AIDS PATIENT CARE and STDs
Volume 23, Number 6, 2009

DOI: 10.1089/apc.2008.0222

Knowledge, Beliefs, and Health Care Practices Relating to Treatment of HIV in Vellore, India

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Abstract

In India, little is known about health care-seeking behavior among HIV-infected individuals. Similarly, little is known about how HIV is being treated in the community, in particular by Indian Systems of Medicine (ISM) providers. Therefore, while ART implementation programs continue to expand, it is important to determine whether the knowledge, attitudes, and treatment practices of HIV-infected individuals and their health care providers are aligned with current treatment recommendations. We conducted in-depth qualitative interviews with persons with HIV ($n = 9$ men and 17 women), family members of persons with HIV ($n = 14$ men and 3 women), and ISM providers ($n = 7$). Many of the patients we studied turned at some point to ISM providers because they believed that such practitioners offer a cure for HIV. ISM treatments sometimes had negative impacts including side effects, unchecked progression of an underlying illness, and financial depletion. Indian women tended to be less knowledgeable about HIV and HIV treatments, and had less access to financial and other resources, than men. Finally, most of the ISM providers reported dangerous misconceptions about HIV transmission, diagnosis, and treatment. While the existence of ART in India is potentially of great benefit to those with HIV infection, this study shows that a variety of social, cultural and governmental barriers may interfere with the effective use of these therapies. Partnerships between the allopathic and traditional/complementary health sectors in research, policy, and practice are essential in building comprehensive HIV/AIDS treatment strategies.

Introduction

Current estimates are that there are 2.4 million HIV-infected persons in India.[1–4] While antiretroviral therapy (ART) has been shown to significantly reduce morbidity and mortality, prolong lives, and improve the quality of life of many people living with HIV/AIDS, access to ART is still limited in India, especially in poor rural areas, and less than 20% of those that qualify for ART are currently receiving it.[3–5]

While most people in India use the allopathic medical system as their primary source of health care, 60%–85% of primary care provision occurs in the largely unregulated private sector, and an estimated 70%–80% of the population uses nonallopathic medicines from one of the various Indian Systems of Medicine, or ISM, at some point in their lifetime.[6–10] ISMs include Ayurveda, Siddha, Unani, naturopathy, homeopathy, and yoga.[11] Ayurveda is the most widely used throughout India, although Siddha is more prevalent in the state of Tamil Nadu. All ISMs believe that disease is due to a disharmony between man and nature disturbing the balance between humors. Therapy, the object of which is the restoration of balance, is based on natural substances, predominantly herbal preparations, and diet; Ayurveda and Siddha also use minerals and metals.[9,11]

Although there is no good literature on the rates at which people in India with HIV are turning to alternative and complementary therapies to treat their HIV, this practice is likely widespread, especially in areas with poor access to health care generally and ART specifically.[12–15] Some clinical studies have suggested that herbal medicines might have the potential to alleviate symptoms, reduce viral load, and increase CD4 cell counts for HIV-infected individuals.[16–20] Based on a small study, a three-drug Siddha regimen (RAN, for *Rasaghanda Mezhugu, Amukkara Chooranam* and *Nellikkai Lehyam*) consisting of 73 ingredients (mostly herbs but also mercury and sulfur) has been approved by the Government of India for treatment of HIV in conjunction with allopathic treatments and is available in a select number of government

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hospitals.[16,21] However, there are increasing reports about adverse events from some herbal products, as well as possible herb–drug and vitamin–drug interactions.[18,19,22–28] There are also concerns about unsafe practices and a growth in claims of traditional cures for AIDS.[15,29]

Although there have been a number of studies looking at knowledge, attitudes and treatment practices relating to ART among HIV-infected persons in India, especially among those attending established allopathic HIV clinics, none to date have investigated how commonly HIV-infected individuals in India seek care from ISM providers, what ISM treatments are being prescribed in the community for HIV and HIV-related conditions, or how the allopathic and Indian systems of medicine interact.[30,31] Consequently, little is known about how HIV is being treated in the community, especially by ISM providers, or about health care-seeking behavior among HIV-infected individuals.

Methods

Study design

We conducted a qualitative study because of the paucity of existing knowledge about health care-seeking behavior and practices among HIV-infected individuals and ISM providers. Qualitative interviews allow investigators to collect narrative data that provide rich descriptions of interviewee's beliefs, attitudes and health care practices.[32] In-depth interviews were used in this study with the goal of obtaining a solid and hypothesis-generating understanding of the range of health care-seeking behaviors and practices involving HIV.

Study site

The study was a collaboration between the Christian Medical College and Hospital (CMCH) in Vellore, India, and the Tufts Medical Center in Boston, Massachusetts, and was approved by the Institutional Review Boards of both institutions. It was carried out in January and February 2006, principally through the Rural Unit for Health and Social Affairs (RUHSA), a community outreach program of CMCH providing health care in a rural development block in Vellore district. At that time, the only site where ART was available in the Vellore district was CMCH, at a cost of $1.00 per day. The closest center providing free ART was the Tambaram Government Hospital in Chennai, more than 150 km away.

Participants

Patients. In order to broadly understand health-seeking behavior and practices relating to HIV among people in the Vellore district, HIV-infected individuals from a variety of service sites and belonging to a wide range of cultures and socioeconomic classes were purposefully sampled so that the study population might represent maximum variation within the study area. Of all patients approached, 2 declined to participate due to fear of loss of confidentiality. Selection of study participants was done as follows. From 33 women and 49 men in the RUHSA HIV database, we obtained information about 9 men and 9 women who had been randomly selected. Of these, 13 were direct patient interviews and 5 were interviews through a family member because the patient either had died or was not available. Two of these patients (1 man and 1 woman) also provided in-depth information about their HIV-infected spouse. We thus obtained information about 20 individuals (10 men and 10 women) from the RUHSA database. The other study participants included 2 men and 1 woman participants in an HIV support group, 4 women working for a local NGO, 2 men and 2 women attending the CMC HIV clinic, 1 former commercial sex worker, and 1 woman whom we accessed through a Siddha practitioner currently treating her HIV. Several of these also provided information about the health seeking behavior and practices of their spouse or other relative, for additional information about 1 woman and 7 men. We also obtained information from 2 women attendees of the CMC HIV clinic about their deceased husbands. In all, we obtained detailed information about 43 patient–subjects, or 23 men and 20 women.

Practitioners. Practitioners were identified through key informants (RUHSA staff, study patients, focus groups held in the community) and public advertisements. Ten worked in the private sector and 1 Siddha practitioner worked in a rural government hospital. Seven provided care to HIV patients; of these, 6 were Siddha, and 1 Unani. Only 1 provider, Unani, declined to participate, although he provided us with a pamphlet he had written about HIV, which included information about HIV disease and its treatment.

Interviews

We consulted with RUHSA staff, published literature, and local practitioners to develop the interview guide and later modified it based on experience with early interviews. S.A., a RUHSA social worker dedicated to the study, and the coinvestigator, A.C., both trained in qualitative methodology, invited potential participants to take part in the study, obtained informed consents and conducted the interviews. These interviews took place in a private location and lasted one to two hours. Open-ended questions focused on knowledge, attitudes and practices relating to HIV, and concentrated on knowledge about, and individual experiences with, HIV treatments. Interviews were conducted in Tamil, translated into English, and transcribed. Interviews with practitioners were informal, took place in their workplace, and focused on understanding their system of medicine, their concept of health and illness, and their knowledge and practices with regards to HIV and HIV patients.

Data analysis

Themes were first identified through investigators' observations during patient interviews, and were revised and refined by multiple readings of interview transcripts. Major emergent themes included knowledge about HIV treatment, barriers to care for HIV treatment, gender-specific issues, reasons for choice of a medical system over another, and experience with HIV treatments. Data analysis began with "open coding" whereby investigators break down, conceptualize, and categorize data according to themes.[33] All transcripts were analyzed on a line-by-line basis and coded for key themes using the data management tool Nvivo7. Themes were then compared qualitatively between important subgroups of participants such as gender, geographic location (urban versus rural), and treatments received for HIV. Quotes were retrieved from coded data to support the data analysis and illustrate major themes.

Results

Patients

Description of patient study participants (Table 1). Patients' ages ranged from 22 to 49 years (mean of 38.4 for men and 32.1 for women). Approximately two thirds resided in rural areas. Eighty-eight percent of the women were widowed. Of the men, 80% were married, and 20% were single with no intention to marry due to HIV. Occupations among men included driver, farmer, construction worker, electrician, road contractor, and small shop owner; among women, housewife, factory worker, small shop worker, and commercial sex worker. A small number were unemployed due to disability.

Most patients were diagnosed with HIV in the private sector, with men being most frequently tested in the setting of symptoms or a known infectious process (tuberculosis [TB], sexually transmitted disease [STD], meningitis) and women, in the setting of an HIV-positive spouse or during routine antenatal testing. Men were usually symptomatic, and women asymptomatic, at the time of diagnosis.

Most study patients reported that the allopathic medical system was the medical system most frequently used in the community, with ISM being used mostly in the treatment of particular conditions including jaundice, joint pains, genital lesions/discharge, and infertility. Most reported using the allopathic medical system for most of their medical care.

Knowledge relating to HIV treatment. Patients generally had poor knowledge of treatments for HIV despite good knowledge of HIV transmission and prevention. Many had heard of ISM treatments for HIV, and most believed that these treatments could be curative. Many had also heard about allopathic treatments for HIV, although only a few understood its role in treatment. A number of patients had no knowledge whatsoever about the existence of either allopathic or ISM treatments for HIV.

Use of ISM treatments since diagnosis with HIV. Most men and a few of the women had used ISM treatments at some point since their diagnosis. Of the 31 patients who were alive at the time of the study, 6 were currently taking ISM treatments: a husband and wife were taking Homeopathic treatments for a cure, 1 woman was taking Siddha treatments for a cure, 2 men were self-medicating with herbs, and 1 man was on Siddha treatments for neck abscesses. Of the remaining 26, 9 (4 women and 5 men) had taken them at some point in the past since their diagnosis. Two men and 14 women had never been on ISM treatments. The 12 deceased individuals (all men) had all used ISM for HIV. Treatments received were most frequently Siddha, but also homeopathic, Ayurvedic, self-medication with herbal substances, and religious healing through Muslim and Hindu priests. Some patients saw practitioners locally while others traveled as far as Kochin or Madurai, both more than 400 km away from Vellore. Costs of treatments ranged from a few hundred to 5,000 Rupees ($110) per month.

Table 1. Patient–Subject Sociodemographic Characteristics ($n = 43$)

	Women		*Men*	
Interviewee	*Subject* (n = *17*)	*Relative* (n = *3*)	*Subject* (n = *9*)	*Relative* (n = *14*)
Age				
Mean	32.1		38.5	
Range	(22–44)		(29–49)	
Marital status				
Single	0		2	
Married	2	2	7	14
Widowed	15		0	
Religion				
Hindu	16	3	8	14
Christian	1		1	
Location				
Urban	6	1	1	6
Rural	11	2	8	8

Patients most often reported seeking ISM treatments for a cure of their HIV infection, usually shortly following diagnosis. As one individual stated, "There is no cure in the allopathic medical system but there is one in the non-allopathic medical system. That is why I went to see the Siddha and Homeopathic doctors." On the other hand, other patients reported seeking ISM for treatment of a specific medical problem or symptom, including neck abscesses, weakness, vaginal discharge, genital lesions, fever, and skin problems. One participant commented, "After my diagnosis with HIV, the allopathic doctors told me that no treatment was necessary, but I developed skin problems and my husband took me to see a Siddha doctor." Other stated reasons for recourse to ISM treatments included fear of side effects from allopathic treatments ("My doctors advised me to have ART, but I didn't go for allopathic treatments because I don't want to experience the side effects"); recurrence of a medical problem despite allopathic therapy; preferential recourse to ISM for certain medical problems or for greater confidentiality; and inability to afford the costs of allopathic treatments ("I think that CMC gives the best treatment, but I cannot afford to go"). Most women who had used ISM treatments reported doing so upon the recommendation of their spouse, another practitioner or a community leader ("When I was diagnosed with HIV, my husband went to Kerala to get Siddha treatment that could cure my HIV.").

Patients who had stopped taking ISM treatments most often reported doing so due to side effects, worsening medical condition, recurrence of illness/symptoms despite ISM treatments, or inability to pay. Patients also mentioned a repeat HIV test that remained positive and inability to tolerate the required food restrictions.

The following cases illustrate some of the reasoning behind HIV treatment choices:

> I had allergies to the medicines that I was given at Tambaram because I developed skin itching. So I went to see [an allopathic doctor] and he referred me to a Siddha doctor, telling me that this doctor had treatment that could lengthen my life by 10 years. This Siddha doctor said that he would be able to lengthen my life, and that he would also be able to decrease my viral load. I was only able to take the treatment for 3 months because I couldn't pay for more. [40-year-old woman, diagnosed 2002]
>
> I took the [Siddha] tablets for 25 days but then developed fevers and was admitted to CMC hospital again. I was told at CMC that HIV can only be controlled by medications but not cured. When I got home from CMC, my sister and daughter-in-law took

me to see a homeopathic doctor because they had seen an advertisement that he could cure HIV. I got treatment from him for one month. Five or six people have been cured by this doctor in this way; they used to be very thin, and now they look a lot better. I took this treatment for 1 month, but again developed fevers and was admitted to CMC. I would like to return to see them [Siddha or Homeopathic doctors] for a cure, but I don't have the money to go. [36-year-old man]

With this treatment [skin of tamarind seed and *keelhanelli* herb], my CD4 count went from 200 to 375 and my viral load from 150,000 to 15,000. I took this treatment for 1½ years, and only stopped taking it because I checked my blood tests again and found that my viral load had risen again to 150,000. I am thinking that I might have developed resistance to *keezhannelli* in the same way that people can develop resistance to ART. I then went to see a Siddha doctor in Vellore who claims he can cure HIV/AIDS. After a few months on Siddha medicines I decided to go for several months without treatment to see what would happen. I would like to start Siddha treatment again because my CD4 count has gone down. If [the Siddha doctor is not willing to provide me with treatment for less than Rs 1,000 per month], I will restart taking *keezhannelli*. If my CD4 count decreases further, I will go to Tambaram for ART. [41-year-old man, diagnosed 1990]

ISM treatment practices and patient experience with ISM treatments. Study patients described tremendous variety in the ISM practices experienced. Treatments received included capsules, tablets, powders, liquids, pastes, and herbal products. Treatment instructions, duration and cost, recommendations for lifestyle modifications, and instructions for follow-up of HIV status all varied widely. A number of patients had been warned that treatments would be ineffective or in some cases highly toxic if not prepared and taken as directed.

Some patients reported improvement in their symptoms with ISM treatments, which in some cases they and their practitioners equated with a cure. One patient "had been having fever, diarrhea and loss of appetite, but these resolved with the Siddha medications. He also gained 4 kg." Another had had "coughing and white [vaginal] discharge when she was initially diagnosed, but she had no more symptoms after the Siddha treatment." In fact, "she had been cured from HIV" and was now remarried and "leading a good life."

Other patients stated that they had stopped taking their ISM medications due to side effects or difficulty following the required food restrictions: "After starting this treatment, his skin turned black and he discontinued treatment"; another: "But I felt very weak with this treatment and I also got diarrhea, so I stopped taking the treatment." Others persisted with the treatment course, encouraged by a steadfast belief in the possibility of a cure, itself perpetuated by their practitioners' own beliefs and downplaying of evolving symptoms. Hence a patient who developed bloody diarrhea while on Siddha treatments was reassured that this was normal and evidence that "the virus [was] leaving the body." Another patient endured deteriorating health:

After he was diagnosed with HIV, [my son] started taking homeopathic medications. His condition has not changed on this medication, except that he has lost a lot of weight and he is having diarrhea and vomiting. He used to weigh 60 kg but he now weighs 48 kg. He is also developing some skin problems. He has been taking these medications for one year now. [The doctor] said that he needs to continue this treatment until he is cured, and to repeat the HIV test every 3 months to check his HIV status. His friends have been recommending him to go to Tambaram hospital for HIV treatment, but he has been refusing because [this doctor] told him that he would be able to cure him with his treatments. [29-year-old man, diagnosed in 2005]

For a number of patients, ISM treatment practices (often aimed at symptom relief and boosting of the "immune power") failed to address a likely serious but treatable underlying condition. For instance, one patient "started having fevers for which he took herbal treatments, but the fevers kept coming back"; he was hospitalized several months later and diagnosed with advanced disseminated TB. Another patient had similarly received no evaluation of her presenting symptoms of weight loss and cervical lymphadenopathy. Since initiating Siddha treatment, she had "put on 10 kg and her neck swelling had decreased and was less tender." In fact, she was happy with the care she was receiving and believed that she would eventually be cured. We suspected that her Siddha practitioner, whom we also interviewed, may have been administering steroids and that a likely underlying infection was merely being suppressed, meanwhile going undiagnosed, untreated, and risking progression.

Gender disparities with regards to HIV and its treatment. Women overall reported less depth and breadth of knowledge regarding various treatment modalities available for HIV than the men. They also reported less access to financial and other resources and a harder time leaving their home and family duties to access care. Many stated not seeking medical care due to perceived good health and a lack of symptoms ("I do not have any symptoms, so I am not interested in finding out about treatment"; "I feel well, and I haven't lost weight, so I haven't gone for treatment") or poor knowledge about available treatments. Others opted to use their limited resources for other needs, including the health care of another family member ("I wasn't worried about me, I just wanted to save my husband's life").

Men were generally more aware of available treatments and appeared to have greater access to them. They reported more frequent proactive and self-initiated health care utilization than did women. They were more likely to consult ISM practitioners for treatment of their HIV or associated conditions, to self-refer to various different practitioners, to self-medicate, and to undergo multiple different treatment regimens throughout their disease course.

Practitioners

Training. Of the 7 practitioners in our study involved in HIV care, only 2 (both Siddha) had been trained institutionally and were registered. All others had acquired their knowledge and skills either from their mentors or on their own. Only 2 practitioners, both Siddha, had received HIV training about allopathic and ISM treatments for HIV.

Knowledge about HIV disease. Most practitioners had poor knowledge about HIV. Some knew that HIV was a "virus," though few could explain the meaning of this term. Most understood HIV as being a disruption of the body's humoral balance and a weakening of the immune system. Some perceived it as an "old disease that has been here since the beginning of human creation but that is only manifesting itself now because people are becoming weaker" and increasingly straying away from the accepted norm of human

behavior, most often through changing dietary habits, a decrease in food quality attributed to "unnatural processing" and "chemicals" used in agriculture, and unnatural sexual activity such as homosexuality or use of "unnatural" barrier methods: "HIV is caused by any change from the norm of sexual behavior, including use of condoms." For others, a small but destructive organism was perceived as being the cause of HIV:

> Invisible lice cause HIV by biting. People will get infected especially if they have intercourse during menstruation. The lice are more powerful than the human body and can enter the tissue and destroy it. They enter the nervous system. If the nervous system is no longer working, it will affect the rest of the body, like the blood and semen. [Siddha practitioner]

Most practitioners believed HIV could manifest itself through a wide range of symptoms, which according to some could be organized into stages:

> There is no one disease system called HIV — but symptoms of diarrhea, weight loss, fevers, etc. [Homeopathic practitioner]
>
> There are three stages of HIV: white discharge and STDs; decreased body weight and burning sensation with urination; and death. [Siddha practitioner]
>
> There are four stages of HIV: in the first, patients are 19–24 years old, able to eat well, look normal, but may have respiratory problems and blisters. In the second, patients are 25–35 years, have cough and TB symptoms. In the third, they have abscesses. The fourth stage is terminal. [Siddha practitioner]

Many confused the terms STD and HIV and believed that both represented different spectrums of a same process: "The first symptom of HIV is white discharge, which progresses to all other HIV symptoms"; "All rashes are sexually transmitted diseases; [those] that affect the genital area are AIDS"; "Someone has HIV if he has blisters in the genital area or discharge."

Knowledge about HIV testing and management. While most practitioners believed that a blood test was necessary to diagnose HIV, others thought that symptoms at the time of presentation and pulse examination (common ISM diagnostic methods) were sufficient and reliable.[30] One Siddha physician reported advising his patients not to get tested for HIV "because results will remain in the chart and can cause discrimination." Another stated "I don't tell my patients about their diagnosis because I don't want to frighten them."

Other stated recommendations made to patients included not to use condoms since their use "could cause HIV," not to take allopathic treatments since "prior exposure to these treatments would render Siddha treatments ineffective," and sometimes to discontinue ISM or allopathic treatments on days when medications from another system are taken. Most believed that their treatments could cure HIV, a cure being most often defined as a restoration of the normal balance of humors, manifested by improved overall health, symptom resolution and weight gain.

Treatment practices. Most patients with HIV cared for by these practitioners had reportedly received their diagnosis in the allopathic medical system, via a blood test. They had consulted the ISM practitioners for a number of reasons, but most often for a cure which the practitioners could offer.

Only two practitioners, both Siddha, were aware of the standard of care treatment of HIV, although only one followed it, referring all his HIV patients to Tambaram hospital in Chennai for HIV care. All others engaged in widely divergent treatment practices, most often aimed at increasing patients' strength and immunity ("Treatment is aimed at increasing the immune system and killing the virus") and at relieving particular symptoms. One Siddha practitioner referred patients for ART if their CD4 counts fell below 200, while continuing to prescribe treatments of his own invention which consisted of various herbs, minerals and metals and "could cure HIV."

While some practitioners reported using only herbal ingredients ("I give only fresh herbs," "I use about 70 different herbs, but no minerals because they can cause renal failure"), others also used minerals and metals. Some admitted to high toxicity of individual ingredients that warranted special processing: "The minerals [sulfur, mercury, iron] are very strong and sometimes toxic, so I have them soak in milk for several days to dilute out the toxicity." All remained secretive regarding the exact contents of their preparations. Most treatments were to be combined with lifestyle modifications, most often involving diet restrictions.

Most claimed that their preparations were of their own invention. Specific ingredients were usually individualized based on a patient's symptoms, stage of illness, and gender: "The treatment I give is different for every patient." One Siddha practitioner stated: "The treatment I use is my own invention. It is the same one that I use for sexually transmitted diseases, but I changed it a little." Another reported: "If women shave their genital hair, they may be able to get rid of the lice; if they are inside, treatment that causes diarrhea will get rid of the lice and cure HIV. If a patient just has lesions in the genital area, or itching, then it is possible to cure HIV." Most carried out their own research investigations into the efficacy of particular treatment regimens, monitoring response either through clinical assessment of symptoms or through laboratory testing of CD4 count, viral load or repeat HIV testing when the patient could afford it. Several were adamant that they had cured some patients, and that they were now leading "normal lives."

Discussion

In India, little is known about health care seeking behavior among HIV-infected individuals. Similarly, little is known about how HIV is being treated in the community. Although rural practitioners can be considered the most utilized health care resource in India today, very few studies have focused on them and data on their practices is scant, including with regards to HIV.[31] A few studies have previously investigated other disease entities, in particular malaria and tuberculosis, and have shown a large disconnect between practices carried out by the allopathic and Indian systems of medicine while also revealing worrisome community practices in the treatment of these conditions.[36–39] Therefore, while ART implementation programs continue to expand, it is important to determine whether the knowledge, attitudes, and treatment practices of HIV-infected individuals and their health care providers are aligned with current treatment recommendations. Failing to acknowledge and address local beliefs and health care practices may compromise the long-term success of HIV treatment programs.[12,13,40–45]

Several important themes emerged from our interviews of patients and local practitioners. First, many of the patients we

interviewed turned at some point to ISM practitioners, especially Siddha, because they believed that such practitioners offer a cure for HIV. Second, there are important gender differences in HIV knowledge and health care seeking behavior and utilization. Third, community providers in India report dangerous misconceptions about HIV transmission, diagnosis, and treatment.

Knowledge of HIV treatment is generally poor among HIV patients in India — a finding echoed by others.[31] The use of ISM providers appears to follow the appeal of a cure — something that the allopathic system fails to offer. A central concept to most ISMs is that disease is due to a disharmony between man and nature that disturbs the balance between humors; therapy aims to restore this balance. Relief of symptoms, perceived as a successful restoration of balance, is generally equated with a cure.[6,9,34] Such a symptom-based concept of health and illness may not be applicable to a disease entity such as HIV without causing great harm. The untoward consequences of this false belief in the possibility of a cure include certain HIV patients living with side effects from ISM treatments, health care deterioration, and financial losses. Perhaps more importantly, it prevents patients from receiving allopathic therapy of proven effectiveness, facilitates transmission of HIV to others and adds psychological torment to already distraught patients.

Other patients reported seeking ISM practitioners for symptom relief or treatment of a particular condition. While in theory it is possible that certain herbs and minerals may boost the immune system, exert antimicrobial activity, relieve symptoms and provide other significant benefits to HIV patients, certain compounds have a high potential for adverse events.[9,16–20,22,29,34,46–49] Patients with HIV are at a particularly high risk for direct toxicity from heavy metals that can cause renal or bone marrow toxicity, steroids that cause further immunosuppression, and substances that might produce drug–drug interactions (e.g., lower ART levels). Some herbs and vitamins have also been found to alter ART levels and may put patients at risk of treatment failure, viral resistance, or drug toxicity.[19,23,24–28] Moreover, the administration of certain compounds may improve symptoms but not treat an underlying infection, resulting in a false sense of "restored health," the delayed diagnosis and treatment of a serious condition, and an ultimate poor outcome.

In high-resource countries, a growing body of literature demonstrates that the use of dietary supplements and other forms of complementary and alternative medications (CAM) is common among HIV-infected persons, with a prevalence of 40%–90%.[50–55] However, in these settings, CAM therapies tend to be used as an adjunct to, and not a substitute for, allopathic medications.[53,56–58] This type of coexistence of allopathic and nonallopathic approaches is likely to be relatively safe, provided that patients communicate clearly with their physicians about the CAM therapies that they are using. We suspect that this type of healthy coexistence will be far more difficult to achieve in India, where traditions of and beliefs about ISM are long standing and deeply held, and where ISM providers will continue to have strong economic incentives to compete against, rather than collaborate with, allopathic providers.

The observation that HIV knowledge and health care-seeking behavior and utilization are quite different between men and women with HIV emphasizes the need for targeted interventions. Other studies have shown that women in India may be at a particularly high risk for poor access to HIV care relative to men, and our interviews support this finding.[31]

On the other hand, while having more ready access to health care overall, men with HIV may be more likely to use ISM treatments and to engage in multiple different treatment regimens, either simultaneously or sequentially. Likely reasons for this include a greater awareness of available treatments, greater mobility, preferential access to financial and other resources, and possibly the presence of more symptoms at the time of diagnosis prompting a greater motivation for seeking care and undergoing treatment regimens. While no studies have evaluated the impact of ISM treatments on ART adherence in India, studies in Uganda, Zambia, the United States, Canada, and Australia have found that use of complementary and alternative medicines is associated with decreased compliance with ART.[13,34,40,43,44]

The practitioners we interviewed had strikingly little knowledge about HIV. We were particularly disturbed to learn that some practitioners believed that condoms should not be used as they can cause HIV; that substances that have a significant risk of harm are routinely administered; that symptoms that may be manifestations of a serious underlying medical condition are often downplayed; that the initiation of treatments of known effectiveness are often delayed or prevented altogether; that some patients are being told that they have been cured of HIV; and that these treatments often deplete scarce family resources. Moreover, community practitioners with poor or no HIV training may start including ART in their treatment regimens, or make treatment recommendations to those already receiving them. A recent study lends support to this concern: out of 200 patients referred to specialist centers in India because of poor response to ART, only 10% had adhered to treatment, 50% had stopped taking drugs on advice of traditional healers, and 80% had been receiving incorrect doses—suggesting poor management of HIV within the community.[13]

This study has several strengths. Accepted methods of qualitative research and analysis were used and enabled the generation of new ideas and hypotheses by providing an in-depth understanding of HIV-patients' and practitioners' knowledge and practices with regards to HIV and its treatment. Grounded theory, in which categories are derived from the data rather than *a priori*, enhance the validity of our findings with respect to the population studied.[33]

The study also has several limitations. Most patients were accessed through the allopathic medical system, which likely imposes a selection bias. However, if anything, this bias would present allopathic medicine in a more favorable light. HIV remains a highly stigmatized illness in India, which may have prevented us from learning more about some beliefs and attitudes. Moreover, Vellore is unusual among other regions in India in the substantial investments that have been made to ensure that people with HIV have access to medical treatment; access to allopathic treatment (including ART) elsewhere in India may be more difficult. Finally, this study was performed at a time of significant changes in ART availability and local practices may have evolved since the time of our data collection.

In conclusion, this study shows that a variety of factors conspire to reduce the quality of HIV care received by persons

we interviewed. These include (1) low levels of basic knowledge about the diagnosis, transmission, and treatment of HIV on the part of both patients and practitioners; (2) traditional systems of practice and economic incentives that permit the marketing and sale of unproven, and sometimes harmful, treatments; (3) government policies that condone these treatments; and (4) striking gender disparities in knowledge of, and access to, medical care.

While the existence of ART in India is potentially of great benefit to Indians with HIV, this study shows that a variety of social, cultural and governmental barriers may interfere with the effective use of these therapies and threaten the scale up of comprehensive HIV/AIDS care and treatment strategies in India. This highlights a worrisome public health problem. Further research on how traditional and allopathic systems of care interact in the care of persons with HIV in India is needed, so as to investigate potential beneficial and synergistic effects but also potential toxicities and drug interactions. In the meantime, there is enough evidence to suggest that tighter government regulation of community ISM providers is warranted, both to decrease ongoing unethical practices involving HIV patients (false promises of a cure, treatment experimentation, administration of potentially harmful substances, and delay in initiation of proven treatments) and to limit harm to this vulnerable patient population. In addition, education campaigns aimed to increase knowledge about HIV, especially about treatments available, are critically needed and should specifically target HIV-infected patients and all community providers. Finally, partnerships between the allopathic and traditional/complementary health sectors in research, policy, and practice are essential in building comprehensive HIV/AIDS treatment strategies.[29] Policies that increase the collaboration between these two care sectors should be strongly encouraged.

Acknowldgments

We would like to thank the staff at RUHSA and CMC for providing us with the facilities to carry out the study. We would also like to thank the personnel that served as liaisons with the community and all those who helped with the implementation of the study. This research was funded in part by: the National Institute of Health through a T32 Training Grant (5T32A1007329-16), Dr. Wilson's K24 grant (K24 RR020300), and Dr. Wanke's K24 grant (1K24A1055293-05) and CFAR grant (1P30A142853-106637); and the Fogarty Foundation through Dr. Isaac's Fogarty Grant (D43TW00237).

Author Disclosure Statement

No competing financial interests exist.

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