

WHEN MEDICINE ISN'T ENOUGH:

*The Benefits of Providing Nutrition Support to
People Living with Life-Challenging Illnesses*

A pilot study conducted at Food & Friends
Washington, DC

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Executive Summary

Food & Friends addresses the challenges of malnutrition and food insecurity among the critically ill in the Washington, D.C. region by providing home-delivered meals that require no additional preparation, as well as nutrition counseling and support to maximize the benefits of healthy food at no cost to clients. Although Food & Friends has long believed that comprehensive nutrition support can improve health outcomes, we have not had data to demonstrate the positive impact of nutrition support on managing disease, improving health, and enhancing quality of life. In an effort to demonstrate that food is medicine, Food & Friends collaborated with the Congressional Hunger Center to implement a pilot study program and collect objective data that captures the impact of nutrition services on the lives of recipients. A series of home visits with a small group of clients conducted during their first three months on meal delivery services revealed the following findings:

Health and Symptom Management

- 100 percent of clients reported that food delivery service gives them more support to manage and recover from their illness.
- 95 percent of clients believe that meal delivery service and nutrition counseling have improved their health.
- 63 percent of clients reported that meal delivery service helps them take their medications regularly. 68 percent of clients reported that the food reduces side effects from their medications.
- 68 percent of clients reported they had benefited from medical nutrition therapy. Clients found nutrition counseling especially helpful when they were advised about eating healthy foods, received suggestions on how to manage their symptoms, and learned about interactions between food and medicines.
- Clients living with HIV/AIDS experienced a dramatic reduction in their symptoms, while clients living with cancer experienced a modest reduction in many symptoms.

Quality of Life

- 74 percent of clients reported they feel more able to take care of themselves and their families due to meal delivery service.
- 90 percent of clients reported that food relieves some of their stress, as well as stress on their families and caregivers.
- Before receiving services from Food & Friends more than 60 percent of clients were too sick to procure and prepare food. Approximately 60 percent had a lack of knowledge about what to eat, 38 percent did not have enough money for food, and approximately 20 percent relied on friends and family for food. Food delivery service eliminated these barriers to food security.
- Clients identified multiple benefits of meal delivery service, including the provision of healthy foods, greater knowledge of nutrition, better health, fewer side effects from medications, greater financial security, greater food security, increased independence, an enhanced ability to take medications regularly, improved ability to care for family, and food for family to eat.
- Clients did not experience significant improvements in their ability to perform the activities of daily living, such as cooking, cleaning, and doing laundry.

Food Intake and Knowledge of Nutrition

- After being diagnosed with a life-challenging illness, 50 percent of clients experienced a decrease in their appetite, and nearly 75 percent of clients were less able to procure and prepare food than before they got sick.
- Clients living with HIV/AIDS experienced a consistent improvement in their appetite, while clients living with cancer experienced a decrease in their appetite.
- Almost 60 percent of clients reported their appetite improved during the first month of food delivery service, and 63 percent reported they were eating more during the first month of food delivery service than previously. 84 percent reported an improvement in their ability to procure and prepare food.
- Almost 80 percent of clients felt the quantity and quality of their diet improved as a result of meal delivery service. Clients felt the quality of their diet improved due to improved food security, increased diversity of food choices, and an increased availability of healthy and unprocessed foods.
- Nutrition counseling helped clients adapt long-term healthy eating habits. Approximately 95 percent of clients indicated they make more of an effort to eat healthy now than they did before starting on meal delivery service. The majority

of clients reported eating more fruits and vegetables, and many reported eating more protein.

Weight Stabilization and Body Composition Analysis

- 67 percent of clients experienced unintentional weight loss before starting on meal delivery service. Thirty percent of these individuals lost more than 20 percent of their usual body weight. 80 percent of clients living with cancer, and 40 percent of clients living with HIV/AIDS experienced unintentional weight loss.
- 60 percent of clients living with HIV/AIDS were overweight or obese during the initial interview, while only 26 percent of clients living with cancer were overweight or obese.
- Clients who were underweight during the initial interview continued to lose weight, while clients who were at a healthy weight, overweight, or obese achieved weight stabilization.
- Clients who were underweight during the initial interview maintained their stores of muscle mass and body water, but they continued to lose fat stores.
- Clients who were at a healthy weight or overweight during the initial interview experienced an increase in their stores of muscle mass and fat. Clients who were obese lost some of their muscle and fat stores.

Comprehensive nutrition support is an effective and necessary supplement to medical treatment and helps patients manage disease, reduce symptoms, and achieve improved health outcomes. At the same time, this study also demonstrates the limitations of comprehensive nutrition support. We must be as realistic as we are hopeful about what nutrition services can achieve. While many clients experienced dramatic improvements in their health and overall sense of well-being, the sickest clients experienced only modest gains in their health.

Without the provision of comprehensive nutrition support, however, it is clear that the overwhelming majority of the clients who participated in this study would not have had enough food to eat, or medically appropriate food to eat. As one client who is at the losing end of his battle with lung cancer stated, “Without the service I wouldn’t be eating as much because I only [get] about \$25 a month in food stamps...your service has made a huge difference.” The resulting malnutrition would have left clients at risk of continued weight loss, a compromised immune system, and in many cases, with a lower chance of survival. Addressing the food insecurity that fuels the cycle of disease and malnutrition cannot reverse the progression of illness, but it can dramatically increase quality of life by helping clients achieve improved health outcomes; stabilizing weight and body composition; and eliminating hunger.

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Introduction

Food and proper nutrition are essential for people living with life-challenging illnesses, such as HIV/AIDS or cancer. Malnutrition has a negative impact on health: low levels of vitamins A, B6, and C impair the immune system;ⁱ iron deficiency causes fatigue;ⁱⁱ and insufficient protein intake delays wound healing and depletes muscle mass.ⁱⁱⁱ Poor nutrition is both a cause and a consequence of serious illness and fuels a vicious cycle of malnutrition and undue disease progression.^{iv} Inadequate intake of nutrients may result in continued weight loss, depletion of muscle mass, and vitamin or mineral deficiencies.^v Each of these conditions is an independent risk factor for the progression of HIV disease to AIDS^{vi} and impairs the body's ability to endure cancer.^{vii} For people living with life-challenging illnesses, the loss of just five to ten percent of body weight is associated with lower rates of survival.^{viii}

Although medical treatment *and* proper nutrition are required to achieve optimal health, the role of nutrition in managing disease and improving health outcomes is often undervalued.^{ix} Many people living with life-challenging illnesses report it is nearly impossible to consume a medically appropriate diet due to the debilitating physical conditions and poverty that frequently accompany illness.^x Some of the many risk factors for food insecurity and malnutrition among the critically ill include:^{xi}

- Increased need for nutrients
- Decreased ability to eat and absorb nutrients
- Medical treatments with complex nutritional requirements
- Need for a specialized diet
- Lack of knowledge about what to eat
- Social isolation
- Poverty

This food insecurity results in negative health outcomes and a decreased quality of life for people living with life-challenging illnesses, as well as higher social costs to treat preventable complications.^{xii}

Food & Friends, like other nutrition service agencies, addresses the challenges of malnutrition and food insecurity among people living with life-challenging illnesses by providing nutritious, home-delivered meals that require no additional preparation, as well as

nutrition counseling and support to maximize the benefits of healthy food. We began providing home-delivered meals in 1988 to meet the nutritional needs of HIV positive people in the District of Columbia. In 1993, we began delivering meals to the families of people living with HIV/AIDS after realizing that many adult clients were giving the food to their children, remaining hungry and malnourished themselves. In 2000, we began serving people with other life-challenging illnesses, such as cancer and Alzheimer's. As of 2006, approximately 50 percent of our clients are living with HIV/AIDS, 40 percent are living with cancer, and 10 percent are living with another life-challenging illness.

Food & Friends operates with two fundamental goals: to keep the principles of medical nutrition therapy at the core of our services and to reduce food insecurity and hunger among the critically ill. Medical nutrition therapy complements medical treatment and seeks to improve health outcomes by maximizing nutrition status and immune function; preventing the development of nutrient deficiencies; promoting stable weight and body composition; and enhancing the efficacy of medication.^{xiii} Medical nutrition therapy involves an in-depth nutritional assessment by a registered dietician; evaluation of nutritional status; and appropriate nutritional counseling and therapy.^{xiv} The benefits of medical nutrition therapy, however, can only be realized with access to nutritious food. Many people living with an illness, such as HIV/AIDS or cancer, experience food insecurity because they do not have the physical or economic capacity to consume a medically appropriate diet.^{xv}

Delivering freshly prepared meals at no cost to recipients eliminates the issue of food insecurity and ensures that patients have the food they need to achieve improved health outcomes.^{xvi} Providing meals in conjunction with nutrition counseling can reduce many of the symptoms associated with illness, improve the tolerance and efficacy of medical treatments, promote stable weight and body composition, enhance quality of life, and eliminate the risk factors for hunger among the critically ill.^{xvii} Home-delivered meals are also cost-effective because good nutrition can prevent the onset of opportunistic infections, reduce the incidence of expensive hospitalizations, and in some cases, help patients maintain economic productivity.^{xviii} Clients do not have to worry about where their next meal will come from and are better able to participate in medical care that will improve their health.^{xix}

Based on a wealth of anecdotal accounts from clients, we at Food & Friends have long believed that comprehensive nutrition support can improve health outcomes. These anecdotal accounts help direct the daily work of our nutrition service providers, but they do not convincingly demonstrate the greatest success that we have witnessed over the years: the positive impact of nutrition services on managing disease, improving health, and enhancing quality of life. In an effort to demonstrate that food is medicine, Food & Friends collaborated with the Congressional Hunger Center to implement a pilot study program and collect objective data that captures the impact of nutrition services on the lives of a small group of recipients.

Our ability to detail the impact of nutrition support on people living with life-challenging illnesses on a large scale is limited because the most needy beneficiaries are too ill to share their experiences, while others are on service for only a short period of time due to frequent hospitalizations or death. But a series of home visits with a small group of clients effectively demonstrates not only the impact that nutrition services have on clients' health, but also how nutrition support fits into the broader context of clients' lives. The results of these interviews highlight what we have long believed to be true: **Addressing the food insecurity that fuels the cycle of disease and malnutrition cannot reverse the progression of illness, but it can dramatically increase quality of life by helping clients achieve improved health outcomes; stabilizing weight and body composition; and eliminating hunger.** It is our sincere hope that the results of this project will serve as a catalyst to increase support for nutrition service agencies and build momentum for addressing the very real, and unmet, nutritional needs of people living with life-challenging illnesses.

Measuring the Benefits of Nutrition Support

Until now, Food & Friends has relied on an annual client satisfaction survey to document the impact of nutrition service on clients. Though this tool provides valuable information, it is problematic because it only provides information about clients at one moment in time and cannot capture many of the potential health benefits of nutrition support, such as reduced symptoms and weight stabilization. This longitudinal study provides information about clients' outcomes by documenting where clients started and how their health and quality of life have changed after receiving comprehensive nutrition support for 90 days.

Recruiting, Retaining, and Interviewing Study Participants

Clients were eligible to participate in the study if they were new to service, over the age of 18, residing in Washington, DC, Prince George's County or Montgomery County, MD, and able to understand the survey questions and provide informed consent. Eligible Food & Friends clients who started on service between September 18 and October 31, 2006 were given information about the background and objectives of the study and asked to participate at the time of intake. Of the 73 eligible clients, 30 clients (41 percent) chose to participate; these clients represent approximately 25 percent of all clients who started receiving nutrition services during this time period.^{xx} Nearly all of the clients who elected not to participate indicated they did not feel well enough to have a visitor.

Clients who agreed to participate were initially interviewed during a home visit on their first day of Food & Friends service to establish a baseline assessment, as well as 30, 60, and 90 days after the first visit. Every effort was made to interview clients exactly one month from the date of their last interview, but this was not always possible due to scheduling conflicts, including doctor's appointments, hospitalizations, and health status. Of the 30 clients who originally enrolled in the study, 15 (50 percent) participated in all four interviews; 19 (63 percent) participated in the 30-day interview, 17 (57 percent) participated in the 60-day interview, and 19 (63 percent) participated in the 90-day interview. The reasons for non-participation were poor health, hospitalization, death, daily cancer treatments, holiday travel, or having moved. All interviews were conducted between September 18, 2006 and January 29, 2007 by trained program staff and volunteers.

Collecting and Analyzing Data

Interviewers spent between 30 minutes and two hours with each client in his or her home, and administered a different survey questionnaire during each visit. Clients were asked open ended and multiple-choice questions about their physical health, mental health, quality of life, food intake, and knowledge of nutrition. Height was measured during the first visit using a standard measuring tape, weight was measured during each visit using a standard portable digital scale (Taylor Electronic Scale), and body composition was measured during the first and last visits using a hand-held Bioelectrical Impedance Analysis (BIA) device (Quantum II, RJL systems). Standard Food & Friends follow-up and charting procedures were followed for clients after each visit, including a follow-up phone call from a staff dietitian.

Survey responses were grouped into five large categories for outcomes analysis: health and symptom management; quality of life; food intake and knowledge of nutrition; weight stabilization; and body composition. All data were analyzed in three ways: with all participating clients, clients living with cancer, and clients living with HIV/AIDS. Since the sample size for the study is small, data for clients living with cancer and clients living with HIV/AIDS are separated only when a relevant difference exists between the two groups. The maximum number of clients that could be included in the analysis of each parameter (depending on when and during how many visits it was measured) was included and the sample size for each measure is noted throughout the report.

All data were analyzed using basic descriptive statistics (percentage, mean, median), except for the results of the body composition test. Body composition testing was conducted with a hand-held portable Bioelectrical Impedance Analysis (BIA) device, which is a well-established technique for estimating body muscle, fat, and water stores.^{xxi} Twenty-eight of the 30 original participants provided consent for a BIA test, and 26 valid test results were obtained; 16 of these clients participated in the final BIA test. Body composition values of interest were the difference between body cell mass (lbs), body fat (lbs), total body water (lbs), and phase angle from the normal expected value. The individual and normal expected values for each client were calculated using Cyrus software (RJL systems) based on formulas developed through the Third Annual National Health and Nutrition Examination Survey (NHANES III).^{xxii}

The individual results of the body composition test were grouped according to weight status at baseline. Average initial and final values were calculated for each weight category to measure group changes over 90 days.

Body cell mass (BCM) represents the body's total cellular mass, including smooth and skeletal muscle, organs, and intracellular water. This is the most important measure of body composition because lean body mass is responsible for metabolic activity. Body fat refers to the pure fat or triglycerides found in the body; TBW refers to intracellular and extracellular fluids. Phase angle is a measure of overall cellular health; a higher number of healthy cells result in a higher phase angle.^{xxiii}

Limitations

This study provides valuable insights about the benefits of comprehensive nutrition support, but it also has several limitations:

- First, the study has a small sample size. This is a significant, but unavoidable limitation, due to the serious illnesses that Food & Friends' clients live with, the five-month time frame available to complete the study, and the amount of time required to complete each interview. The small sample size precludes comprehensive statistical analysis, but the in-depth nature of the interviews provides important information about the impact of nutrition support.

- Second, the short time frame of this study means clients were only followed for their first 90 days on service. Since it took some participants nearly three months to become familiar with the service and settle on an appropriate meal plan, the study may not capture the maximum benefits of nutrition service. In addition, the study ended when some participants were going through the most difficult stages of cancer treatment, which may underestimate the benefits of the services provided. At least two of the nine clients living with cancer who participated in the final interview contacted Food & Friends staff after the study and said they were finally able to eat and benefit from meal delivery service.

- Third, the study population is healthier than the general population of Food & Friends clients. The primary reason eligible clients declined to participate was poor health; thus it is likely that the study population is self-selective and only the healthiest Food & Friends clients were able to participate. It is not clear, however, whether this would under or over estimate the benefits of comprehensive nutrition support.

- Fourth, study participants received more attention via monthly phone calls from staff dieticians than did non-study participants. Food & Friends client follow-up protocol requires staff dieticians to follow up with clients and report the results of a body composition test or address any nutrition related issues that may have come up during a home visit with a non-dietetic staff member. Although this procedure may bias the results in favor of the benefits of nutrition support, it still serves to demonstrate the efficacy of medical nutrition therapy. With additional funding for more staff, dieticians could provide all clients with the same extent of support they were able to provide the study participants.

- Fifth, the study does not use a paired control group of people living with HIV/AIDS or cancer who are without nutritional support for practical and ethical reasons. Without a control group, it is difficult to estimate how much of a benefit nutrition support provides, or the effects clients may have felt in the absence of nutrition support.

- Finally, the study may underestimate the benefits of comprehensive nutrition support because the most needy clients were excluded from participation. Many people living with life-challenging illnesses, particularly those living with HIV/AIDS, find themselves without healthcare, without a home, or without food.^{xxiv} Since Food & Friends requires, in most cases, a referral from a case manager or physician, only those with access to social services and healthcare are able to receive nutrition services and be included in the study. Food & Friends serves clients who are homeless, but they were excluded from the study due to the need to meet in a consistent location. This population

is likely to have more extensive issues with food insecurity and disease-related malnutrition than the study participants.

Study Population Characteristics

The descriptive statistics of the study population are important because they provide the socioeconomic, cultural, and medical context to understand clients' experiences. The demographic composition of the study participants is consistent with the general population of Food & Friends clients. As shown in Table 1, two-thirds of the clients who enrolled in the study are living with cancer, while one-third of clients are living with HIV/AIDS. This proportion is similar among the 15 clients who participated in all four visits. At any given time, Food & Friends serves more clients living with HIV/AIDS than clients living with cancer, but a greater proportion of new Food & Friends clients are living with cancer than HIV/AIDS. This is due to the fact that clients living with cancer are typically on service for a shorter period of time than clients living with HIV/AIDS.

The average age of all clients who participated in the first study is 54.8; the mean age of clients living with HIV/AIDS is 47.9, and the mean age of clients living with cancer is 58.3. The second column shows the average age of the 15 clients able to participate in all four study visits is fairly similar to the original group of study participants. Ninety percent of all study participants are African-American and the majority of participants have an income at or less than \$12,000 per year, which is below the 2007 federal poverty guidelines for a family of two or more (\$13,690 for a family of two).^{xxv}

The majority of clients living with HIV/AIDS were diagnosed more than five years ago, including some clients who have been living with HIV infection for more than 15 or 20 years. The time of diagnosis for HIV/AIDS study participants who completed all four interviews is slightly different, with the majority diagnosed between one and four years ago. The diagnosis time frame for clients living with cancer is different from clients living with HIV/AIDS. Seventy percent of all study participants with cancer, and almost 80 percent of the study participants with cancer who completed all interviews, were diagnosed between zero and seven months before receiving nutrition services. The difference in the diagnosis time frame for clients living with HIV/AIDS and clients living with cancer is consistent with Food & Friends' criteria for service, which includes HIV positive individuals with significant disease progression and clients living with cancer who are on treatment or in hospice.

	All Clients n = 30	Clients Who Completed All Interviews n = 15
Illness		
HIV/AIDS	33%	40%
Cancer	66%	60%
Location		
Washington, DC	70%	53.3%
Prince George's County, MD	20%	33.3%
Montgomery County, MD	10%	13.3%
Mean Age and Range		
All Clients	54.8 (38, 83)	54.0 (38, 79)
Clients living with HIV/AIDS	47.9 (38, 66)	47.2 (38, 66)
Clients living with cancer	58.3 (43, 83)	58.3 (46, 79)
Race		
African-American	90%	86.6%
White	6.7%	6.7%
Hispanic	0%	0%
Native American	0%	0%
Other	3.3%	6.7%
Monthly Income*		
\$0	13.3%	13.3%
\$1-500	16.7%	13.3%
\$501-1000	33.3%	33.3%
\$1001-1500	13.3%	26.7%
\$1501-2000	10.0%	6.7%
\$>2001	13.3%	6.7%
Time of HIV/AIDS Diagnosis*		
0 to 6 months before starting service	20%	16.7%
1 to 4 years before starting service	10%	33.3%
5 to 8 years before starting service	30%	16.7%
More than 8 years before starting service	30%	16.7%
Unknown	10%	16.7%
Time of Initial Cancer Diagnosis*		
0 to 3 months before starting service	40%	33.3%
4 to 7 months before starting service	30%	44.4%
8 to 11 months before starting service	5%	0%
1 to 2 years before starting service	5%	11.1%
>2 years before starting service	20%	11.1%

*Reported by case manager at the time of intake or self-reported during initial interview; may not be accurate

Secondary illnesses are more prevalent among the study participants (and among Food & Friends clients in general) than they are in the general population of healthy adults. Thirty percent or more of the study participants suffer from hypertension, depression, and neuropathy. Twenty percent or more suffer from anemia, arthritis, diabetes, and hepatitis B or C. The high incidence of secondary illnesses among people living with life-challenging illnesses is likely related to the co-morbidity of many of these illnesses. For example, people living with HIV/AIDS are more likely to have diabetes, hepatitis, or dyslipidemia than people who are not infected with the HIV virus or receiving treatment.^{xxvi} These secondary conditions are physically, socially, and economically debilitating and add to the day-to-day challenges Food & Friends' clients face. In addition, many of these conditions, namely hypertension, anemia, diabetes, and renal failure, are significantly affected by nutritional status.

Table 2. Secondary Illnesses among Study Participants (n = 30)

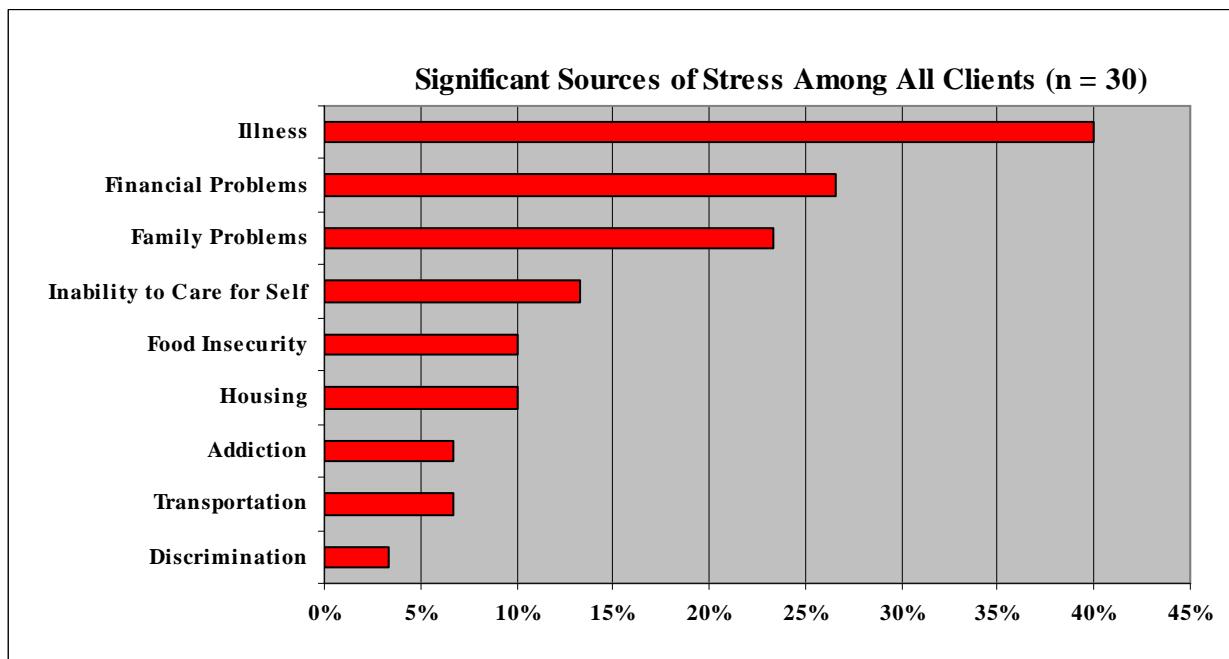
Hypertension	33.3%
Depression	33.3%
Neuropathy	30.0%
Anemia	26.6%
Arthritis	26.6%
Diabetes	23.3%
Hepatitis B or C	20.0%
Dyslipidemia	10.0%
Dementia/Disorientation	10.0%
Cirrhosis	6.7%
Mental Illness	6.7%
Parkinson's	3.3%
Renal Failure	3.3%

*23.3% of clients reported either during an interview or at intake that they have no secondary illnesses. Of the 23 clients who reported a secondary illness, 82.6% reported having more than one illness. These values are based on self-reported data at the time of intake and during study interviews and should be considered estimates.

During the initial interview, clients were asked to describe their most significant sources of stress. More than 80 percent of clients reported at least one major source of stress, while 33 percent reported multiple sources of stress. The most common circumstances that caused clients to feel stress were illness, financial problems, family/personal problems, inability to care for self, food insecurity, unstable housing, addiction, and lack of transportation. **These reports likely**

underestimate the true extent of stress in this population, as many clients specifically said they do not allow themselves to feel stress because their doctor told them it would hurt their prognosis. Clients living with HIV/AIDS tended to experience different sources of stress than clients living with cancer. Circumstances such as illness and inability to care for self were most common among clients living with cancer, while socio-economic factors, such as financial problems, employment, and housing were most common among clients living with HIV/AIDS. Other sources of stress came up during all four interviews, though not always in direct response to the question about stress. Clients often discussed their difficulty accessing public benefits, including Social Security Disability Income (SSDI), Social Security Income (SSI), and Food Stamps, as well as concerns about their health.

Graph 1. Significant Sources of Stress among All Clients



Eleven of the original 30 clients participated in two interviews or less due to hospitalization, death, stopping service, or daily cancer treatments. The two clients who passed away were both underweight and living with cancer, and a third client living with cancer was hospitalized long-term for an inability to tolerate food. This trend confirms the evidence that

being underweight is a significant risk factor for the progression of disease.^{xxvii} Clients who were hospitalized and never came back on service may have also passed away, but this information is not available ($n = 4$). The differences in health status between the clients who dropped out of the study and the clients who were able to complete the study suggests the group of clients who completed all four interviews is, on average, somewhat healthier than the initial group of participants.

Health and Symptom Management

Study participants experienced improvement in their overall health and well-being. One-hundred percent of clients who participated in the final interview ($n = 19$) reported nutrition services gave them more support to manage and recover from their illness. Nearly 95 percent of clients who participated in the final interview believe nutrition service improved their health. More than 60 percent of clients reported nutrition services helped them take their medications regularly, and nearly 70 percent reported nutrition services reduced side effects from medications. Most clients reported during the initial interview that they believe food has a positive impact on health, but many were unaware of how food could actually be used to improve their health until they received services from Food & Friends.

A 38 year old male client who was diagnosed with HIV/AIDS when he came down with Pneumocystis carinii Pneumonia (PCP) and AIDS wasting syndrome four months before he started receiving nutrition services said, *“My energy level is higher and I am participating more in life and I am doing more. I know this is because of the food because now I am eating and I have more energy...The meals have helped me keep up with my doctor’s appointments because now I can go catch a bus. Before I had no energy and needed to get a ride, but now I have the energy to ride the bus.”*

Sixty-eight percent of clients who participated in the final interview reported they had benefited from medical nutrition therapy. Eighty percent of clients living with HIV/AIDS ($n = 10$) and 50 percent of clients living with cancer ($n = 20$) reported during the first interview they had never been told about interactions between food and medicine. These clients learned about managing symptoms and food-drug interactions only from their dietician at Food & Friends. Clients found medical nutrition therapy especially helpful when they received suggestions about how to manage their symptoms and learned what to eat with their medications. Specific instances clients cited included handouts on managing a variety of symptoms, such as constipation, nausea, or dry mouth, and instructions on how to take medications with complex nutritional requirements. Examples of such medications include iron, which has limited absorption in the presence of bread, or blood thinners, which are less effective in the presence of excess vitamin K.

Sixty-eight percent of clients who participated in the final interview reported their health care providers made positive comments about their nutritional status after they started receiving services from Food & Friends. Clients indicated their physicians noticed improvements in weight management, stable blood sugar, red and white blood cells, and food intake. One 68-year old male client who has been living with HIV/AIDS for more than 20 years noted his doctor went of his way to schedule appointments around his food delivery schedule.

Along with general improvements in health and energy, clients experienced reductions in the number of symptoms they experienced. During each interview, clients were asked about the presence of common oral, gastrointestinal, and other symptoms, including:

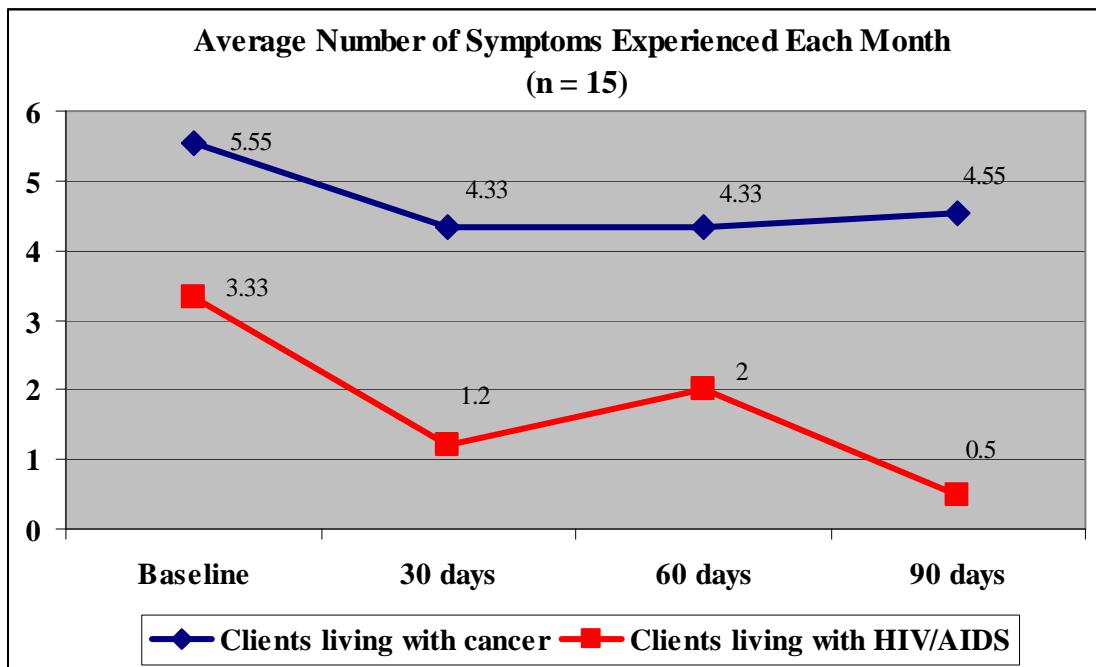
- Chewing or swallowing problems
- Mouth or throat sores
- Taste changes
- Dry mouth
- Smell intolerance
- Early satiety
- Nausea
- Vomiting
- Constipation
- Diarrhea
- Fatigue

A 47 year old woman diagnosed with breast cancer seven months before receiving nutrition services said, *“My doctor is happy that my weight is holding stable. Before service, my blood counts were very low, but when I started on food delivery, my white blood cell count had picked up and my doctor thinks it had to do with the change in my eating habits.”*

Based on data from clients who were able to participate in all four study interviews ($n = 15$), the average number of symptoms clients experienced decreased over the course of 90 days, especially for clients living with HIV/AIDS. As Graph 2 illustrates, during the first interview, clients living with cancer experienced an average of 5.55 symptoms, and clients living with HIV/AIDS experienced an average of 3.33 symptoms. After 90 days, clients living with cancer

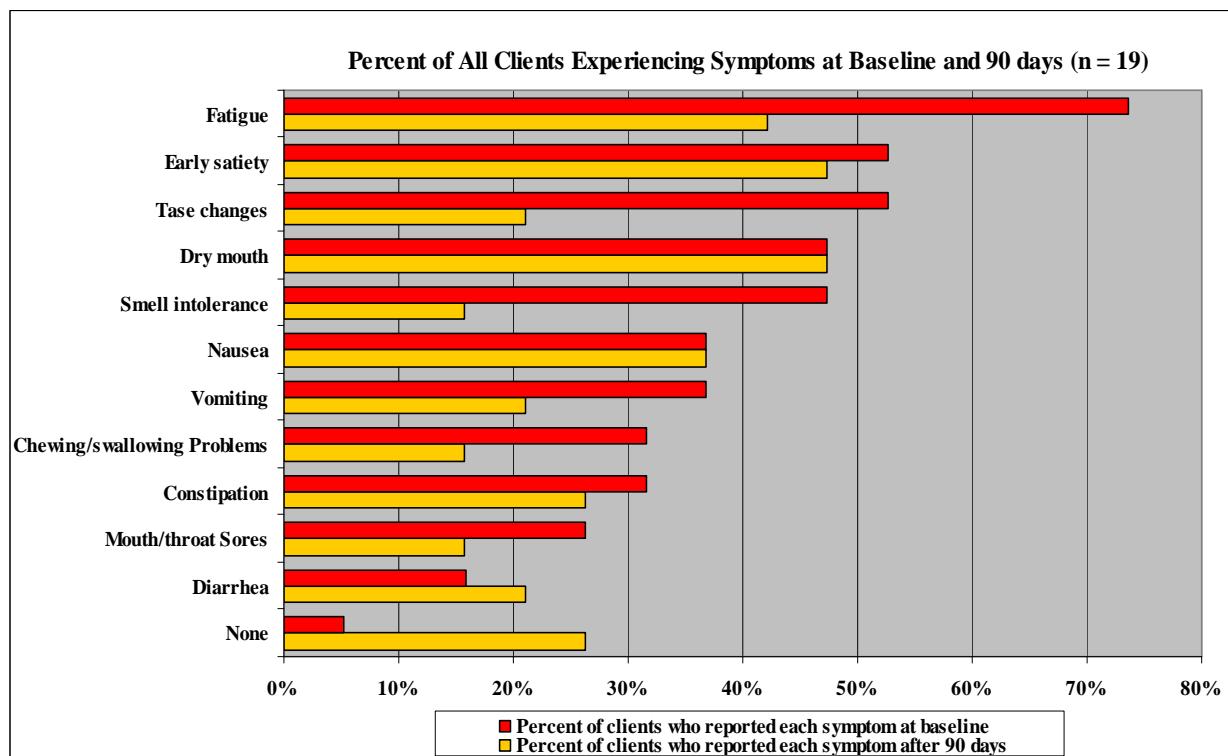
experienced an average of 4.55 symptoms and clients living with HIV/AIDS experienced an average of .5 symptoms. The most dramatic reduction in symptoms for both clients living with cancer and clients living with HIV/AIDS occurred during the first month of nutrition support.

Graph 2. Average Number of Symptoms Experienced Each Month



Based on data from clients who participated in the first and last interviews ($n = 19$), the most common symptom was fatigue followed by early satiety, taste changes, dry mouth, smell intolerance, nausea, vomiting, chewing/swallowing problems, constipation, mouth/throat sores, and diarrhea. Approximately 5 percent of participants reported no symptoms. Clients living with cancer experienced more symptoms prior to receiving nutrition support and at greater intensity than clients living with HIV/AIDS, with the exception of diarrhea. People living with HIV/AIDS are at high risk of experiencing diarrhea, especially without adequate nutrition, because it is a common side effect of many HIV/AIDS medications.^{xxviii} Thus, it is not surprising that clients living with HIV/AIDS experienced a dramatic reduction in diarrhea once they received nutrition support.

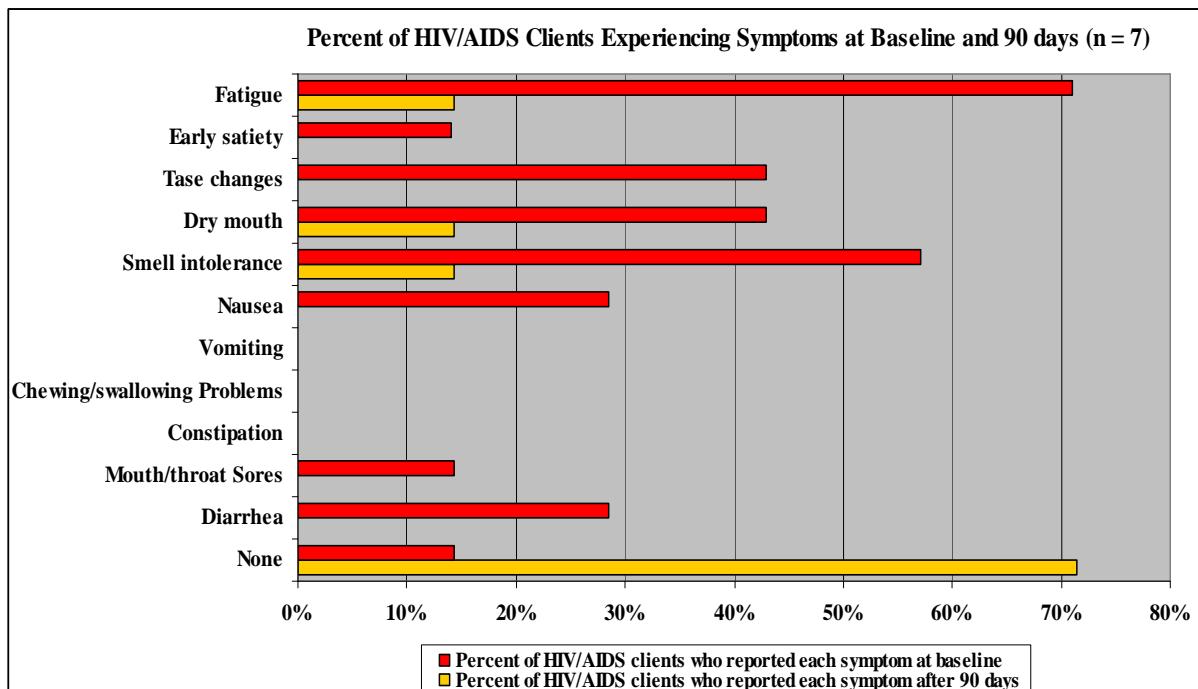
Graph 3. Percentage of All Clients Experiencing Symptoms at Baseline and 90 days



Over the course of 90 days, most of the symptoms clients living with HIV/AIDS ($n = 7$) experienced before receiving nutrition support were completely eliminated, including diarrhea. The only symptoms that remained were fatigue, reduced from 71.4 percent to 14.3 percent; dry mouth, reduced 42.9 percent to 14.3 percent; and smell intolerance, reduced from 57.1 percent to 14.3 percent. The proportion of clients living with HIV/AIDS who experienced no symptoms increased from 14.3 percent to 71.4 percent.

A 38 year old male living with HIV/AIDS explained, “*Certain medications used to give me the runs [diarrhea], but since I started eating better, I haven’t had any problems.*”

Graph 4. Percentage of HIV/AIDS Clients Experiencing Symptoms at Baseline and 90 Days

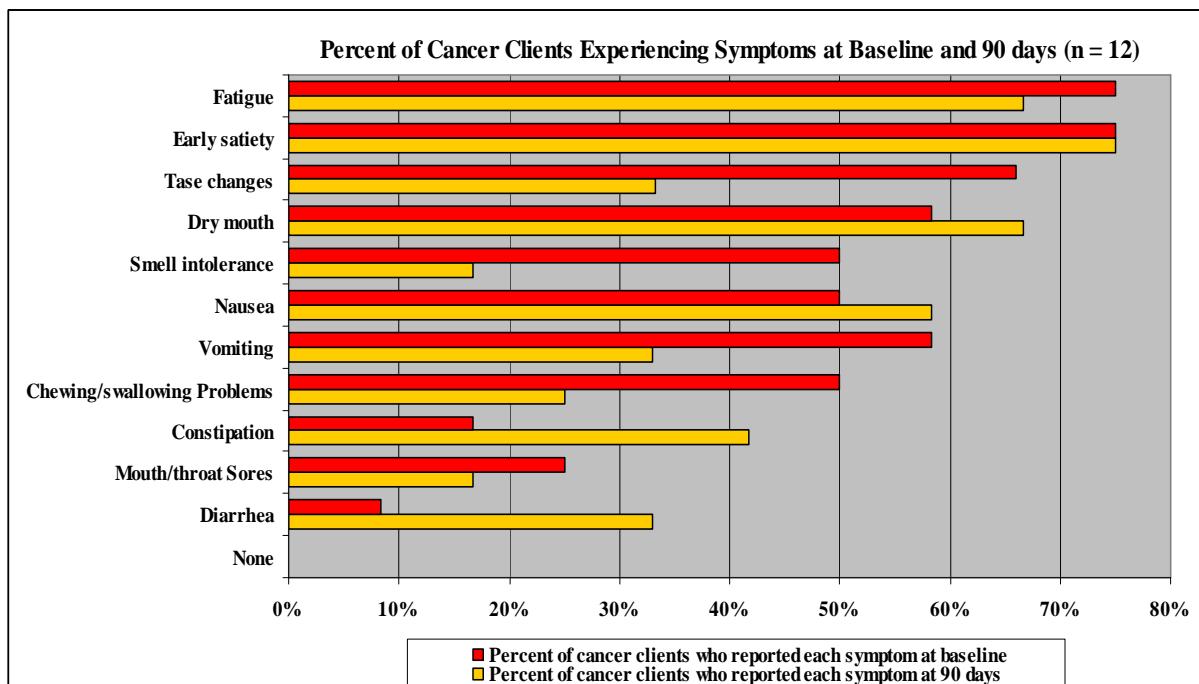


A 45 year old woman living with breast cancer who lost more than 30 percent of her body weight after she became ill said, “*The food has really helped because I have gained weight and I can tolerate my medicines better.*”

Clients living with cancer experienced a significant reduction in many of their symptoms, while other symptoms stayed constant or became more prevalent. Symptoms that were reduced included fatigue, reduced from 75 percent to 66.7 percent; taste changes, reduced from 66.6 percent to 33.3 percent; smell intolerance, reduced from 50 percent to 16.7 percent; vomiting, reduced from 58.5 percent to 33 percent; chewing or swallowing problems, reduced from 50 percent to 25 percent; and mouth or throat sores, reduced from 25 percent to 16.7 percent. The prevalence of dry mouth, nausea, constipation, and diarrhea increased.

chewing or swallowing problems, reduced from 50 percent to 25 percent; and mouth or throat sores, reduced from 25 percent to 16.7 percent. The prevalence of dry mouth, nausea, constipation, and diarrhea increased.

Graph 5. Percent of Cancer Clients Experiencing Symptoms at Baseline and 90 Days

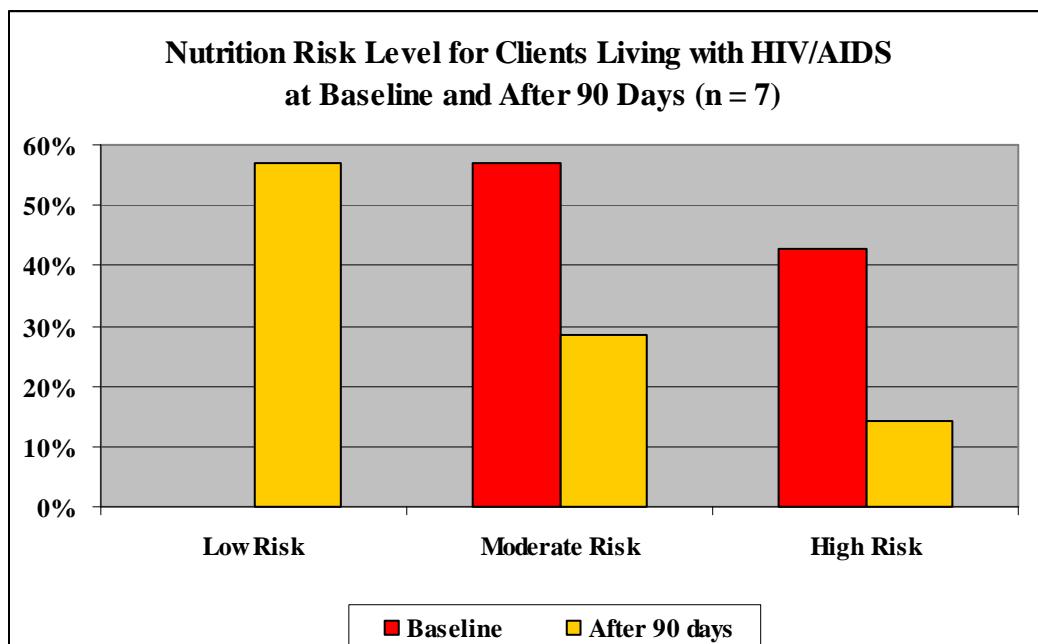


After each interview, staff dieticians followed up with clients via telephone to provide medical nutrition therapy and assign a nutrition risk level of low, moderate, or high, to each client based on standardized guidelines. For example, to be assigned a risk level of high, clients had to meet at least one of the following criteria: unintentional loss of 10 percent of body weight in the past month, or chronic diarrhea occurring more than five times per day in addition to fever lasting at least one month. Data from all clients who participated in the initial interview indicate that 50 percent of clients living with HIV/AIDS were at moderate risk and 50 percent were at high risk ($n = 10$). Among clients living with cancer, 75 percent were at moderate risk, while 25 percent were at high risk ($n = 20$). Nutrition risk levels for clients who were able to participate in the first and last interviews suggest clients living with HIV/AIDS who completed the study were at a slightly lower initial risk level than clients who dropped out. Clients living with cancer were, on average, at the same risk level.

During the initial interview, approximately 43 percent of clients living with HIV/AIDS were at high nutrition risk, while approximately 57 percent were at moderate nutrition risk; none

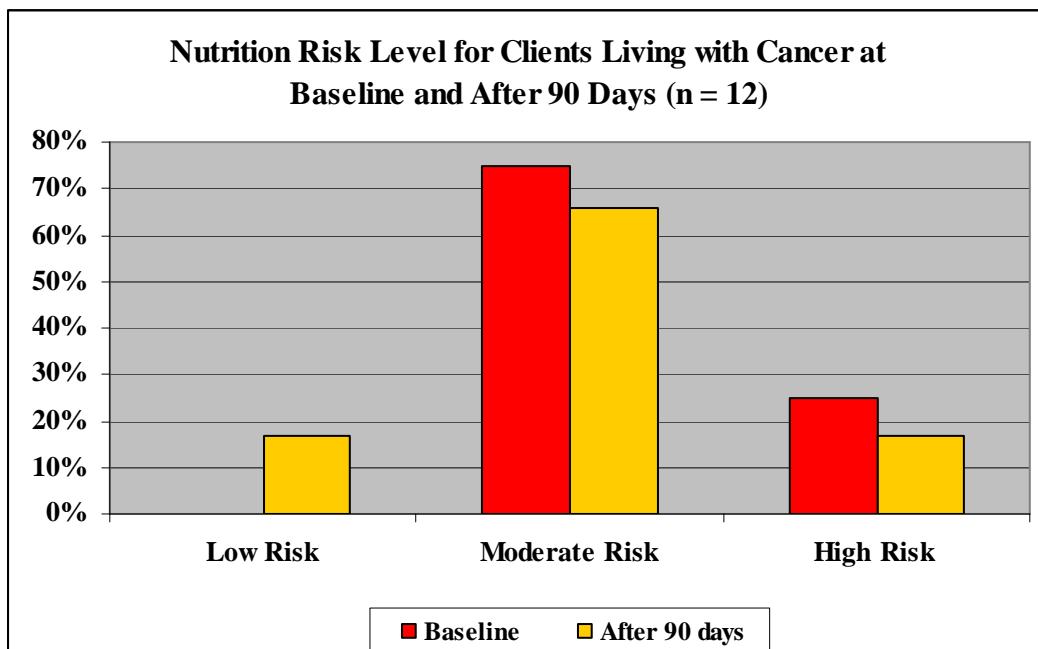
were at low risk ($n = 7$). After 90 days, approximately 15 percent were at high risk, approximately 29 percent were at moderate risk, and 58 percent were at low risk. These results mirror the findings of the symptom analysis, which indicates clients living with HIV/AIDS experienced dramatic improvements in their overall health and nutrition status.

Graph 6. Nutrition Risk Levels for Clients Living with HIV/AIDS



Clients living with cancer also experienced improvement in their level of nutrition risk, though the changes were modest. During the first interview, 25 percent of clients living with cancer were at high risk, 75 percent were at moderate risk, and none were at low risk. After 90 days, approximately 17 percent were at high risk, 68 percent were at moderate risk, and 17 percent were at low risk. Clients living with cancer were likely to remain stable, though some clients did experience significant improvement and moved into the low risk category.

Graph 7. Nutrition Risk Levels for Clients Living with Cancer



Discussion

The health improvements study participants experienced indicate medical nutrition therapy and home-delivered meals have a positive effect on health and symptom management. There are undoubtedly many factors that influence health outcomes, and without a paired control group it is impossible to determine exactly how much of the improvement clients experienced was due to nutrition service. But it is clear that nutrition service played an important role.

First, clients specifically mentioned aspects of nutrition service that made them feel better, such as eating healthy food, learning about interactions between food and medicines, and having more energy to adhere to their medical treatment plans. Second, clients cited specific examples of positive changes their doctors' have noticed in their health and attributed to nutrition services. Third, since most study participants were not eating much before they began receiving nutrition service, it is reasonable that they felt much better once they started eating a nutritious diet. Fourth, clients experienced improvements in symptoms, even when their prognosis and medical treatment plan did not change, which suggests they benefited from medical nutrition therapy.

Supporting this claim is a medical literature that indicates symptoms can be managed through nutritional support. An individual with chewing or swallowing problems can minimize these complications by eating a soft or pureed diet. A study conducted at Columbia Presbyterian Hospital in New York City found that HIV-related diarrhea is reduced with a regular, nutritious diet.^{xxix} Another found that taste changes can be reduced by eliminating bitter foods, such as coffee and chocolate, or consuming more foods with citrus. Smell intolerance can be managed by reducing or eliminating the strong smells associated with cooking.^{xxx} The increase in some symptoms among clients living with cancer may have been the result of heightened intensity of chemotherapy and radiation treatments, higher doses of pain medications, and the progression of disease. Because clients living with cancer are often undergoing harsh medical treatments with unpredictable side effects, it is more difficult to help cancer patients manage their symptoms.

Finally, clients living with HIV/AIDS experienced a significant decline in their level of nutrition risk. Clinical and epidemiological research demonstrates that nutrition status is an important determinant of survival for people living with life-challenging illnesses.^{xxxi} Nutrition risk at baseline can predict mortality and quality of life, which makes it essential to eliminate or reduce the causes of high nutrition risk.^{xxxii} A significant proportion of clients living with HIV/AIDS moved from high nutrition risk to moderate and low nutrition risk which bodes well for their overall health and well being. Achieving optimal nutrition status strengthens the immune system and reduces the risk of excessive weight loss.^{xxxiii}

The improvements clients experienced in their overall health, energy, symptoms, and nutrition status demonstrate the efficacy of medical nutrition therapy and home-delivered meals. These improvements also highlight the important role nutrition service plays in managing health for people living with life-challenging illnesses. At the same time, the study also demonstrates the limitations of nutrition service. Nutrition service cannot replace medical treatment, or reverse the progression of disease; but it can help some clients recover from illness and fight a stronger battle against their disease.

Quality of Life

Study participants experienced an improvement in their quality of life. Approximately 74 percent of clients who participated in an interview one month after starting nutrition services ($n = 19$) felt more able to take care of themselves and their families. In addition, nearly 90 percent of clients who participated in the final interview ($n = 19$) reported the food relieved some of their stress, and many noted it also reduced the burden of stress on their families. Women who have children

A 68 year old man living with thyroid cancer who previously relied on his wife to prepare soft meals for him said, "*The food helps because [my wife] is not always able to fix something and it's easy for me to warm the food. It makes me more independent and...[my wife] can do other things.*"

reported the food was a great relief because it enabled them to take better care of their children - they knew their kids would have enough to eat. Nutrition services reduced the burden of care that spouses and children often carry when their family members are ill and need constant support.

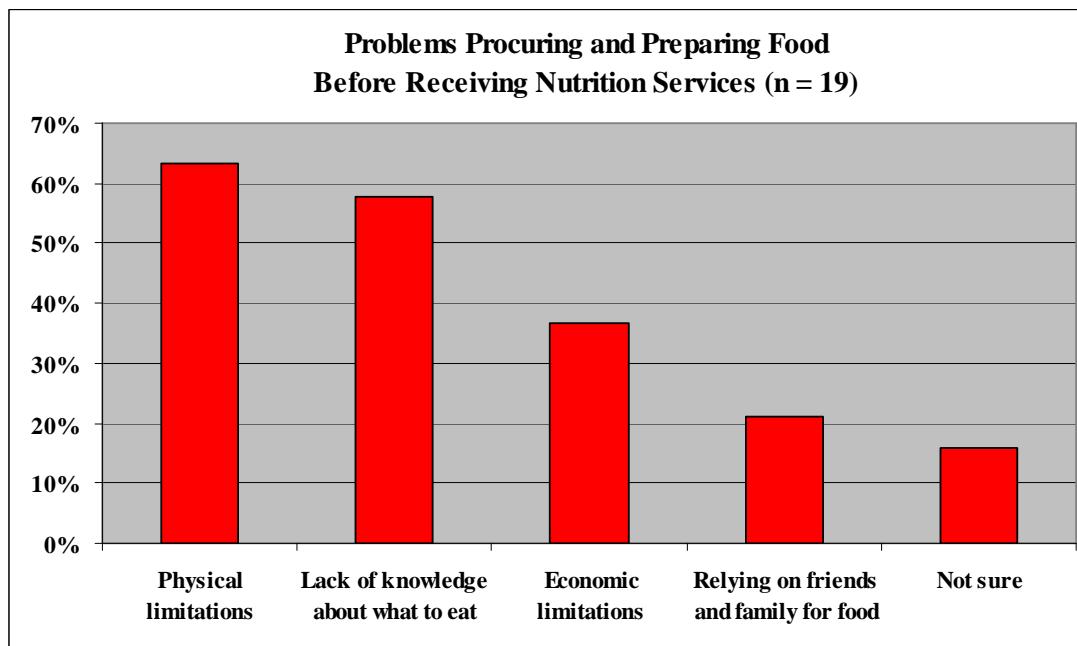
Clients also experienced an improvement in their quality of life because nutrition services eliminated the barriers to food security that clients previously faced. During the final visit, clients were asked about the challenges of procuring and preparing food before receiving nutrition services ($n = 19$); their responses were grouped into four categories: physical limitations, a lack of knowledge about what to eat, economic limitations, and a reliance on family and friends for food. As Graph 8 illustrates, more than 60 percent of clients were too sick to procure and prepare food. A similar proportion had a lack of knowledge about what to eat, 38 percent did not have enough money for food, and approximately 20 percent

A 46 year old mother of seven who receives treatment for colon cancer finds it difficult to cook due to chemotherapy treatments that make her extremely sensitive to hot and cold temperatures. She said, "*The food makes it easier for me – it's a lot of help – 100 percent help – because I don't have to worry about cooking or what I am going to eat or what my kids are going to eat...[when] my hands hurt and I am by myself and my kids can't help me cook something, I can just go into the bag and get something...[and] the kids can come home and just eat what they want, I don't have to worry.*"

A 45 year old man living with HIV/AIDS and renal disease said that nutrition services eliminated his major source of stress – not having enough money to pay for food. He explained, "*[Since I started getting food] life is a lot better. I didn't have money for food before, so everything is 100 percent better now.*"

relied on friends and family for food. Eleven percent of clients were unable to identify the reason(s) for their food insecurity.

Graph 8. Problems Procuring and Preparing Food Before Receiving Nutrition Services



During the final interview, clients were also asked to identify the benefits of nutrition service for themselves and their families. In almost every case, the immediate response was “I don’t have to cook anymore,” but every client supplemented this with multiple additional benefits. As Graph 9 illustrates, the

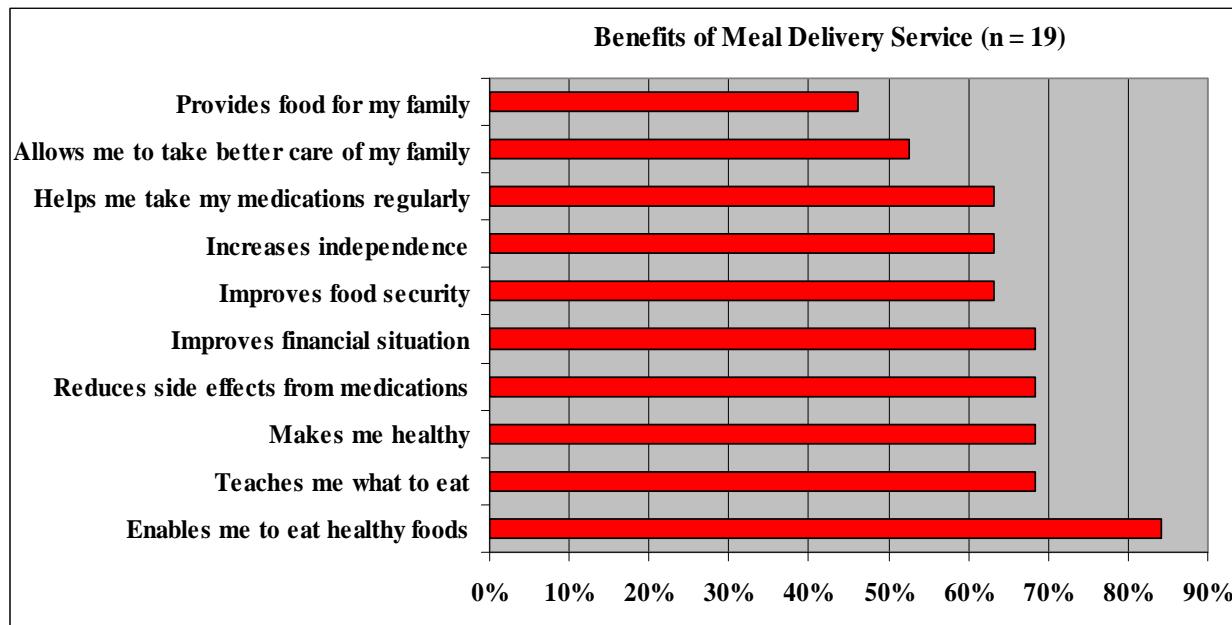
A 47 year old woman living with breast cancer who went into remission during the course of the study said, “*I feel that I have more help to manage my illness now because it’s hard having cancer, and it’s stressful day by day, and I don’t want it to come back. The food helps me take care of myself so I can stop it from coming back.*”

greatest perceived benefit of nutrition service was the provision of healthy foods, followed by greater knowledge of nutrition, better health, fewer side effects from medications, greater financial security, greater food security, increased independence, an enhanced ability to take medications regularly, improved ability to care for family, and food for

A 38 year old male client living with HIV/AIDS said, “*The food has helped a lot. It has helped me to understand a lot of things, like how fortunate I can be and how less fortunate I can be. I am learning to take things one day at a time. And my life is less stressful because I don’t have to depend on [my friends] for food. It makes me more independent*”

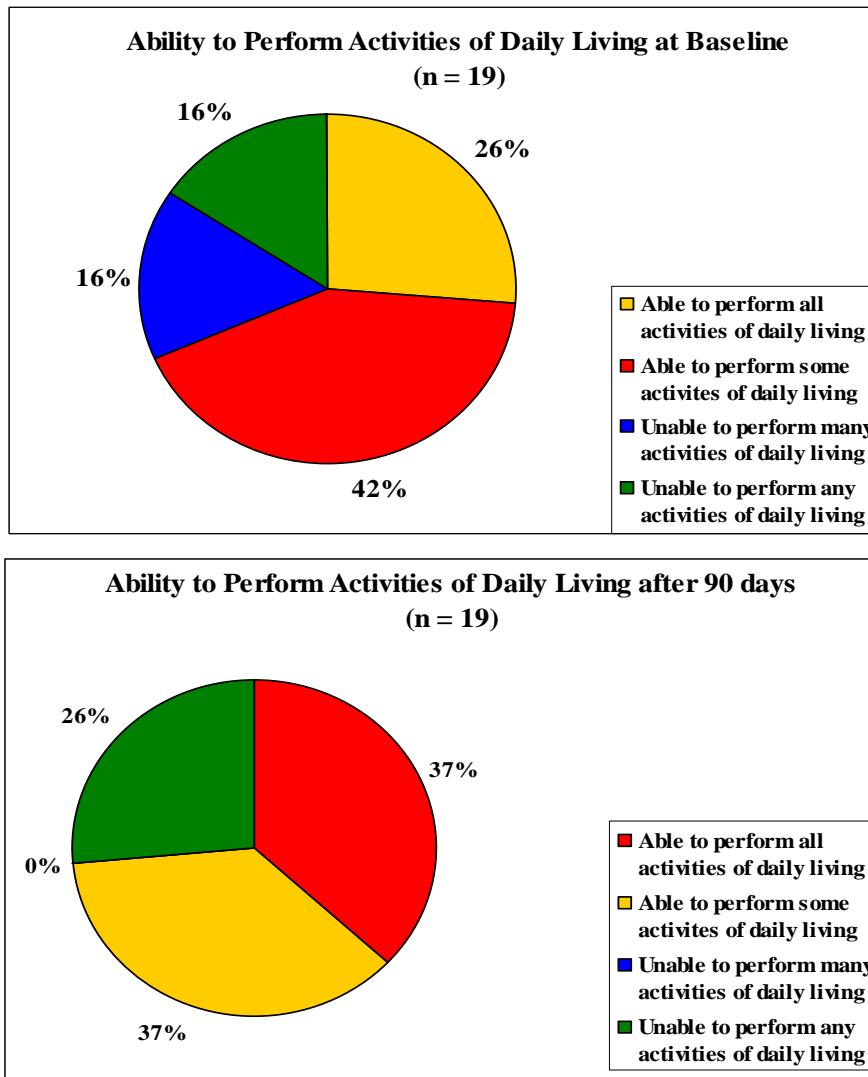
family to eat. The benefits clients identified indicate that nutrition service eliminated nearly every barrier to food security that clients previously faced, along with many additional benefits that improved quality of life.

Graph 9. Benefits of Meal Delivery Service



Some clients were more able to perform activities of daily living after 90 days of comprehensive nutrition support than before receiving nutrition services. During the initial interview ($n = 19$), 26 percent reported they were able to perform all activities of daily living. After 90 days of nutrition support, 37 percent reported they were able to perform all activities of daily living (see graphs 10 and 11). Two clients who experienced an improvement in their functional status indicated it was the result of having enough food to eat, which reduced their fatigue. At the same time, the proportion of clients who were unable to perform any activities of daily living increased from 16 percent during the first interview to 26 percent during the final interview. The clients who experienced this decline are living with cancer, were hospitalized at some point between the first and final visits, or experienced a change in their medical prognosis.

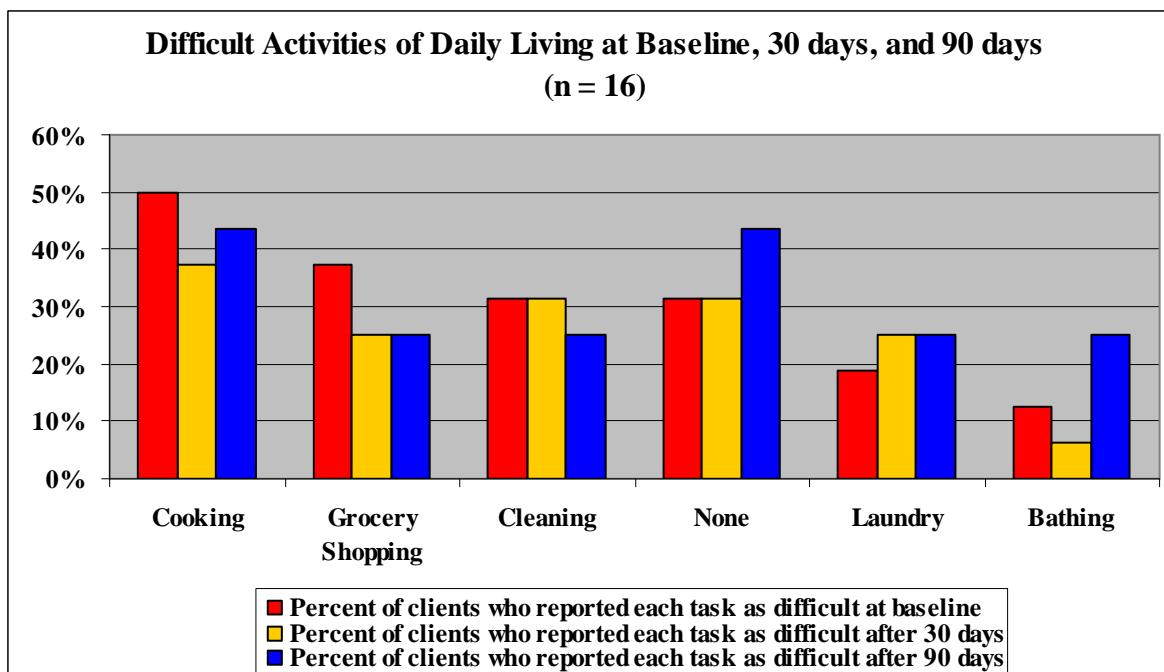
Graphs 10 and 11. Ability to Perform Activities of Daily Living



During the first, second, and final interviews, study participants were asked to describe the specific activities of daily living they found difficult ($n = 16$). As Graph 10 illustrates, the proportion of clients who found each task difficult varied across the three time periods without much consistency. Some tasks became easier and then became more difficult after one month, while other tasks became more difficult after three months. The percentage of clients who experienced no difficulties increased between the second and final interviews. Thus, nutrition service does not appear to have a significant impact on improving functional status, but it does make clients' lives easier by eliminating the need to cook and go grocery shopping.

A 50 year old man living with cancer of the head and neck who went into remission during the course of the study said, *"My life is easier since I started. The food helps because I don't need to figure out what to eat. And I can take better care of my family because I have more energy and I can work more."*

Graph 12. Percentage of Clients Reporting Difficulty with Tasks of Daily Living Baseline, 30 days, and 90 days



Discussion

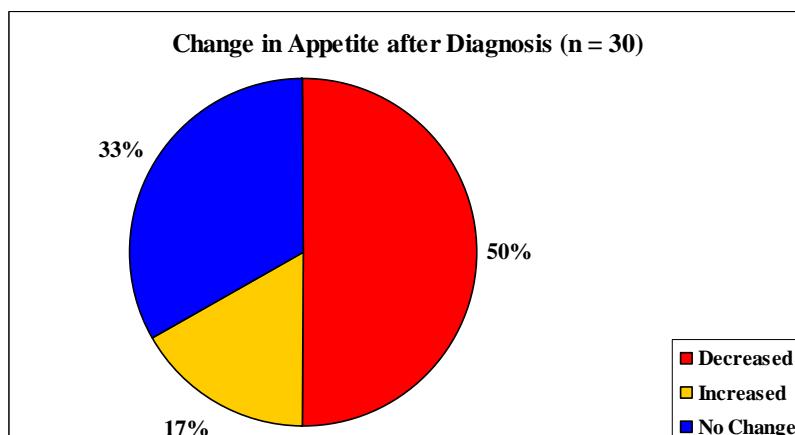
The quality of life improvements clients experienced were almost exclusively due to the provision of nutrition support. Throughout the interviews, clients continually reported that nutrition service made their lives easier and better because it enabled them to take care of themselves and their families; eliminated hunger and food insecurity; and reduced the need to perform difficult activities of daily living, like cooking and grocery shopping. Comprehensive nutrition support also had unintentional benefits, such as improving clients' financial security, which further improved their quality of life.

At the same time, the quality of life analysis revealed the limitations of nutrition service. Clients felt more able to take care of themselves, but most did not experience an improvement in their ability to perform the activities of daily living. This reinforces the importance of nutrition service, and demonstrates why many clients need nutrition support for an extended period of time. People living with life-challenging illnesses have long-term, physical impairments that prevent them from getting the sustenance they need. Nutrition support cannot heal the fundamental physical limitations that bring most clients to Food & Friends, but it can reduce stress, enhance independence, eliminate hunger, and give clients more energy to participate in their medical care.

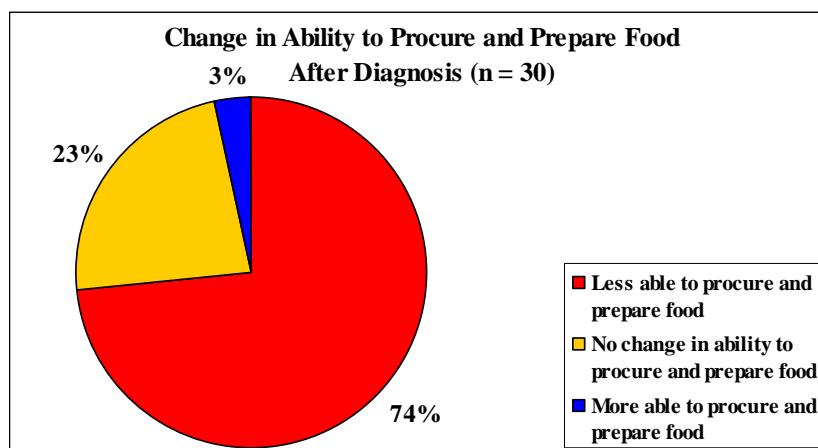
Food Intake and Knowledge of Nutrition

Study participants experienced an improvement in the quantity and quality of their food intake, as well as an increase in their knowledge of nutrition. During the first interview, clients ($n = 30$) were asked to describe how their appetite and ability to procure and prepare food changed when they were diagnosed with their illness or last hospitalized. As Graph 13 illustrates, 50 percent of all study participants experienced a decrease in their appetite, while 17 percent experienced an increase, and 33 percent experienced no change. The overwhelming majority of clients, nearly 75 percent (see Graph 14), were less able to procure and prepare food after their diagnosis or most recent hospitalization. One client who was more able to procure and prepare food explained that his HIV/AIDS diagnosis forced him to take better care of himself.

Graph 13. Change in Appetite after Diagnosis



Graph 14. Change in Ability to Procure and Prepare Food after Diagnosis

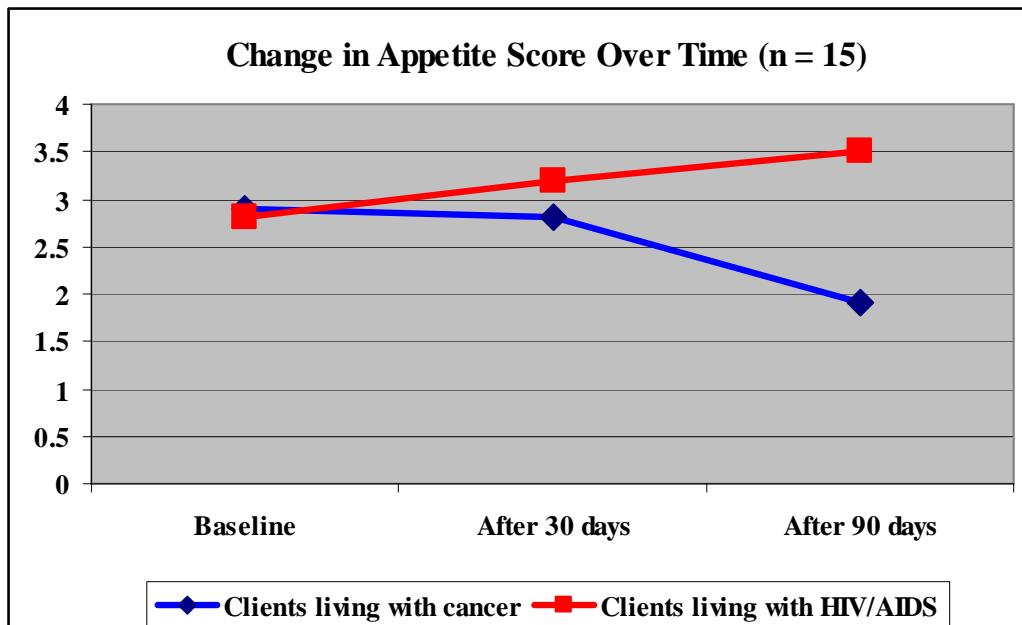


After 30 days and 90 days of nutrition support, study participants were asked to rate changes in their appetite. Clients assigned a numerical score to their appetite on a scale of one to four, with one representing a poor appetite and four representing an excellent appetite. Clients living with cancer ($n = 9$) had a mean appetite score of 2.9 during the first visit,

2.8 after 30 days of service, and 1.9 after 90 days of service. Cancer clients who experienced a decrease in appetite generally attributed it to the intensity of chemotherapy or radiation treatments and the progression of disease. It may also be the case that 90 days is not sufficient time for cancer patients to experience improvements in their appetites, as two of the nine cancer clients included in this analysis have since reported their appetites have improved. Clients living with HIV/AIDS experienced a consistent improvement in their appetite ($n = 6$), with a mean appetite score of 2.8 during the first visit, 3.2 after 30 days, and 3.5 after 90 days.

A 79 year old woman living with cancer of the head and neck has had a very difficult time maintaining her weight due to a constant feeling of fullness. It is a relief for her to know there is food available when she is able to eat. She said, *"My doctor told me to drink three Ensure every day to gain weight, but I just can't do that. I eat the cakes you deliver whenever I can...The food very much takes away some stress. If I get hungry, I just stick the food in the microwave, so it helps a lot."*

Graph 15. Change in Appetite Score Over Time



A 62 year old woman living with lung cancer noted that although she rarely feels like eating because she is worried about her illness, she makes more of an effort now that the food is easily available. She said, “*The food helps my stress because it encourages me to eat when my mind is not on food.*”

Despite the decreasing appetite score among clients living with cancer, almost 60 percent of clients who participated in the second interview ($n = 19$) reported their appetites improved over the month and 63 percent reported an increase in their food intake. A greater proportion, 84.2 percent, reported an improvement in their ability to procure and

prepare food. Clients who had a low appetite score before receiving nutrition service indicated they were more likely to eat after receiving nutrition services than before since the food became readily available and tasty.

Almost 80 percent of clients who participated in the second interview reported the quantity and quality of their diets improved. Clients felt the quality of their diets improved for a variety of reasons, including improved access to food, increased diversity of food choices, and increased availability of healthy and unprocessed foods. In addition to the provision of healthy foods, clients indicated medical nutrition therapy helped them adopt healthy eating habits. As discussed in the section on health and symptom management, approximately 68 percent of clients who participated in the final interviews ($n = 19$) reported they took suggestions from their dieticians that improved their health. Specific suggestions clients mentioned included eating citrus foods to manage chemotherapy-related taste changes; cutting out fats and sweets; drinking diet soda instead of regular; and filling up on whole, high-fiber foods. Clients seeking to gain weight mentioned strategies such as putting ice cream in Ensure drinks and topping bread with peanut butter.

When clients were asked about their knowledge of nutrition during the final interview ($n = 19$), nearly 85 percent reported they knew more about nutrition after receiving nutrition support than before. Almost 95 percent of clients who participated in the final interview

A 67 year old man who has been living with HIV/AIDS for more than 20 years, and was recently diagnosed with Parkinson’s disease and severe anemia, said, “*I wasn’t any good at picking out nutritious foods, [and] I was content with cooking whatever I felt like...but I didn’t feel like cooking healthy foods. And then when my anemia got really bad, I just felt tired all the time. But now my health is better with the food.*”

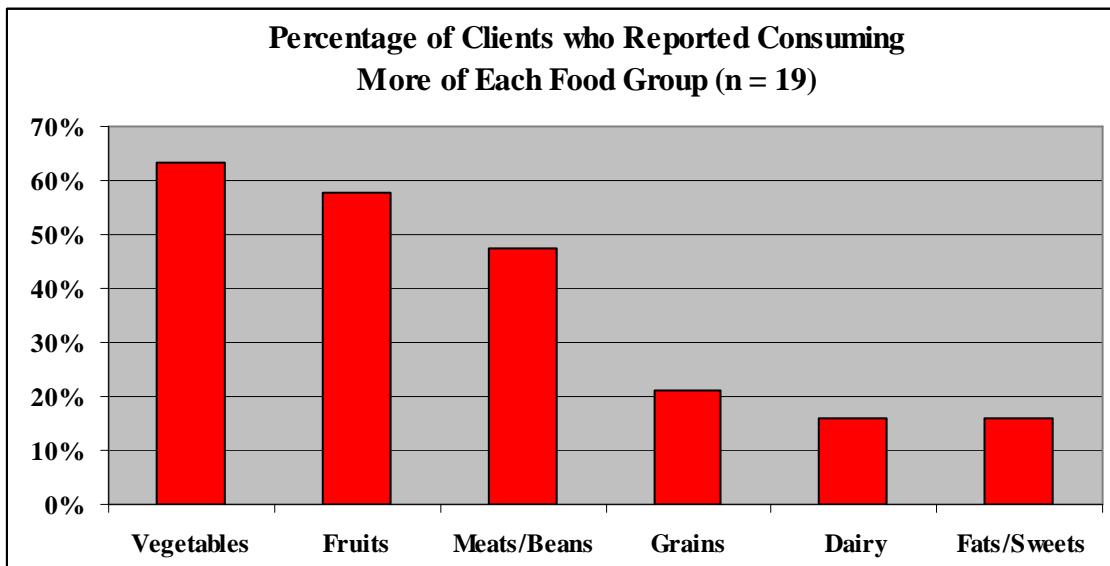
indicated they made more of an effort to eat healthy after receiving nutrition support than before. Many clients noted that although they always knew fruits and vegetables are essential for a

A 47 year old woman living with breast cancer noted that she has learned about healthy eating since she started getting meal delivery service. She saves each menu so she will know which healthy foods to buy at the grocery store once she recovers from cancer and is able to cook again. *She said, "I have learned a lot because before I would just run out to McDonalds or Popeye's or KFC, but after starting food delivery service I find out that these foods are not healthy for me and that I need to eat better. Now I don't have to worry about eating anything bad and I can learn about healthy foods."*

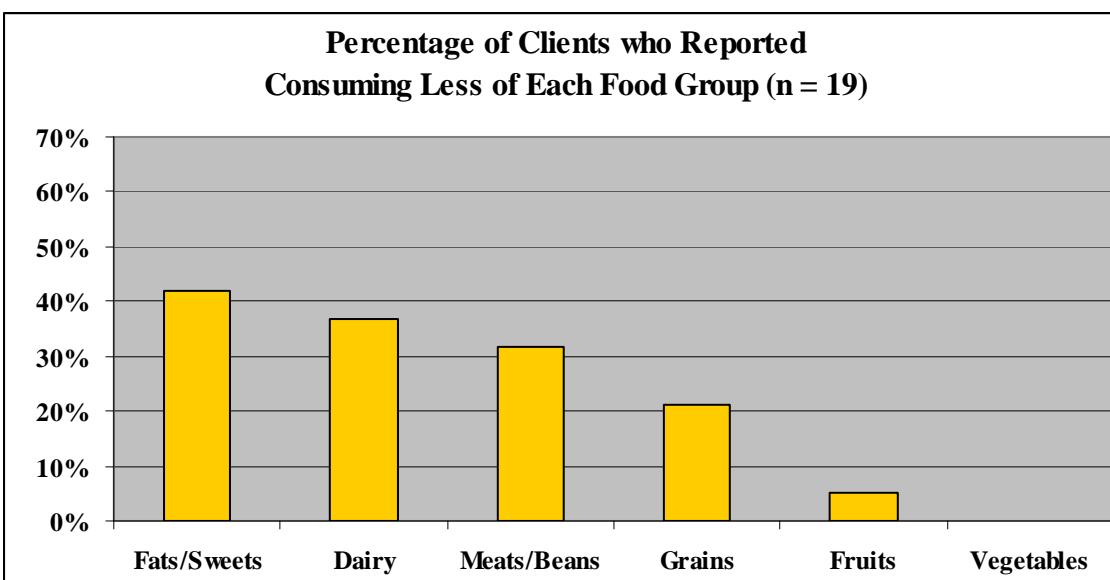
healthy diet, they either did not think about their food choices or did not have the physical or economic capacity to purchase these nutritious foods. During the final interview, clients described how their food choices changed after they started receiving nutrition support. They were asked to determine whether they were eating more, less, or the same amount of vegetables, fruits, meats or

beans, grains, dairy, and fats or sweets. As Graphs 16 and 17 illustrate, the provision of healthy foods, along with nutrition counseling, led many clients to change their food choices. More than 60 percent increased their intake of vegetables, followed by an increase in the consumption of fruit, meat and beans, grains, dairy, and fats and sweets. At the same time, clients also reported reduced intake of many food groups. Over 40 percent reduced their consumption of fats and sweets, followed by dairy, meat and beans, grains, and fruits; no clients reported a decrease in their intake of vegetables. These changes in food intake indicate clients began making healthier food choices, including eating more fruits and vegetables. Three clients reported no change their food choices.

Graph 16. Percentage of Clients who Consumed More of Each Food Group



Graph 17. Percentage of Clients who Consumed Less of Each Food Group



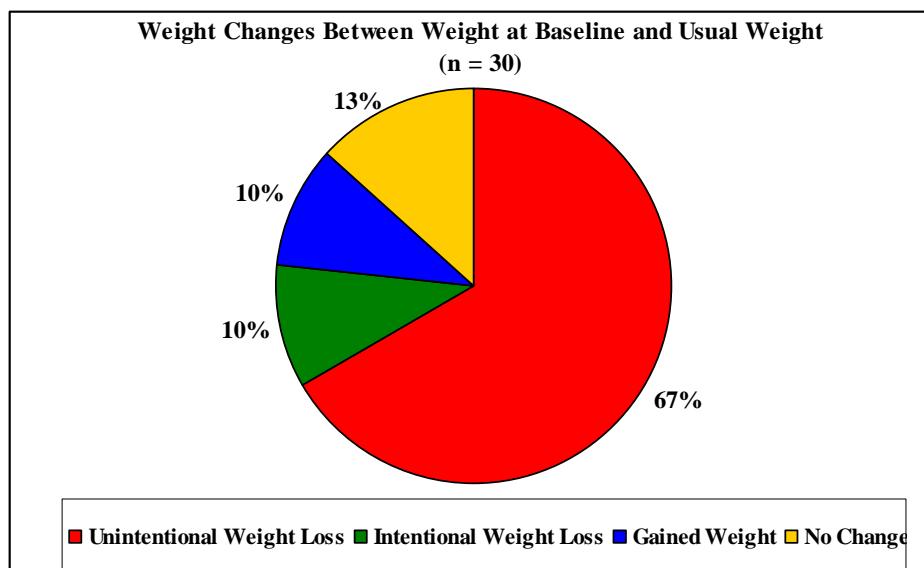
Discussion

Nutrition service helped study participants access healthy foods and gave them the information they needed to make medically appropriate food choices. Most clients indicated they ate less after they were diagnosed with their illnesses, and many experienced an increase in food insecurity. Reasons for food insecurity were a physical inability to grocery shop, cook, or prepare specialized meals; a lack of knowledge about what to eat with an illness; and a lack of money for food. Malnutrition among people living with a life-challenging illness is problematic because illness increases the body's calorie requirements, while decreasing appetite and ability to consume an appropriate diet.^{xxxiv} Over time, this mismatch between calorie requirements and consumption can lead to significant, and dangerous, weight loss.^{xxxv} Food & Friends' services eliminated food insecurity among study participants, informed clients about medically appropriate food choices, and enabled clients to eat meals that met their unique health needs.

Weight Stabilization

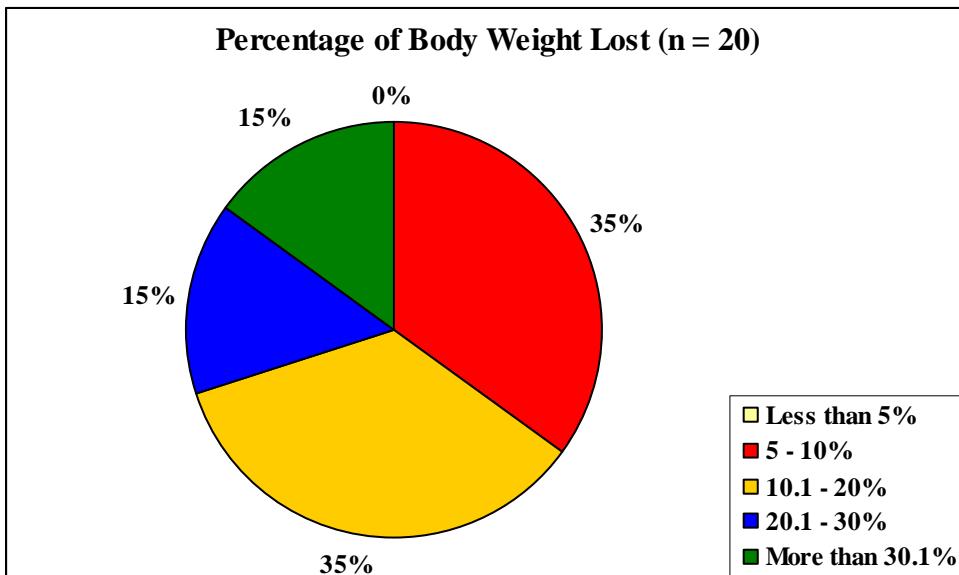
The majority of study participants lost a significant amount of weight after they were diagnosed with their illnesses or in the six months before the first interview. During the initial home visit, interviewers measured each client's weight and collected information about weight history, including what each client considers his or her usual weight to be. As Graph 18 illustrates, 67 percent of study participants experienced unintentional weight loss (defined as the unintentional loss of more than 1.5 kg, or 3.3 lbs)^{xxxvi}, 10 percent had intentional weight loss, 10 percent gained weight, and 13 percent had no change in their weight. The average self-reported weight loss was 30.8 lbs, and the median weight loss was 22 lbs.

Graph 18. Weight Changes Between Weight at Baseline and Usual Weight



Of the 67 percent that experienced unintentional weight loss, 35 percent lost between 5 and 10 percent of their body weight, 35 percent lost between 10 and 20 percent of their body weight, 15 percent lost between 20 and 30 percent of their body weight, and 15 percent lost more than 30 percent of their body weight. The mean percent body weight lost was 16.5 percent and the median body weight lost was 14.7 percent. Based on standard dietetic guidelines, 70 percent of those who unintentionally lost weight experienced severe weight loss, and 30 percent experienced significant weight loss.^{xxxvii}

Graph 19. Percentage of Body Weight Lost



Clients' weights were also analyzed based on standard Body Mass Index (BMI) guidelines, which take height and weight into account to determine standardized weight status. According to these guidelines, a BMI of less than 20 indicates an individual is underweight, a BMI between 20 and 25 indicates an individual is at a healthy weight, a BMI between 25 and 30 indicates an individual is overweight, and a BMI of greater than 30 indicates an individual is obese.^{xxxviii} Based on these guidelines, 20.7 percent of clients were underweight at the first interview, 41.4 percent of clients were at a healthy weight, 13.8 percent of clients were overweight, and 24.1 percent of clients were obese.

The BMI distribution of clients living with HIV/AIDS was different than the distribution of clients living with cancer. As Table 3 shows, 60 percent of clients living with HIV/AIDS were overweight or obese, while only 26.3 percent of clients living with cancer were overweight or obese. The most likely explanation for this difference is that almost twice as many clients living with cancer as clients living with HIV/AIDS experienced unintentional weight loss prior to receiving our services. Many cancer clients who were previously overweight or obese moved into the healthy weight category as a result of their unintentional, severe weight loss.

Table 3. Weight Changes and Body Mass Index

Weight Loss among All Clients (n = 30)	
Unintentional Weight Loss*	67.0%
Intentional Weight Loss	10.0%
Gained Weight	10.0%
No Change	13.0%
Mean Weight Loss (lbs)	30.8lbs
Median Weight Loss	22.0lbs
Percent of Cancer Clients with Unintentional Weight Loss	80.0%
Percent of HIV/AIDS Clients with Unintentional Weight Loss	40.0%
Percent of Weight Lost among Clients with Unintentional Loss (n = 20)	
Less than 5 %	0.0%
5.0 % to 10%	35.0%
10.1% to 20%	35.0%
20.1% to 30%	15.0%
Greater than 30%	15.5%
Mean Percent Body Weight Lost	16.5%
Median Percent Body Weight Lost	14.7%
Extent of Weight Loss (n = 20)	
Severe Weight Loss**	70.0%
Significant Weight Loss***	30.0%
Body Mass Index Status at Baseline for all Clients (n = 29)	
Underweight	20.7%
Healthy Weight	41.4%
Overweight	13.8%
Obese	24.1%
Body Mass Index Status at Baseline for HIV/AIDS Clients (n = 29)	
Underweight	10.0%
Healthy Weight	30.0%
Overweight	40.0%
Obese	20.0%
Body Mass Index Status at Baseline for Cancer Clients (n = 29)	
Underweight	26.3%
Healthy Weight	48.4%
Overweight	0.0%
Obese	26.3%

*Defined as the loss of ≥ 1.5 kg, or 3.3 lbs

**Severe weight loss defined as $>$ than 5% body weight lost over 1 month, $>7.5\%$ body weight lost over 3 months, $>10\%$ body weight lost over 6 months.

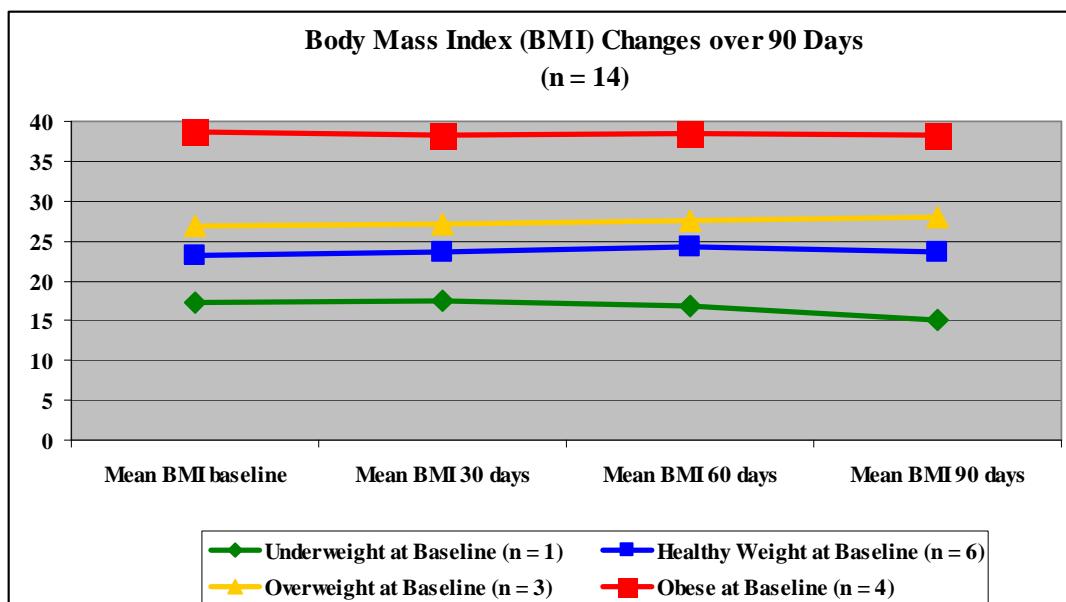
***Significant weight loss defined as $\leq 5\%$ over 1 month, $\leq 7.5\%$ over 3 months, $\leq 10\%$ over 6 months.

A 62 year old woman living with lung cancer and diabetes expressed that her doctor is very happy that nutrition services have improved her health. She said, *“My endocrinologist is really impressed with how stable my weight and blood sugar have stayed since I started on service.”*

The goal of medical nutrition therapy is to help clients achieve and maintain optimal body weight. Most clients, however, were not able to achieve optimal body weight due to difficult medical treatments, an inability to eat, and an inability to exercise. But study participants were able to maintain their weight. Based on clients who participated in all four interviews, it appears that comprehensive nutrition support enabled most clients to achieve weight stabilization.

Graph 20 illustrates average changes in body weight over time for clients who were underweight, at a healthy weight, overweight, and obese at baseline.

Graph 20. Body Mass Index Changes over 90 Days



A 55 year old woman living with lymphoma indicated that meal delivery service has helped her regain some of the weight she lost and achieve weight stabilization. She said, "*I don't lose weight [anymore]. I've gained about 10 lbs since I started, which is good since I lost a lot of weight at first.*"

The data indicate that underweight clients were at especially high risk of malnutrition, even after they began to receive nutritional support. The one underweight client who was able to complete all four interviews continued to experience weight loss because she could not tolerate food. Two of the initial six underweight clients passed away within two months of starting nutrition services, and a third was hospitalized long-term

due to concerns about his weight. Comprehensive nutrition support is extremely important for underweight clients because it increases the likelihood they will consume some nutrients, even though it may not ultimately make a significant difference in their health outcomes.

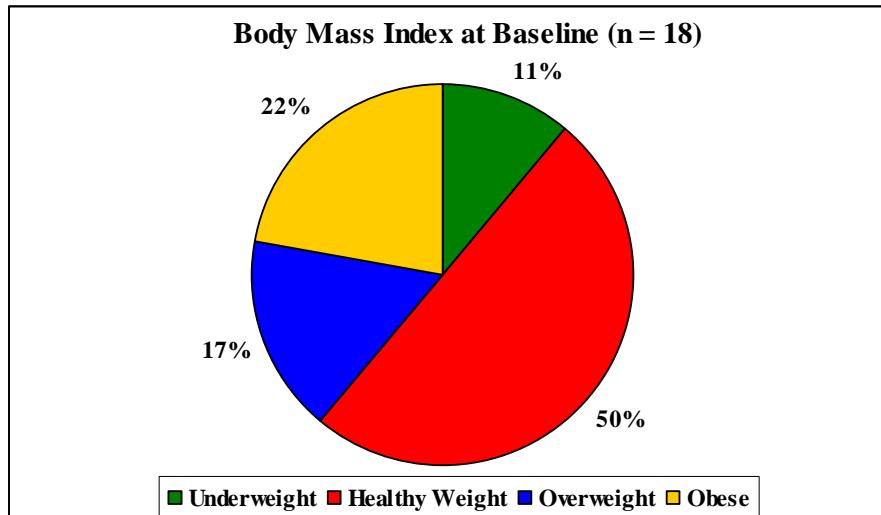
Healthy weight clients maintained their weight, with only slight fluctuations in BMI. Overweight clients experienced the most substantial change in BMI and went from a mean BMI of 26.8 to 28.1. Two of the three overweight participants stayed relatively stable, but one participant who was recovering from HIV wasting syndrome gained 24.5 lbs over the course of 90 days, bringing him back up to his usual weight. Obese clients maintained their BMI, although two of the four obese clients began to achieve their weight loss goals.

Most clients who were able to participate in the first and last interviews achieved weight stabilization and did not move from one BMI category to another, but two clients did experience changes. One client recovering from Pneumocystic carinii Pneumonia (PCP) and HIV wasting syndrome gained more than 20 lbs during his first six weeks on service and moved from the healthy weight category to the overweight category. Another client was diagnosed with lung cancer four months before receiving nutrition service and has been in hospice ever since. He was able to maintain his weight during the first three visits, but lost a significant amount of weight by the fourth visit, despite having adequate food intake. Graphs 21 and 22 illustrate this

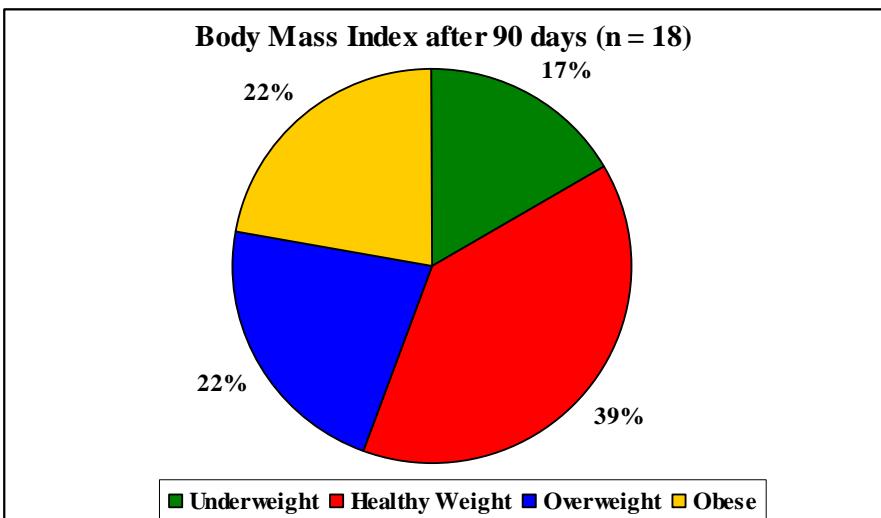
A 44 year old man living with HIV/AIDS, who was hospitalized with Pneumocystis carinii Pneumonia (PCP) and HIV wasting syndrome just before starting meal delivery service, said, "*My doctor is very happy that I have put on some weight, but now he thinks I could lose a few pounds...but he is very happy about the food delivery service and he thinks it will improve my health outlook.*"

shift; 50 percent of clients were at a healthy weight during the initial interview, and 39 percent of clients were at a healthy weight during the final interview. The proportion of underweight clients increased from 11 percent to 17 percent, and the proportion of overweight clients increased from 17 percent to 22 percent.

Graph 21. Body Mass Index at Baseline



Graph 22. Body Mass Index after 90 Days



Discussion

Nutrition services promoted weight stabilization, though some clients were not able to achieve their ideal body weight. Numerous medical studies demonstrate it is difficult for people living with life-challenging illnesses to maintain their body weight.^{xxxix} Before receiving nutritional support, many clients experienced severe weight loss and some continued to lose weight even after receiving comprehensive nutrition support. But the majority of participants achieved weight stabilization over the course of 90 days. This is critical because weight maintenance protects muscle mass, which is essential to fight illness and metabolize medications.^{xli}

Based on the results of this study, clients living with cancer appear to be at higher risk of weight loss and malnutrition than clients living with HIV/AIDS. This may be misleading because the proportion of overweight and obese clients living with HIV/AIDS might over-represented in the population of study participants. Studies have shown that excess weight on people living with HIV/AIDS can have a protective effect, and being overweight is associated with a higher CD4 count and lower viral load.^{xli} Since overweight clients are expected to feel better than healthy weight or underweight clients, it is possible that they are over-represented in the sample of study participants. The incidence of weight loss among study participants living with HIV/AIDS, however, is similar to the incidence reported in medical literature.^{xlii}

Clients living with cancer who experienced significant weight loss may also be over-represented among Food & Friends' clients. Physicians and case managers may be more likely to refer patients who have lost a significant amount of weight to Food & Friends than patients who are independently able to maintain their weight. This seems especially likely since 80 percent of study participants with cancer experienced unintentional weight loss, while other studies have reported an incidence rate around 50 percent.^{xliii}

Although clients achieved weight stabilization, most did not achieve optimal body weight. This is partially due to the fact that most overweight and obese clients were advised by their dieticians to focus on maintaining weight rather than achieving ideal weight due to debilitating symptoms and inability to exercise. Additionally, healthy weight and overweight clients seemed to take great pride in gaining weight because they associate a lower weight with

sickness and hospitalization, though it is not clear why. This may explain why some healthy weight and overweight clients continued to put on modest amounts of weight. Finally, although 90 days was sufficient time for most clients to achieve weight stabilization, it may not be enough time for clients to gain or lose enough weight to achieve optimal weight status. It is clear, however, that nutritional interventions are critical to prevent weight loss and associated health complications.

Body Composition

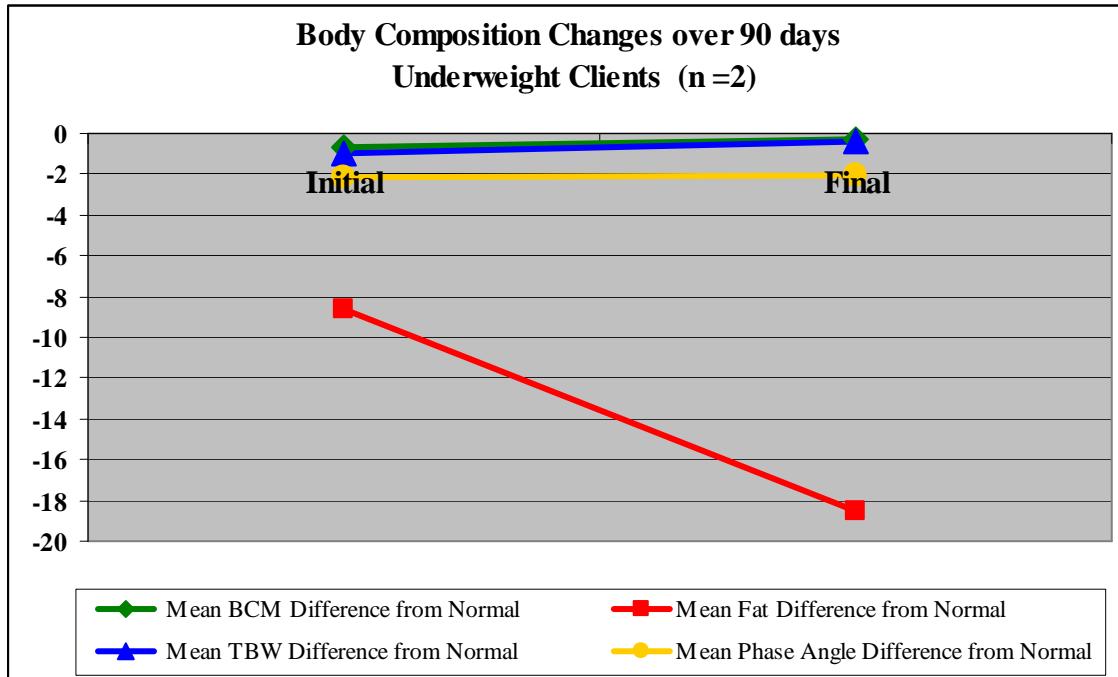
The body composition test provides an estimate of body muscle, fat, and water stores, as well as a measure of overall cellular health (see pages 6-7 for a more detailed description).^{xliv} Clients' body composition goals were based on their weight at baseline. The results of the body composition test were grouped according to weight status during the initial interview. Broadly, an increase in body cell mass (BCM) is always an improvement. An increase in body fat is an improvement for underweight clients, while the loss of fat represents an improvement for overweight or obese clients. Total body water (TBW) values should indicate adequate hydration, and a high phase angle represents cellular health. The individual results of the body composition test were grouped together by weight category and an average value was calculated for each group. Table 4 lists the difference between the mean group values for BCM, fat, TBW, and phase angle and the normal expected value initially and after 90 days.

Table 4. Body Composition Results

	Initial BCM (lbs)	Final BCM (lbs)	Initial Fat (lbs)	Final Fat (lbs)	Initial TBW (lbs)	Final TBW (lbs)	Initial Phase Angle	Final Phase Angle
Underweight	-.65	-.25	-8.6	-18.5	-1	-.35	-2.2	-2.1
Healthy Weight	-.5	1.6	6.9	9.2	2.6	2.6	-2.1	-1.5
Overweight	.55	4.1	18.4	28.6	3.25	4.1	-2.05	-1.5
Obese	14.4	13.7	72.5	71.7	11.9	12.1	-.25	-.5

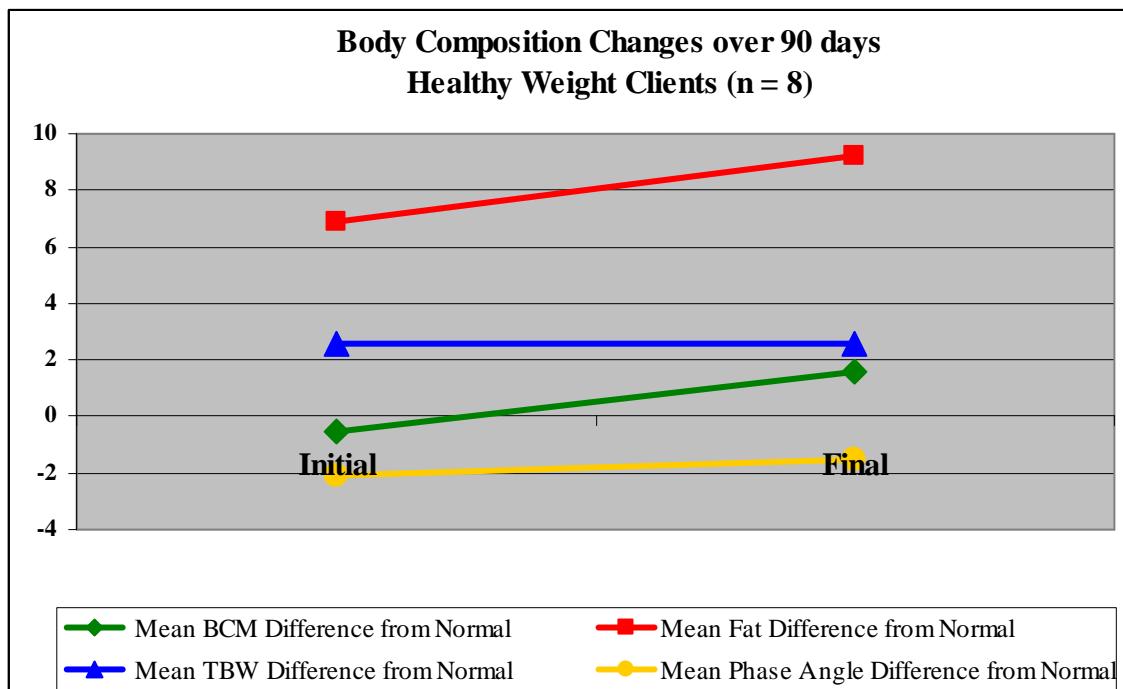
Underweight clients ($n = 2$) are at substantial risk for malnutrition and continued weight loss. As graph 23 illustrates, the two underweight clients who were able to participate in the final phase of the study continued to lose fat. Underweight clients initially had average fat stores 8.6 lbs below the normal expected value, and after 90 days their average fat stores were 18.5 lbs below the normal expected value. Underweight clients did, however, experience slight improvements in their BCM, TBW, and phase angle values. The slight increase in BCM is particularly noteworthy since medical literature indicates that people who are experiencing disease related malnutrition are at high risk of losing lean body mass.^{xlv} The fact that these underweight clients were able to maintain their muscle mass, despite losing a significant amount of fat, suggests that nutritional intervention may prevent the depletion of muscle mass.

Graph 23. Body Composition Changes over 90 days for Clients who are Underweight

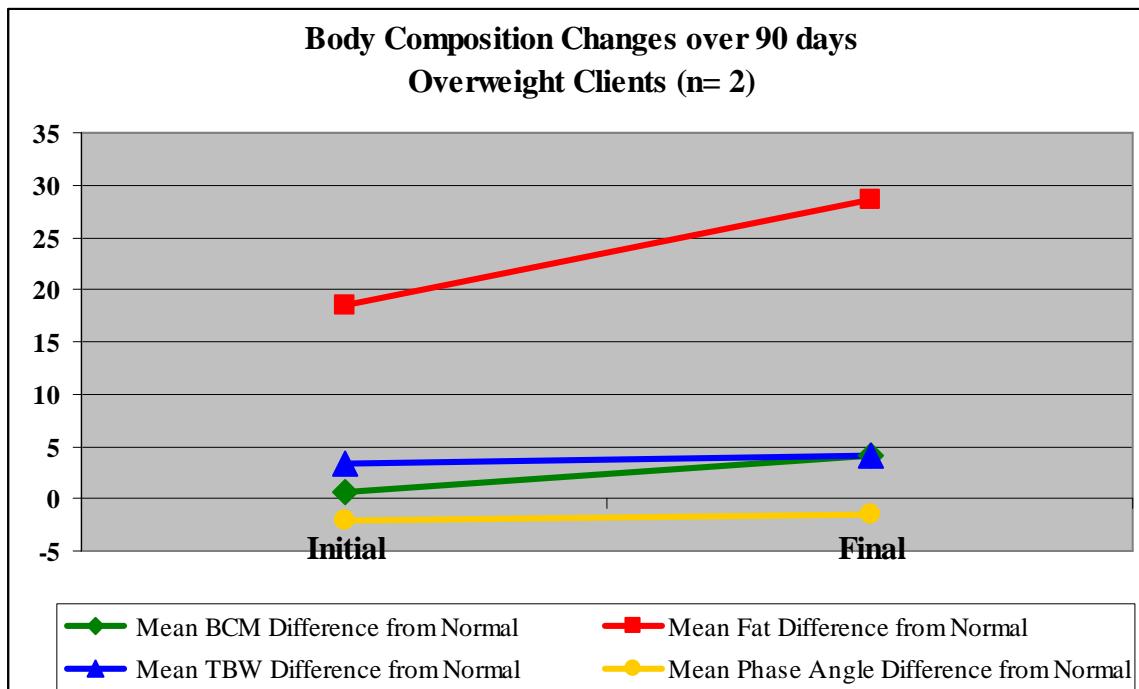


Clients who were initially at a healthy weight ($n = 8$) remained relatively stable, though they experienced a slight increase in their mean BCM, fat, and phase angle values. The slight increase in BCM is noteworthy because it brought the mean value from below the expected value to just above the expected value. Clients who were overweight ($n = 2$) gained BCM. Mean fat also increased, although the mean value in this case is slightly misleading. One client who was recovering from HIV wasting syndrome put on a significant amount of weight, while the other remained stable. TBW and phase angle also increased.

Graph 24. Body Composition Changes over 90 Days for Clients who are Healthy Weight

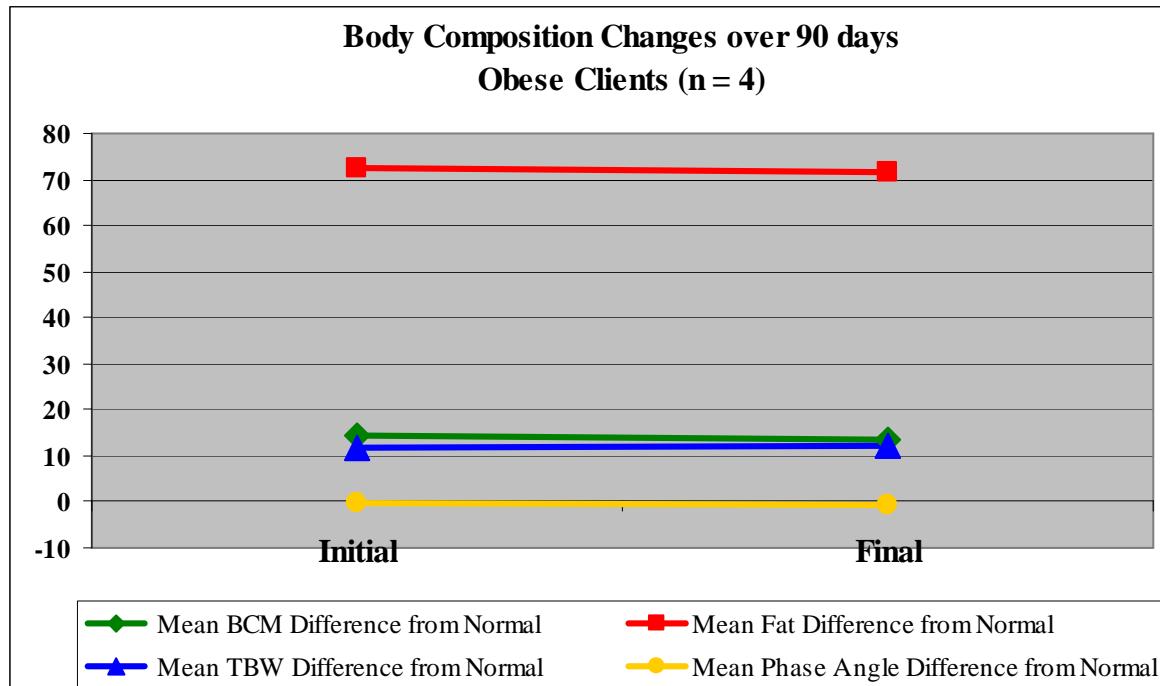


Graph 25. Body Composition Changes over 90 Days for Clients who are Overweight



Obese clients ($n = 4$) experienced a slight decrease in BCM and a slight decrease in fat. Two of the four obese clients gained BCM, while two lost both fat and BCM. It is likely that the weight loss these clients achieved occurred through a combination of fat and muscle depletion, which is not uncommon with intentional weight loss.^{xlvi}

Graph 26. Body Composition Changes over 90 Days for Obese Clients



Discussion

Study participants were able to maintain their body cell mass, although there was greater variation in the maintenance of body fat stores. Underweight clients lost a significant amount of fat, while healthy weight and overweight clients gained fat. The increase in fat stores that healthy weight and overweight clients experienced is not surprising because studies have demonstrated that nutrition intervention typically results in a higher percentage of body fat.^{xlvii} But it is surprising that underweight, healthy weight, and overweight clients were able to maintain or gain BCM because disease-related malnutrition and weight loss tend to preferentially deplete muscle tissue over adipose tissue.^{xlviii} Moreover, most clients who had an initial BCM value below expected had a final BCM value at or above expected. This has significant health implications because maintenance of BCM is important for medical treatment since the

metabolism of nutrients and medications occur primarily in the muscular tissues of the body.^{xlix} In addition, the loss of lean body mass has been associated with increased mortality, accelerated disease progression, and loss of functional status.^l

It is not clear what role nutrition services play in maintaining BCM, but there are several possibilities. First, many healthy weight and overweight clients experienced increases in body fat, and maintaining BCM may be necessary to support the additional fat. This is not a complete explanation, however, because even underweight clients who lost fat managed to maintain their muscle stores. Second, studies have demonstrated that symptoms such as diarrhea or vomiting are associated with a loss of essential nutrients and muscle depletion. The decrease clients experienced in many of their symptoms, including diarrhea and vomiting, enabled them to increase their intake of essential nutrients and prevent muscle depletion.^{li} Finally, protein intake is critical to maintain BCM. Many people living with a life-challenging illness have a poor diet, and comprehensive nutrition support may have enabled clients to eat more protein and maintain their BCM.^{lii}

Conclusion

The results of this study demonstrate that comprehensive nutrition support is an effective and necessary supplement to medical treatment. The nutritional standards for people living with life-challenging illnesses are well documented in medical literature, but these standards can be difficult to meet for individuals who are physically or financially unable to procure and prepare an appropriate diet.^{lvi} Food & Friends addresses the nutritional challenge that people living with life-challenging illnesses face by providing medical nutrition therapy and home-delivered meals. Nutrition service helps patients manage disease and achieve improved health outcomes by reducing symptoms and nutritional risk; improving the quantity and quality of food intake; promoting stable weight and body composition; and increasing independence and food security. Many clients experienced dramatic improvements in their health and overall sense of well-being. Even some of the sickest clients who continued to face tremendous challenges felt nutrition improved their health.

At the same time, this study also demonstrates some limitations of comprehensive nutrition support. We must be as realistic as we are hopeful about what nutrition support can achieve. Medical nutrition therapy cannot reverse the progression of disease or replace medical treatment. But it can ensure that patients have the opportunity to access medically appropriate diets and nutrition information, which can maximize health outcomes, improve quality of life, and reduce the incidence of expensive hospitalizations.

Underweight clients are at significant risk of malnutrition and weight loss, even after receiving nutrition services. Throughout the study, it was clear that clients who were underweight faced tremendous nutritional challenges, including more symptoms, such as diarrhea, vomiting and fatigue, and an inability to consume an appropriate amount of food. Nutrition services did not have a significant impact on health outcomes for underweight clients, but home-delivered meals and medical nutrition therapy were still important. Underweight clients in this study reported they benefited from medical nutrition therapy and were more likely to eat because the food was readily available. Clients who are underweight may also benefit from aggressive nutritional interventions, such as more frequent phone calls or home visits.

Clients living with HIV/AIDS experienced dramatic improvements in their health and quality of life, while clients living with cancer experienced modest improvements. Clients living with cancer faced significant nutritional challenges due to the debilitating effects of chemotherapy and radiation treatments. Although medical nutrition therapy reduced many symptoms, some clients living with cancer still had difficulties consuming their home-delivered meals after treatments due to nausea and vomiting. Providing an assortment of short-term dietary supplements to manage symptoms may be helpful. For example, clients who are experiencing nausea may benefit from a ‘symptom bag’ that includes foods known to curb nausea, such as crackers and ginger ale.

Nutrition services address the nutritional needs of people living with life-challenging illnesses, but clients have a variety of other socio-economic needs that impair their ability to manage and recover from illness. Study participants often asked interviewers for help with other social service needs, including healthcare, Social Security Disability Income (SSDI), food stamps, and housing. Staff dieticians spend a significant amount of time providing clients with referrals to other social service agencies, without having any assurance their needs will be met. Providing clients with access to on-site case managers will allow dieticians to focus exclusively on providing nutritional therapy and enable clients to access the services they need. This will maximize their physical and emotional health.

Clients enjoy the dependability and company that Food & Friends provides. Study participants had positive feelings towards comprehensive nutrition support because they felt the benefits were tangible and dependable. Many reported that nutrition services gave them a reliable schedule. Study participants also appreciated the home visits they received because it gave them companionship, and home visits enabled Food & Friends staff to better address clients' psychosocial and nutritional needs. Establishing a more permanent and regular home visitation program would allow all clients to receive the additional attention that study participants received.

Without comprehensive nutrition support, it is clear that the overwhelming majority of the study participants would not have had enough food to eat, or medically appropriate food to eat. As one client who is on the losing end of his battle with lung cancer stated, “Without the

service I wouldn't be eating as much because I only [get] about \$25 a month in food stamps...your service has made a huge difference." The resulting malnutrition would have left clients at risk of continued weight loss, a further compromised immune system, and in many cases, with a lower chance of survival. Addressing the food insecurity that fuels the cycle of disease and malnutrition cannot reverse the progression of illness, but it can dramatically improve quality of life by helping clients achieve improved health outcomes; stabilizing weight and body composition; and eliminating hunger.

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