FROM THE FIELD

Challenged To Care: Informal Caregivers In A Changing Health System

Social policy must respond to what caregivers are telling us about their experiences.

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ABSTRACT: This report is from a 1998 national survey of 1,002 informal caregivers. Each year 23 percent of Americans provide unpaid assistance to ill, disabled, or elderly persons. Most caregivers (71 percent) do not live with care recipients. Primary caregivers provide more care of all types. Nonprimary caregivers also provide substantial care and services. Caregivers perform complex medical tasks, including medication administration, and errors can result. Few receive assistance from paid professionals or aides because of quality or financial concerns. In many areas, support and instruction could lighten caregivers' burdens and help to ensure high-quality care at home.

CARING FOR ILL or disabled family members is a difficult prospect in the changing U.S. health care system, where hospital stays are shorter, physicians are dissatisfied, and nurses are in short supply. In addition, family structures and demographics are not static. The circle of family members widens through divorce and remarriage. Also, year 2000 census data indicate that 18 percent of the population moved in the past year, 3 percent changed state of residence, and 28 percent lived in a state other than that of their birth.[1] These transitions may mean that people know their neighbors a bit less and are less likely to have family members close by.[2] These changing family dynamics coupled with the desire of most elderly persons to remain in their own homes as long as possible create a need for families to identify and coordinate services and to provide assistance in the home as needed.

Research on informal caregiving has highlighted the intense emotional and physical burdens on some caregivers—particularly those who are the primary supports for people with longer-term or terminal illnesses and when major cognitive impairment is involved.[3] As the population ages, the role of family care-

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givers will become more important, and targeting the right kinds of support will be essential.

The year 2001 marked the implementation of the Family Caregiver Support Act, one of the first new federal initiatives designed to expand services and assistance for family caregivers.[4] The act includes funding for state and community-based support programs and monies for research in innovations in service provision. These measures were designed to broaden and integrate support for those who are burdened in their efforts to care for ill, frail, disabled, and elderly family members.

In this paper we present data from a national survey of informal caregivers to shed light on issues that are critical to providing the kinds of assistance caregivers need. We focus on areas in which the changing health care system and demographics of family life have challenged caregivers in new ways.

Data And Methods

■ **Data source.** The data used in these analyses are drawn from a national survey, Long Term Care from the Caregiver's Perspective, conducted by the Harvard School of Public Health and the National Opinion Research Center (NORC) in collaboration with researchers from the Henry J. Kaiser Family Foundation, the Visiting Nurse Service of New York, and the United Hospital Fund. The survey project was funded to gather a substantial set of information on caregivers' tasks, burdens, and rewards and on support services in a changing health care system.

A national telephone survey was conducted from May through July 1998. An equal probability of selection method (EPSEM) sample was drawn for the continental United States. A simultaneous research effort was conducted in New York City and has been reported elsewhere.[5] A random respondent was selected in each household contacted. Interviews were conducted in English or Spanish.

■ **Screening procedure.** Respondents were interviewed to determine eligibility for a longer informal caregiver interview. The screening procedure asked the respondent if he or she, at the time of the interview or in the course of the year before, had been a caregiver. *Caregivers* were defined as "anybody who provides unpaid help, or arranges for help, to a relative or friend because they have an illness or disability that leaves them unable to do some things for themselves, or because they are simply getting older. This kind of help could be with household chores, or finances or with personal or medical needs. The person who needs help may live with you in your home, in their own home, or in another place such as a nursing home." The screening definition was designed to be sufficiently broad to encompass a range of traditional caregiver activities as well as activities such as general nonmedical assistance and arranging or paying for care. Extensive pretesting demonstrated the value of this measure, which produced findings similar to those of other recent national caregiver surveys and other surveys measuring the health experiences of U.S. families.

To determine eligibility for the caregiver module, 4,874 adults completed the screening interview; 1,002 respondents then completed the caregiver interview, while those ineligible completed a four-minute interview to obtain comparative demographic and health status information. Caregiver interviews lasted an average of twenty-four minutes.

Survey items included demographics and health status of both the giver and recipient of care; caregivers' assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs), medical tasks, and paid support; reasons for caregiving; and burdens and rewards of caregiving. The survey development was informed by previous research conducted by the United Hospital Fund.[6]

■ **Care intensity measurement.** We used a Level of Care index developed by the National Alliance for Caregiving.[7] The measure combines performance of ADLs and IADLs as well as hours of care provided and assigns to each respondent a Level of Care score of 1 to 5, where 1 is the lowest intensity level of care and 5, the highest. This measure offers one way of valuing the different nature of intensive work performed for a brief time versus intensive work performed every day.

■ Strengths and weaknesses of survey instrument. Population sample surveys like this one have a number of strengths and weaknesses. This survey was designed to provide estimates that are generalizable to adults living in households with telephones in the continental United States. All sample surveys are subject to sampling error. The margin of error on estimates in the national sample is ±3 percent. The margin of error increases if estimates are drawn from smaller subgroups of respondents.

Surveys are also subject to sources of nonsampling error such as nonresponse bias, coverage error, item response bias, and question order and contextual effects. Considerable qualitative research, pretesting, and interviewer training and field-work supervision efforts were undertaken to minimize these sources of error. NORC supervisors reviewed all refusals and noncontacts. Depending on the pattern of response to calls, up to fifty but no fewer than sixteen attempts were made to contact a selected eligible respondent.

■ Response rates. Response rates for eligible caregivers were 83 percent for the national sample and 84 percent for the New York City sample. Rates were calculated using standardized response rate reporting criteria developed for random-digit-dialed telephone surveys by two professional organizations: the Council on American Survey Research Organizations (CASRO), and the American Association for Public Opinion Research (AAPOR).

Survey Results

■ Caregiver demographics. During the year prior to the survey, nearly one in four adults (23 percent) provided care to a family member or friend who needed assistance. At the time of the survey, 16 percent were providing such care, and an additional 7 percent said they had done so in the prior year. Among former caregivers, 55 percent reported that care recipients had died, 17 percent reported that the health of recipients had improved, and the rest indicated that recipients had moved to different settings.

Caregivers were women and men of all ages, races, incomes, and educational backgrounds. Half indicated that they were the primary caregivers, and half were secondary caregivers (Exhibit 1).

The majority (79 percent) of respondents cared for immediate family—parents (42 percent), grandparents (17 percent), spouses (7 percent), siblings (7 percent), or children (6 percent)—although large proportions cared for other relatives (5 percent), or partners or friends (18 percent). Respondents reported that 65 percent of the persons they cared for were women and that 27 percent were over age eighty. The majority of caregivers were employed, most full time. Primary caregivers were less likely than secondary caregivers were to be working full time.

Caregivers, most notably primary caregivers, were more likely than people in the general U.S. population are to report having a serious or chronic illness or disability. While primary caregivers were less likely to rate themselves in "excellent" health, they were not more likely to rate themselves in "fair" or "poor" health.

■ Caregiver activities. Caregivers were asked about their assistance with six ADLS and seven instrumental and supportive nonmedical activities. The data reveal a substantial time commitment to all tasks: 20 percent were providing full-time or constant care, 41 percent had been caregivers for five years or more; and 37 percent were providing level 4 or 5 care (Exhibit 2).

More than half (54 percent) of caregivers who helped with an ADL such as feeding, bathing, using the toilet, or lifting said that they received no formal instruction as to how to perform these tasks. Two-thirds said that they were very comfortable providing assistance with ADLs. Primary caregivers were more likely than secondary caregivers were to perform most tasks, although similar proportions reported assisting with three or more ADLs. Secondary caregivers were more likely to provide episodic care and less likely to provide constant care but were equal to primary caregivers in performing part-time duties. Caregivers who lived with care recipients performed higher levels of care than those who

EXHIBIT 1
Demographic Composition Of Adult Caregivers In The United States, 1998

	U.S. population	All caregivers N = 1,002	Primary caregivers n = 511	Secondary caregivers n = 491
Gender				
Male	48%	46%	36%	57%
Female	52	54	64	43
Age (years)				
18–44	54	54	32	57
45–64	28	33	51	36
65+	16	12	17	6
Income				
Less than $19,999	25[a]	29	33	28
$20,000 to $34,999	20[a]	20	22	17
$35,000 to $74,999	35[a]	30	27	31
$75,000 or more	20[a]	12	11	14
Employment				
Full time	52	53	47	58
Part time	11	10	11	10
Other	36	37	42	32
Caregiver health status				
Excellent	26	28	23	33
Very good	30	30	29	30
Good	28	26	29	21
Fair	12	13	14	12
Poor	4	3	3	3
Has serious or chronic illness/disability	25	32	38	25
Lives with care recipient	–[b]	29	38	25

SOURCE: Harvard School of Public Health/NORC/Kaiser/United Hospital Fund/Visiting Nurse Service of New York, Long Term Care from the Caregiver's Perspective, 1998.

[a] Data taken from Current Population Survey, 1998.

[b] Not applicable.

did not. Of live-in caregivers, 67 percent were scored as providing level 4 or 5 care, compared with 27 percent of those who did not live with recipients.

■ **Medical caregiver tasks.** Fifty-four percent of respondents reported that the person they cared for was hospitalized overnight in the year prior to the interview; 74 percent said that the person had a serious or chronic illness that limited his or her ability to function normally.

This survey included several measures that historically have not been captured in caregiver activity measurement: bandaging and wound care (theorized to be more common as patients come home from the hospital sooner after surgery than before), pumps and machines at the bedside (as a proxy for newer home infusion, dialysis, and other machines), and medication administration (thought to be important in an era where the issue of medication safety has been widely discussed in the hospital setting).

As shown in Exhibit 3, 43 percent of respondents performed at least one of these tasks. Primary caregivers were much more likely to assist with each of these tasks than were secondary caregivers (26 percent versus

EXHIBIT 2
Caregivers' Activities And Levels Of Care, 1998

	U.S.	Primary caregiver	Secondary caregiver
Help with activities of daily living (ADLs)			
Bathing or showering	26%	34%	16%
Getting dressed or getting recipient's clothes out of the closet	42	47	36
Feeding recipient	17	15	18
Managing incontinence, such as diapering and cleanup	17	21	12
Getting in or out of bed or chairs	40	40	40
Walking across the room	34	31	37
Caregivers performing 3 or more ADLs	30	33	30
Help with instrumental activities of daily living (IADLs)			
Transportation, either by driving or helping with the use of public transportation	76	82	71
Making telephone calls for or about care recipient	59	68	46
Arranging for government assistance through programs like Medicare, Medicaid, or SSDI	29	38	16
Errands	85	89	81
Housework	71	80	67
Meals	59	70	51
Duration of caregiving (years)			
Less than 1	22	18	28
1–4	37	34	41
5–9	22	24	18
10 or more	19	23	14
Hours spent caregiving (per week)			
Episodic or fewer than 8	44	29	57
9–20	23	25	22
21–40	12	13	12
41 or more and constant	20	33	9
Level of care			
1 (0–1 IADL <21 hours/week, or 2+ IADLs <9 hours per week)	28	20	31
2 (0–1 IADL 21–40 hrs; 2+ IADLs 9–20 hours, 1 ADL <9 hrs)	15	16	13
3 (0–1 IADL 41+ hrs, 2+ IADLs 21–40 hrs, 1 ADL 9–20 hrs, 2+ ADLs <9 hrs)	20	15	28
4 (2+ IADLs 41+ hrs, 1 ADL 21–40 hrs, 2+ ADLs 9–40 hrs)	22	24	21
5 (3+ ADLs 41+ hrs)	15	25	7

SOURCE: Harvard School of Public Health/NORC/Kaiser/United Hospital Fund/Visiting Nurse Service of New York, Long Term Care from the Caregiver's Perspective, 1998.

NOTE: SSDI is Social Security Disability Insurance.

13 percent with dressings, 19 percent versus 11 percent with equipment, and 48 percent versus 30 percent with medications). One in six caregivers helped to give medications in forms other than oral preparations; 26 percent helped to give five or more different medications. One in four caregivers performing these tasks for someone who was hospitalized in the past year indicated that they were doing this work because the care recipient had been sent home from the hospital "too soon."

■ **Instruction and coping skills.** Given the sometimes complex and demanding nature of the tasks that some caregivers perform,

EXHIBIT 3
Medical Tasks Performed By Caregivers, 1998

Task	All caregivers
Change dressings	19%
Help with equipment	15
Help administer medications	39
Number of medications	
Fewer than 5	43
5–9	37
10 or more	12
Errors in administering medications	
Fewer than 5 medications administered	8
5–9 medications administered	14
10 or more medications administered	16

SOURCE: Harvard School of Public Health/NORC/Kaiser/United Hospital Fund/Visiting Nurse Service of New York, Long Term Care from the Caregiver's Perspective, 1998.

we probed the source of instruction they received in performing these tasks as well as their level of comfort with the tasks and possible errors. Eighteen percent of caregivers who helped with medications reported that they received no instruction about how to do so. One-third reported receiving no instruction on changing dressings or bandages or on the use of equipment. Many respondents reported seeking informal instruction: About 10 percent reported receiving assistance from a friend or family member who had medical training.

We also probed the sensitive issues of caregivers' self-perceived capacity to cope with these tasks. Seventy percent and 64 percent said that they felt very capable with dressings and equipment, respectively. The proportion who felt little or no capability was small, but still substantial proportions acknowledged some level of discomfort.

■ **Medication errors.** Approximately one in eight caregivers who assisted with medications (12 percent) reported that they were aware of a mistake they had made in the administration of medication. Medication errors increased with the number of medications administered (Exhibit 3). Those more likely to report medication errors were the elderly (age sixty-five and over) and caregivers with poorer health and less education.

Barriers To Assistance For Caregivers

We asked caregivers if there was a time in the past year when they needed help and could not get it; 18 percent responded that there was. About 28 percent of those who could not get help wanted medical assistance, about 43 percent wanted help with nonmedical care; and the remainder needed both types.

■ **Financial obstacles.** One in three (31 percent) who had an unmet need indicated that finances were the obstacle. One in four (24 percent) said that services were not available or were unknown to them.

Paid professional and paraprofessional care is one of the main sources of formal support for caregivers. Yet, given the range and level of care provided by these informal caregivers, remarkably few reported being assisted by paid professionals in the year prior to the survey.

Nine percent indicated that their care recipients received paid assistance from home aides and attendants and 17 percent from paid professionals such as visiting nurses. Caregivers performing higher levels of care were more likely to report having paid assistance. Twenty-nine percent of those providing level 4 or 5 assistance had paid professional help, and 16 percent had paid home aide and attendant assistance. Caregivers who lived with care recipients were more likely to report having paid assistance than were caregivers who did not. In situations where the care recipient was hospitalized in the past year, 21 percent reported that paid professionals provided help. Forty-three percent noted that professional help was not required, but about four in ten indicated that the care recipient could not afford paid help or was afraid to have strangers in the home.

■ **Arranging for high-quality services.** A substantial proportion of caregivers (35 percent of those who used paid help) said that it was difficult to arrange for these services (Exhibit 4). It was much more difficult to arrange for home care attendants than for nurses. In both paid home aide care and professional nursing care, the majority of caregivers rated the care provided as excellent, very good, or good, although only about one in four said that nursing and attendant care was excellent. Nearly one in five, however, thought that the care was only fair or poor, and 19 percent worried about mistreatment or neglect of their loved ones by paid helpers.

Challenges And Rewards

Considerable research has focused on the burdens and stresses borne by caregivers. We asked respondents to describe their experiences in several dimensions that would allow an expression of both positive and negative caregiving experiences.

■ **Challenges.** Just 8 percent of all caregivers characterized their experiences as very difficult, 33 percent as somewhat difficult, 23 percent as not very difficult, and 35 percent as not at all difficult. Sixty-three percent of those performing the highest level of care (level 5) said that their work was very or somewhat difficult, compared with 27 percent performing level 1 care. In general, primary caregivers were more likely than secondary caregivers were to rate their work as difficult. Primary caregivers who did not live with care recipients (71 percent of caregivers) and provided level 4 or 5 care were as likely to rate caregiving as difficult as were the 29 percent of primary caregivers who did live with the recipients. Secondary caregivers who did not live with care recipients were more likely to rate their tasks as difficult than those who lived with care recipients, regardless of level of care. Caregivers living with care recipients were more likely to report that caregiving has caused financial problems for the family; caregivers who live in other states were somewhat less likely than live-in caregivers to report financial problems and were less likely than the average caregiver to agree with this statement. Primary caregivers were much more likely to report several ill effects and burdens of caregiving than sec-

EXHIBIT 4
Relationships Between Informal And Paid Caregivers, 1998

	Caregivers who arranged paid professional help in past year (n = 187, 17%)	Caregivers who arranged aide/attendant help in past year (n = 99, 9%)
Paid care was difficult to arrange	29%	35%
Rating of care		
Excellent	24	27
Very good	34	24
Good	25	30
Fair	13	8
Poor	4	10
Feared mistreatment by helpers	23	19

SOURCE: Harvard School of Public Health/NORC/Kaiser/United Hospital Fund/Visiting Nurse Service of New York, Long Term Care from the Caregiver's Perspective, 1998.

ondary caregivers were.

■ **Rewards.** While caregiving is often discussed in terms of burden and difficulty, many caregivers reported that their experiences had a positive influence on their life and their relationships with those they care for (Exhibit 5). Seventy-one percent reported an improved relationship with the care recipient, and 89 percent said that the person expressed appreciation. Forty-five percent reported that they were a more religious or spiritual person because of their caregiving experience.

Social Policy Challenges

This survey paints a portrait of a society where many people reach out to help someone in need. What can we learn from this study about formulating policy to assist caregivers?

■ **Wide range of support activities.** First, while primary and live-in caregivers per-

EXHIBIT 5
Caregivers' Experiences, By Primary Caregiving Status And Residence, 1998

	Percent of all caregivers who agree strongly or somewhat (N = 1,002)	Percent agreement		Percent agreement among those who do and don't have recipient living in their home		Percent agreement among caregivers who live in a different state (n = 188)
		Primary (n = 484)	Secondary (n = 429)	Live with (n = 251)	Do not live with (n = 748)	
My relationship with [care recipient] has gotten better since helping	71%	68%	75%	69%	72%	64%
My physical health has suffered because of my experience	21	28	11	27	18	14
I have lost my temper with family or friends because of some of the things I (have/had) to do	25	32	19	31	22	18
My relationship was difficult before I became a caregiver	14	15	13	15	14	8
I am a more religious or spiritual person because of my experience	45	46	45	52	42	41
I drink more alcohol or take more drugs than I should, to help relieve stress or anxiety associated with caregiving	3	4	2	5	2	1
I feel torn between trying to give to [care recipient] as well as to my (other) family	30	33	26	25	31	28
[Care recipient] expresses appreciation for what I do	89	88	91	89	89	92
I feel emotionally hurt or mistreated by [care recipient]	9	12	6	12	8	9

EXHIBIT 5
Caregivers' Experiences, By Primary Caregiving Status And Residence, 1998 (cont.)

	Percent of all caregivers who agree strongly or somewhat (N = 1,002)	Percent agreement		Percent agreement among those who do and don't have recipient living in their home		Percent agreement among caregivers who live in a different state (n = 188)
		Primary (n = 484)	Secondary (n = 429)	Live with (n = 251)	Do not live with (n = 748)	
It bothers me that I had to give up vacations, hobbies, or my own activities as a result of caregiving	13%	17%	8%	18%	11%	8%
I have lost my temper with [care recipient] while caring for [him or her]	21	30	13	29	18	14
Caring for [care recipient] has caused financial problems for my family	14	18	8	24	10	9
I feel torn between trying to give to [care recipient] and my job	16	22	10	17	16	16

SOURCE: Harvard School of Public Health/NORC/Kaiser/United Hospital Fund/Visiting Nurse Service of New York, Long Term Care from the Caregiver's Perspective, 1998.

form extensive caregiving tasks and activities, a large share of caregiving is performed by millions of people who do not live in the same house or the same state, or who designate themselves as a secondary, not primary, provider of care. Policy efforts and community support activities need to recognize that supporting caregivers will require a wide range of approaches that recognize the geographic dispersion of families and the desire of many elderly and disabled persons to live independent lives.

■ **Formal training.** Second, this study documents the extensive amount of assistance that is being provided by caregivers in areas that may once have been the province of paid and trained professionals. The impact of shorter hospital stays is visible in these activities, although no time-trend data are available for comparison. Of particular concern is the degree of activity that is apparently unaccompanied by formal training or instruction. In the case of medications, a fifth of caregivers reported no assistance or instruction with administering multiple medications, and they confirmed that errors were more likely to occur in these situations. Health care providers must be alert to the challenges of providing extensive supportive care at home. It is clear that caregivers frequently find informal sources to provide assistance or instruction that was not provided by health care professionals.

As our society encourages more care in noninstitutional settings, the impact on quality of care must be considered, with particular attention to the burdens on caregivers who are themselves elderly, ill, or infirm and who need instruction, support, and assistance to perform tasks safely and correctly.

■ **Better access to paid assistance.** Third, few caregivers are assisted by paid professionals or paraprofessionals. About one in five users of paid assistance expressed concerns about the quality of available help, and many more caregivers do not have access to paid services because of financial barriers. If we are to provide knowledgeable assistance, people have to be reassured that they can trust the services they are arranging for their loved ones. In this context, care that is only good or fair is probably not good enough.

■ **Better provision of information.** Respondents also raised serious concerns about lack of information about services. There is clearly a need for expanding the provision of information and support to families in these circumstances. The Internet may provide one way of transferring information and decreasing isolation among some caregivers. It provides access to information around the clock, affords families the chance to communicate across barriers of time and geography, and offers a way to form communities with others when caregivers are unable to leave the house. Several services now exist online that offer educational tools, discount purchasing of supplies, and other types of support.

■ **Public awareness of the value of caregiving.** For years we have conceptualized the caregiving experience as something that is difficult and stressful. While it is clear that this is true, it is also true that caregivers see many positive benefits, including even expressions beyond duty and privilege. In an aging population, more and more Americans will assume the role of caregiver. We need to build public awareness of the societal and personal value of rendering these services.

The best kind of social policy in this area can be formulated if we respond to what caregivers are telling us about the impact of our society's changing demographic and health care environment on their lives.

Funding for the national survey was provided by the Henry J. Kaiser Family Foundation. Additional funding was provided by the United Hospital Fund of New York and by the Visiting Nurse Service of New York. The authors acknowledge the considerable and detailed efforts of Alexis Kuerbis, Maryam Navaie-Waliser, Ariana Napier, and Amy Nunez in the course of this project.

NOTES

1. Data from the 2000 census on residence and place of birth are from U.S. Census Bureau, "Profile of Selected Social Characteristics, 2000," factfinder.census.gov/servlet (22 April 2002).
2. R.D. Putnam, *Bowling Alone: The Collapse and Revival of American Community* (New York: Simon and Schuster, 2000).
3. See, for example, K. Schulz and S.K. Beach, "Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study," *Journal of the American Medical Association* 282, no. 23 (1999): 2215–2219; W.S. Shaw et al., "Longitudinal Analysis of Multiple Indicators of Health Decline among Spousal Caregivers," *Annals of Behavioral Medicine* 19, no. 2 (1997): 101–108; and D.P. Vitaliano, H.M. Young , and J. Russo, "Burden: A Review of Measures Used among Caregivers of Individuals with Dementia," *Gerontologist* 31, no. 1 (1991): 76–83.
4. *Older Americans Act Amendments of 2000* (P.L. 106-501).
5. C. Levine et al., *Survey of Family Caregivers in New York City: Findings and Implications for the Health Care System* (New York: United Hospital Fund, 2000).
6. C. Levine, *Rough Crossings: Family Caregivers' Odysseys through the Health Care System,* A United Hospital Fund Special Report (New York: United Hospital Fund, 1998).
7. National Alliance for Caregiving and AARP, *Family Caregiving in the U.S.: Findings from a National Survey* (Bethesda, Md., and Washington: NAC and AARP, June 1997), 1–40.