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# **Chronic Conditions: Making the Case for Ongoing Care**

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# Preface

*Chronic Conditions: Making the Case for Ongoing Care*, is a chart book that was first prepared for the Robert Wood Johnson Foundation by Partnership for Solutions in December 2002 and was then updated in September 2004. Partnership for Solutions was a national program of the Robert Wood Johnson Foundation. The 2007 version of the chart book was prepared for the Pharmaceutical Research and Manufacturers of America (PhRMA) by Professor Gerard Anderson of the Johns Hopkins Bloomberg School of Public Health. Dr. Anderson was the national program director of Partnership For Solutions from 1999 to 2004.

The chart book provides an overview of chronic conditions in the United States and the impact of chronic conditions on individuals and their caregivers, as well as on the U.S. health care system. The data is used to highlight problems encountered by individuals living with chronic concerns as they attempt to obtain a continuum of services in a health care financing and delivery system that is primarily oriented to the provision of episodic care. It also shows that chronic conditions represent a higher percentage of the burden of disease in the United States and the need to foster preventative care.

*Chronic Conditions: Making the Case for Ongoing Care* was created by Gerard Anderson with the assistance of Robert Herbert and Kristina Das. All opinions expressed in this chart book are those of Gerard Anderson.

# Introduction

During the 20th century, advances in modern medicine and public health contributed to steady increases in life expectancy in the United States. Now in the 21st century, Americans can expect to live longer than any previous generation. However, along with the aging of the population, there has been a significant increase in the number of Americans living with one or more chronic conditions. As a result, we have to confront a new reality: the growing numbers of people with chronic conditions are seeking health care in a system that is structured primarily to respond to acute episodes of care.

While the technology of medicine has improved rapidly, the system of financing and delivering care has been slow to recognize the new and changing nature of disease. In the early 20th century, infectious diseases such as tuberculosis, pneumonia, and influenza were the leading causes of death, often exacerbated by public health problems such as poor sanitation, overcrowding in cities, dangerous working conditions, and inadequate nutrition and medical care. Appropriately, the health care system focused on fighting infectious disease and eliminating underlying public health problems. By the 1950s, the population's health had greatly improved and infectious diseases caused by poor public health conditions were greatly diminished in the United States. The focus then became treating acute, non-infectious illnesses such as heart attacks.

## Introduction cont.

From the 1950s to the end of the 20th century, the health care systems all became increasingly proficient at the delivery of episodic care and turned many acute episodes into survivable events. Research, education, payment systems, delivery systems, benefit packages, and financing systems all became oriented to treat acute episodes.

By the late 20th century and continuing into the 21st century, the major reason for mortality and morbidity in the United States and other industrialized countries has become chronic disease. In 2005, 133 million people, almost half of all Americans, had at least one chronic condition. By 2020, as the population ages, the number will increase to 157 million. These people represent all segments of our society – they are of all ages, races, and economic status.

Many chronic conditions are the result of behaviors that are preventable. Smoking, poor dietary habits and lack of physical exercise are three main factors that lend to many chronic conditions.

## Introduction cont.

Approximately half of all people with a chronic condition have multiple chronic conditions, many with functional limitations and disabilities. These are the heaviest utilizers of medical care services. Data show that people with five or more chronic conditions see an average of almost 14 different physicians and fill 50 prescriptions in a year. Care coordination in this population is critical, but the current system provides few financial incentives for clinicians to coordinate care across providers and service settings.

We also know people with chronic conditions report receiving conflicting advice from different physicians and differing diagnoses for the same set of symptoms. People with chronic conditions are getting services, but those services are not necessarily in sync with one another, and they are not always the services needed to maintain health and functioning.

People with different chronic health problems (diabetes, Alzheimer's) often experience similar difficulties with the current health care financing and delivery system. Many people with chronic conditions are looking for fundamental changes. There is also a growing consensus among physicians and the general public that changes are necessary to better serve people with chronic conditions. In addition to improving the coordination of care, the health care system must place a higher priority on primary, secondary, and tertiary prevention to avert disease or slow its progression.

## Introduction cont.

As this chart book details, the prevalence and costs of chronic health conditions in the United States have wide-reaching effects, both on the health care system and individuals, often with negative outcomes and consequences. As a nation, we spent 85 percent of our health care dollar on people with chronic conditions in 2004.

These costs are felt not only in health care spending, but in reduced productivity of our workforce. The challenge is to balance the incentives in our health care system to promote excellence both in acute care and in chronic care that maintains health and functioning in the face of disease progression and is coordinated across multiple providers and payers. The health care system has successfully adapted to meet new challenges in the past, and it must do so again.

## Section I – Demographics And Prevalence

Chronic conditions affect people of all ages and from all walks of life – a child with asthma, a coworker with hypertension and high levels of cholesterol, a neighbor with multiple sclerosis and diabetes, an elderly relative with arthritis, congestive heart failure and Alzheimer’s disease. As the numbers of people with chronic conditions continue to grow and grow, nearly everyone knows someone whose life is in some way altered by one or more chronic conditions.

In their 1996 book, *Chronic Conditions in America: A 21st Century Challenge*, Catherine Hoffman and Dorothy Rice estimated that by the year 2000, there would be 105 million people with chronic conditions and that by 2020 this number would grow to 134 million people. With new and updated data, and data showing an accelerating number of people with chronic conditions, we can now estimate that the number of people with chronic conditions exceeded that projection by reaching 125 million in 2000 and will grow to almost 157 million by 2020. By 2030, half the population will have one or more chronic conditions. Clearly, the number and proportion of Americans living with chronic conditions is continuing to increase.

## Section I – Demographics And Prevalence cont.

There are many reasons for this growth. Advances in medical science and technology – new diagnostic testing, new medical procedures, and new pharmaceuticals – are being used to treat acute illness and maintain a level of health and functionality that results in increased numbers of people surviving with chronic conditions. We are also successfully screening and diagnosing chronic conditions with greater frequency and success. The percentage of Americans who are obese continues to increase very rapidly.

Another cause of the increasing prevalence of chronic conditions is the aging of society. While it is important to note that the majority of people with chronic conditions are under age 65, the likelihood of having a chronic condition increases as one becomes older. For example, hypertension, the most common chronic condition, affects a greater percentage of older than younger people. As the baby boomers age, the number of people living with chronic conditions will grow dramatically. Forty-six million more Americans are projected to have at least one chronic condition in 2030 than in 2000.

Because women tend to live longer than men, they are more likely to have chronic conditions. Over time, we can expect to see a rise in the number of older women living with chronic conditions, many with multiple chronic conditions. Often these women are also caregivers to spouses or other relatives or friends with chronic conditions.

## Section I – Demographics And Prevalence cont.

Almost half of all people with chronic conditions have multiple chronic conditions, or co-morbidities. Not surprisingly, older people are more likely to have more co-morbidities. The presence of multiple chronic conditions has specific implications for the reform of health care financing and delivery systems. For example, we need to begin to think beyond specific disease management to the coordination of medical care and assistive services across care settings and among multiple providers.

Twenty-seven percent of people with chronic conditions have some type of activity limitation. Activity limitations include having difficulty walking, needing help with personal tasks such as dressing or bathing, or being restricted in the ability to work or attend school. Many people with activity limitations need personal assistance or long-term care, and the continuity of their care would likely be improved by creating links between the acute and long-term care systems.

## Section I – Demographics And Prevalence cont.

A significant challenge, both now and for the future, is how to pay for the care – medical treatment and other supportive services – that people with chronic conditions need. Currently, 54 percent of people with chronic conditions are covered by private insurance but many incur substantial out-of-pocket expenses for services not covered by their plans. More than ten million people with one or more chronic conditions are uninsured.

As a society, we need to be aware of the growing prevalence of people with chronic conditions and the problems they face as they interact with a health care system that is currently not well designed to meet their needs.

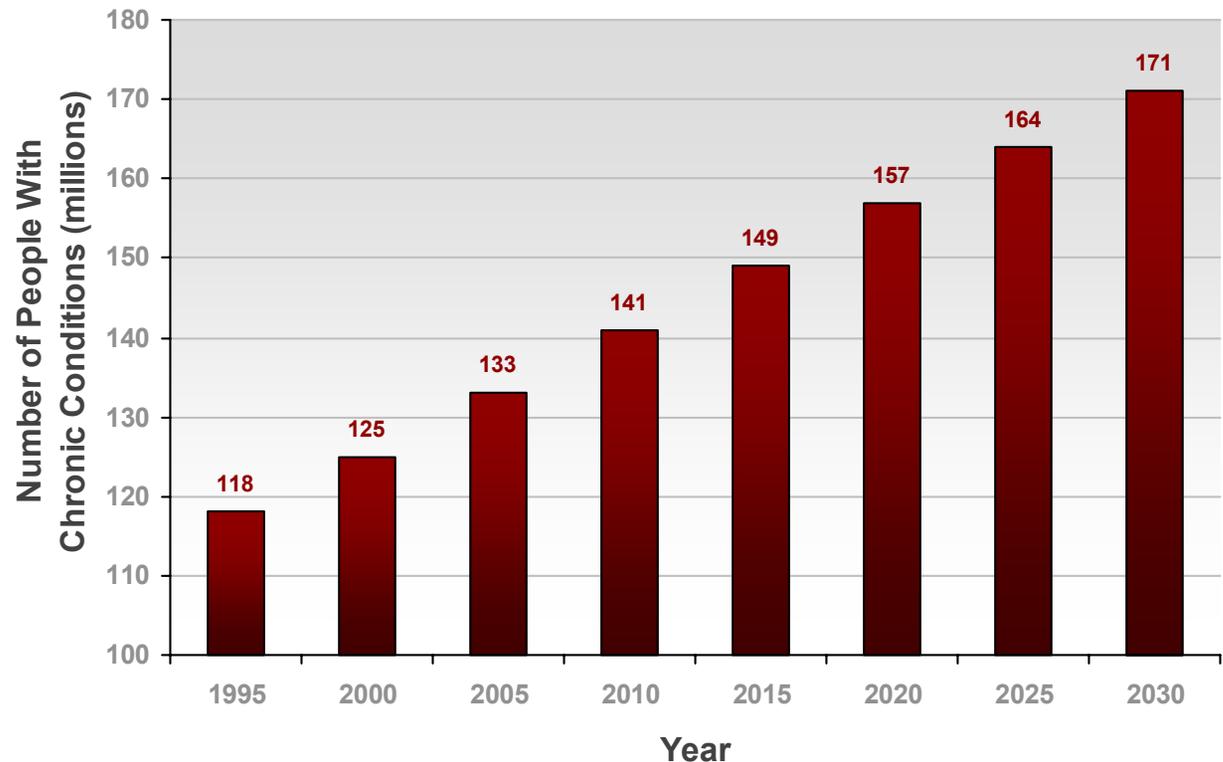
# What Does It Mean To Have A Chronic Condition?

In this chart book we define a chronic condition as a health condition that limits what you can do, requires ongoing care and lasts a year or longer. A team of five internists and five pediatricians went through the entire ICD code book and decided whether the condition was chronic or not based on the definition. It may differ for children and adults.

Chronic conditions affect people's physical and mental health, their social life, and employment status in radically different ways. Some chronic conditions are highly disabling, others less so. Some chronic conditions, especially diabetes, may not disable a person currently, but may lead to severely disabling effects if not treated early and effectively. Some people return to former levels of daily activity after recovering from a stroke or an acute episode; others don't. Some individuals with chronic conditions live full, productive, and rewarding lives; for others, isolation, depression, and physical pain are the consequences of severe chronic illness. As this chart book will demonstrate, the level of utilization and impairment increases with the number of co-morbidities.

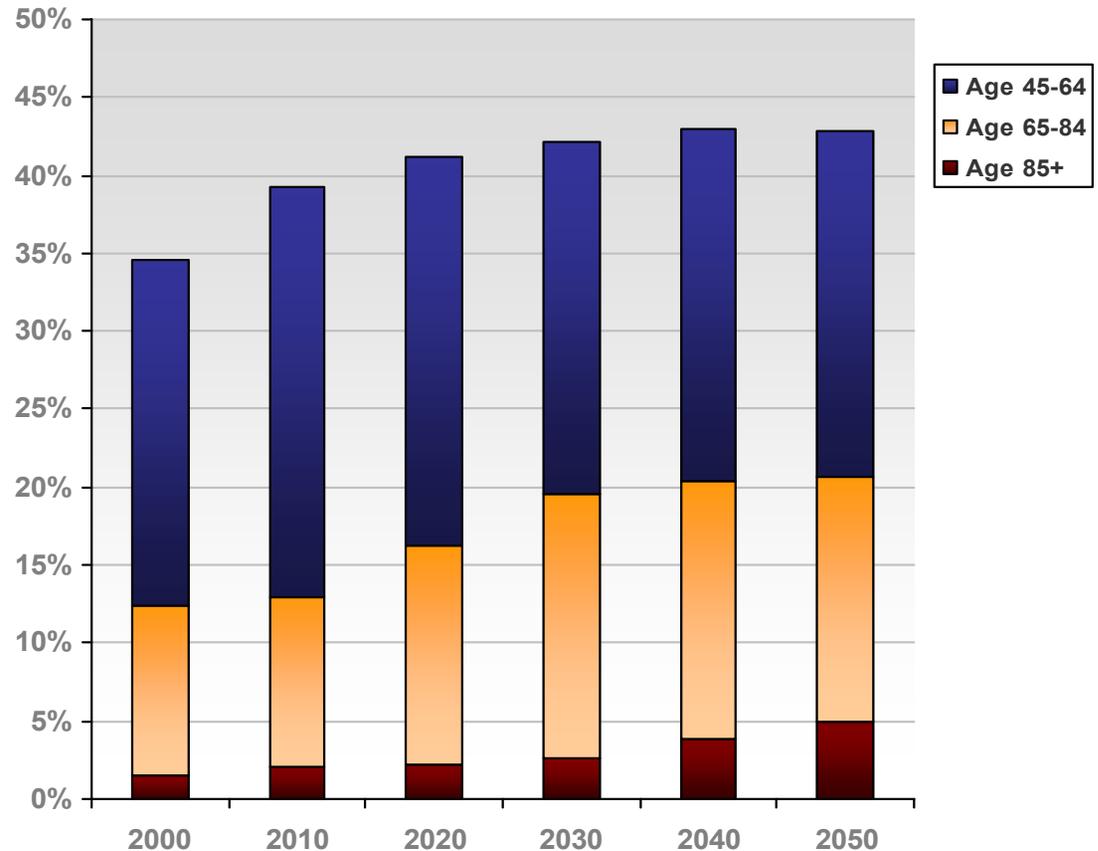
# The Number Of People With Chronic Conditions Is Rapidly Increasing

- In 2000, 125 million Americans had one or more chronic conditions.
- This number is projected to increase by more than one percent each year through 2030.
- Between 2000 and 2030, the number of Americans with chronic conditions will increase by 46 million people.



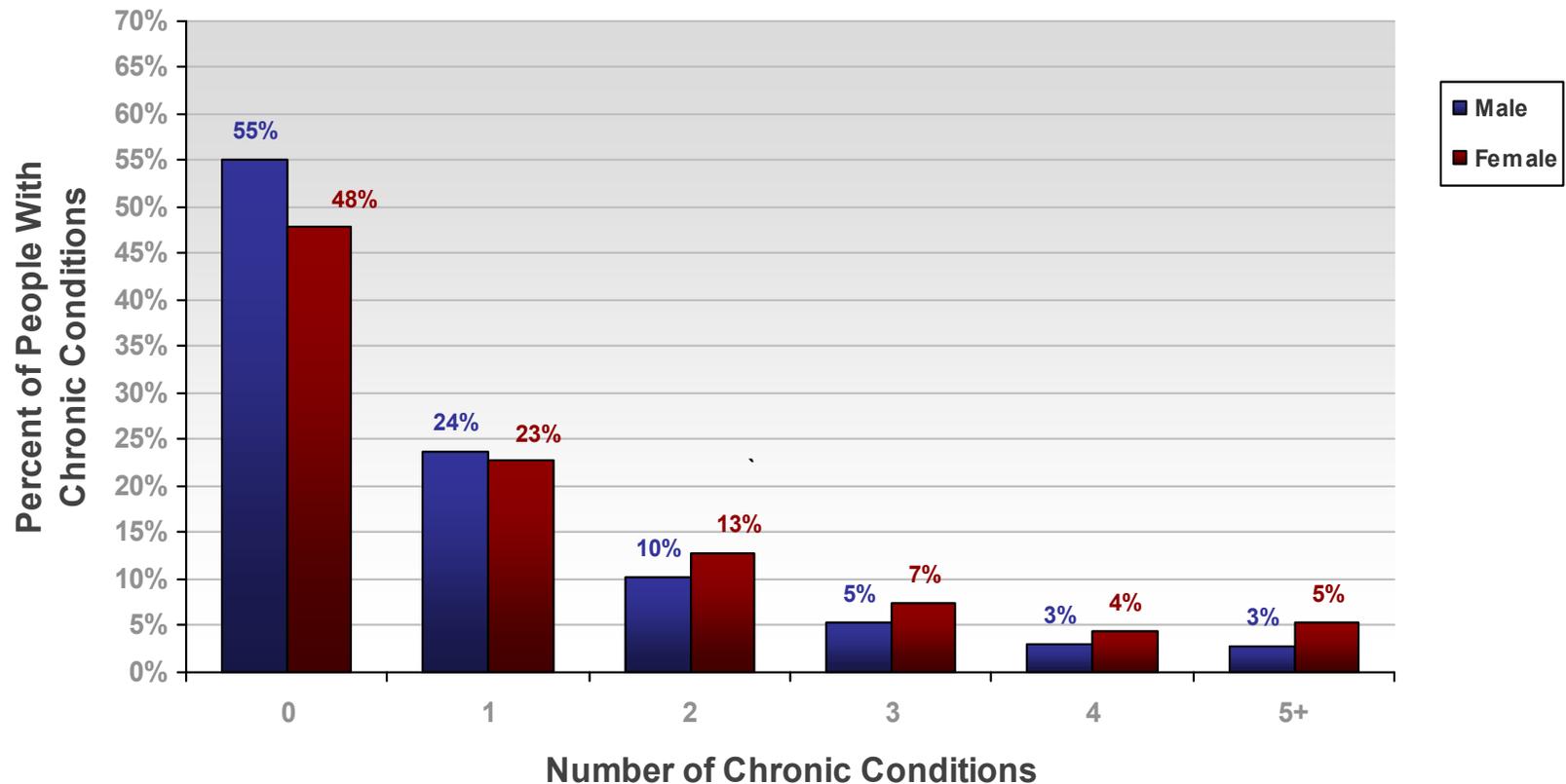
# Americans Are Living Longer

- By 2030, 20 percent of the population will be people age 65 and older and most of them will have one or more chronic conditions.
- Life expectancy at birth increased over 44 percent between 1900 and 1950, 13 percent between 1950 and 2000, and life expectancy is projected to increase by an additional 9 percent between 2000 and 2050.



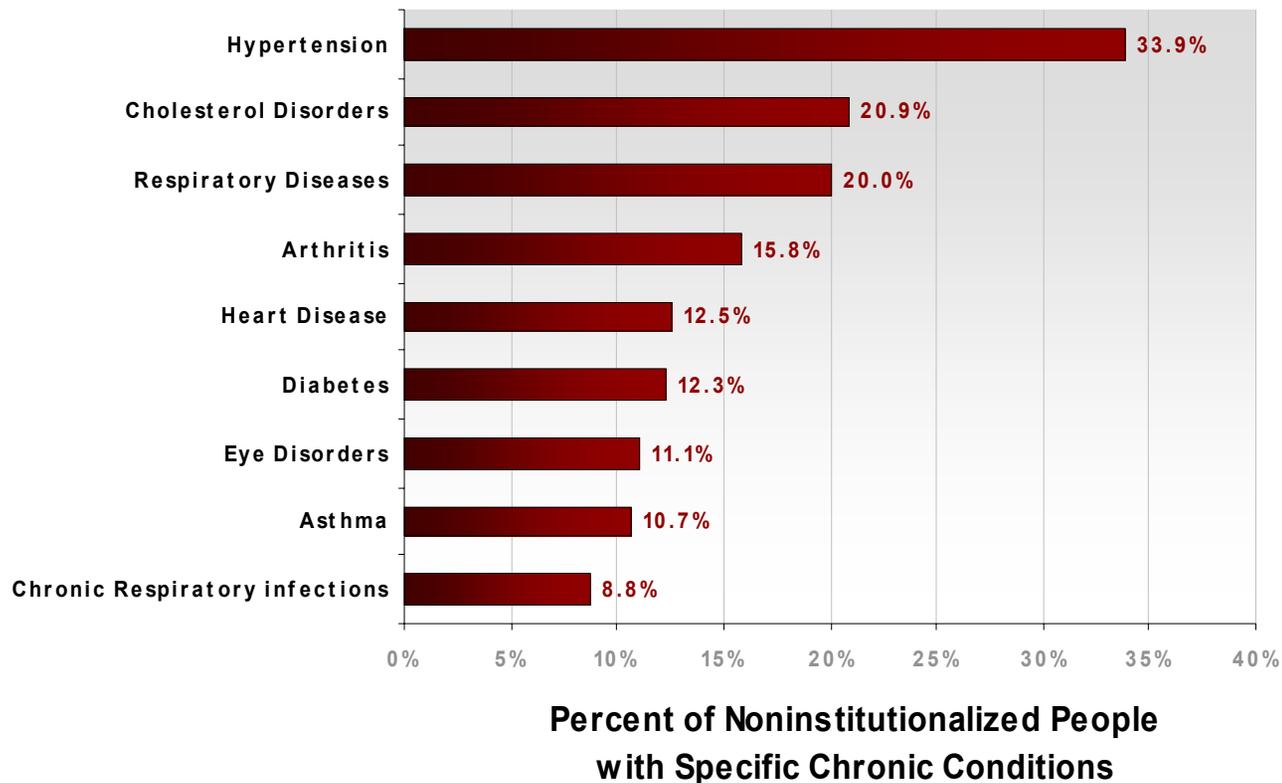
Source: U.S. Bureau of the Census. Projections of the Total Resident Population by 5-Year Age Groups and Sex with Special Age Categories: Middle Series, 1999 to 2100. (NP-T3) Washington, D.C., March 2004.

# Women Are More Likely Than Men To Have A Chronic Condition Primarily Because They Live Longer



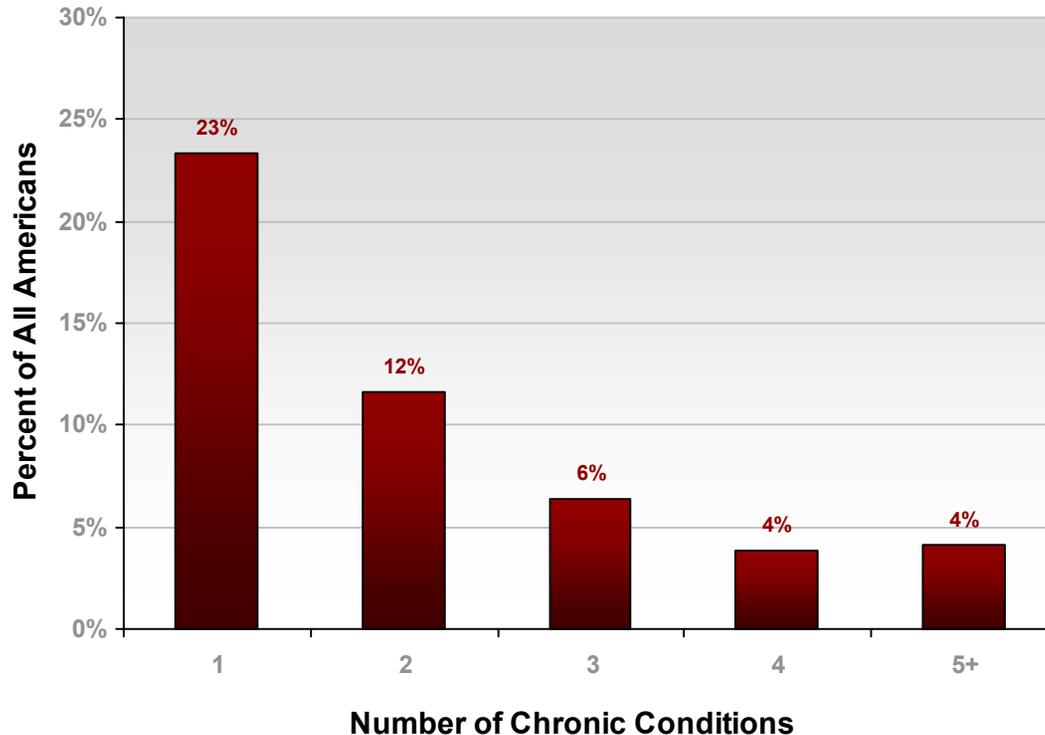
# Hypertension Is The Most Common Chronic Condition Across All Ages

- **The most common chronic conditions vary by age**



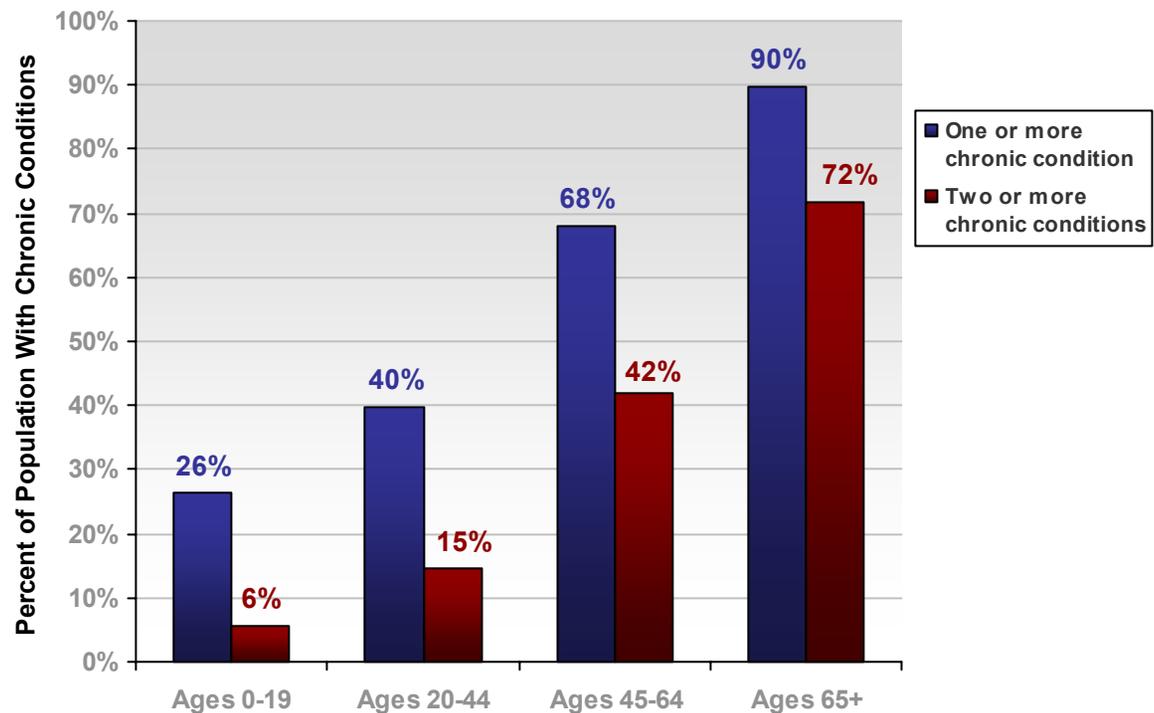
# One In Four Americans Has Multiple Chronic Conditions

- In 2004, 26 percent of all Americans had two or more chronic conditions.

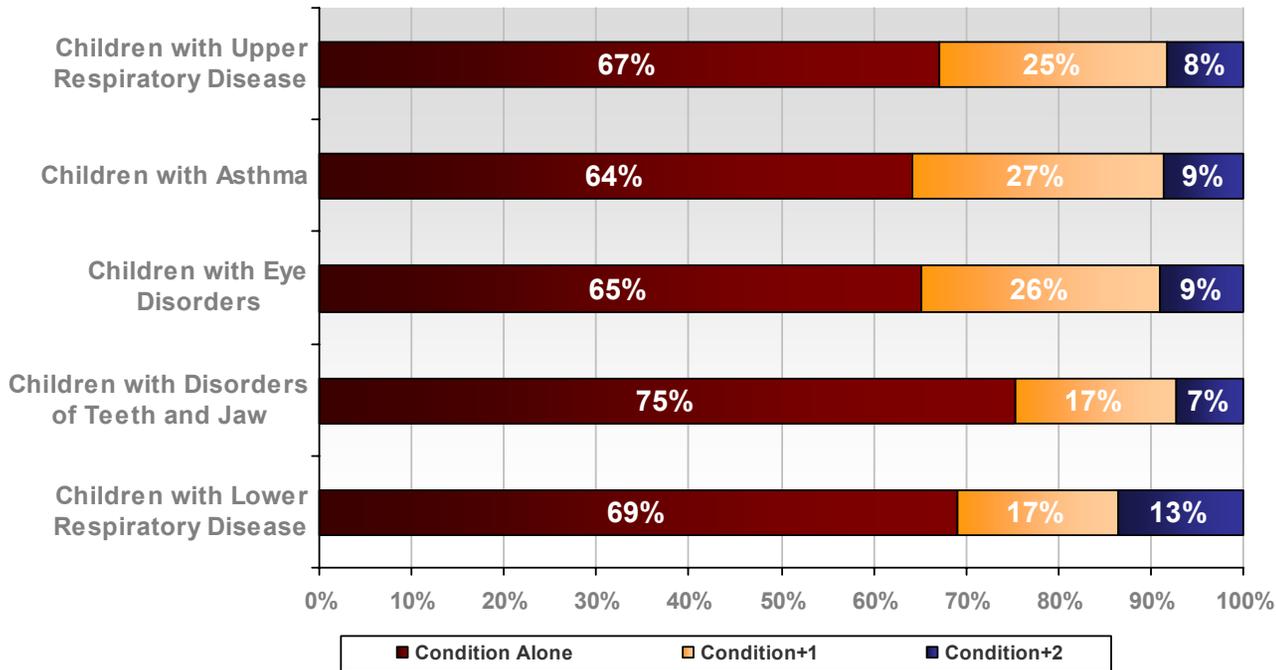


# Older Adults Are More Likely To Have Multiple Chronic Conditions

- The prevalence of multiple chronic conditions increases with age.
- Among people age 80 and older (data not shown), 93 percent have at least one chronic condition and 78 percent have two or more.

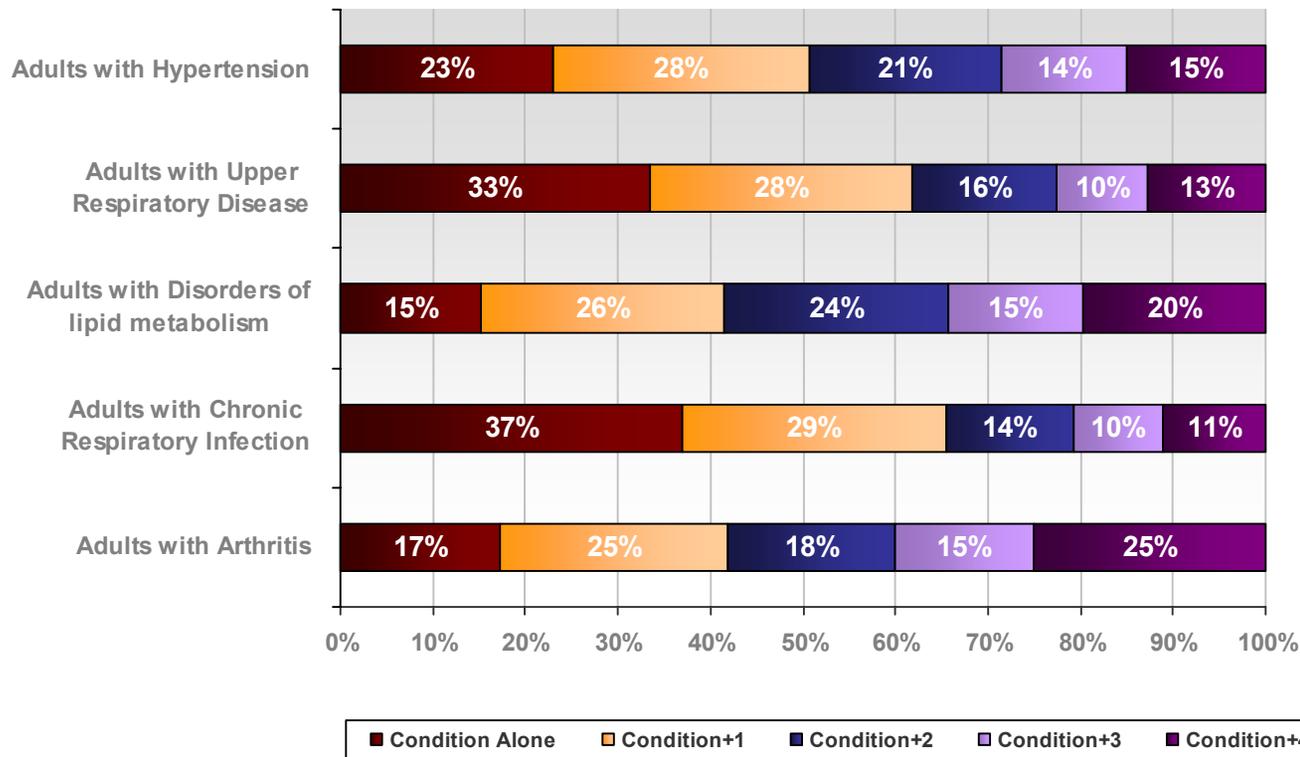


# Children with Chronic Conditions Generally Have a Single Condition



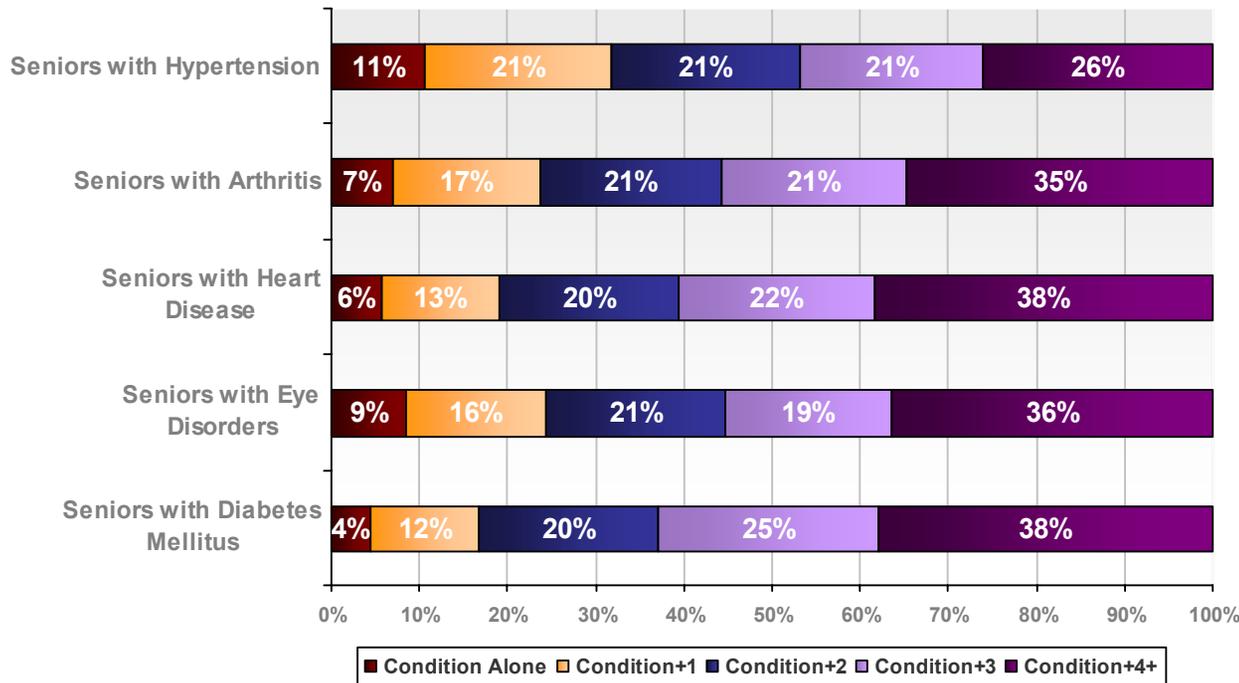
- 26 percent of children have a condition.
- Asthma is one of the five most common chronic conditions for children. 64 percent of children with asthma have no other chronic conditions, 27 percent have an additional condition, and 9 percent have 2 or more additional conditions.

# Most Adults With Chronic Conditions Have More Than One Condition



- Of the adults with hypertension, 23 percent have no other condition, 28 percent have one additional condition, and 15 percent have more than 4 additional conditions.

# Seniors With Chronic Conditions Rarely Have A Single Condition



- 90 percent of seniors have at least one chronic condition.
- Among these seniors with heart disease, 6 percent have no other chronic conditions, 13 percent have an additional chronic disease, and 38 percent have more than 4 additional chronic conditions.

## Section II – The Impact Of Chronic Conditions On Health Care Financing And Service Delivery

People with chronic conditions, particularly those with multiple chronic conditions, are the heaviest users of health care services. Higher utilization appears in all major service categories: hospitalizations, office visits, home health care, and prescription drugs. For example, individuals with multiple chronic conditions account for two-thirds of all prescriptions filled. The more chronic conditions a person has, the more he or she uses these services.

An increasing percentage of health care dollars spent in the U.S. are spent on people with chronic conditions. In 1998, the care given to people with chronic conditions accounted for 78 percent of health care spending. Now they account for 85 percent of health care spending. It must be noted that not all the spending is for the treatment of chronic conditions – these individuals also have acute illnesses and infectious diseases.

The care received by people with chronic conditions is financed by a variety of payers: private employer-sponsored insurance, government programs such as Medicare and Medicaid, and individuals through their insurance premiums and out-of-pocket spending for services. The largest number of people with chronic conditions are of working age and are privately insured: 78 million people with chronic conditions have private insurance coverage and their care accounts for about 73 percent of private insurance spending. Almost all Medicare dollars and about 80 percent of Medicaid spending is for people with chronic conditions.

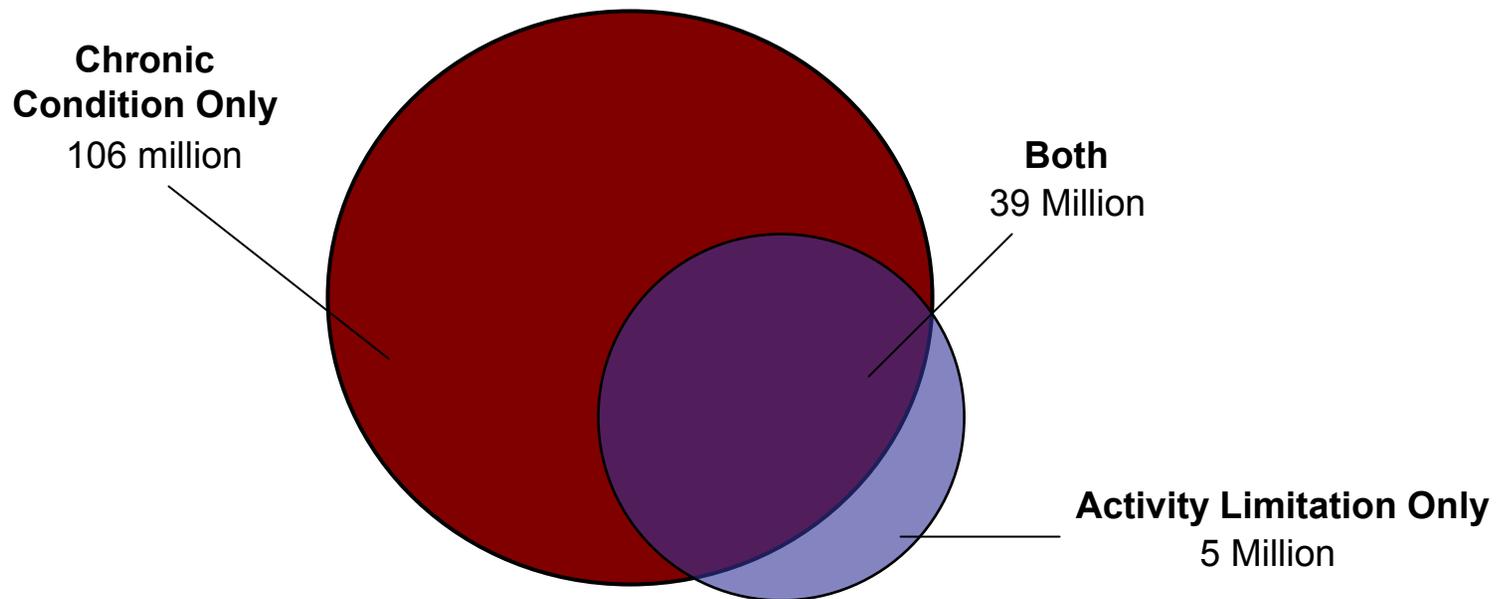
## Section II – The Impact Of Chronic Conditions On Health Care Financing And Service Delivery cont.

Health care expenditures and utilization increase considerably when people develop multiple chronic health conditions. There are a number of reasons to explain the higher utilization including clinical complexity and activity limitations resulting from chronic conditions. In general, health care spending for a person with one chronic condition is almost four times greater than spending for someone without any chronic condition, and spending is about 25 times greater for someone with five or more chronic conditions.

Adjusting the systems of financing and delivering care to better meet the needs of people with chronic conditions will require a renewed focus on preventing disease when possible, identifying it early when it occurs, and implementing secondary and tertiary prevention strategies that slow disease progression and the onset of activity limitations.

All health care providers and payers – from corporations to government to individuals – have a stake in seeing that chronic care is more adequately delivered and paid for in the United States.

# Over One-Quarter Of Individuals With A Chronic Condition Also Have One Or More Activity of Daily Living Limitations



# What Are Chronic Conditions And Activity Limitations?

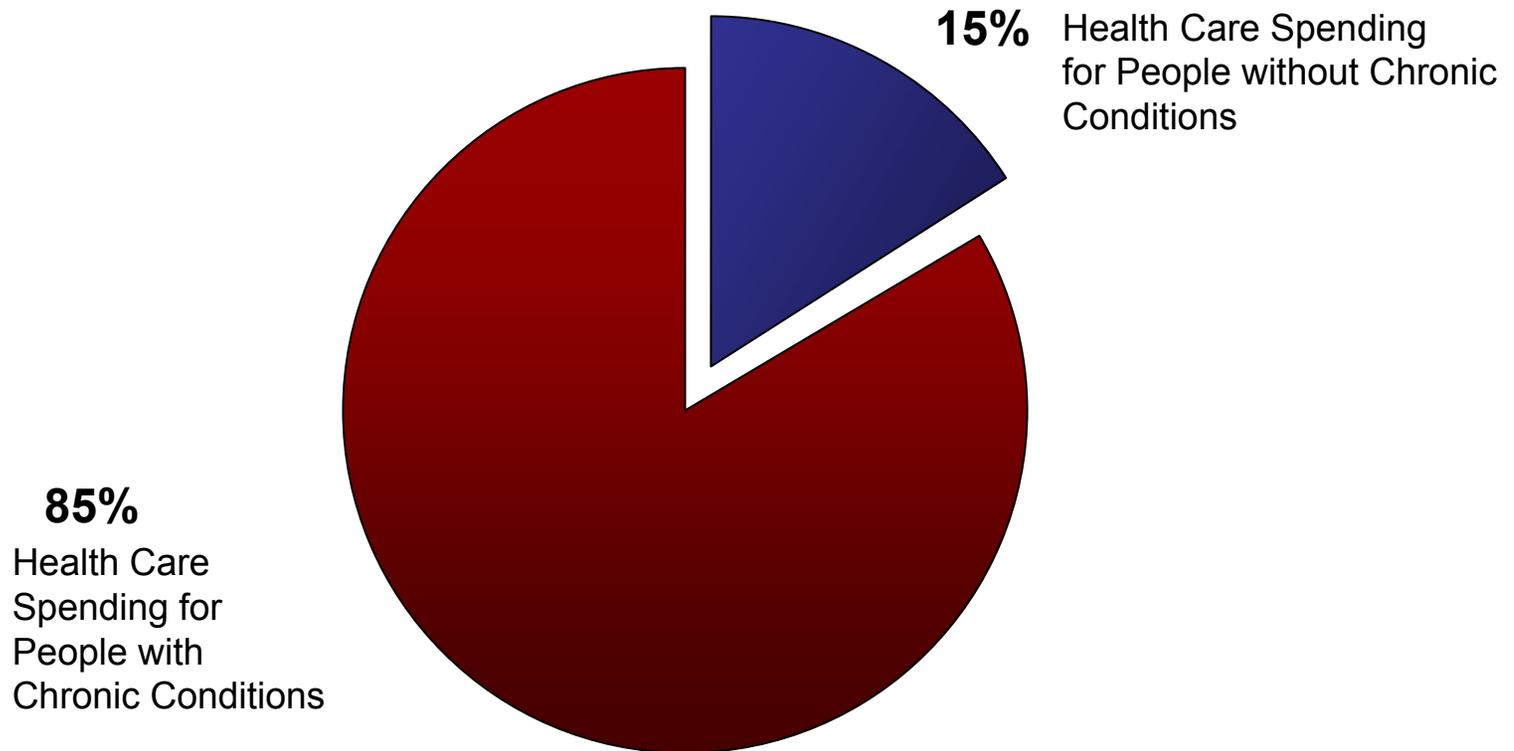
**Chronic conditions** is a general term that includes chronic illnesses and impairments. It includes conditions that are expected to last a year or longer, limit what one can do, and/or may require ongoing medical care.

**Serious chronic conditions** are a subset of chronic conditions that require ongoing medical care and limit what a person can do.

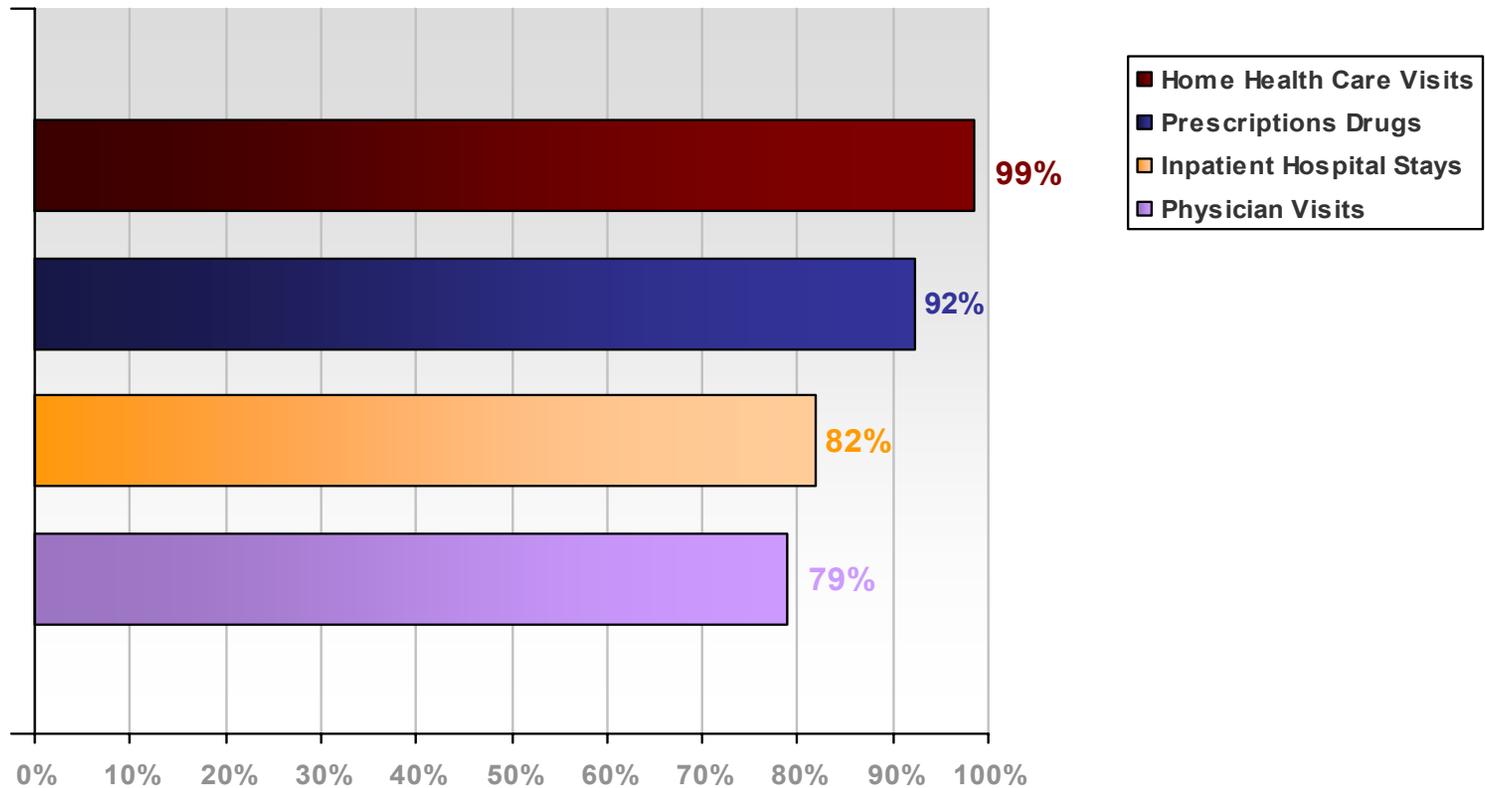
**Chronic illnesses** are conditions that are expected to last a year or more and require ongoing medical care.

**Activity of Daily Living Limitations** are functional limitations and disabilities that restrict a person from performing normal activities without assistance – such as walking, dressing and bathing – or affect a person's ability to work or attend school.

# People With Chronic Conditions Accounted For 85 Percent Of All Health Care Spending In 2004



# People With Chronic Conditions Are The Heaviest Users Of Health Care Services

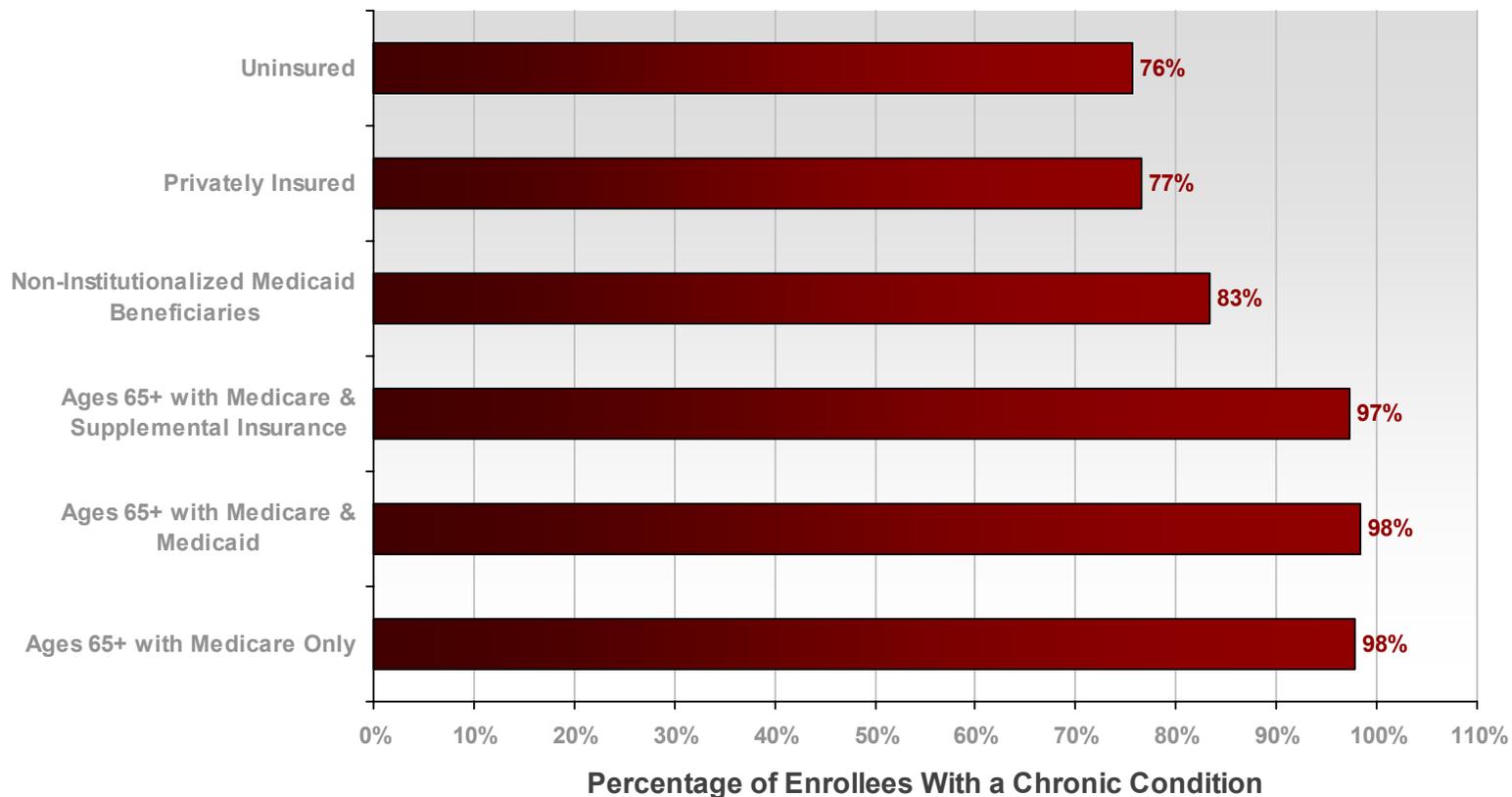


Percent of Services Used by People with Chronic Conditions

# Health Care Spending Is High For People With Chronic Conditions In All Insurance Groups

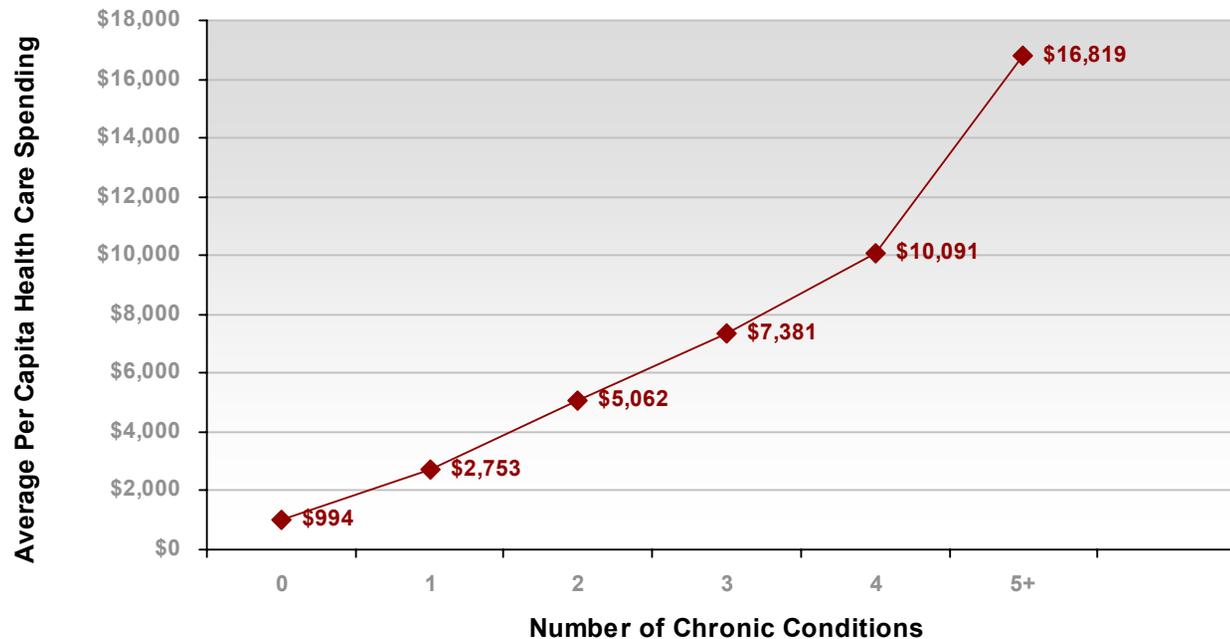
- Ninety-eight percent of Medicare spending is by Medicare beneficiaries with one or more chronic conditions.
- Eighty-three percent of Medicaid spending is by non-institutionalized beneficiaries with one or more chronic conditions.
- Seventy-seven percent of private health insurance spending is attributed to people who have one or more chronic conditions.
- Individuals with one or more chronic conditions are responsible for 76 percent of all spending by the uninsured.

# Percentage Of Health Care Spending For Individuals With Chronic Conditions Varies By Type Of Health Insurance



# Health Care Spending Increases With The Number Of Chronic Conditions

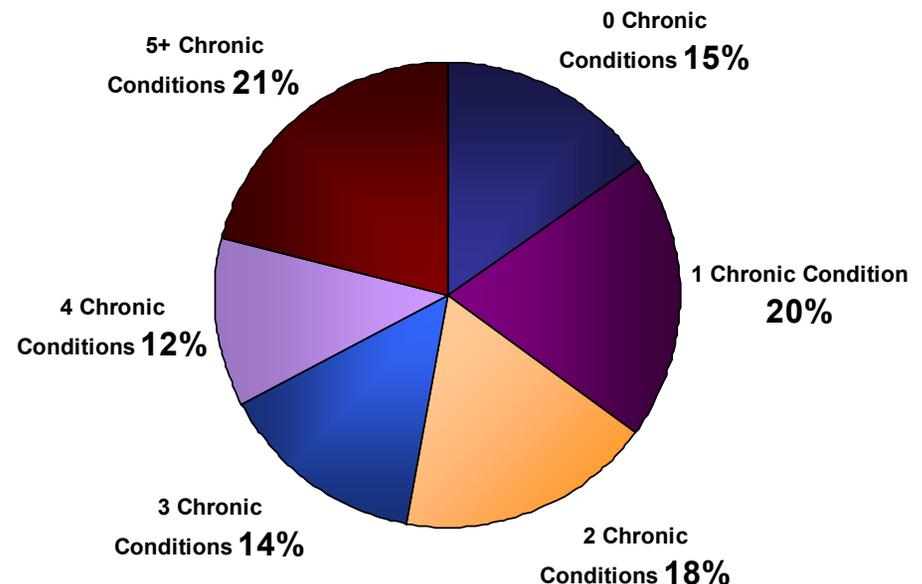
- **Average per capita spending on people with one or more chronic conditions is more than five times greater than spending on people without any chronic conditions.**



# Sixty-Five Percent Of Health Care Spending Is On People With Multiple Chronic Conditions

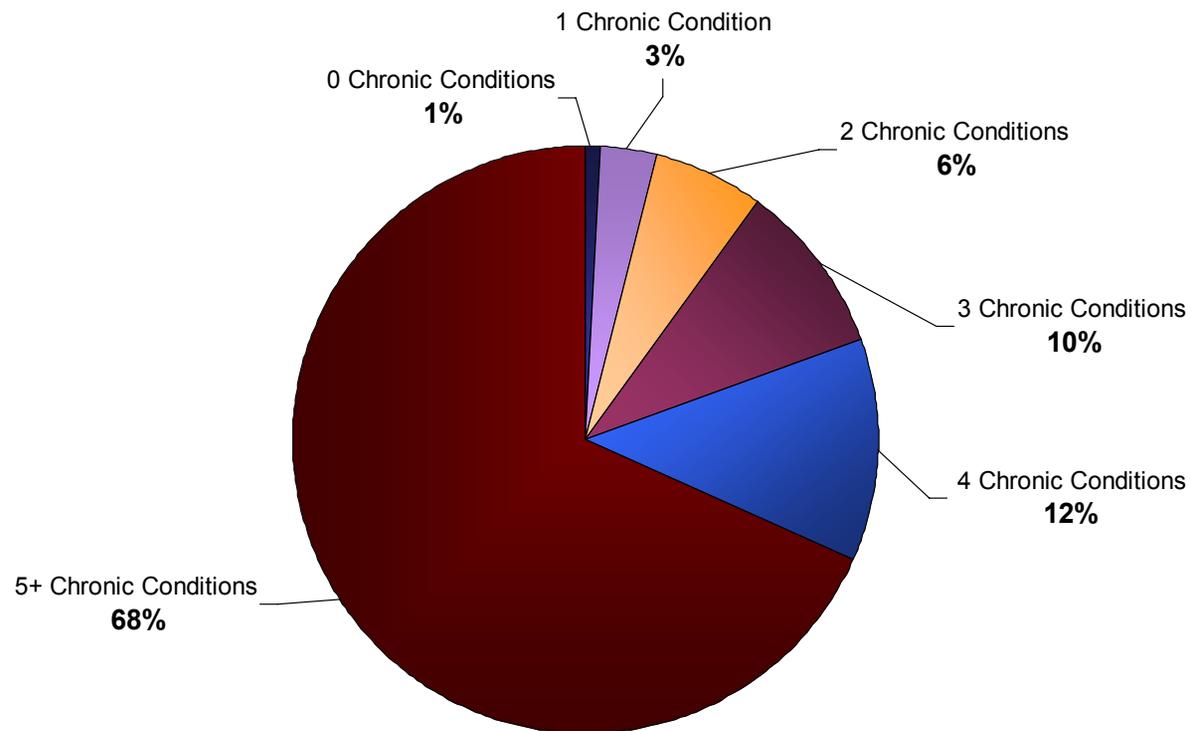
- **Fifteen percent** of spending is for the 51 percent of the population that has no chronic conditions.
- **Twenty percent** of spending is for the 23 percent of the population that has only one chronic condition.
- **Eighteen percent** of spending is for the 12 percent of the population that has two chronic conditions.
- **Fourteen percent** of spending is for the 6 percent of the population that has three chronic conditions.
- **Twelve percent** of spending is for the 4 percent of the population that has four chronic conditions.
- **Twenty-one percent** of spending is for the 4 percent of the population that has five or more chronic conditions.

Percent of Health Care Total Spending by Number of Chronic Conditions



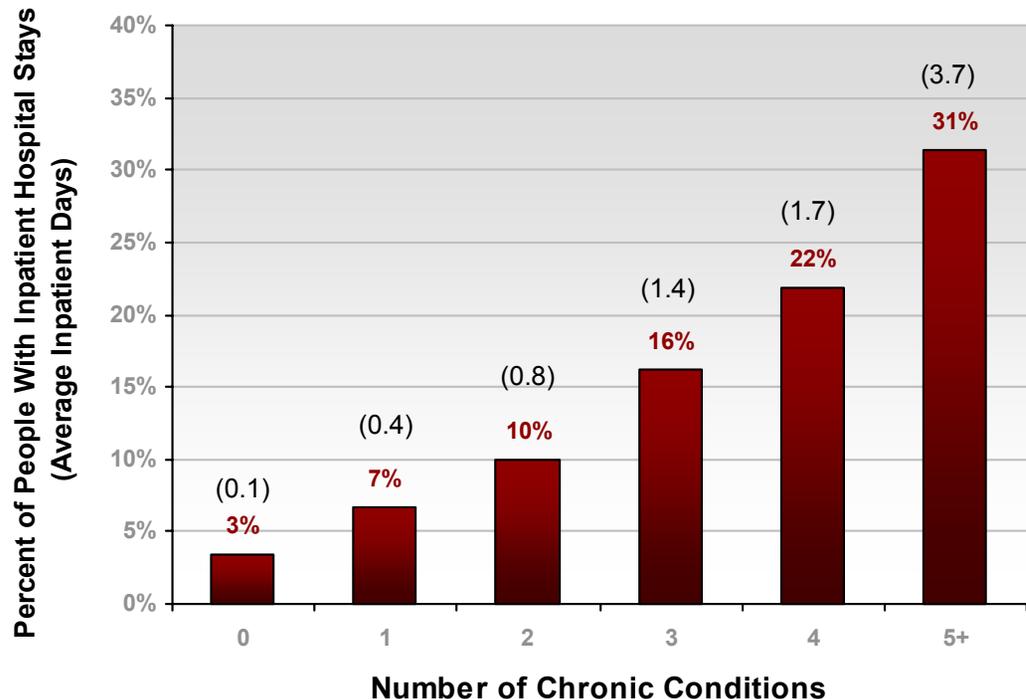
# Two-Thirds Of Medicare Spending Is For Beneficiaries With Five Or More Chronic Conditions

- **Ninety-six percent of Medicare expenditures involve individuals with multiple chronic conditions.**



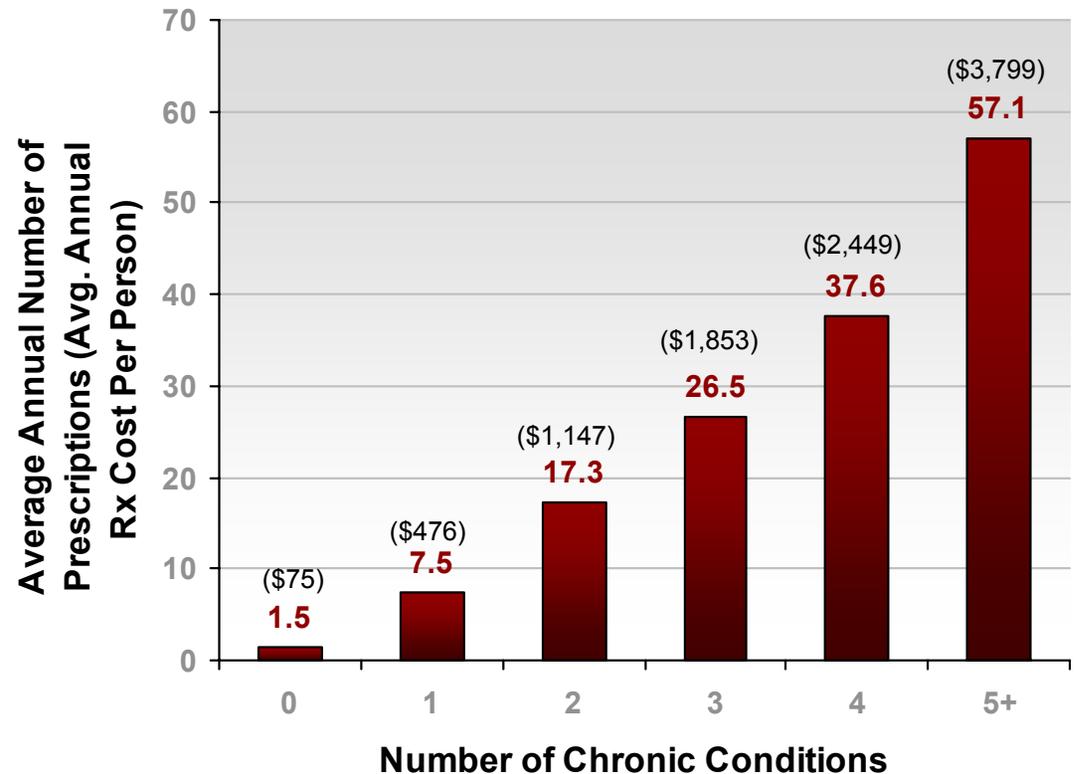
# People With Multiple Chronic Conditions Are Much More Likely To Be Hospitalized

- People with 5+ chronic conditions are ten times more likely to be hospitalized than people with no chronic conditions
- For the four percent of the population with five or more chronic conditions, 31 percent have been hospitalized.



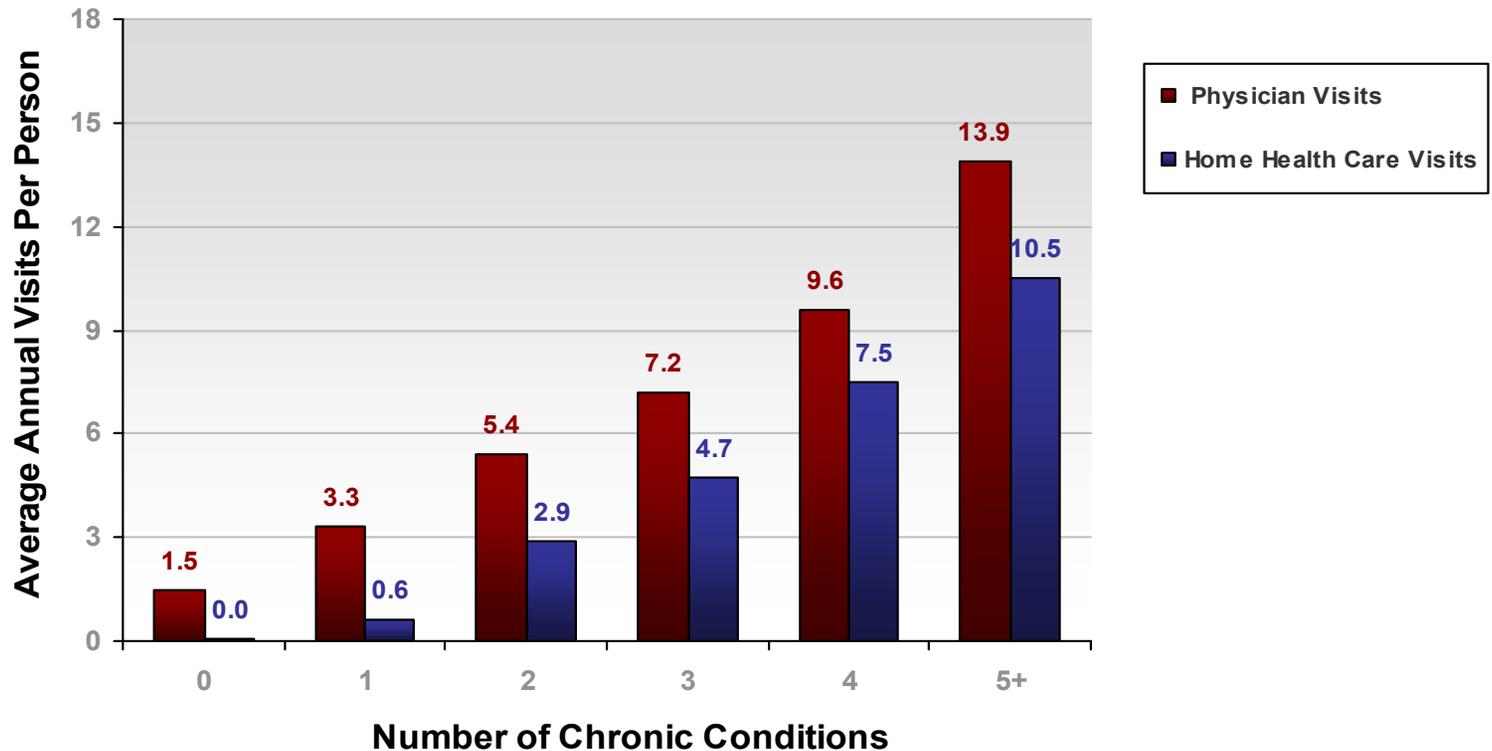
# People With Multiple Chronic Conditions Fill More Prescriptions And Have Higher Drug Spending

- Drug expenditures for people with 5+ chronic conditions are over 50 times what it is for people with 0 chronic conditions
- The four percent of the population with five or more chronic conditions fill an average of 57.1 prescriptions annually.



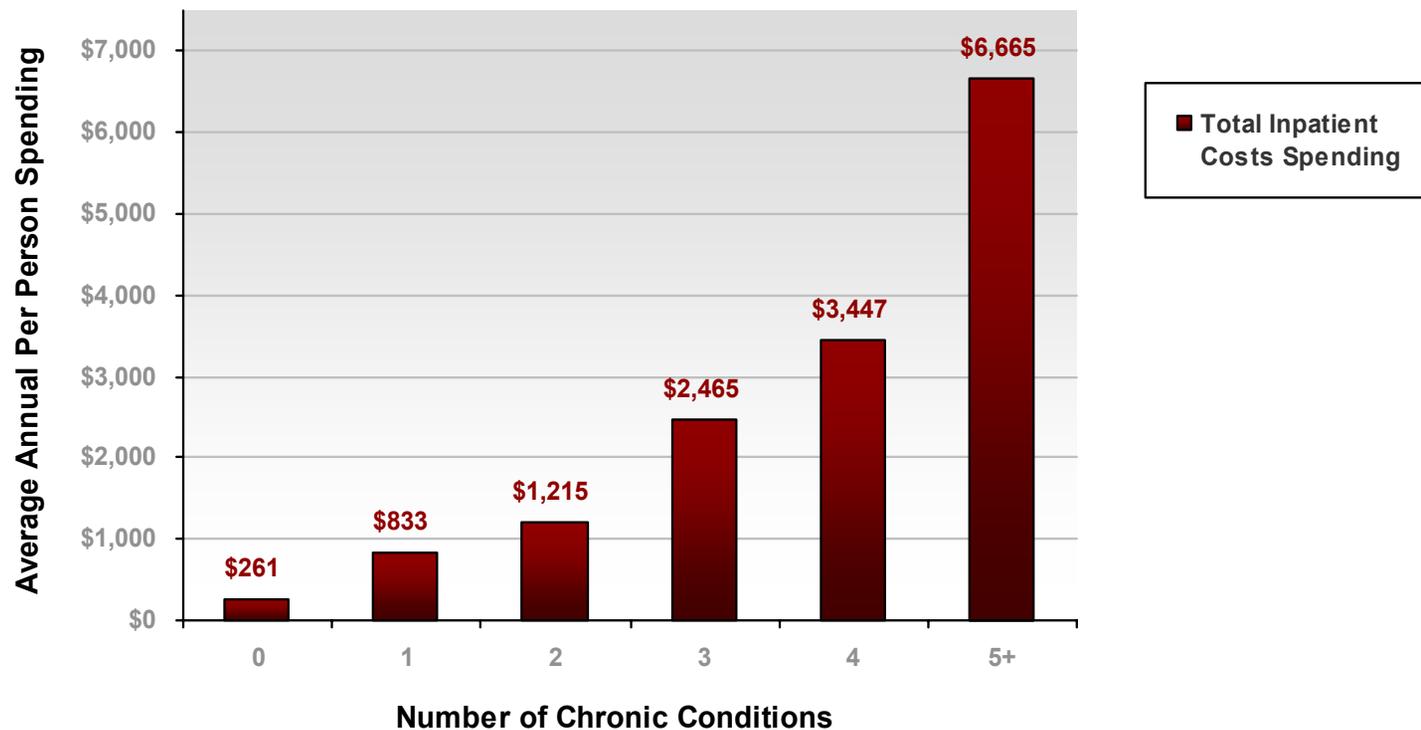
# Physician And Home Health Care Visits Increase With The Number Of Chronic Conditions

- The four percent of the population with five or more chronic conditions has an average of 13.9 physician visits annually.

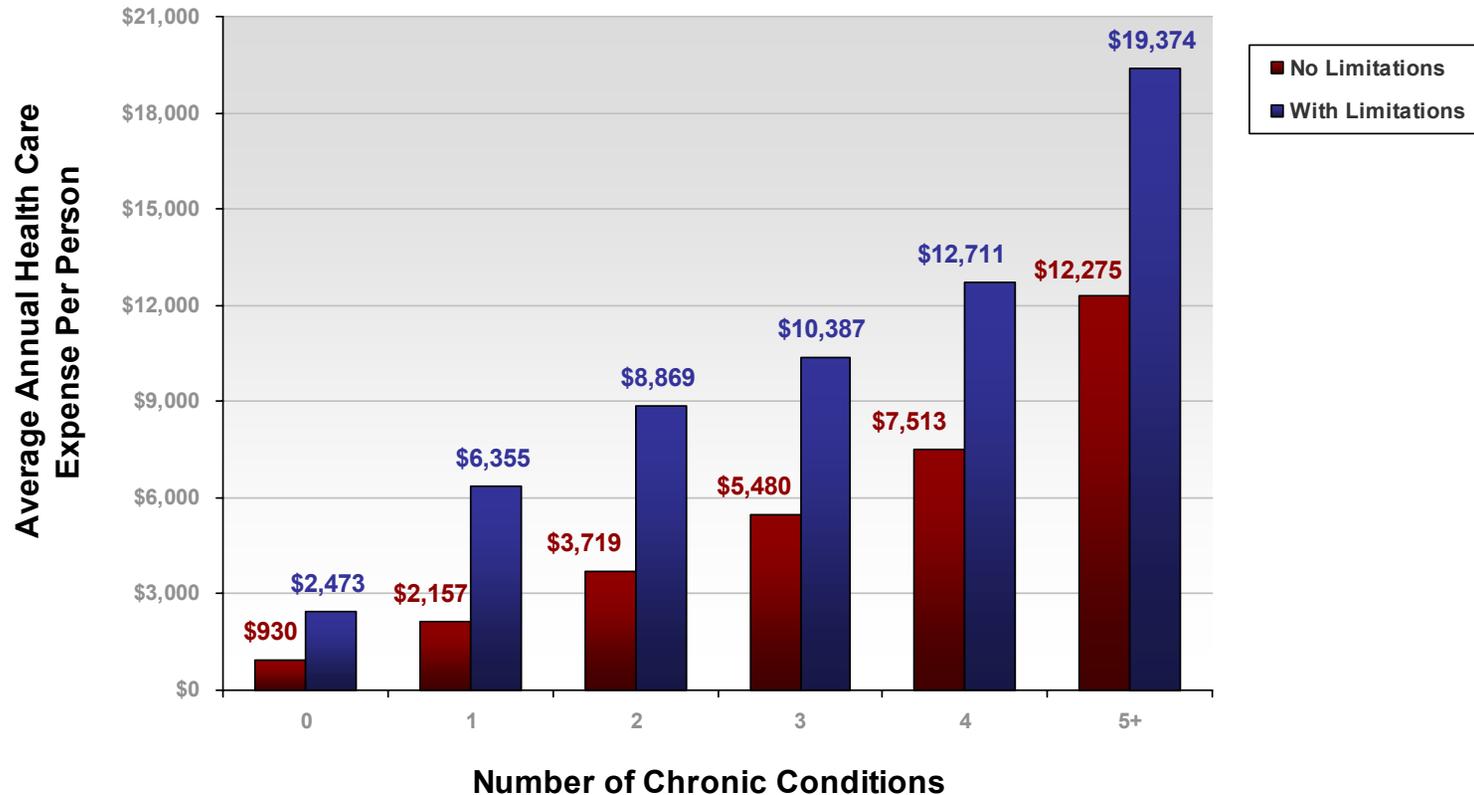


# Spending For Inpatient Hospital Care Increases With The Number Of Chronic Conditions

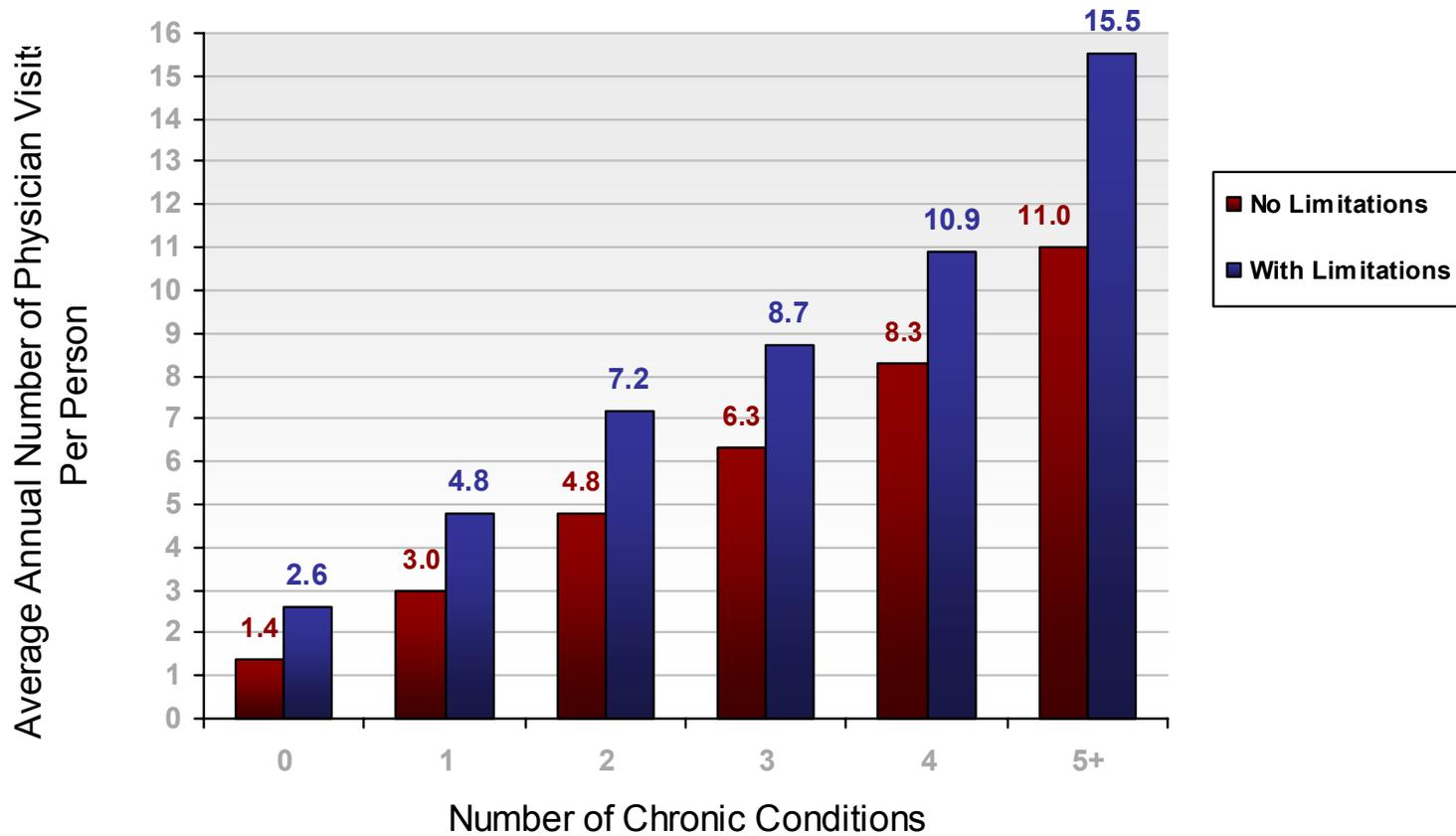
- **People with 5+ chronic conditions have 25 times the inpatient hospital spending of people with 0 chronic conditions**



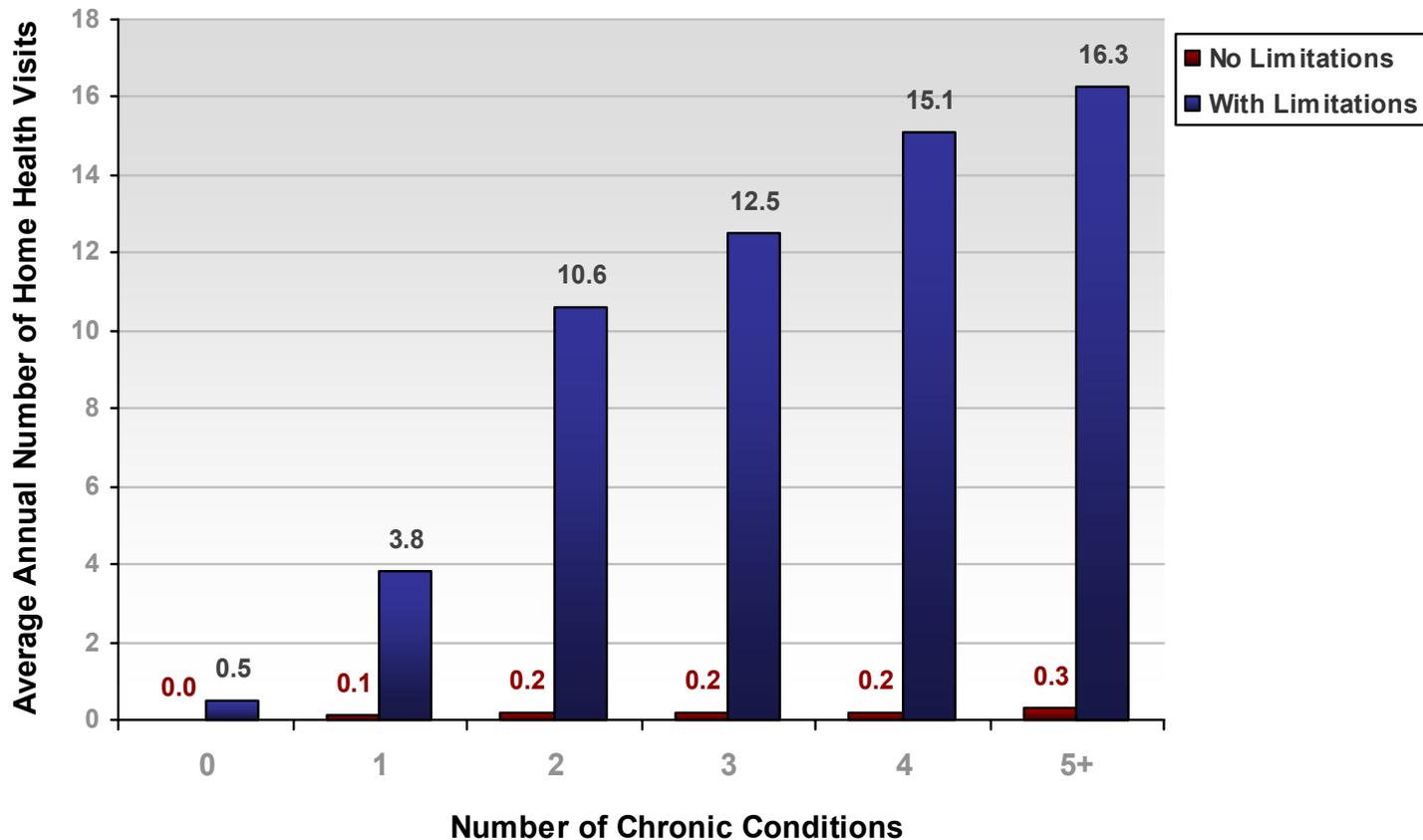
# Health Care Spending Doubles When People With Chronic Illnesses Also Have An Activity Limitation



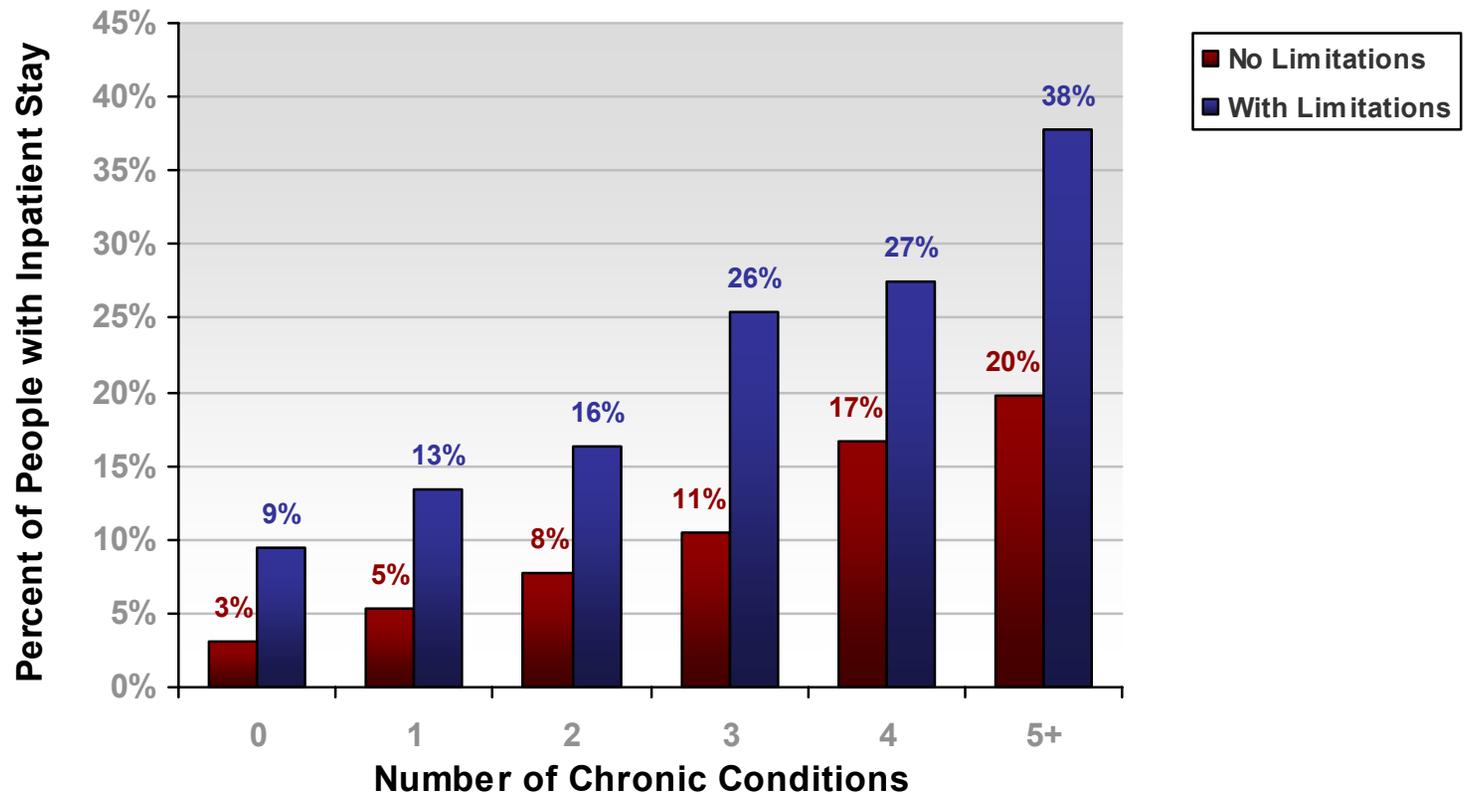
# People with a Combination of Chronic Conditions and Activity Limitations Have More Physician Visits



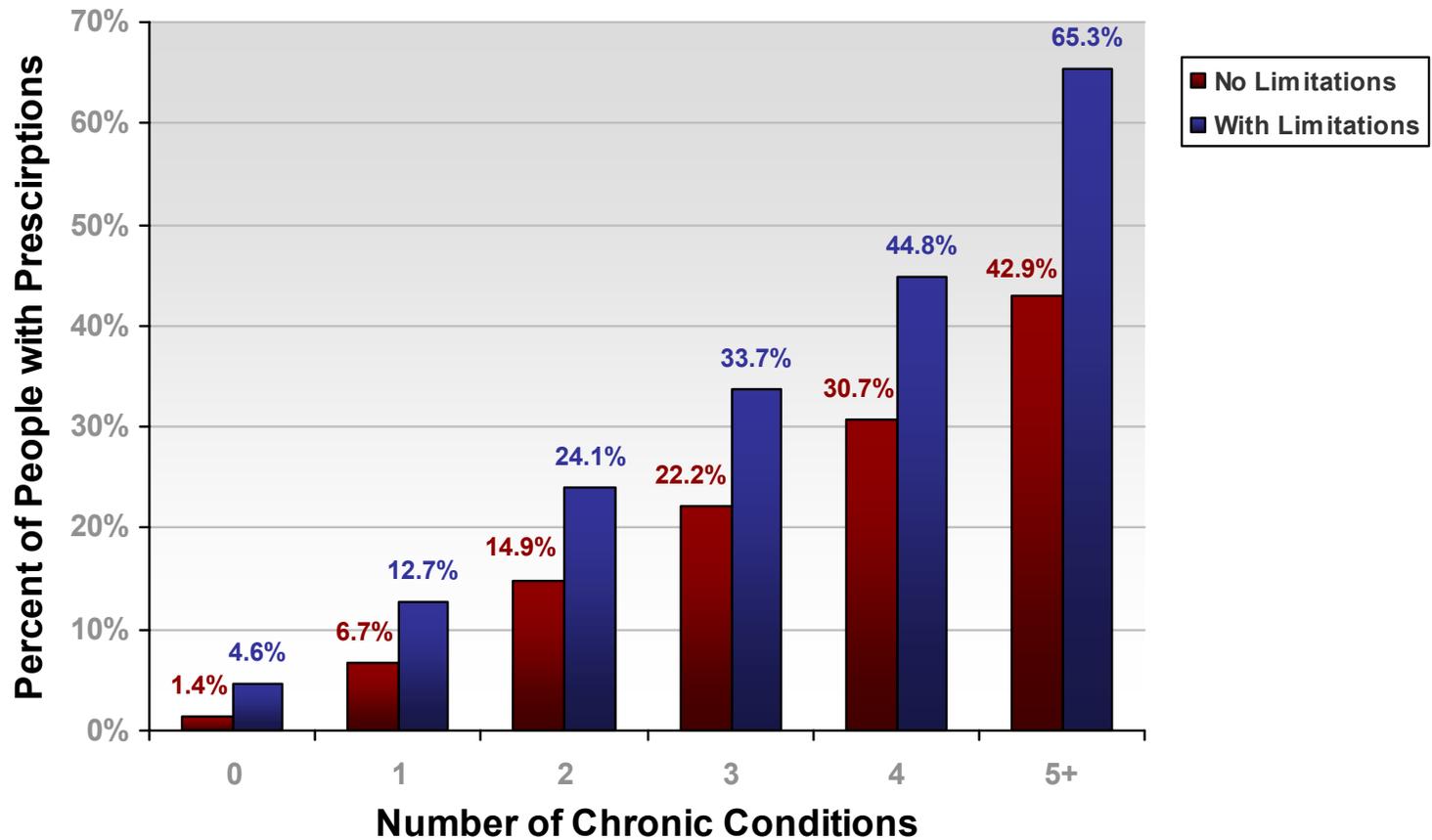
# Individuals With A Combination Of Chronic Conditions And Activity Limitations Have Many More Home Health Care Visits



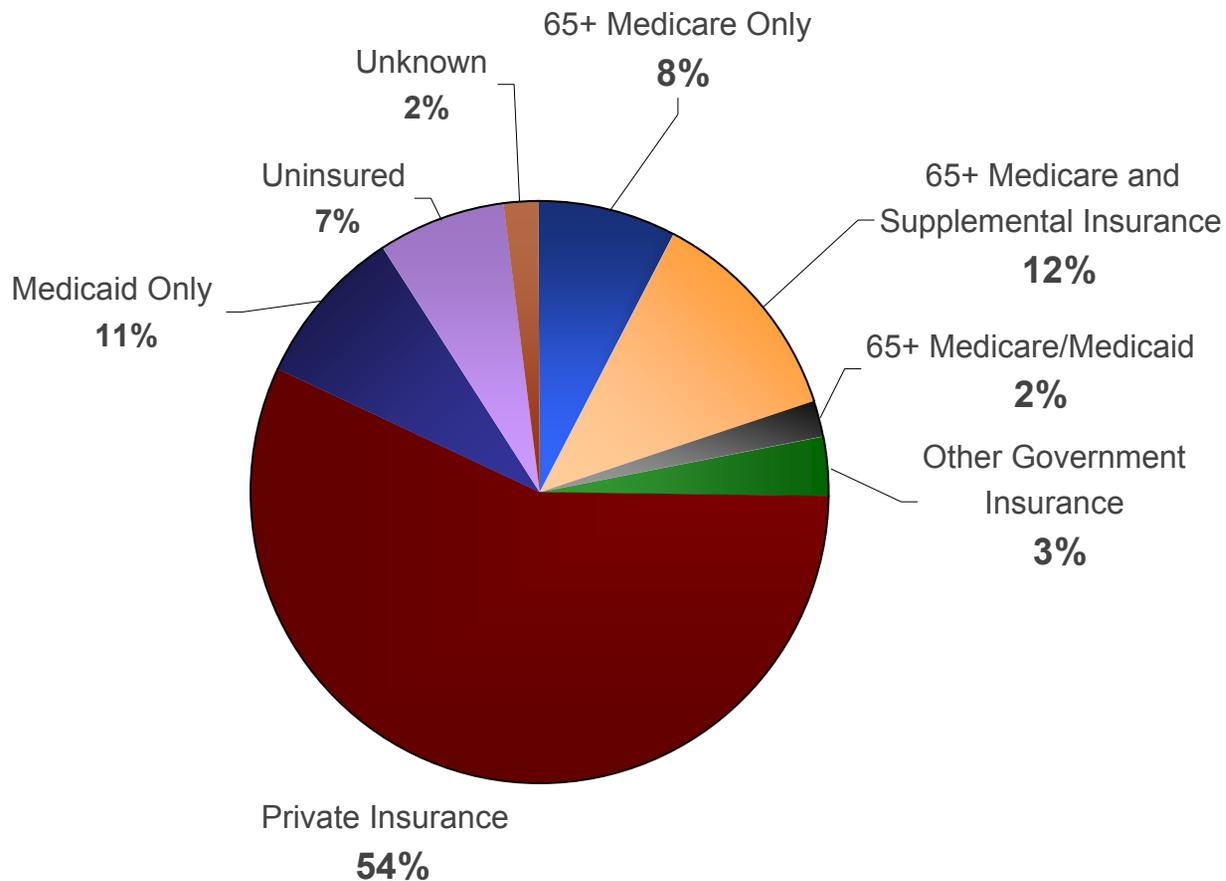
# People With A Combination Of Chronic Illnesses And Activity Limitations Are Twice As Likely To Have An Inpatient Stay



# People With A Combination Of Chronic Conditions And Activity Limitations Fill More Prescriptions

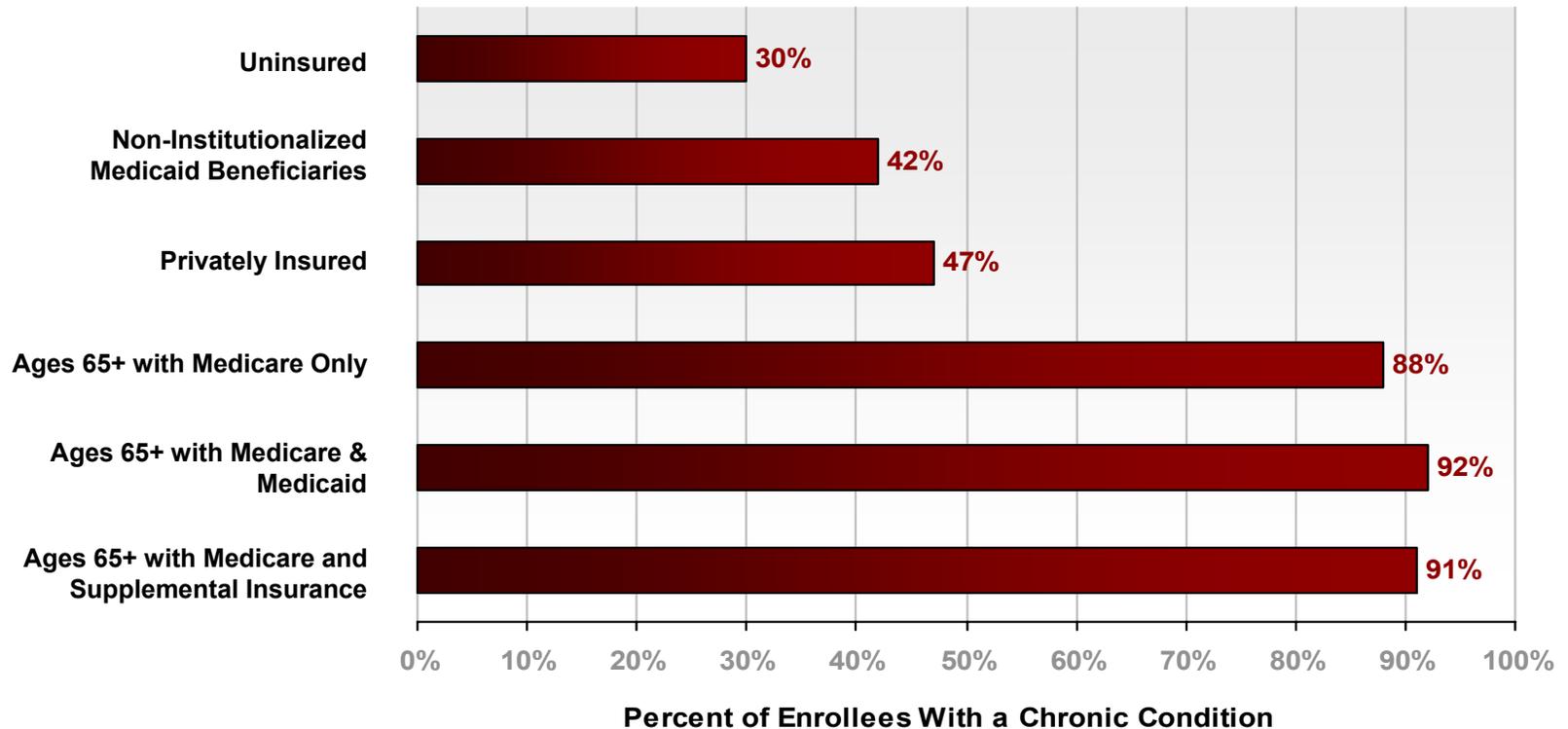


# Most People With At Least One Chronic Condition Have Private Health Insurance



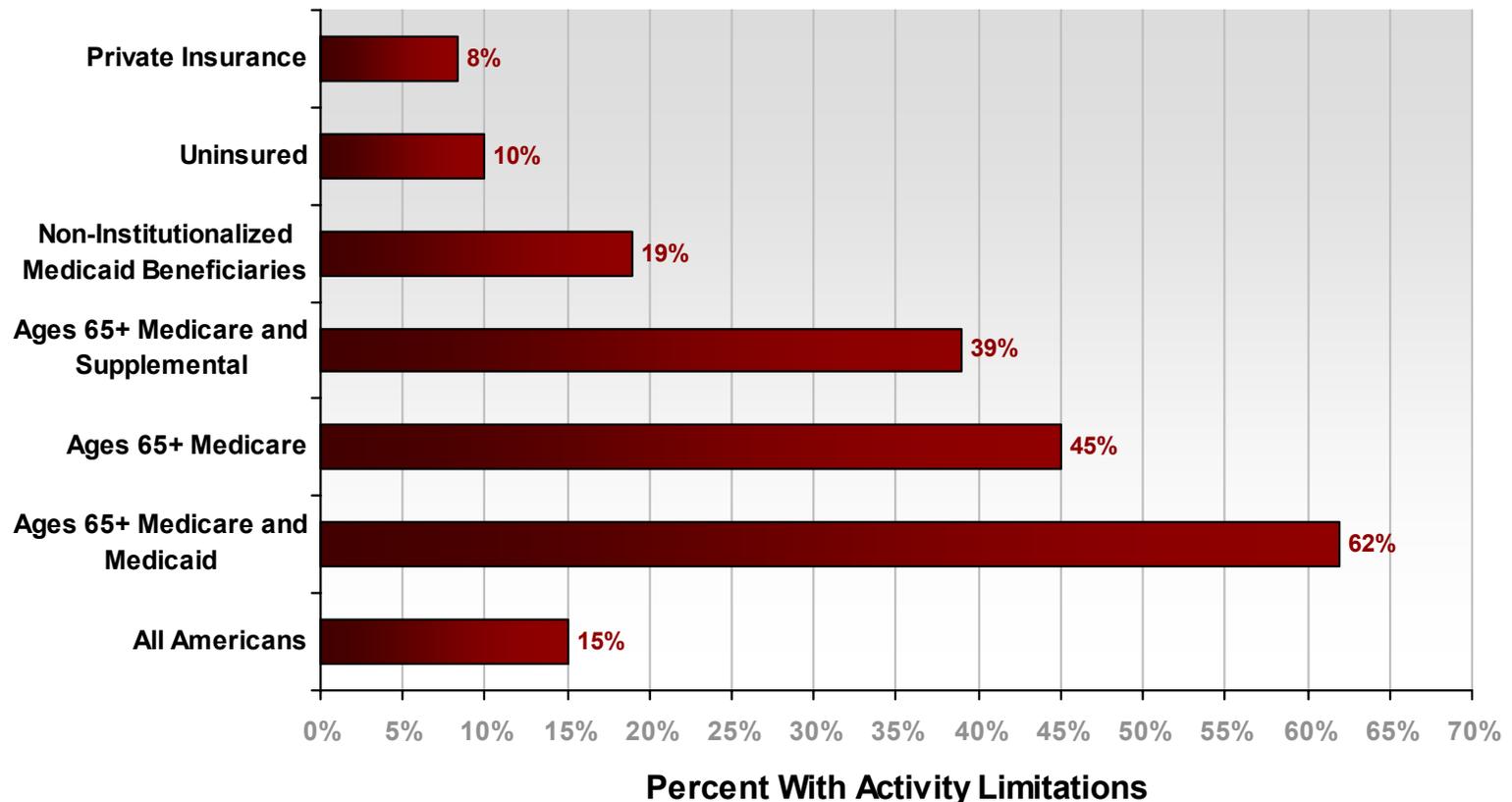
# People With Medicare Coverage Are Most Likely To Have One Or More Chronic Conditions

- Forty-nine percent of all Americans have one or more chronic conditions

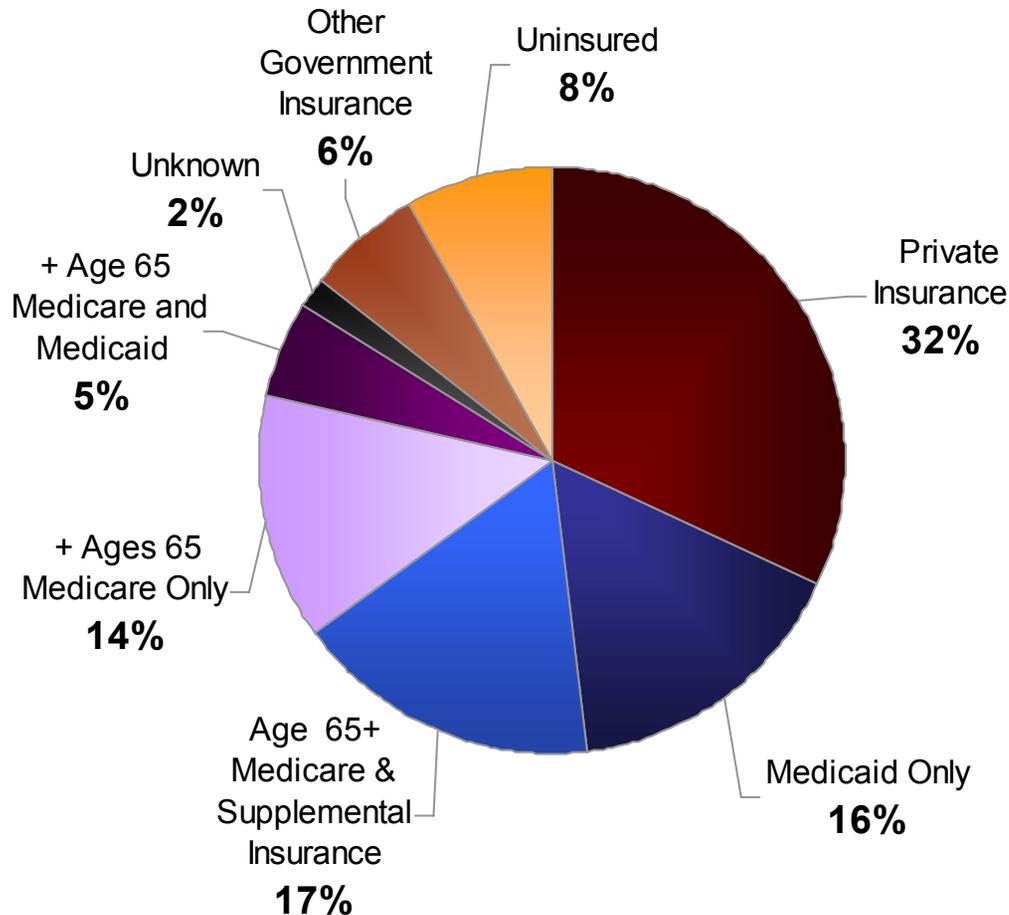


# People With Medicare And Medicaid Coverage Have The Highest Rates Of Activity Limitations

- **Fifteen percent of all Americans have at least one activity limitation**

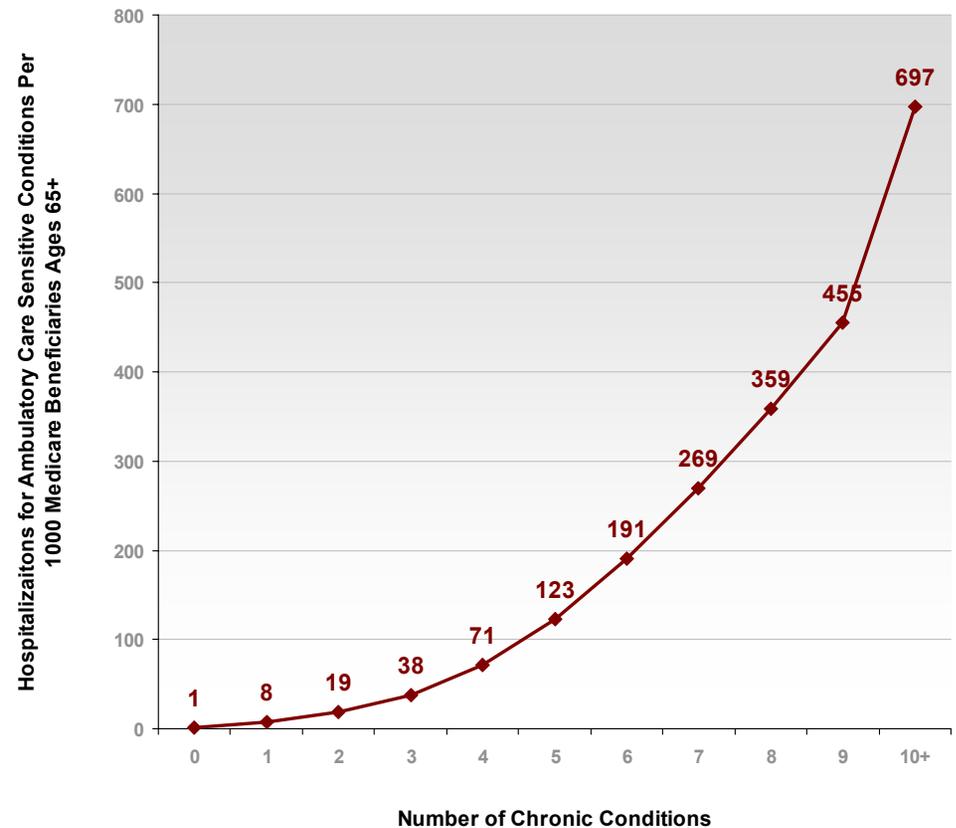


# Most People With Activity Limitations Have Medicare Or Private Coverage



# Poor Care Coordination Leads To Unnecessary Hospitalizations

- Ambulatory care sensitive conditions (ACSCs) are conditions for which timely and effective outpatient primary care may help to reduce the risk of hospitalization.
- Ambulatory care sensitive hospitalizations increase as the number of chronic conditions increases.
- People with multiple chronic conditions use medical goods and services at higher rates than others and they often receive duplicate testing, conflicting treatment advice, and prescriptions that are contra-indicated.
- These factors may play a role in the correlation between increasing numbers of chronic conditions and the increasing percentage of inappropriate hospitalizations.



## Section III – The Impact Of Chronic Conditions On Individuals And Their Caregivers

We know that chronic conditions result in higher health care spending and utilization, but what does all this mean for the people who have these conditions and for their families and friends? Unfortunately, the shortcomings of our current financing and service delivery systems have serious implications for these individuals.

First, physicians believe that poor coordination of care generally leads to unnecessary service utilization: hospitalizations, nursing home placements, and duplicate diagnostic tests.

Another consequence of poor coordination is that many individuals often receive conflicting advice from different providers, leaving them with a dilemma – which provider to believe. Without any real ability to discern which is the correct information or most appropriate course of care or treatment, many people are left guessing, further compounding the stress they are already experiencing from their illness or illnesses.

In the worst care scenarios, they may even be harmed or receive inappropriate care. People with serious chronic conditions (those with long-term illnesses that require ongoing medical care and that limit their activities) have even greater difficulties with the health care system. They are most likely to receive conflicting advice, have trouble accessing needed services, and receive prescriptions that adversely interact with one another.

## Section III – The Impact Of Chronic Conditions On Individuals And Their Caregivers cont.

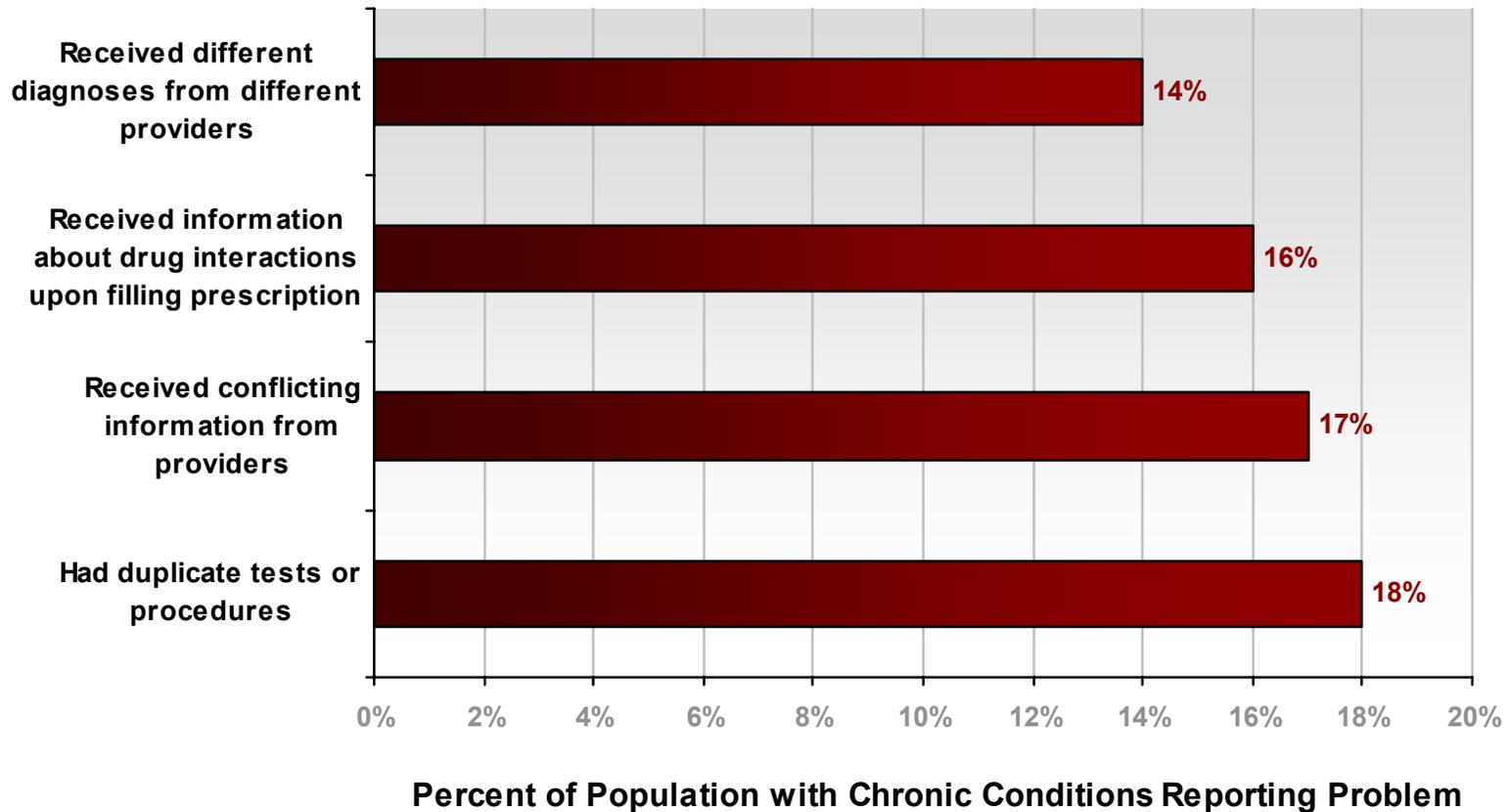
The American public is already aware of the poor state of chronic care in this country. In a survey commissioned by the Partnership for Solutions and conducted in 2000 by Harris Interactive, Inc., Americans reported being fearful of becoming sick and having a chronic condition. They cited the inability to pay for care, the loss of independence, and becoming a burden to family and friends as their biggest concerns. These fears are not unfounded. Personal spending on health care is a significant expense for many people with chronic conditions, and, not surprisingly, as the number of chronic conditions a person has increases, so do the out-of-pocket costs that person incurs. What is surprising, however, is how much more people with chronic conditions pay out-of-pocket for health care than individuals without chronic conditions – up to five times more – regardless of the type of insurance they have.

People with chronic conditions spend much more on prescription drugs than people without such conditions and, unfortunately, they are sometimes receiving drugs that have adverse interactions because care between providers is not coordinated. Among people with insurance coverage, Medicare beneficiaries spend the most out-of-pocket because their coverage is typically worse than coverage for working-age people and because they have more chronic conditions as a group. People with serious chronic conditions report numerous difficulties paying for care: some declare bankruptcy, while others borrow from family or friends to pay for care.

## **Section III – The Impact Of Chronic Conditions On Individuals And Their Caregivers cont.**

People with chronic conditions rely on others not only for financial support but for personal assistance as well. Family and friends devote many hours per week to assisting people with long-term conditions and disabilities. Family caregivers provide personal care, health care, and help accessing services and navigating the often confusing health care system. While these family caregivers may not view their assistance as a burden, people still worry about becoming a hardship to their family and friends. The value of this family caregiving, provided without monetary compensation, dwarfs spending on formal sources of personal assistance.

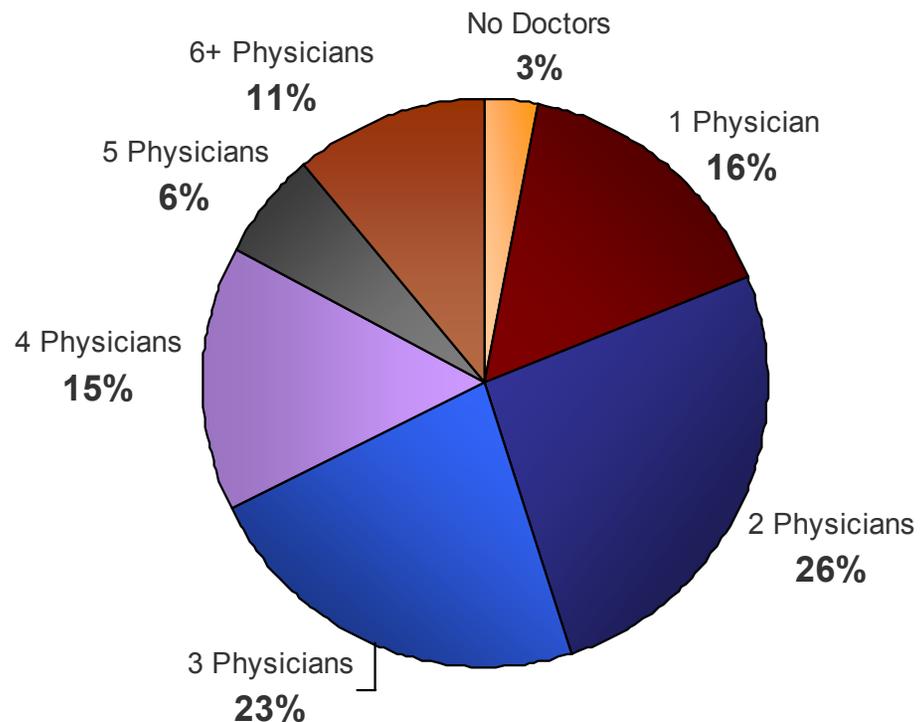
# People With Chronic Conditions Report Not Receiving Adequate Information



# More Than Half Of People With Serious Chronic Conditions Have Three Or More Different Physicians

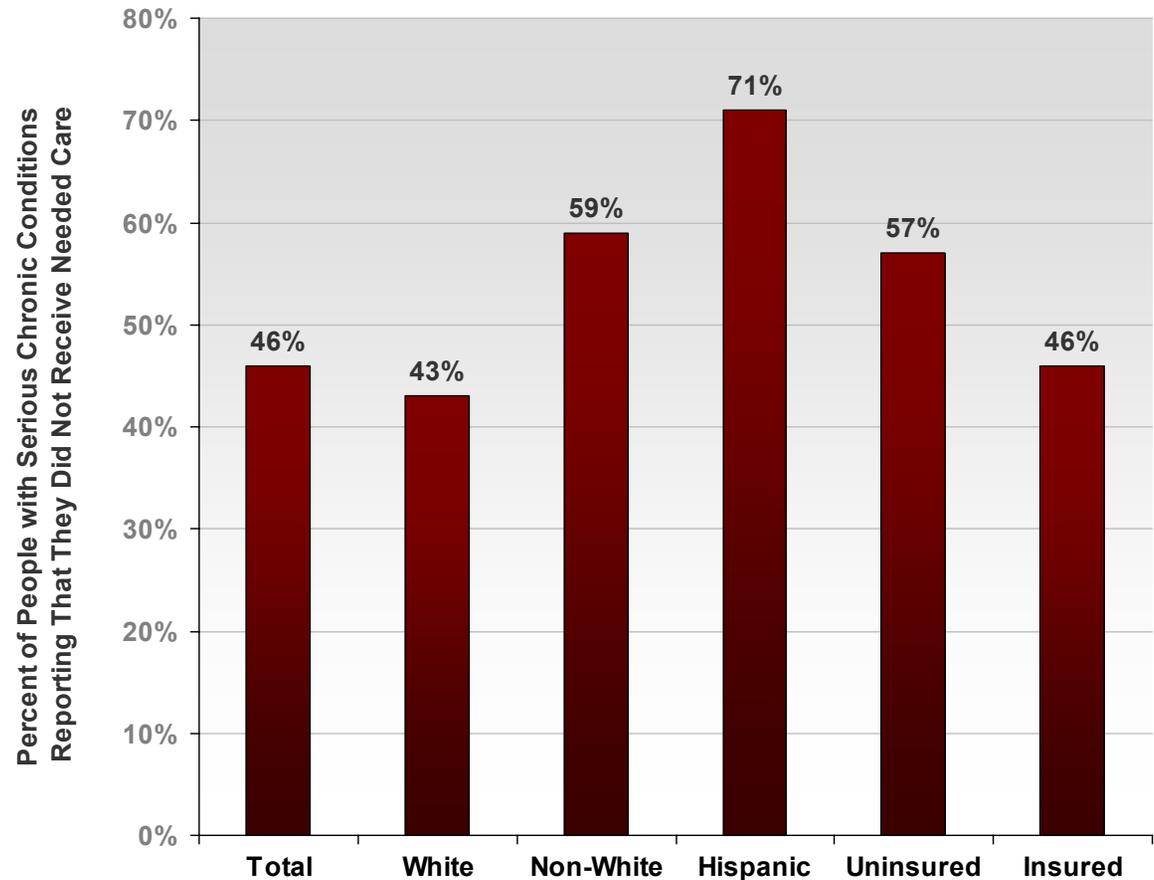
- Eighty-one percent of people with serious chronic conditions see two or more different physicians.
- Thirty-five percent of the population have serious chronic conditions according to the Gallup definition.

**Number of Different Physicians Seen By People with Serious Chronic Conditions**

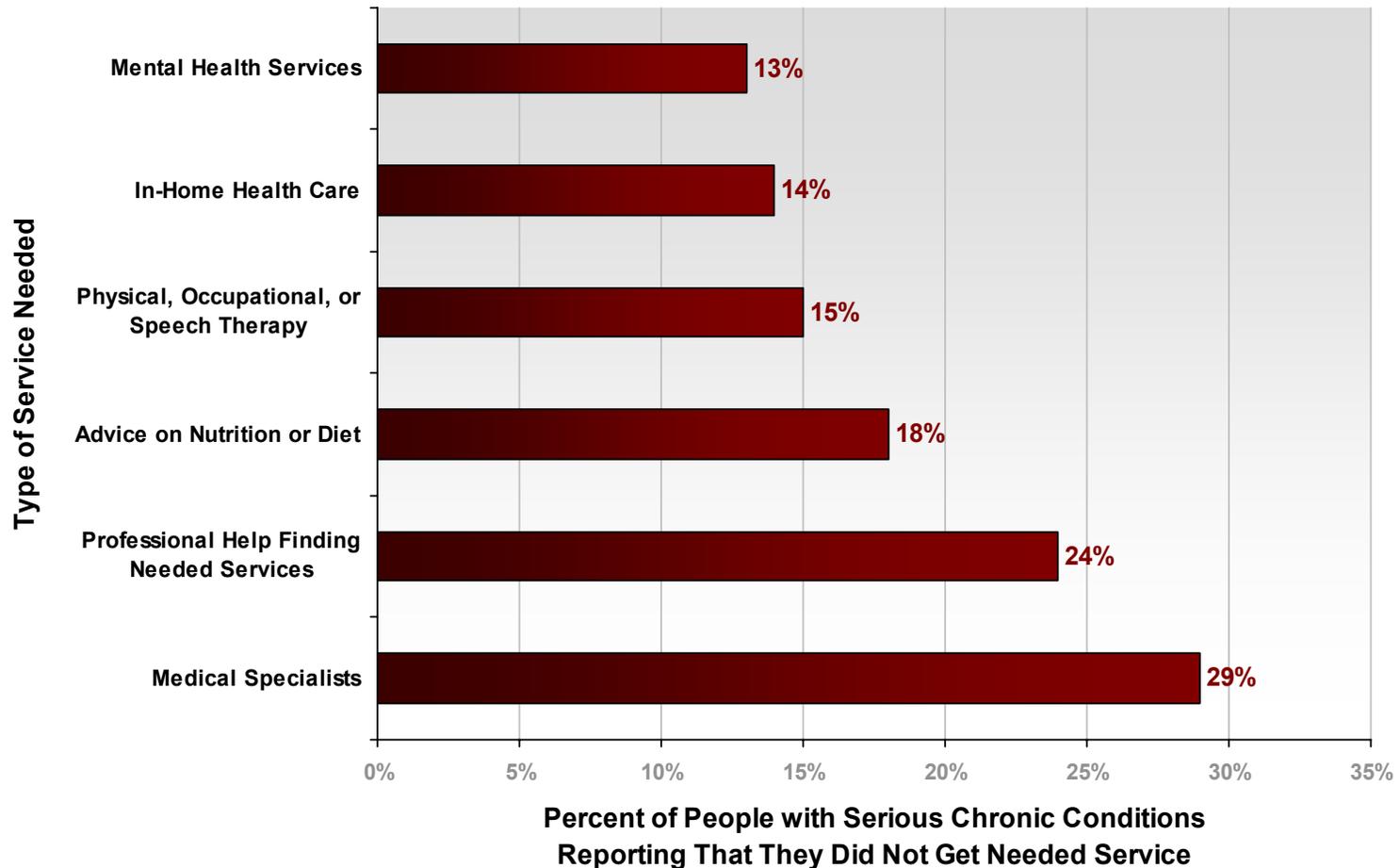


# People With Serious Chronic Conditions Believe They Do Not Receive Needed Treatment

- The uninsured are more likely to report that they go without needed medical care, although insured people with serious chronic conditions also report high levels of unmet service needs.
- Hispanic and non-white persons with serious chronic conditions report high levels of unmet service needs.

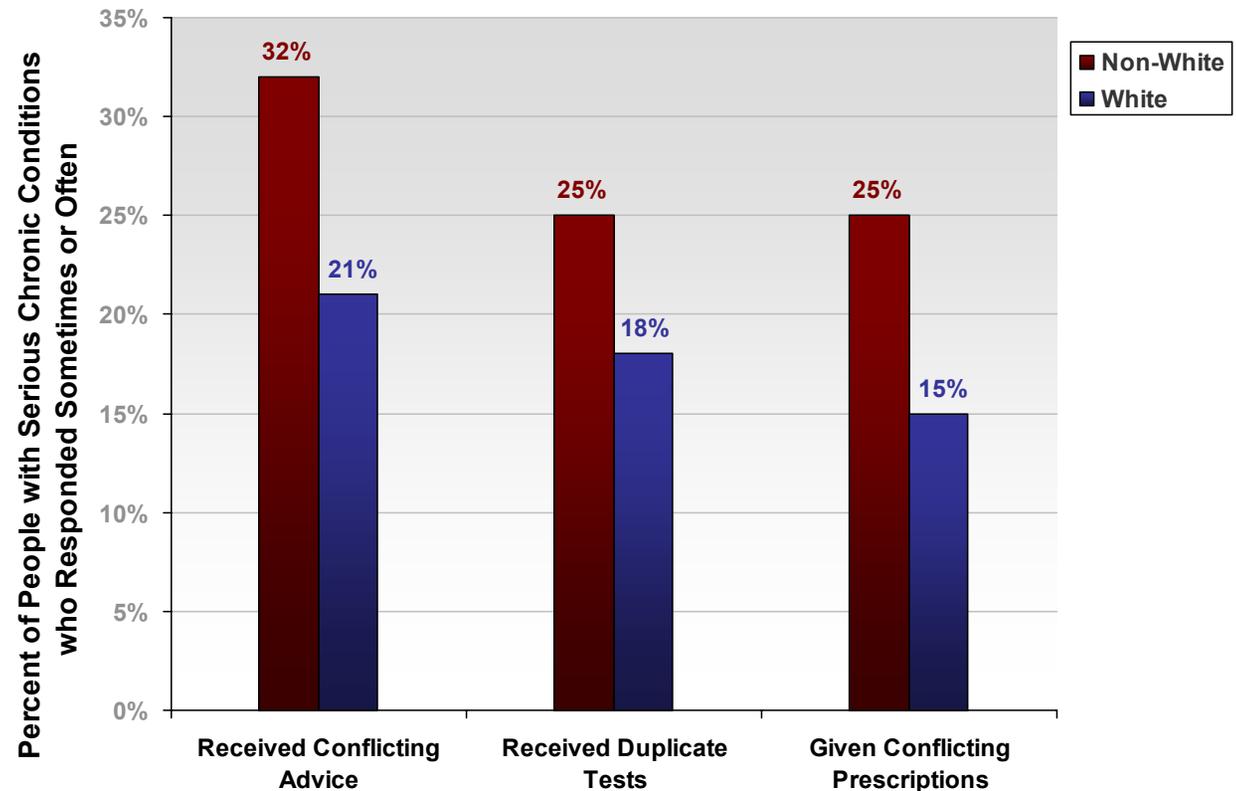


# People With Serious Chronic Conditions Have Trouble Accessing Specific Services



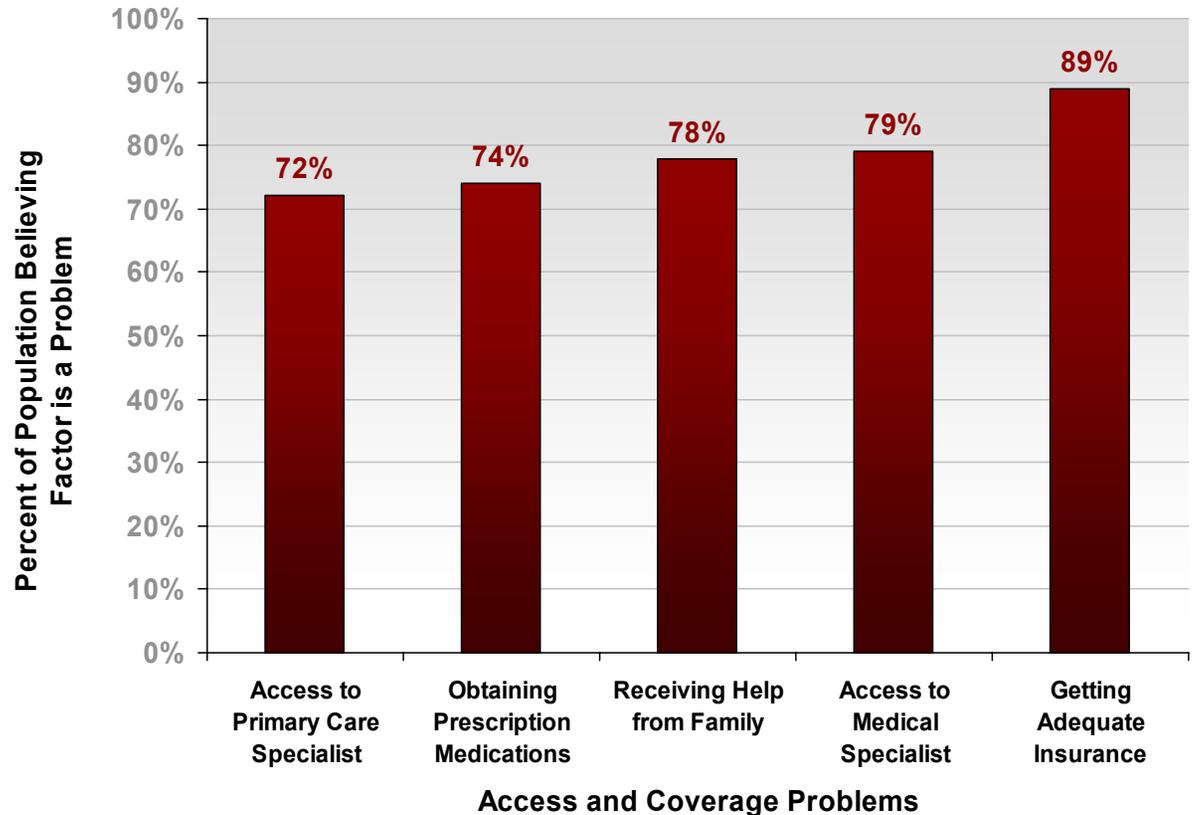
# Quality Of Care For People With Serious Chronic Conditions Varies By Race

- Quality-of-care problems may be exacerbated by lack of insurance, language barriers, and geographic proximity to providers.



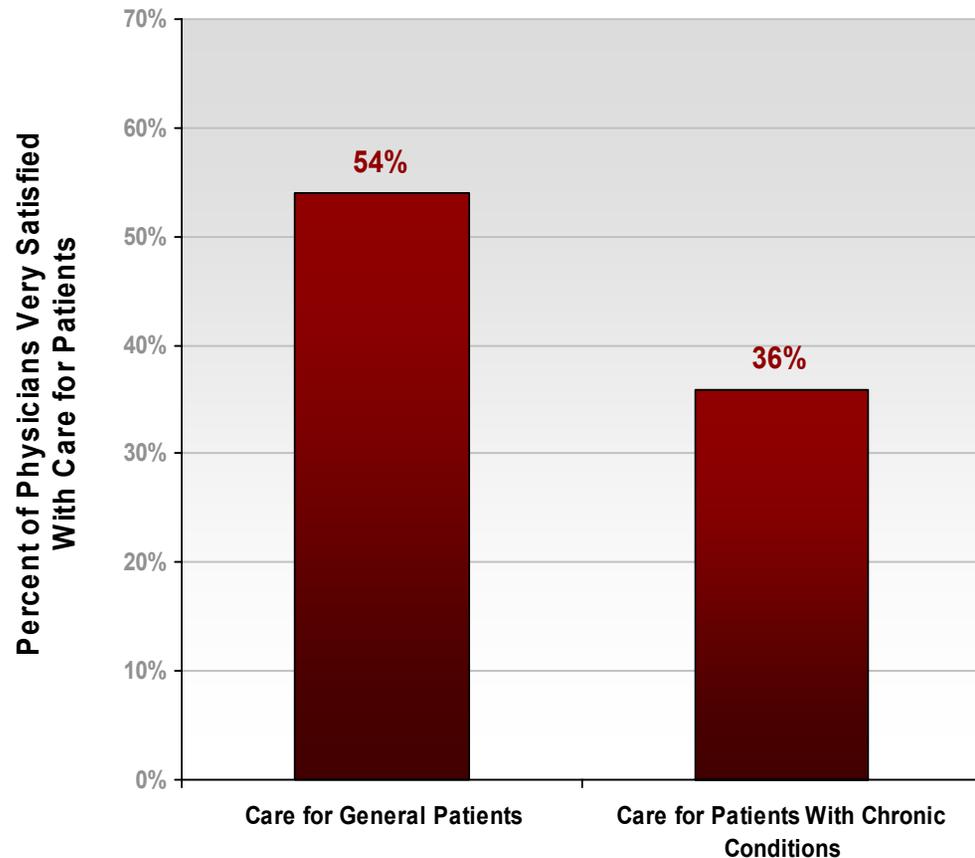
# Americans Believe That Access To Care And Coverage Is A Problem For People With Chronic Conditions

- Approximately three out of four individuals believe that access to medical services is difficult for people who have a chronic condition.
- Uncovered services and high levels of cost-sharing are two reasons why nine in ten Americans believe that health insurance coverage is inadequate for people with chronic conditions.



# Physicians Are Less Satisfied Providing Care To People With Chronic Conditions

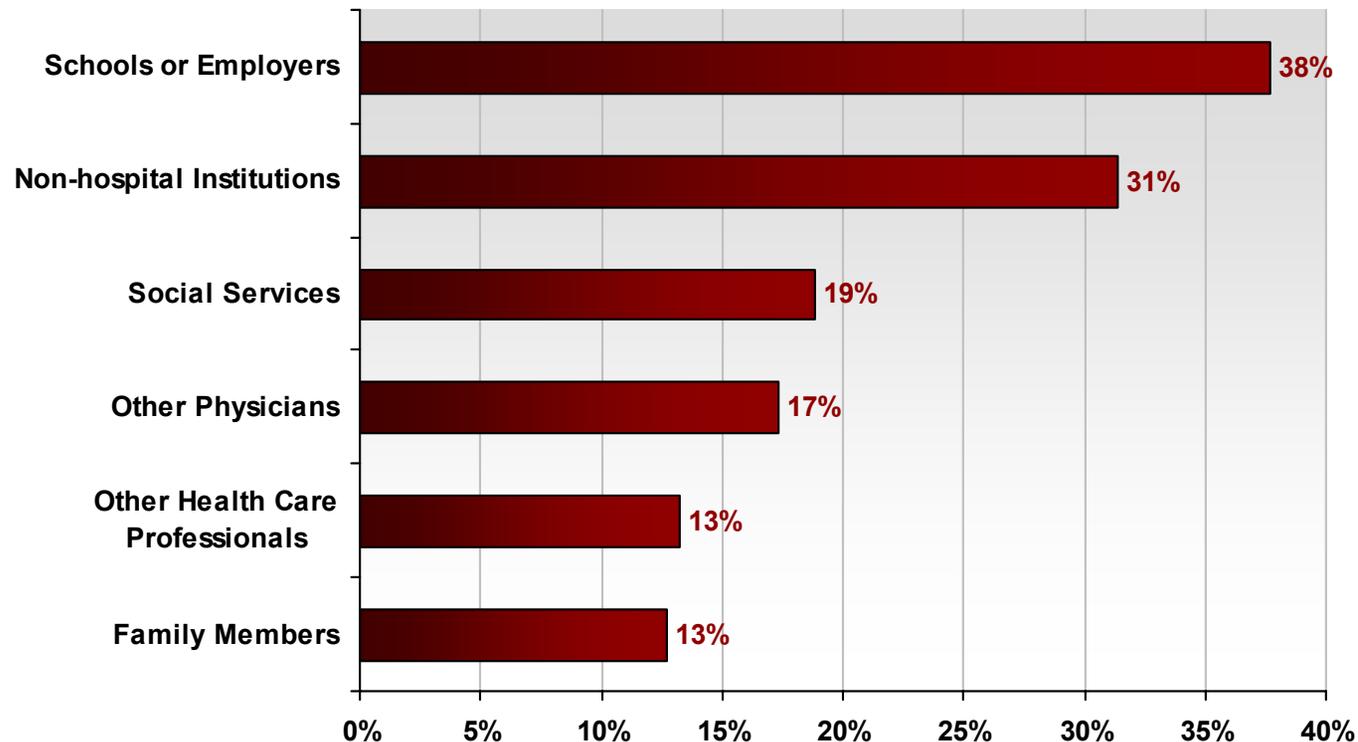
- Physicians report that they are less satisfied providing care to people with chronic conditions than to all patients in general.
- Lower physician satisfaction may result from difficulty coordinating with other providers, inadequate health insurance, inadequate clinical training in the area of chronic care, and reimbursement systems that do not adequately recognize the additional time necessary to care for people with complex or multiple chronic conditions.



## **In Treating Patients With Chronic Conditions, Physicians Believe Their Training Did Not Adequately Prepare Them To:**

- **Coordinate in-home and community services** (66 percent)
- **Educate patients with chronic conditions** (66 percent)
- **Manage the psychological and social aspects of chronic care** (64 percent)
- **Provide effective nutritional guidance** (63 percent)
- **Manage chronic pain** (63 percent)

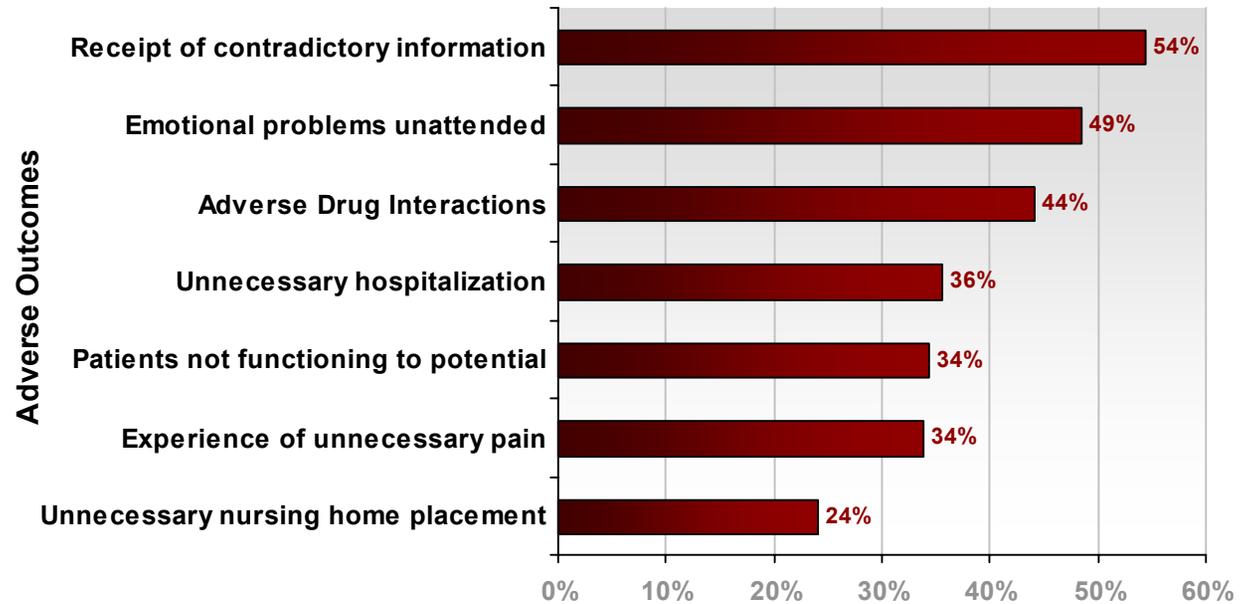
# Physicians Report Difficulty Coordinating Care



Percent of Physicians Identifying Problems Coordinating Care with Different Providers or Entities

# Physicians Believe That Poor Care Coordination Produces Bad Outcomes

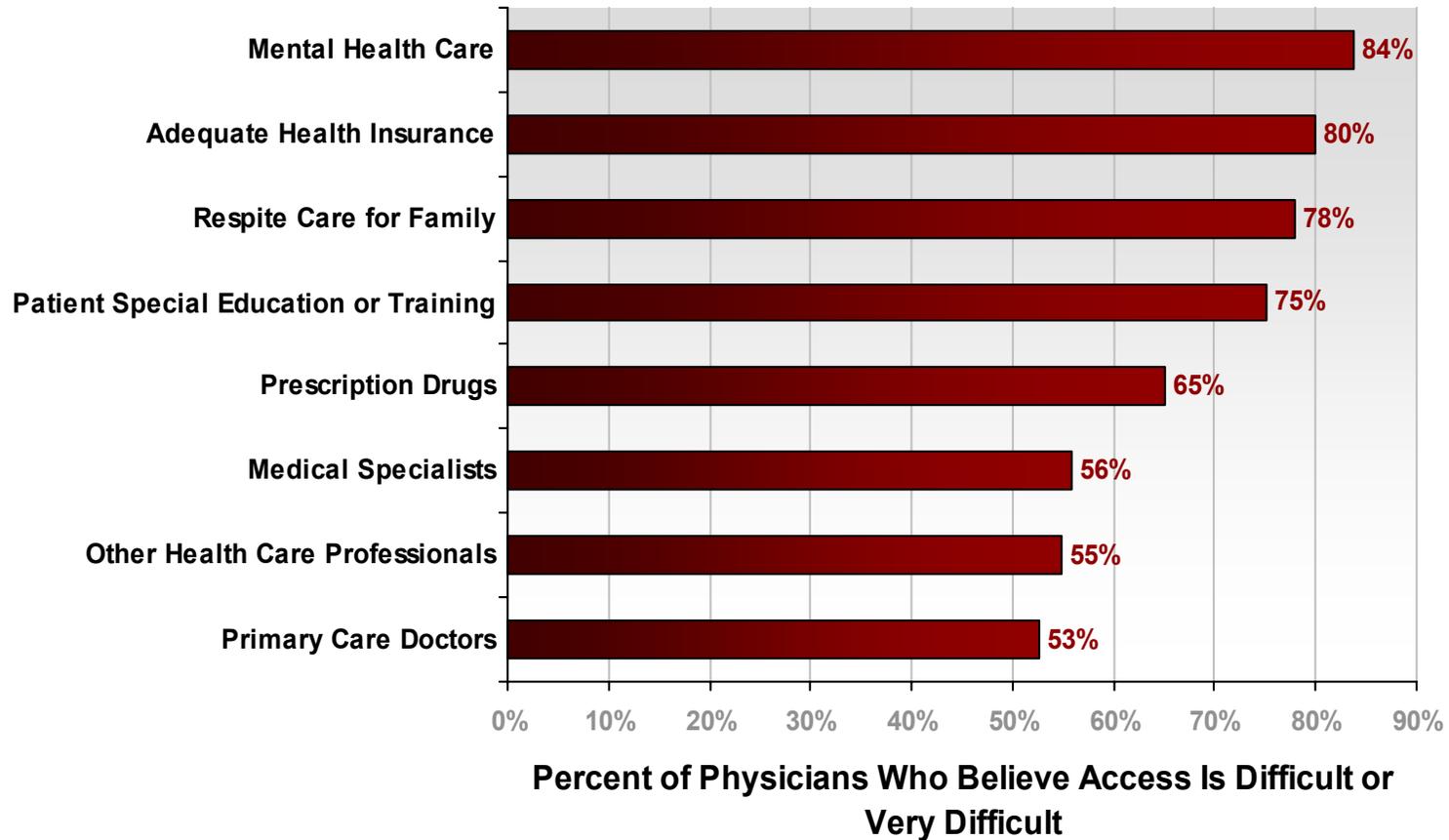
- Inadequate care coordination can be costly for patients and other payers when it leads to unnecessary nursing home placements, inappropriate hospitalizations, or adverse drug interactions.
- Specialists report having greater difficulty coordinating care than general practitioners.
- Good care coordination should be considered a necessary part of high-quality care.



Percent of Physicians Who Believe that Adverse Outcomes Result from Poor Care Coordination

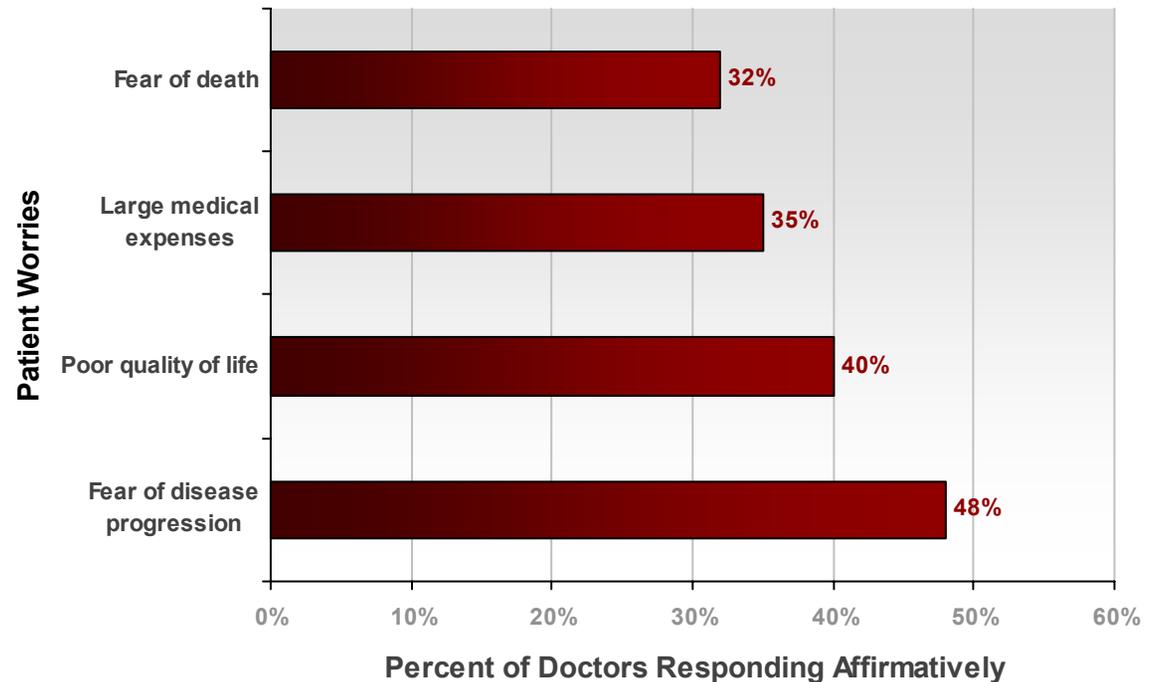
*Johns Hopkins University, Partnership for Solutions*

# Physicians Believe That People With Chronic Conditions Have Unmet Needs



# Doctors Believe That Their Patients Worry About The Impact Of Chronic Conditions

- When asked directly, Americans report that their top concerns about having a chronic condition are: inability to pay for care, losing independence, and being a burden to family and friends.<sup>a)</sup>



Source: National Public Engagement Campaign on Chronic Illness -- Physician Survey, conducted by Mathematica Policy Research, Inc. 2001

a) From *Chronic Illness and Caregiving*, a survey conducted by Harris Interactive Inc., 2000.

## Section IV – Paying For Chronic Care

Individuals with chronic conditions may have difficulty paying for health care services because health insurance often does not pay for all the services they use and because cost sharing increases their out-of-pocket payments.

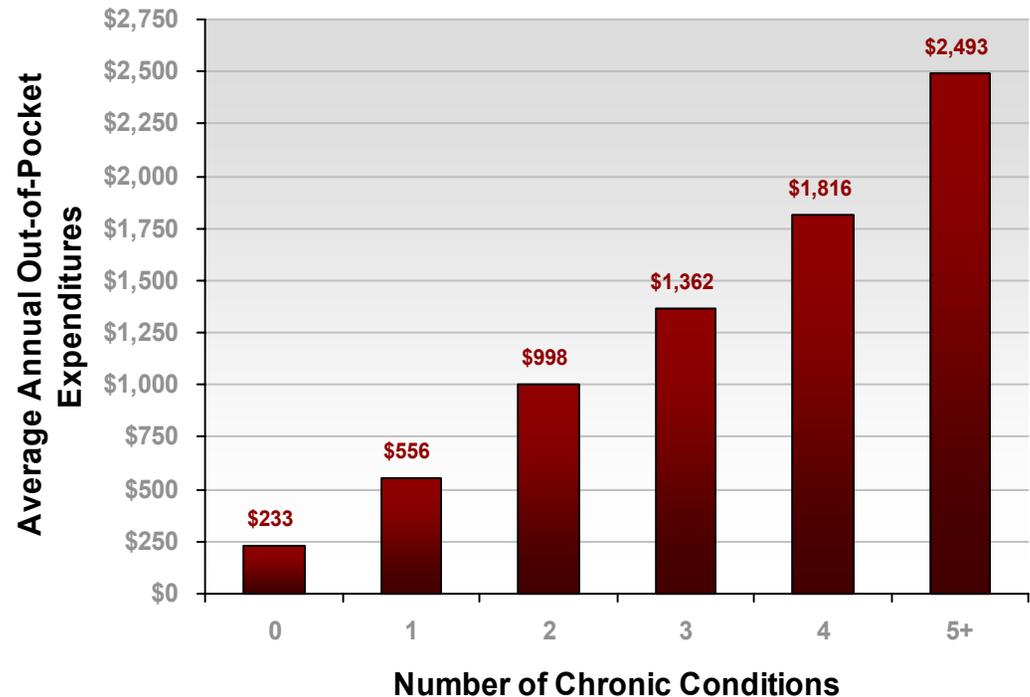
Medicare beneficiaries are the most likely to have high out-of-pocket spending and Medicaid beneficiaries the least.

As a result of high health care bills, people with serious chronic conditions have to make difficult financial choices including: declaring bankruptcy, applying for government assistance, and using savings allocated for another purpose.

Family care givers are an important non-monetary source of care. It is provided by all generations but a high proportion of the care giving burden is the responsibility of the seniors and is disproportionately female.

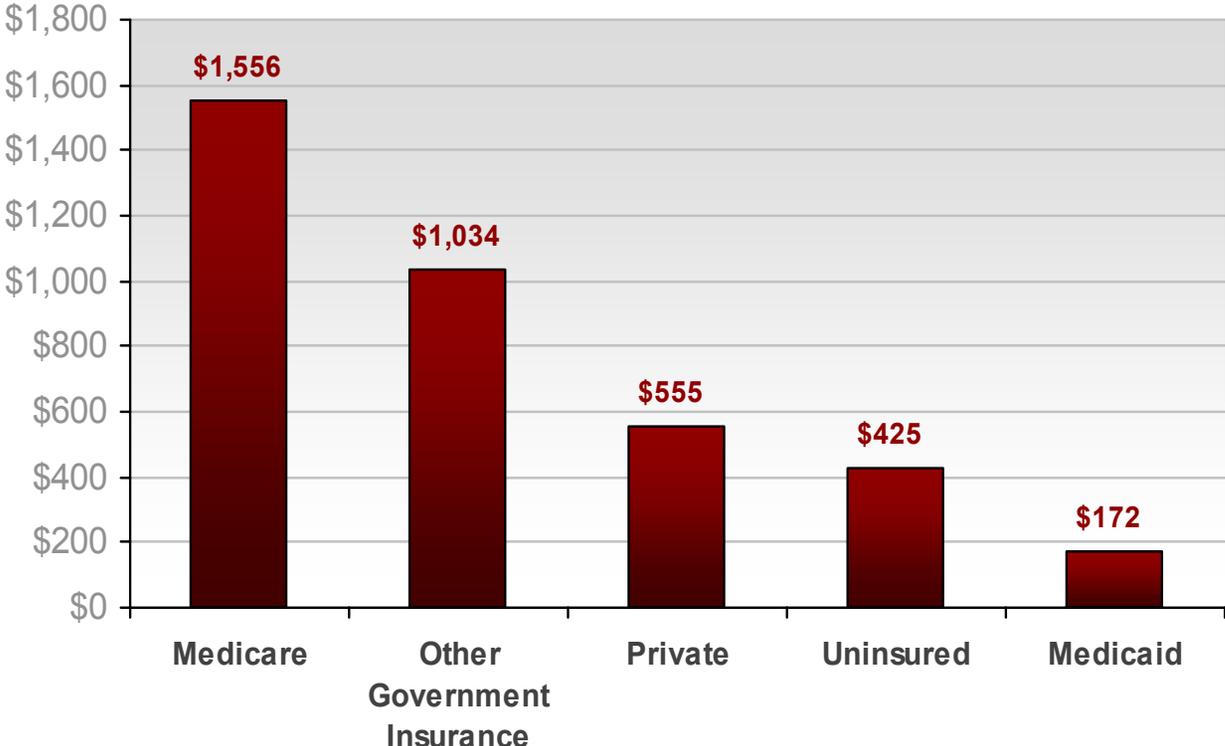
# Out-Of-Pocket Health Care Spending Increases With The Number Of Chronic Conditions

- The average annual out-of-pocket spending on health care for all people is \$623. The average for people with one or more chronic conditions is \$1,024.
- The highest average out-of-pocket expense for people with chronic conditions is prescription drugs, while people without chronic conditions spend the most out-of-pocket on dental care.
- One reason out-of-pocket spending is high for people with chronic conditions is that they often pay for items and services that may not be covered by insurance, such as supportive services that people with chronic conditions often need.



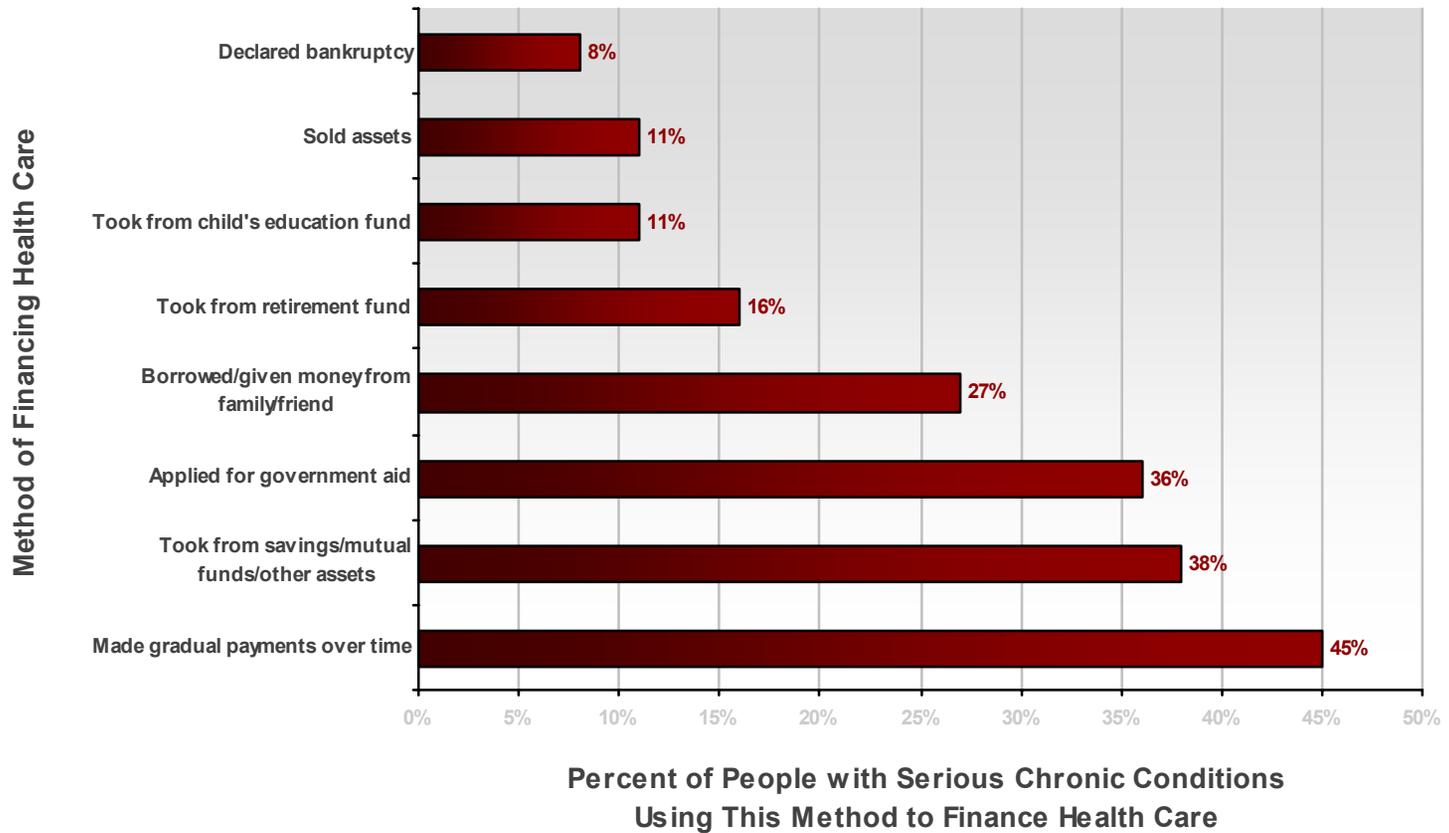
# Out-Of-Pocket Spending Is Highest For People With Medicare Coverage

Average Annual Out-Of-Pocket Expenditures Per Person



Out-Of-Pocket Spending by Type of Insurance

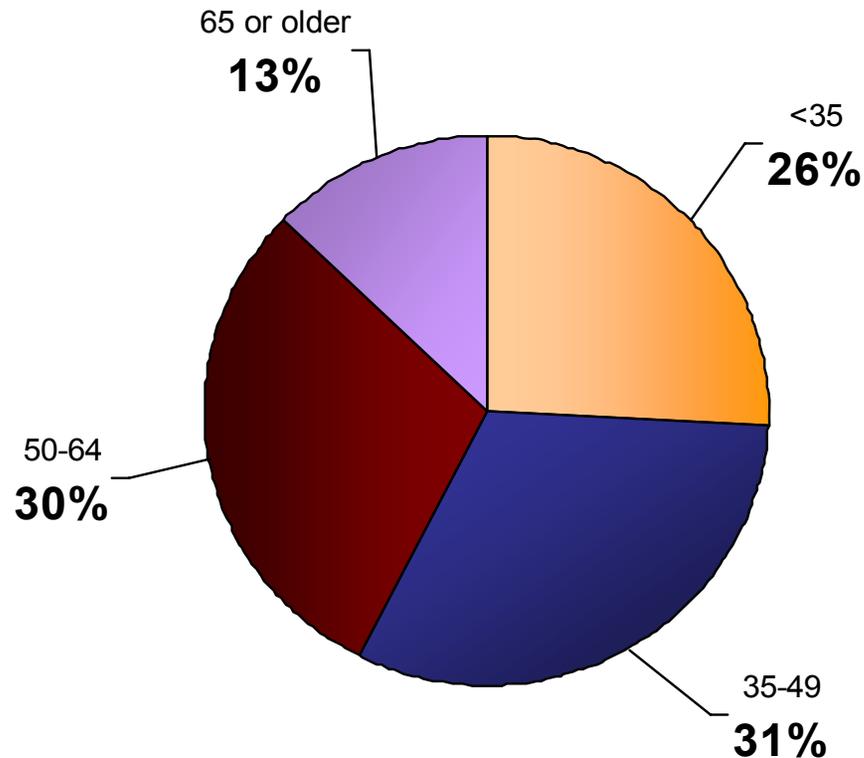
# People With Serious Chronic Conditions Make Difficult Choices



# Informal Caregiving Is A Multigenerational Task

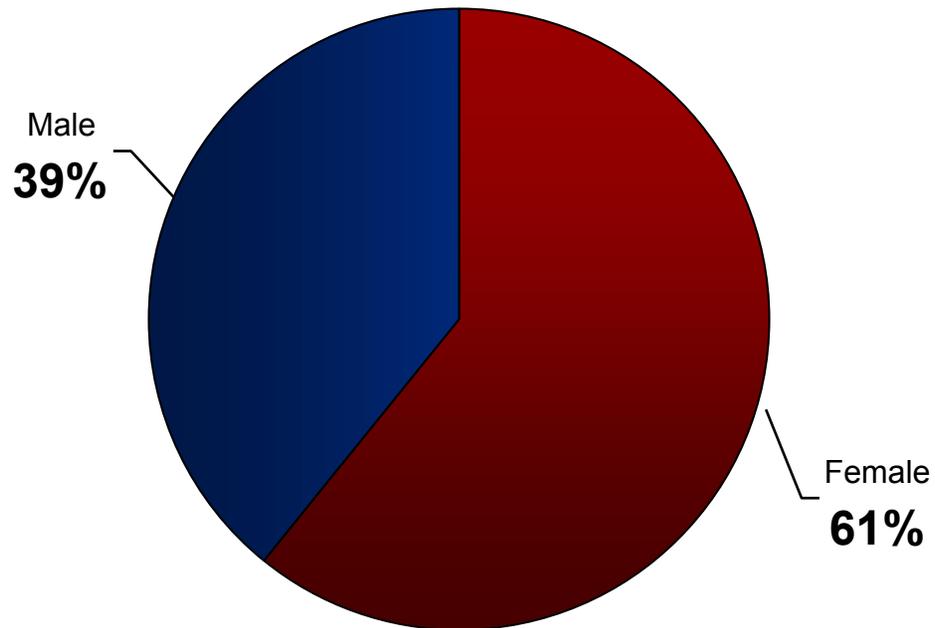
- Forty-four million Americans age 18 and older provide care to relatives and friends.
- Forty-three percent of those providing care are 50 years of age or older.

## Family Caregivers by Age



# Family Caregivers Are Most Often Women

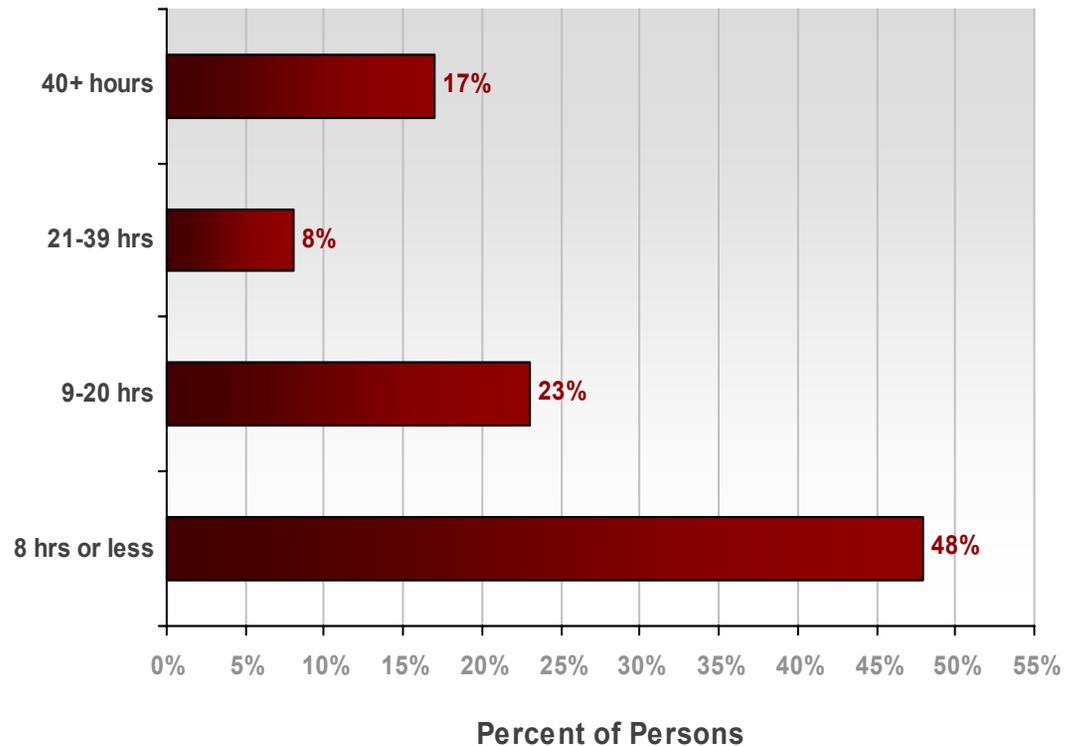
## Family Caregivers by Gender



# Hours Per Week Dedicated To Caregiving

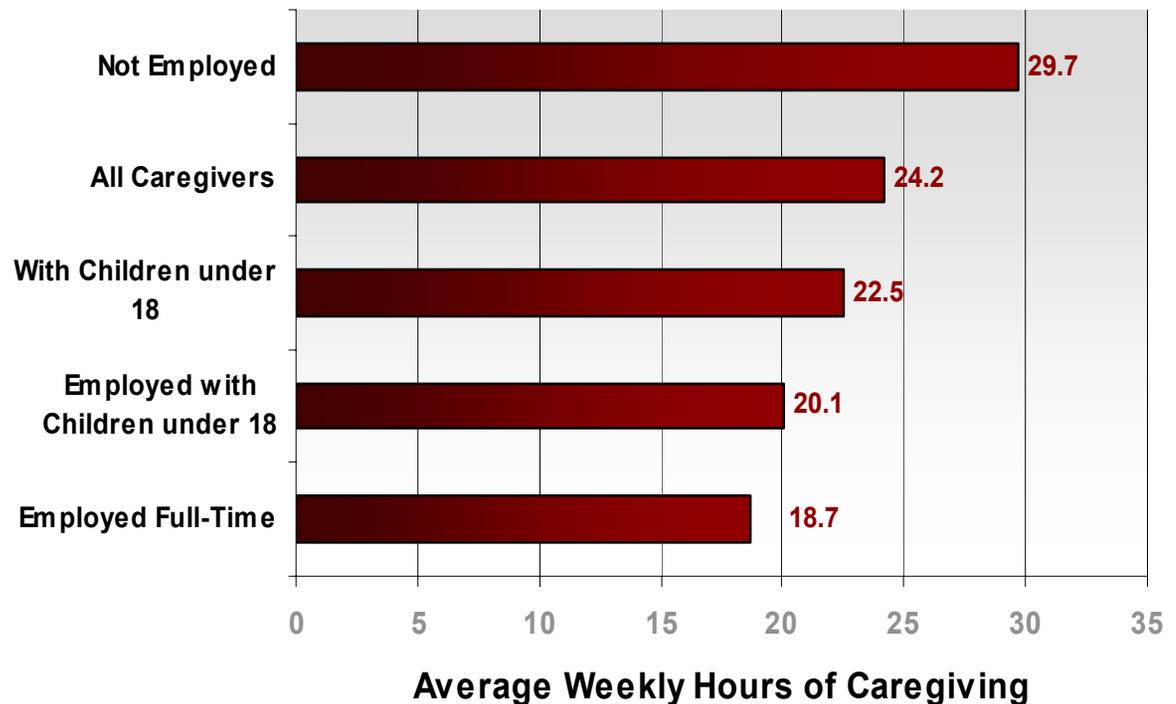
## Caregivers who provide 40 hours or more per week tend to be:

- In fair or poor health (29 percent)
- 65 or older (28 percent)
- Caring for someone with Alzheimer's or dementia (24 percent)
- Lower income (23 percent of those earn less than \$30,000)
- Less well-educated (21 percent of those with a high school education or less).



# Competing Demands Influence The Weekly Hours Of Family Caregiving

- Half of family caregivers are employed.
- Forty percent of family caregivers are employed full-time.
- Almost 20 percent of family caregivers work and care for children in addition to caregiving responsibilities.



\*Children in the household may include children with long-term illnesses or disabilities.

Source: Alecxih, L.M.B., Zeruld, S., and Olearczyk, B. Characteristics of Caregivers Based on the Survey of Income and Program Participation. National Family Caregiver Support Program: Selected Issue Briefs. Prepared for the Administration on Aging by The Lewin Group, July 2001.

## A Caregiving Perspective

One person's condition can affect many other people. For the many millions of Americans who require help with everyday activities, family and friends are the first line of support. In 1998, almost nine and a half million Americans provided some kind of care for people who had chronic conditions.

Overall, the demand and supply trends in caregiving are pulling in opposite directions. Demand for caregivers is increasing. The chances of becoming a caregiver to someone with a chronic condition are much higher today than ever before – and the likelihood will increase over the coming decades as the elderly population, those most likely to be disabled by a chronic condition, increases.

But the supply is decreasing. Among the factors that are shrinking the pool of possible caregivers are decreasing birth rates and family networks that are getting smaller and more top-heavy, with more older than younger family members. Women have entered the workforce in increasing numbers since the 1960s and are no longer as available as they once were for the traditional female role as unpaid family caregiver. People are marrying and having children at later stages in their lives, which increases the size of the "sandwich generation", that is, those simultaneously caring for children and for their own parents or elderly relatives. As average family size decreases, fewer children will be available for caregiving, and sibling support networks will also become smaller.

# Conclusion

In the coming years, our health care system will face an increasing burden of caring for people with chronic conditions. If left unchecked, this growing burden will cost us in dollars spent for treatment, as well as reduced quality of life and productivity of our workforce. The data presented in this chart book are quite clear: adjustments within the health care system are needed to better meet the needs of people with chronic conditions. As a society, we need to find a way to pay for the prevention and early intervention that will save us money down the road. We also need to refocus the medical care system to provide excellent care for those who already have chronic conditions.

The health care system can and will adapt; it has made significant changes before in the face of similar challenges. When infectious disease was the leading public and private health care challenge, the health care system was organized to respond. The scourge of infectious disease gave way to problems associated with acute illnesses and events such as heart attacks and strokes. Again, the health care delivery system was modified to provide high-quality, effective treatments that resulted in improved survival rates, and a system of funding such care was organized to share the financial risk among the population.

## Conclusion cont.

Today, care provided in the current acute, episodic model often is not cost-effective and can lead to poor outcomes for patients with chronic conditions. In clinical practice, chronic conditions require continuous care and coordination across health care settings and providers. People with chronic conditions also often require supportive services such as personal assistance care, home health care or help navigating the health care system. These services need to be more readily available and coordinated as well with clinical treatment in order to make clinical treatment most effective. The goal should be early diagnosis with interventions that maintain health status and minimize episodes of acute illness. When acute episodes do occur, a chronic care model brings together a coordinated array of appropriate services that restore the individual to the highest possible state of functioning.

There are many chronic conditions, and many combinations of chronic conditions, that affect individuals in various ways and in differing degrees. While their individual clinical needs may be different, people with chronic conditions share a common set of problems regarding accessing appropriate and coordinated treatments and services, and paying for such care. Because there is a set of clearly defined problems for people with chronic conditions and the providers who treat them, it is incumbent upon us to look for broad-based solutions that can affect the greatest number of people.

## Conclusion cont.

These reforms are particularly challenging in an environment where services are delivered in a health system that often lacks structures and incentives needed for the most effective coordination of care. Likewise, it is important that consumers begin to focus more on the value of system structured to better coordinate care and on their role in improving coordination.

We can find solutions by re-thinking how our health care financing system values and pays for the care received by people with chronic conditions. We can find these solutions by reexamining how we train our health care providers to better prepare them for the changing realities of medical practice and patient needs. We can find solutions by developing better connections between supportive and clinical care delivery systems. And finally, we can find solutions by encouraging and supporting patient self-management and family caregiving.

In our search for shared solutions, we need to respond to the issue of improving care for chronic conditions as a whole rather than responding one condition at a time. This model is not unlike the response to the crisis of infectious diseases a century ago, in which public health measures were broadly constructed and applied to address a range of diseases affecting individuals. It is this type of broad-based reform that we need to consider to improve care and quality of life for the growing number of people with chronic conditions.

# Methodology And Data Sources

In this chart book, we define chronic conditions as health conditions that last a year or more and require ongoing medical attention and/or limit activities of daily living. This definition includes people with chronic illnesses or disabilities, or both. In some places, we refer to serious chronic conditions, a subset of the larger group consisting of those people with health conditions that last a year or more and that both require ongoing medical care and limit what they can do. We selected a broad definition similar to the previous definition used by Catherine Hoffman and Dorothy Rice in *Chronic Care in America*, in order to make comparisons between that publication and this one more consistent and meaningful. To determine which conditions met our definition, we convened two physician panels to review all medical conditions represented by the International Classification of Diseases, 9th Revision (ICD-9) codes to identify those that are chronic conditions under our definition. We applied the resulting classification applied to data from the Medical Expenditure Panel Survey (MEPS) and the Medicare Standard Analytic File. (See next three slides for a discussion of these two data sources.) An important caveat is that our data analysis using ICD-9 codes does not always capture information on people whose chronic condition is a disability or functional limitation without an underlying chronic illness.

## Methodology And Data Sources cont.

Data in this chart book was drawn from a variety of sources, a few of which require some explanation. We relied heavily on the Household Component of the 2004 MEPS, which is a nationally representative sample of the non-institutional U.S. population. This survey is sponsored by the Agency for Healthcare Research and Quality (AHRQ). Two groups of respondents were interviewed three times each during the survey year. The MEPS Household Component provides information on health status, health services utilization, and health care spending. It is a survey of people living in the community and, therefore, does not provide information on people residing in institutions such as nursing homes. This is an important point. As a result, our data analysis understates the number of people with chronic conditions as well as health care spending on their behalf.

Partnership for Solutions, a national program of the Robert Wood Johnson Foundation, commissioned an analysis by researchers at the RAND Corporation using the MEPS data to produce projections of growth in the population with chronic conditions at five-year intervals, 1995 to 2030.

We also used the MEPS data to examine spending on prescription drugs. The data and analysis include spending and utilization information for prescriptions filled – which includes refills and free samples. The Household Component does not capture information about dosage strength and form, and the data is not disaggregated into unique prescriptions.

## Methodology And Data Sources cont.

We have also relied on data from the 2004 Medicare Standard Analytic File. This is a nationally representative sample of five percent of Medicare beneficiaries and all their associated service claims for Medicare-covered benefits. Our analysis includes all beneficiaries in the sample, including the aged, disabled, and end-stage renal disease beneficiaries. Our analysis excludes people from the file who died during the survey year in an effort to separate costs associated with end-of-life care. There are some important caveats about this data source as well. First, Medicare+Choice (M+C) spending and the Medicare beneficiaries enrolled in managed care are not included in the sample because these payments are not claims-based. It is not clear how these omissions would affect the analysis, although reports by the General Accounting Office and others have highlighted how M+C enrollees are in better health than the Medicare fee-for-service population. M+C enrollment was about 16 percent of total Medicare enrollment in 2006. Total spending represented by the sample will not total all Medicare spending in 2006 because some important spending components that are not claims-based are absent from the file: graduate medical education, Medicare+Choice, and administrative spending are examples. It is unlikely, however, that this spending would greatly affect the analysis in this chart book since most of it is not for beneficiary-specific services.

## Methodology And Data Sources cont.

We also used data from three opinion surveys commissioned by the Partnership for Solutions. All three surveys were designed by researchers at Johns Hopkins. The first was a telephone survey conducted in 2000 by Harris Interactive, Inc. A total of 1,663 people were interviewed to ascertain their perceptions and knowledge of chronic conditions. Of those surveyed, 983 people either had a chronic condition, cared for someone with a chronic condition, or both. The second telephone survey, conducted by Mathematica Policy Research, Inc. from November 2000 to June 2001, interviewed 1,236 physicians with 20 or more hours per week of patient contact. The survey was designed to learn about physician attitudes and problems treating people with chronic conditions and about the adequacy of physician training relative to caring for this population. The third telephone survey, conducted by the Gallup Organization from November 2001 through January 2002, interviewed 1,200 people with serious chronic conditions, as defined above. The survey was designed to learn more about their experiences and perceptions.