Positive Communication

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A descriptive study of medication adherence among HIV-positive adults in an urban clinic

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Introduction

One of the greatest challenges to clinical dietitians working in HIV/AIDS care is ensuring that patients take medications as prescribed. Inner-city clinics are busy, lack funding, are understaffed and overbooked. Clinicians working in inner-city clinics frequently need assistance to support patients' medication adherence. Many clinics do not hire health educators due to budget cuts; therefore, dietitians often juggle many responsibilities, including adherence monitoring and education in such clinics. The participants in this study were courageous in sharing details of their lives. Their stories are used here to educate the medical community about factors and barriers of adherence experienced by an urban population.

Rationale for the study

The primary study objective was to improve understanding about adherence to antiretroviral medications by HIV-infected people recruited from an inner-city clinic, and to elucidate reasons for non-adherence. In order to improve adherence to a medication regimen, it is critical to understand why patients are non-adherent. Are patients forgetting to take medication? Is the medication regimen too complicated, toxic or cumbersome? Does drug abuse or alcoholism predict poor adherence? Interventions to improve adherence can be based on the answers to these types of questions.

Self-reports of reasons why HIV-infected urban adults do not adhere to their medication regimen are underreported, especially from inner-city HIV clinics. Since the early 1990s, most newly reported HIV/AIDS cases have occurred among minorities, women and urban poor individuals (1,2). Research to date on the financial consequences of AIDS has focused largely on middle-class working individuals and cannot account for the experience of those who are already poor and unemployed at the time of their infection (3). This study will add to the knowledge base of research on HIV adherence in this kind of urban population. At this time, research is still unclear as to what factors facilitate or impede adherence to medication regimens in an inner-city population. Finding a way to promote the "near-perfect" adherence required for optimal outcomes is a barrier that needs to be overcome.

The nature of a patient's adherence or non-adherence also has an influence on public-health for the larger popula-

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tion. Most significantly, this impact may be the development of drug-resistant strains of HIV. Non-adherence may also lead to poor health outcomes, leading to complications and loss of productive life years.

Because medication adherence is crucial to preventing resistance to antiretroviral drugs and to maintaining low viral loads, understanding barriers may benefit researchers, dietitians, educators, clinicians, and HIV-infected individuals. Information from this study can be used to plan programs and services for this population.

Study aims and objectives

1. To describe self-reported data collected about factors related to medication adherence for 1) HIV-infected adults who reported being > 95% adherent in taking their HIV medication and 2) HIV-infected adults who reported poor adherence to HIV medications
2. To describe knowledge and beliefs about adherence within the study sample
3. To describe barriers and enabling factors that reportedly affected adherence in the study sample
4. To discuss methods/techniques that may be effective for encouraging HIV-infected adults to respond positively to drug and medical therapy

Methods

Subjects and setting

The study participants consisted of 60 HIV-positive adults who were prescribed highly active antiretroviral therapy (HAART). Subjects were divided into two groups. The first group contained 30 subjects who reported to be adherent to their prescribed medication regimen. The second group contained 30 subjects who reported to be non-adherent with medication regimens. All participants were registered as clients at an urban polyclinic in New York, N.Y. The clinic provides both primary and sub-specialty care for a predominantly indigent inner-urban population of HIV-infected patients. Medicaid is the principal insurer.

Subjects were self-recruited, approaching the researcher after reading posted signs describing the study. A screening of applicants took place before enrollment into the study. The method of sampling was convenience sampling. The gender and ethnic characteristics of the sample are shown in Table 1, and selected characteristics of the study sample by group are shown in Table 2.

Table 1. Demographic and ethnic characteristics of the sample (N = 60)

	N	%
Male	38	63%
Female	22	37%
Hispanic	19	32%
Caucasian	13	22%
African American	22	37%
Other/Unknown	6	10%

Measurements and data collection procedures

Data were obtained by conducting open-ended, semi-structured interviews. Information on adherence was obtained through open-ended questions and prompts. Questions asked by the interviewer included:

- Tell me about your drug regimen.
- What difficulties, if any, do you have

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in taking the medication?
- Tell me about your adherence.
- Have you missed a dose of your HIV medication … in the past day? in the past three days? in the past week?
- Is this normal for you? Are you usually this adherent/non-adherent?
- What do you think accounts for your success and/or failure?
- When did you start taking medication?
- Tell me about your relationship with your clinician?
- Are you satisfied with your medical provider?
- Have you received help or advice in adhering to medication?
- Do your family members/friends know of your HIV-status, and are they supportive of medication adherence?
- What do you think is happening with you and not others who are successful/unsuccessful?

Adherence was self-reported, and was defined as taking pills > 95% correctly (defined as missing less than one dose a week). The instrument used was adapted from a standard questionnaire used in many clinic settings/ research studies on HIV adherence (4,5).

Data analysis

Data from both the adherent and non-adherent groups were used. Immediately following the interview, observations were recorded and verbatim transcripts were made. The researcher transcribed all the data and read all transcripts. Line-by-line coding was done to identify major ideas or factors that emerged from the participants' descriptions of their situations. The researcher looked for indicators of categories from the questionnaire (social support, patient-physician relationship, efficacy beliefs in medications, etc.). Frequently mentioned ideas were grouped into coding categories (e.g., adherence barriers related to side effects), and transcripts were further analyzed to search the text for key words related to each new topic (e.g., help-seeking behaviors, substance abuse, side effects, etc.).

Table 2. Selected characteristics of the study sample by group

	Adherent	Non-adherent	Total
Number of males	17	21	38
Number of females	13	9	22
Mean age	44	38	41
Number of Caucasians	5	8	13
Number of African Americans	13	9	22
Number of Hispanics	7	12	19
Other	5	1	6
1–2 medications	0	0	0
2–4 medications	5	11	16
4–6 medications	6	13	19
> 6 medications	19	6	25
Mean number of years taking medication	8	6	14

Results

Table 3. Frequency and percent of facilitators of adherence among the adherent group

Reasons for adherence	n	%
Positive clinician relationships	21	70%
Positive social support	19	63%
Medication efficacy	16	53%
Help-seeking behavior	7	23%
Belief in adherence	6	20%

Comparisons Between Adherent and Non-Adherent Participants on Selected Interview Items

Table 5 contains a comparison of the responses between the adherent and non-adherent groups to quetions asked of all participants during the interview. Sixteen adherent participants reported they believed that the medication would

Table 4. Frequency and percent of barriers to adherence among the non-adherent group

Reasons for adherence	n	%
Negative physician relationship	23	77%
Low perceived efficacy of medications	19	63%
Negative social support	18	60%
Substance abuse	13	43%
Forgetfulness	11	37%
Medication side effects	9	30%
Complexity of treatment	4	13%
Social/physical environment	3	10%

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work, compared to 11 non-adherent participants. Fourteen adherent participants reported a poor belief in medication compared to 19 non-adherent participants. This suggests that adherence could be related to positive belief in medication.

Twenty-one adherent participants reported a positive relationship with their clinician compared to seven of the non-adherent. Nine adherent participants reported a negative relationship with their clinician compared to 23 of the non-adherent. This suggests that adherence was associated with a positive patient-clinician relationship.

Nineteen adherent participants reported positive social support compared to 12 non-adherent. Eleven adherent participants reported negative social support compared to 18 non-adherent. This shows that adherence may be related to positive social support.

The nature and scope of this study precludes meaningful statistical comparisons between the groups. The sample data above suggest that of the three factors presented, a strong patient/clinician relationship exhibited the strongest association.

Summary and discussion

This study described many difficulties patients have in adhering to their medications. Items that emerged as primary obstacles to adherence included poor patient/clinician relationships, disbelief in the value of medication, lack of social support, substance abuse, forgetfulness, and perceived side effects. Adherent study participants reported positive patient/clinician support, positive social support, and belief in the value of medication.

Table 5. Comparison of selected interview items by adherence status of participant

	Adherent	Non-adherent
Belief in medication		
Yes	16	11
No	14	19
Strong patient/clinician relationship		
Yes	21	7
No	9	23
Strong social support		
Yes	19	12
No	11	18

Adherent n = 30; non-adherent n = 30

Side effects

In this study, medication adherence was found to be related to reported symptom distress in the non-adherent participants. Participants who reported non-adherence appeared to experience chronic distress from a range of symptoms, including diarrhea, nausea, loss of appetite, headaches, fatigue, depression, neuropathy and changes in physical appearance. Many of the participants had changed regimens several times over the course of their illness, each time experiencing an escalation of symptoms.

Adherent participants, in contrast, tended to report that medication side effects were anticipated as part of treatment, and for the most part, they tolerated the side effects. Those reporting adherence considered side effects to be one of the costs of treatment, and they believed it was worth the benefits. It is not clear whether those who were adherent experienced fewer side effects, less intense side effects, or whether they were able to tolerate side effects better. Research supports the concept that those who are adherent to HIV medications actually tolerate high levels of discomfort without discontinuation of regimens (6). Further research is needed to examine the relationship between medication side effects and perceptions about the benefits of treatment in relation to adherence.

Substance abuse

In this study, substance abuse was a significant adherence obstacle. For many, drug use accelerates HIV progression. Without effective substance abuse treatment, HIV management is exceedingly difficult. The relationship of active substance use and non-adherence is well- established in the literature and was supported in this study. Drug use is associated with inconsistent outpatient medical care, low socio-economic status, and poor social support (7–9).

Beliefs about the value of medication and trust in providers

In this study, some patients took their medications as prescribed because they believed that the medications were making a noticeable positive difference in their health status. Adherence was associated with this belief in treatment efficacy. The non-adherent participant group tended to have lower levels of trust for clinicians. The medical and pharmaceutical industries were reportedly viewed as a business, and some participants believed they were more concerned

about making money than helping people.

These results are consistent with current literature (10) which indicates that acceptance and adherence are associated with trust in the health-care system, trust in the medication and interpersonal relationships with clinicians and peers. Combination antiretroviral medication regimens have been credited with extending the lifespan and quality of life for people living with HIV, and consumer education has emphasized the link between adherence to prescribed regimens and treatment efficacy (7).

Social support

The importance of the individual's support network to adherence was evident in the study results. The majority of adherent participants reported a strong social support network. It is interesting to note, however, that members of the social network did not typically include family relations, but rather people they met in support groups or in their clinic. The participants' perception of close personal relationships enhanced their overall sense of well-being and the intent to adhere to medications. Support from family, friends or community was important in their efforts to adhere, helping participants by reminding them to take medications, or by cooking certain foods for them. Family and social support was reported as necessary in resolving problems related to regimens and in resuming adherence.

These results are consistent with current literature. A positive relationship between social support and adherence has been found fairly consistently across a variety of chronic illnesses. Social support and hope have also been proposed to contribute to medical adherence among patients with HIV/AIDS (11–13).

Clinician/patient relationship

This research suggests that clinicians who involve patients in health-care decision-making, spend ample time giving patients information, and thoroughly answer questions give patients the confidence they need to succeed with adherence. A direct relationship was seen between patient/clinician relationships and adherence to their antiretroviral medications. The connection with the provider reportedly influenced beliefs in treatment efficacy and the willingness to renew efforts to adhere. In contrast, the non-adherent participants described an uneasy patient/clinician relationship with a resulting negative impact on patients' adherence to medications. These results are consistent with current literature (14,10,15–17). Clinicians and other care providers who fail to do these things and/or communicate in a judgmental or demeaning manner with patients may inadvertently impair their patients' medication adherence.

Limitations and recommendations for further research

The study results were based entirely on participants' self-reported experiences rather than on medical review and/or pharmacy records. Interviews are subject to bias and provide subjective rather than objective data. Additionally, the data were analyzed by the primary researcher, who was not blind to participants' adherence status. Also, the data were drawn from a single program that treats patients in an urban environment. Although results cannot be generalized to all persons living with HIV/AIDS, they serve as a guide for identifying factors for adherence in patients infected with HIV disease.

This research demonstrates a need to better understand the needs of persons living with HIV and AIDS. To date, many clinical trials evaluating HAART regimens have underrepresented certain groups of patients—notably, ethnic minorities, women and injection drug users. This oversight is problematic because over the past 15 years, the number of new HIV and AIDS cases among these underrepresented patients have increased disproportionately.

Recommendations for practice

There is no other disease for which the treatment regimens can be difficult and prolonged for HIV-positive patients. Intensive adherence counseling should be available, since clinicians are frequently not able to spend extensive time with patients. Achieving an adherence level of at least 95% in the face of challenges, even for a short period of time, is difficult; maintaining a high level of adherence for a lifetime is indeed a formidable task. This research validates prior studies on the difficulty of adherence to HIV medications (18–21).

Most of the adherent participants in this study reported having good clinician relationships, suggesting that strong patient/clinician relationships are vital to adherence. After a positive, non-judgmental relationship is established between the patient and clinician, it appears that there is a better chance for adherence communication to be effective.

Multidisciplinary support from the health-care community, including dietitians in clinical and food support settings, may help improve patient adherence to medications. This research supports the need for educators to work in tandem with clinicians to improve patient/clinician relationships and therefore increase medication adherence. Dietitians and other educators should proactively educate patients about potential side effects of HAART. To encourage adherence, educators should question patients more thoroughly regarding pill-taking behaviors, including time, actual number of pills, food and beverage choices, sleep patterns and day-to-day activities, among other behaviors. Discussing side effects as well as management strategies with patients prior to therapy better prepares them to acclimate to the symptoms. Educators

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may also want to question patients more deeply regarding pill-taking behaviors, including time, actual number of pills, food and beverage choices, sleep patterns, and day-to-day activities, among other behaviors.

Lana Zinger, EdD, RD, CHES, recently completed her EdD in health and behavior studies at Columbia University. This study represents her dissertation research on adherence barriers and facilitators among HIV-positive adults in an urban setting.

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2004 Association of Nutrition Services Agencies presentations

2004 Update: HIV-Associated Metabolic and Morphologic Abnormalities

By Donald P. Kotler, MD
St. Luke's-Roosevelt Hospital Center

Dr. Kotler provided an overview of recent research in HIV-related lipodystrophy studies. He compared lipodystrophy with some of the changes that occur in syndrome X, including insulin resistance, hypercholesterolemia and hypertriglyceridemia. He indicated these changes may result from disease processes and the effects from antiretroviral therapy, immune reconstitution and HIV infection itself. However, as he indicated, these changes are not limited to the HIV-positive population and may be a result of lifestyle and genetic factors, including comorbidities and hormones, among others.

While research has not lead to an easy answer to this difficult issue, Dr. Kotler suggested three approaches to dealing with metabolic alterations. These include avoid (delaying initiation of highly active antiretroviral therapy), switch (changing medications to a better tolerated regimen) and treat (adding lipid lowering, glucose sensitizing or other medications as needed).

Dr. Kotler also mentioned growth hormone (GH) and plastic surgery. GH appears to have a positive effect on body shape, but more research is needed to determine an appropriate maintenance dose to preserve these changes long term. Plastic surgery in the form of buffalo hump removal or facial/buttock implants may help clients overcome the stigma of lipodystrophy, but these are relatively new processes which have not been approved or studied long term for continued efficacy.

Current Trends in Nutritional Management and Blood Glucose Monitoring in Type 2 Diabetes Mellitus (DM)

By Alan Lee, RD, CDE, CDN, CFT
Nutrition and fitness consultant

HIV/AIDS DPG member Alan Lee presented a much-needed report about diabetes. He discussed the background of type 2 diabetes, including related complications and goals of medical nutrition therapy. Alan's presentation included a refresher course on basic nutrition and exercise guidelines for managing diabetes. As most of the information currently available relates to the general population rather than HIV-positive individuals, there are no specific guidelines for people living with HIV/AIDS that differ significantly from the general population. Good glycemic control is considered the goal of diabetes therapy and the best method for preventing the onset of serious complications.

Low Carbohydrate Diets and HIV/AIDS

By CJ Segal-Isaacson, EdD, RD
Albert Einstein College of Medicine, Yeshiva University

Dr. Segal-Isaacson is involved with ongoing research at Albert Einstein investigating the role of reduced-carbohydrate (CHO) diets with weight control in healthy populations. She, like Dr. Kotler, reviewed the similarities between lipodystrophy and syndrome X and suggested, as preliminary evidence indicates that low-CHO diets are successful in inducing weight loss in healthy patients, they may also have a role in helping overweight patients living with HIV/AIDS. She stressed that these diets should be attempted in clients with stable immune status only.

Dr. Segal-Isaacson reviewed the literature available on low-CHO diets to this point, which often shows weight loss, improved insulin sensitivity and reduced triglycerides levels. She also suggested CHO levels need not be as drastically reduced as in some of the more popular low-CHO diets, but CHO at 5%–25% of total kcals (protein of 25%–35%, and fat at 55%–65%), might be sufficient to induce the positive changes. Her research with HIV-positive participants at Albert Einstein indicates weight loss (at one year) has been correlated with reduced CHO intake, higher fiber intake, and more frequent exercise. A controlled feeding trial to evaluate low-CHO diets on metabolic parameters is underway.

Sex, Drugs, and HIV

By Neva Chauppette, PsyD
Los Angeles, Calif.

Back by popular demand, Dr. Chauppette detailed several of the more popular street drugs, including methamphetamine, ecstasy, ketamine, and gamma hydroxybutyrate. She included a discussion about how the drugs are administered and how they affect appetite and metabolic rate. Dr. Chauppette also reviewed how each of these substances can affect sexual behavior and, thus, risk for HIV and other sexually transmitted infections. Once the flow of questions slowed to a trickle, she was able to spend some time reviewing the stages of behavioral change. This is important as nutritionists and other counselors need to tailor the therapy to fit each client's individual needs and readiness to change.

A Statewide Response to the Changing Nutritional Needs of PLWHAs

Panel discussion with Leah Stern, RD; Mary Griffin, RD; Shu-Hui Wu, RD; and Jessica Fronczek, RD

Mary is a registered dietitian (RD) with the New York State Department of Health AIDS Institute (AI). She presented the NYS AI Nutrition Initiative and brought along RDs from several state-wide agencies that are involved in creative solutions to the hunger problems in New York. The AI began with two meal programs in New York City, but based on the increased survival and spread of the disease since the program started in 1990, has expanded to 14 state-wide contractors.

In 2001, AI was awarded $2.3 million in federal and state funds. Several years ago, the AI conducted a needs assessment

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of the nutritional needs of people living with HIV/AIDS, which indicated that clients are very satisfied with the food programs in their areas, but would like options to increase flexibility and independence.

Mary Griffin from Elmira, N.Y., Shu-Hui Wu of APICHA (Asian and Pacific Islander Coalition on HIV/AIDS) and Jessica Fronczek of the Albany Medical Center presented various aspects of their innovative nutrition programs.

Several of these ideas included provision of food vouchers (clients return receipts which are reviewed to ensure compliance with purchasing appropriate, healthy foods) and using incentives (food vouchers) for performance on nutrition quizzes and attendance at nutrition seminars. While these suggestions may not work in every setting, the initiative and creativity of these RDs may help motivate all of us to find improved solutions to the ongoing hunger problems in our own communities.

Lower Your Inhibitions: Interactions between HIV Medications and Food and Nutritional Supplements

By Guy Pujol, DMin
Executive director of AIDS Treatment Initiatives, Atlanta, Ga.

The focus of this presentation was pharmacokinetics, the "how" and "why" behind the nutrition guidelines we give to our clients for improved efficacy and tolerance of HIV medications. Guy reviewed how medications are absorbed, distributed, metabolized and excreted by the body to help lay a foundation for understanding why some work better with food while others must be consumed on an empty stomach for optimal use. A comprehensive review of the specific food recommendations for each currently approved medication used in HIV followed, including some of the more common combination therapies.

HIV/AIDS and Renal Nutrition

By Ida Ortiz, MS, RD, CSR and Iris E. Marchante, MS, RD

Among the common co-morbidities of HIV is the unfortunate and complicated problem of renal disease. Iris gave an in-depth presentation which reviewed the presentation and treatment of renal disease, including different types of dialysis, such as hemodialysis, peritoneal dialysis, and nocturnal dialysis. She stressed the importance of obtaining a detailed nutritional history to determine individual diet needs related to micronutrients, minerals and social issues, including access to food. Ida then answered specific questions about the treatment of renal disease and people living with HIV/AIDS who receive dialysis.

Be the First to Know—Exploring the Current Nutrition Trends in Today's Ever-Changing Marketplace

By Chef Kyle Shadix, CCC, MS, RD

Chef Kyle, well-known for his contributions to *Today's Dietitian* magazine and other forums, regaled conference participants with an informative and entertaining overview of some of the products and trends shaping today's food marketplace. Although this subject is not HIV-specific, HIV-positive clients are certainly affected by their environment. It is crucial that dietitians, as part of their health-care team, are well equipped to answer their inevitable questions about the new food labels, fortified foods and carbonated fruit; all coming soon to a supermarket near you!

Complementary Therapies for Critical Illness

By Guy Pujol; Jennifer R. Bathgate, MPH, RD, LD; and Barbara Craven, PhD, RD, LD

Guy gave an overview of what comprises complementary therapies, and discussed some of the primary reasons why HIV-positive clients may seek them out. Jennifer Bathgate followed with a discussion about yoga, including some basic history and different physical ailments which may be successfully managed using yoga therapy. Finally, Barbara Craven explained the history of reiki and even gave a brief demonstration of how this type of therapy works. When used in concert with traditional Western medicine, these and other practices may have a significant role in improving client outcomes and quality of life.

Join fellow HIV/AIDS DPG members online!

Perhaps one of the most tangible daily benefits of DPG membership is the electronic mailing list (EML), where members can post questions, get answers/ideas/suggestions, share links to current research and news reports, and discuss any topic related to HIV and nutrition.

Joining the HIV/AIDS DPG EML is easy! Go to **www.hivaidsdpg.org** and log into the "Members Only" area (using your ADA registration number). The second option in the Members area is the HIV/AIDS DPG EML, which will walk you through the signup process. (You also can modify your e-mail address from this screen.)

Be sure to reply to the eventual e-mail message you get from Topica and you'll be added to the list.

Hot topics in HIV nutrition

This segment of Positive Communication will feature questions and answers from the HIV/AIDS DPG Electronic Mailing List (EML). EML members are invited to post questions, and other EML members provide answers. For more information or to view the educational archive, visit the DPG Web site at www.hivaidsdpg.org. To join the EML, go to the Members Only section and click on "HIV/AIDS DPG Listserv."

Q: A physician in my clinic feels that bioelectrical impedance analysis (BIA) is not necessarily accurate (and therefore not useful) in individuals with lipoatrophy. The physician is concerned that the muscle mass has hypertrophied in patients with lipoatrophy because there may be some fat deposit in the muscle mass.

A: BIA (as we use it) provides a prediction or estimate of the total body volume of body cell mass (BCM), extra cellular tissue (ECT) and fat. If fat is deposited in the muscle, it will land in the fat compartment on the report, not in the muscle compartment. Because of the way BIA is used with persons living with HIV/AIDS, it deals with total volumes and not with regional deposition. This means that BIA will not help to identify or classify regional body fat changes, but does not mean that BIA is not useful.

The decision that BIA is not useful is like trying to use albumin measurements to determine hair loss and then suggesting that albumin is not useful when it cannot be used that way. This is a greatly exaggerated analogy, but hopefully one that will drive home the meaning. Most of the reading used for BIA calculations is provided by the arm and the leg. The influence of long muscle fibers will be more reflected than the shorter or more horizontal muscle fibers in the torso. Therefore, the influence of changes in the arm and leg are likely to be greater than the influences of a more electrically silent reading provided by the torso.

However, regional measures using BIA are being researched. Quite some time ago, a researcher looking at BIA as a marker of central subcutaneous obesity in a very small sample suggested that the readings were different for subcutaneous fat in obesity (for which he developed an equation) vs. visceral fat obesity which confounded his prediction equation. While I don't know if this has been pursued, it would be interesting to see if BIA could be used in this way to differentiate normal subcutaneous fat from visceral fat deposition.

Meanwhile, just as in other cases where we use multiple measures, using BIA along with anthropometry or other regional measures still seems like a good idea in order to characterize the problems we see and to determine appropriate interventions. We are not "trading" wasting for lipodystrophy ... we need to look at both.

A: In my practice of using BIA, when a person is truly lipoatrophic, the shift in fluid due to loss of fat makes the BCM seem falsely elevated. I have correlated this with tricep skin fold and other anthropometric measures. Using only the BCM to determine wasting can give a false reading in these cases. This shift also occurs when the patient's fat mass is below 12% of his/her total body weight.

Suggested reading: Tang AM, Forrester J, Spiegelman D, et al. Weight loss and survival in HIV-positive patients in the era of highly active antiretroviral therapy. *J Acquir Immune Defic Syndr*. 2002; 1;31(2):230–236.

Publish your work in Pos Com!

Are you interested in writing articles for *Positive Communication*? HIV/AIDS DPG needs authors to provide *Pos Com* articles for the upcoming year. If you are interested in writing an article, contact Editor in Chief Lucia Vining, MS, RD, at editor@hivaidsdpg.org.

Public policy report

By Deane Edelman, MBA, DTR and Katherine Dennison, RD, LD
Public Policy Committee co-chairs

Ryan White CARE Act reauthorization

Recent months have been extraordinarily busy for Public Policy Co-Chairs Deane Edelman, MBA, DTR, and Katherine Dennison, RD, LD. Ryan White CARE Act (RWCA) Reauthorization activities have begun to accelerate. American Dietetic Association (ADA) Government Relations Team member Mary Lee Watts has taken the lead in developing and distributing our legislative proposal for including medical nutrition therapy (MNT) across all Ryan White titles.

In connection with Ryan White, we attended the November meeting of the Health Resources and Services Administration (HRSA)/Centers for Disease Control and Prevention (CDC) Advisory Committee on HIV and STD Prevention and Treatment. The Committee's CARE Act Reauthorization Working Group has generated 23 recommendations, one of which would present opportunities for registered dietitians (RDs) specializing in HIV/AIDS. With people living longer and stronger since the advent of drug therapy, it is recommended that RWCA programs need to shift from the palliative care model to one of chronic disease management. Nutrition services would be a core element of such care.

In December we attended the Senate Health, Education, Labor, and Pension Committee's Ryan White Working Group meeting and shared ADA's legislative proposal summary. The full document has already been submitted to the staff members of Sen. Edward Kennedy (D-Mass.) and Sen. Mike DeWine (R-Ohio), who lead the Working Group.

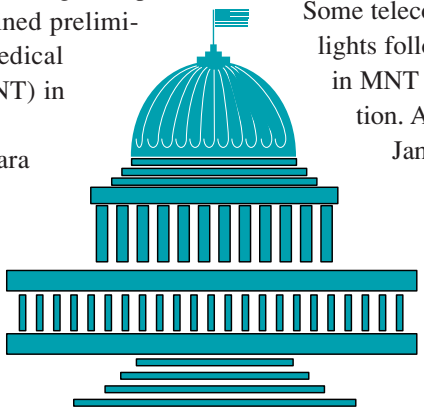
We continue to attend monthly NORA meetings (National Organizations Responding to AIDS.) NORA has been working on its reauthorization priniciples, along with many other national AIDS organizations. We are participating in NORA's Care and Treatment Working Group and appear to have gained preliminary acceptance for medical nutrition thereapy (MNT) in RWCA.

DPG member Barbara Craven, PhD, RD, LD, attended the November meeting of PACHA, the President's Advisory Committee on HIV and AIDS. Barbara presented orally and submitted a paper entitled, The Benefits and Importance of Nutrition in the HIV/AIDS Care Plan.

Because of ADA's strong support and access to members of Congress that ADA affords us, we are well positioned, with or without NORA or PACHA support, to make our issues heard during Ryan White reauthorization. For more information on Ryan White Reauthorization, contact Deane at 202/333-0945, dfedelman@att.net, or Katherine Dennison at 202/745-6130, kdennison@wwc.org.

Another ADA public policy teleconference

Due to last summer's successful public policy teleconference, ADA hosted a similar update on Nov. 16. This time the agenda was extremely comprehensive, and dealt with 10 issue areas that ADA expects to follow during the coming year. The topics were introduced with overall observations about the election results. The environment over the next Congressional session will be very difficult for health-related issues. Not only are key committees changing chairs, but scarce resources—and attempts at deficit reduction—will have far-reaching effects.



MNT legislation

Some teleconference update highlights follow. Progress continues in MNT legislation and regulation. A bill was introduced in January by some of MNT's Congressional champions, Rep. Fred Upton (R-Mich), Sen. Larry Craig (R-Ida.), and Sen. Jeff Bingaman (D-N.M.). The legislation will be known as the Medicare MNT Disease Prevention and Treatment Act of 2005. The bill proposes Medicare MNT coverage for dyslipidemia and hypertension, including borderline conditions, and pre-diabetes. The bill is presently at the Congressional Budget Office for scoring its estimated cost. The provisions may have to be scaled back if the cost is too high. When the bill is introduced, ADA will be urged to help obtain cosponsors.

Regulations are still being developed to implement the Medicare Modernization Act. ADA has submitted comments on several sections. RDs may have opportunities to work with the Chronic CARE Improvement Programs that will be starting around the country. The first contract was due to be awarded in December.

Child Nutrition Act

The Child Nutrition Act was passed in 2004. ADA is working with the Department of Agriculture on implementing regulations. This act provides another chance for RD involvement. School districts are now required by 2006 to produce wellness plans, including guidelines for food, nutrition educa-

tion, and physical activity. Information on how to become involved at the school district level is available online at www.eatright.org. Sign in as a member, go to Policy Initiatives and Advocacy, click on Priority Issues, then choose Child Nutrition.

Labeling legislation

Labeling legislation was passed in 2004, which requires that the eight major allergens be listed in plain English on product packages; however, a restaurant menu labeling bill died. The latter will more likely be handled at the state or local level rather than federal. ADA is now developing its position on restaurant menu labeling.

Labeling legislation

Sen. Tom Harkin (D-Iowa) will introduce new obesity legislation, called the HeLP America Act. It is comprehensive and highly complex with many committees expected to have jurisdiction. The HeLP America Act aims to reduce health-care costs by promoting healthier lifestyles and emphasizing prevention. The IMPACT bill, the Improved Nutrition and Physical Activity Act, which did not advance, may also be re-introduced. This legislation includes provisions for health-professional training grants, community and school-based prevention programs, and demonstration prevention projects for seniors (including MNT.)

Other subjects discussed during the teleconference included the new Nutrition Monitoring Alliance; appropriations; the Older American Act; the new Dietary Guidelines and Food Guide Pyramid, now called the Food Guidance System; and Codex Alimentarius, the international food code used in global trade.

For additional information on any of these topics, please contact ADA's Government Relations Team in Washington, D.C. at 202/775-8277, jdonze@eatright.org. Another way to keep current is to subscribe to *On the Pulse*, the weekly public policy update sent via e-mail from ADA's Government Relations office. Contact an office employee at pulse@eatright.org.

Chair's message

Jennifer Eliasi, MS, RD
2004-2005 HIV/AIDS DPG chair

Let's welcome the new year and all of the potential that 2005 brings with it! I hope that each of you enjoyed the winter holiday seasons and feel refreshed and ready to begin 2005!

The HIV/AIDS Dietetic Practice Group (DPG) board is hard at work on several projects for the coming year. The Public Policy Group is hard at work speaking to members of Congress about Ryan White Reauthorization and will be attending the Public Policy Workshop in Washington, D.C. in February.

The Education Committee is working towards approval of the Evidence Based Guidelines. Having this work completed will be very useful in obtaining medical nutrition therapy for HIV/AIDS nutrition registered dietitians.

The Membership/Alliance Committee is hard at work with the Nutritionists in AIDS Care Committee planning the Fourth Annual HIV/AIDS DPG and Nutritionists in AIDS Care (NIAC) conference entitled, "Leading Edge Update on Nutrition and Psycho-Social Management of HIV." This one-day conference will be held on March 5, 2005 in New York, N.Y. You should receive a brochure shortly, and you may also download a copy on the DPG Web site at www.hivaidsdpg.org. We welcome members from near and far to join us at this conference. Feel free to pass on the information to other health-care providers who would have interest in learning more as well.

The DPG elections will be held a little differently this year than in previous years. I encourage each of you to vote and have your voices heard. You can vote online at our Web site, www.hivaidsdpg.org, or by contacting Sarah Swian at the American Dietetic Association office and asking for a paper ballot (800/877-1600, extension 4815). If your name is not on the ballot and you would like to get more involved with the DPG, please contact the chairs of the various committees and offer your time and ideas. We are always looking to include more members. I would also like to thank Nominating Committee members for their work in getting the ballot together.

As mentioned in the last chair's message, we now accept advertisement of pertinent products to aid the cost of producing *Positive Communication*. I would like to thank Digestive Care, Inc., makers of Pancrecarb, for sponsoring this issue.

Please contact me with any ideas you have for the DPG. We are always looking for ways to improve, new ideas, for program suggetions. You may reach me at JennEliasi@aol.com

Thanks! And again, happy 2005 to you and all your loved ones!

HRSA announces new perinatal HIV consultation and referal service

The new National Perinatal HIV Consultation and Referral Service (Perinatal Hotline) at 888/448-8765 provides free 24-hour clinical consultation and advice on treating HIV-infected pregnant women and their infants. It also offers indications and interpretations of rapid and standard HIV testing in pregnancy.

The Perinatal Hotline is an expansion of the Health Resources and Services Administration National HIV/AIDS Clinicians' Consultation Center (NCCC) at San Francisco General Hospital, which operates the National HIV Telephone Consultation Service (Warmline) and the National Clinicians' Post-Exposure Prophylaxis Hotline (PEPline).

"Despite advances in reducing mother-to-child transmission of HIV, transmission still remains a significant problem in the United States and one that disproportionately impacts women and children of color," stated Dr. Jessica Fogler, MD, a family physician who serves as assistant director of the Perinatal Hotline. "Perinatal HIV transmission remains a tragic yet largely preventable problem. Although the number of transmissions has dropped, each transmission has enormous personal, family, public health and economic consequences."

Testing pregnant women as early as possible in prenatal care, and treating HIV-infected pregnant women and their newborns, as recommended in the Public Health Service (PHS) guidelines, has resulted in a dramatic reduction of mother-to-child transmission.

Dr. Deborah Cohan, MD, an obstetrician who serves as assistant director along with Dr. Fogler added, "As access to rapid HIV testing becomes more available, clinicians who treat pregnant women will have an increased need for readily available 24-hour consultation in interpreting HIV tests and applying the PHS guidelines. We will be available 24 hours a day to not only answer callers' immediate questions and help solve emergent perinatal HIV issues, but also to assist clinicians in linking HIV-infected pregnant women and HIV-exposed infants to the most appropriate care. Callers are also referred to a national network of education, training and consultation services available from their regional AIDS Education and Training Centers (AETCs).

The NCCC is well equipped to provide this service, with more than 75,000 telephone consultations during the past decade treating HIV (the Warmline) and managing exposures to blood-borne pathogens to health-care workers (the PEPline). Dr. Ronald Goldschmidt, MD, director of the NCCC and director of the Family Practice Inpatient Service at San Francisco General Hospital, stated, "Our aim is make sure clinicians nationwide can get readily available expert consultation. For clinicians caring for pregnant women, this not only includes prenatal visits, but during the critical period in the labor and delivery rooms and postpartum."

The NCCC is part of the AIDS Education and Training Centers (AETC) Program funded by the Ryan White CARE Act of the HRSA HIV/AIDS Bureau (HAB) in partnership with the Centers for Disease Control and Prevention and the HAB Division of Community Based Programs.

The Perinatal Hotline (888/448-8765) and the PEPline (888/448-4911) are both available 24 hours, seven days a week. The Warmline (800/933-3413) is available 8 a.m. to 8 p.m. (EST) Monday through Friday. All consultations are free and confidential.

HIV • AIDS
Dietetic Practice Group

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