



Chronic Care in America™



Improving the Patient-Physician Interaction

Findings from a
comprehensive survey
in the U.S.

June 2003

 HarrisInteractive®

 GlaxoSmithKline

Advisory Board

Chronic Care in America™, funded by GlaxoSmithKline, is a comprehensive study that Harris Interactive conducted between November 11 and December 23, 2002. A national advisory board of experts consulted on the survey with GlaxoSmithKline to find day-to-day solutions to the growing health concerns of chronic conditions in America.

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Executive Summary

“My physician is not the sole expert on my body. It is my body and I am the expert on it. We are partners in taking care of it.”

—Patient Comment

“Probably [be] more understanding of how difficult it is to have patients change habits. I used to be less patient.”

—Physician Comment

Why study chronic illness?

GlaxoSmithKline commissioned this landmark survey to provide a current description of how individuals successfully manage chronic health conditions and how the patient-physician relationship can be optimized for success.

What Patients Told Us About Successful Chronic Care Management

Individuals with chronic conditions who consider themselves successful in managing their conditions are likely to be free of symptoms of depression and are oriented to acquiring information.

- They realize that change is difficult but that they are responsible for themselves and must make necessary lifestyle changes.
- They recognize the connection between their personal behavior and staying well, and they rely on family and friends for support.
- Additionally, they are likely to put their beliefs into action by exercising and watching their diet. They carefully monitor symptoms, keep notes with questions for their doctors and, when necessary, they demand time for answers.

To these individuals, their condition is not “chronic” but rather “long-term” and “ongoing”. Patients with chronic conditions firmly believe that their lives still have value and purpose. They also believe in being proactive and knowledgeable.

What Physicians Told Us About Treating/Becoming Partners With Patients

While patients mainly visit physicians to acquire information, physicians consider the relationship itself to be a vital component of treatment – one that can help to motivate healthy behavior.

The survey reveals that the relationship appears to work best:

- when information can be readily exchanged
- when the physician has the tools and strategies for making this happen.

Physicians who have treated chronically ill individuals over the years said that they wished they had known, at the start of their careers, that change is difficult for patients whose lifestyles are unhealthy. They also indicated that there is more to treating an illness than dispensing medications, and that getting family and friends involved is an important component to help support patients in managing their conditions. Physicians also acknowledged that there are advantages for patients who use a “team approach” of involving other doctors and services in managing their health.

Physicians recognized that chronic illness can be debilitating mentally and physically and they believe that they must attend to health behaviors when treating the patient. For this, they may require training in counseling patients. They realize that by demonstrating patience and giving encouragement they can help chronically ill individuals succeed.

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Chronic Care in America

“I wish I knew that I was in control of my therapy, that I had power to participate in discussions about my future. More than that, I had the obligation to learn all I could on my own and present my questions as one adult to another.”

—Patient Comment

Patients and Physicians Together Are Key to Managing Lifelong Conditions

The purpose of *Chronic Care in America* was to explore the dynamics of patient-physician interactions within the U.S. healthcare system. It provides an up-to-date account of how patients successfully manage chronic health conditions and how the patient-physician relationship is evolving to meet their needs.

Historically, the face of chronic illness was dramatically transformed during the 20th century. The U.S. healthcare system was originally designed to meet the needs of individuals with episodes of acute illness and infectious disease. Conversely, advances in public health and medicine significantly reduced the prevalence of infectious disease. During this time, however, older citizens became a larger part of our population, and as a person ages, the greater the likelihood of developing a long-term or chronic condition. As a result, the need for chronic care management emerged.

“Chronic health conditions” – a general term that encompasses both chronic diseases and impairments – have been a leading public health concern since the 1920s.¹ By the 1930s, community-based surveys already had begun to demonstrate the great prevalence of chronic conditions, and while less life threatening than infectious diseases, these conditions were often disabling. Since that time, physicians, patients and an emerging healthcare industry have grappled with the challenges of financing care for these individuals. During the same time though, the functional limitations of chronic conditions have not generated equal attention.

Although medical technology has improved at a tremendous rate allowing people to live longer and healthier lives, the care delivery system has made only incremental adjustments. The current healthcare model still focuses on acute illness and infectious disease and is organized primarily to meet short-term needs. Therefore, patients receiving chronic care are often forced to navigate a system that requires them to coordinate most of the care delivery functions themselves.² In many cases, patients are ill equipped with minimal knowledge, and lacking the tools necessary for managing their conditions successfully.

The current delivery system is often structured in ways that impede, rather than facilitate, beneficial patient-physician relationships. Existing payment systems rarely encourage collaboration among physicians or consistency among practice patterns for patients with chronic illness. In the U.S. healthcare system, few physicians are rewarded for quality improvement, and the substantial cost of improving care for patients with chronic illness is not sufficiently recognized. A recent article in *Health Affairs* described this inconsistency by stating, “the incentives and structure of healthcare in the United States, produces exactly what we should expect in the quality of care for chronic disease: highly variable patterns of care and widespread failure to implement evidence-based practices”.³ Effective chronic care management requires productive collaboration between physicians and patients enabling patients to play active roles in the management of their conditions.

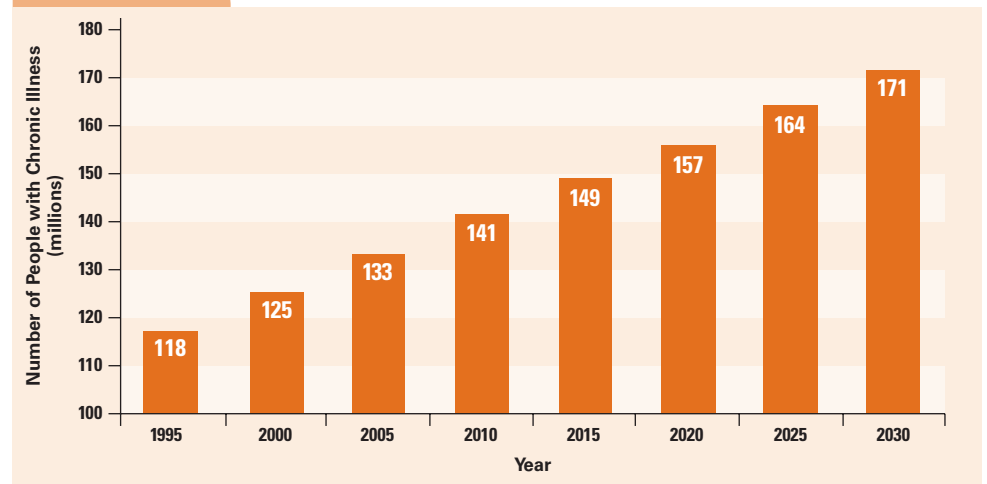
Section I

Chronic Care in America *continued*

Increasing Prevalence and Cost of Chronic Conditions

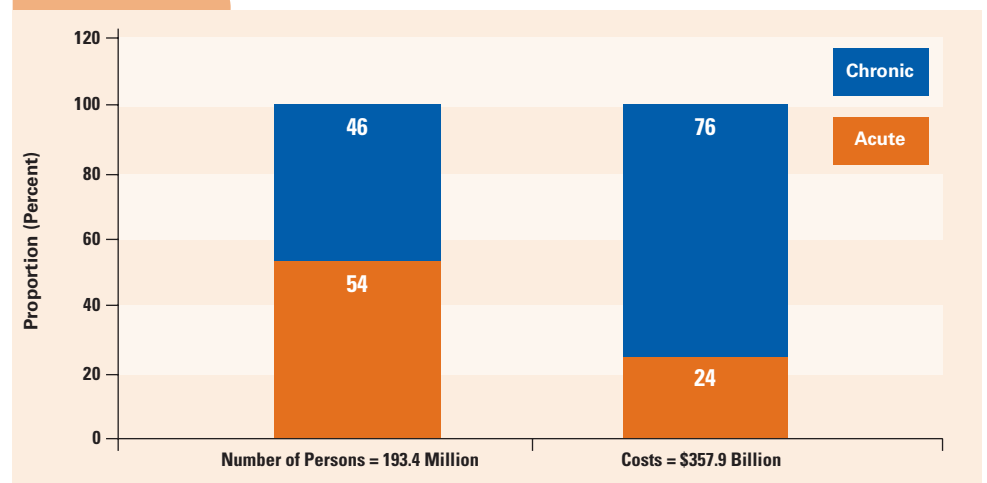
Both the prevalence and cost of treating chronic conditions is increasing dramatically. In 2000, 125 million of 276 million people (45 percent of the population) living in the United States had some type of chronic illness.⁴ Seventy-five percent of all health expenditures went to care for these individuals. By 2020, a projected 157 million Americans will have one or more chronic condition accounting for 80 percent of all health spending,²

FIGURE 1 The Number of People with Chronic Conditions is Rapidly Increasing



Adapted from: Wu, S. & Green, A., Projection of Chronic Illness Prevalence and Cost Inflation. Rand Corporation. 2002.

FIGURE 2 Acute and Chronic Proportions: Persons vs. Healthcare Expenditures, 1987



Adapted from: Hoffman, C., Rice, D. & Sung, H., Persons with chronic conditions: their prevalence and costs. *JAMA*, 1996;276 (18):1473-1479.

Section I

Chronic Care in America *continued*

While more than 45 percent of the population experience some type of chronic condition, four particular conditions – asthma, depression, diabetes and congestive heart failure – affect nearly half of all Americans with chronic conditions. Asthma, depression and diabetes each affect about 15 million Americans while an additional five million suffer from congestive heart failure. In 1999, these four conditions were directly responsible for 140,000 deaths in the United States and generated at least \$173 billion in medical and other costs. The quality of the care these individuals received, combined with their ability to manage their conditions, raises new concerns. In fact, recent studies have indicated that fewer than half of U.S. patients with asthma, depression and diabetes receive appropriate treatment.⁴

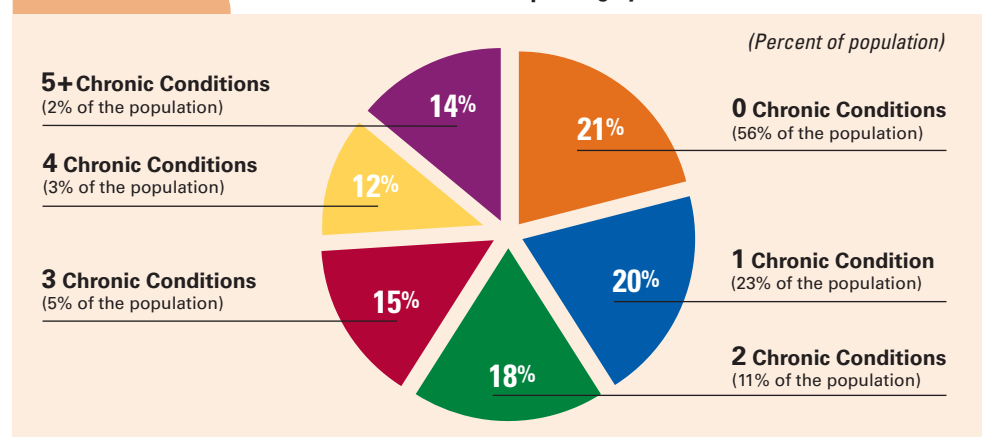
Many people are experiencing more than one chronic condition. Of the 125 million with long-term illnesses, 44 percent have comorbid conditions to manage.¹ According to Hoffman and Rice, managing more than one chronic condition affects over one-quarter of young adults, roughly half of middle-aged adults and 69 percent of the elderly.

TABLE 1 Burden of Chronic Illness in the United States

Chronic Conditions	Mean Total Medical Costs Per Year (\$)	Percent Hospitalized Annually	Mean Number Physician Visits Per Year	Mean Number Prescriptions Per Year	Percent Working or in Full-time Education
None (141 million people)	1,102	3.4	1.7	2.2	81.2
One (87.8 million people)	4,107	7.6	4.6	11.0	74.7
Three or more (22.3 million people)	7,195	17.3	9.4	28.3	47.9

Adapted from: Anderson, G. & Knickman J.R., Changing the chronic care system to meet people's needs. *Health Aff.* 2001:20 (6):146-160.

FIGURE 3 Percent of Total Healthcare Spending by Number of Chronic Conditions



Adapted from Medical Expenditure Panel Survey. 1998.

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Chronic Care in America

continued

“You must keep reading about your condition yourself and discuss it with your doctor. You have more time to be concerned about YOU than anyone else.”

—Patient Comment

Based on Table 1, as the number of chronic conditions that a patient must manage increases, the costs associated with care rise dramatically. As an individual progresses from experiencing one chronic condition to developing three or more, his or her mean total medical costs increase by 75 percent or from \$4,107 to \$7,195 per year. In addition, the number of hospitalizations increased by 127 percent, the mean number of physician visits per year by 104 percent and the mean number of prescriptions per year by 157 percent.

Clearly, individuals with multiple chronic conditions are frequent users of healthcare services as shown in Figure 3. Making up 21 percent of the total U.S. population, they are responsible for 59 percent of total healthcare spending – more than double their share of all American people.

The expense associated with chronic conditions encompasses more than healthcare dollars. Premature deaths of employees from chronic conditions represent a dual loss – for workforce and the economy. In 1990, more than three-quarters of all deaths were due to chronic conditions totaling \$161.3 billion, an average of \$98,304 per death.¹

Why Does Chronic Care Cost More Now Than Previously?

The short answer is that chronic conditions are now diagnosed more frequently, and earlier. Advanced medical technology, diagnostic and treatment procedures, and pharmaceuticals have allowed people to live longer. Earlier diagnoses give patients the opportunity to make lifestyle and treatment adjustments that can help to slow the progression of illness. And treatments cost money.

From 1900-1997, life expectancy for men increased from 46 years to 74 years and from 48 years to 79 years for women.⁵ These figures contributed to a population shift in age distribution. The number of persons older than 65 increased 12 percent between 1900 and 2000.⁶ Future projections indicate that the proportion of the population aged 65 and over could increase from 12.4 percent in 2000 to 19.6 percent in 2030. Stated another way, there were 35 million persons aged 65 and over in 2000, a number that is projected to reach 71 million by 2030. Persons aged 80 years and over experience a disproportionate rate of chronic conditions and also have the highest rates of comorbidity. Their numbers are also projected to increase substantially – from 9.3 million in 2000 to 10.5 million in 2030.

Chronic Care: A New Paradigm

Chronic conditions tend to be influenced by behavioral risk factors, requiring a shift away from the traditional medical model that focuses on pathogens and disease processes. Diet, exercise, tobacco use and exposure to environmental triggers are all behaviorally mediated to varying degrees. Health professionals, including physicians, often receive little formal training on managing these kinds of concerns despite the

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continued

clear influence they may have on chronic conditions. The burden of management falls more directly on the patient, who must frequently adopt lifestyle modifications. Added to this burden of self-management is the psychological departure from the traditional “sick” role of the acutely ill patient whose care stems directly from institutional-management.

In addition to significant demographic changes and technological advances, the way people access medical care has shifted. Patients are no longer passive recipients of care, and they increasingly want to take an active role in the management of their conditions. With the advent of the Internet, patients are able to research physician quality, specific symptoms and treatment, as well as pharmaceutical options. This shift has substantially changed the patient-physician dynamic. Physicians are no longer the sole providers of health information. Patients rely more and more on sources of information that are less personalized than what a physician can provide.

Section II

Method

Study at a Glance

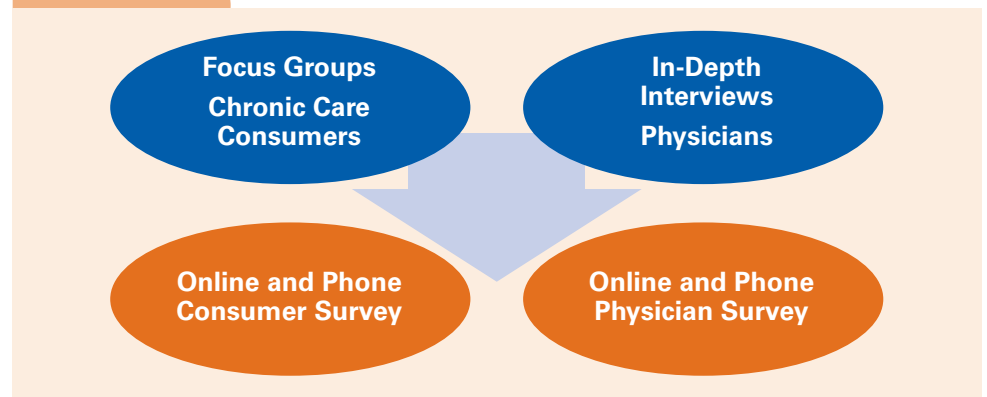
Chronic Care in America relied on primary qualitative and quantitative research, gathering data from those patients and physicians who have the most exposure to the American healthcare system for chronic care.

A multidisciplinary advisory panel, representing leadership from key stakeholder groups in chronic care, provided guidance throughout the design and analysis phases of this project.

The research was conducted from October to December, 2002 and focused on answering the following questions:

- How do patients successfully live with chronic conditions?
- What are the elements of a satisfying patient-physician relationship in chronic care?
- What tools, strategies or technologies are patients and physicians seeking to improve chronic care?

FIGURE 4 Survey Design



Survey Design

Qualitative research was conducted first to define the elements of the subsequent quantitative survey. During this phase of the research, patients and physicians were both interviewed.

Patients with chronic conditions emphasized the importance of personal motivation. They also indicated that the physician plays a key role, particularly in providing access to information. Physicians viewed chronic care as a highly individualized process, one that offers the opportunity to enjoy long and satisfying relationships with their patients. They valued tools or strategies (often derived from their own practices) that enable them to more effectively manage patients receiving continuous care.

On the advisory panel's recommendation, parallel surveys were created to interview large samples of patients and physicians. Though the surveys differed, they both focused on similar topics. One portion of the survey sought to identify best practices, or the actions taken by patients and physicians, which result in successful adaptation to life with a

Section II

Method *continued*

chronic condition. The survey also explored qualities of the patient-physician relationship in chronic care. This data was used to assess the degree to which patients and physicians converge (or diverge) in their perceptions of how this relationship should work. Other portions of the survey addressed topics such as the perceived adequacy of preparation for chronic care (from both patient and physician perspectives), the impact of emerging technologies and the kinds of lifestyle or behavioral changes associated with chronic care.

Patient Survey

Patients who experience significant levels of illness-related interference with their health and daily activities were sought for interviews. These individuals are in contact with the healthcare system most frequently and are most familiar with how chronic conditions affect daily life. Consequently, several screening criteria were applied to assure that the respondents for this research would be able to speak from recent or ongoing personal experience.

TABLE 2 Screening Criteria for Patients

✓ Has good, fair or poor health
✓ Disability/disease prevents full participation in school, work, housework or other activities
✓ Has had condition for at least one year
✓ Visited primary care doctor/medical specialist at least six times in past year
✓ Has at least one chronic illness
✓ Does not work in healthcare industry or do any household members

Within a sample representing patients who experience this level of activity interference, comorbidities were the rule. Only 16 percent (n=527) reported a single diagnosis. Subquotas were targeted for certain high-visibility conditions, such as asthma and diabetes. However, the number of actual cases within the sample ultimately exceeded these quotas by large margins. The most frequent conditions, in terms of point prevalence, were arthritis, chronic back problems and depression. Given the large sample size, certain lower frequency conditions were also represented by a relatively large number of cases, such as obsessive-compulsive disorder (115 cases), lupus (114 cases), and bipolar disorder (189 cases).

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Method *continued*

TABLE 3 Frequency of Chronic Conditions in the Study Population

Condition	Number	Condition	Number
Alzheimer's disease	6	HIV/AIDS	38
Anxiety disorder	696	Kidney disease	160
Arthritis	1,622	Liver disease	105
Asthma	774	Lupus	114
Bipolar disorder	189	Lyme disease	23
Cancer	340	Migraine headaches	771
Chronic back problems	1,374	Multiple sclerosis	102
Chronic Obstructive Pulmonary Disorder (COPD)	306	Obsessive-compulsive disorder	115
Dementia	29	Osteoporosis	387
Depression	1,327	Panic disorder	341
Digestive/Gastrointestinal disorder	827	Phobia	122
Emphysema	233	Parkinson's disease	9
Epilepsy	93	Post-Traumatic Stress Disorder (PTSD)	248
Heart disease	680	Schizophrenia	25
Hepatitis	144	Stroke	220

To obtain a representative sample and to create weighting targets, patients were interviewed over the telephone and online. The telephone sample consisted of 401 respondents identified through random-digit dialing. These were supplemented by 2,890 online survey completions identified through the Harris Poll OnLineSM and representing every state in the United States.

The resulting sample was composed of individuals who were community dwelling but had significant levels of interference from multiple chronic conditions. In terms of contact with physicians and the overall healthcare system, the sample possessed a large aggregate base of experience.

TABLE 4 Patient Demographics: Age, Doctor Visits, and SF-8 Scores

	Mean	SD
Age	50.9	12.9
Number Visits, Past Year, Primary Care	9.0	9.9
Number Visits, Past Year, Specialists	9.5	15.8
SF-8 Physical Component Score	32.73	8.78
SF-8 Mental Component Score	40.94	11.83

Section II

Method *continued*

TABLE 5 Patient Demographics: Gender, Race, Education, Income and Insurance

Demographic	Grouping	Percent	N
Gender	Male	31	1,008
	Female	69	2,283
Race	White	82	2,703
	Black/African American	10	323
	Native American or Alaskan Native	2	58
	Mixed racial background	2	64
	Asian or Pacific Islander	1	27
	Other	1	21
	Decline to answer	3	98
Education	High School or less	50	1,649
	College or more	49	1,617
Income	\$0-\$34,999	33	1,090
	\$35,000-\$99,000	41	1,355
	\$100,000 or more	10	324
	Declined to answer	14	447
	Not sure	2	76
Insurance*	Medicare	37	1,212
	Healthcare coverage through your work or union	26	861
	Healthcare coverage through someone else's work or union	25	833
	Medicaid	14	459
	Other type of health plan	14	456
	Bought directly through some other group	5	162
	No health insurance	7	241

*Will not sum to 100% to account for multiple responses.

Physician Survey Respondents

The physician respondents were sought on the basis of their exposure to patients with chronic conditions. A desire to sample from a large number of specialties was balanced with a desire to achieve adequate sample sizes within specialties.

TABLE 6 Screening Criteria for Physicians

- ✓ Seeing patients 20 hours or more per week
- ✓ Seeing 20 or more patients per week
- ✓ Specialty-specific thresholds were determined for the proportion of patients seen as outpatients
- ✓ Specialty-specific thresholds were determined for the percentage of patients with moderate-to-severe activity interference who were seen in practice

Section II

Method *continued*

TABLE 7 Specialties of Physicians in Study Population

Physician Specialty	Sample Size
Cardiology	100
Endocrinology	101
Neurology	101
Oncology	101
Primary Care	401
Psychiatry	101
Pulmonology	100
Total	1,005

Physician respondents were interviewed by telephone and online. To obtain a random probability sample, the Master File of the American Medical Association was utilized. There were 211 interviews completed by telephone and 794 interviews completed online. Physicians contacted by email were far more likely to respond to an online survey because of convenience.

TABLE 8 Physician Demographics

Mean, (SD)	Hours per week seeing patients	Patients seen per week	Percent moderately to severely chronic	Percent total, outpatient	Percent total, inpatient	Number patients seen per day	Minutes per patient visit	Years beyond residency/fellowship
Cardiology	44.9 (14.9)	97.4 (51.6)	54.6 (19.6)	82.2 (11.4)	18.0 (11.8)	19.5 (7.1)	19.7 (8.6)	15.6 (9.1)
Endocrinology	39.8 (11.9)	92.2 (43.8)	57.6 (19.4)	91.6 (6.8)	8.4 (6.8)	20.4 (7.9)	21.5 (8.5)	12.8 (8.9)
Neurology	44.0 (15.3)	76.4 (50.4)	58.2 (20.2)	80.7 (13.9)	19.6 (13.7)	15.4 (7.5)	30.0 (12.4)	10.6 (8.9)
Oncology	47.0 (15.3)	100.5 (57.9)	61.8 (18.7)	87.3 (8.5)	13.8 (8.3)	21.0 (10.5)	19.9 (10.0)	15.8 (7.5)
Primary Care	43.3 (12.8)	111.4 (46.3)	42.0 (20.1)	91.9 (8.4)	8.5 (9.9)	23.9 (9.3)	17.8 (6.4)	14.5 (10.4)
Psychiatry	40.2 (14.5)	69.6 (39.6)	67.6 (18.6)	93.7 (11.2)	5.7 (10.1)	16.0 (10.4)	30.2 (29.6)	17.6 (11.2)
Pulmonology	47.5 (15.4)	94.4 (50.2)	63.1 (17.6)	67.6 (14.7)	33.3 (16.1)	20.8 (11.5)	19.9 (7.2)	16.7 (7.4)
Total	44.1 (14.0)	97.6 (50.0)	53.1 (21.7)	86.9 (13.1)	13.3 (13.7)	20.9 (9.7)	21.2 (12.0)	14.7 (9.7)

Assuring Representative Findings

Two kinds of weighting were applied. These adjustments corrected for the possibility of interviewing individuals who were not representative of the populations from which the sample was drawn.

Section II

Method *continued*

The first type of weighting was against demographic targets for chronically ill consumers and for physicians (derived from this research, preceding studies, AMA Master file and other sources). The second type of weighting, referred to as propensity weighting, was used to correct for bias that might occur by interviewing respondents online instead of by telephone. These adjustments relied upon proprietary Harris Interactive methods, so that data collected online could be projected to the universe of offline and online individuals. Weighting was ultimately applied to the patient results only. Physician results collected by telephone and online were equivalent, reflecting the current level of acceptance of the Internet among physicians who are now at least as likely to respond to surveys using this method as to telephone surveys.

Interpreting results in this report

This chartbook contains results derived from the main topics of this research:

**How do patients “succeed”
at managing chronic illness?**

***What are the best practices shared
by successful patients?***

**What are the dynamics of a “satisfying”
patient-physician relationship?**

***How can this relationship
be optimized?***

**What are consumer needs
for information?**

***What role do new technologies
play in the relationship?***

Section III

How Do Patients Successfully Manage Chronic Conditions?

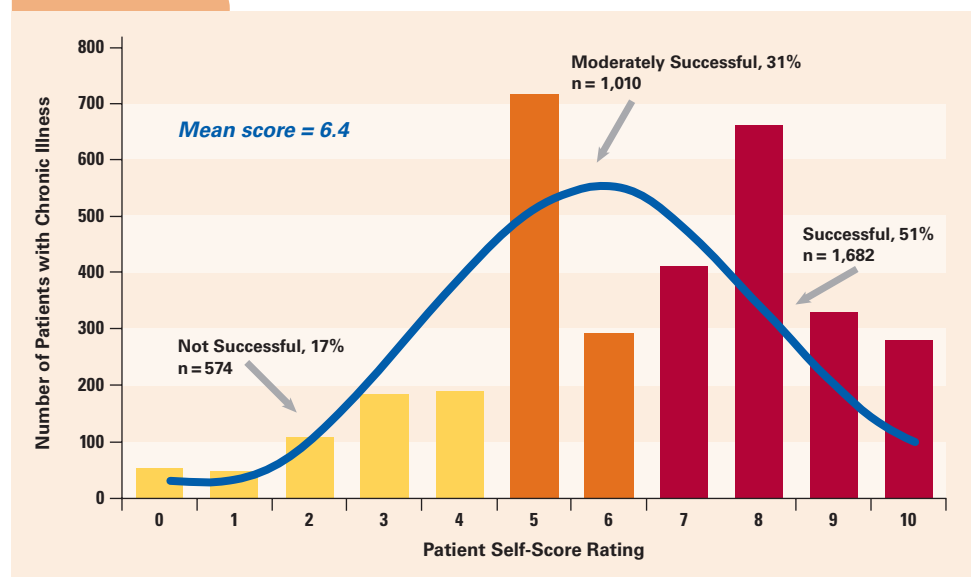
“I think that one must always be proactive and be responsible for their health conditions. Find a doctor who listens, respects you and will be a partner in your treatment.”

—Patient Comment

Defining the Successful Patient

Why is it that some patients fare well in adapting to the demands of chronic conditions while others do not? Currently, there are numerous theories regarding hardiness, optimism and other factors that relate to a patient’s success. In this research, there was a specific interest in understanding how patients live with health restrictions imposed by chronic conditions, and how they viewed the impact of the patient-physician relationship. Patients were asked how “successful” they thought they were in living with chronic conditions. A familiar 0 to 10 scale was used to obtain ratings. Patients giving themselves the highest scores (7 to 10) were classified as “successful.”

FIGURE 5 Success Among Patients With Chronic Conditions



Who are the patients that identify themselves as successful? Factors such as income and ethnicity did not reveal differences among those who considered themselves to be “successful.” A larger proportion of men (21%) than women (16%) considered themselves to be “not successful.” Marital status, ethnicity, race, employment status and income were equivalent across groups. As depicted in Figure 6, older patients generally felt they were living more successfully with chronic conditions, perhaps because such conditions corresponded to their expectations of aging.

Section III

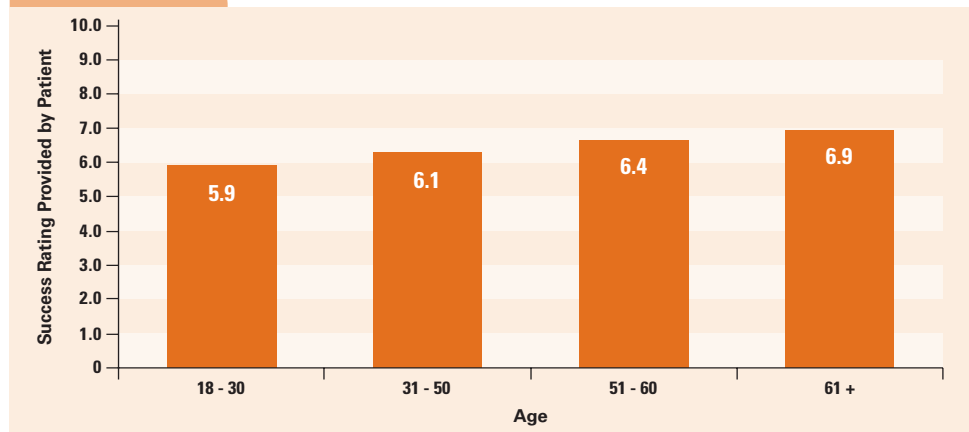
How Do Patients Successfully Manage Chronic Conditions?

continued

“That I needed help emotionally to accept my illness and my limitations.”

—Patient Comment

FIGURE 6 Mean Success by Age

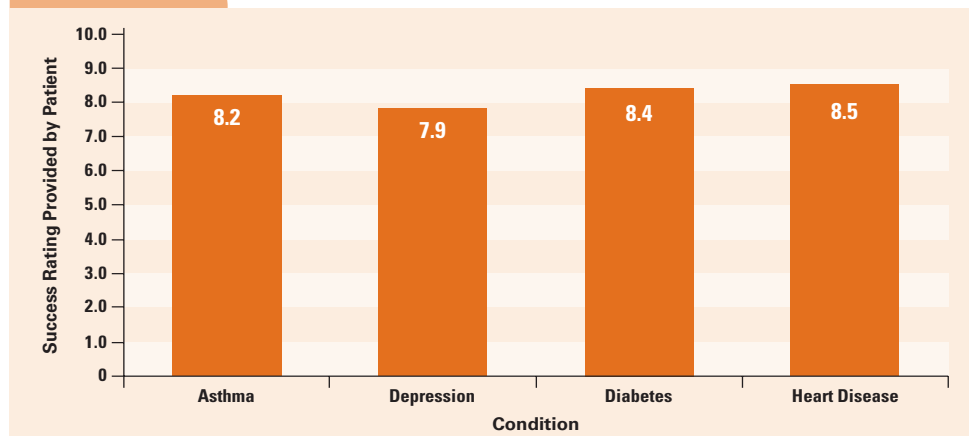


Patients who described themselves as “successful” more frequently reported that they had made lifestyle changes (69% vs. 54% indicated dieting, exercise, taking medication regularly or practicing stress management). Patients classified as “not successful” had more often “tried” to make such changes (36% vs. 24%).

Mood state is probably the most important factor associated with patient ratings of mean success with chronic care. The SF-8 health status survey was used to evaluate general health status: Its Mental Component Score (MCS) specifically evaluated mood and emotional concerns. The MCS was the strongest predictor of perceived success at managing one’s condition.

Moreover, patients reporting a diagnosis of depression are most likely to view themselves as “not successful.” Patients diagnosed with depression viewed themselves as being less successful at managing chronic conditions (either depression or any other conditions they experienced). Fewer of those patients who had been diagnosed with depression reported that they were successful at living with their chronic condition, compared to patients without depression (43% vs. 57%). Because these are cross-sectional findings, the survey design did not make it possible to address whether physical conditions have a causal impact on symptoms of depression. At a minimum, it seems appropriate to assert that chronic conditions are a significant risk factor for depression, and that routine screening is warranted.

FIGURE 7 Successful Management by Condition



Section III

How Do Patients Successfully Manage Chronic Conditions?

continued

“...chronic illness can be very debilitating both mentally and physically and you have to keep in mind treating both aspects of this.”

—Physician Comment

For patients to succeed at living with a chronic condition, it is logical that they must recognize the impact their personal actions have on their overall health. The survey showed that most patients understand and acknowledge the link between behavior and health. When asked “Do you believe that the things you do (such as diet, exercise or taking medication) have an impact on your medical condition?” a large majority of respondents said “yes.” Patients with diabetes and depression were among the most aware of this connection.

Unfortunately, understanding this connection does not necessarily equate to successfully making lifestyle changes that may be required for successful chronic care. More than two-thirds of respondents who said that they “do not expect to make changes” in their health behavior still reported that the things they do have an impact on their medical condition (69%). Presumably, these individuals lack the strategies or motivational support that would enable them to make the lifestyle changes they know are needed to keep them healthy.

Personal actions and attitudes seemed to differ even at the time of diagnosis. Respondents were asked to consider how they reacted when they were diagnosed with a chronic condition. Those patients who viewed themselves as successfully living with their chronic conditions made plans for changes in their life and began to seek further knowledge and information. Patients that ultimately described themselves as less successful were more likely to exercise avoidant-coping strategies, trying not to think about their condition, wishing it would go away or simply becoming upset. These results may suggest that the time of diagnosis is a potentially influential opportunity to instill the kind of outlook that will be beneficial to patients over the course of their chronic conditions.

TABLE 9 Relationship Between Coping Methods and Success

Coping Method	Successful (n = 1,682)	Moderately successful (n = 1,010)	Not Successful (n = 574)
Proactive	%	%	%
I made plans for changes in my life.	36	31	25
I wanted to learn more about the condition.	64	62	57
Avoidant	%	%	%
I tried to avoid thinking about it.	22	29	30
I wished it would just go away.	52	57	65
I kept my feelings to myself.	31	32	39
I felt afraid of becoming a burden.	42	45	51
I got sad or upset.	44	50	52

Patient-Physician Relationships

The majority of patients with chronic conditions described the relationship with their physicians one where treatments were selected collaboratively. This approach was most common among patients who described themselves as successfully managing their condition.

From the patient’s perspective, the patient-physician relationship revolves around a productive and efficient exchange of information. Compared to the least successful patients, patients who saw themselves as living well with their chronic conditions said that their physicians more frequently gave them “pamphlets, brochures, or other ways to learn about the condition” (46% vs. 35%), “explained guidelines from research that has shown what works best to take care of the condition” (40% vs. 30%), and were instructed about “where to get more information” (27% vs. 21%).

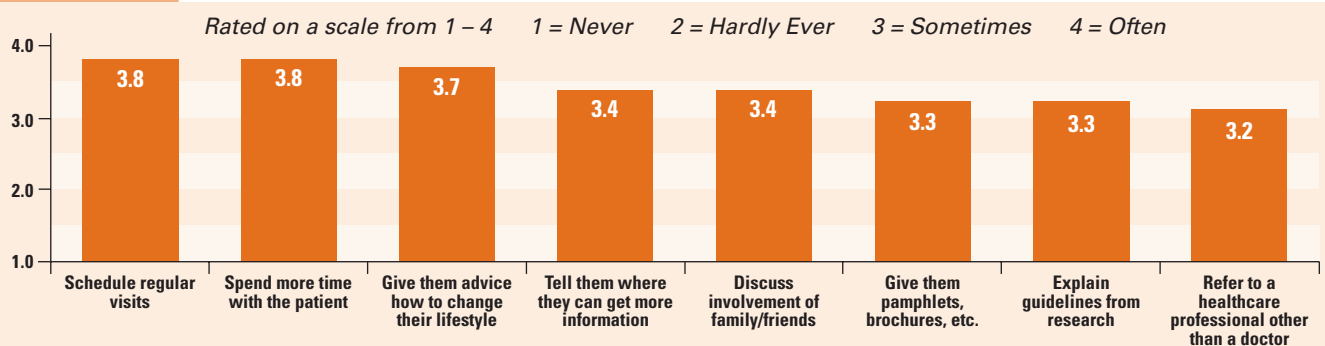
Section III

How Do Patients Successfully Manage Chronic Conditions?

continued

In all cases, younger physicians (those in practice 10 years or less) were more likely to discuss topics involving lifestyle change within chronic care. A majority of physicians, 75 percent, preferred to play a significant role in their patient’s treatment, by discussing options with their patients and families and then coming together to make treatment decisions. There were no significant differences across specialty. Figure 8 illustrates the frequency and type of discussions reported by all types of physicians. When asked specifically what they do to help their patients manage chronic conditions successfully, neurologists, endocrinologists, cardiologists and pulmonologists appeared to be the most directive, providing disease specific information and setting goals and expectations for the patients. PCPs, oncologists and psychiatrists were the least directive.

FIGURE 8 Physician Discussion of Various Topics



Perceived Patient Needs

Over the course of chronic care, patients repeatedly identified access to information and knowledge as a top factor affecting their ability to manage conditions. “Reading or learning more about my condition” was the action that successful patients most felt enabled them to succeed in adapting to life with a chronic condition. Respondents described themselves as “armed” and “in control” when they had access to information about their condition or symptoms. Without this information, they wanted “guidelines from research” showing which treatments are successful.

A small portion of the total sample (n = 204, 6%) told us their doctor did not provide direction to them at the time of diagnosis. Half of these persons (52%) said they would have liked their doctor to “explain guidelines from research that has shown what works best to take care of the condition.” Patients indicated this more often than any other action they wished had been taken.

TABLE 10 Actions Desired by Patients Who Indicate Their Physicians Did Not Provide Direction at the Time of Diagnosis

Action	Percent desiring this
Guidelines from research	53
Where to find more information	46
Spend more time with me	46
Print material	39
Advice about changing lifestyle	38

Section III

How Do Patients Successfully Manage Chronic Conditions?

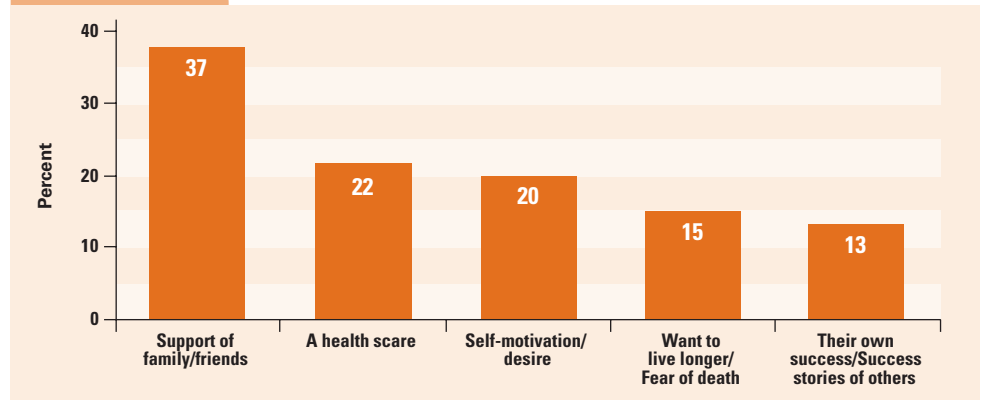
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Physician Perceptions

Physicians indicated that patients particularly benefit from the support of family and friends. This was the leading reason physicians identified to explain which patients would be able to successfully make lifestyle changes as part of chronic care. Motivational factors on the part of the patient are seen as having relatively less influence on outcomes.

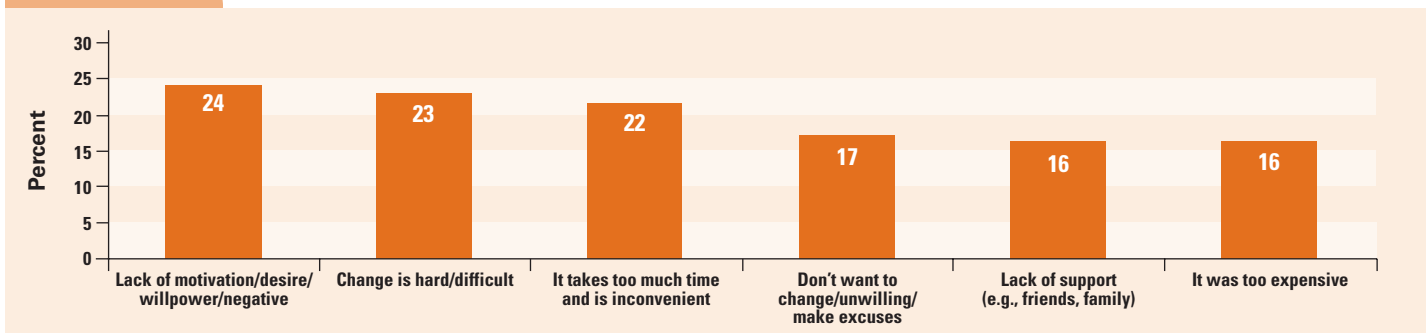
Though they believe such support helps, physicians do not think that the absence of support from family and friends necessarily jeopardizes a patient in the effort to live with a chronic condition. The most frequently cited negative influence was a “lack of motivation” or “willpower.” Throughout the survey, physicians frequently identified attitudinal barriers as one of the most challenging aspects of providing adequate care. Physicians indicate great interest in tools, strategies, and methods for addressing negative moods or behaviors, particularly for depression or insufficient treatment compliance.

FIGURE 9 Physician Perception of Factors Contributing to Patient Success



When it comes to the treatment of chronic illness and what they have learned over the years, physicians wish they had known more about the time-intensive nature of treating chronic illness, how to motivate and educate patients, and the need to express understanding. Physicians commented that “medical training emphasizes episodic care” and that they were not initially equipped to manage chronic, or recurrent care.

FIGURE 10 Physician Perception of Patient Change



Section IV

Dynamics of the Patient-Physician Relationship

“[I’ve learned] not to expect too much – [to] expect that a lot of patients have stresses and other difficulties in their lives, including denial, that make it difficult to succeed. To have patience and work with them over time, and with encouragement, they will succeed.”

—Physician Comment

Why is satisfaction important?

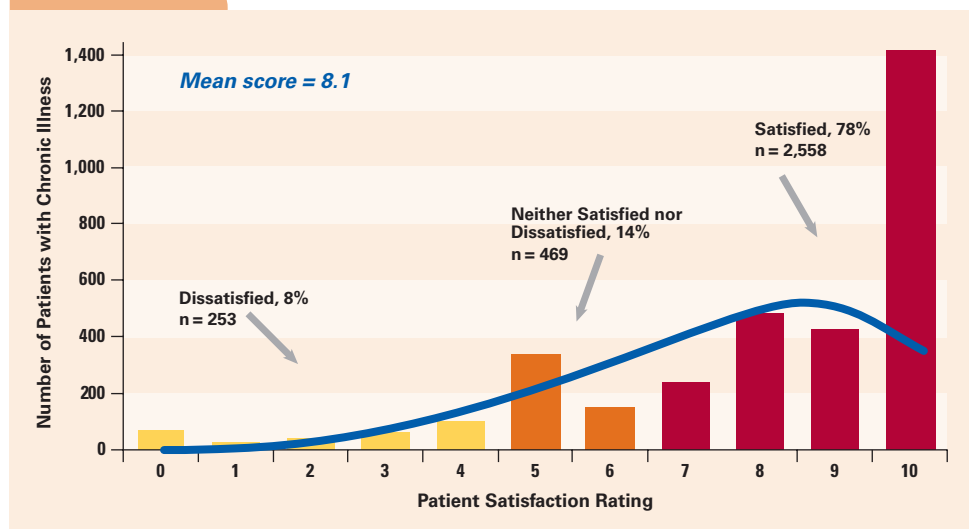
Patients and physicians build a relationship together that becomes the foundation of effective chronic care. A longer, more satisfying relationship may enable patients to comfortably raise concerns about their health and its effect on their lives. It also enhances continuity of care as physicians can obtain a deeper understanding of patient histories and experiences. This potentially equates to efficiencies that are reflected in lower overall costs of care.

The constructs of success and satisfaction were related but were conceptually distinct (correlated at $r = 0.146$). Like other variables in chronic care, such as symptom intensity and distress, they appear to interact while remaining separable. Success was defined in terms of how well the patient viewed himself or herself at living with a chronic condition. Satisfaction referred to the patient’s level of satisfaction with the physician seen most often. Both were rated by patients on a familiar 0 to 10 scale.

Defining the “Satisfied” Patient

Most patients said they are highly satisfied with their physician, regardless of specialty. As depicted in Figure 11, on a scale of 0 to 10, over 40 percent of the patients within the sample gave their physicians a satisfaction rating of 10, with an average rating of 8.1. Patients with diabetes and heart disease were among the most satisfied. In contrast, patients with asthma and depression were among the least satisfied.

FIGURE 11 Patient Satisfaction with Physician

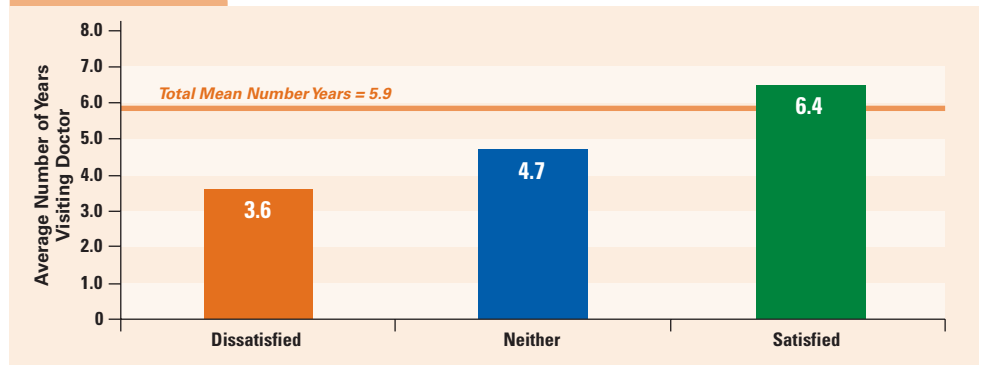


Section IV

Dynamics of the Patient-Physician Relationship

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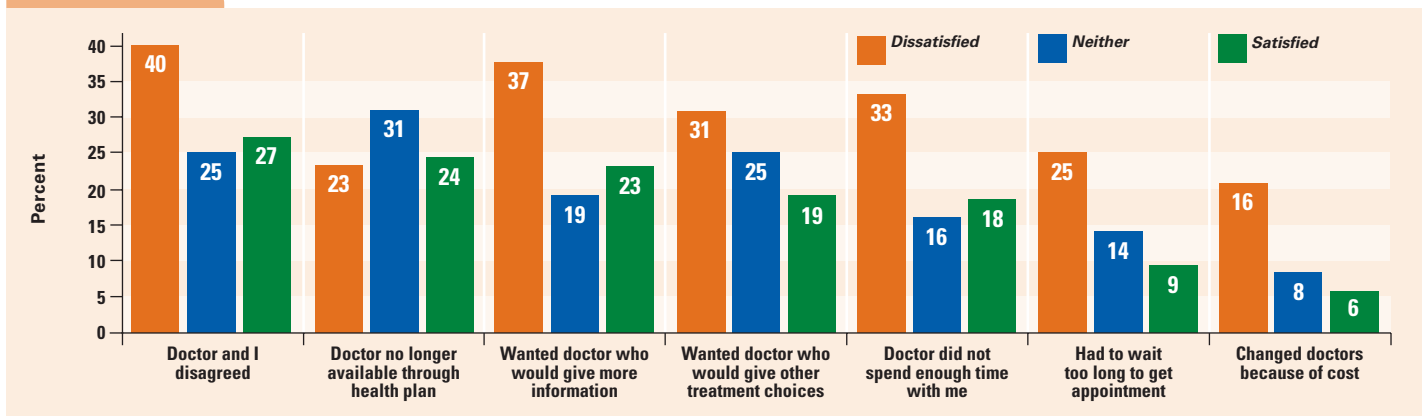
FIGURE 12 Relationship Between Patient Satisfaction and Length of Patient-Physician Relationship



Longer-term physician relationships can be more satisfying to patients. Older patients enjoyed the longest relationship with their physicians while patients who were younger than 30 described less satisfying relationships. The average length of a patient-physician relationship was six years.

When patients were not satisfied with their physician, they were also more likely to find a new doctor and potentially disrupt the continuity of care. Overall, about a third of patients (29%, n=1,682) said they had changed physicians in the past two years. Patients who change physicians more frequently were also more likely to be dissatisfied with the care they are currently receiving.

FIGURE 13 Patients' Reasons for Changing Physicians



Patients said that when they switch physicians, it is most often due to disagreements or because the physician was not providing enough information to them. Others may switch because their physician is no longer available through their health plan. Considering that physician satisfaction is associated with improved health outcomes and greater success at managing one's condition, this may be an especially important finding for managed care organizations and employers.

Section IV

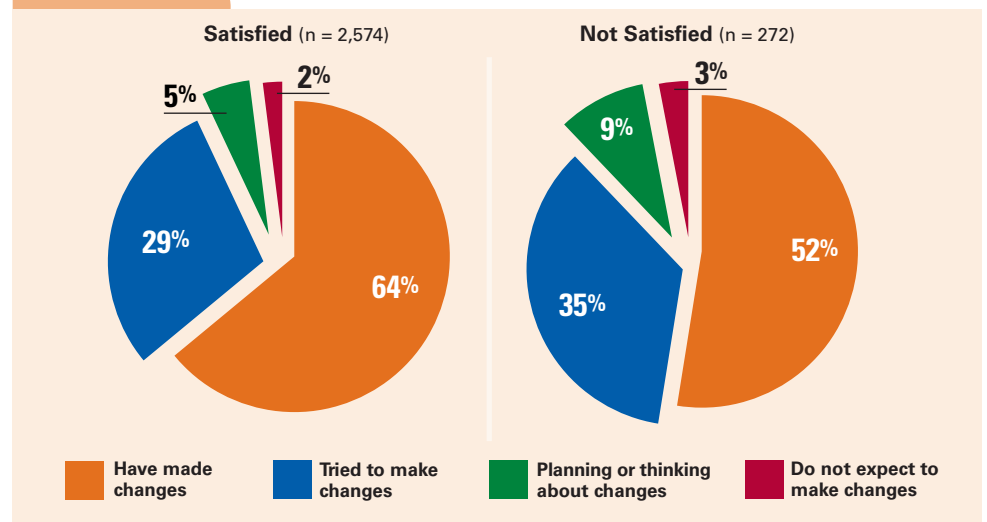
Dynamics of the Patient-Physician Relationship

continued

“It’s ok to tell them what’s going on with me – they are not the enemies and will not ridicule me, or, worst of all, laugh at me because of my problems and feelings.”

—Patient Comment

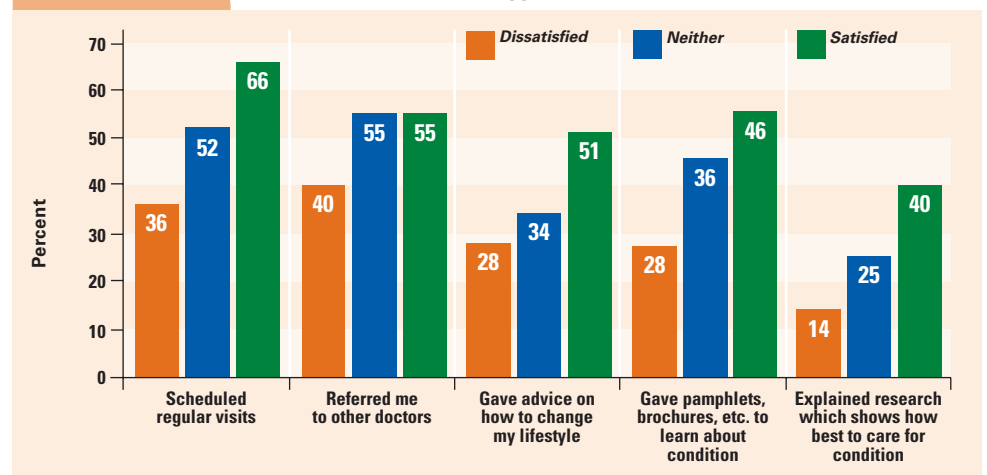
FIGURE 14 Relationship Between Patient Satisfaction with Physician and Success in Making Lifestyle Changes to Benefit Health



As depicted in Figure 14, the study revealed that patients who are satisfied with their physicians are more likely to make the kinds of behavioral lifestyle changes that are frequently necessary as part of adapting to their chronic condition. The least satisfied patients were more likely to have “tried” (and possibly failed) at managing their personal behavior.

Not surprisingly, patients who were satisfied with their physicians viewed them as playing significant roles in enabling change (55% among the satisfied, n=1,274 vs. 20% among the not satisfied, n=41).

FIGURE 15 Relationship Between Patient Satisfaction and Supportive Actions by Physician



The actions that physicians take with their patients seem to be associated with levels of satisfaction. Satisfied patients were more likely to report that their physicians played an active role in their care by, scheduling regular visits, referring them to other doctors or providing information and advice. These actions complement the encouragement and support that satisfied patients reported receiving from their physicians.

Section IV

Dynamics of the Patient-Physician Relationship

continued

“I need to be a partner in my own medical care. I need to arm myself with information about my conditions. It helps me greatly to write down the questions I need answered.”

—Patient Comment

Desired Physician Qualities

Patients were asked to rate the qualities that they value most in their relationship with the physician that they see most often. In short, they were looking for a relationship that is *understandable, informative and collaborative*.

Patients highly value physicians who provide understandable explanations. Beyond this, the physicians are expected to be competent and knowledgeable in providing useful information. The ability to listen, or effectively collaborate, was also among the most highly rated qualities. This combination of technical and personal skills resulted in enhanced patient satisfaction.

TABLE 11 Top-Rated Physician Qualities (as rated by patients and physicians)

Physician Quality	Importance (Percent of share)			
	Patients		Physicians	
Explains things in a way the patient can understand	1	13%	1	22%
Is competent	2	12%	5	6%
Listens	3	11%	2	15%
Is knowledgeable	4	10%	11	3%
Is there when the patient needs him/her	5	8%	4	7%
Treats the patient with respect	6	8%	3	12%

Physicians were also asked what qualities they thought were most important to patients with chronic conditions. Like patients, they felt that providing understandable explanations and being good listeners were of primary importance. They adopted a slightly different view of the relationship, assuming that the patient would value interpersonal skills somewhat more than was reported.

Key Aspects of the Patient-Physician Relationship

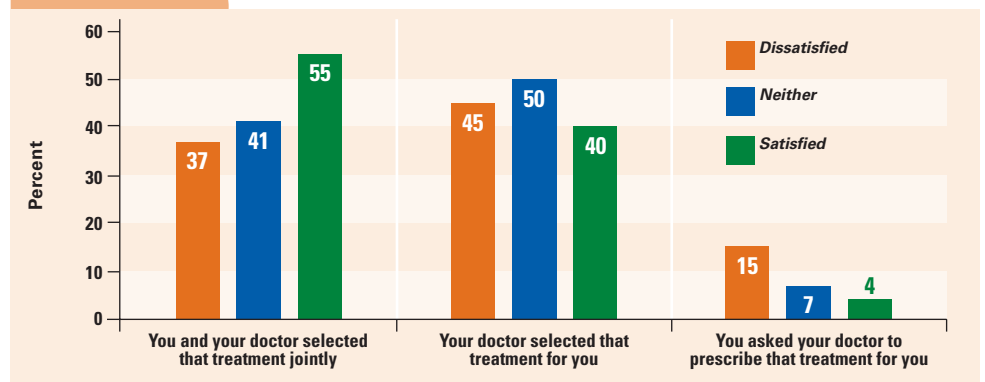
As illustrated in Figure 16, satisfied patients (55%, n=1402) viewed the relationship they have with their physicians as collaborative. Dissatisfied patients were more likely to feel directed and reported that they had told their physician what treatments to select. Satisfied patients did not necessarily exert more control over their physicians. Instead, they wanted their physician to provide as much information as possible, in an easy-to-understand manner, and to arrive at a decision jointly with them. They want specific, step-by-step advice on how they could change their behavior.

Section IV

Dynamics of the Patient-Physician Relationship

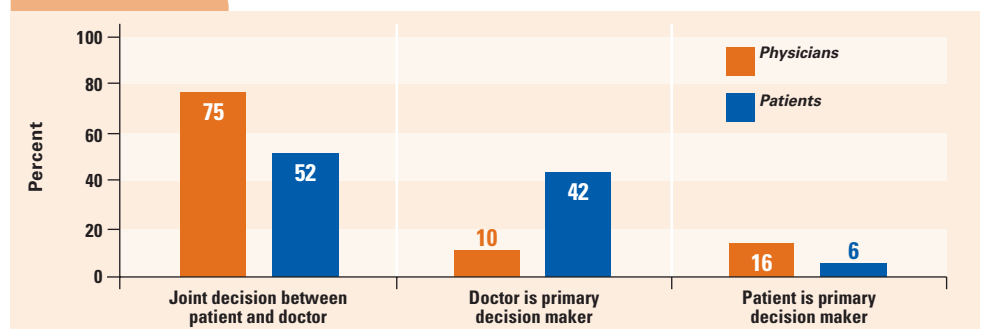
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FIGURE 16 Relationship Between Patient-Physician Collaboration and Patient Satisfaction With Physician



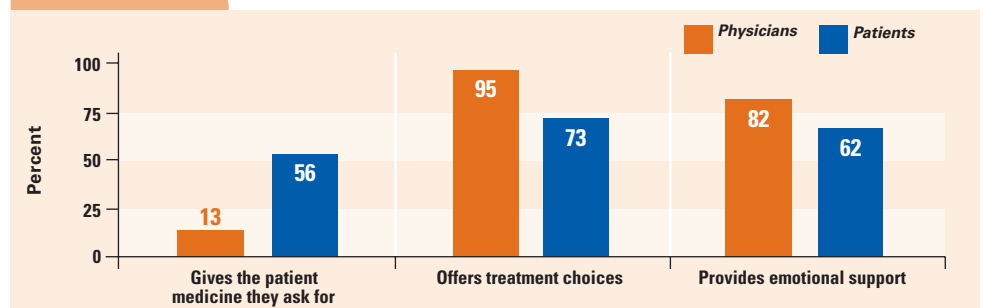
Overall, about 75% (n=753) of physicians, regardless of specialty and years in practice, indicated that they usually made decisions jointly with their patients. In contrast, only about half of patients (52%, n=1,696) thought they were working with their physicians in this way. Patients and physicians differed on whom they viewed as the primary decision maker. Relatively few physicians (10%) said that they were the primary decision maker while a much greater proportion of patients (42%) said that their physician made treatment decisions for them.

FIGURE 17 Perception of Collaboration Between Physicians and Patients



Newer physicians (in practice for 0 to 10 years) viewed themselves as holding a less authoritative role within the patient-physician relationship. They were more likely than older physicians to feel that the statement “I let the patient make decisions” described their practices.

FIGURE 18 Top Three Perceptual Differences Between Patients and Physicians



Section IV

Dynamics of the Patient-Physician Relationship

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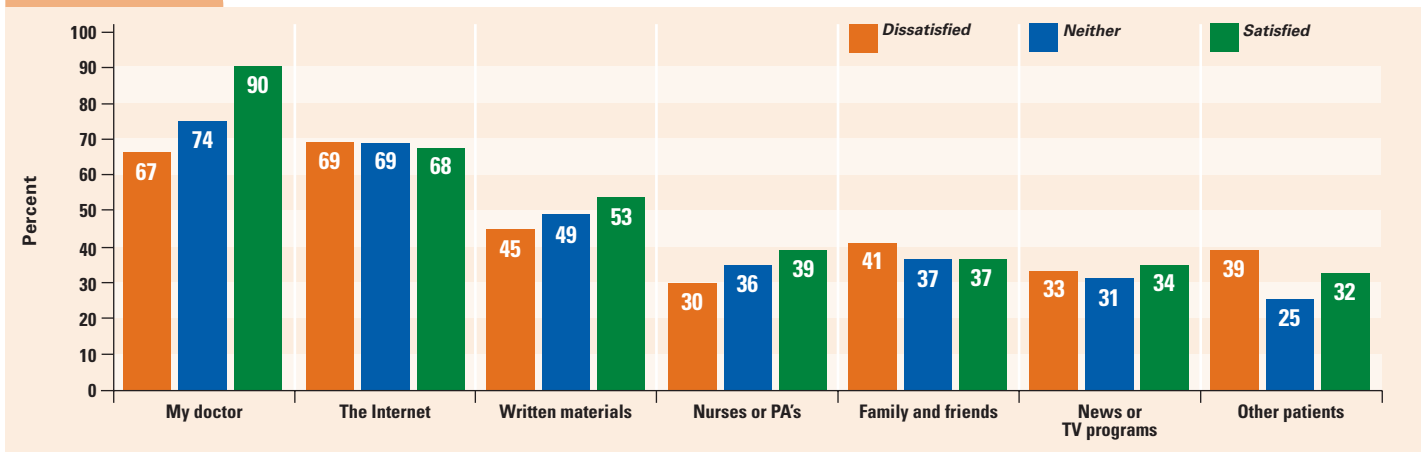
Another area in which patients' and physicians' perceptions differed was in medication requests. Patients viewed themselves as having greater influence over this process than physicians did. More than half (56%) of patients felt that their physician would give them prescription medication at their request while only 13 percent of physicians said they would grant their patients such requests.

Physicians may feel that they are offering their patients a variety of treatment options, but patients do not necessarily agree. While 73 percent of patients felt that their physicians gave them options, virtually all physicians (95%) believed that they did.

When patients are satisfied with their physician, they use information from their doctors more often than information from any other source. Considering all the health information that is available to review, patients especially valued personalized, specific advice on how they could change their lifestyle. The physician has essentially become an "information broker" for patients, sorting out relevant information and delivering it with a personal touch.

The Internet is a strong second choice for health information. Satisfied and dissatisfied patients used it about equally. However, dissatisfied patients used the Internet about as much as they used their physician as a resource (69% vs. 67%). Patients who turned to the Internet may do so somewhat reluctantly, seeing it as an alternative source for information that their physicians failed to provide.

FIGURE 19 Relationship Between Patient Satisfaction and Information Sources Used



When patients are satisfied, they are more likely to disclose important health information. As illustrated in Figure 20, satisfied patients reported being more likely to tell their physician if they had been noncompliant. Compliance was defined by how often patients tell their physician when they have not been successful at changing their behavior. In addition, 40 percent of all patients report disclosing non-compliance to physicians "often" while only 27 percent of physicians perceive their patients to report non-compliance with such frequency. This demonstrates another area where patient and physician perceptions differ significantly.

Section IV

Dynamics of the Patient-Physician Relationship

continued

“[I wish I’d had] more training in counseling patients and psychological training.”

—Physician Comment

FIGURE 20 Percent of Patients Reporting Non-Compliance to Physician

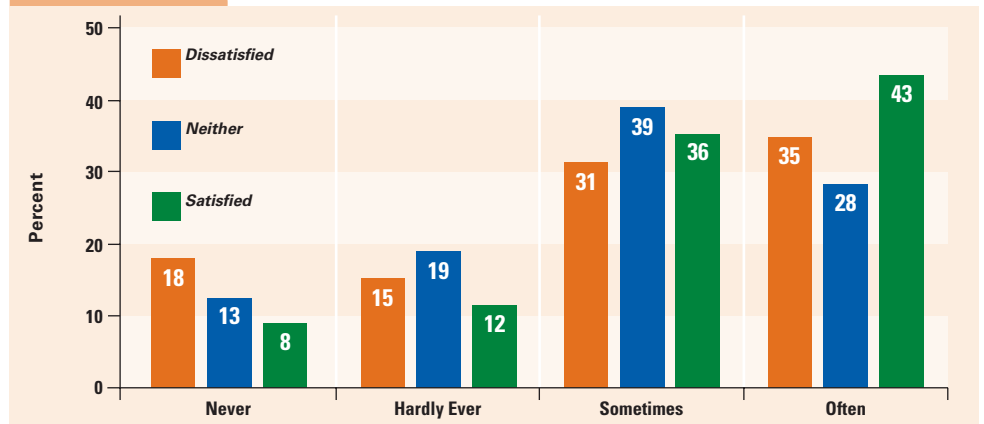
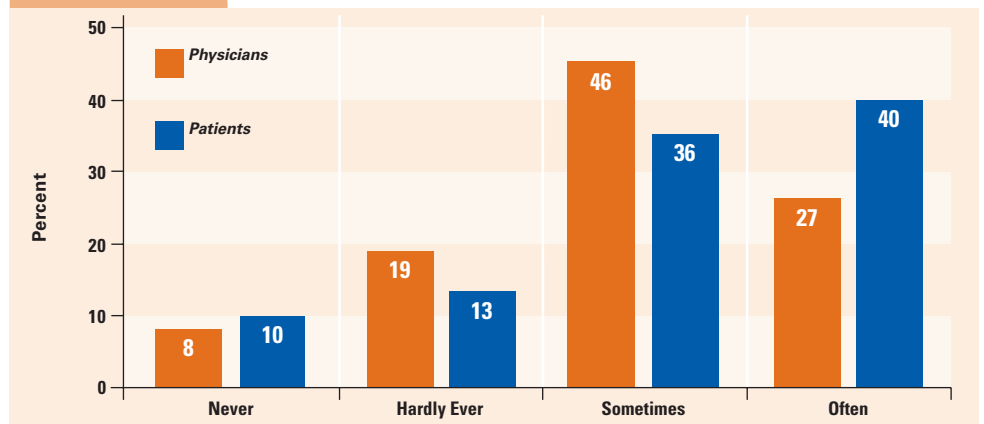


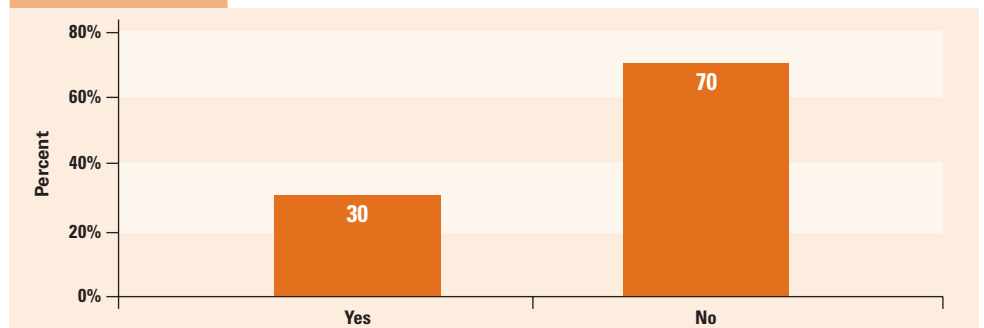
FIGURE 21 Percent of Patients Reporting Non-Compliance to Physician



Facilitating Behavioral Change

A large majority of physicians (70%) reported that they had not received adequate training in chronic care. There were some differences across specialties with primary care physicians and oncologists feeling the most prepared (38 % and 34 % respectively). Newer physicians were more likely to feel well prepared. Among those in practice for 10 years or less, 38 percent thought their preparation was adequate compared to only 24 percent of their more experienced colleagues.

FIGURE 22 Do Physicians Receive Enough Instruction In Chronic Care During Training?

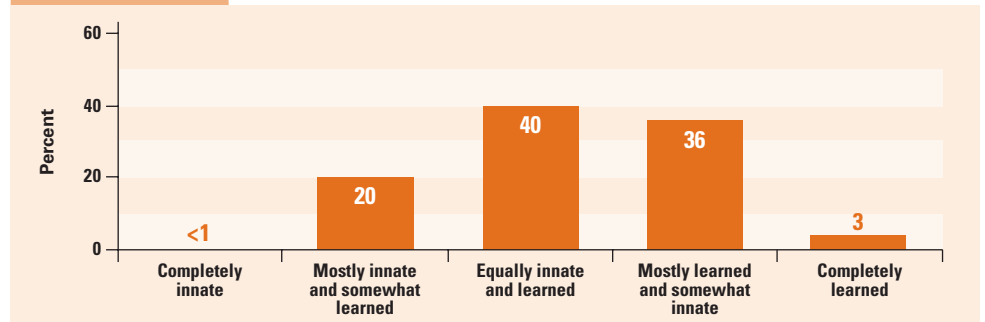


Section IV

Dynamics of the Patient-Physician Relationship

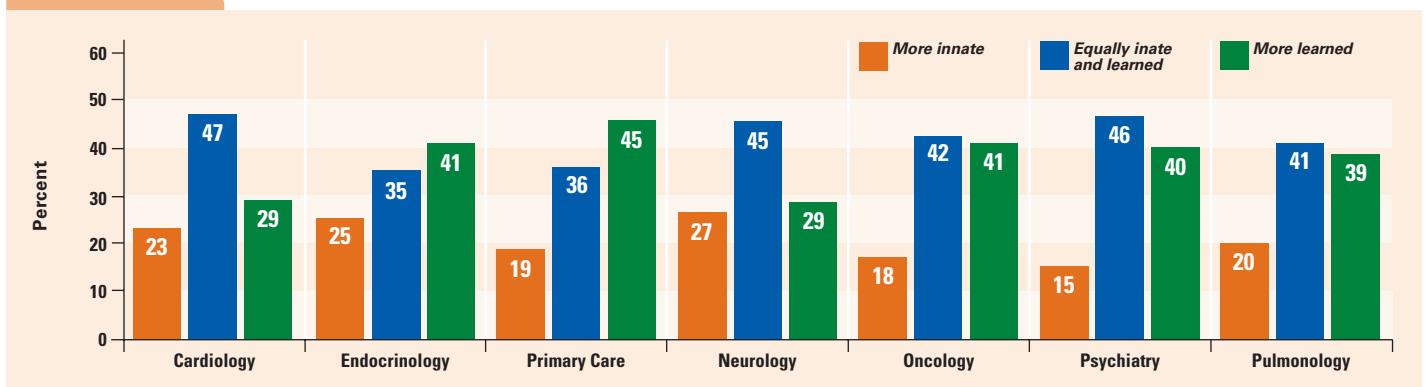
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FIGURE 23 Physician Perspective on Changing Patient Behavior



Most physicians believed the task of behavior change requires skill that is mostly learned or at least equally innate and learned. Primary care physicians were more likely to see behavior change processes as something that must be learned. Neurologists were the most likely to view this activity as requiring an innate, rather than learned, skill.

FIGURE 24 Physician Perspective on Changing Patient Behavior



Section V

Patient and Physician Needs for the Future

“Remember to write down any and all questions you might want to ask the physician no matter how trivial they may seem. Take the notes with you when you go see the Doctor...”

—Patient Comment

Summary of Findings

The patient-physician relationship in chronic care is centered on exchanging information. Physicians also note that it involves changing lifestyle behaviors. Patients who are successful at adapting to chronic conditions have armed themselves with knowledge, ideally through their physicians. More and more frequently, they are using online alternatives for health information, but this source is less personalized and less credible. Private dialogue with a physician is the medium that patients desire most. Dissatisfied patients turn to the Internet more than those who enjoy a satisfying relationship with their physician.

Patients who succeed at handling chronic conditions recognize the importance of their behavior, gather information, make plans, and change their lifestyle. Family and friends may figure prominently in their success. They are also less likely to encounter interference from mood disorders or other mental health concerns. Chronic illness becomes a normal part of life for these persons.

Physicians see a need for more instruction in chronic care. The differences between chronic care and acute care result in strains when treating patients, particularly when addressing health behaviors and attitudes that may jeopardize patient success. Physicians express interest in tools and strategies that may enhance compliance, improve motivation and reduce depression.

Unmet Needs

1. **Training physicians.** Between 62 and 81 percent of physicians across specialties reported that they had not received sufficient instruction in chronic care as part of their training. Endocrinologists and psychiatrists expressed this need most strongly. While newer physicians are more satisfied with their training in this area, the medical model of training remains predominantly focused on diagnosis and symptom relief than on management. Physicians who are oriented to the distinctive parameters of chronic care (e.g., episodic rather than time-limited; management rather than diagnostics) will be better able to help patients with chronic conditions.

TABLE 12 Advice From Physicians on Improving Training for Chronic Care

Advice from physicians: When it comes to chronic illness, what one thing have you learned over the years that you wish you had known at the start of your career in medicine?

1. Managing chronic conditions

- Help motivate patients
- Explain goals to the patient
- Plan strategies to achieve goals

2. Managing depression

- Address depression on its own
- Evaluate impact of depression on other conditions

3. Promoting compliance

- Know what rate of noncompliance to expect
- Identify patients at risk for noncompliance
- Implement strategies to enhance compliance

Section V

Patient and Physician Needs for the Future

continued

“I wish I had more information on my condition and what I should do to help it, and what changes that I needed to make.”

—Patient Comment

2. **Providing patients information and education.** Patients crave knowledge. The study reveals particular patient interest in obtaining guidelines from research that demonstrates which treatments work best. Family, friends and the Internet are frequent sources of information, but the physician is the most esteemed. The consumerization of healthcare has leveled the asymmetry that once existed in which physicians controlled access to health information. Despite this change, physicians retain an indispensable role, personalizing and sorting information for their patients. As the duration of office visits decreases and physicians see more patients with chronic conditions, physicians need better methods for imparting knowledge/information to patients.

TABLE 13 Advice From Patients on Chronic Care

Advice from patients: Thinking about your medical condition, what one thing do you know now about working with your doctor or doctors that you wished you knew when you were first diagnosed?

- * Obtain a great deal of information about your condition
- * Keep notes while meeting with your physician
- * Write down questions you need to ask
- Be a partner in your medical care

3. **Assessing patients.** The path of chronic care is highly individualized. Our study suggested, for example, that some formative actions may occur at the time of diagnosis. One newly diagnosed patient with diabetes may commit to dietary changes and read more about the disease; another patient may simply wish the problem away. Successful chronic care often requires skills that are unfamiliar to many patients. There need to be methods for assessing whether a patient may be at risk for difficulties over the course of a chronic condition. These methods must be efficient enough to fit among other demands. Ideally, enhanced patient assessment would help physicians focus individualized attention on the patients who are most likely to encounter difficulties later.

4. **Delivery system structure.** Chronic care frequently results in an expansion of a physician’s job description requiring more than the traditional acute care responsibilities of diagnosis and treatment. The physician must dispense information, educate the patient and periodically review the patient’s progress. The social support network may be recruited into this process requiring additional time and contact. When there are lifestyle behavior targets, involving actions such as diet, exercise or medication compliance, additional resources are needed. How much can a physician be an agent for behavioral change, and how much of this process is best referred to other specialists? Novel arrangements are needed to address such aspects of chronic care. Such arrangements need to be formed and evaluated to learn which structures will most effectively increase patient access to the full range of potential services.

Section V

Patient and Physician Needs for the Future

continued

5. **Tackling the challenge of comorbidities.** There are high levels of multiple conditions within this survey that focused on patients with the highest levels of interference from chronic conditions: Only 16 percent reported a single diagnosis. Because of their relatively high prevalence, conditions such as arthritis, back problems and depression are particularly likely to occur alongside another chronic condition. Depending upon the condition, the synergy may be unfortunate. A person with diabetes and back problems may have trouble exercising therefore interfering with diabetic care. A person with congestive heart failure accompanied by depression may lose interest in managing a diet resulting in a possible increased severity of heart disease. New approaches are needed to help screen for comorbidities and to make it possible to care for them without jeopardizing continuity of care.

Section VI

From Paper to Practice

Chronic Care in America identifies numerous avenues for improving the patient-physician interaction and the success of patients managing chronic conditions. Some opportunities for physicians include:

Provide a “prescription for information”: Information is a form of therapy, helping patients understand, accept and manage their condition. The survey shows that patients who view themselves as being the most successful at living with their condition are more likely to read and learn about their condition compared with those who are unsuccessful. While they are accessing abundant health information on the Internet, the survey showed that 86 percent of patients relied on their doctors for information, more than any other source. Physicians can also direct patients to credible health websites or other places for health information.

Screen for depression: More than just feeling down, depression is a serious barrier to long-term success. Depressed patients are less likely to succeed in managing their condition: less than half (43%) of those who reported that they had been diagnosed with depression felt they were successful at managing their condition. It is also important to note that those with chronic illnesses have a 25-33 percent chance of being diagnosed with depression in addition to their other condition(s); this is a significantly higher risk than found in the general population.⁷

Make your patient a partner in care: The survey suggests that patients and physicians achieve success if they strike a balance of responsibility, moving toward greater collaboration in the management of illness. Today’s empowered consumer knows there are choices in care and therapy, and while patients look to their physician for information and advice, 55 percent of successful patients say their physician usually selects treatments with them, not for them.

Encourage action immediately after diagnosis: According to the survey, patients who have successfully managed their chronic condition responded to their diagnosis by swiftly thinking about the lifestyle changes needed and how to adapt to them. Conversely, those patients who were less successful tended to avoid the issue, deny the diagnosis, and withdraw. Specifically, 65 percent of unsuccessful patients wished their condition “would just go away” at diagnosis and 51 percent were afraid of becoming a burden. Patients were asked to think back to the diagnosis and talk about what would have been most helpful. The number one answer was learning more about their condition and symptoms earlier. However, an interesting disparity was identified between how much information physicians think they are providing and the amount of information patients believe they are receiving. Few patients said they had received information about websites from physicians, while more than half of the physicians interviewed said that they provided it.

Section VI

From Paper to Practice

continued

Encourage lifestyle changes: Change can be difficult, and most conditions require modifications in diet, exercise, and/or other day-to-day activities. While it is not surprising that successful patients are more likely to have made these types of changes, the question is what enables them to change. Successful patients worked on a plan of action immediately following diagnosis. Successful patients didn't simply separate themselves from the lives they had before diagnosis. Instead, they often relied on the people and things that had always been a source of strength to help them make constructive changes. Fifty-four percent of respondents said that their family and friends encouraged them to make needed changes in their lives.

As a result of these survey findings, GlaxoSmithKline has developed Chronic Care in Action™, a set of tools and resources to help physicians and medical groups better meet the needs of those with chronic conditions. Ask your GSK representative for more information on Chronic Care in Action™.

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