PROSTATE CANCER PATIENTS' OUT-OF-POCKET TRAVEL AND DRUG COSTS

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Title Page

Prostate Cancer Patients' Out-of-Pocket Travel and Drug Costs

By

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Abstract

Prostate cancer patients' reactions to out-of-pocket travel and drug costs in Newfoundland and Labrador

Introduction - How much do prostate cancer patients pay out of pocket for cancer care and how do they manage these costs? To examine:

1) out-of-pocket costs for drugs and travel
2) the use of cost management strategies
3) differences in out-of-pocket drug costs and use of cost reduction strategies between urban and rural patients,

Methods - Using a self-administered questionnaire, we surveyed 170 men with prostate cancer in NL.

Conclusion - A small but substantial proportion of men with prostate cancer had substantial costs. Almost 1 in 5 men (18.8%) paid more than $500 in the last quarter. For roughly 1 in 6, these OOP costs accounted for more than 7.5% of their quarterly income. Aside from higher stress related to OOP costs, there were few other differences in the use of cost saving strategies, quality of life or attitudes of urban and rural men.

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List of Abbreviations

ANOVA – Analysis of Variance

BC – British Columbia

CBC – Canadian Broadcasting Corporation

CBS – Conception Bay South

CCS – Canadian Cancer Society

CHA – Canada Health Act

CLHIA - Canadian Life and Health Insurance Association

CT - computerized axial tomography

DRE – Digital rectal exam

FACT (-G,-P) – Functional Asssessment of Cancer Therapy (-General, -Prostate)

KM - Kilometre

LHRH - luteinizing hormone-releasing hormone

MCP – Medical Care Plan

MRI - magnetic resonance imaging

MTAP – Medical Transportation Assistance Program

NCIC – National Cancer Institute of Canada

NCTRF – Newfoundland Cancer Treatment & Research Foundation

NL – Newfoundland and Labrador

NLPDP – Newfoundland and Labrador Prescription Drug Plan

OOP – Out of Pocket Cost

PSA – Prostate Specific Antigen

SPSS – Statistical Package for the Social Sciences

TNM – TNM Staging system T (tumour size), N (involvement of lymph nodes), and M (metastases)

TRUS - transrectal ultrasound

TURP - Transurethral Resection of the Prostate

US – United States

VOCM – Voice of the Common Man

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Chapter 1

1.1. Problem and Research Question

As rates of cancer are increasing in the province of Newfoundland and Labrador and across Canada (Canadian Cancer Society [CCS], 2004a), there is a growing need to understand the financial burden associated with the disease and its impact on patients. Out of pocket (OOP) expenses are costs associated with cancer treatment that are not covered by insurance (Cohn, Goodenough, Foreman, & Suneson, 2003; Moore, 1998) and can include financial implications from expenses from travel and accommodation to loss of income, medications, and home care. (Mathews, West, & Buehler, 2009a; Cohn et al., 2003).

This study focuses on men in Newfoundland and Labrador who have been diagnosed with prostate cancer, one of the major cancers for men (CCS, 2009a). A primary treatment of prostate cancer is radiation therapy (Carroll, Carducci, Zietman, & Rothaermel, 2005), and in Newfoundland and Labrador, the only radiation therapy clinic is in St. John's (Mathews et al, 2009a). Rural residents are required to travel to and stay in St. John's in order to access these treatments, often at their own expense. In addition, prostate cancer patients may receive hormone therapy for extended periods of time, almost always on an out-patient basis. Patients therefore, bear the auxilliary costs of these often expensive drug regimens. This study will describe the types and amounts of OOP costs incurred by prostate cancer patients. It will also examine whether OOP costs of prostate cancer have any effect on patients' cost management strategies, attitudes and quality of life.

1.2. Objectives

The purpose of this study was to examine the OOP costs associated with prostate cancer patients in Newfoundland and Labrador and to describe any differences that might exist between patients living in urban and rural areas. Specifically the objectives of this study were:

1. to identify the types and magnitude of OOP costs incurred by prostate cancer patients
2. to describe patients' strategies to manage OOP costs for prostate cancer care
3. to determine whether OOP costs affect patients' attitudes, and quality of life
4. to examine differences between urban and rural prostate cancer patients in the types and amounts of OOP costs, management strategies, attitudes, and quality of life.

1.3. Rationale

In the next 30 years, cancer will be a leading health concern in Canada with as many as two in five Canadians facing a diagnosis during their lives (CCS, 2004a). Prostate cancer rates continue to rise in Newfoundland and Labrador. In 2004, it was estimated that there would be 310 new cases of prostate cancer in the province (CCS, 2004b) and in 2009 incidence is projected to increase to 480 new cases (CCS, 2009b), representing an 54.8% increase in the number of cases over five years.

As cancer rates increase, so does the need to understand OOP costs associated with cancer and their impact on patients. There is limited information on the OOP expenses incurred while undergoing cancer treatment (Langa et al., 2004) as well as the effects these hidden costs have on patients' treatment compliance and outcomes (Moore, 1999). A literature review of existing research on OOP costs of cancer, found that these studies have been primarily concerned with costs to the health care system rather than costs to the patient (Lauzier et al, 2005).

Previous studies have found that OOP costs can affect the decisions cancer patients make regarding their treatment. Guidry, Aday, Zhang, and Winn (1997, 1998) found that patients may alter or take more drastic measures such as foregoing treatments due to the OOP costs of cancer. The economic burden placed on those suffering from cancer can add to the concerns about the disease as well as survival (Lauzier et al., 2005).

OOP costs of cancer also differ depending on the type of cancer and subsequent treatment. Lauzier and colleagues (2005) noted that those receiving radiotherapy, as is the case for most prostate cancer patients (Carroll, Carducci, Zietman, & Rothaermel, 2005), can have increased costs related to expenses such as travel and longer stays while receiving treatment. The elderly, rural residents, and the working poor may be at a greater risk of having high OOP costs than their younger, urban, or wealthier counterparts. Cancer is known primarily as a disease of the aging with 88% of new cancer cases in 2009 occurring in Canadians over the age of 50 (CCS, 2009b).

Canadian studies have found that cancer patients living in rural areas are more vulnerable to OOP costs as costs increase for those living more than one hour away from the hospital where treatment is received (Cohn et al., 2003; Lauzier et al., 2005; Mathews et al, 2009a). Moreover, rural residents are more likely to have more children and lower average incomes (Fellegi, 1996) than urban residents. Compared to those in higher socio-economic groups, those in lower socio-economic groups, such as the working poor, will be more affected by the burden of OOP costs, as a greater percentage of their income will be consumed by these costs (Bernard, Banthin, & Encinosa 2006; Moore, 1998; Wagner & Lacey, 2004). In addition, the working poor and rural residents are less likely to have employment related private health insurance that may offset some OOP expenses, particularly for drugs. Moore (1998) has noted a relationship between poverty, cancer and loss of life. Similarly, Wagner and Lacey (2004) found that patients of a lower socio-economic status had a lower survival rate.

Since cancer rates increase with age, assessing the impact of OOP for cancer care is particularly relevant in Newfoundland and Labrador, with its ageing population. In 2000, 11.6% of the total population of Newfoundland and Labrador were seniors, (i.e. those over the age of 65). It is projected that in 2021 this figure is projected to grow to 22.5% (Economics and Statistics Branch, 2005). In 2005, the average age for a resident of Newfoundland and Labrador was 40.5 years; it is projected that the average age will increase to 49.2 by 2031 (Statistics Canada, 2005a).

Newfoundland and Labrador has several other demographic factors that are relevant when assessing the impact of OOP costs of cancer. Over 40% of its residents live in rural communities (Statistics Canada, 2008). In 2004 the median after tax income for families of two or more in NL falls well below the Canadian average $61,800 (Statistics Canada, 2007a). In fact, in 2007, the province had a median after-tax income of $50,900, the second lowest in the country next to New Brunswick with a median after-tax income of $50,600 (Statistics Canada, 2007a). This study increases our understanding of how cancer patients and their families manage the financial burden associated with cancer care. It provides health care providers, system administrators and patient advocates with evidence with which to improve the accessibility of cancer care in the province.

Chapter 2: Review of the Literature

2.1. Prostate cancer

In 2009, 32% of men in NL are estimated to be diagnosed with cancer, and of those estimated to be diagnosed with cancer in 2009, 17.8% will receive a diagnosis of prostate cancer, the most commonly diagnosed cancer for men (CCS, 2009b). Prostate cancer begins in the glandular tissue of the prostate, part of the male sexual reproductive system, and is called adenocarcinoma. The prostate is about the size of walnut and is found at the base of the penis underneath the bladder (CCS, 2006a). The main function of the prostate is to produce seminal fluid (CCS, 2006a).

Prostate cancer tumours grow slowly and can take from five to 15 years to spread (metastasize) from the prostate to other organs in the body. The symptoms of prostate cancer vary depending on the stage of the disease which indicates whether or not the cancer has spread beyond the prostate. Signs of prostate cancer include changes to urination, blood in urine or semen and/or pain during ejaculation (CCS, 2006b). Symptoms of metastatic prostate cancer include bone pain, weight loss and fatigue (CCS, 2006b).

The process of diagnosis generally begins once a man has presented to his physician with specific complaints, or irregularities are detected during regular examinations. Routine screening is done with a digital rectal exam (DRE) and/or a prostate specific antigen (PSA) test. The DRE is recommended annually, by the American Cancer Society and American Urology Association, for all men over 50 years of age. Men with an elevated risk of prostate cancer (e.g. family history) should also have annual DRE (Prostate Disorders, 2006; Jamnicky & Nam, 2003). The PSA test is a blood test used to aid in diagnosing cancer (CCS, 2006b). Prostate cancer cells produce a greater number of PSA than normal cells; levels below 4ng/mL are considered normal. Elevated PSA levels may indicate prostate cancer[1] (Jamnicky & Nam, 2003). Currently, the PSA test is not recommended by most guidelines, particularly for men over the age of 70 who are expected to have less than a ten year life expectancy, in which case the immediate harms of detection and treatment outweigh the potential benefits (Walter, Bertenthal, Lindquist, & Kovety, 2006). There does not appear to be conclusive evidence to indicate that the PSA test lowers mortality or life-expectancy from prostate cancer. Moreover, the test has high levels of false negative and false positive results (Walter et al, 2006; Ilic, O'Connor, Green, & Witt, 2006). If DRE and PSA suggest prostate cancer may be present, transrectal ultrasound (TRUS) may be used to determine the size of the prostate and see any obvious tumours (CCS, 2006a; Jamnicky & Nam, 2003).

The only definite way of determining whether or not prostate cancer is present is through a needle biopsy (Jamnicky & Nam, 2003). Ultrasound is used to aid the physician in guiding the biopsy needle to the prostate gland in order to obtain small pieces of tissue from the prostate. Once tissue samples have been obtained, a pathologist examines the samples and determines whether or not cancer is present (Jamnicky & Nam, 2003).

Once the cancer has been diagnosed the stage and aggressiveness are determined. Stage refers to the size of the tumour and whether or not cancer has spread to other parts of the body. The TNM staging system has four stages with

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[1] This is a reference point and men with lower levels may have prostate cancer (Jamnicky & Nam, 2003)

various levels within. The stage is determined by assessing T (tumour size), N (involvement of lymph nodes), and M (metastases) (Jamnicky & Nam, 2003). Staging is represented by a series of numbers from zero to four, higher numbers indicating a cancer that has spread (CCS, 2006c). The TNM and number system of staging can be combined in order to indicate severity for each aspect (i.e. T1N0M0). Determining the stage of cancer is important, as it will help in deciding which treatment option is best for the patient. Other tests will be done if it is suspected that the cancer has spread. Tests to find any tumours outside of the prostate include computerized axial tomography (CT) scans, magnetic resonance imaging (MRI) and bone scans (Jamnicky & Nam, 2003).

The Gleason score is also used in prostate cancer to assess the aggressiveness of the tumor, (i.e. how likely the cancer is to metastasize). The Gleason score is a number between one and ten, ten being the highest and indicating a very aggressive cancer, while a score between 2 and 5 is an indication that the tumour is most likely benign (Jamnicky & Nam, 2003).

Once a diagnosis has been given and the stage of the disease has been determined, prognosis can be assessed (CCS, 2006b). Factors that influence prognosis include the size of the tumour, the stage and the grade – which is an indication of whether or not the cancerous cells resemble normal cells or whether or not they have been behaving aggressively (CCS, 2006b). Once someone has been diagnosed and the prognosis has been determined, the next step is to determine treatment options. For example, the younger the individual, the more likely he is to be a candidate for surgery or radiation as the cancer has had less time to spread (Jamnicky & Nam, 2003).

There are five main options for treating prostate cancer; the wait-and-see approach (otherwise known as watchful waiting), radiation therapy, hormonal therapy, surgery, and chemotherapy (Jamnicky and Nam, 2003). Treatment can consist of several of the available methods and depends on stage of disease as well as age, general health and the preference of the patient (CCS, 2006b). Watchful waiting[2] is a matter of waiting for signs and symptoms to occur at which point treatment may be administered. This option may be more readily used for elderly men who have non-aggressive tumours or in the case where the adverse effects of other forms of treatment are worse than the symptoms (CCS, 2006b).

Several types of radiation therapy are used to treat prostate cancer including external beam radiotherapy. This form of therapy directs radiation at the prostate from outside the body. External beam radiotherapy requires short treatments of ten to 15 minutes, five days a week, for up to seven or eight weeks (Jamnicky & Nam, 2003). External beam radiotherapy is used as a curative therapy for those with an early stage cancer. It is also used as an adjuvant therapy following surgery with the goal of destroying any cancer cells that have not removed by surgery, lowering the risk of recurrence, and relieving pain and symptoms of more advanced prostate cancer (CCS, 2006b). Other forms of radiation, such as brachytherapy and radioactive isotopes, administer radiation from within the body removing the need to return for treatment day after day. Radiation is directed at the cancerous tissue which

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[2] "Watchful waiting is also called active surveillance. In this thesis, we use the term active treatment to refer to chemotherapy, radiation therapy, surgery, or hormone therapy."

does not repair as quickly as healthy tissue, destroying the cancerous cells while allowing for the areas around the treated region to recover (Jamnicky & Nam, 2003).

Hormone therapy may be used to treat prostate cancer as prostate cancer grows in response to male hormones, called androgens. Controlling hormone levels in the body can slow the growth and spread of cancerous cells. Hormones that are controlled in prostate cancer therapy include luteinizing hormone-releasing hormone (LHRH) agonists, and antiandrogens. Hormone control can be achieved through either drugs (to suppress production of male hormones) or surgery, specifically orchiectomy which is the removal of the testicles. Hormone therapy is often used before and after radiation therapy and for those who have high risk cases of prostate cancer (CCS, 2006b).

There are two main forms of prostate surgery used to treat prostate cancer. Radical prostatectomy is the complete removal of the prostate gland as well as the tissue surrounding the prostate. This form of treatment is often used for men whose cancer has not spread, who are under 70 years old, are expected to live for at least another ten years and who are healthy enough to undergo the procedure including anesthesia (CCS, 2006b). The goal of a radical prostatectomy is to cure the cancer by removing the prostate gland or to relieve the symptoms of the cancer by removing some of the tissue (CCS, 2006b).

For those who may not be able to undergo a radical prostatectomy due to age or health, or for those whose cancer has spread beyond the prostate, Transurethral Resection of the Prostate (TURP) is another option (CCS, 2006b). The TURP procedure is used to reduce the prostate in size and removes the tissue surrounding the urethra. A thin tube with a light (resectoscope) is inserted into the prostate through the urethra and allows the surgeon to see the urethra, prostate and bladder. The surgeon will remove excess tissue from the prostate and possibly from around the urethra as well (CCS, 2006b). This treatment does not cure cancer but relieves some of the symptoms (such as blockage of the urethra) and may be used in conjunction with other treatments such as hormonal therapy. (CCS, 2006b).

Another option for the treatment of prostate cancer is chemotherapy, or the use of "anti-cancer" drugs. These drugs are circulated through the body through an intravenous needle in order to kill cancerous cells. Chemotherapy may reach cancerous cells which have moved away from the tumour (CCS, 2006b). Chemotherapy is generally given in a clinical trial setting as the drugs used are still being studied. This treatment might be useful in the case of prostate cancer patients who have become resistant to hormonal therapy, or to relieve pain or symptoms of palliative patients (CCS, 2006b). The drugs most commonly used for chemotherapy in various combinations include; docetaxel, paclitaxel, vinblastine, etopside, prednisone, and mitoxantrone (CCS, 2006b).

2.2.Canada Health Care System

2.2.1.Medicare

The Canada Health Act (CHA), unanimously passed in 1984, is legislation requiring provinces and territories to provide health care services deemed to be medically necessary. The services covered by the CHA include hospital and physician services as well as drugs used in-hospital (Health Canada, 2002). The overarching goal of the CHA is to ensure that all Canadians have "reasonable" access to health care services that are medically necessary without having to pay for the services directly.

The CHA supports five principles; public administration, comprehensiveness, universality, portability and accessibility. The Newfoundland and Labrador Medical Care Plan (MCP) and the Hospital Insurance Plan cover insured hospital services for in-patient and out-patient services. These plans do not cover the cost of drugs and supplies prescribed for use outside of a hospital setting.

A cancer patient receiving radiation therapy or chemotherapy treatment may get daily treatments for weeks on end, but as they are treated on an out-patient basis, any drugs prescribed that are not administered in-hospital are not covered. These may include "supportive drugs" to combat side effects of treatment such as nausea, anemia, etc.

2.2.2. Supplementary provincial health subsidies

2.2.2.1.Drug Plans

Provincial and federal drug plans exist in order to support those who may be at a disadvantage and would have more difficulty in paying for the costs of drugs prescribed for use outside of a hospital setting. Federal plans such as the Non-Insured Health Benefits program, Veterans Affairs Canada, and Correctional Services Canada cover the cost of drugs for registered Indian and Inuit, veterans, and those incarcerated, respectively. Provinces may also provide programs to cover the cost of outpatient drugs for its residents. In Newfoundland and Labrador, the Newfoundland Prescription Drug Plan (NLPDP) changed in February 2007 to include four programs: the Foundation Plan, the 65 Plus Plan, The Access Plan and the Assurance Plan which offer assistance to eligible residents of the province for medications, and in some instances medical transportation (Government of Newfoundland and Labrador, n.d.).

The Foundation Plan is available for those who qualify for full benefit coverage according to the Department of Health and Community Services due to the high costs of their prescription drugs. Applicants are eligible if they are over 18 years old, residents of the province and receive income support. This program covers the ingredient cost with up to a 10% markup on prescriptions costing more than $30 and a dispensing fee of no more than $6.50[3] (Government of Newfoundland and Labrador, n.d.) and also provides basic and non-basic financial supports including housing, food and clothing expenses, and childcare.

The 65 Plus Plan provides coverage for those who qualify with the following; being 65 years old and over, receiving the Guaranteed Income Supplement and Old Age Security benefits. This plan covers eligible drugs under the NLPDP, which are most drugs that require a prescription as well as some over-the-counter drugs prescribed by a medical professional. Depending on the listing in the provincial governments' drug formulary some drugs are only eligible through special authorization – assessed by the Department of Health and Community Services upon receiving a request from the prescriber. This plan does not cover dispensing fees (Government of Newfoundland and Labrador, n.d.).

The Access Plan provides access for eligible prescription medications to individuals and families deemed to have low income. There are several income thresholds within this program: families with children and a net annual household

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[3] The income support program, formerly known as social assistance provides health with basic and non-basic financial supports including housing, food and clothing expenses and childcare.

income of $30,000 or less, couples without children and a net annual household income of $21,000 or less, and individuals with a net annual household income of $19,000 or less.

And finally, the Assurance Plan was created to aid those financially burdened by the high costs of eligible prescription drugs. Based on income level, there is an "assurance" to families that OOP drug costs will be capped annually at a certain percentage depending on the designated income level. Families with a net income less than $39,999 will have a cap of 5% of their net income for eligible drug costs, those with a net income between $40,000 and $74,999 will have a cap of 7.5% and finally those with a net income between $75,000 and $149,999 will have a cap of 10%. (Government of Newfoundland and Labrador, n.d.).

Despite these provincial drug plans, there are some drug and other costs associated with cancer care that are not covered and must be paid out of pocket by the individual. If an individual is eligible for one of these programs but also has private insurance they are required to apply to the private insurance first.

2.2.2.2.Newfoundland and Labrador's medical travel policy

In addition to drug plans, most provinces also have some form of medical travel subsidy to defray the costs of travel for medically necessary care. These policies vary substantially by province with some provinces lacking a program altogether. Provinces and territories such as Ontario, Manitoba, Quebec, Saskatchewan, Nunavut, the Northwest Territories, the Yukon, and Newfoundland and Labrador offer programs to support the costs of travel for medically required services. All of the provincial medical travel subsidies require that services have been referred by a physician and are not available in the community of residence. The programs vary on which travel costs and how much of those costs they will cover. Ontario and Manitoba's medical travel subsidy programs do not cover any costs for meals or accommodations, while Newfoundland and Labrador and the Yukon offer either per diems and co-payments for costs incurred at a registered accommodation, or a maximum daily amount, respectively (Government of Newfoundland and Labrador, 2007; Yukon Health and Social Services, 2009).

In Newfoundland and Labrador, the Medical Transportation Assistance Program provides a financial subsidy to provincial residents who are required to travel for medically necessary treatment. The program covers 50% of costs for travel, and meals after an annual deductible of $400, and 65% once costs exceed $5,000 for a one year period.[4] However, mileage for private vehicles is not reimbursed. To qualify, the treatment must not be available in their health region and must not require a minimum stay. Up until January of 2006 a minimum stay of 14 days was required. Usually, residents are required to travel more than 200km each way to qualify for the program; however, shorter distances may be considered in exceptional circumstances and where required by a physician to stay overnight. Assistance is available for meals and accommodations for those staying in "registered accommodations". Also, the Department of Human Resources and Employment pays for all medical travel expenses for residents of Newfoundland and Labrador who receive income support or temporary support during their cancer treatment (Mathews & Basky, 2004).

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[4] Residents of Labrador are exempted from the annual $400 deductible.

2.2.3.Private insurance

In addition to public insurance and subsidy programs, supplemental costs for health care are also cost-shared through private health insurance programs such as Medavie, (formerly known as Blue Cross). Private insurance is offered as an employment benefit, although individuals can purchase insurance on their own, although usually at much higher premiums. The costs covered through private insurance schemes vary depending on the plan, and range from 100% coverage for travel due to medical reasons, as well as 20-30% co-payments on prescription drugs with or without an initial $500 deductible depending on the program (Canadian Life and Health Insurance Association [CLHIA], 2006).

As of 2002, compared to other Canadian provinces, Newfoundland and Labrador had the highest percentage of residents, (28%), with no coverage for OOP drug expenses at the $5,000 and $20,000 levels of prescription drug expenses (Fraser Group/Tristat Resources, 2002). All of the Atlantic provinces had comparable percentages of their populations without coverage (for prescription drugs at these levels), while no other provinces had residents without coverage. With the addition of the Assurance Plan to the provincial government's NLPDP, no resident of Newfoundland and Labrador will have more than five to ten per cent of their income consumed by OOP costs with incomes ranging from less than $39,999 up to $149,999.

2.3.Out of pocket costs for cancer care in general

2.3.1.Nature of Out of Pocket Costs

Broadly speaking, OOP costs are costs that are "not covered by government-based allowance or private insurance" (Cohn et al., 2003). Varricchio (1994) found that these costs are not generally included in calculations of medical costs or insurance reimbursement while Moore (1998) stated these OOP costs are those expenses that remain after insurance requirements have been paid.

OOP costs can be direct or indirect care related expenses. Direct OOP costs include drugs, medical supplies, home care and nutritional supplements (Mathews et al., 2009a). Indirect costs include: loss of wages for the patient and family or friends; prostheses; wigs; travel costs such as transportation, accommodation, meals, phone bills; and care for children and dependent family members (Mathews et al., 2009a; Longo, Fitch, Deber, & Williams 2006; Lauzier et al., 2005; Cohn et al., 2003; Guidry, Aday, Zhang & Winn, 1998; Moore, 1998; Moore, 1999).

OOP costs for cancer vary by the type of cancer and the associated treatment required (Moore, 1998; Lauzier et al., 2005). Radiation therapy can greatly affect the amount of OOP costs related to travel since radiation therapy can entail lengthy stays away from home. Radiation therapy can be administered daily for a number of weeks and can create significant costs stemming from accommodations and meals for patients as well as any family member or friend escorting the patient (Lauzier et al., 2005). For example, a study of cancer patients in Newfoundland and Labrador found that the average length of a stay away from home for radiation therapy was 23.11 days (Mathews & Basky, 2004). In a study conducted in Ontario on the financial burden of cancer based on the four major types of cancer (breast, colorectal, lung and prostate), the average length of time over which treatment was received for prostate cancer patients was 339.5 days (Longo et al., 2006)

2.3.2. Out of pocket costs for prostate cancer

A survey of breast, prostate, lung and colorectal cancer patients presenting to cancer clinics in Newfoundland and Labrador found that OOP costs ranged from $0 to $5000 per visit; 43.6% of patients receiving radiation therapy reported the costs of travel and accommodation to be more than $1000 per visit (Mathews et al., 2009a). "Visit" refers to a single trip from the patient's home to the community of the cancer clinic rather than an encounter at the cancer clinic. A single visit may include multiple encounters with cancer care providers.

In addition to the costs related to travel, prostate cancer patients may also bear the costs of drug treatment that is not administered in-hospital. Drugs prescribed for cancer patients to take outside of a hospital situation such as pain medications are not covered. Unless the patient is covered by private insurance or one of the available assistance programs, such as the Newfoundland and Labrador Prescription Drug Program, the patient must pay for these drugs out-of-pocket. For example, costs of common medications used to control cancer pain, such as codeine and morphine, must be borne by the patient unless they are eligible for the NLPDP or other available program (CCS, 2006d)

2.3.3. Cost Management Strategies

Previous studies have described the strategies that patients with cancer or chronic diseases use to manage OOP costs of care. For example, in a study of older homebound people, Sharkey, Ory, & Browne (2005) reported that 15.8% took less medication than prescribed in order to stretch out a prescription, 14% went without prescribed medication, 10.8% reported both these strategies (rationing or omitting prescribed medications), 30.6% asked their physician for free samples, 23% partially filled prescriptions (rather than purchase the full prescription), and 17.6% bought only what they thought was the most important of their medications. The study also found that almost a third of participants chose between food and medication and that a quarter of participants borrowed money or had a family member or friend pay for their medications.

While a US study by Guidry and colleagues (1998) suggested that some patients will forego treatment because of high OOP costs, studies from countries with public health insurance suggest that patients may opt for radical treatment options in an effort to reduce costs. For example, women with breast cancer may choose mastectomy over breast conserving surgery to avoid travel costs associated with radiation treatment. Several Canadian studies have reported lower rates of breast conserving surgery among eligible women who live in rural regions, have longer travel times to a cancer treatment centre, or have a low income (Dicks, 1999; Goel et al., 1997; Hislop et al., 1996; Iscoe, Goel, Wu, Fehringer, Holowaty, & Naylor ,1994; Mackillop et al., 1997). Breast conservation surgery usually requires adjuvant radiation therapy that is normally located in larger urban centers. In these studies, researchers suggested that the considerable financial and social costs associated with this treatment discourage rural patients from choosing breast conservation. Similar findings (and rationales) have been reported in studies in Australia (Collins, 1997). A

US study reported that those with Medicaid or without insurance were less likely than patients with Medicare or private insurance to have breast conserving surgery (Voti, Richardson, Reis, Fleming, Mackinnon, & Coeberg, 2006)

Likewise, the high cost of hormonal therapy for prostate cancer has been found to influence both provider and patient treatment decisions. Using a convenience sample of U.S. urologists and medical oncologists, Matchar, McCrory, and Bennet (1997) found that high OOP costs deterred physicians from prescribing hormone treatment such as an androgen agonist (flutamide). At the time of the 1997 study, meta-analyses reporting no survival benefits for flutamide had not been published and physicians had been asked to consider hypothetical cases, assuming that flutamide was as effective as other drugs used in hormone therapy. In a qualitative study in Newfoundland and Labrador, health providers suggested that men may choose orchiectomy (removal of testes) if they could not afford the costs of ongoing hormone treatment (Mathews, Buehler, & West, 2009b). These findings support an American study of 42 prostate cancer patients who were taking hormonal therapy. All participants reported that avoiding orchiectomy was important to them. However, if their insurance company did not cover the cost of treatment, 48% indicated that they would discontinue hormonal therapy because they would not be able to afford the expense (Chon, Jacobs, & Naslund, 2000).

In addition to the strategies described above, qualitative interviews of cancer care providers in Newfoundland and Labrador found that patients may choose in-patient palliative care, and work during treatment to minimize loss of income to reduce or manage their OOP costs (Mathews, et al., 2009a). Those living in rural areas may take more time between follow-up visits or miss them altogether. In response to patients concerns about costs, cancer care providers may change treatment protocols or admit patients to hospital.

A number of studies have described the emotional and social impact of OOP costs for cancer care on patients (Guidry et al., 1998; Lauzier et al., 2005; Mathews et al, 2009b; Moore, 1999). For example, an Australian study of parents of children with cancer studied the effects of these costs on lifestyle (Cohn et al., 2003). In response to OOP costs, parents gave up a hobby or social activity, reduced their spending for special occasions, sold a car, used their work leave or took on a second job. They also cut back, or cut out activities such as going out to eat, going to movies, or family vacations. Lauzier et al. (2005) described how difficult, if not impossible, it was for patients and their families to recover from paying for OOP costs when patients had used savings or lost wages from disrupting employment (by either reducing hours worked or stopping work completely during and after cancer treatment).

Few studies have evaluated the outcomes of patients' costs management strategies particularly among patients with cancer. In a qualitative study of healthcare providers and their responses to patients OOP cancer costs, patients may opt for older, less expensive but less effective drugs (Mathews et al., 2009b). A second study by Mathews et al (2009a) found that rural cancer patients in Newfoundland and Labrador are more likely than urban patients to consider drug, travel and child care costs when making decisions regarding their treatment. A US study of diabetics found that compliance to the recommended treatment decreases as a result of the burden of high OOP costs (Bernard et al., 2006). Moreover, non-compliance led to higher rates of hospitalization and higher costs in the long term (Bernard et al.,2006). Similarly Sharkey and colleagues (2005) found that patients who used self-management strategies to reduce OOP prescription drug costs used more medical care as a result of adverse drug events and unfavorable outcomes (Sharkey et al., 2005).

Chapter 3: Methods

This study used a self-administered questionnaire to survey men with prostate cancer in Newfoundland and Labrador.

3.1. Survey Instrument

The survey gathered information on each respondent's diagnosis (year, stage, and previous cancer diagnoses), treatment (current and previous treatment), OOP costs, cost coping strategies, attitudes and beliefs (about costs and drug coverage), demographics, and quality of life (using the Functional Assessment of Cancer Therapy – Prostate cancer specific scale (FACT-P) (Appendix A). Survey questions were based on a review of the literature, questions used in previous studies of cancer patients in Newfoundland and Labrador, and in consultation with prostate cancer care providers, the Canadian Cancer Society Newfoundland and Labrador Division, survivors and prostate cancer support group organizers in the province.

The FACT-P includes quality of life items specific to prostate cancer and its treatment effects. In addition to a total score, it includes sub-scales for physical well-being, functional well-being, social well-being, emotional well-being, and satisfaction with their relationship with their physician using five point Likert scales plus an additional twelve items assessing sexuality, bowel/bladder function, and pain (Cella et al. 1993; Esper et al., 1997). Higher scores reflect better quality of life. The instrument is able to distinguish patients at different stages of disease, can be self-administered or administered by a research assistant in-person or over the phone, and is sensitive to change. It can be completed in 5-8 minutes and has a reported grade six reading level, and has good psychometric properties (Esper et al., 1997). The general scale is valid and reliable in adults in general, in people older than 65, and in rural populations.

In order to increase the reliability of the survey it was pre-tested by eight people in total: three cancer survivors, two cancer advocates and three researchers. The survey was created at a grade eight reading level.

3.2. Recruitment

Initially, we had planned to recruit men with prostate cancer through prostate cancer support groups, the prostate cancer retreat, and cancer clinics. However, we were unable to recruit many patients from the cancer clinic (see section 3.2.3 A – Recruitment, Cancer Clinics), and had very few men who were undergoing active treatment in our study. Therefore, we decided to conduct a mailed survey of men with prostate cancer who had been diagnosed within the previous two years of the survey.

3.2.1.Support groups

Six of the seven prostate cancer support groups across the province participated in the study: St. John's, Gander/Kittiwake, Grand Falls-Windsor, Trinity North, Trinity South, and Corner Brook Western. The Labrador group was on hiatus when support groups were contacted and did not take part in the study.

Each group leader was contacted to discuss the study and how to facilitate the distribution of individual surveys to support group participants. Each group leader was then sent a survey kit which contained individual survey packages, instructions and background information, and a return courier envelope (see Appendices B,C).

Each individual survey package included a self-addressed, postage paid envelope for the participant to mail back the completed survey. Inside the envelope there was a cover sheet explaining the survey, the eight-page survey (four pages double sided), and a separate form to request a copy of the study report (and provide a mailing address for the report).

The group leader distributed the individual survey packages in the support groups. The background information was included in the kit to aid the group leaders in describe the survey to support group members. The leader was asked to return undistributed surveys in the courier envelope in order to exclude undistributed surveys from the calculation of response rates

Participants were encouraged to take the survey home with them, review the survey and complete the survey, while omitting any questions they did not feel comfortable in answering. Participants were asked to return completed surveys by mail in the self-addressed envelopes provided. Survey kits were mailed to support group facilitators in April and May of 2007.

3.2.2. Cancer retreat

The Prostate Cancer Support Group Network for Newfoundland and Labrador hosts an annual retreat at Mac Simms Camp outside of Grand Falls-Windsor. A research assistant attended the Fall 2007 (October 5-6th, 2007) retreat to explain the survey, answer any questions and distribute the survey packages to anyone who may not have previously received one through their own support group locations.

3.2.3. Cancer clinics

Cancer patients were also recruited from four cancer clinics across the province: St. John's, Gander, Grand Falls-Windsor, and Corner Brook. Several different methods were used to distribute surveys in the cancer clinics. These methods were tailored to the preferences of the clinic staff at each site.

In central Newfoundland, a research assistant visited the clinic in Grand Falls-Windsor for two days and the Gander clinic for one day. Clinic nursing staff acted as points of contact, informing patients of the study and referring interested participants to the research assistant for a survey package. Patients had the choice to complete the survey package on site and return in to the research assistant, or take it home to complete (and return by mail) in the self-addressed envelopes enclosed in the survey package.

In Corner Brook, surveys were mailed out to the nursing staff who agreed to inform prostate cancer patients of the study and distribute surveys to willing participants.

In St. John's, a number of methods were used to recruit patients from the cancer clinic. Initially, at the medical oncology clinics, registration clerks were asked to inform patients of the study and refer interested participants to the research assistant for a survey package[5]. The research assistant was available in the waiting area of the clinic. However, the registration clerks were unwilling to inform patients about the study (and did not want a research assistant in the waiting room) so boxes were placed at both clinic registration desks along-side a poster (Appendix E) which

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[5] In order to protect patient privacy the ethics committee required that we did not directly contact patients.

introduced the study. Interested patients could pick up a copy from the box and return completed surveys in the return slot in the box. The survey boxes were checked on a regular basis for completed survey packages.

At the radiation clinic, staff agreed to inform each prostate cancer patients of the study as they came in for treatment. Survey packages were provided to the radiation clinic and were given to patients visiting the clinic for the first time. Patients were recruited from the cancer clinics from June to September 2007.

3.2.4.Urology clinics

Information about the study was provided in urology and general surgery clinics at the Health Sciences Centre and St. Clare's Hospital through the posters advertising the study. The posters provided brief information about the study and encouraged individuals interested in participating to contact the research assistant for a survey package. There were no contacts solicited through this method and therefore no surveys were distributed by this method.

3.2.5. Mailed survey

Because we were unable to recruit many patients from the cancer clinics, we did not have a large number of men in our sample who had been diagnosed recently (less than one year) with prostate cancer. Therefore, we decided to conduct a mailed survey of men who had been diagnosed with prostate cancer within the preceding two years.

The Newfoundland and Labrador Cancer Registry provided the names and mailing addresses of men who had been diagnosed with prostate cancer over a year and a half period, dating back to January 2007. In order to comply with privacy requirements, the data were provided to a third party (Ms Sarah Wickham) who prepared mailing labels and mailed the survey packages. Only Ms. Wickham had access to names of individual patients.

For the mail-out, we modified the survey packages by including a letter that explained that the patients name and address had been identified through the Cancer Registry and that this information would be kept confidential and not linked to their individual survey responses . The letter included was signed by thesis supervisor, Dr. Maria Mathews (Appendix A).

The survey was mailed during the last week of January 2008. Because of costs, we only mailed one survey to each individual, with no further follow-up. To increase response rates, we raised awareness of the study through the media. The study was discussed on CBC radio noon, in a news release to all media, VOCM website and radio station, as well as the Rogers Television cable roll-up for a period of one month. Cable roll-ups are ads or public service announcements run only in text on local community cable channels.

3.3. Eligibility

To be eligible for the study, men must have been 19 years of age or older, understand English, reside in Newfoundland and Labrador, not be enrolled in a clinical trial, and have returned their survey by April 30, 2008. Men who had previously been diagnosed with cancer were excluded from the study because they may have had different costs due to their previous diagnosis. Eligibility was assessed through a number of questions posed in the survey itself, such as birth date and whether they were receiving treatment for another form of cancer and taking part in a clinical trial. Patients in clinical trails were excluded since some of their costs may have been covered by the trail. Surveys received after April 30, 2008 were not included in the study.

In addition, we excluded respondents who did not provide at least one of the following fields: income, community or postal code. These fields were used to calculate (or infer) proportion of income spent on OOP costs. For respondents who did not answer the income question, we used the postal code and/or community name to determine median household income (see section 3.5.5 Socio-demographic factors)

Lastly we excluded any duplicate surveys. We identified duplicate surveys by creating a unique identifier from survey responses consisting of diagnosis year + last three digits of postal code + birth year.

3.4. Data management

The data were entered into a database using SPSS data entry software and analyzed using SPSS software. Data entry errors were identified using frequencies and cross-tabulations. Wherever possible, we consulted the original survey to correct responses.

A code was developed to track response rate for surveys distributed for the various methods other than cancer registry mail-out. Before being mailed or handed out, surveys were coded with a code that indicated the town or community and the distribution method. Response rates were calculated for each community and distribution method by dividing the total number of returned surveys by the total number of surveys distributed to a given town and method.

3.5.Variables

Based on survey responses, we created variables to describe OOP costs, coping strategies, attitudes, quality of life, socio-demographic characteristics, and clinical information. A complete list of all variables and their coding scheme is presented in Appendix F.

3.5.1. Costs

The question was designed to ask participants about all of the costs related to their cancer treatment that they paid for OOP. Based on a review of the literature (Mathews et al., 2009a; Longo et al., 2006; Lauzier et al., 2005; Cohn, 2003; Guidry et al., 1998; Moore, 1998; Moore, 1999), we inquired about costs relating to medications, travel and accommodations, supportive costs and any other costs a participant may have had related to their cancer treatment. In this study, respondents were asked to list costs for the last month as well as the last quarter (or three months). We used a limit of three months since recall beyond this time frame may not be reliable. We requested costs for the two time periods (one month and three months) because although recall would be greater for a one month period, the costs may vary substantially from month to month. While recall over a three month period may be less reliable, these figures may provide a more realistic picture of true costs.

We grouped costs into three categories: 1) drugs and supportive costs, 2) travel costs, and 3) all costs. Drugs and supportive costs included the cost of prescription and over-the-counter drugs, complementary and alternative medications, and supplies (eg. bandages, incontinence supplies). Travel costs included transportation (all forms), lodging (all forms), meals and parking. "All Costs" included the costs included under drug and supportive costs, the costs listed as travel costs, and costs associated with an escort, communication costs (e.g. phone) and child or elder care. Costs for each category were calculated by adding the costs reported for each relevant category. Costs were calculated for a one month period as well as a three month period or 'quarter'.

We created two sets of variables to examine costs: actual values and proportion of income consumed by OOP costs. Actual values were grouped into three categories: $0, $0.01-499.99, or $500 or more. These cut-offs were determined by the frequencies of respondents in each group.

The proportion of quarterly income consumed by costs was calculated by dividing each of the three costs categories (drugs and supplies, travel, and all costs) by quarterly income. Annual income was mid-point income in each income category (e.g. $35,000 for $30,000 to $39,999). For the lowest and highest categories, $15,000 and $75,000 were used, respectively. These values were divided by four to calculate quarterly income.

Proportion of quarterly income consumed by costs was grouped into four categories which correspond with the eligibility criteria employed by the Newfoundland and Labrador Prescription Drug Program – Assurance Plan; 0, 0.01 – 4.99 %, 5.00 – 7.49 %, 7.50 – 9.99 % and 10.00 % and more. (Government of Newfoundland and Labrador, 2007). Because of the limited number of respondents in each category, we regrouped the categories into three categories: 0, 0.01 –7.49 % and, 7.50% and greater.

3.5.2. Coping Strategies

A previous qualitative study of cancer patients in Newfoundland and Labrador (Mathews et al., 2009b) suggested that patients might employ coping strategies to deal with the high costs of medications and travel. In this study, we asked participants ten questions relating to the use of strategies to cope with the costs of both drugs and transportation to and from appointments or treatment. These questions used a five point Likert scale describing the frequency of use, where one was "never" and five was "all of the time".

Due to the very small number of respondents who indicated they used any of these strategies, we grouped responses to these questions into two main variables: uses any drug related coping strategy and used any appointment related coping strategy. The categories were coded on a yes/no basis depending on whether or not any of the coping strategies had ever been used. For use of drug related coping strategies, the variable was coded as "yes" if respondents indicated any use of the strategies (answers 2-5 i.e.: "not very often", "some of the time", "most of the time" and "all of the time") for any of the following questions:

- Spread out a medication over a longer period of time to make it last longer
- Replaced the medication your doctor prescribed with another cheaper one
- Skipped one or more dose of medication to save on costs
- Bought only what you thought was the most important medication
- Not filled a prescription because of the cost
- Delayed filling a prescription because of the cost
- Asked my doctor for free samples of a drug

For use of travel related coping strategies, the variable was coded as "yes" if respondents indicated any use of the strategies (answers 2-5 i.e.: "not very often", "some of the time", "most of the time" and "all of the time") for any of the following questions:

- Spread out the time between visit to the doctor for follow-up visit
- Missed or cancelled an appointment with the cancer clinic to save money
- Missed or cancelled scheduled cancer treatment to save money

3.5.3. Attitudes

A series of questions were designed to determine patients' attitudes towards the OOP costs of the potential stressors associated with this. Ten questions used a five-point likert scale. Participants were asked to respond to each sub-question based on the five-point scale ranging from strongly disagree to strongly agree. The questions related to physicians knowledge of costs, stress caused by cost and attitudes towards the assistance and financial support offered for costs such as medications. The questions listed included:

- My OOP costs influenced my decisions about how to treat my prostate cancer
- My cancer doctor is aware of my OOP costs for my prostate cancer
- My doctor takes costs into account when prescribing drugs for me
- My cancer related costs create a lot of stress
- Cancer costs create more stress for me than other sources of stress in my life
- I am having trouble paying for my cancer costs
- I am aware of assistance programs to help me with cancer costs
- All prescription drugs should be free to people with low income

- Assistance programs are well advertised.

Because the responses to the questions were highly skewed, the responses to each item were collapsed into two categories: agreed (which included the responses "agree" and "strongly agree") and disagreed (which included the responses "strongly disagree", "disagree" and "neither agree nor disagree")

3.5.4. Quality of Life

We used the Functional Assessment of Cancer Therapy general scale (FACT-G) and the prostate subscale (FACT-P) in order to determine respondents' quality of life. Scores for the FACT-G and FACT-P scales were calculated according to detailed instructions provided by the originators of the scale (Cella, 2006). Generally, a higher score indicates a higher quality of life.

3.5.5. Socio-demographic Characteristics

3.5.5.1. Age:

Age was calculated by subtracting the birth date from the year and month when the survey was completed. Once age was determined, participants were grouped into two age categories: less than 65 years of age and 65 years of age and older. This grouping was based on the cutoff for senior citizens, benefits (such as the 65 Plus drug insurance plan).

3.5.5.2. Community type

Community type was grouped as either urban or rural. Urban centres had populations of greater than 10,000 such as St. John's, Mount Pearl, Gander, Grand Falls-Windsor, Corner Brook and Conception Bay South (CBS) and their bedroom communities. All of these communities except for CBS and Mount Pearl have cancer clinics. CBS and Mount Pearl are within one hour driving distance to St. John's. Rural communities had populations less than 10,000 and were more than one hour from the nearest cancer clinic. Driving times were determined by road distance through an online map program (Google maps, n.d.).

3.5.5.3. Marital status

Marital status was grouped into two categories: partnered or unpartnered. The "partnered" category included married or living with partner. The "unpartnered" category included single-never married, single-divorced or separated, and widower. The survey question was based on the questions included in the 2007 Canadian Community Health Survey (Statistics Canada, 2007b).

3.5.5.4. Dependents

This variable described the number of children or elderly relatives in the care of the respondent. The survey asked respondents to indicate whether they had dependents and if so, the number of children and/or elderly relatives, for whom they cared.

3.5.5.5. Employment status

Employment status was originally reported with ten categories (full time, part time, self-employed, seasonal/employment insurance, paid sick leave, long term disability, unemployed, semi-retired, retired, other). Because a large number of respondents self-identified as 'retired', the original ten categories were re-grouped into the following four categories: full-time or self-employed, part-time or semi-retired, seasonal, sick leave, unemployed or other, and retired. The survey question was based on the questions included in the 2007 Canadian Community Health Survey (Statistics Canada, 2007b).

3.5.5.6. Education

We regrouped responses into five categories. Less than high school, completed high school, did some community college, technical school or university, some post secondary, completed post secondary, graduate/professional degree. The survey question was based on the questions included in the 2007 Canadian Community Health Survey (Statistics Canada, 2007b). These categories were also used in a previous study on OOP in Newfoundland and Labrador (Mathews & Basky, 2004).

3.5.5.7.Income

The survey asked respondents to indicate their annual household income (pre tax) by checking one of eight categories ranging from less than $9,999 to greater than $70,000. Each category increased in increments of $10,000. The survey question was based on the questions included in the 2007 Canadian Community Health Survey (Statistics Canada, 2007b).

In order to limit missing data, we used the median income of the respondent's community if the respondents had not indicated their income (10.5% of respondents did not complete the income question). If respondents did not identify a community of residence, their postal code was used to identify their community (using the Canada Post Website), (Canada Post, 2008). Once the community was determined, the median annual income was retrieved from the Government of Newfoundland and Labrador Community Accounts website (Community Accounts, 2008).

We regrouped income into seven categories. We combined the lower two categories; less than $10,000 and $10,000 to $19,999 into the category less than $19,999 due to smaller numbers in the original two categories.

3.5.5.8. Private insurance

This variable was coded based on the yes/no response.

3.5.5.9. MTAP

Upon consultation with cancer advocates from the Canadian Cancer Society, a question regarding the Newfoundland and Labrador provincial government's Medical Transportation and Assistance Program (MTAP) was added to the survey. The question asked participants about their knowledge of MTAP and a whether they had applied or were planning to apply to the program. Previous research (Mathews& Basky, 2003) had shown that few patients were aware of the travel subsidy.

3.5.6. Clinical characteristics

3.5.6.1.Time since diagnosis

Time since diagnosis was based on the month and year and calculated into a number (of months) based on the date of survey collection (summer 2007 for support group and clinic delivered surveys, January 2008 for mail-out surveys). The number of months was re-coded into four categories: 0-6 months, 7-12 months, 13-24 months, and more than 24 months.

3.5.6.2. Current treatment

Participants were asked to list all treatments they were receiving for their prostate cancer, if any, at the time they completed the survey. The treatments listed were: radiation, chemotherapy, hormonal treatment, surgery – specify, and no active treatment follow-up. An area to list "other" treatments was also available.

3.5.6.3. Previous treatment

Respondents were also asked to indicate any form of treatment they had received previously for their prostate cancer. Previous treatments listed on the survey were: radiation, hormonal therapy, chemotherapy, surgery (prostatectomy, transurethral resection of the prostate (TURP) orchiectomy, other), as well as a space to identify "other" treatment previously received.

3.5.6.4. Length of time receiving treatment

Respondents were asked to indicate the length of time they had been receiving treatment. The categories listed on the survey were: less than 3 months, 3-6 months, between 6 months and one year.

3.5.6.5. Drugs taken

Respondents were asked to list any drugs they were currently taking as a result of their prostate cancer. Based on responses to this open-ended question, the drugs were then coded into four groups on a yes/no basis. A medical oncologist was consulted regarding the appropriateness of the groupings and assignments of listed medications to the determined categories: Vitamins, Hormonal, Supportive, and Other (Appendix G).

3.6. Statistical Analysis

To assess the representativeness of the sample, we compared community type and age of respondents to data obtained from the Cancer Registry. Using chi square tests, we compared the proportion of men from urban and rural communities in the sample frame and the sample. Rural was defined as communities with less than 10,0000 and one hour (driving distance) or more from an urban centre. To compare age, we obtained the age of incidence for prostate cancer for the province for 2004-2008 (Personal Communication Ms Susan Ryan, Manager Newfoundland and Labrador Cancer Registry, January 5, 2010).

We used frequencies (for categorical variables) and means and standard deviations (for continuous variables) to describe the characteristics of the sample.

For research objective one (to identify the types and magnitude of OOP costs incurred by prostate cancer patients), we used frequencies to describe the amount of OOP costs and proportion of income consumed by OOP cancer care costs.

For research objective two (to describe patients' strategies to manage OOP costs for prostate cancer care), we used frequencies to describe the number of patients in our sample who used any drug or appointment related cost saving strategy.

For research objective three, (to determine whether OOP costs affect patient's cost management strategies, attitudes, quality of life), we used chi-square tests to identify examine differences in the use of costs management strategies and attitudes by patients with different OOP costs (total amount and proportion of income consumed by OOP costs). We used ANOVA to identify differences in quality of life scores (FACT-G and FACT-P) among patients with different OOP costs.

For research objective four (to examine differences between urban and rural prostate cancer patients in the types and amounts of OOP, costs management strategies, attitudes, and quality of life), we used chi square tests (for categorical variables) categorical and ANOVA (for continuous variables) to compare urban and rural patients.

We did not use multivariable statistics because we did not find significant differences between the independent variable (costs and urban/rural) and the main dependant variables (use of cost saving strategies, attitudes, and quality of life).

3.7. Ethical Considerations

The Human Investigations Committee of Memorial University approved this study (Appendix H). The study was also approved by the institutional review board of the Eastern Regional Integrated Health Authority and the cancer clinic's scientific advisory committee (Appendices I, J). An amendment to include the mail out survey as part of the study protocol was approved by the Human Investigations Committee of Memorial University of Newfoundland in December 2007 (Appendix K).

In order to protect confidentiality, data are presented in aggregate only. No individuals are identified in any report or presentation. Moreover when surveys were administered in group settings, we asked all group members to take a survey but to return an incomplete survey if they chose not to take part in the study. For the mailed survey, names of prostate cancer patients were provided to a trusted third party so that study investigators would not be able to connect responses to individual names.

All participants were offered a summary of the study findings by completing a form and returning it with their survey. The forms were separated from the survey upon receipt and no identifying markers were made to the surveys which would make it possible to link the contact information to the survey responses.

All data were stored in a secure room. Only the researcher (Emma Housser) and supervisor (Maria Mathews) had access to the data. Files were password protected.

Chapter 4: Results

4.1 Response rates

Response rates are presented in Table 4.1. The table describes the community where surveys were distributed, method of distribution, and the number of surveys distributed and returned. A response rate is given for each location of distribution and further broken down into the method of distribution used. The overall response rate was 27.21%.

Table 4.1 Survey Response Rates by method and location.

Survey response rates				
Location	Method	Returned	Distributed	Response Rate (%)
St. John's	Clinic	11	42	26.19
Gander	Clinic	1	7	14.29
Grand Falls – Windsor	Clinic	4	6	66.67
Corner Brook	Clinic	3	35	8.57
	Total clinic	**19**	**90**	**21.11**
St. John's	Support group	19	41	46.34
GFW	Support group	7	17	41.18
Gander	Support group	6	6	100.00
Western – Corner Brook	Support group	10	25	40.00
Trinity North	Support group	5	20	25.00
Trinity South	Support group	1	25	4.00
	Total Support group	**48**	**134**	**35.00**
Grand Falls - Windsor	Prostate cancer retreat	3	50	6.00
NL	Cancer Registry Mail out	139	494	26.72
Total:		209	768	27.21

A total of 768 surveys were distributed and 209 surveys were returned. As shown in Table 4.2, 39 surveys were excluded from the study because they were received after the study close date of April 30th, 2008, or because respondents had a previous cancer diagnosis, were receiving treatment for another form of cancer, were taking part in a clinical trial, were not residents of Newfoundland and Labrador, or did not provide income (or community or postal code which were used to infer income). The final study sample consisted of 170 respondents.

Table 4.2 Reasons for excluding returned surveys.

Excluded from Analysis *(n=39)*	n (%)
Received after data collection closed	7 (17.95)
Previous cancer diagnosis	14 (35.90)
Current treatment for other cancer	4 (10.26)
Clinical Trial	8 (20.51)
No income given (no town listed)	1 (2.56)
No community (or postal code given)	4 (10.26)
Not NL resident	1 (2.56)

4.1.1 Sample Size

Given our sample of 170 respondents, we can detect a difference of 3.9 points between urban and rural men and the quality of life score using the FACT-P instrument using a two-tail test with a power of 0.8 (Lenth, 2006-9). We used the FACT-P instrument to assess sample size because it is the only outcome measure that has had extensive testing and reported means and standard deviations. FACT-P has a mean of 67 and standard deviation of 8.7 (Esper et al., 1997).

4.1.2 Representativeness of the Sample

To assess the representativeness of the sample, we compared community type and age of respondents to data obtained from the Cancer Registry. As shown in Table L1 (Appendix L), the sample is representative in terms of community type and age of incidence.

4.2 Characteristics of the sample

Table 4.3 describes the demographic characteristics of the sample of men in this study. The majority of the survey sample is made up of senior citizens, 61.2% were 65 years old or greater. Urban residents made up a slight majority (54.1%) over rural (45.9%) respondents. The sample was largely married or "partnered" (87.9%). Retirement was the most frequently indicated choice for employment status with 72.4% falling into this category. Roughly one third of the sample (33.7%) had less than a high school education, The two most frequently indicated income categories were $20,000 to $29,999 and $30,000 to $39,999, which made up 41.8% of the sample (22.4% and 19.4% respectively). The majority of the sample had some form of private insurance (64.6%) but had never heard about the provincial government's Medical Transportation Assistance Program (59.7%).

Table 4.3 Demographic characteristics of study participants.

Characteristic	n (%)
Age *(n = 170)*	
< 65	66 (38.8)
≥ 65	104 (61.2)
Community Type *(n = 170)*	
Urban	78 (45.9)
Rural	92 (54.1)
Marital Status *(n = 165)*	
Un-partnered	20 (12.1)
Partnered	145 (87.9)
Dependents *(n = 164)*	
Yes	32 (18.8)
No	132 (77.2)
Employment Status *(n = 169)*	
Full-Time/self-employed	18 (10.7)
Part-Time/semi-retired	14 (8.3)
Seasonal/sick leave/unemployed/other	14 (8.3)
Retired	123 (72.4)
Education *(n =166)*	
Less than high school	56 (33.7)
Completed high school	34 (20.5)
Some post secondary	24 (14.5)
Completed post secondary	30 (18.1)
Graduate/professional degree	22 (13.3)
Income *(n = 170)*	
< $19,999	24 (14.1)
$20,000 - $29,999	38 (22.4)
$30,000 - $39,999	33 (19.4)
$40,000 - $49,999	25 (14.7)
$50,000 - $59,999	19 (11.2)
$60,000 - $69,999	10 (5.9)
≥ $70,000	21 (12.4)
Have Private Insurance *(n = 161)*	
Yes	104 (64.6)
No	57 (35.4)
Know about MTAP *(n = 139)*	
Yes	56 (40.3)
No	83 (59.7)

The clinical characteristics of the survey sample are presented in Table 4.4 Men were asked several questions about their current and past treatment. Clinical information including time since diagnosis, any current or previous treatment received, length of time receiving treatment and a listing of drugs are presented.

Table 4.4 Clinical Characteristics of study participants.

Clinical Characteristics	n (%)
Time Since Diagnosis *(n = 167)*	
0 – 6 months	32 (19.2)
7 – 12 months	58 (34.7)
13 – 24 months	39 (23.4)
24 months +	38 (22.8)
Current Treatment *(n = 170)*	
Radiation	19 (11.2)
Hormone Therapy	28 (16.5)
Chemotherapy	0 (0)
No Active Treatment	108 (63.5)
Other	16 (9.4)
Active Treatment or Follow-up	46 (27.1)
Past treatment *(n = 169)*	
Radiation	51 (30.2)
Hormone Therapy	22 (12.9)
Chemotherapy	1 (0.6)
Surgery	85 (50.0)
Prostatectomy	75 (44.1)
TURP	3 (1.8)
Orchiectomy	2 (1.2)
Other	1 (0.6)
Length of Time Receiving Treatment *(n = 75)*	
< 3 months	31 (41.3)
3 – 6 months	12 (16.0)
6 months – 1 year	32 (42.7)
Drugs taken *(n = 170)*	
Hormone Treatment	
Yes	33 (19.4)
No	137 (80.6)
Supportive	
Yes	19 (11.2)
No	151 (88.8)
Vitamins/Supplements	
Yes	13 (7.6)
No	157 (92.4)
Miscellaneous	
Yes	7 (4.1)
No	163 (95.9)

The largest proportion of respondents had been diagnosed seven to 12 months before the survey. Almost two thirds of the sample (63.5%) were on no active treatment. However, in the past, half had some form of surgery, namely prostatectomy, while one third received radiation treatment. The variable length of time receiving treatment should be reviewed with a caution as there was no category given for treatment received for more than one year. Respondents whose treatment was 'watchful waiting' may not have answered this question. This confusion may be reflected by the low response rate for this particular question (n=75). For those responding to the question, there was a fairly even split between the categories less than three months and six months to one year (41.3% and 42.7% respectively). In terms of drug treatment, one fifth of the sample reported taking hormone treatments, (which corresponds closely with reports for current and previous treatments)

Table 4.5 presents the OOP costs incurred by men in the study. Costs were listed for three categories, at two intervals. Costs were given for a one month time period, and a quarter (three months) for drugs and supplies costs, travel costs, and all costs which included the two former categories as well as costs for an escort to accompany the patient on medical visits. Appendix F presents a list of drugs included in the study).

Table 4.5 Out-of-pocket costs incurred by study participants in previous month and previous three months.

Cost	Costs incurred over previous one month n (%)	Costs incurred over previous three months n (%)
Drugs and Supplies *(n = 170)*		
$0	126 (74.1)	121 (71.2)
$0.01 - $499.99	42 (24.7)	44 (25.9)
≥$500.00	2 (1.2)	5 (2.9)
Travel *(n = 170)*		
$0	113 (66.5)	108 (63.5)
$0.01 - $499.99	36 (21.2)	38 (22.4)
≥$500.00	21 (12.4)	24 (14.1)
All Costs *(n = 170)*		
$0	95 (55.9)	91 (53.5)
$0.01 - $499.99	51 (30.0)	47 (27.6)
≥$500.00	24 (14.1)	32 (18.8)

For the "All Costs" category, almost one fifth (18.8%) reported high costs, (costs exceeding $500) over a period of three months, with the bulk of these costs stemming from travel. The vast majority of respondents however did not report any costs. Very few men reported high drug costs ($500 or more) in the previous month or previous quarter.

We also considered costs as the percent of income consumed by out-of-pocket costs. The categories reflect cut-offs for the provincial drug subsidy program (Table 4.6). For each of the three costs categories (Drugs and supplies, travel and all costs) most men reported no costs. A small proportion of men (3.5% -21.5%) reported high costs (costs consuming more than 7.5% of their monthly income). Roughly one in five men reported that cancer related costs (all costs) consumed 7.5% or more of their monthly income. When considered over a three month period, the proportion decreases slightly. Roughly one in nine participants reported that cancer related costs (all costs) consumed 7.5% or more of their quarterly income.

Table 4.6 Percent of monthly and quarterly (3 months) income consumed by OOP costs.

% of Quarterly Income Consumed	n (%)	n (%)
Drugs and Supplies ($n = 170$)		
0%	126 (74.1)	121 (71.2)
0.01 - 7.49 %	38 (22.4)	45 (26.5)
>=7.50 %	6 (3.5)	4 (2.4)
Travel ($n = 169$)		
0%	113 (66.5)	108 (63.9)
0.01 - 7.49 %	25 (14.7)	42 (24.9)
>=7.50 %	32 (18.8)	19 (11.2)
All costs ($n = 170$)		
0%	95 (55.9)	91 (53.5)
0.01 - 7.49 %	39 (22.9)	52 (30.6)
>=7.50 %	36 (21.2)	12 (15.9)

Table 4.7 presents the use of cost related coping strategies as well as attitudes about cancer costs and subsidy programs. Although one fifth of men surveyed reported out-of-pocket costs in excess of $500 for a quarter, very few reported any use of either drug (8.2%) or appointment (3.5%) related coping strategy.

Table 4.7 Use of Coping Strategies and Attitudes regarding OOP costs.

Coping strategies	n (%)
Drug Coping Strategies *(n = 170)*	
Yes	14 (8.2)
No	156 (91.8)
Appointment Coping Strategies *(n = 170)*	
Yes	6 (3.5)
No	164 (96.5)
Attitude Questions	
My OOP costs influenced my decisions about how to treat my prostate cancer *(n=125)*	
Agree	9 (7.2)
Disagree	116 (92.8)
My cancer doctor is aware of my OOP costs for my prostate cancer *(n=115)*	
Agree	31 (27.0)
Disagree	84 (73.0)
My doctor takes costs into account when prescribing drugs for me *(n=114)*	
Agree	15 (13.2)
Disagree	99 (86.8)
My cancer related costs create a lot of stress *(n=121)*	
Agree	33 (27.3)
Disagree	88 (72.7)
Cancer costs create more stress for me than other sources of stress in my life *(n=122)*	
Agree	26 (21.3)
Disagree	96 (78.7)
I am having trouble paying for my cancer costs *(n=120)*	
Agree	15 (12.5)
Disagree	105 (87.5)
I am aware of assistance programs to help me with cancer costs *(n=121)*	
Agree	33 (27.3)
Disagree	88 (72.7)
All prescription drugs should be free to everyone, regardless of their income *(n=127)*	
Agree	78 (61.4)
Disagree	49 (38.6)
All prescription drugs should be free to people with low income *(n=131)*	
Agree	110 (84.0)
Disagree	21 (16.0)
Assistance programs are well advertised *(n=132)*	
Agree	17 (12.9)
Disagree	115 (87.1)

A small proportion of men (7.2%) said that costs influenced their treatment decisions. The majority of respondents indicated that their doctor was not aware of their OOP costs related to prostate cancer (73.0%) and did not take costs into account when prescribing drugs (86.8%). More than one quarter of the men surveyed reported that cancer related costs were causing stress (27.3%), and roughly one fifth agreed that cancer costs caused more stress than other sources of stress (21.3%). One in eight respondents (12.5%) were having trouble paying for their cancer related costs. Most men were not aware of assistance programs (72.7%) and thought they were not well advertised (87.1%). The majority of participants agreed that all prescription drugs should be free to everyone, regardless of income (61.4%); 84% agreed that all prescription drugs should be free to people with low income.

Quality of life scores, based on the Functional Assessment of Cancer Therapy are presented in Table 4.8. Functional Assessment of Cancer Therapy scores are reported for the overall quality of life which can be compared across a diverse group of patients (FACT G Total) while the FACT P Total further narrows down the overall quality of life to prostate cancer.

Table 4.8 Quality of life - Functional Assessment of Cancer Therapy – General, Prostate

Quality of Life	mean (std. dev.)
FACTG Total *(n = 126)* Actual Range 49-108 Theoretical Range 0-108	84.97 (13.96)
FACT P Total *(n=126)* Actual Range 58-147 Theoretical Range 0-156	117.17 (19.03)

The higher the score, the better the quality of life. Scores were prorated to account for missing data. The mean score for the overall FACT-G was 84.97, with a range from 49 to 108 (theoretical range of 0 to 108) while the mean score for the FACT-P was 117.17 with a range of 58 to 147 (theoretical range of 0 to 156).

4.3. Costs

4.3.1. Dollar value of costs

The next series of tables examine the relationship between costs incurred (in dollar value) and demographic and clinical characteristics, use of cost saving strategies, attitudes and quality of life. Costs for the last quarter are presented in this chapter. Tables examining costs in the previous one month are presented in Appendix M.

Table 4.9 presents the cross tabulations and chi-square test results comparing the demographic characteristics and the three categories of costs incurred (in dollar amounts). There were no significant differences across the demographic variables and the dollar amount of out-of-pocket costs.

Table 4.9 Level of OOP costs (dollar amount) for the “All Costs” category in a quarter (3 month period) and demographic characteristics.

Characteristic	$0 n (%)	$0.01 - $499.99 n (%)	≥$500.00 n (%)	p value
Age *(n = 170)*				
< 65	35 (38.5)	14 (29.8)	17 (53.1)	0.112
≥ 65	56 (61.5)	33 (70.2)	15 (46.9)	
Community Type *(n = 170)*				
Urban	49 (53.8)	18 (38.3)	11 (34.3)	0.077
Rural	42 (46.2)	29 (61.7)	21 (65.6)	
Marital Status *(n = 165)*				
Un-partnered	10 (11.2)	5 (10.9)	5 (16.7)	0.699
Partnered	79 (88.8)	41 (89.1)	25 (83.3)	
Dependents *(n = 164)*				
Yes	16 (18.2)	8 (17.4)	8 (26.7)	0.546
No	72 (81.8)	38 (82.6)	22 (73.3)	
Employment Status *(n = 169)*				
Full-Time/self-employed	10 (11.1)	5 (10.6)	3 (9.4)	
Part-Time/semi-retired	7 (7.8)	4 (8.5)	3 (9.4)	0.404
Seasonal/sick leave/unemployed/other	6 (6.7)	2 (4.3)	6 (18.8)	
Retired	67 (74.4)	36 (76.6)	2 (62.5)	
Education *(n =166)*				
Less than high school	29 (33.0)	17 (36.2)	10 (32.3)	
Completed high school	16 (18.2)	12 (25.5)	6 (19.4)	0.828
Some post secondary	16 (18.2)	3 (6.4)	5 (16.1)	
Completed post secondary	16 (18.2)	9 (19.1)	5 (16.1)	
Graduate/professional degree	11 (12.5)	6 (12.8)	5 (16.1)	
Income *(n = 170)*				
< $19,999	13 (14.3)	7 (14.9)	4 (12.5)	
$20,000 - $29,999	19 (20.9)	12 (25.5)	7 (21.9)	
$30,000 - $39,999	17 (18.7)	6 (12.8)	10 (31.2)	0.813
$40,000 - $49,999	13 (14.3)	7 (14.9)	5 (15.6)	
$50,000 - $59,999	12 (13.2)	6 (12.8)	1 (3.1)	
$60,000 - $69,999	4 (4.4)	4 (8.5)	2 (6.2)	
≥ $70,000	13 (14.3)	5 (10.6)	3 (9.4)	
Have Private Insurance *(n = 161)*				
Yes	58 (65.9)	27 (62.8)	19 (63.3)	0.928
No	30 (34.1)	16 (37.2)	11 (36.7)	
Know about MTAP *(n = 139)*				
Yes	29 (43.3)	13 (31.7)	14 (45.2)	0.404
No	38 (56.7)	28 (68.3)	17 (54.8)	

* Statistically significant: $p<0.05$

Table 4.10 displays the cross tabulations and chi-square test results comparing the clinical characteristics and the categories of costs incurred (in dollar amounts). Compared to patients with costs, a larger proportion of patients with no costs were not having active treatment (i.e. treatment was watchful waiting), had been receiving treatment for less than three months, were receiving neither hormone treatment, supportive drugs nor vitamins/supplements.

Table 4.10 Level of OOP costs (dollar amount) for the All Costs category in a quarter (3 month period) and clinical characteristics.

Clinical Characteristics	$0 n (%)	$0.01 - $499.99 n (%)	≥$500.00 n (%)	p value
Time Since Diagnosis *(n = 167)*				
0 – 6 months	15 (17.0)	12 (25.5)	5 (15.6)	
7 – 12 months	29 (33.0)	18 (38.3)	11 (34.4)	0.656
13 – 24 months	20 (22.7)	10 (21.3)	9 (28.1)	
24 months +	24 (27.3)	7 (14.5)	7 (21.9)	
Current Treatment *(n = 170)*				
Radiation				
Yes	8 (8.8)	7 (14.9)	4 (12.5)	0.540
No	83 (91.2)	40 (85.1)	28 (87.5)	
Hormone Therapy				
Yes	11 (12.1)	10 (21.3)	7 (21.9)	0.254
No	80 (87.9)	37 (78.7)	25 (78.1)	
Chemotherapy				
Yes	0(0.0)	0 (0.0)	0 (0.0)	.a
No	91(100.0)	47(100.0)	32(100.0)	
No Active Treatment				
Yes	25 (27.5)	23 (48.9)	14 (43.8)	0.029*
No	66 (72.5)	24 (51.1)	18 (56.2)	
Other				
Yes	7 (7.7)	5 (10.6)	4 (12.5)	0.685
No	84 (92.3)	42 (89.4)	28 (87.5)	
Active Treatment or Follow-up				
Yes	19 (20.9)	18 (38.3)	9 (28.1)	0.091
No	72 (79.1)	29 (61.7)	23 (71.9)	
Past treatment *(n = 169)*				
Radiation				
Yes	26 (28.6)	12 (25.5)	13 (41.9)	0.269
No	65 (71.4)	35 (74.5)	18 (58.1)	
Hormone Therapy				

Yes	9 (9.9)	6 (12.8)	7 (21.9)	0.221
No	82 (71.4)	41 (87.2)	25 (78.1)	
Chemotherapy				
Yes	1 (1.1)	0 (0.0)	0 (0.0)	0.646
No	90 (98.9)	47(100.0)	32(100.0)	
Surgery				
Yes	47 (51.6)	22 (46.8)	16 (50.0)	0.865
No	44 (48.4)	25 (53.2)	16 (50.0)	
Prostatectomy				
Yes	39 (42.9)	22 (46.8)	14 (43.8)	0.906
No	52 (57.1)	25 (53.2)	18 (56.3)	
TURP				
Yes	2 (2.2)	1 (2.1)	0 (0.0)	0.702
No	89 (97.8)	46 (97.9)	32(100.0)	
Orchiectomy				
Yes	1 (1.1)	0 (0.0)	1 (3.1)	0.447
No	90 (98.9)	47(100.0)	31 (96.9)	
Other				
Yes	0 (0.0)	1 (2.1)	0 (0.0)	0.268
No	91 (100.0)	46 (97.9)	32(100.0)	
Length of Time Receiving Treatment *(n = 75)*				
< 3 months	16 (51.6)	8 (34.8)	7 (33.3)	0.015*
3 – 6 months	2 (6.5)	2 (8.7)	8 (38.1)	
6 months – 1 year	13 (41.9)	13 (56.5)	6 (28.6)	
Drugs taken *(n = 170)*				
Hormone Treatment				
Yes	7 (7.7)	15 (31.9)	11 (34.4)	0.000*
No	84 (92.3)	32 (68.1)	21 (65.6)	
Supportive				
Yes	5 (5.5)	9 (19.1)	5 (15.6)	0.037*
No	86 (94.5)	38 (80.5)	27 (84.4)	
Vitamins/Supplements				
Yes	2 (2.2)	8 (17.0)	3 (9.4)	0.007*
No	89 (97.8)	39 (83.0)	29 (90.6)	
Miscellaneous				
Yes	3 (3.3)	3 (6.4)	1 (3.1)	0.655
No	88 (96.7)	44 (93.6)	31 (96.9)	

* Statistically significant; $p<0.05$

a. No statistics available as variable is a constant in this instance.

Table 4.11 displays the cross tabulations and chi-square test results comparing the use of coping strategies and the categories of costs incurred (in dollar amounts).

The proportion of men who used a drug coping strategy increased with total amount of costs.

Table 4.11 Level of OOP costs (dollar amount) for the All Costs category in a quarter (3 month period) and use of coping strategies.

Coping strategies	$0 n (%)	$0.01 - $499.99 n (%)	≥$500.00 n (%)	p value
Drug Coping Strategies *(n = 170)*				
Yes	3 (3.3)	5 (10.6)	6 (18.8)	0.019*
No	88 (96.7)	42 (89.4)	26 (81.2)	
Appointment Coping Strategies *(n = 170)*				
Yes	1 (1.1)	3 (6.4)	2 (6.2)	0.183
No	90 (98.9)	44 (93.6)	30 (93.8)	

* Statistically significant; p<0.05

As shown in table 4.12, there were no differences in quality of life scores based on costs incurred (in dollar amounts).

Table 4.12 Level of OOP costs (dollar amount) for the All Costs category in a quarter (3 month period) and quality of life.

Quality of Life	$0 mean (sd)	$0.01 - $499.99 mean (sd)	≥$500.00 mean (sd)	p value
FACTG Total *(n = 126)*	86.56 (14.597)	84.83(12.077)	81.00(15.208)	0.267
FACT P Total *(n=126)*	119.87(19.813)	116.60(17.436)	111.04(18.953)	0.162

* Statistically significant; p<0.05

Table 4.13 displays the cross tabulations and chi-square test results comparing attitudes regarding costs and the level of income consumed by OOP costs. There were no significant differences.

Table 4.13 Level of OOP costs (dollar amount) for the All Costs category in a quarter (3 month period) and attitudes regarding these costs.

Attitudes	$0 n (%)	$0.01 - $499.99 n (%)	≥$500.00 n (%)	p value
OOP costs influenced treatment decisions				
Agree	3 (5.8)	2 (4.4)	4 (14.3)	0.250
Disagree	49 (94.2)	43 (95.6)	24 (85.7)	
Doctor aware of my OOP costs				
Agree	15 (31.9)	9 (21.4)	7 (26.9)	0.538
Disagree	32 (68.1)	33 (78.6)	19 (73.1)	
Doctor takes costs into account				
Agree	9 (20.0)	4 (9.3)	2 (7.7)	0.214
Disagree	36 (80.0)	39 (90.7)	24 (92.3)	
Cancer costs create a lot of stress				
Agree	11 (22.9)	9 (20.5)	13 (44.8)	0.050
Disagree	37 (77.1)	35 (79.5)	16 (55.2)	
Cancer costs more stressful than other things				
Agree	9 (18.4)	8 (18.2)	9 (31.0)	0.342
Disagree	40 (81.6)	36 (81.8)	20 (69.0)	
Trouble paying for my cancer costs				
Agree	3 (6.2)	6 (13.6)	6 (21.4)	0.149
Disagree	45 (93.8)	38 (86.4)	22 (78.6)	
Aware of assistance programs				
Agree	15 (29.4)	10 (22.7)	8 (30.8)	0.692
Disagree	36 (70.6)	34 (77.3)	18 (69.2)	
Prescription drugs free to everyone				
Agree	39 (70.9)	23 (53.5)	16 (55.2)	0.157
Disagree	16 (29.1)	20 (46.5)	13 (44.8)	
Prescription drugs free to low income people				
Agree	49 (86.0)	40 (88.9)	21 (72.4)	0.146
Disagree	8 (14.0)	5 (11.1)	8 (27.6)	
Assistance programs are well advertised				
Agree	8 (13.3)	6 (14.0)	3 (10.3)	0.895
Disagree	52 (86.7)	37 (86.0)	26 (89.7)	

* Statistically significant; $p<0.05$

4.3.2 Proportion of Income consumed by costs

The next series of tables examine the relationship between proportion of income consumed by OOP costs, demographic and clinical characteristics, use of cost saving strategies, attitudes and quality of life. Costs for the last quarter are presented in this chapter. Tables examining costs in last month are presented in Appendix M.

Table 4.14 displays the cross tabulations and chi-square test results comparing the socio-demographic characteristics and proportion of income consumed by OOP costs. There were no significant differences.

Table 4.14 Percent of income consumed by OOP All costs category in a quarter (three month period) and demographic characteristics.

Characteristic	**0%** **n (%)**	**0.01 – 7.49%** **n (%)**	**≥7.50%** **n (%)**	**p value**
Age *(n = 170)*				
< 65	35 (38.5)	18 (34.6)	13 (48.1)	0.501
≥ 65	56 (61.5)	34 (65.4)	14 (51.9)	
Community Type *(n = 170)*				
Urban	49 (53.8)	20 (38.5)	9 (33.3)	0.075
Rural	42 (46.2)	32 (61.5)	18 (66.7)	
Marital Status *(n = 165)*				
Un-partnered	10 (11.2)	5 (9.8)	5 (20.0)	0.411
Partnered	79 (88.8)	46 (90.2)	20 (80.0)	
Dependents *(n = 164)*				
Yes	16 (18.2)	9 (18.0)	7 (26.9)	0.582
No	72 (88.8)	41 (82.0)	19 (73.1)	
Employment Status *(n = 169)*				
Full-Time/self-employed	10 (11.1)	6 (11.5)	2 (7.4)	
Part-Time/semi-retired	7 (7.8)	4 (7.7)	3 (11.1)	0.968
Seasonal/sick leave/unemployed/other	6 (6.7)	5 (9.6)	3 (11.1)	
Retired	67 (74.4)	37 (71.2)	19 (70.4)	
Education *(n =166)*				
Less than high school	29 (33.0)	18 (34.6)	9 (34.6)	
Completed high school	16 (18.2)	12 (23.1)	6 (23.1)	0.666
Some post secondary	16 (18.2)	6 (11.5)	2 (7.7)	
Completed post secondary	16 (18.2)	11 (21.2)	3 (11.5)	
Graduate/professional degree	11 (12.5)	5 (9.6)	6 (23.1)	
Income *(n = 170)*				
< $19,999	13 (14.3)	6 (11.5)	5 (18.5)	
$20,000 - $29,999	19 (20.9)	10 (19.2)	9 (33.3)	
$30,000 - $39,999	17 (18.7)	10 (19.2)	6 (22.2)	0.722
$40,000 - $49,999	13 (14.3)	8 (15.4)	4 (14.8)	
$50,000 - $59,999	12 (13.2)	7 (13.5)	0 (0.0)	
$60,000 - $69,999	4 (4.4)	5 (9.6)	1 (3.7)	
≥ $70,000	13 (14.3)	6 (11.5)	2 (7.4)	
Have Private Insurance *(n = 161)*				
Yes	58 (65.9)	32 (66.7)	14 (56.0)	0.618
No	30 (34.1)	16 (33.3)	11 (44.0)	
Know about MTAP *(n = 139)*				
Yes	29 (43.3)	15 (32.6)	12 (46.2)	0.417
No	38 (56.7)	31 (67.4)	14 (53.8)	

* Statistically significant; $p<0.05$

Table 4.15 displays the cross tabulations and chi-square test results comparing the clinical characteristics and proportion of income consumed by OOP costs. Compared to patients with costs that consumed any amount of their income, a larger proportion of patients without costs were not having active treatment (i.e. treatment was watchful waiting), and were receiving neither hormone treatment, supportive drugs nor vitamins/supplements.

Table 4.15 Percent of income consumed by OOP All costs category in a quarter (three month period) and clinical characteristics.

Clinical Characteristics	**0% n (%)**	**0.01 – 7.49% n (%)**	**≥7.50 % n (%)**	**p value**
Time Since Diagnosis *(n = 167)*				
0 – 6 months	15 (17.0)	14 (26.9)	3 (11.1)	
7 – 12 months	29 (33.0)	20 (38.5)	9 (33.3)	0.356
13 – 24 months	20 (22.7)	10 (19.2)	9 (33.3)	
24 months +	24 (27.3)	8 (15.4)	6 (22.2)	
Current Treatment *(n = 170)*				
Radiation				
Yes	8 (8.8)	7 (13.5)	4 (14.8)	0.561
No	83 (91.2)	45 (86.5)	23 (85.2)	
Hormone Therapy				
Yes	11 (12.1)	11 (21.2)	6 (22.2)	0.253
No	80 (87.9)	41 (78.8)	21 (77.8)	
Chemotherapy				
Yes	0 (0.0)	0 (0.0)	0 (0.0)	.a
No	91(100.0)	52(100.0)	27(100.0)	
Active Treatment				
Yes	25 (27.5)	23(44.2)	14 (51.9)	0.026*
No	66 (72.5)	29 (55.8)	13 (48.1)	
Other				
Yes	7 (7.7)	5 (9.6)	4 (14.8)	0.537
No	84 (92.3)	47 (90.4)	23 (85.2)	
Active Treatment or Follow-up				
Yes	19 (20.9)	18 (34.6)	9 (33.3)	0.149
No	72 (79.1)	34 (65.4)	18 (16.7)	
Past treatment *(n = 169)*				
Radiation				
Yes	26 (28.6)	13 (25.0)	12 (46.2)	0.141
No	65 (71.4)	39 (75.0)	14 (53.8)	
Hormone Therapy				

Yes	9 (9.9)	7 (13.5)	6 (22.2)	0.243
No	82 (90.1)	45 (86.5)	21 (77.8)	
Chemotherapy				
Yes	1 (1.1)	0 (0.0)	0 (0.0)	0.646
No	90 (98.9)	52(100.0)	27(100.0)	
Surgery				
Yes	47 (51.6)	25 (48.1)	13 (48.1)	0.899
No	44 (48.4)	27 (51.9)	14 (51.9)	
Prostatectomy				
Yes	39 (42.9)	25 (48.1)	11 (40.7)	0.773
No	52 (57.1)	27 (51.9)	16 (59.3)	
TURP				
Yes	2 (2.2)	1 (1.9)	0 (0.0)	0.744
No	89 (97.8)	51 (98.1)	27(100.0)	
Orchiectomy				
Yes	1 (1.1)	0 (0.0)	1 (3.7)	0.349
No	90 (98.9)	52(100.0)	26 (96.3)	
Other				
Yes	0 (0.0)	0 (0.0)	1 (3.7)	0.070
No	91 (100.0)	52(100.0)	26 (96.3)	
Length of Time Receiving Treatment				
(n = 75)	16 (51.6)	8 (33.3)	7 (35.0)	0.054
< 3 months	2 (6.5)	3 (12.5)	7 (35.0)	
3 – 6 months	13 (41.9)	13 (54.2)	6 (30.0)	
6 months – 1 year				
Drugs taken *(n = 170)*				
Hormone Treatment				
Yes	2 (2.2)	8 (15.4)	3 (11.1)	0.013*
No	89 (97.8)	44 (84.6)	24 (88.5)	
Supportive				
Yes	7 (7.7)	15 (28.8)	11 (40.7)	0.000*
No	84 (92.3)	37 (71.2)	16 (59.3)	
Vitamins/Supplements				
Yes	5 (5.5)	9 (17.3)	5 (18.5)	0.041*
No	86 (94.5)	43 (82.7)	22 (81.5)	
Miscellaneous				
Yes	3 (3.3)	2 (3.8)	2 (7.4)	0.636
No	88 (96.7)	50 (96.2)	25 (92.6)	

* Statistically significant; $p<0.05$

a. No statistics available as variable is a constant in this instance.

Table 4.16 displays the cross tabulations and chi-square test results comparing the use of coping strategies and the categories of proportion of income consumed by OOP costs for a three month period. The proportion of patients who used a drug or appointment coping strategy increased with total proportion of income consumed by cancer related OOP costs. The proportion of patients who spent greater than 7.5% of their income on OOP cancer care costs and said they used drug coping strategies and appointment coping strategies was larger than the proportion of patients who did not spend any of their income on cancer related costs.

Table 4.16 Percent of income consumed by OOP All costs category in a quarter (three month period) and use of coping strategies.

Coping strategies	**0%** **n (%)**	**0.01 – 7.49%** **n (%)**	**≥7.50 %** **n (%)**	**p value**
Drug Coping Strategies *(n = 170)*				
Yes	3 (3.3)	5 (9.6)	6 (22.2)	0.007*
No	88 (96.7)	47 (90.4)	2 (77.8)	
Appointment Coping Strategies *(n = 170)*				
Yes	1 (1.1)	2 (3.8)	3 (11.1)	0.046*
No	90 (98.9)	50 (96.2)	24 (88.9)	

* Statistically significant; p<0.05

There were no differences in quality of life scores and the proportion of income spent on out-of-pocket cancer related costs for a three month (Table 4.17)

Table 4.17 Percent of income consumed by OOP All costs category in a quarter (three month period) and quality of life.

Quality of Life	**0%** **mean (sd)**	**0.01 – 4.99%** **mean (sd)**	**≥7.49 %** **mean (sd)**	**p value**
FACTG Total *(n = 126)*	86.56 (14.597)	85.26 (11.631)	78.83 (16.318)	0.117
FACT P Total *(n=126)*	119.87 (19.813)	117.06 (16.906)	108.28 (19.813)	0.075

* Statistically significant; p<0.05

Table 4.18 displays the cross tabulations and chi-square test results attitudes and the categories of costs incurred (in dollar amounts). Compared to patients whose cancer costs consumed less than 7.5% of their income, a larger proportion of patients whose OOP cancer relate costs consumed more than 7.5% of their income agreed that cancer costs created a lot of stress, that cancer costs were more stressful than other things, and that they had trouble paying for their cancer costs.

Table 4.18 Percent of income consumed by OOP All costs category in a quarter (three month period) and attitudes regarding these costs.

Attitudes	**0% n (%)**	**0.01 – 7.49% n (%)**	**≥7.50 % n (%)**	**p value**
OOP costs influenced treatment decisions				
Agree	3 (5.8)	2 (4.1)	4 (16.7)	0.129
Disagree	49 (94.2)	47 (95.9)	20 (83.3)	
Doctor aware of my OOP costs				
Agree	15 (31.9)	8 (17.4)	8 (37.4)	0.156
Disagree	32 (68.1)	38 (32.6)	14 (63.6)	
Doctor takes costs into account				
Agree	9 (20.0)	3 (6.4)	3 (13.6)	0.154
Disagree	36 (80.0)	44 (93.6)	19 (86.4)	
Cancer costs create a lot of stress				
Agree	11 (22.9)	8 (16.7)	14 (56.0)	0.001*
Disagree	37 (77.1)	40 (83.3)	11 (44.0)	
Cancer costs more stressful than other things				
Agree	9 (18.4)	5 (10.4)	12 (48.0)	0.001*
Disagree	40 (81.6)	43 (89.6)	13 (52.0)	
Trouble paying for my cancer costs				
Agree	3 (6.2)	5 (10.4)	7 (29.2)	0.018*
Disagree	45 (93.8)	43 (89.6)	17 (70.8)	
Aware of assistance programs				
Agree	15 (29.4)	10 (20.8)	8 (36.4)	0.361
Disagree	36 (70.6)	38 (79.2)	14 (63.6)	
Prescription drugs free to everyone				
Agree	39 (70.9)	25 (52.1)	14 (58.3)	0.139
Disagree	16 (29.1)	23 (47.9)	10 (41.7)	
Prescription drugs free to low income people				
Agree	49 (86.0)	41 (83.7)	20 (80.0)	0.793
Disagree	8 (14.0)	8 (16.3)	5 (20.0)	
Assistance programs well advertised				
Agree	52 (86.7)	41 (86.7)	22 (88.0)	0.986
Disagree	8 (13.3)	6 (12.8)	3 (12.0)	

* Statistically significant; $p<0.05$

4.4. Urban versus Rural Residents

In the next series of analyses, we compared urban and rural respondents.

Table 4.19 compares the socio-demographic characteristics of urban and rural respondents. Compared to urban residents, a larger proportion of rural residents had less than a high school education, earned less than $30,000 income, and did not have private health insurance.

Table 4.19 Demographic characteristics of urban and rural participants.

Characteristic	**urban% n (%)**	**rural n (%)**	**p value**
Age *(n = 170)*			
< 65	30 (38.5)	36 (39.1)	0.929
≥ 65	48 (61.5)	56 (60.9)	
Marital Status *(n = 165)*			
Un-partnered	8 (10.7)	12 (13.3)	0.601
Partnered	67 (89.3)	78 (86.7)	
Dependents *(n = 164)*			
Yes	17 (22.7)	15 (16.9)	0.349
No	58 (77.3)	74 (83.1)	
Employment Status *(n = 169)*			
Full-Time/self-employed	11 (14.1)	7 (7.7)	
Part-Time/semi-retired	6 (7.7)	8 (8.8)	
Seasonal/sick leave/unemployed/other	5 (6.4)	9 (9.9)	0.510
Retired	56 (71.8)	67 (73.6)	
Education *(n =166)*			
Less than high school	11 (14.7)	45 (49.5)	
Completed high school	17 (22.7)	17 (18.7)	0.000*
Some post secondary	12 (16.0)	12 (13.2)	
Completed post secondary	19 (25.3)	11 (12.1)	
Graduate/professional degree	16 (21.3)	6 (6.6)	
Income *(n = 170)*			
< $19,999	3 (3.8)	21 (22.8)	
$20,000 - $29,999	11 (14.1)	27 (29.3)	
$30,000 - $39,999	18 (23.1)	15 (16.3)	
$40,000 - $49,999	12 (15.4)	13 (14.1)	0.000*
$50,000 - $59,999	12 (15.4)	7 (7.6)	
$60,000 - $69,999	5 (6.4)	5 (6.4)	
≥ $70,000	17 (21.8)	4 (4.3)	
Have Private Insurance *(n = 161)*			
Yes	39 (80.8)	45 (51.1)	0.000*
No	14 (19.2)	43 (48.9)	
Know about MTAP *(n = 139)*			
Yes	28 (49.1)	28 (34.1)	0.077
No	29 (50.9)	54 (65.9)	

* statistically significant; p<0.05

Compared to urban residents, a larger proportion of rural residents had been diagnosed either 7-12 or 13-24 months earlier (Table 4.20). There are no other differences in the clinical characteristics between the two groups.

Table 4.20 Clinical characteristics of urban and rural participants.

Clinical Characteristics	**urban% n (%)**	**rural n (%)**	**p value**
Time Since Diagnosis *(n = 167)*			
0 – 6 months	17 (22.1)	15 (16.7)	
7 – 12 months	25 (32.5)	33 (36.7)	0.016*
13 – 24 months	11 (14.3)	28 (31.1)	
24 months +	24 (31.2)	14 (15.6)	
Current Treatment *(n = 170)*			
Radiation			
Yes	8 (10.3)	11 (12.0)	0.726
No	70 (89.7)	81 (88.0)	
Hormone Therapy			
Yes	15 (19.2)	13 (14.1)	0.372
No	63 (80.8)	79 (85.9)	
Chemotherapy			
Yes	0 (0.0)	0 (0.0)	.a
No	78 (100.0)	92(100.0)	
Active Treatment			
Yes	26 (33.3)	36 (39.1)	0.434
No	52 (66.7)	56 (60.9)	
Other			
Yes	5 (6.4)	11 (12.0)	0.217
No	73 (93.6)	81 (88.0)	
Active Treatment or Follow-up			
Yes	21 (26.9)	25 (27.2)	0.971
No	57 (73.1)	67 (72.8)	
Past treatment *(n = 169)*			
Radiation			
Yes	24 (30.8)	27 (29.7)	0.877
No	54 (69.2)	64 (70.3)	
Hormone Therapy			
Yes	10 (12.8)	12 (13.0)	0.966
No	68 (87.2)	80 (87.0)	
Chemotherapy			
Yes	0 (0.0)	1 (1.1)	0.356
No	78 (100.0)	91 (98.9)	
Surgery			

Yes	44 (56.4)	41 (44.6)	0.124
No	34 (43.6)	51 (55.4)	
Prostatectomy			
Yes	39 (50.0)	36 (39.1)	0.155
No	39 (50.0)	56 (60.9)	
TURP			
Yes	3 (3.8)	0 (0.0)	0.058
No	75 (96.2)	92(100.0)	
Orchiectomy			
Yes	0 (0.0)	2 (2.2)	0.190
No	78 (100.0)	90 (97.8)	
Other			
Yes	1 (1.3)	0 (0.0)	0.276
No	77 (98.7)	92(100.0)	
Length of Time Receiving Treatment *(n = 75)*			
< 3 months	11 (36.7)	20 (44.4)	
3 – 6 months	5 (16.7)	7 (15.6)	0.793
6 months – 1 year	14 (46.7)	18 (40.0)	
Drugs taken *(n = 170)*			
Hormone Treatment			
Yes	13 (16.7)	20 (21.7)	0.405
No	65 (83.3)	72 (78.3)	
Supportive			
Yes	9 (11.5)	10 (10.9)	0.890
No	69 (88.5)	82 (89.1)	
Vitamins/Supplements			
Yes	7 (9.0)	6 (6.5)	0.549
No	71 (91.0)	86 (93.5)	
Miscellaneous			
Yes	5 (6.4)	2 (2.2)	0.166
No	73 (93.6)	90 (97.8)	

* statistically significant; $p<0.05$

Table 4.21 compares the OOP costs (dollar value) of urban and rural patients. Although there was no difference in the costs for drugs and supplies or total, a larger proportion of rural residents than urban residents reported costs up to $500 and greater than $500 in the previous quarter for travel.

Table 4.21 Three month Out-of-pocket costs, All Costs category, for urban and rural participants.

Cost	**urban%** **n (%)**	**rural** **n (%)**	**p value**
Drugs and Supplies 3 Month*(n = 170)*			
$0	59 (75.6)	62 (67.4)	0.074
$0.01 - $499.99	15 (19.2)	29 (31.5)	
≥$500.00	4 (5.1)	1 (1.1)	
Travel 3 month *(n = 170)*			
$0	61 (78.2)	47 (51.1)	0.001*
$0.01 - $499.99	11 (14.1)	27 (29.3)	
≥$500.00	6 (7.7)	18 (19.6)	
All Costs 3 Month *(n = 170)*			
$0	49 (62.8)	42 (45.7)	0.077
$0.01 - $499.99	18 (23.1)	29 (31.5)	
≥$500.00	1 1(14.1)	21 (22.8)	

* Statistically significant; $p<0.05$

Table 4.22 compares the proportion of income consumed by OOP costs of urban and rural patients for a three month period. Although there was no difference in the costs for drugs and supplies or total, a larger proportion of rural residents than urban residents reported costs up to 7.49% and greater than 7.5% in the previous quarter for travel.

Table 4.22 Percent of income consumed for urban rural participants.

% of Quarterly Income Consumed	**urban%** **n (%)**	**rural** **n (%)**	**p value**
Drugs and Supplies *(n = 170)*			
0%	59 (75.6)	62 (67.4)	
0.01 – 7.49%	16 (20.5)	29 (31.5)	0.157
7.50+ %	3 (3.8)	1 (1.1)	
Travel *(n = 169)*			
0%	61 (79.2)	47 (51.1)	
0.01 – 7.49%	11 (14.3)	31 (33.7)	0.001*
7.50+ %	5 (6.5)	14 (15.2)	
All costs *(n = 170)*			
0%	49 (62.8)	42 (45.7)	
0.01 – 7.49%	20 (25.6)	32 (34.8)	0.075
7.50+ %	9 (11.5)	18 (19.6)	

* Statistically significant; $p<0.05$

As shown in Table 4.23 there was no difference in the proportion of urban and rural residents who reported using either drug or appointment related coping strategies.

Table 4.23 Use of coping strategies for urban and rural participants.

Coping strategies	**urban% n (%)**	**rural n (%)**	**p value**
Drug Coping Strategies *(n = 170)*			
Yes	4 (5.1)	10 (10.9)	0.175
No	74 (94.9)	82 (89.1)	
Appointment Coping Strategies *(n = 170)*			
Yes	3 (3.8)	3 (3.3)	0.837
No	75 (96.2)	89 (96.7)	

* Statistically significant; p<0.05

There was also no difference in the quality of life scores reported by urban and rural residents (Table 4.24).

Table 4.24 Quality of life for urban and rural participants.

Quality of Life	**urban% mean (sd)**	**rural mean (sd)**	**p value**
FACTG Total *(n = 126)*	86.02 (13.686)	84.10(14.228)	0.445
FACT P Total *(n=126)*	117.81(17.811)	116.64(20.086)	0.733

* Statistically significant; p<0.05

Compared to urban residents a larger proportion of rural residents reported that cancer care costs created a lot of stress and that cancer costs were more stressful than other things (Table 4.25). There were no other significant differences in the attitudes and beliefs of urban and rural residents.

Table 4.25 Attitudes regarding OOP costs for urban and rural participants.

Attitudes	**urban%** **n (%)**	**rural** **n (%)**	**p value**
OOP costs influenced treatment decisions			
Agree	4 (7.1)	5 (7.2)	0.982
Disagree	52 (92.9)	64 (92.8)	
Doctor aware of my OOP costs			
Agree	14 (26.4)	17 (27.4)	0.904
Disagree	39 (73.6)	45 (72.6)	
Doctor takes costs into account			
Agree	6 (11.5)	9 (14.5)	0.639
Disagree	46 (88.5)	53 (85.5)	
Cancer costs create a lot of stress			
Agree	10 (18.2)	23 (34.8)	0.040*
Disagree	45 (81.8)	43 (65.2)	
Cancer costs more stressful than other things			
Agree	7 (12.7)	19 (28.4)	0.036*
Disagree	48 (87.3)	48 (71.6)	
Trouble paying for my cancer costs			
Agree	4 (7.3)	11 (16.9)	0.111
Disagree	51 (92.7)	54 (83.1)	
Aware of assistance programs			
Agree	14 (25.5)	19 (28.8)	0.682
Disagree	41 (74.5)	47 (71.2)	
Prescription drugs free to everyone			
Agree	36 (64.3)	42 (59.2)	0.555
Disagree	20 (35.7)	29 (40.8)	
Prescription drugs free to low income people			
Agree	49 (83.5)	61 (84.7)	0.795
Disagree	10 (16.9)	11 (15.3)	
Assistance programs well advertised			
Agree	10 (16.4)	7 (9.9)	0.264
Disagree	51 (83.6)	11 (15.3)	

* Statistically significant; $p<0.05$

Chapter 5: Discussion

5.1. Study

Using a self-administered, written survey of a sample of men diagnosed with prostate cancer, we described the OOP costs associated with prostate cancer care in Newfoundland and Labrador. We also examined the association between costs and cost saving strategies and attitudes. Finally, we compared the costs, use of cost saving strategies and the attitudes of men who lived in urban and rural communities.

5.2. Costs

We assessed costs over two time periods and using two measures. We examined costs incurred during the previous one month and during the previous three months (quarter). While recall is better over the shorter period, costs incurred may be highly variable. For example, if prescriptions are filled for six weeks or three months, capturing only the expenses accrued in the previous one month may be inaccurate if the value is too low (if the prescription was not filled) or too high (if the prescription was filled). Although assessing costs over a three month period may provide more stable values, participants may have poorer recall of expenses. By considering costs over the two periods, we were able to address these potential threats to validity.

Costs were measured as actual dollar amounts as well as the proportion of income consumed by these costs. It is important to understand these two variations of costs as an actual dollar amount may hold different consequences for individuals. One thousand dollars of OOP cancer related costs might substantially affect someone with a low income but have less impact on someone with higher income. While it is important to understand actual dollar amounts of OOP cancer related costs, determining the proportion of income that is consumed by OOP cancer related costs provides a better indicator of the financial burden of cancer to individuals (Moore, 1998) Also, measuring OOP costs as a proportion of income allows us to examine costs in relation to means-tested assistance programs such as the public drug plans offered in Newfoundland and Labrador (Government of Newfoundland and Labrador, n d) It also facilitates comparisons between provinces and countries, and at different points in time

Although the majority of men with prostate cancer reported no OOP costs in the previous month or previous quarter, a small proportion of men paid in excess of $500 for OOP cancer costs in the last month (14 1%) or previous quarter (18 8%) When considered in terms of proportion of income, 21 2% spent more than 7 5% of their income on OOP costs in the previous month (15 9% spent more than 7 5% of their income on OOP costs in the previous quarter) These findings are consistent with previous studies of OOP costs for cancer patients in NL (Mathews and Basky, 2004) and Ontario (Longo et al, 2006, Longo et al , 2007) Mathews and Basky (2004) found that 19 8% of cancer patients spent more than $1000 for their last trip for cancer care[6]

There was no relationship between time since diagnosis and amount of costs This finding may be unique to prostate cancer, unlike other cancer diagnoses, there may be little active treatment immediately following discovery OOP costs appear to accrue once treatment other than surveillance (or watchful waiting) begins Further

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[6] The study examines costs for a single trip away from the men's home community One trip could entail multiple visits at the cancer clinic

study of the OOP costs associated with other types of cancer is needed to test this hypothesis.

5.2.1 Drug Costs

Only a very small proportion of men reported high drug costs (in excess of $500 or 7.5% of income) in either the previous month or previous quarter. Although other Canadian studies have reported higher drug costs among cancer patients, these included breast, lung, colorectal and prostate cancer patient together (without providing cancer specific estimates) (Longo et al., 2006; Longo et al., 2007; Mathews and Basky, 2004). Despite reporting higher cancer related drug costs, these studies also found that costs were very high for a small group of patients.

The small proportion of men reporting any drug costs may be explained by the small numbers of men who reported taking any drugs for the prostate cancer; relatively few men reported that they were taking hormone treatment (19.4%), supportive drugs (11.2%) vitamins and/or supplements (7.6%) or other prostate cancer related drugs (4.1%). We found that a larger proportion of men taking hormone treatment, supportive drugs (such as Demerol, viagara, ibuprofen, hydrocortisone, and oxycodone) or vitamins/supplements such as Vitamins B12, C, D, calcium, lycopene and glucosamine) reported higher costs over a three month period (whether considered in actual dollars or proportion of income consumed by OOP cancer costs). While hormone therapy and supportive drugs are prescribed by a physician, with the exception of vitamin D[7], there is little conclusive evidence to support taking vitamins and supplements for prostate cancer. Studies have suggested

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[7] Men with prostate cancer are encouraged to consult their physician about taking one thousand international units (IU) daily during the fall and winter seasons (CCS, 2009b).

that use of supplements such as antioxidants may not only be potentially ineffective but may also be harmful when used in combination with chemotherapy or radiation therapy (D'Andrea, G. M., 2005; Lawenda et al., 2008). Moreover, the Canadian Cancer Society notes that eating a healthy diet is the best way of getting daily requirements of vitamins and supplements (Canadian Cancer Society, 2009c). Given that vitamins and supplements can account for substantial OOP costs, our findings suggest that there is a need to educate men about the potential benefits and drawbacks of taking vitamins and supplements.

Low OOP drug costs may also be due to formal and informal financial subsidies that men may be receiving. Formal programs include public and private insurance programs. Almost two-thirds (64.6%) of the men in our sample had private health insurance. In addition, men may have started to receive subsidies through the Assurance Plan which was added to the Newfoundland and Labrador Drug Plan, in 2007 (Government of Newfoundland and Labrador, n.d). The Assurance Plan subsidizes drug costs above income related thresholds (see Section 2.2.2.1). Men may also benefit from "compassionate release", an informal program offered in the cancer clinic (Mathews et al, 2009c). In these programs, drug companies may provide drug costs at reduced or no costs to patients in need. In Newfoundland and Labrador, the program is informally run with requests made by health care providers in the cancer clinic. The program provides approximately $1.5 million worth of drugs to patients (all cancer types) each year. There are no exclusion criteria; however, staff assigned to the program determine whether other support programs or coverage is available before referring patients to the compassionate care programs (J.

Greenland, personal communication, November 21, 2009). In other parts of Canada, the majority of compassionate release are means tested (based on income)and are available to those who are without private insurance (BC Cancer Agency, 2009). Some programs will assist patients in finding third party insurance or have a co-pay system.

5.2.2 Travel Costs

A larger proportion of men in the study reported high travel related OOP costs, 14.1% had costs in excess of $500 and 11.2 had costs in excess of 7.5% of their income). For men in our study, travel costs were largely responsible for the total amount of costs, accounting for 85% of all costs among men who had any costs in the previous quarter or 63% of costs in the previous month. Not surprisingly, a larger proportion of rural residents reported higher travel costs. These findings are also consistent with previous studies NL (Mathews and Basky, 2004). High travel costs are due to the centralization of specialists (urologists and oncologists) in the larger centres in the province and availability of radiation therapy, one of the main forms of treatment for prostate cancer (Carroll et al., 2005), in St. John's. Patients who live outside of St. John's and who require radiation treatment incur substantial costs in travel and lodging for radiation treatment which can last weeks at a time. Likewise, men who are treated with "watchful waiting" may need to travel to a larger centre to see their urologist. Although our study limited travel costs to those incurred in the previous month and previous quarter, many respondents noted in survey that they had high travel costs (in excess of $1,000) when they had to access treatment in St. John's or outside the province, even though it had not been incurred in the previous one or three months.

5.3. Cost Saving Strategies

Very few men in the study reported using any cost saving strategies; only 8.2% reported *ever* using a drug related coping strategy and only 3.5% reported *ever* using an appointment related strategy. The slightly higher rate of drug versus appointment related strategies may be due to drug-related strategies being "less conspicuous" to health care providers since they would be less likely to know or to notice a missed pill than a missed appointment. Moreover, patients may believe that *some* treatment (e.g. rationing or substituting drugs is better than *no* treatment (missing an appointment). Studies in the US have reported higher rates of cost saving strategies (Piette, Heisler, & Wagner, 2004; Federman, 2004). For example, Piette et al. found that overall 18% of patients surveyed reported using some form of drug coping strategy or "underuse" of medication at least once in the previous year. In addition they also found that 14% of all respondents underused medication at least once a month during the previous year. However, these studies included patients with other chronic conditions such as diabetes and hypertension. We hypothesize that patients may be less willing to compromise cancer related care than care for other chronic conditions. Further research is needed to test this hypothesis.

There was some association between costs and use of any cost saving strategy. Compared to men with no costs, a larger proportion of men with high costs used drug related coping strategies ($500 or more or 7.5% or more of income) and appointment related strategies (7.5% or more of income). Significant results were seen in relation to costs over three month period but not one month. The low rate of drug or appointment related strategies, suggests that although costs may be high for some patients, it does not generally result in patient driven changes to care. Although a previous qualitative study suggested that patients use drug and cost related strategies to curb OOP cancer costs (Mathews et al., 2009b), our study suggests that the use of these strategies is generally rare among prostate cancer patients.

There was also no significant difference in the use of cost saving strategies of urban and rural residents. A previous study of breast, lung, colorectal and prostate cancer patients found rural residents were more likely than urban residents to consider drug and travel related OOP costs as important in the cancer care decisions (Mathews et al., 2009a). However, we did not find differences in the current and previous treatments reported by urban and rural residents in our study. Moreover, few respondents agreed when asked whether OOP costs influenced their treatment decisions for their prostate cancer. There was also no significant difference in the quality of life scores of men with high and low costs. These findings suggest that while costs may be important considerations, they generally affect the treatment decisions of a very small proportion of prostate cancer patients, if at all.

There is also a strong culture and willingness in Newfoundland and Labrador to help those in need. Anecdotally, patients or friends and family of those going through cancer, particularly in rural communities, may find their community rallying around them by raising funds to cover the costs of their cancer care (Mathews & Basky, 2003). This may explain why few men use coping strategies despite one in nine men reporting OOP costs of more than 7.5% of their income.

5.4 Cost Related Stress and Quality of life

Roughly one quarter (27.3%) of the men surveyed reported that OOP costs created stress, 21.3% said those costs created more stress than other things in their life. Although higher costs in the previous month was associated with stress, we did not find a similar association when considering costs over a three month period. This may be due to the way in which costs are incurred, that is, a trip or a prescription may be required every quarter rather than every month. Men who just travelled or filled a prescription may have accumulated a substantial number of expenses (and had a substantial outlay of money) causing a "cash flow" problem. Or, some assistance programs may require men to pay costs "up-front" and then submit claims for subsidies at a later time.

A larger proportion of rural residents than urban residents agreed that OOP cost caused more stress than other sources of stress in their lives. This finding is consistent with other results in the study and previous studies of rural cancer patients that showed that rural residents have greater out-of pocket costs that can amount to thousands of dollars for a single trip away from home (Lauzier et al., 2005; Mathews and Basky, 2004; Mathews et al., 2009a). Lauzier and colleagues, (2005), found that cancer patients from rural areas found OOP costs to be worrisome if they did not have sufficient means to pay for these costs. These financial concerns, added to the stress and worry of the cancer itself.

5.5 Awareness and support of assistance programs

Less than one third of patients (27.0%) discussed cancer related OOP costs with their physicians and less than one in seven (13.2%) agreed that their doctor takes costs into account when prescribing drugs for them. In addition, there was no consistent relationship between the amount of OOP costs incurred and discussing costs with physicians or physicians who took costs into account when prescribing drugs. These findings concur with other studies in the US. For example, US researchers report that only 15-16% of patients discussed OOP drug related costs with their physicians (Alexander, Casalino, & Meltzer, 2003; Piette, Heisler, & Wagner, 2004) and that only one third of physicians discussed drug costs with their patients (Alexander, Casalino, & Meltzer, 2003). Piette and colleagues (2004) listed several reasons why patients did not discuss costs with their physicians: they had not been asked (66%), they did not think their health care providers could help (58%), they were too embarrassed (45%), they did not think the issue was important (45%), there was insufficient time during the visit (31%), there was a lack of trust (11%). In a qualitative study, Mathews and Park (2009) highlighted a number of barriers to identifying patients with financial concerns in Newfoundland and Labrador. These barriers included a lack of a standardized assessment tool, a lack of ongoing screening, and patients' lack of knowledge of financial concerns as well as their unwillingness to disclose these concerns.

It is possible that patients may have discussed financial concerns with other members of the cancer care team besides physicians. Increasingly as cancer care is provided in interdisciplinary teams, health care providers such as social workers or nurses may be tasked with assessing financial risks. Future studies should also examine the role of the team in assessing financial risk.

The 'danger' of health care providers not knowing about patients financial concerns is that the providers may not refer patients to assistance programs (Wagner & Lacey, 2004). In fact, only 27.3% of men in our study were aware of financial assistance programs and only 12.9% believed these programs were well advertised. These findings are in line with previous studies (Mathews and Park, 2009; Mathews et al., 2006; Wagner and Lacey, 2004) and highlight the need to educate patients about resources that are available to them in the province in order to reduce the burden of OOP cancer related costs. For example, a number of respondents could potentially qualify for one of the four plans that make up the NL Public Drug Plan because of their age (61.2% were over 65 years old) or the proportion of the their income consumed by OOP cancer costs (Government of Newfoundland and Labrador, n.d.). There was strong support for public "pharmacare" plans, especially for low income families, among the men in our study, regardless of the OOP costs incurred.

5.6. Limitations

There are a number of limitations to this study. First we had to use a variety of methods to conduct surveys with eligible participants. We had originally planned to recruit patients from the Cancer Clinics and support groups in the province. Although there was a high level of assistance and participation from support groups, we were unable to recruit many new patients, or patients who did not belong to a support group.

For this study, the Human Investigations Committee did not permit researchers to make the first contact with patients. As a result, we were dependent on the cancer clinic staff to tell patients about the study and refer patients to the researcher. However, there was a substantial level of reluctance among staff to recruit patients for the survey or have a researcher available in the cancer clinic waiting rooms. As a result, we had to modify recruitment to passive means, such as using posters. These methods took a substantial amount of time and did not result in many respondents, particularly in the St. John's clinic. Ultimately we resorted to a mailed survey despite the limitations of a mailed survey to collect complete and sensitive data (Aday, 1996). These experiences highlight the need for improved support from the cancer clinics for research projects and facilitating access to cancer patients for researchers. Although we used different methods used to recruit our sample, we obtained a representative sample of respondents in terms of urban/rural residence and age.

We used the Cancer Registry to generate a list of recently diagnosed prostate cancer patients for the mailed survey. Because we decided to use a mail survey when other methods did not work, we did not have a large budget to fund it. Although we had a reasonable response rate given limited resources, future studies using the registry for surveys should allow for multiple mail-outs and reminders (Dillman, 2007). Using the Registry to create the sample frame requires that it be complete, valid, reliable and timely (Menck, Denpen, Phillips, and Tucker, 2007). Although efforts are underway to improve the cancer registry in the province, there are a number of problems with the Cancer Registry in NL. The North American Association of Central Cancer Registries, which assess the completeness and quality of registries, has never certified the Newfoundland and Labrador cancer registry

(North American Association of Central Cancer Registries, 2007). Moreover the Canadian Cancer Statistics noted problems with the quality of the data on the NL registry (CCS/National Cancer Institute of Canada, 2008). Despite these limitations with the registry, it was the only way to identify prostate cancer patients in the province.

Although we asked stage at diagnosis in the survey, we did not report these findings because of the poor quality of the data. Many respondents did not answer this question. Moreover, many responded with qualitative answers (e.g. "early", "good", etc.) rather than Gleason scores. Subsequent discussions with prostate cancer patients suggested that not all physicians inform patients of the stage of the prostate cancer to the patient.

The sample size was smaller than originally anticipated (due in part to the difficulties with recruitment). However, the sample was large enough to detect a difference as small as 3.9 points between urban and rural participants (with a two tail test, power of 0.8 and an alpha of 0.05). The sample size calculation was based on the FACT-P instrument, which has a mean of 67 and standard deviation of 8.7 (Esper et al., 1997).

However, given the very small number of respondents with high costs, we may not have sufficient power to detect significant differences in our comparisons of men with different amounts of costs. Moreover, we did multiple comparisons, thereby increasing the likelihood that some of the differences we found were due to chance.

Chapter 6: Conclusions and Recommendations

This study described the types and amounts of OOP costs incurred by prostate cancer patients in Newfoundland and Labrador and examined whether OOP costs of prostate cancer have any affect on patients' attitudes, use of cost management strategies and quality of life. It also looked at differences in the costs, attitudes, use of cost management strategies and quality of life of urban and rural residents. This study increases our understanding of how cancer patients and their families manage the financial burden associated with cancer care. It provides health care providers, system administrators and patient advocates with evidence with which to improve the accessibility of cancer care in the province.

We found that although most men with prostate cancer incur no, or very little OOP care related costs, a small but substantial proportion of men with prostate cancer had significant costs. Almost 1 in 5 men (18.8%) paid more than $500 in the last quarter. For roughly 1 in 6, these OOP costs accounted for more than 7.5% of their quarterly income. While higher OOP costs were related to greater stress, there were few other differences between men with high and low OOP costs. Very few men reported that they compromised their care, by using drug or appointment related strategies to reduce their OOP costs. We also did not find significant differences in the quality of life or care received by men with different levels of costs. High OOP costs were generally related to the costs of travel and lodging. Therefore, it was not surprising that rural men generally reported higher OOP costs than urban men. Aside from higher stress related to OOP costs, there were few other differences in the use of cost saving strategies, quality of life or attitudes of urban and rural men.

These findings suggest that although OOP costs for prostate cancer care are high for a small group of men, OOP costs rarely affect care. This may suggest that Canadian public health insurance, as well as formal and informal drug (e.g. compassionate leave) programs are working to remove financial barriers to care. Nonetheless, costs related to travel and lodging remain a substantial financial barrier for patients from rural communities. While the provincial government reimburses individuals for some costs relating to travel for health services through the Medical Travel Assistance Program, some costs remain ineligible, such as mileage for a private vehicle. Expanding the eligibility criteria for the programs may reduce the financial burden faced by prostate cancer patients, particularly those in rural areas. However, further research is needed to assess the OOP costs and their consequences among patients with other types of cancer as well as with prostate cancer patients in other provinces.

Despite the concerns regarding OOP costs, relatively few men tell their physicians about their OOP costs or believe that their doctor takes costs into account when prescribing drugs. We also found that most men in our study were unaware of financial assistance programs or felt that they were well advertised. These findings suggest there is a need to educate patients about subsidy programs and promote discussions between patients and health care providers about OOP cancer related costs.

Lastly, we experienced considerable difficulty accessing patients through the cancer clinic. There is a need to improve support for research within the cancer care program. Their support is integral to future applied health research involving cancer.

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Appendix A

The Survey

Prostate Cancer Patients' Out-of-Pocket Costs

First, we would like to find out more about your cancer diagnosis.

1. When were you first diagnosed with prostate cancer?

   ____________(month) ____________(year)

2. What was your stage of cancer when diagnosed? ____________________

3. Is this your first cancer diagnosis?

   ☐ Yes
   ☐ No

4. Are you currently being treated for any other type of cancer?

   ☐ Yes
   ☐ No

5. What treatment are you ***currently*** receiving for your prostate cancer? (*check all that apply*)

   ☐ Radiation
   ☐ Hormonal therapy (eg. LHRH agonists, antiandrogens)
   ☐ Chemotherapy (eg. Docetaxel (Taxotere))
   ☐ No active treatment; regular follow-up
   ☐ Other:_________________________

6. What treatment have you previously had for your prostate cancer? (*check all that apply*)

   ☐ Radiation
   ☐ Hormonal therapy (eg. LHRH agonists, antiandrogens)
   ☐ Chemotherapy (eg. Docetaxel (Taxotere))
   ☐ Surgery, if so, which kind
      ○ Prostatectomy (removal of prostate)
      ○ TURP (enlargement of urethra)
      ○ Orchiectomy (removal of testes)
      ○ Other: please specify__________________
   ☐ Other:_________________________

7. How long have you been receiving treatment?

   ☐ Less than 3 months
   ☐ 3-6 months
   ☐ Between six months and a year

8. Are you taking part in any clinical trials for cancer treatment?

   ☐ Yes
   ☐ No

The next section will ask about the ***out-of-pocket*** costs for your prostate cancer care. We are interested in those costs that were not covered by insurance or assistance programs.

9. Thinking about the ***last month***, please indicate how much you spent for each of the following in the first column? Next, thinking about the last ***three months,*** please indicate how much you spent for each of the following in the second column?

Type of cost	**Amount ($) per month**	**Amount ($) last 3 months**
Prescription drugs for prostate cancer		
Over the counter drugs for prostate cancer		
Natural or alternative medications (such as herbal medications)		
Transportation for cancer care		
Gas and/or Rental Car		
Bus/taxi		
Plane tickets		
Other (please list ____________)		
Lodging while receiving cancer care		
Hotel		
Motel		
Hostel		
Other (please list ____________)		
Meals while at the cancer clinic		
Costs for companion/escort		
Communication while at the cancer clinic (phone, internet, mail)		
Parking (at the cancer clinic)		
Supplies (such as bandages etc)		
Care for a child/ or elder		
Lost wages		
Other (please list ______________)		

10. How did costs for this month compare to other months since you have been diagnosed with prostate cancer?

☐ More than other months
☐ Similar to other months
☐ Less than other months

11. How did/do you pay for these costs? (*check all that apply*)

☐ Savings
☐ Help or loan from family/friends
☐ Sold belongings
☐ Fundraiser
☐ Bank loan
☐ Social Assistance/Income support
☐ Veteran's benefits
☐ Medical Transportation Assistance program
☐ Other assistance program from cancer clinic or hospital
☐ Other: please describe____________________

12. What drugs are you taking in relation to your cancer treatment? (*List all that apply*)

____

____

____

____

13. Are these drugs covered by your insurance?

☐ Yes
☐ No

14. Do you know about the Medical Transportation Assistance Program (MTAP) offered by the Provincial Government?

☐ Yes

If yes, have you or do you planning to apply to it for assistance?
○ Yes
○ No

☐ No

In the next question, we would like to know how you are managing these costs.

15. On a scale from 1 to 5, where 1 is "never" and 5 is "all of the time", since you were diagnosed with prostate cancer, how often do you do the following: (*please circle one number for each point*)

	Never	**Not very often**	**Some of the time**	**Most of the time**	**All of the time**
a. Spread out a medication over a longer period of time to make it last longer	1	2	3	4	5
b. Replaced the medication your doctor prescribed with another cheaper one	1	2	3	4	5
c. Skipped one or more dose of medication to save on costs	1	2	3	4	5
d. Bought only what you thought was the most important medication	1	2	3	4	5
e. Not filled a prescription because of the cost	1	2	3	4	5
f. Delayed fililng a prescription because of the cost	1	2	3	4	5
g. Asked my doctor for free samples of a drug	1	2	3	4	5
h. Spread out the time between visit to the doctor for follow-up visit	1	2	3	4	5
i. Missed or cancelled an appointment with the cancer clinic to save money	1	2	3	4	5
j. Missed or cancelled scheduled cancer treatment to save money	1	2	3	4	5

16. On a scale from 1 to 5, where 1 is strongly disagree" and 5 is "strongly agree", how much do you agree or disagree with the following statement: (*please circle one number for each point)*

	Strongly Disagree	**Disagree**	**Neither Agree or Disagree**	**Agree**	**Strongly Agree**
a. My out-of-pocket costs influenced my decisions about how to treat my prostate cancer	1	2	3	4	5
b. My cancer doctor is aware of my out-of pocket costs for my prostate cancer	1	2	3	4	5
c. My doctor takes costs into account when prescribing drugs for me	1	2	3	4	5
d. My cancer related costs create a lot of stress	1	2	3	4	5
e. Cancer costs create more stress for me than other sources of stress in my life	1	2	3	4	5
f. I am having trouble paying for my cancer costs	1	2	3	4	5
g. I am aware of assistance programs to help me with cancer costs	1	2	3	4	5
h. All prescription drugs should be free to everyone, regardless of their income	1	2	3	4	5
i. All prescription drugs should be free to people with low income	1	2	3	4	5
j. Assistance programs are well advertised.	1	2	3	4	5

17. Below is a list of statements that other people with your illness have said are important. By circling one (1) number per line, please indicate how true each statement has been for you ***during the past 7 days***.

Physical well-being	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
a. I have a lack of energy	1	2	3	4	5
b. I have nausea	1	2	3	4	5
c. Because of my physical condition, I have trouble meeting the needs of my family	1	2	3	4	5
d. I have pain	1	2	3	4	5
e. I am bothered by side effects of treatment	1	2	3	4	5
f. I feel ill	1	2	3	4	5
g. I am forced to spend time in bed	1	2	3	4	5
Social/Family well-being					
a. I feel close to my friends	1	2	3	4	5
b. I get emotional support from my family	1	2	3	4	5
c. I get support from my friends	1	2	3	4	5
d. My family has accepted my illness	1	2	3	4	5
e. I am satisfied with family communication about my illness	1	2	3	4	5
f. I feel my friends and acquaintances avoid me.	1	2	3	4	5
g. I feel close to my partner (or the person who is my main support)	1	2	3	4	5
Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box ☐ *and go to the next section.*					
h. I am satisfied with my sex life	1	2	3	4	5
Emotional Well-being					
a. I feel sad	1	2	3	4	5
b. I am satisfied with how I am coping with my illness	1	2	3	4	5
c. I am losing hope in the fight against my illness	1	2	3	4	5
d. I feel nervous	1	2	3	4	5
e. I worry about dying	1	2	3	4	5
f. I worry that my condition will get worse	1	2	3	4	5
Functional Well-being					
a. I am able to work (include work at home)	1	2	3	4	5
b. My work (include work at home) is fulfilling	1	2	3	4	5
c. I am able to enjoy life	1	2	3	4	5
d. I have accepted my illness	1	2	3	4	5
e. I am sleeping well	1	2	3	4	5
f. I am enjoying the things I usually do for fun	1	2	3	4	5

Additional Concerns	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
a. I am losing weight	1	2	3	4	5
b. I have a good appetite	1	2	3	4	5
c. I have aches and pains that bother me	1	2	3	4	5
d. I have certain parts of my body where I experience significant pain	1	2	3	4	5
e. My pain keeps me from doing things I want to do	1	2	3	4	5
f. I am satisfied with my present comfort level	1	2	3	4	5
g. I am able to feel like a man	1	2	3	4	5
h. I have trouble moving my bowels	1	2	3	4	5
i. I have difficulty urinating	1	2	3	4	5
j. I urinate more frequently than usual	1	2	3	4	5
k. My problems with urinating limit my activities	1	2	3	4	5
l. I am able to have and maintain an erection	1	2	3	4	5

Finally, the following questions will ask a little bit about yourself and will be helpful in describing who is affected by out-of-pocket costs of cancer, and how.

18. In what year were you born? ____________________________

19. In which town/city do you live? ____________________________

20. What is your postal code? ____________________________

21. Which best describes your current situation? (*Please choose one response only*)

☐ Full-time job
☐ Part-time job
☐ Self-employed
☐ Seasonal/EI
☐ Sick leave (paid) / Long term disability
☐ Strike
☐ Unemployed
☐ Semi-retired
☐ Retired
☐ Caring for someone full-time
☐ Homemaker
☐ Student
☐ Other ________________

22. As a result of your cancer diagnosis, did your work situation change? (*check all that apply*)

☐ Yes.

If yes, how?
- ○ Working less
- ○ Working more
- ○ Went back to work
- ○ Had to quit during treatment
- ○ Went on leave during treatment
- ○ Other – please describe: ___________________

☐ No

23. What is your highest level of education?

- ☐ Did not complete high school
- ☐ Completed high school
- ☐ Did some community college, technical school, or university
- ☐ Completed community college, technical school, or university
- ☐ Completed post-graduate or professional training

24. What is your marital status?

- ☐ Married/living with partner
- ☐ Single - divorced/separated
- ☐ Single – never married
- ☐ Single - Widower

25. Do you have any children or elderly relatives to care for?

☐ Yes
- ○ Children
    - ▪ How many? ___________
- ○ Elderly relatives
    - ▪ How many? ___________

☐ No

26. Thinking of all the family members in your household, last year in which category was your 'before tax' household income? Please include income from all sources such as wages, pensions, rent and employment insurance.

☐ Less than $10,000
☐ Between $10,000 and $19,999
☐ Between $20,000 and $29,999
☐ Between $30,000 and $39,999
☐ Between $40,000 and $49,999
☐ Between $50,000 and $59,999
☐ Between $60,000 and $69,999
☐ More than $70,000 +

27. Besides MCP (Medical Care Plan), do you have any other health insurance?

☐ Yes
☐ No

28. Are you part of group insurance (through employer) or private insurance?

☐ Yes
☐ No

29. Are you a member of a support group?

☐ Yes
<u>If yes</u>, is your participation of any benefit to you?
○ Yes
○ No

☐ No

30. Do you have any other comments you would like to add?

____

____

____

You have now completed the survey. Please return it in the envelope provided. If you would like to have a copy of the study results, please complete the postcard and mail it separately.

Thank you for taking part in this study!

Appendix B

Survey Cover Letter

Prostate cancer patients' out-of-pocket costs

Researchers at Memorial University of Newfoundland are surveying men with prostate cancer to find out how much prostate cancer patients pay for their care and how they cope with these costs. We also want to know how these costs affect their quality of life and decisions about their care treatment.

This survey will take roughly 20 minutes to complete. The survey is **voluntary**. Whether or not you choose to participate will **not** affect your treatment in any way. All answers are confidential and you will not be identified in any report or presentation. You do not have to answer every question.

If you would like to take part in this study, please fill in the survey and return it in the envelope provided. If you do not want to participate please return the blank survey in the envelope.

The number on this survey allows us to determine how many surveys have been completed. It is not used to identify you.

If you have any questions or would like information on available support programs please contact Emma Housser at (709) 777-4657 or by e-mail at Emma_Housser@hotmail.com

Thank you for your assistance with this project.

Human Investigation Committee
Research and Graduate Studies
Faculty of Medicine
The Health Sciences Centre

Telephone: 709 777-6974
Fax: 709 777-8776
E-mail: hic@mun.ca

Appendix C

Survey insert – Executive summary request card

Research Summary Mail-out Form

If you are interested in receiving a copy of the summary from this study once completed please fill out the address card. This form will not be associated with your survey in any way and will be kept separately from the collected data. Your contact information will not be linked or used for any other purpose than to send you a copy of the summary once complete.

Thank you once again for taking part in this survey.

____

____

____

____

____

____

____

Appendix D

Survey Cover Letter for Cancer Registry mail out

MEMORIAL
UNIVERSITY

Faculty of Medicine
Division of Community Health and Humanities
The Health Sciences Centre
St. John's, NL Canada A1B 3V6
Tel: 709 777 62[illegible]3/6652 Fax: 709 777 7382 www.med.mun.ca

Date

Dear survey recipient:

Researchers at Memorial University are working with the Canadian Cancer Society and cancer care providers to study the amount of money patients pay out of their own pocket for their cancer care and how they cope with these costs. We also want to know how these costs affect your quality of life and decisions about your care treatment. The study findings will help improve cancer services in the province. I hope you will take a few minutes to fill out and return the survey.

You have received a survey because your name was included on the Cancer Registry, a listing of people diagnosed with cancer each year. We have taken a number of steps to ensure that your personal information (such as your name, address or cancer diagnosis) are kept confidential. We will not share this information with anyone.

This survey will take roughly 15-20 minutes to complete. The survey is **voluntary**. Whether or not you choose to participate will **not** affect your treatment in any way. All answers are confidential and you will not be identified in any report or presentation. You do not have to answer every question.

If you would like to take part in this study, please fill in the survey and return it in the envelope provided. If you do not want to participate please return the blank survey in the envelope.

If you have any questions about this study, please feel free to contact me at (709) 777-7845 or the Human Investigations Committee at (709) 777-6974 or hic@mun.ca (please cite reference 07.37 or 07.18)

Thank you for your help with this important study!

Sincerely,

Maria Mathews, PhD
Associate Professor Health Policy/Health Care Delivery

Appendix E

Clinic Recruitment Poster

Prostate Cancer Patients:

Concerned about drug and travel costs?

Researchers from Memorial University are looking for prostate cancer patients to complete a brief survey. This study will help us understand how much prostate cancer patients pay for their care, and how these costs affect them.

For more information, or to request a survey, please contact:

Emma Housser (Masters' candidate AHSR)
(709)777-8539
emma_housser@hotmail.com

Appendix F

Variable list and coding scheme

Appendix E: Survey variables and coding scheme

Variable Name	**Q #**	**Category**	**Codes**
Diagnosis (Dx_Date)	Q1	Month	Numeric
		Year	
Stage (Dx_Stage)	Q2		String
First Diagnosis (Dx_Fir)	Q3	No	0
		Yes	1
Currently being treated for other types of cancer (Dx_oth)	Q4	No	0
		Yes	1
Type of treatment currently receiving	Q5	Radiation	0=no
		Hormonal therapy	1=yes
		Chemotherapy	
		No active treatment; regular follow-up	
		Other treatment	
		Active or follow up	
Type of treatment previously had	Q6	Radiation	0=no
		Hormonal therapy	1=yes
		Chemotherapy	
		Surgery	
		Surgery - prostatectomy	
		Surgery - TURP	
		Surgery - orchiectomy	
		Surgery - other	
		Surgery - specify	
		Other treatment	
How long have you been receiving treatment	Q7	Less than 3 months	0
		3 and 6 months	1
		Between 6 months and 1 year	2
Taking part in clinical trials for	Q8	No	0

cancer treatment		Yes	1
Indicate OOP costs for last month and last three months	Q9	Prescription drugs for prostate cancer	$ amount for 1 and 3 months
		Over the counter drugs for prostate cancer	
		Natural or alternative medications	
		Gas and/or Rental Car	
		Bus/taxi	
		Plane tickets	
		Other transport	
		Hotel	
		Motel	
		Hostel	
		Other lodging	
		Meals while at the cancer clinic	
		Costs for companion/escort	
		Communication while at the cancer clinic	
		Parking (at the cancer clinic)	
		Supplies (such as bandages etc)	
		Care for a child/ or elder	
		Lost wages	
		Other costs	
How did costs this month compare to other months (cost_com)	Q10	More than other months	0
		Similar to other months	1
		Less than other months	2
How did you pay for costs	Q11	Savings	0=no
		Help or loan from family/friends	1=yes
		Sold belongings	
		Fundraiser	

		Bank loan	
		Social Assistance/Income support	
		Veteran's benefits	
		Medical Transportation Assistance program	
		Other assistance program from cancer clinic or hospital	
		Other	
Drugs taking in relation to cancer treatment	Q12		String
Drugs covered by insurance	Q13	No	0
		Yes	1
Know about MTAP	Q14	No	0
		Yes	1
- if yes, planning to apply		No	0
		Yes	1
Coping strategies	Q15	-Spread out a medication over a longer period of time to make it last longer -Replaced the medication your doctor prescribed with another cheaper one -Skipped one or more dose of medication to save on costs -Bought only what you thought was the most important medication -Not filled a prescription because of the cost -Delayed filling a prescription	1=never 2=not very often 3=some of the time 4=most of the time 5= all of the time

		because of the cost -Asked my doctor for free samples of a drug -Spread out the time between visit to the doctor for follow-up visit -Missed or cancelled an appointment with the cancer clinic to save money -Missed or cancelled scheduled cancer treatment to save money	
How much do you agree or disagree with this statement	Q16	-My out-of-pocket costs influenced my decisions about how to treat my prostate cancer -My cancer doctor is aware of my out-of pocket costs for my prostate cancer -My doctor takes costs into account when prescribing drugs for me -My cancer related costs create a lot of stress -Cancer costs create more stress for me than other sources of stress in my life - I am having trouble paying for my cancer costs - I am aware of assistance programs to help me with cancer costs - All prescription drugs should	1=strongly disagree 2=disagree 3= neither agree or disagree 4=agree 5=strongly agree

		be free to everyone, regardless of their income - All prescription drugs should be free to people with low income - Assistance programs are well advertised.	
Fact-P statements on well being Physical	Q17	- I have a lack of energy - I have nausea - Because of my physical condition, I have trouble meeting the needs of my family - I have pain - I am bothered by side effects of treatment - I feel ill - I am forced to spend time in bed	1=not at all 2=a little bit 3=somewhat 4=quite a bit 5=very much
Social		- I feel close to my friends - I get emotional support from my family - I get support from my friends - My family has accepted my illness - I am satisfied with family communication about my illness - I feel my friends and acquaintances avoid me. - I feel close to my partner (or the person who is my main support)	1=not at all 2=a little bit 3=somewhat 4=quite a bit 5=very much

	- I am satisfied with my sex life - Refused question on sexual activity	
Emotional	- I feel sad - I am satisfied with how I am coping with my illness - I am losing hope in the fight against my illness - I feel nervous - I worry about dying - I worry that my condition will get worse	1=not at all 2=a little bit 3=somewhat 4=quite a bit 5=very much
Functional	- I am able to work (include work at home) - My work (include work at home) is fulfilling - I am able to enjoy life - I have accepted my illness - I am sleeping well - I am enjoying the things I usually do for fun	1=not at all 2=a little bit 3=somewhat 4=quite a bit 5=very much
Additional concerns	- I am losing weight - I have a good appetite - I have aches and pains that bother me - I have certain parts of my body where I experience significant pain - My pain keeps me from doing things I want to do - I am satisfied with my present	1=not at all 2=a little bit 3=somewhat 4=quite a bit 5=very much

		comfort level	
		- I am able to feel like a man	
		- I have trouble moving my bowels	
		- I have difficulty urinating	
		- I urinate more frequently than usual	
		- My problems with urinating limit my activities	
		- I am able to have and maintain an erection	
Year of birth	Q18		Numeric
Place of residence	Q19	Town or city	String
Postal Code	Q20		String
Current employment	Q21	Full time	0
		Part time	1
		Self-employed	2
		Seasonal/EI	3
		Sick Leave/Paid long term disability	4
		Strike	5
		Unemployed	6
		Semi-retired	7
		Retired	8
		Caring for someone-full time	9
		Homemaker	
		Student	10
		Other	11
			12
Did work situation change	Q22	No	0

because of cancer		Yes	1
		Working less	
		Working more	0=No
		Went back to work	1=Yes
		Quit during treatment	
		Leave during treatment	
Level of education	Q23	Did not complete high school	0
		Completed high school	
		Some post-secondary	1
		Completed post-secondary	2
		Post grad-or professional training	3
			4
Marital Status	Q24	Married/living with partner	0
		Single – divorced/separated	
		Single – never married	1
		Single - widower	
			2
			3
Caring for children or elderly relatives	Q25	No	0
		Yes	1
		Elderly	0
		How many	numeric
		Children	1
		How many	numeric
Household income	Q26	> $10,000	0
		$10,000 – $19,999	1
		$20,000 – $29,999	2
		$30,000 – $39,999	3
		$40,000 – $49,999	4
		$50,000 – $59,999	5

		$60,000 – $69,999	6
		<= $70,000	7
Health insurance other than mcp	Q27	No	0
		Yes	1
Group or private insurance	Q28	No	0
		Yes	1
Support Group member	Q29	No	0
		Yes	1
IF yes, is participation helpful		No	0
		Yes	1
Comments	Q30		String

Appendix G

Drug breakdown

Category	Specific drug/supplement names
Vitamins	B12 C D Calcium Lycopene Glucosamine
Hormonal	Bicalutamide (Casodex ®) Cyproterone Leuprolide (Eligard®, Lupron ®) Goserelin (Zoladex®) Bicalutamide (Casodex ®) Buserelin (Suprefact®) Triptorelin (Trelstar®) Cyproterone (Androcur®) Docetaxal Mitoxantrone
Supportive prescription drugs	Tadalafil (Cialis®) Demerol Ditropan (Detrol®) Tamsulosin (Flomax®) Oxybutin (Oxytrol®) Sildenafil (Viagra®) Docusate Terazosin apo-bisacodyl Ibuprofen (Advil®) Hydrocortisone (Anusol HC®) Zoledronic acid (Zometa®) Oxycodone
Other	Metropolol (Lopresor ®) Indomethacin (Indocid®) Ramipril (Altace®) Felodipine Prednisone omeprazole/losec Ciprofloxacin nifedipine (Adalat ®) Pomegranate Pravastatin exetrol/ezetimibe Zopiclone ASA Hydrochlorothiazide/lisinopril (Zestoretic®) finasteride (Proscar®)

Appendix H

HIC submission and approval

Memorial
University of Newfoundland

Human Investigation Committee
Research and Graduate Studies
Faculty of Medicine
The Health Sciences Centre

January 23, 2007

<u>**Reference #07.18**</u>

Ms. Emma Housser
c/o Dr. M. Mathews
Division of Community Health & Humanities
Faculty of Medicine
2nd Floor, Health Sciences Centre

Dear Ms. Housser:

Your application entitled "**Prostate cancer patients out-of-pocket costs of cancer and the effects on treatment decisions**" was reviewed by the Human Investigation Committee at the meeting held on **January 18, 2007**. The Committee granted approval of the application subject to a satisfactory response to the following:

(i) The Committee requested additional information on what the potential participants will be told when handed the surveys.

With respect to the cover letter and poster, the Committee requested specific modifications, which will be outlined in a letter to the investigator. Please forward a copy of the documents, with changes highlighted to the HIC Office for review.

The Committee agreed that the response and revised documents could be reviewed by the Co-Chairs and, if found acceptable, full approval of the study be granted.

Please be advised that a response to the aforementioned concerns **is expected within three months of the date of this correspondence.** If we do not receive a response within this timeframe, the file will be automatically closed by the Co-chairs of the Committee.

We look forward to hearing further from you regarding the above outlined issues.

Sincerely,

John D. Harnett, MD, FRCPC
Co-Chair
Human Investigation Committee

Richard S. Neuman, PhD
Co-Chair
Human Investigation Committee

JDH;RSN\jglc

St. John's, NL, Canada A1B 3V6 • Tel.: (709) 777-6974 • Fax: (709) 777-8776 • email: hic@mun.ca • www.med.mun.ca/hic

Prostate cancer patients' out-of-pocket costs

Explain who this is . . .

We are surveying men with prostate cancer to find out how much prostate cancer patients pay for their care, how they cope with these costs. We also want to know how these costs affect their quality of life and decisions about their care treatment.

15-20 - misleading - will take longer

This survey will take roughly 10 minutes to complete. The survey is **voluntary**. Whether or not you choose to participate will **not** affect your treatment in any way. All answers are confidential and you will not be identified in any report or presentation. You do not have to answer every question.

If you would like to take part in this study, please fill in the survey and return it in the envelope provided. If you do not want to participate please return the blank survey in the envelope.

The number on this survey allows us to determine how many surveys have been completed. It is not used to identify you.

If you have any questions, please contact Emma Housser, master's student. at (709) 777-4657 or by e-mail at Emma_Housser@hotmail.com

Thank you for your assistance with this project.

Insert HIC contact information here.

Prostate Cancer Patients:

Concerned about drug and travel costs?

Researchers from Memorial University are looking for prostate cancer patients to complete a brief survey. This study will help us understand how much prostate cancer patients pay for their care, and how these costs affect them.

For more information, or to request a survey, please contact:

Emma Housser (Masters' Student ~~candidate~~ AHSR)
(709)777-8539
emma_housser@hotmail.com

Memorial
University of Newfoundland

Human Investigation Committee
Research and Graduate Studies
Faculty of Medicine
The Health Sciences Centre

March 7, 2007

Reference #07.18

Ms. Emma Housser
c/o Dr. M. Mathews
Division of Community Health & Humanities
Faculty of Medicine
2nd Floor, Health Sciences Centre

Dear Ms. Housser:

"Prostate cancer patients out-of-pocket costs of cancer and the effects on treatment decisions".

This will acknowledge your correspondence dated, **March 6, 2007**, wherein you provide the following for the above noted study:

- Cover letter
- Poster
- Additional information on what potential participants will be told when handed the surveys
    - Instructions to prostate cancer support group managers

At the meeting held on January 18, 2007 , the initial review date of this study, the Human Investigation Committee (HIC) agreed that the response could be reviewed by the Co-Chairs and, if found acceptable, full approval of the study be granted.

The Co-Chairs of the HIC reviewed your correspondence, approved the cover letter, poster and instructions to prostate cancer support group managers and, under the direction of the Committee, granted ***full approval*** of your research study. This will be reported to the full Human Investigation Committee, for their information at the meeting scheduled for.

Full approval has been granted for one year. You will be contacted to complete the annual form update approximately 8 weeks before the approval will lapse on **January 18, 2008.** It is your responsibility to ensure that the renewal form is forwarded to the HIC office not less than 30 days prior to the renewal date for review and approval to continue the study. The annual renewal form can be downloaded from the HIC website http://www.med.mun.ca/hic/downloads/Annual%20Update%20Form.doc.

The Human Investigation Committee advises THAT IF YOU DO NOT return the completed annual update form prior to or on the aforementioned date of renewal;

The Human Investigation Committee advises THAT IF YOU DO NOT return the completed annual update form prior to or on the aforementioned date of renewal;

- *Your ethics approval will lapse*
- *You will be required to stop research activity*
- *You will not be permitted to restart the study until you reapply for and receive approval to undertake the study again*

In addition, the Human Investigation Committee will inform the appropriate authorities. To ensure proper action is taken; the appropriate officials will be notified to terminate funding.

Modifications of the protocol/consent are not permitted without prior approval from the Human Investigation Committee. Implementing changes in the protocol/consent without HIC approval may result in the approval of your research study being revoked, necessitating cessation of all related research activity. Request for modification to the protocol/consent must be outlined on an amendment form (available on the HIC website) and submitted to the HIC for review.

For a hospital-based study, it is **your responsibility to seek the necessary approval from the Health Care Corporation of St. John's and/or other hospital boards as appropriate**.

This Research Ethics Board (the HIC) has reviewed and approved the application and consent form for the study which is to be conducted by you as the qualified investigator named above at the specified study site. This approval and the views of this Research Ethics Board have been documented in writing. In addition, please be advised that the Human Investigation Committee currently operates according to the Tri-Council Policy Statement and applicable laws and regulations. The membership of this research ethics board complies with the membership requirements for research ethics boards defined in Division 5 of the Food and Drug Regulations.

Notwithstanding the approval of the HIC, the primary responsibility for the ethical conduct of the investigation remains with you.

We wish you every success with your study.

Sincerely,

John D. Harnett, MD, FRCPC
Co-Chair
Human Investigation Committee

Richard S. Neuman, PhD
Co-Chair
Human Investigation Committee

JDH;RSN\jed

C Dr. C. Loomis, Vice-President (Research), MUN
Mr. W. Miller, Director of Planning & Research, Eastern Health

Appendix I

Eastern Health ethics approval

Eastern
Health

St. Clare's Mercy Hospital
St. John's, NL
Canada A1C 5B8
T: (709) 777-5233
F: (709) 777-5272
www.easternhealth.ca

April 23, 2007

Ms. E. Houser
Community Medicine
c/o Dr. Maria Mathews
Associate Professor
Health Policy/Health Care Delivery
MUN

Dear Ms. Houser:

Your research proposal *"HIC # 07.018 – Prostate cancer patients' out-of-pocket costs and the effects on treatment decisions"* was reviewed by the Research Proposals Approval Committee (RPAC) of Eastern Health at its meeting on April 19, 2007 and we are pleased to inform you that the proposal has been approved.

The approval of this project is subject to the following conditions:

- The project is conducted as outlined in the HIC approved protocol;
- Adequate funding is secured to support the project;
- In the case of Health Records, efforts will be made to accommodate requests based upon available resources. If you require access to records that cannot be accommodated, then additional fees may be levied to cover the cost;
- A progress report being provided upon request.

If you have any questions or comments, please contact Lynn Purchase, Manager of the Patient Research Centre at 777-7283.

Sincerely,

Mr. Wayne Miller
Senior Director Corporate Strategy & Research
Chair, RPAC
Eastern Health

cc: Ms. Lynn Purchase
Dr. Maria Mathews, Associate Professor, Health Policy/Health Care Delivery, MUN

Appendix J

Provincial Cancer Centre RPAC

msn® Hotmail®

emma_housser@hotmail.com Printed: July 4, 2007 10:06:52 AM

From : Joy McCarthy <joys.mccarthy@gmail.com>
Sent : May 15, 2007 12:14:17 PM
To : "Dawne Putt" <Dawne.Putt@easternhealth.ca>
CC : <emma_housser@hotmail.com>
Subject : Re: SAC application

Hi Dawne - I already approved this and stamped it - no idea where it went!

Emma can keep this email as proof of approval. I have approved it anyways! I read thru the material - it maybe on my desk and got waylaid when Julia was wanting to be fed!

Emma, this is approved! Good luck with your project!

Joy

----- Original Message ----- From: "Dawne Putt" <Dawne.Putt@easternhealth.ca>
To: "Joy McCarthy" <joys.mccarthy@gmail.com>
Sent: Monday, May 14, 2007 11:23 AM
Subject: FW: SAC application

Hi Joy,

Emma Housser has a study she has been waiting to have approved at the next SAC meeting. She has called a couple of times to find out the status or the date. Since we do not know when the next meeting is, as we are waiting for more information from the studies that have been proposed; could you review this?

Thanks

Dawne

-----Original Message-----
From: Emma Housser [mailto:emma_housser@hotmail.com]
Sent: Monday, May 14, 2007 11:13 AM
To: Dawne Putt
Cc: mmathews@mun.ca
Subject: SAC application

Dawne,

As discussed earlier today, I have included the Application letter for SAC as well as the supporting documents. Please let me know if any other documents are required for this process.

Thank you for your help,

Emma

Emma Housser
Master's student, Applied Health Services Research Division of Community Health and Humanities, Faculty of Medicine

---

Appendix K

Amendment to HIC

MEMORIAL
UNIVERSITY

Faculty of Medicine

FILE COPY

ENTERED DEC 18 2007

December 12, 2007

Reference #07.18

SHIPPED DEC 10 2007

Ms. Emma Housser
c/o Dr. M. Mathews
Division of Community Health & Humanities
Faculty of Medicine
2nd Floor, Health Sciences Centre

Dear Ms. Housser:

This will acknowledge your completed amendment form dated November 21, 2007 wherein you an amendment, cover letter and survey, for your research study entitled "**Prostate cancer patients out-of-pocket costs of cancer and the effects on treatment decisions**"

The Chairs of the Human Investigation Committee have reviewed your correspondence, approved the amendment, cover letter and survey, as submitted. This will be reported to the full Human Investigation Committee, for their information, at the meeting scheduled for **January 10, 2008.**

This Research Ethics Board (the HIC) has reviewed and approved the amendment for the study which is to be conducted by you as the qualified investigator named above at the specified study site. This approval and the views of this Research Ethics Board have been documented in writing. In addition, please be advised that the Human Investigation Committee currently operates according to the Tri-Council Policy Statement and applicable laws and regulations. The membership of this research ethics board complies with the membership requirements for research ethics boards defined in Division 5 of the Food and Drug Regulations.

Sincerely,

Richard Neuman, PhD	John Harnett, MD, FRCPC
Co-Chair	Co-Chair
Human Investigation Committee	Human Investigation Committee

RN/JH/jd

C Dr. C. Loomis, Vice-President (Research), MUN
Mr. Wayne Miller, Director of Planning & Research, HCCSJ

Human Investigation Committee Request for Amendment to an approved application

This form not to exceed one page in length.

Forward 1 copy of this form and any protocol for the amendment to Human Investigation Committee, Room 1755, Health Science Centre.

Title of study. Include protocol number, if any. HIC number: 07.18 Date: Nov 21, 2007

Prostate cancer patients' out-of-pocket costs of cancer and the effects on treatment decisions

APPROVED DEC 12 2007

Would you categorize the changes as minor (e.g. editorial, administrative and similar changes)	**Yes**	No
Will there be any increase in risk, discomfort or inconvenience to the participants?	Yes (Specify below)	**No**
Are there changes to inclusion or exclusion criteria?	Yes (Specify below)	**No**
Is a modification to the consent form required?	Yes (Append form)	**No**

Are there any significant changes to the original objectives? YES **NO** If so, **LIST** new objectives.

1 To...

What is the rationale for the amendment(s)?

Of the 64 surveys we have received to date, only 16 surveys are from recently diagnosed men (i.e. diagnosed within the last 18 months). Most costs are experienced during active treatment (i.e. chemotherapy and radiation) which is done soon after diagnosis. Additional surveys from recently diagnosed patients are needed to obtain credible results.

Summarize the significant changes being requested. It is not necessary to itemize editorial, administrative and similar changes.

We will send a mailed survey to men who were diagnosed with prostate cancer in preceding year (i.e. December 2006). The men will be identified through the cancer registry. The registry will provide names and addresses to a research assistant (Sarah Wickham) who will prepare mailing labels and mail the survey (and then destroy the list of names and addresses). We will not use identification numbers and surveys will not be linked back to names from the registry (thereby protecting anonymity). None of the investigators will have access to the names.

Other pertinent information.

Survey package will include: cover letter from Dr. Mathews, survey, form to request study results, and return envelope (attached)

Erika Heusser

Printed Name of Principal Investigator

Signature of Principal Investigator

Nov. 22, 2007

Date

MEMORIAL
UNIVERSITY

Faculty of Medicine
Division of Community Health and Humanities
The Health Sciences Centre
St. John's NL Canada A1B 3V6
Tel 709 777 6213/6653 Fax 709 777 7382 www.med.mun.ca

Date

Dear survey recipient:

Researchers at Memorial University are working with the Canadian Cancer Society and cancer care providers to study the amount of money patients pay out of their own pocket for their cancer care and how they cope with these costs. We also want to know how these costs affect your quality of life and decisions about your care treatment. The study findings will help improve cancer services in the province. I hope you will take a few minutes to fill out and return the survey.

You have received a survey because your name was included on the Cancer Registry, a listing of people diagnosed with cancer each year. We have taken a number of steps to ensure that your personal information (such as your name, address or cancer diagnosis) are kept confidential. We will not share this information with anyone.

This survey will take roughly 15-20 minutes to complete. The survey is **voluntary**. Whether or not you choose to participate will **not** affect your treatment in any way. All answers are confidential and you will not be identified in any report or presentation. You do not have to answer every question.

If you would like to take part in this study, please fill in the survey and return it in the envelope provided. If you do not want to participate please return the blank survey in the envelope.

If you have any questions about this study, please feel free to contact me at (709) 777-7845 or the Human Investigations Committee at (709) 777-6974 or hic@mun.ca (please cite reference 07.37 or 07.18)

Thank you for your help with this important study!

Sincerely,

Maria Mathews, PhD
Associate Professor Health Policy/Health Care Delivery

Research Summary Mail-out Form

If you are interested in receiving a copy of the summary from this study once completed please fill out the address card. This form will not be associated with your survey in any way and will be kept separately from the collected data. Your contact information will not be linked or used for any other purpose than to send you a copy of the summary once complete.

Thank you once again for taking part in this survey.

Appendix L

Representativeness of the Sample

Appendix L. Representativenesss of Sample

Table K1. Comparison on community type and age of sample and population of prostate cancer patients

Characteristic	**Sample n (%)**	**Prostate Cancer Population n (%)**	**p value**
Age*			>0.05
< 50	3 (1.8)	64 (2.8)	
50-59	25 (14.7)	466 (20.6)	
60-69	86 (50.6)	946 (41.8)	
70-79	47 (27.6)	607 (26.8)	
$\geq$ 80	9 (5.3)	180 (8.0)	
Community Type**			>0.05
Urban	78 (45.9)	206 (50.2)	
Rural	92 (54.1)	204 (49.8)	

* age based on five years (2004-8) of Cancer Registry data; X^2= 8.08, degrees of freedom = 4

** community types based on sample frame addresses; X^2= 1.15, degrees of freedom = 1

Appendix M

Results tables for one month costs

Appendix M

M1. OOP Costs (dollar value) in last month

Cross tabulations and chi-square test results for the comparison of demographic characteristics and the three levels of cost categories (dollar amount in last month) are displayed in Table M1. Compared to men with no costs, a larger proportion of rural patients had costs up to $500 and more than $500.

Table M1. Level of OOP costs (dollar amount) for the All Costs category in a one month period and demographic characteristics.

Characteristic	$0 n (%)	$0.01 - $499.99 n (%)	≥$500.00 n (%)	p value
Age *(n = 170)*				
< 65	39 (41.1)	17 (33.3)	10 (41.7)	0.629
≥ 65	56 (58.9)	34 (66.7)	14 (58.3)	
Community Type *(n = 170)*				
Urban	51 (53.7)	23 (45.1)	4 (16.7)	0.005*
Rural	44 (46.3)	28 (54.9)	20 (83.3)	
Marital Status *(n = 165)*				
Un-partnered	11 (12.2)	6 (11.8)	3 (12.5)	0.995
Partnered	79 (87.8)	45 (88.2)	21 (87.5)	
Dependents *(n = 164)*				
Yes	18 (19.4)	8 (16.7)	6 (26.1)	0.643
No	75 (80.6)	40 (83.3)	17 (73.9)	
Employment Status *(n = 169)*				
Full-Time/self-employed	12 (12.6)	5 (9.8)	1 (4.3)	0.667
Part-Time/semi-retired	6 (6.3)	4 (7.8)	4 (17.4)	
Seasonal/sick leave/unemployed/other	8 (8.4)	4 (7.8)	2 (8.7)	
Retired	69 (72.6)	38 (74.5)	16 (69.6)	
Education *(n =166)*				
Less than high school	28 (30.8)	16 (31.4)	12 (56.0)	0.589
Completed high school	20 (22.0)	11 (21.6)	3 (12.5)	
Some post secondary	13 (14.3)	7 (13.7)	4 (16.7)	
Completed post secondary	19 (20.9	10 (19.6)	1 (4.2)	
Graduate/professional degree	11 (12.1)	7 (13.7)	4 (16.7)	
Income *(n = 170)*				
< $19,999	12 (12.6)	6 (11.8)	6 (25.0)	0.959
$20,000 - $29,999	22 (23.3)	11 (21.6)	5 (20.8)	
$30,000 - $39,999	19 (20.0)	9 (17.6)	5 (20.8)	
$40,000 - $49,999	13 (13.7)	9 (17.6)	3 (12.5)	
$50,000 - $59,999	12 (12.6)	6 (11.8)	1 (4.2)	
$60,000 - $69,999	5 (5.3)	3 (5.9)	2 (8.3)	
≥ $70,000	12 (12.6)	7 (14.7)	2 (8.3)	
Have Private Insurance *(n = 161)*				
Yes	60 (68.2)	32 (65.3)	12 (50.0)	0.254
No	28 (31.8)	17 (34.2)	12 (50.0)	
Know about MTAP *(n = 139)*				
Yes	28 (38.4)	17 (39.5)	11 (47.8)	0.717
No	45 (61.6)	26 (60.5)	12 (52.2)	

Table M2 displays cross-tabulations and chi-square test results comparing the clinical characteristics and cost categories of OOP costs (dollar amounts). Compared to men with costs less than $500, a larger portion of men with costs greater than $500 had previously received radiation treatment. A larger proportion of men with costs reported taking supportive drugs than men without costs. Compared to men with either no costs or with $500 or more, a larger proportion of men who had cost between 0 and $499.99 reported taking vitamins and supplements.

Table M2. Level of OOP costs (dollar amount) for the All Costs category in a one month period and clinical characteristics.

Clinical Characteristics	$0 n (%)	$0.01 - $499.99 n (%)	≥$500.00 n (%)	p value
Time Since Diagnosis *(n = 167)*				
0 – 6 months	21 (22.6)	10 (20.0)	1 (4.2)	
7 – 12 months	28 (30.1)	21 (42.0)	9 (37.5)	0.249
13 – 24 months	21 (22.6)	9 (18.0)	9 (37.5)	
24 months +	23 (24.7)	10 (20.0)	5 (20.8)	
Current Treatment *(n = 170)*				
Radiation				
Yes	8 (8.4)	6 (11.8)	5 (20.8)	0.223
No	87 (91.6)	45 (88.2)	19 (79.2)	
Hormone Therapy				
Yes	11 (11.6)	11 (21.6)	6 (25.0)	0.143
No	84 (88.4)	40 (78.4)	18 (75.0)	
Chemotherapy				
Yes	0 (0.0)	0 (0.0)	0 (0.0)	.a
No	95 (100.0)	51(100.0)	24(100.0)	
Active Treatment				
Yes	34 (35.8)	18 (35.3)	10 (41.7)	0.848
No	61 (64.2)	33 (64.7)	14 (58.3)	
Other				
Yes	11 (11.6)	2 (3.9)	3 (12.5)	0.273
No	84 (88.4)	49 (96.1)	21 (87.5)	
Active Treatment or Follow-up				
Yes	24 (25.3)	14 (27.5)	8 (33.3)	0.727
No	71 (74.7)	37 (72.5)	16 (66.7)	
Past treatment *(n = 169)*				
Radiation				

Yes	24 (25.3)	13 (25.5)	14 (60.9)	0.003*
No	71 (74.7)	38 (74.5)	9 (39.1)	
Hormone Therapy				
Yes	10 (10.5)	9 (17.6)	3 (12.5)	0.473
No	85 (89.5)	42 (82.4)	21 (87.5)	
Chemotherapy				
Yes	1 (1.1)	0 (0.0)	0 (0.0)	0.672
No	94 (98.9)	51(100.0)	24(100.0)	
Surgery				
Yes	49 (51.6)	26 (51.0)	10 (41.7)	0.677
No	46 (48.4)	25 (49.0)	14 (58.3)	
Prostatectomy				
Yes	41 (43.2)	26 (51.0)	8 (33.3)	0.343
No	54 (56.8)	25 (49.0)	16 (66.7)	
TURP				0.300
Yes	3 (3.2)	0 (0.0)	0 (0.0)	
No	92 (96.8)	51(100.0)	24(100.0)	
Orchiectomy				0.197
Yes	0 (0.0)	1 (2.0)	1 (4.2)	
No	95 (100.0)	50(98.0)	23 (95.8)	
Other				0.309
Yes	0 (0.0)	1 (2.0)	0 (0.0)	
No	95 (100.0)	50 (98.0)	24(100.0)	
Length of Time Receiving Treatment *(n = 75)*				0.945
< 3 months	14 (45.2)	11(42.3)	6 (33.3)	
3 – 6 months	5 (16.1)	4 (15.4)	3 (16.7)	
6 months – 1 year	12 (38.7)	11 (42.3)	9 (50.0)	
Drugs taken *(n = 170)*				
Hormone Treatment				0.401
Yes	15 (15.8)	12 (23.5)	6 (25.0)	
No	80 (84.2)	39 (76.5)	18 (75.0)	
Supportive				0.001*
Yes	3 (3.2)	11 (21.6)	5 (20.8)	
No	92 (96.8)	40 (78.4)	19 (79.2)	
Vitamins/Supplements				0.036*
Yes	4 (4.2)	8 (15.7)	1 (4.2)	
No	91 (95.8)	43 (84.3)	23 (95.8)	
Miscellaneous				0.488
Yes	4 (4.2)	3 (5.9)	0 (0.0)	
No	91 (95.8)	48 (94.1)	24(100.0)	

* Statistically significant; $p<0.05$

a. No statistics available as variable is a constant in this instance.

There were no differences in the use of coping strategies and OOP costs (dollar amount), as shown in table M3.

Table M3. Level of OOP costs (dollar amount) for the All Costs category in last month and use of coping strategies.

Coping strategies	$0 n (%)	$0.01 - $499.99 n (%)	≥$500.00 n (%)	p value
Drug Coping Strategies *(n = 170)*				
Yes	5 (5.3)	7 (13.7)	2 (8.3)	0.208
No	90 (94.7)	44 (86.3)	22 (91.7)	
Appointment Coping Strategies *(n = 170)*				
Yes	2 (2.1)	2 (3.9)	1 (8.3)	0.330
No	93 (97.9)	49 (96.1)	22 (91.7)	

* Statistically significant; $p<0.05$

Likewise, there were no significant differences in quality of life and OOP costs incurred (dollar amount) for a one month period (Table M4).

Table M4. Level of OOP costs (dollar amount) for the All Costs category in last month and quality of life.

Quality of Life	$0 mean (sd)	$0.01 - $499.99 mean (sd)	≥$500.00 mean (sd)	p value
FACTG Total *(n = 126)*	85.41 (14.381)	8486.36(12.417)	81.00(15.248)	0.344
FACT P Total *(n=126)*	117.79(19.684)	119.26(16.769)	111.33(20.568)	0.286

* Statistically significant; $p<0.05$

Table M5 presents attitudes by amount of OOP costs. Compared to those who reported costs less than $499.99 for a one month period, a larger proportion of respondents with costs in excess of $500 found OOP costs influenced treatment decisions, that cancer costs created a lot of stress, that cancer costs were more stressful than other things and, and they had trouble paying for cancer costs.

Table M5 Level of OOP costs (dollar amount) for the All Costs category in a one month period and attitudes regarding these costs.

Attitudes	$0 n (%)	$0.01 - $499.99 n (%)	≥$500.00 n (%)	p value
OOP costs influenced treatment decisions				
Agree	4 (6.5)	0 (0.0)	5 (25.0)	0.002*
Disagree	58 (93.5)	43 (100.0)	15 (75.0)	
Doctor aware of my OOP costs				
Agree	16 (28.1)	7 (17.9)	8 (42.1)	0.145
Disagree	41 (71.9)	32 (82.1)	11 (57.9)	
Doctor takes costs into account				
Agree	5 (9.3)	5 (12.2)	5 (26.3)	0.163
Disagree	49 (90.7)	36 (87.8	14 (73.7)	
Cancer costs create a lot of stress				
Agree	13 (22.4)	6 (14.6)	14 (63.3)	0.000*
Disagree	45 (77.6)	35 (85.4)	8 (36.4)	
Cancer costs more stressful than other things				
Agree	11 (19.0)	4 (9.5)	11 (50.0)	0.001*
Disagree	47 (81.0)	38 (90.5)	11 (50.0)	
Trouble paying for my cancer costs				
Agree	5 (8.8)	3 (7.3)	7 (31.8)	0.010*
Disagree	52 (91.2)	38 (92.7)	15 (68.2)	
Aware of assistance programs				
Agree	14 (23.7)	12 (28.6)	7 (35.0)	0.603
Disagree	45 (76.3)	30 (71.4)	13 (65.0)	
Prescription drugs free to everyone				
Agree	40 (63.5)	23 (56.1)	15 (65.2)	0.689
Disagree	23 (36.5)	18 (43.9)	8 (34.8)	
Prescription drugs free to low income people				
Agree	57 (86.4)	35 (81.4)	18(81.8)	0.753
Disagree	9 (13.6)	8 (18.6)	4 (18.2)	
Assistance programs well advertised				
Agree	9 (13.4)	5 (11.6)	3 (13.6)	0.956
Disagree	58 (86.6)	38 (88.4)	19 (86.4)	

* Statistically significant; $p<0.05$

M2 Proportion of Income consumed by costs

The next series of tables examine the relationship between proportion of income consumed by OOP costs and demographic and clinical characteristics, use of cost saving strategies, attitudes and quality of life.

The cross tabulations and chi-square test results comparing socio-demographic characteristics and proportion of income consumed by OOP costs for a one month period are displayed in M6. Compared to men who spent less than 7.5% of their income on OOP costs, men who spent 7.5% or more of their income on OOP costs were from rural communities and did not have private health insurance.

Table M6. Percent of income consumed by OOP All costs category in one month period and demographic characteristics.

Characteristic	**0% n (%)**	**0.01 – 7.49% n (%)**	**≥7.50% n (%)**	**p value**
Age *(n = 170)*				
< 65	39 (41.1)	12 (30.8)	15 (41.7)	0.500
≥ 65	56 (58.9)	27 (69.2)	21 (58.3)	
Community Type *(n = 170)*				
Urban	51 (53.7)	20 (51.3)	7 (19.4)	0.002*
Rural	44 (46.3)	19 (48.7)	29(80.6)	
Marital Status *(n = 165)*				
Un-partnered	11 (12.2)	4 (10.3)	5 (13.9)	0.890
Partnered	79 (87.8)	35 (89.7)	31 (86.1)	
Dependents *(n = 164)*				
Yes	18 (19.4)	5 (13.9)	9 (25.7)	0.453
No	79 (80.6)	31 (86.1)	26 (74.3)	
Employment Status *(n = 169)*				
Full-Time/self-employed	12 (12.6)	5 (12.8)	1 (2.9)	
Part-Time/semi-retired	6 (6.3)	3 (7.7)	5 (14.3)	0.492
Seasonal/sick leave/unemployed/other	8 (8.4)	2 (5.1)	4 (11.4)	
Retired	69 (72.6)	29 (74.4)	25 (71.4)	
Education *(n =166)*				0.666
Less than high school	29 (33.0)	18 (34.6)	9 (34.6)	
Completed high school	16 (18.2)	12 (23.1)	6 (23.1)	
Some post secondary	16 (18.2)	6 (11.5)	2 (7.7)	
Completed post secondary	16 (18.2)	11 (21.2)	3 (11.5)	
Graduate/professional degree	11 (12.5)	5 (9.6)	6 (23.1)	
Income *(n = 170)*				0.214
< $19,999	12 (12.6)	2 (5.1)	10 (27.8)	
$20,000 - $29,999	22 (23.2)	8 (20.5)	8 (22.2)	
$30,000 - $39,999	19 (20.0)	5 (12.8)	9 (25.0)	
$40,000 - $49,999	13 (13.7)	9 (23.1)	3 (8.3)	
$50,000 - $59,999	12 (12.6)	5 (12.8)	2 (5.6)	
$60,000 - $69,999	5 (5.3)	3 (7.7)	2 (5.6)	
≥ $70,000	12 (12.6)	7 (17.9)	2 (5.6)	
Have Private Insurance *(n = 161)*				0.012*
Yes	60 (68.2)	28 (75.7)	16 (44.4)	
No	28 (31.8)	9 (24.3)	20 (55.6)	
Know about MTAP *(n = 139)*				0.888
Yes	28 (38.4)	14 (42.4)	14 (42.4)	
No	45 (61.6)	19 (57.6)	19 (57.6)	

* Statistically significant; $p<0.05$

Table M7 presents the clinical characteristics of the sample by proportion of income consumed by OOP costs in one month. Compared to men who spent either 0% or 7.5% or more of their income on OOP costs, a larger proportion of men who spent between 0.1% and 7.49% of their income on OOP costs took supportive drugs or supplements and vitamins.

Table M7. Percent of income consumed by OOP All costs category in a one month period and clinical characteristics.

Clinical Characteristics	**0% n (%)**	**0.01 – 7.49% n (%)**	**≥7.50 % n (%)**	**p value**
Time Since Diagnosis *(n = 167)*				
0 – 6 months	21 (22.6)	5 (13.2)	6 (16.7)	0.535
7 – 12 months	28 (30.1)	17 (44.7)	13 (36.1)	
13 – 24 months	21 (22.6)	7 (18.4)	11 (30.6)	
24 months +	23 (24.7)	9 (23.7)	6 (16.7)	
Current Treatment *(n = 170)*				
Radiation				
Yes	8 (8.4)	3 (7.7)	8 (22.2)	0.060
No	87 (91.6)	36 (92.3)	28 (77.8)	
Hormone Therapy				
Yes	11 (11.6)	8 (20.5)	9 (25.0)	0.134
No	84 (88.4)	31 (79.5)	27 (75.0)	
Chemotherapy				
Yes	0 (0.0)	0 (0.0)	0 (0.0)	n/a
No	95 (100.0)	39(100.0)	36(100.0)	
Active Treatment				
Yes	34 (35.8)	13 (33.3)	15 (41.7)	0.739
No	61 (64.2)	26 (66.7)	21 (58.3)	
Other				
Yes	11 (11.6)	2 (5.1)	3 (8.3)	0.494
No	84 (88.4)	37 (94.9)	33 (91.7)	
Active Treatment or Follow-up				
Yes	24 (25.3)	10 (25.6)	12 (33.3)	0.633
No	71 (74.7)	29 (74.4)	24 (66.7)	
Past treatment *(n = 169)*				
Radiation				
Yes	24 (25.3)	11 (28.2)	16 (45.7)	0.075
No	71 (74.7)	28 (71.8)	19 (54.3)	

Hormone Therapy				
Yes	10 (10.5)	7 (17.9)	5 (13.9)	0.499
No	85 (89.5)	32 (82.1)	31 (86.1)	
Chemotherapy				
Yes	1 (1.1)	0 (0.0)	0 (0.0)	0.672
No	94 (98.9)	39(100.0)	36(100.0)	
Surgery				
Yes	49 (51.6)	20 (51.3)	16 (44.4)	0.754
No	46 (48.4)	19 (48.7)	20 (55.6)	
Prostatectomy				
Yes	41 (43.2)	19 (48.7)	15 (41.7)	0.795
No	54 (56.8)	20 (51.3)	21 (58.3)	
TURP				
Yes	3 (3.2)	0 (0.0)	0 (0.0)	0.300
No	92 (96.8)	39(100.0)	36(100.0)	
Orchiectomy				
Yes	0 (0.0)	1 (2.6)	1 (2.8)	0.277
No	95(100.0)	38 (97.4)	35 (97.2)	
Other				
Yes	0(0.0)	1 (2.6)	0 (0.0)	0.185
No	95 (100.0)	38 (97.4)	36(100.0)	
Length of Time Receiving Treatment				
(n = 75)	14 (45.2)	8 (40.0)	9 (37.5)	0.848
< 3 months	5 (16.1)	2 (10.0)	5 (20.8)	
3 – 6 months	12 (38.7)	10 (50.0)	10 (41.7)	
6 months – 1 year				
Drugs taken *(n = 170)*				
Hormone Treatment				
Yes	15 (15.8)	8 (20.5)	10 (27.8)	0.296
No	80 (84.2)	31 (79.5)	26 (72.2)	
Supportive				
Yes	3 (3.2)	10 (25.6)	6 (16.7)	0.000*
No	92 (96.8)	29 (74.4)	30 (83.3)	
Vitamins/Supplements				
Yes	4 (4.2)	7 (17.9)	2 (5.6)	0.022*
No	91 (95.8)	32 (82.1)	34 (94.4)	
Miscellaneous				
Yes	4 (4.2)	3 (7.7)	0 (0.0)	0.245
No	91 (95.8)	36 (92.3)	36(100.00)	

* Statistically significant; $p<0.05$

a. No statistics available as variable is a constant in this instance.

There were no significant differences in proportion of income consumed by OOP costs in a one month period and either use of a coping strategy (Table M8) or quality of life scores (Table M9).

Table M8. Percent of income consumed by OOP All costs category in a quarter (three month period) and use of coping strategies.

Coping strategies	**0% n (%)**	**0.01 – 7.49% n (%)**	**≥7.50 % n (%)**	**p value**
Drug Coping Strategies *(n = 170)*				
Yes	5 (5.3)	5 (12.8)	4 (11.1)	0.274
No	90 (94.7)	34 (87.2)	32 (88.9)	
Appointment Coping Strategies *(n = 170)*				
Yes	2 (2.1)	2 (5.1)	2 (5.6)	0.524
No	93 (97.9)	37 (94.9)	34 (94.4)	

* Statistically significant; p<0.05

Table L9. Percent of income consumed by OOP All costs category in a one month period and quality of life.

Quality of Life	**0% mean (sd)**	**0.01 – 4.99% mean (sd)**	**≥7.49 % mean (sd)**	**p value**
FACTG Total *(n = 126)*	85.41 (14.381)	87.77 (10.828)	80.97 (15.456)	0.157
FACT P Total *(n=126)*	117.79 (19.684)	120.52 (15.004)	112.17 (20.879)	0.221

* Statistically significant; p<0.05

Cross tabulations and chi-square test results for attitudes and the cost categories (proportion of income consumed) are displayed in table M10. Compared to patients with less than 7.5% of their income consumed by OOP costs, a larger proportion of those with more than 7.5% of their income consumed agreed that OOP costs influenced treatment decisions, that OOP cancer costs created a lot of stress and more stress than other things in their lives, and that they had trouble paying for these costs.

Table M10. Percent of income consumed by OOP All costs category in a quarter (three month period) and attitudes regarding these costs.

Attitudes	**0% n (%)**	**0.01 – 7.49% n (%)**	**≥7.50 % n (%)**	**p value**
OOP costs influenced treatment decisions				0.029*
Agree	4 (6.5)	0 (0.0)	5 (17.2)	
Disagree	58 (93.5)	34(100.0)	24 (82.8)	
Doctor aware of my OOP costs				0.472
Agree	16 (28.1)	6 (19.4)	9 (33.3)	
Disagree	41 (71.9)	25 (80.6)	18 (66.7)	
Doctor takes costs into account				0.489
Agree	5 (9.3)	5 (15.6)	5 (17.9)	
Disagree	49 (90.7)	27 (84.4)	23 (82.1)	
Cancer costs create a lot of stress				0.001*
Agree	13 (22.4)	4 (12.5)	16 (51.6)	
Disagree	45 (77.6)	28 (87.5)	15 (48.4)	
Cancer costs more stressful than other things				0.013*
Agree	11 (19.0)	3 (9.1)	12 (38.7)	
Disagree	47 (81.0)	30 (90.9)	19 (61.3)	
Trouble paying for my cancer costs				0.032*
Agree	5 (8.8)	2 (6.2)	8 (25.8)	
Disagree	52 (91.2)	30 (93.8)	23 (74.2)	
Aware of assistance programs				0.567
Agree	14 (23.7)	9 (27.3)	10 (34.5)	
Disagree	45 (76.3)	24 (72.7)	19 (65.5)	
Prescription drugs free to everyone				0.782
Agree	40 (63.5)	18 (56.2)	20 (62.5)	
Disagree	23 (36.5)	14 (43.2)	12 (37.5)	
Prescription drugs free to low income people				0.752
Agree	57 (86.4)	27 (81.8)	26 (81.2)	
Disagree	9 (13.6)	6 (18.2)	6 (18.8)	
Assistance programs well advertised				0.721
Agree	9 (13.4)	3 (9.1)	5 (15.6)	
Disagree	58 (86.6)	30 (90.9)	27 (84.4)	

* Statistically significant; $p<0.05$

M3. urban rural residents and one month OOP costs

Table M11 presents the amount of OOP costs incurred by urban and rural men. Compared to urban men, a larger proportion of rural had costs in excess of $500 in one month for travel related costs and all cancer related OOP costs.

Table M11. One month out-of-pocket costs, All Costs category, for urban and rural participants.

Cost	**urban%** **n (%)**	**rural** **n (%)**	**p value**
Drugs and Supplies 1 Month*(n = 170)*			
$0	61 (78.2)	65 (70.7)	
$0.01 - $499.99	17 (21.8)	25 (27.2)	0.284
≥$500.00	0 (0.0)	2 (2.2)	
Travel 1 month *(n = 170)*			
$0	62 (79.5)	51 (55.4)	
$0.01 - $499.99	12 (15.4)	24 (26.1)	0.002*
≥$500.00	4 (5.1)	17 (18.5)	
All Costs 1 Month *(n = 170)*			
$0	51 (65.4)	44 (47.8)	
$0.01 - $499.99	23 (29.5)	28 (30.4)	0.005*
≥$500.00	4 (5.1)	20 (21.7)	

* Statistically significant; p<0.05

Likewise, a larger proportion of rural men than urban men spent 7.5% of their income for travel related costs and all cancer related OOP costs (Tale M12).

Table M12.Percent of income consumed (1 month) for urban rural participants.

% of Income Consumed	**urban%** **n (%)**	**rural** **n (%)**	**p value**
Drugs and Supplies *(n = 170)*			
0%	61 (78.2)	65 (70.7)	
0.01 – 7.49%	15 (19.2)	23 (25.0)	0.513
7.50+ %	2 (2.6)	4 (4.3)	
Travel *(n = 169)*			
0%	62 (79.5)	51 (55.4)	
0.01 – 7.49%	9 (11.5)	16 (17.4)	0.002*
7.50+ %	7 (9.0)	25 (27.2)	
All costs *(n = 170)*			
0%	51 (65.4)	44 (47.8)	
0.01 – 7.49%	20 (25.6)	19 (20.7)	0.002*
7.50+ %	7 (9.0)	29 (31.5)	

* Statistically significant; p<0.05