
Chronic Conditions: Making the Case for Ongoing Care

September 2004 Update



Preface

Chronic Conditions: Making the Case for Ongoing Care, a chartbook first prepared by the Partnership for Solutions in December 2002, is an update of a 1996 publication written by Catherine Hoffman and Dorothy Rice entitled *Chronic Care in America: A 21st Century Challenge*. This updated version of the chartbook, revised in **September 2004**, provides an overview of chronic health conditions in the United States and the impact of these 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 these health concerns as they attempt to obtain a continuum of services in a health care financing and delivery system primarily oriented to the provision of episodic care.

The Partnership for Solutions is a national program funded by the Robert Wood Johnson Foundation and based at Johns Hopkins University. The goal of the initiative is to improve care and quality of life for the more than 133 million Americans with chronic health conditions. To that end, the Partnership is engaged in three major activities: conducting original research and identifying existing research that clarifies the nature of the problem; communicating these research findings to policymakers, business leaders, health professionals, and advocates for people with chronic conditions; and working with these constituencies to identify promising solutions to the problems faced by people with chronic health conditions. Visit our website, www.partnershipforsolutions.org, for further information about chronic conditions and policy implications.

Chronic Conditions: Making the Case for Ongoing Care was created by Gerard Anderson with the assistance of Robert Herbert, Timothy Zeffiro, and Nikia Johnson. Gerard Anderson is the national program director of Partnership for Solutions.

We would also like to thank Chad Boulton, Richard Bringewatt, Barbara Cooper, Robert Friedland, Harriet Komisar, Marlene Niefeld, Neal Powe, Dorothy Rice, John Rother, Laura Summer, and Bruce Vladeck for their review and comments on drafts of the December 2002 version. We also thank the staff of the Robert Wood Johnson foundation, David Colby, and Jim Knickman for their thoughtful guidance, and review. The data and analysis presented here remain the responsibility of the Partnership for Solutions.

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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 an increase in the number of Americans living with one or more chronic conditions. And unlike most infectious diseases or sudden acute illnesses, chronic conditions, by our definition, last a year or longer and limit what one can do and/or require ongoing medical care. In this new century, we have to confront a new reality: growing numbers of people with chronic conditions seeking health care in a system that is not structured to respond to this new dynamic.

While the technology of medicine has improved rapidly, the system of financing and delivering care has been slower to reorient itself to 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. The focus then became treating acute, non-infectious illnesses such as heart attacks and strokes. From the 1950s to end of the 20th century, financing, education, and delivery systems all became proficient at the delivery of episodic care and turned many acute episodes into survivable events. The diseases that cause acute illness have become, in large part, long-term, chronic conditions that require on going monitoring and treatment. Diseases such as diabetes and hypertension can result in acute illness if not properly monitored and treated over time. But, while our health care needs have evolved, the health care system has not. It remains an amalgam of past efforts to treat infectious diseases and acute illnesses. It does not focus on today's current and growing problem – people with chronic conditions.

Today, 133 million people, almost half of all Americans, live with a 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 have multiple chronic conditions, including functional limitations and disabilities. Data show that in the general population, people with five or more chronic conditions have an average of almost 15 physician visits and fill over 50 prescriptions in a year. In the Medicare population, the average beneficiary sees seven different physicians and fills upwards of 20 prescriptions in a year. This information alone should raise concern about whether care is coordinated, but in the current system there are few incentives to coordinate care across providers and service settings. We also know that many people with chronic conditions report receiving conflicting advice from different physicians and differing diagnoses for the same set of symptoms. Drug-to-drug interactions are common, sometimes resulting in unnecessary hospitalizations and even death. 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.

Intro continued

People with different chronic health problems experience similar difficulties with the current health care financing and delivery system and 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. For health care providers, slowing disease progression should be as important as treating acute episodes of an illness. Likewise, health insurers should make standard coverage for these services and others that help people maintain their functional status. Many current benefits can be accessed only if medical improvement is expected.

As this chartbook 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 spend a considerable amount of our health care dollars on people with chronic conditions. The challenge is to use our resources to provide people with access to high-quality care and appropriate services that maintain health and functioning in the face of disease progression and ensure that this care 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, a neighbor with multiple sclerosis, an elderly relative with arthritis or Alzheimer’s disease. As the numbers grow and grow, it is hard not know someone whose life is in some way altered by a chronic condition.

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, 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 continues to increase.

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. Earlier detection means people can live with chronic conditions that used to grow to acute care stages before diagnosis.

Section I continued

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. Thirty-seven percent more Americans are projected to have chronic conditions 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 health concerns. Often these women are also caregivers to spouses or other relatives or friends with a chronic conditions. Even though there has been recent research showing a decline in disability rates among the elderly (K. Manton and X. Gu. *Proceedings of the National Academy of Science of the United States of America*. May 22, 2001) the prevalence of chronic conditions among this population is not expected to decline. These findings raise interesting questions about the relationship of disability to disease and the socio-economic context of disability relative to functional limitations.

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.

Section I continued

Twenty-five 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.

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, fifty-seven 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. Eighty-five percent of elderly Medicare beneficiaries who have only Medicare coverage have chronic conditions. And eight million people with 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.

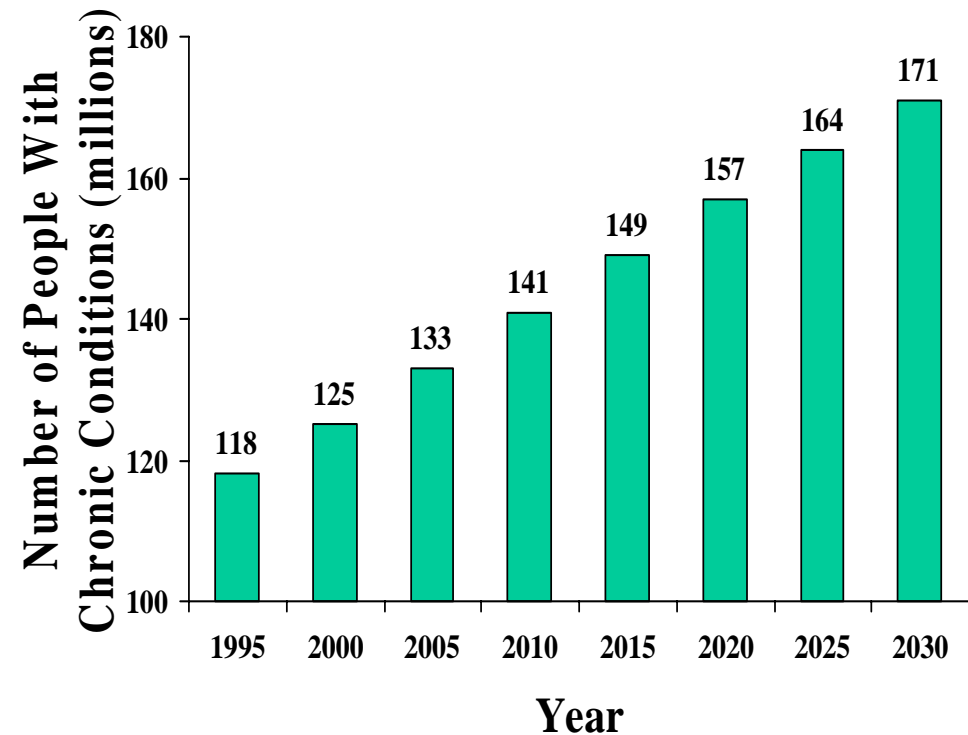
What Does It Mean to Have A Chronic Condition?

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 heart attack, stroke, trauma, or other 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.

Source: Hoffman, Catherine and Rice, Dorothy P. *Chronic Care in America: A 21st Century Challenge*, 1996.

1. The Number of People With Chronic Conditions Is Rapidly Increasing

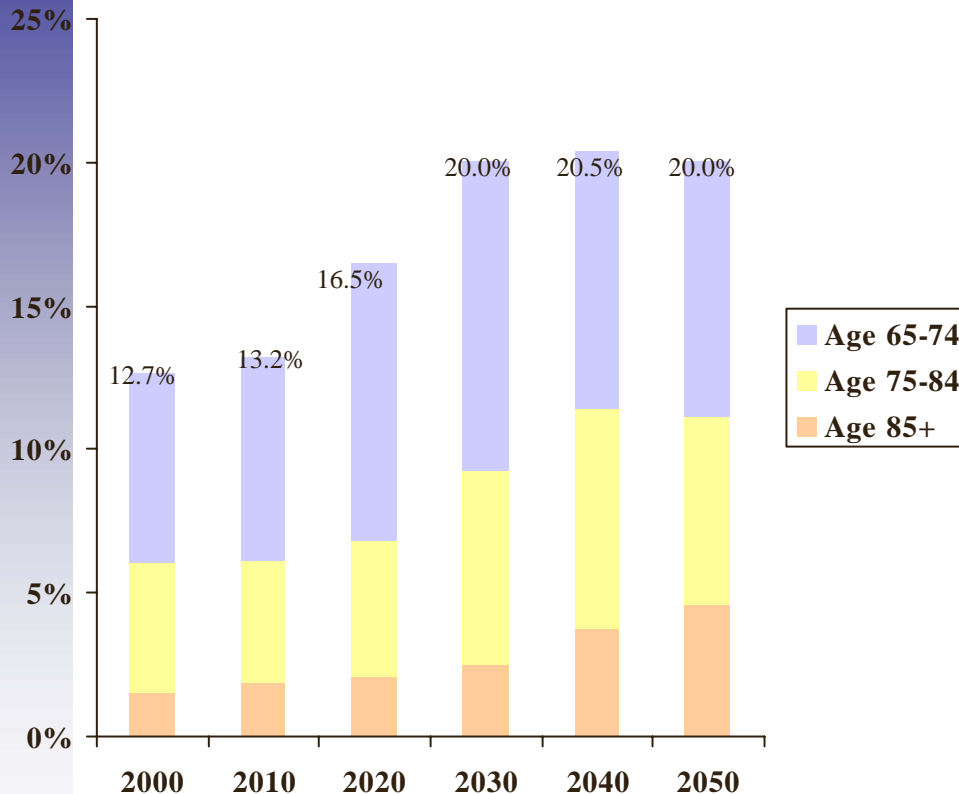
- In 2005, 133 million Americans had one or more chronic conditions.
- This number is projected to increase by more than one percent each year through 2030.
- Between 2000 and 2030, the number of Americans with chronic conditions will increase by 37 percent, an increase of 46 million people.



Johns Hopkins University, Partnership for Solutions

Source: Wu, Shin-Yi and Green, Anthony. *Projection of Chronic Illness Prevalence and Cost Inflation*. RAND Corporation, October 2000

2. Americans Are Living Longer



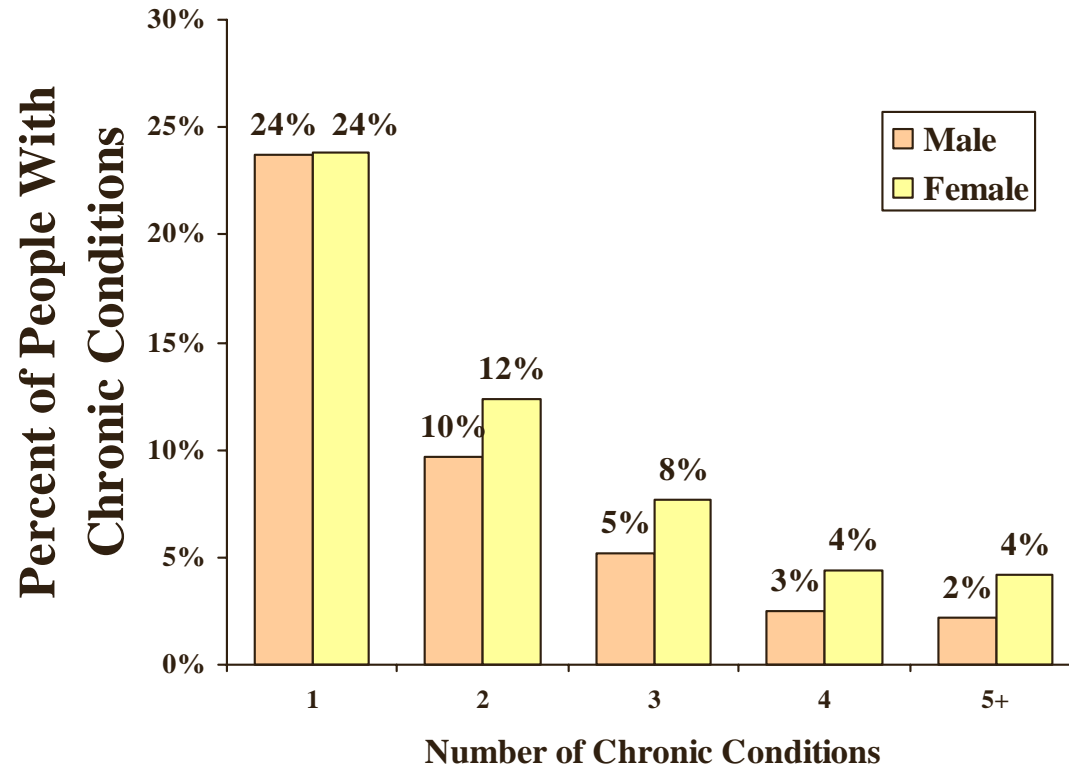
- By 2030, 20 percent of the population will be people age 65 and older with chronic conditions.

- Life expectancy at birth increased over 44 percent between 1900 and 1950, 13 percent between 1950 and 2000, and between 2000 and 2050 life expectancy is projected to increase by 9 percent.

Johns Hopkins University, Partnership for Solutions

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., January 2000.

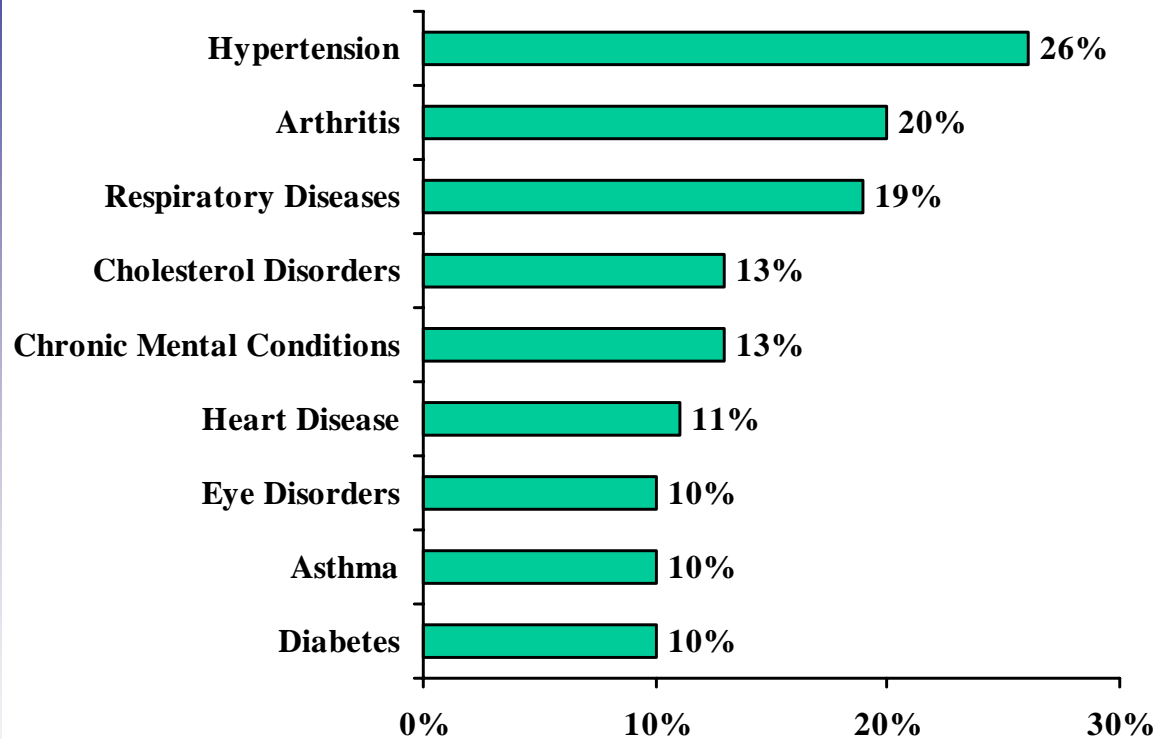
3. Women are More Likely Than Men To Have a Chronic Condition



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Source: Medical Expenditure Panel Survey, 2001

4. Hypertension is the Most Common Chronic Condition



Percent of Noninstitutionalized People with Specific Chronic Conditions

- Leading chronic conditions vary among age groups.

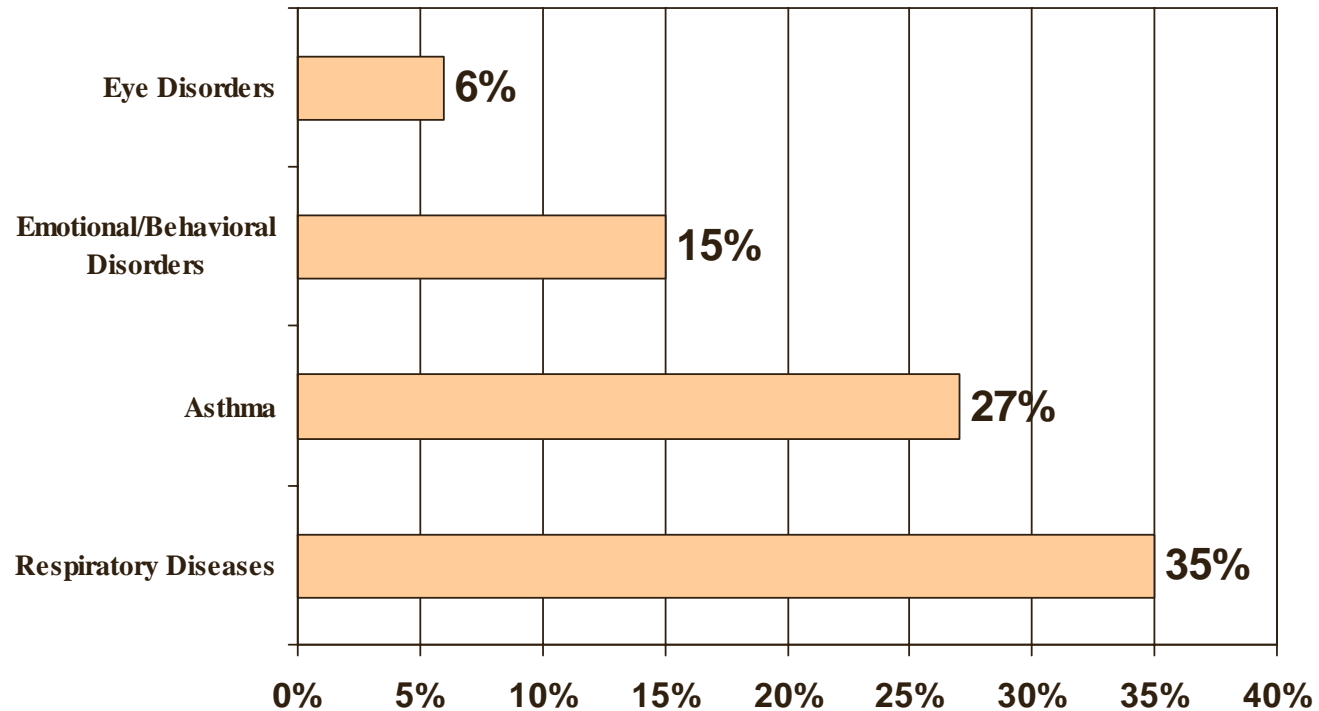
- The leading chronic conditions among people ages 65 and older are: hypertension (51 percent), arthritis (37 percent), heart disease (29 percent), and eye disorders (25 percent).

- The leading chronic conditions among people ages 18 to 64 are: hypertension (23 percent), respiratory diseases (20 percent), arthritis (18 percent), and chronic mental conditions (16 percent).

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Source: Medical Expenditure Panel Survey, 2001

5. Respiratory Diseases and Asthma Are the Most Common Chronic Conditions in Children



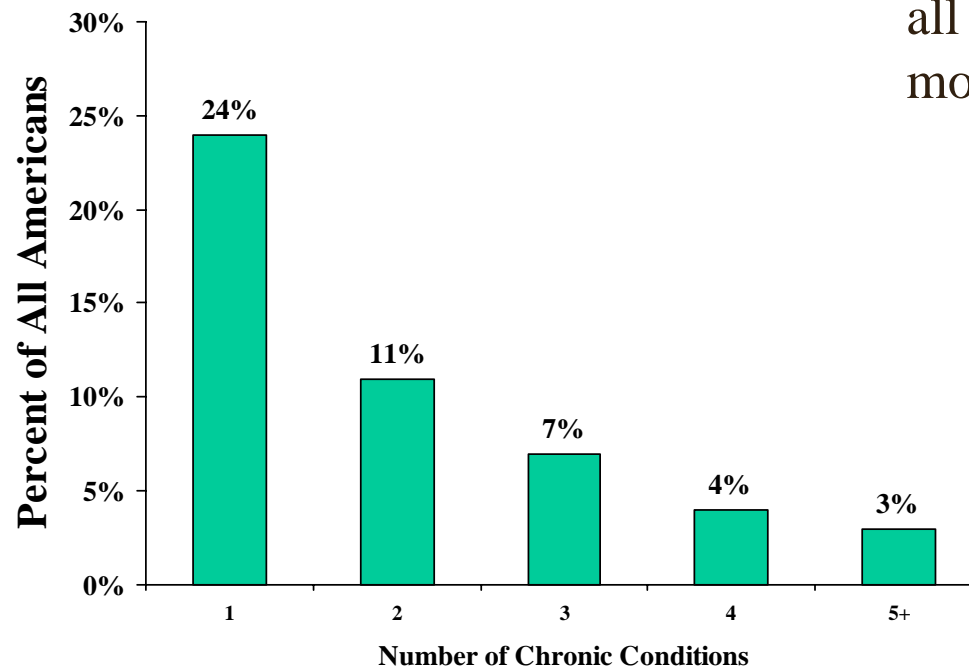
Percent of Noninstitutionalized Children (Ages 0 to 17) with a Chronic Condition

Johns Hopkins University, Partnership for Solutions

Source: Medical Expenditure Panel Survey, 2001.

6. One in Four Americans Have Multiple Chronic Conditions

- In 2001, 24 percent of all Americans had two or more chronic conditions.

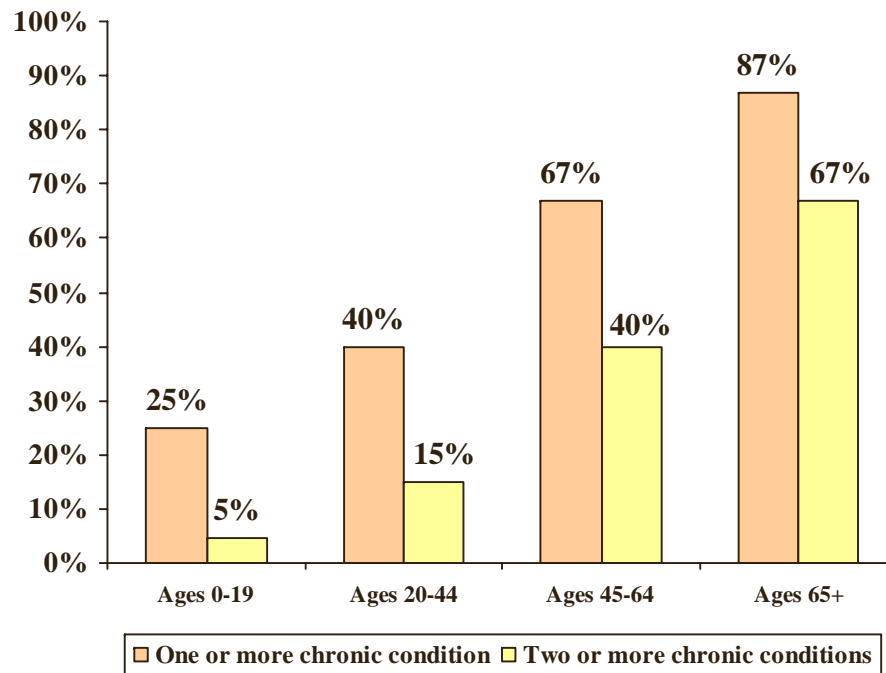


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Source: Medical Expenditure Panel Survey, 2001

7. Older Adults are More Likely to Have Multiple Chronic Conditions

Percent of Population With Chronic Conditions



- The prevalence of multiple chronic conditions increases with age.
- One in 20 children have two or more chronic conditions while two in three people age 65 and older have multiple chronic conditions.
- Among people age 80 and older (not shown), 92 percent have at least one chronic condition and 73 percent have two or more.

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Source: Medical Expenditure Panel Survey, 2001

Consequences of Having Multiple Chronic Conditions

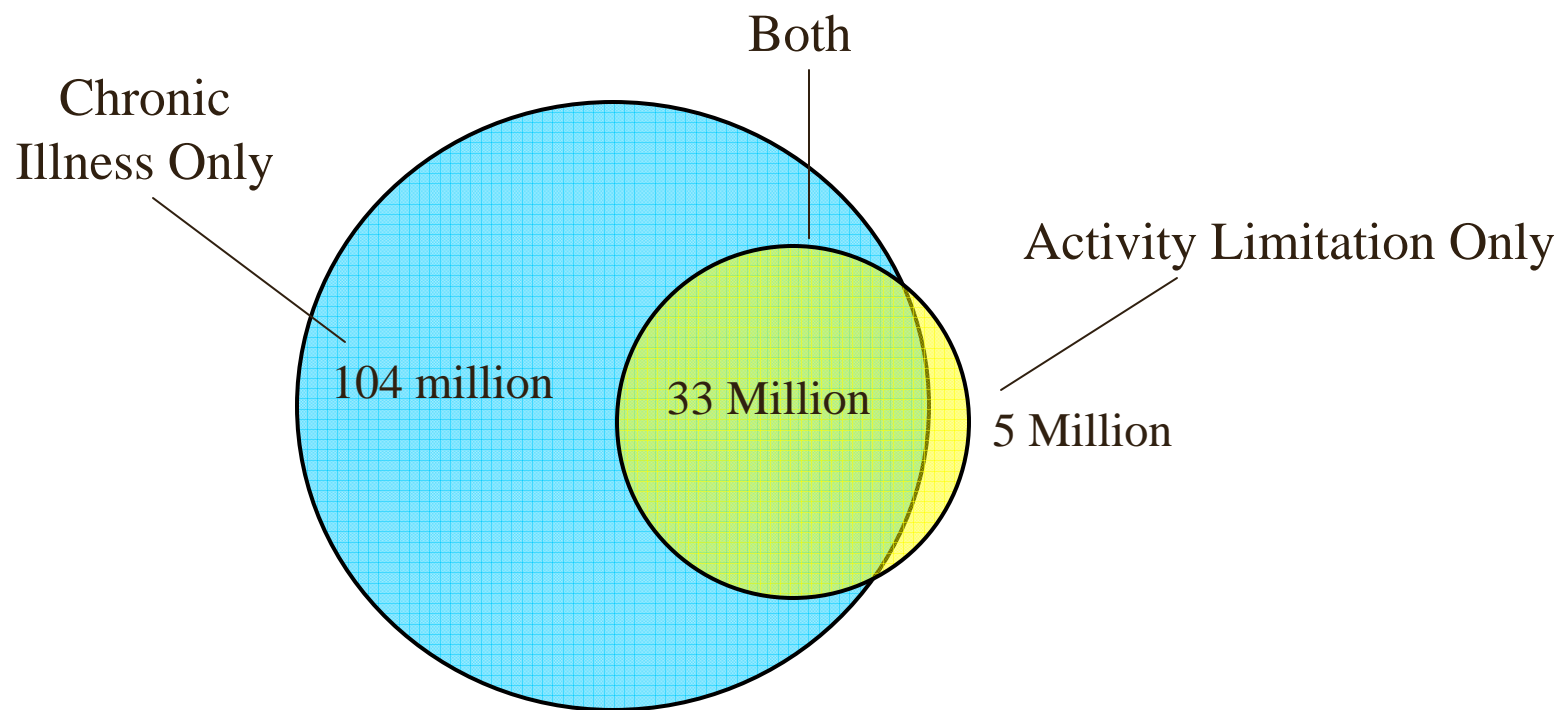
Almost half of people with any kind of chronic condition have more than one condition to manage. Having multiple chronic conditions puts people at greater risk of disability and can result in activity limitations (such as difficulty walking and inability to work).

People with multiple chronic conditions have substantially more physician contacts and are more likely to be hospitalized each year than those with only one chronic condition. They are also far more likely to have difficulty with their personal care, such as eating and bathing.

As the elderly age, they face an increased risk of having multiple chronic conditions.

Although multiple chronic conditions tend to occur with age, five percent of children have more than one chronic condition and experience higher rates of activity limitations compared to children with one chronic condition. For example, these children experience more days spent in bed and have more school absences.

8. One Quarter of Individuals with Chronic Illness Also Have Activity Limitations



Johns Hopkins University, Partnership for Solutions

Source: Medical Expenditure Panel Survey, 2001.

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 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.

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. And the more chronic conditions a person has, the more he or she needs and uses these services. Consequently, the vast majority of health care dollars spent in the U.S. are spent on people with chronic conditions. In 2001, the care given to people with chronic conditions accounted for 83 percent of health care spending. And that number will undoubtedly increase as society ages and the number of people with chronic conditions grows.

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 74 percent of private insurance spending. Almost all Medicare dollars and about 83 percent of Medicaid resources are spent on people with chronic conditions.

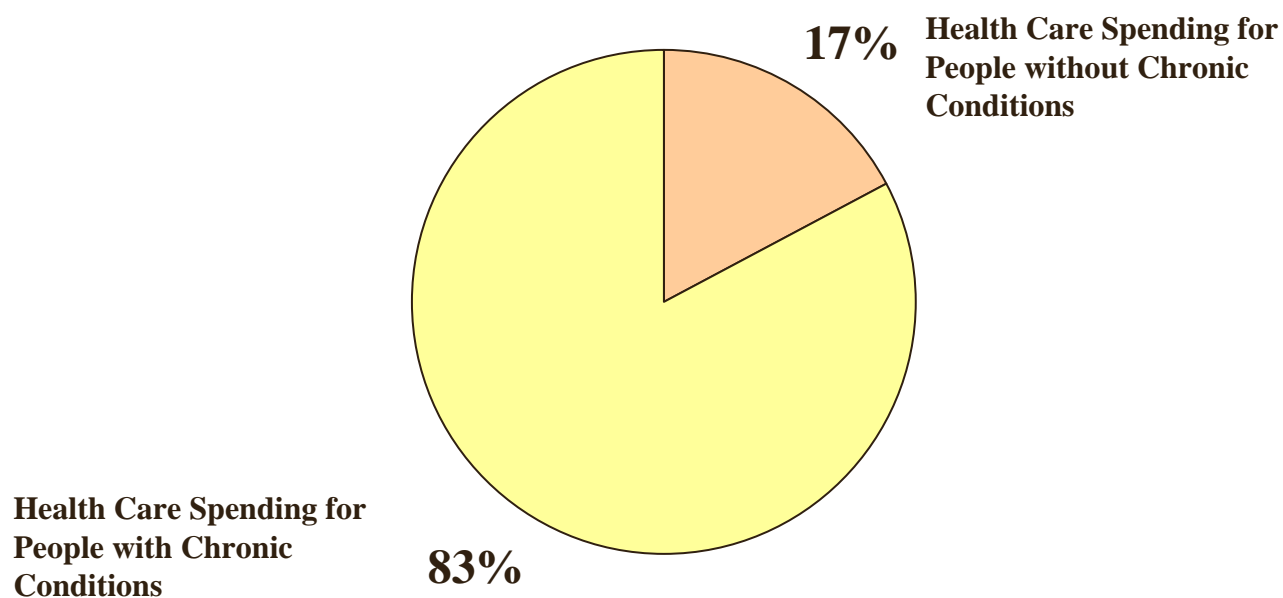
Health care expenditures and utilization also increase considerably when people have multiple chronic health conditions, as do approximately half of all people with chronic conditions. There are a number of reasons why this is so. Age, clinical complexity, and activity limitations resulting from chronic conditions are a few. In general, health care spending for a person with one chronic condition is two and a half times greater than spending for someone without any chronic condition, while spending is almost 15 times greater for someone with five or more chronic conditions. Ninety-six percent of Medicare spending is on behalf of people with multiple chronic conditions.

Section II continued

Adjusting the systems of financing and delivering care to better meet the needs of the chronically ill, 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. A survey of physicians commissioned by Partnership for Solutions and conducted in 2001 by Mathematica Policy Research, Inc., further illuminates some of the obstacles to providing optimal care to people with chronic conditions. The physicians interviewed agreed that the current health care system is not organized to address the many needs of people with chronic conditions, and that health care services can be hard for patients to access. The physicians also reported that coordinating care for people with chronic conditions is difficult and that they felt their training had not adequately prepared them to care for these type of patients – an alarming finding given the changing face of the American health care consumer.

All health care providers and payers – from corporations to individuals – have a stake in seeing that chronic care is more adequately delivered and reimbursed in this country. While managed care service delivery and financing models may have held promise for better treatment of people with chronic conditions, the current market change away from very organized and integrated systems of care only adds to the challenge of better addressing the needs of this growing population. Fortunately, however, there is an increasing interest in these issues and several demonstration projects are underway to look at new models of care. While many of these efforts hold promise, there is much more that needs to be done and the following information points to the need to act sooner rather than later.

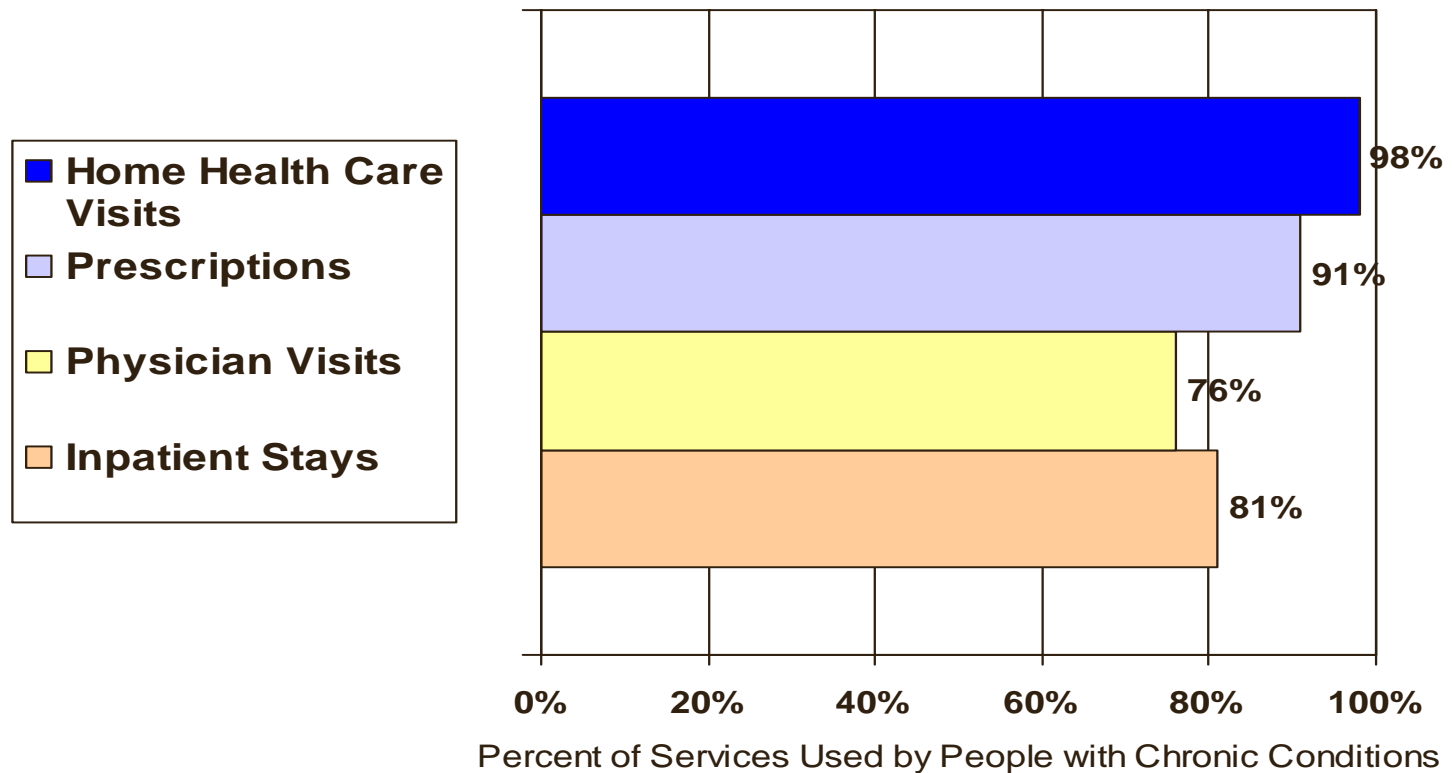
9. People with Chronic Conditions Account for 83 Percent of All Health Care Spending



Source: Medical Expenditure Panel Survey, 2001.

Johns Hopkins University, Partnership for Solutions

10. People with Chronic Conditions Are the Heaviest Users of Health Care Services



Source: Medical Expenditure Panel Survey, 2001

Johns Hopkins University, Partnership for Solutions

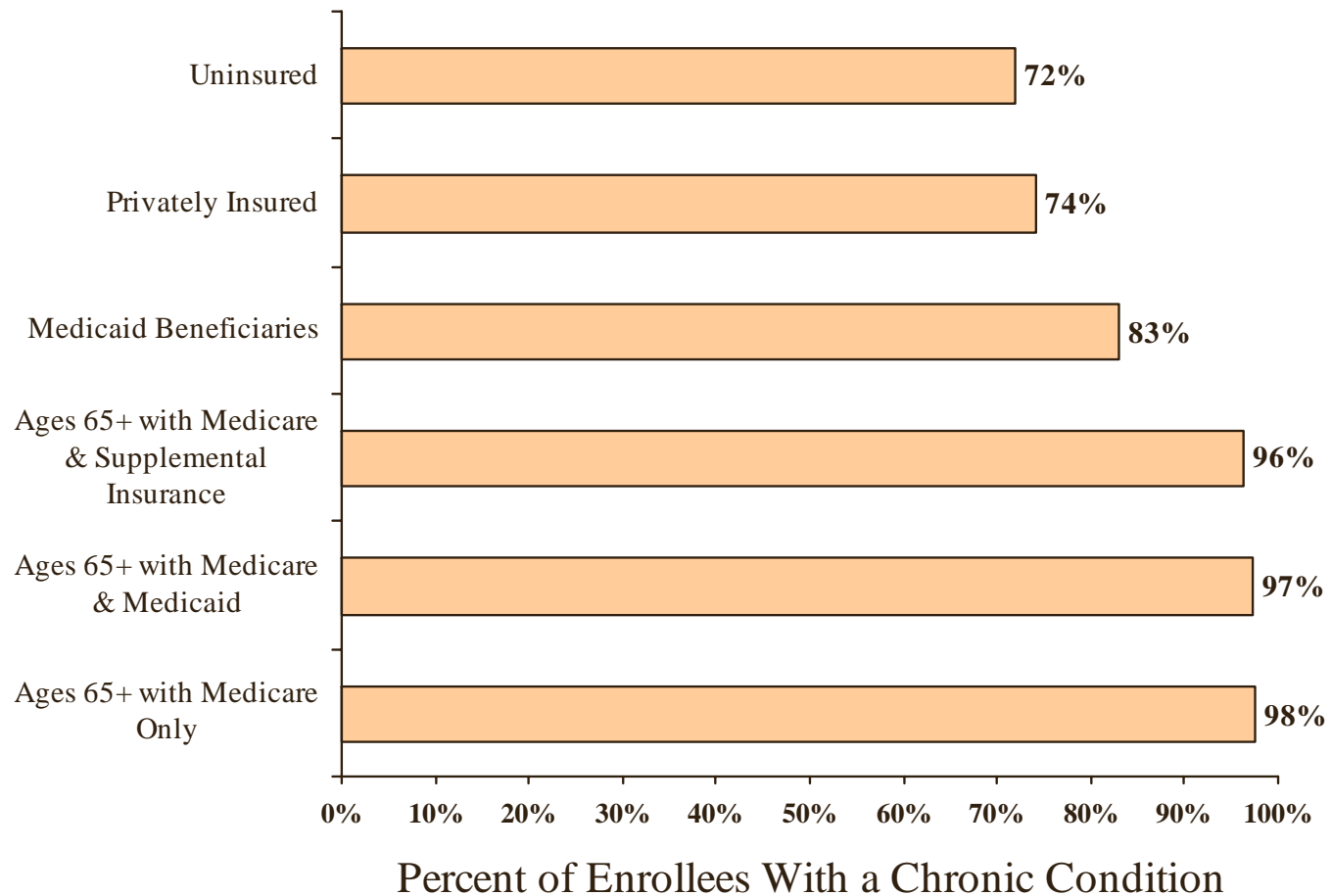
Health Care Spending for People with Chronic Conditions is Disproportional to the Percent of People with Chronic Conditions

- Eighty-three percent of health care spending is attributed to the 48 percent of the noninstitutionalized population that has one or more chronic conditions.
- Seventy-four percent of private health insurance spending is attributed to the 45 percent of privately insured people who have chronic conditions.
- Seventy-two percent of all health care spending for the uninsured is for care received by the 31 percent of uninsured with chronic conditions.
- Eighty-three percent of Medicaid spending is for the almost 40 percent of noninstitutionalized beneficiaries with chronic conditions.

Source: Medical Expenditure Panel Survey, 2001

Johns Hopkins University, Partnership for Solutions

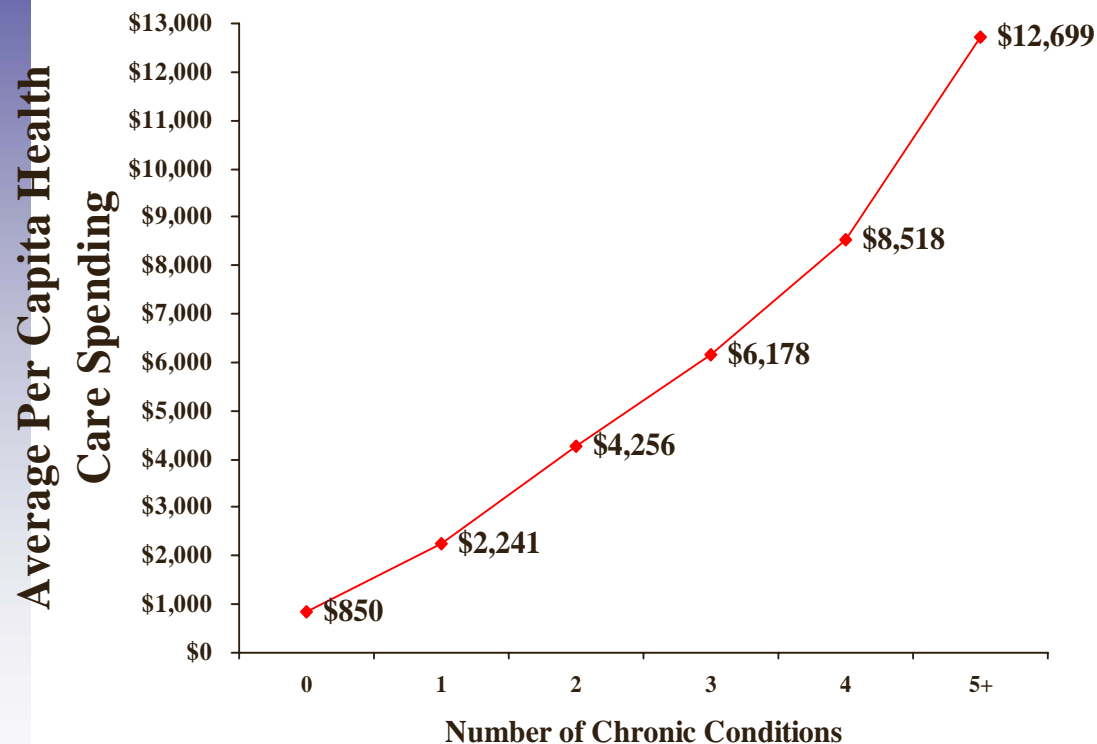
11. Percentage of Health Care Spending for Individuals with Chronic Conditions by Type of Insurance



Johns Hopkins University, Partnership for Solutions

Source: Medical Expenditure Panel Survey, 2001.

12. Health Care Spending Increases With The Number of Chronic Conditions



Johns Hopkins University, Partnership for Solutions
Source: Medical Expenditure Panel Survey, 2001.

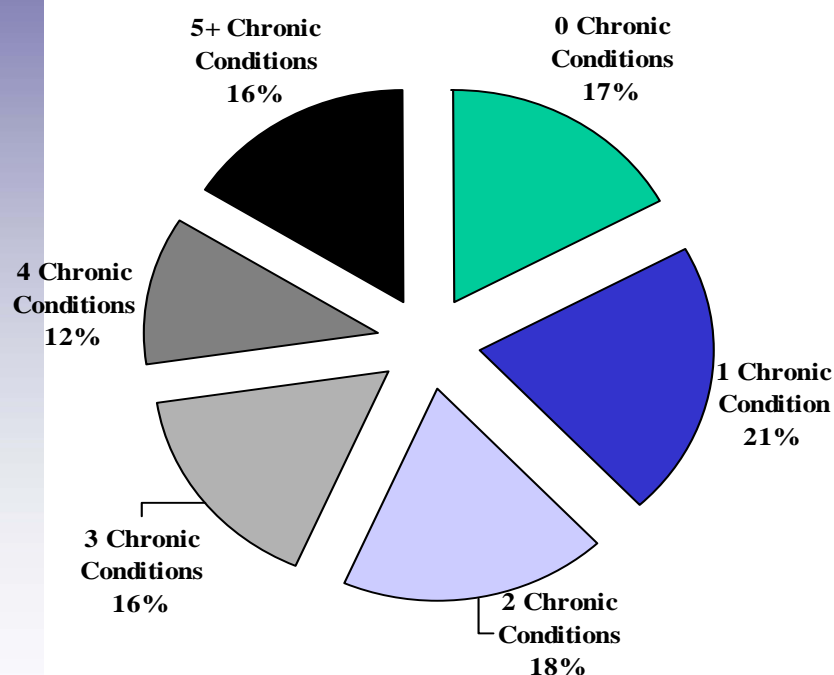
- Average per capita spending on people with one or more chronic conditions is more than five times greater than spending on people without any chronic conditions. (\$850 for people with no conditions compared to \$4,398 for people with one or more conditions.)

- Compared to individuals with no chronic conditions:

- Spending is over two and a half times greater for someone with one chronic condition.
- Spending is over seven times greater for someone with three chronic conditions.
- Spending is almost 15 times greater for someone with five or more chronic conditions.

13. More than Three-Fifths of Health Care Spending is on Behalf of People with Multiple Chronic Conditions

Percent of Health Care Total Spending by Number of Chronic Conditions



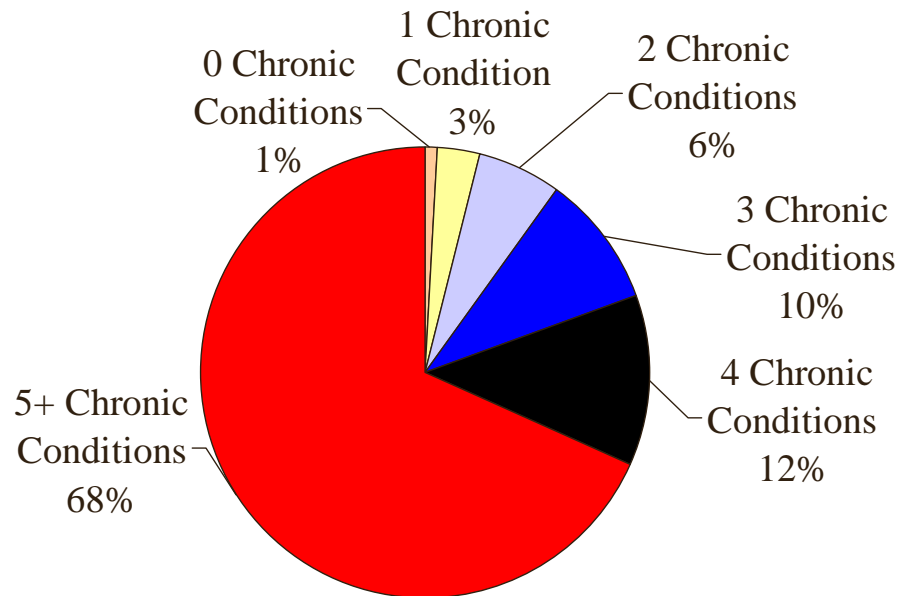
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Source: Medical Expenditure Panel Survey, 2001.

- Seventeen percent of spending is for the 52 percent of the population that has no chronic conditions.
- Twenty-one percent of spending is for the 24 percent of the population that has only one chronic condition.
- Eighteen percent of spending is for the 11 percent of the population that has two chronic conditions.
- Sixteen percent of spending is for the 7 percent of the population that has three chronic conditions.
- Twelve percent of spending is for the 3 percent of the population that has four chronic conditions.
- Sixteen percent of spending is for the 3 percent of the population that has five or more chronic conditions.

14. Two-thirds of Medicare Spending Is for People with Five of More Chronic Conditions

Percent of Medicare Expenditures

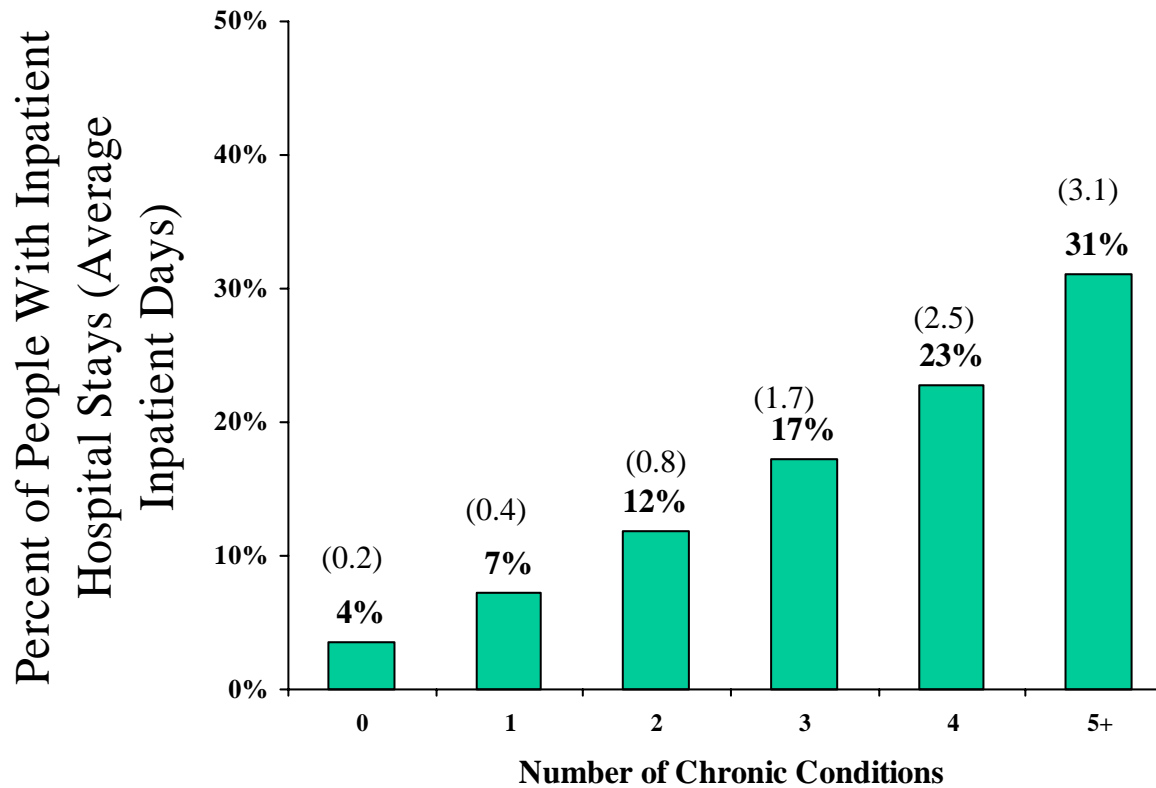


- Ninety-nine percent of Medicare expenditures are for beneficiaries with at least one chronic condition.
- Ninety-six percent of Medicare expenditures involve individuals with multiple chronic conditions.

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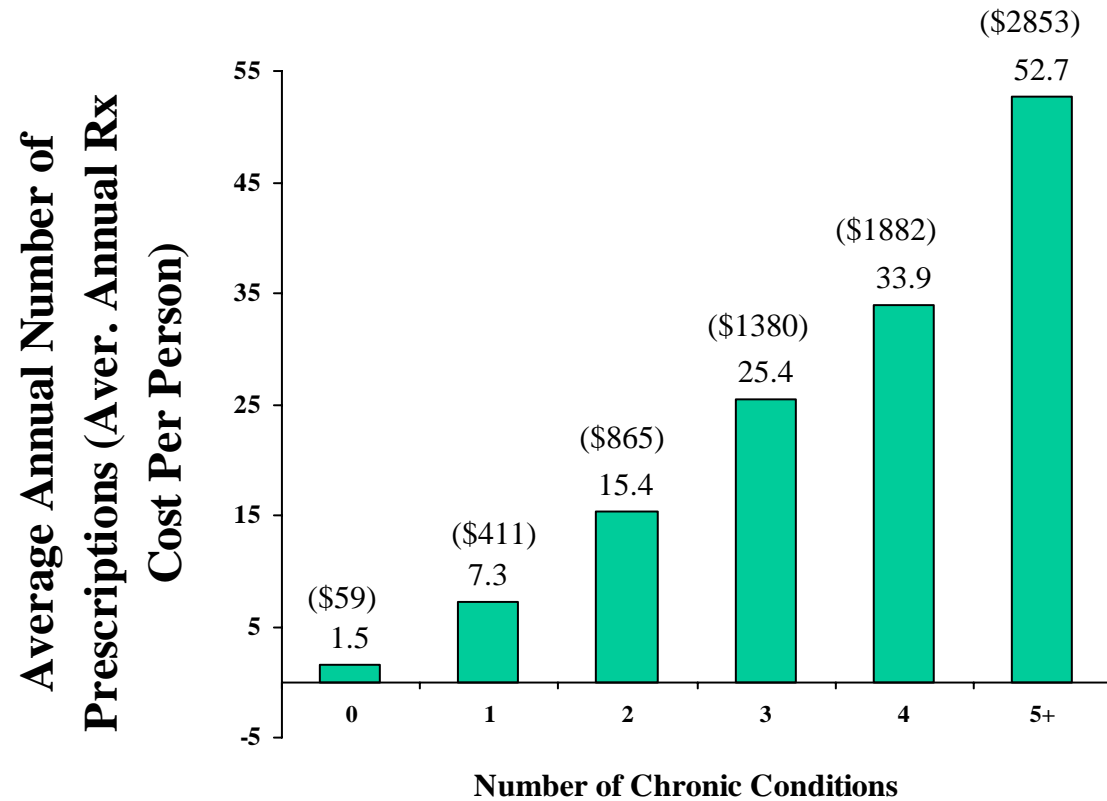
Source: Medicare Standard Analytic File, 2001.

15. People with Multiple Chronic Conditions Are Much More Likely to be Hospitalized



Johns Hopkins University, Partnership for Solutions
Source: Medical Expenditure Panel Survey, 2001.

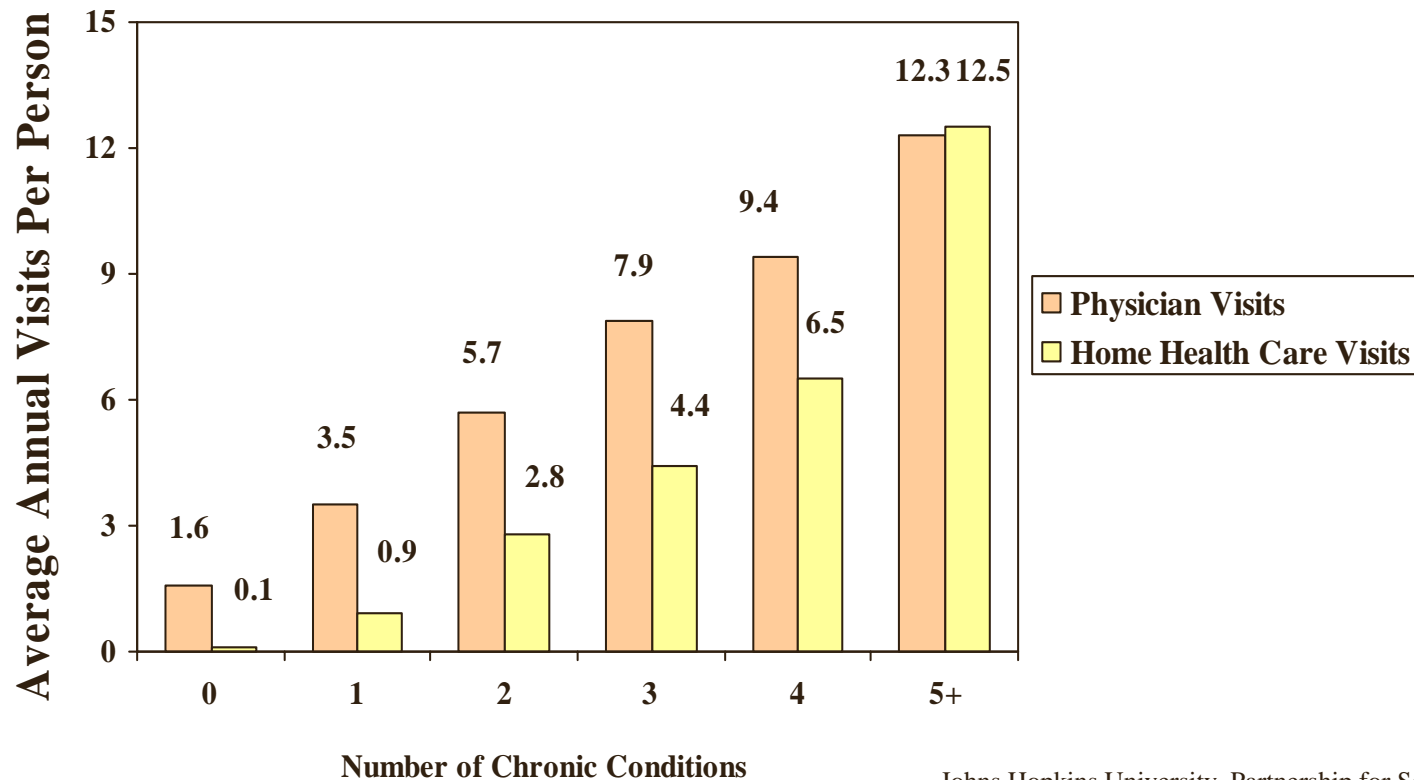
16. People With Multiple Chronic Conditions Fill More Prescriptions



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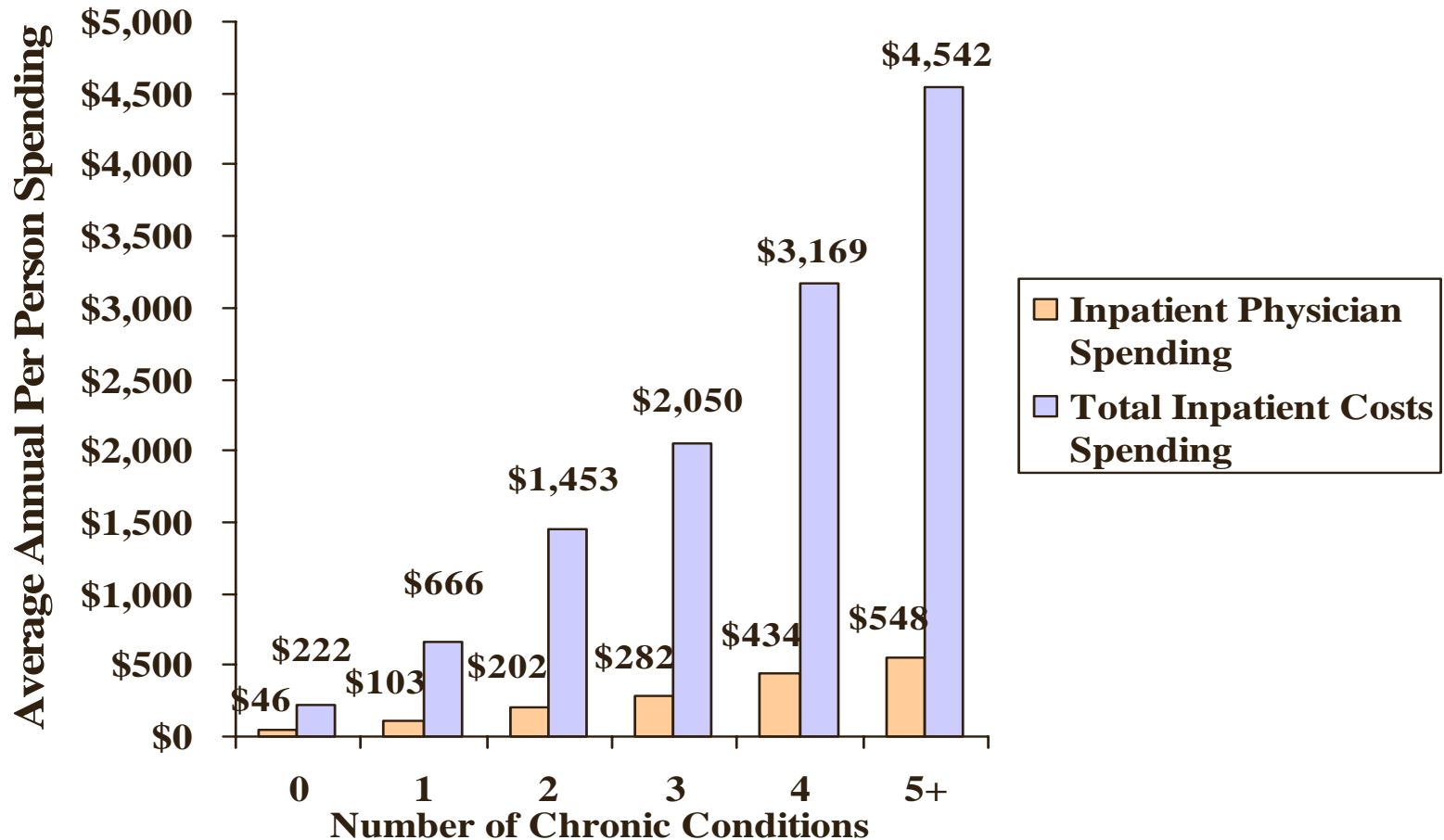
Source: Medical Expenditure Panel Survey, 2001.

17. Physician and Home Health Care Visits Increase with the Number of Chronic Conditions



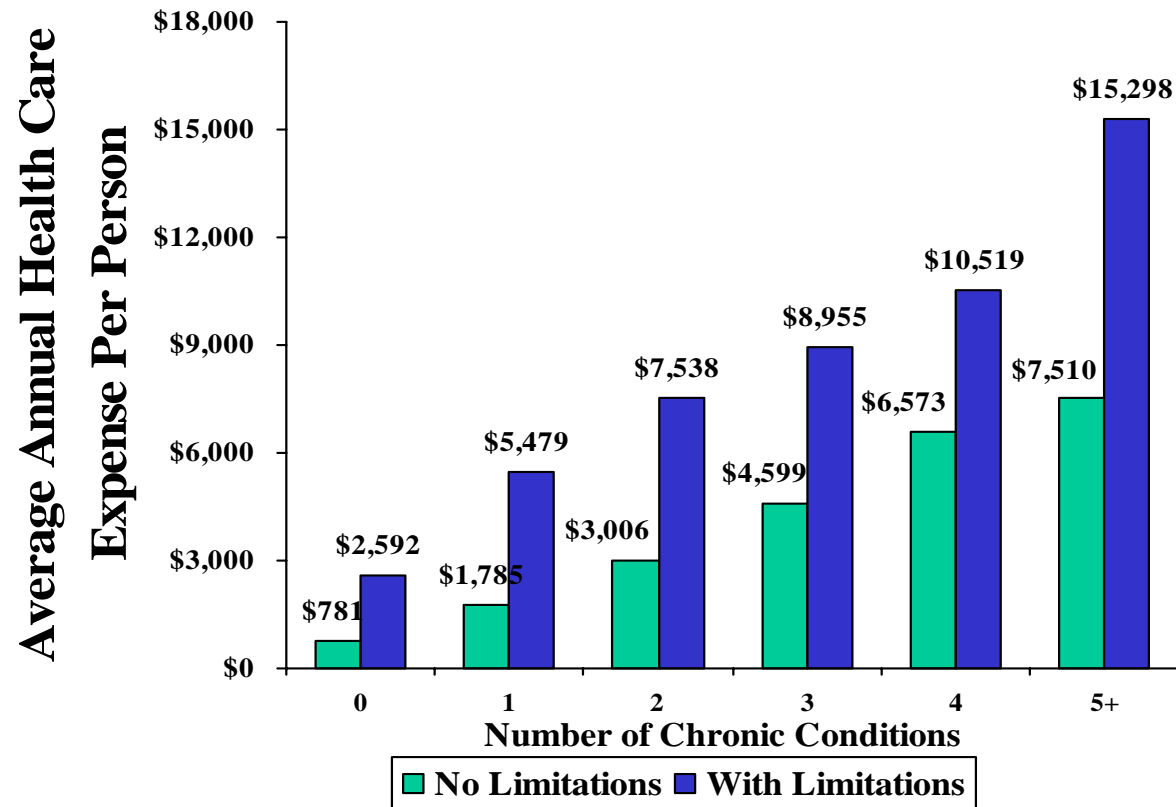
Johns Hopkins University, Partnership for Solutions
Source: Medical Expenditure Panel Survey, 2001.

18. Spending for Inpatient Hospital Care Increases with the Number of Chronic Conditions



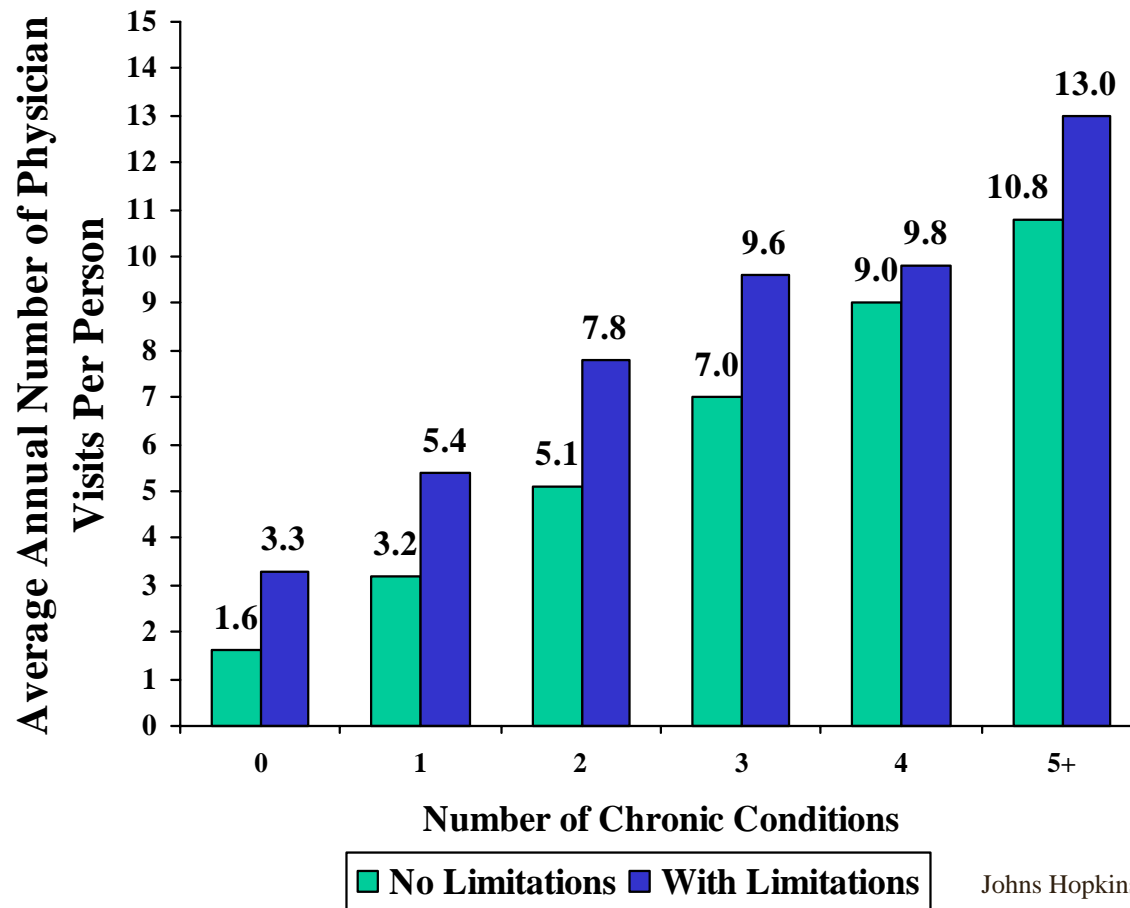
Johns Hopkins University, Partnership for Solutions
Source: Medical Expenditure Panel Survey, 2001.

19. Health Care Spending More Than Doubles for People with Chronic Illnesses and Activity Limitations



Johns Hopkins University, Partnership for Solutions
Source: Medical Expenditure Panel Survey, 2001.

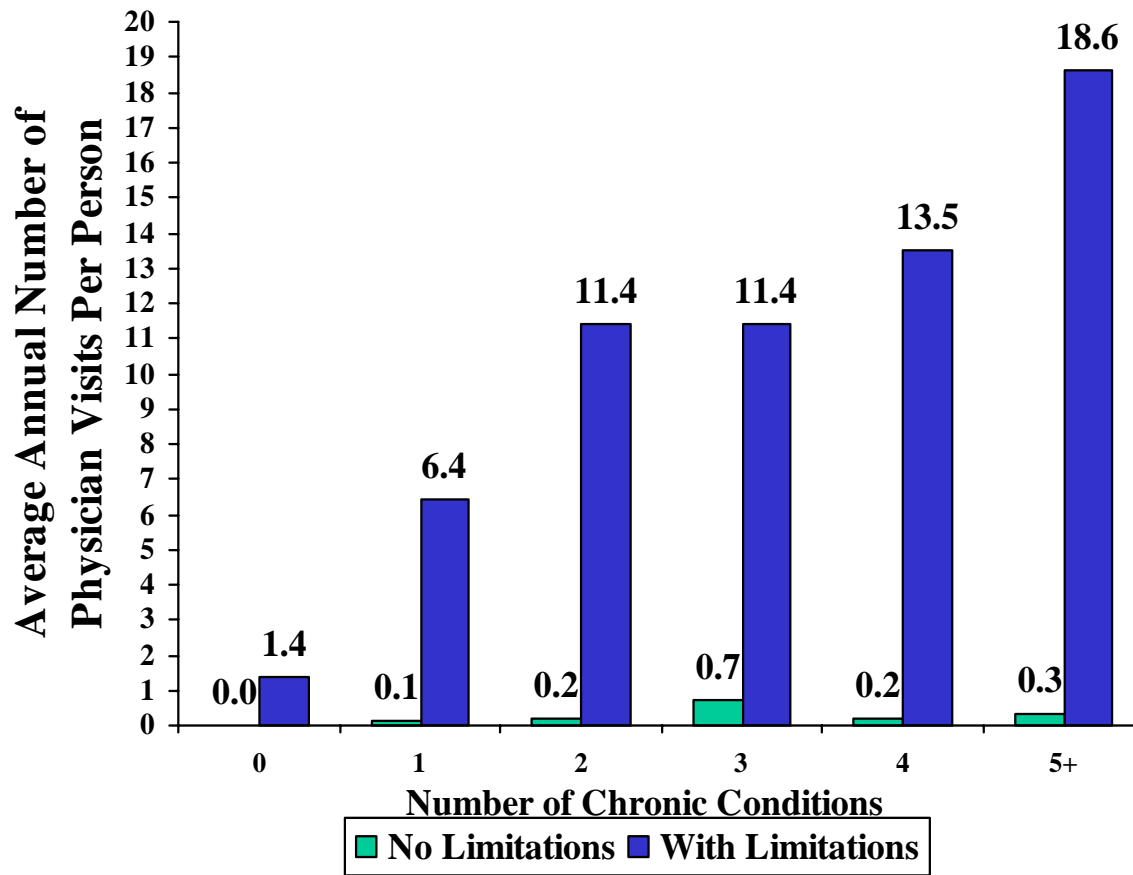
20. People with Chronic Illnesses and Activity Limitations Have More Physician Visits



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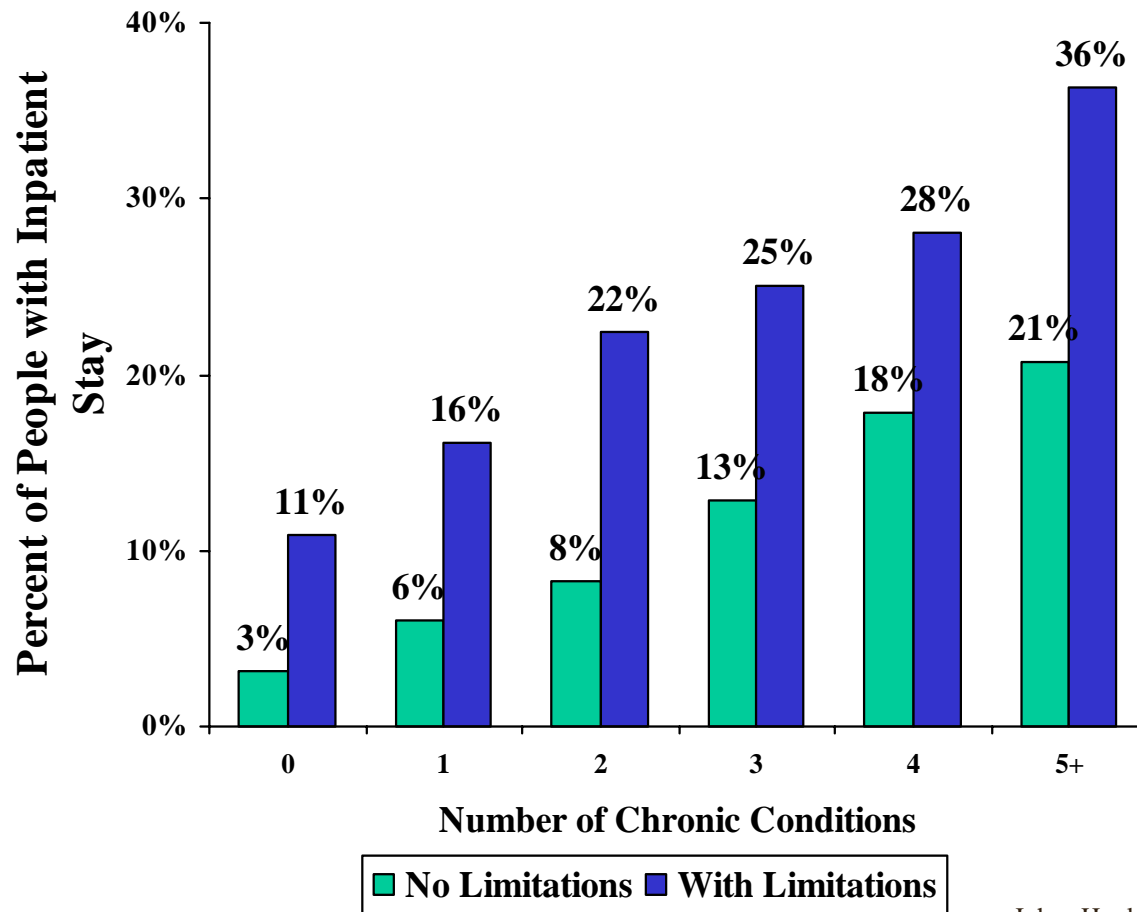
Source: Medical Expenditure Panel Survey, 2001.

21. Individuals with Chronic Illnesses and Activity Limitations Have More Home Health Care Visits



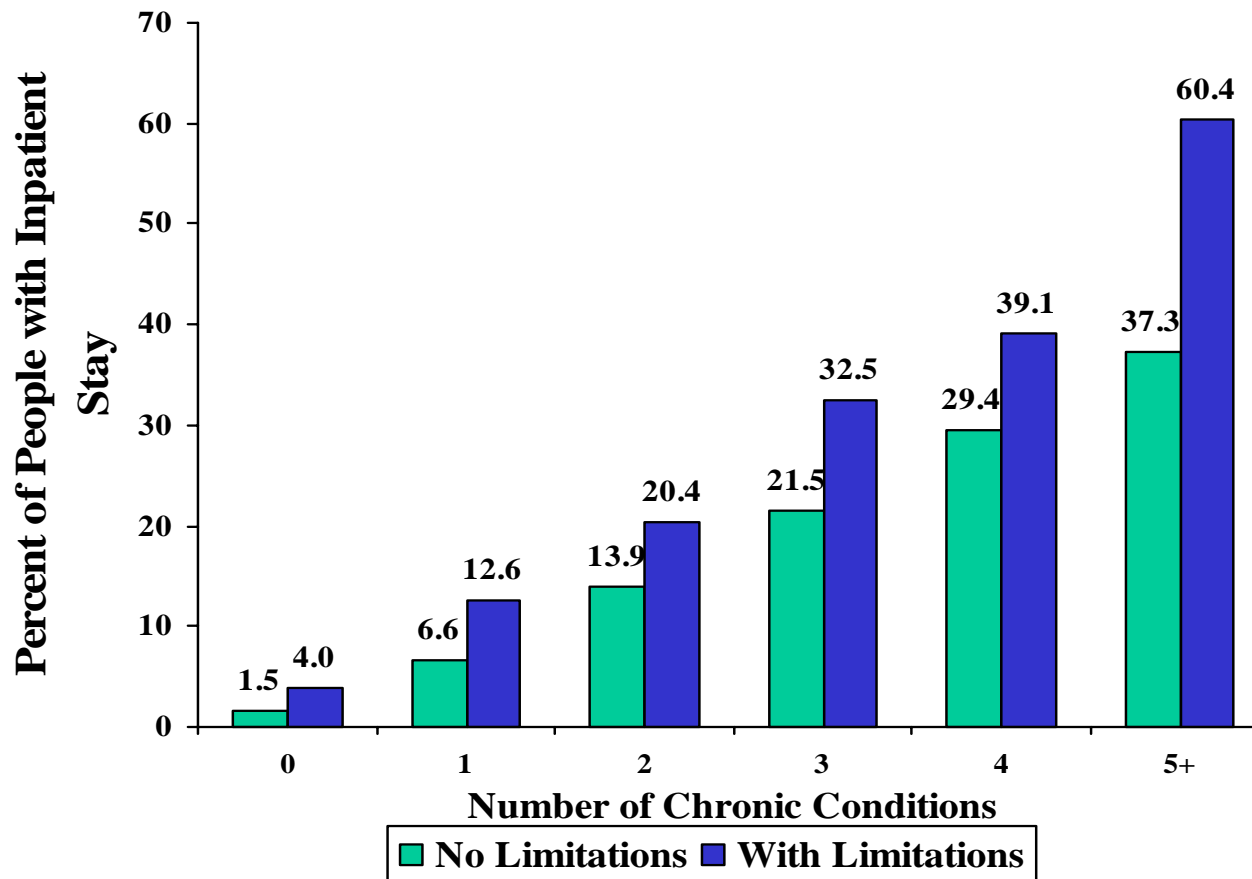
Johns Hopkins University, Partnership for Solutions
Source: Medical Expenditure Panel Survey, 2001.

22. People with Chronic Illnesses and Activity Limitations Have More Inpatient Stays



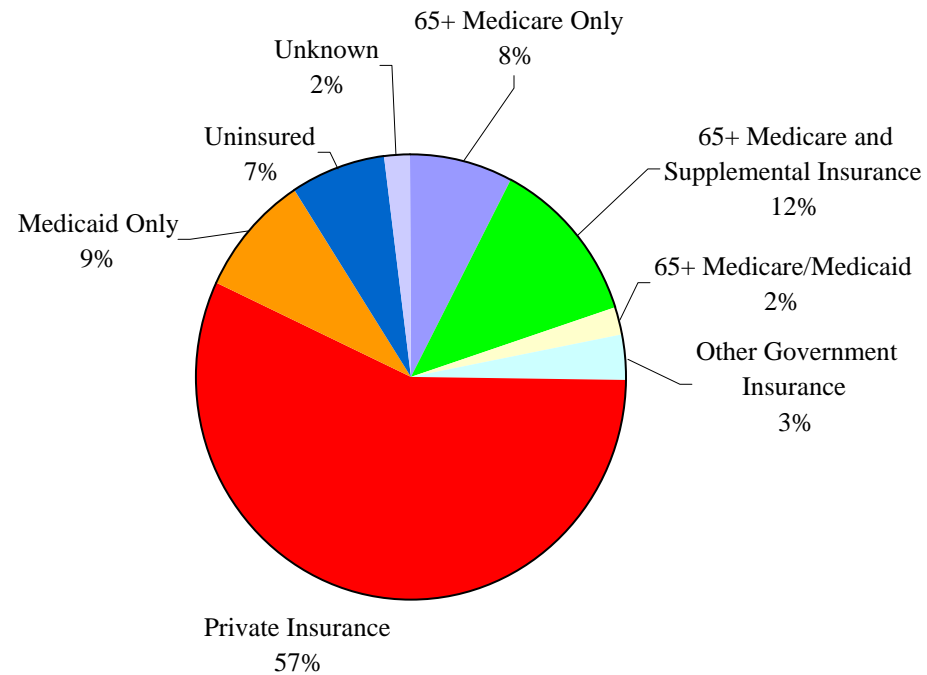
Johns Hopkins University, Partnership for Solutions
Source: Medical Expenditure Panel Survey, 2001.

23. People with Chronic Illnesses and Activity Limitations Fill More Prescriptions



Johns Hopkins University, Partnership for Solutions
Source: Medical Expenditure Panel Survey, 2001.

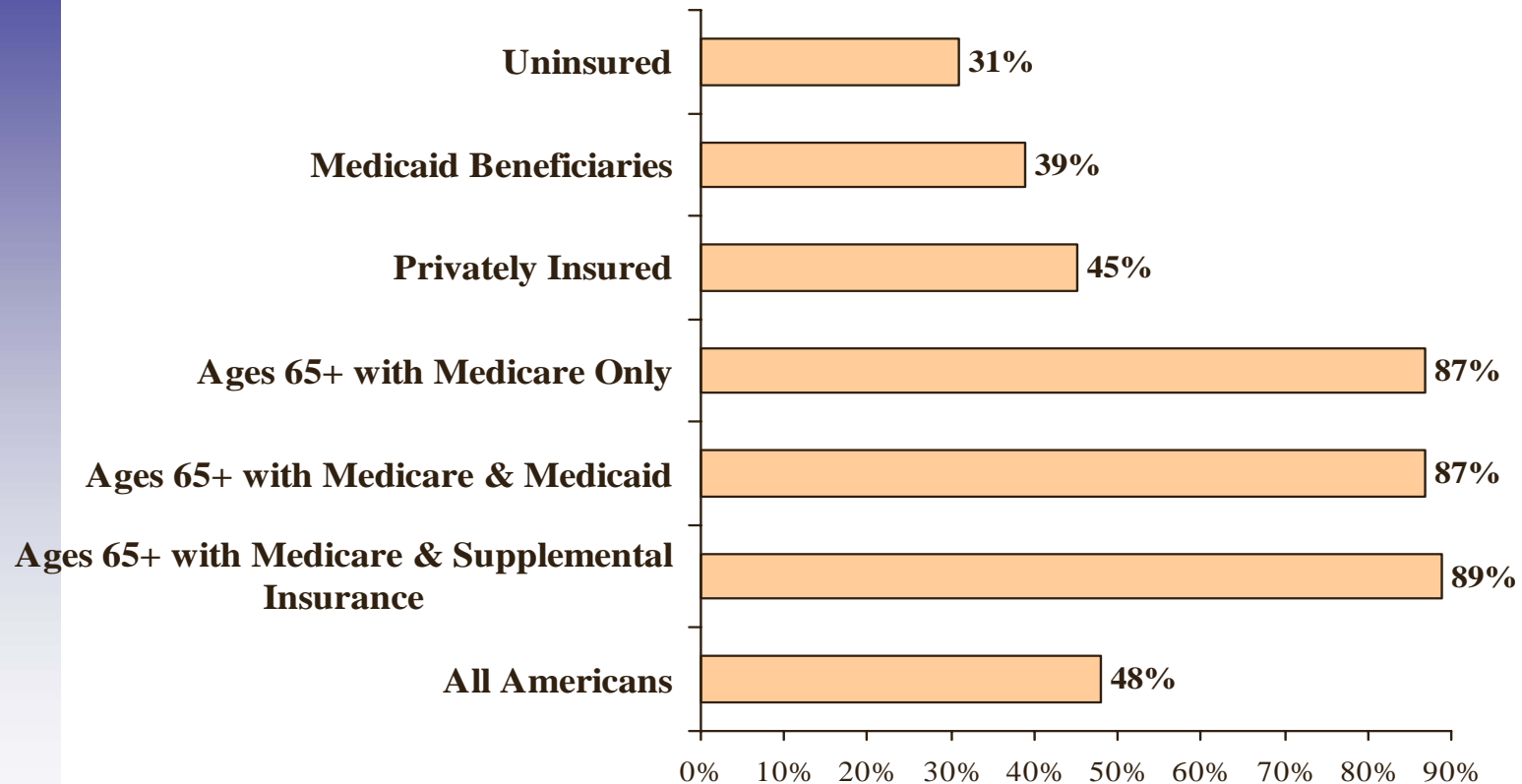
24. Most People with Chronic Conditions Have Private Insurance



Johns Hopkins University, Partnership for Solutions

Source: Medical Expenditure Panel Survey, 2001.

25. People with Medicare Are Most Likely to Have Chronic Conditions

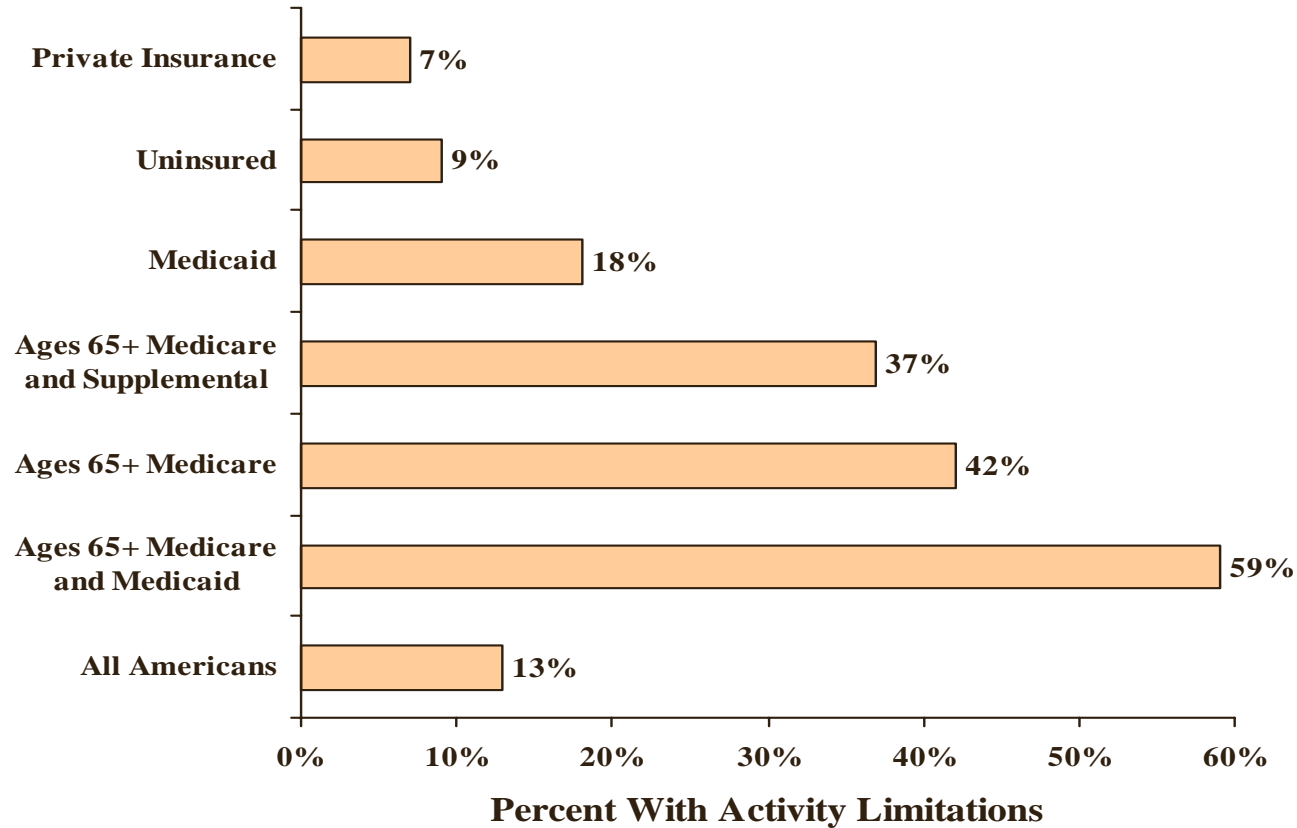


Percent of Enrollees With a Chronic Condition

Johns Hopkins University, Partnership for Solutions

Source: Medical Expenditure Panel Survey, 2001.

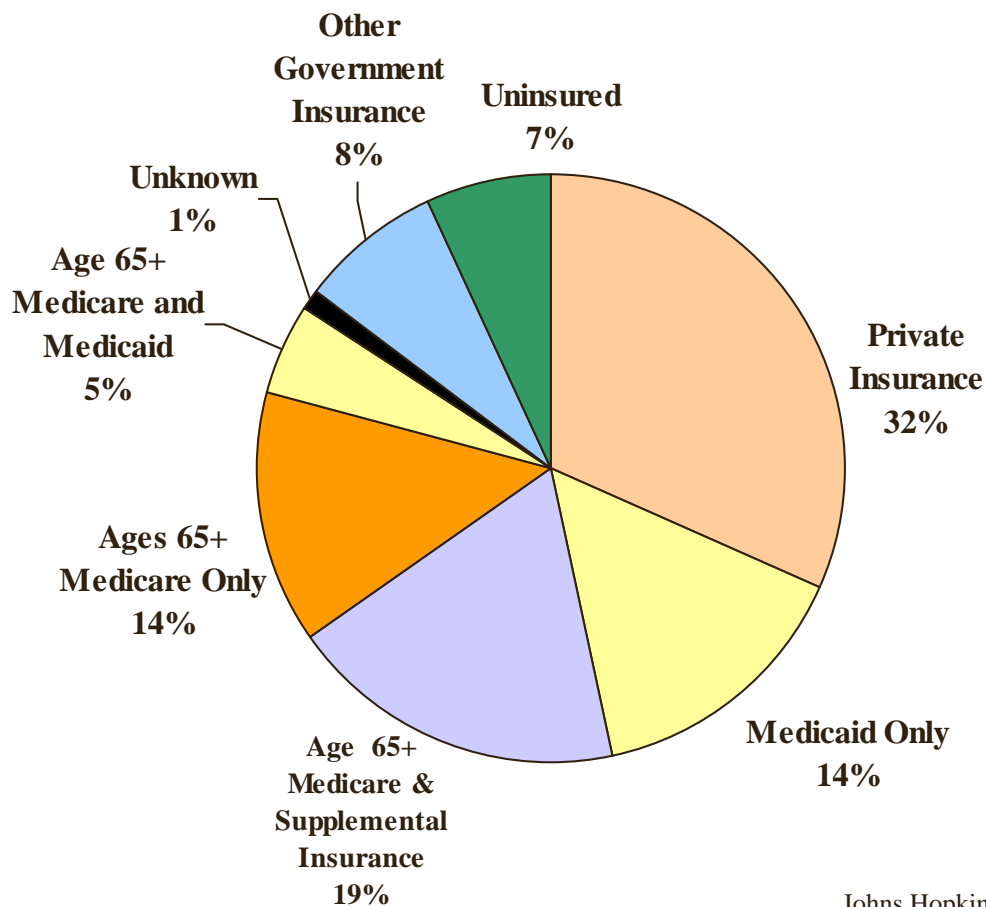
26. People with Medicare and Medicaid Coverage Have High Rates of Activity Limitations



Johns Hopkins University, Partnership for Solutions

Source: Medical Expenditure Panel Survey, 2001.

27. Most People with Activity Limitations Have Medicare Coverage

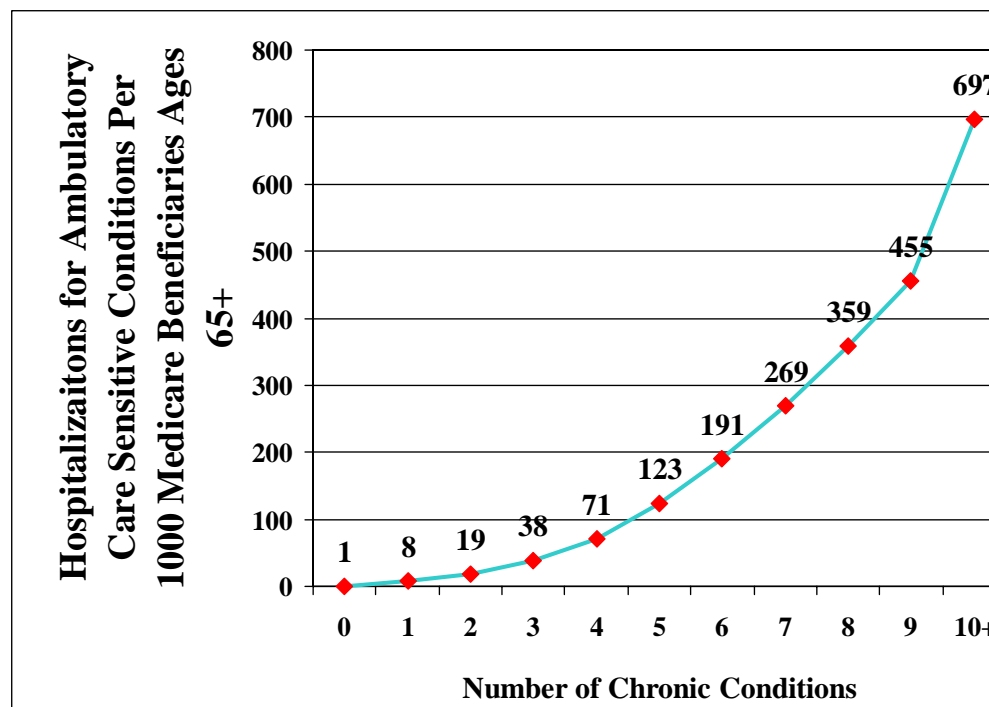


Johns Hopkins University, Partnership for Solutions

Source: Medical Expenditure Panel Survey, 2001.

28. 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.
- Inappropriate hospitalizations increase as the number of chronic conditions increase.
- 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 contraindicated.
- These factors may play a role in the correlation between increasing numbers of chronic conditions and increasing numbers of inappropriate hospitalizations.



Johns Hopkins University, Partnership for Solutions

Source: Medicare Standard Analytic File, 2001.

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, front-line providers – physicians – believe that poor coordination of care generally leads to unnecessary service utilization: hospitalizations, nursing home placements, and duplicate diagnostic tests. We also know that an increase in the number of chronic conditions correlates with an increase in inappropriate hospitalizations. This is likely related to the greater number of providers treating people with multiple chronic conditions and the higher volume of services they receive. This type of inappropriate utilization inflates expenses in an already stressed health care budget, but more importantly, unnecessary utilization can be costly, frustrating, time-consuming, and even dangerous for patients.

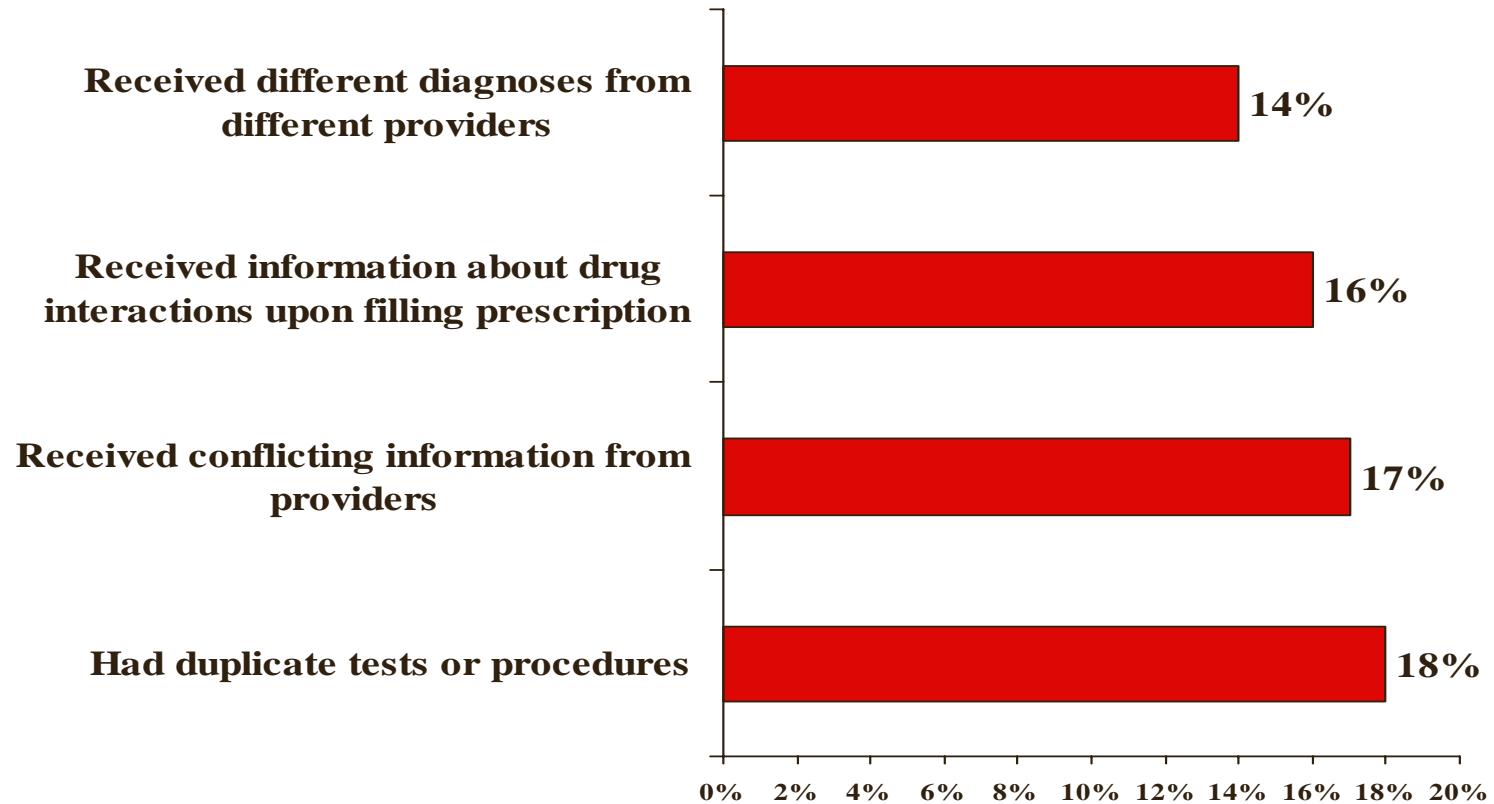
Another consequence of poor coordination is that many individuals often receive conflicting advice from different providers, leaving them with a dilemma—which provider to believe. Without any real ability to discern which is the correct information or most appropriate course of care or treatment, many 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 more likely to receive conflicting advice, have trouble accessing needed services, and receive prescriptions that adversely interact with one another.

Section III continued

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 paying for 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.

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.

29. People with Chronic Conditions Report Not Receiving Adequate Information

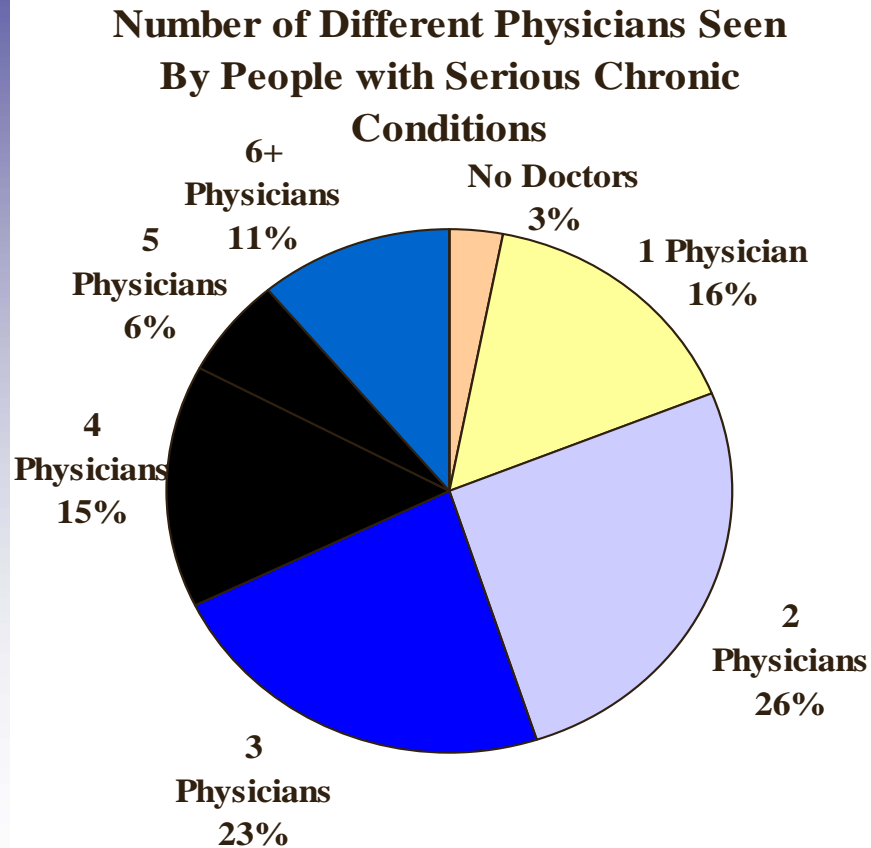


Percent of Population with Chronic Conditions Reporting Problem

Johns Hopkins University, Partnership for Solutions

Source: *Chronic Illness and Caregiving*, a survey conducted by Harris Interactive, Inc., 2000.

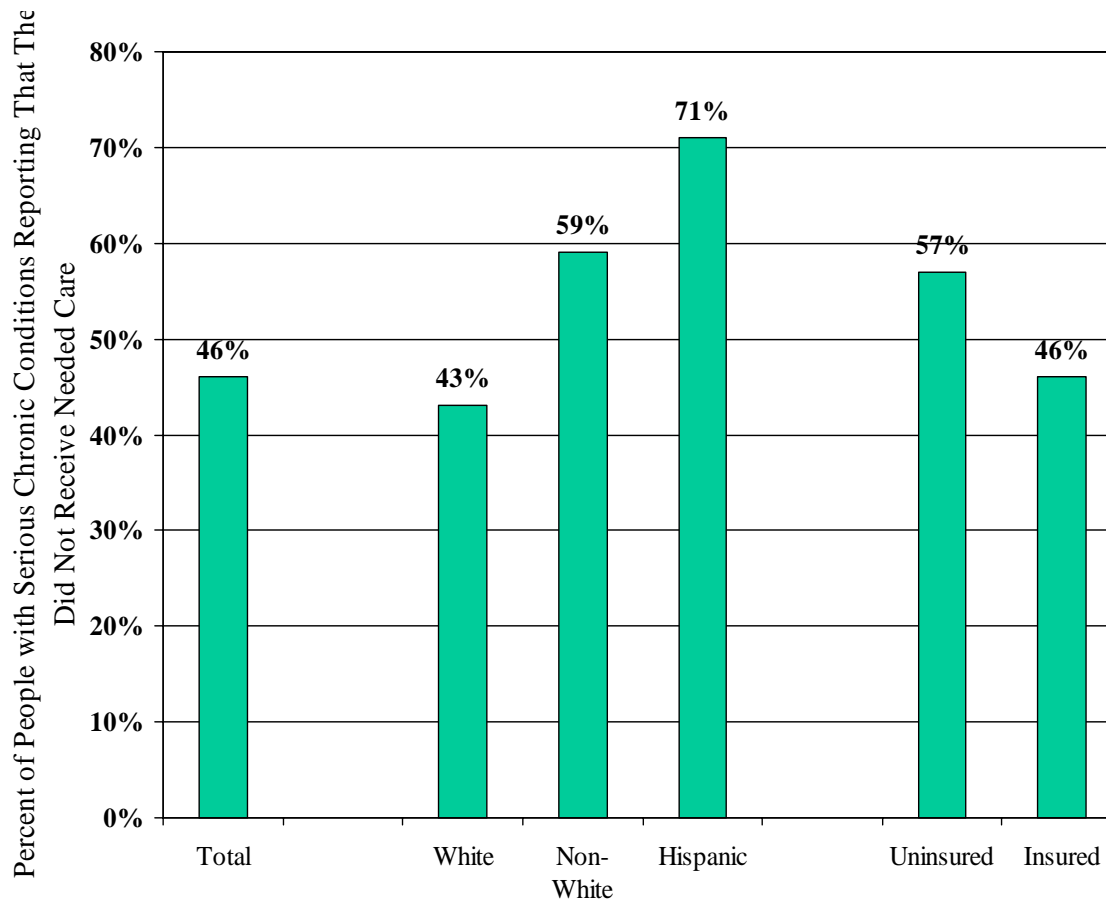
30. More than Half of People with Serious Chronic Conditions Have Three or More Different Physicians



- **Eighty-one percent of people with serious chronic conditions see two or more different physicians.**

Johns Hopkins University, Partnership for Solutions
Source: Gallup Serious Chronic Illness Survey 2002.

31. People with Serious Chronic Conditions Believe They Do Not Receive Needed Treatment



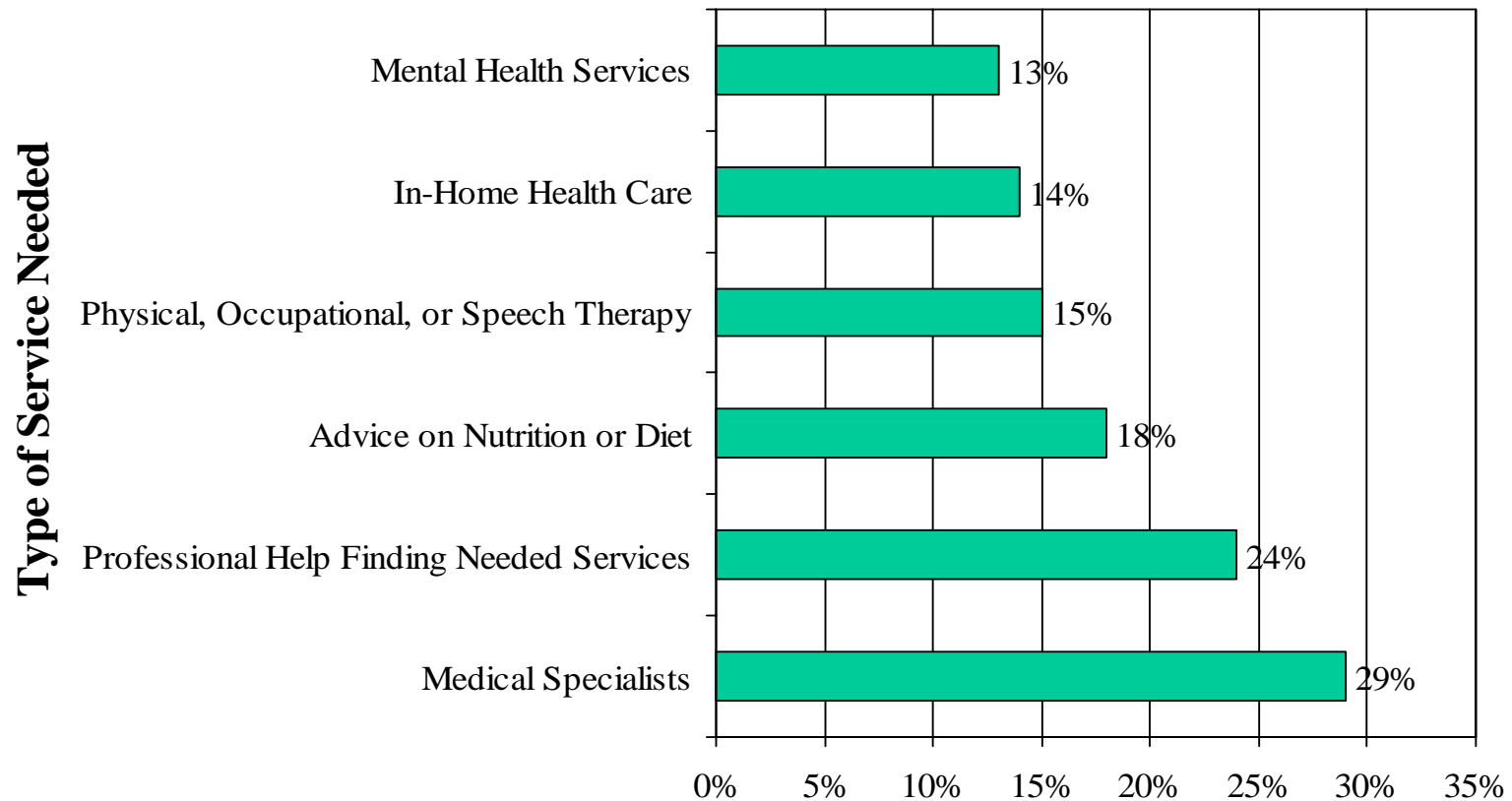
- The uninsured are more likely to report that they go without needed medical care, although insured people with serious chronic conditions also report high levels of unmet service needs.

- Hispanic and non-white persons with serious chronic conditions report high levels of unmet service needs.

Johns Hopkins University, Partnership for Solutions

Source: *Serious Chronic Illness Survey*, conducted by the Gallup Organization, 2002.

32. People with Serious Chronic Conditions Have Trouble Accessing Specific Services

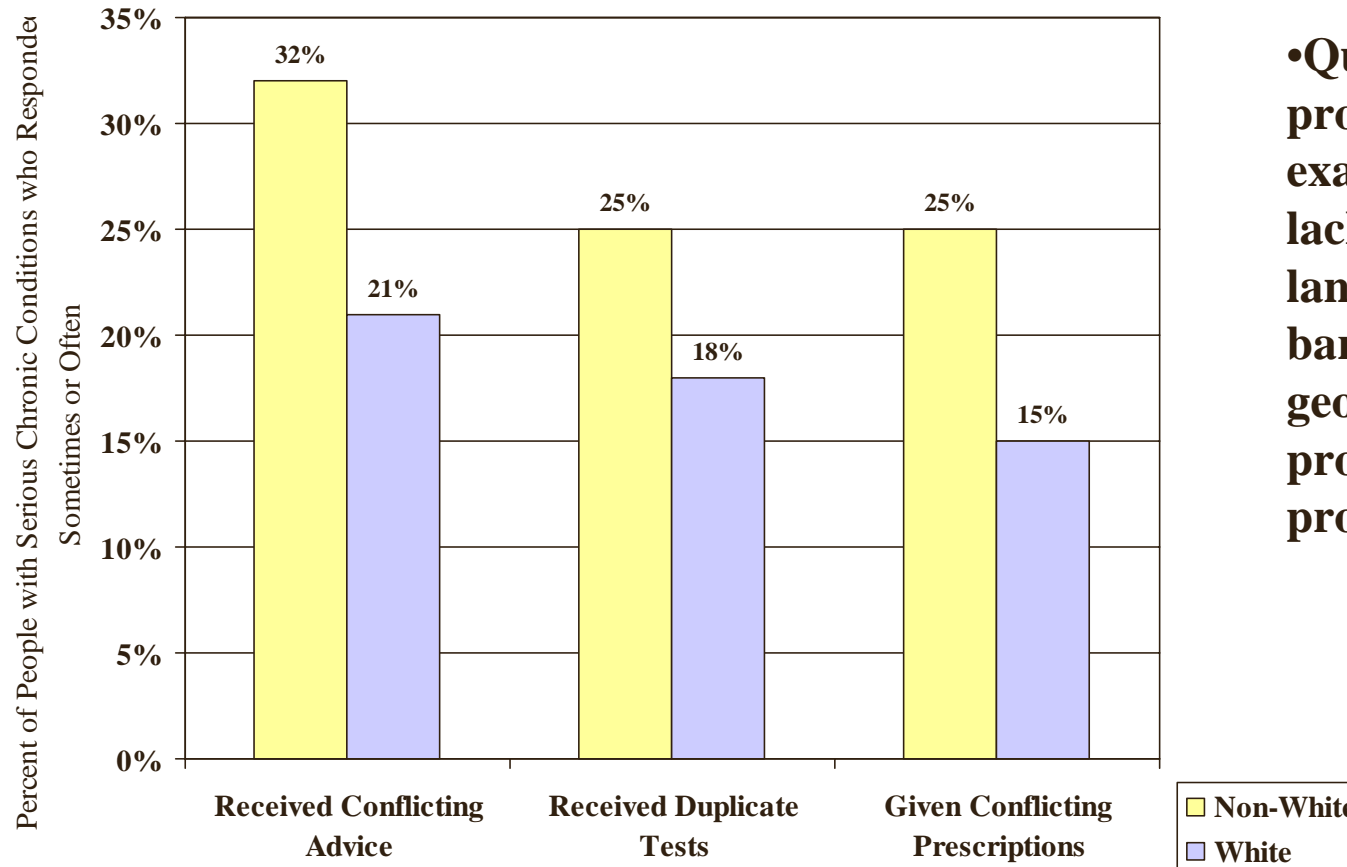


Percent of People with Serious Chronic Conditions Reporting That They Did Not Get Needed Service

Johns Hopkins University, Partnership for Solutions

Source: *Serious Chronic Illness Survey*, conducted by Gallup Organization, 2002.

33. Quality of Care for People with Serious Chronic Conditions Varies by Race

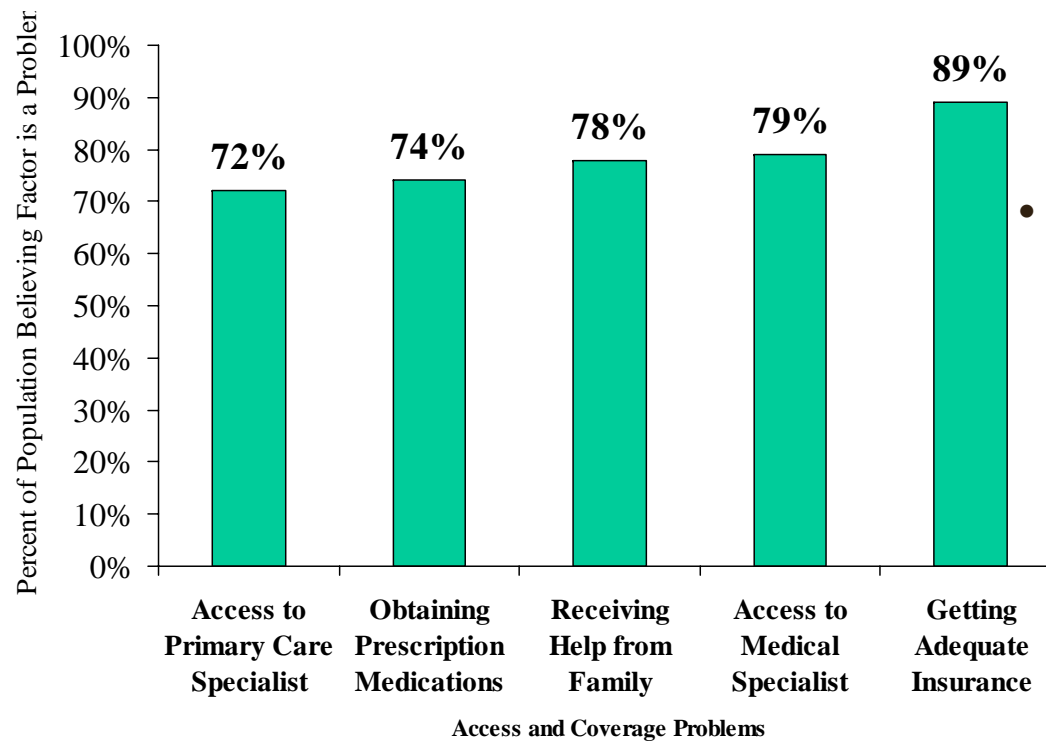


•Quality-of-care problems may be exacerbated by lack of insurance, language barriers, and geographic proximity to providers.

Johns Hopkins University, Partnership for Solutions

Source: *Serious Chronic Illness Survey*, conducted by Gallup Organization, 2002.

34. Americans Believe that Access to Care and Coverage is a Problem for People with Chronic Conditions

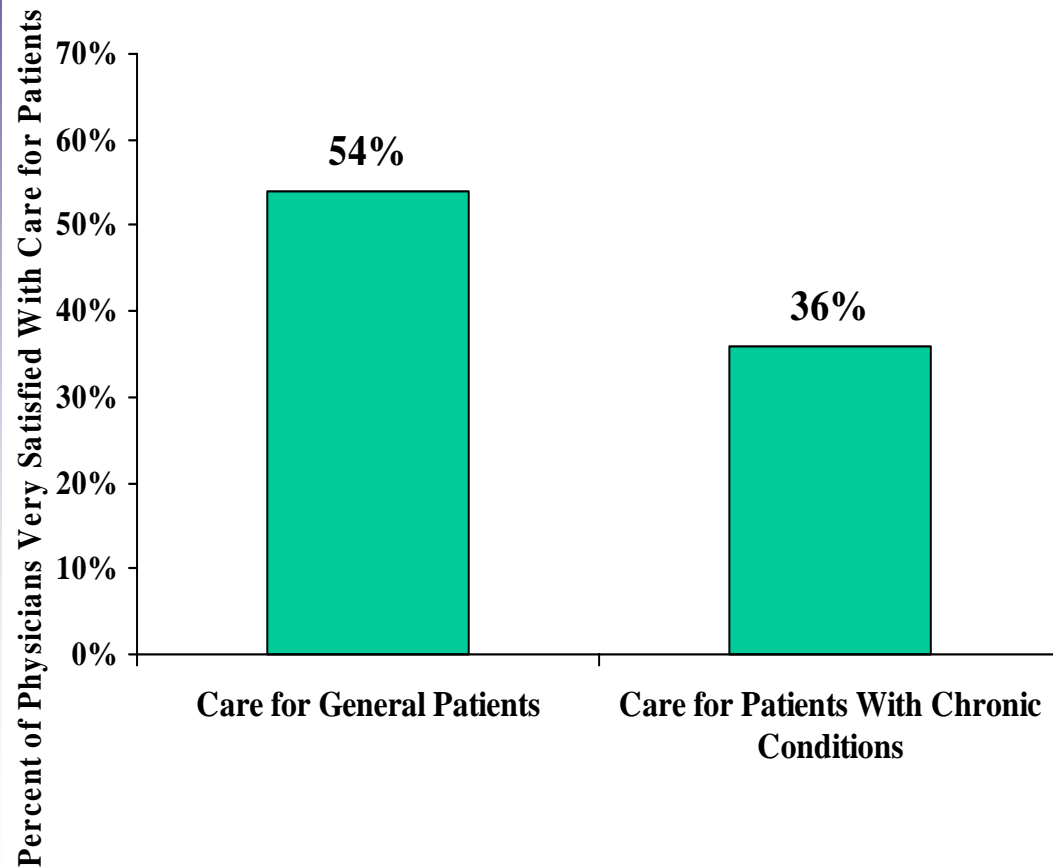


- Approximately three out of four individuals believe that access to medical services is difficult for people who have a chronic condition.
- Uncovered services and high levels of cost-sharing are two reasons why nine in 10 Americans believe that health insurance coverage is inadequate for people with chronic conditions.

Johns Hopkins University, Partnership for Solutions

Source: *Chronic Illness and Caregiving*, a survey conducted by Harris Interactive, Inc., 2000.

35. 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.

Johns Hopkins University, Partnership for Solutions

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

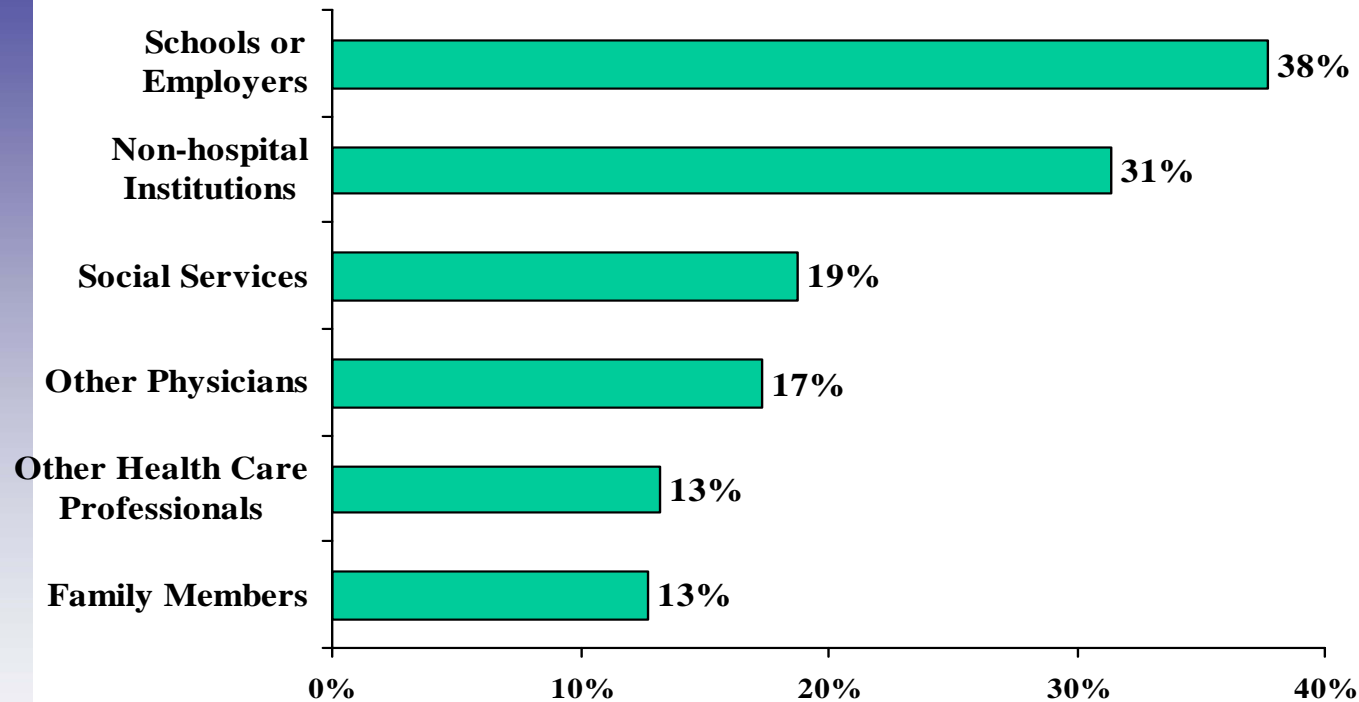
In Treating Patients with Chronic Conditions, Physicians Believe Their Training Did Not Adequately Prepare Them to:

- 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)

Johns Hopkins University, Partnership for Solutions

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

36. Physicians Report Difficulty Coordinating Care

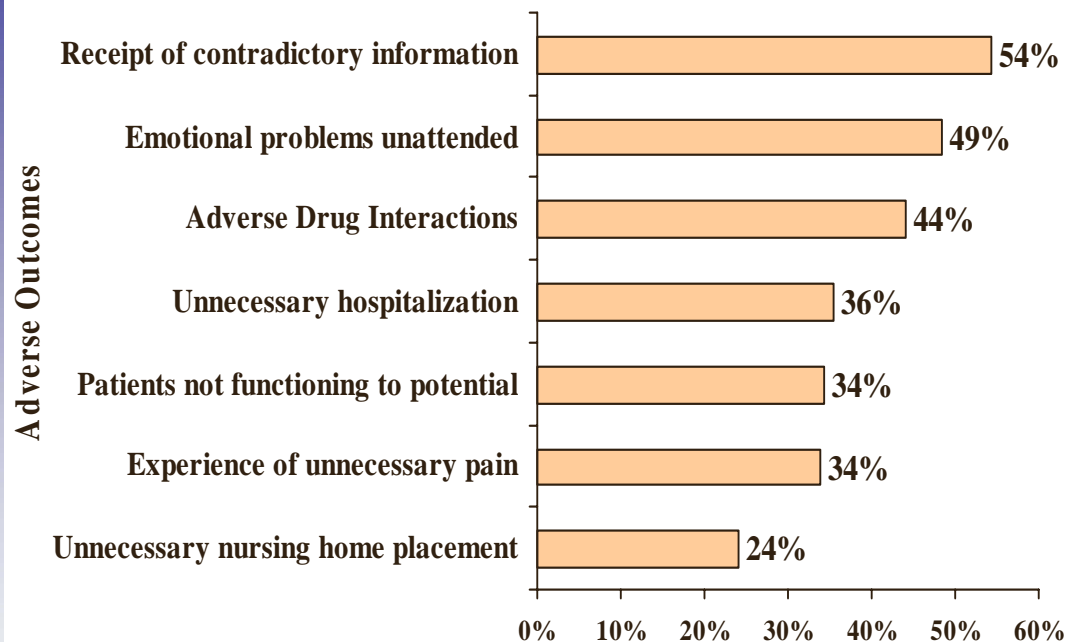


Percent of Physicians Identifying Problems Coordinating Care with Different Providers or Entities

Johns Hopkins University, Partnership for Solutions

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

37. Physicians Believe that Poor Care Coordination Produces Bad Outcomes



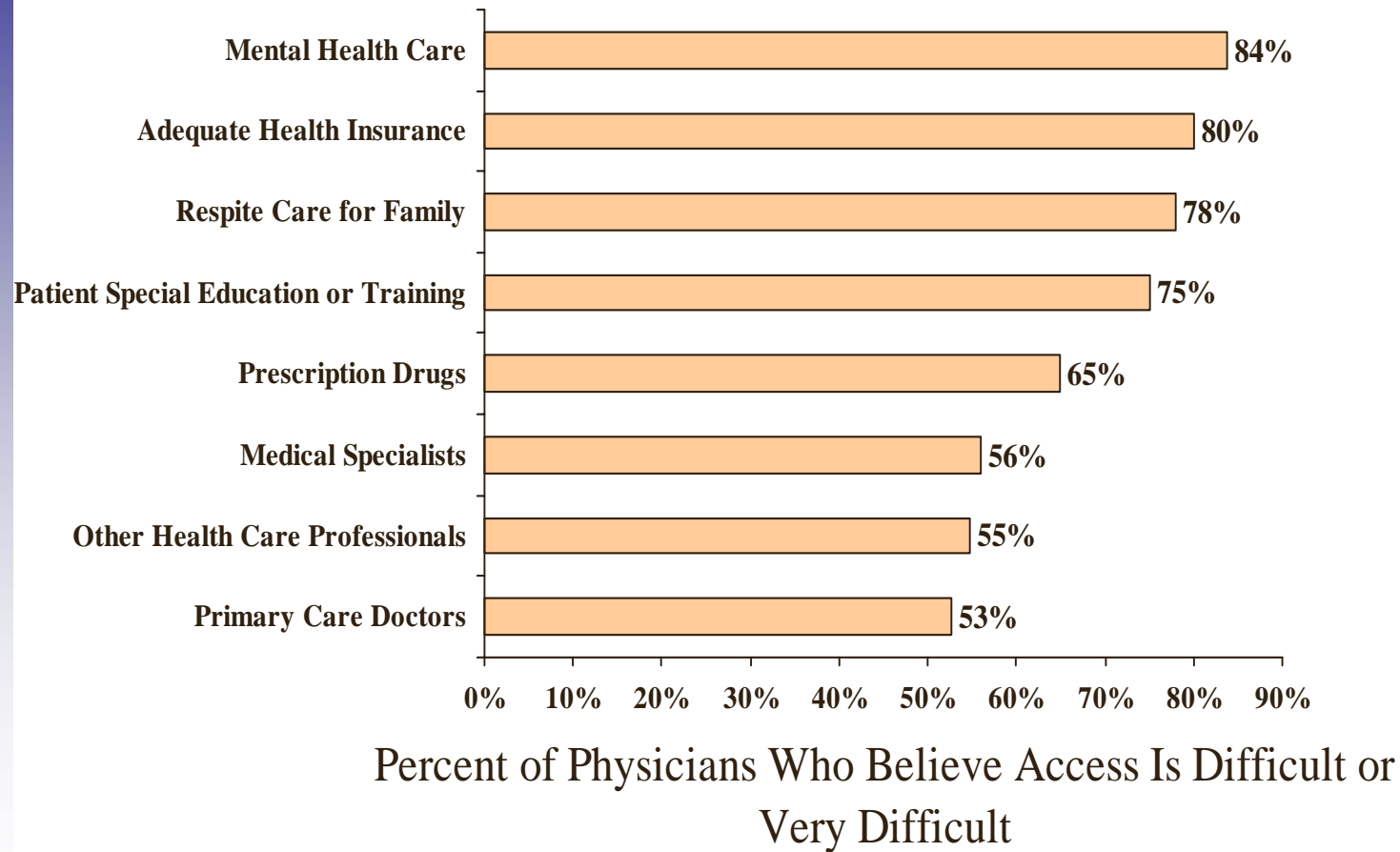
Percent of Physicians Who Believe that Adverse Outcomes Result from Poor Care Coordination

- 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.

Johns Hopkins University, Partnership for Solutions

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

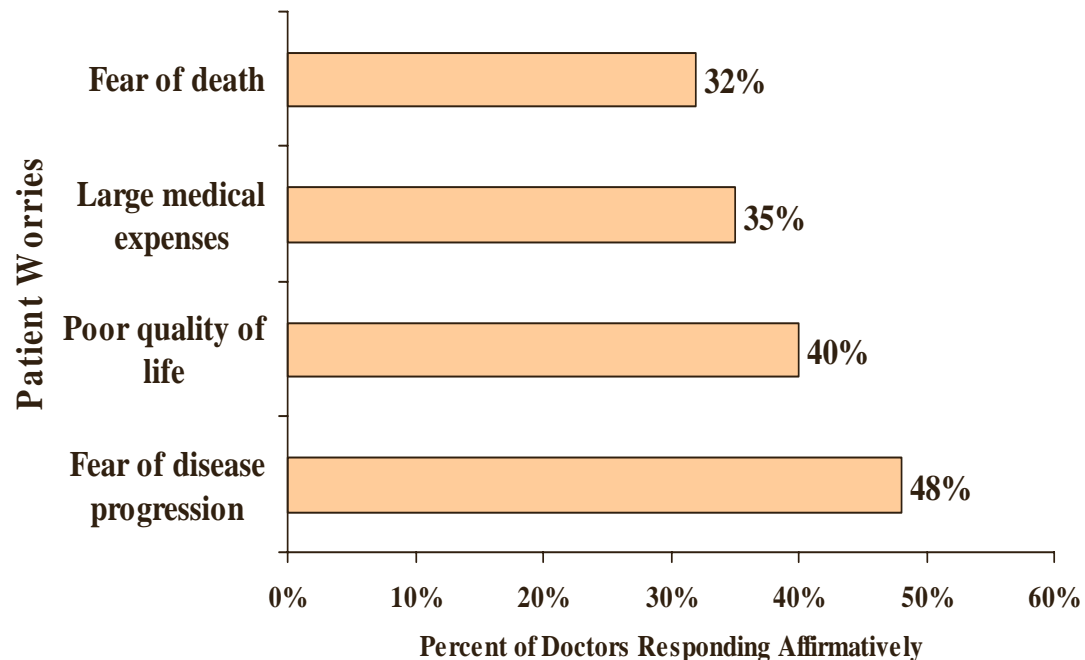
38. Physicians Believe that People with Chronic Conditions Have Unmet Needs



Johns Hopkins University, Partnership for Solutions

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

39. 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.^{a)}

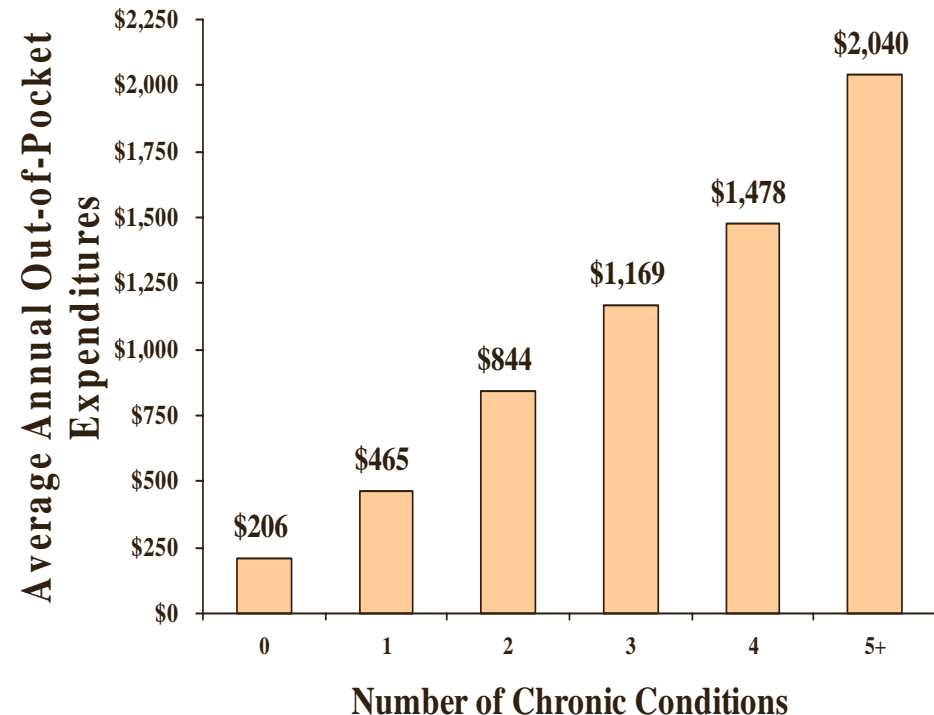
Johns Hopkins University, Partnership for Solutions

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.

40. Out-of-Pocket Health Care Spending Increases with the Number of Chronic Conditions

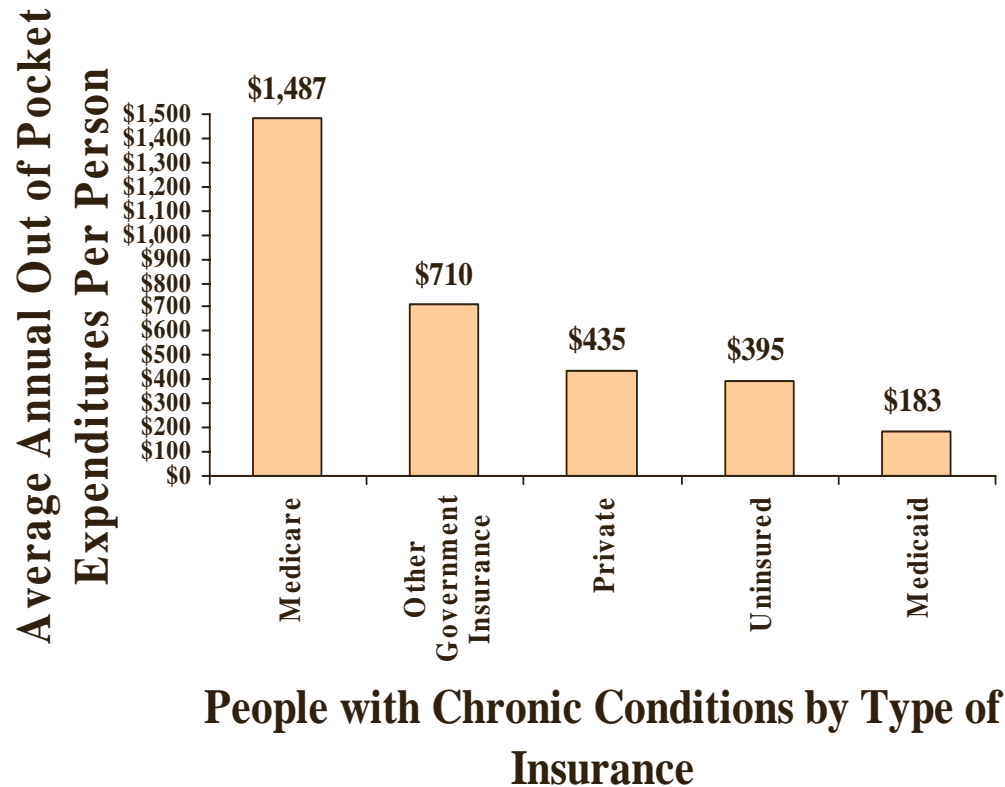
- The average annual out of pocket spending on health care for all people is \$505. The average for people with one or more chronic conditions is \$827.
- The highest average out-of-pocket expense for people with chronic conditions is prescription drugs, while people without chronic conditions spend 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.



Johns Hopkins University, Partnership for Solutions

Source: Medical Expenditure Panel Survey, 2001.

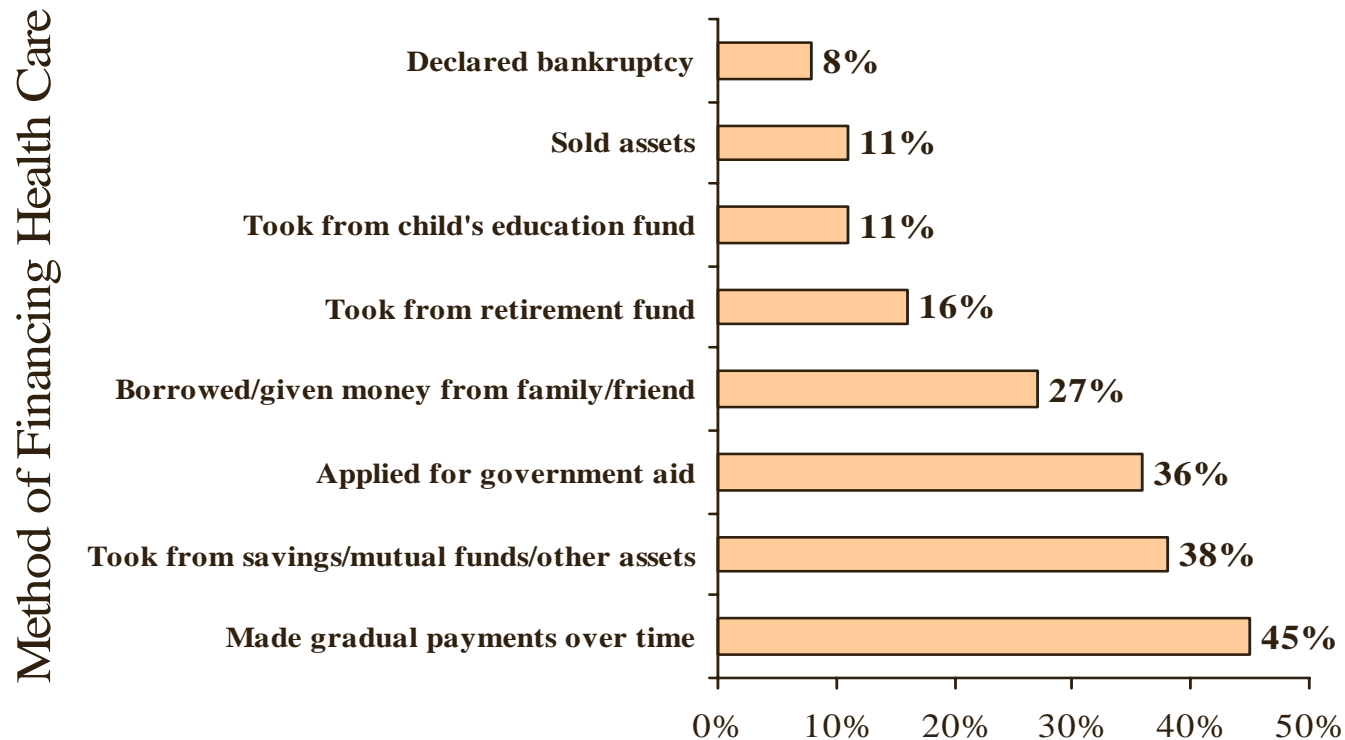
41. Out-of-Pocket Spending is Highest for People with Medicare



Johns Hopkins University, Partnership for Solutions

Source: Medicare Expenditure Panel Survey, 2001.

42. People with Serious Chronic Conditions Have Difficulty Paying for Their Health Care

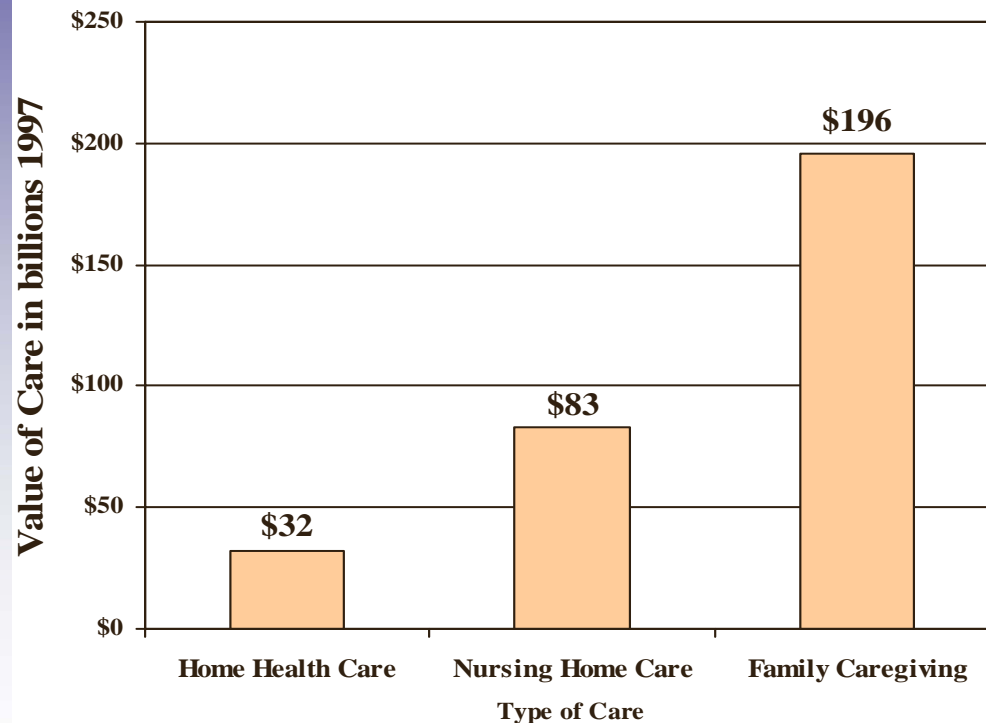


Percent of People with Serious Chronic Conditions Using This Method to Finance Health Care

Source: *Serious Chronic Illness Survey*, conducted by the Gallup Organization, 2002.

Johns Hopkins University, Partnership for Solutions

43. The Estimated Monetary Value of Family Caregiving Greatly Exceeds Spending on Formal Long-Term Care Services

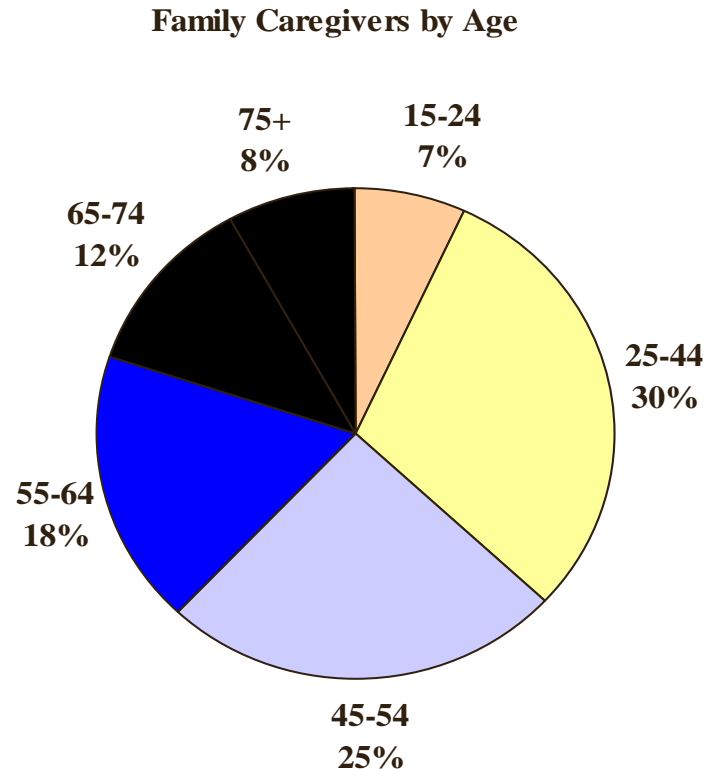


- Family caregiving includes all unpaid services provided by family and friends.
- Because of gaps in the health care system and individual family preferences, much of the care for people with chronic conditions is provided by family and friends.
- One of people's greatest concerns is that they will become a burden to family and friends when they have a chronic condition.

Johns Hopkins University, Partnership for Solutions

Source: Arno, P.S., Levine, C., and Memmott, M.M., "The Economic Value of Informal Caregiving," *Health Affairs* 18: 2, March/April 1999.

44. Informal Caregiving is a Multigenerational Task



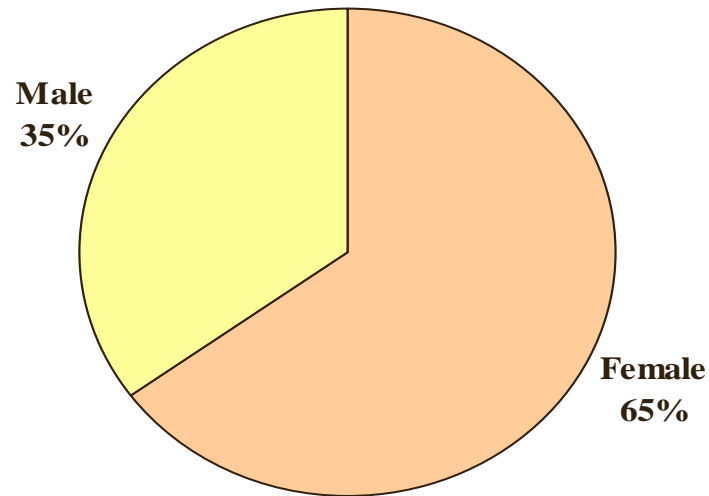
- Today, 9.4 million Americans of all ages provide care to relatives and friends.
- Thirty-eight percent of those providing care are 55 years of age or older.
- Sixty-five percent of family caregivers are women (not shown).

Johns Hopkins University, Partnership for Solutions

Source: Alexih, 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.

45. Family Caregivers by Gender

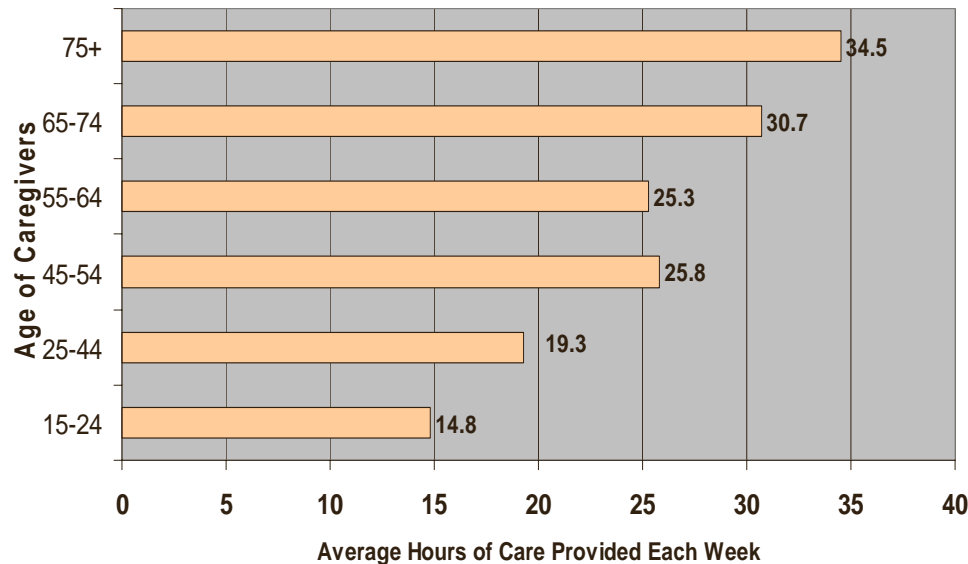
Family Caregivers by Gender



Johns Hopkins University, Partnership for Solutions

Source: Alexih, 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.

46. The Number of Hours Dedicated to Caregiving Increases with the Age of the Caregiver



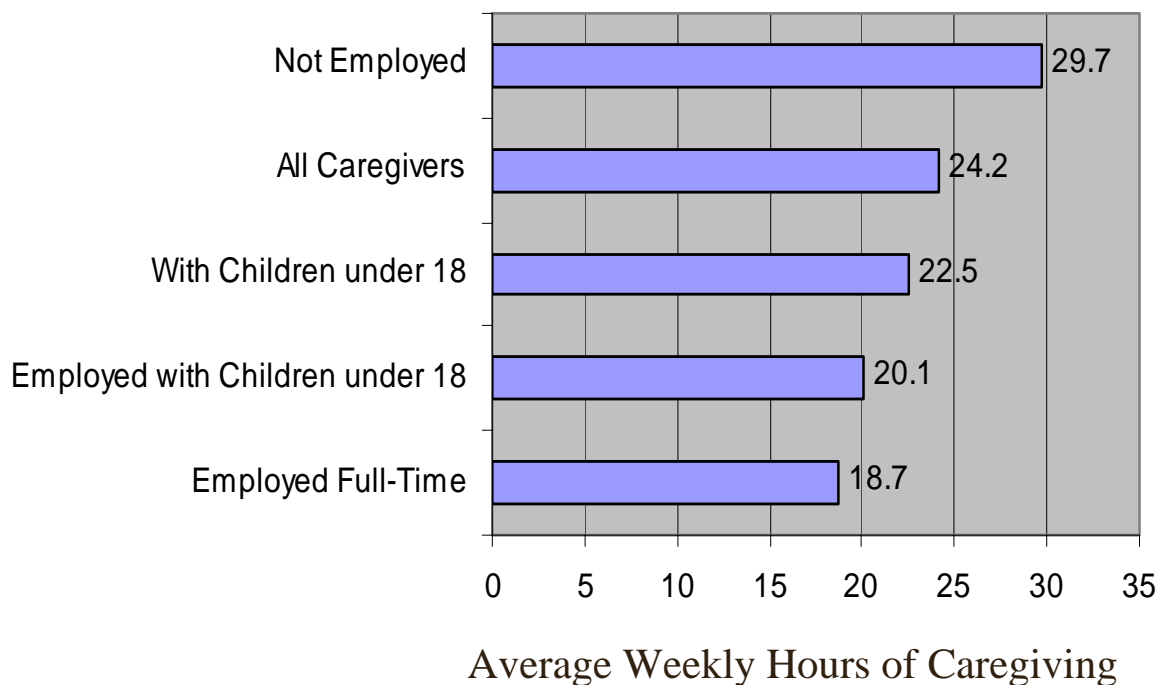
Source: Alexih, L.M.B., Zeruld, S., and Olearczyk, B.
Characteristics of Caregivers Based on the Survey of Income and Program Participation. National Family Caregiver Support Program: Selected Issue Briefs. Prepared for the Administration on Aging by The Lewin Group, July 2001.

Among family caregivers:

- Older Americans (65+) average more informal caregiving each week. They are typically retired and often caring for a spouse.
- Family caregivers that are 65 years old and older often face their own health concerns.

Johns Hopkins University, Partnership for Solutions

47. 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.

Johns Hopkins University,
Partnership for Solutions

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 devote increasing amounts of resources—both services and dollars—to care for people with chronic conditions. As a society, we need to ensure that these resources are spent as effectively and wisely as possible to maintain the health and enhance the individual functioning of this large segment of our population. There is a general recognition among patients, providers, and the public that adjustments within the health care system are needed to improve chronic care in this country.

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.

Today, as chronic conditions have begun to dominate our agenda of health care concerns, another change is in order to address the needs of people with non-acute, ongoing health care concerns. The data presented in this chartbook suggest that care provided in the current acute, episodic model is not cost-effective and often leads 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 of a new, chronic care model of financing and delivering health care services is 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. These reforms are particularly challenging to implement in an environment where service delivery has become less integrated as a result of financial arrangements that pulled together various providers into loose networks without incentives that encourage coordination among these groups. Likewise, the growing consumer preference for a less tightly managed health care system exacerbates the problem of coordinating care.

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 Continued

We can find these 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 chartbook, we define 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, 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. (See the Appendix for a list of these chronic conditions.) We applied the resulting classification applied to data from the Medical Expenditure Panel Survey (MEPS) and the Medicare Standard Analytic File. (See below 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.

Data in this chartbook was drawn from a variety of sources a few of which require some explanation. We relied heavily on the Household Component of the 2001 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. More information about the survey process and instrument can be found at www.AHRQ.gov.

The Partnership for Solutions 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.

Data Sources Continued

We have also relied on data from the 2001 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 2001. Total spending represented by the sample will not total to all Medicare spending in 2001 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 chartbook since most of it is not for beneficiary-specific services.

We also use 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. 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.

Another data source used in developing our chartbook is The Lewin Group's analysis of the 1996 Survey of Income and Program Participation (SIPP) data for characteristics of family caregivers (those who provide care to family and friends without remuneration). This survey identifies and interviews self-reported caregivers to people in need of assistance with daily activities due to a disability or long-term illness (routine child care was not part of the caregiver identification). This sample results in a lower estimated number of caregivers nationally than other surveys of caregiving in the U.S. However, the reported average hours of caregiving provided is slightly higher than that derived from several other surveys. This may, in part, result from interviewing the caregivers directly rather than the recipients of care as is done in those other surveys.