

CHRONIC ILLNESS AND CAREGIVING

**SURVEY OF THE GENERAL PUBLIC,
ADULTS WITH CHRONIC CONDITIONS AND
CAREGIVERS**

CONDUCTED FOR:

The Robert Wood Johnson Foundation
Johns Hopkins University
Partnership for Solutions

CONDUCTED BY:

HARRIS INTERACTIVE INC.

MAIN SURVEY RESULTS

Notes:

- Unless otherwise noted, questions were asked of all respondents (N=1,663).
- An asterisk (*) is used to indicate values lower than 0.5%.
- Column percentages may not add to 100% due to rounding or acceptance of multiple responses.



Methodology

Chronic Illness and Caregiving was conducted by Harris Interactive Inc. on behalf of The Robert Wood Johnson Foundation, Johns Hopkins University, and Partnership for Solutions. The survey was conducted from March 17, 2000 through November 22, 2000 with a total of 1,663 adults 18 years of age and older. This study included a national cross-section of 1,490 adults, with an additional oversample of persons with a chronic illness and adults who provide informal caregiving services, for a total of 663 chronically ill and 320 caregivers. The survey was conducted from the centralized telephone research centers of Harris Interactive Inc. in Youngstown, Ohio and Binghamton, New York.

The survey data were weighted to reflect the demographic composition of the U.S. population to the following variables: age, education, race/ethnicity, insurance status, household size, and number of telephone lines in a household, using the *March 1999 Current Population Survey* from the U.S. Census Bureau. Additionally, the data were weighted to adjust for the oversample of the chronically ill and caregivers.

Health Status

[Note: Unless otherwise noted, questions in Section 200 were asked of all respondents (N=1,663)].

Q215 Would you say your health, in general, is excellent, very good, good, fair or poor?

Excellent	22
Very good	28
Good	35
Fair	12
Poor	3
Not sure	1
Decline to answer	*

Q220 All things considered, how satisfied are you with your life these days – very satisfied, somewhat satisfied, not very satisfied, or not satisfied at all?

Very satisfied	55
Somewhat satisfied	37
Not very satisfied	4
Not satisfied at all	2
Not sure	*
Decline to answer	2

Perceptions Regarding Chronic Illness

[Note: Unless otherwise noted, questions in Section 500 were asked of all respondents (N=1,663)].

Q524 Which well-known person comes to mind when you think of chronic medical conditions?

President Reagan	20
Michael J. Fox	10
Christopher Reeves/Superman	6
Mohamed Ali	3
Franklin D. Roosevelt	2
Bob Hope	1
Liz Taylor	1
John Wayne	1
Jerry Lewis	1
Lou Gehrig	1
Magic Johnson	1
Richard Pryor	1
Annette Funicello	*
Betty Ford	*
George Bush	*
David Letterman	*
Gilda Radner	*
Helen Keller	*
Janet Reno	*
Kirk Douglas	*
Mary Tyler Moore	*
Mayor Guiliani	*
The Pope	*
Bill Clinton	*
Rock Hudson	*
Walter Payton	*
John F. Kennedy	*
Barbara Bush	*
Stephen Hawkins	*
Bob Dole	*
Dudley Moore	*
Sammy Davis, Jr.	*
Katherine Hepburn	*
Nancy Reagan	*

Michael Landon	*
Michael Johnson	*
Katie Couric's family	*
Family members/friends	15
Other not specified	10
None	5
Refused	-
Don't know	12
N/A	9

Knowledge of Chronic Care and Volunteer Organizations

[Note: Unless otherwise noted, questions in Section 600 were asked of all respondents (N=1,663)].

Q600 How difficult do you think it is for most people with chronic medical conditions to get (read each item) – very difficult, somewhat difficult, not very difficult, or not at all difficult?

	Very Difficult	Somewhat Difficult	Not Very Difficult	Not At All Difficult	Not Sure	Decline to Answer
The care they need from primary care doctors	16	56	21	4	2	1
The care they need from medical specialists	24	55	15	3	2	1
The care they need from other professionals like social workers or therapists	19	53	20	5	3	1
The prescription medicines they need	23	51	17	6	2	1
Adequate health insurance	50	39	6	3	2	1
Help from their family to manage their care at home	26	52	14	5	2	*

Personal Worries and Expectations about Chronic Illness and Care

[Note: Unless otherwise noted, questions in Section 700 were asked of all respondents (N=1,663)].

[Note: Only respondents who did not report any chronic illness were asked Question 700 (N=869)].

Q700 Do you think you are very likely, somewhat likely, somewhat unlikely, or very unlikely to develop a chronic medical condition in your lifetime?

Very likely	17
Somewhat likely	47
Somewhat unlikely	17
Very unlikely	12
Not Sure	5
Decline to Answer	1

Q705 What are your biggest worries about having chronic illness?

Not being able to afford needed medical care	15
Having large medical expenses	4
Losing independence	14
Being a burden to family or friends	9
Giving up enjoyable things (e.g., hobbies, interests, activities, etc.)	3
Not being able to live at home	1
Being in pain	2
Fear of death or dying	8
Being stigmatized/feeling self-conscious	*
Being discriminated against in employment or education	*
Being isolated from family and friends	2
Other worry	27
None	12
Not Sure	2
Decline to Answer	1

Q705 (Cont.) Other worry	
<i>Other worry (Net)</i>	27
Not finding a cure/life threatening condition	2
Not wanting certain medical conditions	2
Not getting adequate care or finding good care	6
A change in lifestyle/quality of life	1
Being a financial burden	*
Not being able to work/financial problems	2
Weight control/nutrition	*
Fear of old age	*
Getting cancer	1
Feeling helpless/depressed/emotional problems	*
Not being able to take care of my family/not seeing my kids grow up	4
Having a good doctor/being able to see the right specialist	*
Insurance problems/insurance issues	2
Hereditary problems	*
Life support systems/loss of self control	*
Not having any support	*
Always needing medication or medical treatment	*
Fears	1
Having to go to the hospital	*
Losing my good health	*
Not enough research	*
Other worry not specified	3

[Note: Not all respondents mentioned a second worry in Question 710 (N=1,433)].

Q710 Second worry	
Not being able to afford needed medical care	8
Having large medical expenses	4
Losing independence	7
Being a burden to family or friends	9
Giving up enjoyable things (e.g., hobbies, interests, activities, etc.)	4
Not being able to live at home	1
Being in pain	2
Fear of death or dying	4
Being stigmatized/feeling self-conscious	*
Being discriminated against in employment or education	*
Being isolated from family and friends	2
Other worry	26
No other mention	30
Not Sure	2
Decline to Answer	1

Q710 (Cont.) Other worry	
<i>Other worry (Net)</i>	26
Not finding a cure/life threatening condition	1
Not wanting certain medical conditions	1
Not getting adequate care or finding good care	4
A change in lifestyle/quality of life	1
Being a financial burden	*
Not being able to work/financial problems	4
Weight control/nutrition	*
Fear of old age	*
Getting cancer	*
Family counseling/emotional stress on family	*
Feeling helpless/depressed emotional problems	*
Not being able to take care of my family/not seeing my kids grow up	4
Having a good doctor/being able to see the right specialist	1
Insurance problems/insurance issues	1
Hereditary problems	*
Life support systems/loss of self control	*

Not having any support	1
Being misdiagnosed	*
Always needing medication or medical treatment	*
Not having transportation/trying to get to the doctors	*
Fears	*
Having to go to the hospital	*
Other worry not specified	5

[Note: Not all respondents mentioned a third worry in Question 715 (N=978)].

Q715 Third Worry	
Not being able to afford needed medical care	6
Having large medical expenses	3
Losing independence	4
Being a burden to family or friends	8
Giving up enjoyable things (e.g., hobbies, interests, activities, etc.)	1
Not being able to live at home	1
Being in pain	2
Fear of death or dying	4
Being stigmatized/feeling self-conscious	1
Being discriminated against in employment or education	*
Being isolated from family and friends	2
Other worry	29
No other mention	32
Not Sure	5
Decline to Answer	1

Q715 (Cont.) Other worry	
<i>Other worry (Net)</i>	29
Not finding a cure/life threatening condition	1
Not wanting certain medical conditions	*
Not getting adequate care or finding good care	5
A change in lifestyle/quality of life	1
Not being able to work/financial problems	2
Weight control/nutrition	*
Fear of old age	*
Getting cancer	*
Family counseling/emotional stress on family	1
Feeling helpless/depressed/emotional problems	2

Not being able to take care of my family/not seeing my kids grow up	3
Having a good doctor/being able to see the right specialist	1
Insurance problems/insurance issues	1
Hereditary problems	*
Life support system/loss of self control	*
Not having any support	*
Being mis-diagnose	*
Not having transportation/trying to get to the doctors	1
Fears	1
Having to go to the hospital	*
Losing my good health	*
Other worry not specified	10

Q720 If you needed (or need) ongoing help with your personal or medical needs, household chores or transportation because of a chronic medical condition, who would (do) you rely on most for such help?	
Self/no one	3
Spouse/partner	32
Children/grandchildren	13
Other family members	32
Friends	5
Volunteer organizations, such as churches, charities, or support groups, etc. that provide unpaid help	3
Paid professionals or health workers	3
Parents	3
Rely on another person	2
Not Sure	4
Decline to Answer	1

Q730 If you became seriously ill and needed a lot of care and help for a year or longer, which of these would you prefer?

To receive care in your home	64
To move in with family	15
To move into an institution such as a nursing home	3
To move into housing with supportive services, such as assisted living	15
Not Sure	1
Decline to Answer	1

Chronic Illness and Chronic Care Policy

[Note: Unless otherwise noted, questions in Section 800 were asked of all respondents (N=1,663)].

Q800 I'm going to read a list of proposed health reforms that might be passed by Congress. For each, please indicate if you would strongly support it, somewhat support it, somewhat oppose it, or strongly oppose it.						
	Strongly Support	Somewhat Support	Somewhat Oppose	Strongly Oppose	Not Sure	Decline to Answer
A tax break for people who purchase private long-term care insurance	50	35	7	5	2	1
A tax break for people who provide unpaid care to family members or friends who are old, frail, or disabled	63	29	3	3	1	1
Government funded long-term care insurance for the elderly, disabled, and others who need ongoing care	68	24	3	3	1	1
Adding a new prescription drug benefit to Medicare (which provides health insurance to adults aged 65 and older and some disabled people)	72	22	2	2	1	1
Government funding for volunteer organizations helping the elderly, disabled, and others who need ongoing care	68	24	3	3	1	*
Legislation to help the uninsured get health insurance	70	23	4	2	1	1

Chronic Care and Coverage

[Note: Only respondents who are chronically ill were asked questions in Section 1000 (N=663)].

Q1000 In the past 12 months, have you received the following types of services or care?				
	Yes	No	Not Sure	Decline to Answer
Home health or personal care provided by paid health workers (IF NEEDED: personal care includes help with daily activities like eating, dressing, bathing or other needs.)	6	94	-	-
Special transportation services	6	94	-	-
Meals delivered at home	2	98	-	-
Rehabilitative therapy, like physical, occupational or speech therapy	15	84	*	*
Counseling	9	91	-	*
Adult day care	*	100	-	-
Care at a nursing home	*	100	-	-
Care at an assisted living facility (IF NEEDED: An assisted living facility is a living complex with physical features designed especially for the frail elderly or the disabled, and with personnel and programs that assist residents with the activities of daily living. Meals are provided in a common dining facility. Units usually rent on a monthly basis.)	1	99	-	-

[Note: Only chronically ill respondents who answered “no” to any item in Question 1000 were asked Question 1005].

Q1005 In the past 12 months, was there a time when you <u>needed</u> (read each item) but did not get it?				
	Yes, needed but did not get	No	Not sure	Decline to answer
Home health or personal care provided by paid health workers (IF NEEDED: Personal care includes help with daily activities like eating, dressing, bathing or other needs.) (N=627)	5	94	-	*
Special transportation services (N=632)	5	95	-	*
Meals delivered at home (N=648)	1	99	-	-
Rehabilitative therapy, like physical, occupational or speech therapy (N=566)	2	98	-	*
Counseling (N=604)	5	95	-	-
Adult day care (N=661)	2	98	-	-
Care at a nursing home (N=661)	1	99	-	*
Care at an assisted living facility (IF NEEDED: An assisted living facility is a living complex with physical features designed especially for the frail elderly or the disabled, and with personnel and programs that assist residents with the activities of daily living. Meals are provided in a common dining facility. Units usually rent on a monthly basis.) (N=658)	1	99	-	-

Q1040 Do you have a medical condition that requires you to take any prescription medications on a regular or on-going basis, or not? (For aspirin, vitamins, etc.: This applies if you need a prescription to buy that medication.)	
Yes	89
No	11

[Note: Only chronically ill respondents who answered “yes” to Question 1040 were asked Question 1045 (N=600)].

Q1045 How many separate prescription medications do you usually take?	
1	26
2	22
3 or more	51
Decline to answer	1
Mean = 3 Prescription medicines	
Median = 3 Prescription medicines	

Q1050 How difficult is it for you to pay for all your medications, including over the counter as well as prescription medications – Extremely difficult, somewhat difficult, not too difficult, or not at all difficult?	
Extremely difficult	15
Somewhat difficult	22
Not too difficult	26
Not at all difficult	37
Decline to Answer	1

Q1055 Are there any prescription medicines that you are supposed to use, but you (read each item)?				
	Yes	No	Not Sure	Decline to Answer
Do not use as prescribed because of the cost	16	84	-	*
Sometimes forget to use or refill	15	85	*	*
Do not use as prescribed because of side effects	13	87	*	1
Cannot take as prescribed because of problems or delays in getting the prescription filled	7	93	-	-
Do not use because you think you do not need it	8	91	*	*
Cannot pick them up from the store or get delivered	3	96	-	*
Do not take because you do not know how to use it, that is, what amount or how often to use	1	99	*	*

Q1060 In the past 12 months, have you seen a (read each item) to provide you with medical care or advice?				
	Yes	No	Not Sure	Decline to Answer
Primary care doctor (IF NEEDED: Primary care doctors Include general practitioner, family practitioner, internists and OB/GYNs)	89	11	*	-
Medical specialist (IF NEEDED: Specialists are doctors like surgeons, heart doctors, psychiatrists, allergy doctors, skin doctors, eye doctors, and others who specialize in one area of health care)	57	43	*	-

Q1065 In the past 12 months, was there ever a time when you were not able to see a (read each item), when you thought you needed one?				
	Yes	No	Not Sure	Decline to Answer
Primary care doctor (IF NEEDED: Primary care doctors Include general practitioner, family practitioner, internists and OB/GYNs)	10	90	-	-
Medical specialist (IF NEEDED: Specialists are doctors like surgeons, heart doctors, psychiatrists, allergy doctors, skin doctors, eye doctors, and others who specialize in one area of health care)	11	89	*	-

Q1075 How many different doctors, including specialists did you see in the last 12 months?	
0	1
1	23
2	33
3 or more	40
Not sure	5
Mean = 3 Doctors	
Median = 2 Doctors	

[Note: Only chronically ill respondents who saw at least one doctor in Question 1075 were asked Question 1080 (N=624)].

Q1080 Do you have one doctor you rely on the most for care for your chronic illness?	
Yes, have one doctor	90
No, do not	5
Not Sure	5
Decline to Answer	*

[Note: Only chronically ill respondents who answered “yes” to Question 1080 were asked Question 1085 (N=564)].

Q1085 Is this doctor a primary care doctor or a medical specialist?	
Primary care doctor	68
Medical specialist	30
Not Sure	1
Decline to Answer	1

Financial Burdens

[Note: Only respondents who are chronically ill were asked questions in Section 1100 (N=663)].

Q1100 In the last year, about how much have you and your family had to pay out-of-pocket for all the expenses related to your chronic medical condition? (By out-of-pocket I mean things that you or your family members had to pay from your or their own personal funds and the expenses were not reimbursed by your health insurance)

\$0 - \$49	14	\$500 - \$999	17
\$50 - \$99	4	\$1000 or more	28
\$100 - \$199	8	Not sure	10
\$200 - \$499	19	Decline to answer	1

Q1105 In terms of a financial burden, are the costs of your overall care including any services you may need to help cope with your chronic illness, a major problem for you, a minor problem, or not much of a problem at all?

Major problem	17
Minor problem	28
Not much of a problem at all	55
Not Sure	-
Decline to Answer	1

Q1115 Is your health insurance sufficient to cover all the types of care you need to cope with your medical condition, or not?

Yes, sufficiently covered	76
No, not sufficiently covered	22
Not Sure	2
Decline to Answer	*

Chronic Care Coordination

[Note: Only respondents who are chronically ill were asked questions in Section 1200 (N=663)].

[Note: Only chronically ill respondents who have seen a primary care doctor or medical specialist in the past 12 months were asked Question 1200 (N=624)].

Q1200 Is there any one doctor who you think of as the one who coordinates your overall care? By coordinating, I mean one who keeps in touch with the different doctors or therapists whom you see, who knows the results of all the tests and treatments that you have, and who is aware of all your different prescription medicines?

Yes, one doctor coordinates	79
No one doctor coordinates	15
Not Sure	5
Decline to Answer	1

Q1205 Is there (anyone/anyone else) who helps you with the coordination of your care? By coordination of care I mean help making appointments, arranging schedules of people who come to help you, getting services you need, with your insurance, or giving you information or phone numbers of people or services that you may need.

Yes, someone helps	21
No, no one helps	71
I do it myself	8
Not Sure	*
Decline to Answer	-

[Note: Only chronically ill respondents who answered “yes” to Question 1205 were asked Question 1210 (N=124)].

Q1210 Who does it for you? (read list)	
Nurse	8
Social worker	2
Therapist	-
Hospital discharge planner	4
Case manager	2
Volunteer	*
Relative	50
Friend or neighbor	3
Doctor	28
Someone else not specified	4
Not Sure	-
Decline to Answer	-

Q1215 During the past 12 months, have you felt that you needed (anyone/anyone else) to help you arrange or coordinate your care?	
Yes, have needed someone/someone else	8
Have not needed anyone	92
Not Sure	-
Decline to Answer	*

Q1220 Which of the following statements best describes the level of involvement you would like to have in coordinating your overall care?	
Prefer to coordinate it by yourself	66
Prefer to have occasional assistance from others to help with coordination	21
Prefer to have someone else to take the lead in coordinating it, with some involvement on your part	8
Prefer to have someone else to fully coordinate it for you	4
Not Sure	1
Decline to Answer	1

Q1225 If it were available, how important would it be to you to have one person who could coordinate both your medical care and non-medical care -- would it be absolutely essential, very important, somewhat important, not very important, or not at all important?

Absolutely essential	4
Very important	13
Somewhat important	25
Not very important	22
Not at all important	33
Not Sure	1
Decline to Answer	1

Q1230 In the past 12 months, when getting care for your medical problem, how often have (read list) – often, sometimes, hardly ever, or never?

	Often	Sometimes	Hardly Ever	Never	Not Applicable	Not Sure	Decline to Answer
A. You had to tell the same story about your medical condition multiple times to different doctors, nurses and other Healthcare workers	23	17	23	35	1	*	1
B. Your medical records or test results not reached your doctor's office in time for your appointment	7	10	17	64	1	*	1
C. You been sent for duplicate tests or diagnostic procedures by different doctors, nurses or healthcare workers	7	11	17	64	*	*	1
D. You received contradictory information from different doctors, nurses or other healthcare workers	6	11	14	68	*	1	*
E. You been told by a pharmacist about a possibly harmful interaction between a drug you are already taking and a new one you were about to fill	8	8	15	66	1	*	1
F. You been diagnosed with different medical problems for the same set of symptoms by different doctors	5	9	15	69	1	*	1
G. You been in pain because your doctor didn't know that you needed medication or that your medication was not working well enough	7	14	16	62	*	*	1

Q1235 In the past 12 months, how often have/has (read list) – often, sometimes, hardly ever, or never?

	Often	Sometimes	Hardly Ever	Never	Not Applicable	Not Sure	Decline to Answer
You not been able to get to a medical appointment due to lack of transportation	2	6	6	86	1	*	*
You not received or postponed needed care, because there was no one to make an appointment for you	*	2	5	91	1	-	*
Your health aide or attendant not come when needed because no one arranged or kept track of his or her schedule	1	1	4	74	20	*	*
You not received needed care, because you did not have information about where or how to get it	2	5	6	84	3	*	*
You been limited in your ability to move around your home because no one provided advise about how to make adjustments like adding ramps or handles, or rearranging furniture	1	3	5	85	6	*	*

Experience with Caregiving

[Note: Only respondents who are caregivers were asked questions in Section 1500 (N=320)].

Q1500 You indicated that you are (currently caring/ have recently cared) for someone who is frail, sick or disabled. (Are/ were) you caring for one person or more than one person (in the past 12 months)?

One person	86
More than one person	13
Not Sure	*
Decline to Answer	*

[Note: Respondents who cared for more than one person were instructed to answer the following questions about the person they spent the most time caring for].

Q1510 What (is/ was) this person's relationship with you?

Spouse	7
Mother	19
Father	11
Son	4
Daughter	3
Grandmother	9
Grandfather	3
Grandparent-in-law	1
Aunt	3
Uncle	1
Father-in-law	2
Mother-in-law	6
Brother	2
Sister	4
Brother-in-law	-
Sister-in-law	3
Non-relative/friend	15
Companion/partner	3
Some other relationship not specified	2
Not Sure	-
Decline to Answer	1

Q1515 What is/was the primary medical, mental or other health condition that leaves/left your (relationship) unable to fully care for himself/herself?	
ALS or Lou Gehrig's disease	*
Alzheimer's disease	9
Arthritis	6
Asthma	1
Blindness or other vision impairment	1
Cancer	15
Chronic bronchitis	1
Chronic back problems	1
COPD (Chronic obstructive pulmonary disease)	1
Depression	1
Developmental disability	1
Diabetes	3
Digestive or gastro-intestinal disorder	1
Elderly and frail	9
Epilepsy	1
Emphysema	3
Fibromyalgia	1
Heart disease	9
HIV/AIDS	*
Hypertension or high blood pressure	*
Kidney disease	2
Liver disease, including cirrhosis	1
Lupus	*
Multiple sclerosis	1
Osteoporosis	1
Other mental health condition	4
Paralysis of the extremities	1
Parkinson's disease	1
Stroke	7
Problems with bone joints	4
Other impairment not specified	15
Not Sure	1
Decline to Answer	1

[Note: Only caregiver respondents who provided care in the past year, not currently, were asked Question 1520 (N=131)].

Q1520 Is the person still living?	
Yes, still living	51
No, not living	49
Not Sure	-
Decline to Answer	-

[Note: All caregiver respondents, both current and in the past year, and those who answered “yes” to Question 1520 were asked Question 1525 (N=249)].

Q1525 How old is your (relationship)?	
Less than 51	20
51-70	31
71-80	20
81-85	13
86 and over	14
Not Sure	1
Decline to Answer	-
Mean = 65 years	
Median = 69 years	

[Note: Only caregiver respondents who answered “no” to Question 1520 were asked Question 1530 (N=71)].

Q1530 How old was your (relationship) when he/she passed away?	
Less than 40	2
40-50	4
51-60	16
61-70	19
71-80	19
81-90	27
More than 90 years old	8
Not Sure	5
Decline to Answer	-
Mean = 73 years	
Median = 76 years	

Q1535 (Does/Did) your (relationship) live (read list)?	
In your household	26
Alone, in his/her own home	29
With another family member or friend, in their own home	27
In a retirement community or elderly housing apartment complex	4
In a nursing home	7
In some other facility where some care and supervision is provided, like an assisted living facility or a group home.	4
Somewhere else: not specified	1
Not Sure	-
Decline to Answer	1

[Note: Only caregiver respondents who answered “In your household”, “Alone, in his/her own home”, or “With another family member of friend, in their own home” in Question 1535 and received paid help at home were asked Question 1580 (N=101)].

Q1580 During the past 12 months, how many paid health professionals or home health aides has/did you (relationship) used/use? This could include visiting nurses, visiting or occupational therapists, home health aids and others who provide assistance in the home.

Mean = 6 Health care workers

Median = 2 Health care workers

[Note: Only caregiver respondents who answered “In your household”, “Alone, in his/her own home”, or “With another family member of friend, in their own home” in Question 1535 were asked Question 1585 (N=255)].

Q1585 How many different doctors, including general physicians and specialists, has/had your (relationship) seen in the past 12 months? Please do not include any nursing home physicians.

Mean = 7 Doctors

Median = 4 Doctors

Need for Care Coordination

[Note: Only respondents who are caregivers were asked questions in Section 1600 (N=320)].

Q1600 Is/was there anyone who you think of as the person who coordinates/ coordinated all your (relationship)'s medical and personal care needs? By coordinating care I mean keeping in touch with the different doctors or health care workers whom your (relationship) sees, keeping track of test results, arranging for home health care, scheduling appointments and home visits, and other services.)	
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Yes, someone coordinates needs	72
No, no one coordinates needs	26
Not Sure	1
Decline to Answer	1

[Note: Only caregiver respondents who answered "yes" to Question 1600 were asked Question 1605 (N=243)].

Q1605 Who does/did it for your (relationship)?	
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Doctor	8
Nurse	2
Social worker	2
Therapist	-
Case manager	1
Volunteer	-
Relative	48
Friend	1
Respondent himself/ herself	17
(Relationship) himself/ herself	2
Hospice/services like hospice/nursing home	2
Other not specified	17
Not Sure	*
Decline to Answer	-

Q1610 During the past 12 months, have you felt that you needed anyone/anyone else to help arrange or coordinate your (relationship)'s medical and personal care?	
Yes, needed someone (someone else) to coordinate care	24
No, did not	75
Not Sure	-
Decline to Answer	1

Q1615 Which of the following statements best describes the level of involvement you would like to have/have had in coordinating your (relationship)'s overall care?	
Prefer to coordinate it by yourself	18
Prefer to have occasional assistance from others to help with coordination	33
Prefer to have someone else to take the lead in coordinating it, with some involvement on your part	26
Prefer to have someone else to fully coordinate it for your (relationship)	17
Not Sure	2
Decline to Answer	5

Q1620 How important is/was it to you to have <u>one</u> person to coordinate your (relationship)'s medical and personal care – absolutely essential, very important, somewhat important, not very important, or not at all important?	
Absolutely essential	20
Very important	44
Somewhat important	23
Not very important	6
Not at all important	3
Not Sure	3
Decline to Answer	1

Q1625 In the past 12 months, when getting care for your (relationship) how often have/has (read list)– often, sometimes, hardly ever, or never?

	Often	Sometimes	Hardly Ever	Never	Not Applicable	Not Sure	Decline to Answer
You or your (Relationship) had to tell the same story about their medical condition multiple times to different doctors, nurses and other healthcare workers	34	26	19	14	3	4	1
Your (Relationship)'s medical records or test results not reached their doctor's office in time for their appointment	6	17	22	42	2	10	1
Your (Relationship) been sent for the duplicate tests or diagnostic procedures by different doctors, nurses or healthcare workers	14	19	26	32	2	6	1
Your (Relationship) received contradictory information from different doctors nurses or other healthcare workers	11	25	26	30	2	6	1
Your (Relationship) been told by a pharmacist about a possibly harmful interaction between a drug they are already taking and a new one they were about to fill	8	13	21	44	4	8	1
Your (Relationship) been diagnosed with different medical problems for the same set of symptoms by different doctors	6	22	21	39	3	7	1
Your (Relationship) been in pain because your (Relationship)'s doctor didn't know that he or she needed medication or that the medication was not working well enough	15	21	23	30	4	5	3

Q1630 In the past 12 months, how often has (read list) – often, sometimes, hardly ever, or never?

	Often	Sometimes	Hardly Ever	Never	Not Applicable	Not Sure	Decline to Answer
Your (Relationship) been not able to get to a medical appointment because of a lack of transportation	5	11	19	62	1	1	1
Your (Relationship) has not received or postponed needed care, because there was no one to make an appointment for him/her	1	5	17	72	3	1	1
Your (Relationship)'s health aide or attendant not come when needed because no one arranged or kept track of his or her schedule	2	3	14	61	14	4	2
Your (Relationship) has not received needed care, because you or your (Relationship) did not have information about where or how to get it.	4	10	17	62	2	4	1
Your (Relationship) been limited in his or her ability to move around the home because no one provided advice about how to make adjustments like adding ramps or handles, or rearranging furniture	3	6	20	63	5	2	1

Demographics

[Note: All respondents were asked Section 100 (N=1,663)].

Q103 (Respondent's gender from observation)

Male	48
Female	52

Q106 What is your month and year of birth

Age	
18-24	13
25-34	19
35-44	22
45-54	18
55-64	11
65 and older	16

Q135 What is your marital status? (read list)

Married	58
Single	22
Divorced	9
Separated	1
Widowed	7
Living with partner	2
Not Sure	-
Decline to Answer	*

Q138 Including you, how many adults (age 18 or over) live in this household?

Mean = 2 Adults
Median = 2 Adults

Q141 How many children under the age of 18 live in this household?

Mean = 1

Q146 What is the highest level of education you have completed or the highest degree you have received?

Less than high school	5
Completed some high school	10
High school graduate or equivalent (e.g., GED)	35
Completed some college, but no degree	27
College graduate (e.g., B.A., A.B., B.S.)	16
Completed some graduate school, but no degree	1
Completed graduate school (e.g., M.S., M.D., Ph.D.)	6
Not Sure	*
Decline to Answer	*

Q149 What is your employment status?

Employed full-time	51
Employed part-time	9
Self-employed	7
Not employed, but looking for work	5
Not employed and not looking for work	3
Retired	16
Student	3
Homemaker	4
Not Sure	*
Decline to Answer	1

Q157 Which of the following income categories best describes your total 1999 household income before taxes?

Less than \$15,0000	18
\$15,000 to \$24,999	17
\$25,000 to \$34,999	16
\$35,000 to \$49,999	13
\$50,000 to \$74,999	14
More than \$75,000	13
Not Sure	3
Decline to Answer	6

Q175 Are you of Hispanic origin, such as Mexican American, Latin American, Puerto Rican, or Cuban?

Yes, of Hispanic origin	10
No, not of Hispanic origin	89
Not Sure	*
Decline to Answer	1

Q178 Do you consider yourself (read list)?

White	74
Black	7
African American	5
Asian or Pacific Islander	4
Native American or Alaskan native	2
Mixed racial background	4
Other Specify	3
American/United States citizen	*
Hispanic	2
Other race not specified	1
Not Sure	*
Decline to Answer	2

[Note: Only respondents who answered “mixed racial background” to Question 178 were asked Question 180 (N=44)].

Q180 You indicated that you consider yourself of a mixed racial background. With which of the following racial groups do you most closely identify?	
White	50
Black	19
African American	3
Asian or Pacific Islander	3
Native American or Alaskan native	21
Not Sure	11
Decline to Answer	6
No answer	*

Q185 Would you say that you are a very religious person, somewhat religious person, or not religious at all?	
Very religious	31
Somewhat religious	55
Not religious at all	12
Not Sure	*
Decline to Answer	2

Methodology

Chronic Illness and Caregiving was conducted by Harris Interactive Inc. on behalf of The Robert Wood Johnson Foundation, Johns Hopkins University, and Partnership for Solutions. The survey was conducted from March 17, 2000 through November 22, 2000 with a total of 1,663 adults 18 years of age and older. This study included a national cross-section of 1,490 adults, with an additional oversample of persons with a chronic illness and adults who provide informal caregiving services, for a total of 663 chronically ill and 320 caregivers. The survey was conducted from the centralized telephone research centers of Harris Interactive Inc. in Youngstown, Ohio and Binghamton, New York.

Weighting the Data for the Public

The survey data were weighted to reflect the demographic composition of the U.S. population to the following variables: age, education, race/ethnicity, insurance status, household size, and number of telephone lines in a household, using the *March 1999 Current Population Survey* from the U.S. Census Bureau. Additionally, in order to adjust for the oversample of the chronically ill and caregivers, the data were weighted to represent the appropriate distributions of chronically ill adults and caregivers in the U.S. population.

Telephone Interviewing Procedures

Interviewing was conducted from the centralized telephone research centers of Harris Interactive Inc. in Youngstown, Ohio, and Binghamton, New York, between March 17, 2000 and November 22, 2000. Screening and interviewing for the study was conducted by Harris' large, professional interviewing staff. Interviewing for this study was regularly quality-monitored by Harris' field supervisory staff. The computer-assisted telephone interviewing (CATI) system at Harris permitted on-line data entry and on-line data editing of the telephone interview.

The *Chronic Illness and Caregiving* survey was conducted in both English and Spanish.

Up to twenty attempts were made to identify eligible respondents. Once the respondent was identified, up to ten additional follow-up calls were made to interview the selected respondent. In order to maximize a response rate, in many cases, even more initial and follow-up calls were made to identify and interview the eligible respondent. In addition, there were up to five, and in some cases even more, refusal conversion attempts performed by experienced interviewers who were provided specialized training in refusal conversion techniques. Also, a twenty-five dollar honorarium was offered to all respondents who completed the survey.

Screening for Chronically Ill and Caregivers

Respondents were asked a battery of screener questions to determine if they were chronically ill or if they provide caregiving services to someone in need, either currently or in the past twelve months. Based on responses to screener questions, respondents were categorized as either chronically ill, a caregiver, or neither chronically ill nor a caregiver. The chronically ill and caregivers received specific questions related, respectively, to their experiences with chronic illness and caregiving, in addition to the general battery of questions all respondents received. Respondents who were identified as both chronically ill and caregivers were randomly assigned to one of the specialized sections. Those who were neither chronically ill nor caregivers received the general battery of survey questions only.

Respondents were categorized as chronically ill based on the following five criteria:

- Currently need or use medicine prescribed by a doctor;
- Need or use more medical care, mental health or other health services than usual for others their age;
- Limited or prevented in their ability to do things most people their age can do;
- Need or get special therapy, such as physical, occupational or speech therapy; and

- Have a mental or emotional problem for which they need or get treatment or counseling.

Respondents were considered chronically ill if any one of the above five criteria was present due to a health condition that has lasted, or was expected to last, for at least twelve months.

The screener for caregivers provided a description of caregiving tasks and a question about whether the respondent currently, or in the past twelve months, provided such caregiving service. Respondents were defined as caregivers if they currently, or in the past twelve months, provided caregiving services.

Sampling Procedures

Harris used a random-digit-dialing (RDD) methodology designed to produce representative samples of persons in telephone households in the 48 contiguous United States (excluding Alaska and Hawaii). The telephone sample employs random digit selection procedures to assure the equal representation of persons in both households which are “listed” in telephone directories, and households which are “unlisted”. The sample is also explicitly designed to assure proper representation of households in different regions of the country and in central city, suburban, and rural areas.

The sample was administered in replicates (cross sectional subsets of the total sample) and sample quotas were set by region. Additional quotas for the oversample included persons with either a chronic illness or those who provide caregiving services to someone in need, either currently or in the past twelve months. Both the cross section and the oversample are representative of the U.S. population.

To ensure a random selection of respondents at the household level, respondents were selected based on the “most recent birthday” technique that screens for an adult, 18 years of age or older, living in the household, who has had the most recent birthday.

Reliability of Survey Percentages

It is important to bear in mind that the results from any sample survey are subject to sampling variation. The magnitude of this variation is measurable and is affected both by the number of interviews involved and by the level of the percentages expressed in the results.

Table A-1 shows the range of sampling variation that applies to percentage results for this survey. The chances are 95 in 100 that the survey results do not vary, plus or minus, by more than the indicated number of percentage points from the results that would have been obtained had interviews been conducted with all persons in the universe represented by the sample.

For example, if the response for a sample size of 1,000 is 30%, then in 95 cases out of 100 the response in the total population would be between 27% and 33%. Note that survey results based on subgroups of small size can be subject to large sampling error.

Table A-1
Approximate Sampling Tolerances (at 95% Confidence) to
Use in Evaluating Percentage Results Appearing in This Report

Number of People Asked Question on Which Survey Result is Based	Survey Percentage Result at 10% or 90%	Survey Percentage Result at 20% or 80%	Survey Percentage Result at 30% or 70%	Survey Percentage Result at 40% or 60%	Survey Percentage Result at 50%
2,000	1	2	2	2	2
1,500	2	2	2	2	3
1,000	2	2	3	3	3
900	2	3	3	3	3
800	2	3	3	3	3
700	2	3	3	4	4
600	2	3	4	4	4
500	3	4	4	4	4
400	3	4	4	5	5
300	3	5	5	6	6
200	4	6	6	7	7
100	6	8	9	10	10
50	8	11	13	14	14

Sampling tolerances are also involved in the comparison of results from different surveys or from different parts of a sample (subgroup analysis). Table A-2 shows the percentage difference that must be obtained before a difference can be considered statistically significant. These figures, too, represent the 95% confidence level.

For example, suppose one group of 100 has a response of 34% "yes" to a question, and an independent group of 50 has a response of 28% "yes" to the same question, for an observed difference of 6 percentage points. According to the table, this difference is

subject to a potential sampling error of plus or minus 16 percentage points. Since the observed difference is smaller than the sampling error, the observed difference is not significant.

Table A-2
Approximate Sampling Tolerances (At 95% Confidence) To Use in Evaluating
Differences between Two Percentage Results Appearing in This Report

Approximate Sample Size of Two Groups Asked Question on Which Survey Result is Based	Survey Percentage Result at 10% or 90%	Survey Percentage Result at 20% or 80%	Survey Percentage Result at 30% or 70%	Survey Percentage Result at 40% or 60%	Survey Percentage Result at 50%
2,000 vs. 2,000	2	2	3	3	3
1,000	2	3	3	4	4
500	3	4	4	5	5
200	4	6	7	7	7
100	6	8	9	10	10
50	8	11	13	14	14
1,000 vs. 1,000	3	4	4	4	4
500	3	4	5	5	5
200	5	6	7	7	8
100	6	8	9	10	10
50	9	11	13	14	14
500 vs. 500	4	5	6	6	6
200	5	7	8	8	8
100	6	9	10	11	11
50	9	12	13	14	15
200 vs. 200	6	8	9	10	10
100	7	10	11	12	12
50	9	12	14	15	15
100 vs. 100	8	11	13	14	14
50	10	14	16	17	17
50 vs. 50	12	16	18	19	20

Sampling error is only one type of error encountered in survey research. Survey research is also susceptible to other types of error, such as data handling error and interviewer recording error. The procedures followed by Harris Interactive Inc. however, keep errors of these kinds to a minimum.

CATI System Used for Interviews in the United States

An example of these procedures is the CATI system – computer assisted telephone interviewing – which is used for all interviews conducted in the United States. This system controls complicated skip patterns based on individual responses during the course of the interview, and it also allows consistency checks to be built in for key items. Since interviewers enter the respondents' answers directly into a computer terminal during the interview itself, it also reduces the number of potential clerical errors.