

BEING SERIOUSLY ILL IN AMERICA TODAY

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In a period of sweeping changes in the health care and health insurance systems in the U.S., the question emerges of how those with the most serious illnesses are faring. This survey is relatively unique in that it focuses on the most seriously ill adults in the country, involving people who have hospitalized multiple times and are seeing multiple physicians, related to a serious illness, medical condition, injury, or disability (see Methodology).

The results address seven key questions:

1. Are seriously ill patients today being protected from large medical bills by their existing health insurance coverage?
2. In this environment, is their experience of being hospitalized what they thought they needed in dealing with their serious illness?
3. Similarly, is their experience with their physician care what they thought they needed in dealing with their serious illness?
4. Today, are seriously ill people facing significant barriers to getting the care they need?
5. What are the financial, employment, and psychological consequences of being seriously ill?
6. Seriously ill people often require extensive care at home. Is their experience with their care at home what they thought they needed in dealing with their serious illness?
7. Many seriously ill people try different strategies to make the health care system work better for them as patients. What strategies, if any, are seriously ill people using to try to improve their care situation, and have they been helpful?

1. The Adequacy of Health Insurance Coverage

About nine in ten seriously ill patients (91%) have health insurance coverage. Are they being protected from serious problems paying their medical bills? The survey shows that while most people are financially protected, a substantial minority are not. About one-third (34%) report serious problems paying their hospital bills, and about three in ten (29%) report serious problems paying for their prescription drugs. In addition, 27% report having serious problems paying for dental care and 26% paying emergency room bills, (Table 1).

Among seriously ill patients who have health insurance coverage, these numbers about financial problems are still high. Thirty-one percent report serious problems paying their hospital bills, and 27% say they have problems paying for their prescription drugs.

Table 1. Problems seriously ill adults have in paying medical bills (in percent)

Had a serious problem paying...	
Hospital bills	34
For prescription drugs	29
Dental care bills	27
Emergency room bills	26
Bills for doctor's office visits	23
For ambulance services	20
For home care services	15
For medical equipment for use at home	15

Source: The Commonwealth Fund/The New York Times/Harvard T.H. Chan School of Public Health, Being Seriously Ill in America Today, July 6 – August 21, 2018. N= 749 seriously ill adults.

Prescription drug costs are near the top of the list of serious problems paying bills among this population. In the survey 57% of seriously ill patients say they are taking five or more prescriptions. Eleven percent report taking a prescription medicine that costs them or their health insurance plan more than \$50,000 per year. Of this latter group, 44% report having serious problems paying for these expensive prescriptions.

Nearly half (47%) say that after their last overnight hospitalization they received a bill for doctors or services not fully covered by their health insurance policy. This includes 16% who report receiving a bill for services provided by health professionals not affiliated with their health insurance plan.

About three in ten seriously ill patients (31%) report that when they were getting care from a doctor, they had a problem understanding what their health insurance covered.

2. Hospital Experiences

Hospital care is very important to the seriously ill, who have been hospitalized multiple times with major illness. What are experiences of this group with their hospital care?

The problems with their hospital care most frequently reported by seriously ill patients are the hospital staff not being responsive to their needs (22%) and receiving conflicting information from different health professionals (18%) (Table 2). About one in five seriously ill patients (21%) would not recommend their hospital to someone else who has the same medical or health condition (Table 3).

Table 2. Problems with care experienced by the seriously ill the last time they were hospitalized overnight (in percent)

Each of these was a problem	
Hospital staff was not responsive to (your/his/her/their) needs	22
Receiving conflicting recommendations from different health professionals	18
Getting help at home after (you/he/she/they) left the hospital	15
(You/He/She/They) could not understand what was being done to (you/him/her/them)	15
Difficulty scheduling hospital admission, tests, or discharge	13
Transportation to or from the hospital	13

Source: The Commonwealth Fund/The New York Times/Harvard T.H. Chan School of Public Health, Being Seriously Ill in America Today, July 6 – August 21, 2018. N= 745-750 seriously ill adults.

Table 3. Seriously ill adults' views on whether they would recommend their hospital and doctor to someone else who has the same medical or health condition (in percent)

	Hospital where you received care during last overnight hospitalization	Doctor most responsible for recent care
Would recommend	76	82
Would not	21	14
Don't know/Refused	3	4

Source: The Commonwealth Fund/The New York Times/Harvard T.H. Chan School of Public Health, Being Seriously Ill in America Today, July 6 – August 21, 2018. N=750 and 745 seriously ill adults.

More than eight in ten seriously ill patients (83%) report being satisfied with the role they played with they were given in choices for their treatment the last time they were hospitalized overnight, but 15% were dissatisfied. Less than half of seriously ill patients were asked what their personal preferences would be if a critical situation should arise such as their heart stopping (49%) or their facing the need to be placed on a ventilator or breathing tube (44%).

Nearly one in four seriously ill patients report experiencing a serious medical error, including 14% who said the error or most recent error happened at a hospital, 7% at a doctor’s office or clinic (Table 4)

Table 4. Seriously ill adults’ experiences with medical errors (in percent)

A serious medical error was made in treatment or care	23
At a hospital	14
At a doctor’s office or clinic	7
Somewhere else	2
A serious medical error was not made	75
Don’t know/Refused	3

Source: The Commonwealth Fund/The New York Times/Harvard T.H. Chan School of Public Health, Being Seriously Ill in America Today, July 6 – August 21, 2018. N= 1,495 seriously ill adults.

3. Physician Experiences

Seriously ill people report visits with multiple physicians over the recent period of time. About six in ten (62%) report having seen five or more doctors over the past three years. Nine in ten (90%) say they have a personal doctor. Most (82%) say they would recommend the doctor most responsible for their recent care to someone else who has the same medical condition they have (Table 2).

Across the care experiences received from a number of physicians, a substantial minority of seriously ill patients report significant problems. About three in ten say they were sent for duplicate tests or diagnostic procedures by different doctors (29%). About one in four say having to wait too long for treatments, tests, and appointments (23%) and receiving conflicting recommendations from different health professionals (23%) were problems for them (Table 5).

Most seriously ill patients have not received cost-of-care information from their physician. More than two-thirds (69%) report that their doctor did not discuss the cost and charges of their care with them.

Table 5. Problems with care experienced by the seriously ill when getting care from a doctor (in percent)

Each of these was a problem	
You were sent for duplicate tests or diagnostic procedures by different doctors, nurses or other healthcare workers	29
You had to wait too long for treatments, tests, or appointments	23
Receiving conflicting recommendations from different health professionals	23
Transportation to or from the doctor's office	21
Understanding your doctor bill	21
The doctor was not responsive to your needs	19
You left a doctor's office without getting important questions about your care or treatment answered	19
Your medical records or test results did not reach your doctor's office in time for your appointment	17
You could not understand what was being done to you	14
Understanding the instructions for a prescription medication you were taking	14

Source: The Commonwealth Fund/The New York Times/Harvard T.H. Chan School of Public Health, Being Seriously Ill in America Today, July 6 – August 21, 2018. N= 612-616 seriously ill adults.

About half of seriously ill patients (49%) report having someone designated to coordinate their medical care. Those that have someone playing such a role overwhelmingly feel it was helpful to them (95%). Those who did not have a coordinator were more likely than those who did to report that they were sent for duplicate tests or diagnostic procedures (31% to 16%) and less likely to report that doctor they rely on most had discussed the cost and charges of their care with them (15% to 42%).

4. Facing Serious Barriers to Getting the Care They Needed

Among this seriously ill population, 26% report being denied some type of medicine or treatment they thought they needed because of the type of insurance they had or because they did not have health insurance coverage. Those with household incomes of less than \$25,000 per year (35%) are nearly twice as likely as those with household incomes of \$25,000 or more (18%) to say they have been denied treatment for this reason. One in six seriously ill adults (16%) say they did not receive a treatment, procedure, or prescription drug they thought they needed because their health plan would not pay for it.

In addition, this seriously ill population was asked if they ever felt they were treated unfairly in the health care they received due to their race or ethnicity, gender, or because they have a long-term disability. The proportion among the overall seriously ill patients saying yes is relatively low. However, 22% of those with a long-term disability report unfair treatment because of their disability, while 16% of African Americans and 12% of Latinos report being treated unfairly because of their race or ethnicity.

5. Financial, Employment, and Psychological Consequences of Being Seriously Ill

The impact that being seriously ill has on the financial situation facing seriously ill has not been well-recognized. With 91% having health insurance, it is surprising that 37% of the seriously ill report having used up all or most of their savings dealing with their health and medical condition, and 31% having been contacted by a collection agency. Strikingly, 23% report being unable to pay for basic necessities like food, heat, or housing (Table 6).

Table 6. Problems experienced by seriously ill adults as a result of the financial cost of dealing with their medical or health condition (in percent)

Each of the following happened	Total seriously ill	Age 18-64	Age 65+
(You/He/She/They) used up all or most of (your/his/her) savings	37	42	30
(You were/He/She was/They were) contacted by a collection agency	31	40	17
(You were/He/She was/They were) unable to pay for basic necessities like food, heat, or housing	23	29	13
(You/He/She/They) borrowed money or got a loan or another mortgage on (your/his/her/their) home	13	15	8
(You/He/She/They) couldn't buy health insurance because of having that medical or health condition	11	14	7
(You/He/She/They) declared bankruptcy	4	4	4

Source: The Commonwealth Fund/The New York Times/Harvard T.H. Chan School of Public Health, Being Seriously Ill in America Today, July 6 – August 21, 2018. N= 746 seriously ill adults.

Seriously ill patients age 65 or older were significantly less likely to experience these problems than those age 18-64: used up all or most of their savings dealing with their health and medical condition (30% for age 65+ to 42% for age 18-64; contacted by a collection agency (17% to 40%); unable to pay for basic necessities like food, heat, or housing (13% to 29%).

Only 27% of seriously ill patients report having made a decision on where to go for health care or on the course of their treatment because of cost.

Beyond health care costs, serious illness has a major impact on the lives of many. In the area of job employment, 51% report being unable to do their job as well as they could before, and 29% report they lost their job or had to change jobs.

The serious illness of those surveyed has an impact on the psychological problems experienced by many of these patients. Nearly half (48%) report that their illness resulted in emotional or psychological problems for them. Also, more than one in five reports often feeling isolated from others (23%), feeling left out (21%), and lacking companionship (20%) (Table 7). The seriously ill are significantly more likely than the U.S. adult population as a whole to report each of these experiences. In the overall adult population, 11% report often feeling isolated from others, 8% feeling left out, and 13% lacking companionship.¹

More than six in ten (62%) say there was a time when they felt anxious, confused, or helpless about their health situation. Among those feeling this way, 72% report having discussed their concerns with their doctor, and about three-fourths (74%) of those who did discuss it say their doctor was helpful to them with these concerns.

Table 7. Feelings of stress and social isolation among the seriously ill (in percent)

	Often	Some of the time	Hardly ever	Don't know/ Refused
Felt isolated from others	23	23	53	1
Felt left out	21	22	56	1
Felt that (you/he/she/they) (lack/lacked) companionship	20	19	59	2
Felt that the health care professionals caring for (your/his/her/their) medical or health condition were not very concerned about (you/him/her/them)	14	22	62	2

Source: The Commonwealth Fund/The New York Times/Harvard T.H. Chan School of Public Health, Being Seriously Ill in America Today, July 6 – August 21, 2018. N= 746 seriously ill adults.

¹ Kaiser Family Foundation/The Economist, Survey on Loneliness and Social Isolation in the United States, the United Kingdom, and Japan, April-June 2018, <http://files.kff.org/attachment/Topline-Kaiser-Family-Foundation-The-Economist-Survey-on-Loneliness-and-Social-Isolation-in-the-United-States-the-United-Kingdom-and-Japan>

6. Care at Home

Over half (53%) of the seriously ill report having needed help at home in order to manage their health condition. Three-fourths (75%) of these people say they were able to get the help at home they needed. But 25% report that they could not get the help they required (Table 8). Three in ten (30%) report that there was a time they needed outside help and could not get it due to cost.

Table 8. The ability of the seriously ill to receive the help they needed with their medical or health condition when they were at home (in percent)

Able to get needed care	75
Unable to get needed care	25

Source: The Commonwealth Fund/The New York Times/Harvard T.H. Chan School of Public Health, Being Seriously Ill in America Today, July 6 – August 21, 2018. N= 341 seriously ill adults who were at home and needed help with the medical or health condition.

Family and friends are reported to play an important role in helping seriously ill patients cope with their health and medical conditions. More than six in ten (62%) say that family and friends have helped them a lot once they were home (Table 9).

Table 9. Reported role of family and friends in helping the seriously ill cope with their medical or health condition (in percent)

Helped a lot	62
Helped a little	24
Helped not at all	12
Don't know/Refused	1

Source: The Commonwealth Fund/The New York Times/Harvard T.H. Chan School of Public Health, Being Seriously Ill in America Today, July 6 – August 21, 2018. N= 746 seriously ill adults.

Though often not recognized, that aid given by someone else to seriously ill patients can create problems for the family or friends who are caregivers. Over one-third (36%) of those who receive help from family or friends at home see these caregivers as having problems resulting from their role in aiding them. Among those who report that friends or family members have helped, 31% say it was emotionally stressful for the caregiver and 25% that it was physically stressful (Table 10).

Table 10. Problems experienced by friends or family members who help seriously ill adults at home with their medical or health condition (in percent)

Friends or family members had each of the following problems providing care	
It was a problem for the family member/friend to provide care	36
It was emotionally stressful on them	31
It was a physical strain on them	25
It caused them financial problems	23
It caused him or her emotional or psychological problems	22
It caused him or her to have a lower income	21
It caused conflicts among family members	18
It was affecting their health	16
It caused him or her to lose or change a job or have to work fewer hours	15
It was not a problem for the family member/friend	62
Don't know/Refused	2

Source: The Commonwealth Fund/The New York Times/Harvard T.H. Chan School of Public Health, Being Seriously Ill in America Today, July 6 – August 21, 2018. N= 639 seriously ill adults whose family or friends help them at home with their medical or health condition.

7. Strategies by Patients and Family Members to Cope Effectively

Many seriously ill patients and their families take actions so their care choices can be more effective for them in dealing with a very complex health care system. The survey asked about the prevalence of their strategic efforts here. About one-third (34%) report seeking advice or help from a family member or friend who is a health professional. Of those who have received help, more than half report getting help identifying the most qualified doctor to deal with their health condition (56%) and talking directly to their doctors or nurses (50%). In addition, of those who have received help, 44% say the health professional in their family kept notes for the patient on what their doctors were telling them, and 37% that the person involved themselves in directly arranging health care services needed outside the hospital (Table 11).

Table 11. Advice and help used by seriously ill adults to deal with the health care system (in percent)

Sought advice or help from a family member or friend who is a doctor, nurse, or other health professional	34
<i>Among those who sought advice/help, what that person did</i>	
Tried to identify the doctors most qualified to deal with medical or health condition	56
Talk to your doctors or nurses	50
Take notes and keep records about what doctors were telling you about your care	44
Directly tried to arrange health care services needed outside of a hospital	37
Sought advice or help from a former patient who had a similar medical or health condition	23

Source: The Commonwealth Fund/The New York Times/Harvard T.H. Chan School of Public Health, Being Seriously Ill in America Today, July 6 – August 21, 2018. N= 614 seriously ill adults.

In addition, about one-fourth (23%) say they have sought advice or help from a former patient who has a similar health condition.

Those who were seriously ill were also asked about other things they use to navigate their health care. More than three-fourths report showing their doctor a list of the medications they were taking (78%), and 70% report having brought a written list of things to discuss with their doctor. In addition, 55% say they have brought a family member or someone else to all their medical appointments to assist them.

Beside these actions, seriously ill patients were asked to say in their words what other things, if any, they did that they would recommend as helpful to someone else with their health condition. The top three recommendations were: recommending specific doctors, clinics, or procedures (7%); researching your condition, doctor, or treatment (6%); and talking to the doctor and asking questions (4%).

Conclusions

These poll results present a unique look at the experiences of the most seriously ill patients in America today. They point to significant conclusions.

First, although about nine in ten seriously ill patients (91%) have health insurance coverage, the survey shows that while most people are financially protected, a substantial minority are not. About one-third (34%) report serious problems paying their hospital bills, and about three in ten (29%) report serious problems paying for their prescription drugs.

Among seriously ill patients who have health insurance coverage, these numbers about financial problems are still high. Thirty-one percent report serious problems paying their hospital bills, and 27% say they have problems paying for their prescription drugs.

These unpaid bills have a significant impact. Thirty-seven percent report that they used up all or most of their savings as a result of the cost of their medical condition, and 23% report being unable to pay for basic necessities like food, heat, or housing. For many of these individuals the problem is not that they have no health insurance coverage, but that their coverage is inadequate to deal with a serious illness.

This has implications for the national debate about whether or not governments should require higher levels of basic health insurance coverage for individuals. It also has implications when looking at the scope of public programs, such as Medicare. It is very unlikely that these seriously ill people imagined this high amount of health care expenditures in the years ahead at the time they bought their health insurance coverage or were aware of the level of coverage that Medicare would or would not give them if they were seriously ill.

Second, the hospital care experience is very important to the seriously ill. The problems most frequently reported are the hospital staff not being responsive to their needs (22%) and receiving conflicting information from different health professionals (18%). About one in five seriously ill patients (21%) would not recommend their hospital to someone else who has the same medical or health condition.

In addition, nearly one in four seriously ill patients report experiencing a serious medical error, including 14% who say the error or most recent error happened at a hospital, 7% at a doctor's office or clinic.

Third, seriously ill people report visits with multiple physicians over the recent period of time. About six in ten (62%) report having seen five or more doctors over the past three years.

Across the care experiences received from a number of physicians, many seriously ill patients report significant care problems. About three in ten say being sent for duplicate

tests or diagnostic procedures by different doctors (29%). About one in four say having to wait too long for treatments, tests, and appointments (23%) and receiving conflicting recommendations from different health professionals (23%) were problems for them.

A number of those interviewed mention problems with the coordination of their care. About half of seriously ill patients (49%) report having someone designated to coordinate their medical care. Those that have someone playing such a role overwhelmingly feel it was helpful to them (95%). Those who did not have a coordinator were more likely than those who did to report that they were sent for duplicate tests or diagnostic procedures (31% to 16%) and less likely to report that doctor they rely on most had discussed the cost and charges of their care with them (15% to 42%).

In addition, other problems of concern are mentioned that would include experiences in both hospitals and physicians' offices. Among this seriously ill population, 26% report being denied some type of medicine or treatment they thought they needed because of the type of insurance they had or because they did not have health insurance coverage. One in six (16%) say they did not receive a treatment, procedure, or prescription drug they thought they needed because their health plan would not pay for it.

Also, this seriously ill population was asked if they ever felt they were treated unfairly in the health care they received due to their race or ethnicity, gender, or because they have a long-term disability. The proportion among the overall seriously ill patients saying yes was relatively low. However, 22% of those with a long-term disability report unfair treatment because of their disability, while 16% of African Americans and 12% of Latinos report being treated unfairly because of their race or ethnicity.

Fourth, the survey finds that serious illness has a significant impact on the lives of many, substantially beyond their health care experiences. In the area of job employment, 51% report being unable to do their job as well as they could before, and 29% report they lost their job or had to change jobs.

In addition, the serious illness of those surveyed has a profound impact on the psychological problems experienced by many of these patients. Nearly half (48%) report that their illness resulted in emotional or psychological problems for them.

Fifth, the survey also finds that the needs of the seriously ill do not end when they leave the hospital or physician's office. Over half (53%) of the seriously ill report having needed help at home in order to manage their health condition. One in four of these people (25%) say that they could not get the help they required. Three in ten (30%) report that there was a time they needed outside help and could not get it due to cost.

Beyond paid help, family and friends are reported to play an important role in helping seriously ill patients cope with their health and medical conditions. More than six in ten (62%) say that family and friends have helped them a lot once they were home.

The survey finds something not usually recognized: that aid given by family or friends to seriously ill patients can create problems for those caregivers. Over one-third (36%) of those who receive help from family or friends at home see these caregivers as having problems resulting from their role in aiding them. Among those who report that friends or family members have helped, 31% say it was emotionally stressful for the caregiver and 25% that it was physically stressful.

Six, the survey finds that many patients and family members are often not passive in responding to the problems of the seriously ill. They try to make the complex health care system work for them. About one-third (34%) report seeking advice or help from a family member or friend who was a health professional. Of those who received help, more than half report getting help identifying the most qualified doctor to deal with their health condition (56%) and talking directly to their doctors or nurses (50%). In addition, of those who have received help, 44% say the health professional in their family kept notes for the patient on what their doctors were telling them, and 37% that the person involved themselves in directly arranging health care services needed outside the hospital. Likewise, about one-fourth (23%) say they have sought advice or help from a former patient who has a similar health condition.

Taken together, the survey shows that if we are to improve the health care and health insurance systems in the future for those who are seriously ill, we have to look more carefully at a set of less visible issues that really impact the outcome of their life experiences when seriously ill. Often the broad discussions about health reform miss these critical issues that importantly impact those with a serious illness.

Methodology

This survey was conducted for The Commonwealth Fund, *The New York Times*, and Harvard T.H. Chan School of Public Health, via telephone (landline and cell phone) by SSRS, an independent research company. Interviews were conducted in English and Spanish, July 6 – August 21, 2018, among a nationally representative probability-based sample of 1,495 adults age 18 or older and represent seriously ill adults nationally. The margin of error for the total respondents is +/-3.2 percentage points at the 95% confidence level.

Seriously ill U.S. adults are defined in two ways: (1) those who themselves in the past three years have had a serious illness or medical condition that required multiple hospital visits and visits to multiple physicians, or (2) if the respondent has not had such an experience themselves, those who have a close family member not available to be interviewed who have had such an experience in the past three years.

Throughout this report, the responses of the “seriously ill” include those who are responding about their own experiences and those who are reporting about the experiences of the close family member. The data combined so as to get an overall picture of the experiences of the seriously ill.