

"I did not see a need to get tested before, everything was going well with my health": a qualitative study of HIV-testing decision-making in KwaZulu-Natal, South Africa

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ABSTRACT

Few studies have examined HIV-testing decision-making since the South African national HIV counseling and testing campaign in 2010-2011 and subsequent expansion in antiretroviral therapy (ART) eligibility in 2012. We describe HIV-testing decision-making and pathways to testing among participants in *Pathways to Care*, a cohort study of newly-diagnosed HIV-positive adults in KwaZulu-Natal. Our analysis is embedded within a theoretical framework informed by Arthur Kleinman's work on pluralistic healthcare systems, and the concept of *diagnostic itineraries* (i.e. the route taken to HIV testing). We conducted 26 semi-structured interviews in 2012, within one month of participants' diagnosis. Most (n=22) deferred testing until they had developed symptoms, and then often sought recourse in non-biomedical settings. Of the eleven symptomatic participants who accessed professional medical services prior to testing, only three reported that a healthcare professional had offered or recommended an HIV test. Although ART emerged as an important motivator, offering hope of health and normalcy, fear of death and HIV-related stigma remained key barriers. Despite national policy changes in testing and treatment, health system and individual factors contributed to ongoing high levels of late diagnosis of HIV in this study population. Encouraging local health systems to direct clients toward HIV testing, and continuing to raise awareness of the benefits of routine testing remain important strategies to reduce delayed diagnoses.

INTRODUCTION

The expansion of HIV testing is a core component of UNAIDS' 90-90-90 strategy to establish the majority of those living with HIV on successful antiretroviral therapy (ART) (UNAIDS, 2014), with current World Health Organization (WHO) guidelines recommending initiation of ART at diagnosis regardless of CD4 count (World Health Organisation, 2015). However, only modest increases in CD4 count at diagnosis and/or presentation to care have been achieved in sub-Saharan Africa in recent years, with most studies reporting a median CD4 count ≤ 350 cells/ μL among people newly-diagnosed with HIV or presenting for care (Hoffman et al., 2014; Lahuerta et al., 2014; Lesko, Cole, Zinski, Poole, & Mugavero, 2013; Siedner et al., 2015). In KwaZulu-Natal, South Africa (site of this study), HIV prevalence is 17.4% (Shisana et al., 2014). Late HIV diagnosis continues to be a challenge, with a 2010-11 study in Durban reporting a median CD4 count at diagnosis of 186 cells/ μL (Drain et al., 2013).

In 2010 the South African government launched a national HIV counseling and testing (HCT) campaign that included mass media, opt-out provider-initiated HIV testing, and expanded access to testing outside of public clinics (South African National AIDS Council (SANAC), 2010). According to government estimates, 13 million of the targeted 15 million people were tested by April 2011 (Mbengashe, 2012). Nevertheless, 2012 data revealed that over 40% of men and nearly 30% of women had never undergone HIV testing (Maughan-Brown, Lloyd, Bor, & Venkataramani, 2016; Shisana et al., 2014), although there was an increase in self-reported testing between 2010 and 2012 (Maughan-Brown et al., 2016).

Qualitative studies of HIV testing in KwaZulu-Natal have highlighted the role of stigma, low HIV risk perception, and uncertainty about ART eligibility in explaining delay, and the importance of accessing ART in encouraging people to test (Daftary, Padayatchi, & Padilla, 2007; Ntsepe et al., 2014; Phakathi, Van Rooyen, Fritz, & Richter, 2011; Strauss, Rhodes, & George, 2015). To our knowledge, only one qualitative study of HIV-testing behavior has been conducted since the HCT campaign, a few months after its launch (Ntsepe et al., 2014). In this paper we explore the decision-making process around HIV testing and describe pathways to testing (*diagnostic itineraries*) among adults newly-diagnosed with HIV in KwaZulu-Natal in 2012.

METHODS

Conceptual framework

Individuals' decisions about health are embedded within relationships with family, peers and the wider community. We draw upon Kleinman's work on medical systems as cultural systems (Kleinman, 1978) to understand the complex local "healthcare system" (comprising the professional, popular and folk sectors) in which individuals make decisions about their health. The presence of multiple sectors in which people seek healthcare (and may move between) is known as *medical pluralism*.

We use the term *diagnostic itinerary* to describe the route an individual takes through the local healthcare system before undergoing an HIV test, drawing from

work on *therapeutic itineraries* (Kibadi et al., 2009; Smith & Mbakwem, 2007), which explores the paths individuals follow to manage illness. This approach, which allows us to map the varied, and sometimes complex, journeys individuals make within local healthcare systems in pursuit of a diagnosis, can yield important insights into healthcare utilization, and the strengths and weaknesses within existing local systems (Moshabela, Pronyk, Williams, Schneider, & Lurie, 2011).

Participants and Data

Data were drawn from 26 semi-structured (qualitative) interviews (SSIs) (13 women, 13 men), who comprised a sub-sample of participants in *Pathways to Engagement in HIV Care for Newly-Diagnosed South Africans*. This prospective cohort study recruited 459 newly-diagnosed HIV-positive women and men from three comprehensive public primary healthcare clinics (PHC) in the eThekweni district (Durban metropolitan region) of KwaZulu-Natal, South Africa. All three clinics (one rural, and two urban - in a former black middle class township and in a small town outside Durban) provided a range of primary healthcare services and ART treatment in addition to HCT. Eligible participants for the cohort study were aged 18 years or older, not referred from antenatal services and not previously diagnosed with HIV. Those who tested HIV-positive on the day of recruitment and underwent a structured baseline assessment within 30 days of their diagnosis were enrolled in the cohort study. Detailed study procedures are described elsewhere (Hoffman et al., 2016).

Participants for serial SSIs were recruited in April and May 2012 from among those enrolling in the cohort. National guidelines at the time defined ART eligibility as WHO Stage 4 disease, CD4 \leq 200 cells/ μ L, drug resistant tuberculosis, or CD4 \leq 350 cells/ μ L if pregnant or diagnosed with tuberculosis (National Department of Health Republic of South Africa, 2010). The SSI sub-sample was purposively selected, with a target of 10 participants from each of the three study clinics, equally divided between women and men. We obtained demographic characteristics and participant CD4 count following diagnosis from the structured assessments.

Qualitative data collection

Experienced interviewers conducted SSIs at a study site near the recruitment clinic after participants completed the structured assessment. Interviews were conducted in isiZulu, digitally audio-recorded, and later translated and transcribed verbatim into English by native isiZulu speakers. The 45-minute baseline SSI was organized around five topic areas: pathways to diagnosis, current care- and support-seeking, sexual behavior and fertility intentions, disclosure of HIV-status and management of stigma, and psychological well-being and coping.

Qualitative data analysis

Interview transcripts were analyzed in NVivo 9.0 (QSR International, 2010). Data were reduced by extracting transcript sections that included reference to HIV testing. The first author undertook a thematic analysis of the reduced data, following grounded theory principles (Pope, Ziebland, & Mays, 2000). Interview extracts were initially open-coded inductively. Coded text was then compared across interviews to

develop broader analytic categories and link core themes. The initial codebook was developed by the first author (ST) in discussion with a co-author (SH), who also coded five interviews. Coding discrepancies were discussed until consensus was reached, and the codebook modified as appropriate. The first author conducted the final coding.

Ethical approval

Written informed consent was obtained from participants before conducting SSIs. Participants were reimbursed R75 (approximately \$10 at the time). Procedures were approved by the Institutional Review Board of the New York State Psychiatric Institute/Department of Psychiatry, Columbia University and the Biomedical Research Ethics Committee of the University of KwaZulu-Natal. Approval was also granted by the KwaZulu-Natal Department of Health district- and clinic-level administrators.

RESULTS

Participant characteristics

A comparison of the SSI subsample of 26 participants (13 men, 13 women) and the full cohort is shown in Table 1. Within gender, characteristics were similar between the two. Overall, the median age of SSI participants was 28 years (range: 20-52 years) (data not shown). Late diagnosis of HIV was common, with seven (41%) reporting a CD4 count at diagnosis below the threshold of ART initiation in South Africa at that time (≤ 200 cells/ μ l).

In the following sections, we refer to illustrative quotes (Box 1) from interviews by number and letter (in parentheses).

Diagnostic itineraries

The majority of participants (n=19) reported that their most recent HIV test—at which they were diagnosed with HIV—was their first ever test. This was the case for all men, whereas just over half of women (n=7) reported having had a previous HIV test (all negative), one during pregnancy.

All participants identified a precipitating factor in their decision to test. A minority (n=4) were asymptomatic, reporting that their decision was prompted by a new sexual relationship. Others talked about witnessing the effects of HIV among friends and family, or receiving encouragement by friends who had tested HIV-positive (Box 1, 1a).

In Figure 1 we reconstruct participants' diagnostic itineraries from accounts given in SSIs. The four asymptomatic participants all reported going directly to their primary healthcare clinic (PHC) for HIV testing.

Many participants described the importance of “knowing your status,” echoing public health discourse on HIV testing. However, there was often a discrepancy between reported belief in the importance of “knowing your status” and individual testing behavior. The overwhelming majority (n=22) experienced symptoms prior to their HIV-positive diagnosis, describing this as the impetus to test (Box 1,1b).

Participants most commonly reported headaches, weight loss, sweats and

gastrointestinal symptoms, all of which could indicate HIV-related illness. Of the 22 who were symptomatic prior to their HIV-positive diagnosis, only three (all male) went directly to their PHC for HIV testing (figure 1). The remaining 19 described complex journeys through the pluralistic local healthcare system.

Drawing upon Kleinman's model of "healthcare systems" (1978), we identified four sectors in which participants sought diagnostic recourse. We recognize that there is pluralism *within* each of these healthcare sectors, and therefore use these broad categories heuristically. The professional sector, comprising private and public sector healthcare facilities, was the most commonly accessed source of healthcare, followed by the popular sector, encompassing local chemists--some of which offered herbal treatments--and self-treatment with over-the-counter and home remedies. Some participants described seeking diagnostic or therapeutic guidance from family members, which we categorized separately due to its prevalence. Although participants described the presence of traditional healers and churches, only two described seeking help within the folk sector (Box, 1c). One consulted a family member who was an *isangoma* (Zulu traditional healer who practices divination) with no success, having experienced no improvement in symptoms after attending his local PHC. The other sought advice about unexplained weight loss from her pastor's wife, who encouraged her to test for HIV.

Many interviewees described a process characterized by trial and error, in which they attempted to seek a resolution to their symptoms in one healthcare sector. When this failed and symptoms persisted, they either attended their PHC for an HIV

test or attended a second service in a different sector. All participants described attending a PHC for an HIV test by their third healthcare sector contact; however, for many, their trajectory had delayed HIV testing.

Of note, eleven participants accessed a service in the professional sector with symptoms (many indicative of HIV), but only three reported being offered or advised HIV testing by healthcare professionals. For example, one participant described recurrent episodes of sexually transmitted infection for which he had been treated at a local clinic, reportedly never being offered an HIV test (Box 1, 1d).

Other barriers to testing

As we have already highlighted, the overwhelming majority of participants deferred HIV testing until they had physical symptoms. There was a widespread belief among participants that there was no need to test for HIV if they were well (Box 1, 2a.i and 2a.ii). The close coupling of HIV with both symptomatic disease and high-risk sexual behaviors contributed to a reluctance to acknowledge HIV risk (Box 1, 2b). Once ill, participants pursued multiple therapeutic approaches as discussed previously, with only a minority (n=3) immediately seeking an HIV test. For five participants, these delays in HIV testing may have reflected poor knowledge about HIV within their wider communities (Box 1, 2c).

Another important barrier to testing was fear, with 8 of the 19 participants who had never tested before describing fear as the main reason for delaying. Participants feared both physical and social consequences of an HIV diagnosis, with many

commenting upon the enduring association between HIV and death. Participants' accounts demonstrated that although HIV-related stigma had declined, it remained widespread within their communities. HIV was still seen as a “disgrace,” and participants feared that disclosure of their status would lead to gossip and discrimination, further discouraging them from testing (Box 1, 2d).

Facilitators of testing

Sharing a decision to test within an intimate relationship or receiving encouragement from family members were identified as important catalysts in HIV-testing (Box 1, 3a.i). Although opportunities to suggest HIV testing were sometimes missed within healthcare settings, when healthcare professionals *did* advise testing this was also a major impetus (Box 1, 3a.ii). Furthermore, having made the decision to test, participants found encouragement and reassurance from staff performing pre-test counselling to be important in motivating them to proceed.

Less than half (n=12) of participants reported awareness of the 2010 HCT campaign. In general, men more commonly than women cited the campaign (including President Zuma's well-publicized HIV test) and other media representations of HIV as a motivating factor (Box 1, 3b).

By far the most commonly cited motivation to test for HIV was the knowledge that ART was widely and freely available. Twenty-one participants stated that knowing that they could access ART if needed influenced their decision to test (Box 1, 3c).

Despite participants' concerns about potential side effects, the increasing visibility of

ART within communities had fostered optimism. Witnessing ART's capacity to preserve health served as a powerful demonstration of the importance of testing and accessing treatment. The tangible power of ART to restore normalcy was therefore a critical lever in decisions to test for HIV (Box 1, 3d).

DISCUSSION

Our analysis revealed that the overwhelming majority of participants deferred testing until they became symptomatic, many with symptoms that were indicative of HIV and with CD4 counts below the treatment threshold at the time. Delaying HIV-testing until symptomatic is well-reported in the literature from sub-Saharan Africa, including South Africa (Daftary et al., 2007; Meiberg, Bos, Onya, & Schaalma, 2008; Musheke et al., 2013). What is particularly concerning about the delays in testing reported here is that data were collected *after* a population-level campaign to encourage HIV-testing.

By utilizing the concept of *diagnostic itineraries*, we have demonstrated that symptomatic participants sought diagnostic recourse in a variety of arenas within a pluralistic healthcare system. This “therapeutic eclecticism” (Scorgie, 2007), common in many settings, has been well-described among patients living with HIV in South Africa (Moshabela et al., 2011; Scorgie, 2007), reflecting historical processes and “local logics” about health (Scorgie, 2007). However, this eclecticism often resulted in delayed diagnosis of HIV, something described in one of the only other studies to map pathways to HIV care in South Africa, conducted in 2006-2007 in rural Mpumalaanga (Moshabela et al., 2011).

Also similar to findings in the Mpumalaanga study, use of the folk sector was rarely reported. Instead, participants mainly drew upon the professional sector when ill. However, despite the predominance of the professional sector in our study, only a small proportion of initial contacts with clinics and hospitals resulted in an HIV test. Many participants stated the importance of “knowing your status,” echoing the broader discourse of public health messages about HIV testing. Conversely, reluctance to test for HIV remained relatively common, revealing a discrepancy between beliefs about HIV testing and testing behaviors. We identified significant barriers to testing such as low perception of HIV risk and fears about an HIV-positive diagnosis in the physical, psychological, and social domains. This includes the enduring association between HIV and death, and anticipated HIV-related stigma and discrimination, even in the context of increasing availability of ART.

Despite these fears, the increasing availability of ART and its potential to restore health and normalcy emerged as an important motivating factor to seek HIV testing. The optimism fostered by ART roll-out across sub-Saharan Africa is acknowledged as an important lever in HIV testing throughout the region (Balcha, Jeppsson, & Bekele, 2011; Daftary et al., 2007; Jurgensen, Tuba, Fylkesnes, & Blystad, 2012; Ntsepe et al., 2014; Phakathi et al., 2011; Roura et al., 2009). Furthermore, support and encouragement to test by family, peers and healthcare professionals (once a test had been proposed) was invaluable.

This study focuses on patients attending primary healthcare clinics in KwaZulu-Natal, who by definition have accessed testing services within the professional healthcare sector. This may explain in part why structural factors such as transport, travel time, and work-related responsibilities did not emerge as important testing barriers; the study may therefore not reflect the experiences of those who have limited access to the professional healthcare sector, or indeed those who prefer to seek help within other healthcare sectors. Diagnostic itineraries were recalled retrospectively, which may have led to some inaccuracies, although this is likely to have been mitigated by interviewing all participants within 30 days of their first HIV-positive test. Another limitation is that we were unable to quantify delays in testing due to lack of data on timescales.

However, we present one of few qualitative studies of individuals' HIV-testing decision-making since the 2010-2011 South African HCT campaign. Although there has been continued innovation in HIV testing in the region and further expansion of ART eligibility, this study provides insights into contextual factors that shape HIV-testing decision-making. This is especially pertinent at this critical juncture in the South African response to the HIV epidemic with the implementation of universal testing and treatment (UTT).

Our findings of barriers to testing at both an individual and community level have been borne out by more recent qualitative data from a test and treat trial in Eastern Africa (Camlin et al., 2016). Consequently, multi-level approaches to HIV testing such as a recently-reported mobile and home-based testing campaign focusing on a

variety of medical conditions (Chamie et al., 2016), as well as mass media campaigns, community-based testing, and self-testing (Bolszewicz, Vallely, Debattista, Whittaker, & Fitzgerald, 2014; Hensen, Taoka, Lewis, Weiss, & Hargreaves, 2014; Musheke et al., 2013; Sharma, Ying, Tarr, & Barnabas, 2015) are likely to be most effective. Furthermore, efforts to normalize testing must directly address the widespread belief that HIV testing is only indicated when symptomatic.

Importantly, our study revealed missed opportunities for HIV testing within hospitals and clinics, highlighting the importance of developing interventions to support the national policy of provider-initiated testing. Finally, providers outside the professional sector, such as local chemists (who were the second most commonly-accessed service in our study), may be an under-utilized resource to promote HCT, and continued efforts to engage these practitioners may reduce late diagnosis of HIV (George, Chitindingu, & Gow, 2013; Moshabela et al., 2016).

In conclusion, we have demonstrated that despite a high profile national HIV testing campaign, delayed HIV testing in KwaZulu-Natal remained common. Testing delays were due to a complex interplay between medical pluralism, low perception of HIV risk, fears about a positive diagnosis, and persistent concerns about HIV-related stigma and discrimination. Continued implementation of multi-level interventions to facilitate early and routine HIV testing is of utmost importance in this area of high HIV prevalence and late diagnosis, especially in an era of UTT. Without this, HIV testing will remain a diagnostic tool rather than a tool for prevention.

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Conflicts of interest

We declare that there are no conflicts of interest.

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