Optimal Environments for Integrated Care: Complementary and Alternative Medicine in HIV Management in British Columbia

Des environnements optimaux pour des soins intégrés : la médecine complémentaire et alternative dans la gestion du VIH en Colombie-Britannique

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BRITISH COLUMBIA PERSONS WITH AIDS SOCIETY

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Executive Summary
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Background

Complementary and Alternative Medicine (CAM) is an integral part of the health and wellness strategy of many Canadians, including those who are living with HIV/AIDS. In the general population, 42-50% of adult Canadians currently use some form of CAM (Angus Reid, 1998; Ramsey et al., 1999). Among Persons Living With HIV/AIDS (PWAs), rates of use in the era of Highly Active Antiretroviral Therapy (HAART) is estimated at 39% to 73% (Ostrow et al., 1997; Robinson et al., 1998; Braitstein et al., 2000). In fact, CAM use by individuals taking conventional treatment has effectively doubled since the advent of HAART (Heath et al., 1999). Trends indicate CAM use is increasing over time in HIV positive and HIV negative populations (Heath et al., 1999; Eisenberg et al. 1993 & 1998).

Research Objectives

- To assess PWA and conventional health care provider perception of the risks and benefits of CAM.
- To describe communication between PWAs and conventional health care providers about CAM, and to elucidate associated legal and ethical issues.
- To identify recommendations for improved communication about CAM and the integration of complementary, alternative and conventional medicine. Implementation of such recommendations can optimize the benefits and reduce the risks associated with CAM in the context of HIV/AIDS treatment, care and support.

Research Methods

This was a multi-centre study with purposive sampling to maximize the diversity of participating health care delivery sites, health care providers and Persons Living With HIV/AIDS (PWAs). Twenty conventional health care providers (18 physicians) with HIV positive patients from four urban clinics and five rural family practices completed in-depth, semi-structured interviews. Forty-nine (49) PWAs who were patients of participant physicians and used CAM participated in focus groups and completed surveys on CAM use and communication with health care providers. Interviews and focus groups were analyzed using grounded theory. Quantitative analysis used non-parametric measures.

Research Results

Perception of Benefit

Health care providers and PWAs agreed about many of the benefits of CAM use. Empowerment associated with taking an active role in one's own health care and improved well-being associated with the mind/body connection was a central theme. Managing symptoms of HIV disease, side effects of antiretroviral medication and hepatitis were identified as important benefits of CAM use. CAM was also used to cope with addiction and depression. Successful use of CAM was reported to support adherence to antiretroviral therapy. CAM was also used to promote health prior to antiretroviral therapy and when conventional treatment failed or was interrupted.

PWAs and health care provider perspectives diverged with respect to the impact of CAM on specific measures of immune status. Health care providers stated that they had not seen CAM that directly and measurably impacted on CD4 counts and viral load. Although none of the PWAs who participated perceived the CAM they were currently using as a cure for HIV/AIDS, 81% said they were using CAM to enhance their immune response and 58% were using CAM to lower viral load.

Risks

PWAs limiting food intake and self-medicating because of the cost of CAM were identified as sources of health risk. Lack of communication between conventional health care providers and PWAs about CAM was another source of risk, and increased the potential for adverse interactions between pharmaceutical and natural health products.

Cost and Risk

Poverty makes it difficult for many PWAs to access CAM without diverting money from food and shelter. More than half of the PWAs who participated in this study live on less than $10,000 a year; 16% of the PWAs in this income bracket reported spending $200-400/per month on CAM. Disproportionate spending on CAM is most dramatically illustrated through PWAs limiting the food they eat to buy CAM. Cost also limits access to complementary therapy practitioners and results in self-medication.

Conventional Health Care Provider Attitudes and Communication

The research design permitted analysis of PWA-health care provider relationships and found that PWAs perceive the attitudes of their conventional health care providers towards CAM accurately. Physician attitudes to CAM can be grouped into four categories:

- opposition
- supportive but actively disassociated
- encouraging but not proactive
- active engagement

Physicians with generally supportive and unsupportive attitudes were found at all of the health care delivery sites with the exception of the multidisciplinary clinic. All of the health care providers at the multidisciplinary clinic described themselves as supportive of CAM use and PWAs concurred. The variation in physician attitudes is significant because it suggests attitudes towards CAM are not dependent on needs and capacities of PWAs, size of HIV practice, or years of clinical experience. Further, it indicates that there is a lack of consensus about the appropriate role of CAM in HIV/AIDS management among conventional health care providers.

Variation in physician attitudes towards CAM was associated with philosophical differences that can be described as “science-centered" or “patient-centered" approaches to medicine. Physicians supportive of CAM accepted the PWAs experience of HIV disease as a valuable indicator of the benefit of CAM. Unsupportive physicians rejected the value of such “unscientific" evidence. Physician opinions diverged greatly over the existence and the appropriate approach to currently available evidence about CAM. Physicians who were unsupportive of CAM said that they were aware of no evidence to support CAM use. Physicians who were supportive had done research and argued that available evidence supported CAM use and warranted more research.

Health care provider attitudes determined PWA-health care provider communication about CAM and the role conventional health care providers played in PWA decision-making about CAM. PWAs did not fully disclose their CAM use to physicians who they perceived as opposed or unsupportive of CAM use and some physicians failed to ask PWAs about their CAM use. The research identified specific instances where PWAs planned to use or were using CAM that posed health risks without the knowledge of their physician because the physician did not engage the PWA in a dialogue about CAM. PWAs and physicians not communicating about CAM use is a source of risk.

Health care providers who were more supportive and more knowledgeable about CAM were more likely to ask about CAM use and articulate an awareness of the potential risks of CAM, specifically interactions between natural and pharmaceutical medicines. In turn, patients of physicians who were supportive and relatively knowledgeable about CAM were more likely to identify CAM as a potential source of risk than PWAs who accessed physicians who were not supportive of CAM use.

Further, conventional health care providers who are perceived as knowledgeable and open to CAM have more credibility with PWAs. The research documented that dialogue between knowledgeable conventional health providers and PWAs reduced the potential for adverse interactions between pharmaceutical and natural medicines and reduced risks associated with the cost of CAM. In contrast, PWAs ignored comments about CAM made by conventional health care providers who they perceived to be ignorant of and/or opposed to CAM.

Health care providers who are more open towards and more knowledgeable about CAM are more effective at supporting PWAs in reducing risks and optimizing benefits associated with CAM.

Integration

Patterns of CAM use within and outside the HIV community make it clear that the majority of health care consumers are integrating care 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.

Conclusions

CAM use is common among HIV positive individuals. PWAs and health care providers conceive of a significant beneficial role for CAM in the management of HIV/AIDS. Cost, lack of information and poor communication pose risks. Open communication with knowledgeable and supportive conventional health care providers can reduce the risks and optimize the benefits associated with CAM use.

Prioritized Recommendations

1. Access to CAM

Short-term

- Provincial payment for enhanced health goods and services (including such things as purified water, nutritious diet, vitamins/minerals, herbs, supplements, tactile and spiritual treatments) endorsed as medically necessary by a physician for PWAs who are receiving social assistance.
- Extended health benefits, through Pharmacare, to provide equivalent health benefits to PWAs who are not receiving income assistance.
- Expansion of provincial formularies to provide payment for pharmaceutical compounds prescribed by a physician to address documented deficiencies, such as zinc, or for a specific therapeutic purpose, such as acetyl-l-carnitine for peripheral neuropathy.
- Strike interdisciplinary committees to review research on CAM in HIV disease to advise government on coverage independent of physician prescription.

Long-term

- Integrate CAM fully into the publicly funded Medicare system.

2. Delivery of Care: Establish Integrated HIV Care Clinics

A multidisciplinary clinic with salaried health care providers is a best practice model for effective communication, interdisciplinary learning, commitment to health promotion, and strong support for PWAs' making informed decisions. The ideal would be to integrate complementary and alternative health care providers into such teams, providing a one-stop-shop for health care consumers.

Short-term

- Licensing and regulatory bodies of health care and medical professionals to remove regulatory barriers to joint practice between conventional, complementary and alternative medical practitioners and undertake campaigns to educate health care providers about such regulations.
- Creation and evaluation of models that deliver interdisciplinary and integrated HIV/AIDS treatment, care and support in rural and urban settings.

Long-term

- Integrated and interdisciplinary HIV/AIDS treatment, care and support accessible by all Canadians.

3. Fund Complementary and Alternative Medicine Research

There is a widely recognized need for more research on complementary therapies. This study documented strong support for publicly funded CAM research among both conventional health care providers and PWAs.

- Collaborate with the Canadian Institutes for Health Research to develop a relevant research agenda around complementary and alternative medicine and HIV/AIDS.
- Encourage use and acceptance of a wider range of research methodols for evaluating the efficacy, effectiveness and safety of CAM and interactions between conventional and complementary medicine. See Achilles et al., 19-23, 1999.
- Encourage dialogue and education about appropriate measures for evaluating CAM through interdisciplinary conferences and methodology working groups.
- Implement changes in medical school curriculum to increase physician's knowledge of research methods other than the randomized control trial.
- Conduct randomized control trials of natural health products to determine efficacy and toxicity, alone and in combination with pharmaceuticals. See "Complementary and Alternative Therapy Protocols Development Project" (Health Canada, 1998).
- Use therapeutic drug monitoring technology and other means to do drug-herb and drug-nutrient interaction studies.

4. Educate Conventional Health Care Providers about CAM

- Offer interdisciplinary education through collaborations between conventional and alternative medicine bodies, institutes for integrative medicine, and community- based organizations.
- Provide physician-specific, CME-accredited educational opportunities about CAM. Integrate CAM into pre-existing formats such as Grand Rounds, medical school curriculum and one-day conferences.

5. Educate Persons Living With HIV/AIDS about Treatment

Knowledge of treatment, both conventional and complementary, is necessary for PWAs to make informed decisions. Priorities are:

- Develop educational materials and deliver training in critical thinking and communication skills (i.e. brochures and workshops on how to read scientific studies and evaluate evidence, speak with and make joint decisions with health care providers, identify fraudulent or dangerous health care practices or providers).
- Make treatment information resources accessible to PWAs with low literacy levels or specific cultural needs (e.g. youth).
- Support peer-based lay networks by resourcing treatment information programs that use a peer-based model, funding scholarships for conference attendance and other face-to-face networking opportunities, and develop treatment support groups that use communication technologies, such as teleconferencing and Internet, to connect geographically dispersed PWAs.

6. Regulation

The safety and quality of CAM must be established to protect consumers and to provide a foundation for the promotion of integrative medicine.

- Appropriate regulation and labeling of natural health products to inform consumers about quality control, dosage and method of administration, toxicity, interactions and contraindications.
- Federal encouragement of provincial bodies to review applications of complementary and alternative health care providers to be regulated as health professionals and to review scope of practice of health care professionals.

7. Access to knowledge base about CAM in HIV/AIDS treatment

- Create salaried positions for Complementary and Alternative Medicine Specialists in HIV/AIDS to offer face-to-face and over the phone consultation to health care providers and PWAs.
- Increase awareness of and access to evidence base for CAM by making databases such as Embase and CAMline publicly available and translating and disseminating existing scientific research published in languages other than English or French.

Addressing CAM Use by PWAs in Conventional Health Care Settings: Roles for Conventional Health Care Providers

MINIMUM LEVEL OF CARE

- Physician or pharmacist acts as a safety check with respect to known toxicity and interactions.
- To meet this minimum requirement, physicians need basic education about CAM and more research on toxicity, dosing and interactions must be undertaken.

ADEQUATE LEVEL OF CARE

- Conventional health care providers are proactive in supporting PWAs to explore their treatment options, such as: vitamin and mineral supplementation, exercise, mind/body modalities and connection with community resources.
- Inform PWAs of alternative treatment options for common symptoms and side effects if the PWA expresses interest, or there is a medical reason to do so, such as co-infection with hepatitis.

OPTIMUM LEVEL OF CARE

- Optimal care is multidisciplinary care.
- The ideal model for offering integrated health care is a “one-stop-shop". However, optimal care can be achieved through effective communication between all health care practitioners.
- Priority for adding expertise to conventional health care teams should be placed on
  nutritional interventions and interactions between pharmaceutical and natural health products.

Sommaire

Des environnements optimaux pour des soins intégrés: la médecine complémentaire et alternative dans la gestion du VIH en Colombie-Britannique

Contexte

Les thérapies complémentaires et alternatives (TCA) font partie intégrante des stratégies de santé et de bien-être de nombreux Canadiens et Canadiennes, notamment parmi les personnes vivant avec le VIH/sida. À l'heure actuelle, dans l'ensemble de la population, entre 42% et 50% des Canadiens adultes font usage de TCA (Angus Reid, 1998; Ramsey et coll., 1999). Parmi les personnes vivant avec le VIH/sida (PVVS), les taux de recours à des TCA, en cette ère des multithérapies antirétrovirales, sont évalués à entre 39% et 73% (Ostrow et coll., 1997; Robinson et coll., 1998; Braitstein et coll., 2000). Les tendances de l'usage de TCA sont à la hausse au sein des populations séropositives au VIH et séronégatives (Heath et coll., 1999; Eisenberg et coll. 1993 et 1998).

Objectifs de l'étude

- Évaluer les perceptions des risques et bienfaits des TCA, chez des PVVS et des fournisseurs de soins de santé conventionnels.
- Décrire la communication entre les PVVS et les fournisseurs de soins de santé conventionnels, à propos des TCA, et mettre en lumière les aspects juridiques et éthiques qui s'y associent.
- Formuler des recommandations pour améliorer la communication au sujet des TCA et de l'intégration des thérapies complémentaires, alternatives et conventionnelles dans le cadre des traitements, des soins et du soutien pour le VIH/sida.

Méthodologie

Étude multicentrique à échantillonnage intentionnel visant à optimiser la diversité des participants parmi les points de fourniture de soins de santé, les fournisseurs de soins et les personnes vivant avec le VIH/sida (PVVS). Vingt (20) fournisseurs de soins de santé conventionnels (dont 18 médecins) auprès de patients séropositifs au VIH, dans quatre cliniques urbaines et cinq cliniques familiales en milieu rural, ont répondu à des entrevues approfondies et semi-structurées. Quarante-neuf (49) PVVS qui recevaient des soins de médecins participant à l'étude et qui faisaient usage de TCA ont pour leur part participé à des discussions de groupe et complété des questionnaires sur l'utilisation de TCA et sur les communications avec leurs fournisseurs de soins de santé. Les entrevues et les propos recueillis lors des discussions de groupe ont été analysés par la théorie ancrée. Une analyse quantitative a été effectuée au moyen de mesures non paramétriques.

Conclusions de l'étude

Impression de bienfait

Les commentaires de PVVS et de fournisseurs de soins de santé ont révélé une connivence à propos de plusieurs bienfaits de l'utilisation de TCA. L'habilitation du patient associée au fait d'adopter un rôle actif dans ses soins de santé, ainsi que l'amélioration du bien-être associée au lien esprit/corps, ont été des thèmes centraux. La gestion des symptômes de la maladie à VIH et le contrôle des effets secondaires des médicaments antirétroviraux et des hépatites ont été identifiés comme des bienfaits importants de l'utilisation de TCA. On a aussi indiqué avoir recours à des TCA contre la dépendance et la dépression. L'utilisation de TCA a été déclarée bénéfique au respect du régime de traitement antirétroviral. Par ailleurs, on a eu recours à des TCA pour stimuler l'amélioration de la santé avant d'initier un traitement antirétroviral, ou encore lorsqu'un traitement conventionnel a échoué ou a été abandonné.

Les perspectives de PVVS et de fournisseurs de soins de santé étaient cependant divergentes quant à l'impact des TCA sur les mesures spécifiques de l'état immunitaire. Les fournisseurs de soins de santé ont affirmé n'avoir pas vu de TCA entraîner un effet direct et mesurable sur la numération des CD4 et sur la charge virale. Aucune des PVVS ayant participé à l'étude n'a exprimé l'impression que les TCA qu'elles utilisaient à ce moment étaient une cure contre le VIH/sida; cependant, 81% d'entre elles ont affirmé avoir recours à des TCA pour améliorer l'état de leur système immunitaire et 58% en utilisaient afin de réduire leur charge virale.

Sources de risque

La diminution de la prise d'aliments et l'automédication due au coût des TCA, chez des PVVS, ont été identifiées comme des sources de risque. Le manque de communication à propos des TCA, entre les fournisseurs de soins de santé conventionnels et les PVVS, a été mentionné comme une autre source de risque et un facteur d'accroissement du potentiel d'interactions néfastes entre des produits pharmaceutiques et des produits de santé naturels.

Coût et risque

Pour plusieurs PVVS, la pauvreté entrave l'accès aux TCA, à moins qu'elles détournent une somme d'argent qui est destinée à leur nourriture et à leur logement. Plus de la moitié des PVVS participant à l'étude avaient un revenu annuel inférieur à 10 000$; plus de 16% des PVVS ayant un revenu de cet ordre ont indiqué dépenser entre 200 et 400 dollars par mois pour des TCA. La meilleure illustration des dépenses disproportionnées effectuées pour obtenir des TCA réside dans le fait que certaines PVVS limitent la nourriture qu'elles consomment, afin de pouvoir payer des TCA. Le coût de ces dernières limite aussi l'accès à des praticiens du domaine des thérapies complémentaires, ce qui entraîne l'automédication.

Attitudes et communication chez les fournisseurs de soins de santé conventionnels

La conception de l'étude a permis d'analyser les relations entre des PVVS et leurs fournisseurs de soins de santé, ce qui a révélé qu'elles percevaient correctement les attitudes de leurs fournisseurs de soins de santé à l'égard des TCA – attitudes que l'on peut répartir en quatre catégories :

- opposition
- appui quoique dissocié activement
- encouragement sans geste proactif
- engagement actif

On rencontre dans tous les points de soins de santé des médecins ayant des attitudes de soutien et d'autres qui ont une attitude de non-soutien – à l'exception de la clinique multidisciplinaire, où tous les fournisseurs de soins de santé se sont dit favorables à l'utilisation de TCA et où les PVVS en ont exprimé correctement l'impression. Les variations d'attitudes entre les médecins sont significatives parce qu'elles portent à croire que leurs attitudes à l'égard des TCA ne reposent ni sur les besoins et capacités des PVVS, ni sur la taille de la clientèle séropositive au VIH, ni sur le nombre d'années d'expérience clinique du praticien. De plus, cette variation dans les attitudes révèle une absence de consensus parmi les fournisseurs de soins de santé conventionnels, quant au rôle approprié des TCA dans la gestion du VIH.

La variation des attitudes entre les médecins quant aux TCA était associée à des différences d'ordre philosophiques qui peuvent être décrites comme des approches médicales « axées sur la science » ou « axées sur le patient ». Les médecins qui appuient l'utilisation de TCA acceptaient l'expérience des PVVS, en lien avec la maladie à VIH, comme un indicateur valable du bienfait de TCA. Les autres médecins niaient la valeur de telles preuves « non scientifiques ». Les opinions des médecins divergeaient grandement quant à l'existence de données à propos des

TCA, à l'heure actuelle, et quant à la manière de les considérer. Les médecins qui ne sont pas en faveur du recours aux TCA ont déclaré n'être au courant d'aucune preuve pour l'appuyer. Ceux qui appuient ce recours ont affirmé avoir effectué des recherches et ils ont soutenu que les données actuelles y étaient favorables et justifiaient que l'on fasse des recherches plus poussées à ce sujet.

Les attitudes des fournisseurs de soins de santé étaient déterminantes de la communication des PVVS avec eux, à propos des TCA; ces attitudes étaient aussi déterminantes du rôle des fournisseurs de soins de santé conventionnels dans les décisions de PVVS à l'égard des TCA. Des PVVS ne déclaraient pas complètement leur utilisation de TCA à leur médecin si elles le percevaient comme opposé ou réservé quant à l'usage de TCA; par ailleurs, certains médecins ont déclaré ne pas poser de question aux PVVS à propos de leur recours à des TCA. L'étude a identifié des cas précis de PVVS qui prenaient ou planifiaient de prendre des TCA posant certains risques pour la santé, sans en informer leur médecin parce que ce dernier n'avait pas initié de dialogue avec elles à ce sujet. La non-communication entre une PVVS et son médecin, à propos des TCA, est source de risque.

Les fournisseurs de soins de santé qui accordaient le plus grand soutien au recours à des TCA et qui avaient le plus de connaissances en la matière étaient plus susceptibles de demander à leurs patients s'ils en utilisaient, et d'expliquer leur compréhension du potentiel de risque des TCA, en particulier les interactions possibles entre certains médicaments pharmaceutiques et d'autres naturels. À leur instar, les patients de ces médecins étaient plus susceptibles (que ceux qui croyaient que leur médecin n'appuyait pas le recours à des TCA) d'identifier les TCA comme une source potentielle de risque.

Par ailleurs, les fournisseurs de soins de santé conventionnels qui sont perçus comme ouverts vis-à-vis des TCA et qui s'y connaissent en la matière ont plus de crédibilité aux yeux de PVVS. L'étude a documenté le fait que le dialogue de PVVS avec des fournisseurs de soins de santé conventionnels qui s'y connaissent en la matière s'associait à une diminution du potentiel d'interaction néfaste entre médicaments pharmaceutiques et naturels, et réduisait les risques associés au coût des TCA. En revanche, des PVVS ont indiqué ne pas tenir compte des commentaires faits à propos des TCA par leurs fournisseurs de soins de santé conventionnels si elles ont l'impression qu'il est ignorant à ce sujet ou s'y oppose.

Les fournisseurs de soins de santé conventionnels qui sont plus ouverts et plus informés à propos des TCA sont plus efficaces dans le soutien aux PVVS, pour réduire les risques et optimiser les bienfaits associés aux TCA.

Intégration

Les tendances observées dans le recours à des TCA, dans la communauté touchée par le VIH comme hors de cette communauté, montrent que la majorité des consommateurs de soins de santé intègrent leurs soins sur un plan individuel. Pour intégrer les approches complémentaires et les approches médicales conventionnelles, au niveau des systèmes, il faut un dialogue interdisciplinaire fondé sur l'éducation et sur la recherche. Des médecins et des PVVS ont observé que la hiérarchie professionnelle axée sur la médecine allopathique et le monopole de connaissance qu'exerce l'industrie pharmaceutique en matière de recherche médicale constituent des obstacles à l'émergence d'un dialogue interdisciplinaire.

Conclusions

Le recours à des TCA est commun, chez les personnes vivant avec le VIH. Des PVVS et leurs fournisseurs de soins de santé considèrent que les TCA peuvent avoir un rôle bénéfique important dans la gestion du VIH/sida. Le coût, le manque d'information et la piètre communication posent des risques. Une communication franche avec des fournisseurs de soins de santé conventionnels qui sont informés et qui offrent leur soutien peut réduire les risques et optimiser les bienfaits associés à l'utilisation de TCA.

Recommandations par ordre de priorité

1. Accès aux TCA

À court terme

- Le paiement, par le palier provincial, de biens et de services de santé améliorés (y compris de l'eau purifiée, une diète nutritive, des vitamines et minéraux, des herbes, des suppléments, des traitements tactiles et spirituels) qui sont considérés nécessaires sur le plan médical, de l'avis d'un médecin, pour les PVVS qui reçoivent des prestations d'aide sociale.
- Une augmentation des prestations à la santé, par le biais de l'assurance médicaments, afin que les PVVS qui ne reçoivent pas d'aide au revenu jouissent de prestations équivalentes en matière de santé.
- Une expansion des formulaires provinciaux, afin d'assurer le paiement de composés pharmaceutiques prescrits par un médecin pour des carences documentées (en zinc, par exemple) ou à des fins thérapeutiques précises (comme le L-acétylcarnitine en présence d'une neuropathie périphérique).
- Des comités interdisciplinaires pour examiner la recherche sur les TCA pour la maladie à VIH, afin de conseiller le gouvernement quant à l'admissibilité de certains éléments sans ordonnance d'un médecin.

À long terme

- L'intégration complète des TCA au système public d'assurance santé.

2. Fourniture de soins : créer des cliniques de soins intégrés pour le VIH

Les cliniques multidisciplinaires dotées de fournisseurs de soins de santé salariés sont des modèles de meilleures pratiques en matière de communication efficace, d'apprentissage interdisciplinaire, d'engagement à la promotion de la santé ainsi que d'appui solide à la prise de décisions par les PVVS. L'idéal serait l'intégration de fournisseurs de soins de santé complémentaires et alternatifs, au sein de ces équipes, afin que le patient bénéficie d'un point unique de services.

À court terme

- L'agrément de professionnels des soins de santé et de la médecine, ainsi que l'avènement d'instances de réglementation, pour éliminer les éléments de réglementation qui font obstacle à des pratiques coopératives entre les praticiens des médecines conventionnelle, complémentaires et alternatives; et la tenue de campagnes d'éducation des fournisseurs de soins de santé à propos de cette réglementation.
- La création et l'évaluation de modèles offrant des traitements, des soins et du soutien interdisciplinaires et intégrés pour le VIH/sida, en milieu rural et urbain.

À long terme

- Des traitements, des soins et un soutien intégrés et interdisciplinaires pour le VIH/sida qui soient accessibles à tous les Canadien-ne-s qui en ont besoin.

3. Subventionner la recherche sur les thérapies complémentaires et alternatives

Le besoin de recherches plus poussées au sujet des thérapies complémentaires est largement reconnu. La meilleure utilisation des ressources personnelles et institutionnelles nécessite que l'on étudie les manières par lesquelles les médecines conventionnelles et les TCA pourraient fonctionner de pair, pour promouvoir une santé optimale. On observe un fort appui, parmi les fournisseurs de soins de santé conventionnels et parmi les PVVS, à l'égard de recherches financées par le secteur public, en matière de TCA.

- Collaborer avec les Instituts de recherche en santé du Canada au développement d'un programme pertinent de recherche sur les médecines complémentaires et alternatives pour le VIH/sida.
- Inciter l'utilisation et l'acceptation d'un registre plus large de méthodes de recherche, pour évaluer l'efficacité et l'innocuité des TCA ainsi que les interactions entre la médecine conventionnelle et les médecines complémentaires. (Voir Achilles et coll., 19-23, 1999)
- Encourager le dialogue et l'éducation à propos des mesures adéquates pour l'évaluation des TCA, par l'intermédiaire de conférences interdisciplinaires et de groupes de travail sur la méthodologie.
- Mettre en œuvre des changements aux programmes des facultés de médecine, afin d'améliorer chez les médecins la connaissance de méthodes de recherche autres que l'essai randomisé avec groupe témoin.
- Effectuer des essais randomisés avec groupe témoin pour déterminer l'efficacité et la toxicité des produits de santé naturels et observer leurs interactions possibles avec des produits pharmaceutiques. (Voir le Projet de développement de protocoles de thérapies complémentaires et alternatives [Complementary and Alternative Therapy Protocols Development Project], de Santé Canada,1998.)

4. Éduquer les fournisseurs de soins de santé conventionnels à propos des TCA

- Une éducation interdisciplinaire offerte en collaboration avec des instances médicales conventionnelles et alternatives, des instituts de médecine intégrative et des organismes communautaires.
- Offrir des occasions éducationnelles au sujet des TCA, à l'intention expresse des médecins, comme l'éducation médicale continue moyennant des frais par séance. Intégrer les TCA dans les formes d'éducation continue qui existent déjà, comme les grandes roundes, les programmes des facultés de médecine et les conférences d'une journée.

5. Éduquer les personnes vivant avec le VIH/sida à propos des traitements pour le VIH/sida

La connaissance des traitements, tant conventionnels que complémentaires, est nécessaire pour que les PVVS puissent prendre des décisions éclairées. Les priorités observées sont les suivantes :

- Développer du matériel d'éducation et donner une formation en réflexion critique et en habiletés de communications (i.e. dépliants et ateliers sur la lecture des rapports d'études scientifiques, l'évaluation de données, le dialogue et la prise de décision avec des fournisseurs de soins de santé, l'identification de pratiques ou de praticiens qui s'adonnent à de la fraude ou qui constituent un danger).
- Faire en sorte que des ressources d'information sur les traitements soient accessibles aux PVVS peu alphabétisées.
- Accroître les réseaux de pairs non spécialistes, en accordant des ressources à des programmes d'info-traitements qui fonctionnent selon un modèle fondé sur les pairs, en subventionnant des programmes de bourses pour la participation à des conférences et à d'autres rencontres et occasions de réseautage, et en développant des groupes de soutien en matière de traitement qui ont recours aux technologies de communication comme les conférences téléphoniques et Internet, afin de relier les PVVS qui sont dispersées sur le plan géographique.

6. Réglementation

L'innocuité et la qualité des TCA doivent être établies, pour protéger les consommateurs et pour constituer un fondement à la promotion d'une médecine intégrative.

- Une réglementation et un étiquetage appropriés des produits de santé naturels, pour informer les consommateurs sur le contrôle de la qualité, le dosage et les méthodes d'administration, la toxicité, les interactions et les contre-indications.
- Un encouragement du palier fédéral aux instances provinciales, pour l'examen des demandes de fournisseurs de soins de santé complémentaires et alternatifs qui souhaitent être réglementés en tant que professionnels de la santé, et pour la révision du registre de pratique des professionnels de la santé.

7. Accès à un fonds de connaissance sur les TCA dans le traitement du VIH/sida

- Créer des postes salariés pour que des fournisseurs de soins de santé complémentaires et alternatifs spécialisés dans le domaine du VIH/sida puissent donner des consultations en personne et téléphoniques à des fournisseurs de soins de santé et à des PVVS.
- Accroître la sensibilisation et l'accès à des TCA fondées sur des données probantes, en rendant des bases de données comme Embase et CAMline accessibles au public et en traduisant et disséminant les recherches scientifiques actuelles qui sont publiées dans d'autres langues que le français ou l'anglais.

Aborder l'utilisation de TCA par les PVVS dans le contexte des soins de santé conventionnels : rôles des fournisseurs de soins de santé conventionnels

SOINS MINIMAUX

- Le médecin ou le pharmacien agit comme référence de sécurité, au sujet des toxicités et des interactions connues.
- Pour satisfaire à cette exigence minimale, les médecins ont besoin d'une éducation élémentaire au sujet des TCA et l'on doit procéder à des recherches plus poussées sur la toxicité, les doses et les interactions.

SOINS ADÉQUATS

- Les fournisseurs de soins de santé conventionnels ont une attitude proactive en soutenant des PVVS dans l'exploration des options de traitement qui s'offrent à elles, notamment les suppléments vitaminiques et minéraux, l'exercice, les modalités esprit/corps et le contact avec des ressources de la communauté.
- Informer les PVVS au sujet des options alternatives de traitement de symptômes communs et d'effets secondaires, lorsqu'elles en manifestent l'intérêt ou en présence de raisons médicales de le faire (par exemple une co-infection à hépatite).

SOINS OPTIMAUX

- Les soins optimaux sont de nature multidisciplinaire.
- La formule idéale est un « point unique de services », mais les soins optimaux pourraient être atteints grâce à une communication réelle et efficace entre tous les praticiens des soins de santé.
- La priorité, concernant l'ajout d'expertise aux équipes de soins de santé conventionnels, devrait être accordée aux interventions nutritionnelles et aux interactions entre les produits pharmaceutiques et les produits de santé naturels.

Optimal Environments for Integrated Care Complementary and Alternative Medicine in HIV/AIDS Management in British Columbia

INTRODUCTION

Complementary and alternative medicine (CAM) is an integral part of the health and wellness strategy of many Canadians, including those who are living with HIV/AIDS. In the general population, 42–50% of adult Canadians currently use some form of CAM (Angus Reid, 1998; Ramsey et al., 1999). Among persons living with HIV/AIDS (PWAs), rates of use in the era of highly active antiretroviral therapy (HAART) is estimated between 39–73% (Ostrow et al., 1997; Robinson et al., 1998; Braitstein et al., 2000). In fact, CAM use by individuals taking conventional treatment has effectively doubled since the advent of HAART (Heath et al., 1999). Trends indicate CAM use is increasing over time in HIV-positive and HIV-negative populations (Heath et al., 1999; Eisenberg et al., 1993 & 1998).

Despite the prevalence of CAM use among Canadian PWAs, little research has been conducted on the perceptions of risks and benefits of CAM held by consumers and conventional health care providers. Similarly, studies are needed of the models of health care delivery that promote effective communication between PWAs and conventional health care providers about CAM and of the regulatory and legal implications of CAM in HIV/AIDS management.

Research Objectives

- To assess PWA and conventional health care provider perceptions of the risks and benefits of CAM
- To describe communication between PWAs and conventional health care providers about CAM
- To elucidate legal and ethical issues associated with CAM
- To identify recommendations for improved communication about CAM and the integration of complementary, alternative and conventional medicine. Implementation of such recommendations can optimize the benefits and reduce the risks associated with CAM in the context of HIV/AIDS treatment, care and support.

Research Methods

The research was a multi-centre study with a purposive sample designed to maximize the diversity of health care delivery settings, health care providers, and persons living with HIV/AIDS (PWAs) who participated in the research. Research was carried out at four urban clinics in Vancouver and five rural family practices in the West Kootenay region of British Columbia. Models of health care delivery included a multidisciplinary clinic mandated to treat HIV-positive women and their families (women's clinic), a clinic of five physicians specialized in HIV primary care (West End), drop-in clinics that have a large proportion of HIV-positive patients (Downtown Eastside), and traditional, family practices with a relatively low ratio of HIV-positive patients (West Kootenay). The groups of PWAs who participated can be broadly grouped as women, injection drug users (Downtown Eastside), gay men (West End), and rural people (see appendix 1). Twenty conventional health care providers (18 physicians) and 49 PWAs participated.

To avoid bias created by a sample of physicians supportive of CAM, efforts were made to interview all of the full-time physicians providing HIV care to adult PWAs in the health care delivery setting. This strategy was successful. Only one full-time physician who works with adult PWAs at a participating urban clinic declined to be interviewed. The rural physicians who participated had diverse attitudes about CAM.

Information about participating in the research was provided to PWAs through health care delivery sites and community-based AIDS organizations without inquiring about the PWAs use of CAM. Eligibility was determined in a screening interview with the project coordinator. The criteria for PWA participation were that the PWA had to be currently using at least one type of CAM and had to be receiving health care 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"* (see appendix 2).

Health care providers completed a forty-five minute to one-hour semi-structured interview. PWAs participated in a two to two-and-a-half hour focus group and answered a survey that asked about demographic information, treatment history, information sources, and communication with health care providers. In the rural setting, concerns about confidentiality were addressed by having PWAs complete in-depth interviews rather than participating in a focus group. Health care providers and PWAs received honoraria in recognition of their participation.

Qualitative Analysis

Interviews and focus groups were audiotaped and transcribed verbatim. Transcripts were then coded and analyzed using grounded theory (Glaser and Strauss, 1967). In this analytic technique, theory emerges from themes repeated in the narratives of participants. Data collection continues until the categories of analysis are saturated; that is, until new themes are not being introduced by research participants. All interviews were conducted, coded, and analyzed by the project coordinator.

Quantitative Analysis

A survey collected demographic information, treatment history, and sources of information about CAM. Of the 49 PWAs who participated in the research, twelve (12) were from the women's clinic, fourteen (14) were from the HIV primary care clinic in Vancouver's West End, seventeen (17) were from two drop-in clinics in Vancouver's Downtown Eastside, and six (6) were patients of general practitioners in rural British Columbia. The small sample size resulted in insufficient power to detect statistically significant differences between the four health care delivery sites.

This report includes analysis of patterns and correlates of CAM use among participants in the British Columbia HIV/AIDS Drug Treatment Program (DTP). The DTP distributes, at no charge, state-of-the-art antiretroviral medication province-wide to all eligible persons with HIV infection. Eligibility is broad and requires participants to have a plasma viral load >5,000 copies/ml and/or a CD4 count of <500 cells/mm3. The DTP is the only source of free antiretrovirals in the province.

At initial enrolment in the DTP and annually thereafter, participants are asked to complete a survey that gathers information about socioeconomic status, social support, clinical status, and current and past use of CAM and conventional medicine. Of the 1009 individuals enrolled in the DTP who responded to the 1999/2000 survey, 437 (43%) used CAM.

Statistical analysis used non-parametric measures. All reported p values are two-sided.

RESEARCH FINDINGS

Demographic Profile

The following tables provide a demographic profile of the 49 PWAs who participated in focus groups. Responses are presented in a manner that allows non-statistical comparison between health care delivery settings. Statistically significant differences did not emerge from this small sample. Percentages have been calculated using the number of PWAs who responded to each question.

Table 1: Income

Income	Total n=43	West End n=13	Downtown Eastside n=14	Women's n=10	Rural n=6
<$10,000	56% (24)	23% (3)	86% (12)	60% (6)	50% (3)
$10–30,000	42% (18)	69% (9)	14% (2)	40% (4)	50% (3)
>$30,000	2% (1)	8% (1)	NONE	NONE	NONE

Table 2: Amount Spent on CAM per Month

Spend	Total n=46	West End n=14	Downtown Eastside n=14	Women's n=12	Rural n=6
<$50	33% (15)	7% (1)	43% (6)	33% (4)	67% (4)
$50–99	24% (11)	57% (8)	NONE	25% (3)	NONE
$100–199	29% (13)	36% (5)	27% (4)	17% (2)	33% (2)
$200–400	15% (7)	NONE	27% (4)	25% (3)	NONE

Table 3: Education

Education	Total n=48	West End n=14	Downtown Eastside n=17	Women's n=11	Rural n=6
Elementary	8% (4)	NONE	24% (4)	NONE	NONE
Secondary	52% (25)	36% (5)	52% (9)	73% (8)	50% (3)
Post-secondary	40% (19)	64% (9)	24% (4)	27% (3)	50% (3)

Table 4: Ethnicity

Ethnicity	Total n=48
Caucasian	71% (34)
Aboriginal	17% (8)
Hispanic	6% (3)
Other ethnicity	6% (3)

Table 5: Age

Age	Total n=49
18–25 years	2% (1)
26–35 years	22% (11)
36–45 years	45% (22)
46–55 years	27% (13)
56+ years	4% (2)

Table 6: Gender

Gender	Total n=49
Male	67% (33)
Female	33% (16)
Transgendered	None

Treatment History

Table 7: Current Use of Antiretrovirals

Half of the respondents were taking antiretrovirals at the time of the study and half were not (n=47).

Has never taken HIV medication	23% (11)
Currently taking HIV medication	54% (25)
Has taken HIV medication in the past	23% (11)

Ever and Current Use of CAM

Half of the PWAs had used CAM before being diagnosed with HIV. The median number of therapies currently being used was 6 (range 1–16). The median number of therapies ever used was 10 (range 2–26).

Popularity of Therapies

The most popular therapies being used by participants in this study were vitamins and minerals (76%), exercise (67%), prayer (49%), dietary supplements (47%), massage (47%), marijuana (40%), meditation (39%), and herbs (35%). Types of CAM being used by less than 5% of the respondents were biofeedback (4%), Ayurveda (2%), N-acetylcysteine (2%), ozone therapy (2%), hypnosis (0%), co-enzyme Q (0%), and dinitrochlorobenzene (DNCB) (0%).

The types of CAM popular among this sample of HIV-positive individuals is similar to that found in North American studies with larger sample sizes. A multi-centre study from the United States (n=500) reported that the top ten types of CAM were vitamins and minerals (76%), exercise (70%), acupuncture (61%), massage (60%), meditation (58%), support groups (56%), supplements (56%), herbs (49%), spiritual activities (40%), Chinese botanicals (40%), and chiropractic (39%) (Reeves C. et al, 1998). A later analysis of an expanded group that included the above cohort (n=1,106) identified aerobic exercise (64%), prayer (56%), massage (54%), needle acupuncture (48%), meditation (46%), support groups (42%), visualization and imagery (34%), breathing exercises (33%), spiritual activities (33%), and other exercise (33%) as the forms of CAM used most frequently by HIV-positive individuals (Greene et al., 1999). In 1998/99, of the 1008 individuals who responded to the BC Centre for Excellence Drug Treatment Program participant survey, 424 (42.1%) reported using some kind of CAM. The therapies used by the greatest number of respondents were vitamins (75%), marijuana (32%), herbs (30%), dietary supplements (28%), massage (26%), and meditation.

BENEFITS

PWA / Health Care Provider Consensus on Benefits of CAM

Table 8: PWA Perceptions of Benefits from CAM Use

Reason for using complementary therapy	N=43
To enhance immune response	79% (34)
To lower viral load	58% (25)
To manage side effects	60% (26)
To supplement dietary intake	74% (32)
To have greater control over health	86% (37)
To prevent infections	74% (32)
To improve energy level	93% (40)
I feel good about using CAM	86% (37)
CAM won't do any harm	49% (21)

Empowerment

It is difficult to divide the perceived benefits of CAM into neat categories because most HIV-positive individuals defined CAM as a form of self-empowerment and self-care. Many PWAs said using CAM gave them a greater sense of control and decreased their dependence on conventional health care providers, situating them as active participants and partners in their own health care. CAM was integral to PWAs creating meaning in their own lives and making living with HIV/AIDS manageable and rewarding.

PWAs using CAM to take control of their own health was an important theme in the narratives of health care providers.

> *It's an active decision-making process for them to become involved in their health care, and, at a different level, they're not just being passive and having everyone tell them what to do. (Health Care Provider)*

Many health care providers perceived harmony between the individual's belief system and the treatment modality as integral to the healing process. The multicultural makeup of Canadian society and principles of choice and access that undergird the Canada Health Act highlight the importance of recognizing treatment systems that may be considered “complementary" or “alternative" by Canadian allopathy.

> *I'm feeling sometimes a little isolated by this disease 'cause I realize people are frightened by it. People maybe don't want to have sex with me or be very intimate with me. Doing these nice things for myself helps me. Going for the massage, buying the tuna.... It's part of the self-nurturing which I need, which I'm not getting from other persons.*
>
> *(PWA)*

Prevention and Health Promotion

With respect to general benefits of CAM, health care providers mentioned appropriate nutrition, exercise, mind/body interventions, and spiritual practice as having beneficial effects on immune function and easing AIDS-related complications, such as wasting syndrome. PWAs reported receiving non-specific physical benefits, such as increased energy, improved immune function, and expectation of extended life, from the use of complementary therapies. Increasing and maintaining body mass was cited as a general benefit of CAM use by PWAs.

Managing Depression and Addiction

PWAs and health care providers described successfully coping with addiction and managing depression using CAM. Mind/body interventions were described as particularly useful for coping with these mind-body complexes.

Depression

Depression is common among individuals living with HIV/AIDS. A consensus conference of the National Institutes of Health in the United States estimated that the prevalence of major depression in the general population ranges from 4% to 14% (NIH, 1992). The prevalence of depression among HIV-positive individuals is estimated at greater than 50% (Mayne et al., 1996). Higher levels of depression have been significantly correlated with decreased adherence to antiretroviral medication among HIV-positive adolescents (Murphy et al., 2001). Prior to and during the era of HAART, depression has been associated with mortality among HIV-positive individuals (Mayne et al., 1996; Ickovics et al., 2001).

Health care providers and PWAs in this study stated that depression results in immune suppression and argued that exercise, mind/body interventions, touch therapies, and herbal remedies were important treatment modalities for this condition:

> *I would personally favour making [touch] therapies publicly funded and available, particularly to people who are isolated. [It] would have a significant impact in terms of quality of life, and, indirectly I think, [on] some brain chemicals that would effect their immune systems and so on. (Physician)*

PWAs reported being able to stop taking conventional antidepressants as a consequence of mind/body interventions such as yoga and meditation. Several PWAs stated that using CAM to manage depression had allowed them to adhere to antiretroviral treatment.

Addiction and the Use of CAM

The need to address addiction issues in HIV/AIDS management was underlined when PWAs articulated that addiction can take precedence over HIV/AIDS as a health issue:

> *I have four terrible diseases, and alcoholism is my number one. If I take a drink I have absolutely nothing. I have no choice, no control over anything, and I must remember that. AIDS is second on my list. (PWA)*

Several physicians treating PWAs with addiction issues identified CAM as having a potentially beneficial role in the management of addiction. Support groups, mind/body interventions, and acupuncture were specifically mentioned. Some of these modalities were identified as having specific functions, such as acupuncture for managing withdrawal, whereas others were described as playing a more holistic role in supporting and empowering people to deal with their addiction. For example, one physician stated that meditation and visualization can be particularly useful for drug users to give "*themselves the same experience [of substance use] but with their own mind.... Then people can actually have some real control over their lives" (Physician).*

Among some PWAs in recovery, CAM use was articulated as a means of reducing the use of pharmaceutical drugs. One aspect of using CAM instead of pharmaceuticals was self-identification as a person who did not use or who avoided drugs, as expressed in the statement: "*I am not a piller (PWA)."* Pharmaceuticals were also perceived and, consequently, avoided by some as a trigger for reverting to illegal drug use. Some PWAs who were actively using cocaine, heroin, or alcohol stated that CAM had assisted them with harm reduction: "*[I used] acupuncture for [my drug] addiction, and then I noticed that it helped cut down my cigarette and my coffee intake" (PWA).*

Side Effect and Symptom Management

Health care providers and PWAs reported success in managing common side effects with CAM. Examples are the use of marijuana to decrease nausea or improve appetite and the use of calcium to treat diarrhea . Dietary changes, supplements, and exercise were used to address metabolic changes associated with HAART. For example, health care providers and PWAs reported success using omega-three essential fatty acids (from flax or fish oil) to lower blood lipid levels. Health care providers and PWAs expressed preference for managing symptoms and side effects with CAM because CAM was seen as less likely to provoke more side effects or adverse interactions than pharmaceutical products.

CAM and Hepatitis

Table 9: Co-Infection with Hepatitis

Hepatitis	Hepatitis A	Hepatitis B	Hepatitis C
64%	8%	27%	54%

The majority of the individuals sampled (23/36, 64%) were co-infected with hepatitis. In this group, 26% were currently taking antiretroviral therapy, 30% had never taken antiretroviral medication, and 35% were not currently taking antiretroviral medication. Of the 36 respondents, all that had discontinued antiretroviral therapy were co-infected (10/10).

Of the 1009 individuals enrolled in the British Columbia Centre for Excellence Drug Treatment Program who responded to the 1999/2000 participant survey, 42% of these individuals reported having hepatitis. Among this group of PWAs on antiretroviral treatment, having hepatitis was associated with CAM use (p=0.013).

Co-infected individuals on and off antiretroviral treatment described CAM as an important part of their treatment strategy. CAM was believed to improve liver function and support continuation of antiretroviral therapy:

> *I started taking milk thistle and immediately enzymes came right back to normal. So I'm able to take all the heart medication, and I'm able to take all my HIV medication and all the stuff for diabetes. (PWA)*

Others managed side effects and symptoms with CAM instead of pharmaceutical compounds perceived as more damaging to the liver:

> *I have hepatitis C, and I don't like to pollute my body with a lot of bullshit that [for] every problem, "Oh, take a pill, take a pill. Got this, take a pill, got that, take a pill"(PWA).*

Finally, CAM was a means of promoting and sustaining health for PWAs who chose not to take conventional treatment.

High rates of co-infection and the association between CAM use and hepatitis suggest practical and pressing priorities for education and research. First, alternative treatments for hepatitis abound. Researching the safety, effectiveness, and interactions with HAART of these treatments should be a priority. Treatments deemed safe and of benefit should be aggressively promoted to physicians and co-infected PWAs, particularly given the suggestion that discontinuation of antiretroviral therapy may be associated with hepatitis. Second, PWAs are using complementary therapies because they believe them to be less harmful to the liver than pharmaceuticals. This theme highlights the need for educating physicians and PWAs about the potential risks of liver toxicity associated with CAM.

CAM & Highly Active Antiretroviral Therapy (HAART)

CAM as Prelude to HAART

CAM is used by many PWAs with the aim of promoting health and extending the period of time prior to initiation of antiretroviral therapy. CAM can also be an important part of developing routines and health promoting behaviours that are essential to successful adherence to HAART:

> *I told her [my physician] I don't think I'm ready for it [HAART] because of the lifestyle that I live. I don't think I can take them when you're supposed to take them. So she gave me vitamins and she said, "Well, we'll try this." (PWA)*

CAM Supports Adherence

Managing depression, coping with addiction, and reducing symptoms and side effects all contribute to adherence. Health care providers stated that exploring CAM prior to HAART could increase compliance and adherence with HAART because it built a trust relationship with the physician and a sense of empowerment:*"You're gonna find the persons much more willing to be compliant on the meds if they've already tried what they feel they want to try" (Physician).*

CAM During Structured Treatment Interruptions

PWAs said CAM supported their immune system and benefited their general health, allowing them to stay well during and to extend structured treatment interruptions. CAM can provide much needed treatment options when conventional treatment fails. Conventional physicians not suggesting CAM when conventional treatment fails or is interrupted created resentment and a feeling of abandonment for some PWAs.

Diverging PWA / Health Care Provider Perspectives on Benefits of CAM

Learning about complementary medicine as a cure for HIV — I don't want to spend any time doing that anymore. .... In terms of using it for symptom control and treatment, I'm very much interested in knowing more about it.

(Physician)

PWAs and health care provider perspectives diverged on the impact CAM has on specific measures of immune status. Health care providers stated that they had not seen CAM that directly and measurably impacted on CD4 counts and viral load. Health care providers expressed concerns about PWAs foregoing antiretrovirals for alternative treatments. All of the health care providers interviewed stated that it is their responsibility to communicate that they have not seen CAM directly reduce viral load or increase CD4 counts and to share the evidence supporting conventional treatment strategies:

> *"It's their choice, it's their lives, it's their bodies. We just say we don't believe that this [CAM] is going to alter your viral load and CD4 to your benefit" (Health Care Provider).*

None of the PWAs who participated perceived the CAM they were currently using as a cure for HIV/AIDS. However, 81% of the participant PWAs said they were using CAM to enhance their immune response, and 58% were using CAM to lower viral load.

RISKS ASSOCIATED WITH THE USE OF CAM IN HIV/AIDS MANAGEMENT

The cost of CAM and lack of knowledge about CAM in the context of HIV/AIDS were the sources of risk associated with CAM use.

Cost and Risk

In the context of scarce economic resources available to PWAs, the cost of complementary therapies, which must be paid for out-of-pocket, was noted as a concern by almost all of the conventional health care providers interviewed. Specifically, health care providers in the Downtown Eastside and at the women's clinic were concerned about PWAs limiting food intake to purchase CAM. Health care providers worried that PWAs conceive of vitamins or other nutritional supplementation as a "*life raft"* or "*miracle"* and consequently do not invest energy or money in obtaining adequate nutrition. Unfortunately, PWAs' description of their own behaviours confirmed that in some cases PWAs are limiting food intake and self-medicating because of the cost of CAM.

Lack of Access

The majority of HIV-positive individuals in this sample were living on less than $10,000 per year; only one individual had an annual income of $30,000 or more. Cost limited PWAs' access to CAM and to CAM practitioners. Some individuals were unable to use any type of CAM with a financial cost: "*anything that costs money is out of the question" (PWA).* Among people who found the financial resources, rotation of therapies and natural health products was a common strategy: "*One month it will be no magnesium. Another, no creatine" (PWA).* PWAs were often unable to pay for what they considered health necessities, such as vitamins and purified water, after paying for food and accommodation. Other individuals delayed payment of electric, water, gas, and telephone bills because they deemed regular access to CAM more important for their well-being. The constant economic juggling act associated with finding the money for CAM was identified as a source of stress.

Self-Medication

Individuals were not able to explore the CAM options that interested them or access CAM practitioners because of lack of funds. Inability to pay for professional consultation resulted in self-medication: "*When you can't afford to see your herbalist, you have to do that research on your own" (PWA).*

Limiting Food Intake

Low incomes made it difficult for PWAs to access adequate quantities of quality food. In the Downtown Eastside, living in a dwelling without cooking facilities was identified as a barrier to optimizing nutritional intake. Purchasing seconds (dented cans, food and supplements past their best-before date, or aging vegetables) was common among PWAs from all four health care settings. Aging vegetables are benign, but dented cans or products past their best-before date may pose a threat to the health of immunocompromised individuals. Further, exercising choice over food intake and using therapeutic diets was cost prohibitive. PWAs said wheat-free, sugar-free, and organic diets were beyond their economic means.

Despite these challenges, many of the PWAs interviewed considered diet an essential part of health promotion and put the purchase and preparation of nutritious food before better housing, vitamin and mineral supplementation, and entertainment.

However, other individuals chose to use their resources in a manner that can be considered a health risk. Disproportionate spending on CAM was most dramatically illustrated by PWAs who limit the food they eat in order to buy CAM. For PWAs with a low fixed income, food money is the only “soft money" available:

> *You spend $100 a month on vitamins [and] only get $55 back [from BC Persons with AIDS Society Complementary Health Fund]. You're going into your food money. (PWA)*

Of the PWAs earning less than $10,000 annually, 16% reported spending $200–$400/per month on CAM; no statistically significant relationship between income and the monthly estimate of spending on CAM was found. Limiting food intake to purchase CAM was a more common theme among PWAs accessing health care at the women's clinic and in the Downtown Eastside.

Information and Risk

The research identified multiple barriers to accessing high quality CAM treatment information germane to HIV/AIDS and making informed decisions. Key areas for action are the critical-thinking skills and information-gathering networks of PWAs, scarcity of complementary and alternative health care practitioners specialized in HIV/AIDS, conventional health care provider knowledge and attitudes that result in poor communication, and paucity of research about the safety, efficacy, and adverse interactions associated with CAM products and practices.

PWA Knowledge and Risk Assessment

PWAs lack of knowledge about the CAM that they are choosing to use was identi-

fied as a source of risk. Physicians' assessment of how much knowledge PWAs had about CAM varied by health care delivery site and the physician's attitude towards CAM. All physicians said knowledge levels varied but supportive physicians were more likely to assess PWA knowledge levels favorably. In the rural towns, physicians said PWAs are proactive and well-informed in comparison with their other patients. Health care providers were most concerned about knowledge levels of marginalized PWAs, particularly those living in the Downtown Eastside: "*So those in the Downtown Eastside—they often hear about that from other peoples' indirect referral. So they know it by name but don't know it by principle" (Physician).*

PWAs identified their own lack of knowledge, in conjunction with their health care providers' lack of knowledge or failure to take a proactive role with respect to CAM, as a source of risk: "*You don't know what you don't know. So if you don't know what to ask, then sometimes you simply don't get the information" (PWA).* PWAs also made choices that exposed them to risk, such as taking herbal remedies without knowing what they were: "*I don't even know what it [wormwood] is. I think it might be like wood grain alcohol or something" (PWA).* Some PWAs said they hadn't thought about or were uninformed with respect to interactions between natural health products and pharmaceuticals.

PWAs were evenly divided in their response to the statement: "Complementary therapies won't cause any harm." However, the qualitative research suggests is it rare for PWAs to be ignorant of the potential risks associated with CAM. More commonly, PWAs were aware of the risks but chose to use CAM regardless. Three themes emerged with respect to how PWAs think about risks of CAM in HIV management. First, all forms of HIV treatment are experimental and carry risk. Second, many PWAs conducted a risk benefit analysis that evaluated CAM as lower risk than conventional therapy. Third, individuals chose to assume the risk of CAM because they lacked other options acceptable to them to approach a particular condition.

INFORMATION, COMMUNICATION AND DECISION MAKING

To situate the opportunities for improving informed decision-making about CAM in the context of HIV/AIDS, the sources of information and mechanisms for evaluation that predominate among PWAs must be understood.

Table 10: Major Sources of Information About CAM Reported by PWAs

Source of Information about CAM	Total n=49	West End n=14	Downtown Eastside n=17	Women's n=12	Rural n=6
HIV Specialist	29% (14)	NONE	53% (9)	83% (5 of 6 PWAs)	NONE
General Practitioner	43% (21)	14% (2)	83% (14)	25% (3)	33% (2)
Other Conventional Health Care Provider	45% (22)	36% (5)	41% (7)	83% (10)	NONE
CAM practitioner	10% (5)	21% (3)	NONE	8% (1)	17% (1)
HIV-positive People	63% (31)	86% (12)	35% (6)	83% (10)	50% (3)
HIV-negative Family and Friends	37% (18)	21% (3)	29% (5)	50% (6)	67% (4)
Popular Media	53% (26)	57% (8)	41% (7)	67% (8)	50% (3)
Internet	29% (14)	43% (6)	24% (4)	8% (1)	50% (3)
Health Food Store	39% (19)	43% (6)	29% (5)	58% (7)	17% (1)
Local AIDS Organizations	71% (35)	71% (10)	59% (10)	91% (11)	67% (4)
National AIDS Organizations	31% (15)	29% (4)	12% (2)	42% (5)	67% (4)
Scientific Journal	35% (17)	29% (4)	18% (3)	67% (8)	33% (2)

Table 10 illustrates three key points about the structure of information-seeking among HIV-positive CAM users. First, PWAs emphasize receiving treatment information from other HIV-positive persons; 71% of respondents said local AIDS organizations and 63% said other HIV-positive individuals were major sources of information. The local AIDS organizations to which this research pertains offer peer-based treatment information programs.

Second, popular media (such as television, magazines and newspapers) is a significant source of information. The quality of information disseminated through popular media is variable, and much of it is not HIV-specific. Individuals' ability to safely and effectively evaluate and apply this information depends on their critical thinking skills and connection to community-based and professional treatment information resources.

Third, conventional health care providers were a much more significant information source for PWAs than complementary and alternative health care providers. A marked contrast exists between the 43% of respondents who identified general physicians and the 45% of respondents who identified other conventional health

care providers as a major sources of information about CAM on the one hand and the 10% of respondents who identified CAM practitioners as a major source of information about CAM on the other.

PWA-Centered Information Gathering and Evaluation

The tendency demonstrated in Table 10 of PWAs to depend on their own experience and those of other HIV-positive individuals was further emphasized and elucidated in the qualitative portion of the research. The two central mechanisms that PWAs reported for gathering and evaluating information about CAM can be categorized as body knowledge and lay networks. The quality of information generated using these methods is intimately related to the skills of the individual PWA and the social network to which they belong.

Body Knowledge

PWAs' knowledge and monitoring of their own bodies was an important source of information about the value and effects of CAM. While “My body knows what I need" seems a rather vague basis on which to make treatment decisions, the approach is empirical. Techniques described were adding only one type of CAM at a time, continuing a modality for an adequate period of time before discontinuing, and monitoring reactions when CAM was decreased or discontinued. Keeping a journal and meditation were identified as valuable tools in this process. The ability to use these techniques is mediated by individual PWAs' literacy levels, exposure to the concept of systematically evaluating CAM, and ability to self-monitor. This finding suggests the focus of professional and community-based treatment information should not be narrowly defined as information-provision. Treatment information programs should offer opportunities for PWAs to learn skills that support them in making informed decisions. Skills useful in decision-making would include critical thinking and self-monitoring techniques.

Lay Networks

There was consensus that other HIV-positive individuals were the most credible and valuable sources of treatment information. The relative risk assumed by using information gathered through lay networks is a function of the quality of information circulating in the network and the individual's ability to critically evaluate that information. In this respect there are crucial disparities among PWA populations.

“I think I have listened to other people over the years, like people at other AIDS organizations in Toronto and San Francisco" (West End PWA).

“Word of mouth. If you're in food bank line ups, you know" (Downtown Eastside PWA).

People who actually have the disease and have nothing to gain from what they are saying rather than, you know, representing a certain community, like, you know, a doctor of this, a doctor of that.

(PWA)

One of the initial assumptions of this research was that lay networks introduce risk and that informed decision-making would be improved with professional support. However, PWAs expressed skepticism about the quality of information provided by conventional medical practitioners because of their biases and lack of knowledge about CAM. Likewise, PWAs expressed skepticism about information provided by CAM practitioners because of their perceived lack of knowledge of HIV and their profit motive. The research findings demonstrate that many PWAs have knowledge of CAM in the context of HIV/AIDS that is superior to that of conventional or complementary health care providers. Further, the research underlines the credibility of lay networks and their capacity to disseminate relevant information in a timely fashion. Rather than attempting to redirect PWAs' information-seeking away from lay people and toward professionals, important nodes in existing lay networks should be better resourced and opportunities to create lay networks fostered.

When I remember back to what I was like when I was first diagnosed, as far as going to the doctor, and I was just like okay, I know I'm HIV positive, and I know I have to take these drugs, and that's about it. And when I look at it now, what I know about my health and how to keep my body running right and what these numbers mean and what this $25 word that he just used means.... I'm amazed at how much of an education it has become.

(PWA)

Newly Diagnosed and Marginalized PWAs

PWAs' need for information and support from conventional health care providers varies greatly depending on where they are on the HIV learning curve. The rate at which PWAs progress along this learning curve depends on the resources available (level of literacy, attachment to support networks or CAM community) and personal interest. PWAs described a process in which as they learn more about HIV and CAM, they become more independent and more critical of health care providers' knowledge about CAM. Individuals with lower socioeconomic status tended to assess the CAM knowledge of supportive conventional health care providers more favourably than individuals from higher socioeconomic status in all health care delivery settings. Further, general practitioners tended to play a larger role in treatment decision-making sooner after diagnosis and among disadvantaged or marginalized populations such as street-drug or alcohol users, street-involved people, and mental health consumers.

Information From Complementary and Alternative Health Care Providers

The research demonstrates that very few PWAs consider practitioners of complementary or alternative medicine as major sources of information. In the smaller sample of CAM-using PWAs who were taking and not taking antiretroviral treatment (n=49), only 5 individuals (10%) reported CAM practitioners as a major source of information. In the larger cohort of PWAs taking antiretroviral treatment and using CAM (n=437), 51 individuals (12%) reported CAM practitioners as a major source of information.

One of the barriers to accessing CAM practitioners is cost. However, PWAs identified a lack of CAM practitioners experienced in HIV disease, even in a large urban centre such as Vancouver, as another barrier. CAM practitioners' lack of knowledge about HIV/AIDS was perceived as a risk: *"It is dangerous to listen to a profession, even if they are good, when they don't know about your disease" (PWA).*

Conventional Health Care Provider Attitudes and Communication

The research design permitted analysis of relationships between PWAs and health care providers. The research shows that PWAs accurately perceive the attitudes of their conventional health care providers towards CAM. These attitudes determine the level of communication between PWAs and health care providers about CAM and the role conventional health care providers play in PWA decision-making about CAM.

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

(PWA)

Disclosure

One of the hypotheses explored in this research was that non-disclosure of CAM use to conventional health care providers was a source of risk. Among Canadian and American CAM users in the general population, non-disclosure to general practitioners is estimated between 50% and 70% (Ramsay et al., 1999; Eisenberg et al., 1993 & 1998). In the context of HIV disease, non-disclosure of CAM use is a serious concern because of potential adverse interactions between treatment modalities.

The research shows that 22% of PWAs had never disclosed their CAM use to their HIV specialist and 21% had never disclosed to their general practitioner. The percentage of PWAs not disclosing CAM use in this sample is between the 9% non-disclosure at Seattle's Bastyr University Immune Clinic (Reeves et al., 1998) and the 30% non-disclosure at Boston University (Fairfield et al., 1998). Despite some PWAs' reticence to introduce the topic of CAM use to their physician, the vast majority stated that they would disclose if asked about their CAM use. The hesita-

tion of patients to introduce the topic suggests this query should be standard practice for physicians and pharmacists. The research suggests this dialogue can contribute to a supportive relationship between patient and health care provider; PWAs interpreted questions about CAM as a sign of interest in their well-being and a validation of the role that they can take in their own health care. However, the research also shows that continued disclosure and development of a decision-making partnership is dependent on the attitude of the conventional health care provider.

Physician Attitudes to CAM

The pharmacist and dietician interviewed for this study were generally knowledgeable, supportive, and proactive in the CAM use of their patients. Therefore, this discussion of attitudes and communication focuses on the 18 physicians who participated in the research. The continuum of physician attitudes with respect to CAM can be grouped in four categories:

- opposition
- supportive but actively disassociated
- encouraging but not proactive
- active engagement

I don't even bother telling him about all of this stuff anymore because he really, unless it is scientific, ...he doesn't want to know about it. If I tell him about herbs that I got from Dr. Shen or Dr. Lee or someone, some native shaman that I went to, he wants to know what's in it, what the chemical components are, he wants to see tests.

(PWA)

Opposition

These physicians did not ask about CAM at intake and did not discuss CAM except to state that these therapies are “unproven" or to question patients using scarce resources to pursue these therapies. Physicians in this category confined their knowledge of CAM to the most readily available literature, such as the Canadian Medical Association Journal, and declined to undertake research on CAM at the request of their patients.

Reasons CAM-using PWAs gave for continuing to seek treatment from physicians who did not support their CAM use were the physicians' experience with HIV, their need to receive methadone treatment in conjunction with HIV care, and their personal investment in the relationship. Despite continuing to seek care from these physicians, the physicians' attitude resulted in PWAs not fully disclosing their CAM use or feeling they were at odds with their physician.

While tensions between CAM-using PWAs and unsupportive physicians were found in all health care delivery settings, these relationships were most polarized and antagonistic in the Downtown Eastside. Unsupportive physicians in the Downtown Eastside set managing addiction and complying with conventional medical care as benchmarks to be achieved before they would accept CAM as part of a PWAs treatment package. Further, these physicians did not see CAM as relevant to

the health care delivery setting: *"In the context I'm dealing with here, you'd need a lot of those free radical collectors to overcome the effect that heroin, cocaine, malnutrition has" (Physician).*

CAM-using PWAs in the Downtown Eastside accurately perceived these attitudes. They said unsupportive physicians perceived CAM as a burden, a scam, or an unnecessary extra. PWAs also reported being discouraged from trying alternatives to manage HIV-related symptoms and feeling pressured to take antiretroviral treatment to demonstrate commitment to their health and compliance with their physician:

> *it seems like they're saying you have more respect for you body if you take these [antiretroviral] medications. If you choose not to take them, then they think you're not complying with them. (PWA)*

Physicians failing to ask PWAs about their CAM use because they assessed CAM as irrelevant to the treatment strategy of the PWA and PWAs failing to disclose CAM use because they assessed their physician as opposed to it was not confined to the Downtown Eastside. In addition to the many cases in which PWAs were not fully disclosing their CAM use because of their perception of their physicians' negative attitudes, the research documented two specific instances where PWAs were using or could be expected to use CAM that could cause harm without the knowledge of their physician.

In the first instance, the physician was not opposed to CAM use but made the alcoholism of the patient the focus of treatment counselling. The PWA was co-infected with hepatitis and unable to take antiretrovirals because of liver function. He thought that comfrey, a hepatotoxic plant, was benign:

> *I growed up here in these hills. I know what is good and what's bad. You know simple things like shaggy main mushrooms, huckleberries, comfrey, and stuff like that. I just know it is good for you. (PWA)*

In the second instance, the PWA was aware of his physician's opposition to CAM and reported being pressured take conventional treatment and being discouraged from using CAM. Consequently, he was not disclosing his CAM use to his physician. Among the therapies he was using was echinacea. Echinacea is a non-specific immunostimulant that increases white blood cell production and stimulates production of tumour necrosis factor. Tumour necrosis factor is frequently elevated in HIV-positive individuals, and, therefore, it is widely recommended that PWAs avoid echinacea (Blumenthal, 1998).

Supportive but actively dissociated

Physicians in this category did not dispute or denigrate their patients' use of CAM. Their approach was to draw a strict boundary between conventional medical

care, for which they considered themselves responsible, and CAM. They stated that they are uninformed about CAM and unable to learn because of the demands of their conventional medical practice. These physicians took the position that if their patients want to use CAM, they support them in principle but will take no practical role in assessing safety or evaluating benefit: *"I'm leaving it up to them to be sure what they're taking is safe" (Physician).* Physicians in this category tended to encourage their patients to seek out CAM practitioners, community treatment information programs, or support groups to learn about CAM.

PWAs assessed these physicians as having no knowledge or genuine interest in CAM. Whether PWAs were accepting or angry about their health care provider's attitude, the result was the absence of a decision-making partnership with respect to CAM. This situation left individual PWAs feeling alone: *"I'm on my own (PWA)."*

Not proactive but encouraging

The difference between these physicians and those in the preceding categories is that these individuals saw it as their role to act as a resource and partner in their patients' decision-making about CAM. They reported keeping files on CAM, undertaking research at their patients request, supporting critical analysis of the information, and including the complementary approaches that they know about in their discussion of treatment options. Knowledge and learning was driven by what patients were choosing to use:

> *You have to know something about it. If your patients are taking something, it behooves you to know something about it. Rather than just turning a blind eye and saying, "Well ... you're on your own when you take that stuff...." (Physician)*

PWAs interpreted support for their CAM use as genuine when physicians asked about CAM, gave feedback indicating they believe CAM has value, and acknowledged the impact PWAs' actions can have on their own health. These attitudes towards CAM provided the foundation for a decision-making partnership.

I asked him a couple times over the last ten years or so why I'm still alive and my friends are dead, and he's always raised the fact that I've exercised, taken vitamins. I value that in him too. I've heard a lot of negative statements about other physicians that they don't give any credence to anything other than medical stuff, and I find [he's] not like that.

(PWA)

Active Engagement

The most common form of active engagement described was a health care provider asking about and encouraging modalities such as massage or meditation. A more infrequent form of active engagement was the health care provider recommending CAM to manage symptoms or side effects or even going through the list of vitamins, herbs, and supplements being taken by the PWA to make recommendations with respect to safety and obtaining the best value for money. Active engagement by physicians was rare. Significantly, the health care delivery site where active engagement was common was the multidisciplinary women's clinic. At this

clinic PWAs have regular access to a dietician and pharmacist who are knowledgeable about CAM. Most PWAs did not perceive their physicians as a resource in their decision-making about CAM.

Variations in Physician Attitudes

Physicians with generally supportive and unsupportive attitudes were found at all of the health care delivery sites, with the exception of the women's clinic where physicians described themselves as supportive of CAM and PWAs concurred. The variation in physician attitudes is significant because it suggests attitudes towards CAM are not dependent on needs and capacities of PWAs, size of HIV practice, or years of clinical experience. Further, it indicates that there is a lack of consensus about the appropriate role of CAM in HIV/AIDS management among conventional health care providers. Variations in physician attitudes towards CAM were associated with philosophical differences that can be described as “science-centered" or “patient-centered" approaches to medicine. The use of these categories does not imply that patient-centered physicians are uninterested in science, or that science-centered physicians are uninterested in the well-being of their patients. The dichotomy is used to indicate where the physician put emphasis when evaluating CAM.

Assessing Benefits

Physicians seemed to agree that CAM is evaluated primarily through subjective or non-specific measures, such as PWAs' experience of pain, severity and duration of side effects, body mass, vitality, sleep patterns, and mood. Physicians supportive of CAM accepted PWAs' experience of HIV disease as a valuable indicator of the benefit of CAM. Unsupportive physicians rejected such evidence as non-scientific. The following physician statements contrast patient-centered and science-centered evaluations of the benefits of CAM.

Supportive physician

Physician: I think that my judging of success is based on what the patient tells me. Are they feeling better, are they having less side effects, are they able to cope with medication, those sorts of things. So it's really a subjective evaluation from the patient's perspective.

Unsupportive physician

Interviewer: Do you think that complementary therapies offer any benefit to HIV-positive people?
Physician: I honestly can't tell you. Because I haven't seen a study one way or the other [to suggest] they offer a benefit. I mean again statistically.

Assessing Literature

Health care providers' knowledge of CAM is informed both by their clinical practice and by their reading of the literature. The physicians reached a consensus that more evidence about CAM generated through randomized, placebo control studies would be of assistance in assessing benefits and risks. However, opinions diverged greatly over the existence and the appropriate approach to currently available evidence about CAM.

Physicians who were unsupportive of CAM said that they were aware of no evidence to support CAM use. Strict adherence to the scientific method and rejection of anecdotal, patient-generated evidence characterized these physicians' approach to knowledge. Some of the unsupportive physicians said that CAM research would divert material and intellectual resources away from research areas they perceived as more important

Physicians who were supportive of CAM use had done their own research and argued that available evidence supported CAM use and warranted more research. One physician who practiced acupuncture and was particularly knowledgeable in the area of integrative medicine argued that a great deal of scientific evidence about complementary therapies exists but is not published in the primary care literature. The research activities of supportive physicians can be invaluable for their patients because physicians have the skills, resources, and connections within the medical community to access and evaluate information.

The variation in physician attitudes towards and assessments of the benefits of CAM illustrates lack of consensus about the role of CAM in HIV/AIDS management. Health care provider attitudes determine communication about CAM, and, consequently, the comprehensiveness and quality of care that PWAs receive.

Conventional Health Care Providers Role in Reducing Risks and Optimizing Benefits

Health care providers who were more knowledgeable were more likely to articulate awareness of the potential risks of CAM, specifically interactions between natural and pharmaceutical medicines. Physicians who did not see CAM as an important part of treatment tended to dismiss the risks of CAM as well as the benefits:

> **Interviewer***: Do you think in the context in which you're working that complementary therapies can pose a risk to people's health outcomes?*
>
> **Physician***: That's never been a concern of mine.*

Health care provider awareness of risk was reflected in their patients' conception of risk. Patients of physicians who were supportive and somewhat knowledgeable about CAM were more likely to identify CAM as a potential source of risk than

PWAs who accessed physicians who were not supportive of CAM use. The attitude held by the health care provider seems to have a greater impact on marginalized individuals. In the Downtown Eastside, PWAs who accessed supportive physicians were much more likely to mention risks of CAM than PWAs who did not.

Further, lack of knowledge prevents conventional health care providers from acting as an information resource in PWAs decision-making about CAM:

> *They ask me if it's ok to take a particular therapy or if it's ok to mix with their drugs. And I usually answer that I don't know because a lot of these things haven't been studied well, or I personally simply do not know.*
>
> *(Physician)*

Conventional health care providers lack of knowledge about CAM presented a barrier to communication or eroded the health care provider's credibility when they made statements about CAM:

> *I don't have the confidence in my physician knowing that something is safe. When they say, they don't think it's safe, that's because they have never really studied it, or [it] seem[s] contrary to their beliefs, ...or the trial doesn't come up to their standards of trial. So, I don't really ask my physician about complementary therapies. I tell them what I have done. (PWA)*

PWAs rejected and ignored comments made by conventional health care providers whom they perceived to be ignorant of and/or opposed to CAM. In contrast, dialogue between knowledgeable conventional health providers and PWAs was shown to reduce the possibility of drug/natural product interactions and to reduce the cost and pill burden associated with CAM for PWAs.

This research suggests that health care providers who are more knowledgeable about CAM are more effective in supporting PWAs to reduce risks and optimize benefits associated with CAM use. First, health care providers who were more supportive and knowledgeable were more likely to articulate awareness of risk associated with CAM and communicate the potential for risk to their patients. Second, health care providers perceived as supportive of CAM were seen by PWAs as more credible sources of information than health care providers who were unsupportive of CAM.

MOVING TOWARDS INTEGRATION?

The preceding discussion has looked at the benefits, risks, and communication patterns associated with CAM through the lived experience of HIV-positive individuals and conventional health care providers working in HIV/AIDS. Patterns of CAM use within and outside the HIV community make it clear that health care consumers are integrating care on an individual basis. Yet, integration at a systems level and provision of a seamless continuum of care that maximizes the benefits and minimizes the risks associated with concurrent use of conventional, complementary, and/or alternative medicine seems to demand resolution of epistemological and regulatory issues.

Epistemological Relationship of CAM to Conventional Medicine

Conventional or non-conventional is just from the conventional side looking at it [and] saying, "We are the only real ones."

(PWA)

The epistemological conflict to be resolved in order to integrate CAM and conventional medicine was clearly articulated in the views of the conventional health care providers interviewed for this research. Unsupportive physicians insist the scientific method is the only valid way of knowing and that biomedicine is the only valid treatment system: *"I think it is the role of conventional medicine to either embrace or discard complementary therapy" (Physician).* The dominance and superiority of conventional medicine was challenged by other physicians: *"I think Western medicine is only one part of the puzzle, and I feel very limited in ... what I can offer in terms of care" (Physician).* Consumers who were actively integrating treatment systems called on their physicians to recognize that Western medicine is only one knowledge system among many: *"I'd like them to acknowledge up front that not all knowledge rests with the Western model of medicine, that many other models of medicine keep people alive and well" (PWA).* PWAs attributed unsupportive physicians' attitudes and lack of knowledge about CAM to education in "non-belief of other medical systems" and the dominance of the pharmaceutical industry in the production of medical knowledge. Many PWAs described discussions of their CAM use with their doctor as a form of education and a counterweight to the dominance of the Western medical model: *"I think if I tell him something is working and a few other people do the same thing and say it's working, then he finally might get it" (PWA).*

To move towards integration, the hierarchy of disciplines which privileges allopathic medicine must be addressed. This hierarchy is based on the assumption that conventional medicine and the associated research methodologies are superior. One illustration of this attitude is found in this physician's comment about who would be a credible CAM teacher: *"But for me to take this person seriously, I would have to know it's coming out of—at least it's being looked at through the eyes of—conventional medicine" (Physician).*

A key area that illustrates the conflict of knowledge systems is the contrast between standardized treatment in conventional medicine and the individualized approach that is common to many alternative treatment systems, such as naturopathy, homeopathy, Ayurveda, and Traditional Chinese Medicine. Some physicians expressed skepticism about CAM because individuals with the same condition, according to the diagnosis of conventional medicine, who visit complementary practitioners are often given different treatments. In contrast, a doctor of Traditional Chinese Medicine would argue that different individuals manifest disease differently, and, therefore, treatment should vary from person to person. In conventional medicine, the preferred research method is the randomized control trial, whereas other medical systems could be more effectively evaluated using an outcomes-based approach (Achilles et al., 1999, 19–23).

A hierarchy of disciplines in which allopathic medical providers place themselves and the methodology of their discipline above all others erects barriers to integration in the areas of education, interprofessional communication, and research.

Education

Interprofessional dialogue is difficult in part because the education of allopathic physicians provides little motivation or foundation for understanding complementary or alternative approaches to health and healing:

> *When I first started (again, we had no training in it, we were trained in the conventional model), ...I knew so little about it that it was hard to even be open-minded in some respects. Because we sort of.... I guess we felt that if it was really important, well, they would have taught it to us. So my mind has certainly been opened over that period of time. (Physician)*

With more than half of the Canadian population choosing to use some form of CAM, there is a strong case for the education of allopathic physicians about CAM. Knowledge of the philosophical and methodological underpinnings of other healing systems would allow allopathic physicians to engage in a dialogue with patients and CAM practitioners. The association of physician attitudes to CAM with personal philosophy (rather than the needs and practices of patients, experience as a clinician, or consensus in the conventional medical community) found in this research further strengthens the argument for educating allopathic physicians about CAM.

Interprofessional Communication

The hierarchy of professions that places allopathic health care providers above alternative and complementary practitioners discourages dialogue. Many of the conventional health care providers interviewed felt it would be difficult for CAM practitioners to have an equal relationship with physicians:

It's very threatening, I'm sure, for complementary practitioners to approach medical clinics and doctors and try to deal on an equal footing as partners in health care for a certain person. (Health Care Provider)

PWAs described the professional hierarchy that privileges physicians over nurses, dieticians, and pharmacists as a barrier to these conventional health care providers, whose scope of practice and philosophy may be more aligned to CAM, supporting them in their CAM use.

The promise of interprofessional communication for supporting integration was demonstrated at the women's clinic. In this setting, physicians described themselves as supportive of CAM, noted they had learned a great deal about CAM from the pharmacist and dietician, and stated they depended upon these individuals to provide information both to them and to patients. In turn, the dietician and pharmacist saw value in PWAs consulting individuals specifically trained in the modalities that were being used and stressed the importance of effective communication with CAM practitioners. The experience of PWAs and health care providers at the women's clinic suggests that a multidisciplinary team that includes CAM practitioners is a good model for delivering integrated medical care.

Research, Regulation, and Access

Lack of research and appropriate regulation contributes to CAM not being covered by the publicly funded medical system, and, consequently, to lack of access.

Research and Access

The lower status accorded to CAM within Western medicine discourages scientists and physicians trained in this discipline from engaging in research and education about CAM. This barrier to the production of knowledge could prevent validation of CAM using the scientific method:

You need a commitment from people who ... were basically trained in the scientific method to do something that's to them ... not totally scientific, and so you have a barrier. You're kind of dealing with a thing that you've always thought of as off the wall. (Physician)

The status accorded to CAM research and the feasibility of conducting such research is intimately related to the availability of funding.

Many of the most popular types of CAM, such as nutritional supplements, vitamins, and herbs could be evaluated using the gold standard of scientific research: the randomized double-blind placebo control trial. Why are these studies not done? Physicians' response to this question was unequivocal. Trials of natural health products are not conducted because the products cannot be patented and pharmaceutical

companies are not interested in expenditure on research without the potential for adequate recompense. Physicians saw publicly funded research as the most feasible means of addressing this knowledge gap. PWAs also strongly supported publicly funded research on CAM.

An anecdote told by a PWA about accessing a new allopathic treatment was a telling illustration of the influence pharmaceutical research and marketing has on PWAs' access to treatments. Despite not having any options to treat a condition, the PWA's general practitioner dismissed a new drug because the study he had read was not favourable. Days later, a specialist, who had a sample of the drug sitting on his desk, suggested the product minutes into a consultation. In response to the PWA's recounting of his discussion with his family physician and queries about the value of the product, the specialist stated that further studies had shown benefit. The PWA is now taking the product.

As well as supporting access to new conventional treatments, the research and marketing conducted by pharmaceutical companies can limit the probability that PWAs will receive non-pharmaceutical treatment from their conventional physician. One physician said that he had successfully treated AIDS-related thrush with gentian violet. However, he only sought out this remedy after "*all the new expensive drugs weren't working anymore" (Physician).*

Another example of how lack of research limits PWAs access to CAM had been the unwillingness of conventional physicians to endorse Schedule C applications. Schedule C is a subsection of the British Columbia Disabilities Act that is used to claim the cost of goods and services that are deemed to be medically necessary in the management of HIV/AIDS, such as purified water, nutritious diet, vitamins/minerals, nutritional supplements, and herbs. The application demands that a physician attest to the value of the CAM by "signing off" on each of the goods or services. In many cases, physicians' lack of knowledge about CAM (directly attributable to lack of research and lack of publication of existing research in mainstream medical literature) results in refusal to sign off on many of the products and services requested by PWAs.

The perceived influence the pharmaceutical industry has over physicians created a feeling of skepticism among many PWAs:

> *a doctor can, like, go by whatever he's sent from the chemical companies and stuff, and the more money and power the chemical company has, then the more they can get information out.... (PWA)*

Some PWAs articulated the opinion that physicians are essentially working for the pharmaceutical industry by writing prescriptions and conducting drug research. The confluence of the monopoly of knowledge exercised by the pharmaceutical industry, PWAs position as consumers of experimental pharmaceutical treatments, and lack

> *I think the doctors have an obligation to be sharing more information with us. This is a terminal illness, and they are all doing research with the [BC] Centre for Excellence [in HIV/AIDS] or whoever. We have consented to be in a research project, where we are giving them our blood, so they can monitor the effectiveness of the meds, and I think they have an obligation to us to share all types of therapy. It is not just their own type of therapy.*
>
> *(PWA)*

of integrative dialogue is resented by many.

Regulation and Access

In some cases, current regulation was seen to limit access to natural health products and services. Specifically, regulation of DHEA and marijuana as controlled substances was seen to increase the price and make these natural health products more difficult to procure. Current regulations present difficulties for health care providers as well. Despite 17 out of 18 physicians interviewed stating that marijuana offered benefits for managing symptoms and side effects common in HIV disease, physicians said they were uncomfortable prescribing a controlled substance even when they felt it was medically indicated. Therefore, most physicians limited their endorsement of marijuana to signing a letter stating that their patient was HIV-positive and wanted to use marijuana for medicinal purposes. However, despite these cases where regulation was seen to limit access, health care providers and PWAs were generally supportive of regulating natural health products.

Regulation of Natural Health Products

Quality control and establishing doses were the predominant reasons that PWAs and health care providers supported regulation. PWAs and health care providers also expressed a strong desire for more information about interactions between natural health products and pharmaceutical products, specifically antiretrovirals. All PWAs agreed labels of natural health products should list benefits, risks, maximum dose, contraindications, and interactions. Fifty-eight percent felt that if this information was not available, the product should not be sold. The majority of PWAs indicated that they currently do not receive adequate information about the side effects or potential adverse effects of complementary therapies from labels (66%), HIV specialists (54%), CAM practitioners (58%), or general physicians (61%).

Regulation of Complementary Health Care Providers

PWAs expressed desire for their allopathic physicians to recognize and respect the knowledge and education of CAM practitioners, but few individuals expressed this goal in terms of policy actions, such as regulation of complementary and alternative health care providers. Physicians who were neutral or unsupportive towards CAM raised the lack of regulation of CAM practitioners, and, therefore, the physician's lack of knowledge about CAM practitioners' training as a barrier to establishing integrated care clinics.

Regulation of Conventional Physicians

The practice guidelines established for conventional physicians through the College of Physicians and Surgeons of British Columbia was cited by doctors as a barrier to the integration of CAM and conventional medicine. Physicians' assessment of the College's attitude towards CAM ranged from “fairly open" to “anti-CAM." None of the physicians viewed the College as a leader in integration, instead assigning this role to the Tzu Chi Institute of Integrated Medicine at Vancouver General Hospital and the United States' National Institutes of Health National Center for Complementary and Alternative Medicine (NCCAM). Several physicians indicated that the regulations of the College did not permit them to share office space with a complementary or alternative practitioner and, therefore, integration was not possible. In fact, the stance of the College is that allopathic physicians may share office space with complementary or alternative health care providers that are recognized by the College, but billing, record-keeping, and signage must be distinct (communication with Dr. T. P. Seland, Deputy Registrar, College of Physicians and Surgeons, March 2000). The interpretation of the regulation by the College represents a barrier to truly integrated clinics because it prevents the establishment of an interdisciplinary care team that includes CAM practitioners.

Doctors Taking A Proactive Role in CAM: Legal Liability and Decision-Making

How physicians approached the regulatory morass of “recommending" CAM was associated with whether they took a “patient-centered” or “science-centered” approach to treatment decision-making. Some physicians took the view that they were supporting the PWA and not the therapy:

> *And since I'm not a practitioner of any of the complementary medicine, I cannot advocate for it. But I think supporting the person's self-exploration is not a legal issue at all. (Physician)*

The other broad approach taken by physicians was not to introduce CAM into discussions of treatment and to make it clear that any forays that the PWA made in that domain were their own responsibility. All physicians stated that it was their responsibility to make sure PWAs understand their conventional treatment options and the outcomes that can be expected.

Both PWAs and physicians introduced legal liability of physicians as a barrier to integration. Written documentation of PWAs' refusal of conventional treatment was proposed by physicians as a strategy to avoid legal liability. Models for informed consent, shared decision-making, and shared liability that recognize the agency of health care consumers in treatment decision-making must be developed to permit fully disclosed, cooperative, and integrated treatment.

Integrated Care

I used to view them as two different things. Now I view them as one because, I guess, they've integrated with me.

(PWA)

From the perspective of PWAs, both CAM and conventional medicine have an important role to play in health: *"I think with the HIV medications you can stay alive. With the complementary therapies you can have a quality of life that you wouldn't have otherwise."* The need to effectively integrate treatment regimes is becoming more urgent as life expectancies for HIV-positive individuals increase because of triple combination therapy (Hogg et al., 1999; Wood et al., 2000), as antiretroviral regimes and their complications become more complex, and as increasing numbers of individuals with multiple conditions and barriers to accessing care (such as alcohol and drug addiction) become infected with HIV:

> *I get a lot of pain in my body, and I don't know where it comes from, and so I've tried the chiropractor, [and] I've tried massage. Now I'm trying physio.... My doctor, she's over here with her pain pills, and I get allergic reactions, and I'm edgy, and I'm on too many medications.... I wish, gee, if you could just talk maybe.... Is it a physical problem? Is it my back? Is it my bones? Is it my medicines? Is it.... You know, help me. (PWA)*

CAM-using PWAs expressed a strong desire for knowledgeable health care providers to support and guide their integration of CAM and conventional medicine. Health care providers recognized the need for better communication with CAM practitioners to provide optimal care and make the best use of available resources:

> *I think the dialogue between us and the naturopath or whatever would mean that we could fine tune what we're recommending for our patients. Stuff that would make sense, it would be economical, it wouldn't be wasted money, it wouldn't be wasted stuff going into the bodies. (Physician)*

The consensus among health care providers who were neutral towards or supportive of CAM and CAM-using PWAs is that a multidisciplinary care team that includes complementary health care providers, preferably in a single location, and offers a decision-making process where PWAs play a central role is the ideal mechanism for offering optimal, integrated HIV/AIDS treatment.

CONCLUSION

CAM is a common and important part of the HIV/AIDS management of PWAs in British Columbia. Both PWAs and conventional health care providers identify significant risks and benefits of CAM use. The risks associated with CAM use stem from cost and lack of HIV/AIDS specific information about CAM.

The information gathering and evaluation strategies reported by PWAs indicate two key areas for action. First, PWAs depend on their peers and their own experience to make decisions about CAM. Supporting peer networks and building the capacity of PWAs to self-monitor and critically evaluate treatment information will support individuals to make informed treatment choices. Second, conventional health care providers are identified as more important sources of information about CAM than are CAM practitioners. Educating conventional health care providers would provide increased support to PWAs in treatment decision-making.

The PWAs and many of the health care providers interviewed said that the dominance of Western biomedicine is a barrier to education, interprofessional communication, and research that would support integration. The feeling of superiority articulated by some conventional health care providers suggests this is indeed the case. Further, the dominant role of the pharmaceutical industry in producing and disseminating medical knowledge was seen as a barrier to research in CAM, physicians' knowledge, and access to CAM through the publicly funded health care system.

Increased research, appropriate regulation of natural health products, and improved communication between CAM practitioners and conventional health care providers are necessary foundations for the emergence of integrative medicine. PWAs' integration of CAM and conventional medicine on an individual basis and health care providers' desire to promote the optimal health of their patients will continue to drive systemic changes in health care.

Appendix 1: Description of Health Care Delivery Sites and Sample of PWAs

The research sample was designed to represent the diverse populations of HIV-positive individuals in British Columbia, as well as a range of health care delivery settings. Sampling of PWAs was based on the site where they received health care rather than gender or stated route of infection with HIV. The broad categories of HIV-positive individuals who participated in the research were women, gay men, current or former injection drug users and people living in rural communities.

Women's Clinic

The Oak Tree Clinic (women's clinic) is an ambulatory clinic located at the British Columbia Children and Women's Hospital in South Vancouver. The clinic is mandated to serve HIV-positive women and their families from across the province. Health care providers are salaried and care is multidisciplinary. Health care is arranged by appointment and generally involves consultation with a nurse, an HIV internist, a registered dietician and a pharmacist. HIV-positive women accessing care must have a general practitioner in addition to the Oak Tree care team. All of the PWA participants recruited from this clinic were women.

West End of Vancouver

Spectrum Health is located in the West End of Vancouver, two blocks from St. Paul's Hospital, which houses the British Columbia Centre for Excellence in HIV/AIDS, the Canadian HIV/AIDS Trials Network, and an infectious disease clinic that specializes in HIV/AIDS. The West End is a gay neighborhood, and the patients Spectrum Health serves are predominantly gay men. The clinic is a collaboration of five general practitioners specialized in HIV/AIDS. Service is by appointment and physicians are paid a set fee per patient per year. During the time of data collection, a full-time nurse, a part-time social worker, and a part-time dietician were available to patients.

Downtown Eastside of Vancouver

Two Downtown Eastside clinics, the Vancouver Native Health Society and the Downtown Community Health Clinic, participated in the research. The Downtown Eastside is the centre of the injection drug using community and one of the poorest neighborhoods in Canada. HIV and Hepatitis C infections in this community are at epidemic proportions. A fifteen-month observation of seroconversions among users of a needle exchange during 1996 and 1997 documented that 64 of the 694 participants became HIV-positive (Schechter et al., 1999).

The Vancouver Native Health Society (VNHS) is a drop-in clinic that operates on a fee-for-service basis. Under the umbrella of the VNHS and next door to the clinic is Positive Outlook, a program that offers meals, support groups, drug and alcohol and methadone counselling for HIV-positive people, as well as an acupuncture for addiction program for HIV-positive and HIV-negative individuals. The Downtown Clinic operates on a fee-for-service basis. Physician attention is available by appointment or on a drop-in basis. The Downtown Clinic also offers a methadone program with alcohol and drug counselling, dental services, an in-house pharmacy, a low-cost food store, home support and a community liaison worker. Physicians at both clinics are general practitioners.

Rural: Nelson, Castlegar and Trail

The West-Kootenay Boundary Regional Health Authority is responsible for a population of 82,758 people. Participant physicians were located in Nelson and Area (population 29,313), Castlegar and District (population 13, 892) and Greater Trail (population 20, 929). Conventional HIV care is provided on a fee-for-service basis by general practitioners as part of their family practice. HIV practices tend to be small with physicians treating from one to twelve HIV-positive individuals. Complementary and Alternative Medicine is readily available in Nelson. Nelson has a number of CAM training institutes and a high concentration of CAM practitioners. In addition ANKORS, the local AIDS Service Organization, is located in Nelson.

Appendix 1

Appendix 2: Definition of CAM

This study combined older and newer approaches to defining CAM. The earlier approaches tended to define CAM in terms of what it is not, and is epitomized by the definition used for Eisenberg's ground-breaking 1993 study of CAM use in the United States: "medical interventions not taught widely at U.S. medical schools or generally available in U.S. hospitals" (Eisenberg, 1993). Current definitions of CAM put greater emphasis on individuals defining CAM for themselves and recognize the blurred boundaries between CAM and conventional medicine:

> Complementary and alternative medicine (CAM) is a broad domain of healing resources that encompasses all health systems, modalities, and practices and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health system of a particular society or culture in a given historical period. CAM includes all such practices and ideas self-defined by their users as preventing or treating illness or promoting health and well-being. Boundaries within CAM and between the CAM domain and the domain of the dominant system are not always sharp or fixed (NIH, 1997).

This study defined CAM as "*products or practices used to promote health and manage living with HIV disease that are not prescription drugs or over the counter medications."* In recruiting and screening HIV-positive participants, the project coordinator defined CAM, gave examples (such as acupuncture, massage, healing circles, vitamins, and dietary supplements) and discussed health practices in order to determine eligibility. Vitamin and mineral supplementation operationalized as CAM was taking more than a multivitamin.

Conventional health care providers were given the same definition of CAM and provided with the National Centre for Complementary and Alternative Medicine categorization of CAM if they required clarification. NCCAM divides CAM into seven major categories: mind-body medicine, alternative medical systems, lifestyle and disease prevention, biologically-based therapies, manipulative and body-based systems, biofield, and bioelectromagnetics (http://nccam.nih.gov/nccam/what-is-cam/classify.shtml).

BRITISH COLUMBIA CENTRE FOR EXCELLENCE IN HIV/AIDS

THERAPEUTIC NUTRITION GUIDELINES

Diana Peabody RD, Oak Tree Clinic

INTRODUCTION

Malnutrition is a frequent complication of HIV disease. It may present as starvation and/or metabolic abnormalities and is often of complex etiology. Although there are numerous contributing factors, many studies show that inadequate nutritional intake has the most consistent impact on nutritional status. Anorexia, oral and gastrointestinal complications, side effects of medications, and psychosocial factors are examples of common impediments to nutritional intake. Other determinants of nutritional status include increased losses due to diarrhea and malabsorption, perturbed metabolism, and increased nutrient requirements induced by fever, infection and respiratory complications.

In HIV disease, malnutrition manifests as weight loss and wasting, progressive loss of body cell mass, micronutrient deficiencies, altered metabolism utilization and excretion of nutrients, and lipodystrophy syndrome. Malnutrition has an independent deleterious effect on immune function with a potential increase in the incidence of opportunistic infections. Nutrient deficits have been found to be associated with an increased rate of disease progression and risk of mortality.Undernourished individuals also experience greater debilitation, with a loss of independence and ability to perform activities of daily living. Ultimately, malnutrition impacts on health care costs; the malnourished individual has a greater need for medical care, hospitalization and home care support.

Because of the high risk of nutritional problems and the associated significant potential for adverse outcomes, early nutritional intervention should be an integral component of ongoing health care for people with HIV disease. HIV-positive patients should be referred soon after diagnosis to a registered dietitian, preferably with expertise in HIV disease, for nutritional assessment and counselling. The goals of intervention are to maintain weight, to preserve or restore lean body mass, to ameliorate symptoms and minimize the side effects of treatments, to support the immune system and to optimize overall nutritional health status.

Nutritional Assesment

The goals of a nutritional assessment are to gather information about current nutritional status and adequacy of diet, and to identify risk factors for developing future nutritional complications. A complete nutritional assessment includes (1) assessment of clinical signs of nutritional deficit, (2) anthropometrics, (3) nutrition history, (4) medical history, (5) estimation of nutritional requirements, and (6) biochemical assessment.

1. Physical signs of nutritional deficit

- Assess for clinical signs of wasting, loss of lean body mass, micronutrient deficiency and other indicators of nutritional risk (e.g., poor dentition, IDU).

2. Anthropometrics

Anthropometric assessment should include the following parameters:

- Measured height:
  Stature should be measured rather than self-reported.
- Body weight:
  - Current weight: A weight of less than 90% ideal weight indicates nutritional risk.
  - Weight history: Weight should be documented at each clinic visit. An unintentional weight loss of 5% usual weight is clinically significant and may be predictive of impending complications and increased risk of mortality. Weight loss of 10% (usually in the presence of diarrhea or fever for >30 days) indicates wasting syndrome and high nutritional risk. A weight loss of 30% is a strong predictor of mortality.
  - BMI (weight (kg)/ height2 (m): A BMI of less than 20 or greater than 27 indicate nutritional risk.
- **Body composition**
  Loss of body cell mass is progressive and may not be reflected in weight changes. A critical amount of body cell mass (54% of ideal body cell mass) is necessary to sustain life. Body composition should be assessed at baseline and regular intervals for early identification of body cell mass wasting, to enhance nutritional intervention strategies and to empower HIV-infected individuals to be more committed to their nutritional health.

  Bioelectrical impedance analysis (BIA) is a widely used assessment tool that measures body cell mass, intracellular and extracellular water, extracellular tissue and fat mass. BIA assessments have limitations in that measurements are influenced by fluid shifts in acute infection and do not identify patterns of fat redistribution seen in peripheral lipodystrophy syndrome. However, BIA provides important information when monitoring weight changes, and is consid-

ered a practical clinical tool for body composition studies if appropriate equations are used for HIV disease.

To more accurately determine fat redistribution syndrome, as well as estimate subcutaneous fat and lean body mass measure upper arm circumference, multiple-site skinfolds, waist girth and hip girth using skinfold calipers and a measuring tape. For the most reliable results, serial measurements should be taken by the same clinician.

3. Nutrition history

- Assess usual and current dietary intake, appetite, and factors affecting intake such as nausea, diarrhea, odynophagia, and fatigue. Inadequate dietary intake has been more consistently linked to wasting than any other contributing factor.
- Psychosocial factors, substance use (drugs, alcohol, cigarettes), and economics impact on ability to maintain an adequate diet.
- Complementary and mega-vitamin therapies are common and should be assessed for potential benefit as well as toxicity and adverse side effects.

4. Estimated nutritional requirements

- Energy requirements:

  Energy requirements are highly variable and depend on clinical condition, metabolic rate, activity level, and viral load. In asymptomatic HIV disease, resting energy requirements are elevated by about 10%, but total energy expenditure is not always elevated, due to a compensatory response in terms of decreased physical activity. In the presence of fever, acute infection or the need for weight gain, kcalorie requirements are significantly elevated by as much as 30%-50%. In cases of severe malnutrition, energy needs are initially depressed to provide metabolic support and prevent refeeding complications, followed by incremental increases in kcalories for nutritional rehabilitation. Energy requirements are also decreased to promote weight loss in obese patients (BMI >27) Obesity, which seems to be occurring with greater frequency, may increase potential cardiovascular risks incurred with HAART. The following guidelines are estimates based on actual body weight. A metabolic cart can be used to obtain a more accurate assessment of basal metabolic rate.

  - Asymptomatic, stable weight: 30-35 kcalories/kg/24hr
  - Need to gain weight: 35-40 kcalories/kg/24hr
  - Acute infection: 40-50 kcalories/kg/24hr
  - Severely malnourished: 20 kcal/kg/24hr to start with gradual increase
  - Need to lose weight: 25-30 kcalories/kg/24hr

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- Protein requirements:

  There is huge variation in individual protein requirements, depending mainly on clinical status. There is evidence of a 30% increase in protein turnover during asymptomatic periods, but study results have been conflicting as to whether this is a universal finding. Extra protein is required to provide substrate for immune cell replication, acute phase proteins, and lean body mass maintenance.With acute infection, protein requirements are dramatically elevated to attenuate hypercatabolism of somatic proteins. The following guidelines provide estimates of protein requirements based on body weight. It is essential to concurrently meet energy requirements in order to spare protein.

  - Asymptomatic: 1.1-1.5 g/kg/24hr
  - Symptomatic or malnourished: 1.5-2.0 g/kg/24hr
  - Acute infection with fever: 2.0-2.5 g/kg/24hr

5. Medical history

- Assess clinical factors, such as gastrointestinal disorders and other complications, which impact on nutrition status.
- Medication regimens with adverse effects and complicated drug-food schedules significantly impede dietary intake and may cause metabolic abnormalities with nutritional consequences.
- Assess patient's risk factors for cardiovascular disease.

6. Biochemical assessment

- Micronutrient deficiencies are common due to malabsorption, metabolic aberrations, and increased turnover. Studies indicate a number of vitamins, minerals and amino acids are at risk with the potential for adverse outcomes in terms of symptoms, disease progression and the risk of mortality. The incidence of deficiency increases with advanced disease, but may occur in asymptomatic patients, including those who eat very well. To date, it is unclear whether micronutrient deficiencies have a causal effect on disease progression and mortality or are markers of disease progression. However, in a progressive disease for which there remains no cure, it is prudent to ensure micronutrient status is intact.
- Serum levels of micronutrients are affected by the acute phase response in infective states, and, thus, may not be reliable measures of micronutrient status. However, micronutrient studies typically report serum levels, and negative clinical outcomes have been associated with abnormal serum levels.
- In addition to usual bloodwork consider assessing the following at baseline and regular intervals thereafter, depending on clinical status and disease stage: albu-

min, prealbumin, total protein, selenium, zinc, vitamin B12, RBC folate, magnesium, carotene, testosterone. The risk of abnormal parameters is increased in the presence of persistent diarrhea, unexplained weight loss, or advanced disease. Fasting cholesterol (LDL, HDL, and triglycerides), and fasting blood glucose should be assessed prior to initiating HAART with repeat testing every 6 months.

NUTRITION THERAPY

Early Intervention

Soon after diagnosis patients should consult a registered dietitian, as it is easier to prevent malnutrition than reverse it. This entails the following:

- A rigorous nutritional assessment (see above).
- Teaching about nutrient dense foods, as well as energy, protein and micronutrient requirements in the context of HIV/AIDS.
- Address any nutrition-related complications (e.g. diarrhea, anorexia, weight loss).
- Ensure patients understand the basic principles of food safety with regard to purchasing, handling, preparing and storing of foods. Immune compromised individuals should boil tap water for 1 minute or use purified bottled water (distilled, reverse osmosis or 1 micron filter) from a reliable source
- Exercise, progressive resistance training in particular, is an effective anabolic agent to maintain or build lean body mass. Patients should be encouraged to maintain physical activity as able. Individuals who have been sedentary or bedridden, or who have co-existing impediments to exercise (e.g. neuropathy or back pain) should be referred to a physiotherapist.

Micronutrient Supplements

Micronutrient supplementation remains controversial in the scientific community with lack of consensus on efficacy and appropriate mode of supplementation. Definitive proof of efficacy is difficult to obtain because of the complex interactions between nutrients, the immune system, gastrointestinal function, and viral replication. Moreover, intervention trials are difficult to administer because nutrients cannot be withheld. Proof of benefit tends to come from epidemiological or in vitro studies and anecdotal evidence. The goals of micronutrient support are to prevent or correct deficiencies, to maintain good health, and to prolong life. Micronutrient prophylaxis is widely advocated in PWA publications and may be one avenue of

empowerment for persons living with HIV/AIDS in gaining control over their health. The following strategies have shown promise in maintaining health and treating symptoms:

- Multivitamin-mineral: There is general consensus that all HIV-positive individuals benefit from a broad-spectrum multivitamin-mineral once a day.
- Antioxidants: Studies show an increase in oxidative stress in HIV. Oxidative stress contributes to disease pathogenesis by damaging cell structures, increasing the inflammatory response, increasing viral replication via the NFkB pathway, and inducing apoptosis of immune cells. There is a concomitant decline in endogenous antioxidant production, notably glutathione, as well as a decreased intake of dietary sources. Although there remains no consensus regarding the use of antioxidant supplements, in clinical practice vitamins C and E are widely recommended, as they are relatively inexpensive and non-toxic. Suggested doses are 500-1000 mg of vitamin C and 400-800 IU vitamin E per day (vitamin C, at doses of several grams per day, may cause diarrhea and has been found to have pro-oxidant activity).
- B complex: Epidemiological studies suggest that B vitamins are protective in terms of disease progression. Patients with a history of acute infection, fever, alcohol use, and malnutrition are at particular risk of deficiency, and should consider a B complex supplement.
- Vitamin B12: B12 deficiency has been linked to neuropathy, decreased cognition, increased disease progression, and increased risk of mortality. The primary contributing factors are malabsorption due to gastric hypochlorhydria and intestinal disease, as well as increased turnover. Prophylaxis is widely recommended in PWA literature and clinical settings, and there is abundant anecdotal evidence to support supplementation. When to start prophylaxis and proper dosing regimens remains unclear. Serum B12 levels do not accurately reflect functionality or tissue stores, which limits the reliability of testing and makes it more difficult to determine the appropriateness of supplementation. Persons with low serum levels, advanced disease, neuropathy, declining cognition, and prolonged gastrointestinal complications should be considered for B12 supplementation by injection to bypass absorptive disorders. Typical dosing regimens range from 100-500-1000 mcg anywhere from 2/week to 1/month. A conservative approach would be to prescribe a 1000 mcg loading dose followed by monthly injections of 100mcg.
- Selenium: Research has shown that selenium deficiency is associated with increased risk of mortality by 20 fold and has been associated with wasting syndrome and possibly viral load. The prevalence of deficiency ranges from 16-66%, correlating with declining CD4 cell counts. Whether selenium deficiency has a causal role in mortality or is a marker of disease progression remains to be determined. However, at this stage it is prudent to prevent, or at the very

least, correct abnormally low serum levels. It should be noted that functional tests (e.g., glutathione peroxidase) more accurately reflect selenium status, but serum levels have been widely used to assess selenium status in HIV disease. Selenium is toxic in high doses (>700 mcg), but 100-200 mcg per day is thought to be a safe and adequate dose to prevent or correct deficiency.

- Zinc: Zinc deficiency, a common occurrence in HIV infection, is profoundly immunosuppressive, is associated with an increased risk of mortality, and has a negative impact on taste acuity, wound healing and growth. Zinc supplementation remains highly controversial, as high intakes are also immunosuppressive. The level of zinc intake that causes declining immune function is unknown. The amount of zinc found in a multivitamin-mineral is safe and adequate unless there is a measured deficiency. To correct a zinc deficiency prescribe 25-50 mg elemental zinc three times daily.
- Vitamin A: Deficiency is common in injection drug users and malabsorptive disorders. Deficiency compromises the integrity of the epithelial barrier, increases the risk of opportunistic infection and increases the risk of vertical transmission. Deficiency prophylaxis will be obtained with the use of a daily multivitamin supplement. Doses higher than 20000 IU per day should not be taken without documented evidence of vitamin A deficiency and should be monitored carefully for signs of toxicity. Persons with compromised liver function should not take doses greater than 5000 IU vitamin A per day (the usual amount in a multivitamin).
- Magnesium: There is growing evidence of a significant prevalence of magnesium deficiency, which has widespread implications because of the myriad metabolic functions of magnesium. Serum levels should be included in routine bloodwork 1-2 times per year depending on clinical state. To correct deficiency prescribe 75-125 mg elemental magnesium three times per day (therapeutic doses of magnesium may cause diarrhea).
- Glutamine: Glutamine is an amino acid that has a major role in the maintenance and restoration of gut integrity as well as being an important nutrient for immune cells. Requirements are dramatically increased during infectious periods and decreased serum levels have been found in patients with tissue wasting. Glutamine-enriched enteral formula and/or supplementation is effective in the treatment of diarrhea, possibly reducing reliance on anti-diarrheal medications. The ideal therapeutic dose is not yet certain but doses of up to 0.4 grams/kg/24hours have been suggested, with most anecdotal evidence reporting benefit at 10 grams/24 hr (glutamine supplementation is contraindicated in the presence of renal or hepatic failure).
- Other therapies: A number of potentially beneficial therapies that are being investigated include N-acetyl cysteine, alpha lipoic acid, carnitine, chromium, fatty acids (e.g. omega 3), creatine, DHEA, and whey protein. The therapeutic effect and dosing requirements have yet to be determined but some patients will

decide to self-administer these supplements. It is important to document usage and ensure the patient has obtained information from a reliable source.

Aside from a multivitamin-mineral, which should be taken by all HIV-infected persons, supplementation regimens should be individualized based on clinical condition, measured deficiencies, and economic situation. Individuals with hepatic or renal dysfunction should exercise extreme caution with micronutrient supplementation.

Symptom Management

The goals of symptom management are to improve nutritional intake, maintain weight and body cell mass, enhance adherence to medications, and improve quality of life. The following represent commonly occurring symptoms with nutritional consequences.

- Diarrhea: Diarrhea has nutritional implications due to nutrient losses with rapid transit and malabsorption. Dietary strategies that decrease stimulation to the bowel and delay transit time are effective at reducing diarrhea. Small frequent meals are better tolerated, and patients should avoid foods and beverages that are high in fat, insoluble fibre (e.g. bran), sugar, caffeine and alcohol. Soluble fibre such as oatmeal, rice and Metamucil are beneficial because they slow intestinal transit. Fluids and electrolytes should be replaced with low osmolality fluids and salty foods, or electrolyte replacement drinks such as Gatorade or Pedialyte. Lactose intolerance may occur transiently during episodes of diarrhea, but low lactose dairy products are usually tolerated. Lactase enzyme replacement (pills or drops) may benefit some patients.
- Nausea: Nausea is a frequent, sometimes intractable, side-effect of medications, and can have a significant effect on nutritional intake. Dietary modifications to improve food tolerance may enable some patients to remain on antiviral medications. Small frequent meals and snacks consisting of bland, low fat, low sugar foods and beverages are usually better tolerated. Coffee, alcohol and other gastric irritants should be avoided. In the presence of emesis, fluids and electrolytes should be replaced.
- Dysguesia: A significant number of HIV infected patients experience loss of taste acuity and/or abnormal taste sensations. Malnourished individuals are most susceptible to decreased taste perception because malnutrition blunts the capacity for taste receptor turnover. This results in an overall loss of the number of taste receptors with a subsequent decrease in taste acuity. Medications also influence taste perception, frequently causing abnormal taste sensations such as persistent sweet, metallic or bitter taste. To increase stimulation of taste and smell receptors food should be chewed well and moved around the mouth to stimulate as many receptors as possible. This will also cleanse the oral cavity of any lingering medication residue. Using flavor enhancers such as salt, spices, sauces, and

marinades will increase taste acuity and mask unpleasant flavors. Chocolate and vanilla are particularly effective taste and smell stimulators, especially if used in stronger than normal concentrations.

- Anorexia: Loss of appetite is prevalent, is difficult to treat and may have a profound impact on nutritional status. General strategies include eating small frequent meals at regularly scheduled intervals, eating well when appetite is best, and 'making every bite count'. Enhancement of the eating environment, assistance with shopping and cooking, and use of appropriate community supports will improve nutritional intake for some individuals. Megestrol Acetate (MA) has been used as an effective appetite stimulant for some patients, but the resultant weight gain tends to consist primarily of fat with limited accretion of lean tissue. Moreover, MA therapy has been associated with declining testosterone, which has negative implications for lean body mass status. For persistent anorexia in the presence of weight loss more aggressive nutritional support may be needed.

Nutrition Support

Early, aggressive nutrition intervention is warranted because malnutrition is associated with adverse outcomes and nutrition support may improve the course of HIV disease. The goals of nutrition support are to meet predicted nutrient needs using the appropriate modality, to correct malnutrition, to maintain or replete lean body mass, to preserve gut function and to maintain psychosocial well being. Support is implemented in a step-wise progression at the first signs of nutritional deficit (e.g. an unintentional weight loss of 5% usual weight in 1 month).

Step I: Dietary strategies

- Nutritional counselling is provided on how to maximize nutrient intake with a high calorie, high protein diet and appropriate micronutrient supplementation.
- Oral liquid nutritional supplements may be required to augment dietary intake in order to meet predicted nutrient requirements. Products are selected in accordance with the goals of treatment, gastrointestinal symptoms and patient acceptability.

Step II: Enteral nutrition support

Enteral nutrition provides specialized formula via a feeding tube to the gastrointestinal tract. Selection of the feeding method depends on clinical factors and the goals of treatment. Formula selection is based on gut function, feeding method, nutritional requirements and tolerance.1,9,163

- Nasogastric: A nasogastric tube feeding is recommended for short term feeding,9

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and should be promptly implemented for nutritional repletion of malnourished individuals during hospital admissions . Nasogastric feeding tube placement may be contraindicated in the presence of esophageal lesions, emesis, and severe gastroesophageal reflux.

- Gastrostomy: A percutaneous endoscopic gastrostomy (PEG) feeding tube is placed for long term tube feeding and/or home enteral nutrition.
- Jejunostomy: In cases of recurrent emesis and gastroesophageal reflux, which incur a high risk of aspiration, a gastro-jejunostomy or jejunostomy feeding tube may be more appropriate.

Step III: Total parenteral nutrition (TPN)

- Whenever possible, enteral nutrition is preferred in order to provide nutrients to the gut and maintain the intestinal barrier.
- Parenteral nutrition is used in cases of gut failure or severe gastrointestinal disease.
- Catheter-related sepsis is a significant risk in immunocompromised patients.
- Home TPN is an option for select patients if the appropriate support is available.

Step IV: Anabolic agents to enhance nutrition support

- Anabolic block: Nutrition support will usually result in weight gain, but for some patients, classified as non-responders, there is evidence of an anabolic block, whereby the regained weight is composed of a disproportionately high amount of body fat with limited accretion of lean tissue. This phenomenon can be identified with body composition analysis. Thus, although refeeding is always necessary, it is not always sufficient for some individuals.
- Anabolic therapy: In cases where lean tissue gains are insufficient, an anabolic agent may be required such as exercise and/or testosterone replacement. Other anabolic therapies that have shown favorable results include Oxandrin, Dexadurabolan, recombinant Growth Hormone and cytokine agents, although access to these agents is somewhat limited by cost and availability in Canada.
- Nutrition effect: Even though some patients will preferentially gain body fat, they will inevitably start to feel better because of enhanced nutrient intake, resulting in greater activity with subsequent gains in lean body mass.

Lipodystrophy Syndrome

Peripheral lipodystrophy, a syndrome associated with highly active antiretroviral therapy, includes body composition changes and metabolic abnormalities with nutritional implications. The etiology is uncertain, but ongoing investigations suggest endocrine factors as well as antiviral medications contribute to pathogenesis. There is still no clear understanding of how to classify this syndrome but recent trends suggest that there are essentially two different syndromes, each with a distinct complex of symptoms. The clinical manifestation of lipodystrophy syndrome is variable, and may include any or all of the following symptoms.

- Fat redistribution: Depletion of subcutaneous adipose tissue (SAT) may occur in the face, legs, arms, abdomen, and buttocks. In some cases, there is also loss of the deep fat (functional fat), especially in the face. Deep fat depletion, which may cause painful chewing, and limited facial mobility, appears to be most difficult to reverse. A substantial number of patients will experience an increase in abdominal girth due to accumulation of visceral adipose tissue (VAT), sometimes in conjunction with lipoatrophy of SAT (but not always). Some patients will develop a dorso-cervical fat pad (buffalo hump) or bilateral symmetrical lipomatosis and women tend to experience breast hypertrophy. Body shape changes often occur in the context of significant viral suppression and immune reconstitution.
- Metabolic complications: A number of metabolic abnormalities have been identified including dyslipidemia (especially hypertriglyceridemia), hyperglycemia, hyperinsulinemia and insulin resistance. For some individuals, deranged metabolic parameters precede fat redistribution.

Nutritional therapy for lipodystrophy

Diet and exercise have little effect on fat redistribution syndrome but have shown favorable results, although limited, in treating dyslipidemia and hyperglycemia. For many patients, dietary modifications, in conjunction with aerobic exercise, can induce a modest reduction in triglycerides and cholesterol, and improve glycemic control. Although parameters may not completely normalize, patients may be spared the addition of further medications to an already high pill burden. It is essential to consider dietary strategies in the context of HIV disease, maintaining adequate energy and protein intake to prevent weight loss in susceptible individuals. Refer patients with abnormal serum lipids or blood glucose to a registered dietitian for a trial of diet and exercise.

Dietary strategies

- To lower cholesterol and triglycerides: A moderate fat intake with emphasis on reducing saturated and trans fatty acids in conjunction with regular aerobic

exercise (e.g. walking) will induce a reduction in serum cholesterol in some patients. Patients with hypertriglyceridemia should limit simple carbohydrates (e.g. sugar and juice), and avoid alcohol altogether. Smoking should be avoided because it dramatically increases the risk of cardiovascular disease.

- To treat hyperglycemia: Patients should be counselled to consume consistent, mixed meals (protein, carbohydrate and fat) at regular intervals throughout the day, and limit simple sugars. Aerobic exercise facilitates glycemic control, especially after a meal.

Pregnancy

Both pregnancy and HIV disease engender physiologic stress, with increased nutritional needs for energy, protein and micronutrients. It is well recognized that the nutritional health of a pregnant woman influences pregnancy outcome. Nutritional status has even greater implications for the HIV-infected woman who is at higher risk of premature delivery and having a low birthweight infant. Low birthweight infants have an increased incidence of infant mortality as well as medical and developmental complications. Moreover, vitamin A deficiency has been associated with poor pregnancy outcome and increased risk of perinatal HIV transmission. Other risk factors such as adolescence, substance use, opportunistic infection, low pre-pregnancy weight and inadequate gestational weight gain superimpose further risks of a poor pregnancy outcome.

Pregnant HIV-positive women should be referred early in pregnancy to a registered dietitian with experience in high-risk pregnancy to optimize nutritional status and improve pregnancy outcome. It is essential to assess complementary therapy use, as mega-doses of vitamins and some herbal preparations are contraindicated in pregnancy.

The following nutrient requirements are superimposed on requirements for HIV:

- Additional 300 kcalories per day to support fetal growth and development
- Additional 15 grams protein per day
- Prenatal multivitamin-mineral daily (to include at least 0.4 mg folic acid)
- Other micronutrient supplements as needed (e.g. iron, calcium)

Rate of weight gain is based on pre-pregnancy weight:

- Underweight (BMI <19.8): 12.5-18.0 kg
- Healthy weight (BMI 19.8-26): 11.5-16.0 kg
- Overweight (BMI. >26): 7.0-11.5 kg

Infants and Children

HIV-infected children are at high risk of malnutrition and growth failure. The following problems have nutritional implications and should be addressed without delay:

- Inadequate nutrient intake due to poor appetite, early satiety and a high degree of selectivity around food choices. Abdominal pain and nausea, common side effects of medications, decrease appetite and interest in food.
- Feeding difficulties in infancy include incoordinate suck/swallow/breathe reflex, poor suck and/or formula intolerance.
- Introduction of solid foods with antiretroviral medications mixed into them often leads to food aversions and food refusal.
- Increased nutrient intakes are required for catch-up growth and to ameliorate the hypermetabolic/hypercatabolic effects of fever and opportunistic infection.
- Gastrointestinal complications induce nutrient losses via emesis, diarrhea and malabsorption.
- Dysguesia (altered taste), caused by malnutrition, medications, or HIV infection, decreases interest in feeding.
- Encephalopathy may result in regression of feeding ability with limited food tolerance.
- The feeding relationship between caregiver and child often becomes distorted due to difficulties feeding a child with HIV disease.
- Socioeconomic factors such as poverty and substance use by parents impacts on food access.
- Illness of parent compromises the ability of the parent to implement nutritional recommendations.

Because of the myriad complications experienced by HIV-infected children, nutrition therapy is an important adjunctive therapy in the treatment of HIV disease. The goals of therapy are to maintain normal growth and development, to prevent nutrient deficits, to support the immune system and to enhance quality of life. Nutritional intervention should be implemented in a step-wise fashion. Initially, dietary modifications, possibly with the use of oral liquid nutritional supplements, are recommended. If children experience weight loss, lack of weight gain, delayed height velocity, or crossing of percentiles on a pediatric growth chart a feeding tube may be required. A percutaneous endoscopic gastrostomy (PEG) is the preferred method of providing involuntary feeds as tube feeding is expected to be long term. Children with poor nutritional status who are hospitalized with acute illness and severe gastrointestinal symptoms should be considered for total parenteral nutrition (TPN).

Refer pediatric HIV-infected patients to a pediatric HIV centre with a registered dietitian with pediatric HIV experience. In British Columbia, the Oak Tree Clinic provides consultative HIV care to pediatric patients, including nutrition.

Summary

Nutritional complications in HIV positive individuals are prevalent, impacting on disease progression and risk of mortality. Nutrition intervention can improve health and well being, ameliorate symptoms and enhance adherence to drug therapies. Therefore, nutritional assessment and counselling provide important adjunctive therapy in the treatment of HIV infection. All HIV-positive patients should be given the benefit of referral to a registered dietitian, preferably with expertise in HIV disease, for nutritional assessment and counselling. Optimizing nutritional status in a population coping with a chronic, life-threatening disease may not only prolong life, but also significantly improve the quality of life.

GUIDELINES FOR NUTRITIONAL CONSULTATION

Indications for Referral to a Registered Dietician

- Diagnosis of HIV infection.
- Symptomatic infection: oral/esophageal, gastrointestinal, anorexia.
- Weight changes: unintentional weight loss, rapid excess weight gain.
- Nutritional deficit: inadequate dietary intake, abnormal serum levels of proteins, vitamins, minerals or electrolytes.
- Highly active antiretroviral therapy: management of side effects and food-drug interactions.
- Socioeconomic factors: limited food access, inadequate housing.
- Dyslipidemia.
- Impaired glucose tolerance.
- Co-existing medical condition with nutritional implications.
- Pregnant.
- Pediatric patient.
- Patient requests consult for nutritional assessment or counseling.

Patient profile	Referral guideline
New HIV diagnosis: asymptomatic	Within 6 months
New HIV diagnosis: symptomatic	Within 1 month
Asymptomatic HIV: stable	Every 6- 12 months
Symptomatic HIV/AIDS: stable	Every 2-6 months
Symptomatic HIV/AIDS: acute	Every 1-3 months
Initiation of HAART with food interactions	At time of HAART initiation
Pregnant: new diagnosis	At diagnosis of pregnancy or HIV infection
Pregnant: asymptomatic	Every 1-2 months
Pregnant: symptomatic	Every 2-4 weeks
Pediatric: new diagnosis	At time of diagnosis
Pediatric: asymptomatic	Every 4-6 months
Pediatric: symptomatic	Every 1-3 months

Adapted from "Guidelines and Protocols of Care for Providing Medical Nutrition Therapy to HIV-Infected Persons." Los Angeles County Commission on HIV Health Services. Approved 11/13/97

The Therapeutic Nutrition Guidelines, with selected references, are available by contacting the British Columbia Persons With AIDS Society Treatment Information Program at 1-800-994-2437 ext 243 or 604-893-2243 or by email at treatmen@parc.org.

Appendix 3

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