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Attitudes Toward Antiretroviral Therapy and Complementary and Alternative Medicine in Chinese HIV-Infected Patients

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Abstract

HIV has become a significant health issue in China, and an increasing number of HIV-infected individuals are in need of care. Current reports confirm more than 230,000 cases of HIV infection and estimate that approximately 700,000 people are now infected with HIV, although approximately 70% of these individuals do not realize they are infected (Gill & Okie, 2007).

China's national antiretroviral therapy (ART) program, *Four Frees and One Care*, began in 2003, and ART treatment is now widely available in China (Zhang et al., 2007). Under this program, the following services are available to eligible citizens: (a) free ART for all AIDS patients in financial difficulty, (b) free schooling for AIDS orphans and children of AIDS patients, (c) free counseling and prevention measures to prevent mother-to-child-transmission for HIV-infected pregnant women, and (d) free HIV antibody testing and counseling, provided by the Chinese Center for Disease Control and Prevention (China CDC). "One Care" means providing care to AIDS patients and their families (Zhang, Pan, Yu, Wen, & Zhao, 2005). Prior to 2003, only a few people in China had access to ART, and clinical expertise in HIV medicine was limited to the major centers in a few eastern cities (Zhang et al., 2007). When ART is the dominant method of treatment, however, its use is complicated by the presence of complementary and alternative medicine (CAM), which has remained a substitute and supplement for conventional HIV therapy (Hsiao et al., 2003), even after ART became available (Josephs, Fleishman, Gaist, & Gebo, 2007).

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CAM is a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine (National Institutes of Health, 2008). Commonly, CAM includes a wide range of practices that do not fit within the dominant allopathic model of health care (Bishop, Yardley, & Lewith, 2007), including but not limited to herbalism, traditional Chinese medicine (TCM), acupuncture, and diet-based therapies (Bratman & Steven, 1997). TCM has been used in Chinese society for more than 5,000 years. In the TCM approach, the body is recognized and treated as a whole entity, and diseases are identified as conditions caused by internal imbalances. The role of doctors is to identify imbalances and then correct them; the body is then expected to be able to heal itself (Tsao, Dobalian, Myers, & Zeltzer, 2005). The balancing factors of the yin and yang, or of the cold and hot forces, govern health and modulate some Chinese eating and pain management practices (Wong-Kim & Merighi, 2007). The integration of ART and CAM therefore has important implications in health outcomes, especially in China where the use of CAM is widespread.

Three types of treatment systems are practiced in Chinese society: (a) allopathic Western medicine offered by health care professionals in clinics and hospitals; (b) Buyao, which is over-the-counter popular medicine and includes teas, soups, tablets, herbal preparations, and tonics, which are similar to herb supplements used in some Western countries; and (c) TCM or Zhongyi, provided by trained Chinese herbalists, which incorporates a wide range of theories, therapies, and practices, some of which are medicinal, some physical, and some supernatural (Ma et al., 2008). Many Chinese people use all three types of treatment simultaneously.

In the West, the use of CAM is widespread among HIV-infected individuals. From 1980 to 1996, 27% to 100% of HIV-infected patients used CAM (Ernst, 1997), and the rates of CAM remained steady when compared with the era before highly active ART (Josephs et al., 2007). Some people living with HIV (PLWH) used CAM to replace the prescribed ART treatment regimen (Owen-Smith, Diclemente, & Wingood, 2007), while others used it as a complement to conventional HIV therapy (Hsiao et al., 2003).

A variety of factors influence an individual's decision to use CAM. In Western countries, women who were more educated and who had lived longer with HIV were more likely to use CAM (Owen-Smith et al., 2007). Pain was a strong predictor of CAM use, and increased pain over time was associated with the use of unlicensed or illicit underground drugs that held a potential for harm (Tsao et al., 2005). Overall, the most common source of information about CAM was from patients' friends (Wiwanitkit, 2003). Generally, CAM users perceived complementary therapies as useful, although there is no evidence to suggest that these treatments are particularly effective. CAM is generally perceived as "safe," despite evidence of harmful interactions between some herbal medicines and medical treatments and the evidence of associated risks (Ma et al., 2007). Specifically, recent studies have shown that herbal medicines can interact with ART in such a way as to contribute to treatment failure (Ma et al., 2007). Physicians around the world, however, do not routinely discuss CAM therapies with PLWH, despite knowing that CAM therapies are widely used (Ma et al., 2008; Hsiao et al., 2003).

Studies have examined PLWH attitudes toward ART and CAM in different countries (Littlewood & Vanable, 2008). One study described nurses in Uganda using a traditional, nurse-prepared ointment on PLWH as an alternative medication for skin problems because they "know it works" (Hardon et al., 2008). CAM has also been used to treat the psychological and physical effects of illness and the side effects of ART (Kaufman & Gregory, 2007). Studies show, however, that many PLWH do not report CAM use to their medical providers (Hsiao et al., 2003). To date, there has been little research on CAM use in the Chinese PLWH population.

This qualitative study explored issues related to positive and negative attitudes toward both ART and CAM in Chinese PLWH in Beijing, China. The study was part of a larger project examining behavioral interventions meant to enhance ART adherence in PLWH in China (Chen et al., 2007;

Starks et al., 2008). Semi-structured, in-depth, interviews were used to explore PLWHA attitudes, experiences, and perceptions about ART and CAM.

Methods

Procedures

Setting—All participants were recruited from Ditan hospital in Beijing, China. Criteria for inclusion were that the patients be at least 18 years of age, not cognitively impaired or medically unstable, receiving care at the hospital (either inpatient or outpatient), and either currently on ART or about to initiate treatment.

Recruitment—Potential participants were approached directly by clinic staff and informed about the study; those who were interested (97%) were referred to study personnel. After study personnel explained the nature, risks, and benefits of the study, participants who agreed to participate provided written informed consent. In this qualitative study, participants could choose whether or not to have their interviews audio-recorded; if they declined, detailed notes were taken. All participants received 150 RMB (~\$20 U.S.) as compensation for their participation in a single, semi-structured, in-depth interview.

Interview Process—The interviews were conducted between July and September of 2005. Interviews took approximately 1 hour and were conducted in a private office at the hospital or in another place of the participant's choosing. Interviewers included research staff, physicians, and nurses at the hospital, and researchers from the University of Washington. All interviewers were Chinese and conducted the interviews in the Mandarin language. Interviewers first completed a 2-day training course to familiarize themselves with the goals of the study and to learn standardized procedures for qualitative interviewing. Interviewers used a checklist during the interviews to ensure that the following topics were discussed in addition to the patient's experience with CAM: testing history, disclosure experience, social support, medication history, side effects, adherence to ART, barriers and facilitators to adherence, and social support. All interviews except one were audio-recorded, and all were transcribed into Mandarin verbatim.

Data analysis—Qualitative content analysis (Hsieh & Shannon, 2005) and a commercial software package (Atlas.ti) were used to code and analyze the data. Two Chinese-speaking investigators, trained in qualitative research methods, independently reviewed the transcripts and identified codes to represent concepts in the narratives. The investigators reviewed and discussed the coding to resolve any discrepancy in the meaning and assignment of codes and general patterns observed in the data. After codes were assigned and quotes were retrieved, the researcher presented general themes and the health care providers confirmed that the evolving patterns were congruent with their experiences at Ditan hospital. This paper is based on a descriptive thematic analysis of the codes that related to patient experiences with ART and CAM, their understanding of the risks and benefits of each, and attitudes toward using such treatments. In descriptive thematic analysis, the goal is to explicate the range and meaning of related concepts that are present in the participant narratives. The selected quotations were translated into English by the two bilingual researchers who led this analysis.

Results

Participants

The sample was comprised of 29 HIV-infected patients, of whom 7 were women and 22 were men. Ninety percent were ethnic Han, and 76% lived in Beijing. The average age of the

participants was 38 years (range from 23 to 72 years old). Seventy-two percent had at least a high school education ($n = 20$). Thirty-eight percent of the participants did not willingly reveal their HIV transmission routes ($n = 11$). Among those who did, sexual contact ($n = 10$) and blood transmissions ($n = 8$) were the most common means of transmission. Participants' awareness of their HIV status ranged from 2 to 10 years. More than half (59%) were married, and 4 reported that they were living with a steady same-sex partner.

All participants were on ART when the study was conducted. Twenty-one of these patients had been taking ART for longer than 6 months, and the other 8 had started ART within 2 weeks of joining study.

Attitudes Toward ART

Positive attitudes toward ART—Almost all the participants were positive about ART to some degree. Some of these positive attitudes came from the participants' own experiences; others were driven by cultural and governmental influences (the central government regulates all the HIV-related medication; See Table 1). The participants' positive opinions regarding ART had three primary themes: perceived benefits of ART, confidence in current HIV treatments, and optimism with respect to future treatments.

Among those participants who were positive about ART, 80% stated that they obtained benefits from ART in a variety of ways: prolonging life, improving physical health, enhancing quality of life, allowing for “self-actualization” through career satisfaction, and assisting them in fulfilling family obligations. The major concern for PLWH was prolonging life, and more than half of the respondents ($n = 16$) reported that this was the most significant benefit of ART.

I cannot live without these meds. If I did not take them, I might die very soon... the benefit of the meds is they enable me to survive a few more days... As patients, our lives have been shortened by HIV, but ART can extend our lives a little bit longer ... taking meds on time can prolong my life, which once had been shortened. (66-year-old male)

This perceived benefit, along with the patients' will to survive, was seen as compensating for the undesirable side effects of ART. As a 46 year-old female said, commenting on her willingness to tolerate the effects of ART:

I just want to live... even if there are huge side effects of ART...for the sake of survival, I will take the meds. If you want to live, just take the medicine. If you don't cherish your life, it won't matter to take or not to take the medicine. If you see your life as valuable, then take the meds. (46-year-old female)

In addition to survival, many of the participants ($n = 16$) also felt that they benefited from ART by achieving improved physical health. Some participants used their CD4 counts as an objective measure of health while others assessed improvements in their health based on their personal experiences and feelings. Many participants considered both outcomes as important in determining their physical health status. One male participant mentioned that when his CD4 counts increased, he felt better.

I definitely benefit from ART. My CD4 has increased dramatically. When I first checked my CD4, it was only 102. After I took the meds for less than a month, my CD4 reached up to 240... Two months later, I checked my CD4 again, and it was 340. And also, I have no problems eating and sleeping. I even have not had a cold since last year I found out I was infected ... It is true. I am using air conditioning when the weather is hot. It is pretty cold in my office and my house. I eat ice cream, too. But I am still fine. It is OK. ... See, if I did not tell you that I am a patient, can you tell I am (HIV-infected) by looking at me? (30-year-old male)

For many participants, the perceived improvements to physical well-being gained from taking ART were a major motivating factor in their adherence to the medications, which they learned to integrate into their daily lives. As one 37-year-old female participant remarked:

I think if you treat it (taking medicine) as something like eating, you will feel that it is easy. You will not think that you take the medicine because you are sick. In fact you are taking the medicine because it keeps you even healthier.

One third of the participants reported that they benefited from ART by regaining control of their daily lives and that they, therefore, enjoyed a higher quality of life. As their disease progressed and threatened to interrupt their daily functions, ART helped sustain their health so a sense of “normalcy” could be preserved.

The meds really help. My health was pretty poor before. But now, I am just as healthy as other normal people and as normal as anyone else. No one can tell [that I am infected]. If I did not take the meds, I would feel that the virus is increasing.... Because I gained back my health in a hard way, I am still worried...at the time when I was ill, it felt like that I was losing all my capability to manage my life. (34-year-old male)

One female participant talked about her experience of being hospitalized, when she felt powerless and isolated from the rest of the world. After taking ART, she regained a sense of control.

I am more satisfied with my present situation, because I can work just like others. I don't like to feel that, it is better to die than to live, because I really feel I was confined in the hospital. In the hospital, I was surviving, but not like a normal person. That feeling really made me suffer. Now I am more satisfied.... I mean, I feel much better about my situation now (that I can work again). (32-year-old female)

A number of the interviewees ($n = 8$) mentioned the recovery of their careers as a benefit of taking ART. China is a developing country exhibiting rapid economic growth and opportunity. Many participants, especially those who were professionals residing in metropolitan areas, felt that opportunities for successful careers were abundant, but that their HIV-infected status and poor health deprived them of the ability to capitalize on those opportunities. Taking ART and staying healthy allowed them to pursue career opportunities. For instance, a 40-year-old business owner stated that she wanted to be successful again, even if most of the people around her were not supporting her.

The best benefit I get from the ART is that I can keep doing my business. My friends asked why I still want to keep my business. They insisted I should do nothing but stay at home and take meds. For them, the only task for me is to sustain my life. But I am not that kind of person. I must do my business. In the 1990s, I earned 2,000 RMB (~\$250 U.S.) per day. My business was very good. (40-year-old female)

A highly educated professional said that he obtained much satisfaction from his work. He had always kept his career dreams alive and hoped someday he would be successful in his work once again.

I still work very hard in the organization. Even though my work makes me very tired, I still do my best. If my health condition can improve a little bit, I can do more things, and contribute more of my expertise. I will be more [internally] rewarded too. If there is someday I can do that, I will be very, very satisfied. (30-year-old male)

Some of the participants ($n = 5$) mentioned that they benefited from ART by being able to fulfill familial obligations. This finding echoes other research findings on Chinese conceptualizations of health (Wong-Kim & Merighi, 2007). A common value in China is that health not only means enjoying individual well-being, but also means maintaining a

harmonious relationship with others in the social environment. To achieve this, one is required to successfully perform expected social roles, carrying out responsibilities in one's immediate social circle, particularly with respect to one's family.

My will to live is strong. I feel I need to survive for my family and my kids. You know, even if I am sad, I still want to live. The will to live is so strong. My husband also tries hard to make me feel better. (35-year-old female)

One middle-aged man described his responsibility to his family and how he was motivated to continue in his treatment in order to serve his family members.

It depends on whether you have the sense of obligation. It is not hard to remember to take medications. If you want to survive, and to take the responsibilities of your family, you must be able to remember to take medications...for your family, for your kids, you should have medications on time. If you have parents, you should do that for them ... they are already old, [and they] worry about you still. (40-year-old male)

Additional positive attitudes about ART were related to participant confidence in the efficacy of treatment. More than half of the participants (52%) expressed tremendous faith in ART. For example, one 30-year-old male participant stated, "According to my health condition now, I have 100% confidence. It works!" For others, knowing that there was no cure for HIV, ART provided a sense of hope. One 46-year-old male said, "Taking this med provides me with some hope -- if not a big hope, at least something better than no hope. Although I know this [disease] cannot be cured in a short time, I still have confidence in ART."

These Chinese PLWH attributed their confidence in ART to a range of reasons. One man enthusiastically described his desire to get his life that had been disrupted by HIV "back on track." His strong motivation reinforced his confidence in ART:

Sure, I am pretty confident. I have a dream, I hope I can get better as soon as possible, then go to work, and be on top of my life again. I have this confidence, and this confidence will definitely help me take meds on time. (30-year-old male)

For other participants, improved health boosted their confidence in ART. The improvements perceived by these interviewees came from both objective measures, such as rising CD4 counts and subjective feelings, and they used both in appraising the effectiveness of ART. A 34-year-old man described his gain in confidence as emerging from his own experience and what he witnessed in other patients: "I am pretty confident about HAART treatment.... From my personal experiences in med taking, I was getting better gradually. And, I see others taking meds and getting better. Therefore, I am pretty confident on this med."

Some participants who began taking ART around the time when the *Four Frees and One Care* policy was implemented in 2003 used their experiences or knowledge about the changes in HIV treatments over time to develop confidence in ART. For example, they described how they were able to compare differences in treatment over time. One participant described his experience as follows:

I have confidence in myself, and also in the regimens. I think the regimens work pretty wellI heard that a few years ago they [other patients] suffered from vomiting because of the meds, including the one needing to be dissolved in the water, which was so bothersome for preparation. But now the medicines are easier to take. I take them 3 times a day, in the morning, noon, and at night. It is much easier to take them. (32-year-old male)

Some participants gained their confidence in ART from outside sources, including mass media and health care providers. A 30-year-old male said "I have so much confidence in ART. I believe the future is very positiveI get this sense from mass media." Many of the participants

expressed their confidence in current medical technology, which in turn endorsed their confidence in ART regimens. Although very few of our participants had any medical background, many of them believed that the advances in modern medical technology had “brought back (their) life.”

There are more than 30 kinds of medications...I think, even if there are no new medications, I will have enough medications to try before I die....Anyway, based on contemporary medical science, it seems like the medicine has been improved a lot from the time when I started taking ART. (47-year-old male)

Interviews were conducted in the year following the implementation of the *Four Frees and One Care* policy that made ART more accessible for Chinese PLWH. Many participants (55%) expressed optimism about how this new policy would affect the availability and effectiveness of future HIV medication. Participants had witnessed and experienced changes in the governmental policy on accessibility to ART and knew that before 2003, there were only a few options for ART, and most available regimens were usually too expensive. In addition to the governmental policy changes, some participants mentioned that improved medical insurance systems provided more coverage, easing the financial strains for patients and their families. These positive changes led to more optimistic attitudes toward future treatment among Chinese PLWH. They expected that the future would bring more effective and more affordable medications. A 40-year-old man said, “I think there will be changes in government policies. There won't be just these kinds of medicines. ...I believe the situation will get better. There will be new medicines and new policies. And the medications will all be free.” Another participant was hoping that the cost of the ART would dramatically decrease in the near future.

There must be some changes in the costs of medications. The medication price will become lower and lower and the effectiveness of domestic medications will become better and better. In the future, production of generic medications might become mandated by our government. I am very hopeful [about the future]. (40-year-old male)

Largely based on the confidence in advances of modern medical technology, Chinese PLWH believed that future medications would be more effective in controlling the progress of the disease, prolonging life, and restoring health. As a 32-year-old male noted, “There is hope for future HIV treatments, vis-à-vis international trends and domestic investment on HIV studies... we know that hope is around the corner.” Others believe that there will be “magic” regimens coming in the near future which can truly “cure” HIV and “save their lives.”

In the future, researchers can make better medications; maybe there will be a magic medication. ...I am pretty optimistic. In the past 15 years, there has been a great achievement in medicine! As long as I can take the current medicines and keep healthy for 15 more yearsthen, researchers will work out new meds or vaccines to treat HIV. Maybe HIV then will no longer be a big issue. (30-year-old male)

Another participant expressed his great hope that a magic tablet would become available to treat HIV.

To take the medicines on time would make my shortened life longer....I wish the medicine which can cure [this disease] would appear soon. People might not notice that people in developing countries also wait for the magic meds. Maybe one day, that medicine will come up. Then we [patients] will say “we are saved!” (30-year-old male)

Negative attitudes toward ART—More than 80% of the participants expressed some negative attitudes toward ART. While participants who expressed some negative attitudes were slightly fewer than those who supported ART, most participants held both positive and negative attitudes toward ART. Negative attitudes also derived from participant experiences, as well as

from cultural health beliefs and socioeconomic status in China. As seen in Table 2, the negative themes of ART included “does more harm than good,” “uncertainty of ART effectiveness,” “perceived inferiority of domestic versus imported medications,” “causes financial difficulties,” and “makes one feel forced to take medications.”

More than 40% of the participants expressed serious concerns that ART might be harmful. Side effects of ART, attributed to the “toxic nature” of ART regimens, were mentioned several times. Many participants believed that medicines that had salient and quick effects would be potentially harmful to the human body. The quicker the effects, the more “toxic” the medications were regarded. Some participants even regarded ART as “poisonous.” Although ART was viewed as a “virus-killer,” the fear of health damages related to ART use still deterred some participants from taking part in an ART regimen.

For me, the major concern is the side effects of ART. [ART] can save my life, but if I also become paralyzed, it is meaningless. ... Even if it extends my life, if I can only lie in bed without being able to walk, I see no point in getting treatment. (30-year-old male)

Others were concerned that long-term side effects from ART might lead to organ damage and a permanent disability or other serious long-term impairments.

I know the meds can kill the virus, but also damage other organs. ... I have side effects on my feet, however in the long run, there might be more other problems. ... I heard that nevirapine (NVP) is very harmful to the liver. ... Some people were O.K. before they took ART, but had trouble after they took it. I was afraid of taking ART. ... should I take the meds? I think death is an easier way out. (32-year-old female)

In this study, many of the participants expressed that while Western medicine was more effective in suppressing viruses and bacteria and treating acute symptoms in the short term, it was also more invasive and harmful to the human body.

In our study, participant skepticism might have been due to the extreme uncertainty or ignorance about HIV (Littlewood & Vanable, 2008). One 66-year-old male said, “...in terms of how serious my disease is, and how long I can live, I totally have no idea.” Others doubted the effectiveness of ART. A 40-year-old male said, “The most appealing aspect of ART is survival. However, I really have no idea about whether it works or not... I am always skeptical about the effectiveness of these meds.”

While many of the participants expressed trust in the advances of modern medical technology, they also recognized there were limits to medical science. Drug resistance was one of the most cited concerns about ART effectiveness.

How should I describe the confidence on taking ART... if I take it, for sure, it can decrease something... but deep in my heart, it would not work for a long run because once I stop taking it, virus will explode in number definitely. Therefore, it doesn't work for a long run. These medicines can temporarily ease the problem, but not for long. The technology should not go for this direction. I still have question about the effectiveness and the medicine is not for long. (28-year-old male)

Before the *Four Frees and One Care* policy was implemented, many ART drugs were imported. Many of the ART regimens provided by the government under this policy are generic pharmaceuticals manufactured in China, as imported ART medications are usually too expensive to be accessible (Wu, Sullivan, Wang, Rotheram-Borus, & Detels, 2007). The use of domestic medications increased access but limited the availability of combination therapies. Because of this, participants perceived the domestic medications to be inferior to the imported ones. There were fewer to choose from; they had a larger range in quality; and they had more

severe side effects, as the participants in this study observed. Some participants learned of these differences due to increased access to information technology and the Internet, where they educated themselves about the latest development of ART worldwide. A 46-year-old participant expressed his despair about the currently available ART combination that he was taking.

Basically, Chinese patients have access to free medications now, but the combinations are “out-dated,” and are not used anymore internationally. I wish I could take the best combination, or get the one that is easy to take. The medications now available in our country are those difficult to take and out of production. (46-year-old male)

Few (10%) of the participants receiving medications from the government said they faced current financial difficulties. However, 56% of the participants acknowledged that a financial crisis was possible, particularly when switching to regimens not covered by the government. To purchase expensive medications, patients sought help from their families. As familial collectivism is highly valued in China, family members usually share the financial burden with the patients. In this case, HIV treatments would exhaust not only the patient's personal resources, but also the family's resources. To put a financial burden on the family usually runs against Chinese cultural health beliefs. It would represent a patient's failure to carry out his or her familial responsibilities, which is an integral part of “health” in Chinese culture (Chen et al., 2007).

If the government no longer provides free meds, and I need to pay more than 100,000 RMB (~\$12,500 U.S.) for ART, I would definitely give up the treatments. ... The reason for me to survive is I want my children and my family to have a better life. But, if I need to spend 100,000 (~\$12,500 U.S.) on ART without totally curing the disease, I will give the money to my family to make them live better. I don't want to live poorly, owe others lots of money, and still be sick. (40-year-old male)

One participant also expressed concern about the health-poverty cycle, which he saw in many patients while in the hospital.

I know some patients had to pay medications all by themselves because health insurance did not cover these meds. The costs are about 4,000~6,000 RMB per month (~\$500-\$750 U.S.). How could they afford it? They were broke from purchasing ART, before they got better. Then, they try to earn as much as possible, then buy the medicines, and became poor again. This disease makes poverty -- that is for sure. Until there is one day that one is too poor, and not able to keep taking medications. There are so many cases of family breakdown because of the cycle. (28-year-old male)

ART brings many undesirable side effects, causes damage to the body, and has other negative attributes, according to some of the participants. However, since ART is the only treatment that has been scientifically proven to be effective in suppressing HIV, many of the participants expressed their heavy reliance on ART to save their lives and to maintain their health. Without other options for HIV treatments, ART became the only choice. But taking ART ran against their beliefs about what constituted health, and when there was no other option, it was with some degree of hesitancy that many patients feel that they had to take ART to sustain life. The sense of not wanting but needing ART diminished their sense of control in treatment plans. Many of the participants expressed their sense of powerlessness:

It is just like, I know I should not do it, but I have no other choice. In other words, I cannot help depending on these meds. Because in China, we only have these meds... the most important reason is, the meds do work. If swallowing an iron can cure my disease, I will swallow one... now, this is my only choice. (30-year-old male)

Attitudes Toward CAM

Congruent with the literature that discusses the ways in which Chinese people seek different kinds of medical care (Kaufman & Gregory, 2007), more than 70% of the participants in this study acknowledged that they used three different kinds of CAM: TCM, vitamins, and other conventional medicines. While some of the participants reported only using one kind, many participants used different kinds of CAM in combination, or all of them simultaneously, or different kinds at different times for various purposes. For example, one participant reported that he utilized TCM, vitamins, and conventional medicine in a sequence to relieve the side effects of ART.

Some patients told me that I can use Chinese herbs to wash my feet followed by taking vitamin B1, B6, B12, and vitamin C... I tried all of them for a year. Currently, I am only taking vitamin C. I have stopped other vitamins for 2 months now and plan to take them again later. I took histamine for skin rash. I took it by myself [without consulting my doctor]. After I got HIV, my allergy has been better but I still use it. (47-year-old male)

Positive attitudes toward CAM—Participants held positive attitudes toward CAM and, similar to their attitudes toward ART, these derived from the positive outcome of their personal use of CAM. Three major themes emerged from the study participants' CAM use. CAM was thought to be effective in “reducing side effects,” “dealing with other discomforts,” and “enhancing general health” (See Table 3).

Across the globe, PLWH have used CAM to help manage the side effects of ART (Kaufman & Gregory, 2007; Kirksey et al., 2002). Similar results were shown in our study. Many of the participants who took CAM at some point in their treatment reported a belief in the ability of CAM to reduce the severity of the side effects from ART and intended to continue using CAM for this reason. One participant described how he used CAM to successfully cope with the side effects he experienced from ART:

I have abdominal distention. I felt so uncomfortable even if I only ate a little. I felt that the food was stuck there and was not digested. Taking some herb digestion medicine makes me feel better. ...The old guy who was in the same ward gave that to me. I took two pills and felt very good. Other side effects were that I had skin eruptions and fever on the 11th day after I took NVP. ...I took Vitamin C and *calcii gluconas* to overcome the reaction. I felt much better after I took those medicines. (30-year-old male)

Many participants reported that CAM helped them manage other discomforts not directly caused by ART. Besides the side effects from ART, PLWH might also experience discomfort from colds or hemorrhoids unrelated to their HIV. Participants preferred to use CAM to deal with such singular episodes of discomfort. One participant talked about his experience in treating his hemorrhoids by taking TCM.

Someone referred me to a very famous Chinese medicine clinic. The clinic is the best in Beijing in traditional Chinese anal-intestine specialty. So, I went there, the Chinese herbalist told me that I had a hemorrhoid with inflammation. He needed to treat the inflammation before the hemorrhoid can be operated on. I asked him how long it would take to take care of the inflammation, he told me about 2 weeks. So, I took his regimen, you know, TCM is about smoke, steam, soak, drink, smear, something like that. (30-year-old male)

Many of the participants taking CAM, particularly those using TCM, cited observable changes in their health. One participant talked about how he took TCM soup to improve his health:

I take TCM soup. This kind of TCM soup makes me look better. After I took Western medicine [ART], my face turned pale and I looked terrible. Then, my skin turned black and I no longer looked glowing. But after taking this soup, I obviously look better. [The TCM soup] has a relieving effect in many aspects. It makes me look more energetic and have better skin tone. If I only take the Western medicine, I look horrible. (28-year-old male)

In traditional Chinese philosophy, the human body is dominated and guided by the two forces, yin (negative force) and yang (positive force). When these two forces are balanced, the body operates smoothly and in an orderly manner, but when this harmonious system is disrupted the operation of the body is interrupted, leading to sickness. The restoration of health and balance can only be achieved through a slow adjustment of the two forces within the body. Qi represents an “energy flow” to produce the balance of one's health. Under this cultural belief, while ART functions to suppress the virus, CAM can gently restore the body's necessary balance. One participant described his beliefs about using Chinese medicine as follows:

I believe in Chinese medicines more. The human body is not just a unit, but also a correlated and balanced system. Therefore, I definitely would keep using traditional Chinese medicines to adjust my own balance.... From the perspective of “Qi,” or for my own body's good, I need to increase my body's strengths. Everyone has viruses in his/her body, either this one or that one....when your immune system is strong, those viruses become weak with no doubt. When your positive forces are enhanced, the negative forces must be weakened. So I will boost my own “positive” forces through Chinese medicine. (32-year-old male)

Furthermore, some participants noted that they felt positive about the results of CAM use, citing, as this participant did, that CAM can help increase CD4 counts.

Traditional Chinese medicine works well for me. My CD4 was in the low 300 before I took the traditional medicine. The CD4 counts went up quickly after I took the traditional Chinese medicine. It [CD4 counts] went up pretty fast. Now my CD4 is more than 700. (32-year-old female)

Negative attitudes toward CAM—Four themes of negative attitudes toward CAM were expressed that accounted for discontinuing CAM for about half the participants: “questionable effectiveness in HIV treatment,” “difficulties in preparation,” “bad tastes,” and “making medication schedules more complicated” (See Table 3).

Existing clinical literature (Littlewood & Venable, 2008) shows that CAM is unable to suppress the replication of the HIV virus, and many participants doubt the effectiveness of CAM in HIV treatment. As with CAM believers, non-believers used their CD4 counts as evidence to support their lack of faith in the effectiveness of CAM. One participant questioned the efficacy of boosting his CD4 count based on his recurrent experiences with going on and off ART and CAM treatments:

I joined a scientific research group and the staff there used only Chinese traditional medicine on me. At that time I did not take any Western medicine. ... But my CD4 count remained low, between 50 and 70... so I started to take ART. Later, because I ran out of ART, the researcher asked me to get back on Chinese traditional medicine. Two months later my CD4 count went down to 100. Then, I started taking domestic ART again... this [TCM] doesn't work. (34-year-old male)

Taking CAM, especially TCM, is often very complicated and time consuming, requiring a lot of effort in preparation (Farquhar, 2002). Some study participants complained about the complexity and difficulties in TCM preparation. Two of the participants found the TCM “bothersome” and/or “difficult to cook.”

I am still taking Chinese meds because the Chinese medicine doctor insists that I should keep taking them. However, sometimes I take them, sometimes I do not. I am not taking it every day. It is too bothersome to prepare these meds. I have to cook them by myself. Too much hassle. I believe Chinese medicine is good for my health because it can take care of my body. I wish that it could be more convenient to take Chinese meds. (32-year-old female)

Another participant described how he and his father make the TCM:

My father, who is over 70 years old, helps to extract the flavor by boiling TCM. So sometimes, I took TCM. I know TCM was good for me but I stopped for a while. It is too difficult to extract the essence from the herb by boiling. I will continue taking that when the weather cools down. (30-year-old male)

Many types of CAM include herbs and plants as essential ingredients and people find the strong tastes and/or smell intolerable. In addition, the preparation procedures (e.g., extracting the flavor by boiling) can make the tastes and smells even stronger. Several participants stopped using CAM because of the bad taste, even though they believed in the benefits. One 30-year-old male participant commented that “ART is not like traditional Chinese medicine, which is so bitter; I need to squeeze my nose and force myself to swallow the Chinese medicine.”

Similar to ART, some CAM require complicated dose schedules and high levels of adherence. Many health care providers recommend not taking ART and CAM (especially TCM) simultaneously to avoid unexpected drug interactions. Adding CAM to the ART regimen can significantly increase the complexity of daily medication schedules and may result in a decrease in both ART and CAM adherence. This was exemplified by the experience of one participant as follows:

I forgot to take the medications (ART and TCM) several times last week so now I only take traditional Chinese medicine. There must be some time in between taking ART and TCM, so I take Chinese medicine first in the morning, and then go to work. When the time comes to take ART, after working for a while and before a meal, I forget. ... When I am busy, I forget to take the ART. (34-year-old male)

Discussion

This study revealed the attitudes held by a sample of Chinese PLWH toward HIV treatment in China, including ART and CAM. It showed that they considered both types of medicines to have strengths and weaknesses and chose CAM or ART to relieve suffering from the specific types of illnesses and discomforts they experienced. This pragmatic attitude in medication was consistent with the existing literature (Ma et al., 2008).

Overall, participants in this study were ambivalent about ART. While they thought ART was very necessary to treat their illness, they also had many concerns. As shown in the analysis, a great number of PLWH found themselves trapped in a series of dilemmas. First, ART was thought to be capable of bringing them both clinical and social benefits, including those highly valued by the patients in the context of Chinese culture, particularly being able to return to work and fulfill family obligations as their health status improved. On the other hand, ART was extremely expensive. The benefits brought by ART were compromised by the possibility of a familial financial crisis that would conflict with the Chinese health notion that one must be responsible to the family (Chen et al., 2007). Second, although ART could prolong PLWH's lives, participants felt that taking the medications was complicated. Third, while PLWH recognized ART's ability to promote their health, at the same time, their sense of health drawn from the Chinese notions about the balance of body forces led to the view that ART can harm their health. Fourth, while many of the participants expressed confidence in the effectiveness

of ART, they also had reservations about ART's effectiveness due to profound uncertainty from HIV. Lastly, even if the participants believed in the advances in medical technology and the inevitability of new medications that would sustain their quality of life, many of them complained about the inaccessibility to the newer treatments due to government regulations.

The participants also expressed positive and negative attitudes toward CAM that were more related to their practical and corporeal experiences (Farquhar, 2002). In our study, CAM, especially TCM, was culturally recognized to be effective in adjusting forces and restoring the delicate balance in the human body. Participants believed CAM was efficient in increasing CD4 counts, reducing ART side effects, decreasing other discomforts, and enhancing general health. Still, practically, CAM's effectiveness in HIV treatment has been questioned, and it was difficult to prepare, had bad tastes, and made drug-taking schedules more complicated.

Limitations

The findings from this study should be viewed in light of its limitations. First, some of the interviewers were trained in and professionally committed to Western medicine, so it is possible they might have biased interviews in the direction of more positive attitudes toward ART and negative attitudes toward CAM. Because of this, participants might have felt less comfortable expressing ideas contradicting Western medicine. Second, we analyzed attitudes by dichotomizing them as either positive or negative to manage and present the study findings. In reality, however, the relationships between perceptions of CAM and ART were more complicated and dynamic. Each of the positive attitudes toward HIV treatment might closely correspond with and even lead to another negative attitude, and vice versa. Future studies addressing potential interactions between positive and negative attitudes toward both types of medication might be promising. Third, participants were recruited from the premier hospital in Beijing that is recognized for its quality HIV care. Participants might be biased by hearing more pros and cons of ART and CAM compared to patients in other institutions. Last, most of the interviews were conducted by providers in the hospital, which may have influenced participants' responses.

Clinical Implications

Findings from this study have several clinical implications for HIV care providers. Western-medicine-trained health care providers might want to discuss with their patients the potential interactions between ART and CAM. The side effects and unpleasant feelings associated with ART could lead to non-adherence in the forms of unsupervised medication holidays, taking fewer pills, or skipping doses.

Conclusion

CAM use is common in Chinese society. PLWH and health care providers should be aware of potential toxicities and drug interactions related to the use of CAM and ART (Hsiao et al., 2003). Beginning a conversation with PLWH about the casual use of CAM might enhance the provider-patient relationship. An important focus for these discussions should be on the risks and benefits of taking CAM and ART simultaneously, with explicit information on how to effectively integrate CAM practices into ART regimens to maximize the patient's health and safety (Owen-Smith et al., 2007). Furthermore, providers should explore the pros and cons of each type of treatment with patients, given the individual clinical and social situation of the patient as well as his or her values regarding these different therapies with the goal of supporting a good balance between ART and CAM in Chinese PLWH.

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Table 1
Factors Influencing PLWH Attitudes Toward HIV Treatment

Social	Cultural	Governmental
<ul style="list-style-type: none"> Advances in modern medical science and technology in ART Limits of modern medical science caused PLWH to expect drug resistance 	<ul style="list-style-type: none"> Emphasizing <i>yin</i> (negative) and <i>yang</i> (positive) balance in Chinese health concept <ul style="list-style-type: none"> ART is the “virus killer” but also “poison” CAM is an efficient alternative to enhance general health CAM can manage side effects of ART Collectivism emphasizes the balance of relationships between oneself and social environment <ul style="list-style-type: none"> ART might financially burden family members. ART can assist in fulfilling family obligations. 	<ul style="list-style-type: none"> Expanding ART regimens provided by the government increases optimism for future treatment Providing ART eases financial burdens of treatment Limited possible ART combinations in China

Table 2**Attitudes Toward ART**

Positive	Negative
<ul style="list-style-type: none"> • Perceived benefits of ART <ul style="list-style-type: none"> — Prolongs life — Improves physical health — Enhances quality of life — Allows for “self-actualization” through career satisfaction — Assists in fulfillment of family obligations • Confidence in current HIV treatments • Optimism with respect to future treatments 	<ul style="list-style-type: none"> • Does more harm than good • Uncertainty of ART effectiveness • Perceived inferiority of domestic vs. imported medications • Causes financial difficulties • Makes one feel forced to take medications

Table 3**Attitudes Toward CAM**

Positive	Negative
<ul style="list-style-type: none">• Generally effective in<ul style="list-style-type: none">— Reducing side effects— Dealing with other discomforts— Enhancing general health	<ul style="list-style-type: none">• Questionable effectiveness in HIV treatment• Difficulties in preparation• Bad tastes• Makes medication schedules more complicated