pregnancy/ies.

Let's start at the beginning of your latest pregnancy. How did you find out that you were pregnant? [prompts: What happened next, and then…?]

Locate on timeline. And expand timeline as participant talks.

2b) If it's not clear: Over the course of your pregnancy, did you have any problems, either related to the pregnancy or your health more generally? If so, what happened/what did you do?

2c) If it's not clear already: How did you cope with this pregnancy?

3a) Did you attend antenatal care (ANC) during your pregnancy? [if you use ANC from hereon, please make sure the person understands what you mean and doesn't confuse this with the political party etc]

If no:

Why did you decide not to attend ANC? Did you see anyone for care during your pregnancy? [Whether 'yes' or 'no], please tell me more?

If yes:

When did you first start (i.e how many months pregnant were you?)? Why did you go then (and not earlier or later?)? How often and where did you go?

If yes:

3b) Can you describe a 'typical' ANC visit, including your journey of getting there and back?

3c) Can you tell me about a visit that stands out for you/that you remember?

3d) Can you tell me about a time that you had a good visit? What made it good?

3e) Can you tell me about a time that you had a visit that was less good? What made it so?

3f) if >1 pregnancy: Can you tell me if and how your ANC experience with this pregnancy was different to your previous ANC experinces?

4) In accessing ANC, do you feel that you were treated fairly? Please tell me more.

5) If it's not already clear from the story and timeline so far): Is this the first time that you have been pregnant? [If not], please will you tell me about the other time(s) you were pregnant. When was this and what happened?

6) During your pregnancy, did you need to access any other health-related services? If yes, please tell me more? Did you have any problems in accessing these services? If so, can you tell me what happened?

7a) Let's now talk about your delivery/ies, starting with your most recent experience. When did you go into labour? And then what happened?
[prompts: what happened next?...and then?].

7b) If the woman wasn't in labour when she arrived at the facility:
Why did you come to this/previous facility when you did?

Timeline cont:

7c) What stands out for you/what do you remember most about your delivery?

Depending on how the participant responds to 7c, probe around:

7d) Is there anything in particular that you liked about your delivery?

7e) Is there anything in particular that you didn't like about your delivery?

8) Do you feel that you were treated fairly during your delivery? Please tell me more.

9) (For those who have delivered previously and If it's not already clear from the story and timeline so far): Let's now talk about your previous deliveries. Can you tell me what happened? Follow sequence of questions above.

This question needs to be asked at least 10 weeks after the delivery and therefore depends on when the patient is being interviewed (may have to wait for the second interview or a follow up call if <10 weeks):

10a) In the first ten weeks after you were discharged, did you or the baby need medical care, including inoculations? Please can you tell me more? [Probe around what treatment was needed, where it was received?]

10b) What stands out for you/what do you remember most about this service?

10c) Did you have any problems in accessing this service? Please can you tell me more?

11a) Let's now talk about being a mother. Perhaps you can start by telling me if your pregnancy and delivery were what you expected them to be? Please tell me more.

11b) How is your life now different to how it was before you were a mother?

12) Before we say good bye, please can I get/confirm some basic details from you, like your:

- age,
- home language,
- employment status,
- marital status, and
- who else lives in your household.

If these details have already emerged through the story, 'answer' them to show that you have listened to the respondent.

13) And finally, please can you tell me whether you agree or disagree with these statements when thinking about your general experience in the facility during labour and after birth:

SECTION 5: ACCEPTABILITY		
5.1 The doctors and nurses (*health workers)* explained what to expect when giving birth.	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
5.2 It is a problem that the *health workers* DO NOT speak my language.	Agree	1
	Disagree	0
	Both agree and disagree	2

	Don't know / not sure	99
5.3 The *health workers* understood the difficulty of being in labour and assisted me where possible.	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
5.4 The *health workers* were too busy to listen to my problems.	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
5.5 Some staff DO NOT treat patients with sufficient respect.	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
5.6 The health workers I saw cared about me.	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
5.7 I DID NOT receive sufficient pain relief during my labour	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
5.8 The facilities (including waiting area and toilets) are dirty	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
READ OUT: For the following questions, you are required to answer YES or NO		
5.9 Were you allowed to have a companion during your labour?	Yes	1
	No	0
	Don't know	99

5.10 If no or don't know Would you have liked one?	Yes	1
	No	0
	Don't know	99
5.11 Were you shouted at during labour?	Yes	1
	No	0
	Don't know	99
5.12 Were you ever hit, slapped or pinched during labour?	Yes	1
	No	0
	Don't know	99
5.13 Was your privacy respected?	Yes	1
	No	0
	Don't know	99
5.14 Were you offered fluids?	Yes	1
	No	0
	Don't know	99
5.15 Did you get referred for follow up care for you and the baby?	Yes	1
	No	0
	Don't know	99
5.16 For birth registration, did you get all the necessary documents?	Yes	1
	No	0
	Don't know	99
5.17 Were you told about the child-care grant & where to go for the child care grant if you qualify?	Yes	1
	No	0
	Don't know	99
5.18 How satisfied were you with the service you received during delivery?	Very satisfied/ Satisfied	1
	Neither satisfied nor dissatisfied	2
	Dissatisfied/ Very dissatisfied	3
	Don't know	99
5.19	Agree	1

To what extent do you agree with the following statements about your pregnancy: "I had all the support that I needed during my pregnancy from the father of the child"	Disagree	2
	Don't know	99
	Not applicable	98
5.20 "I had all the support that I needed from my family"	Agree	1
	Disagree	2
	Don't know	99
	Not applicable	98
5.21 "I had all the support that I needed from my friends"	Agree	1
	Disagree	2
	Don't know	99
	Not applicable	98
5.22 In this facility are you able to talk to the doctors or nurses in private?	Always	1
	Sometimes	2
	Never	3

Thank participant for their time, input and willingness to talk. Ask if they would be willing for us to contact them again. If so, what would be the best way to agree on a meeting (get cell number). If they are willing to be contacted again, explain that we may follow up with them in a few weeks if we have any further questions. Leave an updated referral list with relevant service provider contact details, including counselling services.

Appendix 3: Ethics clearance

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Ms Bronwyn Harris

CLEARANCE CERTIFICATE	**M090951**
PROJECT	Not Just Health: Understanding Access to ART, TB Treatment and Maternal Deliveries in Four South African Sites as a Matter of Restorative Justice
INVESTIGATORS	Ms Bronwyn Harris.
DEPARTMENT	School of Public Health/Centre for Health Policy
DATE CONSIDERED	2009/10/02
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 2009/10/02 **CHAIRPERSON** .....
pp (Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Prof John Eyles

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

Appendix 4: PhD presentations and articles

- Harris, B. (2015). Respondent. Access to health care. Migration, urbanisation and health: Interdisciplinary conversations. African Centre for Migration and Society, University of the Witwatersrand: Braamfontein (27-29 July)
- Harris, B. (2014). Respondent. Launch of the Special Issue of Global Public Health: *Critical Ethnographies of Health Systems Policies and Practices, 9 (8).* Third Global Symposium on Health Systems Research- Science and practice of people-centred health systems: Cape Town (30 September-03 October)
- Harris, B., Eyles, J., Penn-Kekana, L., Fried, J., Nyathela, H., Thomas, L. & Goudge, J. (2014). Health systems, transitional justice and some conditions for 'righting' unacceptable health care services: street-level reflections from urban South Africa. Third Global Symposium on Health Systems Research- Science and practice of people-centred health systems: Cape Town (30 September-03 October)
- Harris, B. (2013). *Bringing justice to unacceptable health care services? Street-level reflections from Johannesburg,*Johannesburg Health District Research Conference, District health systems: Research to practice: Johannesburg (13 June)
- Harris, B. (2012). *Bringing justice to unacceptable health care services? Street-level reflections from urban South Africa,* Public Health Symposium, Consortium for Advanced Research Training in Africa (CARTA): Johannesburg (27 Nov)
- Harris, B. (2012). *Affording the right to health.* International meeting on building shared thinking and participatory approached to defining the content of the right to health, Johannesburg (31 May-02 June).
- Harris, B., Eyles, J., Thomas, L & Goudge, J. (2012). *Perspectives from Patients and Providers*, Access and Social Exclusion symposium, Johannesburg (29 March)
- Harris, B. (2011). *Health and human rights.* Social Inclusion and the Right to Health: Establishing a conceptual and methodological basis for research and policy development, Rockefeller Conference Centre, Bellagio: Italy (5-9 Dec)
- Eyles, J., Daries, VC., Fried, J., Govender, V., Harris, B., Penn-Kekana, L. & Munyewende, P. (2011) (presented by Harris) *Resistance and resilience: narratives of patients and providers in South Africa's public healthcare system.* Closing the health equity

gap: Public health leadership, education and practice, Annual scientific meeting of the Public Health Association of South Africa, Johannesburg (28-30 November)

- Harris, B. (on behalf of team) (2009). *The REACH project: preliminary descriptive findings from phase 1*. School of Public Health Research Day, University of the Witwatersrand (14 May).
- Harris, B. & Munyewende, P. (2009). *The REACH project*. City of Johannesburg DHIS and Research Day, Roodepoort, (25 March).
- Harris, B. (2008). *Not just ART: Accessing anti-retroviral therapy as a form of restorative justice?* Symposium on HIV/AIDS. AIDS Research Initiative, Johannesburg, (19 November).
- Harris, B. (on behalf of team) (2008). *The REACH project – an overview*. Joburg Metro Family Medicine and PHC Forum (26 April)
- Harris, B. (2008). *"I know this is a sensitive question but…" Thinking about the acceptability of health care access from a restorative justice perspective.* Faculty Research Open Day, University of the Witwatersrand (20 August)

Peer-reviewed Journal Articles:

- **Harris, B.**, Eyles, J., and Goudge, J. (accepted for publication). Ways of doing: restorative practices, governmentality and provider conduct in post-apartheid health care. *Medical Anthropology.*

  Authors' roles: BH conceptualised and wrote the first and subsequent drafts of the manuscript in light of co-author's inputs. JE and JG commented on, and gave input into, the drafted manuscript. BH and JE contributed to the study design and data collection; and, with JG, to the tool development. All authors contributed to the tool development and data analysis.
- **Harris, B.**, Eyles, J., Penn-Kekana, L., Thomas, L. & Goudge, J. (2014). Adverse or acceptable: negotiating access to a post-apartheid health care contract. *Globalization and Health*, 10(1): 35.

  Authors' roles: BH conceptualised and wrote the first and subsequent drafts of the manuscript in light of co-author's inputs. JE, JG, LPK and LT commented on, and gave input into, the drafted manuscript. BH, LPK and JE contributed to the study design and data

collection; and, with JG, to the tool development. All authors contributed to the data analysis; and read and approved the final manuscript.

- **Harris, B.**, Eyles, J., Penn-Kekana, L., Fried, J., Nyathela, H., Thomas, L. & Goudge, J. (2014). Bringing Justice to Unacceptable Health Care Services? Street-Level Reflections from Urban South Africa. *International Journal of Transitional Justice,* 8(1):141-61 (March 01). (PhD Paper)

  Authors' roles: BH conceptualised and wrote the first and subsequent drafts of the manuscript in light of co-author's inputs. All co-authors commented on, and gave input into, the drafted manuscript. BH, LPK, JF and JE contributed to the study design, and, with HN, the data collection. BH, JE, JG, JF and LPK contributed to the tool development. All authors contributed to the data analysis; and read and approved the final manuscript.

Policy briefs:

- *Make or break? The influence of street-level bureaucrats on access to healthcare (Part 1) (*April, 2015). Parktown: The Centre for Health Policy, available online: http://www.chp.ac.za/PolicyBriefs/Pages/default.aspx
- *Make or break? The influence of street-level bureaucrats on access to healthcare (Part 2): restorative practices and victim offender mediation (*April, 2015). Parktown: The Centre for Health Policy, available online: http://www.chp.ac.za/PolicyBriefs/Pages/default.aspx

Appendix 5: Policy Briefs

The Centre for Health Policy
Health Policy and Systems Research

POLICY BRIEF
APRIL 2015

www.chp.ac.za | 011 717 3427 | Further information: Please contact Bronwyn Harris at bronwyn.harris@wits.ac.za

Make or break? The influence of street-level bureaucrats on access to healthcare (Part 1)

Introduction

The right to access healthcare in South Africa is constitutionally protected and part of a socio-political effort to bring justice after apartheid. Yet, 20 years into democracy, access barriers such as high transport costs, large distances to services, varied quality of care and a fragmented health system continue to disproportionately affect many who experienced the dispossession and violence of apartheid - poor, black, rural and informal-urban communities – as well as newer marginalised groups, including migrants and refugees.

Little attention has been paid to the potential role of the health system and those working in it, in helping to transform the repressive institutions and practices that entrenched the injustice of apartheid.

Street-level bureaucrats (SLBs) – frontline health workers such as doctors, nurses and police officials - are a gauge of both individual and institutional transformation. With discretionary power and flexibility in dealing with clients (e.g. patients or prisoners), SLBs should be well-placed to promote democracy by delivering services in ways that are restorative and participatory, rather than punitive or paternalistic. However, authoritarian provider practices have been identified in post-apartheid health services and negative, even abusive, street-level bureaucracy may impede the right to access health care. In addition, the volume of new policies and their 'top-down' imposition have contributed to providers often prioritising the demands of their managers over patients' needs.

Highlights and policy implications

- Street level bureaucrats have discretionary power in dealing with clients, allowing them to shape and practice policy.
- Negative street-level bureaucracy may be a major barrier to care for patients and continue a culture of disempowerment and deprivation.
- Conversely, positive provider practices are vital for improving access and contributing to the restoration of justice and health in society.
- Strengthening provider accountability and fostering respectful practices that promote patient-provider dialogue are critical for improved access to healthcare, and a transitional justice agenda for reconciliation and equality.
- To foster positive practices, accountability needs to be vertical (to managers, and to patients/ communities), *and* horizontal (to colleagues).
- Individual actions, attitudes and advocacy count and can overcome negative street-level bureaucracy.

This policy brief was based on an article entitled: "Bringing Justice to Unacceptable Health Care Services? Street-level reflections from urban South Africa", Bronwyn Harris [1,2], John Eyles [1,2,3] Loveday Penn-Kekana[1,4], Jana Fried[5], harry Nyathela[1,2], Liz Thomas[2,] and Jane Goudge[1,2,].*The International Journal of Transitional Justice*, 2013, 1-21. References available on request.

[1]Centre for Health Policy, Wits School of Public Health, Johannesburg, Gauteng, South Africa, [2]Health and Development Research Group, SA Medical Research Council, Johannesburg, South Africa, [3]School of Geography and Earth Sciences, McMaster University, Hamilton, Ontario, Canada, [4]Department of Global Health and Development, London School of Hygiene and Tropical Medicine, United Kingdom, [5]University of Western Ontario, Department of Geography, Faculty of Social Science, London, Ontario, Canada.

Methods

This study is part of the Researching Equity and Access to Health Care (REACH) project*, a five-year multi-method study of equity in access to TB treatment, ART and maternal deliveries in four South African provinces.

We interviewed 29 patients and 49 providers about their access experiences in Cape Town and Johannesburg (June 2009 - July 2010), then engaged with stakeholders (February 2011 to April 2012). We developed eight cases from this data; four are included here to reflect on street-level bureaucracy as either improving or impeding access to health care and social justice. We spotlight a patient case where street-level bureaucrats exacerbated the injustice of inaccessible health care; a provider reflection on access barriers; and two cases where street-level bureaucracy has restored justice. Names have been anonymised.

Access denied

Mark Kriel (30) was an unemployed TB patient on directly observed treatment, short course (DOTS). A former drug user who still smoked marijuana, he slept in a car outside his mother's house and was largely ostracised by his family and neighbours. He often went without food, making it difficult to tolerate his TB medication. Transport costs prevented him from making daily visits to the clinic, and he stayed away for two weeks. When he returned, he was 'scolded' by the nurses and told to come daily 'or die':

"It is as if they don't listen when I talk to them. If I tell them I can't make it then they will just say, 'you must make a way to come [daily].' Uhmmm, then I asked them, 'Is there no way to get something [a grant, weekly treatment] to make it better for me?' because they know my circumstances. There is no way that I can get transport to here. It is like I talk but they don't listen to me, they don't hear me. I just get negative answers."

Poverty led this patient to default from his TB treatment. DOTS aims to minimise defaulting by placing those at risk under surveillance, yet in this case it emphasised the risk. The nurses' indifference and lack of sympathy intensified the injustice of unaffordable health care and further marginalised him.

Rights deferred

Nonhlanhla Dube (early 50s) was the operational manager of a busy clinic in a poor community where many patients had no food or accommodation. While sympathetic, her response to patients defaulting from TB treatment was one of frustration, anger and blame towards democracy and patients' rights:

"Before [democracy] we could do our work properly. Our patients were like school children: we could teach them…they would comply with their TB treatment and they got cured. Now patients have rights, the person can refuse to take treatment, and what if he refuses to take treatment? It complicates to MDR [multidrug-resistant TB] (and) XDR [extensively drug-resistant TB]. The person with MDR needs to be admitted so that he doesn't infect other people…these rights they have disrupted a lot of things. I blame all this mess with TB on patients' rights."

She reflected a sense of lost identity and a fall in her professional status, shared by many providers interviewed, leading her to '*want to take your epaulets and hide them because being a nurse is being nobody, is being a doormat where…even the patients, they don't take us seriously*.'

She felt undermined by democracy and new health system challenges such as staff shortages and increased workloads, lack of political support, disdainful patients and communities, and immense pressures from senior officials and the media.

Justice restored

Peter Isaacs (49) was a diabetic and HIV positive, living in a cold, cramped council house when he was diagnosed with TB. He was fired from his job because he was too ill to work, and was not able to access a social grant due to a technicality. He moved in with his sister and niece who cared for him, and where a community health worker visited him daily to administer his medication.

"She encouraged me to go on with life. She said it is just a disease that can be cured and she encouraged me to drink my pills, eat right and healthy...the second month I started to get an appetite and from that time I started to eat and gained weight and felt to live."

*Reach partners: CHP (Wits); Health Economics Unit (UCT); McMaster Institute of Environment and Health; Centre for Health Economics and Policy Analysis (McMaster); School of Public Health (UWC); Africa Centre for Health and Population Studies (UKZN); Rural AIDS and Development Action Research (Wits).

Acknowledgements: The authors thank their colleagues and the patients and providers who generously participated in the Researching Equity and Access to Health Care (REACH) project. The work received support from the Global Health Research Initiative (Canada), a collaborative research 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 (103457). It was also supported in part by the National Research Foundation of South Africa (86472) and the Carnegie Corporation of New York. We acknowledge that the views expressed, findings and conclusions are solely the responsibility of the authors and that the funders accept no liability whatsoever in this regard.

Once stronger, he completed his treatment at a clinic that provided bread daily for TB patients. He looked forward to the clinic visits, mostly to engage with the staff:

"They will ask you how you feel…they were very helpful, they helped me a lot. [The TB coordinator] was my pillar here, she was making me happy. She always smiled and she encouraged me to say that it was worth it to live. It was a pleasure to come to this clinic."

While Peter Isaacs also experienced poverty, unemployment and housing insecurity like Mark Kriel, he received a positive, supportive response through home visits, bread at the clinic, and importantly, provider encouragement and engagement.

Precious Khomo was a private sector occupational nurse who returned to nursing seven months after retiring at 60 to 'give back' to her community. She was placed in the maternity ward of a busy public sector academic hospital, one of two nurses responsible for making the facility 'baby friendly' for accreditation by the UNICEF/WHO 'Baby Friendly Hospital Initiative'.

Here she encouraged mothers to breastfeed and trained colleagues about kangaroo mother care and respectful communication with patients. She introduced a new style of engagement which saw patients as '*customers deserving of a holistic service*', rather than being instructed how to breastfeed:

"It's a customer service because we don't just talk breastfeeding...patients come to us and say, 'Sister, I want to talk to you about something' then you talk to them…you allay their fears."

She emphasised the value of modelling this new behaviour for nurses:

"If I behave the right way and you keep on seeing me behave the right way towards the patients: being customer friendly, the patients talking to me, being happy greeting me, I greeting them. Then you'll also think, 'Is this not nice?' It won't be everybody changing but most of the nurses will think, 'Hey, this is good,' and they'll also change."

Beyond the immediate benefits for patients and providers of positive staff attitudes, she felt that modelling respectful, polite and friendly behaviour was important for the next generation of nurses. She hoped that by improving the hospital's reputation and creating a pleasant working environment, such an attitude shift would help to attract private nurses to the public sector. Specifically employed to change practices, her post reflects a justice-oriented institutional response to 'unfriendly' baby and mother care. Her individual response of 'changing through doing' was based on modelling an alternative, respectful style of interaction.

Conclusion

Many providers felt powerless to improve access for patients or make a difference. Yet, for patients, provider actions could make or break their healthcare-seeking efforts. Nurses reflected that problems at home made them harsher with patients and each other, a reminder that street-level bureaucrats are also individuals like other citizens.

A small but important response to the findings of our study was that providers agreed to be more considerate of each other in the hope that this would also rub off on how they treated patients.

There is a need to examine institutional culture and power relations between providers and patients critically, particularly with South Africa's history of patient abuse which has continued into democracy. Street-level bureaucrats are located in the middle of a 'web' of multi-dimensional relationships and institutions, and are well placed to be agents of change to support a restorative justice agenda. Conversely, without a transformative shift in institutional norms and individual practices, they are potentially agents of resistance, frustrating efforts at social reconstruction.

Restorative justice focuses on identifying and repairing 'broken relationships and communities' through dialogue, community participation and finding locally relevant 'solutions'. Reforms in the South African health system through the National Health Insurance system may invigorate spaces for community dialogue and present opportunities for bringing justice through improved access to health care. Strengthening street-level accountability and building trust for transforming patient-provider relationships is important for creating an acceptable, accountable health system, and a broader restorative justice agenda aimed at nurturing reconciliation and equality.

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POLICY BRIEF
APRIL 2015

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Make or break? The influence of street-level bureaucrats on access to healthcare (Part 2)

Restorative practices and victim offender mediation

Introduction

For fragile and post-conflict states seeking to consolidate democracy, a key policy goal is to transform repressive institutions into respected instruments of justice. In the immediate aftermath of war and mass violation, priority is usually given to rebuilding state security forces due to their role in past violence and importance for keeping (often-fragile) peace.

Yet, little attention has been given to the health system as a potential facilitator of social reconstruction and peacebuilding, 'to the detriment of the whole peacebuilding enterprise'. Additionally, a public health perspective is urgently needed to assess and shape transitional justice policies 'designed to address the effects of war on traumatized communities and bring justice'.

South Africa's right to access health care is part of a broader socio-political endeavour to 'bring justice' in the aftermath of apartheid. Street-level bureaucrats (SLBs) are frontline providers, tasked with delivering health services and enabling this right (e.g. nurses, doctors and police officers), who represent a gauge of both individual and institutional transformation. With discretionary power and flexibility in dealing with clients (e.g. patients or prisoners), SLBs should be well-placed to promote democracy through their attitudes and actions.

However, authoritarian provider practices persist in post-apartheid health services and negative, even abusive, street-level bureaucracy may impede the right to access health care. Furthermore, the volume of new policies and their 'top-down' imposition have contributed to providers often prioritising the demands of their managers over patients' needs.

Highlights and policy implications

- There is an urgent need for a public health perspective to assess and shape transitional justice policies to bring justice to traumatised communities.
- Negative street-level bureaucracy may aggravate inaccessible care for patients and continue a culture of disempowerment, deprivation and poverty.
- Conversely, positive provider practices are vital for improving access and contributing to the restoration of justice and health in society.
- Strengthening provider accountability and fostering respectful practices that promote patient-provider dialogue are critical for achieving improved access to healthcare.
- Accountability for street-level bureaucrats involves a 'web' of relationships. To foster positive practices, accountability needs to be vertical (to managers, and to patients/ communities), *and* horizontal (to colleagues).
- Individual actions, attitudes and advocacy count and can overcome negative street-level bureaucracy.

Restorative justice focuses on identifying and repairing 'broken relationships and communities' through dialogue, community participation and finding locally relevant 'solutions'. It is often used to resolve conflict in criminal cases through victim-offender mediation (VOM). VOM is a carefully facilitated process between victims, offenders and communities in which the victim's needs are prioritised in decisions about how best to remedy or ameliorate (restore) the harm done.

Methods

Case reporting has been used in restorative justice to highlight the process and impact of VOM. We present Harry Nyathela's* story in this tradition. His case, which unfolded alongside the *Researching Equity in Access to Health Care* (REACH) project (a five-year, multi-method study of equity in access to TB treatment, ART and maternal deliveries in four South African provinces), straddles the health and criminal justice systems. It illuminates an approach to transforming abusive institutional norms into accountable, empathetic norms which are important for reforming institutions and positively shifting interpersonal and individual practices.

**In keeping with his activism, Harry requested that his real name be used.*

Health access denied

In 2009, Harry Nyathela an AIDS activist and then-fieldworker on the REACH project, was arrested and detained over the weekend at a police station in Soweto. Although charges were later dropped, his sister delivered his anti-retrovirals and police committed to giving him treatment twice daily as prescribed. However, the night officer refused to give his pills on two consecutive nights, denying his constitutional right to access healthcare during incarceration.

The aggressive refusal of Harry's right to access healthcare by a policeman two decades into South Africa's democracy was reminiscent of the country's apartheid past. Human rights' violations were entrenched in multiple ways, including through petty abuses by SLBs, as well as the broader dispossession, structural violence and institutionalised racism of an unjust system. As an explicit denial of access to healthcare, Harry's case illustrates the difficulty of *implementing* a human rights culture and *transforming* institutional and interpersonal relationships, despite fundamental policy and legislative change.

Restorative justice and victim offender mediation

After his release, he was assisted by a non-governmental organisation, Lawyers for Human Rights, to lay a charge against the officer who was found guilty of withholding medication in an internal disciplinary process. The station commander asked Harry: *"What would make you happy in resolving this?"*

Instead of recommending a fine or suspension for the officer, Harry proposed that he be involved in training all the station staff on human rights, imprisonment and HIV, including ART and treatment literacy. He requested that the offending officer collect him from his house in a courteous manner, bring him lunch provided by the station, and sit in the front row of training.

Training took place over a week and involved all the members of the station. The night officer complied with all the requirements and at the end of the week, apologised to Harry in a genuinely remorseful way. He kept in touch with him regularly.

"Subsequently, I have facilitated similar trainings at two other police stations in the area and am often invited to delivery motivational talks to police and prison officials. It was a bad experience but for me, justice has been served – personally and also, I hope, by avoiding similar victimization for future arrestees through the education and training I helped to deliver." Harry Nyathela

In its resolution, Harry's case is a classic example of restorative justice achieved through victim offender mediation. VOM is not commonly practised in health care but Harry's case suggests some conditions for challenging abusive street-level bureaucracy and restoring broken relationships in the South African health system:

i. *Consider the nature of the case:* Harry's was a straightforward incident involving one perpetrator violating the rights of one victim. This clearly lent itself to identifying the relevant parties, articulating the experience of injustice, and finally mediating a successful outcome.

ii. *Promote a strong civil society:* Harry's VOM process was initiated with *support and intervention* from Lawyers for Human Rights, a long-established non-governmental organisation that provides free legal support to vulnerable individuals and communities. Their involvement confirms the importance of non-state actors in consolidating 'democratic norms, institutions and practices', and holding the state accountable, long after the attainment of formal democracy.

Acknowledgements: The authors thank their colleagues in the Researching Equity and Access to Health Care (REACH) project and at Lawyers for Human Rights. The work received support from the Global Health Research Initiative (Canada), a collaborative research 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 (Grant number 103457). It was also made possible (in part) by a grant from the Carnegie Foundation of New York and the National Research Foundation (South Africa). **We dedicate this publication to Harrison Eugene Nyathela (14 July 1974-23 March 2014)**

iii. *Nurture strong, compassionate leadership within facilities and districts:* The leadership and authority of the station commander contributed through his sensitive arbitration and proper implementation of Harry's proposal.

iv. *Empower patients and citizens to confidently claim their rights*: Harry chose not to seek revenge or retreat, but opted to help the police officer redeem himself as well as tackle attitudes at the station.

v. *Encourage self-reflexive, engaged frontline providers*: The police officer's compliance, genuine apology and ongoing engagement rebalanced their relationship. At a community level, the commitment of all members of the station and their involvement in the training helped to transcend the negative experience.

vi. *Institutionalise account-ability 'webs'*: Hold SLBs accountable upwards (to managers), downwards (to patients and communities) and sideways (to colleagues).

vii. *Grapple with the limits:* Bringing equality to social relationships is a central principle of restorative justice and extends beyond redressing relationships and institutional reform to the broader social determinants of health such as clean water, food security and personal safety. VOM alone cannot resolve the structural barriers that constrain the right to access health care. But an accountable health system, built on caring and respectful provider-patient interactions, would be well positioned to promote and lead inter-sectoral action for change.

Epilogue: The ultimate denial of justice

On the afternoon of Sunday, 23 March 2014, Harry Nyathela said farewell to his wife and went to Tembisa on the East Rand of Johannesburg where he worked during the week. He stopped at a nearby spaza shop to purchase a soft drink and some bread. On his way home, he came across a badly hurt man lying unassisted on the street. The man had been beaten by a group of at least four men. Harry stopped to help the injured man and phoned the police and an ambulance. Two of the assailants returned to warn him off. When he persisted with assisting the victim, they beat Harry to death.

South Africa has an average of 47 murders a day, a rate of 32.2% per 100 000 and five times the 2013 global average. For a country not at war, violence and injury impose an 'unprecedented burden of morbidity and mortality'; of grave public health concern.

It is poignant that Harry – so successful in negotiating his own access to health services - lost his life while securing access to health care (ambulance) and justice (police) for someone else in need. His death is a tragic reminder of structural barriers to healthcare and the need for a holistic approach to restorative justice.

While the health system alone cannot be expected to remedy a complex set of inequities, creating a space for street-level bureaucrats to be flexible in responding to structural barriers may be as important for a transitional justice agenda as encouraging respectful provider-patient relationships.

This policy brief was based on an article entitled: "Bringing Justice to Unacceptable Health Care Services? Street-level reflections from urban South Africa", Bronwyn Harris [1,2], John Eyles [1,2,3] Loveday Penn-Kekana[1,4], Jana Fried[5], Harry Nyathela[1,2], Liz Thomas[2] and Jane Goudge[1,2]. *The International Journal of Transitional Justice*, 2013, 1-21, found at http://ijtj.oxfordjournals.org/content/early/2013/12/30/ijtj.ijt028.abstract. References are available on request.

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