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Personal Financial Effects of Multiple Myeloma and its Treatment

Julia A. Goodwin, PhD,
College of Nursing, University of Arkansas for Medical Sciences, Little Rock, AR

Elizabeth Ann Coleman, PhD,
College of Nursing, University of Arkansas for Medical Sciences, Little Rock, AR

Ellen Sullivan, MNSc,
Celgene Corporation, Little Rock, AR

Robin Easley, MNSc,
Tripler Army Medical Center, Honolulu, Hawaii

Paula K. McNatt, LPN,
College of Nursing, University of Arkansas for Medical Sciences, Little Rock, AR

Nupur Chowdhury, MA, and
Department of Pediatrics, College of Medicine, University of Arkansas for Medical Sciences, Little Rock, AR

Carol Beth Stewart, BS
Myeloma Institute for Research and Therapy, University of Arkansas for Medical Sciences, Little Rock, AR

Abstract

Background—Improvements in some treatment programs for multiple myeloma (MM) are increasing survival. As patients live longer with MM as a chronic disease, the personal financial effects of MM treatment become a serious concern.

Objective—The objective of this study was to identify the personal financial effects of MM and its treatment in five areas: employment, disability, health/medical and life insurance, retirement, and out-of-pocket expenses.

Methods—We mailed a questionnaire about financial issues to 1015 patients who had received intensive treatment for MM at the study site. Data analysis included descriptive statistics and comparisons using independent t-tests.

Results—Our sample (n=762; mean age 61, SD 9.26), experienced issues with employment (66% employed at diagnosis and treatment; 33% employed at questionnaire time), disability (35% applied), health/medical and life insurance (29% lost coverage and 8% changed coverage), retirement (13% retired during treatment), and out-of-pocket expenses (36% of income in first treatment year and 28% of income during most recent 12 months).

Conclusions—Issues of employment, disability, health insurance, retirement, and out-of-pocket costs for treatment are major challenges for patients.

Correspondence: Julia A. Goodwin, PhD, RN, College of Nursing, University of Arkansas for Medical Sciences, 4301 West Markham, Slot 529, Little Rock, AR 72205-7199 (goodwinjuliaa@uams.edu).

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Implications for Practice—In the midst of assessing physical needs during clinical trials for chemotherapy and stem cell transplants, health care providers must keep sight of patients' personal financial needs so that we can intervene promptly with referrals to social work, rehabilitation therapy, and other health care professions to help patients decrease the personal financial effects of MM and its treatment.

Background

Multiple myeloma (MM), a plasma cell cancer, has deleterious effects on bone marrow and skeletal integrity, leading to susceptibility to infection, anemia, elevated serum calcium levels, pain, and bone fractures. Further, excess protein can lead to renal failure. Depending on the data period and data source used, studies have found that MM has a 5-year survival rate of about 40%[1] to 42%.[2] There is no definitive cure at this time; but, recent improvements in treatment programs have increased survival from 3 to 4 years to an average of 7 to 8 years.[3]

Treatment for MM often involves weeks or months at a treatment center, usually away from home, to receive intensive chemotherapy and stem cell transplantation. Protocols vary at different MM treatment centers, but all include intensive treatment and require a large time commitment from patients and their caregivers. Patients receive chemotherapy and daily laboratory monitoring at the treatment center almost a third of the time. Even during rest periods from chemotherapy, daily laboratory monitoring and frequent clinic visits are necessary, though patients may be able to travel home for at least a portion of the rest period if they can see their local oncologist for monitoring.

Clinical trials of MM treatment have collected data on toxicities of intensive treatment, response to treatment and survival; but data on the financial effects of MM treatment usually are not part of these data. The cost of treatment for MM includes the costs of chemotherapy, procedures, tests, and other aspects of care. However, there are additional costs for travel, lodging, and time, as well as co-payments, deductibles, and other cost-sharing components of the overall cost. The way these costs are paid is generally related to whether patients are employed, have health insurance or other insurance benefits related to employment or private coverage, or have benefits through social programs.

The purpose of this study was to identify the long-term personal financial effects of MM and its treatment in five areas identified by researchers in cancer and in public health:[4-8] employment (work for monetary compensation outside the home), disability (formal designation by U. S. Social Security Administration or private insurance company), health/medical and life insurance, retirement (cessation of employment, with or without pension or other retirement funds), and out-of-pocket expenses (costs incurred related to healthcare but not fully paid by insurance or other financial support program).

Methods

This descriptive study used a mailed questionnaire to collect data from a group of 1015 patients who had received intensive treatment for MM at the study site.

Setting

The MM treatment program at this site provides care for over 600 new patients with MM each year, with a cumulative total of over 8500 patients with MM and related disorders. Approximately 2750 of the patients are living with MM, and of those,1015 received treatment with at least one of four treatment protocols, which include varied combinations of medications (melphalan, bortezomib, dexamethasone, thalidomide, cis-platinum, adriamycin, cyclophosphamide, and etoposide) with stem cell transplants (usually autologous stem cells).

Sample

Following approval from the Institutional Review Board (IRB) and the Protocol Review and Monitoring Committee (PRMC), the first author mailed a study questionnaire packet to the 1015 living patients identified by the study site's MM database coordinator. The questionnaire mailing process followed the format suggested by Salant and Dillman[9] and by Edwards and colleagues.[10] Following questionnaire review for content validity by advanced practice oncology nurses and a nurse case manager, we pilot-tested the questionnaire and mailing process with 15 patients before mailing it to the full sample. Twelve of the 15 patients responded and their responses included 2 items addressing ease of use and appraisal of the applicability of response options. Review of the pilot test data allowed us to adjust formatting for improved ease of use for participants and for data entry. After making these adjustments, we proceeded with the full study. First, the questionnaire packet, a cover letter explaining the study, and a postage paid business envelope for return of completed questionnaires were mailed to all 1003 living patients. A reminder postcard was mailed to each individual approximately 4-8 days after the original questionnaire packet was mailed, to remind recipients of the importance of participation. Finally, non-responders were sent a reminder letter with another copy of the questionnaire and a postage-paid return envelope.

Using a 95% confidence level, 5% error rate, and +/- 2% precision range, the target sample size was 430 (which included 1% oversampling for problems with completion of the questionnaire packet). We received 762 responses (76% response rate) to the questionnaires.

Instrument

The investigator-developed questionnaire assessed five areas of personal financial effects of MM: employment, disability, health/medical and life insurance, retirement, and out-of-pocket expenses related to treatment. Additionally, we included one item about the burden of cost of treatment from the Functional Assessment of Cancer Therapy-Bone Marrow Transplant (FACTBMT).[11-13] The investigator-developed financial questions were in three formats: *yes*/*no*, *list with checkboxes*, and *narrative response*. Because questions about financial information may seem intrusive, the content began with simple checkbox and *yes*/*no* items about demographic information, followed with questions about employment and insurance, and finally questions about expenses, to enhance participant comfort in sharing such personal information. Table 1 includes examples of items from the questionnaire.

The questionnaire packet asked for the percentage of income used for out-of-pocket expenses related to MM treatment because percentages appear less intrusive than actual dollar figures. Dollar[14,6] figures also may have different meanings and implications for persons with different incomes. For example, the expense of a $500 deductible would be 10% of a $5,000 monthly income but 50% of a $1000 monthly income. Further, narrative items after each section permitted respondents to provide explanations, rationale, or further details about their answers (Table 1).

Results

On average, participants were 61 years old. The majority of the 762 participants were male, Caucasian, and married and had a college or graduate school education. Demographic information appears in Table 2. Surveys were not coded to identify respondents and self-identification was optional; therefore we were unable to examine characteristics of non-responders.

Employment

Analysis of the financial effects of MM and its treatment began with assessment of employment status. Five hundred (66%) of the respondents reported that they were employed at the time of diagnosis and treatment onset. However, by the time they completed the study questionnaire, only 33% were employed. We explored current employment in participants according to treatment onset (< 5 years; ≥ 5 years) because survival with MM has begun to exceed historical limits of 4 to 5 years past onset of treatment. Surprisingly, more participants within <5 years of treatment onset were employed than those whose treatment began > 5 years prior (36% and 28% respectively). This finding, along with the relatively young average age of our study sample, led us to explore whether participants were no longer working because they had a reached typical retirement age. Numerous participants younger than the retirement age of approximately 65 were not employed at the time of questionnaire completion. Among participants who were initially employed, 41% who were ≤ age 54 and 67% who were ages 55 to 64 no longer worked. More men than women were employed at the time of diagnosis/treatment onset (73% and 55%, respectively) and also at questionnaire completion (41% and 21%, respectively).

Although the questionnaire did not inquire about type of work or career, 6% of the participants indicated their professions; however, the disparate types of work reported did not permit categorization. Other participants listed some of the tasks required in their workplace: standing, walking, driving, operating heavy equipment, lifting heavy objects, or being around children or others who might expose the participant to illness. One hundred fifty-one participants provided narrative explanations for why their employment had ended. The majority of their answers fell into the following categories: physical inability to perform job functions, often related to fatigue and/or pain (35%); time and/or travel required for treatment, including frequent treatment physician appointments, or prolonged treatment stays with out of town travel (21%); and decision to retire (10%). Comments from 14% reflected a combination of reasons (such as time for treatment plus neuropathy or likely exposure to illness in the workplace). Health reasons, whether related to MM, or, related to MM, but *not* to treatment were cited by 4%. Some participants reported that they had decreased work hours or workload; others had used medical leave (paid and/or unpaid), but inconsistent wording of these strategies precluded clear counts or percentages. The narrative comments below shows the consequences of unemployment:

> Financial issues are cumulative. The more treatment required the more I miss work, the lower my income falls.
>
> Since I couldn't work, I had no income, therefore we had only my wife's income. Could not run air conditioning the summer of 2004 or 2005, had small room A/C for bedroom we used. Could not buy much food.

Disability

Two hundred sixty eight participants (35%) applied for disability benefits through workplace or private disability insurance or through government disability programs such as Supplemental Security Income (SSI) or Social Security Disability Income (SSDI). Of the 222 (78%) participants who reported being approved for disability, 39 (18%) had received approval for short-term, 53 (24%) for long-term, and 130 (58%) for permanent disability. At the time they completed the study questionnaire, 113 (55%) of the 204 participants still receiving disability benefits were ages ≤64 and were not currently receiving chemotherapy.

Retirement

Of the 500 employed at diagnosis and treatment onset, 51% reported that their employment had ended at some time during treatment for MM. Only 29 participants retired (11% of those no longer employed) and of those, 5 chose early retirement. Eight participants simply said they retired, but did not give reasons. It is unclear whether the remaining unemployed participants (49%) of the participants actually retired but did not include that information in their questionnaire answers; further, their possible lack of a source of income is concerning.

Health/medical and Life Insurance

Most participants (97%) began treatment with health/medical insurance coverage; but 29% later changed or lost coverage, including 10% who were unable to obtain replacement insurance. Usually the replacement health/medical insurance was Medicare, either through retirement or disability, but private insurance carriers or Medicaid also were listed. Health/medical insurance was changed or stopped because the employer changed benefit offerings, company ownership changed, or the insurance company closed, according to three participants.

Life insurance coverage was less common than health/medical insurance coverage at the onset of treatment. However, of the 533 (70%) with life insurance, 92% still had the same coverage at the time when they completed the study questionnaire.

Out-of-Pocket Expenses and Financial Hardship

Participants reported two primary types of out-of-pocket expenses: those *directly* related to medical treatments and drugs and those *indirectly* related to treatments.[15] Direct costs included insurance deductibles and co-payments for physician visits, medications, treatments, diagnostic tests, and procedures; costs however, varied, depending on the specific insurance company and policy. Approximately one third of the participants at the study site were from out of state or international locations, so their indirect out-of-pocket expenses included transportation, housing and meals for the patient and caregiver(s) during outpatient care, and housing and meals for the caregiver(s) during inpatient care. However, the questionnaire did not inquire whether participants were in state, out of state, or international patients, so analysis did not permit comparisons by location and travel distance.

We calculated the mean percent of income used for MM treatment-related expenses based on the percentages that participants reported on the questionnaire. Participants said they had used 36% of their income on MM treatment related expenses during the first 12 months of treatment, and 28% during the most recent 12 months. The narrative comments below illustrate financial difficulties:

> Medicine was high - Sometimes you have to choose between medicine or food.
>
> I have had to rely on gifts from family and friends to keep from filing bankruptcy. Each year my co-pays increase and covered prescriptions decrease which put additional burdens on my budget. I have very little savings and rely on credit cards when I have unexpected expenses.
>
> We were down to one income, with the same amount of bills.

Because participants were at different points in their treatment trajectory, we made comparisons based on whether they were currently receiving chemotherapy. Those receiving chemotherapy reported using a higher mean percentage of income for out-of-pocket expenses during the first 12 months of therapy (38%) than those who were not receiving chemotherapy (31%) [t (613) = 2.03, p = .025, 95% CI .823-12.443]. There was no significant difference between these two groups in the percentage of income used for out-of-pocket expenses during the most recent 12 months (27% compared with 30%).

Because participants had begun treatment in different years and had different treatment protocols, we used tests of independent means to evaluate possible differences in expenses between groups based on time since treatment started and time since treatment ended. We used a cut point of 4 years for the comparison because treatment protocols at this setting generally begin maintenance treatment after approximately 48 to 52 weeks and maintenance therapy may vary with patient response. Participants who had received at least 4 years of treatment used a smaller percentage of their income for out-of-pocket expenses than participants with less than 4 years of treatment (see Table 3). Findings were similar for the past 12 months.

Overall Financial Effect

Participant responses to the single FACT-BMT item inquiring about the burden of treatment costs provided an overall view of the financial effects of MM treatment. Those on chemotherapy at the time they completed the questionnaire reported a higher burden than those not receiving chemotherapy [$t(721)= -3.51$, $p = .000$, 95% CI: − 0.57 to − 0.16]. Fifty two percent of participants receiving chemotherapy reported that treatment costs were s*omewhat* to *very much* a burden to themselves and/or their families. Even among those not receiving chemotherapy, 42% reported that treatment costs were s*omewhat* to *very much* a burden, as illustrated by the narrative comments they provided on their questionnaires.

> Credit card payments - still paying them after 8 years, credit suffered, sold home, borrowed money from relatives.
>
> We had to withdraw money from IRA in order to keep up with expenses since I have been unable to work since 2005. We have a son going to college & we cannot help with tuition.
>
> We lost everything including our home.

Discussion

Receiving treatment for MM or other types of cancer can be a very expensive process. Adding to the expense is the fact that few institutions in the country have MM treatment programs; therefore, patients with MM and their families often find that treatment requires travel and lodging expenses. Participants in this study reported financial effects in the areas of employment, disability coverage, insurance and retirement. Many reported substantial out-of-pocket expenses.

Employment and Retirement

Decreased employment appeared to result from decreased work hours, decreased productivity, and workplace exposures. Some studies have shown that reduced work hours may necessitate occupational role changes.[16] Also, work hours and/or productivity may decrease because of functional limitations or problems in performing work tasks, and work modifications may not be available.[17-21] Potential or actual exposure to illness in work settings involving childcare or health care can lead to job changes within a particular setting or to the need for a new setting. If sick leave or other paid time off is available, a patient may be able to arrange a schedule that provides income; but the patient may be unable to return to work for months during intensive treatment. Further, attempts to return to work may not be successful:[22] some patients need a year or two to complete and recover from cancer treatment, while others may not be able to return to work at all. Patients with MM may be less likely to return to work than other patients with other cancers;[23] women may be less likely than men to return to work.[24] In our study, 66% of participants were employed at the time of diagnosis, but only 33% held employment when they completed the questionnaire. Yet the mean age of the group when they completed the questionnaire was only 61. This mean age is lower than the national average age of 69 for myeloma diagnosis[2] and many people in the sample were well below the retirement age of 65. Social Security retirement benefits vary depending on age at retirement: workers who wait to retire until they are older receive higher benefits. Taking early retirement, as reported by some of our participants, generally leads to lower benefits—meaning less money to pay expenses.[25]

Disability

Some participants in the study reported short-term, long-term, or permanent disability status, usually after becoming physically unable to perform job functions. Although disability coverage is helpful to the disabled, short-term and long-term disability provide only temporary disability income, and the amount provided is not necessarily adequate to replace all lost income. Some workers when disabled may not have contributed to Social Security for the specified amount of work time (almost 10 years if disabled at age 60). Workers in some occupations or jobs are not covered by Social Security (e.g. railroad workers with >10 years service and some federal employees) and workers who do not pay into the system are not eligible for benefits, including Social Security Disability Insurance (SSDI).[26]

Private insurance policies for short or long-term disability usually provide specified dollar amounts based on a percent of the person's salary; the actual money provided varies, and the length of time benefits are payable also varies, ranging from a few months to as long as 5 years. It is common for disability insurance coverage to end at either age 65 or the Social Security Administration designated retirement age, based on year of birth, because persons are then eligible for Social Security retirement benefits. Also, there is a waiting period of 90, 150,180, or even 365 days from the date of disability until benefits are payable, depending upon the type and source of disability coverage. Given the differences in coverage and waiting periods, income from disability benefits may not be enough to cover both general living expenses and the additional MM treatment related expenses.

Health/medical Insurance

Insurance for health care or medical expenses is often part of employment compensation, but as noted above, many people with MM are retired. A majority of participants in this study were not employed at the time of questionnaire completion. Differences in type of employment and type of insurance coverage mean variations in health insurance benefits in terms of coverage, limitations, exclusions, preferred providers or preferred networks of providers, access to procedures, etc.[27] Rising premiums and decreasing coverage are concerns for many patients.[27] Medicare coverage is available to eligible individuals who can afford the premiums and Medicaid may be an option for individuals with low incomes; but neither Medicare nor Medicaid covers every type of disease treatment or the total cost of care. The gap between the amount insurance covers and the costs left for the patient to pay may cause a large financial burden and may be a factor in where or even whether patients seek care.[15, 27]

Out-of-Pocket MM Treatment Expenses

Out-of-pocket expenses are part of the financial effects of MM treatment, even for patients who have health/medical insurance. Some insurance companies cap the amount permitted for drugs or tests within specific periods of time or over the patient's lifetime, and leave the patient responsible for payment of other charges. In addition, insurance may not cover all of the costs of drugs or treatments for MM, particularly when there is an available lower cost generic form of the drug or a lower cost comparable drug. Insurance companies may also refuse to pay for drugs because they consider the drugs *experimental* since treatment for MM often occurs through clinical trials.

Direct costs of MM treatment include insurance co-payments and deductibles, but indirect costs of treatment may also be burdensome. Because MM treatment is not available at every oncology office and patients often look outside their local area to find new and effective treatments, patients may incur the costs of travel, meals, and lodging near the treatment site. Generally, these costs are not part of insurance coverage and depending upon the income of the patient and family, these expenses may be barriers to care, or to continued care. MM treatment occurs over many weeks in which the patient must reside nearby for daily lab work and clinic visits. For many patients, MM treatment requires relocation to an area near the treatment center for weeks and possibly months. Some participants in this study reported maintaining two complete households—their true home and their temporary home during treatment—each complete with rent, utilities, groceries, etc. The impact of these indirect costs of MM treatment is much greater when income declines because of decreased work hours or work productivity, or paid time off from employment is exhausted.

Limitations

As with any questionnaire study, the self-response format used in this study was a limitation because the sickest or most affected patients may not have participated. Additionally, answers to financial questions were subjective and we did not have confirmation from objective measurements. A longitudinal study might provide different results, given that studies of other cancers have demonstrated improvement in work-related disability after 18 months.[28] The 5-year survival rate for patients with MM is ≤40% [1, 2] and patients have only recently begun living long enough to complete the usual 2-3 years of treatment and face decisions about return to work and other long range financial issues. Therefore limited data are available with which to compare our results. Nevertheless, the 76% response rate to the survey is probably a good indication that patients with MM experience negative financial effects from MM treatment and they want their voices heard through their narrative comments that described hardships: changes in employment status and insurance coverage, loss of home or retirement savings, and difficult choices of managing day to day expenses in the shadows of mounting out of pocket costs and decreased income.

Conclusions and Implications for Practice and Research

In addition to assessing patients for physical side effects and tolerance of treatments, healthcare providers should assess for the financial implications of MM treatment throughout the course of treatment. A typical new patient clinical visit includes recording employment status and insurance information; and as treatment progresses, patients are repeatedly asked if there have been changes in insurance information or insurance coverage so that billing for services can occur. However, we rarely ask patients how well they are functioning in the workplace. Issues of employment, disability, health care insurance, retirement, and out-of-pocket expenses for treatment are major challenges, especially for lower income patients, but these issues are not incorporated into clinic visits or hospital rounds. Like a house of cards[29], decreased work productivity leads to changes in employment that result in changes in health care insurance and income to pay for out-of-pocket expenses. Therefore, it is crucial that oncology healthcare providers ask patients about employment, disability, and financial concerns, and make appropriate referrals to help patients address these challenges.

Appropriate referrals will depend on patients needs. Referral for neuro-psychological testing or for physical or vocational rehabilitation services may help some patients prepare to return to work or re-enter the workforce.[30-32] Referral to social work services or online resources for education about and advocacy related to the Americans with Disabilities Act may assist patients in protecting their jobs, incomes, and insurance coverage by familiarizing them with their rights in the workplace.[32] Patients who have low incomes or are unemployed or self-employed at diagnosis also may benefit from referral to social work services or other departments for help with prescription drugs and assistance in locating free or low-cost temporary lodging near the outpatient treatment facility. Arrangements depend upon availability in the particular locations, but might range from an American Cancer Society Hope Lodge to medical long-stay hotel rooms and apartments or creative solutions such as long-stay recreational vehicle (RV) campsites.[33]

Anguished choices such as groceries versus medications, tolerable ambient temperature versus cramped living space, and even personal embarrassment versus asking friends and family for money to help with treatment and living expenses are realities that many patients with MM face. Providing health care to patients with MM should include considering the financial effects of MM. While assessing physical needs and side effects that occur with chemotherapy and stem cell transplants, it is important that health care providers keep sight of patients' financial needs so that we may intervene promptly to decrease these effects of MM and its treatment.

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Table 1

Example Questionnaire Items

What was your age at MM diagnosis?
What is your gender? ☐ Male ☐ Female
Were you employed when you were diagnosed and began treatment for MM? ☐ Yes ☐ No
If you were employed at diagnosis or during MM treatment, did you apply for disability? ☐ Yes ☐ No
Did you have health/medical insurance when you were diagnosed with MM? ☐ Yes ☐ No
Do you still have the same health/medical insurance? ☐ Yes ☐ No
If not, when did the health/medical insurance stop?
What was the reason?
Were you able to obtain other health/medical insurance?
Approximately what percent of your income was used for expenses related to MM treatment (i.e. insurance co-pay or deductible, prescription medications, home health care, travel to medical care site, lodging for travel to medical care site, etc.) during your first year for MM treatment?
Did you experience any financial hardships due to these treatment-related expenses? ☐ Yes ☐ No
If yes, explain:

Table 2

Participant Demographics

Demographic Category	Value	
Age at Diagnosis	Mean 56 years old (SD 9.34); Minimum 29; Maximum 77	
Current Age	Mean 61 years old (SD 9.26); Minimum 31; Maximum 81	
Gender	Male	61%
	Female	39%
Ethnicity	Hispanic/Latino	3%
	Not Hispanic or Latino	61%
	Not Reported	36%
Race	American Indian/Alaskan Native	1%
	Black or African American	6%
	White	90%
	Asian	1%
	Native/Hawaiian/Other Pacific Islander	0%
	Not Reported	2%
Marital Status At Diagnosis	Married	85%
	Not Married	3%
	Divorced	7%
	Widowed	2%
	Separated	1%
	Cohabiting	1%
	Not reported	1%
Marital Status Change Since Diagnosis		10%
Education	Less than High School	3%
	High School Graduate	19%
	Less than 2 years of College	12%
	2 to 4 years of College; But Did Not Graduate	10%
	College Graduate	26%
	Graduate School	23%
	Other specialty training	7%
Year Treatment Began	Mean (SD): 2003 (3.620) Earliest 1966; Latest 2008	
Years Since Treatment Began	Mean (SD): 5.04 (3.63) Minimum 0; Maximum 42 years	
Year Since Treatment Ended	Mean (SD): 3.16 (3.06) Minimum 0; Maximum 16 years	
Receiving chemotherapy at questionnaire completion	Receiving Chemotherapy	35%
Plans for stem cell transplant	Stem Cell Transplant planned within next 12 months	4%

Table 3
Percentage of Income Spent on Out-Of-Pocket Expenses According to Time Since Treatment Began

	Treatment Began		**Independent t-test**
	<4 years ago	**≥4 years ago**	
% Income Spent During First Treatment Year	40%	33%	t(615) = -2.281, p=.023, 95% CI -13.658 – -1.019
% Income Spent During Past 12 Months	35%	23%	t(408) = -5.465, p=.0005, 95% CI -16.921 – -7.968
	Treatment Ended		Independent t-test
	<4 years ago	≥4 years ago	
% Income Spent During First Treatment Year	37%	37%	t(323) = -0.14, p=.998, 95% CI -11.015 – 10.854
% Income Spent During Past 12 Months	29%	22%	t(308) = -2.143, p =.033, 95% CI -13.21 – -.564