



# **Living With Chronic Illness: A Prescription for Advocacy**

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## **Living With Chronic Illness: A Prescription for Advocacy**

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Almost half of all Americans have a chronic health condition, and by the year 2030, fully half of the United States population will have a chronic illness.<sup>1</sup> The United States spent 85 percent of our health care dollars on people with chronic conditions in 2004.<sup>2</sup> People with chronic conditions are the most frequent users of health care in the United States, accounting for eighty-one percent of hospital admissions, ninety-one percent of prescriptions filled, and seventy-six of all physician visits.<sup>3</sup> Thus, if we are to get a handle on health care costs in America, we are going to have to better understand the experience of the chronically ill.

From March 2008 to March 2009, over 1500 patients with chronic illnesses completed a detailed survey reporting on their experiences as a patient and, in particular, the obstacles they face and the strategies they use to try to surmount those obstacles. The rich trove of data that resulted suggests important directives for advocates. In this paper, we will summarize the data and then draw what we believe are important points to be considered by advocates seeking to improve the experience, both within and outside of the health care system, of individuals with chronic illnesses.

### **I. Survey Methodology**

The National Institutes of Health, National Institute of Neurological Disorders and Stroke, issued an RFP for proposals that would bring researchers and community-based organizations together to study issues of common concern. The University of Michigan Center for Managing Chronic Disease (CMCD) conducts research that aims to build the capacity of individuals, families, communities, and health care systems to effectively prevent and manage chronic disease. Advocacy for Patients provides free information, advice and advocacy services to patients with chronic illnesses nationwide in areas including health and disability insurance, Social Security disability, employment and school-based accommodations, and resource location. Thus, each of us came to this project with a shared interest in chronic illness, but very different perspectives and experience.

At the start of the project, Advocacy for Patients selected twelve former clients – all either patients or caregivers – to act as a Patient Advisory Panel (PAP). The PAP were selected with the goal of diversity; they are spread across the country, both men and women, and several races/ethnicities are represented, and they have, or are caregivers for someone who has, digestive, neurological, or rheumatologic diseases. Through regular email communication and a series of seven group conference calls, the PAP collaborated with the study partners in the study design, recruitment and other implementation strategies, and analysis and interpretation of data.

The study participants comprised 1513 self-selected individuals residing across the United States. Of this number, 1426 completed an internet accessible version of the study questionnaire and 87 provided answers to the same questions in a telephone interview conducted by trained interviewers. The criterion for participation was a chronic physical condition diagnosed by a physician.

The opportunity to provide data for a survey either online or by telephone was publicized through major communication channels of voluntary organizations serving people with neurological, digestive, rheumatologic and other chronic conditions.<sup>4</sup> Advocacy for

Patients contacted over 2300 clients through direct mail, e-mail, and phone describing the opportunity to participate in the survey. In addition, several other organizations provided information on their websites and in newsletters regarding the survey; these included the Arthritis Foundation, Celiac Sprue Association, Crohn's & Colitis Foundation of America, Digestive Disease National Coalition, Hemophilia Federation of America, International Dravet Syndrome Epilepsy Action League, Kakkis Foundation, Lupus Federation of America, National Caregivers Association, National Marfan Foundation, National Multiple Sclerosis Society, and the Neuropathy Association. A raffle drawing of a \$100 gift card per every 250 completed surveys was offered as an incentive to potential respondents.

At the beginning of the survey, respondents reported the chronic diseases they have and then selected one disease on which to focus throughout the survey. Among these "diseases of focus," roughly thirty percent were digestive; thirty percent rheumatologic; seventeen percent neurologic; and the remainders were an array of other chronic illnesses including rare diseases such as Sjögren's syndrome and sarcoidosis. The most common diseases that respondents focused on in the survey were Crohn's disease (thirteen percent), multiple sclerosis (eleven percent), neuropathy (ten percent), and fibromyalgia (six percent). Over one-third of respondents (thirty-eight percent) reported having just one chronic disease, but the rest had more than one; forty percent had between two and four chronic diseases, and twenty-two had five or more chronic diseases.

The survey was divided into nine sections: demographics; respondents' means of financing health care; health care utilization; experience with health care providers; health related quality of life; emotional issues related to chronic illness; social support; self-management; and information seeking.<sup>5</sup> We used several previously created scales, both because they are well tested and to facilitate comparison with data from earlier studies. To gauge experience with health care providers, we used the RAND Patient Satisfaction Questionnaire (PSQ-18).<sup>6</sup> The Short-Form Health Survey (SF-36<sup>®</sup>) was used to assess physical functioning, the role of disease in physical and emotional functioning, bodily pain, general health perceptions, vitality, social functioning, and mental health.<sup>7</sup> The Center for Epidemiologic Studies Depression Scale (CES-D), which measures two key dimensions of depression – cognitive and somatic symptoms – was used to gauge emotional issues and, in particular, depression.<sup>8</sup> Social support was measured using the Perceived Support Scale developed by Krause & Markides.<sup>9</sup>

In addition to quantitative data, we asked several open-ended essay-type questions. In particular, at the end of each section, we asked what the respondent's greatest challenge in that area was, ways in which the respondent has overcome that challenge, and what else the respondent thinks might help to overcome the challenge. Scoring these qualitative responses was a time consuming challenge. Essentially, a codebook was developed through an iterative collaborative process among researchers, and one or more codes were linked to each response within NVivo 8.<sup>10</sup>

The survey took approximately one hour to complete. It was tested by several patients before it was available to the public. Trained interviewers at University of Michigan conducted the telephone surveys. Both the online and telephone versions permitted the respondent to save his/her responses mid-way through the survey for completion at a later time.

The survey was approved by the University of Michigan Institutional Review Board and all staff and volunteers who worked on the survey are certified in research on human subjects to ensure the highest ethical standards.

The data were downloaded, compiled and analyzed by the CMCD by experts in statistical analysis, with input, especially on the essay-type questions, from Advocacy for Patients. Several comparisons were performed at the suggestion of the PAP.

## II. Results

We present the results of the nine survey sections in order.

### A. Demographics

Survey respondents were overwhelmingly female (eighty-one percent female; nineteen percent male), Caucasian, highly educated, and middle to upper-middle class (see Tables 1 & 2). They were spread throughout the United States (see Table 3). Half live in suburban areas, twenty-eight percent in urban areas, and twenty-two percent in rural areas (see Table 4). Thirty-four percent were employed, and twenty-six percent were on either Social Security disability or private disability insurance (see Table 5).

**Table 1:** Race

White/Caucasian	93%
African-American	2%
More than one race	2%
Other	2%

**Table 2:** Highest Educational Level

Some high school	1%
High school graduate or GED	11%
Vocational or technical school	4%
Some college or Associates degree	28%
College degree	27%
Advanced graduate degree	25%
Other	3%

**Table 3:** Geographic Region

Northeast	28%
Midwest	23%
Southeast	20%
West	16%
Southwest	9%
International	4%

**Table 4:** Population Density

Suburban	50%
Urban	28%
Rural	22%

**Table 5:** Employment Status

Employed for wages	34%
On disability insurance or Social Security disability (SSI or SSDI)	26%
Unable to work	17%
Retired	14%
Out of work for more than one year	11%
Homemaker	8%
Self employed	8%
Student	6%
Out of work for less than one year	6%

### B. Health Care Financing

When asked about forms of assistance related to the cost of care for their condition, respondents reported the following sources: sixty-two percent have private health insurance; twenty-three percent have Medicare; and seven percent have Medicaid. In

addition, twenty-one percent indicate that they receive financial assistance from family members, twelve percent receive free medication or medical services, and eleven percent receive reduced cost medical services or medication.

In addition to these means of financing health care, many respondents receive other forms of assistance not specifically focused on medical care. Twenty-two percent receive Social Security disability, six percent are on private disability insurance, six percent receive food stamps, and two percent live in government subsidized housing.

Although over ninety percent of respondents have some form of health care financing – private insurance, Medicaid, or Medicare – over half of them said that they have skipped medical care or treatment due to cost, and twelve percent said that their single greatest challenge related to their disease is financial.

Finally, when asked an open-ended question about the greatest financial challenge, thirty-two percent said the cost of medical care, which is remarkable since most respondents have private insurance, Medicare, or Medicaid. Another fifteen percent said out-of-pocket medical expenses such as copay; eleven percent said they lost their job or were unable to work; another eleven percent said treatments not covered by insurance, including doctors who were outside of their insurer’s network; and another eleven percent said the cost of insurance itself is too high. (N=1384).

C. Health Care Utilization

On average, respondents reported that, in the preceding twelve months, they have visited an emergency department 1.04 times, spent 2.05 nights in the hospital, attended 10.98 scheduled doctor or clinic visits, and seen a doctor or clinic 2.04 times on an unscheduled basis.

When health utilization was examined by disease category, our analysis indicated significant differences among disease categories for each type of utilization ( $p < 0.0001$ ). Notably, those with digestive diseases reported the highest emergency room and hospital utilization, whereas those with rheumatologic and other diseases reported the highest doctor and clinic visits. Those with neurological disease reported the lowest overall healthcare utilization (see Table 6).

**Table 6:** Health Care Utilization by Category of Disease Focus

Disease of Focus	Overnight hospitalizations (past 12 months)		ER visits (past 12 months)		Scheduled doctor/clinic visits (past 12 months)		Unscheduled doctor/clinic visits (past 12 months)	
	Mean	SE	Mean	SE	Mean	SE	Mean	SE
digestive (n=458)	3.97	0.6	1.64	0.3	9.75	0.84	2.25	0.22
neurological (n=460)	1.05	0.21	0.57	0.09	7.7	0.6	1.05	0.11
rheumatologic (n=263)	0.99	0.22	0.91	0.13	14.11	1.48	2.43	0.25
other (n=334)	1.79	0.41	0.9	0.15	14.88	1.31	2.73	0.34

D. Experience with Health Care Providers

The RAND Patient Satisfaction Questionnaire (PSQ-18) yielded seven subscores, each calculated by computing the mean for the relevant items. Possible scores ranged from one to five, with a higher number indicating greater satisfaction (see Table 7).

**Table 7:** Subscores of Patient Satisfaction with Health Care

PSQ-18 Subscore	N	Mean	Std Dev	Std Error
General Satisfaction	1513	2.84	1.21	0.03
Technical Quality	1513	3.28	1.04	0.03
Interpersonal Manner	1513	3.90	0.97	0.03
Communication	1513	3.27	1.07	0.03
Financial Aspects	1487	2.69	1.32	0.03
Time Spent with Doctor	1511	3.14	1.17	0.03
Accessibility, Convenience	1513	3.31	0.96	0.02

An overall summary score was calculated from the PSQ-18; this score was examined by age, gender, and disease category; and an analysis of variance was conducted to determine the relationship between these factors and the summary score (see Table 8). Overall patient satisfaction tends to increase with age. No statistically significant differences in the score existed by gender. When examined by disease category (digestive, neurologic, rheumatologic, and other), statistically significant differences were apparent. Those with neurologic disease reported the greatest overall satisfaction, whereas those with diseases falling into the "other" category were least satisfied.

**Table 8:** Overall Patient Satisfaction by Age, Gender, and Disease Category

	Overall Summary Score of Patient Satisfaction with Health Care	
	Mean	Standard Error
<i>Age categories (yrs.)</i>		
18-29	18.73	0.4
30-39	17.85	0.31
40-49	18.63	0.28
50-59	19.54	0.24
60-69	20.59	0.35
70+	21.54	0.4
p-value	p<0.0005	
<i>Gender</i>		
Male	19.71	0.29
Female	19.11	0.15
p-value	p>0.05	

<i>Disease of Focus</i>		
digestive	19.55	0.24
neurological	20.31	0.23
rheumatic	18.55	0.31
other	17.83	0.28
p-value	p<0.0005	

Care coordination was an issue among respondents. Fully half of respondents said that their doctors do not communicate with each other to coordinate care, and seventy percent said they have to put in a lot of effort to manage health care providers and coordinate their own care. Care coordination was cited as a greater problem by those with rheumatologic diseases, as well as the “other” category.

Over forty percent said they’ve been told by a doctor that they weren’t really sick; twenty-seven percent were told by a doctor that they were mentally ill; nineteen percent said they were told that they were seeking unneeded drugs; and fourteen percent of them said that they have been told that they were taking up too much time. Fully thirty-four percent of respondents reported that a health care provider has given up on them, and fifty-eight percent felt that a doctor they saw did not understand the disease. All of these experiences were used to construct a single variable called “negative clinical experiences” wherein a higher score indicates more negative experiences. This score was slightly lower among respondents with neurological diseases.

Results of separate linear regressions of the “negative clinical experiences” variable described above and the RAND Patient Satisfaction Questionnaire (PSQ-18) on three types of assistance for cost of care (private health insurance, Medicaid, Medicare) are displayed in Table 9a and 9b respectively, below. The “negative clinical experiences” for patients with Medicaid are estimated to be 0.75 higher than those who did not receive Medicaid, suggesting that respondents who receive Medicaid have more negative clinical experiences. Patients who had private insurance, Medicare or both were more satisfied in every aspect of the PSQ-18 than those who did not have any form of health insurance or those who had Medicaid. In all patient satisfaction domains, those with Medicaid were equally or less satisfied with health care when compared with respondents without any health insurance.

**Table 9a:** Relationship between *Negative Clinical Experiences* Score and Insurance Status

Variable	Insurance Status	Estimated effect	SE	p
Negative Clinical Experiences	No health insurance <sup>a</sup> : mean=1.82 ±0.09			
	Private Health Insurance	1.87	0.10	0.61
	Medicare	2.00	0.11	0.12
	Medicaid	2.57	0.19	<.0001

a. no Medicare, Medicaid, or private health insurance coverage. Statistically significant scores are shown when P is 0.05 or less.

**Table 9b:** Relationship between Patient Satisfaction Scores and Insurance Status

Variable	Insurance Status	Estimated effect	SE	p
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<u>General Satisfaction</u> , a dimension of patient satisfaction with health care	No health insurance <sup>a</sup> : mean=2.71 ±0.06			
	Private Health Insurance	2.89	0.07	0.008
	Medicare	2.88	0.08	0.03
	Medicaid	2.53	0.13	0.15
<u>Technical Quality</u> , a dimension of patient satisfaction with health care	No health insurance: mean=3.17 ±0.05			
	Private Health Insurance	3.34	0.06	0.002
	Medicare	3.25	0.06	0.24
	Medicaid	2.98	0.11	0.07
<u>Interpersonal Manner</u> , a dimension of patient satisfaction with health care	No health insurance: mean= 3.74 ±0.05			
	Private Health Insurance	3.96	0.05	<.0001
	Medicare	3.88	0.06	0.02
	Medicaid	3.64	0.10	0.33
<u>Communication</u> , a dimension of patient satisfaction with health care	No health insurance: mean= 3.12 ±0.05			
	Private Health Insurance	3.31	0.06	0.002
	Medicare	3.29	0.07	0.011
	Medicaid	3.03	0.11	0.42
<u>Financial Aspects</u> , a dimension of patient satisfaction with health care	No health insurance: mean= 2.41 ±0.06			
	Private Health Insurance	2.72	0.07	<.0001
	Medicare	2.76	0.08	<.0001
	Medicaid	2.43	0.14	0.89
<u>Time Spent with Doctor</u> , a dimension of patient satisfaction with health care	No health insurance: mean=2.98 ±0.06			
	Private Health Insurance	3.18	0.06	0.003
	Medicare	3.13	0.07	0.04
	Medicaid	2.97	0.12	0.93
<u>Accessibility, Convenience</u> , a dimension of patient satisfaction with health care	No health insurance: mean=3.10 ±0.04			
	Private Health Insurance	3.38	0.05	<.0001
	Medicare	3.32	0.06	0.0002
	Medicaid	2.93	0.10	0.09
<u>Overall Summary Score</u> of patient satisfaction with health care	No health insurance: mean=18.17 ±0.24			
	Private Health Insurance	19.59	0.28	<.0001
	Medicare	19.30	0.32	0.0004
	Medicaid	17.39	0.53	0.14

a. no Medicare, Medicaid, or private health insurance coverage. Statistically significant scores are shown when P is 0.05 or less.

When asked an open-ended question about the greatest challenge related to getting medical care, thirty-two percent said finding competent physicians and getting good medical treatment; sixteen percent said communication with a physician; fourteen percent said financial/insurance problems; and ten percent said finding the right combination of medication to get the disease under control. (N=1480).

E. Quality of Life

The Short Form Health Survey (SF-36®) was used to assess physical functioning, the role of disease in physical and emotional functioning, bodily pain, general health perceptions, vitality, social functioning, and mental health. Two summary measures were calculated – the physical component summary (PCS) and the mental component summary (MCS). The PCS and MCS scales are scored using norm-based methods; the means, standard deviations, and factor score coefficients used in scoring come from the general United States population. All scores above and below 50 are above and below the average, respectively, in the general adult population. The standard deviation is ten (10) for both PCS and MCS.

Results show that all quality of life scores, when stratified by gender and disease category, are below national averages, and many are below the range that accounts for standard deviation. Overall, men tend to score higher in both the physical and mental components, indicating greater quality of life. Among both men and women, those with digestive disease scored higher than other diseases categories, and those with rheumatologic diseases scored lowest in terms of quality of life. Mental component scores did not vary significantly among men according to disease category, but among women, those with rheumatologic disease scored significantly lower than women with neurological disease (see Table 10). When stratified by age, the mean physical health summary score decreases with age, whereas the mental health summary score increases with age (see Table 11).

**Table 10:** Health-related Quality of Life by Gender and Category of Disease of Focus

Gender	Disease-of-Focus Category	SF-36			
		PCS <sup>a</sup>		MCS <sup>b</sup>	
		Mean	SE <sup>c</sup>	Mean	SE
Male	Digestive (N=98, 34%)	40.39	1.23	40.45	1.33
	Neurological (N=109, 38%)	34.84	1.11	43.25	1.23
	Other (N=61, 21%)	32.9	1.45	37.99	1.62
	Rheumatologic (N=18, 7%)	31.17	2.6	41.5	3.47
	p-value	<0.0001		0.08	
Female	Digestive (N=358, 29%)	37.17	0.62	39.37	0.62
	Neurological (N=349, 29%)	33.78	0.65	42.73	0.66
	Other (N=272, 22%)	29.96	0.69	40.83	0.74
	Rheumatologic (N=244, 20%)	27.2	0.56	40.29	0.78
	p-value	<0.0001		0.003	

- a. PCS = physical component summary
- b. MCS = mental component summary
- c. SE = standard error

**Table 11:** Health-related Quality of Life by Age

Factor	SF-36			
	PCS <sup>a</sup>		MCS <sup>b</sup>	
	Mean	SE <sup>c</sup>	Mean	SE
Age				
18-29 (n=137)	37.89	1.09	38.28	0.97
30-39 (n=267)	35.24	0.75	38.26	0.77
40-49 (n=346)	32.48	0.63	39.21	0.66
50-59 (n=452)	31.92	0.55	40.74	0.57
60-69 (n=213)	32.63	0.84	45.58	0.8
70+ (n=93)	31.41	1	48.3	1.09

a. PCS = physical component summary

b. MCS = mental component summary

c. SE = standard error

When asked an open-ended question about the greatest challenge to quality of life, twenty percent said fatigue and lack of energy; fifteen percent said pain; twelve percent said influence on career and career ambitions or work-related challenges; ten percent said emotional challenges; and ten percent of mobility and balance issues. (N=1498).

#### F. Emotional Issues

When asked to report the chronic diseases they had, 234 respondents (fifteen percent) indicated they had clinical depression. All respondents completed the short version of the Center for Epidemiologic Studies Depression Scale (CES-D), which measures two key dimensions of depression – cognitive and somatic symptoms. Possible scores for each dimension ranged from zero to 12, with a higher score indicating more symptomatology. For those aged 40 and older, symptomatology decreased by age (see Table 12). Women scored higher than men on all depression scores: cognitive, somatic, and overall. Similarly, respondents with rheumatologic disease scored highest on all three depression scores, and those with neurological disease had the lowest mean scores.

**Table 12:** Center for Epidemiologic Studies Depression (CES-D) Scores by Age, Gender, and Disease Category

	CES-D: Cognitive Symptoms (range 0-12)		CES-D: Somatic Symptoms (range 0-12)		CES-D: total	
	Mean	StdErr	Mean	StdErr	Mean	StdErr
<i>Age categories</i>						
18-29	3.36	0.3	5.38	0.31	8.7	0.57
30-39	3.28	0.21	5.56	0.23	8.75	0.4
40-49	3.64	0.22	6.06	0.2	9.69	0.38
50-59	3.2	0.17	5.67	0.18	8.95	0.33
60-69	1.85	0.21	4.12	0.24	5.95	0.41
70+	1.6	0.26	3.63	0.33	5.27	0.57
<i>Gender</i>						

Male	2.69	0.21	4.76	0.23	7.43	0.42
Female	3.13	0.1	5.52	0.1	8.68	0.19
<i>Disease of Focus - Category</i>						
digestive	3.1	0.17	5.26	0.18	8.24	0.31
neurological	2.65	0.16	4.75	0.17	7.47	0.33
Other	3.14	0.2	5.9	0.2	9.2	0.36
rheumatologic	3.55	0.24	6	0.22	9.52	0.43

When asked an open-ended question about the greatest emotional challenge, seventeen percent said loss of independence and powerlessness; twelve percent said disappointment in and hurt by others' lack of understanding; twelve percent said depression; and eleven percent said the struggle to keep going and stay positive. (N=1452).

### G. Social Support

Social support was measured using the Perceived Support Scale by Krause & Markides.<sup>11</sup> Ten items measure tangible, emotional, and informational support and are summed to form a composite score (range 11-44) with higher scores indicating more support.

Respondents aged 18-39 reported the most social support, and degree of support varied little among those aged 40 and older. Women reported greater support than men. There were no significant differences in the social support scores based on disease category (see Table 13).

**Table 13:** Social Support Scores by Age, Gender, and Category of Disease of Focus by Age, Gender, and Disease Category

Factor	Social Support	
	Mean	SE
<i>Age</i>		
18-29 (n=137)	27.46	0.6
30-39 (n=267)	25.32	0.42
40-49 (n=346)	24.52	0.36
50-59 (n=452)	23.96	0.33
60-69 (n=213)	23.38	0.5
70+ (n=93)	24.33	0.76
p-value	p<0.0005	
<i>Gender</i>		
Male (n=286)	22.52	0.42
Female (n=1223)	25.06	0.2
p-value	p<0.0005	
<i>Disease of Focus</i>		
Digestive (n=456)	24.68	0.34
Neurological (n=460)	24.6	0.33
Other (n=334)	24.42	0.39

Rheumatic (n=263)	24.68	0.42
p-value	p>0.05	

When asked an open-ended question about the greatest challenge in getting support from family and friends, thirty-six percent said lack of understanding and another ten percent said they can't get enough support from family and friends. (N=1382)

#### H. Self-Management

A constructed variable called "barriers to disease management" was created by averaging scores from items developed by the study's patient advisors. Scores ranged from 1 to 5, with a higher score indicating more barriers. Items used to construct the variable are the following:

- I have difficulty remembering to perform management tasks.
- Lack of energy makes it difficult for me to perform management tasks.
- My mood can make it difficult for me to perform management tasks.
- I am concerned about the potential harms/side effects of management tasks.
- I don't complete certain management tasks because they would take away from my quality of life.
- I have difficulty determining the appropriate management tasks based on my symptoms.
- I have trouble keeping on top of a complex medication regimen.
- I have trouble managing my condition because the condition or medication reduces my ability to think well.

When examined by category of disease of focus, respondents with rheumatologic disease reported the greatest barriers to disease management, whereas those with digestive reported the fewest barriers ( $p < 0.0001$ ). As expected, barriers increase as the number of chronic diseases a person has increases ( $p < 0.0001$ ). Also not surprisingly, higher socio-economic status was associated with fewer barriers; both those with more education and those with higher income reported fewer barriers than those with little education or lower income ( $p < 0.0001$ ). Those covered by Medicare or Medicaid reported more barriers than those with private health insurance. No significant differences in barriers were seen between men and women. Interestingly, reported barriers generally declined with age ( $p < 0.0001$ ).

The score of barriers to disease management is significantly negatively correlated with each of the Patient Satisfaction Questionnaire subscores, indicating a predictive relationship between more barriers to disease management and less patient satisfaction (see Table 14).

**Table 14:** Correlation between Barriers to Disease Management and Patient Satisfaction

		P
PSQ: General Satisfaction	-0.36	<.0001
PSQ: Technical Quality	-0.33	<.0001
PSQ: Interpersonal Manner	-0.30	<.0001
PSQ: Communication	-0.32	<.0001
PSQ: Financial Aspects	-0.31	<.0001

PSQ: Time Spent with Doctor	-0.30	<.0001
PSQ: Accessibility, Convenience	-0.34	<.0001
PSQ: Overall	-0.42	<.0001

When asked an open-ended question about the greatest challenge related to day to day management of your condition, eighteen percent said remembering to take medications and scheduling medication; twelve percent said lack of energy/rest; and eleven percent said dietary changes. (N=1386).

#### I. Information Seeking

We asked several questions about where respondents get information regarding their illness. Sixty-nine percent of respondents believe that they have a lot of knowledge about their disease. About eighty-three percent of them get information from their doctor, and many of them get information from sources including family, friends, the library, and organizations. However, overwhelmingly – ninety-two percent – respondents stated that they get information from the internet. Ninety-seven percent of respondents have a computer and an internet connection.

Approximately half of respondents – forty-six percent – have been unable to get scientific information that they wanted. However, fifty-eight percent are satisfied with the scientific information they have gotten. Only fourteen percent of them have participated in a clinical trial, and ten percent of them were asked to do so but declined. When asked why they declined, common responses were: not interested; unwilling; study required unwanted procedure; fear of side effects; and fear of their condition getting worse. One quarter of respondents said that the most important type of research is research to find treatments; eighteen percent said symptom control and management; and twelve percent said research to find the cause of disease.

#### J. Overall Greatest Challenge

At the end of the survey, when asked about the single greatest challenge overall, twelve percent said financial and insurance difficulties, despite the fact that the vast majority have public or private health insurance. Ten percent said acceptance of the diagnosis and one's limitations, nine percent said pain management, and another nine percent said managing emotional challenges. Eight percent said finding good medical care, and another eight percent said lack of energy/fatigue. (N=1393).

### III. **Limitations of the Data**

Although the survey aimed to recruit a sample reflective of our nation's diversity, a limitation of the study is that respondent's were largely white, highly educated, affluent women. It is striking that, despite these demographic advantages, this group reported significant challenges, as described above. The heavy response by women may suggest that they feel a considerable burden from their conditions and are motivated to seek opportunities to discuss their experience.<sup>12</sup> Problems expressed by women may or may not be the same as those expressed by men. Further, we expect that we would see even greater challenges among minority respondents and those at low socio-economic status. Conscious and deliberate efforts at recruiting more men, minorities, and respondents at low socio-economic status should be made in future study.

#### IV. Lessons for Advocacy

We consider the data's import for health advocacy in three categories: Health care financing; the patient experience with health care; and the use of the internet as a tool in chronic disease management. These affect health care access in different ways. Financing, or the lack thereof, affects access to care in obvious ways; the patient experience may make patients more or less likely to seek access to preventive and routine care maintenance, without which their health deteriorates and we as a society spend more to treat conditions that have spiraled out of control<sup>13</sup>; and the internet is a major source of information for the chronically ill, and may hold great promise for low-cost, effective methods of chronic disease management. Thus, all of these broad categories should be of interest to health advocates.

##### A. Health Care Financing

From the point of view of health advocacy – an area dominated over the past two years by discussions of health insurance and health care reform – perhaps the most striking, albeit unsurprising, data relate to financing of health care. Although sixty-two percent of respondents have private health insurance, twenty-three percent have Medicare, and seven percent have Medicaid, more than half of them reported that they have skipped medical treatment due to cost.<sup>14</sup> Thus, advocates must be mindful of the impact of under-insurance on the ability of people to access the care they need. What is and is not included in the essential benefits package that will become the standard for insurance coverage under health reform, effective in 2014,<sup>15</sup> will have a tremendous impact on the ability of patients to obtain the care they need. One thing is certain: Achieving universal coverage is not the whole answer<sup>16</sup>; what is and is not covered matters just as much if one of our goals is to ensure that patients with chronic conditions adhere to doctors' orders so as to improve health outcomes and reduce costs.<sup>17</sup>

Quite a few respondents reported financial difficulties related to items not typically covered at all by insurance. For example, twenty-three respondents with Celiac disease indicated that their greatest financial challenge is purchasing gluten-free food, and eleven respondents said that their greatest financial challenge is paying for transportation to and from medical appointments. Advocates and policy-makers should consider ways to promote access to non-medical aspects of treatment.

Also relevant to cost is the fact that digestive disease patients go to the emergency room or are admitted to a hospital more often than patients with rheumatologic, neurological, or other illnesses. Further research is needed to determine the reason for these differences. It may be beneficial for digestive disease patients and physicians to discuss strategies for coping with emergencies. The advent of medical homes with 24/7 telephone access to physicians also seems appealing in light of the data.<sup>18</sup>

The data also confirm what many advocates already know, that the clinical experience differs with one's insurance status. Respondents on Medicaid have a significantly more negative experience than do patients with private insurance or Medicare, and patients with private insurance have the most positive clinical experience. Indeed, the experience of patients with Medicaid is not significantly better than that of people with no insurance at all. Table 9b shows that patients with private health insurance have significantly greater general satisfaction than those with no insurance, and that same phenomenon is apparent with every aspect of patient satisfaction. Strikingly, the difference in patient satisfaction among Medicaid recipients and those with no insurance is not

statistically significant in most respects. As advocates know, this probably is largely due to the low provider reimbursement rates in Medicaid, which clearly adversely affect patient satisfaction.

## B. The Patient Experience

Again, if we begin with the widely-accepted view that care costs less when people seek preventive and routine maintenance care, thereby preventing their illness from spinning out of control,<sup>19</sup> then ways to improve the patient's experience in interacting with the health care system and managing their own disease is an important component of good public policy.

If we consider all health care encounters, it appears that the frequency and extent of health care utilization does not necessarily relate to patient satisfaction and quality of life in consistent directions. For example, although patients with digestive diseases have the most hospitalizations, they also have the highest quality of life scores; and although patients with neurological illnesses have the lowest health care utilization, they have the highest patient satisfaction.

However, if we consider just the number of doctor visits per year, there appears to be a strong relationship between number of doctor visits per year, patient satisfaction, and quality of life. That is, groups of patients with higher numbers of doctor visits tend to have lower patient satisfaction scores and lower quality of life scores. If confirmed by other research, this would be an important point for advocates as we attempt to promote the growth of patient-centered care to ensure the issues of satisfaction and quality of life are attended to in the clinical visit.

It is important to note that, when we talk about quality of life, we are focused on a matter of degree. All respondents reported a lower quality of life score – both physical and mental health – than the national average. Indeed, the PSQ-18 subscores indicate less satisfaction among the respondents to our survey when compared with results from earlier studies of adult women with HIV<sup>20</sup> and adults with diabetes, heart disease, hypertension, or depression.<sup>21</sup> The quality of life of the respondents to our survey is not good, by any means.

Interestingly, there appears to be a connection among frequency of doctor visits, somatic symptoms, patient satisfaction, and quality of life. Indeed, the patients with the fewest number of doctor visits (neurological) had the best somatic symptoms scores, the highest patient satisfaction scores, and the second highest quality of life scores. Patients with the second fewest doctor visits (digestive) had the second highest patient satisfaction scores, the highest quality of life scores, and the second best somatic symptom scores. Conversely, those who reported the most doctor visits (rheumatological and other) report more somatic symptoms, lower patient satisfaction scores, and lower quality of life. The rankings are shown in Table 15, with 1 being the most positive scores and 4 being the least positive.

**Table 15:** Rankings

	<b>Digestive</b>	<b>Neurological</b>	<b>Rheumatological</b>	<b>Other</b>
<b>Doctor visits</b>	Second fewest	fewest	Second most	most
<b>Patient satisfaction</b>	2	1 (highest)	3	4 (lowest)
<b>Quality of Life</b>	1 (highest)	2	4 (lowest)	3
<b>Somatic Symptoms</b>	2	1 (fewest)	4 (most)	3
<b>Barriers to Disease Management</b>	1 (fewest)	2	4 (most)	3

The other factor that is very interesting is the variable we constructed called “barriers to disease management.” The PAP assisted us to identify those items that should comprise this variable, and this variable, too, tends to correspond with quality of life scores. In other words, patients with digestive diseases reported the fewest barriers to disease management and the highest quality of life; patients with rheumatologic diseases reported the greatest number of barriers and the worst quality of life.

For health advocates, the associations among patient satisfaction, barriers to disease management, somatic symptoms, and quality of life means that patient satisfaction surveys are not trivialities, nor should they be after-thoughts. One obvious way to improve patient satisfaction is to collect feedback from patients, organize it in a thoughtful way, and present it to health care providers with concrete suggestions.

Similarly, barriers to disease management should be identified and alleviated to the extent possible. While a lack of energy may not be something that can be changed readily, patients can be taught self-regulation skills to help them remember to perform management tasks, stay on top of a complex medication regimen, discuss and alleviate concerns about medication side-effects and so on.

The analysis of barriers to disease management also underscores the importance of caregivers. Where the patient has a lack of energy or cognitive issues related to their illness, a caregiver can help patients surmount these barriers.

Finally, the perceived lack of care coordination and the need for the patient to conduct his or her own disease management without adequate training and supports are significant burdens for all patients. As we move into different delivery systems like patient-centered medical homes and accountable care organizations, hopefully, those burdens will lessen. In addition, as seen in the next section, the internet is an inexpensive resource that may currently be an under-utilized care management tool.

### C. The Internet’s Role in Chronic Disease Management

Finally, we were somewhat surprised that the vast majority of respondents chose to take the survey by internet rather than by telephone. Indeed, had the PAP not strongly urged us to make the survey available online, we would have offered only the telephone version. Almost all of the 1513 respondents have internet access, and the overwhelming majority get information about their illness online. We should be concerned, then, about whether the information they are getting is accurate, and whether it assists them in managing their illness.

The Center for Managing Chronic Disease has pioneered a self-regulation model of chronic disease management.<sup>22</sup> This model differs from other chronic disease self-management programs by incorporating self-regulation – self-observation, making judgments based on those self-observations, and reacting to those judgments, which, over time, will lead to “modification of management strategies and sometimes modification of the goal itself.”<sup>23</sup> Training patients in self-regulation skills has been tested in in-person programs and programs conducted over the telephone, but it has not yet been tested in online programs. There are many possible benefits to the use of the internet for teaching self-regulation as a tool in chronic disease management; primarily, it would allow patients to engage in training modules teaching self-regulation on their schedule, at their pace, which may increase compliance and, thus, the effectiveness of the intervention.

Of course, there are other means of chronic disease self-management. For example, Stanford School of Medicine offers a workshop in chronic disease self-management.<sup>24</sup> Several Medicaid programs have initiated disease management programs,<sup>25</sup> as well, and the Affordable Care Act encourages the advent of medical homes.<sup>26</sup> At the very least, offering courses and programs like these to patients with chronic illnesses using the internet rather than in-person training sessions would make the program more easily available to patients nationwide.

Internet access is a way for patients who have limited mobility and/or are homebound to access chronic disease management tools. Social networking sites like Patients Like Me and EmpowerHER.com recognize the role the internet may play in allowing patients to socialize and feel less isolated. There is every reason to believe that the internet can play a similar role in teaching patients the tools they need to better manage their own illnesses. Researchers developing chronic disease management strategies should incorporate the internet in their plans.

#### D. Further Research

The fact that our sample of respondents is not representative of the general population limits the generalizability of our results, and suggests one critical goal for future research. Efforts must be made to recruit respondents who are more representative of the population as a whole and, in particular, racial and ethnic minorities. While we surely can guess, based on the literature about health disparities, that the experience of racial and ethnic minorities is worse, not better, than that of our respondents, we should not guess. The study also did not ask participants about their sexual orientation, another axis of diversity where health inequities are prevalent.<sup>27</sup> More research is needed.

Although we recruited broadly, not only from among Advocacy for Patients’ clients, but also through national specific disease organizations, we did not succeed in reaching a representative cohort of people. We would suggest, in the future, that researchers actively recruit through hospital emergency rooms, community health centers, and neighborhood or grass roots organizations.

Based on the fact that so much of our recruitment was accomplished via the internet, it is entirely possible that our optimistic view of the use of the internet as a tool in teaching chronic disease management is based, at least in part, on the limitations of our recruitment methodology. Further research is required on this point.

## V. Conclusion

The wealth of data derived from this project provides important information for advocates, as well as for health care providers and patients. The difficulty of affording care for all patients, the particular dissatisfaction among Medicaid recipients, and the correlation between health care utilization, on the one hand, and quality of life, patient satisfaction, somatic symptoms, and barriers to disease management, on the other, is an interesting phenomenon that warrants further study. The internet is an important tool that may hold great promise in assisting patients with chronic disease management.

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<sup>1</sup> Anderson G, *Chronic Conditions: Making the Case for Ongoing Care* 5, 8 (Nov. 2007). <[http://www.fightchronicdisease.org/sites/default/files/docs/ChronicCareChartbook\\_FINAL\\_O.pdf](http://www.fightchronicdisease.org/sites/default/files/docs/ChronicCareChartbook_FINAL_O.pdf)>

<sup>2</sup> *Ibid.* at 7.

<sup>3</sup> Anderson, G. *Chronic Conditions: Making the Case for Ongoing Care* 22 (September 2004, Robert Wood Johnson Foundation).

<sup>4</sup> We deliberately avoided recruiting patients with diabetes and asthma because the CMCD already has done so much work with those diseases, or currently is conducting other research into those diseases.

<sup>5</sup> We also asked about the respondent's perception of the role of the National Institutes of Health. These findings are omitted from this paper.

<sup>6</sup> Marshall GN, Hays RD. *The patient satisfaction questionnaire short-form (PSQ-18)*. Santa Monica, RAND, 1994.

<sup>7</sup> Ware JE, Sherbourne CD. *The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection*. *Medical Care* 1992; 30(6): 473-483.

<sup>8</sup> Radloff LS. *The CES-D Scale: A Self Report Depression Scale for Research in the General*. *Applied Psychological Measurement* 1977; 1(3): 385-401.

<sup>9</sup> Krause N, Markides K. *Measuring social support among older adults*. *International Journal of Aging and Human Development* 1990; 30(1): 37-53.

<sup>10</sup> Not all respondents answered every essay question, so when the data is presented, we also indicate the number of respondents who answered the question.

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<sup>11</sup> See, *supra*, note 9.

<sup>12</sup> Women have greater health needs than men and generally play larger roles in the health care of family members. Robertson R, Collins SR, *Women At Risk: Why Increasing Numbers of Women are Failing to Get the Health Care they Need and How the Affordable Care Act will Help* 1 (Commonwealth Fund May 2011).

<sup>13</sup> Council on State Governments, *State Officials' Guide to Chronic Illness* x (2003) (diabetes, high blood pressure, heart disease and schizophrenia all spiral out of control when preventive and routine maintenance care are not provided). See also *ibid.* at xi ("Improved prevention and treatment for chronic illness is one of the few potential strategies that may manage health care costs while increasing quality and improving client satisfaction.").

<sup>14</sup> In the general population, 54 percent of the chronically ill have private insurance. See *supra* note 1 at p. 11. Among the privately insured with chronic conditions, 9.5 percent reported having unmet prescription drug needs in 2006, compared to thirty-three percent of the uninsured. Hoffman C, Schwartz K. *Eroding Access Among Nonelderly Adults with Chronic Conditions: Ten Years of Change* (July 2008, Kaiser Family Foundation). <<http://www.kff.org/uninsured/kcmu072208pkg.cfm>>. In 2010, thirty-one percent of adults with private insurance had a cost-related problem accessing needed care. Collins SR, et al., *Help On the Horizon: How the Recession Has left Millions of Workers Without Health Insurance, and How Health Reform Will Bring Relief* xiii (Commonwealth Fund March 2011).

<sup>15</sup> Affordable Care Act at § 1302.

<sup>16</sup> Twenty-six respondents stated that the best solution to this problem would be "universal healthcare," and five expressly referred to President Obama's health reform plan.

<sup>17</sup> Michie S, et al., *Patient-centeredness in chronic illness: what is it and does it matter?* Patient Education and Counseling 2003;51:197-206 at 204; Hibbard JH, *Engaging Health Care Consumers to Improve the Quality of Care*. Medical Care 2003;41(1):1-61-1-70.

<sup>18</sup> See, e.g., NCOA Patient Centered Medical Home 2011. <[http://ncqa.org/Portals/0/Programs/Recognition/2011PCMHbrochure\\_web.pdf](http://ncqa.org/Portals/0/Programs/Recognition/2011PCMHbrochure_web.pdf)>.

<sup>19</sup> See *supra* note 13.

<sup>20</sup> Burke, J. & Cook, J. (2000). The validity and reliability of an established patient satisfaction question measure: Does it work for low-income, minority women with HIV?. *International AIDS Conference*, Durban, South Africa.

<sup>21</sup> Marshall, *supra*, note 6.

<sup>22</sup> Clark NM, et al., *A Model of Self-Regulation for Control of Chronic Disease*. Health Education and Behavior 2001; 28(6): 769-782. See also Clark NM, et al., *A Randomized Trial of a Self-Regulation Intervention for Women with Asthma*. Chest 2007;132: 88-97.

<sup>23</sup> *Ibid.* at 771.

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<sup>24</sup> See Chronic Disease Self-Management Program at <<http://patienteducation.stanford.edu/programs/cdsmp.html>>. This program is explained in more detail in Lorig, JR, et al., *Evidence suggesting that a chronic disease self-management program can improve health status while reducing utilization and costs: A randomized trial*. *Medical Care* 1999; 37(1): 5-14.

<sup>25</sup> See *supra* note 13 at xiv-xvi.

<sup>26</sup> Affordable Care Act at § 1115A(b)(2)(B).

<sup>27</sup> Conron KJ, Mimiaga MJ, Landers SJ. *A population-based study of sexual orientation identity and gender differences in adult health*. *Am J Public Health*, 2010;100(10):1953-1960.