Published in final edited form as:

Psychol Men Masc. 2016 July ; 17(3): 265–273. doi:10.1037/men0000025.

“If you don’t take a stand for your life, who will help you?”: Men’s engagement in HIV care in KwaZulu-Natal, South Africa

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Abstract

The needs of South African men with HIV may often be overlooked in the provision of HIV services, leading to care programs that do not adequately serve the unique needs of male patients. Additionally, norms of masculinity guide men’s behaviors as they navigate health decision-making and the healthcare systems. The aim of this study is to examine how masculinity influences healthcare access and utilization in South Africa, and to identify opportunities for interventions. The qualitative study took place at one primary health care clinic in a peri-urban township in KwaZulu-Natal, South Africa. In-depth individual interviews were conducted with 21 HIV-infected men recruited from the study clinic. Direct observations of the clinic waiting area were conducted to provide context. Data were analyzed using a grounded theory-informed approach involving memo writing and thematic exploration with data coding. On average, participants were 42 years old and had been on ART for 3.6 years. Participants expressed a range of ways in which masculine ideals and identity both promoted and inhibited their willingness and ability to engage in HIV care. Notions of masculinity and social identity were often directly tied to behaviors influencing care engagement. Such engagement fostered the reshaping of identity around a novel sense of clinic advocacy in the face of HIV. Our findings suggested that masculinities are complex, and are subject to changes and reprioritization in the context of HIV. Interventions focusing on reframing hegemonic masculinities and initiating treatment early may have success in bringing more men to the clinic.

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Keywords

Health care; HIV; South Africa; male experience; health outcomes

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Introduction

South Africa faces great pressure to respond to the HIV epidemic. With 6 million HIV infected individuals, it carries the largest burden of HIV of any country in the world (UNAIDS, 2013). Given that 60% of South Africa's HIV infections are among women (Shisana et al., 2014), HIV in South Africa has often been framed as a “female epidemic.” The result is a potential for the needs of South African men living with HIV to be overlooked, which may contribute in part to worse outcomes among men living with HIV. Following the scale-up of antiretroviral therapy (ART) in South Africa in 2004, the HIV mortality ratio of women-to-men declined from approximately equal (1.05) to disproportionately male (0.75) by 2011 (Barnighausen, Herbst, Tanser, Newell, & Bor, 2014). Further, while life expectancy increased for both sexes after ART scale-up, the gap in life expectancy between men and women doubled from 2004 to 2011 (with men bearing the lower end). This occurred in tandem with the fact that 57% of male HIV deaths were among men who never sought care for HIV, compared with 41% of female deaths (Barnighausen et al., 2014). The observed gender disparity in HIV outcomes raises important questions about how men who are infected with HIV are able to engage with HIV care in South Africa.

Many factors lead to the disparities in HIV outcomes between men and women in South Africa. South African men access healthcare services less often than women, which has been speculated to have implications for utilization of HIV services, including antiretroviral therapy (ART) (Braitstein et al., 2008; Muula et al., 2007; Nattrass, 2008). South African women utilize ART at a rate between 1.5–2.3 times greater than men, a phenomenon not explained solely by the gender distribution of the disease (Braitstein et al., 2008; Muula et al., 2007). This usage gap is not surprising, given South Africa's focus on HIV testing during antenatal care (Hasnain, 2004), a common path of identifying HIV cases among women that does not have a male equivalent. In addition, a higher percentage of South African men are employed than women, and often in migratory work (Lurie et al., 2003; Statistics South Africa, 2012b). Difficulties in scheduling and losses in income may arise for men who seek to remain employed full-time and simultaneously engage fruitfully in an ART regimen (Abdool Karim, Churchyard, Abdool Karim, & Lawn, 2009; Kuwane, Appiah, Felix, Grant, & Churchyard, 2009; Mills, Ford, & Mugenyi, 2009).

The observed gender gap in treatment seeking behavior, both generally and specifically to HIV treatment, has been linked in part to the elusive “masculinity factor” (Nattrass, 2008). The catch-all term ignores the many different forms of masculinity that exist in men's lives. Reawyn Connell (1995) most famously identified a set of patterns of masculinity by their places in social power structures that better encapsulate the idea of “multiple masculinities” competing for men's social formations – hegemonic, complicit, subordinate, and marginal masculinities. Hegemonic masculinity is a role occupied by the form of masculinity that is presently culturally promoted by the status quo (of patriarchy in particular). Complicit

In order to optimally meet the needs of HIV-infected men in South Africa, more research is needed on how masculinity affects the ways in which men engage with HIV care, and how masculinity may create challenges and opportunities for HIV care engagement. This is particularly true in rural KwaZulu-Natal, where the adult HIV prevalence rate (30.1%) is among the highest in the country (Shisana et al., 2014). Given the breadth of theoretical applications of the interplay of masculinity and healthcare, and the importance of culturally contextualizing findings, this study seeks to provide new insight on which components of masculinity may come into play in the process of HIV care engagement in KwaZulu-Natal. Therefore, the objective of this study is to qualitatively examine the experience of men's HIV journeys in KwaZulu-Natal, with a particular focus on the ways masculinity shapes those journeys.

Methods

Setting

This study took place in the Umdoni municipality of the Ugu district of KwaZulu-Natal, South Africa. According to the 2011 census, about one third of residents of Umdoni municipality were unemployed (Statistics South Africa, 2012a); agriculture is the largest employment sector. English and isiZulu are the main languages spoken, though a subset of isiXhosa speakers is also present. One-third of the men living in Umdoni at the time of the census had some secondary education, with other levels of education varying more widely. The average annual income of all of those living in Umdoni at that time was 73,147 South African Rand (approximately \$10,000 USD).

The study site was a primary health care clinic, which was identified through discussions with the KwaZulu-Natal Department of Health. The clinic was selected based on its location and the large HIV patient load. The clinic is made up of separate outpatient, dental, antenatal, and HIV/TB wings. The HIV wing distributes ART to over 200 patients per day from Monday through Thursday. The HIV patient population is predominantly Black African and speak isiZulu.

Data Collection

The data collection team included one white non-South African man (author SZ) and two South Africans (one Black African man and one Black African woman). Both South Africans were fluent in isiZulu. All three individuals conducted the interviews and observations. All team members had at least some post-secondary training; two team members had previous qualitative research experience and some post-graduate research training. The team frequently met to debrief, review the data, and make changes to the guides in an iterative fashion.

The research team conducted in-depth interviews at the study site over six weeks in July and August 2014. Patients were eligible to participate if they were male, over the age of 18, had been diagnosed with HIV, and were at the clinic at the time to collect ART for themselves. Participants were recruited during the morning hours of the clinic each weekday while the researchers were present. Patients were identified and approached at the HIV clinic with the

help of an HIV clinic nurse. Every male patient in attendance was approached by the nurse; however, due to the small size of the clinic and the disproportionate number of female attendees, this number was very small (on average ten men per day) and many declined to participate. During the patient's appointment to receive ART, the HIV nurse explained the study and asked if he was interested in speaking with the fieldwork team about participating in the study. Eligible patients who were interested in participating in the study then met with the fieldwork team in a private room at the clinic, where they explained the study in detail and obtained informed consent.

All individual interviews were conducted by at least two members of the fieldwork team in isiZulu, and took place in a private room at the study clinic. With permission from each participant, interviews were audio-recorded, and later simultaneously translated and transcribed into English. Though the interviews were conducted at the clinic, the data collection team explained extensively that the study was in no way associated with the clinic, nor would participation affect their care and treatment at the clinic. Each participant received 50 South African Rand (approximately \$5 USD). Table 1 displays a summary of the interview guide.

The research team also conducted direct observations of the HIV clinic waiting area over three weeks during July 2014. Each week they visited the waiting area for blocks of one to two hours at a variety of times (earlier versus later in the day), days (earlier versus later in the week), and occasions (to observe physicians who rotated among several clinics and visited the clinic for one day of the week). During direct observations, the fieldworkers used a field observation guide to take in-depth notes about the physical environment, patient flow, and social interactions amongst patients and between patients and clinic staff. These notes were transcribed as fieldwork notes.

Data Analysis

An approach informed by grounded theory was used to analyze the qualitative data. Techniques fundamental to grounded theory analysis were selectively applied to the data in ways that were most functional for the needs of this study, a common practice among qualitative research (see Bulawa, 2014). Grounded theory is a technique for thorough analysis of qualitative data; it remains rooted in the data and allows the data to "speak" for themselves, guiding the analysis (Charmaz, 2006). Theoretical sampling was employed by recruiting men specifically for their expertise on the research question through their lived experiences; this process continued until theoretical saturation was reached, noted by the continued collection of data until the data gained from each interview became repetitive and added no new insights (Bulawa, 2014). Each interview transcript was synthesized by writing a brief memo by reading interview transcripts multiple times line-by-line, serving as a means of open coding by grouping each part of the interview according to its meaning. Constant comparison of each incident was also used here by comparing each incidence of the interview to each developing code, to other incidences in the same interview, and to incidents in all other interviews. Memos were discussed between authors SZ and MW, and compared to their original transcripts to ensure that the memos remained grounded in the original data and retained the participants' own words in a consistent manner that was

reliable across both researchers. Memos were then imported into NVivo (version 10), a qualitative data analysis software package, to axially code the themes in the data around the categories that emerged during memo synthesis.

Ethical Considerations

Ethical approval for this project was obtained from the ethical review boards at Duke University's Office of Research Support and the University of KwaZulu-Natal's Biomedical Research Ethics Committee. Local approval was also given by Ugu Health District Office of the KwaZulu-Natal Department of Health. Written consent was obtained from each participant both to conduct and to audio-record each interview. Data were de-identified to protect participant confidentiality. The data collection team, including the HIV nurse, extensively described the voluntary nature of the project to each potential participant to avoid coercion into the project.

Results

The participants offered varied experiences of HIV care engagement, their senses of masculinity, and the ways in which these were linked. Overall, a series of beliefs and experiences consistent across the sample emerged to give insight into the HIV journey of a man in this setting. The data revealed three main stages of this journey, each one connected to unique values of masculinity: 1) delayed HIV testing and linkage to care; 2) motivators and challenges for continuous care engagement; and 3) advocacy and long-term perspectives beyond care engagement.

Description of Participants

The interview sample included 21 men who regularly attended the study clinic to receive ART to manage their HIV (Table 2). All participants were Black African and fluently spoke isiZulu. Although 5 participants spoke isiXhosa as their first language, they were able to complete the entire interview in isiZulu. The ages of participants ranged from 24 to 80 years, with an average age of 42 (median age 39). Just over half (11/21) of participants were married and slightly more (13/21) had at least one child; most men (17/21) were currently in a romantic relationship of some kind. A majority of participants (17/21) were formally employed in either part-time or full-time positions. Most working participants were employed by farms, though others worked in security or in factories. The participants had known their status for an average of 4.5 years, and had been on ART for an average of 3.6 years; most participants (18/21) started ART within one month of diagnosis.

Delayed HIV Testing and Linkage to Care

Though some participants reported histories of frequent (every three to six months) HIV testing, most had delayed testing – 15/21 had never tested before some life event pushed them to the test that would diagnose them. Even upon the experience of symptoms, several participants said that they suspected HIV, but they rationalized and dealt with these symptoms in ways that did not involve HIV testing. This willingness to defer testing is related to the degree to which men can continue to function and carry out their everyday activities. One participant, a 43-year-old on ART for less than 1 year, reflected the

importance of functioning: “It hurts for a man to not be able to do the things he once did.” If a man still has the ability to fulfill his role as a provider for himself and those around him, it is assumed that he should carry on doing so, and not disrupt his pathway with something as life-altering as an HIV diagnosis.

A man’s role in his family can also serve as a barrier to HIV testing or linking to care. When asked what it meant to be a “real man,” the participants almost unanimously defined it as “building your own home and building your own family.” They said that a man must be married “with kids and a house.” HIV was seen as an inhibitor to achieving these crucial goals. The participants first noted that HIV creates a barrier to pursuing women who may be potential wives: “Women don’t want to associate with someone who has HIV.” Participants described difficulties in finding partners with whom they can be open about their HIV status. The participants expressed that in addition to having a wife, having children is critical in establishing respect as a man. One participant, a 30-year-old on ART for 8 years, stated, “You’re not a real man when you don’t have a baby.” The complications for fatherhood arising from HIV can pose a great threat to men’s identity; as one participant summarized this theme:

The most painful part about [being diagnosed]...was that since I don’t have a kid, that I will never have a kid in my life ever. So that was very painful. And for being the person that I was in the community, there was that thing that [then] people might not welcome me, might not look at me the same way they used to.

– 32-year-old participant on ART for 2 years.

Anticipation of the potential impact of an HIV diagnosis on one’s role in the family served as an important barrier to learning one’s status.

Due to delayed testing and linkage to care, men often had very advanced disease progression at by the time they finally got diagnosed, as indicated by the fact that the majority of participants (18/21) initiated ART immediately upon diagnosis. Participants often discussed using traditional medicine as a means of treating symptoms instead of clinics. In retrospect, participants related using traditional medicine to a strategy of avoiding the clinic, as they said the healers do not “ask you a lot of questions...they will just mix the medicine for you.” The use of traditional medicine was linked directly to what it means to “be a man” by participants; the sentiments that “men do not go to clinics,” yet “the first thing a man does when he gets ill is run to [traditional healers] to be healed,” were reiterated by most participants. One participant exemplified this theme as such:

My knowledge is that when you are a man, the first thing you need to do when you get sick is to go for traditional healing. ...Before, when I caught flu, the first thing that I would think about doing was to go and look for traditional medicine. That’s the kind of life that most real men live. I’ve stopped doing that, but I still feel there are people who are still doing it.

– 33-year-old participant on ART for 3 years.

Seeking out traditional medicine thus was an expression of one's masculine identity, and also an attempt to receive some care in a context in which they find clinics unwelcoming to men.

Motivators and Challenges for Continuous Care Engagement

Men who make it through the complex social web around testing for HIV and linking to care encounter a new set of factors that either encourage or impede care engagement.

Engagement requires attending the clinic once per month to collect ART, and taking one ART pill once per day. The participants all reported that they adhered to this schedule fairly well. No participants mentioned problems in remembering to take the medication daily. When asked if they had ever missed a monthly appointment to refill their ART, only a small number of participants said yes, but they explained that if they missed the appointment they would either come to the clinic the next day or send someone that day in their place.

One major source of motivation to remain engaged in care can be traced to the strength of the client's support network, which was often fostered by the social expectations placed on men. The participants' networks took on a variety of forms – family members, romantic partners, close friends, employers or coworkers, clinic staff, or other clinic patients. Nearly all participants also described knowing of and admiring men in the community who had been on ART for some time and living healthy, normal lives. Maintaining a presence in the community and being known by others in the community is, for the participants, integral to the idea of being respected within the community as a man. For instance, one participant, a 33-year-old on ART for 3 years, described how “a man...should be someone who gets out to meet his neighbors, talk to his neighbors... He should be there with other people.” Another participant said that spending time with family (who knew his HIV status) was crucial for the family respecting him as a man and vice-versa:

When I came back from work, I would sit with my family and talk to them to understand how the day was, to treat them well and with respect. Then I was respected back as well. Those are the teachings you should give to your child if you want him to be a real man.

– 57-year old participant on ART for 6 years.

This quote was representative of values expressed by many other participants as well. It is thus highly expected of men to garner a strong social presence. This has a beneficial unexpected outcome – it provides men with a broad support network to lean on for emotional, and even logistical, support in general and, when a man has disclosed to them, in living with HIV.

The participants also described connecting with other patients in the HIV clinic waiting area to expand their support networks. The researchers' direct observations noticed this behavior, as patients in the waiting area frequently spoke with one another across gender boundaries. As one participant, a 32-year-old on ART for 3 years, said about the waiting area, “The patients do talk to each other about the disease and taking the pills easier,” and added that it “makes life easier.” The participants frequently described discussing their experiences with HIV and ART with others in the waiting area, such as by asking other patients if they have

had similar side effects from ART or the best time to take ART. One participant's description epitomized this relationship:

The first few days [in the waiting area] you feel awkward, but as you come more often you realize that these people are people as well. You start conversations with them. It's nice that we have our own waiting area. ...Conversations would be different if we were in the same waiting area as other patients not coming for HIV. You wouldn't be comfortable then talking about your situation or how you take the virus.

–30-year-old participant on ART for less than 1 year.

Because the same group of patients are usually present to collect their ART on the same day given the clinic's scheduling system, there seemed to be an informal support group amongst those present in the waiting area.

One challenge to remaining engaged in care was the lingering social stigma around HIV. Some participants said that they believed the community was more accepting now and that people "no longer discriminate against people living with HIV." However, other participants opposed such a view, and even those who claimed that stigma had faded, described stigma around HIV in other ways. The direct observations found that patients tended to sit towards the back of the waiting area. Though the reasons for selecting these spaces are unknown, these spaces were among those least visible to the rest of the clinic and may have served to protect patients from being seen by others. Almost all participants said that they stopped "having as many women" upon their diagnosis. Some men indicated that this change in behavior arose from difficulties in finding female partners as HIV-infected men. However, it is possible that this change may have also been a reflection of a shift in the attitudes of the men and not solely in the difficulty of finding partners. Some participants recounted quitting social organizations and facing pressure from employers to quit their jobs after diagnosis. Masculinity may also be threatened through a different type of stigma; the idea of the clinic as a space for women. Though none of the participants held this perception, they frequently attributed such a view to themselves before diagnosis. "People expect [men] to be strong and not to be seen at the clinic together with women," was the resulting mindset. The participants had believed that a similar sense of stigma was absent for women. They thought women suffered from different diseases, shaping the clinic into a place designed to treat only these diseases of women. The participants also said that the clinic encouraged women to attend for pregnancy check-ups, but men had no analog to call them to the clinic as often.

Beyond Care Engagement: Advocacy and Long Term Perspectives

The fact that all the participants were successfully engaged with the clinic provided participants with a strong sense of advocacy about the clinic that was in stark contrast to their former fear of the clinic. One participant described this shift that many of the men experienced:

I never used to think about coming to the clinic before I started taking my medication. But now I don't have a problem with the clinic, because I understand that's where you get all the help you need health-wise.

– 38-year-old participant on ART for 2 years.

Participants often used very emphatic language in describing their views of the clinic; many described a newfound importance for the clinic and describing clinic attendance as “the only way,” “the place where my life is,” “one of the most important places,” and a place so familiar and comfortable that it was for one participant, a 30-year-old on ART for 2 years, practically “a room in my house.” Participants said they praised the clinic amongst themselves, and even amongst their other male peers. Most men indicated that while they may not fully disclose their status to the general community, they encouraged others around them to visit the clinic and get tested: “I would even tell other people to visit a clinic, that’s how important [it is].” The participants often pinpointed this shift towards clinic advocacy to their initiation onto the ART program; they indicated a shift from feeling “afraid” about the diagnosis to feeling hopeful because they “understand now.” This shift, coupled with the role of men in their communities, could point towards a willingness among men to take on advocacy roles. Behaviors consistent with this mindset were noted by the direct observations. Men were frequently observed laughing and talking to others at the clinic, both patients and nurses, relating that they felt comfortable enough in this space to engage in those behaviors.

This newfound advocacy was related with two other changes in participants’ beliefs. The first is an expressed near-complete disavowal of traditional healing. All participants said they had stopped using traditional medicine completely, because they no longer believed traditional medicine would help them. Participants claimed to have newly learned the merits of clinical medicine, and in the light of this new knowledge they characterized traditional healing as unnecessary. One participant represented this sentiment well:

When I look at the clinic now, I think it’s the place for healing.... I believe that those people who still say they are using traditional healers are just wasting their time. At the end of the day, they will have to come to the clinic. It’s better to just come to the clinic once.

– 43-year-old participant on ART for less than 1 year.

This finding was surprising given the role traditional healing had previously played for men in managing their symptoms. The second change was an enhanced sense of the inevitability of the spread of HIV. The participants said that HIV was “everywhere,” and “just all over the country...all of us will catch it.” One participant, an 80-year-old on ART for 2 years, thought, “Everyone in the world will contract this virus anyway.” This perceived prevalence is what drove the participants to advocate for other men to come to the clinic; in the participants’ minds, most men likely already had HIV. In a more positive sense, though, some participants talked about normalizing attitudes towards HIV, similar to other illnesses and afflictions, which may signal a shift in increased social acceptance of the virus, with one participant, a 57-year-old on ART for 7 years, saying HIV “has become a normal disease like flu.”

The participants had a variety of suggestions as to how their sense of newfound clinic advocacy could be used to engage other men at different points along their HIV journeys. Most of the suggestions revolved around role modelling – using someone “who is popular in

the community and well-respected,” to talk to men about HIV and testing. The participants thought this would be most effective if the person were another HIV-infected individual with experience navigating the clinic who could provide insight into the clinic experience for others. One participant articulated this idea:

One of the ways that I think, since I’m also in the community, if I hear that my neighbor is sick, one of the things that should be done is since I know about the virus and the symptoms, I should go speak to that person who is sick about going to the clinic.

– 54-year-old participant on ART for 12 years.

The participants suggested that knowing people who fit this description and are known to have HIV has provided them with a sense of hope. Another common issue beyond testing is getting men to accept a positive test; many participants said men might not believe it, and some had experience themselves with testing positive and not believing the results. The participants suggested having an otherwise healthy person living with HIV talk to these individuals to show them that they may truly have HIV without exhibiting any symptoms. However, these suggestions are complicated by the above discussion, which described how continued stigma prevents participants, many of whom fit the descriptions of the men they designate as potential helpers, from talking openly to members of the community about their HIV.

Some suggestions by participants appealed directly to men’s senses of masculinity. For example, one participant, a 54-year-old on ART for 12 years, suggested utilizing *isoka* masculinity and redirecting it towards clinic attendance by channeling “the courage you have when pursuing a woman to going to the clinic.” Others mentioned “calling a community meeting,” such as *imbizo* (traditional meetings called for all men in an area to discuss an issue). Another participant, a 42-year-old on ART for 1 year, appealed to the sense of autonomy that men feared they would lose if diagnosed with HIV, saying, “If you don’t take a stand for your life, who will help you?” These suggestions would work within the already-existing context of masculinity to promote HIV advocacy.

Discussion

This study explored men’s journeys engaging with HIV care in KwaZulu-Natal, and how this journey is imbued with notions of masculinity. Interviews with men currently engaged in HIV care revealed a story of the men’s care journeys reshaping their masculinities in subtle yet significant ways. While this is not the first study to explore the experiences of South African men on ART (Beck, 2004; Dahab et al., 2008; Fitzgerald, Collumbien, & Hosegood, 2010; Mfecane, 2008, 2010; Schneider et al., 2012), this study adds to our understanding of the complex ways in which masculinity and HIV care engagement interact, the effects that masculine notions may have on health outcomes for men, and the potential for harnessing masculinity to support a positive response to the HIV epidemic.

We identified a complex, multifaceted interaction between participants’ masculinities and their HIV journeys. The data suggests two characterizations of men in this setting: the “stubborn, naïve” men who are not engaged in HIV care but should be, and the “honorable”

men in submission who are rightfully engaged in HIV care. These characterizations are competing and dynamic, with men shifting between them as they align themselves with clinical care. The “stubborn, naïve” man seems to be characterized from both the participants’ descriptions of men other than themselves and their descriptions of their attitudes and behaviors prior to diagnosis: having multiple sexual partners, utilizing traditional healing as their primary form of health care, fearing HIV testing and the potential for diagnosis, avoiding clinics, and discriminating against individuals living with HIV. The “naïve” characterization arises from the participants’ insistence that many men are not engaged in care because they do not know that they should be. This definition aligns with *isoka*, a South African form of masculinity whereby men distinguish themselves as dominant to women (Connell, 1995; Groes-Green, 2009; Hunter, 2005). In this case, they reinforce *isoka* by having multiple sexual partners and by avoiding women’s spaces such as the clinic. The “honorable” man in submission, conversely, is characterized by the participants’ views of themselves since diagnosis: limiting the number of sexual partners, strengthening relationships with the family and the community, rejecting traditional healing, finding a sense of peace or relief in the knowledge of an HIV status, and strongly advocating the clinic and its services. The “honorable” man aligns more with *umnumzana* (Hunter, 2005), a South African notion of masculinity built around forming and providing for a family.

Interestingly, as noted above, the notion of family was the one men connected most to being a “real man.” This notion suggests that in diagnosis, participants abandon the hegemonic *isoka* identity to adopt, in the participants’ eyes, what Connell’s (1995) framework would term a complicit masculinity – the *umnumzana* identity. Such an identity suggests easy adaptability to the lives of HIV-infected men by shifting the focus away from sexual prowess and towards the health and longevity required to care and provide for a family. There is a sense of irony in this shift, as Hunter (2005) details the ways in which *umnumzana* was previously the hegemonic masculinity among Zulu men before the economic hardships of apartheid and the migratory labor system for men made the notion difficult to enact. This history reinforces the complicity of *umnumzana* masculinity through its connection to the former (and current) hegemony. The consistency of the constructions of masculinity despite the wide age range of participants in this study speaks to the power of this cultural shift. We must also consider, though, how other men might view the participants in this study. Given the participants’ close relationship with the clinic, a place associated primarily with women, it seems that participants may take on what could be perceived by others as a subordinated masculinity (Connell, 1995). This idea would be reinforced by the notion that in limiting their number of sexual partners, participants occupy a role subordinate to *isoka* men. If such a mismatch exists – that is, if the way participants perceive themselves truly differs from the way they are perceived by others – it could also imply a mismatch in the way men perceive HIV stigma and the degree to which stigma still exists.

Also of interest is the commitment to clinic advocacy displayed by the participants. The participants assumed a role completely opposite from the fear of the clinic they said they previously felt, and instead took on a very proactive role of clinic advocacy. Doing so suggests an assumed identity of activism that underpins the concept of therapeutic citizenship (Nguyen, 2008; Robins, 2006). As recipients of life-saving ART, these men

appeared to feel a sense of obligation to the clinic to embody a role that limits certain parts of their identity (such as urging them to abandon traditional healing and multiple sexual partners) in order to promote and publicize other parts of their identity – namely, their HIV-infected status. Mfecane (2011) noted how HIV-infected men in Mpumalanga, South Africa assumed the role of therapeutic citizens as part of their involvement in an HIV support group. Mfecane (2011) attributes men's embraced role of activism to their support group attendance and identifies certain stances the support group expects these men to take – rejecting traditional healing, participating in the support group, and publicly disclosing their HIV status to challenge stigma. The process of imbuing the support group with the perceived power to treat and live with HIV gives the group leverage to generate a new source of hegemonic identity for its participants. Despite lacking a formal support group, the study participants assumed some of the same roles, rejecting traditional healing and participating in their own quasi-support group in the HIV clinic waiting area.

A point of divergence for men in this study, though, is the maintenance of some of their previous autonomy, as exhibited by their resistance to public disclosure. This attitude is consistent with Rager's (2007) findings on men dealing with prostate cancer; while eager to hear from other men (role-models) who were diagnosed with prostate cancer before them, these men were reluctant to share their own experiences, even with those who were diagnosed after them. However, as Baumgartner (2007) explained, disclosure must be thought of as a distinct process interwoven throughout the overall process of incorporating HIV into one's identity. That is, just because the men in this study have not disclosed yet does not mean they will not do so in the future. Nonetheless, maintaining this reluctance allows the men in this study to distance themselves from marginalized masculinities and perceive themselves within a complicit or hegemonic framework.

HIV-infected men who wish to access ART are thus seen to be subjected to at least two major competing forces. On one side, the hegemonic *isoka* masculinity pushes against men interacting with the clinic in any way and promotes alternate ways of healing and conceptualizing masculinity. On the other side, the notion of therapeutic citizenship empowers men in their health and alternate forms of masculinity, yet demands alterations to other sources of identity. The men in this study seemed to carve out a place between the two. They largely embraced the notion of therapeutic citizenship in becoming fierce clinic advocates, but also resisted it by refusing (for the most part) to take this advocacy public in the face of continuing stigma.

The qualitative nature of this study allowed us to contextualize the quantitative trends that indicate a gap in the HIV care engagement among men in South Africa (Barnighausen et al., 2014; Braitstein et al., 2008; Muula et al., 2007; Nattrass, 2008; Shisana et al., 2014), but the study has limitations that must be considered. For instance, despite the wide age range of participants (from 24 year to 80 years), age did not seem to be a factor in the participants' responses. However, some of our participants grew up in very different South African contexts (a 24-year old born in 1990 as Apartheid was ending compared to an 80-year old born whose adulthood was largely influenced by Apartheid), so its influence should be explored further. In addition, qualitative studies are not intended to be generalizable, but do teach us lessons to carry forward. Self-selection may have occurred during the recruitment

process due to the nature of recruitment; in particular, patients who possessed a more positive attitude of the clinic may have been more amenable to join the study when it was presented by the HIV nurse. Because the interviews were all conducted on-site at the clinic and this could have misconstrued the nature of the data collection team, social desirability bias may have had a hand in shaping participants' responses. This bias could have influenced how participants spoke about their attitudes towards traditional healing, and their feelings about the clinic and clinic staff. However, direct observations did help to corroborate some claims that the clinic had a relaxed atmosphere, noting that participants were frequently socializing and laughing with one another. Finally, participants were selected from the HIV clinic waiting area for their ART collection appointments. Such sampling may have excluded the viewpoints of participants who had difficulty making clinic appointments for a variety of reasons, such as work or transportation to the clinic. Because of this possibility, this study cannot be seen as representative of all South African men who are engaged in HIV care.

This study has important implications for future interventions. While the men in this study generally promoted the idea of public disclosure as a means of engaging other men in the community and potentially decreasing stigma, they are reluctant to follow through with this themselves. This attitude echoes Baumgartner's (2007) finding that men living with chronic disease look to other men to serve as role models for the process yet are reticent to take on this role themselves. Interventions focusing on reconceptualization of masculinity, such as the Brothers for Life campaign in South Africa (Jewkes & Morrell, 2010) or the men-focused health policy recommendations described by the Sonke Gender Justice Project (2008) may have success in bringing more men to the clinic. These can be enacted by reframing *isoka* masculinity, as one participant said, in terms of the "bravery" needed to approach women to channel this bravery into clinic attendance. Likewise, emphasizing the ways in which clinic attendance can support men's continued autonomy by securing their health and allow them to keep fulfilling the masculine roles they described may be effective.

Conclusion

The goal of this study was to explore the ways masculinity shapes South African men's HIV journeys, but the participants revealed more accurately how this journey shapes their masculinities. South African men's masculinities are formed by many components, from views on traditional healing to community social involvement. While these are subject to changes and reprioritization in the context of HIV, they can also be used to reach out to other men in attempts to include them in the HIV testing and care process. The novel sense of clinic advocacy encountered is one way of reaching other men. Employing this method to reach men may provide the opportunity for men to reshape their masculine identities to frame themselves in ways that are still valid given their views of masculinity, while simultaneously taking steps to manage the HIV epidemic. These findings also reinforce the idea that reconceptualized masculinities may be harnessed to advocate for early and sustained engagement in HIV care.

More research is needed on this vast topic to better understand the experiences of South African men. In particular, the voices of men who have learned their HIV status and either

never started treatment, or started treatment only to later default, are lacking from the literature. Understanding their motivation and reasoning can help to inform better HIV treatment interventions, in order to address the unique predictors of the HIV treatment cascade for men (Gardner, McLees, Steiner, del Rio, & Burman, 2011; Rosen & Fox, 2011). In reaching this neglected population through their own determined needs, we can more fully work towards winning the fight against HIV.

Acknowledgments

Special thanks to the district health facility authorities and service providers who collaborated in this study; the patients who were willing to share their stories; Phelelane Mkhize for his vital contributions; and Sarah Martin, Lysa MacKeen, Michael Russell, Bernhard Gaede, Merridy Grant, and Tivani Mashamba-Thompson for their contributions. The research was completed when the first author was a Master of Science in Global Health student at Duke University. This study was funded by Duke Global Health Institute (DGHI) of Duke University, and received support from the Duke Center for AIDS Research (P30 AI064518).

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Table 1

Summary of the interview guide

Introduction and Demographics
HIV story
Diagnosis story
Community reactions to men’s diagnoses in general
Lifestyle before and after diagnosis
Lifestyle changes since diagnosis
Relationship changes since diagnosis
Emotional health and support
Masculinity
Meaning of “being a man” in this community
Meaning of “being a man” as it relates to health
“Being a man” who has HIV
Medical engagement
Referral to this clinic
Experience at this clinic
Type of HIV care received at this clinic
Other care received at this clinic
Possible reasons for other men’s lack of engagement

Table 2

Description of the 21 individuals who participated in in-depth interviews

Characteristic	Participants (n = 21)
Average age (standard deviation)	42.4 (12.7)
Age range	24 – 80
Race	
Black African	21 (100%)
Relationship status	
Partnered	17 (81%)
Married	11 (52%)
Have children	13 (62%)
Employed	16 (76%)
HIV experience	
Years since diagnosis (s.d.)	4.5 (4.8)
Years on ART (s.d.)	3.6 (4.5)
Years between diagnosis and ART start (s.d.)	0.9 (2.7)