

Eating Right When Money's Tight:

Evaluating the Need for Food and Nutritional Assistance among Ryan White Part B Case Management Clients

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Background

Hunger and Food Insecurity¹ in Oregon

Food security is a pressing problem for many Oregonians, with about 1 in 8 Oregon households (11.9%) reporting hunger or food insecurity from 2004-2006 (America's Second Harvest, 2007). The Oregon Hunger Relief Taskforce and the Oregon Food Bank agree that hunger is fundamentally an income issue. In Oregon, wages have not kept pace with dramatic increases in the costs of housing, transportation, and utilities, so many low income people cannot afford to pay for all of their basic needs. Because food is often the only flexible part of a household's budget, food is often the first thing cut as low income individuals face the "heat or eat" dilemma (Oregon Food Bank, 2006a; Oregon Hunger Relief Taskforce, 2007).

According to the U.S. Department of Agriculture, the Food Stamp Program "serves as the first line of defense against hunger by helping low-income families buy nutritious food." About 440,000 Oregonians receive food stamps each month (Oregon DHS, 2007): an important source of supplemental income for many Oregonians. However, 64% of food stamp recipients said their food stamp benefits lasted two weeks or less and only 6% said they lasted through the entire month (OFB, 2006b). This shocking figure makes sense when one considers that the average food stamp recipient in Oregon receives about \$89 per month or about \$1 per person per meal (OFB 2006b), while the USDA Low Cost Meal Plan allocates \$1.53-\$1.81 per person per meal (USDA, 2006). This mismatch between inputs and outputs makes it difficult for the average food stamp recipient to eat enough, let alone eat well: a fact publicized by Oregon's Governor Kulongoski when he undertook to live on this allotment for one week in April 2007 (Yardley, 2007).

Other federal nutrition programs, such as Commodity Supplemental Food Program, the National School Lunch Program, and the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC),

¹ America's Second Harvest defines food insecurity as a state where "the availability of nutritionally adequate and safe foods or the ability to acquire acceptable foods in socially acceptable ways is limited or uncertain." (2007)

exist to help meet ongoing needs (America's Second Harvest, 2007), but many PLWH/A in Oregon do not qualify for these programs, which mostly target pregnant women and families with children. Emergency food programs, such as food pantries/banks, soup kitchens, and congregate meal programs, are available statewide, and many PLWH/A in Oregon are eligible for their services. However, emergency programs are designed to meet short-term needs, whereas most PLWH/A who need food have ongoing needs due to their chronic disability. Furthermore, as noted in the focus groups, many PLWH/A face barriers to accessing emergency programs, including lack of transportation and feeling too ill to persevere through long waits for service.

Unique Nutritional Needs of PLWH/A

Although PLWH/A share with other low-income Oregonians many of the same structural barriers to accessing nutritious food, PLWH/A have unique nutritional needs specifically related to their underlying HIV disease. PLWH/A may require more calories, macronutrients and specific vitamins than comparable uninfected individuals (Highleyman, 2006). For example, asymptomatic PLWH/A are estimated to have 10% higher energy needs, while individuals with symptomatic HIV disease may need 20-30% more calories (WHO, 2003).

Furthermore, HIV infected people are at risk of poor nutritional status resulting from multiple factors, including malabsorption, anorexia, and medication-caused nutritional deficiencies (ADA, 2004; ANSA, 2006). As identified by the PLWH/A that participated in the evaluation, gastrointestinal intolerance—particularly diarrhea, nausea, and vomiting—can be caused by infections or may be side effects of antiretroviral therapy (McDermott, 2005). Weight loss and loss of nutrients caused by diarrhea and vomiting can lead to decreased immune function, development of other illnesses, and disease progression (McDermott, 2003; Mass 1998; Sharpstone, 1999). Ensuring that PLWH/A receive an adequate intake of nutritious food can compensate for malabsorption and loss of nutrients. Furthermore, proper nutrition may reduce some medication side effects, making medications easier to tolerate and thereby increasing adherence (McDermott 2003, McDermott 2005).

As management of HIV disease becomes more sophisticated and life spans increase, other nutritional problems are emerging, such as loss of muscle mass and fat redistribution with an accompanying increase in serum triglycerides, glucose, and sometimes insulin (Keithley, 2000; Carr, 1998). Overweight and obesity are also becoming more common problems for PLWH/A in the HAART era than prior to antiretroviral therapy (Tang, 2005; Highleyman, 2006).

Experts in nutrition agree that “food access and proper nutrition are absolutely critical for those suffering from chronic and life-threatening illnesses,” including HIV disease (ANSA, 2006). According to the American Dietetic Association and Dieticians of Canada:

“...efforts to optimize nutritional status, including medical nutritional therapy, assurance of food and nutrition security, and nutrition education, are essential components of the total health care available to people with human immunodeficiency virus infection throughout the continuum of care.” (ADA, 2004)

Food-Related Needs among PLWH/A in Oregon

In 2005, 49% of PLWH/A receiving Ryan White-funded case management services in Oregon said they needed help with food, groceries or prepared meals in the previous year. Of those who needed help, 58% said they had not been able to get their food-related needs met through existing resources (Pickle, 2006). At that time, HIV case managers in some parts of the Ryan White Part B case management service area² distributed grocery gift cards (food vouchers) to clients on an as-needed basis, and as local funds allowed. Gift card amounts were usually small (e.g. \$20-\$50), but helped address urgent needs.

However, the Ryan White HIV/AIDS Treatment Modernization Act of 2006 changed how Ryan White funds can be used at the state and local levels, requiring that more money be spent on “direct health care” for people living with HIV. Specifically, the new law requires that at least 75% of all grant funds be spent on “core medical services,” defined by the Health Resources and Services Administration (HRSA) as: outpatient and ambulatory health services, pharmaceutical assistance, substance abuse outpatient services, oral health, medical nutritional therapy, health insurance premium assistance, home health care, hospice services, mental health services, early intervention services, and medical case management, including treatment adherence services. The remaining 25% of funding may be used for supportive services, defined as “services needed to achieve outcomes that affect the HIV-related clinical status of a person with HIV/AIDS” (US Department of Health and Human Services, 2007). Support services include a wide range of services, such as medical transportation, housing, emergency financial assistance, and food vouchers³. However, Ryan White program administrators at the state and

² The Part B service area includes 31 counties outside of the Portland metropolitan area.

³ The new Ryan White Program service definitions list food bank/home-delivered meals as “the provision of actual food or meals...the provision of essential household supplies such as hygiene items and household cleaning supplies... [and] vouchers to purchase food.” (HRSA 2007)

local levels now have fewer funds to allocate to a wider range of needed services. As a result, Oregon's HIV case managers have had to either substantially restrict or eliminate the distribution of grocery gift cards to clients.

Purpose of the Evaluation

The 2005 needs assessment revealed that food-related needs and gaps were high among PLWH/A, but did not provide information about the context of or causes for food-related needs, nor about barriers to and strategies for getting needs met. The HIV Care Services Program at the Oregon Department of Human Services contracted with Program Design & Evaluation Services (PDES)⁴ to conduct an evaluation of food-related needs and resources in the Part B case management service area of Oregon.

This was a utilization-focused evaluation (Patton, 1990) intended to gather data that could inform program policy and service delivery. The project sought to describe: a) the food-related needs, beliefs, and perceptions of Ryan White Part B clients; b) clients' help-seeking behaviors (e.g. where do clients get help with food and groceries and how many people access food-related resources?); and c) the barriers faced by clients in meeting their food-related needs.

Evaluation Design & Methods

This evaluation project was cross-sectional, using population-based survey and utilization data, as well as qualitative data from focus groups and key informant interviews. Data from a literature review and resource scan provided context for the primary data collected from clients.

Population data to augment the 2005 HIV Consumer Needs Assessment were gathered from two additional data sources: Part B HIV case management client service utilization data from CAREWare 4.1 and two food-related items that were added to the 2007 Part B HIV case management client satisfaction survey. These data helped provide an overall picture of the Part B HIV case management population's reported needs, gaps, and help-seeking strategies related to food and nutrition.

Qualitative data were gathered from four focus groups and one in-depth interview conducted in October 2007 with a total of 25 Part B HIV case

⁴ PDES is a public health research and evaluation unit, jointly administered by the State of Oregon Public Health Department and the Multnomah County Health Department.

management clients in Marion, Lane, and Jackson Counties. The focus groups and interview examined participants' perceptions about:

- how nutritional needs differ for people living with HIV versus other chronic illnesses,
- why PLWH/A might not have the food or nutrition that they need,
- where people could get help with food or nutritional needs,
- why PLWH/A might or might not access those resources, and
- strategies for meeting needs related to food and nutrition.

Focus group participants were recruited through case managers and project staff using a purposeful sampling design with maximum variation sampling to offer a variety of perspectives and experiences. Focus groups were approximately 75-90 minutes long and each participant gave consent and received a \$20 grocery store gift card as a thank you for participating.

PDES staff used a semi-structured questioning route (Appendix A) to guide the focus groups and interview, which were audio taped and transcribed. Data were analyzed for themes using free coding.

Evaluation Results

Population-Based Data

This brief section presents data from two population-based data sources:

- a) service utilization data from CAREWare 4.1 that quantifies the number and distribution patterns of grocery gift cards recently distributed to Part B HIV case management clients and
- b) two food-related items on the 2007 HIV case management satisfaction survey that aimed to quantify how many PLWH/A accessed community resources for food related needs and describe the types of resources accessed.

Grocery Gift Cards from HIV Case Managers

Data from CAREWare 4.1 indicate that about one third of active Ryan White case management clients in the Part B service area (31%, n= 269/861) received a grocery gift card from their case manager between August 1, 2006 and July 31, 2007. Fifteen of 20 Part B case management sites distributed grocery cards to their clients during that time period and just over half of the total Part B clients that received grocery cards (n=138, 51%) were clients of HIV Alliance (Lane County). Distribution practices varied widely between the case management sites. For example, HIV Alliance distributed cards to 90%

of their clients, whereas the next two largest Part B case management sites gave cards to far fewer clients. During the same time period, Marion County distributed cards to 10% of their clients and Jackson County did not distribute any cards.

At the time of the focus groups and interviews (described below), all case management sites had limited the distribution of grocery gift cards.

Data from HIV Case Management Survey

HIV case management clients in the Part B service area were asked about their food needs as part of the annual client satisfaction survey in 2007⁵; 57% (n=220/388) said they had needed financial help getting food or groceries in the past 12 months. The percentage needing help with food and groceries in 2007 was higher than the 49% identified in the 2005 Needs Assessment survey. The most common source of financial help for food came from food stamps, accessed by 47% of respondents. Other common sources of help were food banks/food pantries (27%), friends and family (25%), and grocery vouchers from case managers (23%).

Focus Group and Interview Data

This section presents themes identified during analysis of the focus groups and in-depth interview transcripts. Themes represent the views of multiple individuals across different parts of the Part B service area. Quotes that illustrate the theme are included in italics. These quotes provide good examples of the theme, but are not exhaustive. Opinions or thoughts expressed by only a few individuals or only expressed in one part of the state are classified as minor themes. Minor themes need further exploration among additional clients in order to understand whether the issues are specific to one county or group of individuals or are shared by a broader group of PLWH/A.

Nutritional Needs are Different for PLWH/A

Participants indicated that while healthy eating is important for everyone, regardless of health status, people living with HIV have “less room to slide” when it comes to adequate food intake and proper nutrition. Most broadly, participants recognized the health promotion and disease prevention benefits of maintaining good nutritional habits, and the consequences of cutting corners:

“If you have HIV and have the right nutrition, your body will heal itself better.”

⁵ Full results from the 2007 HIV Case Management Satisfaction Survey and details about methodology, response rates, etc. are available in a separate report.

“A healthy person might be able to get away having one meal a day, but I need to have several small meals a day. I can’t do what other healthy people can do.”

“If I don’t eat three meals a day, I get diarrhea.”

“I’ve had HIV for 22 years. Eating right is the only thing that has kept me alive.”

Participants also mentioned specific nutritional problems caused by HAART, including nutritional deficiencies, malabsorption, elevated cholesterol, and lipodystrophy. Digestive problems such as nausea, vomiting, acid reflux, and diarrhea were cited frequently as side effects of HAART, with diarrhea and vomiting being of particular concern because of the associated fatigue, dehydration, and nutritional depletion they cause:

“You don’t want to spend your money on a meal and then throw it up. What’s the point if you are going to end up in the bathroom?”

“It’s discouraging because you eat and then it’s gone [due to diarrhea]!”

When asked about specific food items that would help them meet their nutritional needs and to which they generally lacked access, participants listed vitamins and supplements, Ensure, milk, juices, and fresh fruits and vegetables.

Why Aren’t PLWH/A Eating the Foods They Need to Stay Healthy?

Participants discussed numerous barriers to eating for optimal health, including lack of transportation, lack of appetite, depression, and fatigue, but the most commonly cited barrier was lack of income.

Lack of Income

Participants spoke at length about how difficult it is to afford healthy foods on a limited income because the best foods cost the most:

“One of the biggest challenges when you have a chronic illness is being able to work to be able to afford the kind of food you need to stay healthy. It’s a conflict because the healthiest and best food costs more than the crap that’s cheaply available.”

“I’m noticing that the gap between what you can afford and what you need is steadily increasing. It’s hard to eat healthy these days.”

“Things are so expensive now. It’s hard to get yourself nourished.”

“We can’t afford the prices that out there to get the right food, decent, healthy. That coupled with the cost of transportation, the cost of plastics for freezer bags and things like that...The general cost [of things], it just doesn’t work...because Social Security is not a living wage.”

Many people reported receiving assistance from the Food Stamp Program, citing amounts ranging from \$10-\$155/month for one individual ⁶ (and proportionate amounts for families), but everyone agreed that the amounts were inadequate. Many people talked about running out of Food Stamps mid-month:

“I get about \$150/month [in food stamps] and it’s just not enough. Halfway through the month, I’m running out, and I go to [discount grocery stores] and it’s still not enough. Today is [date mid-month] and I’m wondering what’s going to happen in the next few weeks. I don’t have disability yet, so I’m just dead in the water.”

“You get into this Catch 22: when you’re getting assistance, the assistance keeps you living well below poverty level, which means you can’t eat well. Your health always ends up being jeopardized.”

“It’s hard to be on a healthy diet on Food Stamps.”

Lack of Transportation

Participants without access to a car said they often need to shop at neighborhood stores that offer more expensive and less nutritious foods than larger grocery outlets. Lack of transportation also made it difficult to buy in bulk or take advantage of resources like food banks or congregate meal programs.

“Transportation is a huge problem. I can’t get to [discount grocery stores] to do that kind of [bulk] shopping to stretch the \$141/month I get [from Food Stamps]. Instead, it’s someone riding a bike up to [a nearby store]. It’s closest to us, but they don’t have a good variety. The easiest thing to get is the 99 cent crap frozen TV dinners. It’s the easiest thing to carry in a backpack.”

“It’s so helpful to be able to cook at home so I can control what goes into my food. But I can’t get to the stores anymore.”

⁶ As of October 1, 2007, the maximum monthly food stamp benefit for one person was raised to \$162.

“Transportation is an issue for nutrition and eating well.”

Low Energy Levels and Depression

Participants indicated that low energy levels often interfere with grocery shopping and preparing home cooked meals:

“I often don’t have the energy to cook...something that requires a lot of chopping is just not going to happen.”

“It’s easier to eat fast food, but it’s not good for you.”

“Getting up and making food is difficult.”

A minor theme, mentioned by a few participants, involved the effect that depression or other emotional or psychosocial issues can have on eating habits:

“[When you are depressed], either you eat a lot or nothing at all. If you are depressed because of HIV, your emotional state plays into your nutrition.”

“I used to eat lots of fast food because I didn’t want to cook, but now it’s a habit. I want to be home. But you have to have a comfortable home life to cook. If you have an enjoyable environment and a happy home, you want to be there. You don’t want to go out.”

“HIV-positive people are up against the same nutritional issues that plague the general American public. Sometimes those issues are magnified for us, sometimes not...[!] question how many HIV positive people truly accept that most of us are here for the long run—it’s time we get motivated and act like it.”

Strategies for Eating Well with Limited Resources

Participants agreed that eating well was a challenge, but many shared common sense strategies they had developed in response to the multiple barriers they faced. Helpful strategies included budgeting, shopping at discount grocery stores, buying in bulk, pooling resources and social support. In addition, participants with credit cards talked about using them to purchase food, especially during the latter half of the month when other resources were already expended. While not a fiscally sustainable strategy, the use of credit cards was seen by some as a necessary stopgap.

Participants who had well-developed self-sufficiency skills prior to their HIV infection appeared to better manage the challenges presented by living with a chronic illness. For example, one person who appeared to manage well on very little income said:

“I was raised this way...You have to be trained when you’re young to know how to do things for yourself as you’re brought up. You have to learn how to take care of yourself before you get to the age where you don’t know what you’re doing...It’s the upbringing.”

Of note, this individual supplemented his family’s diet by hunting and fishing, strategies that are unavailable to most other contemporary urban residents due to lack of access and/or skills.

Budgeting, Shopping at Discount Stores, and Buying in Bulk

Participants emphasized the importance of careful budgeting and shopping, in order to stretch thin resources. Choice of grocery store was an important factor. Discount grocery stores, such as WinCo, Walmart, and Food4Less, compared favorably to chains like Fred Meyer and Safeway⁷ in terms of price, but were said to have poorer selection and quality, most noticeably related to produce. Farmer’s Markets are available in Salem, Eugene, and Medford, but participants rarely used them, citing cost, coupled with the farmers’ inability to accept payment with Oregon Trail Electronic Benefit Transfer (EBT) cards⁸, which is how Food Stamp benefits are administered. Once again, however, the conflict between cheap and healthy came into play, as people noted that the best foods were often out of reach because of cost.

“I’m on a tight budget. I make a grocery list of the usual things we eat on my computer, then print it out, and then go to my cupboards and see what we need and then restock.”

“We have farmer’s markets here and they have really great food, but they don’t accept Oregon Trail cards. They used to accept paper food stamps, but they are not able to do Oregon Trail.”

“We really need to get the most for our dollars. We’re forced to shop at [discount grocery] because of our income, but we’re also supposed to be eating nutritious, leafy green vegetables...but the produce at [discount store] looks like shit! You go to buy greens and they’re yellow and wilted. The section is dirty and unkempt. The produce section at [non-

⁷ Notably, grocery cards typically distributed to PLWH/A by case managers and evaluators (including those given as a thank you for participating in this evaluation project) are from Fred Meyer or Safeway. Participants said they were grateful for the cards, but that “\$50 at Safeway is like \$100 at WinCo.”

⁸ The Oregon Farmer’s Markets Association website indicates that 25 of 87 farmer’s markets currently accept payment via Oregon Trail benefits, including 3 of 3 non-holiday markets in Eugene and 2 of 3 non-holiday markets in Salem.

discount, chain store] is gorgeous, the produce is fresh. But you pay twice as much.”

“It’s like you can’t buy quality when you get help.”

Buying in bulk and vacuum sealing items for longer life in storage were popular strategies for meeting food needs on a limited budget. However, some people faced barriers due to lack of transportation, lack of funds for the initial outlay of large quantities, or lack of funds to invest in supplies like plastic freezer bags:

“[Name of discount store] has a yearly case sale, and I didn’t have money [when it was happening this year], but a friend of mine loaned me \$200 and I went down and bought cases of food that will last me and [my child] six months. Buying in bulk, it lasts. I’ve been doing it every year.”

“When you purchase at one of these big places like [discount stores], you can buy a ten pound package, bring it home, and split it into six individual meals. But plastic bags are a cash expenditure and considered a luxury, so how can we save money at the beginning of the month when we get our food stamps? I can do it because I have a partner who will buy the freezer bags and stuff and we have a big freezer.”

“Personally, I buy in bulk...I was raised that way. Buy half a cow, first of summer; buy half a pig, first of spring...put it in the freezer.”

Sharing and Social Support

Some participants have partners, family members, or friends (some of whom were also living with HIV) that help them cope with barriers to meeting food-related needs. Participants described times when friends and family pooled resources or helped with cooking:

“Some months, three of us will have dinner parties to save money and share expenses. We’ll share food and watch a movie.”

“I eat one good meal a night because my mom cooks it. If she didn’t, I wouldn’t eat nothing.”

“I get \$155 in Food Stamps and that’s the max, but my boyfriend still has to put in \$200-\$400 more a month [for groceries]. I go to [discount store] for bulk meat, but [he has to] cover milk, salad, toiletries, personal hygiene [items], trash bags, cleaning supplies, zip lock bags...”

“My family helps me out, though. Family is the best resource I have. It’s wonderful. But they have to be accepting. A lot of people’s family member’s are not accepting [of the person living with HIV].”

Buying on Credit

Finally, participants with access to credit cards used them to buy groceries. While not considered a sustainable, long-term strategy, credit card users found it a useful way to tread water during times of unusual hardship and at the end of the month when Food Stamps and other resources were gone:

“By the 20th of each month, [I’m out of money]. We call that the plastic week.”

“Half the month is a plastic month.”

“I get my food using my credit card. [After experiencing an illness that almost killed me], I went to an attorney and she said to get a credit card and go to Disney World. I have insurance that will pay off my debts when I die, so in the last few months, I put \$500 worth of food on my credit card! I used to budget better, but now, I figure, the hell with macaroni and cheese.”

Getting Assistance from Community-Based Food Distribution Programs

When asked about non-HIV-related resources for food and nutritional help in their communities, most participants were able to identify multiple programs, including food banks, food distribution programs through churches, and congregate meal programs. Many people had experience using these programs. Some participants said the programs helped, although most past users identified logistical and psychosocial barriers that they considered prohibitive to ongoing use.

Problems with Access

Participants in all three cities (Eugene, Medford, and Salem) described long waits at their local food banks. Waiting in line for hours was problematic for symptomatic PLWH/A because of low energy levels and for asymptomatic PLWH/A because of time constraints and conflicts with hours of employment. In addition, participants from both sides of the wellness continuum said they worried about the prolonged exposure to germs while waiting in line:

“Getting a food box is a 3 ½ hour procedure.”

“I don’t like waiting in line with a lot of people and you don’t know what they have. I tend to stay away from those places because I have full-blown AIDS.”

“I know that [name of another PLWH/A] could not go to [the food bank] and get a food box because his energy level wouldn’t let him. I’d have to go with him, have him sit in my car and rest, while I stood in line with his number.”

“This sounds horrible, but I don’t like being around little children. They are disease factories. And when you go to the food bank, there are always mothers with lots of children.”

“I haven’t taken part in any of those programs because it takes so much time. I’m working, so who has time? But most people probably can’t afford to run around spending the time and the gas. Simplifying the process would make it easier for people who need it.”

Lack of transportation, already mentioned as a barrier to shopping in bulk, constituted a similar barrier to accessing food banks or church-based programs: *“the problem is, you need a way to get [a food box] home. And if you ride the bus, that’s a problem.”*

Concerns about Food Safety and Types of Food Offered

Many participants who had used food banks in the three different cities shared concerns about the safety of the food being offered, particularly in lieu of their compromised immune systems and HAART-induced diarrhea and other digestive problems. People cited various concerns with the food they had received, including packaged food that was beyond the expiration date, food sullied by mold or bugs, repackaged food, and food that was recalled after distribution. In addition, many people indicated that the types of food distributed were not the nutritious foods they needed to stay healthy. Finally, many people said the programs only supplied a small amount of food, lasting a few days, so their other concerns with the program seemed to outweigh the benefit of receiving the supplementary help.

“Out of the food box we got, half of the food was expired. We were grateful for it, but when five cans expired a year ago and the potatoes are moldy and mushy in the bottom of the bag, it’s a problem. Oh, and there was macaroni and cheese that had weevils in it.”

“The [food distribution program] stinks, it’s gross, and you don’t want to eat anything that comes out of there. (Others chimed in: “Yeah, it’s dirty,” “It’s filthy.”) I was there during

the summer and it was like 100 degrees. I had to wait an hour and a half and it smelled like a toilet in there. And then there was a recall of the food they gave me.”

“At the food bank here, you get yogurt that is 2 weeks expired and canned goods with lots of sodium. Maybe that’s not so bad, but the meat products are out of an ice chest and the expiration is past due or they may have been frozen and refrozen. You can’t tell. And then the frozen veggies are repackaged by someone and you don’t know where it came from or how it’s been handled. You just get a generic plastic bag with a twist tie.”

“I quit going to [the food bank]. It’s not that I’m not appreciative, but nine times out of ten, I wasn’t getting nutritious food. It’s nice to get cakes and cookies, but they don’t serve my nutritional needs.”

Stigma, Discomfort, and Competition for Scarce Resources

Many participants felt uncomfortable using food banks and congregate meal programs because they did not see themselves as among the target population being served by those programs. Many people, for example, had always worked and supported themselves prior to HIV, so felt embarrassed by needing the help:

“There’s a pride issue, too, because we were used to being independent. I’ve had to humble myself more as each year passed.”

“You know, I worked all my life. Even when I was an addict, I was a functional addict with kids and a job. We never went without food. It’s not like that anymore. But I don’t feel like I’m asking for a lot. I worked hard all my life.”

In addition, many of the male participants felt that the food programs were “geared for people with children” and some described unpleasant experiences that supported this perception. For example, one person said he had been refused certain food items because he was “a single man” and others had been told they were no longer eligible for services. Others mentioned “rude people at the front” and “really snotty gatekeepers.”

“I don’t feel like I belong on a food line. People look at me like I am dressed better, and I feel really embarrassed [to be there] because I am not a family man.”

“Being a single, white, gay man, you get a crumb because you should be able to take care of yourself.”

“It’s very degrading. Just because we don’t have kids with us doesn’t mean we don’t need help.”

“I hate to say this. I like kids. But it’s all based on procreation and children. If you have children, you get benefits. But if you are a single man with HIV and no children...well, we’re penalized as men with a disease. Everyone says ‘you can still work. You don’t look sick.’”

In some cases, it was difficult to tease out how much actual or perceived stigma was based on gender, as opposed to homophobia or fear of HIV. Some people in one city said that they felt the discrimination was explicitly due to their disease status:

“HIV is still hush hush. And there’s stigma. They figure you’re either a junkie or a fag.”

“[A local church] says they offer a food box. I’ve thought of going there, and I can be pretty bold, but I don’t know what kind of reaction I’m going to get. Am I going to have to hear the Word of the Lord in order to eat?”

“It’s true [that there’s more stigma] for HIV versus other diseases in getting help. It’s true. When I had cancer, there was all sorts of help, lots of support groups.”

Finally, participants in all of the locations voiced their frustration with the competition for scarce resources and said they felt that PLWH/A have dropped to the bottom of the hierarchy of social service needs. The consensus was that resources were being directed away from PLWH/A towards others, although variations emerged between groups about which “others” were being served (e.g. women with children, Hispanics, injection drug users, AIDS in Africa efforts).

“It seems like the government is turning its back on people living with HIV.”

“People living with a chronic illness need more than someone who doesn’t have an illness. They need to look at who needs what the most.”

“We’re getting an unfair slice of the pie.”

In general, people were upset by the lack of resources for food, although one person noted that PLWH/A have more resources overall than uninfected, low income people, and others in that group acknowledged that was true, particularly in relation to health insurance.

Getting Assistance from the Existing HIV Care System

Most participants were keenly aware that Ryan White Care Act funded services related to food and nutrition had changed in the recent past, whether or not they had ever received those services. Some participants spoke of their experiences getting grocery gift cards from HIV case managers, while others had been unaware that food vouchers might be available from case managers or had only heard about the service after it had been discontinued. In addition, participants shared their strategies for supplementing skimpy food budgets through cost shifting (e.g. getting help with utilities or rent, so money could be freed up for food).

Some participants had talked with their doctors or case managers about nutrition, but, for the most part, the information they received appeared to have been inadequate or confusing.

Grocery Gift Cards from HIV Case Managers

Many participants had received grocery gift cards from their HIV case managers in the past. They said the cards had been helpful as a hedge against hard times, but that they either were no longer available or that access had been severely restricted. Participants in one city said that cards were now distributed to people as a weight loss incentive, and that clients needed to lose four pound per month in order to qualify for the benefit.

Cost Shifting

Many participants noted that since direct assistance for food and groceries had been curtailed or eliminated, their need to cost shift had increased. Participants in all of the groups said that there simply was not enough money to cover all of their expenses, citing bills for medical procedures, housing, over-the-counter medicines, toiletries, and food for companion animals as examples of competing needs. They mentioned that accessing existing programs in other service areas frees up resources that then can be used for food:

“I’m on the OHOP (housing) program and that helps take the burden off, so I can free up money for bills and food.”

One competing need had hidden costs associated with it. Participants in all three cities cited medical marijuana as helpful for dealing with nausea and lack of appetite. However, enrollment in the medical marijuana program required payment of application fees they described as

prohibitive and caused them to become ineligible for federally subsidized housing. This further limited people's ability to cost shift:

“For those of us who find that marijuana helps with the digestive tract and with nausea and symptoms, we can't get subsidized housing...Having a medical marijuana card actually disqualifies you because you're using drugs, and they don't tell you that right away.”

“I've got full-blown AIDS and my T-cell count was 30 last month. I can't eat. I'm still not on disability. It's hard to get weed if you don't have money. There's a \$100 fee for the medical marijuana card and I can't keep going like this. I'm going to wither away. I've lost 40 pounds...I can't eat. I need the weed. I'm not some aimless stoner: I really can't eat!”

Finally, participants in all three cities mentioned their gratitude for the CAREAssist Program, Oregon's AIDS Drug Assistance Program. They said that having their health insurance premiums and co-pays covered was their greatest source of cost-shifting, allowing them more money to cover other necessities:

“We're so lucky in some ways that this disease is so well looked after for medical care.”

“My partner and I could never pay for our antiretrovirals if we didn't have CAREAssist.”

“Thank god the cost share for CAREAssist has gone away for a lot of us. We really need to get the most out of our dollars.”

Nutritional Advice from Medical Providers

Some participants indicated that their medical providers and HIV case managers talked with them about their nutritional needs, but many said they had not received any nutritional advice. Some people had received confusing advice from professionals and there was debate among participants in several groups about whether weight loss based on BMI was appropriate for people living with HIV. This conversational thread provides an example:

“The only thing my doctor has said to me [about nutrition] is to lose weight. When I got diagnosed, I was 255 pounds and I said how much should I weigh? He said 185. But I think he's crazy because at the time I was at my height of using meth, I never weighed that little!”

“My doctor is glad I’m keeping weight on. They’re happy I’m fat again.”

“And it’s helpful to have a little weight on you just in case you do get sick. You never know when you might need that.”

“It’s harder to fight [illnesses] when you’re skin and bones.”

Some participants also noted that medical providers don’t understand that food security is a real issue for them and that household economics affects nutritional status:

“You go to the doctor and he says: ‘are you guys eating OK? Why aren’t you eating better?’ Well, does Kaiser want to supplement our food bill?”

“All our doctors say ‘eat leafy green vegetables’ and we can’t afford it!”

Food and Nutrition Programs that Work, Real or Imagined

Participants shared their thoughts about programs that had worked or could work to help them get the food they need. Three main themes emerged: developing HIV-specific food programs; educating PLWH/A about nutrition, budgeting, and cooking; and improving or expanding existing support systems.

HIV-Specific Food Programs

A number of participants had experiences living in other cities with food programs designed specifically for people living with HIV or other chronic illnesses. They said these programs worked well because the food was higher quality than what is offered through mainstream food banks and congregate meal programs. Participants also felt that a food program with easier access and more centralized distribution, such as through HIV case managers or co-located in other places where they already go for services, would solve some of the problems with long waits and exposure to crowds. Several participants in groups both in and outside of Eugene mentioned the now-defunct congregate hot meal program at HIV Alliance as an excellent service. They described the program as a place where people could “come for a meal, eat together, socialize, and take a to-go plate.”⁹

⁹ Although clients described this program in positive terms, HIV Alliance staff (when asked later) said the program was discontinued because of low attendance.

Education about Food and Nutrition

Participants in all three cities mentioned that education was a key component to eating well. Several participants suggested that combining nutritional education with case management would be helpful. Educational components that were mentioned included basic nutrition, how to read food labels, buying and preparing meals with fresh foods, and cooking simple, healthy meals on a budget:

“At [another HIV program], we had cooking classes on how to eat cheap and healthy, like cooking with collard greens and miso. It was perfect! It showed me a different way of cooking.”

“There is an educational component. If you understand that tofu is less expensive than ham, you can save money by looking at alternatives.”

“You can make healthy meals for cheap if you know how.”

“There are lots of ways help can be offered. The biggest problem I have is figuring out what I should eat. If people could get together and develop meal plans that would be nutritionally complete and a grocery list, that would be wonderful. I think most people would appreciate ideas for meals that are interesting, healthy, not expensive and made with common ingredients...If they put recipes in the food boxes, then people would know what to do with the food.”

Expanding Existing Support Systems

Finally, participants felt that many of the existing programs designed to help with food and nutrition could be augmented to meet their needs. Most people felt that the Food Stamp Program worked well, but that the benefit amounts are inadequate. Several people suggested that a doubling of the food stamp benefit amount would more closely approximate a reasonable food budget and “would really help.” Others suggested expanding the number of farmer’s markets that accepted food stamp benefits.

Summary of Focus Group and In-Depth Interview Findings

Although eating well is even more important for people living with chronic illnesses, people living with HIV in Oregon face multiple barriers to meeting their nutritional needs. The primary barrier is income, but lack of transportation, low energy levels, fatigue, psychosocial issues and poor appetite all contribute.

At the individual level, participants shared numerous strategies for stretching limited dollars, including strict budgeting, shopping at discount

stores, buying in bulk, and pooling resources with others. At the community level, people accessed existing support systems whenever possible; these included Food Stamps, food banks and congregate meal programs, and Ryan White Care Act-based services. Still, most described unmet needs for enough food generally and, specifically, for foods that are nutritious. Development of food distribution programs designed for people with chronic illnesses, expansion of existing benefits programs (e.g. higher food stamp benefit levels), and integration of a multi-faceted nutrition education component into the HIV service system were suggested improvements to meet existing needs.

Here are some final words from one participant that provide a fitting summary to the focus group findings:

“The case managers have been incredible and the State has been great. But nutrition has to be a priority for people with chronic illnesses. We need to be taken out of the position of having to choose between paying our electrical bill or putting food on the table. If we’re going to function, then they need to make food a priority.”

Discussion

Although we know that between 49% and 57% of PLWH/A in Oregon’s HIV case management system need financial help with food and groceries, we have no data about hunger and food insecurity among PLWH/A to compare to Oregon’s general population. However, a survey conducted with PLWH/A in nearby Vancouver, British Columbia found that food insecurity was nearly five times higher among PLWH/A than among members of the general Canadian population (Normén, 2005).

The surveys and focus groups indicate that about half of PLWH/A in HIV case management participate in the Food Stamp Program, but like other food stamp recipients, PLWH/A said food stamps rarely last through the month. Despite a host of logistical and psychosocial barriers, about 1 in 4 PLWH/A said they received help from food banks/pantries in the preceding 12 months and an equal proportion said they had depended on friends and family for financial help with food and groceries.

In many ways, the Ryan White clients that participated in this evaluation looked like other low income Oregonians faced with competing financial needs and limited resources. For example, low income Oregonians that participated in focus groups for the Oregon Food Bank (OFB) identified themes that were strikingly similar to those discussed by the PLWH/A in our focus groups. Participants described their struggles juggling bills and

trying to budget for expenses that surpassed their incomes. Like the PLWH/A with whom we spoke, OFB participants said they felt ashamed to ask for help, were frustrated by long waits and poor customer service, and feared that they, too, would be losers in the competition for scarce resources¹⁰. Finally, OFB participants also noted that although they wanted to eat a healthier diet, their income prevented them from doing so. A majority of participants specifically identified as problematic the lack of fresh produce in their diets (OFB, 2006a).

Food Distribution Models in Oregon and the U.S.

Oregon is served by a network of hunger relief agencies and community food programs, including emergency food distribution programs, gleaning groups, and community action agencies. Detailed information on Oregon's community food programs is available in Appendix B.

Esther's Pantry, located in the Portland metropolitan area, is the only food distribution program in Oregon specifically serving PLWH/A. It was founded in 1985 "to provide financially challenged individuals living with HIV/AIDS access to food and personal care items," and serves between 150-200 PLWH/A each month. The Pantry is currently administered by Our House of Portland (<http://www.ourhouseofportland.org>). The Pantry is unique in that it has always maintained a policy of allowing clients to select the food they want from well-stocked shelves, rather than handing out pre-packaged food boxes, which is a standard procedure at most emergency food programs. However, Esther's Pantry does not receive any Ryan White funding, only serves the Portland metropolitan area, and has had to limit services over the years due to budget constraints.

God's Love We Deliver (New York) and Project Open Hand (San Francisco) are two large food distribution programs that serve large numbers of people living with HIV. Both programs began as HIV-specific food programs, but have expanded their missions in recent years to include people with other chronic or life-threatening illnesses. This has allowed the programs to expand their funding bases, while maintaining a focus on providing prepared meals to ill people whose nutritional needs would otherwise be compromised.

God's Love We Deliver (GLWD) was established in 1986 in order to deliver nutritious, prepared meals to PLWH/A; in 2001, it expanded its mission to include people living with other illnesses, such as cancer and Alzheimer's disease. GLWD provides 3,000 meals to individuals in New York and New Jersey every weekday, year-round., as well as providing nutritional education and counseling to individuals and groups. GLWD has an annual budget of just

¹⁰ OFB focus group participants identified Hurricane Katrina survivors as their primary "competitors;" for example, in this comment: "Money is being funneled to hurricane people and the war." (OFB, 2006).

under \$10 million and receives funding from individuals and personal endowments, corporate donations, foundations, and government sources (including Ryan White) (<http://www.godslowedeliver.org>).

Project Open Hand began in 1985 as a grassroots, volunteer-driven meal program for providing meals to PLWH/A in San Francisco; beginning in 2000, the agency expanded its mission to include homebound and critically ill individuals with other diseases and conditions. The program provides hot, nutritious meals, groceries, and nutrition education. The program served over 3500 unduplicated clients in 2005, including over 750,000 meals and 64,000 grocery bags (<http://www.openhand.org>).

How the HIV Case Management System Can Help

Oregon's food distribution network is extensive, but many Oregonians, including PLWH/A, still experience food insecurity and barriers to accessing enough nutritious food. Despite the gaps in the system, HIV case managers can play a crucial role in encouraging PLWH/A that need help with food and groceries to sign up for Food Stamps and avail themselves of available community resources.

Case managers can also facilitate individual-level change through assessment, health education, and referrals. Nutritional interventions appropriate to the early stages of HIV disease include annual screenings, nutritional assessments, and nutritional counseling, which should increase in frequency during later stages of illness, when the focus may need to shift from prevention to symptom management (ADA, 2004; Keithley, 2000). Reality-based nutrition education that incorporates low cost options for healthy eating can help clients make lifestyle changes that can prevent disease, while increasing overall health and quality of life. HIV-specific guides for eating well, such as the "Appetite for Life" guide developed by the American Dietetic Association's HIV/AIDS Dietetic Practice Group (www.eatright.org) can help with these efforts, as can referrals to registered dietitians and doctors.

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Additional Resources:

A special issue of *Clinical Infectious Diseases* was dedicated to nutrition and HIV and full text articles are available on-line, for free at:
<http://www.journals.uchicago.edu/CID/journal/contents/v36nS2.html?erFrom=-6905022024272776913Guest>