Constrained Choices and HIV-Positive Women Accessing

BY TAMIL KENDALL, CHESTER MORRIS AND PAULA BRAITSTEIN

L'usage des médecines alternatives et complémentaires est le privilège des bien nantis et des gens éduqués. L'infection VIH est généralement liée à ceux qui n'ont pas ces privilèges. Toutefois, plusieurs femmes séropositives utilisent ces médecines qui, utilisées dans un contexte de pauvreté, selon les auteures, pourraient réduire les risques d'infection au virus, surtout si les intervenantEs de médecine traditionnelle établissaient avec les femmes une communication plus compréhensive et plus chaleureuse.

Complementary and Alternative Medicine (CAM) is an integral part of the health care of Canadians, including those who are living with Human Immunodeficiency Virus (HIV) or the Acquired Immune Deficiency Syndrome (AIDS). Prior to the advent of Highly Active Antiretroviral Therapy (HAART) in 1996, the success of conventional therapy was limited and HIV-positive individuals actively explored myriad forms of alternative medicine. Life expectancies of individuals with HIV/AIDS have increased dramatically as a consequence of HAART (Hogg, Yip, Kully, Craib, O'Shaughnessy, Schechter, and Montaner; Wood, Low-Beer, Bartholomew, Landolt, Oram, O'Shaughnessy, and Hogg).

Yet, CAM continues to be used by significant numbers of HIV-positive men and women, including those who are taking antiretroviral therapy. In fact, one Canadian study of HIV-positive individuals taking antiretroviral therapy observed that the use of CAM effectively doubled between 1995 and 1998 (Heath, Gatarick, Yip, Montaner, O'Shaugnessy, and Hogg). Benefits associated with CAM in the context of HIV care are empowerment, general health promotion (through stress-reduction and improved nutritional intake), coping with depression and addiction, general improvement in immune function, and management of medication side effects and symptoms of HIV disease (Fairfield, Eisenberg, Davis, Libman, and Phillips; Peabody; Demorest; Antoni, Baggett, Tronson, LaPerriere, August, Limas, Schneidermand, Fletcher; Diego, Field, Hernandez-Reif, Shaw, Friedman, and Ironson; Elion and Cohen; Swanson *et al.*).

Benefits associated with CAM in the context of HIV care are empowerment, general health promotion, coping with depression and addiction, and general improvement in immune function.

Depression among HIV-positive individuals illustrates some of the benefits and risks of CAM use in the context of HIV/AIDS disease. Depression is common among individuals living with HIV/AIDS, and is correlated with decreased adherence to antiretroviral medication and mortality (Mayne Vittinhof, Chesney, Barrett, and Coates; Murphy, Wilson, Durako, Muenz, and Belzer; Ickovics, Hamburger, Vlahov, Shoenbaum, Shuman, Boland, and Moore). Touch therapies, exercise, mind/body interventions, and herbal therapies may all contribute to ameliorating depression. Several of the PWAs who participated in this research reported that mind-body therapies had allowed them to stop taking conventional antidepressants, and others noted that managing their depression with CAM had allowed them to adhere to antiretroviral treatment. Yet, using CAM to treat depression is not without risks. In 2000, it was shown that one of the most well-documented, effective, and widely used herbal antidepressants, St. John's wort, interacted with one of the antiretroviral medications. This interaction was significant enough to result in decreased blood levels of the antiretroviral to the degree that HIV could develop resistance to the medication, and result in the failure of the conventional treatment (Piscitelli, Burstein, Chaitt, Alfaro, and Fallown). Despite controversy over the relative risks and benefits of CAM, CAM use is common.

Rates of CAM use is estimated at 39 per cent; 41 per cent in cohorts where all of the HIV-positive individuals are taking HAART and at 73 per cent in cohorts that also include individuals who are not taking antiretroviral therapy (Ostrow Cornellise, Heath, Craib, Schechter, O'Shaugnessy, Montaner, and Hogg; Braitstein, Kendall, Chan, Montaner, O'Shagnessy, and Hogg; Robinson, Millson, Leeb, Luby, and Rachlis). CAM use by HIV-positive women taking HAART is estimated at

48 per cent (Hankins, Walmsley, Lapointe, Tran, Mum, and the Canadian Women's HIV Study Group).

While CAM use is not confined to any social, cultural, or economic group, studies of the general population in Canada and the United States have consistently associated CAM use with post-secondary education, higher income, and female gender (Millar; Eisenberg, Davis and Ettner). Canadian studies of HIV-positive men and women associate CAM use with higher education, and in some cases, higher income (Hankins *et al.* 1998b; Robinson *et al.*; Braitstein *et al.*). Overall, the demographic profile that emerges for CAM users in the HIV-negative and HIV-positive population is one of economic and educational advantage.

The demographics of HIV-infected women in Canada are in stark contrast to economic and educational privilege. Living in poverty and not having attended post-secondary education are associated with HIV-infection among women in Canada (Hankins *et al.* 1998a; Kirkham and Lobb). HIV-positive women from Vancouver describe discrimination because they belong to socially and economically marginalized groups and the refusal to recognize and fund complementary and alternative health practices as the most common problems with conventional health care providers and health institutions (Kellington). The demographic profile of HIV-positive CAM users provided by a large American study (n=1,675) indicates that women have lower levels of education and are less likely to be represented in the upper-income categories than men (Standish, Greene, Bain, Reeves, Sanders, Wines, Turet, Kim, and Calabrese). How does the tension between pay-out-of-pocket access to CAM and the poverty that characterizes HIV-positive Canadian women impact on the safe and effective use of CAM in this population?

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The objective of this exploratory study was to elucidate risks associated with the use of CAM among HIV-positive women and to analyze patterns of communication with conventional healthcare providers and the impact of that communication, or lack thereof, on quality of care and treatment choices.

Method

This case study is part of a multicentre study of the perceived risks and benefits of, and communication about, complementary and alternative medicine in the context of HIV/AIDS management. The women's research site was the Oak Tree Clinic, a multidisciplinary ambulatory clinic providing care to HIV-positive women and their families. Five health care providers (three physicians, one pharmacist, and one dietician) who represent the range of health care providers regularly accessed by adult women at the clinic completed a 45-minute to one-hour semi-structured interview. Twelve HIV-positive women participated in one of two focus groups and answered a survey that asked about demographic information, treatment history, information sources, and communication with health care providers.

Physicians and other healthcare providers were approached in advance and interviewed privately at the clinic. The HIV-positive patients were recruited directly from the clinic through the clinic's healthcare providers and posters and brochures strategically placed throughout the clinic. Women who provided informed consent were then brought together for a facilitated and semi-structured focus group. Interviews and focus groups were carried out by the first author. Interviews and focus groups were audio-taped and transcribed verbatim. Transcripts were then coded thematically and analyzed using grounded theory (Glaser and Strauss). In this analytic technique the categories of analysis emerge from repetitive themes in the narratives of participants. The value of this technique is that the resulting theoretical framework is "grounded" in the reality of the research participants, rather than based in the preconceptions of the researcher. The survey data was analyzed using parametric and non-parametric measures.

Eligibility criteria for HIV-positive women was that they were currently

using one or more type of CAM and receiving healthcare from a physician who participated in the research. CAM was defined broadly as "products and practices used to promote health and manage living with HIV disease that are not prescription drugs or over-the-counter medications." CAM includes alternative medical systems, body-based systems, mind/body medicine, and biologically-based treatments (National Institute of Health Panel). With respect to vitamin and mineral supplementation, this study defined CAM as taking more than a multivitamin.

The top five types of CAM currently in use were vitamins and minerals (75 per cent), exercise (67 per cent), special diets (58 per cent), herbs (50 per cent), and marijuana (50 per cent). The majority of the women were currently taking antiretroviral therapy as well as using CAM (64 per cent).

The demographic profile of the participants in this study exemplifies the dual challenge of limited income and education common among HIV-positive women in Canada. More than half of the women had not completed high school and 75 per cent reported incomes of less than $20,000 per year, with half earning incomes of less than $10,000 annually.

Risks Associated with the Use of Complementary and Alternative Medicines

Poverty was the source of much of the potential risk associated with CAM use identified in this study. Potentially negative health outcomes associated with the cost of CAM were: inability to access CAM, limiting food intake, and self-medication.

Cost was described by women as the primary determinant of what complementary therapies were used. For some women "anything that costs money is out of the question." For others, limited financial resources resulted in choosing between and rotating the therapies used: "One month it will be no creatine. Another month it will be no magnesium." Inability to access CAM limits women's options for: reducing stress, improving nutritional intake, coping with addiction and depression, supporting immune function, and managing medication side effects and symptoms of HIV-disease.

Despite the fact that women said nutrition from food is superior to vitamins or supplements, they limited or modified food consumption to enable them to purchase complementary therapies.

Cost also denied women access to the benefits of CAM and, in some cases, constrained them to using conventional medicine that does not promote their overall health. An illustration is management of musculoskeletal pain by a woman with Hepatitis C/HIV co-infection. Complementary therapies for treating musculoskeletal pain, such as acupuncture and massage, are not accessible to poor women in a fee-for-service environment.[1] As a consequence, she perceives her options for pain management as limited to Tylenol with codeine prescribed to her by her physician and paid for by Pharmacare. Acetaminophen, the active ingredient in Tylenol, can be liver toxic.

Food is one of the few flexible expenses for individuals living on a fixed income. Consequently, despite the fact that women said nutrition from food is superior to vitamins or supplements, they limited or modified food consumption to enable them to purchase complementary therapies. As one woman explains:

> *It [money for CAM] comes out of my food budget. I starve a week almost a month—I go eat at our [local AIDS organization] kitchen. Or I go to the Food Bank to make up that week of food.*

Purchasing CAM thus resulted in reducing food intake or consuming low-cost food items more frequently. The expense of eating sugar-free, wheat-free, or organic food prevented women from using these diets as treatment options.

The cost of seeing complementary healthcare providers was also prohibitive for most women. Being unable to pay for professional advice about CAM resulted in self-medication: "When you can't afford to see your herbalist, you have to do that research on your own." Women said they depended on lay networks and supportive conventional health care providers for information about CAM. Only nine per cent said a complementary health care provider was a major source of information about CAM, while 100 per cent and 91 per cent respectively said local AIDS organizations and HIV-positive peers were major sources of information about CAM.

Disclosing the Use of Complementary and Alternative Medicines to Health Care Providers

Women said they did not spontaneously disclose CAM use to conventional healthcare providers because they expected them to respond negatively. In some cases, hesitation to disclose was based on assumptions about their conventional health care providers' attitudes and fear of ridicule:

> *When I first got diagnosed and I wasn't on medication I tried a few kind of far out alternative therapies and I didn't really want to tell some of my health care providers*

because I thought they'd—you know—roll their eyes or if not, they would judge me or something like that.

Women expressed concern that conventional health care providers would interpret their use of CAM as a challenge to the healthcare provider's expertise and authority: "As though, you know, you were saying, 'I'm not sure what you know is right.'" Other women did not disclose because they had had negative experiences sharing their CAM use with conventional healthcare providers in the past: "I don't usually bring up the subject myself anymore because they will not usually agree with what I'm doing." Women indicated that they would discuss their CAM use if asked but assumed disinterest on the part of conventional health care providers, stating: "If they don't ask, they don't care."

All of the healthcare providers at the Oak Tree Clinic said that they asked their patients about CAM use at one of their initial visits and at regular intervals thereafter.

Healthcare providers stated that there was a lack of HIV-specific information about some types of CAM and that they were unable to be knowledgeable about all aspects of CAM in HIV care. However, despite these limitations, they perceived themselves as responsible for supporting their patients to obtain and evaluate information about CAM:

I mean a lot of times people are telling me about their therapies and wanting advice. And so you have to try to know the information that's out there, both scientific and anecdotal to be able to help people make those kinds of evaluations.

Health care providers described a variety of information gathering and exchanging activities, from writing information about CAM use in the medical chart, to making a referral to CAM practitioners, to sitting down with a patient and searching the Internet.

Healthcare providers used specific strategies to support disclosure, such as mentioning that other clinic patients used complementary modalities and highlighting the potential for adverse interactions between conventional and complementary medicine. Healthcare providers believed Oak Tree Clinic was an environment where patients would feel comfortable disclosing CAM use:

Women expressed concern that health care providers would interpret their use of CAM as a challenge to the health care provider's authority: "As though you were saying 'I'm not sure what you know is right.'"

I think it's the patients' perception too [sic], that they can actually talk about their therapies here and people are quite open and interested in what they're doing.

The narratives of the HIV-positive women show that these strategies supported disclosure and the development of decision-making partnership about CAM. All of the HIV-positive women said they had discussed their use of CAM with at least one conventional health care provider at Oak Tree Clinic.

Women said they discussed CAM at the Oak Tree Clinic because healthcare providers asked them about CAM use and because they perceived healthcare providers as accepting of and knowledgeable about CAM. Women's perception that healthcareproviders accepted CAM supported them to disclose. As one woman commented:

They're open-minded too and in accepting it, it makes it seem like acceptable. And you know, it's not like I'm going against their grain [...] you can say what you want to say.

Feeling comfortable to fully disclose at the Oak Tree Clinic was contrasted with partial disclosure to healthcare providers perceived as less open to CAM:

I'll tell them everything that's going on with me. But I won't tell my GP I'll be selective. And I'll tell these doctors—people I see here [at Oak Tree], stuff I won't tell my GP, she'd just get upset with me.

In addition, women chose to discuss CAM with healthcare providers at the Oak Tree Clinic because they were perceived as knowledgeable. Research participants described ignorance of CAM and unwillingness to learn among other healthcare providers as a barrier to communication: "I think that's why a lot of doctors prefer us to cover all trace of it [CAM]. They don't have to really look up new things and find new therapies." In contrast, women said they were motivated to discuss CAM with healthcare providers at Oak Tree because they received information that assisted them in making informed treatment decisions: "Well, my doctor doesn't talk to me about vitamins and at Oak Tree they have that information for the asking." Oak Tree Clinic staff were three times more likely to be identified as a major source of information about CAM than the women's general practitioner (87 per cent vs. 27 per cent).

The amount of credence that women gave to CAM information provided by conventional healthcare providers was based on an assessment of that healthcare provider's

knowledge and attitude towards CAM. One research participant described warnings about CAM made by an unsupportive physician as "blowing wind," and disregarded the information in her treatment decision-making.

Implications of the Use of Complementary and Alternative Medicines Among HIV+ Individuals

CAM use is common among HIV-positive individuals and offers significant benefits in the management of HIV/AIDS. This case study identified health risks associated with using CAM while living in poverty. Women reported having no, or limited access to, types of CAM that cost money. Limited access can reduce or negate the benefits of CAM. For example, rotating or taking sub-optimal doses of natural health products may result in missing important synergies, such as vitamin D for calcium absorption, or lack of effectiveness because the dose is too low. Cost was also a constraint in limiting women to conventional medical options that did not promote their overall health because they are funded by the public medical system and CAM is not. Many HIV-positive women are using CAM, but in a pay-out-of-pocket system, they lack the economic resources to use CAM optimally and to access the expertise of complementary and alternative health care providers.

This situation leaves this group of health care consumers and their conventional health care providers in a dilemma, which is only exacerbated by HIV-positive women's general perception of conventional health care providers as opposed to CAM. However, the experience of HIV-positive women at the Oak Tree Clinic demonstrates that health care providers can support their patients to disclose about CAM use, and in doing so, reduce the health risks associated with CAM in HIV care.

Two important lessons about the conditions for effective communication between conventional healthcare providers and patients emerge from this study. First, women's expectation of a negative reaction and fear of endangering the therapeutic relationship means that the onus to initiate a discussion of CAM falls to healthcare providers. Second, women's description of their own behaviour made it clear that a health provider's reactions to their disclosure of CAM use and their perception of the healthcare provider's attitude towards CAM determined whether initial disclosure developed into a productive dialogue. Women's perception of healthcare providers as supportive of and knowledgeable about CAM was a necessary condition for the emergence of a decision-making partnership. When women perceived healthcare providers as ignorant about or opposed to CAM they ignored their opinions and disclosed CAM use selectively. Conventional healthcare providers must ask about, and develop knowledge of, CAM in order to support their CAM-using patients to use these therapies safely and effectively.

Reducing Risks Associated with the Use of Complementary and Alternative Medicines

Communication with knowledgeable and supportive conventional healthcare providers was documented to reduce the risks associated with CAM in the context of HIV care and contribute to a positive health care provider-patient relationship.

Adverse interactions between natural health products and pharmaceuticals, particularly antiretrovirals, is a serious concern. As a result of open communication about CAM, women in this study reported consulting a physician or pharmacist prior to adding any ingested CAM to their healthcare regime, reducing the potential for adverse interactions:

> *[A physician] told me one time not take anything without asking her first in case there were interactions. So I always ask first if it's something I take orally.*

Consultation with knowledgeable healthcare providers also reduced health risks associated with the cost of CAM. Healthcare providers reduced the cost of CAM to patients by identifying good value or eliminating superfluous products. As one woman said about her health care provider: "She's cost efficient too.... You don't need to go and buy some big jar of this because it's already in this food."

Research with HIV-positive men at the other sites in this study revealed that poor HIV-positive men are exposed to the same health risks as poor HIV-positive women when choosing to use CAM. Women being in a disadvantaged position with respect to CAM use in HIV is gendered inasmuch as HIV-positive women who use CAM have lower levels of education than HIV-positive men who use CAM, and are less likely to be represented in the upper income categories than HIV-positive men who use CAM (Standish, Greene, Bain, Reeves, Sanders, Wines, Turet, Kim, and Calabrese).

Patterns of CAM use within the HIV community make it clear that the majority of PWAs are integrating their healthcare on an individual basis. To integrate complementary and conventional approaches to medicine at a systems level, interdisciplinary dialogue based on education and research is necessary. Physicians and PWAs identified the professional hierarchy that privileges allopathic medicine and the monopoly of knowledge the pharmaceutical industry exercises in medical research as barriers to the emergence of an interdisciplinary dialogue. Research which respects the premises of CAM and allopathic medicine and an active dialogue between PWAs, CAM practitioners, physicians, and regulators is necessary to improve quality of care.

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[1]In British Columbia, individuals have access to twelve massage therapy sessions per year with a physician's referral. However, user fees are an economic barrier for individuals living in poverty. Acupuncture is not covered in the public health care system.

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JEAN CHOW

Being Five

Running along the road,
The five year old, my daughter
The same age as those 16 who perished through tragedy
Dunblane, Scotland, 1996
Those poor parents who would never hear the voices
Challenging those around for a race
I saw with my own eyes and heart what those anguished hearts would miss
Do you want to race?
Come on mummy!
I'll beat you!
Hair flying as her body bounces with her five-year-old run
Her face looking back for a glimpse of her lead
I beat you!
She lurches to a stop when she decides the race is over
Lift me up!
I hold her small thin body with her chest heaving from the race
She plants a kiss on my lips
Her eyes sparkle with life, her cheeks glow with the colors of exertion
Her voice delights in life
Returning home, she collects rocks
Plain old rocks but to her, the rocks are treasures
She is my treasure
I have only learned to appreciate more
From the sorrow of others
Seeing her gives me great joy

Jean Chow is a Canadian who is currently discovering her cultural roots in Hong Kong and China.