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Acceptable Care? Illness Constructions, Healthworlds, and Accessible Chronic Treatment in South Africa

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Abstract

Achieving equitable access to health care is an important policy goal, with access influenced by affordability, availability, and acceptability of specific services. We explore patient narratives from a 5-year program of research on health care access to examine relationships between social constructions of illness and the acceptability of health services in the context of tuberculosis treatment and antiretroviral therapy in South Africa. Acceptability of services seems particularly important to the meanings patients attach to illness and care, whereas—conversely—these constructions appear to influence what constitutes acceptability and hence affect access to care. We highlight the underestimated role of individually, socially, and politically constructed healthworlds; traditional and biomedical beliefs; and social support networks. Suggested policy implications for improving acceptability and hence overall health care access include abandoning patronizing approaches to care and refocusing from treating “disease” to responding to “illness” by acknowledging and incorporating patients’ healthworlds in patient–provider interactions.

Keywords

Africa, South; health care; health care, access to; health care, users’ experiences; HIV/AIDS; illness and disease, chronic; illness and disease, infectious; illness and disease, social construction; interviews, semistructured; relationships, patient–provider; research, qualitative; social constructionism; tuberculosis (TB)

South Africa has experienced the world’s fastest growing epidemic of HIV/AIDS, at the same time as going through a dramatic political and societal transition from apartheid to democracy (Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009; Mayosi et al., 2012; Schneider & Fassin, 2002). National HIV prevalence rates among antenatal care attendees exploded from 0.8% in 1990 to 24.5% in 2000 and 30.2% in 2010 (Department of Health, South Africa, 2011). Even though incidence of new HIV cases has recently decreased, South Africa still has the highest number of infected people (6.1 million in 2012) living within one country (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2013). Alongside this epidemic, and linked to the increasing prevalence of immune deficiency, tuberculosis (TB) infections have become the leading cause of death in South Africa with an estimated 87,000 TB deaths in 2011 (UNAIDS, 2013). In addition, nearly two thirds of the 520,000 South Africans with newly diagnosed TB are also coinfecting with HIV (UNAIDS, 2013).

Background

“Constructing” the Policy—Some South African Background

The South African government’s debate of, and response to, HIV/AIDS over the last two decades has been well documented (cf. Butler, 2005; Fassin & Schneider, 2003). In the mid- to late-1990s—the early stages of the post-apartheid government and the HIV epidemic in South Africa—HIV/AIDS policy and politics were sidelined to the health department. However, as the epidemic grew, a

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public debate about the causes of HIV and the required governmental response intensified. This was at a time when the virus causing AIDS had been identified for more than a decade and antiretroviral therapy (ART) was very expensive but nonetheless widely available in developed countries. However, Thabo Mbeki, South Africa's then president, frustrated by the epidemic's rapid spread and existing reasoning focusing on "African promiscuity," was looking for Africa-specific explanations for the high incidence rate, pointing to existing socioeconomic conditions and widespread poverty as probable causes (Schneider & Fassin, 2002). He called for the establishment of an expert panel, where causes and responses were discussed. The invited participation of HIV denialists, who eschewed biomedical evidence linking HIV and AIDS while emphasizing the need to ameliorate the social determinants of health, led to an enormous national and international outcry (for more detailed descriptions of this period, see Schneider & Fassin, 2002; see also Butler, 2005). The ensuing open confrontation between exponents of the "'mobilization/biomedical' paradigm and the 'nationalist/ameliorative' paradigm" (Butler, 2005, p. 592) polarized political and policy stakeholders and undermined the otherwise laudable goal of a specific analysis and greater understanding of the (South) African context and its relevance for dealing with the epidemic. Critics, including the prominent Treatment Action Campaign, noted that the direction of this debate caused a delay in interventions for prevention of mother-to-child transmission (PMTCT) and the delivery of ART (Friedman & Mottiar, 2006; Heywood, 2003), leading to an era of "unscientific health policies and disastrous mistakes" (Mayosi et al., 2012, p. 2029). Here, it appears, was an instance in which different understandings of a disease, different political and social constructions of illness, impacted dramatically on the access to care for millions of people. Faced with mounting pressure over this debate and a delay in a nationwide rollout of PMTCT, in April 2002 Mbeki formally distanced himself from the "AIDS dissident" stance. After courts also ruled against withholding PMTCT, an increased budget for PMTCT was approved and a year later, a comprehensive HIV/AIDS treatment program (including the phased rollout of ART in public clinics) was announced.

In this article, we use individual patient narratives to show how these social constructions of illness at a national policy level have had long-lasting impacts on perceptions of ART (and TB) and hence access to this treatment. We furthermore show how social constructions of illness and healthworlds (Germond & Cochrane, 2010) converge to influence acceptability as one important aspect of access to care. Our fieldwork took place during the early days of South Africa's rollout of ART to primary health care clinics from previously centralized treatment initiation and

collection points. Nationally, this rollout phase has culminated into one of the largest public ART programs, with more than 2 million receiving public-sector ART in 2012 (UNAIDS, 2013). Still, certain populations have lower access rates resulting from individual and system reasons (Adam & Johnson, 2009; Fried, Harris, & Eyles, 2012; Harris et al., 2011). Similar complex interplays between illness constructions and access issues have been noted in regard to the TB epidemic (Pronyk, Makhubele, Hargreaves, Tollman, & Hausler, 2001). We explore these issues to discover some of the access barriers to both TB treatment and ART. We focus here particularly on acceptability as an aspect of access that is often neglected in the practice of health care delivery (see Goudge, Gilson, Russell, Gumede, & Mills, 2009).

Access to TB Treatment and ART in South Africa

Today, South Africa's ART program is administered as a routine, chronic service. According to 2011 national guidelines (Pillay, White, & McCormick, 2012; Rossouw, Richter, Martin, Avenant, & Spencer, 2011), HIV-positive patients should be initiated on ART once their cluster of differentiation 4 (CD4) count (an indicator of immune system strength) has declined to equal or less than 350 cells/ μ L (during our fieldwork, the guideline threshold value was 200 cells/ μ L). ART initiation is accompanied by adherence counseling and regular clinic visits for treatment collection (during our fieldwork, such visits were at least monthly). Although progress has been made since (UNAIDS, 2013), during the time of our study, approximately half of the HIV-infected people (Adam & Johnson, 2009) who—based on their (<200) CD4 count—were in need of ART were still not receiving it. In addition, there appears to be a substantial number of patients on ART who seem, at least temporarily, to be interrupting their treatment (Boulle et al., 2010; Geng et al., 2010), thus endangering their individual health and increasing the chances of viral mutations, further treatment complications, and additional strains on the health sector. Similarly, initiation and uninterrupted access to treatment for TB patients, often coinfecting with HIV, remain problematic.

In 1995, South Africa adopted the World Health Organization (WHO)-recommended directly observed treatment, short-course (DOTS) strategy to provide free TB treatment in the public health care sector. With this strategy, the country achieved a 77% treatment success rate for sputum smear-positive pulmonary TB cases in 2009, 8% below the WHO target (WHO, 2011). For the patient, TB DOTS consists of a standardized, 6-month course of treatment (or a minimum of 8 months for TB reinfection). Here, medication ingestion, at least in the initial phase, is directly observed (and, in the case of

multi-drug-resistant TB, injected) by a health provider. This is usually a health care worker at the local clinic, although a trained lay care worker in the community is also common. Postulated advantages of this “tablet watching” strategy (see Khan, Walley, Witter, Shah, & Javeed, 2005, p. 354) lie in the standardized approach that can be implemented at the nurse-run clinic level, and the possibility for health care workers to regularly “control” the observance of the treatment scheme with a chance to communicate about side effects and other difficulties. However, there are arguments that it also perpetuates a “conveyor belt” approach to nursing (van der Walt & Schwartz, 2002, p. 1001), disempowers patients (Garner & Volmink, 2000), and puts—as we also show—an additional burden on them and their resources because of the need for frequent clinic visits. Acute ill health and transport costs can here create additional access barriers; these issues can be equally problematic for people on ART (Geng et al., 2010; Kapella et al., 2009; Sagbakken, Frich, & Bjune, 2008).

A public service providing free ART and TB treatment is thus a necessary but not sufficient aspect of enabling widespread access to therapy in resource-limited settings. Access to health care is not only influenced by policy decisions regarding the spatial availability of services but is affected by a complex set of interrelated factors that, in South Africa, include the persistent impact of former apartheid policies and current sociopolitical, cultural, and economic conditions, which have in turn shaped the treatment debates at the national level. It is not only a question of the supply side of the health care system but also of the demand for, and appropriateness of, available services (Schneider, Blaauw, Gilson, Chabikuli, & Goudge, 2006). Accordingly, access to health care services, which describes the availability, affordability, and social and cultural appropriateness of services including perceived quality of care and patient–provider interactions (Gilson, 2007; Thiede, Akweongo, & McIntyre, 2007), has received some attention in studies of ART and TB care (e.g., Cleary, Birch, Moshabela, & Schneider, 2012; Fried & Eyles, 2015). In this article, however, we focus less on availability and affordability issues shaping access to services but on the social and cultural appropriateness, on acceptability. Specifically, we examine how acceptability is shaped by, and shapes, experiences of care in patients’ perceptions, that is, in their social constructions of illness and care. To achieve this, we use a series of related theoretical lenses that we introduce below.

Social Construction of Illness and Acceptability of Services

As highlighted by the HIV/AIDS controversy under the Mbeki presidency in South Africa, illnesses are constructed

and imagined at both macro and local levels. Conceptualizing illness as a construct has influenced research and practice over several decades, and we do not attempt a comprehensive review of this well-understood approach (see, for example, Conrad & Barker, 2010; Pierret, 2003). Rather, we use these ideas as a foreground. In brief, the constructionist perspective suggests that individuals, through their beliefs and activities, shape the world they live in (e.g., Berger & Luckmann, 1966). It is impossible to understand the social world without these constructs. Kleinman, Eisenberg, and Good (1978) used these ideas to distinguish between disease (structural and functional abnormality) and illness (experiences of changes to body and self). Kleinman et al.’s (1978) ideas focused on the state of the individual sufferer; however, an individual seeking treatment must engage the health care system. Thus, considering the long-term nature of TB DOTS and ART, we also employ Thorne and Robinson’s (1989) work on health care relationships in chronic illness. Assuming “inherent discrepancies in underlying belief systems between patients and practitioners” (Thorne & Robinson, 1989, p. 153), their work pointed to the evolution of health care relationships over the course of treatment. This evolution of relationships is perhaps not universal, but—as we show—appears to be typical for many of the patients we encountered in South Africa. First, there is “naïve trust” at the start of the relationship, followed by a second “disenchantment” phase characterized by nonfulfillment of expectations, disappointment, and mistrust. Because most chronic patients must nevertheless continue engaging with the health system, this phase is followed for many by “guarded alliance” when trust is reconstituted in a variety of ways, depending on the specific patient–provider relationship (Thorne & Robinson, 1989). Here, the guarded alliance might be adjusted by the experience-based agency of individual patients. The acceptability of services is, however, not solely influenced by the evolution of patient–provider relationships but by broader social contexts. This is well expressed in Germond and Cochrane’s (2010) idea of healthworld in which health experiences are “shaped by, and simultaneously affect, the socially shared healthworld constituted by the collective search for health and well-being” (p. 309). When a narrowly biomedical intervention occurs (targeting disease), the wider healthworld might be undervalued and the illness response (experiencing body and self changes in social context) might be incomplete.

Healthworld formulates the social construction of reality and illness in a collective, shared lifeworld, ensuring that healthworld is fully mediated by all its contexts, including those of the historical development of the health care system (Germond & Cochrane, 2010). Hence, healthworld also has a temporal aspect. Equally, access to and acceptability of specific health services are not in a permanent state but—especially for (chronic) conditions

such as TB and HIV/AIDS requiring long-term treatment—are fluid and influenced by ongoing interactions between changing health system and individual/household issues.

Overtime, with chronic illness, there is therefore a (potentially interrupted) pathway to care, elements of which can initiate, encourage, or discourage particular forms of treatment. Pathways to care are extended from their use in mental health and as a plan for individual patient treatment (Bateman & Gibson, 2012; Vanhaecht, De Witte, & Sermeus, 2007) and might be regarded as (interrupted) ways of achieving the care goals of patients. We therefore recognize the changing nature of health care relationships during the (interrupted) pathways to care. As we show, experiences are a complex matter of patient perceptions and actions, their interactions with the care system, and the overarching societal contexts, which shape the nature of access—potentially shifting healthworlds. Hence, in this article, we explore how patients requiring ART or/and TB treatment utilize their socially constructed and constituted healthworlds to access health care resources, especially around the acceptability of patient–system interactions along the pathways of care.

Setting, Data, Method, and Conceptual Model

This article emerged as part of a 5-year research study that included both quantitative and qualitative data collection strategies in four provinces of South Africa (e.g., Cleary et al., 2012; Fried et al., 2012; Govender, Fried, Birch, Chimbindi, & Cleary, in press; Harris et al., 2014). In the presented analysis, we draw specifically on the qualitative data derived from in-depth interviews conducted at 12 different health care facilities in the three health sub-districts of rural Bushbuckridge (Mpumalanga), urban Mitchell's Plain (Western Cape), and urban Soweto (Gauteng). We chose these facilities with the aim to include different facility sizes, management styles, and geographical and community characteristics, covering some of the multitudes of public health care settings in South Africa. Before beginning data collection, we negotiated access to the facilities with the responsible local management structures as well as provincial and local Department of Health bodies, which provided ethics approval for the research alongside the ethics boards of the Universities of Cape Town and Witwatersrand. Ethical considerations were addressed at all sites with information leaflets and face-to-face discussion with patients. Written consent was obtained for all interviews, which were anonymized and kept on a secure server available only to the research team.

Using a narrative approach, we conducted interviews with 29 patients accessing public health sector TB treatment and ART. A narrative approach finds appropriate grounds in constructionist theory. We adopt Czarniawska's (2004) idea that “narrative is understood as a spoken or written text giving an account of an event/action or series of events/actions, chronologically connected” (p. 17). Narrative can illuminate interviewees' life circumstances and contextualize illness and treatment trajectories, hence enabling a greater understanding of the complex interpretations related to the processes linked to personal health and the health care system. “Healthworld” requires we collect material about the contexts of these narratives. In interpretation, we “restory” these narratives and contexts to provide linkages between topics and individual patients (Ollerenshaw & Creswell, 2002).

All interviews took place between May 2009 and August 2010. We employed a variety of approaches to reach both “successful” and “unsuccessful” users (see discussion of these terms below) of the two health care services. These included the direct contacting of patients at health facilities and tracing in the community via community-based health workers or support groups. We also aimed to have a good representation of gender, age, and locality, although these variations were not required for our analytic plan. In total, 14 men and 15 women were interviewed, of which half were “successful” users (with no self-reported missed collection or taking of treatment). Mean age of patient participants was 37 years, with the youngest aged 23, the oldest 64. We interviewed 9 patients who were HIV-positive, 12 who had TB, and an additional 8 patients with both known TB and HIV-positive status. The number of participants from the urban and rural sites was balanced with 13 from rural Bushbuckridge and 8 each from the two urban sub-districts. All participants were non-White. Participants volunteered their time and received no compensation. We have not only anonymized the patients but also the specific health facilities they used for receiving care.

Specifically trained and supervised fieldworkers conducted most of the patient interviews in local languages, using a semistructured interview guide encouraging interviewees to describe their life circumstances and experiences illuminating illness and treatment trajectories. Interviewees were invited to help develop a timeline of key health and health care events in their lives, exploring their own treatment pathways and reasons for certain care-seeking strategies. Aiming to increase participants' comfort levels, interviews took place in private rooms at facilities, in patients' homes, or in public spaces. After the initial interview, conversations were transcribed and translated into English and then underwent a preliminary analysis by several team members to prepare a follow-up interview aimed to gain an impression of treatment

progress and to clarify patients' narratives. However, given their complex life circumstances, not all patients could be traced successfully, hence only 12 patients (40%) were interviewed twice. After the transcription of patient interviews, the coauthors analyzed and coded all interviews using qualitative data software (Atlas.TI and NVivo, a text software was used to exchange results). Throughout the research process, we employed various verification strategies including an iterative data collection and analysis approach (e.g., individual follow-up interviews guided by questions based on careful reading of each patient's first interview and on our increasing understanding of the already collected data). In our sampling strategy, we incorporated negative cases (we interviewed both "successful" and "unsuccessful" treatment users) and paid attention to data saturation.

Our data analysis utilized a thematic analysis approach. However, codes were both deductively and inductively derived, being informed not only by existing literature linked to our theoretical frameworks but also by emerging themes that were revealed through careful reading of our data. To ensure rigor, we shared, evaluated, and discussed the themes throughout, ensuring that we achieved good congruence with respect to major and minor codes. All transcripts were read several times by the team and the quotes by individual researchers were also interrogated by the team to ensure representativeness and comprehensiveness through searching for counterfactual comments. In all, these procedures were required to ensure the restorying of the narratives around various plot lines (see Polkinghorne, 1995), concerning access to care in precarious circumstances in postapartheid South Africa.

There are of course challenges that limit our interpretations. We relied on fieldworkers who spoke local languages to carry out the interviews. The fieldworkers were inducted into ethical research practice and provided patients with referral guides and information about nearby advice centers if required. We did also regularly debrief and discuss results with all interviewees during their field work, obtaining their insights and providing feedback. We interviewed 29 people, the majority of whom could not be recontacted for a second interview. Therefore, for some patients, our data to restory are limited, affecting specifically our ability to analyze recently experienced changes over time and to interpret the HIV/AIDS and TB narratives separately.

To cure TB or "normalize" HIV as a chronic, but treatable condition, the pathways of care model suggests a "complex intervention" of care steps, processes, and milestones (Moshabela, Pronyk, Williams, Schneider, & Lurie, 2011; Vanhaecht et al., 2007), including testing and diagnosis, followed by treatment initiation and successful adherence, to attain the desired result of healing or successful symptom control. In contrast to this "ideal,"

our interviews and literature reveal numerous challenges that can delay or interrupt such pathways. In the following section, we present our patients' healthworld narratives by focusing on factors enabling and challenging the different steps along the ideal care pathway, emphasizing the acceptability of health care provision. In selecting these narratives, we have tried to give voice to as many participants as possible, choosing direct quotes that articulate a wider set of shared issues, while communicating the specifics and authenticity of each story. We recognize the constraints of second-language translation and, for clarity reasons, have made minor stylistic and grammatical changes.

Findings

Testing and Diagnosis

To initiate a biomedical response to HIV and TB, health system guidelines are based on the assumption that patients will be correctly diagnosed through testing. This requires either symptom recognition or, as with voluntary counseling and testing (the national policy in place during our fieldwork), patient education about HIV and testing in the absence of symptoms. Success of this ideal scenario also requires that patients present themselves to appropriate facilities and provide informed consent. In the context of HIV, many interviewees spoke of entering the health system in this way, agreeing to test for HIV after sensitive counseling from providers, or sometimes proactively seeking diagnoses. For example, a young interviewee from Mitchell's Plain requested a test after recognizing the possibility of being HIV-positive through gossip and personal tragedy:

I did go to the doctor because I found out from others saying "[Ayabong], why does your girlfriend like to go to the clinic. . . . Is something wrong with your girlfriend?" [We broke up] because I suspected [her status and later she died]. . . . I [was hoping] something saying maybe, luckily, I might not have it. But because they say if you sleep with someone then [I] could have it because she was my girlfriend. So when I came to the clinic, maybe I will be lucky or maybe God would help me not to have it, yes. There was that thought.

For interviewed women, HIV testing in the absence of symptoms mostly happened during antenatal care, coinciding with counseling as part of a wider intervention to prevent mother-to-child transmission of HIV. Since 2010, the South African Department of Health has intensified its efforts to test and screen all people entering health facilities for HIV and TB, moving from voluntary counseling and testing to "provider-initiated counseling and testing" (Pillay et al., 2012, p. 77). In our study, however, a female interviewee from Soweto related a very different

way of learning about her HIV status 14 years earlier, “without precounseling” or consent, when during antenatal care:

The nurse asked me and another pregnant woman to tell her if we know HIV. I explained that it is a virus . . . in the blood that makes people to get sick as time goes on and then . . . very ill and that is when we say the person has got AIDS, you see. Then the sister [nurse] asked, “Why do you think that I am telling you about HIV?” Then I said: “I don’t know, but I think that the information is important for people to know. . . . Maybe you want us to be informed.” Then the sister said, “As you both are here, I will like to tell both of you that you’re HIV-positive.”

This incident happened at a time before the introduction of stricter guidelines around counseling but was nonetheless devastating for her. Her “naïve trust” moved fairly rapidly through bewilderment and “disenchantment” to a “guarded alliance” after this short interaction. She focused less on the violation of her rights and apparent insensitivity of the nurse than on her HIV-literacy and concern for her unborn child at a specific point in history:

There was no AZT [azidothymidine, a particular antiretroviral drug], by those times, nothing. That was in 1995. . . . So it was that thing: now that I am HIV-positive, now what? Then I was asking myself, “what about the baby is she going to be infected?”

Futility and fear—a kind of disenchantment—prevented a man from Bushbuckridge from testing in the years before publicly available ART:

It took me a long time to know my status; I delayed to do the blood tests [until 2007] . . . convinced myself that I am fine. . . . It was very different [then]. Most people, like my friends, were afraid to do the tests. And I was afraid, too, saying that why should I do the tests? . . . We have seen that people are dying.

Although this man’s awareness of then medical and political limitations challenged the acceptability of available services and delayed him from even getting tested, the female HIV patient from Soweto instead “restored” her trust in the health system, as she actively embarked on a care pathway of expertise, ultimately becoming an HIV counselor:

[I said] 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. . . . I found a support group. . . . They taught me about how to take care of myself and taught me about HIV/AIDS.

In this way, she actively engaged in making the available services more acceptable—to herself, and ultimately,

through her counseling role, to others. For others, strong physical symptoms triggered their entry into TB/HIV care pathways, including the man from Bushbuckridge, who eventually tested but “ignored” his HIV test results until falling seriously ill. His story points to a tendency—especially among male patients—to not only delay testing and diagnosis, but to treat test results as “unacceptable” by ignoring them because they are not consistent with one’s healthworld. Unlike HIV, active TB usually has more clearly identifiable symptoms including coughing and shortness of breath that often trigger a clinic visit. A number of interviewees especially in rural Bushbuckridge referred, however, to *Mafularha*, a traditional illness characterized by similar if not identical symptoms to TB. An identification of illness as *Mafularha* prompts care pathways consistent with traditional beliefs and healing, even if contradictory from a biomedical perspective (see Niehaus, 2013; Niehaus & Jonsson, 2005). A display of complex, sometimes competing healthworlds—with their importance of family and culture for interpreting symptoms—emerged in the experiences described by a woman in Bushbuckridge with both a TB DOTS and ART history:

Yes, [my family] gave me traditional medicine and I took it for a while. And others came with the suggestion that it is better to send me to the hospital first to have a better idea of what I was suffering from. And it would be easy for them to give me traditional medicine after knowing my illness.

This is but one example of how competing interpretations emphasize the role of the social construction of illness and complex healthworlds in determining acceptability of services. Acceptability, as all of the other access variables, is not a static characteristic but can change over time as the patient moves through the pathways of care. According to the pathways of care model, it can be assumed that once a patient is tested, a correct diagnosis will be given, leading to appropriate treatment. However, we heard testimonies from people who tested but did not return to the health facility to learn their diagnosis. Conversely, an absence of clear-cut symptoms or the run-of-the-mill nature of diagnostic practice based on narrowly defined biomedical evidence can lead to a delay in diagnosis, as happened to one interviewee, an employed man from Mitchell’s Plain. At the time of the interview, he was receiving daily streptomycin injections for his second bout of TB, but only after proactively seeking a correct diagnosis and challenging the knowledge and authority of clinic staff:

[At the clinic], the sister [charge nurse] said I must spit . . . in the first pot, . . . the second pot . . . and they said: “alright come the following day for the results.” I went and they said, the first pot showed negative and the second one was also negative but they will [test again and] I must come back after

eight weeks. But I said . . . “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 because if I walk, and the road is steep, I need to sit and wait till I can breathe more freely before I can walk again.”

Based on his prior TB experience and recognition of key physical symptoms, he then bypassed the clinic, going immediately “to the doctor at the Day Hospital [who] said: ‘you have TB’ . . . take the [referral letter back] to the Day Clinic,” where he was put onto the correct treatment. This story reveals a conflict between his “feeling” of illness and the providers’ narrow reliance on (faulty) sputum results, even though both perspectives were informed by a biomedical understanding of TB. It also highlights the dangers of a paternalistic approach to health care that neglects open, respectful provider–patient communication.

Experiencing Diagnosis and Treatment Initiation

Problematic diagnostic patterns might not only result in unproductive relations or delays around helpseeking, they can also undermine acceptability of services and lead to provider-shopping, including for traditional healers and self-care (see Moshabela, Schneider, Silal, & Cleary, 2012). As an example, despite a long history of health system engagement following severe burns as a child, one interviewee, an unemployed woman from Mitchell’s Plain, turned (with support from her mother and aunt) to a traditional healer after an incorrect TB diagnosis. Her experience was compounded by a mix-up with her ART treatment that left her feeling unwell and disillusioned. In a cathartic visit, the healer “exorcised” her and prescribed traditional medication, so she deliberately stopped taking her antiretroviral medication (ARVs) and TB treatment because “we were told in our classes that . . . these ARVs do not mix with traditional medicine.” Nonetheless, a week later, after the nurses phoned and “pleaded,” she displayed some level of reconstructed trust and returned to the clinic. Having “permission” to reinstate ART and TB treatment alongside the traditional medicine added to the acceptability of the service and furthered her trust in the system. Asked about a particular nurse’s opinion on traditional medicine, she explained, “She said if I do not have diarrhea or vomiting she won’t say I must stop, so I decided to continue taking it.” Here, the nurse’s willingness to engage with this patient’s healthworld contributed to make her feel comfortable with and accepting of her biomedical treatment.

Ideally, a correct, clinically determined diagnosis would be followed by treatment initiation, for TB DOTS,

and possibly for ART depending on the patient’s clinical indicators, including CD4 count. Such a direct pathway was described by a woman from Bushbuckridge:

It started through pains in my stomach, having a diarrhea. Then I went to the clinic and they asked me if I would like to test for HIV. And I have tested where I found that I am HIV-positive and they have collected blood to check my CD4 count where they found that it was less than two hundred.

Within 2 months, she was initiated on ARVs. In contrast to this, a number of patients reported self-delay in initiating treatment. For some, this was because of a reluctance to start ART before finishing TB DOTS:

I don’t want to mix the treatment because I am still taking six tablets for TB every day and it will be too much to take another treatment. So I have to finish this one first. I know that when I get to mix, the treatments would not come along.

For the female interviewee from Soweto, despite embracing the health system and developing her HIV expertise as we mentioned above, the need to start ART created fear. This fear emerged because she linked the death of two close friends to the treatment itself, a fear perhaps also driven by concerns previously expressed about ART safety by Thabo Mbeki and his Minister of Health:

And there in my mind came this thing of saying antiretroviral kills. . . . I do not want to die and leave kids. I will die if the HIV virus kills me. I don’t want to die because of this treatment. I refused.

A while later, concerted efforts from within the local health system and this woman’s own social network, especially her family, persuaded her to initiate ART.

The doctor said: “there is nothing to be afraid of . . . at this point in time. You need to take the treatment because if you don’t . . . , you might still die because your CD4 count is too low. . . . I went back . . . and the doctor said to me, “I beg you, take the treatment and I will be responsible if anything happens to you.” . . . I went home and told my mother. . . . She said, we will pray. . . . At the [TB] clinic . . . they also said I need to take ART. . . . Otherwise this TB is going to come back and be double TB. Then I thought about it; then I started taking it.

Her narrative clearly displays the multitude of health-seeking experiences (the insensitive diagnosis of the HIV status, her own activism, public and political narratives, friends’ health experiences, religious beliefs, and interactions with health care workers) that shape and are shaped by her socially shared healthworld.

Fear, stigma, and patients' life circumstances can postpone treatment initiation. In addition to this, delays created by the health system itself, including limited resources, unreliable tests and an inflexible observance of guidelines, were also reported. Hence, patients reported not being initiated on ART despite feeling very weak, because their CD4 counts were not "clinically" low enough (a threshold value that has been changed since the research was carried out, testifying to the changing and constructed nature of what might often seem to be immutable biomedical indicators). For a female Bushbuckridge patient, the requirement to disclose and have one treatment supporter created access difficulties because of her family circumstances:

I took a long time to receive the ARVs because they said that I have to come with an elder person [from] home to teach him on how to take the treatment and about the treatment, but they finally gave [the treatment to] me because at home, there was no other person to come with.

Maintaining Appropriate Access to Treatment

Beyond testing, diagnosis, and treatment initiation, maintaining treatment—over many months (TB) or life-long (ART)—presents a huge challenge for patients and the health system. Once treatment is initiated, what keeps patients continuing to access it? Important reasons for continuation are effective therapy and direct improvements in the well-being of patients on treatment, and the creation of hope beyond the treatment itself (see Fried et al., 2012).

A mother of a 1-year-old child living in Bushbuckridge described how her own experience with treatment was strongly influenced by her mother's suffering and death without ART, her sister's recovery on ART, and her own positive experience both with the medication itself as well as good provider interactions at the facility level. There is in her story a socially derived acceptability of this chosen pathway with her healthworld shaped by the experiences of close others:

[Unlike our mother who] suffered for a long time, [my sister] survived because of taking the treatment. . . . She was on ARVs for more than two years before I started to receive the HIV treatment, so . . . I saw that the treatment is so helpful and that is why I accepted that I am HIV-positive. . . . Things that made it good for me is that I came here to find life and I got it. I was feeling unwell before I came here, so now I am feeling very well. That is why I like to keep on coming here because they are treating me very well and I didn't have any unfair treatment when I visited this clinic.

The importance of respectful treatment and a positive personal relationship with (a specific) health care

provider(s) for continuing access is also noticeable in this narrative from a divorced man from urban Western Cape on ART and TB DOTS:

Yes, it was my third month. I started to know the [nurses] that helped me and I started to talk with them. . . . And they were very helpful, they helped me a lot. [The DOTS 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 till I finished.

This again is an example of how "sharing" of healthworlds can contribute to the acceptability of health care services. Furthermore, family and social support also help shape individuals' healthworlds, requiring biomedical "buy-in" from more than "just" the patient. An example here is the experience of this young woman from Mitchell's Plain:

They are very concerned [at home]: Did you eat? Are you alright? Did you take your pills? You must rest and don't do the dishes. . . . They just want me to relax. . . . I eat a lot of . . . vegetables, chicken and meat. . . . Everybody [is] supportive, asking, "Are you alright? Is there anything we could do for you or bring?"

Although she described feeling supported by her family, she was also quite isolated, reluctant to go out because the physical symptoms of her illness made her feel "too thin," her clothes "too big." Commenting also on appearance in judging treatment success, the divorced Western Cape resident successful in completing his above-mentioned TB DOTS regimen, underlined what made him continue with the difficult treatment:

Now I can carry on. Now that was the past and I feel more healthy and I am proud of my body again. My body is coming to normal. . . . I don't have pain; I don't feel disappointed in myself. I am motivated and I feel to go on.

Maintaining treatment portrays the complexities of regular access and the importance of healthworld and orientation toward treatment. It involves expectations about treatment outcomes: Those expecting and experiencing physical relief might continue, with trust in the provider and medication affirmed. Support from broader personal, social (including religious), and provider networks is also relevant here, helping to overcome emotional, financial, and other challenges and interruptions, improve motivation and endurance, and better integrate this care pathway into a patient's healthworld. Nonetheless, there are numerous challenges to continuous treatment access for both TB and ART. For example, those who suffer from side effects—often not anticipated or seemingly well

explained—might default. A young TB patient from Soweto described some of the challenges linked to his medication: “I felt tired, sweaty and [although] the coughing stopped after 2 to 3 weeks close to a month. . . . [The medication] sometimes made me dizzy and tired.”

Also, those who feel better might ironically stop their treatment, assuming that their health problem has been resolved, which happened for an unemployed man from Soweto, living with both HIV and TB: “I thought that I had enough pills and when they were finished, I told myself that now I am cured or something. That’s how I defaulted, never knowing that I am making myself sick.”

It is therefore important to appear to get back to “normal” with healthworld shaping and refracting its contexts. Furthermore, challenges of treatment might affect this world as patient perceptions of treatment-related factors—side effects of drugs, dependence on drugs, or failure of drugs to relieve pain—are “disenchanting” factors that can jar against health beliefs and unsettle a healthworld. Here, context—economic circumstances and policy and public constructions of disease—adds vulnerabilities to patients, who, with limited resources, have to juggle health care as one of many competing priorities. The employed man from Mitchell’s Plain, on his second course of TB treatment, described such a conflict and his hope for an easier acceptable health care solution:

I will ask them if it is my last week of injection. Then I will tell them of the [community-based TB DOTS supporter], . . . the one who gave me my pills. Because I must work, because at home, there is nothing [food]. I can’t come here every day. What is my child going to eat and she is going to school.

A woman from rural Bushbuckridge also referred to financial constraints, making access to facilities, and hence maintaining continuous treatment, challenging:

My problem is that I don’t have money to come to the hospital and you find that at some point, I missed my appointment dates to come to collect my treatment due to the lack of money. . . . It is too far from there to here.

Here, unavailability of services might result in “defaulting.” The effect of difficult living conditions can also be worsened by an inflexible and hierarchical, sometimes patronizing system—still a feature of postapartheid care (see Hull, 2012; Penn-Kekana, Blaauw, & Schneider, 2004), as a TB patient from urban Western Cape recalled:

My mother . . . doesn’t have money to give me to go every day to [the clinic]. . . . I have to walk to the town center and I just stayed away [from the clinic] for two weeks. And I went back and they [nurses] scolded me and I explained to

them. But it was like they did not want to listen. . . . I explained to them that I am not working and I can’t make it. Then they said if I want to be cured, then I must make a way [or] . . . I will die.

Although affordability of transport is the greatest access challenge for him, it is further complicated: The actual taking of treatment can be affected by lack of food and lack of family support, work commitments, and unsympathetic employers. Appreciating the positive influence of ART, a female Bushbuckridge patient did her utmost to regularly take treatment without endangering her precarious relationship with an unsupportive boyfriend, a situation that also highlights the roles of gender, blame, and stigma around HIV/AIDS and ART:

You could not tell him. [Laughing] . . . I am afraid because he would leave me. [Laughing] . . . I was taking the treatment while my boyfriend was working night shifts and I didn’t take them when he was around. I was afraid. But when he left to work, I was taking them.

This “medical adjustment” to accommodate her social reality was acceptable for this interviewee because she did not notice any physical impact of occasionally missing tablets. It is, however, also noteworthy that within the notion of healthworlds, access to health care goes beyond medication alone, relating to social and physical living conditions and broader ideas of health and well-being. Another interviewee’s narrative indicates the impact of regular treatment on his social life, hinting at the role of stigma related to both his illness and treatment, while showing his resilience and determination:

Ey, because it closes doors for me in some other things. I cannot drink [alcohol] or smoke. The things that I like the most I cannot do. Yes, even if I have sex they stressed that I must use condoms even if I do not want to. . . . I don’t tell my friends that I’m taking treatment. Even when we are watching TV at my friend’s place, I ask the time and they say it is five to nine. Then I will estimate those minutes and then I ask for a jug and I go to the toilet and drink my tablets.

Maintaining treatment thus requires not only a trusting relationship with the health care system but also a constructed healthworld, which allows for incorporation of the broader lifeworld.

Discussion and Ways Forward

In this article, we investigate the influence of patients’ healthworlds on access to ART and TB treatment, presenting a complex case study of healthworlds and HIV/AIDS and TB treatment. Here, we particularly emphasize the evolving nature of access along treatment

pathways of care and evolving patient approaches to the health system, that is, naïve trust, disenchantment, and guarded alliance (Thorne & Robinson, 1989). We demonstrate that for complex chronic diseases such as TB and HIV, acceptability of and access to treatment cannot be once achieved but has to be continuously secured. We carry this out with a complex methodological design, which brings together patients with two health conditions being treated in several health care facilities. The concept of pathways of care is here particularly relevant to understanding the shifting nature of access to treatment within all the commonalities of experience within very difficult lives. We extend the ideas of healthworld and of health care interactions to the complex world of living with HIV/AIDS and TB on the social and economic margins of society.

HIV/AIDS and TB are much more than chronic diseases, which need treatment. Rather, they are illnesses, dynamic states of being that are constantly (re)constructed within a “socially shared healthworld” (Germond & Cochrane, 2010, p. 309). As can be seen in the stories of our interviewees, the impacts of these illnesses go beyond physical discomforts and difficulties of the disease: They can put a strain on family, friends, and wider social networks, often through illness-related stigma, prolonged reduction of social activities, and a stranglehold on financial resources because of additional expenditures (and often reduced income). Many of the patients also reported a substantial impact of the disease on their overall emotional well-being and self-worth. This is especially relevant in the absence of successful treatment (access), when physical symptoms of illness are the most pronounced. With regard to access and specifically to the acceptability of services, as some of the presented narratives show, treatment is likely more successful if providers actively engage and reach out to patients (Bissel, May, & Noyce, 2004, in a UK context). Although a patient-centered approach was envisaged from the outset by post-apartheid health policy (see, for example, the patients’ rights’ charter and Batho Pele [People First Principles]), the implementation of this approach—as many other stories here suggest—remains challenging (Hull, 2012; Nkosi, Govender, Erasmus, & Gilson, 2008). However, present reengineering of primary care and piloting of a national health insurance system in South Africa offer an opportunity to revisit patient–provider relationships (see Pillay et al., 2012; Republic of South Africa, 2011), and we assert that there is a need for providers to connect from the immediacy of the treatment environment to the patients’ wider context and healthworld, thereby recognizing their humanity. As our findings show, this active engagement must occur during diagnosis and treatment initiation and maintenance—along all dimensions of pathways of care.

The narratives also show that patients’ precarious living conditions in combination with an often rigidly implemented diagnosis and treatment approach (e.g., no flexibility in collection or appointment times, sole reliance on test results) fairly frequently interrupt, at least temporarily, access to services, and thus directly impact on long-term treatment success. We note that these forces affect all patients but suggest that future research should examine narratives in gendered or class-based ways. The anecdotal evidence of a successful communication-centered approach to patient–provider interaction—applied by some health care providers (in some facilities)—not only supports arguments for a change in provider practice but also highlights existing dangers in the more common authoritarian/hierarchical approach to health care provision. A patronizing health care system (or even a single provider), which imagines the patients in a subservient and unsympathetic light, can undermine patients’ agency and thus fuel mistrust in the suitability and fit of offered health care, leading to a reduction in service acceptability. In contrast, ensuring acceptability has the potential to transfer relations between provider and patient from disenchantment to reconstructed trust, an important way forward for appropriate treatment in South Africa (Gilson, Palmer, & Schneider, 2005). Without this trust, patients may expand their search for health and well-being by reaching out to alternatives, often offered through competing healthworlds at the family, social, and cultural nexus. Especially, but not only, in the studied rural area, religious, traditional, and biomedical spheres intersect and merge frequently, creating a potpourri of health-seeking alternatives (see Fried et al., 2012; Moshabela et al., 2011, 2012). Although these might seem at odds with a narrow biomedical perspective (and might undermine related therapies), they are holistically integrated into a patient’s healthworld, and socially shared, lending collective wisdom to individual actions, including responses to the health system (Germond & Cochrane, 2010). Hence, we encourage the acknowledgment of traditional medicine, closely linked to spiritual beliefs and practices, as a relevant health-seeking behavior with its own specific healthworlds (see King, 2012). We propose an appropriate inclusion of traditional healers as key parts of healthworlds for education and counseling, as has happened with diabetes (see Mbeh et al., 2010).

In many respects, our findings confirm previous research on treatment challenges in resource-constrained settings (e.g., Kagee et al., 2011; Mukherjee, Ivers, Leandre, Farmer, & Behforouz, 2006), though by invoking life circumstances and patient perceptions of the health system, for the first time we place not only healthworlds at the center of attention but also how these shape access to care through a complex set of pathways within difficult life conditions and community constructions. As Coovadia et al. (2009) noted, South Africa’s history with

its discrimination, income inequalities, the destruction of family life, and persistent violence consolidated by apartheid in the 20th century has affected not only life circumstances and resource availability but also policy choice and direction, as shown specifically by the Mbeki-era debates about the causes of and responses to HIV/AIDS (see also Mayosi et al., 2012). This history shapes individual healthworlds and the access to treatment. Our findings portray the cries of patients through their experiences. Although formulated in early postapartheid policies, acceptability is back on the policy agenda and is slowly being put into practice through patient rights, advocacy, and integrated care (Pillay et al., 2012).

Our findings also reveal the determinants that continue to influence lives, setting parameters of historical, social, and political spaces in which people navigate, imagine, create, sometimes challenge their own understandings and explorations of illness and access, and decide whether they trust, are disenchanted by, or find ways to work with health care providers. Thus, in the delivery and reform of primary care treatment of chronic illnesses, policy makers must continue to clearly acknowledge that people construct their experience of illness. Accordingly, how treatment is provided plays a crucial role in shaping such constructions. These constructions, in turn, influence experiences and acceptability of health care. Policy is interpreted and practiced in health care settings not only by providers but by the users of the system, too, who appropriate and apply (parts of) it to support their healthworld. We assert that some way must be found to involve these sick and poor individuals in health care reforms, a challenging task as debate and communicative action is not in the forefront of hungry, exhausted people. Nonetheless, understanding patient pathways to care, including their interruptions, is vital. In many ways, our interviewee's narrative of a nurse who accepted traditional and biomedical treatments is indicative of the importance of acknowledging complex patient healthworlds.

In addition, the wider context cannot be ignored by health policy makers and practitioners: Acknowledging and addressing the social determinants of health might permit life circumstances to be shifted and enable easier access and adherence to care. This is because social determinants, including health policy itself, provide the space for the construction of illness and access. At the same time, the acceptability of services plays a pivotal role in influencing the ways that patients access care and whether they persist with such access. With chronic illnesses such as HIV and TB, requiring regular and ongoing interactions with the health system, it is crucial to make the system as acceptable to patients as possible. Acceptability, while perhaps subject to localized conditions and interpretations, must be broadly characterized by respectful

interactions (Gilson, 2007). "Communicative action" (Habermas, 1987, cited in Germond & Cochrane, 2010) that fosters individual agency while respecting patients' collectively mediated healthworlds is required from individual providers and at a health system level. Thus, addressing the sometimes patronizing approach to treatment provision and appreciating the importance of a communicative rationality that gives greater emphasis to nurse/doctor-patient dialogue around "illness" is vital. We reemphasize, what is being accessed is treatment not just for a disease but for an illness, located in a healthworld as well as a body—difficult but not impossible for nuanced policy development and practice.

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