‘Mind the Gap’: Access to ARV medication, rights and the politics of scale in South Africa

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Abstract

Global access to anti-retroviral medication (ARVs) has increased exponentially in recent years. As a relatively recent phenomenon for the global South, much knowledge is being added, but analysis of ‘access’ to ARVs remains partial. The main research objective is to gain a fuller picture of the range of forces constituting ‘access’ to ARVs by providing a local community case study from Hammanskraal, South Africa. A qualitative and relational approach situates specific points of ‘local’ access to ARVs within relations stretched over space. Spatial awareness enables us to consider the reinforcing effects of local geographies upon access to health care but also simultaneously sees this in relation to non-local geographies. The concept of scale is pivotal to creating linkages across space and reveals a number of ‘gaps’ in access that otherwise might not be shown. Elaborating on the meaning of “access” to treatment produces a more rounded picture of the context that people-living-with-AIDS encounter. A multi-scale and multi-disciplinary analysis of ‘access’ is therefore also highly informative in a related sense, namely, for closing the gap between human rights standards and actual implementation. A geographical imagination is useful not only to ‘mind’ but also to close the ‘gap’ in both senses.

Keywords: HIV/AIDS, anti-retrovirals, geography, scale, human rights, South Africa
Introduction

Assertions of the international human right to health are increasingly impacting access to health services. One of the most dramatic manifestations of this influence in recent years is the exponential increase in global access to anti-retroviral medicine (‘ARVs’) for the treatment of AIDS. An extensive global campaign for expanding coverage was based within a rights-based idiom that proved catalytic to enhancing access (Jones, 2009; de Waal, 2006; A’desky, 2004). ‘Scaling-up’ access to treatment remains especially important in regions characterised by low levels of access. In Sub-Saharan Africa, for example, treatment coverage (that is, the per cent age of those who could benefit from ARVs who actually receive them) remains inadequate at approximately fifty per cent (WHO, 2009). Barriers to access to ARVs tend to be depicted mainly as determined by limits upon finances (both personal/household and institutional) and physical geography (as in distance to point of access) (WHO, 2007, 2008, 2009). Knowledge is rapidly being added to deepen our understanding associated with the operationalisation of ARV provision (WHO, 2009; Jones, 2009; Rosen et al, 2007; Heywood, 2004).

The huge increase in resources and global commitment to extend access to ARVs, however, remains a relatively recent phenomenon in the global South. Understanding access to health services more generally can be of use in developing analyses that map access against factors deemed to enable or constrain it. Contributory factors include, amongst others, the specific characteristics of places (Macintyre et al, 2002), social exclusion and/or the roles of cultural identity, gender and conflict (Varley, 2010). The main research question was to show what constitutes barriers in ‘access’ to ARVs, using a specific field site in South Africa. A related objective in identifying barriers to access was to lend these to implementing better human rights approaches. More often than not, incantation of human rights obligations and standards tend to be disappointed by the unevenness of local implementation (Ruiz-Caseres,
Human rights research and practice is therefore also increasingly interested in the concept of ‘access’ to a particular right and therefore the need to address measures in different contexts (Ruiz-Caseres, 2010; Carmalt, 2007). The ‘gap’ in question is therefore two-fold: what factors constrain access to ARV services and also, in relation, what factors undermine implementation of human rights in places? An important overall consideration is whether analysis of ARV programmes, although situated in specific places -or points on a map- can be properly understood without a broader qualitative analysis of multi-scale factors (Evensen and Stokke, 2010).

**Theoretical approach: Dynamic geographies of ‘access’**

A major challenge is therefore to develop a theoretical understanding that can capture a multi-faceted understanding of ‘access’. A geographical imagination is used to identify a fuller range of processes and complexities encompassing access to health care. Being located in a particular context can, of course, have effects upon health and patterns of disease. Locality, in its most obvious sense, denotes a specific place on the map wherein social relations and institutions are characterised by a high degree of *place specific* embeddedness (Cox, 1998). In recognising the special characteristics of places, however, two analytical problems nonetheless quickly confront any static view of locality (Castree et al, 2004). One problem lies in implying that boundaries can be drawn unproblematically between the local and non-local. The second is that places are not only interconnected but also interdependent. A more *relational* understanding of places implies that ‘what makes a place has everything to do with “distanciated” events, processes, and institutions stretched out over a larger space’ (Castree et al, 2004:66). Connectivity to other places and processes renders localities ‘porous’ and therefore related to more distant geographies. Spatial awareness certainly enables us also
to consider the reinforcing effects of local geographies upon access to health care but it simultaneously also sees this in relation to non-local geographies.

Rethinking localities as overlapping social and spatial networks, for example, acts against conceiving of them as homogeneous and separate spatial entities. It also assists in identifying the role of broader context upon localities. To give an example, the lack of availability of a life saving drug in a hospital obviously implicates the immediate local point of access. It is also associated, however, with much wider chain of connectivity: to national supply and management, and even globally in terms of the global pharmaceutical industry and international patent law. One of the advantages in developing analysis around spatial understandings of access is to show these wider relations implicated in how a patient’s access to AIDS drugs is enabled or constrained. An important entry point into discussions of understanding of the relation between local and non-local geographies is the concept of scale.

**Scaling ‘access’**

Geographic scale is pivotal to conceptualising more dynamic geographies of access. A highly textured theoretical debate has taken place within human geography in recent years with different understandings of scale being the substance of this debate. Different social actors by working at different spatial levels can change authority and power and therefore alter access to resources (Lebel et al, 2005). The implication for understanding the relationship between the social and the spatial is that they are mutually reinforcing. Scale matters and that, in recognising this; a more plural, relational meaning of scale is required (Brenner, 2001). Such an understanding of scale as relational and embedded in other scales provides a more simultaneous conception of scale along side other scales. These discussions of scale have “freed our narratives from the singular and limiting preoccupation of locality on the one hand
and of globality on the other” (Jonas, 2006:400). Such a multilevel understanding of localities has important implications for understanding ‘access’ to ARVs.

“Access,” can itself be understood as “able to get, have, or use something.” “To have access” in terms of a rights-based claim means that a government must facilitate access or create an enabling environment for everyone to access a service (Khoza, 2007). Struggles over access to retroviral medication (ARVs) in South Africa have gained global notoriety during former President Thabo Mbeki’s period as leader. What makes South Africa such an apposite case is that it is a country depicted as a global leader in terms of constitutionally enshrined justiceable socio-economic rights, such as access to health care (Brand and Russell, 2002) but where health indicators have worsened since 1994, mainly attributable to HIV/AIDS. (Lancet 2009; and see Table 1, below).

<table>
<thead>
<tr>
<th>Life Expectancy (years)</th>
<th>48</th>
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<tr>
<td>Under-5 mortality (per 1 000 live births) 2004</td>
<td>67</td>
</tr>
<tr>
<td>Maternal mortality (per 100 000 live births) 2000</td>
<td>230</td>
</tr>
<tr>
<td>People living with HIV/AIDS</td>
<td>5.7 million</td>
</tr>
<tr>
<td>HIV prevalence, national level (based on antenatal attendee survey) 2007</td>
<td>28%</td>
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| Prevalence according to selected Provinces (based on antenatal attendee survey) 2007 | Highest- Kwa Zulu Natal 37.4%  
North West one of worst affected 29%  
Lowest- Western Cape 12.6% |

Table 1: Key Health Indicators in South Africa

1 All from World Health Statistics 2006,  
2 See http://www.avert.org/saficastats.htm  
3 See http://www.avert.org/saficastats.htm
In addition to health, a number of other socioeconomic rights (land, housing, food and water, and social security) in the South African Constitution are often phrased in terms of “to have access to” the right in question (South Africa, 1996). It alludes to enabling a process or environment, a “qualified right,” rather than a direct right to the service or product in question. Indeed, constitutional socio-economic rights have been a critical national site for overturning poor policy on HIV/AIDS (Jones, 2005; Heywood, 2005). The challenges in local implementation concerning access to ARVs, however, remain and are illustrated through this case study from Hammanskraal-Temba in South Africa. The approach taken is therefore directed towards highlighting the structured spaces and processes confronting (rights-based) ‘access’.

Methods

The study draws on material from a larger qualitative case study that took place between 2004-2007 in Hammanskraal-Temba, a peri-urban settlement approximately 40 kilometres north of Pretoria (Jones, 2009).

The purpose was to identify local characteristics of access to medication in relation to broader geographical scales that also constitute access. Analysis derives from two particular qualitative methodological tools: 25 semi-structured key informant interviews in the local study area. These included the full range of service providers at the ARV clinic- clinicians, dieticians, psycho-social and adherence support; and chair of the hospital board; also key informants in the community- traditional leaders, police and others. In addition, four focus groups with People living with AIDS (PLWAs) consisted of approximately 50 participants in total, using an interpreter and transcribed into English. These groups consisted of members of different support groups (a local HIV/AIDS hospice, and the ARV clinic support group, in particular) but also as a control, one other further from the clinic. Limitations of the data
collection include the sampling of PLWAs (based on support groups rather than those who were not supported) but who were therefore more likely to be using services and more open about their status. Two other focus groups, consisting of non-PLWAs, provided an important control and verification function to the key informants and PLWAs. Policy documents, local census data and secondary material, such as newspaper articles, and academic work, supplemented the qualitative data. A good degree of triangulation was created by different qualitative methods and ensured the validity of the data collected. The project followed the ethical guidelines used by the local partner, the Centre for the Study of AIDS, University of Pretoria. Information was given to participants concerning the purpose of the study and consent given by participants, especially PLWAs, whose real names have been changed.

Findings: Unpacking ‘Access’

_Provincial scale_

Like many other areas in post-apartheid South Africa, Hammanskraal-Temba, has been characterised by its highly complex political, socioeconomic, and cultural geography. Much of the transformation post-1994 is directed toward untangling the intricate spatial webs of the apartheid era - namely provincial, Bantustan and municipal boundaries. Post-apartheid municipalities were demarcated in 2000 and in the amalgamation of some places in former Bophuthatswana (a nominally ‘independent’ Bantustan created in the apartheid era) areas within the newly formed City of Tshwane (Pretoria) Metropolitan Council, whilst incorporated areas were still under provincial jurisdiction of the North West province. This resulted in what are termed “cross-border” municipalities, forming a northern and western peri-urban fringe to Pretoria. The official motivation for the amalgamation was to meet the developmental needs of these disadvantaged areas by including them within the tax base and local economy of a well-serviced conurbation (Tshwane, IDP 2005:29). Undoubtedly, these
were important efforts to create geographies of inclusion rather than exclusion but despite these worthy intentions some localities therefore remain caught between jurisdictions.

Hammanskraal-Temba is an extensive geographic area that is often taken by locals and others to mean also several surrounding villages and settlements, with total population approximately 150,000. Some of the major characteristics are that the area is extremely ethnically diverse and with cultural practices (such as traditional marriage and traditional leadership) that tend to be associated more with rural South Africa. It also has profound developmental challenges with large variations in access to water and electricity based on proximity to the ‘urban’ core of the settlement. Economically, it is estimated that on average across the area, approximately 66 per cent adults are either unemployed or not officially economically active. The area is therefore, in general, “peri-urban” socio-economically and in terms of access to services.

Cross-border governance has impacted greatly upon service delivery, from responsibility for traffic light maintenance, police telephone help lines, to the local hospital and access to ARVs. In 2005, the confused jurisdictional imprint upon health service delivery was related to a highly spatialised delay in rollout of ARV drugs. For a period access to ARVs was restricted to a handful of selected sites in South Africa (Jones, 2009), which did not include Temba-Hammanskraal in the North West Province:

The district hospital is in the North West province and falls short of being part of Gauteng by a millimetre, the width of a fence. On provincial maps, the boundary is literally the hospital’s southern fence. Most mornings, on his way to the clinic, Robinson [the pseudonym given to the doctor] drove across the boundary line between living and dying. (Rossouw, 2006).
This quotation captures the stark nature of the challenges confronting Hammanskraal-Temba. Provincial scale has numerous implications for ‘access’ in Hammanskraal-Temba. First, there were already large variations existing across provinces in terms of financial and human resource capacity to implement policies and, furthermore, in burdens of ill-health encountered. Jubilee hospital lay in the North West, one of the more poorly resourced provinces, with large rural populations and which had also experienced over 30 years of autocratic rule (as a Bantustan). It was also a province, where, following the quotation, above, ARVs came relatively late, partly due to the ruling African National Congress political control and whose national leaders at that time opposed ARVs. Second, the cross province location of Hammanskraal-Temba exacerbated poor access because many areas of service provision fell between provinces. Often either province (North West and Gauteng) used the location’s geographical uncertainty as a reason not to commit scarce resources while the uncertainty continued about its final jurisdiction. Despite these scale disadvantages, as ‘roll out’ of ARVs gathered pace, the local ARV clinic at Jubilee could also use provincial scale to its advantage (see later).

Local and non-local scales

From 1994, as mentioned, the district hospital was administered by the North West province. ARV services began at the Wellness clinic, with the initiation of treatment eventually taking place in September 2005. I was unable to obtain hard data at clinic level but in discussions with clinic staff, however, the following breakdown was observed. First, the ratio of female to male patients appears to be approximately 60 per cent to 40 per cent. Clinic staff identified as particularly problematic the lack of men coming forward for treatment. Approximately 10 per cent of patients were children. The majority of patients was not employed and was given nutritional substitutes due to food insecurity. Despite high numbers of foreigners in the area, they were totally underrepresented at the clinic because they were effectively excluded from access due to non-residency status. According to the Senior
Registrar, there has been a dramatic increase in ARV patient numbers, almost by ten fold, from 966 in 2006 to 8,729 adults and children currently enrolled on treatment as at 31 April 2010. These rapid changes inevitably produce significant challenges for the clinic and hospital.

The hospital consistently featured negatively in the interviews with PLWAs. Indeed, the clear majority of responses across groups of PLWAs and also those not living with HIV or AIDS indicated widespread dissatisfaction with health services at the district hospital. Built in the 1960s, and under management of a Baptist mission, poor services have long been associated with it and reflect the more general neglect of and lack of resourcing for rural health care. According to one resident, the quality of service did improve during the Bophuthatswana era, with more nurses and shorter waiting times that were also generally on time if you wished to see a doctor. Good care and also medication were apparently always available. The quality appears to have declined since 1994.

These resident views therefore reflect broader shifts in national health policy that is set ‘up stream’ from this locality. Studies of the restructuring of national health reveal that since 1994, there has been a decline in hospital staff numbers, including, critically, a sharp decline in the number of nurses, and prioritisation of the strengthening of primary health care (von Holdt and Murphy, 2007; Schneider, Barron, and Fonn, 2007). These national processes are captured in qualitative terms in responses by long-term residents with regards to the profound sense of changes in attitudes of nursing staff. Whereas previously, nurses commanded great respect and were well liked, now, even when the nurses can see that a person is critical, they will still take their time before attending to the patient. Complaints raised by people in the focus groups who were not living with AIDS concerning the waiting periods, the lack of doctors available and the irregular supply of drugs. They were generally dissatisfied with the treatment that they received when visiting the hospital. The implication can be quite dramatic for access. As one female social club member said about being ill and
having to go to hospital:

I won’t go there, I will stay away.

Getting the wrong medication and also being placed in specific “HIV” wards were additional issues. But it is the oft-cited tendency to be neglected that was particularly troubling for PLWAs. Although the inadequate care cited appeared generalised, specific AIDS-related discriminatory practices were also common (Jones and Zuberi, 2005). ‘Access’ therefore implicates hospital governance more generally. This starts with one of the most important entry points to the hospital—the need to negotiate hospital clerks. Clerks were regarded as surveying patient files unnecessarily and gossiping about their HIV status. The implication was that this behaviour impacts upon the people’s confidence in whether to go back to the hospital, with:

people…afraid to go to the clinic…they throw the medication away… (Person living with HIV/AIDS, 2006).

Patients at Wellness clinic were acutely aware of the problems in negotiating care and treatment on wards outside the ARV clinic. In some other wards, the level of care given can be influenced by whether a patient is deemed “good” in terms of their level of adherence or not to TB medication. In one instance the harsh treatment was due to the nurses’ exasperation that the patient had apparently failed, for a second time, to adhere to TB medication. A basic level of care and compassion was deemed to be lacking. This was linked to a strong sense of injustice by almost all in the focus group discussions.
These concerns were also shared by some staff. The previous clinical head of Wellness had himself been concerned about the treatment of his patients at the hospital. He also discovered that a special “code 279” was being used to identify AIDS patients on their files (since removed). Often, he claimed, these patients would be placed deliberately in the last cubicle on a ward, be seen by junior doctors and would have minimal care.

The consequences of local scale of access at Jubilee are apparent in the specific challenges associated with rural and semi-urban health care settings. Not least, severe local poverty and human resource challenges at the hospital are of particular concern. In addition to these place ‘effects’, non-local factors, i.e. national policy changes, have clearly impacted upon local characteristics. The struggle to retain staff and to fill vacancies is an often-cited structural problem confronting South African health services. These difficulties are disproportionately experienced in more rural areas (von Holdt and Murphy, 2007; Schneider et al, 2007). This has an impact on both current and future patients’ level of care. The turnover in staff can be critical for some patients in terms of adherence and other issues in quality of care and compounded by place ‘effects’.

*Place ‘effects’ upon quality of care*

The explanations for why patients were apparently treated badly in the hospital (rather than Wellness) are indeed complicated. They span structural, historical, and cultural dynamics. While there is not the space to provide much detail here (Jones, 2009), the overall point to emphasise is that health care workers, whilst implicated in violations, may also be victims themselves, along with patients, within hospitals described as “highly stressed institutions.” (von Holdt and Murphy, 2007). Staffing shortages have already been mentioned as a critical factor in affecting the quality of care and are a notable ‘place effect’. In discussions with Congress of South African Trade Unions (COSATU) representatives, a
litany of grievances having to do with forced testing, stigmatisation, and breaches of confidentiality directed against employees (not only health but also more generally) became apparent. Broader staff-management relations were structured also by national level policy and planning to reflect external ‘up stream’ constraints, such as staffing and budgets, but also specific local characteristics. In this specific case, hospital management had traces of authoritarianism characteristic of the lack of accountability from the Bophuthatswana era. Upon approaching management a situation of bullying of employees appeared to overshadow any sense of ethical entitlement workers may have (COSATU representative, 2006).

The Wellness clinic was newly created. Both successive heads of Wellness described their various frustrations regarding attempts to collaborate with the hospital management. Studies indicate the lack of the hospital manager’s control over administrative decision-making in an overly centralised system—hence with great powers for, often autocratic, provincial decision-makers (von Holdt and Murphy, 2007). However, within this district hospital, managers appeared to exert a lot of power. Wellness staff experienced frustration, with collaboration initiatives becoming unnecessary power tussles, particularly concerning the management’s reluctance to working with “outside” institutions. One trade union respondent highlighted the lack of transparency and lack of consultation associated with a culture of institutional secrecy. I was told that, “they [the hospital] don’t like to transform.” Recently, the hospital has been transferred to the jurisdiction of the province of Gauteng, with high hopes that these management issues would be resolved.

The obstacles posed by the local hospital indicate the role of micro-geographies of institutions and organisations in shaping ‘access’. Decision-making, resource allocation and resistance to collaboration with outside agencies were all imprinted by the place effects of local governance of the hospital, which deeply impacted staff-manager relations. Management arguably used the local scale consciously to keep decision-making as
autonomous as possible. Using a relational analysis, however, again shows that other scales can also be used to manoeuvre such ‘local’ obstacles. As the ARV roll-out proceeded, the provincial administration, for example, became more proactive as it was concerned about meeting targets for number enrolled. The head of the clinic travelled to provincial headquarters to tap into the concerns expressed at the provincial scale about slow enrollment. By demonstrating how enrollment could be increased through collaboration with outside organisations (who would fund human resource positions), some leverage was provided over the local management. This use of the provincial scale therefore, at least on this occasion, circumvented local micro-geographies of power.

Socio-cultural attitudes and national scale politics

Even before the patient approaches the hospital, social attitudes vested in individual perceptions of ARVs are another critical dimension in shaping access. ARVs tended to be associated with death and desperation in that people take ARVs as a last resort when they are already in an advanced stage of illness. One current patient at the Wellness clinic relayed that she had been “very scared when people talked about ARVs” because she thought that people only take then when they are already dying. People living with AIDS talked about people they knew who were adamant they would not take ARVs because they do not help and actually kill. This appears to reflect, as recounted by the respondents themselves, a fundamental problem in that people are going to access ARVs very late, when they are already seen as ill, even terminal. Many recounted how they only found out about ARVs when they were ill and had been tested and introduced to the Wellness program. This represents something of a catch-22: ARVs remain associated with death but people only hear about them when they have already approached the clinic, usually after having fallen ill.

Some of the more commonly cited negative attitudes to ARVs involve side effects and
associated rumors. ARVs are associated with “problems” and this is what people hear about. Others indicated their fear at being told by health care workers that the ARVs would be for life, “then I ask myself this is for life and what happens if I miss the time [when I should take pills]?” (“Sibo”). Uncertainties circulate within this community, culminating for one patient’s association of ARVs with being a “gamble.” The head of Wellness, Dr. Mathibedi, explained that when patients are about to start treatment, the majority does so with reservations. The most common questions concern the toxicity of ARVs and especially whether they work. The dietician at Wellness also confirmed these perceptions that ARVs “are dangerous or they are toxic” and reflect inadequate information.

There is a resilient stigma associated with HIV/AIDS that is transferred on to ARVs themselves (Jones, 2009). What is significant in the discussion of access is how this stigma is also constructed by non-local debates occurring at national scales. Controversy, for example, has been a defining feature of responses to HIV/AIDS. Former President Mbeki and his Minister of Health, Manto Tshabalala-Msimang not only held very negative views of ARVs, depicting them as highly toxic but also promoted various discredited treatment ‘alternatives’. Such views, although expressed at national level, had apparently affected preparations at the local hospital with some health care and social workers alluding to the role of politics:

…the whole ARV thing, I think it had too much controversy around it and that is actually affecting the delivery of services…it is too political...(social worker).

Local patients’ attitudes to ARVs also related to national level controversies:

…our leaders should not say negative things about ARVs. People were going to go for ARVs freely without any fear. But we are not free. (“T”).
Patients suggested information was limited because “no [one] beyond Wellness clinic are talking about them, the general clinics they don’t talk about them” (“Florence”). The scant access to information in surrounding rural areas was considered a particular disadvantageous ‘gap’, with suggestions that this is “why the person is weak that he can not take the ARVs, you see. It is because of the information that we get” (“Thando”). Another dimension to the paucity of information was that it served to encourage speculation about ARVs. One respondent expressed concern at what they felt was perhaps their government deliberately hiding information from them. The point is that local scale of ‘access’ is also impacted by national attitudes and utterances by leaders and politics of ARVs. This was also true in terms of the reinforcing of particular cultural interpretations of treatment, and, as mentioned, so-called ‘alternatives’. Some of these alternatives included illegal trials for multi-vitamins and herbal based treatments. It was the former Minister of Health’s promotion of a concoction of lemon, garlic, olive oil and African potato, as a sort of ‘home grown’ remedy (in a form also sold as “Africa’s solution” product) that was one of the most visible so-called alternatives.

While the depth and spread of traditional and alternative medication cannot solely be attributed to the AIDS dissidents in government, the latter undoubtedly contributed to sowing the seeds of confusion in this community. The contested nature of ARVs and the generally negative debates about them and broader explanations of HIV/AIDS itself surely play into pre-existing strong local belief systems.

Negative views of human rights were expressed by key informants such as police men, parents, traditional leaders and health care workers who all expressed how their authority was challenged by rights discourse. One respondent claimed that the local culture is an issue in that “some cultures don’t talk.” Echoing the work of Hog (2006), therefore, a “silence of rights” acts against a rights discourse. People can also be inhibited from
complaining for fear of repercussions. This deeply constrains the operationalisation of a rights-based approach.

A relational understanding of local socio-cultural attitudes in shaping access is therefore significant in two senses. First, it underscores the significance in Aids-related research literature and policy that is given to responsible national leadership and a rights-based approach, which was found lacking in the Mbeki era. Second, the relational dynamic, however, goes both ways, namely, with the socio-cultural variations that exist between places. In other words, the implication that strong national leadership taken on HIV/AIDS, should somehow automatically over-ride deep-lying local perceptions and beliefs, is false. These locally rooted identities pose a particular challenge to the ‘universal’ scale at which human rights standards are defined.

*National clinical guidelines for local access*

Jubilee, they want many things before you can get ARVs (“Thandi”).

Clinical criteria for accessing ARVs, such as CD4 counts and viral load tests, are relatively well established. A much more vague area concerns in what circumstances non-clinical factors should also be considered in defining eligibility for access to ARVs. A critical caveat to local access of ARVs concerns the national policy process surrounding national treatment and clinical guidelines. In South Africa, treatment criteria are stated according to the “National antiretroviral treatment guidelines,” which, more recently, in 2008, were revised in the “Guidelines for the management of HIV & AIDS in health facilities.” The two main areas of criteria are both clinical and non-clinical. In the revised guidelines, Mr. T. D. Mseleku, then the director-general of the Department of Health, states that adherence should receive
even greater attention (2008:5) as non-clinical criteria than it did in previous guidelines (see Jones, 2009). In drawing attention to the emphasis given to adherence, the purpose is in no way to deny the obvious benefits of adhering. Rather, it is to suggest whether this can ask an awful lot of some patients who are in any case those least likely to comply. A paradigm of “community mobilization” and “participation” (DoH, 2008) while intrinsically important implies that a degree of disclosure is apparently preferred. This should therefore raise the question of what burdens these criteria, if exercised literally, may have on people living with AIDS.

Respondents, for example, cited anxieties related to the requirement they heard about regarding adherence. This implied, for them, that friends or family also need to be involved:

You know, if you hear about something you don’t know about, there are so many things that come to your mind. The first time I heard about ARVs was ‘come with your buddies.’ I began asking myself many questions, why did they want my buddies?” (“Rose”).

Another was scared to access ARVs because she was told her parents had to accompany her to the clinic. Generally, while most were encouraged to disclose, there was a wide variety of experiences in doing so. For most, the benefits of disclosing were apparent, especially in accompanying or being accompanied by a “buddy”. So, disclosure and support reflect the ideal of mutual support and, hopefully, that both appear to go hand in hand for adherence. Even when the patient does not disclose, the clinic can make an assessment and the patient may, as suggested, nonetheless receive treatment. Some, however, were surprised that someone got treatment when their own family did not know: “Yah, if you do not come with your family they are not going to give you your medication” (“Thandi”). Indeed, there is a
cost in disclosing that can be an immense burden in seeking treatment. This was duly acknowledged by the head of clinic, who suggested that disclosure did create “domestic” problems for “a minority of patients.” Reflecting the emphasis upon disclosure promoted at the clinic, many respondents claim that they were told to disclose, or at least this was their perception. There is inevitably a thin line between encouragement of disclosure and the patient’s perception of this as a prerequisite for access. But many patients interpret disclosure as necessary in terms of needing to be accompanied before they could receive ARVs. One claimed that they could not go alone to get medication, whereas another was not asked to bring anyone. For some, a signed declaration was necessary, adding to difficulties in getting treatment.

Therefore, on one level, it certainly appears that disclosure can be a problematic and painful experience for people living with AIDS that can heighten exclusion and “domestic problems.” But on another level, does this necessarily mean that people living with AIDS are actively turned away or forced to disclose? Interviews with clinic staff clearly demonstrate that the clinic does not think so and that they have been cautious in handling this issue. But, nonetheless, people living with AIDS claimed that they had seen others turned away from the hospital because, apparently, “they couldn’t answer questions.” As the following exchange reveals, it is not uncommon to know of people refused treatment:

We have seen them. (“Thandi”)

There are many of them. (“Thando”)

They [the clinic] keep on postponing. (“Sibo”)

In one case, “Florence” confronted clinic staff to explain why someone she had seen was turned away from the clinic. The response given to her was that they had not adhered to a course of Bactrim (an anti-biotic given to those enrolling for ARV treatment).
The geographical significance for understanding access is therefore that policies and guidelines set at a national scale, which may appear intrinsically constructive, are misinterpreted or even abused when it comes to the local operationalisation. Some observers indicate that, for example, judgemental attitudes of health care workers may be projected onto potential patients, in effect filtering out those ‘deserving’ from the ‘undeserving’. Lack of relational understanding of policy setting and implementation can therefore even contribute to uneven implementation and exclusion.

**Local scale and socio-economic issues**

Across all people interviewed and focus groups, when asked about key characteristics of the area, most—if not almost all—associate it with high levels of poverty and unemployment. Unemployment is endemic, particularly among school-leavers and younger people. Another key and related dynamic concerns dismissals from work, poor job security, and problems with receiving employment-related payouts such as pensions. Often, links were also made between poverty, joblessness, and vulnerability to HIV/AIDS. In such a context, it should appear necessary to explore what challenges are posed by the political economy of the locality to ARV programmes. Concerns were stated as follows, in order of the most commonly cited. First, food, money, and transport were all cited most and equally significantly. The dietician at Wellness, who, in response to being asked if nutrition was a problem confronting patients, also confirmed the problem of inadequate nutrition as a “huge problem.” She estimated that of the ten people she sees daily, nine of them would receive nutritional supplements and that “it is only one out of the ten I see a day that you find they do not need supplements.” Second, these were followed by the importance of bringing treatment closer through decentralisation of ARV access points to local communities. Third, also cited, again in decreasing significance, social grants, clean water (particularly important for one
rural dweller), and costs involved in eating healthy. Fourth, transport is another major issue, as mentioned, with 66 per cent of those specifically citing it, also living outside of the “core” area of the hospital. One respondent mentioned the burden of having to travel 23km to Wellness clinic when they did not have money to do this regularly. Another recalled how she ‘skips’ treatment appointments because of lack of funds to travel. Of ten patients who the clerk tells the social worker do not come on a given day, typically, she says that nine of these are due to lack of transport money. The obvious issue of distance was important:

You cannot walk from your place of residence to the hospital. (“Thandi”)

So you miss appointments, for example? (Facilitator)

Yah! I do miss appointments. (“Thandi”).

“T” spoke about his own transport problems “[P]articularly if I am having problems, side effects, or even to go back to collect treatment.” The implication of having to fetch treatment regularly proved to be devastating for one patient, a domestic worker. She told of how she had lost her job because of the lack of flexibility in the system for treatment provision and subsequent need for time from work spent queuing. When she inquired about getting treatment for a month she was told: “There is no hospital that will ever give you monthly treatment. I went there to get my treatment every second week. They do not give you any [more] treatment. You have to come back now and then. Imagine, I was working as a domestic worker and had to miss work every Tuesday to come and get the treatment? So I was fired. That is not fair” (“Gloria”).

The significance of geographical analysis for understanding access is perhaps most apparent in these discussions of physical distance to the point of access. In recent years, the influence of geography has been acknowledged in efforts to decentralise points of access for ARVs. While this undoubtedly alleviates some of the burden for patients, and indeed hospital clinics, localised access raises additional concerns. One, for example, concerns the ongoing role of stigma and community level gossip that may be worsened at more localised community level ARV service delivery points. Another concerns the reality of highly mobile populations and that a more relational understanding of ARV access would therefore contribute to greater institutional flexibility for patients involved in seasonal, circular or other types of shorter or long term migration or visits.
Discussion and Conclusion

A multi-scale relational approach enables a more dynamic analysis of ‘access’ as shown in the case study.

First, a geographic approach, in its most basic sense, shows the importance of local context if implementation of ‘universal’ rights and policies is to be achieved. The case study showed the specific challenges associated with a semi-urban settlement, amongst others, in terms of the severely constrained human resources at the hospital, poverty, limited information, and, especially, physical distance of patients to clinics. Furthermore, another lesson for understanding ‘access’ concerns the governance of health facilities and, in the case study, how exclusionary decision-making prevented the ARV clinic from initiating relations with other local actors.

Second, a geographical analysis is therefore also concerned with the different flows and relational networks that shape ‘places’. The jurisdictional power allocated at different scales is an obvious case in point illustrated by the provincial administration’s initial decision not to provide access to ARVs at the hospital. In the case study, the issue of being a ‘cross-province’ locality was a graphic instance of the imprint of scale with services literally falling between jurisdictions. It has been argued that a geographical imagination can therefore capture both the importance of context and also a more relational understanding of places as the inter-linkages between scales. Places both shape but also more often have their room for manoeuvre shaped by scale. The roles of national economic and health policy, treatment guidelines, and, especially, national leadership all constitute local access. The complicated relationship between local beliefs and attitudes and national level leadership highlighted the dynamic linkage between both scales. The implication is that focusing attention on one or the
other fails to establish the full picture shaping views of health and illness. In relation, whereas a rights-based approach focuses on the highest attainable level of care at modern health facilities, a geographic analysis showed the tendency of patients to approach first other spaces of care, especially traditional alternatives. By highlighting these linkages an important ‘gap’ in a rights-based approach can be overcome. In addition, the mobility of patients across different places poses particular challenges for creating more flexible and less rigid place bound ‘access’.

Third, a geographical approach is particularly useful in acknowledging “how actors interests may be bound to particular levels, spatial relationships and places” (Lebel et al, 2005). The usefulness of a scale approach to understanding access is that it can show the interrelated spaces that shape patient care but are not reducible to the latter. These scales are also constantly remade and contested. The hospital administration, for example, attempted to confine governance of ‘access’ to the local scale of the hospital. But the example of the local clinic actively using the provincial scale showed that actors can shift, or ‘jump’, between scales to exert advantage and leverage. Geographical analysis also “helps make the case for more innovative mechanisms” (Lebel et al, 2005) and approaches. These mechanisms should be premised upon greater attention towards multi-scale approaches that seek to disrupt established scale constraints to instead focus upon thinking and acting at a variety of different scales. The implication of such analysis is for ‘scaling-up’ from localities to form broader alliances and to build capacity to act in different arenas at different levels. Since 2005, the Centre for the Study of AIDS, at the University of Pretoria has built training and legal interventions and partnerships with other stakeholders in the case study area. These interventions are underpinned by the creation of ‘The Place’, a paralegal service for PLWAs in the area. Although the full impact is still to be assessed, hundreds of cases have been dealt with, many resulting in redress for rights violations. A locally driven project, Tswelopele also
links to other levels through the networks, resources and experiences provided by CSA at the University of Pretoria and into national arenas.

Access is therefore a composite of a variety of social, cultural, and political dynamics captured in spatial arrangements. Presented in this way, the value of a relational use of scale is to illuminate better understanding of why human rights approaches often founder on the rocks of non-implementation. One of the implications is that the patient focus of a rights-based approach should be linked to other relational dimensions, as mentioned above. A rights-based approach, in other words, needs to engage with the governance and institutional environment that also determines access. The case study showed how relations between patients and health care providers, in turn, are also conditioned by staff and management relations. Focusing only on patient rights in a right to health perspective can obscure the specific challenges encountered by health care providers. In seeking to blame and even prosecute health care workers, for example, a rights-based approach might even be counterproductive and result in further polarisation of patient-health care worker relations. One of the overall implications for a rights-based approach is that ‘universal’ entitlements and ‘universal’ legal norms need to consider local context and influence of different scales. It is impossible to talk of ‘universal’ access, for example, if provincial administration disallows access. Similarly, while legal norms provide clarity and guidance, without local contextualisation, as suggested, they may also be counterproductive. Guidelines on adherence, for example, can be subject to very different local interpretations and challenges patients encounter related to context.

All of these findings suggest that when a rights-based approach, like treatment programmes, engages with a geographical awareness new approaches can be envisaged. While the appeal of human rights reasoning is usually anchored in legal norms, these also should be subject to local circumstances and also the social, economic, political and cultural
relations that extend across scales. A more multi-disciplinary approach does not replace the normative nor legal strength of human rights, but emboldens it. Elaborating on the meaning of “access” to treatment, and by implication a rights-based approach, produces a more rounded picture of the dilemmas, anxieties, community, and institutional and contextual pressures -the grey areas- that people-living-with-AIDS encounter. It is precisely such spaces and the complicated geographic mosaics they comprise, that human rights practice and research should increasingly engage with in order to genuinely respect, protect and fulfil the human right to health in the years to come.

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