

**OUT-OF-POCKET EXPENDITURES BY CANCER PATIENTS
IN THE UNITED STATES: A POPULATION-BASED ANALYSIS**

A Capstone Project Presented

by

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ABSTRACT

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BACKGROUND: High out-of-pocket expenditures are associated with nonadherence to treatment and may impede access to care. The purpose of this study was to describe the out-of-pocket (OOP) expenditures of cancer patients in the US using a population-based approach.

METHODS: This study used pooled Medical Expenditures Panel Survey data from 1996-2005 to evaluate OOP costs for patients being actively treated/monitored for cancer. Total OOP costs were defined as patient-level OOP expenditures plus family-level premiums, and patients spending more than 10% of family income were considered to have a high OOP burden. OOP expenditures on prescription drugs were evaluated, as were the expenditures of various subgroups by age, income, and payor.

RESULTS: A total of 10,308 patients who were under treatment or surveillance for cancer were identified (weighted n=11,491,220). The average OOP expenditure (including insurance premiums) was around \$5700 per year. Of the total, about 11% was spent on prescription drugs. Over 40% had a high burden—75% of low-income, 51% of middle-income, and 18% of high-income patients. About 56% of seniors had a

high burden, compared to 31% of younger patients. Nearly 90% of low-income patients over age 75 had a high burden. Low-income patients over age 55 paid an average of 23% of their family income OOP for healthcare, compared to around 6% for high-income patients. Patients with Medicare plus private insurance had the highest percentage of patients with high burden (63%), whereas the uninsured had the lowest (24%). Comparing the OOP burdens of the general population to the cancer population, roughly twice as many cancer patients have a high burden than non-cancer patients, and the biggest differences are among the low- and middle-income groups.

CONCLUSIONS: Using a 10-year, representative sample, this study documented the burden of OOPs and disparities in burdens across different segments of the population of cancer patients. More than 4 out of 10 cancer patients have high out-of-pocket expenses, and the burden falls disproportionately on the poor and elderly.

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LIST OF ABBREVIATIONS

Abbreviation	Definition
AHRQ	Agency for Healthcare Research and Quality
CCS	Clinical Classification Software
FPL	Federal poverty level
FU/LV	Fluorouracil plus leucovorin
GDP	Gross domestic product
HI	Hospital insurance (Part A Medicare)
MCBS	Medicare Current Beneficiary Survey
MEPS	Medical Expenditure Panel Survey
MFSS	Medicare fee-for-service
MMA	Medicare Modernization Act
MMC	Medicare managed care
NHE	National healthcare expenditures
OOP	Out-of-pocket
OOPE	Out-of-pocket expenditures
PHE	Personal healthcare expenditures
SCHIP	State Children's Health Insurance Program
SMI	Supplementary medical insurance (Part B Medicare)
TRICARE	Military healthcare program
VA	Veteran's Administration

CHAPTER 1: INTRODUCTION

Healthcare costs in the United States have been increasing for decades. In 1960, expenditures on healthcare totaled 5.2% of the gross domestic product (GDP), rising to 9.1% in 1980, 12.3% in 1990, and 16% in 2005 (Centers for Medicaid and Medicare, 2007b). The latest government projection is that nearly one-fifth of the GDP will be devoted to healthcare spending by 2016 (Poisal et al., 2007). Growth in healthcare spending has outpaced growth in the rest of the economy every year since the 1970s. Most of the growth in spending can be attributed to the increased size of the population and increased utilization, especially as people live longer and the proportion of the population over age 65 increases. Some of the growth is also attributable to price increases: hospitals, insurance companies, and pharmaceutical companies have seen record profits over the past 10 years.

Healthcare services are typically paid for by a mix of private and public insurers, but a portion is also paid out-of-pocket (OOP) by patients. Out-of-pocket expenditures (OOPEs) generally consist of:

- Premiums: flat monthly amounts paid whether or not services are used
- Deductibles: a percentage or dollar amount that must be paid OOP before the insurer will begin to pay for services
- Coinsurance: a percentage paid every time a patient uses a service
- Copayment: a flat dollar amount that is paid every time a patient uses a service

OOPEs can be measured in several ways:

- The proportion, or share, of total healthcare spending paid by patients (this includes premiums)
- The share of personal healthcare spending paid by patients (not including premiums)
- The dollar amount paid by patients
- The growth rate in OOPEs
- The proportion of family income paid OOP to purchase health services

As healthcare costs rise, it becomes increasingly difficult for employers to afford to offer health insurance, for the government to pay its share, and for families to afford premiums, copayments, and other OOPEs. The total OOP burden, including premiums paid for private insurance, has increased from \$162B in 1997 to \$236B in 2004 (Banthin & Bernard, 2006). Growth in drug spending accounted for more than two-thirds of the total growth in OOPEs from 96-01 (Merlis, Gould, & Mahato).

Cancer and Out-of-Pocket Expenditures

Cancer is the second-leading cause of all deaths in the US (and the leading cause for people under age 85), responsible for 23% of all deaths in 2005 (Kung, Hoyert, Xu, & Murphy, 2008). The total cost of cancer to the US economy in 2006 was an estimated \$206.3 billion; about 38% of the total cost was for medical treatment (American Cancer Society, 2007).

Cancer patients are particularly affected by high OOPEs and high OOP burdens for several reasons. First, most cancer care is now being done on an outpatient basis.

This exposes patients to a greater share of total costs than two decades ago, when most cancer treatment was done on an inpatient basis, since outpatient care generally has a different cost-sharing structure than hospital care. Second, improvements in medical technology mean that cancer is now more likely to be a chronic condition, necessitating long periods of treatment. Third, the costs of the newest cancer drugs are some of the highest in medicine. Drugs prescribed by oncologists accounted for 58% of Medicare (Part B) drug spending in 2001 (Meropol & Schulman, 2007).

The case of colorectal cancer is an excellent example of the impact of new drugs on the cost of care. Before 1996, only fluorouracil plus leucovorin (FU/LV) was available for the treatment of patients with colorectal cancer. The drug cost of FU/LV is less than \$100 for a 6-month course. There are now 6 new drugs commonly used in addition to FU/LV: capecitabine (an oral version of FU [i.e., prodrug]), irinotecan, oxaliplatin, cetuximab, bevacizumab, and panitumumab. Adding irinotecan or oxaliplatin to a 6-month course of FU/LV costs \$20,000 to \$30,000, bevacizumab contributes an additional \$24,000, and the cost of cetuximab alone exceeds \$50,000. With these new treatments, the aggregate drug cost for patients with metastatic colorectal cancer is \$150,000 to \$200,000 for an additional year of survival compared with FU/LV alone (Meropol & Schulman, 2007). With the cost of these new cancer treatments, insurance coverage and financial resources may determine who has access to the most effective treatments to a greater extent than ever before (Ward et al., 2008).

It is well established that lower socioeconomic status affects cancer outcomes, including a higher risk of being diagnosed at a later stage, lower survival rates, and higher rates of recurrences and complications (Moore, 1998). Of course, the

interactions between socioeconomic status, education, occupation, income, and health are extremely complicated, with all sorts of confounding factors, including environmental resources and constraints, psychological influences, exposure to carcinogens and pathogens, health-affecting behaviors, and biological influences.(Adler & Ostrove, 1999). Nevertheless, OOPs associated with cancer have a disproportionate effect on low-income patients.

Insurance coverage also has a significant impact on cancer outcomes. Patients with Medicaid and the uninsured are 1.6 times more likely to die of cancer within 5 years of diagnosis as people with private insurance (Ward et al., 2008) and are more likely to be diagnosed with late-stage disease (Chen, Schrag, Halpern, Stewart, & Ward, 2007; Halpern, Bian, Ward, Schrag, & Chen, 2007; Ward et al., 2008). Beyond socioeconomic status, several insurance-specific factors have been suggested as possible explanations for the link between insurance type and cancer outcomes. For example, patients with public insurance or no insurance may have difficulty finding a provider (Ward et al., 2008), and the uninsured may be charged more for medical services than are insured patients (Anderson, 2007; Melnick & Fonkych, 2008).

The out-of-pocket burden on cancer patients is a threat to treatment adherence, which could be a factor in the poor cancer outcomes seen for patients of lower socioeconomic status. In a recent analysis of annual OOP spending for nonelderly families of cancer patients, 29% had a high OOP burden (more than 10% of family income spent OOP), and another 11% had very high burden (more than 20% spent OOP)(Banthin & Bernard, 2006). For families with elderly cancer patients, 29% spent \$5000 or more and 7% spent \$10,000 or more in one year. Over 46% of families

covered by Medicare and private nongroup insurance and over 35% of families covered by Medicare and private group insurance spent \$5,000 or more (Banthin & Bernard, 2006). High OOP spending is a serious problem if it reduces patients' abilities to seek needed care or comply with care recommendations. It is equally serious if the burden of OOP spending forces patients to forego or cut back on other necessities.

Theories Related to Insurance and Out-of-Pocket Expenditures

The pure intent of insurance is to protect against unpredictable losses, but health insurance in the United States has evolved into something quite different. Coverage for routine, relatively low-cost preventive services (i.e., annual check-ups) and for events that can be planned for, such as pregnancy, has led toward a policy of entitlement to coverage for a wide array of services. This makes health insurance vulnerable to what is sometimes called *moral hazard*—the tendency of insured individuals to behave differently from uninsured individuals. Moral hazard has been most widely used to describe the tendency of insured individuals to seek out more medical care than they would if they lacked insurance (Field & Shapiro, 1993).

The primary objective of deductibles, copayments, and coinsurance, at least in theory, is to counteract moral hazard and reduce unnecessary demand for health services, such as the use of high-cost drugs when lower-priced generic substitutes are available. Not all expensive medical services are appropriate for every patient, but without cost-sharing, patients may insist on getting treatments that will not help and might even hurt. On the other hand, cost-sharing may become so burdensome that it negates the benefits of having health insurance in the first place.

The Problem

The purpose of this study was to use Medical Expenditure Panel Survey (MEPS) data from 1995-2006 and the published literature to accomplish the following:

1. Produce comprehensive, up-to-date, nationally representative estimates of the OOP burden of cancer patients; and
2. Identify groups within cancer patients that are most likely to face high burdens.

Hypotheses

This study tested the following three hypotheses:

1. The OOP expenditures of cancer patients are different from those of the general population; and
2. OOP burdens vary widely within the cancer population.

Delimitations

This study was focused on cancer patients over age 18 and their families in the United States between 1996 and 2005. Patients with negative or extremely low incomes were excluded (\$100 floor). Patients with cancer who did not report any cancer-related treatment were also excluded.

Limitations

Because the study used retrospective survey data (the MEPS), it was subject to the limitations of MEPS, of survey data, and of retrospective studies in general.

Limitations that may have affected the results of the study include the following:

- Patients tend to under-report their use of healthcare resources. Verifying MEPS against other national surveys has not shown any serious under-reporting problem for encounters, but a potential under-reporting problem for expenditures by Medicaid and Medicare. Reimbursement amounts and diagnosis codes for self-reported encounters are collected directly from providers (Howard, Molinari, & Thorpe, 2004).
- As a survey, rather than a claims database, MEPS does not contain certain clinical data. In the case of cancer, costs vary greatly by stage, but this variability within the MEPS population cannot be accurately quantified.
- MEPS does not collect data for people who are institutionalized (such as in a hospice or nursing home), although some people may be interviewed before or after being institutionalized for part of the 2-year period in which they are participants in MEPS. Costs for institutionalized patients are generally higher than for patients in the community, so the calculations generated by MEPS may be underestimates of the true burden and may not fully capture costs related to terminal care (Howard, Molinari, & Thorpe, 2004).

- MEPS does not collect expenditures on complementary and alternative medical services, vitamins/supplements, homemaking services, unpaid family care, accommodations, meals, travel expenses, or lost work time.
- MEPS does not have complete information on dates of diagnosis. Since costs in first year after diagnosis and last year of life are much higher than continuing costs, not being able to categorize patients by treatment phase is a shortcoming of the analysis.

Assumptions

The burden of OOPs was calculated on the family level, since it was assumed that family members share expenses and since most family members also share insurance coverage. In addition, patients are assumed to have been truthful in their self-reports and the data are assumed to have been coded correctly.

Operational Definitions

This study used the following definitions:

- Medical costs: costs that could potentially be covered by insurance, including all expenditures paid out-of-pocket for medical “encounters”, a catch-all term that includes hospital stays, ambulatory care visits (office-based, outpatient department, emergency room), prescription medications, and all other (home health, dental, durable medical equipment, etc.).

- OOPes: deductibles, coinsurance and copayments, payments for non-covered services, and premiums. Although some researchers exclude premiums when calculating OOPes, not including them leaves out a large portion of OOPes, especially for self-employed patients and others who have nongroup private coverage, but also for low-income patients. In addition, cancer patients may have their premiums increased after diagnosis and must continue to pay premiums in order to maintain their necessary medical coverage, so premiums can be considered cancer-related expenditures.
- Cancer patients: MEPS survey participants who have an encounter (visit, prescription, etc.) coded as cancer. Hence, all patients are being actively treated or monitored for cancer.
- Low-income family: income is $\leq 200\%$ of federal poverty level (Banthin & Bernard; Merlis, Gould, & Mahato)
- High burden: $\geq 10\%$ of income *or* $\geq 5\%$ if low-income (Merlis, Gould, & Mahato, 2006)
- Senior: age 65 or older
- Payors: providers of insurance or payments for medical care, categorized as:
 - Private, group (e.g., employer, union)
 - Private, other (e.g., self-employed, Medigap)
 - Medicare
 - Medicaid

- Other (e.g., SCHIP, VA, TRICARE)
 - None (self-pay/charity)
- Uninsured: Lacking insurance at any point during the year. Lack of insurance, even for brief periods, is associated with a lack of usual source of care and with delays in getting care or not getting care at all (Ward et al., 2008).

The next chapter will delve more deeply into the literature on insurance and OOPes.

CHAPTER 2: LITERATURE REVIEW

The purpose of this chapter is to provide the reader adequate context and background related to this study. The topics include medical costs, the insurance industry, and Medicare. In addition, a comprehensive review of the literature on OOPes for various populations is provided in order to allow for comparisons to the results of this study.

Healthcare Costs and the Insurance Industry

Healthcare costs are categorized in multiple ways. When analyzing government reports on national health spending, it is important to understand the two categories of spending: national healthcare expenditures (NHE) (including research funding, program costs, and government public health activities) and personal healthcare expenditures (PHE). PHE is the subset of NHE that includes spending by the Federal and state governments, private payors, and individuals on health services and supplies (hospital care, physician/clinical services, home health and nursing home, prescription drugs, and other medical products).

One of the drivers of rising healthcare costs is rising expenditures on prescription drugs. Spending on prescription drugs has risen greatly in recent years, with growth rates of 6.4% in 1994 to 15.5% in 2002 (Smith, 2004). Growth in spending has been driven both by increases in drug prices (about 4% annually from 1994 to 2002) and increases in utilization (10.6% from 1994-2002) (Smith, 2004).

Spending on prescription medications makes up just 10% of total healthcare spending, yet drug prices and drug spending get much more attention than spending on

other kinds of medical services (e.g., hospital care, which consumes 30% of spending) (Centers for Medicaid and Medicare, 2007b). There are several reasons for the spotlight on drug spending. Most importantly, drug prices are visible, unlike the prices for hospital stays and ultrasounds. In addition, most people pay a share of drug prices that varies by the cost of the drug, unlike the share for other services, and patients' share of the cost of drugs is higher than the share for other costs, such as hospital stays. Finally, some drug spending is discretionary, unlike most spending on hospitalizations.

Beginning in the 1970s, the insurance industry began to address rising healthcare costs with managed care, a term used to describe a number of techniques including negotiating discounts from providers, establishing quality benchmarks, controlling access to specialists through the use of mandatory referrals, setting up preferred provider networks, etc. Many providers and patients have been dissatisfied with the results of managed care, claiming that the focus on costs has resulted in lower-quality care (Blendon et al., 1998). More recently, other cost-containment techniques have become common, such as "consumer-driven" plans, high-deductible plans, and higher cost-sharing designed to influence patient behavior by providing financial incentives to limit use of services or direct use toward specific services (Rowe, Brown-Stevenson, Downey, & Newhouse, 2008).

As of 2005, employer-sponsored private health insurance covered 62% of the US population. (Fronstin, 2006) These workers paid an average of 16% of the premium for single coverage and 27% of premiums for family coverage in 2006 (Kaiser Family Foundation, 2007), compared to 11% for single and 29% for family in 1988 (Levitt et al., 2000). Most (82%) employees pay a flat co-payment for doctor's visits, instead of

coinsurance. For hospitalizations, about 25% of employees pay a flat deductible or copayment, while another 22% pay a coinsurance percentage. About 79% of people with employer-sponsored private insurance have an annual OOP maximum amount, which may or may not count spending on deductibles or prescription drug copayments toward the cap. About 30% of people with employer-sponsored private insurance pay a deductible of some kind. (Claxton et al., 2006)

In response to increases in drug prices, many insurance companies have introduced three- or four-tier copayment schemes and other cost-containment strategies (Steinberg et al., 2000), now a fixture in about three-quarters of employer-sponsored health plans (Claxton et al., 2006). These formulary tiers are intended to limit the use of branded drugs and encourage the use of generics, in order to reduce costs associated with prescription drugs. For example, a clinician will offer a patient several choices for a particular prescription: a generic, with a \$10 copayment (tier 1), a preferred brand-name drug, with a \$20 copayment (tier 2), or a non-preferred brand-name drug, with a \$35 copayment (tier 3, the majority of which have generic or preferred brand-name alternatives). The rise in consumer-driven strategies to contain costs, as well as changes in benefit structures such as three-tier pricing and cost-sharing, have been effective in slowing the growth in drug spending (Poisal et al., 2007).

Out-of-Pocket Expenditures

Americans pay a lower share of total healthcare expenditures than they used to, but declining OOP shares are obscured by the higher dollar amounts being paid (Poisal et al., 2007). Between 1960 and 2005, the share of PHE paid OOP fell from about 55%

of all costs to about 15% (Centers for Medicaid and Medicare, 2007a; Kaiser Family Foundation, 2007). In 1960, more than 90% of prescription drug costs were paid OOP, compared to about 22% in 2006 (Centers for Medicaid and Medicare, 2007b). Most economists believe that declining OOP shares encouraged consumers to use more healthcare services (i.e., moral hazard), leading to growth in spending.

Whereas premium increases have averaged 8-14% per year since 2000, wages typically increase by 3-4% per year (Kaiser Family Foundation). From 1996-97 to 2001-02, the dollar amount of OOP spending per family increased 35% — faster than overall medical spending (Merlis, Gould, & Mahato, 2006). Meanwhile, incomes were rising more slowly — incomes increased an average of 19.5% from 1996-97 to 2001-02 (Merlis, Gould, & Mahato, 2006). Moreover, low-income eligibility guidelines for Medicaid and SCHIP are typically some multiple of the federal poverty level (FPL). The FPL has not increased fast enough to account for the growth in medical spending, since it is tied to inflation (Kaiser Family Foundation, 2007).

Table 1. An Overview of Recent Studies on OOPs

Reference	Data source	Population	Result
Banthin et. al, 2006	MEPS (1996 and 2003)	Non-elderly patients, including some with cancer	About 29% of cancer patients had a high burden, and 11% had very high burden.
Howard et. al, 2004	MEPS (1996-1999) and MedStat MarketScan (1999)	Non-elderly cancer patients	Patients spent about 5% of income OOP for healthcare
Langa et. al, 2004	Asset and Health Dynamics Study (1995)	Elderly cancer patients	Low-income cancer patients spent about 27% of their income OOP, compared to 5% of annual income for high-earning patients without cancer
Merlis et. al, 2006	MEPS (1996-96 and 2001-02)	Families with and without persons over age 65	An average of 23% of all families had high burden - 44% of families with seniors and 17% of families without seniors

Reference	Data source	Population	Result
Neuman et. al, 2007	MCBS (2003)	Medicare beneficiaries	Medicare patients spent an average of 16% of income OOP for healthcare
Shen et. al, 2006	National Survey of America's Families (2002)	Families (low-income vs. high)	About 28% of low-income families paid >5% of income OOP (not including premiums), compared to 7% of higher-income families
Waters et. al, 2007	MEPS (2000)	Uninsured persons	The uninsured paid about 27% of income OOP for medical services

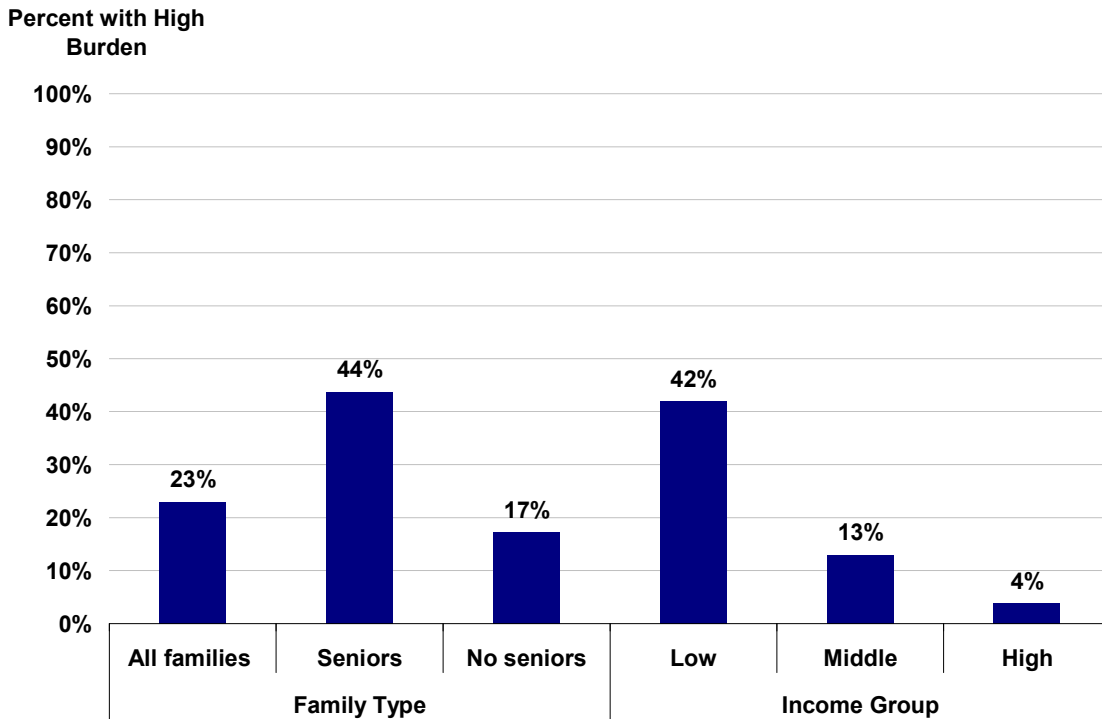
Out-of-Pocket Expenditures of the Nonelderly Population

The US elderly population has nearly universal health insurance coverage (Medicare), with protection against high OOPs for the low income and chronically ill. This is not the case for those under age 65. Medicaid is only available to low-income pregnant women, children, teenagers, blind and disabled persons, and those leaving welfare, and even the Medicaid-eligible low-income population frequently experiences gaps in coverage. Stringent documentation requirements are in place, and citizenship is a requirement for eligibility. Only 6.6% of the entire nonelderly adult population was covered by Medicaid in 2006, including fewer than 1 in 5 adults earning less than 200% of the FPL (Kaiser Family Foundation, 2008).

Almost everyone is at risk of a high OOP burden if they become ill, but many have high OOP burdens for personal healthcare expenses even without having a serious illness (Banthin & Bernard, 2006). Figure 1 shows a summary of OOP burden for personal healthcare spending according to an analysis of the 1996-96 and 2001-02 MEPS (Merlis, Gould, & Mahato, 2006). Using an expanded definition (10% or 5% if low income) and including premiums, about 23% of all families had a high burden and about 44% of families with seniors had a high burden in 2001-02. Including premiums,

almost 25% of all families (of all incomes and ages) spent $\geq 10\%$ of their income on healthcare OOP ($\geq 5\%$ for low-income) in 2001-02.

Figure 1. Percentage of families with high annual out-of-pocket expenditures relative to income by presence of member(s) age 65 or older and income group, 2001-02



Source: Merlis et. al, 2006

The average family's OOPs, not including premiums, rose from \$922/year in 1996-97 to \$1,245/year in 2001-02 (Merlis, Gould, & Mahato, 2006). In addition, almost 2/3 of low-income families with private insurance have high burdens if premiums are included (Merlis, Gould, & Mahato, 2006). Of the poor, 24% had a very high burden (more than 20% of income paid OOP for healthcare services), and of the near-poor, 10% had a very high burden. The percent of nonelderly families with a high OOP burden increased from 16% in 1996 to 19% in 2003, with wide variations by

income (Banthin & Bernard, 2006). Of nonelderly families with nongroup private insurance (i.e., the self-employed), 53% paid more than 10% of their incomes OOP in 2001-02 (Merlis, Gould, & Mahato, 2006) and about 20% paid more than 20% of their income OOP for healthcare in 2003 (Banthin & Bernard, 2006).

Shen and McFeeters used the 2002 National Survey of America's Families to compare the OOP spending of low and higher-income populations (Shen & McFeeters, 2006). Their definitions of OOPE burden (not including premiums) were: low burden – 0% to 0.5% of family income; moderate burden – 0.5% to 5% of family income; and high burden – greater than 5% of family income. Their rationale for the 5% threshold was that this is the threshold used by the Federal government in determining eligibility for SCHIP. Using this definition, they found that 28% of low-income families had a high OOP burden, compared to 7% of higher-income families. Stratifying the low-income group by insurance type, 62% of those with employer-sponsored insurance had a high burden, compared to 24% of those with non-group private insurance and 14% of those with public insurance (Shen & McFeeters, 2006). The high burden of low-income persons with employer-sponsored insurance is in contrast to the situation for higher-income families, who were significantly more likely to have a high burden if they were covered under a private non-group plan (adjusted OR: 2.36).

About 20% of all adults aged 18-64 were uninsured in 2006, with this proportion being much higher for low-income adults (41.2%) (Kaiser Family Foundation, 2008). The uninsured paid about 27% of their total healthcare expenditures OOP in 2000—an average of about \$2,400 (Waters, Steinhardt, Oliver, Burton, & Milner, 2007). Over 14% of all uninsured Americans had OOPEs of more than 10% of

disposable family income in 2003, and 9% spent more than 20% of their income on healthcare (including premiums) (Banthin & Bernard, 2006).

Out-of-Pocket Expenditures of Seniors

Medicare beneficiaries as a whole paid about 16% of their income OOP for healthcare in 2003, according to a recent analysis of the Medicare Current Beneficiary Survey, an annual nationally representative survey of about 12,000 Medicare beneficiaries that uses both self-reported data and administrative/claims data (Neuman, Cubanski, Desmond, & Rice, 2007). One subgroup at particular risk of high OOP burden is those in institutions (i.e., nursing homes/long-term care), who spent an average of 82% of their income on OOP medical expenses in 2003. Dual eligibles (those with Medicare and Medicaid), in contrast, paid less than 5% of their income OOP. Medicare beneficiaries over age 85 paid about 22% OOP, compared to 12% for disabled beneficiaries under age 65. The poorest beneficiaries, earning less than 200% of FPL, paid about 22% OOP. The OOP burden increased as health deteriorated, with a median OOP burden of 20% for those with poor health compared to 13% for those with excellent/very good health. For the entire Medicare beneficiary population's OOP expenditures—an average of \$3,765 in 2003—about 38% was spent on premiums, 20% on facility care, 15% on physician services, and 14% on prescription drugs.

With the passage of the Medicare Modernization Act, as of 2006 millions of seniors will have prescription drug coverage for the first time. Analysts disagree on the potential impact of this new benefit on beneficiaries' OOPs. According to a report by Mays and colleagues, Part D beneficiaries earning less than 150% of the FPL are

projected to spend 83% less, on average, on prescription drugs under the MMA, while those earning above 150% of FPL are expected to spend 28% less (Mays, Brenner, Neuman, Cubanski, & Claxton, 2004).

Two other recent studies have examined the potential impact of Part D on OOP spending by Medicare beneficiaries (Patel & Davis, 2006; Stuart et al., 2005). Patel and Davis analyzed MCBS data for 1997-2001 for Medicare enrollees (not including dual-eligibles) and stratified the sample into those with and without end-stage renal disease (ESRD). Patients with ESRD require high levels of healthcare services because of the complexity of the disease and the high incidence of comorbidities, with the average patient taking 8 to 13 prescription medications. Patel and Davis projected mean total and OOP drug costs for patients with and without ESRD before and after the introduction of Part D (the standard benefit). They found that that after Part D, ESRD patients would spend \$176 more OOP and non-ESRD patients would spend \$121 more OOP.

Stuart and colleagues took a similar approach, applying the standard Part D benefit to 1998-2000 data from the MCBS (Stuart et al., 2005). As with Patel, Stuart et al excluded institutionalized and low-income persons from the analysis. They identified potential Part D enrollees (those with no drug coverage or Medigap/HMO coverage in 1998-2000), and stratified them into average spenders, high spenders (those with projected spending above \$2,250 in 2006) and catastrophic spenders (those with projected spending of more than \$5,100 in 2006). They projected that the catastrophic spending group would pay about 42% of their drug costs OOP in 2006, 53% in 2007, and 60% in 2008. High spenders would face even higher cost-sharing requirements,

paying 65% of drug costs OOP the first year (about \$3,600), 69% the second year, and 68% the third year.

Out-of-Pocket Expenditures of Cancer Patients

While there have been numerous analyses of US cancer patients' OOPs, all have focused on specific populations, such as nonelderly cancer patients (Banthin & Bernard, 2006; Howard, Molinari, & Thorpe, 2004; Thorpe & Howard, 2003), elderly cancer patients (Langa et al., 2004), small samples of breast cancer patients (Arozullah et al., 2004; Given, Given, & Stommel, 1994; Moore, 1999), or cancer patients receiving specific treatments (Moore, 1998).

Banthin and colleagues, using 2003 data from MEPS, estimated that 29% of nonelderly cancer patients had a high total OOP family burden (i.e., paid more than 10% of disposable family income OOP for healthcare services and premiums), and 11% had a very high burden (paid more than 20%). Not including premiums, 16% of nonelderly cancer patients had a high burden and 7% had a very high burden (Banthin & Bernard, 2006). Howard and colleagues also used MEPS data to look at nonelderly cancer patients, although they used data from 1996-99 and compared it to 1999 data from the MedStat MarketScan database, a national claims file from 45 large employers (Howard, Molinari, & Thorpe, 2004). They estimated that total spending by cancer patients under age 65 was \$46.7 billion in 1999 (2001 US\$), of which \$2.3 billion was spent OOP (about 5%). Thorpe and Howard used the same 1996-99 MEPS data to examine differences in spending by insured and uninsured nonelderly cancer patients (Thorpe & Howard, 2003). They found that 11% of nonelderly cancer patients were uninsured

(10% of whites, 14% of blacks, and 20% of Hispanics). The uninsured spent about 55% of the amount that insured patients spent on healthcare and paid more OOP in both absolute and percentage terms.

Elderly cancer patients would be assumed to have very different OOP patterns compared to nonelderly patients, given that 99% of the elderly are covered, at least in part, by Medicare. Langa and colleagues examined this population using data from the 1995 Asset and Health Dynamics Study (AHDS), a nationally representative survey of noninstitutionalized elderly persons (Langa et al., 2004). Only 176 (3%) of the sample of 6,370 respondents were being actively treated for cancer, which limited the usefulness of the analysis somewhat. The researchers found that low-income cancer patients in treatment spent about 27% of their income OOP, compared to 5% of annual income for high-income individuals with no history of cancer. Cancer patients spent \$670 more than seniors without cancer, even after adjusting for sociodemographic characteristics, other chronic conditions, supplemental insurance status, etc.

There have been at least three qualitative studies of breast cancer patients that attempted to collect more comprehensive data on costs that would not be incurred if it were not for a cancer diagnosis, but that insurance would not cover. Arozullah and colleagues administered a questionnaire to insured breast cancer patients at an academic hospital between October 1999 and November 2002 (Arozullah et al., 2004). A total of 156 patients participated, 19% of whom had household incomes under \$30,000 and 91% of whom were covered by private insurance. Mean monthly expenditures were categorized as direct medical costs, direct nonmedical costs, and indirect costs (lost income). Across all patients, the mean total OOP cost per month was \$1,455, of which

about half was lost income. Of the direct costs incurred, about 18% was for expenses such as childcare, transportation and lodging, and restaurant meals. About one-third of patients incurred OOP costs for prostheses and 48% had expenditures for herbs, supplements, and vitamins. The authors found that for patients with household incomes <\$30,000/year, the total financial burden of breast cancer represented 98% of their household income. The study showed that only 41% of patients' OOPs were for direct medical costs, meaning that much of the burden on cancer patients is overlooked by national surveys that neglect to question patients about their nonmedical expenses and losses.

Three previous studies have been conducted involving surveys of small samples of cancer patients. Given, et. al administered a survey to 49 survivors and the families of 13 nonsurvivors of breast cancer and found that over a 3-month period, the survivors spent \$548 and the decedents spent \$1,125 OOP on medical costs (Given, Given, & Stommel, 1994). Moore queried 30 insured breast cancer patients and found that average monthly nonmedical OOPs were \$360, including expenses such as transportation, special clothing/wigs, housekeeping services, and counseling (Moore, 1999). Moore also queried 20 adult cancer patients (11 with breast cancer and 9 with other cancers) about their OOPs associated with undergoing one month of chemotherapy at a Midwestern medical center, finding that the total average amount spent was \$741, with an additional \$801 in lost income (Moore, 1998).

Implications of High Out-of-Pocket Expenditures

A number of studies have shown that the use of healthcare services declines as OOPs rise. For example, a study in Quebec showed that after the introduction of cost-sharing for prescription drugs in 1996, the use of essential drugs decreased by 9% in elderly persons and by 14% in welfare recipients, accompanied by a significant increase in serious adverse events and emergency department visits (Tamblyn et al., 2001). Less medical care may save money in the short-term but can lead to higher costs in the long run if patients fail to receive preventive care. For example, a number of studies have suggested that lower rates of cancer screening (e.g., mammography) may lead to higher mortality rates as well as higher rates of expensive late-stage cancers compared to less expensive early-stage cancers (Norman et al., 2006; Sassi, Luft, & Guadagnoli, 2006; Smith-Bindman et al., 2006).

In addition, patients' drug-purchasing behaviors are strongly influenced by the OOP costs they will incur. Adherence to treatment with prescription drugs can prevent or delay costly medical complications, whereas noncompliance leads to higher rates of hospitalization and other undesirable health outcomes (i.e., cancer recurrence). Families with high OOPs are much more likely to delay care or not receive needed care (16% of those with high burden vs. 7% with lower burden) (Merlis, Gould, & Mahato).

In addition to clinical implications, high OOP burdens can have serious repercussions for family finances. Medical debt has been shown in numerous studies to be an important factor in bankruptcies (Merlis, Gould, & Mahato, 2006; Shen & McFeeters, 2006). As OOPs rise, a vicious circle is created: debt leads to poverty,

poverty contributes to poor health, and poor health reduces income. One obvious but important factor related to OOP burden is that most OOP costs are the same for all patients with no adjustments for income. In other words, if two families purchase the same service, but one has a lower income, that family has spent a higher share of their income to receive the same services.

This review has shown that the current literature on OOPEs is incomplete. There have been no studies, to my knowledge, that have looked at both senior and nonelderly cancer patients. In addition, no researchers have yet examined the potential influence of Part D on OOPEs for cancer patients. Because high OOPEs can have such serious implications for the chronically ill, this is an issue that deserves to be examined in full.

The next chapter will describe the data analytic and statistical methods used in this analysis of the OOPEs of cancer patients in the US.

CHAPTER 3: METHODS

Overview

This study used data from the 1996-2005 Medical Expenditure Panel Surveys and published literature to produce comprehensive, up-to-date, nationally representative estimates of the OOP burden of cancer patients and to identify groups within cancer patients that are most likely to face high burdens.

Data Source

The source of data for this study was the MEPS, a large-scale, nationally representative survey of a random sample of families and individuals, their medical providers, and employers conducted annually since 1996 by the Agency for Healthcare Research and Quality (AHRQ) and the US Census Bureau (Cohen, 2003). MEPS gathers data on the frequency of use and costs of specific health services and on private health insurance use, availability, and costs. MEPS also collects important demographic, employment, insurance, and health status information, which allows for the analysis of differences within or between special populations of interest (e.g., ethnic/racial minorities, elderly). All 10 available years (1996-2005) were pooled and weighted to generate nationally representative “average annual” estimates.

Patient Selection and Study Measures

Using the International Classification for Diseases, 9th Edition – Clinical Manual (ICD-9-CM) codes for cancer (140.xx – 239.xx, inclusive), all cancer patients over age

18 with at least one claim in the event files for cancer treatment (doctor's visit, inpatient hospital stay, prescription drug, chemotherapy, or radiotherapy treatment, surgery, etc.) were identified. Once cancer patients were identified, all of these patients' expenditures (not limited to cancer-related spending) were compiled using patient identification numbers, and family-level measures of income were created. An income floor of \$100 was imposed to account for errors in income reporting and to exclude families with negative incomes, in accordance with standard methods (Banthin 2006, Bernard 2006). After calculating family income, families were stratified by poverty status as low income (earning less than 200% of the Federal poverty level (FPL)¹, middle income (200 to 400% of the FPL), or high income (400% or more of the FPL).

Patients were classified as insured/uninsured and type of insurance by age, race/ethnicity, and income. "Uninsured" was defined as not covered by Medicare, Medicaid, other public programs, employer-based or individual private insurance, or TRICARE at any point during the year. Single-service insurance coverage (e.g., dental or vision) was not counted as insurance. Those eligible to receive care at Indian Health Service or Veteran's Administration facilities who were not otherwise covered by insurance were classified as uninsured. Persons with multiple payors were assigned coverage based on the payor of longest duration.

OOP burden was defined by the person-level OOPs in excess of a specified percentage of family income (10% or 5% if low income). Total burden was thus defined as total person-level OOP expenditures on healthcare services plus family-level insurance premiums, as a proportion of total family income. This method reduces bias

caused by errors in income reporting and outlier values and also results in an intuitive measure of exposure to the risk of a high burden (Banthin & Bernard, 2006).

Data Analyses

This study used the Statistical Analysis Program (SAS) version 9.1 (Cary, NC) for all analyses. Descriptive analyses were performed to estimate means, and all proportions were weighted to be nationally representative. All cost and income figures were adjusted for inflation to 2007 dollars using the applicable Consumer Price Index inflation factor.

MEPS data do not include Medicare Part B premiums or premiums paid in some states by some Medicaid/SCHIP enrollees; in addition, premiums for private insurance were not collected prior to 2001. Therefore, calculation of the premiums paid by cancer patients in this sample was accomplished as follows: First, Part B premium amounts were added to OOPEs for Medicare enrollees using published data on annual premiums (Social Security Administration, 2008). Part B premiums for dually eligible patients were assumed to be covered by Medicaid. For premiums paid on private insurance, OOPEs for all patients covered by private insurance during 1996-2000 were adjusted by the actual mean amount paid for premiums by all patients covered by private insurance in 2001-2005.

Notes

¹ In 2006, the poverty line for a family of 4 with 2 children was \$20,444, and for a single person over age 65 it was \$9,669 (US Census Bureau, 2006).

CHAPTER 4: RESULTS

Patient Demographics

The 1996-2005 pooled MEPS data yielded a total of 10,308 cancer patients (weighted N=11,491,220 patients). Selected demographic characteristics are presented in Table 2. About 40% of the sample was over age 65 and nearly 90% were white. A majority had at least a high school education and earned over 200% of the FPL.

Table 2. Demographic Characteristics of Sample

Measure	Value
Unweighted N	10,308
Age	
<45 years	27.5%
45 to 54 years	15.8%
55 to 64 years	17.7%
65-74 years	20.5%
75+ years	18.4%
Race/ethnicity	
White, non-Hispanic	88.0%
African American, non-Hispanic	5.9%
Hispanic, any race	4.0%
Asian or Pacific Islander	1.5%
Multiple races/other	0.6%
Education	
Less than 12 years	18.2%
12 years or GED	30.1%
More than 12 years	50.3%
Missing	1.5%
Income	
Low income	24.1%
Middle income	29.3%
High income	46.7%

Note: Low income = <200% of Federal poverty line (FPL); middle income = 200-400% of FPL; high income = 400% or more of FPL

Insurance Characteristics

Most patients under age 65 were privately insured, whereas most patients over 65 had both Medicare and private insurance (Table 3). Across all ages and income

groups, the most common coverage was private only; however, fewer than 20% of low-income patients had private insurance.

Table 3. Insurers of Cancer Patients by Age and Income

Age/Payor	All Incomes	Low Income	Middle Income	High Income
All ages				
Medicare only	13.5%	22.6%	15.8%	7.4%
Medicaid only	2.3%	8.2%	0.7%	0.2%
Private only	46.7%	19.5%	43.4%	62.8%
Medicare + Medicaid	2.5%	7.9%	1.8%	0.2%
Medicare + Private	24.3%	25.2%	27.2%	21.9%
Uninsured	7.6%	13.1%	8.1%	4.5%
<45				
Medicare only	3.5%	8.5%	3.4%	0.8%
Medicaid only	5.6%	20.7%	1.5%	0.3%
Private only	69.5%	32.7%	73.1%	86.8%
Medicare + Medicaid	1.2%	3.1%	1.3%	0.2%
Medicare + Private	4.1%	8.0%	3.2%	2.8%
Uninsured	14.3%	25.4%	15.1%	7.6%
45-54				
Medicare only	0.8%	4.3%	0.5%	0.0%
Medicaid only	2.4%	14.2%	1.0%	0.2%
Private only	81.5%	37.4%	79.1%	92.8%
Medicare + Medicaid	1.1%	6.3%	0.4%	0.0%
Medicare + Private	1.1%	2.2%	2.7%	0.2%
Uninsured	10.6%	32.1%	13.8%	4.3%
55-64				
Medicare only	3.4%	10.8%	2.9%	0.8%
Medicaid only	2.0%	8.7%	0.8%	0.2%
Private only	74.9%	42.9%	73.2%	85.7%
Medicare + Private	3.2%	5.2%	3.2%	1.3%
Uninsured	10.3%	20.4%	8.1%	6.5%
65-74				
Medicare only	26.2%	32.6%	29.5%	19.9%
Private only	5.6%	3.6%	6.1%	6.5%
Medicare + Medicaid	4.4%	13.1%	1.7%	0.2%
Medicare + Private	59.7%	46.2%	58.4%	68.8%
Uninsured	0.9%	0.9%	0.9%	0.0%
75+				
Medicare only	34.8%	40.6%	35.3%	27.3%
Medicare + Medicaid	4.3%	9.1%	2.5%	0.8%
Medicare + Private	55.0%	43.6%	57.2%	65.8%

Note: Categories were mutually exclusive. Not all totals sum to 100% due to missing data.

Patient Expenditures and Out-of-Pocket Burden

The average cancer patient in this sample paid \$5,730 OOP annually (including premiums), or about 8% of his or her family income. OOPes ranged from a low of \$3,678 among low-income patients under age 45 to a high of \$6,983 among high-

income patients aged 55-64 years. In general, the highest OOP expenditures were made by the highest-income patients. Low-income patients paid the highest share of income OOP, averaging about one-fifth of total family income paid OOP for medical expenses.

Table 4. Income, OOPs, and OOP Share of Family Income, by Age and Income

Age/Income	Mean Annual Family Income	Mean Annual OOP Costs*	OOP Share of Family Income
All ages, all incomes	\$73,068	\$5,730	8%
<45	\$79,752	\$5,823	7%
Low income	\$29,887	\$3,678	12%
Middle income	\$61,435	\$6,318	10%
High income	\$118,520	\$6,580	6%
45-54	\$96,351	\$5,998	6%
Low income	\$28,601	\$4,051	14%
Middle income	\$57,514	\$6,170	11%
High income	\$126,344	\$6,379	5%
55-64	\$84,352	\$6,287	7%
Low income	\$21,535	\$4,847	23%
Middle income	\$46,293	\$5,612	12%
High income	\$118,133	\$6,983	6%
65-74	\$59,883	\$5,407	9%
Low income	\$19,405	\$4,729	24%
Middle income	\$38,618	\$5,041	13%
High income	\$99,895	\$6,083	6%
75+	\$46,865	\$5,188	11%
Low income	\$17,915	\$4,110	23%
Middle income	\$36,733	\$5,401	15%
High income	\$91,247	\$6,172	7%

*Includes person-level OOP expenditures and family-level premiums

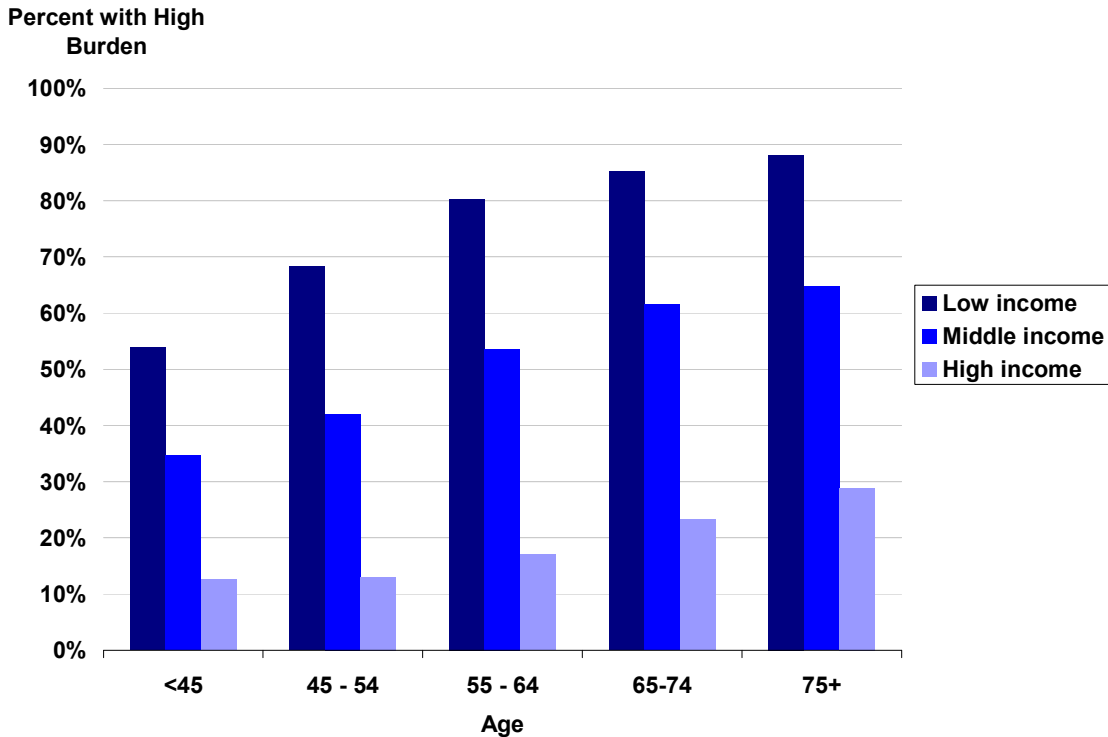
Note: Low income = <200% of Federal poverty line (FPL);

Middle income = 200-400% of FPL; High income = 400% or more of FPL

During the study period, more than half of patients over age 65 had a high OOP burden (i.e., paid more than 10% of income OOP, or more than 5% OOP if low-income), rising to almost 90% for low-income patients over age 85. In contrast, less than a third of patients under age 55 had a high burden and 37% of 55-64-year-old patients had a high burden (Figure 2). Across all ages, 75% of low-income, 51% of middle-income, and 18% of high-income patients had a high burden. Nearly 90% of the oldest and worst off (i.e., low-income patients over age 75) had a high burden. Low-

income patients over age 55 paid an average of 23% of their family income OOP for healthcare, compared to around 6% for high-income patients.

Figure 2. Percent of Cancer Patients with High Burden, by Age and Income



When examined by payor, OOPes ranged from a low of \$668 for Medicaid patients to a high of \$7,121 among the privately insured (Table 5). Patients with Medicaid had the lowest OOPes (\$668), and patients with private insurance had expenditures more than 10 times higher than those of Medicaid patients. Interestingly, the uninsured, with an average income of \$60,268, were better off (in terms of income) than all patients except those with private insurance and paid less in terms of OOP share of income (4%) than any except those with Medicaid (2%) or Medicare plus Medicaid (3%).

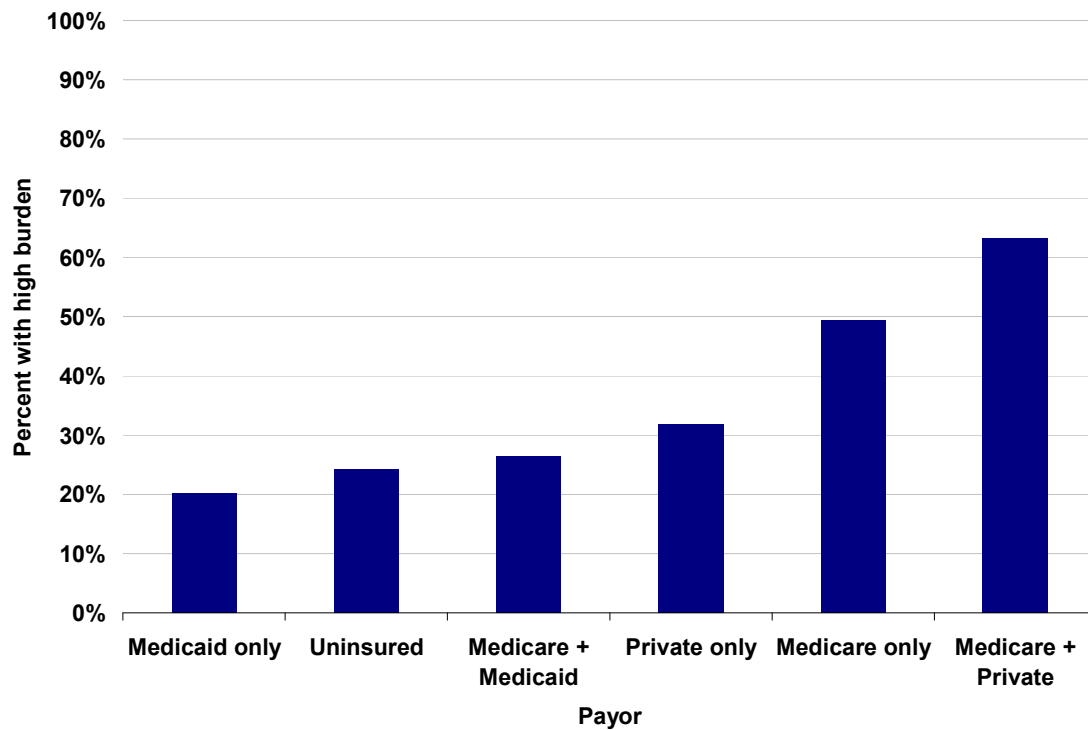
Table 5. Income, OOPs, and OOP Share of Family Income by Payor

Payor	Mean Annual Family Income	Mean Annual OOP Costs*	OOP Share of Family Income
All payors	\$73,068	\$5,730	8%
Medicare only	\$44,293	\$3,221	7%
Medicaid only	\$28,027	\$668	2%
Private only	\$95,697	\$7,121	7%
Medicare + Medicaid	\$28,512	\$942	3%
Medicare + Private	\$58,114	\$6,635	11%
Uninsured	\$60,268	\$2,581	4%

*Includes person-level OOP expenditures and family-level premiums

As shown in Figure 3, patients with Medicare plus private insurance had the highest percentage of patients with high burden (63%), whereas the uninsured had the lowest (24%). The average across all payors was 41%.

Figure 3. Percent of Cancer Patients with High Burden, by Payor



Patients in this sample paid an average of \$621 OOP per year for prescription drugs—about 11% of their total OOP costs. This fraction varied greatly by payor, however, ranging from only 6% for privately insured patients to 65% for patients with Medicare plus private insurance.

Table 6. Prescription Drug Costs by Age, Income, and Payor

	OOP Costs for Prescription Drugs	Mean Annual OOP Costs*	Rx Share of OOP Costs
All patients	\$621	\$5,730	11%
<45	\$973	\$5,823	17%
Low income	\$397	\$3,678	11%
Middle income	\$825	\$6,318	13%
High income	\$466	\$6,580	7%
45-54	\$750	\$5,998	13%
Low income	\$269	\$4,051	7%
Middle income	\$422	\$6,170	7%
High income	\$238	\$6,379	4%
55-64	\$597	\$6,287	9%
Low income	\$232	\$4,847	5%
Middle income	\$139	\$5,612	2%
High income	\$456	\$6,983	7%
65-74	\$882	\$5,407	16%
Low income	\$403	\$4,729	9%
Middle income	\$1,149	\$5,041	23%
High income	\$578	\$6,083	9%
75+	\$630	\$5,188	12%
Low income	\$708	\$4,110	17%
Middle income	\$1,791	\$5,401	33%
High income	\$567	\$6,172	9%
Payor			
Medicare only	\$1,147	\$3,221	36%
Medicaid only	\$316	\$668	47%
Private only	\$397	\$7,121	6%
Medicare + Medicaid	\$612	\$942	65%
Medicare + Private	\$825	\$6,635	12%
Uninsured	\$466	\$2,581	18%

*Includes person-level OOP expenditures and family-level premiums

CHAPTER 5: DISCUSSION AND CONCLUSIONS

Summary

The purpose of this study was to describe the out-of-pocket expenditures (OOPEs) of cancer patients in the US using a population-based approach. Using a 10-year, representative sample of 10,308 cancer patients who were under treatment or surveillance for cancer, this study found that the average OOPE of a cancer patient is around \$5700 per year, including insurance premiums. Of the total, about 11% is spent on prescription drugs.

In this population, the mean annual family income was about \$73,000. The OOP burden is considered to be high if a person spends more than 10% of his or her family income on healthcare. By that measure, over 40% of cancer patients in this sample would be considered to have a high burden—75% of low-income, 51% of middle-income, and 18% of high-income patients.

Of the non-elderly cancer patients, about 31% had a high burden. However, the burden of OOP healthcare costs is considerably greater for the elderly—even those with relatively high incomes. Of all patients aged 65 or older, 56% had a high burden. Nearly 90% of the oldest and worst off (i.e., low-income patients over age 75) had a high burden. Low-income patients over age 55 paid an average of 23% of their family income OOP for healthcare, compared to around 6% for high-income patients.

Patients with Medicare plus private insurance had the highest percentage of patients with high burden (63%), whereas the uninsured had the lowest (24%). As a share of family income, patients with Medicaid, Medicare plus Medicaid (i.e., dual

eligibles), and the uninsured paid very little OOP—around 3%. The group of patients with what should be the most comprehensive insurance coverage (Medicare plus private) had the greatest proportion of patients with a high OOP burden: 63%. In contrast, only 24% of the uninsured had a high OOP burden.

Comparisons to Other Literature

This study appears to be the first to evaluate the OOP burden of both elderly and nonelderly cancer patients using MEPS and the first study of OOPs to combine all 10 years of MEPS data. Despite the broader scope, the results of this study are mostly aligned with previous studies of the OOP burden of cancer patients. For example, the study of nonelderly cancer patients in MEPS (1996-99) by Howard et. al found that patients spent about 5% of their income on OOP costs, not including premiums (Howard, Molinari, & Thorpe, 2004). This study's nonelderly cancer patients spent about 7% of family income on OOPs, including premiums.

Another study of non-elderly individuals in MEPS (comparing 1996 and 2003) found that 29% of cancer patients spent more than 10% of family income on OOPs, including premiums (Banthin & Bernard, 2006). In our study, 56% of nonelderly cancer patients had a high burden. Several factors may account for the difference, including a smaller sample size and more limited time period in the Banthin study.

Langa et. al used a different source of data, the Asset and Health Dynamics Study of 1995, to analyze elderly cancer patients' OOPs (Langa et al., 2004). They found that low-income elderly cancer patients spent about 27% of their income OOP, compared to 5% of annual income for high-earning patients without cancer. These

results compare favorably with the results of this study, which found that low-income seniors spent about 24% of their income OOP, compared to about 6% for high-income seniors.

An earlier study using 1996-97 and 2001-02 MEPS data and looking at the general population, rather than cancer patients, found that an average of 23% of all families had a high burden in 2001-02, using the same definition as this study (10% or 5% if low-income and including premiums) (Merlis, Gould, & Mahato, 2006). In addition, 17% of nonelderly families and 44% of elderly families had a high burden. In the present study of cancer patients, the same general pattern was seen of a larger proportion of elderly patients facing a high OOP burden. Comparing the burden in the general population to the cancer population, we see that roughly twice as many cancer patients have a high burden than non-cancer patients, and the biggest differences are among the low- and middle-income groups (Figure 4).

Figure 4. Comparison of Percent with High OOP Burden, General Population vs. Cancer Patients, by Age and Income

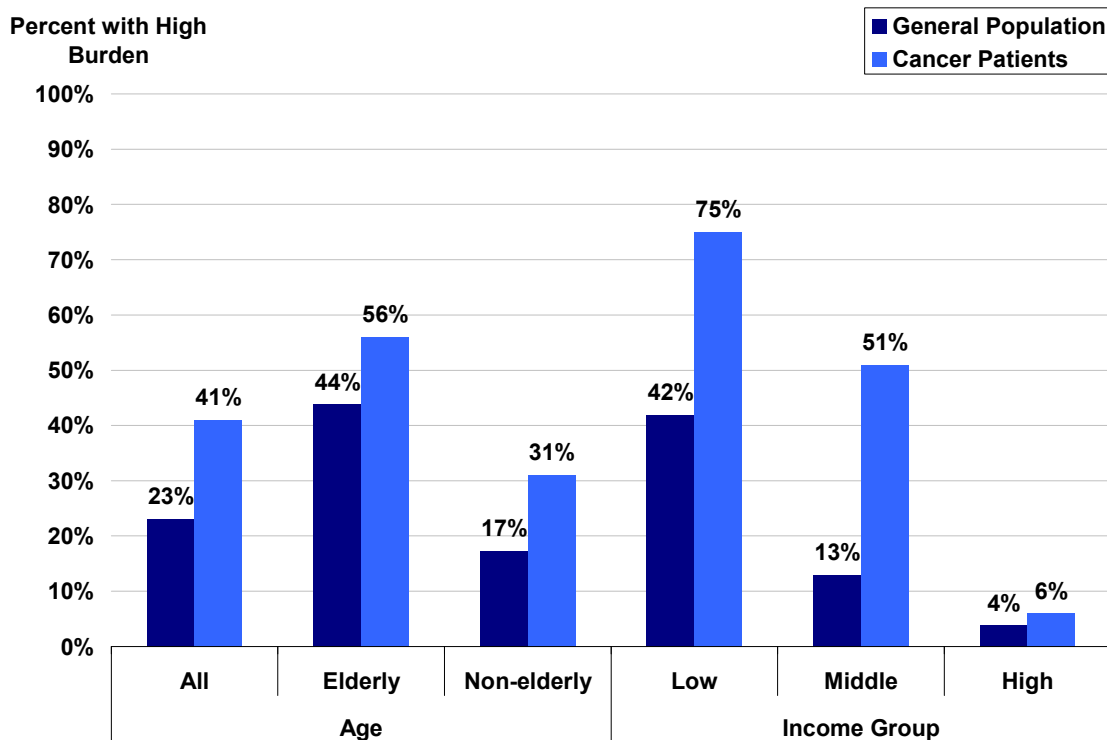


Figure shows data from the present analysis and from Merlis, Gould, & Mahato, 2006.

Implications

The burden of out-of-pocket financial costs on patients is an issue of growing concern to the medical community as well as to the policy community. High out-of-pocket costs are associated with noncompliance and may also pose barriers to receiving necessary services (Guidry, Aday, Zhang, & Winn, 1998; Ward et al., 2008). This analysis shows how certain demographic characteristics are strongly associated with high financial burdens.

Several other interesting facts were brought to light by this analysis. First, uninsured cancer patients in this study (about 8% of the sample) had higher incomes than any other group other than patients with private insurance. In addition, their annual

medical expenditures and OOP share of family income were among the lowest. This suggests that these patients may be healthier than average, leading them to forgo health insurance because of a lack of need rather than the inability to pay.

Second, Medicaid patients and dually eligible patients paid only about 2-3% of their incomes OOP in this study, on average, and had OOPs of less than \$1000. Interestingly, the bulk of their OOPs were for prescription drugs (see Table 6). This suggests one of two things: either 1) these patients are better insured than their privately insured peers, or 2) these patients are consuming fewer non-drug healthcare services than they should be. Unfortunately, the limitations of this dataset do not allow for the analysis of outcomes for different payor groups in relation to differences in OOPs.

It could be argued that the definition of burden should be different for cancer patients and other seriously ill individuals. The ability/willingness to pay for treatment when one is very ill has not been explored in great depth in the literature, but it is a topic of interest to many economists. Presumably, if the options are to spend 90% of one's income on a life-saving treatment or to die, one will choose to spend. Whether this is a fair or just choice is a different question, and one that is much debated among policymakers and the medical community.

Conclusion

This study documents the burden of OOPs and disparities in burdens across different segments of the population of cancer patients. Using nationally representative data from a large household survey, this study found that 4 out of 10 cancer patients have high out-of-pocket expenses and that the burden falls disproportionately on the

poor and elderly. Compared to individuals without cancer, patients with cancer are about twice as likely to spend more than 10% of their family income on OOP expenses for healthcare.

BIBLIOGRAPHY

- Adler, N. E., & Ostrove, J. M. (1999). Socioeconomic Status and Health: What We Know and What We Don't. *Ann NY Acad Sci*, 896(1), 3-15.
- American Cancer Society. (2007). Cancer Facts & Figures 2007. Retrieved February 10, 2008, from <http://www.cancer.org/downloads/STT/CAFF2007PWSecured.pdf>
- Anderson, G. F. (2007). From 'Soak The Rich' To 'Soak The Poor': Recent Trends In Hospital Pricing. *Health Aff*, 26(3), 780-789.
- Arozullah, A. M., Calhoun, E. A., Wolf, M., Finley, D. K., Fitzner, K. A., Heckinger, E. A., et al. (2004). The financial burden of cancer: estimates from a study of insured women with breast cancer. *J Support Oncol*, 2(3), 271-278.
- Banthin, J. S., & Bernard, D. M. (2006). Changes in financial burdens for health care: national estimates for the population younger than 65 years, 1996 to 2003. *JAMA*, 296(22), 2712-2719.
- Blendon, R. J., Brodie, M., Benson, J. M., Altman, D. E., Levitt, L., Hoff, T., et al. (1998). Understanding the managed care backlash. *Health Aff*, 17(4), 80-94.
- Centers for Medicaid and Medicare. (2007a). Health Care System: Facts and Figures 2007 Edition. Retrieved February 16, 2008, from <http://www.cms.hhs.gov/MedicareMedicaidStatSupp/LT/list.asp>
- Centers for Medicaid and Medicare. (2007b). National Health Expenditures by type of service and source of funds, CY 1960-2006. Retrieved February 10, 2008, from http://www.cms.hhs.gov/NationalHealthExpendData/02_NationalHealthAccountHistorical.asp
- Chen, A. Y., Schrag, N. M., Halpern, M., Stewart, A., & Ward, E. M. (2007). Health Insurance and Stage at Diagnosis of Laryngeal Cancer: Does Insurance Type Predict Stage at Diagnosis? *Archives of Otolaryngology- Head and Neck Surgery*, 133(8), 784.
- Claxton, G., Gil, I., Finder, B., DiJulio, B., Hawkins, S., Pickreign, J., et al. (2006). Employer Health Benefits 2006 Annual Survey. Retrieved February 9, 2008, from <http://www.kff.org/insurance/7527/index.cfm>
- Cohen, S. B. (2003). Design Strategies and Innovations in the Medical Expenditure Panel Survey. *Medical Care*, 41(7), 5-12.
- Field, M. J., & Shapiro, H. T. (Eds.). (1993). *Employment and Health Benefits: A Connection at Risk*. Washington, DC: The National Academies Press.
- Fronstin, P. (2006). Sources of Health Insurance and Characteristics of the Uninsured: Analysis of the March 2006 Current Population Survey. *EBRI Issue Brief*, 298.
- Given, B. A., Given, C. W., & Stommel, M. (1994). Family and out-of-pocket costs for women with breast cancer. *Cancer Pract*, 2(3), 187-193.
- Guidry, J. J., Aday, L. A., Zhang, D., & Winn, R. J. (1998). Cost considerations as potential barriers to cancer treatment. *Cancer Pract*, 6(3), 182-187.
- Halpern, M. T., Bian, J., Ward, E. M., Schrag, N. M., & Chen, A. Y. (2007). Insurance status and stage of cancer at diagnosis among women with breast cancer. *Cancer*, 110(2), 403-411.

- Howard, D. H., Molinari, N. A., & Thorpe, K. E. (2004). National estimates of medical costs incurred by nonelderly cancer patients. *Cancer, 100*(5), 883-891.
- Kaiser Family Foundation. (2007). Health Care Costs: A Primer. Key Information Health Care Costs and Their Impact. Retrieved February 8, 2008, from <http://www.kff.org/insurance/upload/7670.pdf>
- Kaiser Family Foundation. (2008). What Happened to the Insurance Coverage of Children and Adults in 2006? Retrieved 2/24/08
- Kung, H. C., Hoyert, D. L., Xu, J., & Murphy, S. L. (2008). Deaths: Final Data for 2005. Retrieved February 10, 2008, from http://www.cdc.gov/nchs/data/nvsr/nvsr56/nvsr56_10.pdf
- Langa, K. M., Fendrick, A. M., Chernew, M. E., Kabeto, M. U., Paisley, K. L., & Hayman, J. A. (2004). Out-of-Pocket Health-Care Expenditures among Older Americans with Cancer. *Value in Health, 7*(2), 186-194.
- Levitt, L., Holve, E., Wang, J., Gabel, J. R., Whitmore, H., Pickreign, J., et al. (2000). Employer Health Benefits 2000 Annual Survey. Retrieved February 9, 2008, from <http://www.kff.org/insurance/3028-index.cfm>
- Mays, J., Brenner, M., Neuman, T., Cubanski, J., & Claxton, G. (2004). Estimates of Medicare Beneficiaries' Out-of-Pocket Drug Spending in 2006: Modeling the Impact of the MMA. Retrieved April 15, 2008, from www.kff.org/medicare/upload/Report-Estimates-of-Medicare-Beneficiaries-Out-Of-Pocket-Drug-Spending-in-2006-Modeling-the-Impact-of-the-MMA.pdf
- Melnick, G. A., & Fonkych, K. (2008). Hospital Pricing And The Uninsured: Do The Uninsured Pay Higher Prices? *Health Aff*, hlthaff.27.22.w116.
- Merlis, M., Gould, D., & Mahato, B. (2006). *Rising Out-of-pocket Spending for Medical Care: A Growing Strain on Family Budgets*: Commonwealth Fund.
- Meropol, N. J., & Schulman, K. A. (2007). Cost of Cancer Care: Issues and Implications. *J Clin Oncol, 25*(2), 180-186.
- Moore, K. A. (1998). Out-of-pocket expenditures of outpatients receiving chemotherapy. *Oncol Nurs Forum, 25*(9), 1615-1622.
- Moore, K. A. (1999). Breast cancer patients' out-of-pocket expenses. *Cancer Nurs, 22*(5), 389-396.
- Neuman, P., Cubanski, J., Desmond, K. A., & Rice, T. H. (2007). How much 'skin in the game' do Medicare beneficiaries have? The increasing financial burden of health care spending, 1997-2003. *Health Aff (Millwood), 26*(6), 1692-1701.
- Norman, S. A., Localio, A. R., Zhou, L., Weber, A. L., Coates, R. J., Malone, K. E., et al. (2006). Benefit of screening mammography in reducing the rate of late-stage breast cancer diagnoses (United States). *Cancer Causes and Control, 17*(7), 921-929.
- Patel, U. D., & Davis, M. M. (2006). Falling into the Doughnut Hole: Drug Spending among Beneficiaries with End-Stage Renal Disease under Medicare Part D Plans. *Journal of the American Society of Nephrology, 17*(9), 2546.
- Poissal, J. A., Truffer, C., Smith, S., Sisko, A., Cowan, C., Keehan, S., et al. (2007). Health spending projections through 2016: modest changes obscure part D's impact. *Health Aff (Millwood), 26*(2), w242-253.

- Rowe, J. W., Brown-Stevenson, T., Downey, R. L., & Newhouse, J. P. (2008). The Effect Of Consumer-Directed Health Plans On The Use Of Preventive And Chronic Illness Services. *Health Aff*, 27(1), 113-120.
- Sassi, F., Luft, H. S., & Guadagnoli, E. (2006). Reducing Racial/Ethnic Disparities in Female Breast Cancer: Screening Rates and Stage at Diagnosis. *Am J Public Health*, 96(12), 2165-2172.
- Shen, Y. C., & McFeeters, J. (2006). Out-of-pocket health spending between low-and higher-income populations: who is at risk of having high expenses and high burdens? *Med Care*, 44(3), 200-209.
- Smith-Bindman, R., Miglioretti, D. L., Lurie, N., Abraham, L., Barbash, R. B., Strzelczyk, J., et al. (2006). Does Utilization of Screening Mammography Explain Racial and Ethnic Differences in Breast Cancer? *Ann Intern Med*, 144(8), 541-553.
- Smith, C. (2004). Retail Prescription Drug Spending In The National Health Accounts. *Health Aff*, 23(1), 160-167.
- Social Security Administration. (2008). Medicare Part B Premiums: New Rules for Beneficiaries with Higher Incomes. Retrieved 2/24/08, from <http://www.ssa.gov/pubs/10161.html>
- Steinberg, E. P., Gutierrez, B., Momani, A., Boscarino, J. A., Neuman, P., & Deverka, P. (2000). Beyond survey data: a claims-based analysis of drug use and spending by the elderly. *Health Aff (Millwood)*, 19(2), 198-211.
- Stuart, B., Briesacher, B. A., Shea, D. G., Cooper, B., Baysac, F. S., & Limcangco, M. R. (2005). Riding The Rollercoaster: The Ups And Downs In Out-Of-Pocket Spending Under The Standard Medicare Drug Benefit. *Health Affairs*, 24(4), 1022.
- Tamblyn, R., Laprise, R., Hanley, J. A., Abrahamowicz, M., Scott, S., Mayo, N., et al. (2001). Adverse Events Associated With Prescription Drug Cost-Sharing Among Poor and Elderly Persons. *JAMA*, 285(4), 421-429.
- Thorpe, K. E., & Howard, D. (2003). Health insurance and spending among cancer patients. *Health Aff (Millwood)*, *Suppl Web Exclusives*, W3-189-198.
- US Census Bureau. (2006). Poverty Thresholds for 2006 by Size of Family and Number of Related Children Under 18 Years. Retrieved March 2, 2008, from <http://www.census.gov/hhes/www/poverty/threshld/thresh06.html>
- Ward, E., Halpern, M., Schrag, N., Cokkinides, V., DeSantis, C., Bandi, P., et al. (2008). Association of insurance with cancer care utilization and outcomes. *CA Cancer J Clin*, 58(1), 9-31.
- Waters, H. R., Steinhardt, L., Oliver, T. R., Burton, A., & Milner, M. (2007). The Costs of Non-Insurance in Maryland. *Journal of Health Care for the Poor and Underserved*, 18(1), 139-151.