

# BEING SERIOUSLY ILL IN AMERICA TODAY

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**THE COMMONWEALTH FUND  
THE NEW YORK TIMES  
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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)**

<b>Had a serious problem paying...</b>	
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)**

<b>Each of these was a problem</b>	
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)**

	<b>Hospital where you received care during last overnight hospitalization</b>	<b>Doctor most responsible for recent care</b>
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)**

<b>Each of these was a problem</b>	
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.<sup>1</sup>

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)**

	<b>Often</b>	<b>Some of the time</b>	<b>Hardly ever</b>	<b>Don't know/ Refused</b>
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.

<sup>1</sup> 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)**

<b>Friends or family members had each of the following problems providing care</b>	
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.

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*Except where noted, the questions are asked about both of these groups, with the data combined so as to get an overall picture of the experiences of the seriously ill.*

## I. Introduction and Specific Diseases

Throughout this survey, we will refer to (your/your [RELATIONSHIP]'s/this person's) serious illness, medical condition, injury, or disability as (your/their) medical or health condition.

In answering these questions, please think about the time [your RELATIONSHIP/ this person] was being treated before (he/she/they) passed away.

2. Over the past three years, how many different doctors did (you/your [RELATIONSHIP]/this person) see? Was it less than five doctors, five to nine, or 10 or more?

	<b>Total</b>
Less than five doctors	37
<b>Five or more doctors (NET)</b>	<b>62</b>
Five to nine doctors	51
10 or more doctors	11
Don't know	1
Refused	*

3. Was (your/your [RELATIONSHIP]'s/this person's) medical or health condition associated with any of the following? How about (INSERT ITEM)?

### Q3 Yes Summary Table (Base: Total seriously ill)

	<b>Total</b>
Anxiety or depression	27
Heart disease, heart failure, or heart attack	26
A serious injury or accident	26
Diabetes requiring insulin	19
Cancer, not including skin cancer	18
Stroke	14
Opioid addiction	3

## II. Physician Care

4. Your personal doctor is the one you would see if you need a check-up, want advice about a health problem, or get sick or hurt. (Do you/(Does/Did) your [RELATIONSHIP]/(Does/Did) this person) (currently) have a personal doctor, or not?

	Total
Yes	90
No	10
Don't know	*
Refused	-

**(Base: Those who have a personal doctor; n=1385)**

4a. Is (Was) (your/your [RELATIONSHIP]'s/this person's) personal doctor a general doctor who treats many different types of problems, or a specialist doctor who focuses on one major area or problem?

	Total
A general doctor	77
A specialist doctor	19
Don't know	3
Refused	*

### Q4/Q4a Combo Table

**(Base: Total seriously ill)**

	Total
Yes, has a personal doctor	90
A general doctor	69
A specialist doctor	17
Don't know	3
Refused	*
No, does not have a personal doctor	10
Don't know	*
Refused	-

**(Base: Half-sample C; n=745)**

5. (Would you/Do you think your [RELATIONSHIP] would (have)/Do you think this person would (have)) (recommend/recommended) the doctor most responsible for (your/his/her/their) recent care to someone else who had the same medical or health condition as (you have/he/she [has/had]/they [have/had]), or not?

	Total
Yes, would	82
No, would not	14
Don't know	3
Refused	1

**(Asked only of seriously ill respondents about their own experiences)**

6. In recent years, when getting care from a doctor for your medical or health condition, were any of the following a problem for you? How about (INSERT ITEM)? Was that a problem, or not?

**(Base: Half-sample A seriously ill respondents about their own experiences; n=612)**

- a. The doctor was not responsive to your needs

	<b>Seriously ill respondents</b>
Yes, it was a problem	19
No, it was not a problem	80
Don't know	1
Refused	-

**(Base: Half-sample A seriously ill respondents about their own experiences; n=612)**

- b. You could not understand what was being done to you

	<b>Seriously ill respondents</b>
Yes, it was a problem	14
No, it was not a problem	85
Don't know	1
Refused	-

**(Base: Half-sample A seriously ill respondents about their own experiences; n=612)**

- c. You had to wait too long for treatments, tests, or appointments

	<b>Seriously ill respondents</b>
Yes, it was a problem	23
No, it was not a problem	76
Don't know	1
Refused	-

**(Base: Half-sample A seriously ill respondents about their own experiences; n=612)**

- d. You left a doctor's office without getting important questions about your care or treatment answered

	<b>Seriously ill respondents</b>
Yes, it was a problem	19
No, it was not a problem	81
Don't know	1
Refused	-

**(Base: Half-sample A seriously ill respondents about their own experiences; n=612)**

e. Transportation to or from the doctor's office

	<b>Seriously ill respondents</b>
Yes, it was a problem	21
No, it was not a problem	79
Don't know	*
Refused	-

**(Base: Half-sample B seriously ill respondents about their own experiences; n=616)**

f. Understanding your doctor bill

	<b>Seriously ill respondents</b>
Yes, it was a problem	21
No, it was not a problem	78
Don't know	1
Refused	*

**(Base: Half-sample B seriously ill respondents about their own experiences; n=616)**

g. Understanding what your health insurance covers

	<b>Seriously ill respondents</b>
Yes, it was a problem	31
No, it was not a problem	68
Don't know	*
Refused	*

**(Base: Half-sample B seriously ill respondents about their own experiences; n=616)**

h. Understanding the instructions for a prescription medication you were taking

	<b>Seriously ill respondents</b>
Yes, it was a problem	14
No, it was not a problem	85
Don't know	-
Refused	*

**(Base: Half-sample B seriously ill respondents about their own experiences; n=616)**

i. Receiving conflicting recommendations from different health professionals

	<b>Seriously ill respondents</b>
Yes, it was a problem	23
No, it was not a problem	76
Don't know	1
Refused	1

**(Base: Half-sample B seriously ill respondents about their own experiences; n=616)**

- j. Your medical records or test results did not reach your doctor’s office in time for your appointment

	<b>Seriously ill respondents</b>
Yes, it was a problem	17
No, it was not a problem	81
Don’t know	1
Refused	*

**(Base: Half-sample B seriously ill respondents about their own experiences; n=616)**

- k. You were sent for duplicate tests or diagnostic procedures by different doctors, nurses or other healthcare workers

	<b>Seriously ill respondents</b>
Yes, it was a problem	29
No, it was not a problem	69
Don’t know	1
Refused	*

**Q6 a-k Yes Summary Table**

**(Base: Half-samples A or B of seriously ill respondents about their own experiences; n=612-616)**

	<b>Seriously ill respondents</b>
Understanding what your health insurance covers	31
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



7. In recent years, when getting care for (your/his/her/their) medical or health condition, was a serious medical error ever made in (your/your [RELATIONSHIP]'s/this person's) treatment or care, or not?

	<b>Total</b>
Yes	23
No	75
Don't know	3
Refused	-

**(Asked of those who say a serious medical error was made)**

8. Where did this error take place: at a hospital, at a doctor's office or clinic, or somewhere else?

**Q7/Q8 Combo Table**

**(Base: Total seriously ill)**

	<b>Total</b>
Yes, a serious medical error was made in their/the target person's treatment or care	23
Hospital	14
Doctor's office or clinic	7
Somewhere else	2
Don't know	*
Refused	-
No, a serious medical error was not made	75
Don't know	3
Refused	-

**(Base: Half-sample C; n=745)**

9. Some patients want a real say in what medical treatments they receive. Other patients think these decisions should be left to doctors. In recent years, how satisfied (were you/was your [RELATIONSHIP]/was this person) with the role (you were/he/she was/they were) given in the choices for (your/his/her/their) treatment? Would you say...?

	<b>Total</b>
<b>Satisfied (NET)</b>	<b>84</b>
Very satisfied	54
Somewhat satisfied	30
<b>Dissatisfied (NET)</b>	<b>14</b>
Somewhat dissatisfied	8
Very dissatisfied	6
Don't know	1
Refused	1

**(Base: Half-sample C; n=745)**

10. In recent years, (were you/was your [RELATIONSHIP]/was this person) ever denied some type of medical care or treatment (you/she/he/they) thought (you/she/he/they) needed because of the kind of health insurance (you/she/he/they) had or because (you/she/he/they) had no health insurance, or didn't this happen?

	<b>Total</b>
Yes, was denied	26
No, this didn't happen	73
Don't know	1
Refused	*

**(Base: Half-sample C; n=745)**

11. In recent years, do you think (you were/your [RELATIONSHIP] was /this person was) ever treated unfairly in the health care (you/they) received or did not receive because (INSERT), or didn't this happen?

- a. of (your/his/her/their) race or ethnicity

	<b>Total</b>
Yes, treated unfairly	6
No, this didn't happen	92
Don't know	1
Refused	*

- b. of (your/his/her/their) gender

	<b>Total</b>
Yes, treated unfairly	6
No, this didn't happen	93
Don't know	1
Refused	*

- c. (you/he/she/they) had a long-term disability

	<b>Total</b>
Yes, treated unfairly	16
No, this didn't happen	83
Don't know	1
Refused	*

**(Base: Half-sample C; n=745)**

12. (Is/Was) there someone who (works/worked) with (you/your [RELATIONSHIP]'s/this person's) personal doctor to help (you/him/her/them) coordinate (your/his/her/their) medical care? For example, helping (you/him/her/them) understand (your/his/her/their) health information or get access to community resources.

	<b>Total</b>
Yes	49
No	48
Don't know	3
Refused	*

**(Base: Half-sample C respondents who say there was a medical care coordinator; n=363)**

13. (Has/Was) this person (been) helpful to (you/your [RELATIONSHIP]/this person), or not?

	<b>Total</b>
Yes	95
No	5
Don't know	1
Refused	-

### III. Hospital Care

14. In the past three years, how many times (were you/was your [RELATIONSHIP]/was this person) hospitalized overnight?

	<b>Total</b>
2-3	64
6-10	14
11 or more	12
Don't know	8
Refused	2

**(Base: Half-sample D; n=750)**

15. (Would you/Do you think your [RELATIONSHIP] would [have]/Do you think this person would [have]) (recommend/recommended) the hospital where (you/he/she/they) received care the last time (you were/he/she was/they were) hospitalized overnight to someone else who had the same medical or health condition as (you have/he/she [has/had]/they [have/had]), or not?

	<b>Total</b>
Yes, would	76
No, would not	21
Don't know	3
Refused	-

16. Thinking about the last time (you were/your [RELATIONSHIP] was/this person was) hospitalized overnight, were any of the following a problem for (you/him/her/them)? How about (INSERT)? Was that a problem, or not?

**(Base: Half-sample A; n=745)**

a. Understanding what (your/his/her/their) health insurance covers

	<b>Total</b>
Yes, a problem	21
No, not a problem	77
Don't know	1
Refused	-

**(Base: Half-sample A; n=745)**

b. Receiving conflicting recommendations from different health professionals

	<b>Total</b>
Yes, a problem	18
No, not a problem	79
Don't know	2
Refused	-

**(Base: Half-sample A; n=745)**

c. Getting help at home after (you/he/she/they) left the hospital

	<b>Total</b>
Yes, a problem	15
No, not a problem	83
Don't know	1
Refused	*

**(Base: Half-sample B; n=750)**

d. Hospital staff was not responsive to (your/his/her/their) needs

	<b>Total</b>
Yes, a problem	22
No, not a problem	76
Don't know	1
Refused	*

**(Base: Half-sample B; n=750)**

e. (You/He/She/They) could not understand what was being done to (you/him/her/them)

	<b>Total</b>
Yes, a problem	15
No, not a problem	83
Don't know	1
Refused	*

**(Base: Half-sample B; n=750)**

f. Difficulty scheduling hospital admission, tests, or discharge

	<b>Total</b>
Yes, a problem	13
No, not a problem	86
Don't know	*
Refused	*

**(Base: Half-sample B; n=750)**

g. Transportation to or from the hospital

	<b>Total</b>
Yes, a problem	13
No, not a problem	86
Don't know	*
Refused	*

**Q16 a-g Yes Summary Table**

**(Base: Half-samples A or B; n=745-750)**

	<b>Total</b>
Hospital staff was not responsive to (your/his/her/their) needs	22
Understanding what (your/his/her/their) health insurance covers	21
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

**(Base: Half-sample D; n=750)**

17. After the last time (you were/your [RELATIONSHIP] was/this person was) hospitalized overnight, did (you/he/she/they) receive a bill for doctors or services that were not fully covered by (your/his/her/their) health insurance policy, or not?

	<b>Total</b>
Yes, received a bill	47
No, did not receive a bill	49
Don't know	4
Refused	-

**(Asked of half-sample D if received a bill for doctors or services after the last hospitalization that were not fully covered by health insurance policy; n=316)**

18. Did the bill charge (you/him/her/them) for services provided by health professionals who were not affiliated with (your/his/her/their) health insurance plan, or didn't this happen?

**Q17/Q18 Combo Table**

**(Base: Half-sample D; n=750)**

	<b>Total</b>
Yes, received a bill that was not completely covered by health insurance AND	47
The bill charged for services provided by health professionals who were not affiliated with their health insurance plan	16
The bill did not charge for services provided by health professionals who were not affiliated with their health insurance plan	26
Don't know	6
Refused	-
No, did not receive a bill that was not completely covered by health insurance	49
Don't know	4
Refused	-

**(Base: Half-sample D; n=750)**

19. Some patients when in the hospital want a real say in what medical treatments they receive. Other patients think these decisions should be left to doctors. The last time (you were/your [RELATIONSHIP] was/this person was) hospitalized overnight, how satisfied (were you/was he/she/were they) with the role (you were/he/she was/they were) given in the choices for (your/his/her/their) treatment? Would you say...?

	<b>Total</b>
<b>Satisfied (NET)</b>	<b>83</b>
Very satisfied	55
Somewhat satisfied	27
<b>Dissatisfied (NET)</b>	<b>15</b>
Somewhat dissatisfied	6
Very dissatisfied	9
Don't know	2
Refused	-

**(Base: Half-sample D seriously ill respondents about their own experiences; n=615)**

20. Sometimes when a person is in the hospital, critical situations arise where the doctor would like to know that person's preferences for care. Often they ask the person these questions when they are admitted to the hospital. The last time you were hospitalized overnight, were you asked about each of the following, or not? How about (INSERT)?

- a. If your heart were to stop, whether or not you would want chest compressions, or CPR, in an attempt to bring you back to life

	<b>Seriously ill respondents</b>
Yes, was	49
No, was not	46
Don't know	5
Refused	*

- b. Whether or not you would want to be hooked up to a ventilator or breathing tube to breathe for you

	<b>Seriously ill respondents</b>
Yes, was	44
No, was not	49
Don't know	6
Refused	1



#### IV. Medical Bills/Cost

(Base: Half-sample E; n=749)

21. In recent years, (have you/[has/did] your [RELATIONSHIP]/[has/did] this person) (had/have) a serious problem paying (INSERT 1ST ITEM), or not? How about paying (INSERT NEXT ITEM)?

- a. Bills for doctor's office visits

	<b>Total</b>
Yes, had a serious problem	23
No, did not	75
Did not need (vol)	*
Don't know	1
Refused	-

- b. Hospital bills

	<b>Total</b>
Yes, had a serious problem	34
No, did not	65
Did not need (vol)	*
Don't know	1
Refused	*

- c. Emergency room bills

	<b>Total</b>
Yes, had a serious problem	26
No, did not	71
Did not need (vol)	1
Don't know	2
Refused	*

- d. Dental care bills

	<b>Total</b>
Yes, had a serious problem	27
No, did not	69
Did not need (vol)	3
Don't know	1
Refused	*

- e. For ambulance services

	<b>Total</b>
Yes, had a serious problem	20
No, did not	74
Did not need (vol)	4
Don't know	1
Refused	*

f. For home care services

	<b>Total</b>
Yes, had a serious problem	15
No, did not	74
Did not need (vol)	9
Don't know	1
Refused	1

g. For medical equipment for use at home

	<b>Total</b>
Yes, had a serious problem	15
No, did not	77
Did not need (vol)	6
Don't know	1
Refused	*

h. For prescription drugs

	<b>Total</b>
Yes, had a serious problem	29
No, did not	70
Did not need (vol)	*
Don't know	1
Refused	*

**Q21 a-h Yes Summary Table**  
**(Base: Half-sample E; n=749)**

<b>Had a serious problem</b>	<b>Total</b>
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

**(Asked if had a serious problem paying more than one item; n=263)**

22. Thinking back, which of one of these types of bill caused (you/your [RELATIONSHIP]/this person) the most serious problem paying for it?

**Q21/Q22 Combo Table**

**Total most serious problem, including those with only one problem**  
**(Base: Half-sample E; n=749)**

	<b>Total</b>
Hospital bills	20
Prescription drugs	10
Dental care bills	9
Ambulance services	5
Emergency room bills	3
Bills for doctor's office visits	3
Home care services	2
Medical equipment for use at home	2
None of these	45
Don't know	*
Refused	-

**(Base: Half-sample E; n=749)**

23. Was there any time in recent years when (you/your [RELATIONSHIP]/this person) did not receive a given medical treatment, surgical procedure, or prescription drug (your/his/her their) doctor suggested might help (you/him/her/them) with (your/his/her/their) medical or health condition, or don't you think this happened?

	<b>Total</b>
Yes, happened	23
No, did not happen	74
Don't know	3
Refused	-

**(Asked of half-sample E if did not receive a given medical treatment, surgical procedure, or prescription drug their doctor suggested might help with their medical or health condition; n=153)**

23a. Was that because (your/his/her/their) health plan would not pay for it, or was it for some other reason?

**Q23/Q23a Combo Table**

**(Base: Half-sample E; n=749)**

	<b>Total</b>
Yes, they did not receive a given medical treatment, surgical procedure, or prescription drug their doctor suggested might help with their medical or health condition	23
Health plan would not pay for it	16
Some other reason	7
Don't know	*
Refused	-
No, did not happen	74
Don't know	3
Refused	-

**(Base: Half-sample E; n=749)**

24. In recent years, did the doctor that (you rely/your [RELATIONSHIP] [relies/relies]/this person [relies/relies]) on most for (your/his/her/their) medical care discuss the cost and charges of (your/your [RELATIONSHIP]'s/their) care with (you/him/her/them), or not?

	<b>Total</b>
Yes, did	27
No, did not	69
Don't know	4
Refused	*

**(Base: Half-sample E; n=749)**

25. In recent years, did (you/your [RELATIONSHIP]/this person) feel (you were/he/she was/they were) adequately informed by the hospital and health professionals about what costs (your/his/her/their) insurance would cover, or not?

	<b>Total</b>
Yes, did	46
No, did not	50
Don't know	4
Refused	*

**(Base: Half-sample E; n=749)**

26. In recent years, was there ever a time when (you/your [RELATIONSHIP]/this person) made a choice about where to go for health care or on the course of (your/his/her/their) treatment because of price or cost, or not?

	<b>Total</b>
Yes, was	27
No, was not	72
Don't know	2
Refused	*

## V. Prescription Medicines

**(Base: Half-sample E; n=749)**

27. At (the current time/time of their passing), how many prescription medicines (are you/[is/was] your [RELATIONSHIP]/[is/was] this person) taking?

	<b>Total</b>
None	9
At least one (NET)	89
1 to 4 prescription medicines	33
5 to 9 prescription medicines, or	33
10 or more	24
Don't know	2
Refused	*

**(Asked of half-sample E if currently taking/deceased target person was taking at least one prescription medication; n=690)**

28. (Are you/[Is/Was] your [RELATIONSHIP]/[Is/Was] this person) taking any prescription medicines that cost (you/him/her/them) or (your/his/her/their) health insurance plan more than \$50,000 per year, or not?

### Q27/Q28 Combo Table

**(Base: Half-sample E; n=749)**

	<b>Total</b>
Taking Rx \$50K+	11
Not taking Rx \$50K+	89
Not taking or don't know if taking any Rx	11
Taking Rx, but not \$50K+	64
Don't know/Refused	14

**(Asked of half-sample E if taking any prescription medicine that cost more than \$50,000 a year; n=67)**

29. (Have you/[Has/Did] your [RELATIONSHIP]/[Has/Did] this person) (had/have) a serious problem paying for this drug, or not?

	<b>Total</b>
Yes, has had a serious problem	44
No, has not had a serious problem	56
Don't know	-
Refused	-

**Q27/Q28/Q29 Combo Table**  
**(Base: Half-sample E; n=749)**

	<b>Total</b>
No prescription medicine	9
<b>At least one prescription medicines (NET)</b>	<b>89</b>
Taking Rx that costs over \$50,000 per year	11
Has had a serious problem paying	5
Has not had a serious problem paying	6
Don't know	-
Refused	-
Not taking Rx that costs over \$50,000 per year	64
Don't know	14
Refused	*
Don't know	2
Refused	*

## VI. Consequences of Medical or Health Condition

**(Base: Half-sample F; n=746)**

30. In recent years, did any of the following things ever happen to (you/your [RELATIONSHIP]/this person) as a result of the financial cost of dealing with (your/his/her/their) medical or health condition, or not? How about (INSERT ITEM)?

- a. (You/He/She/They) used up all or most of (your/his/her) savings

	<b>Total</b>
Yes, happened	37
No, did not happen	62
Don't know	1
Refused	*

- b. (You were/He/She was/They were) unable to pay for basic necessities like food, heat, or housing

	<b>Total</b>
Yes, happened	23
No, did not happen	77
Don't know	*
Refused	*

- c. (You/He/She/They) borrowed money or got a loan or another mortgage on (your/his/her/their) home

	<b>Total</b>
Yes, happened	13
No, did not happen	87
Don't know	*
Refused	-

- d. (You were/He/She was/They were) contacted by a collection agency

	<b>Total</b>
Yes, happened	31
No, did not happen	67
Don't know	2
Refused	-

- e. (You/He/She/They) declared bankruptcy

	<b>Total</b>
Yes, happened	4
No, did not happen	95
Don't know	1
Refused	*



- f. (You/He/She/They) couldn't buy health insurance because of having that medical or health condition

	<b>Total</b>
Yes, happened	11
No, did not happen	88
Don't know	1
Refused	*

**Q30 a-f Yes Summary**  
**(Base: Half-sample F; n=746)**

	<b>Total</b>
(You/He/She/They) used up all or most of (your/his/her) savings	37
(You were/He/She was/They were) contacted by a collection agency	31
(You were/He/She was/They were) unable to pay for basic necessities like food, heat, or housing	23
(You/He/She/They) borrowed money or got a loan or another mortgage on (your/his/her/their) home	13
(You/He/She/They) couldn't buy health insurance because of having that medical or health condition	11
(You/He/She/They) declared bankruptcy	4

**(Base: Half-sample F; n=746)**

31 As a result of (your/your [RELATIONSHIP]'s/this person's) medical or health condition, did any of the following happen, or not? How about (INSERT ITEM)?

a. (You were/He/She was/They were) unable to do (your/his/her/their) job as well as (you/he/she/they) could before

	<b>Total</b>
Yes, happened	51
No, did not happen	39
Retired before illness occurred (vol)	10
Don't know	*
Refused	*

b. (You/He/She/They) lost a job or had to change jobs

	<b>Total</b>
Yes, happened	29
No, did not happen	63
Retired before illness occurred (vol)	8
Don't know	*
Refused	*

c. (You/He/She/They) stayed in a job longer than (you/he/she/they) otherwise would in order to maintain health insurance coverage

	<b>Total</b>
Yes, happened	20
No, did not happen	73
Retired before illness occurred (vol)	6
Don't know	*
Refused	*

d. (You/Your [RELATIONSHIP]/This person) had a problem caring for another family member who was dependent on (you/him/her/them) for their care

	<b>Total</b>
Yes, happened	26
No, did not happen	73
Don't know	*
Refused	*

e. (You/He/She/They) wanted to work but (were/was) unable to

	<b>Total</b>
Yes, happened	53
No, did not happen	46
Don't know	*
Refused	1

f. It caused (you/him/her/them) emotional or psychological problems

	<b>Total</b>
Yes, happened	48
No, did not happen	50
Retired before illness occurred (vol)	1
Don't know	*
Refused	1

**Q31 a-f Yes Summary**

**(Base: Half-sample F; n=746)**

	<b>Total</b>
(You/He/She/They) wanted to work but (were/was) unable to	53
(You were/He/She was/They were) unable to do (your/his/her/their) job as well as (you/he/she/they) could before	51
It caused (you/him/her/them) emotional or psychological problems	48
(You/He/She/They) lost a job or had to change jobs	29
(You/Your [RELATIONSHIP]/This person) had a problem caring for another family member who was dependent on (you/him/her/them) for their care	26
(You/He/She/They) stayed in a job longer than (you/he/she/they) otherwise would in order to maintain health insurance coverage	20

**(Base: Half-sample F; n=746)**

32. In recent years, how much of a burden on (your/your [RELATIONSHIP]'s/this person's) family were the costs of (your/his/her/their) overall medical care, including services (you/he/she/they) needed to cope with (your/his/her/their) serious medical or health condition? Would you say....?

	<b>Total</b>
Major burden	27
Minor burden	30
Not a burden at all	42
Don't know	1
Refused	*

## VII. Stress/Social Isolation

**(Base: Half-sample F; n=746)**

33. The next few questions are about how (you feel/your [RELATIONSHIP] [feels/felt]/this person [feels/felt]) about different aspects of (your/his/her/their) life. For each one, tell me how often (you feel/your [RELATIONSHIP] [feels/felt]/this person [feels/felt]) that way. In recent years, how often (have/had) (you/your [RELATIONSHIP]/this person) (INSERT)? Would you say...?

- a. Felt that (you/he/she/they) (lack/lacked) companionship

	<b>Total</b>
Often	20
Some of the time	19
Hardly ever	59
Don't know	1
Refused	*

- b. Felt left out

	<b>Total</b>
Often	21
Some of the time	22
Hardly ever	56
Don't know	1
Refused	*

- c. Felt isolated from others

	<b>Total</b>
Often	23
Some of the time	23
Hardly ever	53
Don't know	1
Refused	*

- d. 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)

	<b>Total</b>
Often	14
Some of the time	22
Hardly ever	62
Don't know	1
Refused	1

**Q33 a-d Often Summary**  
**(Base: half-sample F; n=746)**

	<b>Total</b>
Felt isolated from others	23
Felt left out	21
Felt that (you/he/she/they) (lack/lacked) companionship	20
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

**(Base: Half-sample F; n=746)**

34. In recent years, was there ever a time while (you were/your [RELATIONSHIP] was/this person was) receiving health care that (you/he/she/they) felt anxious, confused, or helpless about (your/their) situation?

	<b>Total</b>
Yes	62
No	37
Don't know	1
Refused	*

**(Asked of half-sample F if felt anxious, confused, or helpless; n=409)**

35. Did (you/he/she/they) talk to (your/his/her/their) doctors about these concerns, or not?

	<b>Total</b>
Yes	72
No	26
Don't know	1
Refused	-

**(Asked of half-sample F if felt anxious, confused, or helpless and talked to their doctors about these concerns; n=294)**

36. Were (your/his/her/their) doctors helpful in dealing with these concerns, or not?

	<b>Total</b>
Yes	74
No	23
Don't know	3
Refused	-

## VIII. Health System Workarounds/Hacks

**(Base: Half-sample G seriously ill respondents about their own experiences; n=614)**

37. In recent years, did you seek advice or help from a family member or friend who is a doctor, nurse, or other health professional, or didn't you do this?

	<b>Seriously ill respondent</b>
Yes, did this	34
No, did not do this	66
Don't know	*
Refused	*

**(Base: Half-sample A seriously ill respondents who sought advice or help from a family member of friend who is a doctor, nurse, or other health professional; n=193)**

38. Did this person do any of the following things for you, or not? Did that person (INSERT), or not?

- a. Try to identify the doctors most qualified to deal with your medical or health condition

	<b>Seriously ill respondents</b>
Yes	56
No	44
Don't know	*
Refused	-

- b. Directly try to arrange health care services you needed outside of a hospital

	<b>Seriously ill respondents</b>
Yes	37
No	62
Don't know	*
Refused	-

- c. Talk to your doctors or nurses

	<b>Seriously ill respondents</b>
Yes	50
No	49
Don't know	1
Refused	-

- d. Take notes and keep records about what doctors were telling you about your care

	<b>Seriously ill respondents</b>
Yes	44
No	53
Don't know	3
Refused	-

**(Base: Half-sample G seriously ill respondents about their own experiences; n=614)**

39. Did you seek advice or help from a former patient who had a similar medical or health condition, or not?

	<b>Seriously ill respondents</b>
Yes	23
No	77
Don't know	*
Refused	-

**(Base: Half-sample G seriously ill respondents about their own experiences; n=614)**

40. In recent years, have you done either of the following to deal with your medical care, or not?

- a. Showed your doctor a list of medications you are taking

	<b>Seriously ill respondents</b>
Yes	78
No	21
Don't know	*
Refused	1

- b. Brought a list of things to discuss with your doctor

	<b>Seriously ill respondents</b>
Yes	70
No	29
Don't know	*
Refused	1

- c. Made an audio or video recording of a visit with your doctor

	<b>Seriously ill respondents</b>
Yes	6
No	93
Don't know	*
Refused	1

- d. Brought a family member, friend, or someone else to all of your medical appointments

	<b>Seriously ill respondents</b>
Yes	55
No	45
Don't know	*
Refused	1



**Q40 a-d Yes Summary Table****(Base: Half-sample G seriously ill respondents about their own experiences; n=614)**

	<b>Seriously ill respondents</b>
Showed your doctor a list of medications you are taking	78
Brought a list of things to discuss with your doctor	70
Brought a family member, friend, or someone else to all of your medical appointments	55
Made an audio or video recording of a visit with your doctor	6

**(Base: Half-sample G seriously ill respondents about their own experiences; n=614)**

41. Besides the things we have been talking about, were there any other things you did in recent years that you would recommend as helpful for someone else who had the same medical or health condition?

	<b>Seriously ill respondents</b>
Would recommend specific doctor/clinic/procedure	7
Research your condition/doctors/treatment	6
Talk to your doctor/Ask questions	4
Get a second opinion	3
Exercise/physical therapy/rehab	3
Don't delay going to the doctor/Act sooner/Visit regularly	2
Have good insurance/supplemental insurance	2
Join a support group/Talk to people with same condition	2
Find a good/caring/qualified doctor/specialist	1
Follow your doctor's directions	1
Take your medication	1
Keep notes/records	1
Maintain a healthy diet	1
Find someone to help you/advocate for you	1
Be assertive/Advocate for yourself	1
Seek spiritual guidance	1
Take care of yourself	*
No, nothing	48
Other	16
Don't know	2
Refused	2

## IX. Caregiving by Family/Friends

**(Base: Half-sample H; n=746)**

42. In the past three years, was there ever a time when (you were/your [RELATIONSHIP] was/this person was) at home and needed help to deal with (your/his/her/their) medical or health condition, or not?

	<b>Total</b>
Yes, there was	53
No, there was not	46
Don't know	1
Refused	-

**(Asked of half-sample H if at home and needed help; n=341)**

43. (Were you/Was he/she/Was this person) able to get the help (you/he/she/they) needed at home to deal with (your/his/her/their) medical or health condition, or not?

	<b>Total</b>
Yes, was able	75
No, was not able	25
Don't know	-
Refused	-

**(Asked of half-sample H if at home, needed help, and were not able to get it ; n=82)**

44. Was the problem [mainly that (you/your [RELATIONSHIP]/this person) could not get help from health care professionals and paid home care service providers], or [mainly that (you/he/she/they) could not get help from family or friends]?

	<b>Total</b>
Mainly could not get help from health care professionals and paid home care service providers	65
Mainly could not get help from family or friends	19
Don't know	14
Refused	2

**Q43/Q44 Combo Table**

**(Asked of half-sample H if at home and needed help; n=341)**

	<b>Total</b>
Yes, was able to get help	75
No, was not able to get help	25
Mainly could not get help from health care professionals and paid home care service providers	16
Mainly could not get help from family or friends	5
Don't know	4
Refused	1
Don't know	-
Refused	-

**(Base: Half-sample H; n=746)**

45. In terms of various things (you need/your [RELATIONSHIP] [needs/needed]/this person [needs/needed] at home to deal with (your/his/her/their) medical or health condition, how much (have/did) family or friends (helped/help) (you/him/her/them) in recent years? Would you say a lot, a little, or not at all?

	<b>Total</b>
A lot	62
A little	24
Not at all	12
Don't know	*
Refused	*

**(Asked of half-sample H if friends or family helped at home; n=639)**

46. In recent years, was it a problem for (your/your [RELATIONSHIP]'s/this person's) family member or friend to provide (you/him/her/them) this care, or not?

	<b>Total</b>
Yes, a problem	36
No, not a problem	62
Don't know	2
Refused	*

**(Asked of half-sample H if friends or family helped at home and it was a problem for the friend or family member who provided their care; n=194)**

47. Were each of the following a problem for (your/your [RELATIONSHIP]'s/this person's) family member or friend, or not? First/Next (INSERT)? Was this a problem or not?

**Q46/Q47 Combo Table**

**(Base: Half-sample H if friends or family helped at home; n=639)**

	<b>Total</b>
Yes, it was a problem for the family member/friend	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
No, this was not a problem for the family member/friend	62
Don't know	2
Refused	*

**(Base: Half-sample H; n=746)**

48. In recent years, was there ever a time when (you/your [RELATIONSHIP]/this person) did not get help that (you/he/she/they) needed from an outside source because of the cost, or not?

	<b>Total</b>
Yes	30
No	69
Don't know	1
Refused	-

## X. Demographics of the Seriously Ill

Responses about...	Total
Respondent who is seriously ill	74
Close family member not available to be interviewed who is/was seriously ill	26
Living	20
Passed away	6

49. (Does/Did) any long-term disability keep (you/your [RELATIONSHIP]/this person) from participating fully in work, school, housework, or other activities?

	Total
Yes	62
No	37
Don't know	1
Refused	*

50. (Are you/[Is/Was] your [RELATIONSHIP]/[Is/Was] this person) (now, or) (have you/have they) ever (been) a member of the U.S. military?

	Total
Yes	15
No	85
Don't know	*
Refused	*

51. (Are you/[Is/Was] your [RELATIONSHIP]/[Is/Was] this person), (currently) covered by any form of health insurance or health plan or (do you/[does/did] he/she/[do/did] they) not have health insurance (at this time)?

**(Asked if insured; n=1393)**

52. Which of the following (is/was) (your/your [RELATIONSHIP]'s/this person's) MAIN source of health insurance coverage? (Is/Was) it...?

**(Asked if currently covered by Medicare or Medicaid; n=852)**

52aa. Do/Does/Did (you/he/she/they) also have coverage from (Medicare/ Medicaid or [INSERT STATE-SPECIFIC NAME]), or not?

**(Asked if currently covered by a health insurance purchased by self; n=95)**

52a. Did (you/he/she/they) purchase it from a government exchange or agency, or not?

**Q51/Q52/Q52aa/Q52a Combo Table I**  
**(Base: Total seriously ill)**

	<b>Total</b>
Yes, covered by health insurance	91
A plan through your or your spouse's employer or union	21
A plan you purchased yourself	6
Purchased it from a government exchange or agency	2
Did not purchase it from a government exchange or agency	3
Don't know	*
Refused	-
Not asked	*
Medicare and Medicaid	11
Medicare (total)	43
Medicare only	30
Medicare – don't know if only or with Medicaid	2
Medicaid (total)	20
Medicaid only	5
Medicaid – don't know if only or with Medicare	4
The VA or Tricare	5
Some other form of insurance	1
Plan through your parent/mother/father	1
Private insurance (purchaser unspecified) (BCBS/Aetna/United Healthcare, etc.)	3
Tribal health insurance plan	*
Marketplace/ACA	1
Through retirement plan	*
Don't know source	2
Refused source	*
No, not covered by health insurance	9
Don't know	*
Refused	*

**GENDER**

	<b>Total</b>
Male	46
Female	54

**AGE**

	<b>Total</b>
18-29	8
30-49	25
50-64	29
65+	37
Refused	2

**RACE/ETHNICIT**

	<b>Total</b>
Hispanic	10
White Non-Hispanic	67
Black Non-Hispanic	12
Asian Non-Hispanic	1
Native American (Native American/Alaska Native)	2
Other Non-Hispanic	2
Native Hawaiian/Pacific Islander	1
Non-Hispanic No Answer	3

58. (Last year, that is in 2017,) what was (your/your RELATIONSHIP's/this person's) total annual household income from all sources, BEFORE taxes? Just stop me when I get to the right category.

58a. Could you tell me if (your/his/her/their) total annual household income is less than \$50,000, \$50,000 but less than \$100,000, or over \$100,000?

58b. Is that \$100,000 to under \$150,000, \$150,000 to under \$200,000, \$200,000 to under \$250,000, or \$250,000 or more?

**Q58/Q58a/Q58b Income Summary Table**  
**(Base: Total seriously ill)**

	<b>Total</b>
<b>Less than \$50,000 (NET)</b>	<b>63</b>
Under 15 thousand dollars	22
15 to under 20 thousand	10
20 to under 25 thousand	9
25 to under 35 thousand	9
35 to under 50 thousand	10
Less than \$50,000 unspecified	4
<b>\$50,000 but less than \$100,000 (NET)</b>	<b>18</b>
50 to under 75 thousand	10
75 to under 100 thousand	6
\$50,000 but less than \$100,000 unspecified	1
<b>Over \$100,000 (NET)</b>	<b>12</b>
\$100,000 to under \$150,000	7
\$150,000 to under \$200,000	3
\$200,000 to under \$250,000	*
\$250,000 or more	2
Over \$100K+ unspecified	*
Don't know	3
Refused	5



**(Asked about close family member not available to be interviewed who is/was seriously ill; n=267)**

A01. What is this person's relationship to you?

	<b>Close family member not available to be interviewed who is/was seriously il</b>
Spouse (wife/husband)	40
Unmarried partner	-
Boyfriend	*
Girlfriend	*
Friend	*
Significant other	-
Son	6
Stepson	*
Daughter	4
Stepdaughter	-
Grandson	*
Granddaughter	-
Mother	20
Father	12
Brother/Step-brother/Half-brother	5
Sister/Step-sister/Half-sister	3
Grandmother	4
Grandfather	-
Aunt	1
Uncle	*
Niece	-
Nephew	-
Cousin	-
Mother-in-law	1
Father-in-law	1
Brother-in-law	*
Sister-in-law	-
Son-in-law	1
Daughter-in-law	-
Other relative	1
Other non-relative	-
Don't know	-
Refused	-

## XI. Respondent Demographics

*These demographics apply to the person who was interviewed, not the seriously ill person being asked about in the survey*

57. What is the last grade or class that you completed in school?

	<b>Respondent</b>
<b>High school or less (NET)</b>	<b>39</b>
Less than high school (grades 1-11, grade 12 but no diploma)	12
High school graduate or equivalent (e.g. GED)	27
Some college but no degree (incl. 2 year occupational or vocational programs)	32
<b>College or post-graduate (NET)</b>	<b>29</b>
College graduate (e.g. BA, AB, BS)	16
Postgraduate (e.g. MA, MS, MEng, Med, MSW, MBA, MD, DDs, PhD, JD, LLB, DVM)	13
Don't know	*
Refused	1

59. Are you currently married, living with a partner, divorced, separated, widowed or have you never been married?

	<b>Respondent</b>
<b>Married/Partnered (NET)</b>	<b>52</b>
Married	48
Living with a partner	5
<b>Not married/Partnered (NET)</b>	<b>46</b>
Divorced	14
Separated	2
Widowed	11
Never been married	19
Refused	2

PARTY. In politics today, do you consider yourself a (Republican), (Democrat), an Independent, or what?

	<b>Total</b>
Republican	22
Democrat	33
Independent	32
Other/None	5
Don't know	4
Refused	4

**(Asked if independent, other party, don't know or refused to say; n=620)**

PARTYLEAN. Do you LEAN more towards the (Republican) Party or the (Democratic) Party?

**Party/Partylean Combo Table  
(Based: Total respondents)**

	<b>Total</b>
Republican/Republican leaners	31
Democrat/Democratic leaners	46
Independent	13
Other party (Vol.)	1
Don't know	4
Refused	5

## XII. Screening Questions

*The following questions were used to screen for the seriously ill sample used in the survey*

- S2. In the past three years, have you had a serious illness, medical condition, injury, or disability, or not?
- 1 Yes, have
  - 2 No, have not
  - 8 (DO NOT READ) Don't know
  - 9 (DO NOT READ) Refused

(ASK Q.S3 IF Q.S2 = 1)

- S3. During the past three years, have you had two or more overnight stays in a hospital as a patient, or not?
- 1 Yes, have
  - 2 No, have not
  - 8 (DO NOT READ) Don't know
  - 9 (DO NOT READ) Refused

(ASK Q.S4 IF Q.S3 = 1)

- S4. Apart from these overnight hospital stays, have you been seen by three or more doctors during the past three years, or not?
- 1 Yes, have
  - 2 No, have not
  - 8 (DO NOT READ) Don't know
  - 9 (DO NOT READ) Refused

(ASK Q.S5 IF Q.S2 = 2, 8 OR 9 OR Q.S3 = 2, 8, OR 9 OR Q.S4 = 2, 8 OR 9)

- S5. Do you have a **family member** age 18 or older who is or was living in your household, who has or had a serious illness, medical condition, injury, or disability during the past three years, **but cannot take part in a survey because of their condition**?
- 1 Yes
  - 2 No
  - 8 (DO NOT READ) Don't know
  - 9 (DO NOT READ) Refused

(ASK Q.S6 IF Q.S5 = 1)

- S6. During the past three years, has that person had two or more overnight stays in a hospital as a patient, or not?
- 1 Yes, has
  - 2 No, has not
  - 8 (DO NOT READ) Don't know
  - 9 (DO NOT READ) Refused

(ASK Q.S7 IF Q.S6 = 1)

- S7. Apart from these overnight hospital stays, has that person been seen by three or more doctors during the past three years, or not?
- 1 Yes, has
  - 2 No, has not
  - 8 (DO NOT READ) Don't know
  - 9 (DO NOT READ) Refused

(ASK Q.A00 IF Q.S7 = 1)

A00. Thinking about this family member, how much did you know about this person's health care situation?

- 1 A lot
- 2 Some
- 3 Only a little
- 4 Nothing at all
- 8 (DO NOT READ) Don't know
- 9 (DO NOT READ) Refused

**[FOR R TO QUALIFY FOR SCREENER, S4=1 OR (S7=1 and A00=1-2)]**