A national estimate of the cost of illness in Parkinson's disease using retrospective data analysis

Katherine Anderson

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A national estimate of the cost of illness in Parkinson's disease using retrospective data analysis

Abstract
The purpose of this study was to estimate the cost of illness of Parkinson's disease in the United States. Direct medical expenditures, with the exception of nursing home costs, were estimated using data from the 1999-2003 Medical Expenditures Panel Survey Household Component (MEPS-HC). Nursing home costs were estimated using the Medical Expenditures Panel Survey Nursing Home Component (MEPS-NHC). Indirect costs for lost productivity due to missed work or bed-days (morbidity) were estimated using the MEPS-HC and the Bureau of Labor Statistics (BLS). Indirect costs for lost productivity due to death (mortality) were estimated using the National Vital Statistics System.

Direct and indirect costs of Parkinson's disease in the United States were estimated at $39,661,102,321 for the five year period of 1999-2003. Direct medical costs totaled $25,686,503,575 and direct non-medical expenditures accounted for $328,048,817. The majority of direct medical costs were found to be associated with nursing home care for patients with Parkinson's disease and prescription medications for the treatment of Parkinson's disease. Indirect costs resulting from lost workdays, bed-days, and mortality totaled $10,870,870,402. The majority of indirect costs was due to bed days ($9,619,603,534), followed by mortality costs ($861,530,870) and lost workdays ($389,735,998).

There were no statistically significant differences in total cost of illness between gender, education, age, marital status, income level and region of residence found in this study for patients with Parkinson's disease. This study concluded that there are statistically significant differences in direct medical costs for male and female patients with Parkinson's disease. This study also concluded that there are statistically significant differences in direct medical costs for patients who live in the South compared to patients in the Northeast. Direct non-medical costs were the least frequently reported cost by patient's with Parkinson's disease in this study. Patients who live in the South reported the largest proportion of indirect costs due to morbidity. However, there were no statistically significant differences in selected demographic characteristics and morbidity costs for patients with Parkinson's disease.

The overall total cost of illness was estimated by this study to be over six billion dollars annually for patients with Parkinson's disease. While not as costly a disease state as Alzheimer's, Parkinson's disease is a more costly disease when compared to Multiple Sclerosis, a disease state with a similar prevalence. This cost of illness estimate has provided an initial understanding of the costs associated with Parkinson's disease. Forthcoming research of the cost of illness of Parkinson's disease will now have a solid foundation to expand upon.

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A NATIONAL ESTIMATE OF THE COST OF ILLNESS IN PARKINSON’S DISEASE USING RETROSPECTIVE DATA ANALYSIS

A Dissertation
Presented for
The Graduate Studies Council
The University of Tennessee
Health Science Center

In Partial Fulfillment
Of the Requirements for the Degree
Doctor of Philosophy
From The University of Tennessee

By
Katherine Anderson
December 2006
DEDICATION

This dissertation is dedicated to my maternal grandmother, Katherine S. Bowling.

Thank you for always believing in me, even when I didn’t believe in myself.
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I would like to thank my major professor, Dr. Richard Faris, for his dedication, patience, and encouragement as I worked through this dissertation. I would also like to thank my committee members, Dr. Lawrence Brown, Dr. Dick Gourley, Dr. Greta Gourley, Dr. Carol Likens, and Dr. Shelley White-Means for their assistance, guidance and support. A big thank you also goes to Dr. Andy Bush for always being patient and taking time to assist me with my questions.

To my parents, Beverly (Kay) and Lynn Anderson, thanks for loving me. Mom, I hope this research makes a difference for you. To my sister Kimberly Anderson, thank you for all your love and support as I made my way through this chapter in my life. Kimberly, words cannot express how thankful and proud I am to have you as my big sister. To my sister Kaara Anderson, thank you for always being the sunshine in my life. Kaara, you are a strong, intelligent, and beautiful person, and the world is blessed by your existence. I would like to thank my brother Joshua Anderson for always making me laugh. Joshua, I am glad our parents didn’t allow me to send you back.

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Sclerosis, a disease state with a similar prevalence. This cost of illness estimate has
provided an initial understanding of the costs associated with Parkinson's disease.
Forthcoming research of the cost of illness of Parkinson's disease will now have a solid
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<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
</tr>
<tr>
<td>AHRQ</td>
<td>Agency for Healthcare Research and Quality</td>
</tr>
<tr>
<td>APMED</td>
<td>Antiparkinsonian Medications</td>
</tr>
<tr>
<td>BLS</td>
<td>Bureau of Labor Statistics</td>
</tr>
<tr>
<td>CHDS</td>
<td>California Hospital Discharge Dataset</td>
</tr>
<tr>
<td>CNS</td>
<td>Central Nervous System</td>
</tr>
<tr>
<td>COI</td>
<td>Cost of Illness</td>
</tr>
<tr>
<td>CoMT</td>
<td>Catechol-o-Methyl Transferase</td>
</tr>
<tr>
<td>CPI</td>
<td>Consumer Price Index</td>
</tr>
<tr>
<td>CPS</td>
<td>Current Population Survey</td>
</tr>
<tr>
<td>CR</td>
<td>Controlled Release</td>
</tr>
<tr>
<td>DBS</td>
<td>Deep Brain Stimulation</td>
</tr>
<tr>
<td>DBS-B-STN</td>
<td>Deep Brain Stimulation of the Sub-thalamic Nucleus</td>
</tr>
<tr>
<td>DC</td>
<td>Direct Costs</td>
</tr>
<tr>
<td>HRQOL</td>
<td>Health Related Quality of Life</td>
</tr>
<tr>
<td>IADL</td>
<td>Instrumental Activities of Daily Living</td>
</tr>
<tr>
<td>IC</td>
<td>Indirect Costs</td>
</tr>
<tr>
<td>ICD-9-CM</td>
<td>International Classification of Diseases, 9&lt;sup&gt;th&lt;/sup&gt; Revision, Clinical Modification</td>
</tr>
<tr>
<td>ICUR</td>
<td>Incremental Cost Utility Ratio</td>
</tr>
<tr>
<td>MAO-B</td>
<td>Monoamine Oxidase-B</td>
</tr>
<tr>
<td>MEPS</td>
<td>Medical Expenditures Panel Survey</td>
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<tr>
<td>MEPS-HC</td>
<td>Medical Expenditures Panel Survey-Household Component</td>
</tr>
<tr>
<td>Acronym</td>
<td>Description</td>
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<tr>
<td>MEPS-IC</td>
<td>Medical Expenditures Panel Survey-Insurance Component</td>
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<td>MEPS-MPC</td>
<td>Medical Expenditures Panel Survey-Medical Provider Component</td>
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<tr>
<td>MEPS-NHC</td>
<td>Medical Expenditures Panel Survey-Nursing Home Component</td>
</tr>
<tr>
<td>MMSE</td>
<td>Mini-Mental State Exam</td>
</tr>
<tr>
<td>MPTP</td>
<td>Methyl Tetrahydorphidine</td>
</tr>
<tr>
<td>MSA</td>
<td>Metropolitan Statistical Area</td>
</tr>
<tr>
<td>NCHS</td>
<td>National Center for Health Statistics</td>
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<tr>
<td>NMES</td>
<td>National Medical Expenditure Survey</td>
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<tr>
<td>NVSS</td>
<td>National Vital Statistics System</td>
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<tr>
<td>PET</td>
<td>Positron Emission Tomography</td>
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<tr>
<td>QALY</td>
<td>Quality Adjusted Life Year</td>
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<tr>
<td>QOL</td>
<td>Quality of Life</td>
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<tr>
<td>SF-36</td>
<td>Short Form-36</td>
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<td>United Parkinson’s Disease Rating Scale</td>
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CHAPTER I. INTRODUCTION

Data on the economic burden of Parkinson's disease is limited, but it is considered to be one of the most expensive neurological disorders to treat.\(^1\) Parkinson's disease is a common chronic neurodegenerative disease for which there is currently no cure.\(^2,^3\) In the United States, an estimated 500,000 to 1.5 million people have Parkinson's disease, with approximately 50,000 new cases are diagnosed each year.\(^4,^6\) Existing estimates of medical expenses for Parkinson's disease range between $5.6 billion and $25 billion dollars annually.\(^7,^8\) Parkinson's disease has a dramatic impact on a person's quality of life and results in severe disability despite the availability of a variety of pharmacological and surgical treatments.\(^3\)

**Definition of Parkinson's Disease**

Parkinson's disease is the most common form of Parkinsonism and was originally referred to in 1817 as "Shaking Palsy."\(^9\) During the 1960s, research on Parkinson's disease revealed the pathology and biology of the disease.\(^9\) The physiological causes of Parkinson's disease are generally agreed upon. In the substantia nigra, the brain cells or neurons of persons with Parkinson's disease become impaired or die.\(^10\) These neurons are responsible for the production of the chemical messenger dopamine that enters nerve cells.\(^10\) Patients with Parkinson's disease experience a loss of more than 80% of neurons that produce dopamine.\(^10\) The lack of dopamine causes nerve cells to fire out of control, leaving patients with Parkinson's disease unable to control movements normally.\(^10\)

Most people diagnosed with Parkinson's disease are over the age of 65; however, approximately 10% of cases occur in persons under the age of 50.\(^11\) The prevalence of
Parkinson’s disease increases with age. Prevalence of the disease is estimated to be 1 out of 100 people over the age of 65, and 3 out of 100 for those over 85. The average age of individuals at diagnosis of Parkinson’s disease ranges between 55 and 60 years. In the United States, there are varying estimates on the number of persons with Parkinson’s disease, ranging from 500,000 to 1.5 million. Currently more males than females suffer from Parkinson’s disease. Specifically, males have a relative risk 1.5 times higher than that of females for developing Parkinson’s disease.

**Description of the Problem**

In 1900, only 3 million persons in the United States were over the age of 65. However, by the year 2000, 39 million persons were 65 years or older. In 2002, healthcare expenditures accounted for 14.9% of the gross domestic product, with older persons accounting for the highest percentage of healthcare resources and services. By the year 2030, population estimates predict that one in five Americans will be 65 years or older, with the most rapidly growing population segment being those 85 and older. Given the increasing prevalence of Parkinson’s disease with advancing age, the number of persons developing Parkinson’s disease will increase dramatically over the next several decades. Between the years of 1990 and 2040, neurodegenerative disease mortality is expected to increase in the United States by 166%.

Parkinson’s disease has no cure and is considered one of the most expensive neurodegenerative diseases to treat. While a variety of pharmaceutical options exist to reduce symptoms, no treatment exists to slow the progression of Parkinson’s disease. Patients with Parkinson’s disease require increasing amounts of care as the disease progresses, increasing amounts of assistance from informal (unpaid) caregivers, and in
the latter stages of the disease, a high level of formal care. Although Parkinson’s disease is the second most common neurodegenerative disease, there are only limited data on the economic impact of Parkinson’s disease.

Based on a review of the peer reviewed literature, a detailed national estimate of the burden of Parkinson’s disease does not exist. Existing cost of illness estimates published on the Internet or by foundations for Parkinson’s disease lack a clear explanation of the methodology used to obtain the estimates. These existing estimates vary between $5.6 billion and $25 billion- a $20 billion range in cost of illness for Parkinson’s disease. Because of the wide variation and lack of peer review in these estimates, there is a need for conducting a detailed analysis of the cost of illness, or more specifically the direct and indirect costs of Parkinson’s disease.

Other medical conditions have been previously studied and the results used for the healthcare policy setting. In 2002, Druss used the Medical Expenditures Panel Survey (MEPS) database to compare the costs of 15 different medical conditions and then used these findings to discuss how cost of illness studies and economic burden studies may be used in setting healthcare priorities. The Druss study revealed that, ischemic heart disease, which affects 3.4 million persons, was the most expensive at $21.5 billion annually. Druss also studied congestive heart failure, a condition which affects approximately the same number of people as Parkinson’s disease. The annual cost for the 1.1 million people with congestive heart failure was $5.2 billion. Having a baseline estimate of the costs for Parkinson’s disease would be useful for comparison and ranking the disease with other medical conditions to set priorities given our limited healthcare dollars.
With the aging of the population and the increasing importance of healthcare expenditures, it would be valuable to have the cost of illness (i.e., economic outcomes) information specific to the United States. Several reasons exist regarding why the initial focus should be on cost of illness. First, 3 out of every 100 people over the age of 85 have Parkinson’s disease. Second, the population of people living over 85 continues to rise. Third, drug treatments for Parkinson’s disease are already expensive and as new, more expensive treatments are released, total drug-related costs will continue to rise. Fourth, the available healthcare dollars are limited, and finally, cost of illness studies are useful in defining the magnitude of disease in monetary terms, assisting in the allocation of resources, providing a foundation for policy, and serving as an economic framework for program evaluation.

Description of Cost of Illness

A branch of health economics, pharmacoconomics is the study of the application of economic theory to drugs and pharmaceutical services. A pharmacoeconomic analysis seeks to identify and measure the costs and consequences of drug use. Specifically, pharmacoeconomic analyses measure clinical health, quality of life, and economic outcomes related to drug therapy. Pharmacoeconomic methods are increasingly being used by researchers and practitioners to study the impact of the use of pharmaceuticals on the health of patients. Information obtained from pharmacoeconomic studies is used by a variety of individuals and organizations, including consumers, physicians, payers, federal and state governments, and healthcare analysts. One pharmacoeconomic model is the cost of illness analysis. Theoretically, a cost of illness analysis examines the total costs
that are the result of a specific disease. A cost of illness model may take into account
direct medical, direct non-medical, indirect, and intangible expenses.

In 1966, Rice introduced cost of illness as a methodology that measures the economic
burden placed on society due to disease or illness. The cost of illness framework has
been popular among researchers and policy makers, and the number of cost of illness
studies has proliferated. Typically, cost of illness studies are used to compare the
economic impact of various health problems, either on a national or international level.

Cost of illness studies were initially used to support the need for additional healthcare
resources. In the early 1990s, the pharmaceutical industry started using cost of illness
information to support the idea that if a disease has a large impact on the economy, it
should receive more resources in research and development.

Cost of illness studies provide insight into diseases and resource allocation in a way
that morbidity and mortality rates do not. Morbidity and mortality data provide a
measure of the physical impact of a disease. With costs being an important component of
health care in the United States, a cost of illness study serves an important role. A
condition such as arthritis may contribute to significant healthcare resource use but is not
a life-threatening disease. Drummond suggests that using mortality and morbidity data
alone to allocate resources could overlook many chronic diseases that require significant
healthcare resources.

Two approaches exist for conducting a cost of illness study. The first approach is
referred to as incidence based and calculates the lifetime cost of an illness. The
second approach is referred to as prevalence based and estimates the costs during any
given year.
The cost of caring for patients can be separated into three categories: 1) direct costs, 2) indirect costs, and 3) intangible costs. Direct costs are those that are directly related to the illness and for which there is a monetary exchange. Direct costs may be further divided into direct medical and direct non-medical costs. Direct medical costs are defined as costs that are related to medical care, including treatment, diagnosis and continuity of care. Examples of direct medical costs include hospitalization, emergency department visits, medications, rehabilitation, nursing home care, and treatment by medical professionals. Depending on an individual’s geographic location, direct medical costs associated with a particular disease may vary.

A second component of direct costs is non-medical costs. Direct non-medical costs are those incurred by the patient to access medical care. Examples of direct non-medical costs are transportation to access the healthcare system, child care, and household expenses related to managing the illness. These costs are not accounted for as consistently in cost of illness studies as the direct medical costs.

Indirect costs are those not related to the delivery of health care and where there is no monetary exchange. Indirect costs are primarily related to a loss in productivity by the individual or by family members caring for the individual. Given the impact of Parkinson’s disease on a patient’s ability to function, these costs may be substantial. Indirect costs are the loss of output by an individual with an illness or disability because they are no longer being able to perform their job (morbidity costs) or because they have died due to the illness (mortality costs). Both indirect morbidity and mortality costs should include considerations for age and gender.

Intangible costs are associated with emotional pain and suffering, and measure the effect of a disease on a person’s quality of life. Intangible costs are hard to quantify.
because of the difficulty associated with assigning a dollar value to emotional stress. Because of this, intangible costs are typically excluded from cost of illness estimates.\textsuperscript{31,32}

Figure 1-1 depicts visually the components of a cost of illness model, as outlined by Rice.\textsuperscript{28}

Figure 1-2 depicts the components of the Parkinson’s disease cost of illness model that was used in this study with an expanded description of each of the included components and the data source used. One entire component of the cost of illness model, intangible costs, was not included in this study. At present, no one has successfully quantified this component of cost of illness.\textsuperscript{33,34}

The primary research question to be investigated in this exploratory descriptive study was: What is the cost of illness of Parkinson’s disease in the United States?

**Purpose of the Study**

The purpose of this study was to provide a prevalence-based retrospective national estimate of the cost of illness (direct and indirect costs) of Parkinson’s disease in the United States in 2003.

**Objectives of the Study**

The objectives of this study were to:

1. Use a national database to estimate the direct and indirect costs (cost of illness) for persons with Parkinson’s disease in the United States.
Figure 1-1. Cost of Illness Model. A Visual Representation of the Components Outlined by Rice.

Figure 1-2. Cost of Illness Model for Parkinson's Disease. A visual representation of the components outlined by Rice and the categories of cost used to measure direct and indirect costs of Parkinson's disease used in this study.

Dotted line (---) = not measured.
Italicized = not captured by any of the databases
*Data from the National Vital Statistics Survey (NVSS) and Bureau of Labor Statistics (BLS).
MEPS = Medical Expenditures Panel Survey, the database used for collecting direct and indirect costs.

3. Determine if there is a statistically significant relationship between gender and cost of illness for Parkinson's disease.

4. Determine if there is a statistically significant relationship between education level and cost of illness for Parkinson’s disease.

5. Determine if there is a statistically significant relationship between age and cost of illness for Parkinson’s disease in the United States.

6. Determine if there is a statistically significant relationship between marital status and cost of illness for Parkinson’s disease.

7. Determine if there is a statistically significant relationship between income level and cost of illness for Parkinson’s disease.

8. Determine if there is a statistically significant relationship between region of residence and cost of illness for Parkinson’s disease.

9. Determine if there is a statistically significant relationship when adjusting for demographic characteristics (gender, education level, age, marital status, income level, and region of residence) jointly and cost of illness for Parkinson’s disease.

Definitions of Terms and Concepts

The following is a list of terms and concepts utilized throughout this study.

1. Bureau of Labor Statistics (BLS)—Government agency that supplies labor force data and information on the demographics, productivity, wages, and employment rates for persons in the United States.35

3. **Cost of illness**—A measurement of economic burden placed on society because of a disease or illness.\(^ {28}\) Cost of illness is determined by the following equation:

\[
\text{direct costs (DC)} + \text{indirect costs (IC)} + \text{intangible costs} = \text{cost of illness (COI)}. 
\]

4. **Direct medical costs**—Costs related to the provision of medical care, including the screening, prevention, diagnosis, and treatment of diseases. Direct costs include costs for emergency room visits, hospital inpatient visits, hospital outpatient visits, nursing home care, (prescription and over-the-counter) medications/treatments, and treatment by medical professionals.\(^ {26}\)

5. **Direct non-medical costs**—Costs related to the illness borne by the patient that do not involve treatment. Examples of direct non-medical costs are transportation or lodging in order to access the healthcare system and childcare while obtaining medical treatment. Household expenses such as home modifications because of a medical condition are also contained in the category of direct non-medical costs.\(^ {26,28}\)

6. **Emergency room services**—Includes visits to healthcare providers in an emergency room. These charges are only for patients who were seen and discharged from the emergency room. The expenses in this category include both payments for services covered under the general facility charge and separately billed physician services. If a patient is admitted to the hospital, emergency room services are not included in this category. Emergency room charges for patients admitted to the hospital through the emergency are included in the hospital inpatient services category.

7. **Home health visits**—Expenses for care that was provided by home health agencies and independent home health providers.
8. *Hospital inpatient services*—Room, board, and all hospital diagnostic and laboratory expenses associated with the basic facility charges. Separately billed physician services and emergency room expenses that occurred immediately prior to admission are also included in this category. Charges from the emergency room are only included in this category if the patient was admitted. If the patient was seen in the emergency room and discharged, those charges appear in emergency room services.

9. *Hospital outpatient services*—Expenses for visits to physicians and other medical providers seen in hospital outpatient departments. Separately billed physician services and facility charges are also included in this category.

10. *Household expenses*—Any expenses related to home modifications that are necessary because of a specific disease or medical condition. An example of a home modification would be the addition of hand rails near the bathtub.

11. *Human capital method*—Technique that quantifies indirect costs by calculating non-medical costs associated with a particular disease state. The human capital method calculates the value of lost productivity due to absence from the work place caused by disability (morbidity) or death (mortality).

12. *Indirect costs*—Costs of illness related to loss in productivity by the individual who is ill and by family members who care for that individual. Two components of indirect costs are morbidity and mortality costs. Morbidity costs are those costs associated with a loss in productivity, and mortality costs are calculated using the present value of future earnings lost.

13. *Institutionalized population*—Population under formally authorized, supervised care or custody. Population restricted to an institution, under the care or
supervision of trained staff, and includes individuals who are patients in health
care facilities or inmates in prison or jail. For the purposes of this study,
institutionalized population refers to patients in nursing home facilities who were part of the Medical Expenditures Panel Survey Nursing Home Component (MEPS-NHC).

14. **Intangible costs**—Costs of illness related to emotional pain and suffering and measure the effect of a disease on a person’s quality of life. Intangible costs were not addressed in this study.

15. **Medical Expenditures Panel Survey (MEPS)**—A national healthcare database that collects data on specific health services that Americans use, the cost of these services, and frequency of use. Data on the cost, scope, and breadth of health insurance in the United States are also collected.

16. **Morbidity costs**—Costs associated with the loss of paid or unpaid productivity due to an illness.

17. **Mortality costs**—Costs associated with the loss of paid or unpaid productivity due to death from an illness or disease. Mortality costs are calculated using the present value of future earnings lost.

18. **National Vital Statistics System (NVSS)**—Data provided through the National Center for Health Statistics (NCHS) and vital registration systems that are responsible for the registration of vital events (births, deaths, marriages, divorces, and fetal deaths).

19. **Non-Institutionalized Population**—Civilian population who live in the United States and reside somewhere other than an institution. For the purposes of this
study, non-institutionalized population refers to patients who were in the Medical Expenditures Panel Survey Household Component (MEPS-HC).

20. Nursing home care—A facility that specializes in providing care to people who are chronically ill and/or who are unable to take care of necessary daily living needs.

21. Office-based medical provider services—Included in this category are expenses for visits to medical providers that were seen in either office-based settings or clinics.

22. Parkinson’s disease—The most common form of Parkinsonism; it is a chronic, progressive, neurological disease resulting from a loss of dopamine-producing brain cells. Parkinson’s disease affects different areas of the body and causes difficulty with starting movements. Known also as a motor system disorder, stiffness, slowness, and tremors are all symptoms associated with Parkinson’s disease. The International Classification of Diseases, Ninth Revision, Clinical Modification Code (ICD-9-CM) for Parkinson’s disease is 332.0–332.1.

23. Prescription medicines—Any medication that requires an order (prescription) from a physician to be obtained. This category includes expenses for all prescription medications (i.e., initial purchases of prescribed medications and refills of them).

24. Treatment by medical professionals—Treatment received from any type of healthcare worker in either a healthcare setting or the home. The types of healthcare provider, as specified in the Home Health Services database, includes (among others): certified nursing assistant, dietitian, home-health aide, hospice worker, homemaker, IV therapist, medical doctor, nurse’s aide, nurse practitioner,
occupational therapist, personal care attendant, physical therapist, respiratory therapist, social worker, and speech therapist.

Assumptions

The following assumptions were made regarding this research:

1. The data in the MEPS database are valid and reliable;
2. The model used is reliable and valid;
3. The national sample is representative of the U.S. population with Parkinson’s disease; and
4. Direct and indirect costs are captured by the data sources.

Limitations of the Study

The limitations of this research were:

1. The data to be analyzed for this project might not provide a complete or accurate estimate of the direct and indirect costs associated with Parkinson’s disease;
2. Respondents to the MEPS survey may inaccurately report the existence or non-existence of a condition.
3. Intangible costs are not measured as part of the study.

Relevance to Health Science Administration

A cost of illness analysis is an excellent tool for policy makers and legislatures to determine where resource allocation occurs. MEPS is a resource that provides comprehensive and timely information about direct and indirect healthcare costs in the United States. 40 It is currently used by policy makers and healthcare administrators to
formulate economic projections related to health care. A cost of illness analysis of Parkinson’s disease using MEPS will provide understanding of how healthcare spending (direct and indirect costs) for Parkinson’s disease is distributed in the United States. This research will assist in determining if the existing health policies need to be changed, or if new policies need to be created. By knowing that healthcare dollars for an illness such as Parkinson’s disease were spent in a specific area, such as treatments, administrators can make better financial plans for their organizations.

Organization of the Study

This dissertation is organized into five chapters. Chapter II provides a review of the literature encompassing a description of Parkinson’s disease, the epidemiology of Parkinson’s disease, as well as the economic, clinical and humanistic outcomes of Parkinson’s disease. Chapter III presents the methods used in the research, while Chapter IV provides the results of the research. Chapter V is a discussion of findings and possible future directions that the research may suggest.
CHAPTER II. REVIEW OF LITERATURE

Introduction

The goal of this chapter is to provide a review of literature relevant to the purpose of this research. The chapter is outlined as a brief history of Parkinson’s disease, followed by an overview of the pathological and clinical features of Parkinson’s disease. The literature review continues with a description of how Parkinson’s disease is diagnosed and how the severity of Parkinson’s disease is assessed. The next section provides a detailed description of the epidemiology of Parkinson’s disease. The etiology, incidence, prevalence, risk factors, and protective factors for Parkinson’s disease are discussed. Next, pharmaceutical treatments, surgical treatments, and ancillary treatments for Parkinson’s disease are discussed. The remainder of this review focuses on cost of illness, the Medical Expenditures Panel Survey (MEPS) database, and pharmacoeconomic studies of Parkinson’s disease. The cost of illness section provides the history and description of cost of illness. The MEPS database section provides a description of MEPS and a review of other cost of illness studies that utilize the MEPS database. The review of pharmacoeconomic studies of Parkinson’s disease covers previous cost of illness studies of Parkinson’s disease, as well as economic studies of the costs of treatment.

Description of Parkinson’s Disease

Parkinson’s disease is the most common form of Parkinsonism and was initially referred to in 1817 as “Shaking Palsy.” Known as both chronic and progressive, Parkinson’s disease has recently become more widely publicized. During the 1960s,
research on Parkinson’s disease revealed the pathology and biology of the disease. Most people with Parkinson’s disease live an average of 10 years before dying, typically from an infection. The most common type of infection causing death in a patient with Parkinson’s disease is pneumonia. For a variety of reasons, Parkinson’s disease symptoms become more severe after the first five years.

**Pathological Features**

The physiological causes of Parkinson’s disease are generally agreed upon. The brain cells or neurons in the substantia nigra of patients with Parkinson’s disease become impaired or die. These neurons produce the chemical messenger dopamine that goes into the nerve cells. Patients with Parkinson’s disease may experience a loss of more than 80% of neurons that produce dopamine. The loss of dopamine causes nerve cells to fire out of control, thus destroying normally controlled movements.

**Clinical Features**

Parkinson’s disease is characterized by four major neurological signs: resting tremor, bradykinesia, cogwheel rigidity, and impaired postural reflexes. Typically a patient may experience signs and symptoms of Parkinson’s disease for one year before being evaluated by a doctor. The most common symptom of Parkinson’s disease is unilateral tremor involving a single limb. However, it is often revealed, after taking the patient history, that a patient may have also been experiencing difficulty buttoning shirts, chewing food, and walking. Additional signs and symptoms include loss of facial expressions, difficulty rising from a sitting position, and difficulty turning over in bed.
Diagnosis

The presentation of Parkinson’s disease varies, making it difficult to clinically diagnose early in the disease process. Various guidelines have been created to assist in the diagnosis of Parkinson’s disease. Typically the clinical diagnosis of Parkinson’s disease is based on the detection of a combination of selected motor signs and symptoms. The cardinal motor signs of Parkinson’s disease are rigidity, tremor, bradykinesia, and postural instability. Symptoms of Parkinson’s disease include altered gait, depression, constipation, and dementia.

Currently, there is no clinical gold standard for diagnosing live patients. Autopsy provides the only definitive method to diagnose Parkinson’s disease, since it can reveal the pathological trait of Parkinson’s disease, the depigmentation of the substantia nigra. The presence of Lewy bodies in the affected nerve cells is also a pathological characteristic of Parkinson’s disease; however, Lewy bodies also appear in other neurological disorders.

Assessing Disease Severity

Parkinson’s is a chronic, progressive disease. After the clinical diagnosis is made, assessment scales are used to monitor the progression of the disease. The United Parkinson’s Disease Rating Scale (UPDRS) measures functional status, disease progression, and the effectiveness of medication. The Hoehn and Yahr scale is a multi-stage system that focuses on the existence and severity of postural instability. The Schwab and England Activities of Daily Living Scale assesses quality of life issues such as speech, handwriting, walking, and pain.
The UPDRS was developed in 1984 and is the most commonly used scale due to the comprehensive list of Parkinson’s disease symptoms included. The scale runs from 0 to 199, with zero representing no disability and 199 representing total disability. Four major subscales comprise the total score: 1) Mentation, Behavior, and Mood, 2) Activities of Daily Living, 3) Motor Exam, and 4) Complications of Therapy During the Previous Week. Each of these subscales is further broken down into subscales with a range of 0 (normal) to 4 (most severe). The UPDRS is considered a validated tool to monitor the progression of Parkinson’s disease and the patient’s response to medication therapy.

The Hoehn and Yahr scale ranks patients based on their level of clinical disability. Patients are assigned stages from 0 to 5, with 0 being no signs of the disease and 5 being completely disabled. In stage 2, patients have bilateral movement without balance problems. In stage 3, patients have impaired balance and body movements. In stage 4 the patients have very severe symptoms but are still able to stand or walk without assistance.

The Schwab and England Activities of Daily Living Scale ranges from 0 to 100% and rates patient disability due to Parkinson’s disease. A rating of 0 indicates the patient is bedridden with no swallowing, bladder, or bowel function. A rating of 100 indicates total independence.

**Epidemiology of Parkinson’s Disease**

The cause of Parkinson’s disease is unknown. The clinical characteristics of Parkinson’s disease include bradykinesia, resting tremor, postural reflex impairment, and cogwheel rigidity. The chief pathological features of Parkinson’s disease are the loss of
pigmented neurons, primarily in the substantia nigra, and the presence of Lewy bodies in the affected nerve cells.\textsuperscript{22} Clinical symptoms are produced by the loss of the nerve chemical dopamine.\textsuperscript{50} The levels of dopamine are usually reduced by approximately 80\% before a patient begins to experience clinical symptoms of Parkinson’s disease.\textsuperscript{50}

**Incidence and Prevalence**

Worldwide, the highest prevalence of Parkinson’s disease is reported in North America, South America, and Europe.\textsuperscript{11} The lowest prevalence is reported in Japan, China and Africa.\textsuperscript{11} In the United States, estimates for the prevalence of Parkinson’s disease range from 100 to 300 per 100,000 persons.\textsuperscript{22,51} The annual incidence of Parkinson’s disease in the United States is 20 per 100,000 lives.\textsuperscript{51} Estimates on the number of persons with Parkinson’s disease in the United States, rang from 500,000 to 1.5 million.\textsuperscript{6}

**Risk Factors**

**Age**

The average age for Parkinson’s disease to be diagnosed ranges between 55 and 60 years of age.\textsuperscript{12} The incidence and prevalence of Parkinson’s disease increases with age.\textsuperscript{11,52} It is unknown why this relationship between increased age and increased incidence and prevalence exists. One possible explanation for the correlation between increased age and prevalence of Parkinson’s disease is age-related neurological vulnerability.\textsuperscript{22} Another explanation is that a causal mechanism of Parkinson’s disease is dependent on the passage of time.\textsuperscript{22}
Gender

If risk were equal among men and women for developing Parkinson’s disease, one would expect that because women live longer the prevalence of Parkinson’s disease would be greater in women.\textsuperscript{22} Incidence rates for Parkinson’s disease increase with age for both men and women; however, men have a higher incidence rate in all age groups.\textsuperscript{53} An increasing number of studies have shown that men have an increased age-adjusted prevalence of Parkinson’s disease.\textsuperscript{22,53-56} Baldereschi reported in 2000 an age-adjusted relative risk in men of 2.13 compared with women for Parkinson’s disease.\textsuperscript{53}

Race

The highest prevalence of Parkinson’s disease is in North American and Europe.\textsuperscript{22} The prevalence rates in Africa, China, and Japan are significantly lower.\textsuperscript{22} In the United States and Africa, several studies have found the prevalence of Parkinson’s disease to be much lower among blacks.\textsuperscript{56-59} The findings of these studies imply that whites are at greater risk for Parkinson’s disease.\textsuperscript{22}

Genetics

Heredity is another risk factor for Parkinson’s disease.\textsuperscript{22} In 1991, Maraganore studied relatives of 20 Parkinson’s patients in Britain and found that 13 of 69 living first-degree relatives had idiopathic Parkinson’s disease.\textsuperscript{60} The authors proposed there was an autosomal-dominant pattern of inheritance.\textsuperscript{60} Payami found the risk of developing Parkinson’s disease among the relatives of patients with Parkinson’s disease to be 3.5 times higher than in relatives in the control group.\textsuperscript{61} While both of these studies are
significant, neither of them used population-based methods and therefore, the results are not generalizable.\textsuperscript{22}

While some studies have found a significant genetic link for Parkinson’s disease risk, other studies report a less prominent role for genetic factors.\textsuperscript{62-64} Studies that use twins support the less prominent role of genetic factors in Parkinson’s disease.\textsuperscript{65-68} Since Parkinson’s disease is a disorder that occurs late in life it is possible that if one twin dies before developing symptoms, that the twins would appear to be discordant.\textsuperscript{22} Burn et al. used positron emission tomography (PET) scan to demonstrate that 30-40\% of asymptomatic twins had a significantly lower uptake of F-dopa.\textsuperscript{69}

\textit{Toxic Exposure}

Research into exogenous agents causing Parkinson’s disease was triggered when narcotic addicts injected methyl-tetrahydophridine (MPTP) and began experiencing Parkinson’s symptoms. Until this discovery, Parkinson’s disease was known to result from chemical injuries; however, MPTP-induced Parkinson’s strictly mimics anatomic and clinical features without causing additional CNS injury. This discovery initiated the research for naturally occurring environmental factors that may be related to Parkinson’s disease.\textsuperscript{22} The symptoms induced by the MPTP exposure were immediate; however, the symptoms from environmental causes are slower to develop. It is possible that mildly toxic substances could take a longer time to accumulate in the brain and the significance may be missed.\textsuperscript{70}
**Trauma**

Retrospective case control studies have shown a relationship between head trauma and Parkinson's disease. However, prospective studies do not find this relationship. The association between head trauma and Parkinson's disease is thought to be due to recall bias. In 1991, Goetz found that Parkinson's patients who reported head trauma had no change in the long-term course of their disease. Trauma should therefore not be considered to increase the risk of Parkinson's unless prospectively collected data show an association.

**Protective Factors**

**Diet**

It has been proposed that antioxidant vitamins protect against the development of Parkinson's disease. The consumption of foods rich in tocopherol in two case-control studies demonstrated decreased risk of developing Parkinson's. The use of vitamins, vitamin E and cod liver oil have also been associated with a decreased risk for Parkinson's disease. While these studies are few, they do suggest that eating foods rich in tocopherol may have a protective effect against Parkinson's disease. These studies also open another research avenue between environmental toxins and the protective effects of diet.

**Cigarette Smoking**

Some studies have demonstrated an inverse relationship between smoking and Parkinson's disease. In the 1960s, a study of U.S. military veterans demonstrated an
inverse relationship between smoking and Parkinson’s disease. Additional studies have confirmed this finding in the United States and Europe. There are studies that have found no relationship between smoking and Parkinson’s disease or raise questions as to the protective effect of cigarette smoking. There is a potential for multiple confounding factors related to smoking and Parkinson’s disease, including the possibility that patients with Parkinson’s disease who smoke die before signs and symptoms of Parkinson’s disease manifest.

Treatments for Parkinson’s Disease

The three categories of treatment modalities for Parkinson’s disease are medications, surgery, and ancillary treatments. Originally, surgery was the only option for patients with Parkinson’s disease. However, surgical intervention creates a variety of severe side effects, including stroke, loss of vision, difficulty swallowing, confusion, and speech problems. Since being introduced in the 1960s, levodopa has been the primary pharmacological treatment for Parkinson’s disease. There are five categories of ancillary treatments for Parkinson’s disease: psychological support, social support, occupational therapy, physical therapy, and speech therapy.

Pharmaceutical Treatments

There is no cure for Parkinson’s disease; therefore, the goal of pharmacotherapy is to control the signs and symptoms of the disease. Research is lacking in multiple areas of pharmaceutical treatment for Parkinson’s disease, and there exists a wide variation in the management of the disease. Patients in the early stages of Parkinson’s disease require a different pharmacotherapy regimen than patients who are in the later
stages. In the early stages of Parkinson’s disease, the goal of pharmacotherapy is to alleviate symptoms, keep the patient functioning independently, and use the smallest amount of pharmaceutical therapy necessary. In the later stages of the disease, the goal of treatment is to reduce medication-related issues such as motor fluctuations, psychiatric problems, and dyskinesias.

There are five categories of pharmaceutical treatments for Parkinson’s disease: levodopa, catechol-o-methyltransferase inhibitors, dopamine agonists, anticholinergic drugs, and amantadine. The primary goals of these treatments are protection from destruction by the degeneration process, the rescue of dying neurons, and replacement of damaged pathways. To achieve symptom control, it is necessary to either replace or mimic the replacement of dopamine or adjust the actions of other neurotransmitters located within the basal ganglia.

**Levodopa.** Levodopa was introduced in the 1960s and remains the most effective symptomatic pharmaceutical therapy for Parkinson’s disease. Since dopamine is unable to cross the blood-brain barrier and causes nausea, levodopa is given with a peripheral decarboxylase inhibitor (PDI). The PDI reduces nausea and allows for a limited amount of levodopa to cross the blood-brain barrier intact. Once in the brain, levodopa is then converted to dopamine by decarboxylase located in the dopaminergic neurons in the substantia nigra.

In the early stages of Parkinson’s disease, patients experience an excellent response to levodopa. However, serious side-effects are associated with extended use of levodopa. The most common side-effects are motor fluctuations and dyskinesias. Over time, the patient experiences a decline in the duration of effect for each dose.
The patient’s Parkinson’s disease advances, the medication stops working and begins causing motor fluctuations which are unpredictable and debilitating.43

The primary reason for delaying use of levodopa is to limit the side effects and delay dyskinesias, which are associated with continued use of levodopa.104 Dyskinesia is the inability to control voluntary movements, which results in fragmented movements. Some experts think that if the initiation of levodopa is delayed, the onset of dyskinesias will be postponed.105 Other experts believe that combining levodopa with another anti-Parkinson’s drug will delay the dyskinesias.

**Catechol-O-Methyltransferase Inhibitors.** Catechol-o-methyltransferase inhibitors are required for the catabolism of dopamine.43 When levodopa is taken orally with a peripheral decarboxylase inhibitor (PDI), only 5 to 10% of the levodopa reaches the central nervous system because of the presence of catechol-o-methyl transferase (COMT).106 Entcapone and tolcapone are two drugs that inhibit COMT and allow for the increased bioavailability and extended action of dopamine.43 By maintaining stable levels of levodopa in the brain and plasma, the amount of time between “wearing off” will be extended.107 The amount of levodopa needed will be reduced as this time period is extended.107 There are adverse events related to the use of COMT inhibitors, including nausea, sleep disorders, and diarrhea.107

**Dopamine Agonists.** Dopamine agonists mimic endogenous dopamine by acting directly on dopamine receptors.43 Introduced in 1974, dopamine agonists can be used as either a mono-therapy or in combination with levodopa.43,108 There are two advantages to using dopamine agonists in the treatment of Parkinson’s. First, when dopamine agonists
are used early in the onset of Parkinson’s disease, the need for levodopa may be
delayed.\textsuperscript{108} Second, when used in combination therapy, dopamine agonists allow patients
to take lower doses of levodopa.\textsuperscript{43}

\textbf{Anticholinergic Agents.} Anticholinergic agents were prescribed and used to treat
Parkinson’s disease before levodopa and dopamine agonists became available.\textsuperscript{109,110}
Anticholinergic agents relieve tremor and stiffness associated with Parkinson’s disease.\textsuperscript{43}
The side effects of anticholinergic medications limit their use.\textsuperscript{43} The side effects include
dry mouth, blurred vision, constipation, urinary retention, and mental confusion.\textsuperscript{43}
Because of the adverse events related to anticholinergics, their use is limited to younger
patients with Parkinson’s disease.\textsuperscript{102}

\textbf{Amantadine.} Amantadine can be used in combination with anticholinergic
medications and levodopa.\textsuperscript{43} The mechanism of action of amantadine is unknown;
however, it is effective at reducing or eliminating drug-induced dystonia and akathisia. It
is unknown whether amantadine is effective at reducing levodopa-induced dyskinesias.\textsuperscript{43}
There are numerous side effects associated with amantadine; including hallucinations,
insomnia, confusion, ankle edema, and nightmares.\textsuperscript{111}

\textbf{Surgical Treatments}

The purpose of the surgical treatment of Parkinson’s disease has changed considerably
over the last fifty years.\textsuperscript{43} Pallidotomies and thalamotomies were performed in the 1940s
and 1950s as a way to treat the tremor associated with Parkinson’s.\textsuperscript{112} Once drug therapy
was developed, surgery for Parkinson’s disease virtually halted.\textsuperscript{8} Today, surgery is
generally used only when patients have severe side effects from drug therapy. The decision to perform a surgical procedure is determined by the severity of the patient’s symptoms and the availability of an appropriate surgical procedure.

**Pallidotomy.** Pallidotomy is a surgical procedure that may reduce some of the symptoms of Parkinson’s disease. The procedure reduces the dyskinesias caused by drug therapy. In this procedure, a small lesion is made using heat to correct the nerve cells that are discharging abnormally in the globus pallidus internus. Candidates for this procedure are patients who have responded well to levodopa.

Pallidotomy can be done on one or both sides of the brain. A unilateral pallidotomy improves symptoms on the opposite side. In other words, if the patient has dyskinesias on the left side, the unilateral pallidotomy is done on the right side of the brain. It is recommended that pallidotomies only be done on one side of the brain. Bilateral pallidotomy is controversial, and its safety has not been established.

**Thalamotomy.** Thalamotomy was introduced in the 1950s as a surgical procedure to treat Parkinson’s tremor. This treatment is for patients with benign essential tremor and dystonia. A lesion is made on the ventro-lateral thalamus to relieve the tremor. Thalamotomy may improve rigidity and dyskinesias. Thalamotomy does not improve bradykinesia and gait problems and may even cause those symptoms to worsen.

**Deep Brain Stimulation.** Deep Brain Stimulation (DBS) is used to control tremors in patients with Parkinson’s disease. The target areas for DBS are dependent on where the patient is experiencing a predominant amount of symptoms. A multi-electrode lead is
inserted into a portion of the nucleus in the thalamus. The other end of the lead is attached to a generator that is implanted in the upper chest. The generator can be turned on and off by the patient with the use of a hand-held magnet that is passed over the chest area. DBS has been shown to effectively reduce tremor; however, it does not relieve bradykinesia.

Ancillary Treatments

Many areas of a patient’s life are disrupted because of Parkinson’s disease. The treatment and care for patients with Parkinson’s disease requires both an individualized and multidisciplinary strategy. Patients frequently need psychological and social support, speech therapy, physical therapy, and occupational therapy to maintain their safety and independence. Research is needed to determine the efficacy of ancillary treatments. If ancillary treatments are proven to be effective, physicians could make appropriate referrals to patients with Parkinson’s.

New Treatments

The estimate presented in this cost of illness for Parkinson’s disease covers the years 1999-2003; however, since 2003, four new medications have been approved by the FDA for treatment of Parkinson’s disease. The first medication that was approved since 2003 by the FDA for patients with Parkinson’s disease is Apomorphine Hydrochloride (Apokyn). This medication was approved for use in the treatment of Parkinson’s disease in 2004 and is indicated to treat the approximately 10 percent of patients who are unresponsive to standard Parkinson’s disease medications. This medication is also
used in patients with Parkinson’s disease who have reached stage 4 of Parkinson’s
disease and are experiencing severe on/off motor fluctuations.\textsuperscript{120}

Other medications that have been approved by the FDA since 2003 include Stalevo,
Parcopa, and Azilect. Stalevo and Parcopa were both approved in 2004 and Azilect was
approved in 2006 for the treatment of Parkinson’s disease. Stalevo is a combination of
levodopa, carbidopa and entacapone.\textsuperscript{121} Stalevo allows some patients with Parkinson’s
disease to take only one pill per day instead of two.\textsuperscript{121} Stalevo is also less expensive than
taking the same medications (carbidopa, levodopa, and entacapone) separately.

Parcopa is another medication that was approved by the FDA since 2003 for the
treatment of Parkinson’s disease. Parcopa is a combination of carbidopa and levodopa
that dissolves on the tongue and can be taken without water.\textsuperscript{122} Since being released in
2004, some doctors have reported that Parcopa may be beneficial to patients with
gastrointestinal issues.\textsuperscript{123} Parcopa may be of practical use when patients with
Parkinson’s disease are having swallowing problems or patients that are undergoing
procedures that do not allow anything to be taken by mouth.\textsuperscript{123} Currently there are no
published studies of Parcopa and it is more expensive than the existing generic and brand
name combinations of carbidopa and levodopa.

Azilect is a mono-therapy that was approved in May 2006 by the FDA for the
treatment of Parkinson’s disease.\textsuperscript{124} Because this medication was recently approved by
FDA, there are no published studies on the cost-effectiveness of Azilect. However,
Azilect has been shown to significantly improve Unified Parkinson’s Disease Rating
Scale (UPDRS) total score in clinical trials.\textsuperscript{125} In summary, treatments for Parkinson’s
disease include pharmaceutical, surgical, and ancillary treatments. Figure 2-1 provides a
visual explanation of the various ways in which Parkinson’s disease is treated.
Figure 2-1. The Management of Parkinson’s Disease.

**COMT** = catechol-**O**-methyltransferase; **CR** = controlled release; **MAO-B** = monoamine oxidase B; **tid** = 3 times daily; **↑** = increase.

Used with permission from Olanow C, Koller W. An algorithm (decision tree) for the management of Parkinson’s disease: Treatment guidelines. Neurology 1998; 50(3 (Supplement 3)):S1.
Cost of Illness Overview

History of Cost of Illness

Cost of illness studies first appeared in the literature in 1913 and were among the first economic studies. In the 1950s and 1960s, cost of illness was developed further by Mushkin, Fein, and Rice. In 1959, Mushkin outlined a classification of costs in an attempt to clarify the cost concepts of the time. Mushkin wanted to determine what the impact of an illness was on economic resources. Specifically, he wanted to classify costs based on their effects on the use, distribution, and quantity of economic resources to determine the true economic impact of disease. In 1966, Dorothy Rice developed a method for estimating cost of illness using existing data sets. This method would later become the de facto standard for cost of illness studies. Since 1966, Rice has updated and refined the cost of illness methodology.

In the 1970s and 1980s, cost of illness studies were initially used in health economics to win support for more resources being devoted to health care. By calculating the cost of illness, health economists could provide an actual dollar amount associated with letting a disease run its course. In the early 1990s, cost of illness studies started being used by pharmaceutical companies to highlight specific diseases. For pharmaceutical companies, the cost of illness is used to justify that more resources should be dedicated to a given disease if that particular disease has an enormous economic burden. Currently, health economists, pharmaceutical companies, clinicians, and policy makers use the cost of illness approach to set research agendas and allocate resources.
Description of Cost of Illness

The cost of illness methodology places economic costs into two categories: direct costs and indirect costs. Direct costs of an illness include two separate categories, direct medical and direct non-medical. Examples of direct medical costs are expenditures for hospitalizations, nursing home care, home health services, medications, physician services, etc. Direct non-medical costs involve costs associated with travel to and from the doctor, family time that is spent directly caring for the illness, and community time spent caring for the illness.

Retrospective Database: Medical Expenditures Panel Survey (MEPS)

The MEPS survey is a longitudinal study utilizing an overlapping panel design to collect healthcare expenditure and utilization data at both the person and household levels. The four components of the MEPS survey are the household component (HC), insurance component (IC), nursing home component (NHC), and medical provider component (MPC).

The HC portion of the survey provides estimates of national healthcare use and expenditures. The HC portion also provides estimates on insurance coverage and payment sources for the United States population. The IC portion of MEPS has two components: the household sample and the list sample. The household sample contains information on health insurance coverage carried by and offered to respondents. The list sample portion of the survey allows for national-, regional-, and state-level estimates to be made on the amount, type, and costs of health insurance available in the workplace.
The NHC portion of the MEPS survey gathers information on three components of nursing home care. The first component of the NHC survey gathers information on the facilities and services of a particular nursing home. The second component of the NHC survey gathers information on expenditures and sources of payment. The third component looks at the characteristics of the residents. This section gathers information on the functional and cognitive limitations of patients as well as their age, income, and insurance coverage.

The MPC portion of the survey serves as a supplement to the HC portion of the MEPS. The MPC provides information on hospitals, physicians, and home healthcare providers. This component also gathers information to estimate the expenses of people enrolled in either a health maintenance organization or another type of managed care plan.

Cost of Illness Studies Using MEPS

A review of the literature found a number of studies that measured economic burden or cost of illness using the MEPS database. The studies focused on obesity, cancer, back pain, asthma, childhood disabilities, arthritis, musculoskeletal disorders and chronic conditions. Eight of the 17 studies found measured both direct and indirect costs, with none of the studies estimating intangible costs. Two of the 17 studies used MEPS data in combination with the California Patient Discharge dataset.

Max and colleagues provided a prevalence-based estimate of the cost of prostate cancer in California. This 1998 study estimated direct and indirect healthcare expenditures for individuals with prostate cancer in California to be $360 million. Hospitalization costs for this study were derived from the California Hospital Discharge
dataset (CHDS), and other direct costs were derived from MEPS.\textsuperscript{34} Indirect costs were calculated by multiplying the number of deaths due to prostate cancer and the expected value of future earnings.\textsuperscript{34} This study concluded that due to the high costs of prostate cancer it is critical to identify cost-effective early prostate cancer detection methods.\textsuperscript{34}

Max and colleagues also provided a prevalence-based estimate of the cost of gynecologic cancers in California.\textsuperscript{33} This study estimated direct and indirect healthcare expenditures in California for cervical, ovarian, and uterine cancers to be $624 million in 1998.\textsuperscript{33} Indirect costs were estimated to be twice the direct medical care costs. Hospitalization costs accounted for more than half of the total direct costs for cervical, ovarian, and uterine cancers.\textsuperscript{33} This study concluded that total costs of ovarian cancer are highest among gynecologic cancers in California.\textsuperscript{33}

Liu et al. estimated the direct costs of back pain in the United States using MEPS as the only data source.\textsuperscript{134} This national estimate compared expenses among people with back pain and people without back pain.\textsuperscript{134} This study was done because despite the high prevalence of back pain, there were no recent studies using a nationally representative database.\textsuperscript{134} This study found that total incremental expenditures due to back pain were approximately $26.3 billion. This study concluded that expenditures for back pain have a wide variation among individuals with different demographic and socioeconomic characteristics.

Three studies examined the costs of health care for children with special needs, disabilities, or behavioral disorders.\textsuperscript{138-140} Newacheck and colleagues used the 2000 MEPS dataset to estimate the healthcare utilization and direct costs for children with special healthcare needs.\textsuperscript{138} Children with special healthcare needs were found to have healthcare costs three times higher per year ($2,099 compared to $628) than children
without special healthcare needs. Using the MEPS data, the authors were able to determine that children with special healthcare needs had about four times the number of hospitalizations of other children. The study also found that children with special healthcare needs spent an average of 7 more days per year in the hospital. This study concluded that families have much higher out-of-pocket expenditures when there is a child in the home with special healthcare needs. This study did not specify which ICD-9-CM codes were used to define a child as having special needs.

Prior to the study on children with special healthcare needs, Newacheck and colleagues used the MEPS databases to estimate health services use and healthcare expenditures for children with disabilities. This study did not specify the ICD-9-CM codes that were used to define disability. The study reported only the direct costs for children with disabilities compared to children without disabilities. An estimated 5 million children (7.3%) in the United States reported a disability between 1999 and 2000. The authors defined disability as “the presence of a limitation in age-appropriate social role activities, such as school or play, or receipt of specialized services through early intervention or special education programs.” Children with disabilities had an annual average of $2,669 in healthcare expenditures compared to $676 for children without disabilities. After controlling for insurance status, this study concluded that lower-income families encountered more out of pocket expenses than higher-income families.

The third study on children with special needs focused on behavioral disorders. Guevara and colleagues estimated the annual direct costs of various behavioral disorders of $1,492 per child compared to $834 for children without behavioral disorders. This study also compared children with behavioral disorders to children with physical
conditions, and found that the overall healthcare costs were similar in these two groups ($1,492 compared to $1,245). Children who were classified as having an emotional condition had twice the healthcare costs of children with disruptive disorders. MEPS has been used in two studies to assess the direct medical costs of adults who are obese. Wang used the 1996 MEPS data to estimate the direct medical costs of cardiovascular disease (CVD) associated with excess body weight (EBW). The study included subjects that were adults age 25 or older, excluding pregnant women. Body mass index (BMI) was used as the marker for assessing obesity. In 2001 dollars, EBW led to $22.17 billion in direct medical costs. The authors concluded that there is economic impact due to EBW associated with CVD and that there is a need to prevent EBW among adults in the U.S.

Arterburn and colleagues used MEPS to compare the healthcare expenditures of people who are morbidly obese with the healthcare expenditures of people of normal weight. Body mass index (BMI) was used to classify people into 1 of 6 weight categories. Adults who are morbidly obese had healthcare expenditures 81% higher than adults of normal weight. This study found that total healthcare expenditures due to excess body weight was $56 billion in the year 2000 and that morbidly obese adults were responsible for $11 billion of the total. This study concluded that while morbidly obese adults represent less than 3% of the U.S. population, they are responsible for more than 20% of the healthcare expenditures due to excess body weight. The authors propose that future research is needed to identify interventions that will reduce the incidence and prevalence of morbid obesity.

One study and one follow-up report were reviewed that used MEPS data to determine the direct and indirect costs of arthritis and other rheumatic conditions. Yelin et al.
used MEPS to estimate the direct and indirect costs of arthritis and other rheumatic conditions (AORC) for the United States in 1997. The study used ICD-9-CM codes and divided persons with an AORC into the following categories: 1) persons with AORC and no other chronic condition, 2) persons with AORC and non-AORC chronic conditions, 3) persons with AORC and 1 non-AORC chronic condition, and 4) persons with AORC and 2 or more chronic conditions. The total healthcare expenditures specifically attributable to AORC were $51.1 billion. The indirect cost component measured lost wages and found a total of $35.1 billion in lost wages specifically attributable to AORC. The authors concluded that persons with AORC had a total of $269.3 billion in direct and indirect costs for 1997 and that approximately one-third of these costs ($86.2 billion) were due to their AORC.

Cisternas and colleagues reported on costs by state and found that total costs attributable to AORC ranged by state from $163 million (Wyoming) to $11.3 billion (California). A total of 38.4 million people in the United States (14.2%) have an AORC. The report concluded that as the population in the United States continues to age and more interventions become available, the treatment costs and overall costs of AORC will rise. To reduce the costs of AORC, the authors suggest expanding AORC self-management programs, maintaining healthy weight, and increasing physical activity.

Three MEPS studies focused on conditions of the respiratory system, with one specifically focusing on asthma, one on rhinitis, and one on respiratory conditions in general. Yelin and colleagues used MEPS to determine the direct costs associated with respiratory conditions. The specific respiratory conditions were selected by ICD-9-CM codes and included asthma, chronic bronchitis, emphysema, bronchiectasis,
chronic obstructive disease, coal workers' pneumoconiosis, and asbestosis. The study used data from the 1996 MEPS and found that on average persons with respiratory conditions spent $3,753 per year and that the national total for respiratory conditions in the United States was $45.3 billion. Hospital stays represented forty-five percent of costs associated with respiratory conditions, making it the largest component of direct medical costs. This study also reported that individuals with the highest 5% of expenditures accounted for 45% of the total expenditures for these conditions. The authors concluded that interventions that reduce the use of costly asthma action plans and improve self-management of asthma could greatly reduce the high direct costs of respiratory conditions.

Law and colleagues estimated the direct costs of allergic rhinitis using 1996 MEPS data. This study estimated the direct costs of allergic rhinitis to be $3.4 billion annually, with the majority attributable to outpatient visits and prescription medications. This study found that 58% of patients with allergic rhinitis received at least one prescription for its treatment. However, the direct costs of allergic rhinitis increased dramatically since the introduction of second-generation antihistamines and intranasal corticosteroids. Finally, this study found that individuals without insurance coverage had higher out-of-pocket expenditures for prescription medications than individuals with insurance coverage.

Using 1996 MEPS data and the National Vital Statistics System, Wang et al. measured the direct and indirect costs of asthma from a societal perspective. The total economic impact of childhood asthma was $1.9 billion annually in 1996. This study compared expenses for children with asthma to children without asthma and found that parents' loss of productivity from asthma-related school absence days was $719 million. To
determine the value of lost wages, the authors used estimates from a previous study.\textsuperscript{143} Mortality costs were estimated using the National Vital Statistics System.\textsuperscript{136} A total of 211 school-aged children died of asthma, resulting in a loss of $264.7 million in lifetime earnings.\textsuperscript{136} By using two data sources, Wang et al. were able to provide a comprehensive estimate of cost of illness for childhood asthma.\textsuperscript{136}

Yelin estimated the costs associated with musculoskeletal conditions in two studies using MEPS data from 1996 and 1997.\textsuperscript{144,145} Both studies used ICD-9-CM codes for musculoskeletal conditions and compared healthcare expenditures for people with and without musculoskeletal conditions.\textsuperscript{144} In the 1996 study, Yelin used MEPS to estimate all the direct medical expenditures for persons with musculoskeletal conditions and to determine whether the existence of health insurance or managed care had an impact on those medical expenditures.\textsuperscript{144} Yelin estimated an overall national total for musculoskeletal conditions of $193 billion, with the largest component being hospital admissions (37%).\textsuperscript{144} Among those with health insurance, a total of $3,249 in healthcare expenditures per person was reported compared to $723 in persons without health insurance.\textsuperscript{144} This study concluded that lack of insurance did have a significant effect ($P=0.0001$) among persons with a musculoskeletal condition.\textsuperscript{144}

In 1997, Yelin again used MEPS to estimate the direct and indirect costs associated with musculoskeletal conditions and for the subset of arthritis.\textsuperscript{145} The national total for persons with musculoskeletal conditions was $239.6 billion; the largest components of medical care expenditures were hospital-related costs (38%).\textsuperscript{145} Among persons with musculoskeletal conditions, the average per capita expenditures were $4,251 compare to $2,312 for persons who reported having no musculoskeletal conditions.\textsuperscript{145} This study estimated the overall national total for arthritis conditions to be $186.9 billion, with the
largest component being hospital-related costs (39%).\textsuperscript{145} Among persons with arthritis, the average per capita expenditures were $4,865 and among persons without arthritis, the average expenditures were $2,397.\textsuperscript{145}

The indirect costs for musculoskeletal conditions were estimated in two stages: First, the raw earnings gap due to lower employment rates of persons with a musculoskeletal condition was compared to those without a musculoskeletal condition, and second, earnings losses for persons with musculoskeletal conditions who were employed were estimated.\textsuperscript{145} The raw earnings gap due to lower employment was $98.2 billion in 1997 and the estimated loss of earnings for those who were employed was $5.5 billion. The net effect of the loss due to lower employment rate ($98.2 billion) and loss among those who were employed ($5.5 billion) was $103.7 billion. The incremental aggregate net earnings gap attributable to musculoskeletal conditions was $90.6 billion after controlling for demographic characteristics, occupation, and industry.\textsuperscript{145}

The indirect costs for arthritis were also estimated using the same two-stage process for musculoskeletal conditions. The raw earning gap due to lower employment rates of persons with arthritis compared to those without arthritis was $73.2 billion in 1997, and the estimated loss of earnings for those who were employed was $9.2 billion. Yelin reported that the net effect of the lower employment rate and loss of earnings to be $82.4 billion. Once demographic characteristics, occupation, and industry were controlled for, the incremental aggregate net earnings gap attributable to arthritis was $65.2 billion.\textsuperscript{145}

Druss used 1996 MEPS in two studies to compare direct and indirect costs between various conditions.\textsuperscript{21,146} In the first study, Druss used MEPS data to examine the patterns of economic burden among five chronic conditions: mood disorders, diabetes, heart diseases, asthma, and hypertension.\textsuperscript{146} Druss found that hypertension had the highest
total for direct health costs at $110.3 billion. Of the five conditions, heart disease had the highest treatment cost total at $21.5 billion. Two conditions (mood disorders and hypertension) had the highest total for indirect cost at an estimated work-loss cost of $11.5 billion. Heart disease had the highest per capita costs for services directly resulting from the condition. This study found that these high costs were associated with elevated rates of hospitalization for heart disease compared to the other conditions.

Druss also used data from the 1996 MEPS to identify the 15 most expensive conditions nationally. On a population level, the most expensive conditions were ischemic heart disease ($21.5 billion annually) and motor vehicle accidents ($21.2 billion annually). Per capita, the two most expensive conditions were respiratory malignancies ($5 billion annually) and ischemic heart disease. After ranking each of the conditions by cost of treatment, Druss then ranked each condition by the amount the person was disabled because of the condition. Mood disorders, chronic obstructive pulmonary disease, and arthropathies were the three conditions with the lowest treatment costs relative to their disability level. Genitourinary cancers, motor vehicle accidents, and cardiac dysrhythmias were the three conditions with the highest expenditures relative to their disability level. Druss concluded that the most costly conditions are not necessarily the most disabling conditions.

Table 2-1 provides an overview of each of the cost studies discussed that used MEPS. This table begins with the most recently published study using MEPS.
Table 2-1. Overview of Cost of Illness Studies Using MEPS.

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Disease Topic</th>
<th>Number in Study</th>
<th>Costs Measured</th>
<th>Objective</th>
<th>Conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wang</td>
<td>2005</td>
<td>Asthma</td>
<td><em>n</em> = 248</td>
<td>Direct and indirect</td>
<td>Estimate the direct and indirect costs of childhood asthma and compare to children without asthma.</td>
<td>The cost of asthma on children, families, and society is high ($1.9 billion annually).</td>
</tr>
<tr>
<td>Arterburn</td>
<td>2005</td>
<td>Morbid obesity</td>
<td><em>n</em> = 9,812</td>
<td>Direct costs only</td>
<td>Examine the impact of morbid obesity on healthcare expenditures compared to persons who are not morbidly obese.</td>
<td>The economic burden of morbid obesity in U.S. adults is substantial ($11 billion annually).</td>
</tr>
<tr>
<td>Newacheck</td>
<td>2005</td>
<td>Children with special needs</td>
<td><em>n</em> = 949</td>
<td>Direct costs only</td>
<td>Provide total healthcare expenses and out-of-pocket expenses for families with special needs children.</td>
<td>Families with special needs children have higher annual expenditures ($2,099) than families who do not have a special needs child ($628).</td>
</tr>
<tr>
<td>Yelin</td>
<td>2004</td>
<td>Arthritis and other rheumatic conditions (AORC)</td>
<td><em>n</em> = 4,776</td>
<td>Direct and indirect</td>
<td>Estimate the total medical expenditures and earning lost associated with AORC.</td>
<td>Persons with AORC earned less than those without AORC. AORC explained $1,500 of the lost wages.</td>
</tr>
</tbody>
</table>
### Table 2-1. (continued).

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Disease Topic</th>
<th>Number in Study</th>
<th>Costs Measured</th>
<th>Objective</th>
<th>Conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Luo147</td>
<td>2004</td>
<td>Back pain</td>
<td>n = 25.9 million (weighted)</td>
<td>Direct costs only</td>
<td>Estimate the total healthcare expenditures of individuals with back pain.</td>
<td>There is a wide variation of costs among different demographic and socioeconomic groups. Estimated overall cost of back pain is $26.3 billion annually.</td>
</tr>
<tr>
<td>Newacheck139</td>
<td>2004</td>
<td>Children with disabilities</td>
<td>n = 963 (unweighted)</td>
<td>Direct costs only</td>
<td>Examine healthcare expenditure patterns for children with disabilities.</td>
<td>There is an uneven financial burden on families with children who have disabilities. Low income families bore a lot of out of pocket expenses.</td>
</tr>
<tr>
<td>Guevara140</td>
<td>2003</td>
<td>Behavioral disorders in children</td>
<td>n = 3,955 (unweighted)</td>
<td>Direct costs only</td>
<td>Identify if children with behavioral disorders have similar healthcare expenditures when compared to children without behavioral disorders.</td>
<td>Children with emotional disorders incurred higher costs than children with disruptive disorders. Children with physical conditions had similar expenses as those children with behavioral disorders.</td>
</tr>
<tr>
<td>Author</td>
<td>Year</td>
<td>Disease Topic</td>
<td>Number in Study</td>
<td>Costs Measured</td>
<td>Objective</td>
<td>Conclusions</td>
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<tr>
<td>Law^{137}</td>
<td>2003</td>
<td>Allergic rhinitis</td>
<td>20.9 million weighted</td>
<td>Direct costs only</td>
<td>Update estimate of the direct costs of allergic rhinitis in the U.S.</td>
<td>Direct costs have increased since the introduction of second-generation antihistamines and corticosteroids.</td>
</tr>
<tr>
<td>Max^{33}</td>
<td>2003</td>
<td>Gynecologic cancers</td>
<td>( n = 8,241 ) (unweighted)</td>
<td>Direct and indirect costs</td>
<td>Estimate the direct and indirect costs of gynecologic cancers in California.</td>
<td>A cost-effective method for screening is needed. Early detection and management could reduce morbidity and mortality costs.</td>
</tr>
<tr>
<td>CDC^{148}</td>
<td>2003</td>
<td>Arthritis and other rheumatic Conditions, (AORC)</td>
<td>Direct and indirect costs</td>
<td>Report a summary of cost findings for AORC in the 1997 MEPS study of all states.</td>
<td>Total costs were $116.3 billion in the U.S. Treatments will grow more costly and therefore state and local health officials should implement programs to reduce the costs of AORC.</td>
<td></td>
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</tbody>
</table>
Table 2-1. (continued).

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Disease Topic</th>
<th>Number in Study Unweighted and Weighted</th>
<th>Costs Measured</th>
<th>Objective</th>
<th>Conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Max34</td>
<td>2002</td>
<td>Prostate cancer</td>
<td>$n = 9,043$ (unweighted)</td>
<td>Direct and indirect costs</td>
<td>Study the annual costs of prostate cancer in California.</td>
<td>Cost-effective screening is critical in the efforts to reduce the high costs of prostate cancer.</td>
</tr>
<tr>
<td>Yelin135</td>
<td>2002</td>
<td>Respiratory conditions</td>
<td>$n = 1,027$ (unweighted)</td>
<td>Direct costs only</td>
<td>Estimate the medical expenditures of persons with respiratory conditions.</td>
<td>Total medical expenditures were estimated to be $45.3 billion in 1996.</td>
</tr>
<tr>
<td>Druss21</td>
<td>2002</td>
<td>Most expensive medical conditions in the U.S.</td>
<td>$n =$ not reported</td>
<td>Direct and indirect costs</td>
<td>Identify the most expensive medical conditions in the U.S.</td>
<td>The most expensive conditions in the U.S. have very little in common except for their high costs.</td>
</tr>
<tr>
<td>Wang132</td>
<td>2002</td>
<td>Cardiovascular disease (CVD) due to excess body weight (EBW)</td>
<td>$n = 12.5$ million (weighted)</td>
<td>Direct costs only</td>
<td>Estimate the direct costs of CVD due to EBW.</td>
<td>EBW needs to be prevented in order to lower economic burden.</td>
</tr>
<tr>
<td>Author</td>
<td>Year</td>
<td>Disease Topic</td>
<td>Number in Study</td>
<td>Costs Measured</td>
<td>Objective</td>
<td>Conclusions</td>
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</tr>
<tr>
<td>Yelin</td>
<td>2001</td>
<td>Musculoskeletal conditions</td>
<td>( n = 4,161 )</td>
<td>Direct costs only</td>
<td>Estimate the cost of medical care for persons with musculoskeletal conditions.</td>
<td>Persons with musculoskeletal conditions had high total medical expenditures due to their condition.</td>
</tr>
<tr>
<td>Druss</td>
<td>2001</td>
<td>Five most chronic conditions in the U.S.</td>
<td>( n = 5,176 )</td>
<td>Direct and indirect costs</td>
<td>Examine the patterns of the costs of the five most chronic conditions in the U.S.</td>
<td>Each condition represented a substantial economic burden. The characteristics driving these costs are unique to each condition.</td>
</tr>
<tr>
<td>Yelin</td>
<td>1997</td>
<td>Musculoskeletal conditions</td>
<td>( n = 6,875 ) (unweighted)</td>
<td>Direct and indirect costs</td>
<td>Summarize the direct and indirect costs of persons with chronic musculoskeletal conditions.</td>
<td>In 1997, persons with musculoskeletal conditions experienced $239.6 billion in medical expenditures.</td>
</tr>
</tbody>
</table>
Pooling Consecutive Years of MEPS Data

To enable researchers to generate reliable estimates and to facilitate the analysis of low prevalence disease states, the method of pooling multiple years of the MEPS data is used. Pooling data is done by dividing the annual person weight (PERWT) by the number of years being analyzed. The PERWT is how many people a person in the MEPS survey represents for a particular year. For example, one year a person may represent 1,000 people in the United States. The following year that same person represents 2,000 people in the United States. So if a researcher were analyzing two years of the MEPS data, the PERWT for each person in the analysis file would be divided by two. For the person in the example, their pooled PERWT would be: 1,000 (year 1 PERWT) + 2,000(year 2 PERWT) = 3,000 / 2 (number of years being pooled). By using pooled years of data, standard errors of the estimate(s) are reduced, the types of statistical analyses are extended, and any variations for expenditure estimates are reduced. Two studies were reviewed that analyzed the MEPS data using the pooling methodology. The first study was conducted to show the improvement in the precision of estimates that can be obtained when the MEPS data are pooled. This study pooled data from four years of the MEPS. It demonstrated how more specific statistical analyses could be done on a subgroup of children. Specifically, the study wanted to provide detailed statistics on healthcare expenditures for children who were Asian/Pacific Islander and under the age of six years old. The single year files for the MEPS contained fewer than 100 children who met these criteria. By using the pooling method, the researchers were able to provide an accurate estimate of healthcare expenditures for this small subgroup. The second study pooled four years of the MEPS data to assess the relationship of access to health care and the number of missed workdays for patients with migraine
headaches. The study population was between the ages of 18 and 65 years old, and had complete data in the MEPS on the number of missed worked days. A total of 1,628 patients in the four years of the MEPS data used in this study reported having migraine headaches and of those, 703 met the criteria for inclusion. The study reported a statistically significant relationship \( (P=.025) \) between missed work days and access to care. This study concluded that high access to care is positively associated with the probability to both miss work and to have a higher number of missed workdays.

**Pharmacoeconomic Studies and Parkinson’s Disease**

While a national estimate of Parkinson’s disease in the United States does not exist, seven studies have been conducted on the economical impact of Parkinson’s disease. Four of the seven studies used patient interviews to examine costs. One of the seven studies used national databases as the data source. Another study used a managed care database of a large healthcare plan in the Midwest region of the United States. The other study used medical records of patients with Parkinson’s disease and compared utilization of services with patients who did not have Parkinson’s disease.

Three of the four studies that used patient interviews measured the health status and financial costs. The fourth study compared the costs of patients with Parkinson’s disease who were on levodopa therapy with patients who were not on levodopa.

In 2002, Parashos used medical records of 89 patients with Parkinson’s disease and 89 patients without Parkinson’s disease to determine differences among patients’ utilization of medical services. Medical records from the Rochester Epidemiology Project in Minnesota were reviewed from 1979 until 1988. Patients with Parkinson’s disease
were found to have a statistically significantly higher median number of doctor visits per year (7.9 compared to 5.9 in the non-Parkinson’s group; \( P=0.001 \)).\textsuperscript{153} Overall, patients with Parkinson’s disease used more outpatient and nursing homes services than patients without Parkinson’s disease.\textsuperscript{153} Parashos also reported that education and clinical characteristics influenced utilization of medical services and outcomes.\textsuperscript{153}

To establish a baseline cost of Parkinson’s disease in a healthcare plan, Littlefield, et al. conducted a retrospective study of healthcare claims data.\textsuperscript{51} Covering approximately 1.8 million people in the Midwest, the healthcare plan database contained all claims for medications, home health care, nursing home care, office-based visits, inpatient hospital visits, and outpatient hospital visits.\textsuperscript{51} The study population consisted of 450 patients with a diagnosis of Parkinson’s disease and enrollment in both medical and pharmacy plans continuously from January 1, 1995 through June 30, 1998.\textsuperscript{51} The total healthcare costs for the 3-year period were $6,575,450, with 60% of those costs were medication costs ($3,945,270).\textsuperscript{51} The authors concluded that there is a need for healthcare plans to establish guidelines for the cost-effective use of pharmaceuticals and that case management strategies need to be developed to deliver optimal care to Parkinson’s patients.\textsuperscript{51}

Two studies measured the health and economic burdens of Parkinson’s disease.\textsuperscript{23,151} The first study used a cross-sectional survey of patients from the Neurology Clinic at the University of Iowa Hospitals and Clinic (UIHC) and Iowa Methodist Hospital (IMH).\textsuperscript{151} The sample included both men and women with a diagnosis of idiopathic Parkinson’s disease.\textsuperscript{151} The patients were also required to have stable Parkinson’s disease and be able to be observed during a period without symptoms.\textsuperscript{151} Exclusion criteria were secondary Parkinsonism resulting from drugs, metabolic disorders, or exposure to toxins and
surgery in the last 90 days.\textsuperscript{151} Multiple survey instruments were used in this study to assess both health and economic impact of Parkinson’s.\textsuperscript{151} To assess the health impact the following instruments were used: the UPDRS, the Medical Outcome Study Short Form (SF-36), the Visual Analog Scale (VAS), the Mini-Mental State Exam (MMSE), and Center for Epidemiology Studies Depression Scale (CESD); general physical function was assessed by 12 questions about activities of daily living and instrumental activities of daily living.\textsuperscript{151} The direct economic burden of Parkinson’s disease was measured by the use of primary, ancillary, and community services.\textsuperscript{151} In addition, patients were asked if they had to make modifications to a home or automobile because of their condition.\textsuperscript{151} To calculate the indirect economic burden of Parkinson’s disease, patients were asked about the number of days that illness or injury kept them in bed or restricted their normal activities.\textsuperscript{151} In addition, patients were asked about their inability to do certain kinds or amounts of work because of health problems.\textsuperscript{151} Finally, patients were asked if they retired early or became unemployed due to Parkinson’s disease.\textsuperscript{151}

The results of the study found that as Parkinson’s disease advances, so does the use of health-related resources.\textsuperscript{151} The use of physician services was not related to disease stage; however, the Parkinson’s disease stage was related to hospitalization, emergency room use, and the need for special equipment.\textsuperscript{151} Ancillary community services and home or car modifications were also associated with Parkinson’s disease stage.\textsuperscript{151} When compared with the general population, patients with Parkinson’s disease had lower scores in most health related quality of life (HRQL) dimensions on the SF-36. Patients with Parkinson’s disease in this study reported that as their disease progressed, there was a substantial increase in physical limitations that led to decreased work productivity.\textsuperscript{151} This study did
not report the actual dollar amounts for the direct and indirect costs of Parkinson’s disease.\textsuperscript{151}

The second study measured the health and economic burden of Parkinson’s disease using in-home interviews in Central North Carolina.\textsuperscript{23} This cross-sectional study used 109 patients with Parkinson’s disease to examine the burden of Parkinson’s disease on the individual, the family, and society.\textsuperscript{23} The Duke survey was the primary survey instrument used in this study.\textsuperscript{23} Information on health status (activities of daily living and instrumental activities of daily living), informal care, medical care, and alterations to home and automobiles was gathered.\textsuperscript{23}

The study found that direct health costs were not the largest component of family burden.\textsuperscript{23} The largest component of family burden was the burden of providing informal care-giving and loss of earnings.\textsuperscript{23} Informal care cost was calculated for people who received both formal and informal care, and for people who only received informal care.\textsuperscript{23} If the person received both formal and informal care, the cost for the informal care was calculated using the price the survey respondent reported paying for formal care.\textsuperscript{23} An average hourly wage of $12.95 from the Panel Study of Income Dynamics (PSID) was used to calculate care-giving costs for those who only received informal care.\textsuperscript{23} The average dollar amount for informal care-giving was $5,386 and the average dollar amount for lost earnings was $12,082.\textsuperscript{23}

The average societal burden per individual with Parkinson’s disease was approximately $6,000 annually.\textsuperscript{23} Compensation for earnings loss was the highest single element and was highest for those less than age 65.\textsuperscript{23} The highest healthcare costs were for physician visits, with an average of $1,324 annually.\textsuperscript{23} The overall average cost for study participants was estimated to be $25,001 annually.\textsuperscript{23}
Regarding the individual burden of Parkinson’s disease, study participants were found to spend an average of 326 hours on housework per year and 23 hours on yard work per year. A previous study of high functioning older individuals provided the average of 739 hours for housework per year and 210 hours for yard per year. The same study found in low functioning older individuals an average of 512 hours for housework per year and 86 hours for yard per year. The large burden of Parkinson’s disease is not related to financial burden, but rather the majority appears to fall into the category of personal burden.

Following the previous study, a 3-year longitudinal evaluation of Parkinson’s disease was conducted by the same authors between 1997-2000. The study data were collected through an in-home interview and utilized surveys regarding health status, disease symptoms, and functional status. In addition, data were collected on direct and indirect costs. Health status was categorized as either good health or poor health. Persons who rated their health as excellent, good, or very good were placed in the “good health” group, and those who rated their health as fair or poor were placed in the “poor health” group.

The functional losses, co-morbid illnesses and disease symptoms were greater among those in the poor health group than those in the good health group. Functional losses included activities of daily living, instrumental activities of daily living, and whether or not the person had to use walking aids. Nearly half (48.5%) of the poor health group reported using a walking aid, compared to 19.4% in the good health group. The most frequently reported co-morbid illness was arthritis (37%), followed by heart disease (28%). Among the poor health group, 23% reported having a stroke, while only 2.7% of the good health group reported having a stroke. Disease symptom variables included
fatigue, pain, psychosocial issues, and cognitive impairment. Patients in the poor health category reported having experienced depression almost twice as frequently (59.4%) as those in the good health category (30.6%).

The direct costs captured by this study included expenditures for nursing homes, hospitals, physicians, other health professionals, prescription drugs, formal care, and other expenditures. In year one of the study, the good health group reported an average of $5,146 in expenses for direct costs. The year three average for the good health group was $6,362 in expenses for direct costs. The poor health group reported an average of $4,949 in expenses for direct costs in year one and an average of $9,591 in year three.

The indirect costs captured included costs for informal care and lost wages. The largest difference between the two groups in costs was found in indirect costs. In year one, the good health group reported an average of $2,664 for informal care expenditures, compared to $6,340 among those in poor health group. The poor health group reported an average of $15,508 in lost wages, compared to $5,261 for the good health group.

The impact of Parkinson’s disease on health status, health expenditures, and productivity were estimated by Rubenstein, et al. using the 1987 National Medical Expenditure Survey (NMES). The author had established, in a previous study of the burdens of Parkinson’s disease, a significant association between the stage of Parkinson’s disease and the use of most health resources that persisted even after controlling for co-morbid conditions. The purpose of this 1987 study was to determine if NMES was useful in providing estimates on health status, health expenditures, and productivity. The estimates for Parkinson’s disease patients were then compared with patients with other chronic medical conditions but not Parkinson’s disease. A total of 43 patients in NMES were identified as having Parkinson’s disease. Each of these patients were
matched according to race, gender, age group, presence of specific target conditions, and urban-rural status with three patients without Parkinson’s disease (controls).20

The health status portion of this study found that 81.4% of patients with Parkinson’s disease perceived their health as fair or poor, compared with 46% of the controls.20 In the Parkinson’s group, 53.5% of patients could perform all ADL tasks without difficulty or help, compared with 85% of controls.20 Only 46% of the Parkinson’s patients were able to perform all 6 IADL tasks, compared with 79% of controls.20 In the control group, 88% reported no use of aids for ADL tasks, compared with 39.4% of patients with Parkinson’s disease.20 A total of 46.5% of patients with Parkinson’s disease, compared with 17.1% of controls, reported difficulty using cars or buses to get around, making it the most frequently reported IADL task for both cases and controls.20

For the category of healthcare resource use and expenditures, patients with Parkinson’s disease had significantly more home healthcare visits and physician visits than the control group.20 While there was no significant difference in the proportion of Parkinson’s and control patients reporting at least one hospital visit, patients with Parkinson’s disease had a higher average length of stay than the non-Parkinson’s patients (controls).20 Patients with Parkinson’s disease received significantly more prescription medications than controls, 26.5 compared to 16.4 respectively.20 Prescription medication costs for patients with Parkinson’s disease were on average more than $400 higher than patients without Parkinson’s disease.20 The total average expenditures for patients with Parkinson’s disease (10,168) were significantly greater than total average expenditures for the control group ($4,743).20

Patients with Parkinson’s disease were 5 times more likely to report that their health had prevented them from working or carrying out normal activities.20 Significantly more
bed days were reported by patients with Parkinson’s disease (44.2%) compared with controls (31.8%). The authors did not report comparisons for work-loss days because the number of people reporting work-loss days were too small for analysis.

The authors concluded that patients with Parkinson’s disease have serious health and economic burdens as a result of their disease. The authors further concluded that the data from the NMES provided a description of the areas in which these burdens occur. The authors concluded that patients in the NMES sample did not adequately represent patients in the early and the late stages of Parkinson’s disease. Therefore, estimates of expenditures and resource use are probably more applicable to patients in the middle stages of Parkinson’s disease. The reason the authors speculated that this population did not represent patients in the early stages of Parkinson’s disease was because those patients in the earliest stages often do not receive medications that are identifiable as Parkinson’s medications. The authors further speculated that patients in the later stages of Parkinson’s disease would be in nursing homes and therefore not captured by the NMES.

In 1973, Singer measured the social costs of Parkinson’s in 169 patients from 23 specialty clinics. The study found a decrease in the percentage of patients who remained employed compared with the general population. Eighty-one percent of men between the ages of 55-64 in the general population reported participation in the labor force, compared to 51.2% in the Parkinson’s sample. Men over the age of 65 in the general population reported a 25.8% participation in the labor force, while men over the age of 65 with Parkinson’s disease reported only a 7.1% participation in the labor force. A reduction in median income was also found among patients with Parkinson’s disease compared to patients without Parkinson’s disease. The median annual income
for married couples over the age of 65 who reported not having Parkinson’s disease was $4,835, while the median annual income for married couples reporting Parkinson’s disease was $4,632. Patients with Parkinson’s disease were also found to miss more days of work compared to people without the disease.

Finally, Singer reported that persons with Parkinson’s disease reported a reduction in the ability to participate in housework and leisure activities. Specifically, 75% of persons under 65 with Parkinson’s disease reported spending some portion of their day either napping or idle. When compared to the oldest general population group (over 80), only 73% reported spending some portion of their day either napping or idle. This study concluded that the consequences of Parkinson’s disease are not equal across all areas; however, the younger Parkinson’s patients incurred greatest social costs.

Table 2-2 provides an overview of previous Parkinson’s disease cost studies done in the United States.

**Treatment Costs**

**Medication Treatment Costs**

*Cost Utility Analysis.* In 1998, Hoerger et al. conducted a cost utility analysis of pramipexole in two settings. In the first setting the authors compared pramipexole without levodopa therapy in the early stages of Parkinson’s disease. In the second setting, the authors compared pramipexole plus levodopa in advanced Parkinson’s disease. To distinguish early stage from late stage Parkinson’s disease, the patient’s score on the United Parkinson’s Disease Rating Scale (UPDRS) was used. To predict
Table 2-2. Overview of Previous Parkinson’s Disease Cost of Illness Studies Done in the United States.

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>N</th>
<th>Objective</th>
<th>Data Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parashos</td>
<td>2002</td>
<td>89</td>
<td>Investigate outcomes and utilization of medical services of Parkinson’s patients to determine predictors of utilization.</td>
<td>Rochester Epidemiology Project</td>
</tr>
<tr>
<td>Littlefield</td>
<td>2002</td>
<td>912</td>
<td>Establish baseline costs of Parkinson’s disease in a midwestern healthcare plan.</td>
<td>Health plan database</td>
</tr>
<tr>
<td>Schenkmann</td>
<td>2001</td>
<td>70</td>
<td>Use Parkinson’s disease state status, disease symptoms, and functional status to explain financial costs.</td>
<td>Survey of patients in North Carolina</td>
</tr>
<tr>
<td>Chrischilles</td>
<td>1998</td>
<td>193</td>
<td>Provide a description of the patient report HRQOL and economics of Parkinson’s disease stage.</td>
<td>Survey of patients in 2 Iowa neurology hospitals</td>
</tr>
<tr>
<td>Whetten-Goldstien</td>
<td>1997</td>
<td>109</td>
<td>Examine the economic burden of Parkinson’s disease on society, family, and the individual.</td>
<td>Survey of patients in North Carolina</td>
</tr>
<tr>
<td>Rubenstein</td>
<td>1997</td>
<td>43</td>
<td>Match patients with and without Parkinson’s disease to estimate additional resources used by Parkinson’s patients.</td>
<td>National Medical Expenditure Survey</td>
</tr>
<tr>
<td>Singer</td>
<td>1973</td>
<td>169</td>
<td>Compare social costs of patients using levodopa ((n = 149)) to patients not using levodopa ((n = 20)).</td>
<td>23 treatment centers in all regions of the United States, except the South</td>
</tr>
</tbody>
</table>
hospital visits and working status, the authors used probit models. Logarithmic regression was used for costs, and linear regression for utilities.

For both groups, incremental cost utility-ratio (ICUR) was below $35,000 per quality-adjusted life year (QALY). The study concluded that the use of pramipexole alone is cost effective in early-stage Parkinson’s disease. In late stage Parkinson’s disease, the authors concluded that pramipexole in combination with levodopa is also cost effective. In 2001, Shimbo et al. compared the use of the dopamine agonists bromocriptine and pergolide with levodopa mono-therapy among Japanese patients.\textsuperscript{154} The study used a 10-year Markov model that consisted of 6 Markov stages based on the Hoehn-Yahr stages 1-5 and death.\textsuperscript{154} The results of this study concluded that both of the dopamine agonists (bromocriptine and pergolide) are cost effective in Hoehn-Yahr stages 3-5 of Parkinson’s disease when compared to levodopa mono-therapy.\textsuperscript{154} There are limitations to this study; first, the model used did not incorporate drug dosage, and second, it is not generalizable to other countries because of the variation in therapy costs.

A Markov model was developed by Tomaszewski and Holloway to determine the lifetime incremental cost-effectiveness between Deep Brain Stimulation (DBS) in late stage Parkinson’s disease compared with the best medical treatment.\textsuperscript{155} In the model, if DBS was chosen, the patient risked one of four outcomes: 1) death during the operation, 2) permanent complications from the operation, 3) temporary complications from the operation, or 4) no complications.\textsuperscript{155} Baseline utility estimates were obtained from a previous study that reported utilities from a visual analog scale where 0 was equal to death and 100 was equal to best possible health.\textsuperscript{151} In that study, 20\% of patients were in the advanced stages of Parkinson’s disease and reported health-related quality of life between 53.5 and 60.1.\textsuperscript{151} Therefore, the authors assumed the quality of life (QOL) for
patients entering the model to be 0.55 on a 0-to-1 scale.\textsuperscript{155} The results of the study found that DBS cost $45,200 per patient and best medical management cost $41,700 per patient.\textsuperscript{155} The number of quality adjusted life years (QALY’s) for DBS was 7.80 compared to 7.08 for best medical management.\textsuperscript{155} The DBS cost $35,000 more than best medical management and provided an additional .72 QALY’s.\textsuperscript{155} The preliminary conclusion of this study was that DBS is a more effective treatment for patients in the late stages of Parkinson’s disease when compared to best medical management.\textsuperscript{155} The authors suggest that further testing and refinement are necessary to determine if the initial result of increased QALY’s when DBS is used instead of best medical treatment occurs under more rigorous experiments.\textsuperscript{155}

\textbf{Cost-Effectiveness Analysis.} In 2001, Davey et al. developed a decision-analytic model to assess the cost-effectiveness of pergolide compared to bromocriptine in the treatment of Parkinson’s disease. The authors used a Markov model that ran for 2 cycles of 6 months duration to examine cost-effectiveness. The model assessed patient progress through the 6 stages—the same Hoehn-Yahr stages 1-5 and death stage that Shimbo utilized. Over the ten year period, the total healthcare cost per patient in the pergolide treatment arm was $46,323 and $47,351 in the bromocriptine arm. Patients receiving the pergolide treatment also spent longer time in Hoehn-Yahr stages 1, 2, and 3. The authors concluded that because pergolide was cost saving and more efficacious than bromocriptine, it was cost effective.
**Surgical Treatment Costs**

A retrospective study by Charles, et al. found that Deep Brain Stimulation of the subthalamic nucleus (DBS-B-STN) reduces the medication costs for patients with Parkinson's disease. Sixteen patients (10 men and 6 women) with advanced, idiopathic Parkinson's disease who were not responding to optimal medication therapy and who had been implanted with deep brain stimulators were included in the study. Following the surgery, the average daily cost of antiparkinsonian medications (APMED) was $13.25 per patient, compared to an average daily cost prior to the operation of $19.53 per patient. Overall, medication costs decreased for 12 patients, remained the same for two, and increased slightly for two. The authors concluded that the 32% reduction in medication costs two years following surgery warranted further research to confirm long-term (APMED) savings after DBS-B-STN.

Using data from the Nationwide Inpatient Sample, Eskandar, et al. conducted a retrospective cohort study of surgery for Parkinson's disease in the United States between the years 1996 and 2000. The purpose of the study was to investigate surgery practice patterns and short-term outcomes following surgery. A total of 1,761 patients in 71 hospitals underwent surgical treatment during the study period. The study found a change in the surgical procedures being chosen between 1996 and 2000. In 1996, approximately 93% of surgeries were pallidotomies and 7% were thalamotomies. By the year 2000, the percentage of surgical procedures for Parkinson's disease were dramatically different, with 88% DBS, 7% pallidotomies, and 5% thalamotomies. During the overall study period of 1996-2000, 6% percent had thalamotomies, 33% had DBS and 60% had pallidotomies. At the time of this study, there were no randomized controlled trials comparing pallidotomy and DBS. Pallidotomy involves creating a
permanent lesion that may cause permanent complications, while DBS uses high-frequency stimulations to create a reversible lesion effect.157

Short-term outcomes for Parkinson’s surgery were measured by mortality and morbidity immediately following surgery.157 Hospitals were categorized based on the number of Parkinson’s disease surgeries performed annually.157 Hospitals with high volume of Parkinson’s disease surgeries (>54 surgeries annually) had better short-term outcomes for both mortality and morbidity than hospitals with low volume (<17 surgeries annually).157 Of the four deaths that occurred, three were at hospitals with a low volume of Parkinson’s disease surgeries.157 Discharges to short-term or long-term care facilities occurred in 11.4% of operations at low volume hospitals and in 3.4% of high volume hospitals.157

The authors stated that for other neurosurgical procedures, better outcomes are reported for patients treated at high volume facilities.157 The authors concluded that the results of their study reinforce previously reported mortality and morbidity rates for other neurological procedures.157 The authors pointed out that these differences may be due to the presence of more experienced staff (neurologists, physical, and occupational therapists) that have a higher comfort level with discharging patients straight home after Parkinson’s disease surgery.157 Finally, the authors suggested that future studies should focus on comparing long-term functional end points and cost-benefit of Parkinson’s disease surgery.157

In order to obtain an assessment of pallidotomy for Parkinson’s disease, Alkhani et al. conducted a review of published literature in 2001.158 In the 85 articles reviewed, 1,959 patients with Parkinson’s disease had pallidotomies at 40 centers located in 12 countries.158 The average length of time with Parkinson’s disease symptoms in these
patients was 12.3 years, with a standard deviation of 1.9 years, and the average age of patients was 61.4, with a standard deviation of 3.6 years.\textsuperscript{158} The majority of the pallidotomies were unilateral (88.6\%) compared with bilateral (11.4\%).\textsuperscript{158} In 501 of the cases (25.6\%), outcomes were reported using the Unified Parkinson's Disease Rating Scale (UPDRS) at 6 months, in 218 (11.1\%) of the cases at 1 year, and 59 cases (3\%) at 24 months.\textsuperscript{158}

A total of 142 patients were accessible six months after the surgery, and 34.2\% reported an improvement in UPDRS sections 2 and 3 (ADL assessment and motor examination) during their first "off" period.\textsuperscript{158} Ninety-nine patients were accessible 12 months after surgery and 35.7\% reported an improvement in UPDRS sections 2 and 3.\textsuperscript{158} When section 3 (motor examination) of the UPDRS was reported alone, a total of 256 patients were accessible six months after surgery and the improvement was 40.6\%. Of the 161 accessible patients that were accessible 12 months after surgery, 45.3\% reported an improvement in UPDRS section 3.\textsuperscript{158} The authors concluded that pallidotomy is safe and effective for treatment of patients with advanced Parkinson's disease.\textsuperscript{158} Pallidotomy improved motor performance and ADL during "off" periods as well as during drug-induced dyskinesias.\textsuperscript{158} Finally, the authors concluded that there is a lack of long-term results after pallidotomy and that there is a need for prospective studies to compare pallidotomy with best medical treatment and also with other surgical options.\textsuperscript{158}

This chapter provided a review of literature relevant to the cost of illness, retrospective data analyses and Parkinson's disease. Chapter three will provide the detailed methodology that was used to estimate the cost of illness for Parkinson's disease in the United States.
CHAPTER III. METHODOLOGY

Purpose

The purpose of this study was to provide a prevalence-based retrospective national estimate of the cost of illness (direct and indirect costs) of Parkinson’s disease in the United States for the year 2003. The methodology to estimate the cost of illness for Parkinson’s disease in the United States is detailed in this chapter.

Research Design

The research method employed to measure the cost of illness for Parkinson’s disease was a multi-year retrospective database analysis. The estimation of the cost of illness was accomplished by using the data from the Medical Expenditures Panel Survey (MEPS), the Bureau of Labor Statistics (BLS), and the National Vital Statistics Survey (NVSS), which provided the direct and indirect costs for Parkinson’s disease.

Direct costs include both direct medical and direct non-medical costs. Direct medical costs are related to medical care and include costs for hospitalization, rehabilitation, nursing home care, prescription medications and treatment by a medical professional. Direct non-medical costs are those costs, borne by the patient, that do not involve treatment but are required to access the healthcare system, such as transportation, childcare, and household expenses.

Indirect costs are those that are related to a loss in productivity by the individual or family members who may care for the individual. The two components of indirect costs are morbidity and mortality costs. Morbidity costs are those costs associated with a
loss in productivity due to a person’s inability to work in the labor market or at home. Mortality costs are due to premature death and are an estimate of future earnings lost.

**Data Overview**

The data sources for this study were 1) the 1999-2003 Medical Expenditures Panel Survey Household Component (MEPS-HC), 2) the 1996 Medical Expenditures Panel Surveys Nursing Home Component (MEPS-NHC), 3) the 1999-2003 National Vital Statistics System (NVSS), and 4) the 1999-2003 Bureau of Labor Statistics (BLS). The purpose of MEPS is to provide nationally representative estimates of healthcare utilization, expenditures, sources of payments, and insurance coverage for the United States civilian non-institutionalized population. The civilian non-institutionalized population includes anyone who is not on active duty in the United States Armed Forces and who is not institutionalized. Institutionalized persons are those under supervised care in long-term care facilities other than nursing homes.

The Agency for Healthcare Research and Quality (AHRQ), in collaboration with the National Center for Health Statistics (NCHS), began collecting data for the MEPS in 1996. The MEPS survey is a longitudinal study utilizing an overlapping panel design to collect healthcare expenditure and utilization data at the person and household levels. The four components of the MEPS survey include the household component (HC), the insurance component (IC), the nursing home component (NHC), and the medical provider component (MPC). To calculate the direct and indirect costs of Parkinson’s disease, the household component (HC) and the nursing home component (NHC) were used. The most recent set of complete data for the MEPS-HC (2003) was used in this study along with the 2003 NVSS and 2003 BLS to make a 1-year estimate of
the direct and indirect costs of Parkinson's disease. However, it was necessary to use all 5 years (1999-2003) of MEPS-HC data in order to have a large enough sample to conduct statistical analysis. The MEPS-NHC was last collected in 1996; therefore, nursing home costs were calculated using 1996 data and then adjusted to 1999-2003 dollars. The base year for the consumer price index for nursing home costs was 1996. To adjust Nursing Home Costs from 1996 dollars to 2003 dollars, the following formula was used:

\[
(1996 \times 2003 \text{ CPI for NHC}) / 1996 \text{ CPI for NHC} = \$ \text{ amount for the year 2003}
\]

Where: CPI = Consumer Price Index and NHC = Nursing Home Costs

Mortality data are not collected by the MEPS survey; therefore, mortality was estimated using data from the 1999-2003 National Vital Statistics Survey (NVSS) and the 1999-2003 Bureau of Labor Statistics (BLS). The NVSS provides the number of deaths due to Parkinson's disease in the United States according to the demographic characteristics of age, gender, and race. The BLS collects data on labor force participation rates and wages according to the same demographic characteristics (age, gender, and race) as the NVSS.

Survey Design

The MEPS-HC collects data through five in-person interviews conducted over a 2-year calendar period. The data collected during the in-person interviews are then linked with the information collected from the respondent's employer, medical provider, and insurance provider. Figure 3-1 shows a diagram of the panel design. By using this design, longitudinal and point-in-time estimates of healthcare expenditures can be made for individuals and households. To gather data for the calendar year 2003, data from panels 7 and 8 were used. Panel 7, round 1, started in January of 2002 and concluded in
Figure 3-1. MEPS Overlapping Panels: 2003 Annual File. See Appendix.

December 2003 with round 5. Data for Panel 8, rounds 1, 2, and 3 were collected beginning in January 2003 and concluded in December of 2003. The two panels overlap for the entire year of 2003, with Panel 7 participants being in rounds 3, 4, and 5 of the survey and Panel 8 participants being in rounds 1, 2, and 3.

The MEPS survey process includes direct contact by a trained interviewer with the respondent. The MEPS interviewer specifically documents the medical conditions and procedures reported by the respondent. The data are then re-coded by professional coders into specified ICD-9-CM codes. This data collection process is repeated every year using a new sample of households and overlapping panels of survey data.

The core interview content of the MEPS-HC includes patient demographics, health status, utilization of health care, employment, health insurance, and charges and payments. The utilization portion of the MEPS-HC collects event-level data on hospital stays, office-based physician care, home health care, prescribed medications, medical equipment, and medical supplies. The event portion of MEPS-HC collects data on the types of provider (physician, specialists, allied health workers, etc.) seen by the respondent, the amount of time spent with the provider, and the type of care received. The event file also collects data on the condition for which the respondent was seen and the charges and payments made for each event.

Pooling the MEPS-HC

To generate reliable estimates and to facilitate the analysis of low prevalence disease states, the method of pooling multiple years of the MEPS data was used. By using pooled years of data, the standard errors of the estimate(s) are reduced, the types of statistical analyses are extended, and any fluctuations for cost estimates are reduced. The
MEPS-HC file HC-036 contains the variables necessary to put data from multiple years into a shared structure and to form the standard error estimates for pooling MEPS. Two variables, STRA9603 and the PSU9603, were used in place of the assigned Stratum (STRATA) and Population Sampling Unit (PSU) to account for the complex survey design when conducting the analyses of data that are pooled. These variables were matched to each DUPERSID (unique person identification number) used in the MEPS between 1996 and 2003 and are found in the HC-036 file.

MEPS-NHC

The MEPS-NHC was a survey of nursing homes and persons residing in or admitted to nursing homes at any time during calendar year 1996. The MEPS-NHC collects information on demographic characteristics, residence history, health and functional status, use of services, use of prescription medications, and healthcare expenditures of nursing home residents. The NHC sample was selected by using a two-stage probability design. The first stage was used to select facilities; the second stage was used to sample facility residents. The sample frame for the facilities portion is derived from the National Health Provider Inventory. The sample of facility residents was selected from persons both in the nursing home residence on January 1, 1996, and those admitted between January 1 and December 31, 1996. The survey captures approximately 800 nursing home facilities and 3,100 patients that were residents as of January 1, 1996, and an additional 2,200 eligible patients admitted after January 1, 1996.

The MEPS-NHC is only accessible through the Center for Financing, Access, and Cost Trends (CFACT) located in Rockville, Maryland. In order to obtain data on nursing
home costs, application was made to the CFACT Data Center to request access to the
data.

NVSS and BLS

Mortality data from the 1999-2003 NVSS and wage data from the 1999-2003 BLS
were used to calculate lost wages due to death from Parkinson's disease. The NVSS
data are collected and disseminated by the National Center for Health Statistics
(NCHS). The NCHS collects data on all births, deaths (mortality), marriages, divorces,
and fetal deaths for the nation, which includes 50 states, 2 cities (Washington DC, and
New York City), and 5 territories (Puerto Rico, the Virgin Islands, Guam, American
Samoa, and the Commonwealth of the Northern Mariana Islands). The mortality data
available from the NVSS includes age (broken into 5 year age groups), race (white,
black, and other) and gender. The NVSS also provides data on the probability of
survivorship by age, race, and gender.

The BLS provides information on labor force participation, wages, earnings and
benefits for workers in the United States by using the Current Population Survey (CPS). The CPS is a survey conducted by the Bureau of Census for the BLS and provides data
on the United States labor force, employment, unemployment and persons not in the
labor force. The CPS data includes demographic data for age (broken into 5-year age
groups), race (white and black), and gender. The probability of being in the labor force
was calculated using demographic categories and labor force participation information.
Wage information for the years 1999-2003 was available from BLS and provided the
average wage earned for the same demographic categories used in the CPS.
Study Setting

This study was completed at the University of Tennessee Health Science Center, Memphis, TN.

Sampling Plan

Using a nationally representative sample, the sampling plan for this prevalence-based cost of illness study used data from the complete 1999-2003 MEPS-HC data files and the 1996 MEPS-NHC file. From these data, all patients with a diagnosis of Parkinson’s disease were selected for inclusion. The ICD-9 code 332 was used in MEPS to identify patients with Parkinson’s disease. The source of costs from each file provided all the direct medical, direct non-medical, and morbidity costs for persons with Parkinson’s disease. The 1999-2003 NVSS Mortality Data and 1999-2003 BLS data were used to estimate the remaining portion of indirect costs (mortality costs) for Parkinson’s disease.

MEPS Sampling Frame

The MEPS sample was derived from participants in the previous year’s National Health Interview Survey (NHIS) with an over-sampling of persons who are African American and Hispanic. Because this was a nationally representative sample, respondents are weighted based on demographic factors to allow for extrapolation to the United States population as a whole. A person-level weight was developed to allow extrapolation. A person-level weight was developed for each person during round 1 as a base weight and then adjusted for non-response in rounds 2 and 3. In order to be assigned a person-level weight, the person had to be considered an “in-scope, key person.” If the person was a member of the civilian non-institutionalized portion of the
population, the person was defined as "in-scope." In order to be defined as a "key" person, the person had to be a member of a household in the NHIS. A person-level weight was designated for each "in-scope, key person" who responded to MEPS for the full 2003 time period. Using five demographic variables (census region, metropolitan statistical area, race/ethnicity, gender, and age), post-stratification estimates were obtained by controlling to the Current Population Survey (CPS) population estimates.

Each year (1999-2003) a composite weight was formed by multiplying each panel weight by 0.5. Specifically, each person represents a certain number of people in the United States population and his/her person weight indicates how many people in the United States that one person represents.

Protection of Human Subjects

This study was a secondary data analysis of the MEPS database. Prior to obtaining any data from MEPS, approval from the University of Tennessee Health Science Center Institutional Review Board (IRB) was obtained (see Appendix B).

Study Procedures

This study estimated the direct and indirect costs of Parkinson’s disease in the United States. The ICD-9 codes for Parkinson’s disease include 332.0-332.9. MEPS-HC collapses the diagnosis codes for various diseases, including Parkinson’s, to the three-digit code categories. Therefore, the code 332 was the only ICD-9 code necessary for this study. All patients in the 2003 MEPS-HC and the 1996 MEPS-NHC databases with a diagnosis of Parkinson’s disease were used to estimate the cost of illness of Parkinson’s disease. All persons whose cause of death was reported as Parkinson’s disease in the
2003 NVSS were used to estimate mortality costs. The costs of Parkinson's disease presented are prevalence-based, estimating the direct and indirect costs incurred in 2003 as a result of Parkinson's disease.

MEPS-HC data are provided in both an event-level and person-level format and are made available to the public in SAS format. Seven event-level files (inpatient hospital, emergency room, outpatient hospital, office-based visits, home-health care, other medical expenses, and prescription drugs) and three person-level files (full year population characteristics, jobs file, and medical conditions) from the MEPS-HC were used in the study. Event-level files provide information on the utilization and costs of medical services. The person-level file for population characteristics reports the demographics of the MEPS-HC participant, while the medical conditions file reports medical conditions experienced by the participant.

Nursing home data from the MEPS-NHC are available in person-level and facility-level files at the CFACT Data Center in Rockville, Maryland. Data from the MEPS-NHC were merged to create an event-level file.

Figure 3-2 details the cost of illness framework used. The figure includes the components to be measured and the corresponding MEPS event-level and person-level files.

The following event-level files from the 1999-2003 MEPS-HC were used to conduct this cost of illness study: prescription medications (HC-033A, HC-051A, HC-059A, HC-067A, and HC-077A), other medical expenses (HC-033C, HC-051C, HC-059C, HC-067C, and HC-077C), hospital inpatient stays (HC-033D, HC-051D, HC-059D, HC-067D, and HC-77D), emergency room visits (HC-033E, HC-051E, HC-059E, HC-067E, and HC-077E), outpatient visits (HC-033F, HC-051F, HC-059F, HC-067F, and
Figure 3-2. Expanded Cost of Illness Model. Author's visual representation of the components outlined by Rice\textsuperscript{28} and the MEPS, NVSS, and BLS databases and variables being used to measure direct costs and indirect costs of Parkinson's disease.

Components of Direct Medical Costs
- Medications/Treatments
- Hospital Visits
- Emergency Room Visits
- Treatment by Medical Professionals
- Nursing Home Care
- Other Medical Expenses

MEPS Event Level Files
- Prescribed Medicines (HC-077A)
- Hospital Inpatient Stays (HC-077D)
- Emergency Room Visits (HC-077E)
- Outpatient Visits (HC-077F)
- Office-Based Medical Visits (HC-077G)
- Home Health Visits (HC-077H)
- Nursing Home Component (NHC-001, 002, 003, 007)
- Other Medical Expenses (HC-077C)

Components of Direct Non-Medical Costs
- Transportation
- Child Care
- Household Expenses

MEPS Person Level Files
- Jobs File (HC-074)
- Other Medical Expenses (HC-077C)

Components of Indirect Costs
- Morbidity

MEPS Person Level Files
- Full Year Population Characteristics (HC-073)
- Jobs File (HC-074)
- Medical Conditions (HC-078)

Components of Indirect Costs
- Morbidity

NVSS & BLS
- Final Data 2003 Deaths
- Employment statistics and wage
HC-077F), office-based medical provider visits (HC-033G, HC-051G, HC-059G, HC-
067G, and HC-077G), and home health visits (HC-033H, HC-051H, HC-059H, HC-
067H, and HC-077H). The following person-level data files from the 1999-2003 MEPS-
HC were used to conduct this cost of illness study: full year population characteristics
(HC-038, HC-050, HC-060, HC-070, and HC-073), jobs file (HC-032, HC-040, HC-056,
HC-063, and HC-074), and medical conditions (HC-037, HC-052, HC-061, HC-069, and
HC-078). Variables selected from each of the event-level and person-level files were
based on their usefulness in this particular cost of illness study. Appendix C contains a
complete listing of the variables selected for this study. The variable name, a description
of the variable, and the MEPS file from which the variable came are included in
Appendix C. Appendix C also contains a listing of the variables which contain cost data
and what category of cost (direct medical, direct non-medical or indirect) each variable
represents.

Event-level cost data are available in MEPS for seven types of healthcare services:
Inpatient hospital visits, emergency room visits, outpatient visits, prescription
medications, office-based medical visits, other medical expenses, and home health visits.
Costs of prescription medications (HC-033A, HC-051A, HC-059A, HC-067A, and HC-
077A), other medical expenses (HC-033C, HC-051C, HC-059C, HC-067C, and HC-
77C), inpatient hospital stays (HC-033D, HC-051D, HC-059D, HC-067D, and HC-
077D), emergency room visits (HC-033E, HC-051E, HC-059E, HC-067E, and HC-
077E), outpatient visits (HC-033F, HC-051F, HC-059F, HC-067F and HC-077F), office-
based provider visits (HC-033G, HC-051G, HC-059G, HC-067G ,and HC-077G), and
home healthcare visits (HC-033H, HC-051H, HC-059H, HC-067H, and HC-077H) were
estimated using expenditures reported for persons with Parkinson’s disease in the 1999-
2003 MEPS databases. Each medical condition reported by a respondent is linked to a medical event code in MEPS. Medical care expenses incurred in the treatment of Parkinson's disease can therefore be determined from Parkinson's disease medical events that are linked by the specific medical condition code, ICD-9-CM 332. For each of these services, MEPS provides sample estimates that can be extrapolated to the entire United States population, allowing the costs for each of these services to be estimated as a weighted sum and as a weighted average cost.

MEPS Data Files

The following are the MEPS data files used in this study and a brief description of each file:

**Inpatient Hospital Visits.** An event-level data file containing characteristics associated with the hospital inpatient stay. Information in this file includes date of the hospital inpatient stay, reason for the stay, types of services received, condition(s) and procedure(s) associated with the hospital inpatient stay, whether or not medicines were prescribed, and imputed expenditure data.

**Emergency Room Visits.** An event-level data file that contains characteristics associated with the emergency room visit. Information in this file includes the date of the visit, types of care and services received, types of medicine prescribed during the visit, condition codes, expenditures, sources of payment associated with the visit, and imputed expenditure variables.
**Prescription Medications.** An event-level file that represents a unique prescribed medicine event. A prescribed medicine that was reported as being purchased or otherwise obtained by the household respondent includes the following: an identifier for each unique prescribed medicine; detailed characteristics associated with the event (e.g., national drug code [NDC], medicine name, etc.); conditions, if any, associated with the medicine; the date on which the person first used the medicine; total expenditure and sources of payments; and types of pharmacies that filled the household’s prescriptions.

**Outpatient Visits.** An event-level file that contains characteristics associated with the outpatient visit including the date of the visit, whether or not a doctor was seen, type of care received, type of services provided, expenditures, sources of payment, and imputed sources of payment.

**Office-Based Medical Provider Visits.** An event-level file that contains characteristics associated with the office-based visit, such as date of the visit, time spent with the provider, type of provider seen by the patient, types of treatment and services received, types of medicine prescribed, condition codes, expenditures, source of payment associated with the visit, and imputed expenditure variables.

**Home Health Visits.** An event-level file that contains information on expenditures for home health visits, including the type of provider, type of services received, length of the visit, reason for the visit, expenditures, and sources of payment.
Other Medical Expenses. An event-level and person-level file that provides information on the purchase of and expenditures for medical equipment, supplies, glasses, and other medical items. This file also provides information on expenses, such as transportation to the healthcare providers’ office, lodging, childcare, and any other household expenses not reported in a previous section.

Nursing Home Component. This component of MEPS contains two types of files: person-level and facility-level. In the person-level file, variables include demographics, health status, insurance coverage, and medical conditions as reported by facility sources. The facility-level file contains variables pertaining to characteristics of the facilities including detailed information on the facility’s structure. The variables include number of beds by licensing and certification categories, ownership, number of residents, special care units by type and size, and staffing. Both the facility-level file and the person-level file contain expenditure information.

Jobs File. This person-level file includes variables pertaining to household-reported jobs; including wages, hours, industry, and occupation.

Medical Conditions. This file provides information on the household-reported medical conditions.

Full Year Consolidated. This person-level file consolidates all of the final person-level variables into one file. This file contains the following variables: survey administration, demographics, employment, health status, quality of care, patient
satisfaction and health insurance. The file also includes additional variables: parent identifiers, access to care and days of disability variables, language of interview variable, income variables, additional health insurance variables (including summary indicators), and use and expenditure variables.

NVSS Data

The NVSS data used in this study are the Death: Final Data Reports. These reports detail the national annual mortality statistics and provide data on deaths and death rates by demographic characteristics such as age, gender, and race.

BLS Data

The following are the BLS data used in this study and a brief description of each file:

Labor Force Statistics. This file provides information on employment and unemployment rates by age, race, and gender.

Wages and Earnings Statistics. Information on wages are available by occupation for the nation, region, and state, age, race, and gender.

Data Analysis File Creation

The complex design of MEPS-HC requires that sample data be weighted to obtain unbiased national estimates for the U.S. non-institutionalized civilian population. The sample weights used to obtain unbiased estimates were necessary because of the disproportionate sampling used in NHIS to over-sample minority populations. The
sample weights also account for non-response of eligible sampling units, partial responses by survey participants, and post-stratification.\textsuperscript{37} The weights were used to estimate population values and vary among individuals in the sample to correct for variance in response rates by age, gender, race/ethnicity, region of the country, and poverty status. All utilization and cost estimates used in this study were weighted to reflect national population estimates. Thus, for each person included in the MEPS survey, his/her responses were weighted according to the demographic group (age, gender, race/ethnicity, region of the country, and poverty status) he/she represents. National census data were used to determine the weights used for each demographic group.

In order to perform the final data analysis, it was necessary to merge all of the 1999-2003 MEPS data files into one file and then generate a pooled weight for each person. This final analysis file was created in five steps. The first step linked the Medical Conditions File with the Consolidated Full Year File and identified persons with Parkinson’s disease. In this step, if the person reported having Parkinson’s disease (ICD-9-CM code 332) in the Medical Conditions File, then the person’s unique identifier (DUPERSID) was used to link with the Consolidated Full Year File. This resulted in the creation of a single file that contained only persons with Parkinson’s disease. The second step of merging linked the resulting first step file of persons with Parkinson’s disease to each of the Medical Event Files. This resulted in the creation of a single file that contained only persons with Parkinson’s disease and the medical events reported by that person that were related to Parkinson’s disease. By creating this file, it was possible to aggregate costs by person and by category of medical event. An overall total sum of costs could also be calculated from this file. Figure 3-3 visually depicts how the 2003
Figure 3-3. MEPS-HC Data Files Linking Diagram. Construction of file for estimated direct and indirect costs for Parkinson's disease in the United States from 2003 MEPS data files. Figure design used with permission from Dr. Norm Carroll, Virginia Commonwealth University. See Appendix A.


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MEPS-HC data files were linked together to create one data file for analysis. The third step was to repeat steps one and two for the other four years (1999-2002). The fourth step of merging merged all years of MEPS-HC data (1999-2003) into one file for a five-year analysis. It is possible that a person could be in multiple years of the MEPS-HC. Each year the person received a new person weight (PERWT), stratum (STRATA), and population sampling unit (PSU). Once all data were in file, the person weight (PERWT) variable for each person and each year was divided by five (the number of years of the MEPS data used) to obtain the pooled weight. The process of dividing each person weight (PERWT) variable resulted in the creation of a new variable that was named POOLWT and represented one-fifth the value of each person weight (PERWT). Also, for the process of pooling the MEPS-HC files, the two variables, stratum (STRA9603) and population sampling unit (PSU9603), were used in place of the assigned stratum (STRATA) and population sampling unit (PSU). These variables were matched to each unique identifier (DUPERSID) in the merged file containing the MEPS-HC for 1999 through 2003.

In order to get cost variables from 1999-2002 to the 2003 dollar amount, the cost variables were multiplied by each year’s CPI. For example, the total dollar amount associated with the MEPS-HC for 1999 was multiplied to the CPI for 2003 and so on. The following formula represents how CPI was calculated for the year 1999 to 2003 dollars.

\[
\text{Year Cost Total 1999} \times \left( \frac{\text{CPI 2003}}{\text{CPI 1999}} \right) = \text{Amount in 2003 dollars}
\]

For example: If MEPS-HC costs in 1999 were found equal to $3 billion dollars, the amount in 2003 dollars would be calculated as follows:

\[
$3,000,000,000 \times \left( \frac{184}{166.6} \right) = 3,313,325,330
\]
Where:

\[
\begin{align*}
\$3,000,000,000 &= \text{Hypothetical 1999 MEPS-HC Costs} \\
184 &= \text{actual 2003 Medical Care CPI} \\
166.6 &= \text{actual 1999 Medical Care CPI} \\
\$3,313,325,330 &= \text{Hypothetical 2003 MEPS-HC Costs}
\end{align*}
\]

This formula was repeated for each year and the product for each year was then added together and the final total represented the pooled CPI total for cost of illness for Parkinson’s disease in 2003 (minus nursing home costs and mortality costs). Figure 3-4 visually depicts how all five years of MEPS-HC data were merged into one single file for pooled analysis.

Figure 3-5 visually depicts how the Nursing Home Component (NHC) data files were merged together to create one file for data analysis. The person-level files (NHC001P, NHC-002, and NHC-007) were merged using the person identification number (ORIGPERSID), resulting in the creation of one person-level file. The Facility-level files (NHC-001F and NHC-003) were merged using the facility identification number (SFID), which resulted in one facility-level file. The SFID appeared in NHC-002 of the person-level files and was used as the common variable to merge the single person-level file and facility-level files that were created into one final merged file.
Figure 3-4. Merge of Five Years of MEPS-HC Data Files for a One-Year Pooled Estimate of Direct and Indirect Cost of Parkinson’s Disease in the United States MEPS Data Files.
Figure 3-5. Nursing Home Component Data File Creation. Construction of file for estimated costs for Parkinson’s disease in the United States from 1996 MEPS Nursing Home data files. Figure design used with permission from Dr. Norm Carroll, Virginia Commonwealth University. See Appendix A.

Costs

**Determination of Direct Medical Costs**

Data were used from seven event-level files to estimate direct medical costs of Parkinson’s disease in 2003: Prescription medications (HC-077A), other medical expenses (HC-077C), hospital inpatient stays (HC-077D), emergency room visits (HC-077E), outpatient visits (HC-077F), office-based medical provider visits (HC-077G), and home health visits (HC-077H). Nursing home data were also used from the patient-level file (NHC-007) and the facility-level file (NHC-003) to estimate direct medical costs.

The following steps were necessary to determine the overall cost for each of the MEPS files:

1. The first step was to sort patients by their identification number (DUPERSID) and add together the cost associated with each Parkinson’s-related event reported. For example: Patient 1001 reported the condition Parkinson’s disease and stated that he/she had three prescriptions filled for treatment of Parkinson’s; the total cost for one prescription was captured by the variable RXXP03X. This patient’s DUPERSID appears in the prescription medications file three times and the RXXP03X variable also appears. Each of the dollar amounts were added together to get a total sum of prescription medications for this patient. Hypothetically, if the three RXXP03X variables were $217, $75, and $65 for patient 1001 for prescription medications, these were totaled together. A new variable was then created and labeled RXXP03XUWPT (prescription medication unweighted patient total).
2. The next step was to take this unweighted patient total and multiply it by the patient's person-level pooled weight (POOLWT) value. A new variable was created to represent the resulting product of multiplying POOLWT and RXXP03XUWPT. This value was labeled RXXP03X WPT (prescription medication weighted patient total). The POOLWT value was the same for the patient throughout all MEPS files. (The POOLWT value varies for each patient and the value was determined by using census data and demographic characteristics.) In this example, the patient had a total unweighted cost of $357 in prescription medication costs. The patients' POOLWT value was 2,365, meaning this patient represented 2,365 people in the United States. The $357 spent by the patient actually represents $844,305 spent for medications to treat Parkinson's disease.

\[
\text{POOLWT} \times \text{RXXP03XUWPT} = \text{RXXP03XWPT}
\]

\[
2,365 \times 357 = 844,305
\]

3. The next step was to repeat steps 1 and 2 for all patients with Parkinson's disease in the MEPS database. All of the RXXP03X WPT values for each person were then added together to get an overall total for prescription medication costs. This process required creating a new variable RXXP03XWOT (representing the weighted overall total of prescription medications).

\[
(\text{RXXP03XWPT}_1 + \text{RXXP03XWPT}_2 + \ldots + \text{RXXP03XWPT}_{54}) = \text{RXXP03XWOT}
\]

This procedure was repeated for each of the MEPS files to arrive at weighted overall totals for other medical expenses (HC-077C), hospital inpatient stays (HC-077D), emergency room visits (HC-077E), outpatient visits (HC-077F), office-based medical provider visits (HC-077G), and home health visits (HC-077H). The specific direct
medical cost variables used from the various event files appear in Table 3-1. Figure 3-6 visually depicts the prescription medication (HC-077A) example. Appendix D contains each of the formulas for each individual event files (other medical expenses, HC-077C, hospital inpatient stays, HC-077D, emergency room visits, HC-077E, outpatient visits, HC-077F, office-based medical provider visits, HC-077G, home health visits, HC-077H, and nursing home stays (NHC-003, and NHC-007).

**Direct Medical Costs-Nursing Home**

Nursing home costs were estimated using the 1996 Nursing Home Component (NHC) of MEPS, which is the most recent set of data available. The NHC is divided into person-level files (NHC-001P, NHC-002, and NHC-007) and facility-level files (NHC-001F, NHC-003). To adjust Nursing Home Costs from 1996 dollars to 2003 dollars, the following formula was used:


Where:

CPI = Consumer Price Index  
NHC = Nursing Home Costs  
*Base Year = 1996

For example: If nursing home costs in 1996 were found equal to $2 billion dollars, the amount in 2003 dollars would be calculated as follows:

$2,000,000,000 X 135.2/100 = $2,704,000,000

Where:

$2,000,000,000= Hypothetical 1996 Nursing Home Costs  
135.2 = actual 2003 Nursing Home CPI
<table>
<thead>
<tr>
<th>Variable Name</th>
<th>Description</th>
<th>MEPS File</th>
<th>Cost Component Measured</th>
</tr>
</thead>
<tbody>
<tr>
<td>RXXP03X</td>
<td>Sum of payments for each prescribed medicine</td>
<td>Prescription Medications (HC-077A)</td>
<td>Direct Medical Medications</td>
</tr>
<tr>
<td>IPEXP03X</td>
<td>Sum of facility payments for inpatient stays</td>
<td>Hospital Inpatient Stays (HC-077D)</td>
<td>Direct Medical Hospital Visits</td>
</tr>
<tr>
<td>IPDXP03X</td>
<td>Sum of doctor payments for inpatient stays</td>
<td>Hospital Inpatient Stays (HC-077D)</td>
<td>Direct Medical Hospital Visits</td>
</tr>
<tr>
<td>OMXP03X</td>
<td>Sum of all 12 sources of payments</td>
<td>Other Medical Expenses (HC-077C)</td>
<td>Direct Medical Other Medical Expenses</td>
</tr>
<tr>
<td>ERFXP03X</td>
<td>Facility sum of payments for emergency room</td>
<td>Emergency Room Visits (HC-077E)</td>
<td>Direct Medical Emergency Room Visits</td>
</tr>
<tr>
<td>ERDXP03X</td>
<td>Doctor sum of payments for emergency room</td>
<td>Emergency Room Visits (HC-077E)</td>
<td>Direct Medical Emergency Room Visits</td>
</tr>
<tr>
<td>OPDXP03</td>
<td>Sum of doctor payments for outpatient visits</td>
<td>Outpatient Visits (HC-077F)</td>
<td>Direct Medical Outpatient Visits</td>
</tr>
<tr>
<td>OPFXP03</td>
<td>Sum of facility payments for outpatient visits</td>
<td>Outpatient Visits (HC-077F)</td>
<td>Direct Medical Outpatient Visits</td>
</tr>
<tr>
<td>OBXP03X</td>
<td>Sum of payments for office based provider visits</td>
<td>Office-Based Medical Provider Visits (HC-077G)</td>
<td>Direct Medical Treatment by Medical Professionals</td>
</tr>
<tr>
<td>HHXP03X</td>
<td>Sum of payments for home health visits</td>
<td>Home Health Visits (HC-077H)</td>
<td>Direct Medical Treatment by Medical Professionals</td>
</tr>
<tr>
<td>TOTPEXP</td>
<td>Total patient expenses</td>
<td>Nursing Home Component (person level)</td>
<td>Direct Medical Nursing Home Care</td>
</tr>
</tbody>
</table>
Table 3-1. Continued.

<table>
<thead>
<tr>
<th>Variable Name</th>
<th>Description</th>
<th>MEPS File</th>
<th>Cost Component Measured</th>
</tr>
</thead>
<tbody>
<tr>
<td>POOLWT</td>
<td>The final person-level weight divided by 5 that was previously adjusted to match census population estimates on the following demographic characteristics: sex, age, race/ethnicity, and geographic area</td>
<td>Contained in all MEPS files</td>
<td>Weighting Variable All</td>
</tr>
<tr>
<td>DUPERSID</td>
<td>Person identifier that remains the same for duration of survey participation</td>
<td>Contained in all MEPS files</td>
<td>Patient Identifier All</td>
</tr>
</tbody>
</table>
**Step One:** Add together all reported medication events for the prescription medication event file.

\[ \text{RXXP03X} + \text{RXXP03X} + \text{RXXP03X} = \text{RXXP03XUWPT} \]

\[ ($217) + ($75) + ($65) = ($357) \]

**Step Two:** Multiply unweighted cost variable total by PERWT01F (patient weighted value) to get amount that 2,365 Parkinson's patients would spend on medications.

\[ \text{RXXP03XUWPT} \times \text{POOLWT} = \text{RXXP03XWT} \]

\[ ($357) \times (2,365) = ($844,305) \]

**Step Three:** Add together all weighted totals for Prescription Medications to arrive at a national estimate for 2003.

\[ \sum (\text{RXXP03XWPT}) = \text{RXXP03XWOT} \]

Figure 3-6. Example of the Calculation of Medication Costs. Visual example of how overall costs for prescription medications were calculated.
$2,704,000,000 = \text{Hypothetical 2003 Nursing Home Costs}

This formula was calculated for each year of data included in the study (1999-2003) and the base year will always be 1996 because that is the only year of data available for Nursing Home Costs.

**Direct Non-Medical Costs**

Direct non-medical costs were identified from the MEPS database based on information on the health status of family members and condition-specific limitations. Variables from the Other Medical Expenses (HC077C) database were used to calculate cost information on direct non-medical costs. If a patient reported that they had a direct non-medical expense (OMOTHOS), then the events for this specific person were reviewed to see if the event (EVNTIDX) was related to Parkinson’s disease. The total for direct non-medical expenses (OMOTHOS) that were related to Parkinson’s disease were then multiplied the individuals person weight (POOLWT) to arrive at direct non-medical expenses for each individual. The specific direct non-medical cost variables used from the various event files appear in Table 3-2.

**Indirect Costs**

Indirect costs of Parkinson’s disease were determined by using the human capital method. The human capital method quantifies indirect costs by calculating non-medical costs associated with a particular disease state. The human capital method calculates the value of lost productivity due to absences from work (labor market work force and housework), disability (morbidity costs), or death (mortality costs).
Table 3-2. Variables Used to Calculate Direct Non-Medical Expenses.

<table>
<thead>
<tr>
<th>Variable Name</th>
<th>Description</th>
<th>MEPS file</th>
<th>Cost Component Measured</th>
</tr>
</thead>
<tbody>
<tr>
<td>OMOTHOS</td>
<td>Captures expenses for transportation, lodging, child care, and home modifications</td>
<td>Other Medical Expenses (HC-077C)</td>
<td>Direct Non-Medical Expenses, Transportation, Child care, Household Expenses</td>
</tr>
<tr>
<td>EVNTIDX</td>
<td>Identifies that the expense was due to Parkinson's disease</td>
<td>Other Medical Expenses (HC-077C)</td>
<td>Event Identifier, All</td>
</tr>
<tr>
<td>POOLWT</td>
<td>The final person-level weight divided by five and was previously adjusted to match Census population estimates on the following demographic characteristics: sex, age, race/ethnicity, and geographic area</td>
<td>Contained in all MEPS files</td>
<td>Weighting Variable, All</td>
</tr>
</tbody>
</table>
The MEPS databases provide the number of persons who missed work due to Parkinson’s disease, the average earnings per hour of each person, the average number of hours the person worked per day, and the number of days of lost work for each person who reported missing work due to Parkinson’s disease. Morbidity costs were estimated from the number of patients with Parkinson’s disease reporting either a loss of paid employment or inability to perform non-paid housekeeping duties. The variables that were used to measure morbidity costs came from the jobs file (HC-063) database, the full year consolidated data file, and the medical conditions file (HC-078) database. The specific morbidity cost variables used from the three files appear in Table 3-3.

The number of days of missed work and the daily wage rate are available in the Jobs File (HC-074). If the person had bed days, this was reported as a Yes or No response in the Jobs File (HC-074), and the total number of bed days are in the Full Year Consolidated File (HC-073). A bed day is defined as staying in bed for fifty percent (or more) of the day due to a specific condition.\textsuperscript{164} The value of lost housekeeping services and bed days are based on the human capital methodology.\textsuperscript{165} If a person reported that they had bed days, but were not employed, then the number of bed days was multiplied times the value of a bed day. The value of a bed day (for individuals not in the labor force) is estimated as the value of lost housekeeping services. The human capital methodology estimates the present value of lifetime earnings based on the assumption that earnings reflect the contribution workers make to the value of goods and services.\textsuperscript{165} Housekeeping and bed days are valued as a loss of goods and services that the individual would have contributed to the household in the absence of illness.\textsuperscript{165} The morbidity
Table 3-3. Variables Used to Calculate Indirect Cost (Morbidity).

<table>
<thead>
<tr>
<th>Variable Name</th>
<th>Description</th>
<th>File</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>DW</td>
<td>Persons daily wage rate</td>
<td>Jobs File</td>
<td>Calculation of Indirect Costs (Morbidity)</td>
</tr>
<tr>
<td>VBD</td>
<td>Value of a bed day</td>
<td>BLS</td>
<td>Calculation of Indirect Costs (Morbidity)</td>
</tr>
<tr>
<td>MISSWORK</td>
<td>Missed work days</td>
<td>Jobs File and Medical Conditions File</td>
<td>Calculation of Indirect Costs (Morbidity)</td>
</tr>
<tr>
<td>INBEDFLG (BED DAY)</td>
<td>Person reports being in bed ½ day or more due to reported condition</td>
<td>Full Year Consolidated File</td>
<td>Calculation of Indirect Costs (Morbidity)</td>
</tr>
<tr>
<td>DDBDYS31</td>
<td>Number of bed days reported in specific panel and round</td>
<td>Full Year Consolidated File</td>
<td>Calculation of Indirect Costs (Morbidity)</td>
</tr>
<tr>
<td>DDBDYS42</td>
<td>Number of bed days reported in specific panel and round</td>
<td>Full Year Consolidated File</td>
<td>Calculation of Indirect Costs (Morbidity)</td>
</tr>
<tr>
<td>DDBDYS53</td>
<td>Number of bed days reported in specific panel and round</td>
<td>Full Year Consolidated File</td>
<td>Calculation of Indirect Costs (Morbidity)</td>
</tr>
<tr>
<td>DDNWRK31</td>
<td>Number of days of missed work reported in specific panel and round</td>
<td>Full Year Consolidated File</td>
<td>Calculation of Indirect Costs (Morbidity)</td>
</tr>
<tr>
<td>DDNWRK42</td>
<td>Number of days of missed work reported in specific panel and round</td>
<td>Full Year Consolidated File</td>
<td>Calculation of Indirect Costs (Morbidity)</td>
</tr>
<tr>
<td>DDNWRK53</td>
<td>Number of days of missed work reported in specific panel and round</td>
<td>Full Year Consolidated File</td>
<td>Calculation of Indirect Costs (Morbidity)</td>
</tr>
<tr>
<td>POOLWT</td>
<td>The five year pooled person-level weight</td>
<td>Medical Condition File</td>
<td>Calculation of Indirect Costs (Morbidity)</td>
</tr>
</tbody>
</table>
estimate for this study was calculated from a sample of people with Parkinson’s disease, and it was necessary to apply patient weights (POOLWT) to the estimate in order to accurately reflect the morbidity costs for the U.S. population.

The following steps were necessary to reach an overall cost of morbidity:

1. The first step in reaching an overall cost of morbidity for Parkinson’s disease was to determine if a person reported having missed work and/or had bed days due to Parkinson’s disease.

2. Next, the number of days of missed work and bed days had to be calculated. A person reports the number of missed work days and bed days in each round of the survey panel. There are three rounds of interviewing in a year; therefore, there are three separate variables to be totaled to get the actual yearly total of missed work days (DDNWRK31, DDNWRK42, and DDNWRK53) and bed days (DDBDYS31, DDBDYS42, and DDBDYS53). A separate variable was created to represent the total number of missed work days (DDNWRKTOT) and bed days (BDOT).

3. The number of missed work days (DDNWRKTOT) was then multiplied by the person’s daily wage rate (DW), which came from BLS. The number of bed days (BDOT) was then multiplied by the value of a bed day (VBD).

4. In order to account for Parkinson’s patients that didn’t work, but had lost productivity due to bed days, it was necessary to create a separate variable to value their lost productivity. The variable “value of a bed day” (VBD) is not contained in MEPS, so it was necessary to use wage data from the BLS to calculate the value of a bed day based on the age and gender of those who reported bed days. The if/then function in SAS was used to calculate the
appropriate value of a bed day (VBD) by race, age, and gender. For example, if the person reporting bed days was a white female age 55 and the value of a bed day for a white female age 55 is $40, then VBD for this person would be $40.

5. As with the previous MEPS data files, it was necessary to calculate a total for each individual patient and to then multiply that total by the individual patient weight (POOLWT). The variable that was created was titled MORBTWPT (individual patient weighted total for morbidity), and all MORBTWPT variables were summed to calculate a grand total that was called MORBWOT (overall weighted total for morbidity).

The formula used to calculate morbidity costs was:

\[ \sum [\text{NMWDT} \times \text{DW}] + (\text{BDOT} \times \text{VBD})] \text{POOLWT} = \text{Morbidity Costs} \]

Where:

- NMWDT = overall total number of missed work days;
- DW = daily wage rate;
- BDOT = overall total number of bed days;
- VBD = value of bed day;
- POOLWT = five year pooled person-level weight.

Mortality costs are not specifically gathered by the MEPS database. For the purposes of this study, the 1999-2003 NVSS and the 1999-2003 BLS variables were used to calculate the mortality costs portion of this cost of illness estimate that appear in Table 3-4.

The NVSS contains the number of deaths due to Parkinson’s disease by gender, race, and age (broken into five-year age groups). The formula following Table 3-4 was used to
Table 3-4. Variables Used to Calculate Indirect Cost (Mortality).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Description</th>
<th>Data Source</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Age of person at time of death</td>
<td>NVSS/BLS</td>
<td>Calculation of Indirect Costs (Mortality)</td>
</tr>
<tr>
<td>Gender</td>
<td>Male or female</td>
<td>NVSS/BLS</td>
<td>Calculation of Indirect Costs (Mortality)</td>
</tr>
<tr>
<td>Race</td>
<td>Race (black, white, or other)</td>
<td>NVSS/BLS</td>
<td>Calculation of Indirect Costs (Mortality)</td>
</tr>
<tr>
<td>Employment</td>
<td>Labor force participation rates</td>
<td>BLS</td>
<td>Calculation of Indirect Costs (Mortality)</td>
</tr>
<tr>
<td>Wage</td>
<td>Average wage by demographic characteristics</td>
<td>BLS</td>
<td>Calculation of Indirect Costs (Mortality)</td>
</tr>
<tr>
<td>Life Expectancy</td>
<td>Average life expectancy of a person, based on race and gender</td>
<td>NVSS</td>
<td>Calculation of Indirect Costs (Mortality)</td>
</tr>
<tr>
<td>Life Tables for Probability of Survival</td>
<td>Probability that a person will survive to a certain age, based on gender and race</td>
<td>NVSS</td>
<td>Calculation of Indirect Costs (Mortality)</td>
</tr>
</tbody>
</table>

NVSS = National Vital Statistics Survey
BLS = Bureau of Labor Statistics
calculate mortality costs, for each race, age, and gender combination (black males, black females, white males, and white females):

\[ \sum_{n=a}^{85} \frac{W_nL_nS_n}{(1+r)^n} = W_nL_nS_n + W_nL_nS_n + W_nL_nS_n + \ldots \]

Where:

- \( W_n = \) wage amount at particular age (BLS)
- \( L_n = \) probability of still being in the labor force at a given age (BLS)
- \( S_n = \) probability of surviving to a given age (NVSS)
- \( r = \) discount rate
- \( a = \) age at death (NVSS)
- \( n = \) life expectancy (NVSS)

Discounting future earnings is necessary to determine their net present value. The discounting process uses a discount rate to convert a stream of future earnings to its present value. The discount rate is generally between 2 and 4%. If a higher discount rate is selected, the present value of a given stream of future earnings will be lower. Conversely, if a lower discount rate is selected, the present value of future earnings will be higher. For purposes of this study, future earnings were discounted using a 3% discount rate. By using an average 3% discount rate, the risk of underestimating or overestimating the actual value of future earnings was reduced.

The NVSS is not a sample of the U.S. population because it collects information on all deaths nationally; therefore it is not necessary to apply any weights to the mortality estimate. The total amount of indirect costs was calculated by adding the total from the morbidity estimate to the total from the mortality estimate:

\[ \text{Morbidity Costs} + \text{Mortality Costs} = \text{Indirect Costs} \]
Objectives and Hypotheses

Following is a list of the objectives and hypotheses for this research. Objectives 1 and 2 were descriptive in nature and do not have corresponding hypotheses. Objective 8 also has no corresponding hypothesis. Objectives 3 through 8 do have hypotheses and they are listed below.

1. Objective 1: To use a national database to determine the direct and indirect costs (cost of illness) for persons with Parkinson’s disease in the United States.

2. Objective 2: To describe healthcare utilization for persons with Parkinson’s disease in the United States.

3. Objective 3: To determine if there is a statistical difference between gender and cost of illness for Parkinson’s disease in the United States.

   Null Hypothesis: There is no difference between the average costs of Parkinson’s disease for males compared to females.

4. Objective 4: To determine if there is a statistically significant relationship between education level and cost of illness for Parkinson’s disease in the United States.

   Null Hypothesis: There are no differences between the average costs of Parkinson’s disease when comparing levels of education.

5. Objective 5: To determine if there is a statistically significant relationship between age groups and cost of illness for Parkinson’s disease.

   Null Hypothesis: There are no differences between the average costs of Parkinson’s disease when comparing age groups.

6. Objective 6: To determine if there is a statistically significant relationship between income level and cost of illness for Parkinson’s disease.
Null Hypothesis: There are no differences between the average costs of Parkinson's disease when comparing income levels.

7. Objective 7: To determine if there is a statistically significant relationship between marital status and cost of illness for Parkinson's disease.

Null Hypothesis: There are no differences between the average costs of Parkinson's disease when comparing marital status.

8. Objective 8: To determine if there is a statistically significant relationship between region of residence and cost of illness for Parkinson's disease.

Null Hypothesis: There are no differences between the average costs of Parkinson's disease when comparing region of residence.

10. Objective 9: To determine the relative influence of each demographic variable (gender, education level, age, income level, marital status and region of residence) when controlling for the influence of other variables.

Data Analysis-Total Cost of Illness

Calculating the total cost of illness of Parkinson's disease for a single year was the primary purpose of this study. Therefore, the fundamental analysis was conducted using all of the components of cost of illness (direct medical costs + direct non-medical costs + indirect morbidity costs + indirect mortality costs). The overall total cost of illness for Parkinson's disease was calculated by adding direct medical, direct non-medical costs, and indirect morbidity costs obtained from the MEPS-HC, the MEPS-NHC, and BLS with indirect mortality costs obtained from the NVSS and BLS. As discussed previously, the MEPS-NHC was only conducted in 1996, so the estimate for nursing home costs was inflated to represent 2003 dollars. For each year of data (1999-2003), a total overall cost
of Parkinson’s disease was calculated. Figure 3-7 shows the formula for the overall cost of illness for Parkinson’s disease.

For each of the demographic variables (age, gender, education level, marital status, and income) descriptive statistics were used to describe the cost of Parkinson’s disease. In addition, results for objectives 1 and 2, the total number of events were reported that occurred in each of the individual event-level files (prescribed medicines, hospital inpatient stays, emergency room visits, outpatient visits, office-based medical visits, home health visits, other medical expenses, missed worked days, bed days, and deaths).

For objectives 3 and 4, a t-test was used to test for a difference between costs for males and females. For objectives 5 through 8 a series of one-way ANOVA analyses were used with each of the demographic variables (age, marital status, income and region of residence) serving as the independent variable and the cost of Parkinson’s disease (minus costs from MEPS-NHC and mortality) as the dependent variable. For objective 9, each of the demographic variables (age, gender, education level, marital status, income and region of residence) was considered concurrently to determine multivariate significance. Post-hoc contrasts were performed to determine multivariate significance. Post-hoc contrasts were performed to determine where the statistically significant differences occurred between demographic groups. In this research study, a $P$-value of 0.05 (or less) was considered statistically significant. In order to reduce the risk of type 1 error, Bonferroni Adjustments were applied to the $P$-values. The Bonferroni Adjustment was done by dividing the accepted $P$-value of 0.05 by the number of comparisons being made between the demographic groups. For example, the
Figure 3-7. Formula Used to Determine the Overall Direct and Indirect Cost of Parkinson’s Disease for One Year.
demographic marital status had three groups (single, married, widowed) and therefore in order to be statistically significant, the P-value would have to be less than 0.016.

**SAS**

SAS version 9.13 was used for all statistical analyses in this study. For objective 3 and 4, the SAS procedure PROC TTEST (t-test) was used to compare total costs (minus nursing home costs and mortality costs) between gender (males and females) and between education levels (less than high school and greater than high school). For objectives 5 through 8 the SAS procedures Proc Surveymeans and Proc Surveyreg and were used. Proc Surveyreg provided the one-way ANOVA tests for objectives 5-8. This SAS procedure was done for each of the selected demographics in objectives 5-8. For objective 9, the Proc Surveyreg procedure was done while holding the selected demographics constant using the Estimate step in the Proc Surveyreg procedure. Once SAS produced the P-value for each of the selected demographics, Bonferroni Adjustments were applied to each of the selected demographic categories to determine if the P-value was significant.
CHAPTER IV. RESULTS

Introduction

The results of this study of cost of illness in Parkinson’s disease are presented in three sections. The first section describes the demographic data from the MEPS-HC and the MEPS-NHC. The first section also describes the direct and indirect costs (cost of illness) as well as total costs for persons with Parkinson’s disease in the United States, corresponding with objective 1. The second section describes healthcare resource utilization for persons with Parkinson’s disease and corresponds with objective 2. The third section provides statistical analysis of the direct and indirect costs obtained from the MEPS-HC and corresponds with study objectives 3 through 9.

Demographic Data

Table 4-1 provides an overview of each year of MEPS-HC data used in this study. When all 5 years were combined, an unweighted total of 242 patients were in the MEPS-HC sample. Of the 242 patients with Parkinson’s disease in the MEPS-HC sample, 9 had non-positive patient weights and were excluded from the study, making the final sample total 233 patients. The average age of the 116 females in the MEPS-HC with Parkinson’s disease was 68.9 and the average age of the 117 males was 67.8. These 233 patients represented a weighted total of 2.6 million people with Parkinson’s disease over a 5 year period. Using the MEPS-HC assigned patient weights, 1.18 million (45%) of the non-institutionalized patients with Parkinson’s disease were female and 1.43 million (55%) were male.
Table 4-1. Overview Demographic Data for Gender and Patients with Parkinson's Disease from MEPS-HC 1999-2003.

<table>
<thead>
<tr>
<th>Year</th>
<th>Unweighted Number</th>
<th>Females</th>
<th>Males</th>
<th>Weighted Number</th>
<th>Females</th>
<th>Males</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td>37</td>
<td>15</td>
<td>22</td>
<td>512,265</td>
<td>210,574</td>
<td>301,691</td>
</tr>
<tr>
<td>2000</td>
<td>43</td>
<td>26</td>
<td>17</td>
<td>483,273</td>
<td>278,812</td>
<td>204,461</td>
</tr>
<tr>
<td>2001</td>
<td>52</td>
<td>36</td>
<td>16</td>
<td>560,014</td>
<td>369,704</td>
<td>190,310</td>
</tr>
<tr>
<td>2002</td>
<td>60</td>
<td>27</td>
<td>33</td>
<td>585,287</td>
<td>179,637</td>
<td>405,650</td>
</tr>
<tr>
<td>2003</td>
<td>50</td>
<td>21</td>
<td>29</td>
<td>484,929</td>
<td>149,956</td>
<td>334,973</td>
</tr>
</tbody>
</table>

Table 4-2 provides a breakdown of the selected demographics of the 233 MEPS-HC patients with Parkinson's disease. This table shows the values of the “poolwt” variable that represents the persons' weight for the five year period of the study. The majority of patients (67%) in the weighted sample were between 65-84 years of age and 52.8% were widowed. Males made up 54.7% of the weighted sample and 70% had a high school education or greater. The majority (66.8%) of patients with Parkinson’s disease in the sample reported an income of less than $20,000 annually. The largest percentage (37.4%) of patients with Parkinson’s disease in the sample lived in the South.

Table 4-3 provides a breakdown of the nursing home patients with Parkinson's disease from the MEPS-NHC used for this study. In 1996, there were a total of 5,899 patients in the MEPS-NHC survey; 208 of these patients had a diagnosis of Parkinson's disease. Using the patient weights assigned, these 208 patients represented 99,989 Parkinson’s patients in nursing home facilities in the United States (65,928 females and 34,061 males). Table 4-3 provides the selected demographics for the 1996 Nursing Home data. The majority of nursing home patients with Parkinson’s disease were white (94.23%) and over the age of 80 (60.58%). Almost half (48%) were widowed and 29% were married. The remaining 23% of patients with Parkinson’s disease were single, divorced or separated.

**Direct, Indirect, and Total Cost of Illness**

Table 4-4 provides the weighted overall annual cost of Parkinson’s disease broken down by direct medical costs, direct non-medical and indirect costs. The cost of
Table 4-2. Breakdown of All Selected Demographics Data for Patients with Parkinson’s Disease from MEPS-HC 1999-2003 Combined.

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Unweighted Number</th>
<th>Unweighted Percent</th>
<th>Poolwt Number</th>
<th>Poolwt Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>117</td>
<td>50.3%</td>
<td>287,417</td>
<td>54.7%</td>
</tr>
<tr>
<td>Female</td>
<td>116</td>
<td>49.7%</td>
<td>237,737</td>
<td>45.3%</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 65</td>
<td>43</td>
<td>18.5%</td>
<td>75,507</td>
<td>14.3%</td>
</tr>
<tr>
<td>65-84</td>
<td>156</td>
<td>70.0%</td>
<td>352,233</td>
<td>67.0%</td>
</tr>
<tr>
<td>&gt;85</td>
<td>34</td>
<td>14.5%</td>
<td>97,414</td>
<td>18.7%</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; High School</td>
<td>90</td>
<td>38.6%</td>
<td>157,324</td>
<td>30.0%</td>
</tr>
<tr>
<td>&gt; High School</td>
<td>143</td>
<td>61.4%</td>
<td>367,830</td>
<td>70.0%</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>41</td>
<td>17.6%</td>
<td>74,830</td>
<td>14.2%</td>
</tr>
<tr>
<td>Widowed</td>
<td>115</td>
<td>49.3%</td>
<td>277,495</td>
<td>52.8%</td>
</tr>
<tr>
<td>Single</td>
<td>77</td>
<td>33.1%</td>
<td>172,829</td>
<td>33.0%</td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; $20,000</td>
<td>164</td>
<td>70.3%</td>
<td>350,861</td>
<td>66.8%</td>
</tr>
<tr>
<td>$20,000-$29,999</td>
<td>28</td>
<td>12.0%</td>
<td>71,494</td>
<td>13.6%</td>
</tr>
<tr>
<td>&gt;$30,000</td>
<td>41</td>
<td>17.7%</td>
<td>102,799</td>
<td>19.6%</td>
</tr>
<tr>
<td>Region</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northeast</td>
<td>37</td>
<td>15.9%</td>
<td>95,170</td>
<td>18.1%</td>
</tr>
<tr>
<td>Mid-West</td>
<td>51</td>
<td>21.9%</td>
<td>118,132</td>
<td>22.5%</td>
</tr>
<tr>
<td>South</td>
<td>93</td>
<td>39.9%</td>
<td>196,153</td>
<td>37.4%</td>
</tr>
<tr>
<td>West</td>
<td>52</td>
<td>22.3%</td>
<td>116,699</td>
<td>22.0%</td>
</tr>
</tbody>
</table>

Table 4-3. Selected Nursing Home Demographics Weighted and Unweighted for Patients with Parkinson’s Disease from the MEPS-NHC, 1996.

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Unweighted Number</th>
<th>Weighted Number</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Males</td>
<td>74</td>
<td>34,061</td>
</tr>
<tr>
<td>- Females</td>
<td>134</td>
<td>65,928</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Under 80</td>
<td>82</td>
<td>33,149</td>
</tr>
<tr>
<td>- Over 80</td>
<td>126</td>
<td>66,570</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Single</td>
<td>47</td>
<td>22,166</td>
</tr>
<tr>
<td>- Married</td>
<td>60</td>
<td>29,115</td>
</tr>
<tr>
<td>- Widowed</td>
<td>100</td>
<td>48,184</td>
</tr>
<tr>
<td>- Unknown</td>
<td>1</td>
<td>524</td>
</tr>
<tr>
<td><strong>Education Level</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Less than High School</td>
<td>84</td>
<td>35,233</td>
</tr>
<tr>
<td>- High School</td>
<td>31</td>
<td>12,923</td>
</tr>
<tr>
<td>- College</td>
<td>35</td>
<td>28,286</td>
</tr>
<tr>
<td>- Don’t Know</td>
<td>58</td>
<td>23,547</td>
</tr>
<tr>
<td><strong>Overall</strong></td>
<td>208</td>
<td>99,989</td>
</tr>
</tbody>
</table>


<table>
<thead>
<tr>
<th>Component</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct Medical</td>
<td>$4,266,866,331</td>
<td>$4,670,693,881</td>
<td>$5,820,637,444</td>
<td>$5,629,814,316</td>
<td>$5,298,491,603</td>
<td>$25,686,503,575</td>
</tr>
<tr>
<td>Direct Non-Medical</td>
<td>$306,203,804</td>
<td>$2,195,358</td>
<td>$5,260,885</td>
<td>$3,704,973</td>
<td>$10,683,797</td>
<td>$328,048,817</td>
</tr>
<tr>
<td>Indirect</td>
<td>$1,537,093,738</td>
<td>$1,971,778,359</td>
<td>$3,070,872,134</td>
<td>$3,287,857,779</td>
<td>$1,003,268,392</td>
<td>$10,870,870,402</td>
</tr>
<tr>
<td>Total</td>
<td>$6,110,163,873</td>
<td>$6,644,667,598</td>
<td>$8,896,770,463</td>
<td>$8,921,377,068</td>
<td>$6,312,443,792</td>
<td>$36,885,422,794</td>
</tr>
</tbody>
</table>

illness for Parkinson’s disease from 1999-2003 was $36.8 billion dollars. The majority (69.6%) of costs for Parkinson’s disease were direct medical costs, and 29.5% were indirect costs. Direct non-medical costs comprised less than 1% of total costs due to Parkinson’s disease.

Table 4-5 further breaks down direct medical costs into those from MEPS-HC and those from MEPS-NHC. The majority (53.5%) of direct medical costs were due to nursing home care (MEPS-NHC). The largest percentage (88.5%) of indirect costs was morbidity due to bed days.

**Healthcare Resource Utilization and Costs**

The following section presents the utilization of healthcare resources and is reported for each of the MEPS-HC components. These components are: prescription medication costs, office-based visits, emergency room visits, inpatient hospital stays, outpatient visits, home health visits, and other medical expenses. For each component, the year, the unweighted and weighted total number of times a resource was utilized, and the unweighted and weighted cost for the resource, are reported.

Direct medical costs are provided in Tables 4-6 through 4-12. Tables 4-6 through 4-11 provide a break down of the weighted and unweighted utilization and costs for each of the MEPS-HC components for 1999-2003. Table 4-12 provides the cost of nursing home care using the 1996 MEPS-NHC. Table 4-13 provides direct non-medical costs, while indirect costs are presented in Tables 4-14 through 4-17.

Table 4-6 provides an overall breakdown of prescription medication utilization and costs for 1999-2003. The second largest direct medical cost reported by patients with Parkinson’s disease was for prescription medications. The greatest percentage (25.9%)

<table>
<thead>
<tr>
<th>Variable</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
<th>Category Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct Medical</td>
<td>$673,708,446</td>
<td>$903,673,518</td>
<td>$1,899,072,656</td>
<td>$1,511,849,321</td>
<td>$945,490,294</td>
<td>$5,933,794,235</td>
</tr>
<tr>
<td>MEPS-HC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MEPS-NHC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Direct Non-Medical</td>
<td>$306,203,804</td>
<td>$2,195,358</td>
<td>$5,260,885</td>
<td>$3,704,973</td>
<td>$10,683,797</td>
<td>$328,048,817</td>
</tr>
<tr>
<td>MEPS-HC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indirect Morbidity</td>
<td>$187,785,712</td>
<td>$130,294,446</td>
<td>$0</td>
<td>$70,016,070</td>
<td>$1,639,770</td>
<td>$389,735,998</td>
</tr>
<tr>
<td>MEPS-HC (Missed Work)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indirect Morbidity</td>
<td>$1,222,119,449</td>
<td>$1,690,317,670</td>
<td>$2,896,295,014</td>
<td>$3,018,991,118</td>
<td>$791,880,283</td>
<td>$9,619,603,534</td>
</tr>
<tr>
<td>MEPS-HC (Bed Days)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indirect Mortality</td>
<td>$127,188,577</td>
<td>$151,166,243</td>
<td>$174,577,120</td>
<td>$198,850,591</td>
<td>$209,748,339</td>
<td>$861,530,870</td>
</tr>
<tr>
<td>NVSS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Annual Total</td>
<td>$6,110,163,873</td>
<td>$6,644,667,598</td>
<td>$8,896,770,463</td>
<td>$8,921,377,068</td>
<td>$6,312,443,792</td>
<td>$36,885,422,794</td>
</tr>
<tr>
<td>Annual Total in 2003 Dollars</td>
<td>$7,132,887,874</td>
<td>$7,427,839,237</td>
<td>$9,522,046,166</td>
<td>$9,265,885,252</td>
<td>$6,312,443,792</td>
<td>$39,661,102,321</td>
</tr>
</tbody>
</table>

Table 4-6. Unweighted and Weighted Number and Cost of Prescription Medication from the MEPS-HC 1999-2003 for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Year</th>
<th>Unweighted Number</th>
<th>Weighted Number</th>
<th>Unweighted Cost</th>
<th>Weighted Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td>330</td>
<td>5,092,013</td>
<td>$28,087</td>
<td>$420,603,519</td>
</tr>
<tr>
<td>2000</td>
<td>473</td>
<td>4,917,244</td>
<td>$37,121</td>
<td>$377,857,783</td>
</tr>
<tr>
<td>2001</td>
<td>613</td>
<td>5,301,378</td>
<td>$49,015</td>
<td>$398,453,297</td>
</tr>
<tr>
<td>2002</td>
<td>514</td>
<td>4,980,544</td>
<td>$37,912</td>
<td>$361,345,738</td>
</tr>
<tr>
<td>2003</td>
<td>432</td>
<td>4,764,877</td>
<td>$36,377</td>
<td>$422,955,793</td>
</tr>
<tr>
<td>Overall</td>
<td>2,362</td>
<td>25,056,056</td>
<td>$188,512</td>
<td>$1,981,216,130</td>
</tr>
</tbody>
</table>


Table 4-7. Unweighted and Weighted Number and Cost of Office-Based Visits from the MEPS-HC 1999-2003 for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Year</th>
<th>Unweighted Number</th>
<th>Weighted Number</th>
<th>Unweighted Cost</th>
<th>Weighted Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td>61</td>
<td>961,463</td>
<td>$6,378</td>
<td>$94,378,654</td>
</tr>
<tr>
<td>2000</td>
<td>66</td>
<td>654,821</td>
<td>$7,108</td>
<td>$71,916,205</td>
</tr>
<tr>
<td>2001</td>
<td>202</td>
<td>1,922,768</td>
<td>$23,218</td>
<td>$243,053,730</td>
</tr>
<tr>
<td>2002</td>
<td>165</td>
<td>1,716,046</td>
<td>$15,063</td>
<td>$141,817,647</td>
</tr>
<tr>
<td>2003</td>
<td>148</td>
<td>1,559,291</td>
<td>$12,201</td>
<td>$117,064,110</td>
</tr>
<tr>
<td>Overall</td>
<td>642</td>
<td>6,814,389</td>
<td>$63,968</td>
<td>$668,230,346</td>
</tr>
</tbody>
</table>

Table 4-8. Unweighted and Weighted Number and Cost of Emergency Room Visits from the MEPS-HC 1999-2003 for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Year</th>
<th>Unweighted Number</th>
<th>Weighted Number</th>
<th>Unweighted Cost</th>
<th>Weighted Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td>0</td>
<td>0</td>
<td>$0</td>
<td>$0</td>
</tr>
<tr>
<td>2000</td>
<td>1</td>
<td>16,933</td>
<td>$279</td>
<td>$4,725,475</td>
</tr>
<tr>
<td>2001</td>
<td>4</td>
<td>38,898</td>
<td>$1957</td>
<td>$18,270,344</td>
</tr>
<tr>
<td>2002</td>
<td>1</td>
<td>13,813</td>
<td>$518</td>
<td>$7,166,445</td>
</tr>
<tr>
<td>2003</td>
<td>3</td>
<td>29,551</td>
<td>$703</td>
<td>$9,347,535</td>
</tr>
<tr>
<td>Overall Total</td>
<td>9</td>
<td>99,195</td>
<td>$3,459</td>
<td>$39,509,801</td>
</tr>
</tbody>
</table>


Table 4-9. Unweighted and Weighted Number and Cost of Inpatient Hospitals Stays from the MEPS-HC 1999-2003 for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Year</th>
<th>Unweighted Number</th>
<th>Weighted Number</th>
<th>Unweighted Cost</th>
<th>Weighted Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td>0</td>
<td>0</td>
<td>$0</td>
<td>$0</td>
</tr>
<tr>
<td>2000</td>
<td>1</td>
<td>9,943</td>
<td>$16,656</td>
<td>$165,632,204</td>
</tr>
<tr>
<td>2001</td>
<td>2</td>
<td>32,588</td>
<td>$21,322</td>
<td>$397,575,101</td>
</tr>
<tr>
<td>2002</td>
<td>2</td>
<td>29,118</td>
<td>$7,926</td>
<td>$333,957,291</td>
</tr>
<tr>
<td>2003</td>
<td>3</td>
<td>19,567</td>
<td>$42,407</td>
<td>$194,340,095</td>
</tr>
<tr>
<td>Overall Total</td>
<td>8</td>
<td>91,216</td>
<td>$88,311</td>
<td>$1,091,504,691</td>
</tr>
</tbody>
</table>

Table 4-10. Unweighted and Weighted Number and Cost of Outpatient Visits from the MEPS-HC 1999-2003 for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Year</th>
<th>Unweighted Number</th>
<th>Weighted Number</th>
<th>Unweighted Cost</th>
<th>Weighted Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td>23</td>
<td>201,333</td>
<td>$3,709</td>
<td>$28,505,556</td>
</tr>
<tr>
<td>2000</td>
<td>8</td>
<td>80,603</td>
<td>$ 594</td>
<td>$ 5,968,446</td>
</tr>
<tr>
<td>2001</td>
<td>3</td>
<td>39,913</td>
<td>$6,170</td>
<td>$77,255,493</td>
</tr>
<tr>
<td>2002</td>
<td>13</td>
<td>186,100</td>
<td>$7,456</td>
<td>$88,032,415</td>
</tr>
<tr>
<td>Overall Total</td>
<td>74</td>
<td>807,181</td>
<td>$21,201</td>
<td>$229,870,733</td>
</tr>
</tbody>
</table>


Table 4-11. Unweighted and Weighted Number and Cost of Home Health Visits from the MEPS-HC 1999-2003 for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Year</th>
<th>Unweighted Number</th>
<th>Weighted Number</th>
<th>Unweighted Cost</th>
<th>Weighted Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td>49</td>
<td>665,495</td>
<td>$8,382</td>
<td>$130,220,717</td>
</tr>
<tr>
<td>2000</td>
<td>38</td>
<td>369,242</td>
<td>$25,890</td>
<td>$277,573,403</td>
</tr>
<tr>
<td>2001</td>
<td>99</td>
<td>1,653,407</td>
<td>$59,839</td>
<td>$764,464,690</td>
</tr>
<tr>
<td>2002</td>
<td>62</td>
<td>965,950</td>
<td>$36,519</td>
<td>$579,529,784</td>
</tr>
<tr>
<td>2003</td>
<td>47</td>
<td>335,115</td>
<td>$50,423</td>
<td>$171,673,936</td>
</tr>
<tr>
<td>Overall Total</td>
<td>295</td>
<td>3,989,209</td>
<td>$181,053</td>
<td>$1,923,462,530</td>
</tr>
</tbody>
</table>


<table>
<thead>
<tr>
<th>1996 Nursing Home Costs</th>
<th>CPI&lt;sup&gt;a&lt;/sup&gt; (Year)</th>
<th>Adjusted Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>$3,219,675,524</td>
<td>X 111.6 (1999)</td>
<td>$3,593,157,885</td>
</tr>
<tr>
<td>$3,219,675,524</td>
<td>X 121.8 (2001)</td>
<td>$3,921,564,788</td>
</tr>
<tr>
<td>$3,219,675,524</td>
<td>X 127.9 (2002)</td>
<td>$4,117,964,995</td>
</tr>
<tr>
<td>$3,219,675,524</td>
<td>X 135.2 (2003)</td>
<td>$4,353,001,309</td>
</tr>
</tbody>
</table>

<sup>a</sup>Consumer Price Index for Nursing Homes (1996 base year)

Table 4-13. Unweighted and Weighted Number and Cost of Direct Non-Medical Expenses from the MEPS-HC 1999-2003 for Patients with Parkinson's Disease.

<table>
<thead>
<tr>
<th>Year</th>
<th>Unweighted Number</th>
<th>Weighted Number</th>
<th>Unweighted Cost</th>
<th>Weighted Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td>2</td>
<td>17,462</td>
<td>$35,070</td>
<td>$306,203,804</td>
</tr>
<tr>
<td>2000</td>
<td>4</td>
<td>37,264</td>
<td>$233</td>
<td>$2,195,357</td>
</tr>
<tr>
<td>2001</td>
<td>6</td>
<td>56,006</td>
<td>$574</td>
<td>$5,260,885</td>
</tr>
<tr>
<td>2002</td>
<td>4</td>
<td>48,015</td>
<td>$435</td>
<td>$3,704,972</td>
</tr>
<tr>
<td>2003</td>
<td>11</td>
<td>155,318</td>
<td>$765</td>
<td>$10,683,797</td>
</tr>
<tr>
<td>Overall</td>
<td>27</td>
<td>314,065</td>
<td>$37,077</td>
<td>$328,048,815</td>
</tr>
</tbody>
</table>

Table 4-14. Morbidity: Missed Work Days Weighted and Unweighted from the MEPS-HC 1999-2003 for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Year</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>115</td>
<td>109</td>
<td>0</td>
<td>145</td>
<td>1</td>
<td>370</td>
</tr>
<tr>
<td>Total # Days of Missed Work (Unweighted)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Males</td>
<td>115</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>115</td>
</tr>
<tr>
<td>- Females</td>
<td>0</td>
<td>109</td>
<td>0</td>
<td>145</td>
<td>1</td>
<td>255</td>
</tr>
<tr>
<td>Total # Days of Missed Work Weighted</td>
<td>1,362,669</td>
<td>1,728,723</td>
<td>0</td>
<td>673,231</td>
<td>13,224</td>
<td>3,777,847</td>
</tr>
<tr>
<td>- Males</td>
<td>1,362,669</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1,362,669</td>
</tr>
<tr>
<td>- Females</td>
<td>0</td>
<td>1,728,723</td>
<td>0</td>
<td>673,231</td>
<td>13,224</td>
<td>2,415,178</td>
</tr>
<tr>
<td>Cost Unweighted</td>
<td>$15,510</td>
<td>$10,205</td>
<td>$0</td>
<td>$15,080</td>
<td>$124</td>
<td>$40,919</td>
</tr>
<tr>
<td>- Males</td>
<td>$15,510</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
<td>$15,510</td>
</tr>
<tr>
<td>- Females</td>
<td>$0</td>
<td>$10,205</td>
<td>$0</td>
<td>$15,080</td>
<td>$124</td>
<td>$25,409</td>
</tr>
<tr>
<td>Cost Weighted</td>
<td>$187,785,712</td>
<td>$130,294,446</td>
<td>$0</td>
<td>$70,016,070</td>
<td>$1,639,770</td>
<td>$389,735,998</td>
</tr>
<tr>
<td>- Males</td>
<td>$187,785,712</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
<td>$187,785,712</td>
</tr>
<tr>
<td>- Females</td>
<td>$0</td>
<td>$130,294,446</td>
<td>$0</td>
<td>$70,016,070</td>
<td>$1,639,770</td>
<td>$201,950,286</td>
</tr>
</tbody>
</table>

Table 4.15. Morbidity: Bed Days Weighted and Unweighted from the MEPS-HC 1999-2003 for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Year</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total # bed days (Unweighted)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Males</td>
<td>1228</td>
<td>1423</td>
<td>1812</td>
<td>2029</td>
<td>964</td>
<td>7456</td>
</tr>
<tr>
<td>- Females</td>
<td>1</td>
<td>411</td>
<td>1026</td>
<td>715</td>
<td>426</td>
<td>2579</td>
</tr>
<tr>
<td>Total # bed days Weighted</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Males</td>
<td>12,899,666</td>
<td>6,626,179</td>
<td>12,561,305</td>
<td>24,655,415</td>
<td>3,056,579</td>
<td>59,799,144</td>
</tr>
<tr>
<td>- Females</td>
<td>16,819</td>
<td>10,866,542</td>
<td>17,767,699</td>
<td>5,477,419</td>
<td>3,920,400</td>
<td>38,048,879</td>
</tr>
</tbody>
</table>

Cost

<table>
<thead>
<tr>
<th>Cost</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unweighted</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Males</td>
<td>$127,743</td>
<td>$145,466</td>
<td>$174,282</td>
<td>$196,071</td>
<td>$116,632</td>
<td>$760,194</td>
</tr>
<tr>
<td>- Females</td>
<td>$74</td>
<td>$30,710</td>
<td>$83,106</td>
<td>$59,345</td>
<td>$35,709</td>
<td>$208,944</td>
</tr>
<tr>
<td>Weighted</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Males</td>
<td>$1,220,874,852</td>
<td>$1,194,018,178</td>
<td>$1,457,111,337</td>
<td>$2,564,365,346</td>
<td>$460,270,577</td>
<td>$6,896,640,290</td>
</tr>
<tr>
<td>- Females</td>
<td>$1,244,596</td>
<td>$496,299,492</td>
<td>$1,439,183,677</td>
<td>$454,625,772</td>
<td>$331,609,706</td>
<td>$2,722,963,243</td>
</tr>
</tbody>
</table>

Table 4-16. Mortality due to Parkinson’s Disease from the 1999-2003 NVSS.

<table>
<thead>
<tr>
<th>Year</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total # of deaths</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total # Males</td>
<td>8,262</td>
<td>8,804</td>
<td>9,405</td>
<td>9,593</td>
<td>10,183</td>
<td>46,247</td>
</tr>
<tr>
<td>-Black Males</td>
<td>270</td>
<td>308</td>
<td>294</td>
<td>313</td>
<td>352</td>
<td>1,537</td>
</tr>
<tr>
<td>-White Males</td>
<td>7,880</td>
<td>8,367</td>
<td>8,982</td>
<td>9,130</td>
<td>9,632</td>
<td>43,991</td>
</tr>
<tr>
<td>-Other Males</td>
<td>112</td>
<td>129</td>
<td>129</td>
<td>150</td>
<td>199</td>
<td>719</td>
</tr>
<tr>
<td>Total # Females</td>
<td>6,331</td>
<td>6,878</td>
<td>7,139</td>
<td>7,366</td>
<td>7,819</td>
<td>35,533</td>
</tr>
<tr>
<td>-Black Females</td>
<td>237</td>
<td>226</td>
<td>257</td>
<td>244</td>
<td>278</td>
<td>1,242</td>
</tr>
<tr>
<td>-White Females</td>
<td>6,006</td>
<td>6,575</td>
<td>6,775</td>
<td>7,005</td>
<td>7,416</td>
<td>33,777</td>
</tr>
<tr>
<td>-Other Females</td>
<td>88</td>
<td>77</td>
<td>107</td>
<td>117</td>
<td>125</td>
<td>514</td>
</tr>
<tr>
<td>Deaths prior to life expectancy</td>
<td>5,190</td>
<td>3,616</td>
<td>7,014</td>
<td>3,774</td>
<td>8,275</td>
<td>27,869</td>
</tr>
</tbody>
</table>

Table 4-17. Mortality Costs due to Parkinson’s Disease from the 1999-2003 NVSS.

<table>
<thead>
<tr>
<th>Total Mortality Costs by year, gender and race</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>$92,163,647</td>
<td>$104,530,444</td>
<td>$130,760,828</td>
<td>$138,443,536</td>
<td>$131,584,795</td>
<td>$597,483,250</td>
</tr>
<tr>
<td>White</td>
<td>$90,666,767</td>
<td>$100,932,467</td>
<td>$122,942,250</td>
<td>$135,254,453</td>
<td>$127,833,039</td>
<td>$577,628,976</td>
</tr>
<tr>
<td>Black</td>
<td>$1,496,880</td>
<td>$3,597,977</td>
<td>$7,818,578</td>
<td>$3,189,083</td>
<td>$3,751,756</td>
<td>$19,854,274</td>
</tr>
<tr>
<td>Females</td>
<td>$35,024,928</td>
<td>$46,635,798</td>
<td>$43,816,291</td>
<td>$60,407,054</td>
<td>$78,163,542</td>
<td>$264,047,613</td>
</tr>
<tr>
<td>White</td>
<td>$32,718,630</td>
<td>$44,817,877</td>
<td>$41,469,299</td>
<td>$57,921,266</td>
<td>$73,971,395</td>
<td>$250,898,467</td>
</tr>
<tr>
<td>Black</td>
<td>$2,306,297</td>
<td>$1,817,920</td>
<td>$2,346,991</td>
<td>$2,485,787</td>
<td>$4,192,147</td>
<td>$13,149,142</td>
</tr>
<tr>
<td>Average Mortality Costs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>$27,651</td>
<td>$70,390</td>
<td>$36,322</td>
<td>$81,822</td>
<td>$33,657</td>
<td>$249,842</td>
</tr>
<tr>
<td>White</td>
<td>$27,811</td>
<td>$69,608</td>
<td>$13,687</td>
<td>$84,534</td>
<td>$33,516</td>
<td>$229,156</td>
</tr>
<tr>
<td>Black</td>
<td>$20,505</td>
<td>$102,799</td>
<td>$26,593</td>
<td>$34,663</td>
<td>$38,677</td>
<td>$223,237</td>
</tr>
<tr>
<td>Females</td>
<td>$18,861</td>
<td>$21,884</td>
<td>$10,915</td>
<td>$29,013</td>
<td>$17,910</td>
<td>$98,583</td>
</tr>
<tr>
<td>White</td>
<td>$18,106</td>
<td>$21,851</td>
<td>$6,120</td>
<td>$28,448</td>
<td>$17,417</td>
<td>$91,942</td>
</tr>
<tr>
<td>Black</td>
<td>$46,125</td>
<td>$22,724</td>
<td>$9,132</td>
<td>$54,038</td>
<td>$35,830</td>
<td>$167,849</td>
</tr>
<tr>
<td>Total Mortality Costs</td>
<td>$127,188,577</td>
<td>$151,166,243</td>
<td>$174,577,120</td>
<td>$198,850,591</td>
<td>$209,748,339</td>
<td>$861,530,870</td>
</tr>
</tbody>
</table>

of weighted and unweighted prescription medications were reported in 2001 by patients with Parkinson's disease. Unweighted medication costs were highest in 2001, however weighted prescription medication costs were the highest in 2003.

Table 4-7 provides the overall breakdown of office based utilization and costs for 1999-2003. Office based visits was the second most frequently occurring MEPS-HC component reported by patients with Parkinson's disease. Approximately seven million weighted visits were reported from 1999-2003. The year 2001 had the most (28.2%) weighted visits and the most (31.4%) unweighted visits. The year 2001 also had the highest weighted costs (36.2%) and unweighted costs (36.3%) for office-based visits.

Table 4-8 provides an overall breakdown of the number and cost of emergency room visits for patients with Parkinson's disease from 1999-2003. Emergency room visits had the second lowest occurrence of the MEPS-HC components and had the lowest cost of all the MEPS-HC direct cost components. In 1999, no one reported visiting an emergency room due to Parkinson's disease in the MEPS-HC sample. The largest percentage (39.2%) occurred in 2001 and represented almost half of the five year total costs for emergency room visits.

Table 4-9 provides the overall breakdown of the number and cost of inpatient visits for patients with Parkinson's disease. Inpatient hospital stays had the lowest occurring frequency of visits reported, but represented the fourth highest weighted direct medical costs. In 1999, no one with Parkinson's disease in the MEPS-HC sample reported an inpatient hospital stay.

Table 4-10 provides an overall breakdown of the outpatient utilization and costs for patients with Parkinson's disease. The highest number of outpatient visits occurred in 2003. The largest percentage (38.2%) of the outpatient visit costs occurred in 2002. The
fewest outpatient visits occurred in 2001; however, the second highest percentage (33.6%) of outpatient visit costs occurred in 2001.

Table 4-11 depicts an overall breakdown of the number and cost of home health visits for patients with Parkinson’s disease between 1999 and 2003. Home health visits for patients with Parkinson’s disease represented the third highest direct medical costs. Between 1999 and 2003 a total of just over $1.9 billion was spent on home health visits for patients with Parkinson’s disease. The largest percentage (33.3%) of home health visits and costs for home health visits occurred in 2001.

**Nursing Home Cost**

Table 4-12 provides nursing home costs for patients with Parkinson’s disease using the Nursing Home Consumer Price Index for 1999-2003. The weighted total for nursing home costs for patients with Parkinson’s disease in 1996 was $3.2 billion. The weighted total nursing home expenses for males in 1996 was $1.14 billion and for females the weighted total was $2.08 billion. Using the Nursing Home Consumer Price Index for 2003, nursing home costs in 2003 dollars would be approximately $4.4 billion. Nursing Home costs were estimated for each of the corresponding years for which MEPS-HC data were analyzed. Between 1999 and 2003, the total Nursing Home costs were $19,752,709,342, and the annual average was $3,950,541,868. Table 4-13 presents an overall breakdown of direct non-medical expenses for patients with Parkinson’s disease in the MEPS-HC for the years 1999-2003. These other medical expenses include modifications to the home, such as handrails in the shower and raised toilet seats. Other medical expenses were the third lowest cost component of MEPS-HC. The fewest other medical expenses occurred in 1999, however this was also the highest year for costs due
to other medical expenses. Over ninety-three percent of the costs for other medical expenses occurred in 1999. The smallest amount for other medical expenses was reported the following year in 2000.

**Morbidity Costs: Missed Work and Bed Days**

Tables 4-14 and 4-15 provide a breakdown of the morbidity costs (weighted and unweighted) associated with Parkinson’s disease for 1999-2003. The total cost of missed work days was $389,735,998 for the five year period. Table 4-14 provides a full breakdown of missed work days by gender. In 2001, no one in the MEPS-HC sample reported having missed work due to Parkinson’s disease. The largest number of work days missed were reported in 1999. Also, in 1999, the highest cost for missed work days was reported by patients with Parkinson’s disease. The majority of work days missed (68.9%) were reported by females at a cost of $201,950,286. Table 4-15 provides a breakdown of the number of bed days reported by patients with Parkinson’s disease. At a five year total cost of $9,619,603,533 bed days represented the largest portion (96%) of morbidity costs for patients with Parkinson’s disease. The largest percentage (65.4%) of bed days were reported by men with Parkinson’s disease.

**Mortality Costs**

The previous Tables provided an overview of the number of deaths (Table 4-16) and mortality costs (Table 4-17) for people with Parkinson’s disease between the 1999 and 2003. Table 4-16 provides a brief overview of the number of people who died from Parkinson’s disease by gender. The number of deaths due to Parkinson’s disease increased every year from 1999-2003. Of the 81,870 deaths due to Parkinson’s disease
between the years 1999-2003, males accounted for 56.5% of the total. Based on race and gender, a total of 34% (27,869) of deaths due to Parkinson’s disease occurred prior to life expectancy. The largest number of deaths prior to life expectancy due to Parkinson’s disease occurred in 2003.

Table 4-17 expands the mortality data further by gender and race. In addition, Table 4-17 provides the average mortality cost for Parkinson’s disease and the overall cost of mortality by gender and race. The overall mortality cost due to Parkinson’s disease was $861,530,870. Approximately one-fourth (24.3%) of mortality costs due to Parkinson’s disease occurred in 2003. From 1999-2003, mortality costs due to Parkinson’s disease increased steadily. Overall, from 1999-2003 mortality costs due to Parkinson’s disease were highest for white males at $577,628,976 followed by white females at $250,898,467. Black females represented the lowest mortality costs ($13,149,142) due to Parkinson’s disease.

Statistical Analysis of Direct and Indirect Costs

The following section provides the statistical analysis of the direct and indirect costs obtained from the MEPS-HC for study objectives 3-9.

Table 4-18 provides the overall mean for total cost of Parkinson’s disease (minus mortality costs and nursing home costs) for the patients in the combined or “pooled” sample. The unweighted total number of people in the MEPS-HC was 233. In order to have these patients in a single file representing one year, the assigned patient weights for each person were divided by 5 (the number of years of MEPS-HC data used) and the cost totals for each year were multiplied by the CPI for the year 2003 (the last year of data
Table 4-18. Mean Overall Total Costs (Minus Nursing Home and Mortality Costs) from the Combined MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Weighted Number (unweighted number)</th>
<th>Mean</th>
<th>Standard Error</th>
<th>Overall Total Pooled Cost</th>
<th>95% Confidence Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>525,154 (233)</td>
<td>$5,365</td>
<td>$819</td>
<td>$2,817,451,210</td>
<td>$3,712-$7,019</td>
</tr>
</tbody>
</table>

used in this study). These 233 patients with Parkinson’s disease represented 525,154 United States citizens and accounted for a total cost (minus mortality costs and nursing home costs) of $2,817,451,210. The mean overall cost for Parkinson’s disease per home patient was $5,365 per year.

For objective 3, a t-test was used to determine if there was a statistically significant difference in the mean cost of illness between men and women. Table 4-19 provides the results of the t-test between the mean cost of illness (excluding nursing home and mortality costs) for men and women with Parkinson’s disease. The mean cost of illness for males with Parkinson’s disease was $6,256 and the mean cost of illness for females with Parkinson’s disease was $4,287. Based on the results of the t-test, a statistically significant difference does not exist between males and females and the mean cost of illness in Parkinson’s disease.

Table 4-20 provides the mean, standard error and 95% confidence limits for cost of illness in Parkinson’s disease (minus nursing home and mortality costs) based on age groups. The 233 patients with a positive weight values were divided into three age categories: 1) under age 65, 2) age 65 to 84 and 3) age 85 and older. Those under the age of 65 reported the highest mean average for overall expenses related to Parkinson’s disease. The lowest mean average for overall expenses related to Parkinson’s disease was reported by those over the age of 85.

Table 4-21 provides the results of the One-Way ANOVA that was used to test for a significant mean difference in the cost of illness (minus nursing home and mortality costs) for patients with Parkinson’s disease among age groups. Age group did not have a statistically significant impact on the mean overall cost of Parkinson’s disease.
Table 4-19. T-Test Between Males and Females for Overall Total Costs (Minus Nursing Home and Mortality Costs) from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Gender</th>
<th>Weighted Number (unweighted number)</th>
<th>Mean</th>
<th>Weighted Cost</th>
<th>S.E.</th>
<th>t-Value</th>
<th>Probability of t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>287,417 (117)</td>
<td>$6,257</td>
<td>$1,798,343,627</td>
<td>$1,261</td>
<td>1.16</td>
<td>.2483</td>
</tr>
<tr>
<td>Female</td>
<td>237,737 (116)</td>
<td>$4,287</td>
<td>$1,019,136,621</td>
<td>$1,121</td>
<td>1.16</td>
<td>.2483</td>
</tr>
</tbody>
</table>


Table 4-20. Mean Overall Total Costs (Minus Nursing Home and Mortality Costs) for Age Categories from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Age</th>
<th>N</th>
<th>Mean</th>
<th>Standard Error</th>
<th>95% Confidence Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 65</td>
<td>75,507 (43)</td>
<td>$5,691</td>
<td>$1,635</td>
<td>$2,440-$8,942</td>
</tr>
<tr>
<td>65-84</td>
<td>352,233 (156)</td>
<td>$5,420</td>
<td>$1,156</td>
<td>$3,102-$7,739</td>
</tr>
<tr>
<td>85 and Over</td>
<td>97,414 (34)</td>
<td>$4,912</td>
<td>$1,881</td>
<td>$1,174-$8,649</td>
</tr>
</tbody>
</table>

Table 4-21. ANOVA Results for Age Categories for Overall Total Costs (Minus Nursing Home and Mortality Costs) from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Degrees of Freedom</th>
<th>F Value</th>
<th>Probability of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>2</td>
<td>0.04</td>
<td>0.956</td>
</tr>
</tbody>
</table>

Table 4-22 provides the results of the t-test for a significant difference in the cost of illness (minus nursing home and mortality costs) for Parkinson’s disease among different education levels. Education level and mean cost of illness for Parkinson’s disease was not statistically significant at the 0.05 significance level.

Table 4-23 provides the mean, standard error and 95% confidence limits for cost of illness in Parkinson’s disease for the variable income. Patients with incomes over $30,000 a year had the highest mean for total overall costs.

Table 4-24 provides the results of the One-Way ANOVA that was used to test for differences in overall total cost of illness between income categories. A significant relationship was not found to exist between income level and overall cost of illness for Parkinson’s disease.

Table 4-25 provides the mean, standard error and 95% confidence limits for the overall cost of illness in Parkinson’s disease for the variable marital status. The largest mean difference between marital status categories for patients with Parkinson’s disease was found to exist between patients who were widowed and patients who were single.

Table 4-26 provides the results of the One-Way ANOVA that was used to test for differences in overall total cost of illness and marital status. No significant difference was found between marital status and the mean overall total cost of illness for patients with Parkinson’s disease.

Table 4-27 provides the mean, standard error and 95% confidence limits for cost of illness in Parkinson’s disease for the variable region. The largest mean cost of Parkinson’s disease was found in the South. Thirty-seven percent of the weighted sample and forty percent of the unweighted sample resided in the Southern region of the United States. The largest difference in mean overall total costs for Parkinson’s disease among

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Table 4-22. T-Test Between Education Level and Mean for Overall Total Costs (Minus Nursing Home and Mortality Costs) from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Education Level</th>
<th>Weighted Number (unweighted number)</th>
<th>Mean</th>
<th>95% Confidence Limits</th>
<th>t-Value</th>
<th>Probability of t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than High School</td>
<td>157,324 (90)</td>
<td>$7,119</td>
<td>$2,878-$11,360</td>
<td>1.75</td>
<td>0.0812</td>
</tr>
<tr>
<td>High School or Higher</td>
<td>367,830 (143)</td>
<td>$4,615</td>
<td>$2,689-$6541</td>
<td>1.75</td>
<td>0.0812</td>
</tr>
</tbody>
</table>


Table 4-23. Mean Overall Total Costs (Minus Nursing Home and Mortality Costs) and Income Level from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Income</th>
<th>Weighted Number (Unweighted Number)</th>
<th>Mean</th>
<th>Standard Error</th>
<th>95% Confidence Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than $19,999</td>
<td>350,861 (164)</td>
<td>$5,183</td>
<td>$1,051</td>
<td>$3,070-$7,296</td>
</tr>
<tr>
<td>$20,000-$29,999</td>
<td>71,494 (28)</td>
<td>$4,143</td>
<td>$1,474</td>
<td>$1,212-$7,073</td>
</tr>
<tr>
<td>$30,000 and over</td>
<td>102,798 (41)</td>
<td>$6,836</td>
<td>$2,040</td>
<td>$2,776-$10,896</td>
</tr>
</tbody>
</table>

Table 4-24. ANOVA Results and Income Level for Overall Total Costs (Minus Nursing Home and Mortality Costs) from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Degrees of Freedom</th>
<th>F-Value</th>
<th>Probability of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Income</td>
<td>2</td>
<td>0.50</td>
<td>0.6095</td>
</tr>
</tbody>
</table>


Table 4-25. Mean Overall Total Costs (Minus Nursing Home and Mortality Costs) and Marital Status from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Marital Status</th>
<th>Weighted Number (unweighted number)</th>
<th>Mean</th>
<th>Standard Error</th>
<th>95% Confidence Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>74,830 (41)</td>
<td>$5,330</td>
<td>$1,903</td>
<td>$1,548-$9,112</td>
</tr>
<tr>
<td>Widowed</td>
<td>277,494 (115)</td>
<td>$5,530</td>
<td>$1,304</td>
<td>$2,925-$8,134</td>
</tr>
<tr>
<td>Single</td>
<td>172,829 (77)</td>
<td>$5,116</td>
<td>$1,348</td>
<td>$2,430-$7,801</td>
</tr>
</tbody>
</table>

Table 4-26. ANOVA Results Between Marital Status Categories for Overall Total Costs (Minus Nursing Home and Mortality Costs) from the MEPS-HC for Patients with Parkinson's Disease.

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Degrees of Freedom</th>
<th>F Value</th>
<th>Probability of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marital Status</td>
<td>2</td>
<td>0.02</td>
<td>0.9808</td>
</tr>
</tbody>
</table>


Table 4-27. Mean Overall Total Costs (Minus Nursing Home and Mortality Costs) and Region of Residence from the MEPS-HC for Patients with Parkinson's Disease.

<table>
<thead>
<tr>
<th>Region</th>
<th>Weighted Number (unweighted number)</th>
<th>Mean</th>
<th>Standard Error</th>
<th>95% Confidence Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northeast</td>
<td>95,170 (37)</td>
<td>$2,828</td>
<td>$638</td>
<td>$1,560-$4,095</td>
</tr>
<tr>
<td>Mid-West</td>
<td>118,132 (51)</td>
<td>$4,663</td>
<td>$1,783</td>
<td>$1,121-$8,205</td>
</tr>
<tr>
<td>South</td>
<td>196,153 (93)</td>
<td>$6,765</td>
<td>$1,605</td>
<td>$3,572-$9,958</td>
</tr>
<tr>
<td>West</td>
<td>115,699 (52)</td>
<td>$5,796</td>
<td>$1,712</td>
<td>$2,394-$9,198</td>
</tr>
</tbody>
</table>

regions in the United States was found between the Northeast and South. The smallest difference between the means among regions was found between the South and West.

Table 4-28 provides the results of the One-Way ANOVA procedure that was used to test for differences in overall total cost of illness by region of residence. A significant relationship was not found to exist for region of residence and overall cost of illness for Parkinson’s disease.

Table 4-29 provides the results of the multiple regression model for overall total cost of illness for Parkinson’s disease (minus nursing home costs and mortality costs). When selected demographics were held constant, no significant difference was found to exist between any of the selected demographics and overall total cost of illness for Parkinson’s disease.

Table 4-30 provides the coefficients for the linear regression model for overall total cost of illness for Parkinson’s disease (minus nursing home costs and mortality costs). No significant difference was found to exist between any of the selected demographics and overall total cost of illness for Parkinson’s disease.

The following section provides the statistical analysis for direct medical costs of Parkinson’s disease (minus nursing home costs) for the selected demographics.

Table 4-31 shows the overall mean and standard error for direct medical costs (minus nursing home costs) for the 525,154 patients with Parkinson’s disease. The mean direct medical cost of Parkinson’s disease was $1,755 per year.

Table 4-32 provides the results of the t-test for direct medical costs (minus nursing home costs) between males and females. The difference between mean direct medical costs for males and females was $571 annually. A significant difference between males and females and the mean direct medical costs for was not found to exist.
Table 4-28. ANOVA Results Between Region of Residence for Overall Total Costs (Minus Nursing Home and Mortality Costs) from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Degrees of Freedom</th>
<th>F Value</th>
<th>Probability of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Region of Residence</td>
<td>3</td>
<td>1.84</td>
<td>0.147</td>
</tr>
</tbody>
</table>


Table 4-29. F Value and Degrees of Freedom for the Overall Regression Model Results for Overall Total Costs (Minus Nursing Home and Mortality Costs) and Selected Demographics from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Effect</th>
<th>Degrees of Freedom</th>
<th>F Value</th>
<th>Probability of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Model</td>
<td>11</td>
<td>1.29</td>
<td>.248</td>
</tr>
<tr>
<td>Gender</td>
<td>1</td>
<td>1.94</td>
<td>.168</td>
</tr>
<tr>
<td>Age</td>
<td>2</td>
<td>0.00</td>
<td>.995</td>
</tr>
<tr>
<td>Education</td>
<td>1</td>
<td>.99</td>
<td>.323</td>
</tr>
<tr>
<td>Income</td>
<td>2</td>
<td>.48</td>
<td>.618</td>
</tr>
<tr>
<td>Marital Status</td>
<td>2</td>
<td>.12</td>
<td>.888</td>
</tr>
<tr>
<td>Region of Residence</td>
<td>3</td>
<td>1.69</td>
<td>.173</td>
</tr>
</tbody>
</table>

Table 4-30. Coefficients for Linear Regression for Overall Total Costs (Minus Nursing Home and Mortality Costs) and Selected Demographics from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Estimate</th>
<th>Probability of t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>-$2,652</td>
<td>0.1680</td>
</tr>
<tr>
<td>Education Level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than High School</td>
<td>$2,761</td>
<td>0.3232</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 65</td>
<td>-$171</td>
<td>0.9611</td>
</tr>
<tr>
<td>65-84</td>
<td>-$251</td>
<td>0.9260</td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $20,000</td>
<td>-$2,737</td>
<td>0.3373</td>
</tr>
<tr>
<td>$20,000-$30,000</td>
<td>-$2,309</td>
<td>0.3902</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>-$1,498</td>
<td>0.6765</td>
</tr>
<tr>
<td>Widowed</td>
<td>-$1,017</td>
<td>0.6616</td>
</tr>
<tr>
<td>Region of Residence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northeast</td>
<td>-$3,112</td>
<td>0.1975</td>
</tr>
<tr>
<td>Mid-West</td>
<td>-$1,515</td>
<td>0.5931</td>
</tr>
<tr>
<td>South</td>
<td>$725</td>
<td>0.7495</td>
</tr>
</tbody>
</table>

Table 4-31. Mean Direct Medical Costs (Minus Nursing Home Costs) from the MEPS-HC 1999-2003 for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Weighted Number (unweighted number)</th>
<th>Mean</th>
<th>Standard Error</th>
<th>95% Confidence Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>525,154 (233)</td>
<td>$1,755</td>
<td>$140</td>
<td>$1,472-$2,039</td>
</tr>
</tbody>
</table>


Table 4-32. T-Test Between Males and Females for Direct Medical Costs (Minus Nursing Home Costs) from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Gender</th>
<th>Weighted Number (unweighted number)</th>
<th>Mean</th>
<th>95% Confidence Limits</th>
<th>t-Value</th>
<th>Probability of t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>287,417 (117)</td>
<td>$2,014</td>
<td>$1,573-$2,455</td>
<td>1.74</td>
<td>0.0858</td>
</tr>
<tr>
<td>Female</td>
<td>237,737 (116)</td>
<td>$1,443</td>
<td>$1,028-$1859</td>
<td>1.74</td>
<td>0.0858</td>
</tr>
</tbody>
</table>

Table 4-33 presents the mean direct medical costs (minus nursing home costs) for patients with Parkinson’s disease among age categories. Persons between the ages of 65 and 84 reported the lowest overall mean direct medical costs and comprised sixty-seven percent of patients with Parkinson’s disease in this study. Patients with Parkinson’s disease under the age of 65 reported the highest mean average for direct medical costs in this study. The largest difference between mean direct medical costs for Parkinson’s disease exists between patients under the age of 65 and those patients between 65 and 84 years old. The smallest difference between mean direct medical costs was found between patients under the age of 65 and those over 85 years old.

Table 4-34 provides the results of the One-Way ANOVA that was used to test for a significant mean difference in the direct medical costs (minus nursing home costs) for patients with Parkinson’s disease among age groups. Age group did not have a statistically significant impact on the mean direct medical costs of Parkinson’s disease.

Table 4-35 provides the results of the t-test and the mean direct medical costs (minus nursing home costs) for Parkinson’s disease and education level. The difference between the mean direct medical costs for Parkinson’s disease by education level was $25 and was found not to be statistically significant.

Table 4-36 provides the mean, standard error and 95% confidence limits for direct medical costs (minus nursing home costs) and income category. The largest mean direct medical costs were found among patients who had an annual income over $30,000. The majority (67%) of patients with Parkinson’s disease in this study reported having an annual income of less than $19,999. The smallest mean direct medical costs were reported by those patients whose income was between $20,000 and $29,999. The largest
Table 4-33. Mean Direct Medical Costs (Minus Nursing Home Costs) for Age Categories from the MEPS-HC for Patients with Parkinson's Disease.

<table>
<thead>
<tr>
<th>Age</th>
<th>Weighted Number (unweighted number)</th>
<th>Mean</th>
<th>Standard Error</th>
<th>95% Confidence Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 65</td>
<td>75,507 (43)</td>
<td>$2,291</td>
<td>$438</td>
<td>$1,420-$3,162</td>
</tr>
<tr>
<td>65-84</td>
<td>352,233 (156)</td>
<td>$1,497</td>
<td>$271</td>
<td>$953-$2,040</td>
</tr>
<tr>
<td>85 and Over</td>
<td>97,414 (34)</td>
<td>$2,276</td>
<td>$753</td>
<td>$780-$3,772</td>
</tr>
</tbody>
</table>


Table 4-34. ANOVA Results for Age Categories for Direct Medical Costs (Minus Nursing Home Costs) from the MEPS-HC for Patients with Parkinson's Disease.

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Degrees of Freedom</th>
<th>F Value</th>
<th>Probability of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>2</td>
<td>0.98</td>
<td>0.379</td>
</tr>
</tbody>
</table>


Table 4-35. T-Test Between Education Level and Mean for Direct Medical Costs (Minus Nursing Home Costs) from the MEPS-HC for Patients with Parkinson's Disease.

<table>
<thead>
<tr>
<th>Education Level</th>
<th>Weighted Number (unweighted number)</th>
<th>Mean</th>
<th>95% Confidence Limits</th>
<th>t-Value</th>
<th>Probability of t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than High School</td>
<td>157,324 (90)</td>
<td>$1,773</td>
<td>$909-$2,636</td>
<td>-0.04</td>
<td>0.9684</td>
</tr>
<tr>
<td>High School or Higher</td>
<td>367,830 (143)</td>
<td>$1,748</td>
<td>$1,270-$2,227</td>
<td>-0.04</td>
<td>0.9684</td>
</tr>
</tbody>
</table>

Table 4-36. Mean Direct Medical Costs (Minus Nursing Home Costs) and Income Level from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Income</th>
<th>Weighted Number (unweighted number)</th>
<th>Mean</th>
<th>Standard Error</th>
<th>95% Confidence Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than $19,999</td>
<td>350,861 (164)</td>
<td>$1,758</td>
<td>$298</td>
<td>$1,159-$2,358</td>
</tr>
<tr>
<td>$20,000-$29,999</td>
<td>71,494 (28)</td>
<td>$1,190</td>
<td>$260</td>
<td>$672-$1,708</td>
</tr>
<tr>
<td>$30,000 and over</td>
<td>102,798 (41)</td>
<td>$2,139</td>
<td>$617</td>
<td>$912-$3,367</td>
</tr>
</tbody>
</table>

difference between mean direct medical costs was between patients whose annual income was between $20,000 and $29,999 and those patients whose income was over $30,000 annually. The smallest difference between the mean direct medical costs for patients with Parkinson’s disease was between those who income was less than $19,999 and those whose income was over $30,000 annually.

Table 4-37 provides the results of the One-Way ANOVA that was used to test for differences in direct medical costs (minus nursing home costs) between income categories. A significant relationship was not found to exist between income level and overall cost of illness for Parkinson’s disease.

Table 4-38 provides the mean, standard error and 95% confidence limits for direct medical costs of Parkinson’s disease among the various marital categories. The smallest mean direct medical costs were reported by patients with Parkinson’s disease who were married. Married patients reported mean direct medical costs that were more than 50% less than patients who were single or widowed. The largest difference between mean direct medical costs for Parkinson’s disease was reported between married and single patients. The smallest difference in mean direct medical costs was reported between single and widowed patients.

Table 4-39 provides the results of the One-Way ANOVA for marital groups for direct medical costs (minus nursing home costs) for Parkinson’s disease. A significant difference was found to exist between marital groups and the mean direct medical cost of illness for patients with Parkinson’s disease at the 0.05 level.

Table 4-40 provides the mean, standard error and 95% confidence limits for direct medical costs for patients with Parkinson’s disease by region of residence. The largest mean direct medical costs for Parkinson’s disease were reported by patients living in the
Table 4-37. ANOVA Results Between Income Categories for Direct Medical Costs (Minus Nursing Home Costs) from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Degrees of Freedom</th>
<th>F-Value</th>
<th>Probability of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Income</td>
<td>2</td>
<td>2.32</td>
<td>0.105</td>
</tr>
</tbody>
</table>


Table 4-38. Mean Direct Medical Costs (Minus Nursing Home Costs) and Marital Status from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Marital Status</th>
<th>Weighted Number (unweighted number)</th>
<th>Mean</th>
<th>Standard Error</th>
<th>95% Confidence Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>74,830 (41)</td>
<td>$897</td>
<td>$287</td>
<td>$327-$1,476</td>
</tr>
<tr>
<td>Widowed</td>
<td>277,494 (115)</td>
<td>$1,895</td>
<td>$347</td>
<td>$1,203-$2,588</td>
</tr>
<tr>
<td>Single</td>
<td>172,829 (77)</td>
<td>$1,903</td>
<td>$404</td>
<td>$1,097-$2,708</td>
</tr>
</tbody>
</table>


Table 4-39. ANOVA Results Between Marital Status Categories for Direct Medical Costs (Minus Nursing Home Costs) from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Degrees of Freedom</th>
<th>F Value</th>
<th>Probability of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marital Status</td>
<td>2</td>
<td>3.14</td>
<td>0.049</td>
</tr>
</tbody>
</table>

Table 4-40. Mean Direct Medical Costs (Minus Nursing Home Costs) and Region of Residence from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Region</th>
<th>Weighted Number (unweighted number)</th>
<th>Mean</th>
<th>Standard Error</th>
<th>95% Confidence Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northeast</td>
<td>95,170 (37)</td>
<td>$1,306</td>
<td>$147</td>
<td>$1,015-$1,597</td>
</tr>
<tr>
<td>Mid-West</td>
<td>118,132 (51)</td>
<td>$1,645</td>
<td>$349</td>
<td>$951-$2,338</td>
</tr>
<tr>
<td>South</td>
<td>196,153 (93)</td>
<td>$2,219</td>
<td>$267</td>
<td>$1,689-$2,750</td>
</tr>
<tr>
<td>West</td>
<td>115,699 (52)</td>
<td>$1,452</td>
<td>$264</td>
<td>$928-$1,976</td>
</tr>
</tbody>
</table>

South region of the United States, with a reported mean direct medical cost (minus nursing home costs) of $2,219 per year. The second largest mean direct medical costs were reported by patients in the Mid-West. The largest difference for mean direct medical costs and region of residence existed between patients with Parkinson's disease living in the South and patients living in the Northeast. Patients living in the South reported mean direct medical costs 42% higher than patients living in the Northeast.

Table 4-41 provides the results of the One-Way ANOVA that was used to test for differences in direct medical costs (minus nursing home costs) and region of residence. A significant relationship was found to exist at the 0.05 significance level for direct medical costs for Parkinson's disease and region of residence.

Table 4-42 provides the results of the overall regression model with selected demographics as the independent variables and direct medical costs (minus nursing home costs) as the dependent variable. Gender, marital status and region of residence were all statistically significant at the 0.05 level when all other selected demographics were held constant.

Gender did not have statistically significant differences in the mean direct medical costs (minus nursing home costs) when the t-test procedure was used and other demographic variables were not taken into consideration. Marital status and region of residence were both statistically significant in the One-Way ANOVA and the overall regression model results presented in Table 4-42.

Table 4-43 provides the coefficients for the linear regression model for direct medical costs for Parkinson's disease (minus nursing home costs). No significant differences were found to exist between the selected demographics gender, marital status and region of residence for direct medical costs for Parkinson's disease.
Table 4-41. ANOVA Results for Region of Residence for Direct Medical Costs (Minus Nursing Home Costs) from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Degrees of Freedom</th>
<th>F Value</th>
<th>Probability of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Region of Residence</td>
<td>3</td>
<td>2.71</td>
<td>0.050</td>
</tr>
</tbody>
</table>


Table 4-42. F Value and Degrees of Freedom for the Overall Regression Model Results for Direct Medical Costs (Minus Nursing Home Costs) and Selected Demographics from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Effect</th>
<th>Degrees of Freedom</th>
<th>F Value</th>
<th>Probability of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Model</td>
<td>11</td>
<td>2.57</td>
<td>0.0078*</td>
</tr>
<tr>
<td>Gender</td>
<td>1</td>
<td>6.73</td>
<td>0.0113*</td>
</tr>
<tr>
<td>Age</td>
<td>2</td>
<td>2.84</td>
<td>0.0646</td>
</tr>
<tr>
<td>Education</td>
<td>1</td>
<td>0.00</td>
<td>0.9495</td>
</tr>
<tr>
<td>Income</td>
<td>2</td>
<td>0.75</td>
<td>0.4746</td>
</tr>
<tr>
<td>Marital Status</td>
<td>2</td>
<td>3.14</td>
<td>0.0491*</td>
</tr>
<tr>
<td>Region of Residence</td>
<td>3</td>
<td>4.24</td>
<td>0.0079*</td>
</tr>
</tbody>
</table>

* Statistically significant at the 0.05 level
Table 4-43. Coefficients for Linear Regression for Direct Medical Costs (Minus Nursing Home Costs) and Selected Demographics from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Estimate</th>
<th>Probability of t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>-$1,069</td>
<td>0.0113</td>
</tr>
<tr>
<td>Education Level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than High School</td>
<td>-$48</td>
<td>0.9495</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 65</td>
<td>-$3.69</td>
<td>0.9971</td>
</tr>
<tr>
<td>65-84</td>
<td>-$1,095</td>
<td>0.2651</td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $20,000</td>
<td>-$303</td>
<td>0.8001</td>
</tr>
<tr>
<td>$20,000-$30,000</td>
<td>-$593</td>
<td>0.4123</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>-$1,598</td>
<td>0.0254</td>
</tr>
<tr>
<td>Widowed</td>
<td>-$587</td>
<td>0.4017</td>
</tr>
<tr>
<td>Region of Residence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northeast</td>
<td>-$147</td>
<td>0.7191</td>
</tr>
<tr>
<td>Mid-West</td>
<td>$328</td>
<td>0.5487</td>
</tr>
<tr>
<td>South</td>
<td>$1,058</td>
<td>0.0113</td>
</tr>
</tbody>
</table>

Tables 4-44 and 4-45 provide the results of the post-hoc contrasts that were performed to determine which mean direct medical costs (minus nursing home costs) were significantly different between the selected demographic groups. Contrasts were run only on those demographic characteristics that were found to be statistically significant at the 0.05 level to determine between which groups the difference occurred.

To reduce the likelihood of type I error, a Bonferroni Adjustment was performed on the data. The Bonferroni Adjustment involved dividing the significance level of 0.05 by the number of comparisons being made in each of the selected demographic categories. For gender, the significance level would be 0.025 or less \((\frac{0.05}{2}=0.025)\) and for region of residence the significance level would be 0.0083 \((\frac{0.05}{6}=0.0083)\). After adjustment, both gender and region of residence were still statistically significant for direct medical costs.

For the category marital status, 3 comparisons were made. The resulting \(P\)-value must be lower than 0.016 \((\frac{0.05}{3}=0.016)\), in order for the reported \(p\)-value to be significant for marital status. Marital status was not statistically significant after the Bonferroni Adjustment was made. Post-hoc contrasts were conducted on the two selected demographic characteristics (gender and region of residence) and direct medical costs (minus nursing home costs) that were found to be statistically significant after Bonferroni Adjustment. The results of those post-hoc contrasts appear in Tables 4-44 and 4-45.

Table 4-44 provides the results of the contrast between mean direct medical costs (minus nursing home costs) for males and females when all other selected demographics were held constant. The mean direct medical costs for males with Parkinson’s disease were $571 higher than the mean direct medical costs for females with Parkinson’s disease.

Table 4-45 provides the results of the contrast between region of residence and direct medical costs (minus nursing home costs) for patients with Parkinson’s disease. Patients
### Table 4-44. Contrast Results for Gender for Direct Medical Costs (Minus Nursing Home Costs) from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Gender</th>
<th>Difference Between the means</th>
<th>T-Value</th>
<th>Probability of t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male vs. Female</td>
<td>$571</td>
<td>-2.59</td>
<td>0.0113*</td>
</tr>
</tbody>
</table>


*Statistically significant after Bonferroni Adjustment

### Table 4-45. Contrast Results for Region of Residence Between Categories for Direct Medical Costs (Minus Nursing Home Costs) from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Region</th>
<th>Difference Between the means</th>
<th>Probability of t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northeast vs. Mid-West</td>
<td>$339</td>
<td>0.3943</td>
</tr>
<tr>
<td>Northeast vs. South</td>
<td>$913</td>
<td>0.0013*</td>
</tr>
<tr>
<td>Northeast vs. West</td>
<td>$146</td>
<td>0.7191</td>
</tr>
<tr>
<td>Mid-West vs. South</td>
<td>$574</td>
<td>0.1902</td>
</tr>
<tr>
<td>Mid-West vs. West</td>
<td>$193</td>
<td>0.5487</td>
</tr>
<tr>
<td>South vs. West</td>
<td>$767</td>
<td>0.0113</td>
</tr>
</tbody>
</table>


* Statistically significant after Bonferroni Adjustment
with Parkinson’s disease who live in the South have mean direct medical costs (minus nursing home costs) that are $913 higher than patients with Parkinson’s disease who live in the Northeast. After Bonferroni Adjustment (0.05/6=0.0083), the only p-value for patients living in the South compared to patients living in the Northeast was found to be statistically significant. The mean direct medical costs difference between patients living in the South compared to patients living in the West were statistically significant at the 0.05 level, however after Bonferroni Adjustment were not found to be statistically significant. In order to be statistically significant, the probability of t would need to be less than or equal to 0.0083.

The following section provides the statistical analysis for direct non-medical costs of Parkinson’s disease for the selected demographics.

Table 4-46 provides the mean direct non-medical costs of illness reported by patients with Parkinson’s disease. A mean of $1,401 for direct non-medical costs were reported by patients with Parkinson’s disease.

Direct Non-Medical Costs due to Parkinson’s disease were reported only reported by 9% (21) of the patients in the sample. Because of this low sample size, ANOVA and regression models were not run on direct non-medical costs for Parkinson’s disease. Descriptive information is provided in Tables 4-46 and 4-47 for direct non-medical costs.

Table 4-47 provides the mean, standard error and 95% confidence limits for direct non-medical costs of patients with Parkinson’s disease when broken down by various demographic variables. Due to one female patient reporting a large amount of home repairs ($35,000), the mean direct non-medical costs for females was much higher than the mean direct non-medical costs for males.
Table 4-46. Mean Direct Non-Medical Costs (Minus Nursing Home Costs) from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Weighted Number (unweighted number)</th>
<th>Mean</th>
<th>95% Confidence Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct Non-Medical Costs (Overall)</td>
<td>51,607 (21)</td>
<td>$1,401</td>
<td>$1,251-$1,552</td>
</tr>
</tbody>
</table>

Table 4-47. Means for Selected Demographics for Direct Non-Medical Costs from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Selected Demographic</th>
<th>Weighted Number (unweighted number)</th>
<th>Mean</th>
<th>95% Confidence Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>39,011 (13)</td>
<td>$95</td>
<td>$95-$95</td>
</tr>
<tr>
<td>Female</td>
<td>12,596 (8)</td>
<td>$5,547</td>
<td>$4,892-$6,002</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 65</td>
<td>4,400 (2)</td>
<td>$15,639</td>
<td>$15,639-$15,639</td>
</tr>
<tr>
<td>65-84</td>
<td>39,048 (17)</td>
<td>$75</td>
<td>$58-$91</td>
</tr>
<tr>
<td>85 and Over</td>
<td>8,159 (2)</td>
<td>$72</td>
<td>$72-$72</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than High School</td>
<td>11,900 (8)</td>
<td>$123</td>
<td>$83-$162</td>
</tr>
<tr>
<td>High School or Higher</td>
<td>39,707 (13)</td>
<td>$1,784</td>
<td>$1,784</td>
</tr>
<tr>
<td>Income Level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $19,999</td>
<td>24,320 (12)</td>
<td>$84</td>
<td>$82-$86</td>
</tr>
<tr>
<td>$20,000-$29,999</td>
<td>8,735 (3)</td>
<td>$84</td>
<td>$30-$138</td>
</tr>
<tr>
<td>$30,000 and over</td>
<td>3,748 (6)</td>
<td>$3,748</td>
<td>$3,748-$3,748</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>8,439 (4)</td>
<td>$8,234</td>
<td>$8,234-$8,234</td>
</tr>
<tr>
<td>Widowed</td>
<td>32,597 (12)</td>
<td>$62</td>
<td>$62-$62</td>
</tr>
<tr>
<td>Single</td>
<td>10,571 (5)</td>
<td>$77</td>
<td>$27-$126</td>
</tr>
<tr>
<td>Region</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northeast</td>
<td>8,125 (4)</td>
<td>$8,398</td>
<td>$8,398-$8,398</td>
</tr>
<tr>
<td>Mid-West</td>
<td>7,129 (3)</td>
<td>$214</td>
<td>$214-$214</td>
</tr>
<tr>
<td>South</td>
<td>24,638 (9)</td>
<td>$80</td>
<td>$58-$101</td>
</tr>
<tr>
<td>West</td>
<td>11,715 (5)</td>
<td>$51</td>
<td>$51-$51</td>
</tr>
</tbody>
</table>

The majority of patients (81%) reporting direct non-medical costs were between 65 and 84 years of age. The majority of patients (62%) reporting direct non-medical costs had a high school education or greater. Patients whose income was less than $20,000 annually had reported the largest number of direct non-medical costs. Patients who were widowed reported the largest percentage (57%) of direct non-medical costs for Parkinson’s disease. The majority (43%) of patients reporting direct non-medical costs for Parkinson’s disease reside in the South.

The following section provides the statistical analysis for indirect costs of Parkinson’s disease (minus mortality costs) for the selected demographics.

Table 4-48 provides the mean indirect costs (minus mortality costs) for patients with Parkinson’s disease. Patients with Parkinson’s disease reported a mean indirect cost of $15,035 annually. Approximately 22% (52) of the unweighted total patient sample (233) reported having missed work or bed days due to Parkinson’s disease.

Table 4-49 provides the results of the t-test between means for males and females for indirect costs (minus mortality costs) due to Parkinson’s disease. Males reported their annual mean indirect costs due to Parkinson’s disease to be $2,229 higher than females. No significant difference for male and female patients with Parkinson’s disease existed between the mean indirect costs.

Table 4-50 provides the mean, standard error and 95% confidence limits for indirect cost (minus mortality costs) of Parkinson’s disease by age category. Only four people over the age of 85 reported having indirect costs due to Parkinson’s disease. Patients under the age of 65 reported having the lowest mean indirect costs due to Parkinson’s
Table 4-48. Mean Indirect Costs (Minus Mortality Costs) from the MEPS-HC for Patients with Parkinson's Disease.

<table>
<thead>
<tr>
<th>Weighted Number (unweighted number)</th>
<th>Mean</th>
<th>Standard Error</th>
<th>95% Confidence Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>121,278 (52)</td>
<td>$15,036</td>
<td>$1,046</td>
<td>$12,669-$17,402</td>
</tr>
</tbody>
</table>


Table 4-49. T-Test Between Males and Females for Indirect Costs (Minus Mortality Costs) from the MEPS-HC for Patients with Parkinson's Disease.

<table>
<thead>
<tr>
<th>Gender</th>
<th>Weighted Number (unweighted number)</th>
<th>Mean</th>
<th>95% Confidence Limits</th>
<th>t-Value</th>
<th>Probability of t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>76,698 (29)</td>
<td>$15,855</td>
<td>$14,374-$17,335</td>
<td>.52</td>
<td>0.6070</td>
</tr>
<tr>
<td>Female</td>
<td>44,580 (23)</td>
<td>$13,626</td>
<td>$8,300-$18,952</td>
<td>.52</td>
<td>0.6070</td>
</tr>
</tbody>
</table>


Table 4-50. Mean Indirect Costs (Minus Mortality Costs) for Age Categories from the MEPS-HC for Patients with Parkinson's Disease.

<table>
<thead>
<tr>
<th>Age</th>
<th>Weighted Number (unweighted number)</th>
<th>Mean</th>
<th>Standard Error</th>
<th>95% Confidence Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 65</td>
<td>17,595 (10)</td>
<td>$10,686</td>
<td>$2,521</td>
<td>$5,537-$15,835</td>
</tr>
<tr>
<td>65-84</td>
<td>92,459 (38)</td>
<td>$14,918</td>
<td>$1,299</td>
<td>$12,164-$17,671</td>
</tr>
<tr>
<td>85 and Over</td>
<td>11,224 (4)</td>
<td>$22,825</td>
<td>$1,851</td>
<td>$19,064-$26,587</td>
</tr>
</tbody>
</table>

disease. The largest percentage (74%) of patients reporting indirect costs for Parkinson's disease were between 65 and 84 years of age.

Table 4-51 provides the results of the One-Way ANOVA procedure to test for differences in indirect costs (minus mortality costs) and the selected demographic category age. A significant relationship was found to exist at the 0.05 significance level for indirect costs for Parkinson's disease and age.

Table 4-52 provides the results of the t-test for the selected demographic variable education and indirect costs (minus mortality costs) for Parkinson's disease. A significant difference between education level and mean indirect costs was not found to exist at the 0.05 level. Indirect costs were higher for patients without a high school education.

Table 4-53 provides the mean, standard error and 95% confidence limits for mean indirect costs (minus mortality costs) and income levels for patients with Parkinson's disease. Patients with incomes less than $20,000 annually reported the highest mean for indirect costs due to Parkinson's disease. Patients with income levels between $20,000 and $29,999 reported the lowest mean for indirect costs due to Parkinson's disease. Seventy-one percent of patients reporting indirect costs had incomes of less than $20,000 annually.

Table 4-54 provides the results of the One-Way ANOVA with indirect costs (minus mortality costs) as the dependent variable and income level as the independent demographic. A significant relationship was not found to exist between indirect costs and income levels.

Table 4-55 provides the mean, standard error and 95% confidence limits for marital status and indirect costs (minus mortality costs) of Parkinson's disease. The largest
Table 4-51. ANOVA Results and Age Categories for Indirect Costs (Minus Mortality Costs) from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Degrees of Freedom</th>
<th>F Value</th>
<th>Probability of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>2</td>
<td>3.36</td>
<td>0.048</td>
</tr>
</tbody>
</table>


Table 4-52. T-Test Between Education Level and Mean for Indirect Costs (Minus Mortality Costs) from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Education Level</th>
<th>Weighted Number (unweighted number)</th>
<th>Mean</th>
<th>95% Confidence Limits</th>
<th>t-Value</th>
<th>Probability of t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than High School</td>
<td>44,250 (27)</td>
<td>$18,975</td>
<td>$16,737-$21,212</td>
<td>-1.37</td>
<td>0.1797</td>
</tr>
<tr>
<td>High School</td>
<td>77,028 (25)</td>
<td>$12,773</td>
<td>$9,228-$16,318</td>
<td>-1.37</td>
<td>0.1797</td>
</tr>
</tbody>
</table>

Table 4-53. Mean Indirect Costs (Minus Mortality Costs) and Income Level from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Income</th>
<th>Weighted Number (unweighted number)</th>
<th>Mean</th>
<th>Standard Error</th>
<th>95% Confidence Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than $19,999</td>
<td>71,532 (36)</td>
<td>$16,772</td>
<td>$1,297</td>
<td>$14,046 - $19,497</td>
</tr>
<tr>
<td>$20,000-$29,999</td>
<td>19,032 (6)</td>
<td>$11,054</td>
<td>$2,893</td>
<td>$5,162 - $16,946</td>
</tr>
<tr>
<td>$30,000 and over</td>
<td>30,715 (10)</td>
<td>$13,460</td>
<td>$632</td>
<td>$12,166 - $14,753</td>
</tr>
</tbody>
</table>


Table 4-54. ANOVA Results Between Income Categories for Indirect Costs (Minus Mortality Costs) from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Degrees of Freedom</th>
<th>F-Value</th>
<th>Probability of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Income</td>
<td>2</td>
<td>0.88</td>
<td>0.426</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Marital Status</th>
<th>Weighted Number (unweighted number)</th>
<th>Mean</th>
<th>Standard Error</th>
<th>95% Confidence Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>13,531 (8)</td>
<td>$19,388</td>
<td>$1,525</td>
<td>$16,281-$22,495</td>
</tr>
<tr>
<td>Widowed</td>
<td>68,520 (23)</td>
<td>$14,690</td>
<td>$928</td>
<td>$12,760-$16,621</td>
</tr>
<tr>
<td>Single</td>
<td>39,227 (21)</td>
<td>$14,137</td>
<td>$3,004</td>
<td>$7,951-$20,324</td>
</tr>
</tbody>
</table>

percentage (44%) of patients reporting indirect costs for Parkinson’s disease were widowed. Patients who are married represented the smallest percentage (11%) of patients with Parkinson’s disease reporting indirect costs. Married patients also reported the highest mean for indirect costs among patients with Parkinson’s disease.

Table 4-56 provides the results of the One-Way ANOVA for marital groups for the indirect costs (minus mortality costs) of Parkinson’s disease. A significant difference was not found to exist between marital groups and the mean indirect medical (Minus Mortality Costs) for patients with Parkinson’s disease at the 0.05 level.

Table 4-57 provides the mean, standard error and 95% confidence limits for the indirect cost (minus mortality costs) of Parkinson’s disease and the region of residence. Patients living in the Northeast region of the United States reported the lowest mean total for indirect costs. The largest number of patients reporting indirect costs lived in the South. Patients living in the West reported the highest amount of indirect costs due to Parkinson’s disease.

Table 4-58 provides the results of the One-Way ANOVA used to determine if the mean indirect cost (minus mortality costs) of Parkinson’s disease was statistically different depending on region of residence. A significant difference was not found to exist between region of residence and the mean indirect cost (Minus Mortality Costs) for patients with Parkinson’s disease at the 0.05 level.

Table 4-59 provides the results of the multiple regression model with selected demographics as the independent variables and indirect costs (minus mortality costs) as the dependent variable. When selected demographics were held constant, no significant difference was found to exist between any of the selected demographics and indirect cost for Parkinson’s disease. However, the overall model was significant.
Table 4-56. ANOVA Results Between Marital Status Categories for Indirect Costs (Minus Mortality Costs) from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Degrees of Freedom</th>
<th>F Value</th>
<th>Probability of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marital Status</td>
<td>2</td>
<td>0.58</td>
<td>0.568</td>
</tr>
</tbody>
</table>


Table 4-57. Mean Indirect Costs (Minus Mortality Costs) and Region of Residence from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Region</th>
<th>Weighted Number (unweighted number)</th>
<th>Mean</th>
<th>Standard Error</th>
<th>95% Confidence Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northeast</td>
<td>11,461 (3)</td>
<td>$6,684</td>
<td>$0</td>
<td>$6,684-$6,684</td>
</tr>
<tr>
<td>Mid-West</td>
<td>20,364 (6)</td>
<td>$17,441</td>
<td>$1,140</td>
<td>$15,121-$19,761</td>
</tr>
<tr>
<td>South</td>
<td>64,340 (31)</td>
<td>$13,828</td>
<td>$1,122</td>
<td>$1,689-$2,750</td>
</tr>
<tr>
<td>West</td>
<td>25,114 (12)</td>
<td>$19,989</td>
<td>$2,944</td>
<td>$928-$1,976</td>
</tr>
</tbody>
</table>


Table 4-58. ANOVA Results for Region of Residence Between Categories for Indirect Costs (Minus Mortality Costs) from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Degrees of Freedom</th>
<th>F Value</th>
<th>Probability of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Region of Residence</td>
<td>3</td>
<td>2.33</td>
<td>0.094</td>
</tr>
</tbody>
</table>

Table 4-59. F Value and Degrees of Freedom for the Overall Regression Model Results for Indirect Costs (Minus Mortality Costs) and Selected Demographics from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Effect</th>
<th>Degrees of Freedom</th>
<th>F Value</th>
<th>Probability of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Model</td>
<td>11</td>
<td>3.82</td>
<td>0.0019</td>
</tr>
<tr>
<td>Sex</td>
<td>1</td>
<td>1.27</td>
<td>0.2685</td>
</tr>
<tr>
<td>Age</td>
<td>2</td>
<td>1.11</td>
<td>0.3422</td>
</tr>
<tr>
<td>Education</td>
<td>1</td>
<td>1.75</td>
<td>0.1966</td>
</tr>
<tr>
<td>Income</td>
<td>2</td>
<td>0.68</td>
<td>0.5151</td>
</tr>
<tr>
<td>Marital Status</td>
<td>2</td>
<td>0.52</td>
<td>0.6001</td>
</tr>
<tr>
<td>Region of Residence</td>
<td>3</td>
<td>2.09</td>
<td>0.1233</td>
</tr>
</tbody>
</table>

Table 4-60 provides the coefficients for the linear regression model for indirect costs for Parkinson’s disease (minus nursing home costs and mortality costs). No significant difference was found to exist between any of the selected demographics and indirect costs for Parkinson’s disease.

Chapter 5 will provide discussion and conclusions of the findings from this chapter, limitations of this study, implications of the study, and recommendations for future research.
Table 4-60. Coefficients for Linear Regression for Indirect Medical Costs (Minus Mortality Costs) and Selected Demographics from the MEPS-HC for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Estimate</th>
<th>Probability of t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>-$7,965</td>
<td>0.2685</td>
</tr>
<tr>
<td>Education Level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than High School</td>
<td>$6,430</td>
<td>0.1966</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 65</td>
<td>-$10,389</td>
<td>0.1711</td>
</tr>
<tr>
<td>65-84</td>
<td>-$1,805</td>
<td>0.7471</td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $20,000</td>
<td>$4,484</td>
<td>0.3145</td>
</tr>
<tr>
<td>$20,000-$30,000</td>
<td>$394</td>
<td>0.9469</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>$4,913</td>
<td>0.4258</td>
</tr>
<tr>
<td>Widowed</td>
<td>$1,466</td>
<td>0.8692</td>
</tr>
<tr>
<td>Region of Residence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northeast</td>
<td>-$16,989</td>
<td>0.0591</td>
</tr>
<tr>
<td>Mid-West</td>
<td>-$2,811</td>
<td>0.7478</td>
</tr>
<tr>
<td>South</td>
<td>-$10,862</td>
<td>0.0845</td>
</tr>
</tbody>
</table>

CHAPTER V. DISCUSSION

The final chapter will review the purpose and objectives of the study, discuss the results of the study, present limitations of the study, provide implications of the study, and recommend future research opportunities. The discussion portion of this chapter includes the following sections: 1) overall cost of illness for Parkinson’s disease, 2) direct medical costs, 3) direct non-medical costs, 4) indirect morbidity costs, and 5) indirect mortality costs. The limitations of this study focus on two main areas: data sources and study methodology. The implications section of this chapter covers the following four areas: 1) implications for patients with Parkinson’s disease and for caregivers of patients with Parkinson’s disease, 2) implications for healthcare policy, 3) implications for healthcare providers and insurers, and 4) implications for healthcare administrators.

Despite continued advances in the medical treatment of Parkinson’s disease, little research has been done with regard to the economic consequences associated with medical costs and lost productivity costs due to Parkinson’s disease. Limitations of previous economic studies of the impact of Parkinson’s disease include 1) incomplete measures, 2) small sample sizes, and 3) nongeneralizable results to the United States as a whole.

The purpose of this study was to determine the cost of illness for Parkinson’s disease in the United States. The first two objectives of the study were to determine the direct and indirect cost of illness for Parkinson’s disease and to describe healthcare resource utilization for patients with Parkinson’s disease. Other objectives were to determine if, when considered individually, any of the selected demographic variables (gender, education level, age, income, marital status, and region of residence) were statistically
significant with respect to the overall cost of illness for Parkinson's disease. The study also sought to determine if the selected demographic characteristics, when considered individually, were statistically significant with respect to direct medical costs, direct non-medical costs and indirect costs of Parkinson's disease. The final objective of this study was to determine if any statistically significant relationship existed when adjusting for selected demographic characteristics jointly for overall total costs. This was also done for direct medical costs, direct non-medical costs and indirect costs.

This study estimated the number, gender and age of patients with Parkinson's disease to be similar to previously reported national estimates of patients with Parkinson's disease. This study found a weighted total of 525,154 non-institutionalized patients (MEPS-HC) with Parkinson's disease and a weighted total of 99,989 institutionalized patients (MEPS-NHC) with Parkinson's disease for a total of 625,143. Previous estimates have estimated between 500,000 to 1.5 million people have Parkinson's disease in the United States, which would contain this estimate. This study estimated the percentage of the non-institutionalized (MEPS-HC) patient population with Parkinson's disease to be 54.7% male and 45.3% female. This estimate is similar to previous estimates of gender differences in patients with Parkinson's disease. The smallest percentage of patients in this study were in the youngest age group (under 65) and the majority of patients in this study were between 65-84 years of age. When compared to previous estimates these data demonstrate similar age and incidence trends of Parkinson's disease.
Overall Cost of Parkinson's Disease

The estimate presented in this study has followed the cost of illness methodology as originally outlined by Rice. This study estimated the total cost of illness from 1999-2003 to be $39,661,102,321 in 2003 dollars for Parkinson's disease. This estimate was based on data from the 1999-2003 MEPS-HC, 1999-2003 BLS wage tables, 1999-2003 NVSS and the 1996 MEPS-NHC. In 2003, this study estimated the cost of illness for Parkinson's disease to be $6,312,443,792. This estimate of overall cost of illness for Parkinson's disease is in the lower range of previous estimates between $5.6 billion and $25 billion annually. Compared to the $2.5 billion annual estimate of the cost of illness for Multiple Sclerosis, a disease with similar prevalence as Parkinson's disease, Parkinson's disease is a more costly disease state. However, compared to Alzheimer's disease, a similar neurological disease state, Parkinson's disease is a less costly disease. Alzheimer's has been estimated to cost between $5.6 billion and $88 billion annually. However, the prevalence of Alzheimer's disease is estimated to be between 4.2 million and 15.4 million compared to 500,000 to 1.5 million for Parkinson's disease.

Table 5-1 provides a breakdown of the cost of illness for one year for patients with Parkinson's disease, the average cost of each economic component and an overall average cost of illness per patient. To determine an overall average cost for patients with Parkinson's disease for one year, the direct medical costs, direct non-medical costs and indirect costs for 2003 were totaled. The total number of patients with Parkinson's disease was 625,143 and was calculated using the population from the MEPS-HC (525,154) and the population for the MEPS-NHC (99,989). The average direct medical costs for patients with Parkinson's disease were $8,476 annually. The average cost for patients reporting direct non-medical costs were $17 per patient with Parkinson's disease.
Table 5-1. Overall Costs and Averages for 2003 for Patients with Parkinson's Disease Using MEPS-HC, MEPS-NHC, BLS and NVSS.

<table>
<thead>
<tr>
<th>Cost Component</th>
<th>Overall 2003 Cost of Component</th>
<th>Overall Average of Component</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct Medical</td>
<td>$5,298,491,603</td>
<td>$8,476</td>
</tr>
<tr>
<td>Direct Non-Medical</td>
<td>$10,683,797</td>
<td>$17</td>
</tr>
<tr>
<td>Indirect</td>
<td>$1,003,268,392</td>
<td>$1605</td>
</tr>
<tr>
<td>All Components</td>
<td>$6,312,443,792</td>
<td>$10,098</td>
</tr>
</tbody>
</table>

Indirect costs had averaged $1,605 annually for patients with Parkinson's disease. The overall annual average cost was $10,098 per patient with Parkinson's disease.

**Direct Medical Costs**

Direct medical costs included in this study were: prescription medications, office-based visits, emergency room visits, inpatient hospital stays, outpatient visits, home health visits and nursing home stays. The majority (76%) of the direct medical costs included in this study for Parkinson's disease were for nursing home costs. This is in contrast to one study that measured only the direct medical costs of Parkinson's disease and reported nursing home costs to be lower than most other direct medical costs. The study used data from an insurance company that served patients in the Midwest. The patient population of the Midwest study was younger on average and therefore tended to use less nursing home care.

The second largest portion of direct medical costs for patients with Parkinson's disease was for prescription medications, at 7.7%. This finding is similar to other studies that have measured direct medical costs. Schenkman, et al. found that the prescription medication costs made up a large percentage (26%-37%) of direct medical costs for patients with Parkinson's disease, regardless of whether their health rating was good or poor. Littlefield, et al. reported that prescription medication costs increased dramatically between the first and third year after diagnosis of Parkinson's disease. Prescription medication costs accounted for 60% of total costs for treatment of patients with Parkinson's disease who reported having Parkinson's disease longer than three years.

Another healthcare resource service that was frequently used and carried a large five
year cumulative cost was home health visits. Over a five year period, home health visits
cost over $1.9 billion. Home health visits were the third largest cost category of the
direct medical costs measured in this study. In addition to being one of the highest direct
medical cost categories, home health visits were also one of the most utilized direct
medical services. Approximately 4 billion home health visits were reported for
Parkinson’s disease during the five year period between 1999 and 2003.

Inpatient hospital stays carried a direct medical expenses burden. Costs of inpatient
stays totaled approximately $1.1 billion over the five year period. This is similar to a
previous 2002 study in which Littlefield, et al. reported that inpatient stays for
Parkinson’s disease were the second largest direct medical cost after prescription
medication costs.51

One health care resource frequently used by patients with Parkinson’s disease in this
study was office-based visits. A weighted total of 6.8 million office visits were reported
by patients in this study. Despite being frequently used, the cost for office-based visits
was low ($668,230,346) compared to the cost and frequency of use of the other patient
services in this study. Previous studies of direct medical costs found similar findings as
those found in this research.19,51

In estimating the cost of illness due to Parkinson’s disease, questions were raised
regarding the proper methodology for measuring and estimating the cost of illness.
Specific to direct medical costs, current national data for nursing homes are lacking. The
estimate in the current study used existing MEPS-NHC data. However, it is very likely
that present day nursing home costs for patients with Parkinson’s disease are much higher
than reported here. The estimate presented here for nursing home costs in patients with
Parkinson’s disease cannot take into account a variety of events that may alter the
estimate if the estimate were from more current data. Life expectancy has continued to rise for both males and females across all racial and ethnic groups, making it possible that more people are in nursing homes today than were in 1996.

Table 5-2 provides a listing of 1999-2003 totals for direct medical costs that were included in this study. The largest percentage of direct medical costs for Parkinson’s disease was for nursing home stays, followed by prescription medications. Emergency room visits and outpatient visits comprised the smallest percentage of direct medical costs for Parkinson’s disease.

**Direct Non-Medical Costs**

The direct non-medical costs reported by patients with Parkinson’s disease in this study were primarily for home modifications. The items reported in this study included modifications such as raised toilet seats and handrails in the shower. The MEPS-HC other medical expenses category allows patients to write in items that did not fit into the specified. Due to the small unweighted number of patients reporting direct non-medical costs, inferential statistical analyses were not possible. However, this study did provide insight into the direct non-medical items reported by patients with Parkinson’s disease.

Two previous studies on the burden of Parkinson’s disease have reported on direct non-medical items that patients require for their Parkinson’s disease.\(^{23,151}\) Chrischilles et al. reported in a study of 193 patients with Parkinson’s disease, 40% had installed handrails in the bathtub and 20% installed shower seats.\(^{23}\) Whetten-Goldstein et al. reported an annual average of $242 for direct non-medical costs.\(^{23}\) The cost of the direct non-medical costs were not provided in the Chrischilles study and the number of patients with Parkinson’s disease who reported direct non-medical costs was not provided in the
Table 5-2. Overall Total and Percentage of Overall Total of Each Component of Direct Medical Costs for 1999-2003 for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Direct Medical Cost Component</th>
<th>Overall Direct Cost Amount</th>
<th>Percentage of Direct Medical Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prescription Medication</td>
<td>$1,981,216,130</td>
<td>7.7</td>
</tr>
<tr>
<td>Office-Based Visits</td>
<td>$668,230,346</td>
<td>2.6</td>
</tr>
<tr>
<td>Emergency Room Visits</td>
<td>$39,509,801</td>
<td>.15</td>
</tr>
<tr>
<td>Inpatient Visits</td>
<td>$1,091,504,691</td>
<td>4.2</td>
</tr>
<tr>
<td>Outpatient Visits</td>
<td>$229,870,733</td>
<td>.89</td>
</tr>
<tr>
<td>Home Health Visits</td>
<td>$1,923,462,530</td>
<td>7.5</td>
</tr>
<tr>
<td>Nursing Home Stays</td>
<td>$19,752,709,340</td>
<td>76.96</td>
</tr>
<tr>
<td>Overall Total</td>
<td>$25,686,503,575</td>
<td>100%</td>
</tr>
</tbody>
</table>

Indirect Costs

Morbidity

Indirect costs for Parkinson’s disease due to morbidity were divided into two categories: bed days and missed work days. Of the 233 patients in this study, 52 (22%) reported either having bed days or missing work due to their Parkinson’s disease. Bed days made up the largest percentage (96%) of morbidity costs for patients with Parkinson’s disease. Of the 52 patients reporting morbidity costs due to Parkinson’s disease, the majority (86%) were reporting morbidity costs due to bed days. Patients experiencing bed days averaged 166 bed days per year. The average number of missed work days for patients with Parkinson’s disease was 45 days. Because the average age of Parkinson’s disease diagnosis is 55 years of age and Parkinson’s disease medications are effective at alleviating symptoms during the first 10 years after diagnosis, the majority of the Parkinson’s disease population are likely to be retired when their Parkinson’s disease symptoms become debilitating. Thus, this may account for the low number of missed work days and the high number of bed days.

Mortality

The number of deaths due to Parkinson’s disease increased every year from 1999-2003. The number of deaths prior to life expectancy fluctuated each year, with the greatest number of deaths prior to life expectancy occurring in 2003. There are at least two reasons why the mortality costs due to Parkinson’s disease may have been
underestimated in this study. First, only mortality costs for people who died prior to their respective life expectancy due to Parkinson’s disease were estimated. Around one-third (34%) of patients with Parkinson’s disease died prior to life expectancy. Because this study did not include or place a value on the loss of life after life expectancy it is likely that mortality costs due to Parkinson’s disease were underestimated. Second, because the source of the mortality data in this study came from death certificates, it is possible that the number of deaths due to Parkinson’s disease was underestimated. The accuracy of death certificate data is reliant upon the knowledge of the person filling out the death certificate information. It is possible that some individuals who died of Parkinson’s disease were inadvertently missed due to lack of knowledge regarding the deceased’s health status.

Table 5-3 provides a breakdown of 1999-2003 indirect costs included in this study. The largest percentage (88.5%) of the indirect cost components for Parkinson’s disease was due to morbidity due to bed days. The smallest percentage of indirect costs for Parkinson’s disease was due to missed work days.

Results of Statistical Tests

This study looked for statistically significant cost differences for overall total cost, direct medical costs, direct non-medical costs, and indirect costs of Parkinson’s disease for gender, education level, age, income, marital status and region of residence. Previous studies for other disease states have typically studied differences in the cost of illness for patients with a particular disease when compared to patients without a particular disease. While these studies are useful in comparing costs and utilization between diseased versus
Table 5-3. Indirect Cost Components, Overall Amount and Percentage for 1999-2003 for Patients with Parkinson’s Disease.

<table>
<thead>
<tr>
<th>Indirect Cost Component</th>
<th>Overall Indirect Cost Amount</th>
<th>Percentage of Indirect Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morbidity (Missed Work)</td>
<td>$389,735,998</td>
<td>3.6</td>
</tr>
<tr>
<td>Morbidity (Bed Days)</td>
<td>$9,619,603,534</td>
<td>88.5</td>
</tr>
<tr>
<td>Mortality</td>
<td>$861,530,870</td>
<td>7.9</td>
</tr>
<tr>
<td>Overall Total</td>
<td>$10,870,870,402</td>
<td>100%</td>
</tr>
</tbody>
</table>

non-diseased populations, they do not provide insight into cost differences for patients within a disease population.

For overall total cost of illness for Parkinson's disease, none of the mean differences in costs for selected demographic characteristics were statistically significant. Also, no statistically significant differences existed between the mean indirect costs for selected demographics for Parkinson's disease. With the exception of direct medical costs for males compared to females, and those patients residing in the South compared to patients residing in the Northeast, the differences between direct medical costs of Parkinson's disease and the selected demographics presented in this study were not found to be statistically significant.

One of the possible reasons why direct medical costs were found to be statistically significant for males compared to females is that males do not access healthcare as frequently as females with Parkinson's disease. Therefore males require more expensive services (i.e., home health visits) and treatments (i.e., prescription medications) when they do access healthcare. If females with Parkinson's disease are less likely to delay accessing care they may require fewer healthcare services than males. Another possible reason for gender differences in direct medical costs may be associated with treatment patterns of physicians. Previous studies have established that physicians are less likely to prescribe pain medications and are less aggressive in their prescribing patterns for female patients compared to male patients.\textsuperscript{169,170} Physicians may prescribe a more aggressive and costly treatment plan for males compared to females with Parkinson's disease, therefore explaining the additional direct medical costs that males experience.

There are four possible reasons why patients with Parkinson's disease who live in the South experience higher direct medical costs compared to patients who live in the
Northeast. First a difference may exist in treatment patterns of physicians in the South compared to physicians in the Northeast. Previous research has demonstrated different patterns of treatment for the same disease state by physicians depending on geographic location. Second, patients in the South and Northeast may differ in when and how frequently they access healthcare services related to direct medical costs. It is possible that patients living in the South do not access healthcare until later in the disease process when more expensive and costly treatments will be necessary. Previous studies have established that patients living in rural areas are more likely to rank poorly on health indicators such as health behaviors, mortality and morbidity. Third, geographic distribution of the elderly may also play a role in the increased cost for patients with Parkinson’s disease who live in the South. Between 1990 and 2000, the greatest proportion of increases in the elderly population was reported in the South and West. Specific to the South, the increases in the elderly population were seen in the South Atlantic states. The South and West regions of the United States have also experienced the greatest increases in the oldest of the old population, which are those people age 85 and older. Finally, Parkinson’s disease differences may exist between the two regions that are not known. For example, Parkinson’s disease is thought to be caused by exposure to environmental toxins. Patients living in the South may be experiencing more severe symptoms due to more environmental exposure to these toxins and therefore they require more healthcare services than patients with Parkinson’s disease residing in the Northeast.

There are three possible reasons why so few statistically significant differences were found in this study. First, it is possible that statistically significant cost differences do exist within each of the components (direct medical costs, direct non-medical costs and
indirect costs) of cost of illness when they are further broken down. For example, mean
direct medical costs were not statistically significant between various age groups,
however prescription medication costs may be significantly higher for people in the under
65 age group. Second, other variables outside of the selected demographics for this study
may be predictors of cost of illness for Parkinson’s disease. Finally, no other variables
may exist that are predictive of costs for Parkinson’s disease.

Implications of the Study

Implications for Patients and Caregivers

Patients with Parkinson’s disease primarily will find this study useful in financial
planning. When institutionalized (MEPS-NHC) and non-institutionalized (MEPS-HC)
costs were considered together, the majority of direct medical costs were due to nursing
home costs and prescription medication costs. One implication of the prescription
medication costs for patients with Parkinson’s disease is the introduction of Medicare
Part D. This is important specifically because Medicare Part D limits the uptake of new
medications that Parkinson’s disease patients sometimes require. In addition to financial
planning, patients will find it useful to know that the most frequently utilized healthcare
services related to Parkinson’s disease are office based visits and home health visits.
Direct non-medical costs due to Parkinson’s disease in this study were primarily for
home modifications. The direct non-medical costs most commonly reported in this study
were bathroom aides such as handrails for the shower and raised toilet seats. Patients will
find it useful to know that the direct non-medical items in this study were generally
inexpensive and related to mobility in the home.
The majority (88%) of indirect costs were due to bed-days (morbidity). Patients will find it useful to know that approximately 20% of patients in this study reported having bed-days due to Parkinson’s disease. This is important information because patients restricted to the bed due to their Parkinson’s disease will require the assistance of either a formal or an informal caregiver. Informal care giving has previously been established as the largest financial burden on family members of patients with Parkinson’s disease.23

**Implications for Healthcare Policy**

Although the prevalence of Parkinson’s disease is low compared to other chronic disease states, the cost of Parkinson’s disease in the United States was found to be substantial. Previous to this study, the clinical impact of Parkinson’s disease was known to be overwhelming; however, little was known regarding the economic impact. It has been hypothesized that new medications for Parkinson’s disease that slow the progression of the disease potentially improve not only the Health Related Quality of Life (HRQL) but also reduce the use of healthcare resources.151 Healthcare policy makers can use these findings to plan for future resource allocation to efforts geared at reducing the effects of or potentially searching for cures for Parkinson’s disease. One final policy implication from this study would be that nursing home data needs to be collected on a more regular basis in order to track trends in nursing home admissions.

**Implications for Healthcare Providers and Insurers**

The greatest portion of costs for patients with Parkinson’s disease came from nursing home care. As the number of people with Parkinson’s disease rises due to increased life expectancy, the need for healthcare providers in nursing homes may also increase. This
study found that the high utilization of a healthcare service was not always associated with high costs and low utilization of a particular healthcare service was not always associated with low costs.

For the non-institutionalized population (MEPS-HC) healthcare services for direct medical costs that had the highest costs were prescription medications and home health visits. The weighted number of prescription medications was six times higher than the weighted number of home health visits however, the cost of home health visits were only slightly lower than the cost of prescription medications. Healthcare insurers may find this information useful if a prescription medication reduces the need for or the frequency of home health visits.

For direct medical costs, one healthcare service with high costs, but low utilization was inpatient stays. Hospital stays are the most expensive component of healthcare. Healthcare providers and insurers may need to find out why the cost of inpatient stays are so expensive for so few patients with Parkinson’s disease and see what, if any, preventive measures could have been instituted. For example, if the inpatient stays were related to falls, healthcare insurers may want to cover the cost of inexpensive items such as handrails in the shower that would reduce the risk of a fall. Another source of the high cost of inpatient stays in this study was the length of stay for the patients with Parkinson’s disease. Healthcare providers and insurers may want to look at other cost-effective alternatives that shorten the length of a patient’s stay in the hospital.

Two of the largest components of direct medical costs that were found as a result of this study were nursing home costs and prescription medications. This trend will continue for two reasons. First, as life expectancy increases, so does the likelihood of
developing Parkinson’s disease. It is very likely that the number of people entering
nursing homes with Parkinson’s disease will increase over the next several years.

Second, as new and more costly treatments are developed, medication costs for
Parkinson’s disease will remain high or increase. New medications used for treating
Parkinson’s disease have been approved by the Food and Drug Administration (FDA)
since 2003. The utilization of these new medications will initially increase the direct
medical cost of Parkinson’s disease. Eventually, however, the number of people entering
nursing homes may be reduced, or at least delayed, due to the use of new medications.
This may reduce the direct medical costs for nursing home care.

Since 2003, four new medications have been approved by the FDA for treatment of
Parkinson’s disease. While these medications were not included in the medication cost
estimates for this study, they do have important implications for the cost of Parkinson’s
disease, especially to healthcare providers and insurers. The first medication that was
approved by the FDA for patients with Parkinson’s disease is apomorphine hydrochloride
(Apokyn®). This medication was approved for use in the treatment of Parkinson’s
disease in 2004 and is indicated to treat the approximately 10 percent of patients who are
unresponsive to existing Parkinson’s disease medications. This medication is also used
in patients with Parkinson’s disease who have reached stage 4 of Parkinson’s disease and
are experiencing severe on/off motor fluctuations. Apomorphine hydrochloride
(Apokyn®) has received “orphan” drug status due to the low number of patients it is
targeted to treat. Orphan drug status means that this medication will have an extended
patent life, making the manufacturer the exclusive marketer of this medication for several
years.
Health insurers, such as Medicare, that insure the elderly, (the primary age group with Parkinson’s disease) will find new medications of particular interest. The implications for healthcare providers and insurers of this new medication are two-fold. First, the initial expense of the medication to patients and healthcare insurers will be higher than previous medications used to treat Parkinson’s disease. However, the patients using this medication should eventually require fewer healthcare services. Healthcare insurers should therefore, begin to see reduced healthcare expenses for these patients, but only in the small percentage of patients with Parkinson’s disease who require apomorphine hydrochloride (Apokyn®). A final implication of this medication is that since the medication is under an extended patent, a less-expensive generic version will not be available for awhile. This means that if a healthcare insurer has a patient requiring apomorphine hydrochloride (Apokyn®), there will not be a viable cheaper option for at least seven years.

Additional new medications approved by the FDA since 2003 include Stalevo®, Parcopa®, and Azilect®. Stalevo® and Parcopa® were both approved in 2004 while Azilect® was approved in 2006 for the treatment of Parkinson’s disease. Since these medications will treat more patients with Parkinson’s disease than Apokyn®, there are some additional implications to healthcare providers and insurers.

Stalevo® is a combination of levodopa, carbidopa and entacapone.121 Stalevo® allows some patients with Parkinson’s disease to take only one pill per day instead of two.121 Stalevo® is also less expensive than taking the same medications (carbidopa, levodopa, and entacapone) separately. Healthcare insurers may find Stalevo® a viable option for reducing medication costs for their patients with Parkinson’s disease.
However, this is not a new therapeutic modality, so all previous limitations and side effects still apply.

Parcopa® is another medication that was approved by the FDA since 2003 for the treatment of Parkinson’s disease. Parcopa® is a combination of carbidopa and levodopa that dissolves on the tongue and can be taken without water. Since being released in 2004, some doctors have reported that Parcopa® may be beneficial to patients with gastrointestinal issues. There have also been reports that Parcopa® may be of practical use when patients with Parkinson’s disease are having swallowing problems or patients that are undergoing procedures that do not allow anything to be taken by mouth. Currently there are no published studies of Parcopa® and it is more expensive than the existing generic and brand name combinations of carbidopa and levodopa. Healthcare providers may find this new medication an option for a patient experiencing gastrointestinal issues or swallowing issues.

Azilect® is a mono-therapy that was approved in May 2006 by the FDA for the treatment of Parkinson’s disease. Because this medication was recently approved by FDA, there are no published studies on the cost-effectiveness of Azilect®. However, Azilect® has been shown to significantly improve Unified Parkinson’s Disease Rating Scale (UPDRS) total score in clinical trials. Healthcare providers may find the single therapy (mono-therapy) useful to patients that are having difficulty with other Parkinson’s disease medications. Healthcare insurers may find it useful to know that UPDRS total scores improved in clinical trials. The improved UPDRS total scores may correlate with decrease patient needs for medications patients require and visits with medical professionals (i.e., doctors, physical therapists etc.).
Implications for Health Care Administrators

This cost of illness study has provided the first initial insight into the cost of illness and pattern of expenditures for Parkinson’s disease on a national level. In addition, this study has provided insight into utilization patterns of healthcare services by patients with Parkinson’s disease. Using this study as a baseline, future cost of illness studies on Parkinson’s disease will be able to track the patterns of expenditures and utilization of patient services. The cost of illness study presented here may provide health care administrators with insight into the categories of spending that may be modified so that total expenditures are decreased. Finally, this research will be useful to health care administrators when applying for grants because the National Institutes of Health (NIH) use cost of illness studies such as this one when making decisions on the allocation of research funding.

Limitations of the Study

The primary limitation of this study was that multiple data sources were used to make an estimate of the cost of Parkinson’s disease. Because of this, the population used to make the cost of illness estimate was not from one sample of people. Therefore, data analyses beyond descriptive statistics were limited to within population samples from the same source. Another limitation of this study is due to the source of the nursing home data. While the primary data source for this research was the 1999-2003 MEPS-HC data, the estimate for the nursing home portion came from the 1996 MEPS-NHC data. Despite using the CPI for nursing home costs, it is likely that the estimate presented in this study is low. The number of patients reporting Parkinson’s disease increased each year in the MEPS-HC. The CPI for nursing home was multiplied by the cost for the number of
patients who reported having Parkinson’s disease in 1996, assuming no volume increase. The estimate for nursing home costs presented here is lower than the actual cost for nursing home cost for patients with Parkinson’s disease.

Another limitation is that this study did not take into account any new prescription medications for Parkinson’s disease that have come onto the market since 2003. The introduction of new medications may initially increase the medication cost component for Parkinson’s disease. However, later gains may be realized due to improved health. Therefore the cost of illness for Parkinson’s disease may start to decline.

Two additional limitations are related to the estimate of direct non-medical costs for patients with Parkinson’s disease. The first limitation was due to the methodology utilized for calculating direct non-medical costs. Items selected for inclusion in this category had to be classified as either a home modification, a bathroom aid, or a specified other. The cost specified “other” had to be clarified further by the patient as an item that would be necessary due to Parkinson’s disease (i.e., a lift on a van for a wheel-chair). It is possible that a patient reported items in another direct non-medical cost category (i.e., glasses, exercise equipment, etc) that were not captured using the above methodology. The second limitation of the direct non-medical cost estimate was due to patients failing to report direct non-medical expenditures. A patient may not have associated their Parkinson’s condition as the source of a non-medical expense. For example, a patient may have purchased handrails for their bathtub because of poor balance due to their Parkinson’s disease, but when reporting expenses in the other medical expenses category, the patient failed to associate the poor balance with their Parkinson’s disease state.

A data limitation of this study related to the indirect costs was the frequency of missing daily wage rate data for morbidity costs related to missed work days. Missing
daily wage rates was a limitation because it was necessary to know daily wage rates to estimate morbidity costs due missed work days. In order to make an estimate of the morbidity costs due to missed work, the Bureau of Labor Statistics (BLS) wage data were used to estimate the daily wage rate for patients who reported missing work due to Parkinson’s disease. To overcome this limitation and make an estimate of daily lost wages due to Parkinson’s disease, the demographics (age, race and gender) of patients in this study were used to determine the daily wage amount that their labor would have earned. This daily wage amount was calculated for each of the individuals reporting missed work days and allowed for an estimate or morbidity costs due to missed work days.

There were limitations of the sources of data used in this study. For the MEPS data, the first limitation is that sample size precludes some analysis. Specifically, analysis at the state level is not possible and single year analyses of rare diseases are not possible due to the sample size limitations. The second limitation of the MEPS-HC data is due to responder bias. Household respondents may not accurately report information related to their health (i.e., diagnosis) and their healthcare (i.e., type of health plan). One final limitation related to the data sources of this study is that caregiver costs are not collected by the MEPS and thus reported cost estimates underestimate the true cost.

The other data sources, National Vital Statistics Survey (NVSS) and Bureau of Labor Statistics (BLS), also had some limitations. Both the NVSS and the BLS reported limited race category information. The race categories reported included white, black and other. In 2002, the NVSS began to expand the categories of race to include Asian and American Indian. However, BLS only incorporated wage information for the Asian race
category, making it difficult to obtain an exact estimate of lost wages. While the majority of patients with Parkinson’s disease are white, it is important to note this data limitation.

Three limitations of the study methodology need to be noted. The first of the study methodology limitations is related to the way in which morbidity and mortality costs were estimated in this study. This study used the human capital approach to calculate the indirect cost of Parkinson’s disease. According to the human capital method, a person generates a stream of earnings valued at market earnings. The value of human life is based on market earnings and therefore likely underestimates the value of children and retired persons. Since a relatively large number of Parkinson’s disease patients are elderly and retired, the cost estimates presented here for mortality and morbidity are likely underestimated.

The second limitation is due to the methodology used to calculate wage for morbidity costs. The BLS data provided an average wage based on gender, race and age for people in the United States. The BLS data could be a source of bias because the wage data are averaged for the United States as a whole and averages for individual regions (Northeast, West, South and Mid-West) of the country were not available. The average wage an individual earns may differ depending on the region of the United States that an individual resides. If wage data had been used based on each region in the United States, the estimate presented here may have been different.

The third methodological limitation of this study was that it did not include an estimate for intangible costs. The difficulty of measuring the intangible costs of any disease has previously been established. However, it would be reasonable to expect that a chronic, progressive disease such as Parkinson’s disease would have high intangible costs.
Conclusions

The overall total cost of illness in 2003 was estimated by this study to be over six billion dollars annually for the 625,143 patients with Parkinson’s disease. Mean annual overall total costs (minus nursing home costs and mortality costs) for males with Parkinson’s disease were $1,970 higher than females with Parkinson’s disease. Patients with Parkinson’s disease who were widowed had the highest mean total cost of illness. Patients living in the South and patients with less than a high-school education reported higher mean overall total cost of illness for Parkinson’s disease. Also, patients under the age of 65 had the highest mean overall cost of illness for Parkinson’s disease. However, none of the selected demographic characteristics were found to be statistically significant for predicting the overall cost of illness in Parkinson’s disease.

Statistically significant differences for the non-institutionalized were found among patients with Parkinson’s disease for direct medical costs. Specifically, this study concluded there are statistically significant differences in direct medical costs between male and female patients with Parkinson’s disease. This study also concluded that there are statistically significant differences in direct medical costs for patients who live in the South compared to patients residing in the Northeast.

In this study, direct non-medical costs were the least frequently reported cost by patients with Parkinson’s disease. Less than 10% (21) of patients with Parkinson’s disease in this study reported having direct non-medical costs due to their illness. Of those patients reporting direct non-medical costs, the majority were reporting costs related to home modifications such as raised toilet seats and shower handrails. The majority of these direct non-medical costs were low with the exception of one person
who reported that because of their Parkinson’s disease they had made $35,000 in home modifications.

For non-institutionalized patients with Parkinson’s disease, indirect costs, specifically bed-days, made up a large percentage (26%) of the overall total cost estimate reported here. Mean indirect costs were highest for patients living in the West and lowest for patients living in the Northeast. Patients who live in the South comprised the largest portion (60%) of patients reporting indirect costs due to morbidity. However, there were no statistically significant differences in selected demographic characteristics and indirect costs for patients with Parkinson’s disease.

The cost of illness presented here is the first one ever conducted at the national level for Parkinson’s disease using the MEPS database. This study utilized a comprehensive methodology to estimate the national cost of illness of Parkinson’s disease. By selecting out only costs specific to Parkinson’s disease, the methodology used in this study eliminated the possibility of including costs for co-morbid conditions. All components of cost of illness for Parkinson’s disease were measured in this study with the exception of intangible costs. The methodology used in this study gathered costs in all categories of direct medical costs and included; prescription medications, office-based visits, emergency room visits, inpatient stays, outpatient visits, home health visits, and nursing home stays. Direct non-medical costs were also included in this cost of illness estimate as well as indirect costs for morbidity (bed days and missed work days) and mortality.

None of the previous cost and burden of illness studies for Parkinson’s disease measured all the direct medical costs that were measured in this study, and none of the previous studies that measured a specific segment of direct medical costs were at the national level. Direct non-medical costs were measured in only two of the

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previous studies of cost and burden of illness for Parkinson's disease.\textsuperscript{23,151} Neither of the previous cost studies for Parkinson's disease that measured direct non-medical costs was at the national level. Indirect costs for morbidity costs due to Parkinson's disease were measured by five previous studies; however, none of the previous studies included mortality costs.\textsuperscript{19,20,23,151,152} Also, none of the previous morbidity estimates were at the national level.

The estimate of approximately six billion dollars annually for non-institutionalized patients is within the lower range of previous national estimates of the cost of Parkinson's disease.\textsuperscript{7,8} However, because those estimates lacked clear methodology, the reproducibility and reliability of those estimates are questionable. The methodology utilized and described in this study are reproducible, reliable, and comprehensive. As with this study, future cost of illness studies should continue to follow the methodology outlined in 1966 by Dr. Dorothy Rice.\textsuperscript{28}

**Recommendations for Future Research**

The purpose of this study was to determine the cost of illness due to Parkinson's disease. This section proposes ideas for future research to advance the knowledge of the cost of illness for Parkinson's disease. First, each component of the cost of illness (direct medical costs, direct non-medical costs, and indirect costs) will be discussed and suggested methodological improvements for future research.

For direct medical costs, future research should focus on nursing home patients and study the length of time between when the patient was diagnosed with Parkinson's disease to when they were admitted into the nursing home. Such a study would look at gender differences in admissions, and marital status of the person being admitted to the
nursing home. With regards to marital status and nursing home admissions for patients with Parkinson’s disease, it would be useful to see if patients who are married are admitted later in the Parkinson’s disease process than patients who are single, divorced, or widowed. Finally, it would be useful to look at the region of the country where the nursing home is located to see if there are any regional variations in costs and admissions of patients with Parkinson’s disease.

One previous burden of illness study in North Carolina reported that informal caregiver costs were a significant portion of the cost burden in the Parkinson’s population. Due to the high frequency and cost of morbidity related to bed days reported in this study, research to better estimate the caregiver costs for patients with Parkinson’s disease should be conducted. It is likely that many of the people reporting bed days for Parkinson’s disease received some type of informal or non-paid care. Since the data sources used in this study did not include this type of information, it would be useful to know the informal care costs for patients with Parkinson’s disease. This type of informal care costs for patients with Parkinson’s disease would not only provide insight into the costs, but also the sources (i.e., spouse, sibling, or children) of informal care.

Cost of illness studies provide valuable information when the methodologies used are comprehensive and clearly stated as this study has demonstrated. An additional recommendation for future research is to conduct another national cost of illness study for Parkinson’s disease that compares costs for patients with Parkinson’s disease to people without Parkinson’s disease. This type of study would provide insight into healthcare resource utilization differences for patients with Parkinson’s disease compared to people who do not have Parkinson’s.
One final recommendation for future research is to examine cost differences between different categories of services (i.e., prescription medications, home health services, etc.) and selected demographic factors. The cost for each particular category of service would be the dependent variable and the selected demographic factors would be the independent variables. If significant cost differences were found in a particular demographic category for a particular healthcare service, then patients, healthcare providers, and healthcare insurers would have a better idea of what to expect once a diagnosis of Parkinson’s disease is made.

Although this study answered the primary research question and subsequent objectives, it has created other questions. Future research questions should therefore address the following:

1. What are the demographic characteristics that are predictive of higher overall total cost of illness for patients with Parkinson’s disease?
2. What are the other demographic characteristics that were not used in this study that are predictive of higher direct medical costs for patients with Parkinson’s disease?
3. What are the demographic characteristics that are predictive of higher indirect cost of illness for patients with Parkinson’s disease?
4. Based on gender, which specific component(s) of direct medical costs were significantly higher for patients with Parkinson’s disease?
5. Based on region, which specific component(s) of direct medical costs were significantly higher for patients with Parkinson’s disease?
6. Based on region, which specific component(s) of direct medical costs were significantly higher for patients with Parkinson’s disease?
7. What impact (cost-effectiveness, cost benefit, cost utility) will new medications that have been approved since 2003 have on the burden of illness for patients with Parkinson's disease?

8. Will new medications approved since 2003 prove effective at reducing direct medical costs (i.e., will nursing home costs be lowered) for Parkinson's disease?

9. Will new medications approved since 2003 increase quality of life such that patients with Parkinson's disease require less informal care, thereby reducing lost income and increasing productivity of informal care-givers?

10. What effect will increasing life expectancy have on the overall total cost, direct medical costs, direct non-medical costs, and indirect costs of Parkinson's disease?

11. What are the other costs of Parkinson's disease (i.e. humanist costs) that were not covered in this study?

Cost of illness studies provide valuable information and insight into disease states when the methodologies used are comprehensive and clearly stated as this study has demonstrated. While not as costly a disease state as Alzheimer's, Parkinson's disease is a more costly disease when compared to Multiple Sclerosis, a disease state with a similar prevalence. This study has provided an initial and crucial stepping stone in understanding the costs associated with Parkinson's disease. Future research of the cost of illness of Parkinson's disease will now have a reliable baseline foundation from which to work.
LIST OF REFERENCES


170 McDonald DD. Gender and ethnic stereotyping and narcotic analgesic administration. Res Nurs Health 1994; 17(1):45-49.


APPENDIX A. LETTERS OF PERMISSION
September 4, 2005

Karen Beauregard
Medical Expenditures Panel Survey
Agency for Healthcare Research and Quality
540 Gaither Road
Rockville, MD 20850

Dear Karen Beauregard,

I am requesting permission to use the material cited below in my dissertation. I am a graduate student in the Health Science Administration program at the University of Tennessee Health Science Center, Memphis Tennessee.

Request permission for:

Title of website: Medical Expenditures Panel Survey
http://www.meps.ahcpr.gov/PufFiles/H60/H60toc.pdf

Author: Agency for Healthcare Research and Quality

Figure: Sample Design of the Medical Expenditure Panel Survey Household Component.

This request shall include all future revisions and editions of the dissertation in all languages. Proper acknowledgement of title, author and publisher will be given.

Please feel free to contact me either at 901-448-1765 or kander16@utmem.edu if you have questions regarding this request. If you would like to grant permission, please sign and return a copy of this letter using the enclosed stamped envelope. Please indicate permission below.

Sincerely,

Katherine Anderson
Graduate Student
Health Science Administration Program
The University of Tennessee Health Science Center
847 Monroe Avenue, Suite 205M
Memphis, TN 38163

Permission granted:

Signature

Sept 9, 05 Date
September 4, 2005

Dr. Norman Carroll
School of Pharmacy
410 N. 12th Street
P.O. Box 990533
Richmond, VA 23298-0533

Dear Dr. Carroll,

I am requesting permission to use the material cited below in my dissertation. I am a graduate student in the Health Science Administration program at the University of Tennessee Health Science Center, Memphis, Tennessee.

Request permission for:

Title of article: The Cost of Falls Among the Community-Dwelling Elderly

Author: Norman V. Carroll, PhD

Publication appears in: Journal of Managed Care Pharmacy, Volume 11, No. 4, May 2005

Illustration: Figure 1. Development of Analysis File for Estimating Fall-Related Costs for the Noninstitutionalized Elderly Population of the United States From 1997 MEPS Data Files

This request shall include all future revisions and editions of the dissertation in all languages. Proper acknowledgement of title, author and publisher will be given.

Please feel free to contact me either at 901-448-1765 or kander16@utmem.edu if you have questions regarding this request. If you would like to grant permission, please sign and return a copy of this letter using the enclosed stamped envelope. Please indicate permission below.

Sincerely,

Katherine Anderson
Graduate Student
Health Science Administration Program
The University of Tennessee Health Science Center
847 Monroe Avenue, Suite 205M
Memphis, TN 38163

Permission granted:

Signature

Date 9-8-05
September 4, 2005

Dr. C. Warren Olanow
One Gustave L. Levy Place
Box 1137
New York, NY 10029

Dear Dr. Olanow,

I am requesting permission to use the material cited below in my dissertation. I am a graduate student in the Health Science Administration program at the University of Tennessee Health Science Center, Memphis, Tennessee.

Request permission for:

Title of article: An algorithm (decision tree) for the management of Parkinson's disease: Treatment guidelines.

Author: Dr. C. Warren Olanow

Publication appears in: Neurology, Volume 50, No. 3 Supplement 3, March 1998

Figure: Algorithm 1. The management of Parkinson's disease

This request shall include all future revisions and editions of the dissertation in all languages. Proper acknowledgement of title, author and publisher will be given.

Please feel free to contact me either at 901-448-1765 or kander16@utmem.edu if you have questions regarding this request. If you would like to grant permission, please sign and return this letter using the enclosed stamped envelope. Please indicate permission below.

Sincerely,

Katherine Anderson
Graduate Student
Health Science Administration Program
847 Monroe Avenue, Suite 2155M
Memphis, TN 38163

Permission granted: [Signature]

Date: 9/12/05

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Submission requires original and 2 copies.

DO NOT WRITE BELOW THIS LINE

IRB ACTION: Approved ☑️ Approved w/provision(s) Refered For Board Review

COMMENTS: This study qualifies for exempt status under 45 CFR 46.101(b) in that it does not involve human subjects as defined therein. Informed consent is waived in accord with 45 CFR 46.116(b). There is no necessity in that a FPI is being used.

Consent Required: No ☐ Yes ☑️ Not Applicable ☐ Wait/see ☐ Signed ☑️

RB Review:

Title

Date 3-28-05

(Rev. 1/2008)
APPENDIX C. LISTING OF ALL VARIABLES
MEPS HC - 077A - Prescribed Medicines Data 2003

DUPERSID - 8 character variable that uniquely identifies each person

PERWT03F - final person level weight

RXICD1X - the first reported medical condition associated with the prescribed medicines

RXICD2X - the second reported medical condition associated with the prescribed medicines

RXICD3X - the third reported medical condition associated with the prescribed medicines

RXNAME - prescription name reported by the pharmacist

RXRECIDX - uniquely identifies each prescription medication record on file

RXXP03X - sum of payments for prescribed medicines, sums all the expenditures from various sources of payment


MEPS HC- 077C - Other Medical Expenses 2003

DUPERSID - 8 character variable that uniquely identifies each person

EVNTIDX - event identification number

OMOTHOS - other medical expenses that do not fall into the OMTYPE categories

OMOTHOX - edited other medical expenses not included in OMTYPE

OMTYPE - other medical expenses (glasses, orthopedic items, ambulance services, hearing devices, bathroom aids, medical equipment, diabetic equipment, prostheses, alterations to home, and disposable supplies)

OMTYPEX - other medical expenses (edited)

OMXP03X - sum of all 12 sources of payments

PERWT03F - final person level weight

VARPSU03 - variance estimation PSU
MEPS HC - 077D - Hospital Inpatient Stays Data 2003

ANYOPER - any operations or surgeries performed
DUPERSID - 8 character variable that uniquely identifies each person
EVNTIDX - event identification number
IPDXP03X - sum of doctor payments for inpatient stays
IPFXP03X - sum of facility payments for inpatient stays
IPICD1X - first medical condition linked to patient stay
IPICD2X - second medical condition linked to patient stay
IPICD3X - third medical condition linked to patient stay
IPICD4X - fourth medical condition linked to patient stay
NUMNIGHX - number of nights in hospital
PERWT03F - final person level weight
RSNINHOS - reason in hospital
SPECCOND - was hospital stay related to condition
VARPSU03 - variance estimation PSU
VARSTR03 - variance estimation stratum

MEPS HC - 077E - Emergency Room Visits Data 2003

DUPERSID - 8 character variable that uniquely identifies each person
ERDXP03X - doctor sum payments (ERDSF03X-ERDOT03X)
ERFXP03X - facility sum payments (ERFSP03X-ERFOT03X)
ERICD1X - first medical condition linked to emergency room visit
ERICD2X - second medical condition linked to emergency room visit
ERICD3X - third medical condition linked to emergency room visit
EVNTIDX - event identification number
PERWT03F - final person level weight
VARPSU03 - variance estimation PSU
VARSTR03 - variance estimation stratum
VSTCTGRY - best category for care patient received
VSTRELCN - was this visit related to specific condition

**MEPS HC - 077F - Outpatient Visits Data 2003**

DUPERSID - 8 character variable that uniquely identifies each person
EVNTIDX - event identification number
MEDPRESC - any medicine prescribed for patient this visit
MEDPTYPE - type of medical care provider seen by patient on this visit
OPICD1X - first medical condition linked to outpatient department visit
OPICD2X - second medical condition linked to outpatient department visit
OPICD3X - third medical condition linked to outpatient department visit
OPICD4X - fourth medical condition linked to outpatient department visit
OPDXP03X - sum of doctor payments (OPDSF03-OPDOT03X)
OPFXP03X - sum of facility payments (OPFSF03X-OPFOT03X)
PERWT03F - final person level weight
VARPSU03 - variance estimation PSU
VARSTR03 - variance estimation stratum
VSTCTGRY - best category for care patient received
VSTRELCN - was this visit related to specific condition

**MEPS HC - 077H - Home - Health Visits Data 2003**

DUPERSID - 8 character variable that uniquely identifies each person
EVNTIDX - event identification number

HHXP03X - sum of payments for home health visits

PERWT03F - final person level weight

VARPSU03 - variance estimation PSU

VARSTR03 - variance estimation stratum

**MEPS HC - 073 - Full Year Population Characteristics Data 2003**

VARPSU03 - variance estimation PSU

VARSTR03 - variance estimation stratum

DUPERSID - 8 character variable that uniquely identifies each person

AGE03X - age (December 31, 2003)

HIDEG03 - highest educational degree completed (December 31, 2003)

RACEX - ethnic/racial origin

RACETHNX - ethnicity category of the person

HISPANX - Hispanic ethnicity

HISPCAT - specific Hispanic ethnicity group

COMBINEDRACE - This variable was created by combining RACE01X, RACETHNX, HISPANX, and HISPCAT to get a detailed race of the person

SEX - gender

TTLP03X - person's total income

MARRY03X - marital status as of December 31, 2003

REGION03X - census region where the person lived as of December 31, 2003

POVCAT03 - poverty level as of December 31, 2003

**MEPS HC - 074 - Jobs File Data 2003**

DUPERSID - 8 character variable that uniquely identifies each person
OCCPCODX - condensed occupation code

JOBTYPE - self-employed or work for someone else

JSTOPD - job stop date – day

JSTOPM - job stop date – month

JSTOPY - job stop date – year

JSTRTD - job start date – day

JSTRTM - job start date – month

JSTRTY - job start date – year

HRLYWAGE - how much person makes per hour

MAKEAMT - how much does person make

Y_CHANGE - why change in full or part-time status

WHY_LEFT - reason why not at job now

RETIRJOB - person retired from job

SICKPAY - is there paid sick leave

PAYDRVST - is there paid sick leave for doctor visits

WORKSTAT - full or part-time

HRSPRWK - number of hours worked per week

APXHRDAY - approximate number of hours worked per day

DW - daily wage rate

HRSPRDY - number of hours worked per day

WKLYAMT - usual weekly gross income

MEPS HC - 078 - Medical Conditions Data 2003

PERWT03F - final person level weight

VARPSU03 - variance estimation PSU
VARSTR03 - variance estimation stratum
DUPERSID - 8 character variable that uniquely identifies each person
CONDIDX - condition id
ICD9CODX - ICD-9 code for condition
CONDBEGD - day condition started
CONDBEGM - month condition started
CONDBEGY - year condition started
MISSWORK - was condition associated with missed work days
INBEDFLG - flag, associated with bed days
MEPS NHC - 00IP - Nursing Home Component 1996
DUPERSID - 8 character variable that uniquely identifies each person
AGEY - age (December 31, 1996)
SEX - gender
BRACE - racial background
BRACEOS - other specify race
PARKNSON - did person have Parkinson's disease
BHISPAN - is sample person Hispanic
EDULEV - level of education
BMRKSA D - marital status at admission
SADD D - admission date (day)
SADMM - admission date (month)
SADYY - admission date year
MEPS NHC - 00IF - Nursing Home Component 1996
BASEID - nursing home identifier
NUM95ADY - number of admissions in 1999

MEPS NHC - 002 - Nursing Home Component 1996

PERSNUM - person number
SFID - original sampled facility identification
PERSNUM - person number
ORIGPERS - original identification for this person
AKADXMMB - key admission date (month)
AKADXDDB - key admission date day
AKADXYYB - key admission date year
ALIVE - vital status
HISPANX - Hispanic decent
SADMMB - original admission date (month)
SADDDB - admission date (day)
SADYYB - admission date (year)
DODMMX - date of death (month)
DODDDDX - date of death (day)
DODYYX - date of death (year)
AGEXY - end date age
STRATM7Y - strata for variance estimation
PSU - PSU for variance estimation

MEPS NHC - 003 - Nursing Home Component 1996

NHID - nursing home identification
TOTPREV - total patient revenues
TOTPDAY - total patient days
<table>
<thead>
<tr>
<th>Variable</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>TOTPEXP</td>
<td>total patient expenses</td>
</tr>
<tr>
<td>TOTNPREV</td>
<td>total non-patient revenues</td>
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<tr>
<td>MEPS NHC 003</td>
<td>Nursing Home Component 1996</td>
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<tr>
<td>STRATM7Y</td>
<td>strata for variance estimation</td>
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<tr>
<td>FRAKEWT</td>
<td>final full year facility weight (ranked)</td>
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<tr>
<td>PSU</td>
<td>PSU for variance estimation</td>
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<tr>
<td>MEPS NHC 007</td>
<td>Nursing Home Component 1996</td>
</tr>
<tr>
<td>SFID</td>
<td>original facility identification</td>
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<td>basic expenditures summed</td>
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<td>ancillary expenditures summed</td>
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<td>total expenditures</td>
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<td>per diem of EXPTOTX</td>
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<tr>
<td>PSU</td>
<td>PSU for variance estimation</td>
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<td>age of person at the time of death</td>
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<tr>
<td>GENDER</td>
<td>was person who died male or female</td>
</tr>
<tr>
<td>RACE</td>
<td>race of person who died (white, black, or other)</td>
</tr>
</tbody>
</table>
APPENDIX D. FORMULAS FOR COST CALCULATIONS
Formula for Costs in Other Medical Expenses Event File (HC-077C)

Step One: Add together all reported events for the Other Medical Expenses Event file.

\[ \text{OMXP03X} + \text{OMXP03X} + \text{OMXP03X} = \text{Unweighted Patient Total for Other Medical Expenses} \]

Where: \( \text{OMXP03X} \) = sum of all payments for Other Medical Expenses.

Step Two: Multiply unweighted cost variable total by POOLWT to get amount that Parkinson's patients would spend on Other Medical Expenses.

\[ \text{OMXP03XUWPT} \times \text{POOLWT} = \text{OMXP03XWPT} \]

(person weight)

Step Three: Add together all weighted totals for to arrive at a national estimate for other medical expenses.

\[ \sum (\text{OMXP03XWPT}) = \text{OMXP03XWOT} \]
Formula for Costs in Hospital Inpatient Stay Event File (HC-077D)

**Step One:** Add together all reported events for the specific event file.

\[
\text{IPFXP03X} + \text{IPFXP03X} + \text{IPFXP03X} = \text{IPFXP03UWPT}
\]

Where: \( \text{IPFXP03X} \) = sum of facility payments for inpatient stays and \( \text{IPDXP03X} \) = sum of doctor payments for inpatient stays.

**Step Two:** Multiply unweighted cost variable total by \( \text{POOLWT} \) to get amount that Parkinson’s patients would spend on Hospital Inpatient Stays.

\[
\text{IPFXP03UWPT} \times \text{POOLWT} = \text{IPFXP03WPT}
\]

(person weight)

**Step Three:** Add together all weighted totals for Hospital Inpatient Stays to arrive at a national estimate.

\[
\sum (\text{IPFXP03XWPT}) = \text{IPFXP03WOT}
\]
Formula for Costs in Emergency Room Events File (HC-077E)

**Step One:** Add together all reported events for the specific event file.

\[
\text{ERFXPO3X} + \text{ERDXP03X} + \text{ERDXP03X} = \text{ERDXP03XUWPT}
\]

Where: \( \text{ERFXPO3X} \) = sum of facility payments for Emergency Room Visits and \( \text{ERDXP03X} \) = sum of doctor payments for Emergency Room Visits.

**Step Two:** Multiply unweighted cost variable total by \( \text{POOLWT} \) to get amount that Parkinson’s patients would spend on Emergency Room Visits.

\[
\text{ERDXP03XUWPT} \times \text{POOLWT} = \text{ERDXP03XWPT}
\]

(person weight)

**Step Three:** Add together all weighted totals for Emergency Room visits to arrive at a national estimate.

\[
\sum (\text{ERDXP03XWPT}) = \text{ERDXP03XWOT}
\]
Formula for Costs in Outpatient Visits Event File (HC-077F)

**Step One:** Add together all reported events for the specific event file.

\[
\text{OPDXP03X} + \text{OPDXP03X} + \text{OPDXP03X} = \text{OPFXP03XUWPT}
\]

Where: \( \text{OPDXP01X} = \text{sum of doctor payments for outpatient visits} \) and \( \text{OPFXP01X} = \text{sum of facility payments for Outpatient Visits} \).

**Step Two:** Multiply unweighted cost variable total by POOLWT to get amount that Parkinson’s patients would spend on Outpatient Visits.

\[
\text{OPFXP03XUWPT} \times \text{POOLWT} = \text{OPFXP03XWPT}
\]  
(person weight)

**Step Three:** Add together all weighted totals for Outpatient Visits to arrive at a national estimate.

\[
\text{OPFXP03XWPT} = \text{OPFXP03XWOT}
\]
Step One: Add together all reported events for the specific event file.

\[ \text{OBSF03X} + \text{OBSF03X} + \text{OBSF03X} = \text{OBSF03XUWPT} \]

Where: \( \text{OBSF03X} \) = sum of payments for Office Based Provider Visits.

Step Two: Multiply unweighted cost variable total by \( \text{POOLWT} \) to get amount that Parkinson's patients would spend on Office Based Provider Visits.

\[ \text{OBSF03XUWPT} \times \text{POOLWT} = \text{OBSF03XWPT} \]

(person weight)

Step Three: Add together all weighted totals for to arrive at a national estimate.

\[ \sum (\text{OBSF03XWPT}) = \text{OBSF03XWOT} \]
Formula for Costs in Home Health Visits Event File (HC-077H)

Step One: Add together all reported events for the specific event file

\[ HHXP03X + HHXP03X + HHXP03X = HHXP03XUWPT \]

Where: \( HHXP03X \) = sum of payments for home health visits.

Step Two: Multiply unweighted cost variable total by \( POOLWT \) to get amount that Parkinson’s patients would spend on Home Health Visits.

\[ HHXP03UWPT \times POOLWT = HHXP03XWPT \]

(person weight)

Step Three: Add together all weighted totals for to arrive at a national estimate.

\[ \Sigma (HHXP03XWPT) = HHXP03XWOT \]
Formula for Nursing Home Costs (NHC-003 and NHC-007)

**Step One:** Add together all reported events for the specific event file

$$\text{EXPTOTX} + \text{EXPTOTX} + \text{EXPTOTX} = \text{EXPTOTXUWPT}$$

Where: \( \text{EXPTOTX} = \text{sum of all payments for Nursing Home Expenses.} \)

**Step Two:** Multiply unweighted cost variable total by \( \text{POOLWT} \) to get amount that Parkinson’s patients would spend on Nursing Home costs.

$$\text{EXPTOTXUWPT} \times \text{POOLWT} = \text{EXPTOTXWPT}$$  
(person weight)

**Step Three:** Add together all weighted totals for to arrive at a national estimate.

$$\sum (\text{EXPTOTXWPT}) = \text{EXPTOTXWOT}$$
Formula for Overall Direct and Indirect Cost of Parkinson’s Disease

The following formula was used to determine the overall direct and indirect cost of Parkinson’s disease.

\[
\text{Overall Total Cost for Prescription Medications} + \text{Overall Total Cost for Home Health Visits} + \text{Overall Total Cost for Emergency Room Visits} + \text{Overall Total Cost for Inpatient Visits} + \text{Overall Total Cost for Outpatient Visits} + \text{Overall Total Cost for Other Medical Expenses} + \text{Overall Total Cost for Office Based Visits} + \text{Overall Total Cost for Nursing Home} + \text{Overall Total Cost for Mortality} + \text{Overall Total Cost for Office Based Visits} = \text{Overall Total Cost for Morbidity} = \text{Overall Total Cost for Mortality}
\]
VITA

Katherine Anderson was born in Knoxville, TN, on November 8, 1971. She completed her Bachelor of Science degree at the University of Tennessee in Knoxville, TN, in 1996 and received her Master of Science degree at the University of Tennessee in Knoxville, TN, in 2000. She worked at the Knox County Health Department from 1998 to 2001, serving as the Tobacco Prevention and Reduction Coordinator, and from 2001 to 2002 she worked as a Project Director for the Centers for Disease Control and Prevention on the Appropriate Antibiotic Use in the Community Campaign. From 2002 to 2006 she worked as a Research Assistant for the University of Tennessee Health Science Center in the College of Pharmacy. In 2006, she accepted an Assistant Professor position with the Uniformed Services University of Health Sciences, in Bethesda, Maryland.