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Traditional Health Practices in HIV Management:
Perceptions of Patients, Providers, and Traditional Healers in Durban, South Africa

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By

Hannah Appelbaum

Bachelor of Arts (BA)
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An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
In partial fulfillment of the requirements for the degree of
Master of Public Health
in Global Health
2012

Abstract

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By Hannah Appelbaum

Local cultural norms and Western medicine (WM) can collide for people living with HIV (PLHIV) in the era of antiretroviral therapy (ART). This situation can be observed in South Africa's province of KwaZulu-Natal (KZN), where patients receiving ART—most of whom are of Zulu culture—are often discouraged from consulting Traditional African Medicine (TAM) by their WM providers out of concern for harmful drug interactions with ART. The aim of this study is to understand the current intersection of TAM and WM by exploring the beliefs and perceptions of health care providers, PLHIV and traditional healers, for the ultimate purpose of providing a safe and effective standard of care for individuals balancing both approaches. In-depth interviews (IDIs) were conducted with five WM practitioners (doctors, nurses, counselors) and six patients receiving ART from Sinikithemba Clinic (McCord Hospital, Durban). Three focus group discussions (FGDs) were conducted with traditional healers and one with PLHIV receiving ART. Interviews with patients and traditional healers were conducted outside of McCord Hospital, in Zulu, and by local Zulu researchers with no affiliation to McCord. Results show that there is a complex intersection of beliefs towards the concurrent use of TAM and ART amongst PLHIV. Both health care providers and patients possess implicit knowledge regarding TAM and explicit awareness and knowledge regarding ART for HIV management. Further, TAM and ART were perceived to serve distinct purposes among patients in this study population, indicating in particular that TAM use is not necessarily a departure from ART, nor viewed as an alternative treatment, nor always taken as medication (ingested or inhaled). Sometimes TAM use means receiving counseling from a traditional healer, or having the traditional healer consult with ancestors to determine the cause of illness. Visions of a collaborative system of healthcare delivery differed between Western health care providers and traditional medical providers, particularly as they relate to HIV treatment and care. Future research should explore ways to create a dialogue among stakeholders for the purposes of education, understanding, collaboration, and mutual respect in this realm. Large-scale research is needed to further understand the use of TAM in this context.

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Acknowledgments

Nothing that I did here would have been possible without the support and wisdom of Monique Hennink, Vince Marconi, and Claudia Ordonez. Monique, thank you for your wisdom and for expecting more of me than at times I knew I had in me. Vince, thank you for your endless perspective, humility, and intellect. I am grateful to have crossed your path. I am beyond appreciative of the unwavering support, nurture and determination of Claudia Ordonez. Thank you for you positivity, and for sacrificing your time, sleep, and laptop to make the vision of this research a reality.

I am indebted to the South African members of this study team who had faith in this project and helped make it possible: Henry Sunpath, Sally John, Jane Hampton, and Eleanor Preston-Whyte. Thank you for sharing your lives, your livelihoods and your knowledge graciously. Phacia Ngubane and Neliswa Dladla: thank you for your commitment to giving this project a voice. Sifiso, Sabelo, Roma and Melisha: thank you for your generosity in all you do. I am thankful for the funds from "Risk Factors for Virological Study: A Case Control Study" that kept me afloat. To the people of McCord Hospital, Sinikithemba Clinic, Durban and South Africa, who continue to refine my ever-changing world view: Ngiyabonga.

To the people I love the most in the world, who evidently still love me: thank you for keeping me whole, each in your own way. Mom and Dad, you are the perfect combination of intellectual and unconditionally loving. I cannot express my appreciation for the support you have ever so readily volunteered. Mom, for putting my thesis before your own advisees', Dad, for coming out of retirement and always having the right words—you are forever my favorite advisors.

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INTRODUCTION and RATIONALE

The use of traditional medicine and Western or "allopathic" medicine (WM) by people living with HIV (PLHIV) has been studied widely across disciplines and geographic areas. Much of this research has centered in Africa, a continent arguably more affected by the HIV/AIDS epidemic than anywhere else in the world. The use of a wide variety of traditional African medicine (TAM) is known to be prevalent across the continent. While the interface of biomedicine and culture is hardly a new phenomenon, research on the complex intersection of biomedicine and TAM in the context of HIV management is surprisingly scarce considering the known prevalence of both traditional beliefs and HIV. In an era of increased access to life-saving medicine to treat HIV infection (antiretroviral therapy, or "ART"), recognizing the roles of these beliefs and behaviors in the lives of PLHIV receiving ART is vital in attempting to fight the continuing epidemic sensitively and sustainably.

As of 2010, 34 million adults worldwide were estimated to be living with HIV/AIDS (UNAIDS, WHO and UNICEF estimates). In 2009, UNICEF, WHO and the South African National Department of Health (Ministry of Health) estimated the prevalence of HIV among South African adults 15-49 to be 17.8%. Despite being among the smallest provinces geographically, with a rate of 15.8% KwaZulu-Natal (KZN) is known to have the highest prevalence of HIV/AIDS in the whole of South Africa (avert.org). Further, studies from antenatal clinics and have reported a prevalence of close to 40% in Durban and rural areas in KZN (avert.org; Rice et al., 2007). Durban, a city located in the Eastern part of KZN, has been at the forefront of efforts addressing the

epidemic in terms of provision of care and treatment, especially since the onset of the South Africa National ART rollout. In spite of notable progress in the delivery of ART, HIV continues to extract a notable toll on South Africans—socially and economically. As problems such as ART treatment failure and drug resistance become more prevalent, the priorities for combating the epidemic, too, are shifting. Contextual considerations like cultural norms and practices are being examined in hopes that they will give insight into innovative ways to control the far-reaching effects of HIV/AIDS.

One of these considerations in South Africa, TAM, has been widely cited as a barrier to ARV adherence (Dahab et al., 2008; Reid et al., 2008) and researchers at McCord Hospital in KZN are examining this as a potential risk factor for HIV treatment failure and drug resistance. A 2006 UNAIDS estimate reported that the prevalence of TAM use in South Africa was as high as 80-85% among black South Africans, a figure that was validated in KZN by Peltzer and Mngqundaniso (2008). Additionally, both literature and anecdotal reports point to the possibility of dual use of TAM and WM by HIV patients in South Africa (Cook, 2009; Dahab et al., 2008; Hammond-Tooke, 1989; Karim et al., 2009; Malangu, 2007; Peltzer, 2001; Peltzer et al., 2006; Peltzer & Mngqundaniso, 2008; Peltzer et al., 2008; Peltzer et al., 2010). Thomas et al. explain, "The diversity and plurality of health-seeking approaches, or what we here call mixing of health systems….is common [among member of their ART program]. Mixing strategies while on ART is a controversial, even dangerous matter. But it is more often than not the norm in the context in which [their ART program] works, perhaps even pervasive, and it has its own logic…" (2006, p. 5).

This notion t is supported by the historical relationship of TAM and HIV in South Africa, which includes inaction of the Apartheid South African government during the first decade of the epidemic (1980s-1990s), the inaccessibility of HIV treatment for South African PLHIV throughout in the next decade (1990s-early 2000s), and the outward political endorsement of TAM for managing HIV after even ART became more accessible in 2003-2004 (Karim et al., 2009).

In the spirit of understanding the implications of these realities—i.e., (1) that HIV remains a widespread concern in KZN, (2) that TAM use is ubiquitous in the region, and (3) that patients may consult both TAM and WM concurrently—this study was designed to explore and better understand the current situation of traditional African medicine use from three perspectives diverse perspectives: patients attending Sinikithemba Clinic ("Sinikithemba") at McCord Hospital ("McCord") in Durban, South Africa; their doctors, nurses and HIV counselors at the clinic; and TAM practitioners in the Durban area. Investigators chose to capture the perspectives of these varied stakeholder groups in order to gain a more nuanced understanding of TAM use for HIV management. Ultimately, it is the hope that researching these stakeholder groups will help identify steps that may be taken to safely and sensitively enhance the delivery of care for HIV patients who, to date, may balance different approaches to their treatment.

Problem Statement

TAM and ART can collide for HIV positive patients managing their illness and balancing both treatment approaches. This can be observed in South Africa's province of KwaZulu-Natal. On the one hand, patients receiving treatment at most WM facilities are

discouraged from using TAM out of fear that it could cause adverse drug interactions and/or do patients harm; on the other hand, traditional cultural values abide among Zulus in Durban and KZN, including HIV positive patients, many of whom are Zulu South Africans. This tension can cause undue stress for patients already under pressure to manage HIV, an illness that remains stigmatized across much of South Africa and the world. Patients who may turn to traditional beliefs out of habit, comfort, or because their social circles encourage them to, may also be asked to abandon that element of their lives.

In an era of improved access to antiretroviral therapy, a divide of this nature may be counterproductive and the antithesis of progress in the arena of HIV care. It could encourage clandestine use of TAM and less than honest relationships between patients and their providers; it juxtaposes WM practitioners against their TAM counterparts, science against faith. Ultimately, the patient—whose health and wellbeing are the primary interest of both approaches—can feel obligated to make concessions. Is such a choice necessary? This research represents one step of many in answering that question. The project seeks to understand the complex intersection of TAM and WM for PLHIV in the specific context of McCord Hospital in Durban.

In summary, this research is driven by the notion that PLHIV in South Africa might be balancing TAM and WM. This can cause them unnecessary stress during an already stressful time. The health community—which includes traditional and WM practitioners—should bridge the divide between currently competing approaches for the benefit of patients who value both. This bridge should be rooted in mutual understanding and respect and should seek to improve the delivery of care and quality of life for

patients. McCord Hospital has been at the forefront of treating patients with HIV in KZN in terms of service delivery and care; however, there are many unanswered questions surrounding the perceptions and feelings that patients may have about the use of TAM in the context of their own HIV treatment. It is fitting that McCord's outpatient HIVclinic, Sinikithemba, be at the cutting edge of beginning to understand how the intersection of TAM and WM exists for patients receiving ART so that, if appropriate, they can work to address the divide that may currently exist.

Purpose Statement

To better understand how the intersection of TAM and WM impacts on patients receiving treatment at Sinikithemba, this project focuses on the following question:

- What are Sinikithemba patients' and WM/TAM practitioners' perceptions of the role of TAM in HIV treatment?

Investigators answered this by seeking out the perspectives of three varied stakeholder groups: Sinikithemba patients receiving treatment for HIV (ART); WM providers (including doctors, nurses and counselors) from Sinikithemba; and TAM practitioners from Durban and KZN. The following questions will guide exploration within these sub-groups:

- What are the experiences and attitudes regarding TAM among HIV patients receiving treatment at Sinikithemba?
- What are the attitudes towards TAM within the context of HIV treatment among providers at Sinikithemba?
- What are the opinions of TAM's role for treating PLHIV among TAM practitioners in the Durban community?

Significance Statement

The ultimate, future goal of this research is to improve the wellbeing of patients, which in the context of HIV in South Africa may be complicated by a divide between TAM and WM. In addressing this challenge, there needs to be a mutually respectful, equal relationship-building process between these two medical traditions focusing on a common goal: the welfare of patients. The relationship between TAM and WM in the context of HIV treatment at McCord Hospital is a complex but important area of investigation. By engaging many of the major players around this intersection, this pilot study began to uncover how to appropriately design future research and programs that could lead to a reconsideration of the standard of care and policies regarding TAM use for patients on ART. Given the complex nature and history of the relationship between the two traditions, building trust with McCord patients will be a long process. We expect findings from this study to result in informed tools to continue trust building as well as deeper inquiry through future, larger-scale research.

DEFINITION OF TERMS

HIV Management

Refers to any action taken in direct response to HIV infection. Includes HIV-related health seeking behaviors such as blood testing and taking antiretroviral therapy (ART).

People living with HIV (PLHIV)

In the context of this study, the term PLHIV is inclusive of any person living with HIV/AIDS, whether diagnosed in a biomedical facility or elsewhere.

Western Medicine (WM)

The terms Western medicine and "Western health care" were used interchangeably to represent allopathic-based biomedical approaches to health care (also known as "allopathic medicine").

Traditional African Medicine (TAM)

TAM includes a variety of healing treatments, practices and modalities. In this paper, TAM was self-defined among participants and often included, but was not limited to traditional herbs, herbal concoctions (including steamed herbs, mixed herbs for drinking and herbal mixtures applied topically to the skin for healing). This term also includes divining and faith healing. (See p. 28 for definitions of each of these modalities of healing).

Practitioners of Traditional African Medicine (PTAM)

Also referred as "traditional healers"; PTAM discussed herein include the prevalent types of TAM practitioner in South Africa—Isangoma, Inyanga and Umthandazi

Focus group discussion (FGD)

A group interviewing technique common in qualitative research methodology. Focus group discussions in this project occurred one time for each distinct group of participants and engaged 4-5 participants who were asked a series of semi-structured questions designed to engage them in a ninety minute discussion about the topic(s) of interest, in this case, the intersection of TAM and WM for patients managing HIV.

In-depth interview (IDI)

An individual interviewing technique characteristic of qualitative research. IDIs in this project were conducted by a trained interviewer who asked participants a serried of semi-structured interview questions regarding the topic(s) of interest, in this case, the use and intersection of TAM and WM for patients managing HIV.

LITERATURE REVIEW

Introduction

Traditional African Medicine in the Literature

Traditional medicine use is a vast topic in the academic literature, spanning decades, continents, and cultures. The topic exists within and underlies a multitude of disciplines; as a result, it is challenging to narrow the scope of a review on the subject systematically, while covering the literature comprehensively. In an attempt to address these challenges, this chapter examines selected works that concern the intersection of traditional African medicine (TAM) and Western medicine (WM, sometimes also referred to as "allopathic" medicine or "biomedicine") in the Republic of South Africa, specifically in the context of HIV/AIDS treatment and care.

Procedures for this Review

The literature reviewed herein was identified by conducting queries using the search engine PubMed in October, 2011. Searches were restricted to include only published English language research studies and articles involving humans. The initial search of works regarding "HIV Africa", "Medicine, African Traditional", and "HIV treatment" produced 159 results. Adding the search criterion "South Africa" produced 82 results from which approximately 50 articles were selected. Articles were read to determine whether or not they informed the purpose and/or background of the present study. Studies excluded at this phase were primarily studies conducted in or about Southern Africa (as opposed to the Republic of South Africa). The researcher identified

several additional articles that were fitting and informative of the present topic while reading the retrieved articles. Those articles were added to those reviewed as appropriate. Two relevant articles were added in March of 2012, following an updated search using the same search criteria.

Despite limiting the search of literature to South Africa and HIV/AIDS treatment and care, research in this area remained extensive, with investigations and interventions crossing disciplines, methodologies, and study populations. It was clear in examining the literature that traditional medicines and practices are a part of African and South African culture, that the issue is multifaceted, and a relevant area of exploration. This review discusses varied approaches that have been used to study the complex intersection of TAM and WM in the context of HIV management in South Africa, and in doing so, exemplify the current knowledge and gaps that were the impetus for the investigation that followed.

The Body of Literature

Researchers have employed varied techniques to examine the phenomenon of TAM use in South Africa; in fact, research methods employed are as varied as the topic itself. The qualitative, quantitative and mixed methods used across studies are a function of the cross-disciplinary nature of TAM research in South Africa. There are studies in the realms of biomedicine, anthropology, ethnography, sociology, behavioral sciences, and epidemiology (among others), many of which take different approaches or have different motivations for examining a topic that, across disciplines, is regarded as a relevant aspect of South Africa's ethos.

In spite of the wide scope of the research regarding the intersection of TAM, WM and HIV in South Africa, a number of themes are prevalent across the literature reviewed herein: 1) accessing TAM by patients is ubiquitous in South Africa; 2) feelings about the utility of TAM are varied; 3) feelings of mistrust are prevalent between and among stakeholder groups (WM doctors, patients, TAM community), and 4) there is increasing support for unifying the traditional and biomedical paradigms.

Findings to Date

TAM in South Africa: Pervasive But Often Not Discussed by Patients. In 2006, UNAIDS estimated that 80-85% of black South Africans made use of traditional healers' services in both rural and urban areas (cited in Peltzer &Mngqundaniso, 2008). Most studies recognize this and acknowledge TAM and its practitioners ("traditional healers") as pervasive in South Africa; one study even reported that traditional healers outnumber Western medical practitioners ten to one in resource poor settings within South Africa (Shuster et al., 2009). In 2008, Peltzer et al. systematically sampled HIV positive patients from three hospitals in KZN and used a questionnaire to determine their use of traditional, complementary and alternative medicines. The findings from that study indicated that 80% of the patients who participated, none of whom had started receiving antiretroviral therapy (ART) for treating HIV, voluntarily reported using any TAM in the past 6 months (Peltzer et al., 2008a). Another review of the literature on the prevalence of traditional, complementary and alternative medicine in South Africa concluded, generally, that TAM and complementary medicines are likely to be used by "substantial proportions of the general population" in South Africa (Peltzer, 2009, p.

175). Many researchers site wide use of TAM as a rationale for investigating the topic in the context of HIV management (Cook et al, 2009; Littlewood et al., 2011; Peltzer, 2009; Peltzer et al., 2008; Peltzer, et al., 2008a; Tshibangu et al., 2004).

Several investigators have called for further research to better understand the scope of TAM use in South Africa, but these investigators also acknowledge that the inherent sensitivity and complexity of the topic make it difficult to do so (Littlewood et al., 2011; Peltzer, 2009; Peltzer and Mngqundaniso, 2008), For example, one article suggested that HIV positive patients receiving ART may be reluctant to disclose TAM use to their medical providers because they fear they will receive worse medical treatment if their doctor(s) knows they consult TAM (Reid, 2008, p. 448) . Another study reported that Western health care providers' perceptions of TAM may influence whether or not their patients report it, suggesting, for instance, that if a patient believes that his/her doctor thinks TAM is ineffective, it will not necessarily discourage the patient from using TAM; rather, that patient would use it in secret, and not report it (Thomas et al., 2010).

The literature attributes the widespread use of TAM to several factors, including the accessibility and affordability of TAM practitioners, as opposed to WM practitioners. In their case study of one community in KZN, Campbell et al. (2008) found that traditional healers are easily accessible to community members, and that many accept credit as payment for services—attributes that researchers believe facilitated the success of these practices in the setting, as opposed to seeking out WM care. Other studies affirm behavioral models suggesting direct relationships between long-standing traditional beliefs and health behavior (Golooba-Mutebi, et al., 2007, Liddell, et al., 2006). One

study in a rural district found that "folk beliefs concerning illness and illness causation influence the decision whether to select traditional or [traditional herbal] therapy" (Golooba-Mutabei et al., 2007, p. 177). A different study out of South Africa involving traditional healers (Shuster et al., 2009) noted the utility of TAM as opposed to Western medicine for treating the ultimate cause of illness (as opposed to the proximate cause of illness, which explains "how an illness physically occurred") (Shuster et al., 2009, p. 19). The authors upheld the importance of biomedicine in treating physical symptoms that result from illness), but suggested that TAM is still necessary and as a result, widespread (Shuster et al., 2009).

A Nuanced Understanding of TAM's Role in Treating HIV

Across the literature, messages regarding TAM—its prevalence, accessibility, utility, history, efficacy and safety—are varied (Cook et al., 2009; Nyika, 2007; Peltzer et al., 2009; Peltzer et al., 2010). This could be the result of distinct methodologies used across studies; for example, a 2010 study out of South Africa found that ART-naïve (and HIV-status unknown) survey respondents thought it would be difficult to stop using traditional medicine after initiating ART (Simon et al., 2010). Other researchers have reported decreases in TAM use (at least *reporting* TAM use) among patients on ART, especially within the first six months of initiation (Dahab et al., 2008; Peltzer et al., 2009).

Many studies embrace the range of findings (some even contradictory) about TAM, WM and HIV as an indication of a complex intersection of tradition, beliefs and health-related behavior. For instance, while a number of studies posit TAM as a barrier

to safe and effective HIV management, the same studies (and many others) discuss the importance of TAM in the provision of care for PLHIV. Specifically, Dahab et al. (2010) examined baseline factors potentially predictive of poor ART treatment outcomes, and reported that positive attitudes towards TAM were associated with poor ART adherence, yet for that reason, concluded that training and counseling paradigms for HIV care providers must evolve to include traditional medical practitioners (Dahab et al., 2010). Similarly, Simon et al. determined that not believing folk remedies can cure or treat HIV was associated with ART acceptance, but thought it was important to consider traditional beliefs in the provision of ART for PLHIV (2010).

A review of international literature about complementary treatments in the context of HIV/AIDS between 2007 and 2010 (Littlewood et al., 2011) further stressed the diverse opinions and findings around the intersection of complementary/alternative treatments and HIV/AIDS. Findings from the review indicated that there is no consensus across the literature regarding the use of TAM and ART in HIV management and that more research is needed to understand the quality-of-life implications that are inherent to the intersection (Littlewood et al., 2011).

Mutual Distrust is an Impediment to Successful Treatment

The relationship between trust and TAM use is implicit and explicit throughout the literature involving patients, Western and traditional health care providers alike. Some studies have discussed trust in the context of patient/health care provider relationships. For example, Peltzer et al., suggested that TAM use among HIV patients might decline following initiation of ART (Peltzer et al., 2009; Peltzer et al., 2008a), but

the same authors urged medical providers to screen for TAM in their patients, “keeping in mind, that patients may not fully disclose other therapies” (Peltzer, et al., 2008a, p. 267). The suggestion that patients may not be honest about their use of TAM is supported in other literature (Reid et al., 2008; Thomas et al., 2010). On the other hand, studies that have examined the role(s) of traditional healers as “guardians of community values” have noted the honesty and trust characteristic of most patient/traditional healer relationships (Liverpool et al., 2004, p. 824).

Other studies have discussed distrust towards biomedicine among patients and traditional healers. Specifically, a study regarding the rollout of highly-active ART in South Africa suggested that broad distrust of government-sponsored programs, including ART, is common among HIV patients (Simon, et al., 2010, p. 471). A different study involving traditional healers supported the notion that trust in biomedicine is lacking. That study reported that traditional healers in one community felt strongly that biomedicine had failed patients (Campbell et al., 2008). Yet another qualitative study published in 2008 reported mixed (but mostly negative) attitudes of nurses and traditional healers toward one another professionally, despite anecdotal discussions of positive experiences with TAM practices among (Western-medicine practicing) nurses (Mngqundaniso et al., 2008).

It is reasonable to say that mistrust among and between patients and health care providers concerning Western or traditional approaches to healthcare does not only lead to poor ART adherence in patients (as Dahab et al. suggest [2010]), but more broadly is a barrier to progress in the provision of a safe and effective standard of care for PLHIV (Dahab et al. 2010; Peltzer et al., 2009; Littlewood et al., 2011).

A Need to Build a Collaborative Bridge Between Two Traditions

A number of studies provide insight into the status on the ground regarding traditional and Western medicine, and the potential for collaboration between practitioners from both traditions, particularly in the context of managing and/or preventing HIV (Peltzer et al., 2006). "…Traditional healers…constitute an extensive network potentially capable of expanding and simplifying access to comprehensive HIV care through various entry points" (Homsy et al., 2004, p. 1724). Another study goes further, concluding that if traditional healers are excluded from the struggle against AIDS, "the social, behavioral and cultural factors that allowed the AIDS pandemic to flourish on this continent will never be eliminated, even in the idealistic situation where an effective drug or vaccine reaches the majority of the Africa people" (King et al., 1997, p. S223).

Other researchers, too, posit TAM and its practitioners as central to an effective fight against HIV/AIDS, despite difficulties in unifying the approaches (Cook, 2009; Liverpool et al., 2004; Mills et al., 2006; Morris, 2001). A 2006 controlled study out of KZN found significant effects following an intervention in which traditional healers were trained in HIV/AIDS, STI and TB prevention. The study found that traditional healers were highly prepared to work with and refer patients to WM facilities, but that willingness did not result in a greater number of referrals to biomedical practices following the intervention (Peltzer et al., 2006a).

Progressive collaboration between TAM and WM traditions and efforts to regulate and credential traditional health practitioners have been many, and the literature

refers to a number of TAM practitioner unions, associations and collaborative initiatives throughout Africa (Baleta, 1998; Giarelli, 2003; Green et al., 1995; Tshibangu et al., 2004). Still, despite the African Union naming the past decade one for traditional medicine, a significant gap between the approaches still exists on the ground (Bateman, 2004; Chinsembu, 2009; Liverpool et al., 2004; Littlewood et al., 2011). Traditional health care remains largely "marginalized, unregulated, and unsubsidized" (Morris, 2001, p. 1190), and to date, many collaborative efforts have slowed (Bateman, 2008).

There remains continued support for adapting current medical paradigms and standards of care to include both traditions and there is an acknowledged need in the literature for more research into the efficacy and safety of common traditional medicines (Bateman, 2008; Campbell et al., 2008; Dahab et al., 2010; Dahab et al., 2008; Liddell et al., 2006; Mills et al., 2006; Reid et al., 2009; Tshibangu et al., 2004; VanBogaert, 2007). In the context of HIV care, research supports the notion that "…collaboration is not a departure from ART" (Chinsembu, 2009, p. 32), that the two belief systems are complementary, not competing, and offers insight into how the two traditions could work together safely (Homsy et al., 2004; Shuster et al., 2009). This was recently supported by a study in Zimbabwe that found two herbal drugs to be effective in *reducing* adverse reactions to ART among HIV patients receiving the treatment (Mudzviti et al., 2012). Homsy, et al. (2004) propose a "triple role" for TAM practitioners in HIV care, which could include complementary care provision, adherence counseling, and advising referral (p. 1724). Pinkoane et al. have even suggested a model for the incorporation of traditional healers into the national health care delivery system of South Africa. Their proposed model calls for governmental policy change and legitimization of traditional

healing, so that traditional healers can act as "official partners" to the biomedical community, essentially allowing patients to have an equal choice in the modality of care they receive (2012).

Limitations in the Body of Literature

A Largely Silent Voice: Traditional Healers Are Seldom Engaged Directly in Studies

One of the primary limitations in this body of literature is the disproportionately small number of studies that engage traditional healers (or other practitioners of traditional medicine). This is not to say that literature fails to consider the role of TAM or traditional healers; indeed, all of the articles and studies reviewed here do. Still, the populations that comprise most research on TAM and HIV management do not often include traditional healers themselves. Study populations have engaged HIV positive and HIV-status-unknown patients, patients receiving ART (Dahab et al., 2010), patients who have not yet initiated ART (Peltzer et al., 2009; Ragnarsson et al., 2009), community members who have any experiences with TAM, and myriad members of the biomedical community who participate in and have opinions regarding the intersection of TAM and WM in the provision of care for PLHIV across varied hospitals (Campbell et al., 2007; Golooba-Mutebi and Tollman, 2007; Liddell et al., 2006; Peltzer et al., 2008a). Engaging these participants is entirely appropriate, and researchers have learned a great deal about individual and structural motivations for health seeking behaviors, including traditional and biomedical approaches to care.

Nevertheless, engaging traditional healers' voice in the academic literature that informs so much policy change seems critical, particularly as momentum for a dual

system of healthcare that includes both biomedicine and traditional medicine increases. Few studies reviewed herein sought the perceptions of traditional healers. One study that did was conducted by Shuster, et al. and examined motivational factors that could increase ART acceptance among traditional healers (2009). A study by Green, Zokwe, and Dupree in 1995 engaged traditional healers in their assessment of a training program for HIV/STI prevention. Another study that included traditional healers was conducted by Peltzer, Mngqundaniso and Petros (2006) to investigate the knowledge, beliefs and practices of traditional healers in South Africa. The only other study (of those reviewed herein) that included traditional healers as participants was conducted by Mngqundaniso, Nolwande and Peltzer in 2008 and captured the attitudes of both traditional healers and Western health care nurses towards one another. With the exception of the latter two, even the studies that did include traditional healers reflected an evident bias toward the Western medicine paradigm. Instead of seeking a richer understanding of the experiences of traditional healers, researchers appeared more interested in TAM's instrumental value – that is in learning how traditional healers might better serve the Western medical community with ART adherence or STI prevention programs, for example.

That there are at least twice as many works that reference traditional healers and TAM, but do not share the voices of TAM practitioners themselves, is noteworthy, particularly because the majority of these studies support a dual system of health care that includes Western and traditional medical paradigms (Baleta 1998; Bateman 2004; Cook 2009; Giarelli 2003; Homsy 2004; Mills 2006; Morris, 2001; Reid, 2008). The near absence in most studies' methodology of going to the TAM practitioner source directly

results in a commensurate gap in the literature that might otherwise give voice to the traditional healing community and advance a better understanding of its practices. If progress is to be made in addressing the HIV crisis in South Africa, more research should directly engage TAM practitioners.

Investigators Incorrectly Assume That TAM Use is Primarily to Manage HIV

Another pervasive limitation in the literature about TAM and WM in the context of HIV management is the assumption of a direct relationship between TAM use and HIV management that is not necessarily correct. Studies that suggest TAM as a barrier to ART adherence, for instance Peltzer et al., 2009, ask patients about TAM use in the context of ART and position TAM use as binary. This approach is not sensitive to the subtle difference between TAM use for HIV (i.e. in competition with ART) and TAM use for reasons unrelated to HIV (e.g. to protect the house from spirits or to communicate with ancestors). The finding from Thomas et al. (2010) that patients did not tell their Western health care providers about traditional medicine use that was unrelated to their health, supports that it is critical to capture the subtle distinction(s) regarding *intention* of TAM use (and to include intention of use in the discussion of TAM as a barrier to ART adherence), rather than approaching TAM use as a binary behavior. Several studies reviewed herein (Dahab 2010; Dahab 2008; Peltzer et al. 2009, Peltzer 2008a; Simon 2010) could be reexamined in this light.

Conclusion

An increasing amount of research supports the integration of biomedical and traditional systems of health care delivery. As such, it is critical that researchers and practitioners alike understand the many factors that influence the use TAM in varied circumstances and among diverse populations. There is ample room for research that fully describes TAM use in a way that illuminates efforts toward a safe and effective collaboration between traditional and biomedical traditions.

To date, research has comprised different segments of the South African community at large. In spite of the cultural, societal and institutional barriers to conducting research that engages traditional medical practitioners, qualitative approaches that engage varied stakeholder groups pertinent to TAM use in HIV management will complement the vast amount of research that already exists around this topic. Complete integration or even consensus building need *not* be a goal of future research in this realm; however, synthesizing new perspectives with findings to date will greatly support understanding and advancement, ideally for the benefit of the people who live in this context.

Equipped with the knowledge that TAM is ubiquitous, that perceptions about it are varied, that issues of trust are prevalent throughout stakeholder groups, and that support for mutual understanding and collaboration is growing, the present investigation sought to help close the gap in the literature by engaging traditional health practitioners (among others) in working toward productive collaboration between traditional and western medicine. None of the research on this topic in this region has been conducted in the context of a semi-private, faith-based institution, like McCord Hospital, where perceptions of patients and staff could be unique. Exploring a widely studied

phenomenon in this distinct setting and incorporating the viewpoints of medical providers from different paradigms at the same time will provide fresh insight into TAM use among ART patients A new understanding will not only provide the basis for future collaborative efforts at McCord and places like it, but will also inform the larger discussion of how to better bridge two health care paradigms which share the common goal of providing efficacious treatment and care to HIV patients in South Africa.

METHODS

This exploratory study was designed to better understand concurrent use of TAM and ART among PLHIV who receive ART at Sinikithemba Clinic (Sinikithemba), a renowned subsidiary of McCord Hospital in Durban, South Africa. This research is a sub-study of an ongoing investigation entitled "Risk Factors for Virological Failure and HIV-1 Drug Resistance in Durban: A Case Control Study" (herein referred to as RFVF). RFVF is a study out of McCord examining potential factors for HIV positive patients to be failing their first ART regimen (VL > 1000 copies/mL), including the potential use of TAM (among other things). RFVF investigators proposed this sub-study to explore TAM further as a potential risk factor for HIV treatment failure, and to determine how to best discuss the topic with patients and providers. This study addressed the research questions presented in Table 1.

Table 1. General and Specific Research Questions addressed by this study.

	Research Question(s)
General	• What are Sinikithemba patients' and WM/TAM practitioners' perceptions of the role of TAM in HIV treatment?
Specific	• What are the experiences and attitudes regarding TAM among HIV patients receiving treatment at Sinikithemba? • What are the attitudes towards TAM within the context of HIV treatment among providers at Sinikithemba? • What are the opinions of TAM's role for treating PLHIV among TAM practitioners in the Durban community?

Research Context

McCord Hospital, the location of this study, is located in Durban, South Africa. Durban is a port city on the eastern coast of South Africa in the province of KwaZulu-Natal (KZN). Though geographically among the smallest of South Africa's nine provinces, KZN has the second largest population of all the provinces and is arguably among the places in the world most affected by the HIV/AIDS epidemic. At 17.8%, KZN has the highest reported HIV/AIDS prevalence of all provinces in South Africa, with prevalence estimates for particular subgroups within the population (e.g. women who visited antenatal clinics in KZN) as high as 31.8-40.8% (Rice, et al., 2007). Durban and McCord Hospital (McCord) were selected as the study site because of the tremendous impact of the HIV epidemic in the area and because of McCord's reputation for being at the forefront of managing patients on HIV treatment. There are also a number of established research collaborations between doctors/researchers at McCord and Emory University, which helped facilitate adding this investigation to the ongoing RFVF study.

Conducted between June and July 2011, this study was based in Sinikithemba, a clinic located within the McCord campus. McCord and Sinikithemba are semi-private facilities. Whereas services provided in the public sector are free of charge and those obtained at privately operated hospitals are paid for entirely by the patients, semi-private hospitals like McCord provide partially subsidized services, with government grants, private donations, subsidized government programs and/or patients covering the remainder of their incurred costs. McCord houses a 142-bed inpatient facility, three operating rooms, a day surgery ward, and support services including a pharmacy, laboratory, and an X-ray center (McCord Hospital website, "Main Hospital", 2011).

McCord self-identifies as a Christian hospital, but provides services to all patients, regardless of religious affiliation. Since its founding over 100 years ago, the hospital has become a central institution in its community by contributing education, research, and training "well beyond its size and location," particularly in the realm of HIV management and treatment (McCord Hospital website, "About Us", 2011, par. 2). McCord is regarded as a model of what a semi-private institution can offer in the way of standard of care and access to medical services including ART and other services for PLHIV in South Africa. It has spearheaded innovative programs and initiatives in HIV/AIDS management and care and has contributed novel and rigorous research to the global body of literature on the subject.

Started in 1996, Sinikithemba currently provides comprehensive services for HIV treatment and management. Its patients are mostly black South Africans. The predominant language spoken among patients is isiZulu (many patients speak English as a second language). In realizing its vision of providing "cutting-edge, comprehensive care for patients with HIV and their families," Sinikithemba offers on-site consultation, HIV testing and counseling, education, and adherence counseling for ART users (McCord Hospital website, "Care and Treatment Services at Sinikithemba," 2011, par. 2). It also provides wellness and palliative care services for adults and children and has been at the forefront of the 2004 increased ART rollout in South Africa, helping 8,000 people in accessing ART, including 1,000 children (McCord Hospital website, "Care and Treatment Services at Sinikithemba," 2011). Sinikithemba also houses an on-site pharmacy and childcare center. The various research initiatives at McCord and Sinikithemba largely focus on the "spectrum of immunological, psycho-social and health

economic facets of the HIV pandemic" (McCord Hospital website, "HIV Research," 2011, par. 2). RFVF and this investigation represent such efforts.

Study Design

This exploratory, cross-sectional study is the first to use exclusively qualitative methods within RFVF and is intended to describe the current perceptions of TAM among HIV positive patients receiving treatment at Sinikithemba. This topic is complex and sensitive, particularly in the context of a hospital like McCord, where the use of traditional medicines is strongly discouraged due to concerns that it could negatively affect ART adherence or, possibly, cause harm from adverse effects or medication interactions. An interpretive approach and qualitative research methods were thus used to "… understand the contextual influences on the research issues" (Hennink et al., 2011, p. 9)—specifically, TAM and HIV management in this context. The investigators wanted to emphasize "the meaning of human behavior; the context of social interaction, and the connection between subjective states and behavior" (Patton, 2008, p. 431) for various key stakeholder groups: patients who might be balancing both approaches, WM providers and TAM practitioners. What does it mean for a patient to have available TAM and ART in the context of HIV management? How do TAM practitioners interact with patients managing HIV? How do Sinikithemba providers understand their patients' perceptions and behaviors regarding TAM and ART?

This study employed a team of researchers and investigators from Emory University in the United States and from McCord Hospital in South Africa, all of whom played key roles in study design, ethics approval and data collection.

Data Collection Process: Local Research Team Members. To address the challenge of capturing accurate and unrestricted information about this sensitive topic, two local, Zulu-speaking study personnel were engaged in the study, who had no affiliation to Emory or McCord: one, a South African TAM practitioner and psychologist from Durban who served as a co-investigator, and the other, a graduate student from the University of KwaZulu-Natal (UKZN) who served as a research assistant. These study personnel were experienced in using qualitative methods and received additional training by the study team on ethnographic methods, qualitative field research, and the specifics of the present investigation over a four week period, which included practical interviewing sessions. .

Data Collection Process: Participant Recruitment, Enrollment, and Consent. The study population comprised three groups: 1) HIV+ Sinikithemba patients on ART; 2) medical providers at Sinikithemba (doctors, HIV counselors, and nurses); and 3) TAM practitioners from the Durban and KZN communities. Seeking the perspectives of these three stakeholder groups was important in understanding different perspectives and experiences about TAM among patients, Sinikithemba providers' perceptions of patients accessing TAM, and the feelings of TAM practitioners regarding their role in HIV management. All participants were over the age of 18.

Patients. A total of 24 HIV+ patients receiving ART at Sinikithemba were recruited to participate in the study from among those already participating in the RFVF study. Recruitment was limited to RFVF participants present at the clinic on recruitment

days to overcome difficulties of contacting patients in the community. Patients were recruited immediately after a clinic visit upon completion of RFVF study procedures. Recruitment was conducted by a research assistant who provided potential participants with information about the study in a private location at Sinikithemba and invited them to participate. If they were interested, the research assistant administered the consent document in isiZulu (or English if requested by the patients), collected contact information, and added them to a list of potential study participants from which final participants were selected. As was explained on the consent form, not all patients who consented became study participants. Four of the 24 recruited patients declined to participate during the consent process.

The principal investigators and co-investigators purposively selected patients for participation from among the remaining 20 ‘screened and consented’ patients. Patients were selected to provide diversity in gender and VF status (indicative of success or failure of first-line ART). Willingness to participate in an in-depth interview (IDI) versus a focus group discussion (FGD) and patient availability were also considered in participant selection. A total of twelve patients were selected and enrolled as participants in the study, four men and eight women. Two enrolled patients (one male and one female) failed to show up for the FGD; thus six participants were participated in IDIs and four took part in a FGD. Across all selected patients, five patients were failing ART (“with VF”) and five patients were not failing ART (“without VF”).

Sinikithemba providers. Fourteen providers, including doctors, counselors and nurses, were recruited from among all Sinikithemba health providers. Recruitment criteria included working at Sinikithemba for over six months and working specifically in

the adult HIV management program as opposed to the pediatric, obstetric, or male circumcision programs. Providers were recruited in person at Sinikithemba, offered information about the study, and asked if they would be interested in participating in one 60-minute IDI. Providers who agreed were told that they might be contacted for participation. Six providers were selected for participation based on their position within Sinikithemba and their availability for an interview, including two counselors, two certified nurses, and two doctors. Five of the providers were female and one was male. Participating Sinikithemba providers were contacted via telephone to arrange an interview time. One recruited provider was unable to complete study procedures due to illness. Consent from the remaining five was obtained, and they were enrolled at the time of their interview.

TAM practitioners. A total of 11 active TAM practitioners were recruited from the greater Durban area. Recruitment criteria included having an active clientele at the time of recruitment and self-identifying as one of the three prevalent types of TAM practitioners in South Africa relevant to this study: Isangoma (diviner), Inyanga (herbalist) or Umthandazi (prophet or faith healer) (Table 2).

Table 2. Descriptions of three prevalent TAM practices in South Africa. (Adapted from Cook, 2009, p. 262)

TAM practice (Zulu name)	**Description**
Isangoma (diviner)	"…intermediaries between humans and the supernatural world. They are called to their profession by the ancestors and/or a prolonged illness that Western medicine is unable to treat."
Inyanga (herbalist)	"…people who have a knowledge of natural substances, i.e., plants and animals that can be used for therapeutic purposes."
Umthandazi (prophet or faith	People who "…diagnose and treat patients with prayer, candles, or water."

healer)	

A research team member, who was also a Traditional Healers (Inyanga) and the gatekeeper to the TAM practitioner community identified TAM practitioners for recruitment based on her knowledge of TAM practitioners in the community. After phoning TAM practitioners to provide information about the study and assess their interest in participating, the gatekeeper selected 11 participants to balance gender and type of traditional healing practice (Isangoma, Inyanga or Umthandazi). Through the FGDs, investigators found that many participating TAM practitioners identified with multiple practices (not just one), further widening the representation of each type of practitioner across the FGDs (Table 3).

Selected TAM practitioners included individuals known personally to the gatekeeper, individuals reachable by telephone, and individuals whom the gatekeeper felt would contribute varied experiences and opinions in an FGD. Although there were three FGDs conducted on three different days, two of the FGDs comprised all but one of the same TAM practitioners. This is due to the fact that one FGD had to be repeated. That is to say, FGD1 and FGD3 comprised nearly all the same participants (only one participant in FGD3 had not participated in FGD1).

Table 3. Breakdown of type of TAM practitioner by FGD. Most individuals identified with multiple TAM practices. Numbers reflect the distribution of representation of each traditional practice across FGDs.

TAM practice	**FGD 1 (n= 5)**	**FGD 2 (n=5)**	**FGD 3 (n=5)**
Isangoma	3	1	3
Inyanga	2	1	3
Umthandazi	3	4	4

Upon selection, all TAM practitioners were telephoned by the gatekeeper and given the time and location of their group discussion. Participating TAM practitioners provided consent and were enrolled at the time of their FGD.

Data Collection Process: Instrument Development for IDI and FGD. In preparation for data collection, the research team developed both IDI and FGD research instruments over several months after reviewing relevant literature and narrowing the scope and objectives of the investigation. Additionally, the McCord Research Ethics Committee (MREC) which consists of community members, healthcare providers and researchers, offered valuable insight and suggestions into both the study design and instruments used. South African members of the research team read the instruments to ensure that the meaning and motivation behind questions was clear and to ensure that South African culture was accounted for. Concerns were communicated to the whole research team and changes made where necessary, prior to data collection. All instruments were translated into isiZulu by a local translator then back-translated into English by local research assistants prior to data collection to ensure that the questions in isiZulu communicated what the investigators had intended when writing them in English. Changes to IsiZulu translations were made where needed.

During data collection, research staff took field notes, either during the interview/discussion or immediately following. This was helpful in strengthening data collection in response to real-time experiences in interviews with participants. For example, in early interviews with Sinikithemba providers, one of the opening questions that intended to serve as an ice-breaker elicited an emotional and extremely personal

answer from a respondent, who disclosed that she was HIV positive within only minutes of beginning the interview. Although the questions were not changed in subsequent interviews, the interviewer was able to anticipate the responses to this opening question better, and delivered the question with more caution than in the initial interview.

Data collection methods and procedures were approved by the MREC and the Emory University IRB prior to data collection.

Data Collection Process: A Combination of Instruments for Different Study Participants. A total of eleven IDIs and four FGDs were completed. Six IDI were conducted with patients and five with Sinikithemba providers. One FGD was conducted with patients and three with TAM practitioners (Table 4). In addition to understanding the perceptions and varied experiences of participants regarding TAM in the context of HIV management, employing IDIs and FGDs across the different groups was helpful in exploring their utility in different segments of this population.

Table 4. IDI and FGD used in different segments of the participant population.

	IDI	**FGD (N total participants)**
Patients	6	1 (4)
Sinikithemba providers	5	
TAM practitioners		3 (11)
Total	**11**	**4 (15)**

IDIs and FGDs with Patients. Research team members determined it would be most appropriate for patients to speak one-on-one with an interviewer in a location away from Sinikithemba because the topic of TAM and HIV management is sensitive, complex, and largely proscribed in clinical settings. Investigators hoped this format and

setting would help to elicit candid answers and build trust between participants and the interviewer. Because TAM use is strongly discouraged in this setting, a FGD format was chosen hoping it could allow patients who otherwise would not have felt comfortable discussing the topic speak freely (i.e., if they saw that they are not alone in their experiences or beliefs). As this study was the first step in investigating within a study conducted at McCord, investigators chose to use both formats—IDIs and one FGD—with patients to see if and how findings differed and to get a better sense of which format may be more suitable for future research on the subject in this context.

In both the IDIs and the FGD, patients were asked to describe their experiences at the clinic and with ART, their experiences with TAM practices, and if and how their access of TAM had changed since they started receiving ART at the clinic. Patient IDIs and the FGD were conducted in isiZulu in locations away from Sinikithemba. IDIs lasted 60 minutes and took place in a public park or at the participants' residences, when requested. The FGD lasted 90 minutes and was conducted at a private office in downtown Durban, easily accessible to patients via public transportation.

IDI with Sinikithemba Providers. Investigators used IDIs to gather information from Sinikithemba providers for three reasons: 1) investigators thought providers would have a wide range of beliefs and experiences with TAM use in HIV management and wanted each person to be able to speak about his/her feelings in detail; 2) investigators were concerned that having providers from varied positions of power within Sinikithemba (doctors, nurses, and counselors) in a group discussion might inhibit free discussion; and 3) logistically, because Sinikithemba is generally understaffed, getting

multiple providers together at the same time and date for a FGD would have been challenging and/or insensitive to the providers' time.

In their interviews, Sinikithemba providers were asked to describe their experiences related to Sinikithemba patients receiving ART and their use of TAM, if any. They were also asked about their perspectives on the practice of TAM in the treatment of HIV. IDIs were 60 minutes in length and were conducted in English at a private space within Sinikithemba, after business hours.

FGDs with TAM Practitioners. TAM practitioners participated in FGDs to ensure that they were as comfortable as possible in discussing TAM use in HIV management. Investigators were concerned that TAM practitioners might feel defensive if requested to speak one-on-one with an investigator. They wanted to make sure that the TAM practitioner community felt it had a strong voice, strong representation, and that its perspectives were truly valued and respected. To capture potential differences in opinion between genders, both genders were represented in all FGDs. The three predominant types of TAM practitioner (Isangoma, Inyanga, and Umthandazi) were also represented across FGDs because investigators wanted their potentially different roles and perspectives in HIV management represented in the discussions.

TAM practitioners were asked about their experiences with managing HIV/ AIDS as traditional African medicine practitioners. They were asked about PLHIV who seek their services as TAM practitioners, as well as their feelings and perspectives about ART and the future of TAM and Western medicine in managing HIV.

All participants (patients, Sinikithemba providers and TAM practitioners) were compensated 150 South African Rand (SAR) [US$20] at the time of their IDI or FGD.

Ethical Issues in Data Collection

The researchers were highly sensitive to potential ethical concerns in this investigation, the most critical of which were the medical implications of talking about strongly discouraged practices (i.e. TAM) in the context of McCord. It was critical that patients not equate the present study with McCord's longstanding position on concurrent TAM and ART use. There was legitimate concern that merely asking questions about TAM use might be seen as endorsing it. Investigators consulted with the MREC on how to address this problem and took several steps to dissuade patients from misunderstanding the study as a validation of concurrent TAM/ART use. During the recruitment and consent phase, the research assistant introduced herself, highlighting that she was not a doctor and not affiliated with McCord. Following each interview and the group discussion, patients were given an informational sheet (in isiZulu) explaining the potential risks associated with concurrent TAM/ART use. The form, which bore the McCord Hospital logo, also encouraged patients to speak to their medical provider(s) if they were consulting TAM or thinking about doing so.

Investigators, however, worried that by assuring confidentiality at the outset of the interview and then giving patients an informational sheet from McCord following the interview, which discouraged TAM practices, patients could feel their trust had been betrayed after opening up to researchers. The MREC specifically requested this stipulation be included, and that TAM use be discouraged following interviews with patients. Ultimately, for the safety of the patients, the delivery of McCord's

informational sheet at the end of the interview accommodated the ethics committee's request.

Data Analysis

IDIs and FGDs were digitally recorded with participants' consent and were stored on a password-protected server (accessible on the Internet). Interviews conducted in English were transcribed verbatim by a research assistant; interviews conducted in isiZulu were simultaneously translated and transcribed verbatim into English by a hired, professional interpreters/transcribers who were native isiZulu speakers. All transcripts were spot checked for accuracy by a research team member (who is a native isiZulu speaker) and de-identified prior to importing them into MAXQDA10.

Data analysis was completed over a four-month period from January to April, 2012. All transcripts were read and reviewed numerous times throughout data analysis and analytic memos, or "…sites of conversation with ourselves about our data" (Saldana, 2009, p. 32) were used to notate themes and interesting points throughout the data, to raise questions, and to pinpoint areas in need of further investigation. Codes were developed using four transcripts and were validated in two ways: 1) by having a non-study team member read the same transcripts and note themes and "potential codes;" and 2) applying developed codes to more data and verifying that all themes were captured in the current code structure. Once developed, defined, and refined, final codes were applied across the data. Investigators then reviewed groups of related codes for emergent themes.

Investigators invoked Grounded Theory as a general approach to data analysis to account for the "multiple and shifting standpoints of the researcher and the researched" (Charmaz and Bryant, 2010, p. 406) and to understand TAM use in HIV management in the context of Sinikithemba, based on themes grounded in data. Data from each stakeholder group (patients, Sinikithemba providers, TAM practitioners) were analyzed separately first because investigators wanted to uncover the underlying "story" and develop a narrative for each stakeholder group that was grounded in data. Prevalent themes in all three stakeholder narratives were cross-validated using a sequential process of defining emergent themes in one subset of the study population then comparing those themes to what other subsets of the study population said.

Data Quality

IDI and FGD facilitators asked the appropriate questions of participants across FGDs and IDIs, however, in all FGDs, the format of discussion was heavily facilitator-based (i.e. the facilitator asked one question of the first participant; when that participant finished speaking, the facilitator asked the same question of the next participant, and went around the circle like so). There was very little participant-to-participant discourse because most participants directed their answers to the facilitator(s), rather than one another. This could have influenced the data by making it difficult to understand how topics play out in the context of a group, because they were not engaging in the discussion of a topic as a group, rather as individuals.

In IDIs specifically, there were several instances when the interviewer asked leading questions (e.g. "So you are saying you do this?", as opposed to an open-ended

question, like “Do you do this?”). Instances of interviewer leading were noted during data analysis, and answers in response to a leading interviewer question were not considered, unless the interviewer was clarifying something a participant had already said.

Study Limitations

Selection and/or Recruitment Bias. Not all Sinikithemba providers were available or interested in participating in this research. When approached for recruitment, many expressed that they were too busy. Others felt they had little experience or knowledge of TAM and or had “nothing to say.” Only one doctor participated in an IDI; therefore, the perspective of doctors was disproportionate to that of nurses and HIV counselors.

That the research team member recruiting TAM practitioners and facilitating FGDs was an active member of the TAM practitioner community could have biased the participants selected and may have narrowed the population of TAM practitioners selected. Also, different social and professional statuses of participating TAM practitioners, compounded by gender and age differences, certainly influenced the context of the TAM practitioner FGIs. There may have been hidden cultural and social norms at play throughout the FGDs that influenced responses. Both of the aforementioned limitations were not addressed and could have influenced the discussion and themes that emerged from those FGDs.

Despite investigators’ effort to overcome barriers to open and honest dialogue about this topic, participants may still not have felt entirely free to share their deepest

thoughts about the issue of TAM use in HIV management, for fear that there would be negative repercussions. This was an inherent component of this investigation, and apart from conducting IDIs and FGDs outside of McCord with facilitators unaffiliated to McCord, investigators were not able to address this limitation.

RESULTS

HIV Patient Perspectives and Use of TAM

Traditional African Medicine (TAM)

When patients referred to traditional medicines they typically cited “traditional herbs,” “herbs,” and “the roots of plants,” which were commonly boiled and ingested, steamed and inhaled. Few patients mentioned non-herbal healing, such as communicating with ancestors to determine the cause of illness, or similarly, providing a “spiritual examination.” Patients mentioned few traditional medicines that they indicated were specific for HIV treatment. Those that were mentioned included Ubhejane, a well-known traditional herb found in Durban, rumored to “cure” the HIV virus, and a treatment described only as being “from Dr. Gumede’s workshop” in Durban.

TAM as Cultural Identity

Most patients described the use of TAM as a vital part of Zulu and African culture. Even patients who did not use TAM themselves acknowledged it was integral to African cultural identity. Many patients had used TAM during their lifetime, attributed their use of TAM to traditional beliefs and practices, and stated that it reflected simply “living in an African setting.” One patient described how TAM practitioners are vital to African beliefs in a “spiritual realm.” When explaining reasons for TAM use, many patients began with “As a Zulu person….” or “As Africans…,” indicating that traditional medicine use is implicit in their beliefs and behavior. One woman described that despite one of her relatives dying after using TAM, she still believed that TAM is an important

and effective tradition for Zulu people. The following excerpts highlight patients' use of traditional medicine in daily life.

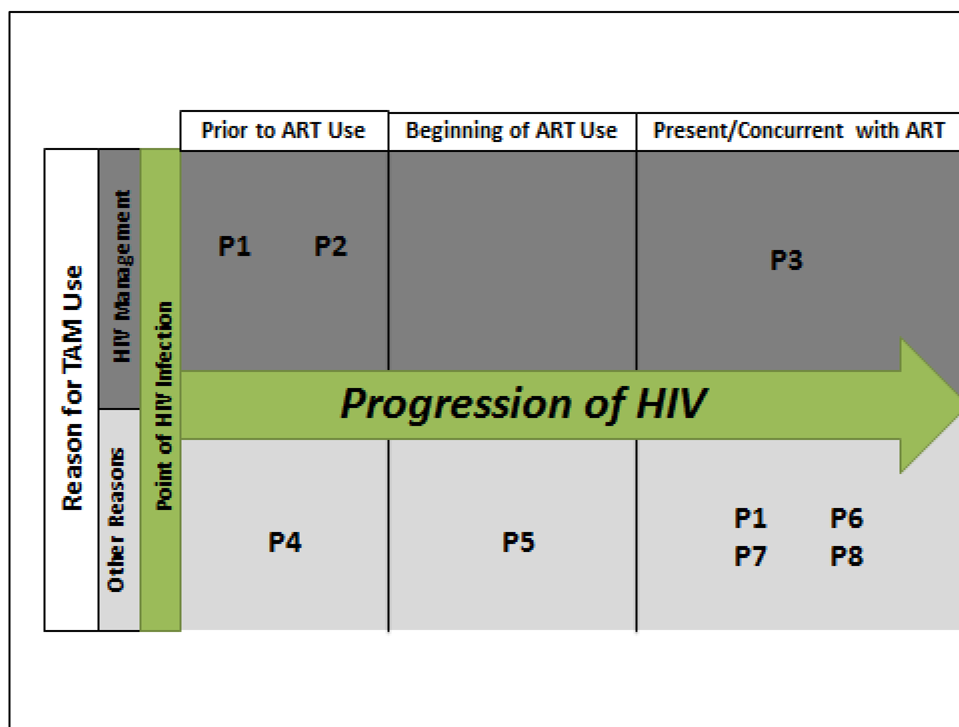
> *….due to the fact that I grew up and still live in an African setting, in the neighborhood there is a traditional healer that I like to visit when I've got headache. – Female patient*
>
> *It is through our belief as Africans that we believe in the spiritual realm. So the traditional healers act as mediators between us and the ancestors. Most people visit traditional healers seeking a spiritual examination, and some believe that their problems can only be solved by traditional healers. Faith in the healers plays a vital role in the African community. – Male patient*
>
> *As Zulu people we use [traditional medicine] in the home….Sometimes it does help. Yes, that's how I would define it, that back in our religion and in rural areas people are still using it for particular things. These are old beliefs, but they do work. – Female patient*

While the majority of patients reported participation in TAM practices at some point in their lifetime, only two patients had never accessed TAM at all. One stated "To be precise, I am clueless [about traditional medicine]."

Intersection of TAM and HIV Treatment

Figure 1. Reported Use of TAM for HIV Management and Other Reasons[1].

[1] P1, P2, etc. each represent a distinct patient who reported ever using TAM in his or her lifetime. P1 appears twice in the diagram because this participant indicated that she used TAM for HIV and non-HIV related reasons at different stages of her management of HIV.



Of those patients who used TAM, the context of its use was varied. While some patients stated that their use of TAM was directly related to managing their HIV, most patients reported using TAM for other reasons that they did not perceive as related to HIV management. Figure 1 shows the context of TAM use and its intersection with HIV management. Only three patients reported using TAM directly to manage their HIV. One patient (P1 in Figure 1) used TAM at the early stages of the disease as she believed it would boost her CD4 count. Another patient (P2 in Figure 1) used the traditional herb 'Ubhejane' at the beginning stages of his illness as he believed it would "heal" HIV. The excerpts below illustrate these patients' beliefs.

> *Before I started to go to Sinikithemba, my CD4 count was high so I didn't have to take [ART]. But there are traditional herbs that help to boost a patient's CD4 count. Many people are using traditional herbs. For example, traditional herb mixtures are contained in bottles, and I have used them in the past to boost my*

CD4 count. (Long pause) Yes, I have used them, but I stopped when I began taking [ART] because they don't work together. - Female patient

I began using a famous traditional herb called Ubhejane, but it failed to heal the disease (HIV). Initially Ubhejane created an illusion that I was getting better, but it didn't really help. In addition, I tried using Dr. Gumede's medicine [in downtown Durban], but it didn't help and I gave it away…My health improved when I started using [ART], and I could even feel it in my body. – Male patient

Both patients who reported using TAM to manage HIV at the early stages of the disease (P1 and P2) reported that they stopped upon initiating ART, although P1 reported using TAM while on ART at a later stage, but not to manage HIV (that is why this patient appears in the diagram twice; her use of TAM for non-HIV reasons will be discussed below).

Only one patient in this study (P3 in Figure 1) reported using TAM concurrently with ART directly to manage her HIV. This patient was using TAM long before she was diagnosed with HIV and continued to drink and steam the roots of plants after she began ART. Although she reported "mixing" TAM and ART only "once a year," she described that using TAM was part of her Zulu heritage that she is proud of and she believed that it "brings [her] health" to use both TAM and ART concurrently to manage HIV. This patient's story of TAM use and HIV management is described in Case Study 1.

Case Study 1:
Pride and Concurrence:
A Case of TAM Use

"I myself, as an African I'm proud of my culture and I deeply believe in traditional herbs and I am not ashamed to tell you straight that I practice the art of traditional herbs as well as western medicine." – Winnie Mbatha [2]

Winnie Mbatha "grew up in a house that [used] traditional herbs" and remembers going through a coming of age ceremony during which traditional herbs were mixed

[2] Name has been changed to conceal patient's identity.

with water and used for “steaming and drinking as a way of cleansing your body. It’s a ritual performed for a person to move from childhood to adulthood.” When she thinks of traditional medicine, the first thing that comes to mind “is that it can cure me.” Winnie has seen evidence of this in her sister, who gave birth to two HIV negative children while living with HIV and using only traditional medicines. Winnie has “strong faith” in traditional medicine for treating HIV and says her own use of traditional herbs has changed little since beginning ART. She believes traditional herbs are very helpful for managing HIV and that they “work perfectly in [her] body,” saying that she has benefited from using traditional medicines and ART concurrently for the past six years.

Winnie uses traditional medicines for HIV management in various ways, but usually by drinking and steaming the roots of plants suggested by myriad traditional healers she regularly visits. She also drinks a traditional herb given to her by her aunt: “Even though it is not supposed to be mixed with [ART], I do it once a year.” Because she feels traditional practitioners are less strict than Western providers, Winnie says she is able to use traditional herbs prescribed “in [her] own way.” For example,

> *The traditional healer will tell me to take a quarter of a particular herb, and I will dilute that with water. Then I will drink the mixture. But I won’t dilute it if I’m feeling strong. That is where the Western doctors lack understanding. They never listen to how you go about taking the herbs; they just reject them immediately.*

In addition to increasing her appetite, Winnie feels that traditional herbs have helped to manage her HIV by “giving me health” while allowing her to continue her traditions. Winnie feels strongly that traditional treatments do the same job as Western medicine, but are more natural, less permanent, and easier to recover from. Winnie understands how traditional herbs work in her body. On the other hand, she does not understand how or why Western medications work and finds some biomedical “jargon” difficult to grasp. She is not pleased with the service she receives at the clinic where she receives ART and says going to the clinic is frustrating and “disgusting” because the staff nurses give preference to their friends.

The majority of patients reported using TAM for reasons they did not attribute directly to HIV management. Among these patients, one (P4 in Figure 1) said he used TAM before learning he was HIV positive because he felt his health “was not in good shape.” Another patient (P5 in Figure 1) described using TAM briefly and in secret when

she first initiated ART to manage her high blood pressure, but not to treat HIV specifically. For example,

> *I remember very well when I began taking [ART], my blood pressure was high and I secretly bought traditional herbs to try to bring my blood pressure down. But it didn't work out; whenever I tried to use [the traditional herbs], I would throw up….I ended up not finishing those traditional herbs. – Female patient*

Other patients also described using TAM for reasons unrelated to HIV management. These patients (P1, P6, P7, and P8 in Figure 1) gave varied reasons for using TAM. One patient (P6) described visiting a traditional healer to treat headaches and swollen feet. Though these symptoms might in fact be related to HIV infection or a side effect of ART use, this patient did not explicitly discuss these symptoms or subsequent TAM use in the context of HIV (or as side effects of ART).

> *…in the neighborhood there is a traditional healer that I like to visit when I've got headache. She usually makes me inhale some incense. Yes, sometimes if my feet are aching or swelling, she prickles me with her needles …. drawn from the bowl that contains traditional herbs…. – Female patient*

P1 in Figure 1 described her use of traditional medicine (CD4 boosters) prior to initiating ART but reported that she stopped using TAM to manage HIV when she began ART. The same participant said she uses TAM despite being on ART for reasons unrelated to HIV, because "as a Zulu person [my] home needs to be protected." This participant did not elaborate upon or describe the TAM used for such protection. A different participant (P7) described using TAM while on ART because "besides HIV/AIDS there are still other diseases which affect us." This patient did not explain which diseases she was referring to, or what TAM she consulted to address them, but added "at least we are educated about [HIV], so if we continue taking traditional herbs, we will not take stronger ones which will conflict with the [ART]." This notion of taking less 'strong'

TAM while on ART to treat other illnesses was confirmed by other participants in the focus group discussion, even those who had not reported using TAM concurrently with ART.

> *Interviewer: So, in other words you all are saying that even though you stick to taking [ART], you will never stop taking traditional herbs because you still believe in them and they can cure other diseases?*
> *All Participants: Yes.*
> *P2: Absolutely, we will stick to those traditional herbs which are not strong. No induced vomiting.*
> *P6: We use traditional herbs for steaming ourselves.*
> *P5: You should take holy water from the traditional healers and drink it.*

The remaining patient who used TAM while receiving ART (P8 in Figure 1) stated that it was never used to treat HIV, despite her work as a traditional healer herself, as described below.

> *I specialize as a traditional healer, but I don't personally use traditional herbs to combat HIV/AIDS…I carry a lot of traditional herbs with me, but I don't use them for my health. I rely entirely on the [ART]. Whenever I have problems, I consult my ancestors and they give me guidance. – Female patient*

Although many patients reported concurrent use of TAM and ART, none considered this as "mixing" treatments because each was used for a different purpose: ART was used for HIV treatment, and TAM for other illnesses or purposes. Even the patient who acknowledged using both TAM and Western medicine at the same time (P3) said she "mixed" only once a year. Patients reported hearing several reasons for not mixing TAM and WM. For many, refraining from mixing reflects the advice of Western health care providers who have told patients not to combine TAM and ART because it may have a harmful interaction with ART. During the focus group discussion participants tried to explain why Western doctors discouraged TAM while on ART, as shown below.

If you mix the two, you have jeopardized the [ART] the doctor has given you. It will reverse the positive effects of that treatment. – Female patient

I think the negative effect of mixing traditional herbs with [ART] is that traditional herbs are strong and that [ART is] strong, and they clash. That clash has a negative effect on the kidneys. That is why you find cases where patients taking [ART] end up dying of kidney failure all of a sudden. – Female patient

Mixing the two means you are not taking responsibility for your own life. – Male patient

Still other patients thought that TAM is ineffective in treating HIV and that nothing is as effective as ART. One patient said she did not mix TAM and ART because she wanted to know which medication was responsible for improving her health. While the predominant feeling across all patients was that "mixing" TAM and WM is a bad idea, a few patients felt doing so posed no threat:

Mmmm, well, in my opinion, I wouldn't say that it's a bad thing to mix the two. People can use both medicines simultaneously. – Male patient

That is the only frustration I've encountered for using Western medication because we don't have to mix them up with our own traditional herbs. My biggest desire is take both medications at the same time….– Female patient

Support for "mixing" TAM and ART did not correlate with whether a patient was currently using TAM. One patient who supported mixing TAM and ART was not currently using TAM for any reason; the other, a traditional healer, had never used TAM for HIV management.

Western Health Care Provider Perspective and Knowledge of TAM

All participating doctors, nurses, and HIV counselors from Sinikithemba were able to identify different types of TAM practitioners and distinguish the healing rituals/practices typically related to each. Providers described that an "Isangoma"

consults with ancestors to understand the illness within a patient's body, whereas an "Umthandazi" uses prayer and "holy water" for healing and believes "he has the spirit in him," and "Inyangas" are herbalists who suggest herbal treatments without explaining the cause of the illness. When asked to describe TAM, providers stated specific medicines their patients had discussed, for example, CD4 boosters and "Ubhejani" (a well-known mixture of herbs in South Africa said to cure HIV), "traditional herbs," and other plants or roots that come in "those bottles." The herbs described are typically boiled, ingested, or applied topically to alleviate illness or ailments. The following excerpts illustrate different providers' descriptions of three common types of South African TAM practitioners. The detail given by providers about TAM and providers of TAM seemingly contradicts reports from patients in this study that Western health care providers dismiss TAM without understanding how it is used. The following quotations from Western health care providers indicate that their knowledge of TAM is factual, based on what patients and traditional healers in this study reported themselves. For example,

> *[An "Isangoma"] is a sort of a diviner…. [They] will actually use different things like bones and try and contact the [ancestral] spirit…to try and cure a problem that you have. Try and find out what's a problem that you have. – Male doctor*

> *Eh, also, we find that some [traditional faith healers, "Umthandazis"] will help people by praying. They will pray….for the water [and give it to] you to drink. – Female nurse*

> *[A traditional herbalist, "Inyanga"] just knows that if this person comes with this abdominal pain I have to give this [traditional medication]. If the person comes with a headache I have to give [a different traditional medication]. That's what Inyanga does. –Female nurse*

Western Healthcare Providers' Perceptions of TAM for HIV Treatment

All providers had negative attitudes towards using TAM specifically for HIV management, and many discussed negative clinical consequences associated with TAM use. The common example given was organ damage. Other providers implicated TAM as a barrier to open and honest discussion between patients and providers, reporting that "we only find out clients are using TAM when there is a problem." Again, the most common "problem" providers referred to as evidence of TAM use was organ damage. The following passages illustrate two providers' perceptions about physical consequences of TAM use.

> *… [TAM use] has serious effects and implications on different organ systems, and we see that very commonly. Very, very commonly. We see it in surgery; we see it in general medicine. I mean across the board in every speciality. – Male doctor*

> *Patients used to have this traditional medicine, but they. . . it was not helping. It would just help for few days. Then after a couple of days it would start to destroy the patient inside. The liver would not function. The kidneys [would not] function because of this medication. Patients used to say, "Hey, you know at so and so there's a bottle that is sold there for 200 rand." Going there because they were sick. They would go there and for couple days the patient would become brighter, but after that the patient would just drop down and then we would check and the blood results would be just haywire. Everything is haywire. Everything is not functioning well because of this traditional [medicine]. – Female nurse*

An additional concern, described by a nurse, was that TAM treatments for HIV can initially give the illusion of treating HIV by boosting a patient's CD4 count, but ultimately patients end up at the hospital in worse condition and near death. As the national treatment requirement states that only patients with CD4 counts under a certain threshold can receive ART, TAM was criticized for raising a patient's CD4 count and thereby denying them ART, as shown in the following passage.

> *There [was a patient] that came with a CD4 count of 500. And he was dying and we [could not] do anything because the CD4 count was high. He [had] been taking [traditional medicines] that boosted the CD4 count…..- Female Nurse*

Several Western health care providers believed traditional herbs to be efficacious, but like patients, the majority of these providers reported that TAM cannot be used to manage HIV. Though few Western health care providers shared anecdotes of exceptional patients who have reported using TAM alongside ART to manage HIV, no Western providers supported the use of TAM to manage HIV because they said it "clashes in the [body]." As expressed in the following excerpts, Western health care providers thought patients should only use ART to treat HIV because there is no traditional alternative to ART.

> *…. there is nothing…that can help… a person with HIV except [ART], that's what I believe. And also, like, it's the same [as tuberculosis] treatment. There is nothing, no…traditional healer or, or anyone [who] can heal [tuberculosis] or HIV AIDS with traditional medication….There is nothing so far that I know. – Female nurse*

> *… [ART] is the second best thing to a cure. It's not even the second; it's the first best thing to a cure. You have [ART] or you die. –Female counselor*

Some providers also expressed strong mistrust for TAM practitioners. Nurses and counselors reported that many TAM practitioners are illiterate and so lack medical knowledge and "don't understand what's going on in the body." As a result, some Western providers felt that TAM practitioners cannot accurately diagnose illnesses. In the passage below, a nurse castigates TAM practitioners who convince patients to pay for ineffective traditional treatments for HIV.

> *And every two weeks [patients] just to go for that bottle to take it because they want to stabilize HIV in the system. And so, I feel sorry for the people then, because…it's robbery. For certain it is not true. - Female Nurse*

Western Healthcare Providers' Perceptions of Dual Use of TAM and ART

Nurses and doctors believed few patients at Sinikithemba use TAM. In contrast, HIV counselors believed that TAM was widely used among patients. There were two prominent beliefs among all providers: First, an acceptance that TAM is an integral part of Zulu culture and thus necessary for treating some illnesses; and second, a strong belief that TAM cannot effectively treat HIV and should not be used concurrently with ART.

First, Western health care providers and patients shared similar beliefs that TAM is a critical component of traditional Zulu culture, stating that the first thing that often comes to mind in thinking of Zulu culture is that using TAM is simply "the way we were raised." Providers felt traditional beliefs in TAM are deeply rooted and difficult to change because they are tied to cultural identity. In the following quotation, a nurse discusses the expectation of Zulu culture to use TAM for health care.

> *Mmm, I think we, as Africans, and black people, we strongly believe in our culture. Because sometimes…. if you are a Zulu person or you are from a Zulu nation, you have to use the roots from there to treat yourself or to deal with whatever problem that you will have. So if you believe in that, yah, then you have to use it. - Female nurse*

Second, although some Western health care providers accepted the cultural relevance of TAM, these providers (one doctor and one nurse) felt strongly that only ART should be used to treat HIV. They stated that some ailments can only be treated by TAM for example, "tagata" (witchcraft), while HIV should only be treated with ART. The following excerpts juxtapose the conflicting perceptions among providers that ART must be used to treat HIV, but that TAM may be necessary for other ailments.

> *So, I don't think that there will be a place [for TAM] if the patient is gonna be starting on [ART]. If the patient is gonna be starting on [ART], the patient should be solely on [ART]…. - Male doctor*

If the person is being [bewitched] by the other person, the herbal medication it does help…. Really, there are things that need to be treated by [traditional healers]. Because when we go to the Doctor with (short pause) [hysteria], the Dr. will say "I don't know," because everything is fine. Vital signs, they are fine, what is wrong with the child? ….those things, need to be treated by [traditional healers] because they know what is happening. - Female Nurse

The notion among WM providers that traditional beliefs compel TAM use is also supported by patients' reports that TAM is used for non-HIV ailments (albeit at the same time as ART); for example, TAM may be used to protect their homes from evil spirits, while ART is used to manage their HIV. In sum, patients and providers both felt that ART must be used to treat HIV and that TAM is necessary for treatment of other ailments according to cultural tradition.

Providers also highlighted familial pressures on patients to use TAM. They indicated that familial pressure was explicit for treating a range of health ailments, but also implicit in that *not* seeking TAM for illness would be seen as socially unacceptable. One provider described her own familial pressure to use TAM when she was first diagnosed with HIV:

You know, the first thing that my mother bought for me, it was traditional meds. Because….by that time they had this strong belief that [traditional medicines] can cure the HIV. And I used to drink this, those herbs until I came to know and to understand that this thing was not helping me at all. - Female counselor

Some providers stated that patients' disclosure of their HIV status to family members led to pressure from family to use TAM. Patients whose families practice TAM might also feel pressure to conform and use TAM to be respectful of these cultural practices (when they visit their families). One counselor described the importance of taking TAM in front of family members who offer it, to show them that you are

"accepting their help." This can lead to dual use of TAM and ART among patients who do not want to refuse TAM offered by family members.

Some providers discussed patients' use of TAM out of "desperation" to cure HIV. Counselors stated that many patients simply want to be cured of HIV and that TAM, such as Ubhejani, boast a "cure" for HIV in a short period of time. Therefore, patients use traditional medicines seeking to be cured, because they know that ART will not actually eliminate the disease and must be taken for rest of their lives only to manage the disease. In the following excerpts, Western healthcare providers highlight desperation to cure HIV as a reason why patients may consult TAM.

> *So some of the people, they are trying to get rid of HIV from their bodies by taking traditional stuff. And also because, if you go to Isangoma or Inyanga who's [claiming] to cure HIV, he will tell you that… you have to buy a certain number of bottles of traditional stuff, then you'll be cured…so you won't take it for the rest of your life. It won't even take you a year to be healed from HIV. So some of the people they are just going there because they are desperate. They want to be HIV free, and they are hoping they will just get rid of it, but it doesn't happen. – Female counselor*

> *[Patients with HIV] know that there is no cure for HIV, and they strongly believe that something that cannot be cured with Western medicines, it can be cured by traditional meds. So, most of the people when they come here, most of them have used different kinds of, eh, traditional meds because they are so desperate. – Female counselor*

It is important to note that providers' perception that patients sought TAM out of desperation for a cure was not reported by patients themselves. Instead, patients expressed *hope* that Western and traditional practitioners would collaborate to find a cure for HIV, but no patients receiving ART attributed their current use of TAM to desperation.

The majority of providers felt that patients who used TAM to manage HIV did so out of ignorance or lack of knowledge about HIV/AIDS and the efficacy of ART. Many

providers felt that patients would not consult TAM if they understood how HIV works in the body and ART's effect. Nurses and counselors felt that the patient counseling at Sinikithemba was effective in discouraging concurrent use of TAM and ART. This was validated by patients who discontinued TAM for HIV management once initiating ART. In the quotation below, a nurse explains how informing patients on ART about the consequences of mixing ART and TAM is enough to discourage TAM use.

> *Yeah, [using TAM and ART at the same time is due to a] lack of, it's lack of understanding, lack of knowledge. Really, it's lack of knowledge. Because when you inform [patients] and when you give them information about [ART] and the consequences of this [traditional] medication, they will stop [using TAM]. – Female nurse*

Only a few Western health care providers acknowledged that patients may use TAM while they are on ART for reasons apart from HIV management, such as bringing success to business, sexual performance, or other life problems. Though patients verified the sentiment of using TAM while on ART for reasons outside of HIV, the reasons given by providers in the following examples differ from those patients reported.

> *Mostly it's the men. Women really they are afraid of taking this stuff; they are good. But the males, they do because they say it makes them stronger. Even if they go for sexual intercourse it will make them stronger if they will take this [traditional] medication. – Female nurse*

> *…many business people [use] traditional meds to protect their businesses… Mostly men, they think that for their sexual entertainment they need to use traditional meds….for their sexual entertainment. [Females] strongly believe some of them, they're going to be very sexually active on these traditional meds…. – Female counselor*

> *…. what is it that is wrong with me? Why I'm not getting married? Why I'm not getting someone who loves me? Why I'm not getting children? Then, maybe, even why I'm not getting employed? Because I've been looking for a job for a long time and I'm not getting employed. Then [patients] will start going to [traditional healers]. – Female counselor*

Traditional African Medicine Practitioner ("Traditional Healer") Perspective Regarding TAM

Why Patients Visit Traditional Healers

Traditional healers gave two principal reasons why TAM plays an important role in health care provision for many patients. First, they felt that TAM is central to Zulu cultural identity and health care. Second, they believed patients trust traditional healers more than Western health care providers. As a result, traditional healers said many patients seek their services to address a range of issues, both medical (clinical) and nonmedical. For medical issues, traditional healers reported consulting with patients for many different illnesses, which included diabetes, stroke, back pain, problems sleeping and swollen feet. Patients confirmed that traditional healers are sought for symptoms such as headaches and swollen feet. Traditional healers also stated that many people consult their services for reasons unrelated to disease. Patients and Western health care providers agreed, recognizing that people consult traditional healers often for nonmedical problems like "tagata" (bewitchment). One traditional healer described nonmedical issues she has seen in her patients below:

> *People come to us because they have problems; they are hindered….The most challenging issues that we encounter with these patients are poverty and the lack of food, having many children to feed, high unemployment, and the lack of shelter. – Female traditional healer*

Traditional Healers and Cultural Identity. The majority of traditional healers reported that patients use TAM for treating illness or solving problems related to patients' and healers' shared Zulu identity. Traditional healers believed it was common "as black people who also live together" for patients, especially those who think they are HIV

positive, to consult a traditional healer before going to a hospital. One traditional healer said, simply, "….that is how it happens." In the following excerpt, one traditional healer described how patients' cultural identity as Africans entrusts patients' faith in traditional healers above Western healthcare providers.

> *I would say that the belief of Africans is that they have a strong faith in traditional healers. That is why they consult with us first when they become sick…There is a role that we play, particularly amongst Africans. Africans really believe in our methods of healing more than those of the Western doctors. – Male traditional healer*

In addition to strong faith in traditional healers, several traditional healers believed that patients seek their treatment because they attribute illnesses to Zulu diseases (e.g., witchcraft) that only traditional healers can treat. Some traditional healers felt that, in the case of HIV, patients were ascribing their HIV status to bewitchment due to an inability to accept their HIV status. In this situation, traditional healers explained that they encourage patients who do not know their HIV status to get an HIV test at a biomedical facility because traditional healers themselves are unable to test for HIV status, as the passage below explains.

> *Sometimes you can see and the symptoms [of HIV] are obvious, but as traditional healers we don't have the means or expertise to detect the virus. We've been trained in the clinics about the symptoms of HIV/AIDS, so we can identify them. But we don't have the authority to make a clear diagnosis. Sometimes, due to the fact that we like to help our patients, I admit that we befriend them and give them advice to go and see the doctor because all of the symptoms are present. For example, we will tell our patients that they are losing weight or that their skin color is changing. We tell them go to the clinic and have their blood tested. – Female traditional healer*

Traditional Healers as Trustworthy. All traditional healers believed common Zulu identity and language create a strong and trusting patient/healer relationship, saying "patients want us to solve their problems because they trust us." Whereas traditional

healers described themselves as compassionate and welcoming, they said their Western healthcare counterparts are money-hungry and in the business of healthcare for the wrong reasons. Several traditional healers felt that Western healthcare providers lack confidentiality and are outwardly critical of patients who are HIV positive. As a result, traditional healers believed patients prefer being treated by healers, who are sympathetic and non-judgmental. As evidenced in the following excerpts, traditional healers gave different reasons for gaining patients' trust.

> *…when a person with HIV comes [to me]… he comes because he wants to tell me which may happen that he hasn't told other people. He has kept it a secret. So he comes to tell me because…he trusts me… I am not the member of the family. I am different. So it is at that point he comes to tell me everything. – Female traditional healer*

> *…[A patient] may trust me because I am a faith healer, I believe greatly in the man above. – Female traditional healer*

Traditional Healers in the Context of HIV Management

All traditional healers acknowledged that HIV/AIDS is a legitimate concern in their communities. They described HIV as a "cunning" disease that has affected the Zulu community in epidemic proportions and is difficult to control. Although traditional healers recognized that they are often unaware of patients' HIV status because as healers they do not have the means to detect HIV and many patients themselves have not been tested, the majority of traditional healers felt many of their patients exhibit symptoms of HIV infection.

Traditional healers discussed their role in HIV management as two-fold: 1) to give and restore patients' hope for life, and 2) to treat opportunistic illnesses associated with HIV infection. No traditional healers believed they could "cure" HIV; rather, the

predominant feeling among traditional healers was that "you will help [a patient with symptoms of HIV] but you are not going to cure him completely."

Traditional Healers for Treating Symptoms of Opportunistic Infection. Many traditional healers described the efficacy of "traditional liquid medicine[s] that we will concoct with some ingredients" in treating what they define as symptoms of opportunistic infections that are characteristic of HIV infection, including sores, swollen lymph nodes or loss of appetite. In this role, traditional healers supported concurrent use of TAM and ART for managing HIV. This differed from the feelings of patients, most of whom felt that TAM and ART should not be used concurrently for HIV management. "…By and large," said a male traditional healer, "we feel that [ART is] complementary to traditional medicine." Traditional healers described the parallel role of TAM for treating various opportunistic infections in patients receiving ART.

> *Firstly we will give him that liquid traditional medicine to get rid of sores and then we'll give him the traditional liquid medicine that stimulate[s] appetite so that he will like food and thereafter a person gets better as he continues to take [ART]… - Male traditional healer*

> *Traditional herbs are strong, they really help. If a patient has a wound, then the traditional herbs will heal it. If a patient has swelling, the herbs will reduce the swelling, all while a patient is taking [ART]. So traditional herbs have their own way of working and [ART has its] own way of working. Both are necessary. – Female traditional healer*

Traditional Healers for Giving Hope. Giving patients hope in life was a role many traditional healers felt was central to their healing practice and their role in helping patients manage HIV. Several traditional healers explained that the first thing they do for HIV positive patients is restore their hope in life through counsel. Many traditional healers felt they were effective in restoring patients' hope in life because patients trust

them. When patients consult traditional healers with personal problems or feel "scared and lost," traditional healers said of themselves that they are welcoming, comfortable for patients, confidential, and trustworthy. The following excerpts illustrate how traditional healers view their role in managing HIV as tied to the restoration of hope for patients.

> *[For] me in particular [my role in helping patients manage HIV] is to restore hope where he has lost it and tell him that you can still make it. You can move forward. This is not the end. Life does not end here. – Female traditional healer*

> *…. [The role of traditional healers in managing HIV is] advising [patients] and giving them hope because….once you [contract] HIV, [having seen] the majority of people who ended up passing in this world, [patients start] counting the days and will give up. - Male traditional healer*

> *I comfort my patients so that when they discover that they are HIV positive, they won't hurt or lose hope. – Female traditional healer*

Among all traditional healers, there was an overarching sentiment that Western health care providers and traditional medicine providers are working toward a common end—the welfare of patients, many of whom are living with HIV. As a male traditional healer stated, "…the only thing is the culture that separates us; otherwise we are the same." Both Western health care providers and traditional healers felt they should come together in mutual understanding and respect, for the sake of patients who are sick.

> *Ah, according to my opinion, that would be a very good thing if traditional healers and Western doctors could work together, because they both share the desire to heal people. The problem is that we were divided from the start… We have to unite because Western doctors are healers just as I am a healer. We both direct our prayers to God in order to help our patients; we both ask for divine powers from the same God. –Female traditional healer*

DISCUSSION

Implications and Conclusion

This research captured the perspectives on the role of traditional African medicine(s) in HIV management of three distinct stakeholders in Durban, South Africa: HIV positive patients receiving ART at Sinikithemba Clinic, Western health care providers from Sinikithemba, and traditional healers from within the Durban community. Previous studies that have explored the intersection of TAM and ART in the context of HIV management have viewed TAM either as a barrier to or a mediator of safe and effective HIV treatment and/or adherence to ART, without taking into consideration the overall context and motivators of TAM and its relation to HIV management (Dahab et al., 2010; Dahab et al., 2008; Peltzer et al., 2009). This study identified the perceptions of key stakeholder groups to develop a more comprehensive examination of the nature and context of TAM use among patients managing HIV with ART. This study demonstrated that a complex intersection of beliefs and practices surrounds both TAM and Western medicine, particularly in relation to the treatment of HIV and provision of care for PLHIV.

Prominent Themes Across Stakeholder Groups

Findings from this research comprise three prominent themes. First, both health care providers and patients possess implicit knowledge regarding TAM and explicit awareness and knowledge regarding ART for HIV management. Further, TAM and ART were felt to serve distinctly different purposes for PLHIV amongst patients in this study population, indicating in particular that TAM use is not necessarily a departure from ART

(and vice versa), nor viewed as an alternative treatment. Additionally, visions of a dual or collaborative system of health care delivery differ between Western health care providers and traditional medical providers, particularly as they relate to HIV treatment and care.

Knowledge and Attitudes about the Role of TAM

Study findings show that all three groups--patients, Western health care providers and traditional healers alike--have a general knowledge of TAM such as "traditional herbs," "the roots of plants," "holy water," nondescript "CD4 boosters," and Ubhejane, a traditional "cure" for HIV popular in the Durban area.. This contrasts with findings of a recent study in Durban (Mbutho et al., 2012) which found that participating health care workers (including doctors, nurses, counselors, psychologists and social workers) did not possess a basic knowledge of TAM, based on self-reported answers to a voluntary survey, (Mbutho et al., 2012). Patients and traditional healers also noted the role of TAM and traditional healers in consulting with ancestors to predict (or understand the cause of) illness, "protecting the house", performing a "spiritual assessment" and counseling patients. Although findings from this study show general knowledge of TAM, feelings about the utility and efficacy of TAM appear to be context-driven and dependent on the reasons for TAM use. For example, most patients and Western health care providers acknowledge traditional herbs are useful in Zulu tradition (such as those used for "protecting the home") or treating illnesses that are the result of witchcraft, but neither patients nor Western healthcare providers believe traditional herbs are effective in treating HIV. These groups agree that only ART should be used for directly managing HIV.

Consistent with studies that have noted an ideological acceptance of ART among traditional healers (Shuster et al., 2009), traditional healers in this study are accepting of ART as an effective treatment for HIV, but more readily than any other stakeholder group support a complementary role for TAM in the direct management of HIV: treating the symptoms associated with HIV-related opportunistic infections (OIs) and restoring patients' hope in life through counsel and/or spiritual healing (prayer). This partially aligns with a number of studies that have encouraged the integration of traditional healers into HIV management, identifying them as talented (and culturally relevant) HIV-support or ART-adherence counselors. To date, however, these studies have not endorsed the use of traditional healers for the treatment of opportunistic infection symptoms (Cook, 2009; Homsy et al., 2004; Giarelli et al., 2003; Peltzer et al., 2009), an additional role identified in this study.

Duality of TAM and ART Use: Different Horses for Different Courses?

Patients in this study illuminate the important finding that individuals on ART who ascribe to TAM for cultural uses like protecting their home do not conceptualize TAM as an HIV-related health-seeking behavior; rather, use of TAM as a cultural phenomenon is perceived as entirely independent of behaviors related to HIV management among patients. Even patients who described TAM use for symptoms that are consistent with known side effects of ART (i.e. headaches, swollen feet), did not discuss their use of TAM to treat these symptoms as TAM use directly for HIV management. Additionally, although patients in this study discussed also using TAM for

culturally motivated reasons (e.g. protecting their homes), most patients indicated that cultural motivation to use TAM did not reflect an intention to treat HIV with TAM.

Previous studies have linked cultural beliefs directly to health seeking behaviors (including TAM use) in the context of HIV (Golooba-Mutebi & Tollman, 2007), but for the patients receiving ART in this study (many of whom noted the importance of Zulu culture in their lives), a strong connection to Zulu culture and use of TAM in daily life did not necessarily undermine their exclusive use of ART for treating HIV. Across the study population, results indicated widespread support for directly managing HIV with ART, even among patients who believed in the need for TAM (for other reasons). This finding differs from studies that have examined TAM as a culturally mediated behavior that negatively impacts adherence to ART (Dahab et al., 2010; Peltzer et al., 2009; Simon et al., 2010).

It is important to note that patients' acceptance of ART as a viable treatment for HIV did not make TAM use irrelevant in this study population. Patients who reported concurrent use of TAM and ART articulated that a commitment to ART for HIV management does not eliminate the perceived necessity for TAM for other reasons. That is to say, cultural reasons for TAM use do not disappear because a patient initiates ART.

The duality of TAM and ART use is further suggested by patients who use TAM and ART concurrently, but feel strongly that they should not be "mixed." These patients express a clear understanding of potentially harmful interactions between the TAM and ART and do not believe that they are mixing the two by using ART to manage HIV and TAM for other reasons apart from HIV. This discontinuity—that ART should be used independent of TAM for managing HIV, and the simultaneous understanding that TAM

is necessary in certain situations—raises an important practical question for patients who both believe TAM is necessary (culturally) and use ART to manage HIV. Presumably, a person living with HIV should use only ART for treatment. However, if the same individual seeks protection from spirits or wishes to observe a cultural practice that necessitates TAM use, he or she must use TAM. In this way, TAM and ART lead a parallel, often paradoxical existence. Patients themselves do not perceive this duality as 'mixing' treatments for HIV; rather, each type of treatment serves a different ailment—ART for HIV treatment and TAM for other issues even if there could be potential harm from concurrent use through drug interactions and/or adverse effects.

Western health care providers, by far the strongest proponents of ART in this study population, implicitly understand the notion of TAM and ART as distinct but parallel phenomena. They strongly encourage exclusive use of ART for managing HIV, yet understand the cultural reasons (specifically, witchcraft), that would necessitate TAM use. Findings from this study do not discredit the notion that consulting TAM to treat HIV is a barrier to ART acceptance or positive health outcomes. The findings here contextualize the use of TAM among patients managing HIV and note the important differentiation between ascribing to traditional African medicine treatments for HIV (which was not found in this study, but has been suggested in others i.e. Thomas et al., 2006) which could potentially undermine adherence to ART, and ascribing to TAM for reasons perceived by patients as unrelated to HIV at all (which was found in this study) and did not affect patients' positive feelings or commitment to ART.

The notion of TAM use among patients *with* HIV as opposed to TAM use *for* managing HIV is an important finding. It hints that TAM use is not an act of desperation

or ignorance, as some Western health care providers suggested, but a conscious and informed choice for different purposes than HIV treatment—one that does not necessarily compromise a patient's adherence to ART. This supports the shift in academic literature that recognizes TAM and ART (or Western medicine in general) not as competing paradigms that must be balanced, but as parallel traditions that are not by definition at odds with one another (Liddell et al., 2006; Shuster et al., 2009). This further supports findings from a 2006 case study regarding a faith-based AIDS program in South Africa, that suggested dual use of diverse health-seeking approaches was common among members of the study community, and dual use of ART and other modalities of care "has its own logic" among patients who use both (Thomas, et al., 2006, p. 4). Safety, rather than changes in ART adherence patterns, during concurrent ART and TAM practices then becomes the primary issue to address.

Different Visions of Collaboration Between TAM and WM

Findings in this study suggest support for the increasing perception that common ground exists for integrating TAM and biomedicine (Bateman, 2008; Giarelli & Jacobs, 2003; Homsy et al., 2004; Liddell et al., 2006; Littlewood & Vanable, 2011; Liverpool, 2004; Mills et al., 2006; Shuster et al., 2009; Tshibangu et al., 2004). On the one hand, Western health care providers in this study recognize TAM as central to Zulu patients' identities and acknowledged that TAM might be necessary recourse for patients suffering from a traditional illness (e.g. illness that results from witchcraft). On the other hand, traditional healers acknowledge the limitations of their practices in diagnosing HIV due to a lack of equipment and inability to perform blood tests. With the understanding that

TAM is implicit in the lives of the majority of patients managing HIV (whether or not they use TAM to manage HIV directly), Western health care providers and traditional healers discussed the importance of a dialogue between both traditions to better understand the practices of both paradigms.

The discourse around coming together herein illustrates the importance of considering the strengths of both traditional African and Western medical paradigms *from the varied perspectives of Western and traditional health care providers* in moving forward. Traditional healers and Western health care providers in the current study envision their roles in an integrated system of health care quite differently. This was evident in the contrasting ways the two groups discussed their roles in HIV management. Traditional healers stressed TAM as complementary to ART and described an active role in an integrated system, which included treating opportunistic infections and restoring hope for PLHIV. Western health care providers acknowledged TAM as necessary for some ailments, but not HIV, and described a role for traditional healers that included "raising awareness" of illnesses and using their extensive networks within communities to increase patient referrals to Western medical facilities for illnesses that traditional healers cannot treat (e.g. HIV). Discussions among traditional healers and Western health care providers supported coming together—physically and intellectually—to learn about each other's healing practices for different afflictions. However, traditional healers were skeptical of Western health care providers' ability to accept their healing practices without judging healers' training or education. This is consistent with the few findings in the literature that have addressed tension between traditional and Western health care practitioners and have found that traditional healers felt "nurses undermined their work

(did not accept TAM's efficacy in treatment and consequently did not refer patients" (Mngqundaniso & Peltzer, 2008, p. 380).

Previous studies on the use of TAM in the context of HIV management have posited TAM and Western medicine as parallel, sometimes polarized approaches whose use depends on multiple factors like availability and access to treatment and (Littlewood & Vanable, 2011). This, however, is not consistent with how patients in this study reportedly use TAM in practice. The findings here suggest implicit cultural motivators for TAM use that are independent of a patient's HIV-related health-seeking behavior(s). TAM for patients on ART is not binary, as is evident from the concurrent but complementary role of TAM for patients using both. For these patients, TAM is not a mediator of or a barrier to safe and effective HIV related health-seeking behaviors; it works in tandem and for a different purpose. To conflate the independent identities of TAM use for cultural reasons with TAM use for HIV management is to lose the nuanced distinctions that characterize TAM use for patients like those in this study population. Silo-ing TAM and WM as independent approaches to managing HIV justifies further research to understand the efficacy and physiological effect of herbal treatments for the treatment of HIV (Tshibangu et al., 2004). While critical for expanding, refining, and redefining the role of TAM in HIV management, that research does not inform the other substantial roles of TAM to treat symptoms of OIs (as opposed to HIV infection) or the role of TAM used outside HIV management.

Strengths and Limitations

This study was an exploratory study that employed qualitative methods to allow for rich data that captured perspectives of diverse stakeholder groups regarding the use of TAM for and in the context of HIV. This study design addressed a noted gap in literature by directly involving traditional healers. Other studies (e.g., Mngqundaniso & Peltzer, 2008) have engaged varied perspectives (e.g., nurses and traditional healers), but to date, none in South Africa have engaged doctors, Western health care providers, and traditional healers in the same study. The perspectives of traditional healers contributed immensely to the findings and themes revealed here.

This study worked to address the "taboo" nature of the discourse around TAM in clinical settings and by clinical practitioners, many of whom oppose TAM use (Peltzer et al., 2009; Peltzer et al., 2008a) by engaging local, isiZulu-speaking researchers with no affiliation to McCord hospital to conduct interviews and focus group discussions in locations outside of McCord. Investigators believe this added credibility to the interviews, put patients at ease, and allowed them to speak openly and candidly about a topic that often goes undisclosed among patients in clinical settings (Thomas et al., 2010).

In spite of the strengths of this study, it was not without limitations. Out of necessity, traditional healers were recruited through a single gatekeeper, which may have limited the range of experiences and/or opinions among traditional healers selected for participation.

Conducting interviews and group discussions with patients and traditional healers in isiZulu was a strength of the study design from the perspective of data collection, but the translation of data from isiZulu into English opened the possibility of inconsistencies

in translation. Two Zulu translators/transcribers were hired to translate recordings of patient IDIs and traditional healer FGDs from isiZulu into English. Translator/transcribers divided the recordings among themselves, that is, each recording was only translated/transcribed once, by one of the translator/transcribers. Transcripts were spot-checked for accuracy by a native isiZulu-speaking study team member, however, inner and inter-translator reliability were not assessed or accounted for with this approach.

Public Health Implications

This study provides a greater understanding of the way patients managing HIV conceptualize their own use of TAM, as individuals who value their Zulu cultural identities and as patients who value their health and wellbeing. The perspectives of Western health care providers and traditional healers in this study help contextualize patients' discussion of TAM use and HIV management by giving insight into the current situation regarding TAM and ART from the perspective of different modalities of health care (traditional African and biomedical).

This study was helpful both in illustrating that Western health care providers possess a basic understanding of traditional African practices and modalities of healing and in highlighting the need for future research that defines exactly how ART and TAM exist separately for PLHIV. The findings of this research suggest that recognition and understanding on the part of Western medical providers regarding TAM use among patients who also value ART could be helpful and contribute to a more harmonious standard of care for these patients. Previous research has noted the tendency of patients

not to disclose TAM use to their Western medical providers for fear of being judged or reprimanded (Peltzer et al., 2009; Peltzer et al., 2008a; Thomas et al., 2010); similar feelings were echoed among patients in this study as well. If patients feel that their Western health care providers understand that TAM use is not inherently a rejection of ART, however, this fear could diminish, and they could be more open to disclosing TAM use.

Changing the way Western medical providers regard TAM use could be challenging because of the popularity of research that has identified traditional beliefs as a barrier to ART adherence. However; many of these studies have regarded TAM use as a binary (yes/no) behavior and one directly related to HIV-health seeking behaviors, which as this study indicated, is not always the case. Larger-scale research that supports TAM as a separate phenomenon from HIV management and illustrates *safe* traditional practices among patients on ART could catalyze a departure from historically polarized feelings regarding TAM, towards a more nuanced understanding of TAM not as a threat (necessarily) to HIV management. Many Western and traditional health care practitioners are poised for this shift, as is evident in the proliferation of literature on collaborative efforts (Cook, 2009; Giarelli & Jacobs, 2003; Homsy et al., 2004; Reid et al., 2008).

If Western health care providers could embrace the idea that TAM use among patients on ART is not inherently a rejection of ART, support for finding safe and healthy ways to merge TAM and WM could continue to grow, provided ample knowledge of specific TAM that is safe for use among patients on ART is obtained. Researchers and policy makers might then be able to re-examine the status quo surrounding TAM in

specific care institutions (hospitals, clinics) and revise policies and practices to reflect up-to-date knowledge about the use of TAM among patients receiving ART. Revisiting current rules against TAM use in many Western health care facilities to reflect specific TAM that is known to have a negative effect on ART, for instance, could have positive implications for the patients and traditional healers who identify with these practices.

Engaging native Zulus who have been trained as Western medical practitioners in future exploratory research in order to deeply understand the ways these practitioners reconcile traditional beliefs and health paradigms with their Western medical training would be useful for identifying effective communication and/or education strategies as part of future collaborative efforts. This research in conjunction with research that engages traditional healers in understanding how to reconcile both medical paradigms (akin to Shuster et al., 2010) could also help inform the establishment of roles for TAM practitioners in and outside of Western care that maximize the strengths of both traditions.

Considering the future of the TAM, WM and HIV intersection highlights the critical need to understand different stakeholders' values—personal, cultural, professional and political—and makes evident that compromise will be crucial for progress. It also calls into question the ethical implications surrounding collaboration between TAM and Western medicine, some of which have surfaced in the literature about collaboration (i.e. intellectual property rights of traditional healers [Morris, 2001] and, conversely exploitation by traditional healers [Mills et al., 2006]). Is it ethical to impose national regulatory standards on traditional treatments, or does that miss the point? If it is ethical, how are the rights of traditional healers protected? If it is not ethical, where can

regulation begin? Even evaluating collaborative efforts would be an exercise in balancing competing values, as different stakeholders would likely have different criteria for success.

Conclusion

This study used qualitative research methods to capture the unique perspectives of PLHIV, their Western medical providers, and traditional healers in their community regarding the complex intersection of TAM and Western Medicine in the context of HIV treatment and care. Findings revealed implicit and explicit knowledge of TAM and ART, respectively, among all members of the study population, and among patients, a nuanced understanding of TAM's utility in the context of their management of HIV. Specifically, patients and providers in this study illustrated that TAM does not necessarily undermine adherence to ART and further, that TAM is not limited to herbal treatments that are ingested. The latter is important in recognizing the role of TAM moving forward, despite not yet having ample evidence that TAM does or does not result in adverse effects and drug interactions that could cause harm or limit the effectiveness of ART. That traditional healers and patients note the critical role of TAM and traditional healers for counseling or communicating with ancestors (practices that do not have the potential for drug interactions or adverse physiological effects in the body), gives hope to the possibility that distinct modalities of healing could each have a place in the delivery of care for PLHIV in South Africa someday.

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APPENDIX A

GUIDE FOR PATIENT FOCUS GROUP DISCUSSION

This group discussion will be moderated by research assistant.

Greeting in Zulu
Good afternoon and welcome. Thank you for taking the time to join our discussion. Today we are here because we have asked for your contribution to a research study called: "Perceptions of Traditional African Medicine and Antiretroviral Therapy at McCord Hospital in Durban". We will conduct a group conversation about your experiences with treatment for HIV.

I will start the recording of this meeting, please let me know if you are still comfortable with this.

*****Recording starts** (Start with **date** and **place**)

Personal Introductions in English
My name is Neliswa Dladla and I work for this project as a research assistant. I am also a student at UKZN where I am doing a Master's degree on Population Studies. Today I will be moderating this conversation. This is Ms. Claudia Ordonez; she is an anthropologist and one of the Principal Investigators for the study. She works for Emory University in the United States. This is Ms. Hannah Appelbaum from Emory University in the United States; she is a co-investigator in this study and is also doing the research work with the study for her Master of Public Health thesis.

General Information and "ground rules"
We will be conducting this conversation in Zulu, but please feel free to express your selves in English if you wish or to let me know if you will prefer to have all of our discussion in English. This group conversation will last approximately 2 hours.

We are doing this research study at Sinikithemba clinic because we are interested in learning about patients' experiences with ART and "umuthi wesintu" and also want to understand better how patients view Traditional African Medicine in their lives. We are aware of the importance of Traditional African Medicine in the Zulu culture and are not going to judge any practices or behaviors. You were invited to participate because you receive treatment at Sinikithemba. We want to listen to your opinions about the things we will discuss.

If you agree to take part in this research, we will be asking you some questions, but there is no right or wrong answer. We expect that you will have different points of view. Please feel free to share how you feel even if it is different from what other people have said. We are recording this session because we don't want to miss any of your comments. Your name and identifying information will not be included with your responses. No names will be included in any reports and your comments are confidential. The names of people here and what is said today should not be shared with others who are not part of this group.

Don't feel that you always have to respond to me. Please feel free to respond to something that has been said by someone else and also to agree, disagree, or give an example about what is being discussed. I am here to guide the conversation, listen and make sure everyone has a chance to share. We are interested in hearing from each of you. So, if you are talking a lot, I may ask you to give others a chance to talk. And if you aren't saying much, I may ask you if you would be interested in participating on what is being discussed. We just want to make sure you all have a chance to share your thoughts.

Let's begin.

PATIENT FOCUS GROUP DISCUSSION GUIDE

Opening Questions

1. Tell us your first name and why you started going to Sinikithemba for your ARV treatment.

Introduction

2. What do you know about Traditional African Healers and their treatment(s) for HIV and AIDS?

Traditional African Practices and Western Medicine care

3. Is the use of umuthi wesintu mentioned when you visit Sinikithemba clinic? Probe: What do you think providers at Sinikithemba think about using?
4. How do you think providers at the clinic view the treatment(s) that Traditional Healers (iSangomas) use for patients living with HIV and AIDS?
5. In terms of HIV treatment, describe the roles of iSangoma, Inyanga, and Umthandazi?
6. Why would someone living with HIV and AIDS visit a Traditional Healer instead of going to a clinic?
   Probe: For what reason(s) would people receiving ART use umuthi wesintu? For treatment of the disease or to treat side effects?
7. Can patients receiving ART speak comfortably to their Western Medicine providers about also using?
8. What are the opinions among patients at Sinikithemba about using umuthi wesintu while receiving ART?
   Probe: What are the opinions about visiting iSangoma, iNyanga or Umthandazi while receiving ART? Does using umuthi wesintu affect ART?
9. Do people's feelings towards using umuthi wesintu for HIV and AIDS change when they start receiving ART?
   Probe: How do you feel about being counseled against using umuthi wesintu while receiving ART?

Closing Questions

10. What do you think that Western Medicine providers should know about the use of Traditional African Medicine in HIV and AIDS management?
    Probe: Do you think that it is important to build a bridge between Western Medicine and Traditional African Medicine? Why?
11. Of the things we have talked about today, which are the most important?

12. Is there anything you wanted to say that you didn't get a chance to say? (or anything I should have asked that I didn't ask?)

"Thank you for your time today and for your participation."

Script for Informational Sheet from McCord Hospital:
"This is important information about your health that McCord Hospital has requested we pass on to you as a Sinikithemba patient and also as a participant in this research. As I explained it to you before, I don't work for McCord Hospital. However, I have been asked to read some statements from this informational sheet before I give it to you. Please take the time to read this information I am giving you on behalf of McCord Hospital."

The research assistant will then read the following statements from the informational sheet:

'If you have stopped taking your ART, are considering stopping, or if you are considering taking traditional or alternative medications, please talk to your medical provider to explain the reasons'

'ART should never be stopped unless your doctor has told you to do so'

'*You are encouraged to have an open and honest discussion with your doctor about all aspects of your health and health care'*

APPENDIX B

GUIDE FOR PATIENT INTERVIEW

This interview will be conducted by a research assistant. Claudia Ordonez (co-principal investigator) and Hannah Appelbaum (co-investigator) will be available on the site of the interview but will not participate in the interview. The entire interview will be conducted in Zulu unless the participant requests otherwise.

Greeting
Good afternoon and welcome. Thank you for taking the time to come to this interview. Today we are here because we have asked for your contribution to a research study called: "Perceptions of Traditional African Medicine and Antiretroviral Therapy at McCord Hospital in Durban." We will have a conversation about your experiences with treatment for HIV.

I will start the recording of this conversation; please let me know if you are still comfortable with this.

*****Recording starts** (Start with **date** and **place**)

Good day, my name is Neliswa Dladla and I work for this project as a research assistant. I am also a student at UKZN where I am doing a Master's degree on Population Studies. Today we will be talking about your experiences with Antiretroviral Therapy and some other issues connected with being on Antiretroviral Therapy.

General Information and "ground rules":
We will be conducting this conversation in Zulu, but please feel free to express yourself in English if you wish, or to let me know if you would prefer to have our discussion in English. This conversation will last approximately 1 hour.

We are doing this research study at Sinikithemba clinic because we are interested in learning about patients' experiences with ART and umuthi wesintu and also want to understand better how patients view Traditional African Medicine in their lives. We are aware of the importance of Traditional African Medicine in the Zulu culture and are not going to judge any practices or behaviors. You were invited to participate because you receive treatment at Sinikithemba. We want to listen to your opinions.

You have already agreed to participate in this study by signing the consent form, but there are a few things I would like to remind you before we begin. This interview is

voluntary. We are going to be talking about different things that may be related to your experience with treatment for HIV. You may skip any question you do not feel comfortable answering, or ask to stop the interview at any time. There is no right or wrong answer to anything I ask you; I am only interested in knowing how you feel or what you think about the things we talk about. I am recording our discussion so that I can remember all the things we talk about, but no one besides the research staff will be able to listen to the recording or know what you said. Your name and identifying information will not be included with your responses. Also, your name will not be given if we report or write about anything that we discuss today. Thank you again for your time.

Opening Questions
Let's start with a few general questions about you.

1. Can you tell me a little bit about how you started coming to Sinikithemba?
   Probe: How long have you been coming to the clinic? How do you feel about coming to the clinic?

(Transition)

2. When you think about your experiences receiving ART at Sinikithemba, what things come to mind?
   Probe: Tell me more about how you feel receiving ART at Sinikithemba.

Traditional health practices, medicines and healers
We are moving on to some questions about different health practices some people might use.

3. Have you heard of other types of treatments or medicines for HIV besides Antiretroviral Therapy (ART)? If yes, is any of these umuthi wesintu ?

Probe: Describe them? Tell me about your experience(s) with umuthi wesintu?

4. How would you describe 'umuthi wesintu '?
   Probe: What is your first memory of umuthi wesintu? Who uses umuthi wesintu? Do you know of people living with HIV and AIDS using umuthi wesintu?

5. What is your opinion about using 'umuthi wesintu ' and ART at the same time?
   Probe: What do you think about using umuthi wesintu to treat side effects? Is it common?

6. Why do you think some people might use Traditional African Medicines instead of ART?

7. Have you had experiences using umuthi wesintu while receiving ART? Tell me more about that. **(IF YES, GO TO 7a, IF NO SKIP TO 9.)**

7.a Has your <u>use</u> of umuthi wesintu changed since you started Antiretroviral Therapy?

> Probe: How do you feel when you use umuthi wesintu and ART? How have your <u>feelings</u> towards umuthi wesintu changed since you started receiving ART?

7.b. Besides umuthi wesintu, what other kinds of Traditional African Practices or treatments do you or other people you know use?

> Probe: Umthandazi? How are those practices related to how you manage HIV (if they are at all)? Tell me about your experiences with these other Traditional African practices.

8. In thinking about any experience you have had with iSangomas, iNyangas, Umthandazis, umuthi wesintu or with Traditional African Medicine in general, how are these things different than the ART you receive at Sinikithemba?

> Probe: What are the main differences between them? What do you like about the medical treatment at Sinikithemba? What do you like about Traditional African Medicine?

9. **(SKIP THIS QUESTION IF 7 THROUGH 8 HAVE BEEN ANSWERED)** Why would someone visit iSangoma, iNyanga or Umthandazi instead of going to a clinic?

> Probe: What is the role of Traditional African Healers and Traditional African Medicine in managing HIV and AIDS?

10. How do you feel about the current relationship between Traditional African Medicine and Western Medicine in treating HIV and AIDS?

> Probe: What do you think iSangoma, iNyanga, Umthandazi should know about doctors at clinics? Should doctors at clinics know more about umuthi wesintu and Traditional African treatments for HIV and AIDS?

Wind down and closing questions

11. Do you think that it is important to build a bridge between Western Medicine and Traditional African Medicine? Why?

12. Of the things we discussed, which do you feel are the most important?
    Probe: Why do you think they are the most important?

That's all the questions I have for you, do you have any questions for me?
    Probe: Is there anything you would like to add? Is there anything else I should have asked?

"Thank you for your time today and for your participation."

Script for Informational Sheet from McCord Hospital:
"This is important information about your health that McCord Hospital has requested we pass on to you as a Sinikithemba patient and also as a participant in this research. As I explained it to you before, I don't work for McCord Hospital. However, I have been asked to read some statements from this informational sheet before I give it to you. Please take the time to read this information I am giving you on behalf of McCord Hospital."

The research assistant will then read the following statements from the informational sheet:

'If you have stopped taking your ART, are considering stopping, or if you are considering taking traditional or alternative medications, please talk to your medical provider to explain the reasons'

'ART should never be stopped unless your doctor has told you to do so'

'*You are encouraged to have an open and honest discussion with your doctor about all aspects of your health and health care'*

APPENDIX C

PROVIDERS INTERVIEW GUIDE
(Physicians, Nurses and Counselors)

This interview will be conducted by co-investigator.

The interviewer (Ms. Hannah Appelbaum) will introduce herself to the key informant interviewee by greeting and providing general information about herself such as institutional affiliation (Emory University School of Public Health, Master Program) and research affiliation (co-investigator). The interviewer will also provide the name of the sub-study and will briefly explain the general goals of the sub-study and its affiliation with the Risk Factors of Virological Failure (RFVF) Study. Logistical information will also be provided such as duration of interview and compensation for study participation.

Script (following personal introduction):

*********Recording starts now (this will be announced)**

Good evening and welcome. Thank you for taking the time to come to this interview. Today we are here because we have asked you to contribute to a research study called: "Perceptions of Traditional African Medicine and Antiretroviral Therapy at McCord Hospital in Durban." We will have a conversation about your experiences working at Sinikithemba clinic.
You have already agreed to participate in this study by signing the consent form, but there are a few things I would like to remind you before we begin. The interview should take about one hour and it is completely anonymous. I will use a number or code instead of your name, therefore your name will not appear on any of the study's documents. I will only record your occupation and title. This interview is voluntary. We are going to be talking about different things related to your work at McCord and/or Sinikithemba. You may skip any question you do not feel comfortable answering, or ask to stop the interview at any time. There is no right or wrong answer to anything I ask you; I am only interested in knowing how you feel or what you think about the things we talk about. I am recording our discussion so that I can remember all the things we talk about, but no one besides the study doctors and research staff will be able to listen to the recording or know what you said. Thank you again for your time.

Opening Questions

1. Quickly, for my records, briefly explain your position or job at Sinikithemba? What is your weekly schedule? What days of the week do you work and how many hours?

2. How did you come to work at Sinikithemba?

3. How would you describe McCord Hospital's mission?

Probe: How does McCord compare to other hospitals in KZN? How is the patient population different? The providers (doctors, nurses and counselors) who work at the hospital?

Transition

We will now move on to some questions about different health traditions, practices some people might use.

4. To begin, because we are interested in exploring Traditional African Medicine and its intersection with Western medicine, can you explain what you think of when someone speaks of "Traditional African Medicine"?

Probe: What do you consider Traditional African Medicine? "Umuthi'?

5. What is your experience with the presence of Traditional African Medicine at Sinikithemba?

Probe: How will you describe the patients that use Traditional African Medicine? Have you come across evidence of the use of Traditional African Medicine in patients? Are they in-patients or out-patients, both? Have you heard of the use of Traditional African Medicine by anyone else in contact with the patients?

6. I have heard that when a patient whose health is (generally) improving suddenly takes a "turn for the worse" or passes it is often attributed to traditional practices. Tell me more about when things like this happen.

Traditional African health practices, medicines and healers

7. Have patients told you about treatments or medicines for HIV besides Antiretroviral Therapy, particularly Traditional African Medicines?

Probe: How often do you hear about Traditional African Medicine treatments? What are your opinions about these treatments? What types of

treatments do you hear about the most? How common do you think each of these treatments is among patients at McCord?

8. Why do you think patients at McCord may use both 'umuthi' (Traditional African Medicine) and Antiretroviral Therapy, simultaneously or independently?

Probe: Why do you think some people might use traditional medicines instead of Antiretroviral Therapy? Why do you think people use traditional medicines at the same time as Antiretroviral Therapy?

9. Besides umuthi, what other kinds of traditional practices or treatments do you see evidence of at McCord?

Probe: Have you heard of the use of Umthandazis? Do people speak freely about these practices? Why or why not?

10. Are you familiar with the difference between iSangoma, iNyanga or Umthandazi?

IF YES ask **10.a. and 10.b**, **IF NOT** continue to **question #11**:

10.a. Could you please describe the difference?

10.b. Why would someone visit iSangoma, iNyanga or Umthandazi instead of going to a clinic?

Probe: Do most people feel that way? Is this a problem, as you see it?

11. What do you think of having an open, mutually respectful dialogue with patients at McCord about traditional African health practices they might consult?

Probe: Would you say that other providers at McCord feel that way? Why?

12. How do you see the role of Traditional Healers and Traditional African Medicine in treating HIV?

13. Would you consider the possibility of a dialogue at McCord between Traditional Healers and providers like yourself?

Probe: What should Traditional Healers know about providers at clinics like Sinikithemba? What would you like to know about Traditional African Healers and Practices?

Wind down and closing questions

14. Do you see the any need for change of the current relationship between Western Medicine and Traditional African Medicine at McCord?

Probe: Do you have any ideas to realize this change (these changes)?

15. Of the things we discussed, which do you feel is (are) the most important?

Probe: Why?

Ending Question

[Leave tape recorder on, unless asked to turn off]

That's all the questions I have for you, do you have any questions for me?

Probe: Is there anything you would like to add? Is there anything else I should have asked?

Thank you again for your time today.

APPENDIX D

GUIDE FOR TRADITIONAL AFRICAN MEDICINE PRACTITIONER FOCUS GROUP DISCUSSION

INTRODUCTION

This group discussion will be moderated by a study co-investigator and Traditional Healer/Psychologist. A research assistant will help in the facilitation and translation into English for present co-investigators if needed. The research assistant will be also responsible for the recording of the group discussion.

SCRIPT

Greeting in Zulu:
Good afternoon and welcome. Thank you for taking the time to join our discussion. We would like you to know that we appreciate very much you taking time away from your practices to come to this discussion. Today we are here because we have asked for your contribution to a research study called: "Perceptions of Traditional African Medicine and Antiretroviral Therapy at McCord Hospital in Durban". We will conduct a group conversation about your work and experiences with HIV/AIDS in the context of your practice as Traditional Healers. I will be the conversation moderator.

I will now start the recording of this meeting.

*****Recording starts** (Start recording with **date** and **place**)

Personal Introductions in English by Research Assistant:
My name is Neliswa Dladla and I work for this project as a research assistant. I am also a student at UKZN where I am doing a Master's degree on Population Studies. This is Ms. Sally John; she is a Psychologist at McCord Hospital and the Co-Principal Investigator for this study. She is also doing other studies related to traditional African beliefs and children. This is Ms. Claudia Ordonez; she is an anthropologist and the other Co-Principal Investigator for the study. She works with Emory University in the United States. This is Ms. Hannah Appelbaum from Emory University in the United States; she is a co-investigator in this study and is also doing research work for her Master of Public Health thesis.

General Information and "ground rules"

We will be conducting this conversation in Zulu. The duration of this group conversation will be approximately 2 hours.

I would like to give you some general information about this study, please feel free to ask me any questions once I am done with my explanations. The study is trying to better understand the use of "umuthi wesintu" or Traditional African Medicine in HIV treatment. To find information about this topic we are interviewing patients receiving ART at Sinikithemba clinic, Traditional African Healers in the Durban area and Western Medicine providers at Sinikithemba clinic. You were invited to participate because we would like to learn about Traditional African Medicine treatment for HIV and AIDS. We also would like to ask about your perspective on Western Medicine treatment for HIV and AIDS (ART).

We are recording this session because we don't want to miss any of your comments. No names will be included in any reports, unless you request differently. Your comments are confidential. In this conversation there are no right or wrong answers. However, all opinions should be shared with respect to others. I am here to guide our conversation, listen and make sure everyone has a chance to share. We are interested in hearing from each of you. So, if you are talking a lot, I may ask you to give others a chance to talk. And if you aren't saying much, I may call on you. We just want to make sure you all have a chance to share your ideas.

Let's begin.

GUIDE FOR TRADITIONAL AFRICAN MEDICINE PRACTITIONER FOCUS GROUP DISCUSSION

Opening Questions

1. Tell us your name and what kind of Traditional African Medicine you practice.

Introduction

2. Could each of you please briefly tell us how you define what Western doctors call "HIV and AIDS"? Please tell us if there is another name that you use for this disease.
   Probe: Do you know of any difference between what is called HIV and what is called AIDS?

3. Is it common for patients with HIV to seek your services?
   Probe: Please tell us about patients with HIV who seek your services? What do you do for them?

Traditional African Medicine and western medicine in the community

4. What are your opinions as Traditional African Medicine practitioners about Antiretroviral Therapy (ARV) and other "Western" practices to treat HIV and AIDS?
   Probe: What do you know about Western doctors' treatment for HIV and AIDS?

5. What is the role of traditional healers in managing HIV and AIDS?
   Probe: How Traditional African Medicine practitioners help their communities in managing other diseases or illnesses?

6. Why might a person leaving with HIV visit a Traditional African Medicine practitioner instead of going to a hospital or clinic?

7. How do you feel about Western doctors' view of Traditional African Medicine treatment for HIV and AIDS?

8. What should Western doctors know about Traditional African Medicine treatment(s) for HIV and AIDS?

Probe: What would you like to know about the Western medical treatment of HIV and AIDS?

9. What do you think about the possibility of a respectful and equal dialogue between Traditional African Medicine practitioners and Western medical doctors to collaborate on the treatment of HIV and AIDS?

Probe: How can this dialogue be started?

Closing Questions

10. Of the things we have talked about today, which are the most important?

11. Is there anything you wanted to say that you didn't get a chance to say? (Or anything I should have asked that I didn't ask?)

Thank you very much for your time!

APPENDIX E

INFORMATIONAL SHEET FOR PATIENTS FROM MCCORD HOSPITAL

McCord
HOSPITAL

Bringing Care, Hope and Excellence

IF YOU HAVE STOPPED TAKING YOUR ART, ARE CONSIDERING STOPPING, OR IF YOU ARE CONSIDERING TAKING TRADITIONAL OR ALTERNATIVE MEDICATIONS, TALK TO YOUR MEDICAL PROVIDER TO EXPLAIN THE REASONS.

Stopping taking your antiretroviral therapy (ART) for any reason can cause your viral load to increase very quickly. This may be followed by a drop in CD4 count.

Many Doctors are concerned that taking traditional and/or alternative medications together with your ART could also result in a rise of the viral load.

WHAT ARE THE RISKS OF A HIGH VIRAL LOAD AND LOW CD4 COUNT?

- **Opportunistic infections:** The biggest risk of taking a break in your treatment is that, as your CD4 count drops, you may develop an opportunistic infection such as tuberculosis.
- **Viral resistance to medication**: Stopping and re-starting medications may make it easier for the virus to develop resistance to medications. This means your treatment may become ineffective.

ART should never be stopped unless your doctor has told you to do so.

You are encouraged to have an open and honest discussion with your doctor about all aspects of your health and health care.

Questions?
If you have any further questions, please contact the clinic at 0312685718 and ask to speak to your provider.

Sources: http://www.aidsinfonet.org/fact_sheets/view/406, http://www.aidsinfo.nih.gov/guidelines/GuidelineHTML.aspx?GuidelineID=7&docID=1&NodeID=18