

Physician, Public, and Policymaker Perspectives on Chronic Conditions

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Background: Chronic conditions are the leading reason why people seek medical care, yet the current financing and delivery system has been criticized for not promoting ongoing care. The perceptions of physicians, policymakers, and the general public were compared on how well the current system addresses the needs of people with chronic conditions.

Methods: National surveys of 1238 physicians and 1663 Americans and a convenience sample of 155 policymakers were compared. All 3 groups were given the same definition of a chronic condition and asked similar questions.

Results: There was strong agreement that chronic medical conditions affect men and women of all ages, ethnicities, and income levels (>90% strongly or somewhat agree). However, compared with the public and physicians, policymakers were less likely to respond that people

with chronic conditions usually receive adequate medical care, that health insurance pays for most needed services, or that government programs are adequate. The public was most positive about the current system and policymakers the least. A majority of all 3 groups agreed that it is somewhat or very difficult for people with chronic conditions to obtain adequate care from primary care physicians, medical specialists, and other health care professionals.

Conclusions: A majority of physicians, policymakers, and the general public are concerned that the current health care system is not addressing the needs of people with chronic conditions. Changes in how medical care is financed and delivered are necessary to respond to these concerns.

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A MAJOR CHALLENGE to the medical care system of the 21st century will be to provide appropriate care to the growing number of individuals with chronic conditions. Between 2000 and 2020, the number of Americans with chronic conditions is projected to increase from 125 million to 157 million, and the number of Americans with 2 or more chronic conditions is projected to increase from 57 million to 81 million.¹ People with chronic conditions accounted for more than 78% of health expenditures in 2000, and this percentage is projected to increase in the coming decades.^{1,2} Chronic conditions are now the leading reason why people seek medical care in the United States, yet it has been suggested that the current medical care financing and delivery system is still more oriented to providing episodic than ongoing care.³⁻⁹

Although there is a growing body of analysis that concludes that the medical care system is not oriented to provide the best

care and treatment for people with chronic conditions, it is important to understand how key stakeholders perceive the current health care system and whether they believe the medical care system is meeting the needs of people with chronic conditions. The perceptions of key stakeholders—physicians, the general public, and policymakers—could have a major influence on how rapidly the health system changes. The degree of agreement among these key stakeholders could also be an important predictor of change. There have been relatively few studies of physicians or the general public on the topic of chronic conditions, and most of these have focused on a specific chronic illness.¹⁰⁻¹² We did not identify any surveys of policymakers to assess their perceptions of how well the current system is addressing chronic illness. To elicit their concerns and preferences, we asked physicians, the public, and policymakers a series of questions about the current status of chronic illness care in the United States. We wanted to determine whether there is general agreement on the extent of the prob-

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lem and their level of agreement on potential solutions. Agreement on the extent of the problem and specific solutions will be important if medical care policies as well as financing and delivery systems are going to change to respond to the needs of the growing numbers of Americans with chronic conditions.

METHODS

PHYSICIANS

A nationally representative, random sample of 1741 physicians was identified from the American Medical Association Master File database. Eligibility was limited to physicians who provided direct patient care for at least 20 hours a week and who were not residents or fellows. Primary care practitioners were oversampled so that they would compose half of the final sample. A 15-minute telephone survey was administered to the 1238 physicians (71% who agreed to participate. Nonresponse and poststratification adjustment procedures were used before assigning the final weights.¹³ The concept underlying nonresponse adjustments is to find groupings of physicians that respond with a similar probability and to compute an adjustment value for each of these groupings. This reduces the bias associated with nonresponse patterns (ie, more difficulties in locating certain categories of physicians). Survey results were then weighted so as to represent all physicians providing at least 20 hours of direct patient care per week who are currently practicing in the United States. The survey was administered by Mathematica Policy Research, Inc, Princeton, NJ, from November 1, 2000, through June 30, 2001.

AMERICAN PUBLIC

A nationally representative sample of 1663 Americans was interviewed by means of random-digit dial procedures.¹⁴ The telephone survey consisted of 51 questions and required approximately 15 minutes. The adult (aged 18 years or older) household member with the most recent birthday was identified and asked to participate. Eligibility was limited to English and Spanish speakers. The survey results were weighted according to age, sex, race, level of education, and income so that the sample would be representative of the US public with regard to those attributes. The survey was administered by Harris Interactive Inc, New York, NY, from March 1 through November 30, 2000. Efforts were made to increase the response rate and to encourage participation. The overall response rate to the household survey was 54%, which has been cited by other researchers as an acceptable rate for a random-number telephone survey.¹⁵⁻¹⁸

POLICYMAKERS

A convenience sample of 155 health policymakers, predominantly in the Washington, DC, area, was interviewed by telephone in fall 2000.¹⁹ The polling firm Lake Snell Perry & Associates, Inc, Washington, DC, conducted the interviews. The policymakers were employed by Congress, the Executive Branch, state governments, policy organizations, and advocacy groups. Nearly all policymakers contacted agreed to participate; however, because it was a convenience sample, no response rate could be calculated.

MEASUREMENTS

There are several ways to define a chronic condition.²⁰ In an attempt to standardize the definition for all respondents, participants in each survey were given the following definition of

a chronic condition: "a condition that has lasted or is expected to last a year or longer, limits what one can do, and may require ongoing care." This definition served as the basis for all subsequent questions regarding knowledge, attitudes, and perceptions of chronic conditions.

Survey items were generated on the basis of focus groups. The focus groups included a cross section of adult Americans, adult Americans with specific chronic conditions, caregivers of individuals with chronic conditions, policymakers, and physicians. On the basis of items generated through the focus groups, respondents were asked a series of questions in the following 3 areas: (1) knowledge regarding the prevalence, cost, and types of major chronic conditions in the United States today and in the future; (2) perceptions regarding the characteristics of persons with chronic conditions as well as the adequacy of the health care system to finance and deliver care to persons with chronic conditions; and (3) personal attitudes and concerns regarding chronic conditions. A 5-item Likert-type response scale was used to measure perceptions and attitudes (eg, strongly agree, somewhat agree, somewhat disagree, strongly disagree, not sure). For some questions, response categories were collapsed in the final tables (for example, "strongly agree" and "somewhat agree" responses were combined). Some of the questions were asked of only 2 of the 3 groups.

In one of the open-ended questions, individuals were asked their "3 major worries about having chronic illness." Physicians were asked, "What are your patients' 3 biggest worries about having a chronic illness?" The responses were then coded by the interviewing firms (Mathematica Policy Research, Inc, and Harris Interactive Inc) into a common set of precoded responses based on answers given by focus groups. Responses not on the precoded list were also recorded. The Johns Hopkins Bloomberg School of Public Health Institutional Review Board, Baltimore, Md, approved all 3 surveys.

RESULTS

CHARACTERISTICS OF RESPONDENTS

Of the 1238 physicians responding to the survey, 74% were male, 76% were white, 12% were Asian, 5% were black, and 7% were Hispanic or other. Of the respondents, 51% were primary care physicians and 49% were specialists. The mean number of patient visits during an average week was 104. Physicians were asked to state the prevalence of chronic conditions among their patients. Eighteen percent of physicians reported that fewer than 20% of their patients had a chronic condition, 38% of physicians reported a prevalence between 20% and 59%, and 42% of physicians reported that 60% or more of their patients had a chronic condition.

Of the household survey respondents, 52% were female and 48% were male, 32% were aged 18 to 34 years, 51% were aged 35 to 64 years, and 16% were 65 years or older. Among respondents, 38% reported that they had a chronic condition, 16% reported that a family member residing with them had a chronic condition, and 14% reported that they currently provided unpaid care to help a relative or friend with a chronic condition.

The policymakers were employed by various organizations, including think tanks and advocacy organizations (34%), the Executive Branch of government (23%), physicians' and nurses' organizations (13%), business and insurance organizations (12%), congressional staff (6%), and other organizations, including voluntary health or-

ganizations, media, caregiver organizations, unions, and religious organizations (12%). Of the 155 respondents, 120 were located in the Washington, DC, metropolitan area. The 2 most common professions were health policy analyst (34%) and administrator (29%). The 3 most common places of work were federal government (27%), health care association (23%), and state government (17%). The respondents were 40% male and 60% female, with a median age of 48 years. Among the 155 policymakers, 24% reported that they currently provided unpaid care to help a relative or friend with a chronic condition, 26% reported that they had a chronic condition, 34% reported that a family member residing with them had a chronic condition, 56% reported having an immediate family member not residing with them who had a chronic condition, and 65% responded that it was very likely they would be responsible for someone with a chronic condition at some time in the future.

PERCEPTIONS OF PREVALENCE OF CHRONIC CONDITIONS

Physicians and the public were asked the following question: "What percent of Americans would you say have some type of chronic medical condition?" The distribution of responses to the question about prevalence is shown in **Table 1**. The public showed a wide range of responses to the question, with 25% of the respondents believing it was 20% or less and 12% believing it was 61% or greater. The distribution of physicians was similar, with 30% of physicians believing it was 20% or less and 9% of physicians believing it was 61% or greater. The mean response for the public was 36% and for physicians it was 35%. The median response for the public was 31% and for physicians it was 30%.

We then asked both groups if they believed the percentage would increase, decrease, or remain the same in the next 10 years. Physicians were more likely than the public to respond that the percentage would increase; 91% of physicians responded that the percentage would increase, compared with 66% of the public. Thirteen percent of the public anticipated a decline in the percentage of the population with a chronic condition, compared with only 1% of physicians. The public was more likely than physicians to believe that the percentage of people with chronic conditions would remain constant (18% vs 8%). Three percent of the public was unsure of the trend.

MAJOR WORRIES ABOUT HAVING A CHRONIC CONDITION

We asked the public to list their 3 major worries about having a chronic condition and asked physicians their perceptions of their patients' 3 major worries about having a chronic condition (**Table 2**). The public was most concerned about not being able to afford needed medical care and having large medical expenses. A comparison of physicians' responses with the public's responses suggests that physicians were well aware of the public's concerns about the cost associated with having a chronic condition. There were, however, important differences in the relative rankings.

Table 1. Response to Question About Prevalence of Chronic Conditions

Prevalence, %	% of Responses	
	Public*	Physician†
0-20	25	30
21-40	37	40
41-60	20	21
61-80	9	8
81-100	3	1
Not sure	6	0

*Harris Interactive Inc survey of 1663 Americans, conducted in 2000.

†Mathematica Policy Research, Inc, survey of 1238 physicians, conducted in 2001.

Table 2. Responses to Question About the 3 Major Worries About Having a Chronic Condition

	% of Responses	
	Public Concerns*	Physician Perceptions of Public Concerns†
Not being able to afford needed medical care	25	31
Losing independence	22	18
Being a burden to family or friends	21	14
Fear of death or dying	13	32
Not getting adequate care or finding good care	13	13
Not being able to take care of family	9	1
Having large medical expenses	7	35
Not being able to work	7	3
Giving up enjoyable things (eg, hobbies)	7	14
Being in pain	5	22

*Harris Interactive Inc survey of 1663 Americans, conducted in 2000.

†Mathematica Policy Research, Inc, survey of 1238 physicians, conducted in 2001.

The public appeared to be more concerned about quality-of-life issues such as losing independence, being a burden to family and friends, not being able to take care of their family, and not being able to work than physicians perceived they are. On the other hand, physicians believed that the public is more concerned about clinical aspects, such as death and being in pain, than the public reported that they actually are. Perhaps most surprising, however, is that the second most common response on the physicians' list did not appear anywhere on the public's top 10 list. According to physicians, fear of progression, paralysis, or incapacitation (reported by 46% of all physicians) is a major concern of their patients. The response given by the public that was closest to fear of progression, paralysis, or incapacitation was not wanting to be on a life support system or loss of self-control. Together they represent less than 1% of the public's responses.

Table 3. Agreement With Statements About Chronic Conditions

	% of Respondents Who Strongly or Somewhat Agree		
	Public*	Physicians†	Policymakers‡
Chronic medical conditions affect men and women of all ages, ethnicities, and income levels	91	94	NA
Chronic medical conditions nearly always limit a person's ability to work or attend school	65	52	24
The cost of caring for people with chronic medical conditions accounts for most of medical spending in this country	63	79	60
The poor are more likely than others to have chronic medical conditions	51	NA	71
People with chronic medical conditions usually receive adequate medical care	48	45	22
Most people who have chronic medical conditions are elderly	47	NA	28
Government programs are adequate to meet the needs of people with chronic medical conditions	38	20	16
Health insurance pays for most of the services chronically ill people need	37	28	23

Abbreviation: NA, not available.

*Harris Interactive Inc survey of 1663 Americans, conducted in 2000.

†Mathematica Policy Research, Inc, survey of 1238 physicians, conducted in 2001.

‡Lake Snell Perry & Associates, Inc, survey of 155 policymakers, conducted in 2000.

Table 4. Perception of Difficulty for People With Chronic Conditions to Obtain Certain Services

	% of Respondents Answering Very or Somewhat Difficult to Obtain		
	Public*	Physicians†	Policymakers‡
Adequate health insurance	89	76	89
Care they need from medical specialists	79	56	74
Help from family to manage their care at home	78	76	74
Prescription medicines they need	74	67	80
Care from primary care physicians	73	51	65
Care from other health professionals (such as social workers or therapists)	72	54	85

*Harris Interactive Inc survey of 1663 Americans, conducted in 2000.

†Mathematica Policy Research, Inc, survey of 1238 physicians, conducted in 2001.

‡Lake Snell Perry & Associates, Inc, survey of 155 policymakers, conducted in 2000.

PUBLIC POLICY CONCERNS ABOUT CHRONIC CONDITIONS

We asked physicians, the public, and policymakers their level of agreement with a series of statements about chronic conditions. **Table 3** shows the percentage of respondents who reported that they strongly or somewhat agreed with each statement. More than 90% of physicians and the public somewhat or strongly agreed with the statement that medical conditions affect men and women of all ages, ethnicities, and income levels. At least 60% of physicians, the public, and policymakers somewhat or strongly agreed that the cost of caring for people with chronic medical conditions accounts for most medical spending in this country. There is less agreement on

other statements. For example, a majority of the public, physicians, and policymakers somewhat or strongly disagreed with the statements that government programs are adequate to meet the needs of people with chronic medical conditions and that health insurance pays for most of the services chronically ill people need.

While generally there was good agreement among physicians, the public, and policymakers on certain issues, particular attention should be given where there were differences among the 3 groups. Compared with the public and physicians, policymakers were more pessimistic about the current system. Policymakers were less likely to believe that people with chronic conditions usually receive adequate medical care, that health insurance pays for most needed services, and that government programs are adequate. Compared with policymakers and the public, physicians were more aware that the cost of treating chronic conditions accounts for most health care spending. Generally, the perceptions of physicians were intermediate between those of the public and policymakers. It is somewhat surprising that the general public was the most positive about the ability of the current system to treat people with chronic conditions and policymakers were generally the most pessimistic.

Policymakers, the public, and physicians were asked a series of questions about their perceptions of how difficult it is for people with chronic conditions to receive specific services (**Table 4**). There was general recognition in all 3 groups that the current health care system is not addressing the needs of people with chronic conditions. There was the greatest agreement that it is somewhat or very difficult for people with chronic conditions to receive adequate health insurance. A majority of physicians, policymakers, and the public agreed that it is somewhat or very difficult for people with chronic conditions to obtain adequate care from primary care physicians, medical specialists, and other health care professionals. Physicians were the least likely to assess that these services were somewhat or very difficult to obtain. Nevertheless, a majority of physicians reported that they believe that it is very or somewhat difficult for people with

chronic conditions to receive adequate health insurance or obtain a range of services.

COMMENT

There is a general perception among physicians, policy-makers, and the general public that it is difficult for people to receive certain services. Approximately three quarters of the public believes it is somewhat or very difficult for people with chronic conditions to obtain care from medical specialists, primary care physicians, or other health care professionals. Although physicians are less likely than policymakers or the general public to perceive difficulties, a majority of physicians still perceive problems in all 3 areas.

Studies have suggested that greater attention to coordination of care,²¹ restructuring the medical education system to emphasize ongoing care,²² changing the health insurance benefits package to cover more services used by people with chronic conditions, and restructuring the delivery system⁴ are 4 specific changes that could result in better care for people with chronic conditions. These are changes that will require time, and they should occur in tandem to be successful.

Physicians recognized that the public's major worry is that they will not be able to afford medical care when they develop a chronic condition. More than three quarters of physicians and the public and almost 9 in 10 policymakers agreed that obtaining adequate health insurance is difficult for people with chronic conditions. Studies demonstrate that health benefits are generally more oriented toward the provision of episodic, not ongoing, care.²³ Changes in health benefits will be necessary if coverage is going to be designed to meet the needs of people with chronic conditions.

In the Medicare program, for example, 82% of beneficiaries older than 65 years have a chronic condition and 65% have multiple chronic conditions.²⁰ However, the Medicare benefit package does not provide prescription drugs or extended nursing home or home health services, 3 services used disproportionately by those with chronic conditions.²⁴ Some of the medical necessity decisions made by the Medicare program terminate benefits once the Medicare beneficiary stops improving. This can deny coverage for services designed to slow the progression of chronic conditions or maintain the current level of functioning. Co-insurance amounts can be especially onerous for beneficiaries with chronic conditions, since they are likely to be the heaviest users of medical services.²⁵ The level of dissatisfaction by the public, physicians, and policymakers suggests that a careful examination of how current benefit packages are meeting the needs of people with chronic conditions is warranted. Both public and private health insurance benefit packages warrant scrutiny.

All 3 groups recognized that it is difficult to obtain help from the family to manage care at home. Given that the home is where most people with chronic conditions prefer to obtain care,¹⁴ survey results suggest that an expansion of home and personal care services by public and private insurers may be received favorably. When the general public was asked if they would be willing to pay \$250 in higher taxes to provide tax incentives for people who

provide unpaid care to old, frail, or disabled family members, 27% of the public were very willing and 54% were somewhat willing to pay the higher taxes.¹⁴ In most states, the Medicaid program offers relatively generous benefits for home care services including transportation services. In contrast, the Medicare program offers relatively sparse benefits; home health care services are limited by the patient's need for skilled medical care and by the patient being homebound.

While there was general agreement between the public and physicians about the public's major concerns, a comparison of the survey results suggest that physicians should become more aware of specific worries held by the public about chronic conditions. The public appears to be more concerned about certain quality-of-life aspects associated with chronic conditions, including losing independence, becoming a burden to family and friends, and not being able to work, than most physicians perceive. In addition, the public appears to be more concerned about obtaining adequate access to care (health insurance, care from generalist and specialist physicians, prescription drugs, etc) than physicians are.

When a broad definition of chronic conditions has been used to determine the prevalence of chronic conditions in the United States, the range is from 38% to 45%.^{1,2,20} In the 3 surveys analyzed herein, a broad definition of a chronic condition was provided to the respondents. The mean and median estimates of the percentages of Americans with a chronic condition given by both the public and physicians was slightly lower than published estimates, suggesting that the majority of the public and physicians are aware of the prevalence of chronic conditions in the United States. However, as shown in Table 1, both the public and physicians gave a wide range of estimates of the percentage of Americans with chronic conditions. This could be the result of different perceptions of what constitutes a chronic condition. While both surveys attempted to provide each respondent a common definition of a person with a chronic condition, the respondents may have applied their own definition. Alternatively, many physicians and members of the public may not be well informed of the actual prevalence of chronic conditions. Their own experiences may have influenced their estimates.

Studies have projected that the prevalence of chronic conditions will increase in the coming decades, although there is evidence that the prevalence of disability may be declining.²⁵ Although two thirds of the public believe the prevalence of chronic conditions will increase in the next 10 years, some members of the public may be confused by the distinction between *disability* and *chronic condition*. Physicians appear to be more in agreement with the projections that the percentage of chronic conditions will increase in the coming decades.

More than three quarters of the respondents in each of the 3 groups responded that chronic conditions affect all ages, ethnicities, and income levels and that most of health care spending is for people with chronic conditions. Available data suggest that both of these perceptions are correct.²⁶

The survey results should be interpreted with some caution. Although the response rates to the physician and

public surveys are within professional norms, there were considerable numbers of nonrespondents. Statistical techniques were used to adjust for nonrespondents. The policymaker survey was a convenience sample and therefore cannot be stratified, nor can one extrapolate. The survey responses do not identify specific changes to the current system that the respondents would prefer, and therefore specific modifications to the current system that could be undertaken cannot be discussed.

CONCLUSIONS

At the beginning of the 20th century, the health care system focused on treating infectious diseases. By the middle of the 20th century, most of the attention and innovation focused on the treatment of acute episodes. Health insurance systems developed, medical education curriculum were formulated, delivery systems were organized, and payment systems developed around the treatment of acute episodes. One reason why Americans are living longer is that the medical care system has become more proficient at treating infectious diseases and acute episodes. Unfortunately, as they grow older, they are more likely to develop chronic conditions. The survey results suggest that the public, physicians, and policymakers are well aware of the shortcomings of the current system. A challenge of the 21st century will be to reorganize the medical care system around the treatment of chronic conditions and especially those with multiple chronic conditions.

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