How People With HIV/AIDS Manage and Assess Their Use of Complementary Therapies: A Qualitative Analysis

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The objective of this article is to provide a qualitative analysis of the practical concerns that people with HIV/AIDS have with regard to their use of complementary therapies. In-depth semistructured interviews were conducted with a diverse range of people with HIV/AIDS (N = 46). An inductive grounded approach was used to collect and analyze the data. There were five central concerns: (a) selecting which therapies to use, (b) judging which therapies work, (c) combining Western medicine with complementary therapies, (d) assessing the safety of complementary therapies, and (e) dealing with the barriers to the use of complementary therapies. A better understanding of the practical dimensions of complementary therapy use highlights the treatment and care issues that people with HIV/AIDS face and offers insights into the role that nurses might play in addressing some of these issues.

Key words: complementary therapies, HIV/AIDS, practical considerations

A significant number of people living with HIV/AIDS use complementary therapies. Stine (1993) estimated that between 30% and 50% of people with HIV/AIDS have tried one or more complementary therapies. In a study by Barton, Davies, Schroeder, Arthur, and Gazzard (1994), complementary therapies were used by 44% of the sample of HIV-infected individuals. Dwyer et al. (1995) found that 70% of their sample of HIV-positive men in California made use of complementary therapies. In Canada, a national survey by the Canadian AIDS Society (1995) found that 75% of people with HIV/AIDS had used complementary therapies to manage their health. People with HIV/AIDS use complementary therapies at a greater rate compared to those with other health problems (Anderson, O’Connor, MacGregor, & Schwartz, 1993; Cohen, Mayer, Eisenberg, Orav, & Delbanco, 1990; Furin, 1997; O’Connor, 1995). This turn toward complementary and alternative medicine has prompted a growing interest among health care practitioners in understanding the place of complementary therapies in the management of HIV infection.

In this article, we examine a series of practical considerations with regard to the use complementary and alternative therapies from the perspective of a diverse group of people with HIV/AIDS. Practical considerations, in this instance, refer to the range of “how to” decisions that are required by people who are interested in, or involved in, using complementary or alternative therapies in the management of HIV/AIDS. Studies on the use of complementary and alternative medicine (Kelner & Wellman, 1997) have pointed to the central role of practical knowledge in decisions with regard to health and health care. However, there

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has been limited research done on this topic in the
social or health sciences in the area of HIV/AIDS.

The practical aspects of making health care deci-
sions have been addressed only indirectly in the litera-
ture on complementary or alternative therapy use among
people with HIV/AIDS. The focus in health sciences
research has been on identifying the types of therapies
that are being used and evaluating their clinical ben-
efits for people with HIV/AIDS (Greene et al., 1999;
MacIntyre, Holzemer, & Philippek, 1997; Nokes,
Kendrew, & Longo, 1995; Sparber et al., 2000). Greene
et al. (1999), for instance, identified the therapies and
activities most often used by people with HIV/AIDS—
aerobic exercise, prayer, massage, needle acupunc-
ture, meditation, support groups, visual imagery, breath-
ing exercises, spiritual activities, and nonaerobic
exercise—and evaluated the current state of scientific
evidence published in peer-reviewed journals for each
therapy. The authors concluded by identifying factors
that prevent complementary or alternative therapy from
becoming a more acceptable health care option.

This research points to practical issues that arise
from institutional barriers to research on complemen-
tary and alternative therapies. Greene et al. (1999) sug-
gested that one of the barriers that people with HIV/
AIDS face when making health care decisions is gain-
ing access, either through their own research or through
consultation with health care professionals, to scien-
tific clinical research on the efficacy of the therapies
that they most often use to manage HIV/AIDS. The
marginality of many complementary or alternative
therapies in relation to conventional scientific medical
research limits the kind and amount of information
that is available. Journals and publications that have
been developed within alternative and complementary
therapy institutions are highlighted as valuable infor-
mation sources.

Research in the social sciences has been concerned
with understanding the ways in which complementary
and alternative medicine is used and the meanings of
these approaches for people with HIV/AIDS. Studies
have documented the variations among people with
HIV/AIDS with different social backgrounds and in
different social contexts. For instance, the use of com-
plementary therapies is most common among women
and gay men (Ariss, 1997; Meneilly, Carr, & Brown,
1996; O’Connor, 1995). Furthermore, gay men from
middle-class backgrounds are more likely to have used
complementary therapies (O’Connor, 1995). In our
previous research, we found that the meaning of com-
plementary therapy use varied according to social
background (Pawluch, Cain, & Gillett, 2000). Gay
men of color with HIV/AIDS, for instance, viewed
complementary therapies as an aspect of their cultural
heritage, whereas injection drug users situated their
use of complementary and alternative approaches to
health care in relation to issues concerning addiction
and rehabilitation. Literature on differences in social
background raises the question of the extent to which
social background and social context have an impact
on the practical aspects of health care decisions with
regard to complementary or alternative therapies.

Another relevant theme in the social science litera-
ture has been the value that people place on their use
of complementary or alternative therapies. Much of this
work has focused on the political and ideological
dimension of complementary therapies (Furin, 1997;
Whittaker, 1992). Ariss (1997, p. 97), for instance,
argued that for many gay men and women, comple-
mentary therapy use “constitutes a challenge to the
heterosexual male-dominated regime of biomedicine.”
Again, in our previous research, we found that people
with HIV/AIDS cite multiple, at times overlapping,
reasons for using complementary therapies: feelings
of empowerment in taking charge of their health care;
an improved ability to manage their health; the ability
to promote healing in a broad physical, emotional, and
spiritual way; a way of maximizing their quality of
life; and a way of coping with the stressors of HIV/
AIDS (Pawluch et al., 2000).

This research addresses the practical concerns of
those people with HIV/AIDS who use complementary
therapies. We are interested in the issues that arise
from users of complementary therapies and in the
ways users incorporate them into their everyday lives.
To this end, the analysis presented in this article focuses
on the range of practical considerations encountered
by a diverse group of people with HIV/AIDS in mak-
ing decisions with regard to their use of complemen-
tary and alternative therapies. The analysis is divided
into five sections that reflect the concerns of those who
participated in this study. They are (a) how to select
which therapies to use, (b) how to judge which thera-
pies work, (c) how to assess the safety of different ther-
apies, (d) how to approach Western medicine along with complementary or alternative therapies, and (e) how to address and possibly overcome barriers to the use of therapies. In the conclusion, we address the relevance of understanding the practical dimension of complementary therapy use for the management of HIV infection.

The Study

We conducted 46 in-depth interviews with a diverse range of people with HIV/AIDS in the greater Toronto area between 1997 and 1999. The interviews were semistructured and between 1 and 2 hours in duration. All of the interviews were conducted by the authors of this article, with the exception of 7 interviews with Aboriginal men that were done by an interviewer of Aboriginal heritage. This interviewer was informed about the interview process and given basic training in qualitative interviewing techniques but was not supervised during the actual interviews with respondents. The interviews took place either in the homes of the respondents or at a local community organization. All respondents allowed us to audiotape the interviews. The tapes were transcribed and coded. To assist with the coding and analysis, we used the qualitative software program FolioViews. Quotations from respondents included in the analysis have only been revised for the purposes of clarity. The study received ethics approval from the McMaster University Research Ethics Board. Respondents provided signed documentation of their informed consent to be involved in the study before each interview.

The interviews covered several areas, including factors involved in the decision to use complementary or alternative medicine, sources of information about them, belief systems about illness generally and HIV infection in particular, the negotiation of alternative therapies along with the use of more conventional health services, judgments about efficacy, and factors encouraging and discouraging the use of alternative therapies. We used a list of topics to guide ourselves through the interviews and to ensure that we elicited responses in the areas we were exploring. However, for the most part, we let respondents determine the course the interview took and allowed ourselves to inquire further into any comment that seemed significant. Only one interviewer was present during each interview. Field notes were taken during interviews and discussed in research team meetings.

Our sample included 10 women and 36 men. Five women were White and represented a range of ethnic backgrounds, including Anglo-Saxon, French, and Ukrainian. Another 5 were women of color and included Native women as well as women of African, Caribbean, and East Indian descent. Twenty of the men were White, describing their ethnicity as Italian, German, Québécois, French, Anglo, Irish, or Scottish; 8 of the men were Native Canadians and another 8 were Black, including men of African and Caribbean descent. Of the male respondents, 33 were gay and 3 were heterosexual. At least 4 of the respondents had used injection drugs. Respondents ranged in age from 21 to 50 years. The average age was 33. Annual incomes ranged from $3,500 to $25,000; the source of this income was typically some form of disability insurance or social assistance. All respondents lived in south-central Ontario. At the time of the interview, most respondents were asymptomatic or experiencing relatively mild symptoms; however, many had previously experienced serious acute illnesses related to their HIV infection.

We were specifically interested in recruiting respondents who were using or were interested in using complementary or alternative therapies. Respondents were recruited through community organizations that allowed us to put up posters and in some cases brought our study to the attention of specific individuals. The organizations included the AIDS Committee of Toronto, Community AIDS Treatment Information Exchange, Two Spirited People of the First Nations (an organization for Aboriginals), the Black Coalition for AIDS Prevention, Voices of Positive Women, the Hamilton AIDS Networks, and health clinics in Hamilton and Toronto. We were able, as well, to recruit some respondents through “snowball” sampling, a process in which we were referred to individuals via those who had participated in the study. Our sample was self-selected insofar as most respondents called us after seeing one of our posters. To keep the sampling manageable, we decided to limit the scope of the study to include HIV-positive women, gay men, individuals with different ethnocultural backgrounds, and individuals with a history of drug use. Within these bound-
aries, we sought to reach the point of saturation in the collection of data from respondents, with the understanding that there are practical limitations to the number of interviews that can be conducted within any specific research study.

In both the collection and analysis of the data, we used an inductive grounded approach (Glaser & Corbin, 1990; Glaser & Strauss, 1967). After each interview, we would meet to discuss both the substance of respondents’ remarks and aspects of the interview process itself. It was at these meetings that certain analytical categories and themes began to emerge. As they did so, we incorporated them into the list of issues to address in subsequent interviews. The analysis of the transcribed data that occurred once all the interviews had been completed allowed us to refine and develop our initial categories. There was an advisory committee for this study made up of a diverse range of people with HIV/AIDS. We submitted our preliminary analysis to the advisory committee for its comments and feedback with regard to the themes and categories in our analysis.

What constitutes a complementary or alternative therapy has been a central concern among scholars (Aakster, 1986; Deierlein, 1994; Goldstein, 1999; Sharma, 1992; Wardwell, 1994). As Adler (1999) noted, definitions of complementary therapies have tended to be unclear and inconsistent and have been developed either intuitively or from previous literature (Eidinger & Schapira, 1984; Eisenberg et al., 1993; Faw, Ballentine, Ballentine, & van Eys, 1977; Yates et al., 1993). Rather than establish our own parameters, we were interested in knowing how respondents approached this issue and what they defined as complementary therapies. Using an empirical basis for deriving the boundaries of complementary or alternative therapies is consistent with our focus on understanding the perspective of those people with HIV/AIDS in the study and helps to ensure that our analysis reflects their knowledge and usage.

The complementary therapies that respondents discussed included many of the therapies typically referred to in the literature: massage, reiki, reflexology, marijuana, meditation, visualization, oxygen therapy, anthroposophic medicine, vitamin therapy, diets, fever bush, exercise, tai chi, aroma therapy, spirituality, Chinese herbal medicine, chiropractic, acupuncture, naturopathy, homeopathy, and traditional Native American remedies such as herbal medicine, healing ceremonies, sweat lodges, and smudge pots. However, respondents also talked about activities that, although not normally thought of as therapies, they felt were powerfully therapeutic and a necessary part of any discussion on complementary approaches. Among these were dancing, drumming, mask making, painting, stand-up comedy, body building, biking, hiking, gardening, cigarette smoking, and going back to school. In addition to the term “complementary,” respondents described the approaches they employed as alternative, natural, holistic, traditional, or nonconventional. One respondent who was committed firmly to Native healing traditions described Western medicine as complementary therapy. These responses underscore the conceptual difficulties involved in any effort to objectively define and categorize complementary therapies.

Managing and Assessing Complementary Therapies

The respondents in our study faced a set of common practical issues in their use of complementary therapies. Below, we examine five considerations that emerged as central.

Selecting Which Therapies to Use

We know little about how people go about selecting which complementary and alternative therapies they feel best suit their health and health care needs. Health care decisions were based on several considerations. Respondents relied heavily on those around them. They would consider the experiences of friends or family members and seek the advice of others. A few sought the advice of their Western physicians, although many did not feel comfortable doing so. The few who did felt that their doctor had little interest in, or knowledge of, complementary approaches. Respondents largely relied on the positive experiences of others to help guide their decision making:

[I value] other people’s experiences with them. Other Black, gay, HIV-positive men. . . . It makes me feel better when I read other people’s stories. They have similarities, and that in itself breaks
The isolation of living with HIV, through other people’s stories.

The negative as well as positive experiences of friends were seen as relevant. Those whom they felt were taking too passive a role with respect to their health care or who had problems dealing with particular therapies were seen as providing valuable lessons on how not to manage their health and which therapies to be cautious of or avoid. Some respondents went beyond simply relying on the advice of those around them and took a more active role in exploring the options available to them. They reported that they did considerable personal research before selecting an approach. They might, for example, conduct research at community organizations or use resources such as the Internet to seek out information.

For many respondents, selecting a particular approach was a secondary concern to the more general decision to “do something” to take more control over their health. This finding is consistent with a recent study on the experiences of asymptomatic people with HIV/AIDS (MacIntyre, 1999). Complementary approaches expand the range of options available to them to manage their health and help them feel less dependent on health care professionals.

It’s incredibly important to have that feeling of being in charge and being a participant in your own regimen, whatever that regimen may be. It’s more important than ever to take that role, to be in charge to some degree.

Because complementary therapies increase the possibility for choice, and because these choices are not necessarily mediated by a health care professional, most respondents felt that complementary therapies gave them more control. For some, particularly the more politically conscious gay men, choosing to use some form of complementary therapy was seen as a way to take charge of their lives and their health.

**Judging Which Approaches Work**

In the health sciences, the recent trend has been to evaluate the efficacy of complementary and alternative therapies by examining clinical outcomes (Freeman & MacIntyre, 1999; Greene et al., 1999). In contrast, the primary criterion used by our respondents to determine the effectiveness of their therapies was subjective experiences. Clinical outcome studies, they felt, are overly standardizing and do not reflect the reality that everyone is different and may therefore respond differently both to HIV infection and to treatment. As a result, respondents felt the need to depend chiefly on their own experience of any given therapy. Their experience of physical or mental benefits demonstrated to them that a therapy worked. For instance, one respondent said that the use of massage simply made him feel better—he had more energy and felt more relaxed and less stressed:

> I think one of the biggest things for HIV-positive people is we evaluate ourselves based on energy. How did I feel this morning when I got up? If I were to look for something natural or holistic, I would be looking for something to boost my energy. . . . All I know is that when I feel like shit, I want something to make me feel better. Right now, to boost my energy level, I work out. That gives me energy.

In other words, respondents felt that the personal experience of the effects of a therapy was a valid way of judging whether the therapy worked. Clinical outcome studies may be useful, they felt, but they are not seen as the only legitimate source of knowledge about treatment efficacy.

The results of laboratory tests were used on a selective basis by most respondents to judge the effectiveness of the approaches they employed. Test results indicating an improvement of their health were often seen as a sign that complementary therapies were effective. In contrast, respondents tended to question the significance of results indicating a worsening of their condition:

> At first I used to rely on the lab tests, and I used to worry about the results. I just got to the point where lab tests did not measure how I am feeling. There have been times where I went in and my T-4s were down to 12, but I felt great. I had lots of energy. I was not ill. I got to the point where these numbers didn’t really mean anything in terms of
how I perceive my health. Now I listen to them and say, “whatever.” I’ll let you know when I feel sick. That is what I am worried about. I guess they are saying that viral load means a lot more than the T-cells. And I am not going to worry about that either because I still think that how I am feeling is most important.

At the same time, however, they were unable to completely ignore the implications of lower T-cell counts or an increased viral load for their health. For many respondents, it was not the case that medical measures were rejected outright as illegitimate. Rather, they were seen to be inconsistent and not always reliable. Subjective measures of health, in contrast, were perceived to be important and figured prominently in respondents’ decision making.

At times, respondents found it difficult to judge the effectiveness of a complementary therapy or a set of therapies. They acknowledged that many factors influence health and that it is difficult to judge particular therapies when several are used concurrently, often along with Western medications. The response to this uncertainty varied. Some respondents required obvious signs of effectiveness either in the form of feeling better or better test results in order to continue using a particular therapy. For others, signs of effectiveness were less important, so long as the therapy was not harming them and they knew others who had experienced benefits. Finally, for some, being involved in a particular therapy had symbolic value; effectiveness was measured not in terms of actual benefits but in terms of the satisfaction it gave them to know that they were approaching their health care proactively and resisting conventional views of “what works.”

Safety Concerns

A recurrent theme in the literature on complementary therapies is the safety of “unproven” and “unorthodox” approaches (Dwyer et al., 1995; O’Neill, 1994). Our respondents generally viewed the complementary therapies that they employed as relatively benign. There was little concern about side effects. Respondents did not feel they had to weigh “costs” against the “benefits” of a particular approach in the same way or to the same extent as they did when considering a new allopathic medication:

Instead of pumping your body with drugs, the alternative approaches are from the other way around: you are helping your body take care of itself. With the Western medicine, you are relying on a medication.

Additionally, because judgments about what works were based on subjective experience rather than laboratory tests, respondents could try an approach to determine whether they felt better. If it did, they might continue; if it did not, they would simply stop.

Complementary approaches were not seen to involve the same risks as Western medicines. Because they were seen as less intrusive and more natural, complementary approaches were seen as less harmful. Approaches such as massage, supplements, or exercise were seen to reduce stress and otherwise strengthen the body’s natural recuperative powers:

I don’t think that it is damaging in any way, I don’t think that they are going to screw up your energy because they don’t know what they are doing or anything like that. But at the same time, if someone is massaging your feet, massaging your feet anywhere feels great. If they massage the toe and they are supposed to be massaging the heel for that particular problem it is not like I am losing a great deal of benefit. I am getting benefit, though it might not be the focused benefit.

A few respondents had experienced physical side effects from the complementary approaches they employed. A respondent who had placed himself on a high-fat diet in an effort to combat his HIV infection found that it had contributed to his high blood pressure. Another tried oxygen therapy but stopped when he did not like his reaction to it. These kinds of problems did not seem to be a significant worry to respondents because they simply needed to listen to their bodies and cease or modify the therapy as they felt necessary. Because they felt in control of, and more knowledgeable about, the chosen therapy, they were less concerned about safety than they were with prescribed medications.
In stark contrast, the medications prescribed by physicians were described as “toxic” or “poison” and were seen to have significant side effects. A number of respondents said they used complementary approaches specifically to counteract the negative side effects of their Western medications. Herbal remedies, for example, might be helpful if Western medicines make them feel nauseous. The general impression in interviews was that complementary approaches were seen by most respondents to add a measure of safety to their Western regimens.

There was an additional area that was identified as a potential safety concern. Some approaches, such as massage, reiki, or reflexology, involve physical contact between practitioner and client. A small number of respondents expressed concern and uncertainty about the intrusiveness of such therapies and the risk that relationship boundaries might be crossed. Inappropriate touching could have negative repercussions if practitioners do not act professionally and sensitively.

**Approaching Western Medicine**

The respondents in this study, despite concerns about the safety of allopathic treatments, were open to using Western medicines. They thought that a variety of approaches to health and systems of medicine should be combined in treating and preventing health problems. However, many respondents did confront difficulties in their efforts to combine Western medicine and complementary therapies. A major concern was the lack of knowledge about and interest in complementary therapies on the part of Western physicians. This made it difficult for respondents to share with their doctors their experiences with complementary therapies:

We are going to another doctor. He is very good, but he only knows what is in the computer and what studies have been done on the drugs. He doesn’t know anything about alternatives: what about tea tree oil, what about vitamin C? . . . They will say, “Go try it,” but they have no idea about what is out there.

Respondents relied on the advice of their physician when making health care decisions. However, respondents expressed frustration about how uninformed physicians were with regard to complementary therapies. Most were open to the idea of using alternatives but were not willing to become a resource for them in this regard. Respondents generally felt that their complementary therapy practitioners were more open to other forms of health care and more willing to address a wider range of health issues.

Respondents were also very cautious and ambivalent about the prospect of using Western medications. As mentioned, AIDS medications in particular were thought to be experimental, unproven, dangerously toxic, and likely to cause long-term health problems. On more than one occasion, respondents referred to themselves as scientific guinea pigs. Many were also frustrated with the serious and prolonged, even possibly fatal, side effects that accompanied Western medications:

I stopped taking medications because they weren’t really doing anything for me. I knew other people . . . I knew a lot of people who were dying because they were taking medications, because of the toxic level in their system. I thought, I don’t want all this toxic crap. I decided that I didn’t want to take the medication anymore. Now, thinking about the cocktail, I want to read more about it.

The general sentiment was that it was not worth enduring the side effects of medications because it meant a decrease in quality of life. There were some respondents that preferred using complementary therapies and only turned to medications as a last resort.

In general, respondents approached Western medicine with the hope that a new medication would bring real benefits. However, they also felt strongly that Western medicine has focused too much on fighting the virus. The resulting AIDS medications have helped some people but they have also caused serious health problems. This view has been expressed by scholars critical of the extent to which biomedicine has focused on the virus without consideration of broader social, political, and cultural factors that affect AIDS support and prevention (Ariss, 1997; Epstein, 1996). Complementary therapies, in contrast, were considered to take a more balanced and holistic approach, addressing not
only physical health but emotional, spiritual, and mental health as well.

**Barriers to the Use of Complementary Therapies**

Access to treatments for HIV infection has been a contentious issue. In a Canadian context, there are resources available to assist people with HIV/AIDS in receiving medication and care, although only for allopathic medicine. Fewer provisions have been made that make complementary and alternative approaches more accessible for people with HIV/AIDS. As a result, there are still many barriers to the use of complementary therapies. The barriers to care were a significant practical consideration for those people with HIV/AIDS who participated in this study.

The greatest barrier by far—and one that clearly cut across the different groups we interviewed—was cost. For most respondents there were complementary therapies they would have liked to try or particular types of treatment that they would have liked to receive more often but could not because of cost. Indeed, many respondents’ experiences with complementary therapies were limited to those therapies that they could get for a minimal fee or free of charge through community service organizations:

I’d like to eat organic. But you can’t. Not here, anyway. I mean how do you eat organic here? I mean you have to be able to afford it, you know, and I just can’t afford it. On my salary, and my rent and everything, I just can’t afford it. I would like to do it. I would like to eat stuff that’s organic. But I can’t.

However, not all respondents felt comfortable using the services of community-based AIDS organizations. Moreover, the growing demand for these free services has meant long waiting lists and increasingly limited access. For many, choosing an approach was ultimately a question of what they could afford. In Canada, complementary approaches are not typically covered by Medicare or private insurance policies, and few respondents had the financial resources to pay for them. Respondents often had little choice but to pursue approaches that were free of charge through community AIDS organizations.

Access to therapies was a second related barrier. Respondents often knew of practices, traditions, therapies, or herbs that they would have liked to use but could not obtain. A Caribbean respondent talked about herbal remedies that she used only when a friend or family member brought them back from Jamaica. An Aboriginal respondent observed that he could not find locally the healing traditions that he had grown up with, and could not afford to return to his home—several hundreds of miles away—to gain access to them. Another respondent described trying to visually identify among the herbs he had access to locally, the remedies that his mother in Africa had used for various complaints while he was growing up.

In addition to cost and access, the time, discipline, and energy connected to complementary therapy use acted as barriers. Many of the therapies involve rigid scheduling and complicated regimens and call for considerable time, care, commitment, and effort. Even in good health, respondents reported finding it a struggle to keep on top of the regimens—to count out vitamins and supplements, to take them at the right time, in the proper amounts and in the right combination, to prepare special meals and shop for special ingredients, to set time aside regularly to meditate or pray, to get to the gym, to do the required reading, or to book the necessary appointments:

The thing with me is that I don’t have the time. I have two jobs and a 4-year-old, and I just don’t have the time. Like today’s my only day off and I’m cleaning, basically. So I really don’t have the time to go for massages. I did the massage thing twice. It was glorious. But the thing is, I can’t. PWA provides free massages and that’s great. But I don’t have the time and when I do, there’s always a list. You know what I mean. So it’s hard.

This was especially so for those who were still working or those with family responsibilities. Women in particular spoke about how difficult it was to find any time for themselves as they juggled jobs and families. When energy wanes or moods flag, it becomes even more difficult to find the motivation, concentration,
and energy to continue with certain therapies. Not surprisingly, then, a pattern of irregular and inconsistent use was common. Other respondents managed to keep up with their regimens but worried about whether they would be able to do so as they got sicker. This raises questions about the relationship between complementary therapy use and stage of infection.

The wide degree of choice was also a barrier, especially for those just discovering complementary therapies. Respondents talked about feeling “overwhelmed” and “confused” by the broad range of treatment options available. Those determined to gather what information they could about complementary therapies and to do the personal research they felt was necessary were particularly struck by the mountains of information to wade through and the maze of possibilities. How to choose from among the therapies available, how to discriminate between the valid and invalid, and how to determine whether one has made the “right” choice were common concerns. Another barrier was the Western sensibilities and attitudes that many respondents brought to their use of complementary therapies. Even where there was an openness to complementary therapies, Western biases toward the “scientific” and the “proven” could still get in the way:

If it has been used for centuries, like ayurvedic medicine or Chinese medicine or acupressure, where they do the bottle suction, and people are bleeding and it looks really gross and you’re thinking, “How can that be helping?” But it must be.

Some respondents, particularly White, educated, middle-class respondents, needed to work constantly to set aside their Western notions of how things work and to keep an open mind on the possibilities of complementary therapies. One respondent described therapies that he believed in and used but at the same time found “laughable” when viewed through a Western lens. Many of the respondents felt uncertain about their combined use of complementary therapies and Western medicine. On a cultural and institutional level, there are many factors that continue to support a polarized understanding of health care: Western medicine and complementary and alternative medicine as separate and unrelated entities (Goldstein, 1999). Although few of the health care professionals that respondents spoke of actively promoted this view, none actively challenged prevailing conceptions of health care. This scenario meant that people with HIV/AIDS had to work toward articulating their own position between Western medicine and complementary therapies without the assistance or support of health care professionals.

Besides their own Western biases, respondents had to deal with others’ views of complementary therapies and those who use them. Despite the growing popularity of complementary therapies, the view that many of these therapies are no more than quackery, and their users no more than desperate “flakes,” persists. For many non-White respondents, there were concerns about the stereotypical view of those who use folk remedies as “uneducated,” “foreign,” “superstitious,” or “backward.” Some respondents found these concerns difficult to dismiss.

**Nursing Implications**

Research on complementary and alternative medicine has expanded dramatically over the past decade, and considerable attention has been devoted to the use of complementary therapies among people with HIV/AIDS. This study contributes to this growing literature by focusing attention on some of the common practical considerations that people face when using complementary therapies to manage their HIV infection. Health care decisions often rest on the social and material resources they have available to them. The decisions of many people who use complementary therapies are influenced by finances, access to treatment, and the availability of knowledgeable social and community supports (Higgs & Murphy, 2001). Health care professionals can represent an important source of information, but our respondents typically drew on other resources. Many of the health care professionals with whom they have contact do not seem to possess enough knowledge about or interest in complementary therapies to provide them with much advice. Respondents felt uncomfortable even discussing their use of complementary therapies with their physicians for fear of disapproval (Eisenberg et al., 1993, 1998). In
the end, although all of our respondents continued to use Western medicine and continued to value the advice and input of their Western health care providers. Their interactions with their physicians with regard to their use of complementary therapies can be characterized as “don’t ask, don’t tell.”

Nurses can play an important role in assisting those people with HIV/AIDS who wish to take a complementary approach to their health care. They can inform themselves about the dominant complementary approaches, and they can encourage other health care providers to do so. Nurses can play a supportive role with patients and physicians alike in encouraging a more open dialogue with regard to the broad range of health care approaches that people living with HIV may be employing. Moreover, nurses can play an important role in linking patients to community supports that will help actively involve them in making informed decisions about possible strategies for managing their health and in overcoming barriers to accessing the care they desire. These roles fit nicely with the “new” nursing role in which nurses emphasize their caring—as opposed to curing—function (Witz, 1994). More than ever, nurses are emphasizing a holistic view of the patient and defining patient care needs more expansively. Whereas doctors generally attend to the disease, nurses attend to the whole patient. The professional ethos of nurses who adopt this approach encompasses a much broader view of illness and of caring (Kreitzer & Jensen, 2000; Witz, 1994). This holism makes nurses more receptive to the idea of using complementary therapies and increases the professional role that they can play in supporting patients who want to draw on a broader range of health care options (Ho, 2000; Manzella, 2000; Stevenson, 1997).

Our study reveals some of the ways in which people living with HIV/AIDS exercise their own knowledge and judgment in the use of health care alternatives along with conventional medicine. Rather than rejecting Western biomedicine, they viewed as legitimate and relevant other forms of knowledge in making their health care decisions, including their own subjective knowledge or experience of their bodies. Many individuals, then, are faced with the task of negotiating their combined use of complementary therapies and Western medicine. Health care professionals, and nurses in particular, can play a critical role as a resource and as a form of support for people with HIV/AIDS who are dealing with the practical challenges of integrating different types of health care options, both complementary therapies and Western medical treatments.

References


