The meaning of complementary and alternative medicine practices among people with HIV in the United States: strategies for managing everyday life

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Abstract

The meanings of complementary and alternative medicine (CAM) practices in the everyday lives of people with HIV in the United States were investigated. Interviews of people with HIV revealed that two out of three interviewees (N = 62) used some form of CAM over the course of their ongoing HIV infection. Management of their everyday lives as ill persons was improved to the extent that CAM meanings addressed self-regulation of treatment practices and strategies to cope with uncertainty. Four main strategies are dealt with: managing symptoms, medications and emotions; self experimenting to evaluate disease progression; gaining freedom from medical regimens; and managing AIDS stigma. It was shown that CAM practices are one way people with HIV can increase control over their illness and attempt to normalise health status. CAM practices were discussed in the context of self-regulation in relation to other illnesses.

Keywords: complementary and alternative medicine, HIV/AIDS, meaning, stigma, control

Introduction

Complementary and alternative medicine (CAM) has increasingly become the focus of social scientific research. CAM refers to diverse therapeutic practices that are not presently considered a part of medical training or practice in countries, such as the United States, Canada, and Great Britain, where allopathic medicine forms the basis of the national health care system (WHO 2002). Examples include herbs, acupuncture and reiki. Questions about reasons for using CAM have engendered the most concern and attention. Researchers have often answered these questions in terms of either/or...
explanations. Users are either pushed (dissatisfied, desperate, and irrational) or pulled (consumerist, ideological, or rational) toward CAM (Furnham and Vincent 2000, Pawluch, Cain and Gillett 2000). These studies locate the source of CAM use in attitudes and beliefs about the medical and alternative health care systems.

I offer a complementary perspective on CAM use, one situated in the ill person’s experience of illness. Drawing on findings from a qualitative study examining the use of CAM for HIV in the US, I argue that from an ill-person-centred perspective the meanings of CAM in people’s everyday life are important for understanding why people use CAM. Although ill people may experience both push and pull factors, from their perspective, CAM is more a matter of self-regulation of treatment regimens aimed to manage everyday life by increasing personal control and normalising health status.

This article begins with a review of the literature on CAM use, which I then build on to develop the idea of ‘CAM practice’ to aid in understanding why people in the US use CAM for HIV/AIDS. The data, methods and sample are discussed followed by a description of four different CAM strategies used by people with HIV. The significance of the findings and future research are highlighted.

Background

Perspectives on CAM use
The World Health Organisation estimates that internationally, the vast majority of people rely on what is considered CAM from a Western perspective (2002). Although the bulk of this use resides in Africa, Asia and Latin America, increasingly CAM is used by people in Australia, Europe and North America particularly for the management of chronic and serious disease (WHO 2002). No longer on the fringes of Western societies, CAM is increasingly meeting the health needs of people throughout countries in which allopathic medicine dominates as the primary system of health care delivery.

The widespread and growing use of CAM in Western countries may be most apparent in the US. Once considered quackery and fraudulent, CAM therapies, such as acupuncture, herbs, and meditation, entered into US mainstream healing practices in the 1980s and 1990s. Although CAM use concentrates in the Northeast and Western parts of the United States, recent studies suggest the trend toward CAM is not limited to these areas; more than 40 per cent of Americans use CAM at a cost of over $27 billion, and visits to such practitioners exceeded visits to primary care physicians in 1997 (Eisenberg et al. 1998). Along with the widespread diffusion of CAM into mainstream health practices came research aimed to shed light on this phenomenon. Of primary concern was the need to explain why people in the US increasingly choose CAM.
Two major perspectives emerged to explain CAM use. The first one states that people are ‘pushed’ toward CAM because they have become dissatisfied with standard medical care. CAM use results from negative attitudes towards the medical profession such as declining medical confidence (McGregor and Peay 1996, Astin 1998) and concerns with standard medicine’s aggressive and costly management of chronic illness (Illich 1976, Vincent and Furnham 1996). People find CAM attractive because of its potential to improve both personal and public health while at the same time producing considerable savings to medical costs.

The importance of positive attitudes toward CAM practices are central to a second perspective focusing on factors which ‘pull’ people toward CAM. CAM use results when people perceive these approaches as congruent with their own world views and personal health beliefs (Astin 1998, Furnham and Bhagrath 1993, Goldstein 2000, Vincent and Furnham 1996). For example, researchers found high levels of CAM use among people who desired greater personal control over their health (Furnham and Bhagrath 1993), and those who perceived health and illness holistically (Goldstein 2000). Rather than seeking an alternative to standard medicine, people consider a wider range of practices to improve health.

A third complementary perspective that is rarely mentioned in CAM studies presumes the centrality of the ill person’s experience of illness. This ill-person-centred perspective is found in the literature on compliance with prescribed medical regimens (Conrad 1985) and the illness experience (Charmaz 1991, 1995, Weitz 1991). It understands people as active agents who reflect and act on the uncertainties and contingencies of daily life with chronic illness, rather than as passive recipients of medical cultural norms. Wietz argues, for example, that to understand HIV positive people’s illness behaviour it is important to account for several factors that are part of the illness experience such as threats to future goals, stigma management, debilitating health complications, and increasing dependency on others (1991). People with any chronic illness continuously face uncertainties as they reassess who they are and what their future holds. In the ongoing reassessment process people try to reconstruct normal lives, to whatever extent possible, so that the situation becomes manageable (Charmaz 1991, 1995). The medical compliance literature, which examines reasons for not complying with physician-prescribed medical regimens, also stresses the importance of examining how ill people manage their daily existence, of which taking medications and interacting with the medical institution is only a small part (Conrad 1995). These issues lead to examining the meaning of CAM as it is used by people in their daily lives.

**HIV, CAM, and treatment practices**

Although CAM in the US is most often used by people with chronic and terminal illnesses, researchers suggest that people with HIV are more likely to use CAM than people with other serious illnesses such as cancer or
arthritis (Hand 1989, Anderson et al. 1993). Researchers estimate that as many as two-thirds of people with HIV have tried CAM (Katz 2001). Additionally, use has not significantly declined since the widespread use of antiretroviral triple drug therapies, i.e. AIDS medications (Onstott and Horn 1998, Katz 2001).

A recent Canadian study reports that people are attracted to CAM for a number of reasons: ‘as a health maintenance strategy, a healing strategy, an alternative to Western medicine, a way of mitigating the side-effects of drug therapies, a strategy for maximizing quality of life, a coping strategy, and a form of political resistance’ (Pawluch et al. 2000: 251). A US study suggests that CAM use may be one way people with HIV reveal a desire to increase personal control in their lives; ‘control becomes objectified in CAM’ (Furin 1995: 158). These findings suggest that the reasons people use CAM may centre on a person’s everyday life coping with a life-threatening and stigmatised diagnosis.

The concept of ‘medication practice’ may assist in understanding the meaning of CAM in a person’s daily life with illness. This concept refers to a patient-centred perspective of how people manage their medications that focuses on the meaning of medications in daily life (Conrad 1985). The doctor’s orders are understood as the ‘prescribed medication practice’. For example, HIV doctors may prescribe three kinds of medication taken two times a day. People interpret the prescribed medication practice and then create a medication practice that may deviate from the prescribed practice. For example, people with epilepsy often intentionally reduce or raise their prescribed medication dose in efforts to test for progression of their disease, reduce dependency on others, to destigmatise their illness, and for practical reasons (Conrad 1985). In creating different medication practices, ill people self-regulate their medical regimens to fit their daily lives rather than simply noncomply with doctor’s orders.

Extending this perspective, taking medications can be understood as part of a person’s overall ‘treatment practice’. This includes the prescribed medication practice and the medication practice. In addition, this study identified a third kind of practice, a ‘CAM practice’ that deviates from both the prescribed medication and medication practice by including non-doctor prescribed therapies. The CAM practice, however, is functionally similar to the medication practice. Both are not part of the prescribed medical practice, are self-regulated by the ill person, and assist people to maintain personal control over their daily lives. Because people can create CAM practices without ever entering the patient role, the meaning of such practices represents an ill person rather than a patient-centred perspective.

This paper elaborates on current understandings of CAM by developing an ill-person-centred perspective on why people with chronic illness resort to using CAM. I develop the thesis that CAM use is an issue of self-regulation of treatment regimens and is one way people with chronic illness manage the uncertainties of everyday life with illness, and assert personal
control. Using data from a study on CAM use and HIV in the US, I examine what CAM means to the people who reported using these therapies; and how these meanings explain why people find these therapies appealing.

**Methods, sample and data analysis**

I collected data for this article during a four year qualitative interview study examining the use and meaning of CAM from the perspective of people with HIV. The research took place in a major metropolitan area in the western United States. Falling within the opportunistic research tradition (Riemer 1977), the motivation for this research stems from my own personal experiences as a person living with HIV. Before beginning this research, I was an active user of CAM. These therapies formed the foundation of my health strategy for a number of years before starting AIDS medications, and continued to a lesser extent thereafter. My membership of this stigmatised group facilitated this project through existing contacts in the field, familiarity with the AIDS treatment world, valuable personal insights, and the legitimacy needed to recruit, and connect with, others living with HIV.

In the Spring of 1998, I began attending community AIDS forums and conversing with activists and forum speakers to learn more about CAM. In these same settings, I developed a rapport with people who could help me gain access to relevant groups and provide information that would help in developing a sound research design. During this preliminary fieldwork, I became familiar with the HIV CAM world. I learned the names of CAM practitioners who treat large numbers of persons with HIV, and collected hundreds of published instances of CAM for HIV, including scientific articles, popular magazines, activist documents, and publications at practitioners’ offices, forums, and conferences.

To obtain more in-depth data, from May 2000 through to June 2001, I completed 62 qualitative interviews with a diverse sample of persons with HIV. Using a modified version of Watters and Biernacki's targeted sampling (1989), I recruited people for the study through a core group of persons with HIV from my own personal networks and from contacts made through my preliminary fieldwork. To broaden the sample outside these pre-established networks, I also advertised my study in places that would attract a diverse group of users from which to sample: AIDS service organisations, CAM clinics, buyers’ clubs, medical clinics, HIV community events and HIV news letters. Finally, through the respondents who contacted me, I received more referrals of other persons with HIV. Respondents were paid $15.00 for their time.

I shared my HIV status with all respondents in study advertisements, during initial phone conversations, and again when we met to complete the interview. Because of my shared status, I was seen by nearly all respondents as extremely approachable and empathic to their situation. Although the
interviews were conducted with an interview guide, they were for the most part conversational, with probes used whenever a respondent volunteered information that seemed important or needed clarification. The interviews took the form of a life history focused primarily on the years of HIV infection. I identified key topic areas and questions that I wanted to address with respondents, including factors around their treatment decisions, their understandings of CAM, why they found such therapies appealing, their ideas and beliefs about HIV, and experiences with medical doctors. Interviews lasted around two hours and were tape recorded and transcribed verbatim.

Of the 62 interviews I conducted, 16 were with women and 46 were with men. Just over half of the sample was homosexual or bisexual (n = 37, three of whom were bisexual); 25 stated that they were heterosexual. Yearly incomes ranged from less than $5,000 to over $70,000 with most respondents making less than $15,000 (n = 40). The majority (n = 40) were on public insurance and 22 were on private insurance. Respondents ranged in age from 25 to 65 years with a mean age of 43 years. Thirty-six respondents described their race as White, 11 as Black, and 15 as Hispanic or Latino. The date of the first positive HIV test ranged from 1985 to 1999 and was fairly evenly divided across this time frame. Forty respondents had been diagnosed with AIDS, 18 of whom had experienced an opportunistic infection. Almost all respondents were taking (n = 50 or 81%) or had taken AIDS medications (n = 7 or 11%).

I used QSR NUD*IST to organize and code the data. My analysis strategy employed a combination of hermeneutic and grounded theory (Geertz 1973, Glaser and Strauss 1967). I developed a series of qualitative topic codes to facilitate content analysis and interpretive understanding. This involved starting with an initial set of broad categories, drawn from the literature and my preliminary fieldwork, that were likely to be of theoretical importance in understanding people's experiences with CAM. These included categories such as ‘meanings of CAM’, ‘barriers to use’, and ‘health beliefs’. As the data gathering and analysis proceeded, I refined and extended these categories to reflect and incorporate themes that emerged from the data. These included newer categories such as use of CAM for ‘psychological reasons’, ‘self experiments’, and ‘resisting medical dependency’. Interview data were then used to further refine, test, verify, or reject theoretical conclusions within each category based on common findings and themes that emerged. My aim was to gain depth of understanding and fully describe how persons with HIV understood their experiences using CAM.

Findings

The meaning of CAM practices

This section provides an ill-person-centred perspective and focuses only on respondents who regulate their own treatment practices by using CAM. Of
the 62 people interviewed, this involves a sub-group of 40 (65%) people who reported using CAM to manage HIV and/or its complications. Overall, users are more likely to be White, have some education at college or a higher level, with incomes above $15,000, and to have private insurance. Their health status, sexual orientation, gender, age, and HIV risk factor resembles that of respondents who do not use CAM. CAM for the using group consists of ever using therapies that are not traditionally available from a medical doctor, such as herbal medicine, visualisation, or homeopathic remedies, for any period of time for the management of HIV-related health conditions.

Although 65 per cent (n = 40) of respondents used CAM at some point over the course of their HIV infection, users might not be distinguished as a group from non-users. About half of the users were pragmatic users, meaning that even though they used CAM regularly, they only used these therapies for short periods of time or for practical reasons such as during times of high stress or with the onset of a cold. Others wanted to use them more often but did not and five per cent (n = 3) had stopped using CAM altogether. At the same time, nearly 60 per cent (n = 13) of the non-using group (n = 22) expressed interest in using CAM. These findings reveal an overlap in interest and illness behaviours between the two groups. While certain limitations exist in forcing people into an either/or category of use (Pescosolido 2000), the CAM-using group provides a unique opportunity for study because they may reveal meanings of illness behaviours common to all people with HIV, and offer new understandings into CAM treatment practices.

CAM use can be understood as one kind of treatment practice used by people to manage living with HIV and construct a sense of normalcy in their daily lives. By normalcy, normalisation, or normal, I mean the internalisation of images of a self that can fulfil regular social roles without experiencing impairment or discrimination because of one’s health status.

The vast majority of users reported using CAM to manage health complications, especially as a means to control medication side-effects. While these instrumental reasons are commonly an underlying reason for using any type of therapy, whether alternative or standard, psychological grounds were equally important for the sample. Many reported using CAM because it helped them effectively to cope with emotional problems and stress. In addition to these manifest reasons, the meaning of CAM for HIV extends beyond seeking physical and emotional relief. These therapies also offer users strategies to self-regulate their treatment practices in ways which allow them to perform self-experiments to evaluate disease progression, gain freedom from medical constraints, and manage stigma. These meanings reveal that complementary to push and pull factors, people with HIV use CAM as a strategy to self-regulate their treatment practices in efforts to normalise their everyday lives. Although users may report using more than one kind of strategy, for clarity of presentation, I discuss each strategy separately.
Managing symptoms, medications and emotions

Users spoke often of how they used CAM for physical relief and to manage the emotional effects of living with HIV. Receiving an HIV positive diagnosis means having to cope with the uncertainties of living with a life-threatening disease and a variety of family, financial, relationship, legal, and work-related concerns (Pawluch et al. 2000, Weitz 1991, Siegel and Krauss 1991). The stress of living with HIV can profoundly affect emotional states and increase feelings of anxiety and depression (Fleishman and Fogel 1994). Can people with HIV use CAM practices as part of strategies to reduce the physical and emotional uncertainties of their illness?

CAM was most often used as complementary medicine, particularly as a way to manage symptoms and mitigate the side-effects of AIDS medication. For example, users expressed deep concerns about the short- and long-term complications of taking medications. One man who believed some of his friends were killed by AIDS medications explained: ‘I asked my doctor the last time I was in, how realistic is it that I am going to be able to take these drugs for 10 or 15 years before my heart shuts down or my kidney shuts down or my liver is completely destroyed?’.

Respondents reported experiencing AIDS medication side-effects ranging from milder problems such as fatigue, nausea, and diarrhoea to severe vomiting, anaemia, neuropathy, and pancreatitis. Instead of abandoning standard care altogether, they found practical ways to continue the medicine. Users had several strategies to deal with side-effects: ride out the side-effects, switch medications in hopes of finding a tolerable regimen, or continue their existing regimens and use CAM in complementary ways to mitigate side-effects. For example, acupuncture could reduce pain from neuropathy, Chinese herbs could control nausea, and marijuana could increase appetite and lead to weight gain. Of primary concern was how to increase the chance of a positive response from the AIDS medications, improve adherence, and keep the medication side-effects from interfering with everyday life. One respondent explained how he tolerated his medications by using CAM to manage rising cholesterol levels that he attributed to AIDS medication:

> It makes me feel very good that alternative therapies can work and just that natural viewing, exercising, eating right can work and you don't have to wait until [cholesterol levels] are 700 or 1000. I think that's just absurd to wait until that point. So I'm pretty pleased so that to me, that means that maybe I am going to be able to stay on these medications longer without having to go off of them because of side-effects.

Respondents such as this man would often tell their physicians about these experiences in an effort to educate providers that CAM was another option available to people having problems with their medication regimen. When
used in conjunction with standard therapies, not only was adherence to HIV medications more likely, but the experience of using medications was generally more positive.

Using CAM practices to manage symptoms and side-effects enabled some users to maintain normal social roles. For example, women who had young children often framed their decisions for using CAM largely in terms of their care-giving responsibilities as mothers. Side-effects and periodic episodes of sickness rendered them occasionally unavailable as mothers to their children. CAM offered a practical way to manage their illness so that they could ‘be around’ to take care of their children. By controlling symptoms and side-effects such as nausea and pain, CAM practices enabled women to remain in the motherhood role. Likewise, in controlling physical problems, people who worked could also manage their employment roles better.

In addition to using CAM in practical ways to manage symptoms and medications, CAM was also used because it helped maintain a positive psychological state by minimising stress and managing anxiety and depression. Several respondents perceived stress as the biggest threat to their health and wellbeing. One man who became ill after leaving a corporate job, and having faced the stress of unemployment, said ‘I think stress in this disease is the biggest killer: eliminating stress in HIV positive people is key to survival’. This man and others like him often resorted to mind-body therapies, such as meditation, prayer, music, or massage to manage their emotions. The common belief was that by reducing stress, the body can then fight more effectively. It was no longer fighting a ‘two-front war’, as ‘eliminating stress was half the battle’. Another woman who used CAM for stress management explained: ‘It’s because stress is hard on my immune system, so if I’m listening to soft music and using my oils, my stress goes down’. Others talked of being alone and isolated and how just seeing an alternative care provider lifted their moods and fostered positive attitudes.

In sum, people with HIV used CAM practices practically in efforts to improve physical and psychological wellbeing, as another man explained:

I think in many cases that you are gonna have a complementary effect upon the drug regimen as far as reducing side-effects . . . and that’s like in using vitamins or acupuncture. The other alternative therapies are more for dealing with the side that the drugs will never get to, you know, that relaxation, the mental stress, the tiredness from doing this.

Such practical uses of CAM to manage emotions and medications are common ways of trying to normalise daily life with HIV.

**Self-experimentation**

People with serious disease can evaluate the severity of their disease for themselves by reducing or stopping their medications (Conrad 1985). How...
do people with HIV self-evaluate disease progression? Large variations exist in the progression from an HIV diagnosis to AIDS. If left untreated, some people progress relatively quickly within two to three years of initial exposure to HIV. Most progress more slowly, averaging 10 years to develop AIDS. A small group never progress and maintain healthy immune systems. Once people begin taking AIDS medication, they usually stay on medication indefinitely. At this time, it is near impossible to tell how fast one would have progressed had they never started medication, particularly if infection started early. There are several questions relevant to persons with HIV. How long can one go without medication? How can one know if one is a fast progressor, slow progressor, or non-progressor? Is it possible to control HIV by means other than medication?

Whereas CAM could be used as complementary medicine to manage physical and emotional health, it could also be used as an alternative to standard medicine as part of a strategy to evaluate disease progression and test for themselves whether they can control HIV by means other than AIDS medication. Users who had not yet taken AIDS medications resorted to CAM in hopes of finding a specific treatment that would cure them or put them in remission. As a self-experiment, they had some marker they would use to indicate that CAM was not working and they would need to start, continue, or restart medications. These markers were similar to the markers used by medical doctors to evaluate health. For some this was a steady rise in their viral load, for others it was a drop in their CD4 cells to a certain level, whereas others used how they felt physically or emotionally as a gauge. These individuals perceived the possibility of negative effects of the HIV medications on their health as much more of a threat to their health than the effects of AIDS-defining illnesses and complications. As such they readily experimented with other less ‘toxic’ and more ‘natural’ therapies to see if they really would become sick and to test whether they could manage their illness with an alternative approach, as one man explained:

My t-cells were gradually decreasing but even despite that I was still pretty healthy. I had very few minor problems and when they dropped to 200 I should have taken bactrim prophylaxis but at that time I resisted, still feeling that with alternative therapies I could control this. I was really resistant. I mean darn it, I knew I could control this with alternative therapies. [When I eventually started the medications] I think that what had happened to me, there really was no other alternative at that point. I had exhausted any alternative therapy that I thought had any potential of reversing what had happened to me as I was very sick at that point.

While this strategy provided individuals with a profound sense of personal control over their illness and answered questions regarding whether they would progress to AIDS using a CAM practice, the outcomes were not always favourable. In some cases, such as this man, the experiment of prolonging
medication avoidance and instead using CAM led to the development of opportunistic infections. Even though he no longer believed he could rid himself of HIV through using CAM, he still regulated his treatment practices by including CAM alongside his prescribed medication practice.

Other people had more favourable outcomes to their self-experiments. For example, despite pressures from her physician to start medication, one woman chose a ‘wait and see’ approach combined with diverse CAM therapies that included mega-nutritional supplements, yoga, and exercise. She explains:

I am glad to know that I made that decision [to postpone medication use] and that it seems to have worked out ... to me it just seems like common sense! I will get back my most recent test results today, but I don’t expect them to be so different that it will require meds. Thankfully, I think I have a little way to go on that one!

She said that when she tested positive for HIV most doctors were of the philosophy ‘hit hard and hit early’. This meant treating with medications as early as possible and as soon as her CD4 cells dropped to 500, a range she has been in since diagnosis. Recently, the HIV treatment guidelines were revised to encourage physicians to delay antiretroviral therapy in asymptomatic patients, such as this woman, until a more advanced disease stage was reached (Carey 2001). In addition to providing her with scientific legitimacy for her experiment’s outcome, this revision affirmed that her experiment to ‘wait and see’ and use CAM had worked. People who self-experimented expressed the view that waiting and using CAM therapies provided them with the additional benefit of having more medication options down the road when they ‘really needed them’.

**Freedom from medical constraints**

Illness is often upsetting because it is experienced as disrupting the order and meaning by which people make sense of their lives. Disease inflicts uncertainty, unpredictability and loss of control. There can be shortness of breath or memory, intermittent pain, fatigue, organ deterioration, and all other ‘failures’ of a sick body (Frank 1991). For persons with HIV, this loss of control often means increasing interactions with medical care providers, and taking highly regimented medications which can lead to a profound loss of freedom and dependence on others (Siegel and Krauss 1991). Can people create CAM practices to reduce feelings of medical dependency and constraint?

Issues of control over one’s illness and treatment decisions were also cited as important reasons for using CAM. Respondents who experienced feelings of medical dependency said that AIDS medications symbolised bondage,
dependence, and constraint. In contrast the meaning of CAM centred on choice, freedom, and independence. These respondents resented taking medications and felt that their lives were constrained by doctor appointments, lab tests, and medication regimens. Though most people at some point will depend on HIV medications to control their disease, these do not cure them, often require adjusting daily life to time and food restrictions, and can have mild to severe side-effects. Respondents talked about feeling immense pressures from medications, describing their experiences as ‘overwhelmed’ or ‘crunched’ by the ‘whole drug thing’. For example, one man who had stopped taking AIDS medications commented on how it was near impossible to live, given the time demands of most drug regimens:

Well, if it wasn't at first, back in the early 90s, it was time, you know, your scheduling. You had to do it, and they were swearing up and down don’t miss an hour, don’t do this, you know, and nobody's life is conducive to that much unless you're homebound, and I’m not. So I started just saying well, what the heck. I'll look at my nutritional side.

Given that many respondents felt controlled by medications, its not surprising that this man, and others like him, stopped taking medications or avoided use altogether. In looking to his nutritional side and creating a CAM practice, this man gained more freedom and flexibility in his health options.

Maintaining personal control over treatments is important to people with HIV. This means what to use and when to stop, start, or change therapies. One woman clearly articulated this when discussing her lack of control over standard medicines, but having tremendous freedom over CAM:

But I know where I did have control was how many yoga classes I went to or how many acupuncture classes I went to. If I missed one, I knew I wasn’t going to damage myself or that kind of stuff. So that gave me permission to just kind of come and go as to where when you’re with the meds, you feel like so choked, if you don’t take it, you die. If you do take it, you could die.

As this quote illustrates, an understanding of CAM as having more flexibility was tied to the perceived risk of these therapies when compared to the risk of AIDS medications. All of the users attributed little risk to using CAM. They could miss doses, stop, and restart any time with few consequences. With AIDS medications, however, in addition to often causing unpleasant and sometimes health-threatening side-effects, ‘if you make a wrong decision you can’t go back and change it’.

In sum, relying on doctors for advice and medications was far from the only option available to people. The very act of having a choice itself and doing things like using acupuncture or ingesting herbs not prescribed by
Complementary and alternative medicine and HIV in the US 493

doctors enhances personal control and reduces medical dependence. By not relying solely on others for help, people who practice CAM take on greater personal responsibility for their health. For users, CAM was another way of keeping yourself well, and lessened dependence on the medical system. Even some respondents who reported dissatisfaction with CAM continued to use such therapies because it was the one thing in their lives they could control.

Stigma management strategies

People with stigmatised illnesses often attempt to control information about their illnesses to minimise the effects of stigma (Conrad 1985, Weitz 1991). Information control can be compromised by taking medications, showing physical symptoms in the presence of others, and already being a member of a stigmatised group. People may therefore try to avoid others when they are ill, take their medications in private, or tell others they have a less stigmatising illness (Conrad 1985, Weitz 1991). Can people use CAM to manage disease information as a way to minimise the effects of AIDS stigma?

Managing AIDS stigma is another reason for creating CAM practices. CAM could be used as part of a strategy to hide one’s HIV status from other people. Taking HIV medications was a constant reminder that respondents had HIV. Medication use acknowledges difference between well bodies and sick bodies and symbolises the deviation from normal bodily control. Many respondents felt they could control these differences on their own by using CAM and postponing HIV medication. One man explained how his friends tried to avoid occupying the status of HIV positive through developing a CAM practice:

A lot of my friends, even though they have family and stuff, they have virtually the same kind of obstacle because some of them haven’t come out to their parents, some of them haven’t even disclosed, or have come out, but haven’t disclosed their health issues, and like in that instance, what happens if an OI [opportunistic infection] hit? Do you want your friends to tell your parents? Or do you want a man in a white lab coat to tell your parents? You know. And so their approach is if I eat healthy, if I concentrate on my body, that may never come.

By doing as many CAM therapies as they could, his friends would maximise their chances of staying well. This health strategy helped avoid occupying the status of HIV positive (and for some, other stigmatised statuses) in the presence of others. In maintaining wellbeing, whether perceived or actual, CAM practices helped minimise potential stigmatisation from AIDS.

CAM practices also helped users manage stigma by reducing the ‘shock value’ of HIV/AIDS. It does this by resisting terminal understandings of HIV, avoiding potential stigmatisation from disclosure, and by reducing
interactions that may be constrained by the constant awareness of HIV. One woman reported that when she visited her medical doctor, she often left feeling very ‘diseased’ and felt as if she only had a few years to live. In contrast, when she visited her practitioner of Chinese medicine, she left feeling terrific, believing that she was going to live to 100. Interactions with alternative care providers reinforced images of HIV as a chronic illness. In contrast, medical encounters reinforced images of HIV as a terminal illness. To reduce the stigma of the medical encounter she completely stopped receiving care from her medical doctor for two years and increased interactions with alternative care providers. Interactions with alternative care providers gave her a framework by which to construct meanings about herself and her illness in non-terminal ways. By developing a CAM practice, she reduced the stigma of AIDS by resisting fatalistic constructions of her future.

Another woman explained how she did not want to be treated by medical providers for endometriosis and a foot problem because she was afraid of how they would react to her HIV status. Particularly of concern was that she received medical care in her place of employment. Disclosing her status to her doctor could also mean disclosing her status in the workplace and risking stigmatisation, something she was not prepared to do. Instead she contemplated seeing an acupuncturist. Alternative care clinics were perceived as places where people did not have to worry about being treated differently because of their HIV status.

Respondents also managed AIDS stigma by restricting their social circle to individuals who responded positively to them and who shared the stigma of AIDS. People commonly did this by developing CAM practices that included support groups, HIV healing retreats or health classes. People in these settings were less likely to treat people with HIV differently from non-infected people. Respondents spoke of how affirming it was to be around people with HIV because ‘they could finally be themselves’, ‘they did not have to worry about who knows about their HIV status’ and ‘having a great weight lifted off of their shoulders’. For example, one woman came to terms with her HIV positive status by joining a local yoga class for people who were HIV positive:

I thought I was gonna die before I ever had to face the real fact [that I was HIV positive], and here I am now, I know that I have to live and I have to live with this so if it’s CAM that’s gonna keep me going, and I think part of maybe even the CAM, I think maybe it was the place where I could go [my yoga classes] and I could start to say out loud, you know, I’m HIV positive which I think has been another reason why that [CAM] helps.

Sharing the company of others who are also stigmatised helps avoid the full impact of stigma by decreasing interactions that may be strained by the constant awareness of HIV.
Discussion

In this research, my aim has been to provide an ill-person-centred perspective on CAM. Push and pull factors are clearly at work in the strategies discussed by respondents. For example, users are pushed away from standard medicine because of negative attitudes towards medications and their dependency on standard medical care. At the same time, they are pulled toward CAM because of positive attitudes towards these therapies; people perceive them as additional therapeutic options with minimal harmful effects. However, when examining the meaning of CAM from the perspective of people with HIV in the US, respondents did not understand their use in terms of push and pull factors from modern medicine and toward CAM. Rather, CAM practices are more about self regulation and strategies to manage the contingencies of everyday life with an HIV positive diagnosis. Contingencies include the uncertainties of managing symptoms, medications, and emotions which make it difficult to maintain normal social roles, increasing dependency on others, effects of stigmatisation, and possibilities of a shortened lifespan. CAM practices were used as part of coping strategies to help users increase personal control and attain a sense of normality in their daily lives.

These practices are similar to findings reported in a study using a Canadian sample, suggesting that commonalities in the experience of living with HIV and using CAM may exist cross-nationally (Pawluch et al. 2000). This study, however, differs from previous findings in that the data were collected well after the widespread use of promising AIDS medications in 1996. Earlier studies either collected data before then (Furin 1995) or soon after such therapies gained widespread usage (Pawluch et al. 2000). The current findings suggest that the use of CAM continues to play an important role in the everyday lives of people with HIV/AIDS well after researchers identified associations between using the new AIDS medications and significant declines in AIDS mortality and morbidity rates.

This research also extends the illness experience literature and complements previous findings in an important way. It presents a theoretical framework based on Conrad’s model of the social meaning of modifying medication practices (1985) that can be used to understand the variety of ways people cope with and manage a serious and stigmatised disease in their everyday lives. Conrad argued that epileptic medications were a ‘ticket to normality’ for epileptics. Epileptics ‘self regulated’ their medications as a means to assert some degree of control and to test for themselves if they had achieved a normal state. Modifiers either reduced the dose of a drug, stopped for some time, or took extra doses of medication. This self-regulation of the prescribed medicine practice allows epileptics to increase personal control over their illness and to achieve a sense of normality by enabling them to test for disease progression, destigmatise their illness, reduce medical dependence, and manage social interaction.
CAM practices are functionally similar to medication practices. People with HIV used CAM for nearly the same reasons that epileptics modified their medications. CAM can be used for several reasons. AIDS medication side-effects that make managing everyday social interaction difficult can lead people to use CAM. People will use CAM as a strategy to cope with the emotional challenges of everyday life with HIV. Because having HIV also means dealing with stigma, using CAM can be a form of destigmatisation. Having HIV also involves the possibility of a shortened life span; people can use CAM to test for themselves how their disease is progressing. Finally, many people use CAM to control the perceived level of dependence on standard medicine and its practitioners. Just as the epileptics in Conrad’s study self-regulated their conventional medicines in similar ways to achieve normality, CAM users can be understood as self-regulating CAM as a strategy to achieve normality. In both cases, people self-regulate medications (standard and CAM) and normalisation of health status is the goal.

These similarities of meanings are not surprising. Some CAM studies have conceptualised modifying medications as another form of alternative medicine in that people use such therapies in creative ways not prescribed by medical doctors (Furin 1995). Interestingly, however, hardly any respondents reported modifying their AIDS medications from the prescribed regimen. For the most part, people went to great lengths to incorporate AIDS medications in their lives and adhere to the prescribed regimen as close to the doctor’s orders as possible. Intentional medication practices were rare. In contrast, CAM practices were more commonly seen as the preferred form of self-regulation among people with HIV.

The kinds of treatment practices that people create when confronted with serious illness may vary significantly because of the differences in the prescribed medication practice for each disease. Unlike other diseases such as epilepsy where doctors typically alter drug doses in times of increased seizure activity or adverse side-effects, HIV doctors almost never alter the dose of drugs. If HIV replication is not completely controlled or a person’s immunological markers worsen, doctors respond by changing their AIDS medications to include [a] new drug[s]. The reasons that doctors of people with HIV less often modify prescribed medication practices may be because of the meaning of AIDS medications.

Although many respondents constructed images of medications as toxic and symbolising all the loss and pain that accompanies an HIV positive diagnosis, most respondents had no doubt about their dependence on these medications for survival. The perceived and actual risk of altering AIDS medication is much greater than for most other diseases as it can lead to medication resistance which renders the drugs ineffective. For most people with HIV and their care providers, this means following the path towards disease progression and social and physical death. Therefore, people with HIV must find other ways to self-regulate treatment practices to achieve a sense of normality. In contrast to the perceived high risk of altering AIDS medications,
Complementary and alternative medicine and HIV in the US

CAM was perceived as more flexible and rarely posing a risk to health and wellbeing if used or modified. Self-regulation of treatment practices in the form of CAM practices is a more viable option to people with HIV than creating medication practices. The meaning of differences in prescribed medication practices for HIV may explain why current research reports higher rates of CAM use in the HIV infected population than among people with other diseases, despite successful advances in the medical management of AIDS.

Although this research has generated useful findings on the use of CAM, its limitations should be kept in mind. In particular, the sample used was not representative of all people with HIV. I recruited the majority of the sample through community-based groups. Though most of these people were also receiving medical care, their experiences of using CAM may differ from people sampled from medical clinics. Given the highly stigmatised nature of AIDS, the fact that people signed up for the study and risked disclosure suggests a more active orientation toward their illness. This, in conjunction with ties to community-based groups, may bias the sample towards people, whether users or non-users, who are generally more active in their health care. Further research needs to be done with HIV positive people who are not active participants in their health care to investigate differences in CAM experiences. Likewise, intravenous drug users and African American women were highly under-represented in the sample. More efforts need to be made to recruit these extra hidden populations of people with HIV.

These findings also suggest the need for more comparative work that focuses on CAM use among people with different kinds of illness. Do people with cancer or rheumatoid arthritis use CAM to self-regulate their treatment practices? If so, do they attach the same meanings to their usage as people with HIV? How might AIDS research inform research on other diseases and vice versa? Do additional ways of self-regulating treatment practices in efforts to normalise health status exist for other diseases? Examination of CAM practices and self-regulation in the context of different illnesses is an arena of further research with many possibilities.

Whether these findings generalise to the experiences of people with HIV in other countries is also difficult to determine. Certainly people in Great Britain or Australia develop CAM practices for serious and chronic illnesses. This may be most true for diseases such as AIDS in which no cure exists or in which managing stigma and side-effects from standard medications is common. The meaning of CAM practices, however, may vary depending on the degree to which particular CAM therapies are already integrated into the existing health care system or the prevalence of AIDS medication usage. Meanings may differ in countries whose health care systems primarily rely on therapies identified as CAM from a Western perspective. Further research might then examine cross-national CAM practices and not limit such comparisons to the Western world.

Finally, this article has only reported the experiences of CAM users in the sample. The finding that users were better off financially than non-users
suggests that CAM practices are more readily available to people with greater economic resources. People have to cover CAM as an out-of-pocket medical expense because, for the most part, insurance programmes do not cover CAM (Pelletier et al. 1997, Tillman 2002). Future research might then examine the kinds of practices (CAM, medication, or something else) that poor people use to manage their illness. The data in this study suggest some strategies such as a widespread use of pro-bono CAM services used among the poorer CAM users. Non-users may also desire to use CAM but lack of knowledge of such services may constrain use. Examining the kinds of barriers that keep people from engaging in CAM practices will further increase understanding about why people use CAM to manage their illness.

In conclusion, this study found a large number of people who said they regularly use CAM. Although push and pull factors are important for explaining why people in the US use CAM, the meanings people attribute to these therapies in their everyday lives also prove determinative. Many people find CAM attractive because of its healing power to address diverse aspects of not just a person’s health, but a person’s everyday life. Its use is not only sustained in its perceived ability to contribute to the realisation of desirable ends – managing side-effects, symptom relief, and reducing anxiety – but in its sense-making capacities to manage stigma, evaluate health status, and increase personal control over the illness experience. CAM may fill a void in standard medical practice, suggesting the need to evaluate the role of CAM in the care of the chronically ill and to recognise the diverse needs that CAM meets. It is hoped that these findings will stimulate more research regarding the potential value of CAM in the care of people with HIV as well as for all people with chronic illness.

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Acknowledgments

I want to thank the following for their guidance and helpful comments: Timothy Brock, Patrick Gillham, Kris Gilmore, Andrew London, Tom Mayer, Jane Menken, Glenn Muschert, Fred Pampel, Dorothy Pawluch, Jay Watterworth, and the anonymous reviewers for Sociology of Health and Illness. I am also grateful to the study participants for sharing their time and experiences with me, and to the members of the AIDS service organisation where most of my interviews took place. Support for this research was provided by the Center for Complementary and Alternative Medicine at the National Institutes of Health, F-31 AT00055. An earlier version of this article was presented at the 2001 annual meeting of the Pacific Sociological Association.
References


