

“If You Don’t Take a Stand for Your Life, Who Will Help You?”: A Qualitative Study of
Men’s Engagement with HIV/AIDS Care in Rural KwaZulu-Natal, South Africa

by

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Thesis submitted in partial fulfillment of
the requirements for the degree of
Master of Science in the Duke Global Health Institute
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ABSTRACT

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Abstract

The needs of South African men with HIV are often overlooked in providing healthcare for people living with HIV/AIDS, leading to unique needs and experiences for men seeking HIV/AIDS healthcare. Compounding this phenomenon are norms of masculinity guiding these men's behaviors as they navigate health and healthcare systems. The aim of this study is to provide new insight on which components of masculinity interplay with healthcare access in South Africa. The study took place at one primary health care clinic in a peri-urban township in rural KwaZulu-Natal, South Africa. In-depth individual interviews were conducted with 21 HIV-positive men recruited from the clinic. Direct observations of the HIV clinic waiting area were also conducted. Data was analyzed using a grounded theory-informed memo-writing approach. 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.

Dedication

I dedicate this thesis to all members of my family, especially my late (paternal) grandfather Carroll Zisette and (maternal) great-grandmother Marie Tyer, for their guidance and support in achieving every goal I set. I cannot thank you all enough.

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1. Introduction

More than three decades after the discovery of HIV, the virus and ensuing AIDS crisis still bear a heavy impact on virtually every nation in the world. Halting the spread of HIV/AIDS and ensuring treatment for those affected has been a major international focus; this was highlighted by its inclusion in both the Millennium Development Goals and the Sustainable Development Goals that followed them (United Nations, 2013, 2014). It is estimated that 35 million people globally are living with HIV, with the large majority (25 million) in Sub-Saharan Africa (UNAIDS, 2013). South Africa in particular faces great pressure to contain the HIV/AIDS epidemic, having the greatest number of individuals living with HIV/AIDS of any country in the world at an estimated 6 million (UNAIDS, 2013). Within South Africa, the province of KwaZulu-Natal has a higher HIV prevalence than any other province at 16.9%, resulting in an estimated 1.7 million people living with HIV (over one quarter of South Africa's HIV population) (Shisana et al., 2014; Statistics South Africa, 2012b). The eThekweni (Durban) metropolitan area in KwaZulu-Natal also has the highest HIV prevalence (14.5%) of any of the South African metropolitan areas (e.g., Cape Town and Johannesburg) (Shisana et al., 2014).

Given that 60% of South Africa's HIV are among women (Shisana et al., 2014), HIV has often been framed as a "female epidemic." The result is that the needs of HIV-positive South African men are often overlooked, which may have contributed 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 predominantly male (0.75) by 2011 (Baringhausen, 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 (Baringhausen et al., 2014). This raises important questions about how men who are infected with HIV engage with HIV care in South Africa.

A variety of factors lead to the difference in HIV outcomes for men and women in South Africa. Overall, South African men tend to access general healthcare less than women, which carries over to antiretroviral treatment (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. Research that shows men in general access health care services less readily than women and children reinforces the idea that men are in some ways excluded from the care process (Galdas, Cheater, & Marshall, 2005).

The observed gender gap in treatment seeking behavior, both generally and specifically to HIV/AIDS treatment, has been linked to the elusive “masculinity factor” (Nattrass, 2008). The often-used catch-all term ignores the many different forms of masculinity that exist in South African 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. Most notably, Connell defined hegemonic, complicit, and subordinate masculinities. Hegemonic masculinity is the largely culturally dominant masculinity that retains the power balance in favor of men over women, usually emphasizing male heterosexual conquest of women, aggressive behavior, and general notions of strength (Connell, 1995; Donaldson, 1993). Hegemonic masculinity is dynamic, constantly adapting to preserve power structures that favor men. For instance, as historical and economic changes in South Africa made it difficult to retain one form of hegemonic masculinity (becoming *umnumzana*, or the head of one’s own household), the concept of *isoka*, took its place, which reinforced male norms of attaining multiple sexual partners as an expression of dominance over women through sexual prowess (Groes-Green, 2009; Hunter, 2005). Other patterns of masculinity emerge from the construction of hegemonic masculinity. For example, complicit masculinity is that which benefits from the existence of hegemonic masculinity while negotiating around its complete embodiment, and subordinate masculinity is that which collects the components barred

from hegemonic masculinity and thereby becomes closely associated with femininity (Connell, 1995).

These theories of masculinity have been applied in order to describe the utilization of health care services as an arena in which masculinity is exercised and performed (Courtenay, 2000; Myburgh, 2011; Noone & Stephens, 2008). These applications posit that by employing risky behaviors and dismissing healthy behaviors, men hegemonically legitimize themselves as the “stronger sex” and maintain the status quo (Courtenay, 2000). This mindset leads to the creation of two distinct social positions among the hegemonically masculine: frequent health care users, who are usually female and use services “trivially”, and (masculine) infrequent healthcare users, who are usually male and uses services “legitimately” (Noone & Stephens, 2008). The characterization of female frequent health care users imbues the clinic as a space with a feminine identity; especially in South Africa, the presence of large numbers of female clinic clients and an overwhelmingly female health care staff (primarily nurses) exhibits a sense of clinics as female domination, driving men to avoid this space where their masculinity may be threatened (Myburgh, 2011).

If we are to usefully apply these theories of masculinity, it is important to understand the lived experience of South African men, especially those living with HIV. Previous research has described different beliefs that South African men hold about HIV and health in general, such as an ideal to take charge of one’s own health, which Beck

(2004) refers to as “stubbornness.” Taking charge of one’s health can often manifest itself in either the delay of seeking health care or the utilization of traditional healing, which may be preferred over the “feminine” spaces of Western biomedicine. This preference is related to the belief that seeking treatment in clinics is associated primarily with women, just as men frequently define HIV as a women’s disease (Beck, 2004). South African men also have certain social structural constraints imposed upon them. Generally, South African men, especially those from rural areas, seek to fulfill two key roles expected of them – the role of man as a provider for his family and the role of (hetero)sexual prowess in defining masculinity (Mfecane, 2008), both of which are strongly impacted by living with HIV. The role of the provider is fulfilled commonly through employment. Difficulties in scheduling and losses in income arise for men who seek to remain employed full-time and simultaneously engage fruitfully in an ART regimen. These difficulties may arise due to overlapping clinic hours and work shifts, or due to the largely migratory nature of South African labor impeding long-term clinic engagement (Karim, Churchyard, Karim, & Lawn, 2009; Kuwane, Appiah, Felix, Grant, & Churchyard, 2009; Mills, Ford, & Mugenyi, 2009). The role of sexual prowess is primarily expressed through the hegemony of *isoka* masculinity, which emphasizes higher numbers of female sexual partners (Hunter, 2005). South African men have also reported feeling more hazardous effects of discrimination, such as losing a job or place to stay, upon having their HIV status disclosed (Beck, 2004; Simbayi et al., 2007). The

virus also throws the role of men and their senses of masculinity into a crisis that makes men more willing to rethink masculinity and incorporate new masculine identities (Mfecane, 2008). This attitude points to a need to explore the shifting nature of these masculinities.

In order to optimally meet the needs of HIV-positive men in South Africa, there is a need for more research on how masculinity affects the ways in which men engage with HIV/AIDS care. This is particularly true in rural KwaZulu-Natal, where HIV/AIDS prevalence rates are among the highest in the country. 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 are at play in these processes in KwaZulu-Natal. This goal is undertaken by qualitatively examining the experience of men's HIV journeys in KwaZulu-Natal, with a particular focus on the ways masculinity shapes those journeys.

2. Methods

2.1. Setting

This study took place in Umzinto, a peri-urban town located approximately 70 kilometers south of Durban, in the Umdoni municipality of the Ugu district of KwaZulu-Natal, South Africa. Umzinto is 10 kilometers inland from the coast and approximately 15 kilometers away from Scottsburgh, the largest nearby city where G.J. Crookes Provincial Hospital is located. Farms surrounding Umzinto are the largest employers for many residents; however, according to the 2011 census, about one third of residents of Umdoni municipality were unemployed (Statistics South Africa, 2012a). Umzinto is unique in having a larger Indian population than the municipality as a whole; Umzinto is 55% Black African and 42% Indian, while the Umdoni municipality as a whole is predominantly (77%) Black African and only 13% Indian (with Coloured and White filling the remainder) (Statistics South Africa, 2012a). English and isiZulu are the main languages spoken, though a subset of isiXhosa speakers is also present.

The study site was a primary health care clinic – Umzinto ‘Fixed’ Clinic. The clinic was identified following discussions with the KwaZulu-Natal Department of Health, based on its location and the large number of patients seen daily for HIV services. 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 (Fridays are reserved to initiate new clients onto ART). The HIV patient population is predominantly Black African and speak isiZulu.

2.2. Data Collection

The data collection team included one white American 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. Before data collection began, the team worked together to review the interview guide and practice qualitative methods. The team frequently met to debrief and review the guides. We also considered the clinic's head HIV nurse part of the data collection team. The data collection team met with the HIV nurse prior to data collection to brief her on the objectives and methods of the study so that she could help with participant recruitment (see below).

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. Clinic patients were identified and approached at the HIV clinic with the help of the HIV nurse. During patients' appointments to receive their ART, the HIV nurse explained the study to eligible clients and asked if they were interested in speaking with the fieldwork team about participating in the study. (When the data

collection team briefed the HIV nurse on the study and recruitment, we extensively discussed how to avoid coercing patients into the study in favor of explaining the study to allow participants to join voluntarily.) Eligible clients who were interested in participating in the study were then sent to the fieldwork team in a private room at the study 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) as appreciation for his time spent at the interview.

The fieldworkers also conducted direct observations of the HIV clinic waiting area on three different occasions 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 with clinic staff. These notes were transcribed as fieldwork notes.

2.3. Data Analysis

An approach informed by grounded theory was used to analyze the qualitative data. 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). While it cannot be stated that a purely grounded theory methodology was employed, grounded theory contributed largely to the theoretical underpinnings of the data analysis process. Even though the study was initiated with theoretical frameworks about masculinity, the data was analyzed with a view to elucidating theoretical concepts, which in turn could inform a theoretical framework. Gaining familiarity with the data was a crucial first step. Each interview transcript was synthesized by writing a brief (3-5) page memo, in order to identify major themes within and across interviews. Memo writing is critical to a grounded theory approach, as it provides an expeditious method of familiarizing oneself with the data in a way that advances analysis by organizing and condensing the vast data (Bernard & Ryan, 2010; Charmaz, 2006; Saldana, 2012). Transcripts were read and re-read multiple times before the memos were written, in order to ensure a thorough understanding of each interview. Memos were discussed with a qualitative expert to ensure their validity. This ensured that the memos remained grounded in the original data and retained the participants’

own words. Memos facilitated the use of constant comparative analysis, another crucial component of a grounded theory approach. By organizing data more efficiently and into major themes, the statements within each transcript could constantly be compared against each other, and the themes emerging in each transcript could be compared across transcripts (Thorne, 2000). Constant comparison of newly-analyzed data against that which had already been analyzed pointed out consistencies and trends in the data, as well as differences and contradictions in attitudes and experiences. Memos were then imported into NVivo, a qualitative data analysis software package, to code the themes in the data. Memos were coded to identify sections that reflected context about men's HIV stories, "what it means to be a man," and clinic experiences. Coded memos were reviewed to identify primary themes of (1) context and decisions influencing HIV testing and linkage to HIV care, (2) motivations and challenges to care engagement, and (3) patient advocacy and long-term perspectives.

2.4. Ethical Considerations

Ethical approval for this project was obtained from the respective Institutional 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 was 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. Once participants agreed to be interviewed, they were ensured that the interviews were not being conducted by the clinic and would in no way affect their care and treatment at the clinic. Participants were given the opportunity to end the interview at any point without penalty.

3. Results

The participants offered varied experiences of HIV care engagement, what it means to “be a man,” and the ways in which these were linked. I will first describe characteristics of the participants, then describe the findings of the study. 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 various masculine values: 1) delayed HIV testing and linkage to care; 2) motivators and challenges for care engagement; and 3) advocacy and long-term perspectives.

3.1. Description of Participants

Table 1: Description of the 21 individuals who participated in in-depth interviews.

	Participants (n = 21)
Age (s.d.)	42.4 (12.7) 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)

The interview sample included 21 men who regularly attended the study clinic to receive ART to manage their HIV (Table 1). 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). While age- and gender-specific ART use rates are not available, this average age does seem to be slightly older than would be expected given the age distribution of HIV in South Africa; 40-44 year old men have the fourth highest HIV prevalence rate among men (15.8%), behind 35-39 year old men (28.8%), 30-34 year old men (25.6%), and 25-29 year old men (17.3%) (Shisana et al., 2014). 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 the participants (17/21) were formally employed in either part-time or full-time positions. 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.

3.2. Delayed HIV Testing and Linkage to Care

The participants described a variety of reasons for delaying testing for HIV. One noted factor was that the participants described feeling no need to do so before they began to exhibit symptoms of HIV. Several participants said that they long suspected they had HIV due to various symptoms before they finally agreed to be tested, but they

rationalized and dealt with these symptoms in other ways than seeking care for HIV. The participants said other men they knew as well would wait until they had more severe, nearly debilitating symptoms before considering going to a clinic to be tested for HIV. This willingness to defer testing is related to how well a man can continue to function and carry out his everyday activities. One participant phrased it: "It hurts for a man to not be able to do the things he once did." If a man is able to continue carrying out his daily duties, there is less impetus to seek testing. In terms of masculinity, if a man is still able to fulfill his role as a provider for himself and those around him, he will carry on doing so. Participants also discussed how once men reached the point where they could no longer deny illness, they used traditional healing as a means of treating symptoms while prolonging the time before they actually test for HIV itself. The participants admitted to using different forms of traditional healing before their diagnosis as a way of treating illness, but they agreed that "it doesn't reach what the clinic medicine reaches." Participants rationalized the use of traditional healers in many ways. For instance, some tied it to the idea that witchcraft is the cause of severe HIV symptoms. One participant admitted that he delayed attending a clinic for his illnesses because he suspected witchcraft. The participants also related using traditional healing to a form of ignoring the cause of the illness, as they said the healers do not "ask you a lot of questions...they will just mix the medicine for you." The participants said that this method of treatment did not address the cause of the illness because traditional healers

do not examine or use blood from the patient, while the participants said everyone knew that the clinic does draw blood for tests. The use of traditional healers was linked directly to what it means to “be a man” by the 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 the participants. Seeking out traditional healing thus becomes a critical means of expressing one’s masculine identity.

At some point in his journey, each of the participants was tested for HIV, but not without a degree of reluctance common among men. Participants described intense fear among both themselves and other men in their communities around testing for HIV, and many of the participants expressed this as a fierce reluctance to get tested for HIV. Some participants did, though, have an array of testing habits before diagnosis, with some never testing before they were diagnosed and some testing occasionally, either with friends, with partners, or on their own. The participants described men in their community as “scared to talk about it or even to go test” for many layered reasons. They said that other men feel that “HIV is something that is far away from them,” or, as one participant described it, “it is something that is not close to them, not coming to them, not for them.” This attitude distances themselves from any personalized sense of risk of HIV. The participants said that once symptoms reached the point of being unable to carry on with their usual activities (thus impeding their ability as “the provider”), men acquiesced to visiting a clinic, but that they saw no reason to as long as they could carry

on. Delaying testing in this way often allows the virus to progress to more advanced stages before it is noticed. The majority of participants (18/21) initiated ART immediately upon diagnosis, indicating that the virus had markedly progressed by the time they were tested. However, even frequent testing habits and a positive diagnosis did not result in acceptance of the positive diagnosis once it was received. Multiple participants expressed that when they received a positive diagnosis from a test, they initially “didn’t believe that it was true,” though after talking with nurses they did agree to start ART. At least three participants, however, “decided not to use the medication,” and either stopped using ART after a few initial rounds (only to return to it at a later date) or delayed the start of their ART for some time. These participants attributed their disbelief in the diagnosis to the fact that they had no observable symptoms at the time when they were diagnosed, indicating a gap in understanding the difference in infection and illness. Most of the participants, even those who suspected their status, described feeling “hurt” or “frightened” at receiving their diagnosis, with one man saying “it was painful to find out.” They described hearing others in the community equate an HIV diagnosis to a death sentence either way: “if they find out, they will just commit suicide, if they tested positive.”

Even if a man is able to overcome his fears of testing and pain of diagnosis, one integral part of masculinity can serve as an obstacle to HIV testing and diagnosis - a man’s role in his family. 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 a potential 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. They said this permeates to other men’s willingness to test, as men are afraid to be seen by women at the clinic for fear that the women will already assume they are HIV positive. Even if the challenge of finding a woman is overcome, having a wife in and of itself can cause issues for men who want to test. As one participant said, “Should he decide to go get tested, he would have to sit his wife down first and talk to her about that. That has become an obstacle for him.” The participants expressed that in addition to having a wife, having children with her is critical in establishing respect as a man. One participant 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 related, “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.” Such fears lead men further into remaining ignorant of their HIV status to deny its potential existence.

3.3. Motivators and Challenges for Care Engagement

Men who manage to 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. In this setting, full engagement requires attending the clinic once per month to collect ART and taking one ART pill once per day. The participants all adhered to this schedule fairly well. No participants reported 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. This network took on a variety of forms – family members, romantic partners, close friends, employers or coworkers, clinic staff, or other clinic clients. Every participant described having some network (often of people to whom they had disclosed their status) that helped them to remain engaged.

Most participants described personally knowing someone else who was engaged with HIV treatment personally outside of the clinic setting. Nearly all described knowing of and admiring men in the community who had been on ART for some time and living healthy, normal lives. Also, just as family can serve as barrier to testing, it can also serve as an impetus to engage in care. The participants explained that once they

were engaged in care, their families and romantic partners helped them in specific ways. Nearly all participants had disclosed to their immediate family and, while some reported difficulties mainly in disclosing to their parents, they described their families as taking the news fairly well and providing commitments of support. Men who had disclosed to their families said that they “[encourage] me to keep taking my medicine.” Family members, especially those also take ART, remind participants of “the times,” or when it is time for participants to take their ART. This was true of romantic partners as well. The participants with partners who were also HIV-positive described reminding each other of times to take ART and the time of each other’s next clinic appointments; some even described sharing ART with their partners if one of them misses a clinic appointment and runs out of pills. Close friends, as well, were said to play a critical role, with many participants identifying a small number of close friends or coworkers as easier to talk to about their HIV experience than family members. Almost all participants described knowing at least one close friend who they “will ask...to go and fetch medication [ART] for me” if they could not make it on the days of their appointments.

The relationships described above in particular tend to be shaped by masculinity that favors “respect” in the community, enacted by maintaining a strong role in the family and a close group of male friends. For instance, one participant described how a

man is expected to take on an extroverted role in his community, making efforts to get to know those around him and participate in community gatherings:

I believe that, especially in my community, they believe that a man should not be a person who stays only in his house, but should be someone who gets out to meet his neighbors, talk to his neighbors, and visit other neighbors. When there are gatherings...he should be there. He should participate. He should be there with other people. He should be seen at those things in his community.

It is important to note, though, that this was referred to in a general sense; this participant had not disclosed to his community at large. 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.

As these quotes illustrate, it is 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.

Beyond just the outside community, the participants overwhelmingly categorized the clinic as a critical component of their support networks. Though the participants described other men as fearing the idea of the clinic, a sentiment the participants often said they shared before diagnosis, the participants now described the study clinic in a highly positive way – “open,” having a “good atmosphere,” “well-organized,” and generally “a good clinic.” Similarly, while participants said they had

heard other men in the community say the nurses can be “mean,” the participants described the nurses at the study clinic as “friendly,” “helpful,” and “good people.” One participant said, “If you have a problem, you can sit and chat with the nurse about that problem.” Another said of the HIV nurse that she is “always, always smiling and happy.” This was evident as well in the direct observations. A sense of rapport was observed in the interactions between nurses and clinic clients, with both groups frequently laughing with each other. There also seemed to be a general air of levity about the HIV clinic waiting area, with the observers noticing frequent conversation and laughter in addition to people selling snacks and other goods to the patients in the HIV clinic waiting area.

The participants also described connecting with other patients in the HIV clinic waiting area to expand their support networks. As one participant said about the waiting area, “The patients do talk to each other about the disease and taking the pills easier,” and added that “that makes life easier.” This relationship can sometimes expand outside of the clinic – some participants said that when they run into other clients who they recognize from the clinic, “We remind each other about our [clinic appointment] dates and stuff like that.” The participants frequently described discussing their experiences with HIV and ART with others in the waiting area, such as by asking other clients if they have had similar side effects from ART or the best time to take ART. Because the same group of clients are usually present to collect their ART on the same

day given the clinic's scheduling system, they seem to form a quasi-support group amongst those present in the waiting area. This appeared to cross genders; though the men admitted that women by far dominate the clients in the waiting area, they claimed that both men and women openly engage in conversations. All of this was similarly seen in the direct observations; women were observed by far to make up the majority of the waiting area, yet both women and the few men present actively engaged in conversation with the larger group. The conversation appeared to be gender-neutral, with men responding to statements or questions posited by women and vice-versa.

One challenge to remaining engaged in care is the lingering social stigma around HIV. The very existence of such stigma is openly debated by the participants. Some participants said that they believed the community was more accepting now and that people "no longer discriminate against people living with HIV." Other participants opposed such a view, and even those who claimed that stigma had faded described stigma around HIV in other ways. For instance, one man who claimed that the community did not discriminate said that his friends told him that if they were diagnosed as HIV-positive, "they will just commit suicide." Another participant who doubted overt stigma indicated that he sees people make fun of people living with HIV and is himself reluctant to go to the clinic sometimes for fear of being seen by those he knows; although he still attends the clinic regularly, he does so with a sense of anxiety. Most participants were not comfortable discussing their status with members of the

community outside of a close-knit group (namely family, close friends, and other clinic attendees), even when they said they suspected someone is HIV positive and wish to suggest he get tested. Some participants did point out more overt stigma. One man said that he was worried when he was diagnosed because, “especially in the community...there are people who are still negative about [HIV],” and he believes this led to the fact that, “The number of friends was reduced after I found out I was infected.” Similarly, the participants echoed the sentiments mentioned above that it was hard to find women who would accept their HIV status. Almost all of the participants said that they stopped “having as many women” upon their diagnosis, though this decrease may also be due to a shift in the attitudes of the men and not solely difficulty in wooing women as an HIV-positive man. Some participants recounted quitting social organizations, such as soccer teams, and facing pressure from employers to quit their jobs after diagnosis. These pressures of stigma seem to be why non-governmental organizations (NGOs), some of which are present in the area to help HIV patients, were not described as part of the participants’ social networks: “There...is that stigma if those people [NGOs] come to your house.”

Masculinity may also be threatened through a different type of stigma; the idea of the clinic as a space for women. “It’s the woman who gets more chances of going to the clinic,” seemed to be the reasoning behind this perception of clinics dominated by women, and it has led to the idea that, “People expect [men] to be strong and not to be

seen at the clinic together with women.” The participants believed that a sense of stigma similar to this was absent for women, who were thought by the participants to suffer different diseases, shaping the clinic into a place designed to treat women and not men. Women were also expected by the participants to attend the clinic for pregnancy, but the participants said they had no analog of required attendance for themselves. Though stigma around HIV may not be as overt as it once was, it was still present in the lives of the participants.

3.4. Advocacy and Long Term Perspectives

By the nature of the study design, all of the men interviewed had, at the time of the interview, overcome the barriers to care engagement and were currently receiving treatment. The fact that they were successfully engaged with the clinic provided participants with a strong sense of advocacy about the clinic that was in stark contrast to the fear of the clinic that the participants said other men feel. Participants often used very emphatic language in describing their views of the clinic, with many describing 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,” “a place for healing,” and a place so familiar and comfortable that it was for one participant 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 newfound advocacy was related with two other changes in the participants' beliefs. The first is a near-complete disavowal of traditional healing. All of the participants said they had stopped using traditional medicines completely. They said that they no longer believed traditional healing would help them. Some participants said that traditional healers in the past had been legitimate and today's are "no longer the truth," while others simply said all of traditional healing in itself was false. The participants, as stated above, often described traditional healing as the primary source of health care for men in general (though they no longer used it), yet renouncing traditional healing did not seem to cause the participants any conflicts of identity. The second change was an enhanced sense of the inevitability of the spread of HIV. The participants expressed bleak outlooks for preventing the spread of HIV in their communities. They said that HIV was "everywhere," and "just all over the country...all of us will catch it." "Everyone in the world will contract this virus anyway." Participants also indicated that prior to their diagnosis, their families sometimes expected them to be infected simply based on the prevalence of the virus. One man said, "My mom did have this belief that all of her kids were supposed to suffer with 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 saying HIV “has become an 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 “go to where they are,” such as in taverns or sports stadiums, to talk to men about HIV and testing. The participants thought this would be most effective if the person were another HIV-positive individual with experience navigating the clinic who could provide insight into the clinic experience for others. The participants indicated the importance of having older male role models to admire. 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 the 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 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 mention "calling a community meeting," such as *imbizo* (traditional meetings called for all men in an area to discuss an issue). These would work within the already-existing context of masculinity to promote HIV advocacy.

4. Discussion

This study explored men's journeys engaging with HIV care in KwaZulu-Natal, and how this journey is imbued with notions of masculinity in each step. In-depth interviews with HIV-positive men currently engaged in care revealed a story of shifting masculinities on the frontlines of the fight to contain the HIV epidemic. While this is not the first study to explore the experiences of South African men on ART (Dahab et al., 2008; Fitzgerald, Collumbien, & Hosegood, 2010; Mfecane, 2008, 2010; Schneider et al., 2012), this paper 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 the participants' masculinities and their HIV journeys. Two characterizations of South African men are described by the participants: the "stubborn, naïve" men who are not engaged in HIV/AIDS care but should be, and the "honorable" men in submission who are rightfully engaged in HIV/AIDS care. The "stubborn, naïve" man seems to be characterized from both the participants' descriptions of men other than themselves and their descriptions of how they have changed since diagnosis: having multiple sexual partners, utilizing traditional healing when some form of health care is needed, fearing HIV testing and the potential for diagnosis, avoiding clinics, and discriminating (either

overtly or more subtly) against individuals living with HIV. This definition aligns well with *isoka*, or multiple sexual partner masculinity, and would place it in the frame of hegemonic masculinity in this context (Connell, 1995; Groes-Green, 2009; Hunter, 2005). The alignment with *isoka* here comes from the manner in which men distinguish themselves as dominant to women, namely 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, completely rejecting traditional healing, finding a sense of peace or relief in knowing his 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 is likely a complicit masculinity (Connell, 1995) – the *umnumzana* identity. Such an identity suggests easy adaptability to the lives of HIV-positive 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 view the participants in this study. Given the participants' proximity to the clinic, a place associated primarily with women, it seems that the participants may take on what is 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, the participants occupy a role subordinate to *isoka* men. If such a mismatch of the way the participants perceive themselves and the way they are perceived by others is true, it could also imply a skew in the way men perceive HIV stigma and the degree to which stigma still exists.

Also of interest is the degree of clinic advocacy displayed by the participants. To our knowledge, such a degree of clinic advocacy has not been uncovered in previous literature. The participants assumed a role completely opposite from the fear of the clinic they said most men feel; the participants instead took on a very proactive role of clinic advocacy. Doing so suggests an assumed role 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 assume 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-positive status. Mfecane (2011) noted how HIV-positive men in Mpumalanga, South Africa assumed the role of therapeutic citizens as part of their involvement in an HIV/AIDS 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 new hegemonies for its participants. Despite lacking a formal support group, the study participants assumed some of the same roles, adopting similar views on traditional healing and participating in their own quasi-support group in the HIV clinic waiting area. Men in this study, though, maintained some of their previous autonomy as exhibited by their resistance to public disclosure. Doing so allows them to distance themselves from marginalized masculinities and perceive themselves hegemonically.

HIV-positive 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 (Baringhausen et al., 2014; Braitstein et al., 2008; Muula et al., 2007; Nattrass, 2008; Shisana et al., 2014), but the qualitative methods used also have limitations. The analysis of qualitative research is inherently subjective, though extensive efforts to remain grounded in the data were applied. 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. Though this is not a major concern because the results of the study are not intended to be generalizable to any degree, it should be considered. 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 the participants' responses. For example, it is unlikely that all participants had completely given up use of all forms of traditional healing as they suggested. This bias could have influenced how positively the participants spoke about the clinic, though direct observations did help to corroborate

some claims that the clinic had a relaxed atmosphere. Social desirability bias could also explain the way participants positively described the clinic staff, despite literature describing public perceptions of South African nurses as generally impolite to patients (Jewkes, Abrahams, & Mvo, 1998; Mathai, 1997; Wood, Maepa, & Jewkes, 1997).

Participants were purposively selected from the HIV clinic waiting area because they regularly attended the clinic 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/AIDS care. In addition, the unique racial composition of Umzinto relative to the rest of the municipality may limit generalizability of these results, though the participants did report living in various locations around the municipality, limiting this effect.

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. 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.

5. Conclusion

The initial 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 many 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. Doing so allows 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 phenomena also speak to advocating for early engagement in care to utilize this reshaping of masculinity.

More research is needed on this vast topic to better understand the experiences of all 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 the reasoning behind their actions 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/AIDS.

Appendix A: In-Depth Interview Guide for Men Engaged

in HIV/AIDS Care

1. Introduction: Isingeniso

Let's start by telling me a little about yourself.

Asiqale ngokuthi ungixoxele ngawe

- What is your age?
Ithini iminyaka yakho?
- Where do you stay? How far is that from the clinic?
Uhlalaphi? La uhlala khona kukude kangakanani naseemtholampilo?
- Where are you from? How did you come to live in this place?
Usukaphi? Wafika kanjani kulendawo ohlala kuyona manje?
- Who do you live with? Do you live with a romantic partner?
Uhlala nobani? Ngabe uhlala nomuntu othandana naye?
- Do you work?
Uyasebenza?
- (IF HE SAID "NO" ABOVE:) How do you get income? What do you do?
Imali uyithola kanjani? Wenza hlobo luni lomsebenzi?

2. HIV story: Umlando wakho wegciwane lesandulela ngculaza

The next few questions are about the sensitive topic of how you were diagnosed with HIV. You may find some of them embarrassing or hard to answer. Please let us know if any of the questions are too difficult. Please remember that you are not required to answer any question. You can skip any question for any reason.

Lemibuzo elandelayo imayelana nesihloko esibucayi mayelana nokuthola kwakho ukuthi unugciwane lesandulela ngculaza. Kungenzeka kubekhona imibuzo ozwa ukuthi ayikuphathi kahle noma ikwenza ube namahloni. Ngicela ukhumbule ukuthi awuphoqiwe ukuphendula imibvuzo. Uvunyelwe ukuyeqa imibuzo noma ngabe inini.

2A. Can you tell me about how you found out you were HIV positive?

Ngicela ungixoxele ukuthi wathola kanjani ukuthi unegciwane lesandulela ngculaza?

- When did you get tested?
Wahlolwa nini?
- Where did you get tested? When was the first time you came here?
Wahlolwa kuphi? Waqala nini ukuza lapha?
- How was it when you got tested? How did you feel?
Kwakunjani ngesikhathi uhlolwa? Wazizwa kanjani?
- Why did you decide to get tested?
Yini eyenza wathatha isinqumo sokuhlolwa?
- Did you ever think about getting tested in the past, but put it off? Why?
Wake wacabanga ukuthi uyohlolwa kodwa wangaya? Ngobani?

- How did you react when you were told the diagnosis? How did you feel? What were you thinking?
Kwabanjani ngesikhathi bekutshela ukuthi unegciwane lesandulela ngculaza? Wazizwa kanjani? Wawucabangani?
- Have you told anyone about your diagnosis? If so, how did they react? If not, why?
Ukhona osumtshelile ukuthi uphila negciwane lesandulela ngculaza? Uma ekhona, kwaba yinto ayithatha kanjani leyo? Uma engekho, ngobani?

2B. Can you tell me about what it is like for other men in the community when they are diagnosed?

Ngicela ukuthi kubanjani kwabanye abantu besilisa emphakathini uma sebetholile ukuthi baphila negciwane lesandulela ngculaza

- How do men in the community feel about getting tested? What are the attitudes of the nurses about getting tested? Are people willing to talk about testing?
Abantu besilisa emphakathini bazizwa kanjani ngokuhlololwa igciwane? Uma ucabanga bazizwa kanjani onesi ngokuhlololwa kwabantu besilisa? Ngabe abantu bayavuma ukukhuluma ngokuhlololwa?
- How open are men about HIV? Are they willing to talk to others about it?
Abantu besilisa bakhululeke kangakanani negciwane lesandulela ngculaza? Ngabe bayavuma ukukhuluma ngalo kwabanye abantu?
- What is the reaction of the community to HIV? Are they accepting of people with HIV? Why or why not?
Umphakathi uzizwa kanjani ngegciwane lesandulela ngculaza? Umphakathi uyabamukela abantu abaphile negciwane lesandulela ngculaza? Ngobani?
- How easy is it to get tested? Do most people know where to go? Are the staff there willing to help? Why or why not?
Kulula kangakanani ukuhlololwa? Abantu abaningi bayazi ukuthi kufanele bayekuphi uma befisa ukuhololwa? Abasebenza la kuhlololwa khona bayavuma ukubasiza? Ngobani?
- In a relationship, who usually gets tested first-the man or the woman? Why? What is that like?
Ebudlelwaneni phakathi komuntu wesifazane nomuntu wesilisa, ubani ojwayele ukuhlololwa igciwane leandulela ngculaza kuqala-owesilisa noma owesifazane? Ngobani? Kubanjani lokho?

3. Lifestyle before and after diagnosis: **Impilo ngaphambi nangemuva kokuthola imiphumela**

The next few questions are about the sensitive topic of how it has been for you living with HIV. You may find some of them embarrassing or hard to answer. Please let us know if any of the questions are too difficult. Please remember that you are not required to answer any question. You can skip any question for any reason.

Lemibuzo elandelayo imayelana nokuphila negciwane lesandulela ngculaza. Kungenzeka eminye imibuzo uyizwe inzima noma ikubangela amahloni. Ngicela ungazise uma kukhona umbuzo onjalo. Ngicela ukhumbule ukuthi awuphoqiwe ukuphendula imibuzo. Uvunyelwe ukuyeqa imibuzo noma ngabe inini.

3A. How has your life changed since you were diagnosed?

Isishintshe kanjani impilo yakho kusukela utholile ukuthi uphila negciwane lesandulela ngculaza?

- In general how has your lifestyle changed since you were diagnosed? What things do you do differently?
Uma ubheka impilo yakho, isishintshe kanjani kusukela uthola ukuthi uphila negciwane lesandulela ngculaza? Iziphi izinto osu zenza ngendlela ehlukele?
- How has your health changed since being diagnosed? Have you felt ill or felt healthier? Have you gained or lost weight? How have you felt?
Isimosempilo (health) yakho sesishintshe kanjani kusukela uthola ukuthi uphila negciwane lesandulela ngculaza? Uzizwa ugula noma uphill kakhulu? Ngabe isisindo sakho sehlile noma sikhuphukile? Uzizwa kanjani emzimbeni?
- Do you think differently about HIV and people who have it now? How so?
Ngabe indlela osucabanga ngayo ngegciwane lesandulela ngculaza kanye nabantu abaphila nalo isishintshile? Ngayiphi indlela?
- Do you think differently about yourself now? How so?
Ngabe uzibona ngenye indlela manje? Ngayiphi indlela?
- Do you think differently about the clinic now?
Ngabe indlela ocabanga ngayo ngomtholampilo ihlukile manje?
- What challenges do you face as a result of HIV?
Ibuphi ubunzima obhekana nabo ngengxa yegciwane lesandulela ngculaza?

3B. How have your relationships changed since diagnosis?

Ngabe ubudlelwano bakho nabantu abahlukile lube noshintsho kusukela uthola ukuthi uphila negciwane lesandulela ngculaza?

- With family and friends?
Nomndeni wakho kanye nabangani bakho?
- With girlfriends or your wife?
Nezintombi zakho noma nonkosikazi wakho?
- With other sexual partners?
Nabantu oya nabo ocansini?
- With an employer or colleagues?
Nomuntu okuqashile kanye nabantu osebenza nabo?
- With others in the community?
Nabanye abantu emphakathini?

4. Emotional health and support: **Ukwesekwa nokuxhaswa**

Does anyone help support you in terms of HIV?

Ukhona umuntu okwesekayo mayelana negciwane lesandulela ngculaza?

- Do family and friends help support you in any way? How?
Ngabe ikhona indlela umndeni kanye nabangani abakweseka ngayo? Ngayiphi indlela?
- Is there support from the community? How so?
Kukhona ukwesekwa umphakathi? Ngayiphi indlela?

- Is there support from the clinic? How so?
Kukhona ukuthola ukwesekwa emtholampilo? Ngayiphi indlela?
- Are there NGOs or campaigns in the community about HIV? Do they help you?
Ikhona imikhankaso emayelana negciwane lesandulela ngculaza emphakathini? Bayakusiza wena?

5. Masculinity: **Ukuba Indoda**

5A. What is the meaning of being a man in your community?

Kusho ukuthini ukuba indoda ngempela emphakathini wakho?

- What is expected of a 'real' man from the community?
Umphakathi ulindela izinto ezinjani kumuntu wesilisa oyindoda yangempela?
- What kind of power does a 'real' man have, in his relationships and in the community?
Umuntu wesilisa oyindoda yangempela unamandla mani ebudlelwanane bakhe nasemphakathini?
- How does a 'real' man act in a relationship?
Umuntu wesilisa oyindoda yangempela uziphatha kanjani ebudlelwaneni anabo nomuntu ajola naye noma ashade naye?
- What influences what a 'real' man is? Who are the role models? Are they from the community or from the media?
Iziphi izinto noma ibaphi abantu abafundisa abantu besilisa ukuthi babe amadoda ngempela? Abantu besilisa bakubukela kobani ukuba amadoda angempela? Labobantu basemphakathini noma basemaphepheni, emsakazweni noma kwiTV?

5B. What does being a 'real' man mean for your health?

Ukuba yindoda yangempela kunomthelela onjani empilweni yakho (health)

- What do 'real' men do when they are ill? Where do they go?
Abantu besilisa abangamadoda angempela enza njani uma begula? Bayakuphi uma befuna usizo uma begula?
- How do men feel about going to the clinic?
Abantu besilisa bazizwa kanjani ngokuya emtholampilo?
- How do men feel about getting ill?
Abantu besilisa bazizwa kanjani ngokugula?
- What do people think when of a man when he has HIV? How do you see yourself living with HIV?
Abantu bacabangani ngomuntu wesilisa onegciwane lesandulela ngculaza? Wena uzibona kanjani njengoba uphila negciwane lesandulela ngculaza?
- How does the community see you? How do other men see you?
Umphakathi ukubona kanjani? Abanye abantu besilisa bakubona kanjani?

5C. What is it like for a man when he has HIV?

Ngabe kunjani kumuntu wesilisa uma enegciwane lesandulela ngculaza?

- What do people think of a man when he has HIV?
Abantu bacabangani ngomuntu wesilisa uma enegciwane lesandulela ngculaza?
- How do you see yourself living with HIV?
Wena uzibona kanjani njengoba uphila negciwane lesandulela ngculaza?

- How does the community see you?
Umphakathi ukubona kanjani?
- How do other men see you?
Amanye amadoda akubona kanjani?

6. Medical engagement: **Ukuthola usizo lwezempilo**

6A. How did you come to this clinic?

Ufike kanjani kulomtholampilo?

- Why did you come?
Kungani uza kulomtholampilo?
- How long was it between when you were diagnosed with HIV and when you started coming here for treatment? If you waited in-between, why did you wait?
Kwaba isikhathi eside kangakanani kusekela ngesikhathi uthola ukuthi unegciwane lesandulela ngculaza nesikhathi uqala ukuza kulomtholampilo ukuze uthole ukwelashwa? Uma kukhona isikhathi owasilinda ngphambi kokuthi uzothola ukwelashwa, yini eyadala ukuthi ulinde?
- How often do you come to the clinic?
Ujwayele kangakanani ukuza kulomtholampilo?
- Tell me about the last time you didn't come to the clinic when you were supposed to
Ngcela ungixoxela ngesikhathi la ekwakufanele emtholampilo kodwa wangeza ngesikhathi esifanele

6B. How has your experience at this clinic been?

Ithini imibono yakho ngalomtholampilo? Uphatheke kanjani kulomtholampilo?

- What do you like about this clinic?
Yini uthanda ngalesi emtholampilo?
- What do you not like about this clinic?
Yini awuthandi ngalesi emtholampilo?
- How long do you have to wait in the queue?
Ulinda isikhathi eside kangakanani kulayini?
- What do you do while waiting in the queue?
Wenzani ngesikhathi ulindile kulayini?
- How many men and women are usually in the queue with you? How does that make you feel?
Kujwayele ukuba abantu besifazane nabantu besilisa abangaki abalinde nawe kulayini? Lokho kukwenza uzizwe kanjani?
- Do you interact with other patients? What is it like?
Ngabe uyaxoxa nezinye iziguli? Uzizwa kanjani ngalokho?
- What are your interactions with nurses like?
Ngabe ubudlelwano bakho nonesi bunjani? (interaction)
- Do you think that nurses treat the male patients differently from the female patients? How? Why?
Ngabe ucabanga ukuthi onesi baphatha abantu besilisa ngendlela ehlukile kunabantu besifazane? Kanjani? Ngobani?

- How do you feel you are treated by the nurses compared to other patients?
Uzwe engathi wena uphathwa kanjani uma uqhathanisa nezinye iziguli?
- What are your interactions with doctors like?
Ngabe ubudlelwano bakho nodokotela bunjani? (interaction)
- How long do appointments last?
Uvakasho lakho luthatha isikhathi eside kangakanani (ngesikhathi ubonana nonesi noma nodokotela)
- What is the atmosphere in general like at the clinic?
Isimo sinjani emtholampilo ngokujwayelekile? (atmosphere)

6C. What kind of HIV care do you receive at this clinic?

Uthola hlobo luni lkwelashwa kulomtholampilo?

- Are you taking ARVs here? If so, how long have you been taking ARVs here?
Uyithola lana imishanguzo? Uma kunjalo, usithole lana imishanguzo isikhathi eside kangakanani?
- Do you always take ARVs as the doctor tells you to? Is it ever difficult to take them on schedule?
Ngabe imishanguzo uyisebenzisa ngendlela otshelwe udokotela ngaye ngasosonke isikhathi? Nagbe kunzima ukuwasebenzisa njalo ngesikhathi esibekiwe?
- Are there challenges to taking ARVs?
Bukhona ubunzima obukhona ngokusebenzisa imishanguzo?
- What other kinds of HIV care are offered here? Do you use them?
Ukuphi okunye ukwelashwa kwegciwane lesandulela ngculaza okutholakala kulomtholampilo? Uyakusebenzisa?

6D. What other forms of treatment do you use?

Iziphi ezinye izinhlobo zokwelashwa ozisebenzisayo?

- Do you use home treatments?
Uyakusebenzisa ukwelashwa kwasekhaya?
- Do you go to traditional healers?
Uyaya kubelaphi bendabuko?
- Do you go to a church or anywhere for treatment?
Uyaya esontweni noma kwenye indawo ukuyothola ukulashwa?

6E. Why do you think some men with HIV do not come to the clinic?

Ngokubona kwakho, yini edala ukuthi abanye abantu besilisa bangayi emtholampilo ukuyothola unakekelo legciwane lesandulela ngculaza?

- What are the current barriers?
Ibuphi ubunzima ababhekana nabo njengamanje?
- How can we change this in the future?
Singakushintsha kanjani lokhu esikhathini esizayo?
- Who are your HIV role models for living with HIV?
Obani abaphila negciwane lesandulela ngculazi abayisibonelo kuwena?

- What are the most important needs HIV-positive men have? How can we support them?
Abantu besilisa abaphila negciwane lesandulela ngculaza banaziphi izidingo ezibalulekile?
- How can we get more men to get tested for HIV?
Singenzani ukuze kwande isibalo sabantu besilisa abahlolile igciwane lesandulela ngculaza?
- How can we get men who test positive to follow through with care?
Singenza kanjani ukuthi abantu besilisa abathola ukuthi banegciwane lesandulela ngculaza baqhubeke ngokuthola unakekelo?
- How good is the HIV knowledge in the community? Do men know the symptoms? Do they know the procedures for getting tested? For getting care? (symptoms, procedures)
Umphakathi unolwazi legciwane lesandulela ngculaza olungakanani? Abantu besilisa bayazazi izimpawu zegciwane lesandulela ngculaza? Ngabe abantu besilisa bayazi ukuthi kufanele benzenjani uma befisa ukuhlolile igciwane lesandulela ngculaza? Ngabe abantu bayazi ukuthi kufanele benzenjani uma befisa ukuthola unakekelo legciwane lesandulela ngculaza?

Is there anything else you would like to add before we end?

Thank you for taking the time to talk with me. Your views and experiences will help us to provide support for men with HIV in this community.

Ikhona enye into ofisa ukuyengeza ngaphambi kokuthi sivale?

Ngiyabonga ngokuthatha isikhathi sakho. Imibono yakho izosisiza ukuthi sikwazi ukweseka abantu besilisa abaphila negciwane lesandulela ngculaza.

Appendix B: Clinic Queue Observation Guide

Observation #:		Day of week:	
Observer:		Time started:	
Date of observation:		Time ended:	

Sketch of waiting area

Note entrances and exits, worker areas (e.g. front desk), and where you are seated.

Number of patients

Record numbers of people every hour, with time recorded in top line. Exclude workers.

Time						
Men <35 y.o.						
Men >35 y.o.						
Total MEN						
Women <35 y.o.						
Women >35 y.o.						
Total WOMEN						
Total CHILDREN						
Total PATIENTS						

General notes on clinic setup

General notes on the day of observation

Description of the people in the waiting area

Add any comments on the patients in terms of dress, personality or behavior. Are people alone or with other people? Do they keep to themselves or talk to each other? Note if this changes over the course of the day.

Groupings and interactions

Describe how people are grouped (by gender, families, age groups, etc.). How are people interacting within the group, and how do the groups interact with each other?

Staff-patient interactions

Describe how various staff members (all levels) are interacting in the waiting area. How do workers treat patients? How do patients respond?

Additional notes and events record

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