Potential and Active Family Caregivers: Changing Networks and the "Sandwich Generation"

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As the Baby Boom generation nears retirement and old age, concerns about how the United States will meet the long-term-care needs of its growing elderly population are intensifying. The Social Security Administration projects that one in five Americans will be aged 65 or older by the year 2030, compared with about 13 percent now. Most of the increase will occur between 2010 and 2030 as the Baby Boom generation turns 65. Whereas the family has long been the primary source of long-term care for the elderly, the steep increase in the elderly population casts doubts on whether it can continue in this role as the number and proportion of older adults increases.

In particular, there is concern that demographic trends affecting the number of potential family caregivers and the competing demands for their time threaten their willingness and ability to continue assume most of the responsibility for long-term care. Trends toward delayed childbearing and increased female labor-force participation, for example, suggest a growing "sandwich generation," especially of women, who are caught between the demands of child rearing and elder care while attempting to play a more demanding role in the work force. Reduced availability of family caregivers clearly could affect the economic and physical well-being of the elderly and their families. Public budgets will

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also come under pressure if public programs are called upon to replace what previously has been informal, or unpaid, family care.

Recent evidence suggesting a downward trend in the age-adjusted prevalence of disability and functional limitation among the elderly has raised hopes that long-term-care burdens on families and public programs will be less than feared. However, even with a lower disability prevalence, growth in the size of the elderly population could result in a constant or larger absolute number of elderly persons needing assistance, depending on the relative rates of change. Any increase in the level of disability among the disabled also could imply greater burdens on affected families and public programs. Thus, there is a pressing need for information on how disability is changing and how families are responding to those changes.

We rely on the 1984 and 1994 National Long Term Care Surveys (NLTCS) to update the estimates of potential and active family caregivers presented by Stone and Kemper (1989) and to examine changes over the decade in informal family caregiving. We use consistent methodology to measure the prevalence of chronic disability among the elderly in each year and the distribution of the disabled elderly by receipt of informal and formal care and by the presence of spouses or children who might provide care. Finally, we examine the characteristics of both potential family caregivers and those who actually provide care and discuss the implications of observed changes.

Background

Concerns that an aging population and demographic changes affecting the availability of informal caregivers will overwhelm families' willingness and ability to be the primary providers of long-term care are not new. Nor is the accompanying concern about how public programs and informal caregiving interact. In the mid-1980s, for example, concerns arose that the then-new Medicare prospective payment for hospital care and the resulting release of elderly patients "sicker and quicker" would add to the pressure on families already bearing the primary responsibility for long-term care. Simultaneously, there were hopes that publicly financed home- and community-based services could support families' efforts and save public dollars by delaying or avoiding expensive institutional care. Finally, there were fears that publicly financed formal care would substitute for informal care and place unsupportable pressure on constrained public budgets (Stone 1987; Kemper, Applebaum, and Harrigan 1987).

All of these issues remain in one form or another. The Health Care Financing Administration currently is extending prospective payment to all Medicare post–acute care options. This change is prompted, in part, by the rapid increases in Medicare home health care spending that occurred in the early 1990s and by the fear that post–acute home health care was becoming de facto a long-term-care benefit. At the same time, states are struggling to contain Medicaid long-term-care costs, largely by expanding alternatives to institutional care, such as personal-care homes and home- and community-based service programs. Overlaid on this policy background are demographic and disability trends that will affect how the scenario plays out over time.

The two most compelling population trends affecting the need for long-term care and the supply of potential family caregivers are increases in life expectancy at age 65 and declines in fertility among the Baby Boom generation. The Social Security Administration projects the remaining life expectancy for the first wave of Baby Boom men and women turning 65 in 2010 to rise to 16.8 and 20.1 years, respectively, and to increase consistently thereafter. The fertility rate for Baby Boom cohorts, on the other hand, was generally less than 2 children, compared with rates of between 2.4 and 3.6 children for their parents' cohorts. Beginning with the Baby Boom cohorts and continuing thereafter, there also has been a trend toward delayed fertility and increased female attachment to the labor force. This implies that there will be fewer adult children to care for the Baby Boomer cohorts when they begin to require long-term care in 2020 and beyond, and that those children will be more likely to have simultaneous responsibilities for minor children. With upward trends in female labor-force participation, employment is more likely to represent a competing demand for the time of family caregivers. Some recent evidence suggests care recipients receive fewer hours of informal care and more hours of formal, or paid, care when female primary caregivers are employed (Doty, Jackson, and Crown 1998).

All else being equal, declines in the prevalence of disability could offset some of the potential gap between the number of elderly persons requiring long-term care and the supply of family caregivers to provide it. Recent research supports a downward trend. In 1993 the Committee on National Statistics of the National Research Council found evidence in existing literature of declines in both incidence and prevalence of lower levels of disability, namely, limitations in instrumental activities of daily living (IADLs), but the underlying causes were unclear (Freedman and Soldo 1994). More recent studies have found unequivocal declines in prevalence of age-adjusted IADL and ADL disability (Manton, Corder, and Stallard 1997) or functional limitations (Freedman and Martin 1998), while others raise doubts whether a persistent downward trend has been demonstrated (Crimmins, Saito, and Reynolds 1997; Reynolds, Crimmins, and Saito 1998).

The net impact of these trends on family caregiving depends on the relative magnitudes of changes in the prevalence of disability, the number of elderly persons, the number of potential family caregivers, and competing demands for potential caregivers' time. We document how these factors changed between the mid-1980s and the mid-1990s.

Data and Methods

Data for this analysis are drawn from the 1984 and 1994 waves of the NLTCS. The NLTCS is a nationally representative survey of persons aged 65 or older, and it is designed to identify those who are chronically disabled in one or more ADLs or IADLs. The samples are drawn from Medicare enrollment files and represent both community and institutional residents. The survey is refreshed each wave with a new sample of persons who have turned 65 since the previous survey, and in 1994 a supplemental sample of those aged 95 or older was added to increase the precision of estimates for the very old. Because the survey collects detailed information on demographic and health-related characteristics as well as on receipt of disability help and those who provide it, data from the two waves offer a unique opportunity to examine changes in chronic disability, service use, and the caregiving experience over the course of a decade.

Sample

Because our focus is caregiving, our sample is limited to those who received hands-on or standby human assistance with one or more ADLs or IADLs because of health or disability for at least three months, and those who were in institutions. For simplicity, we refer to this sample of persons using human assistance for help with chronic limitations as the "chronically disabled," although, of course, other definitions are possible. Persons who reported using special equipment to perform these activities but did not use human help are excluded from our analysis. The ADLs considered in this study are bathing, dressing, toileting, transferring, getting around inside, and eating. The IADLs are meal preparation, grocery shopping, laundry, light housework, financial management, taking medication, telephoning, and outside mobility. The small number of elderly persons who reported only the inability to perform at least one IADL but had no human help (about 0.5 percent of those with a limitation) also were excluded from this analysis. Our final unweighted sample for 1994 consists of 3,643 chronically disabled persons: 2,313 residing in the community and 1,330 residing in institutions. In 1984, the unweighted sample is 5,798 chronically disabled elderly: 4,108 in the community and 1,690 in institutions.

For each sampled person, the survey collected rosters of all household members, regardless of relationship, and all children living outside the household, as well as information on all additional persons actually providing disability help. Our caregiver-level analysis file was constructed by creating a caregiver record for every household member, nonresident child, and additional person reported to be providing help. This resulted in final caregiver-level files with 9,030 unweighted observations in 1994 and 14,533 in 1984. We determined whether each person on the file provided disability assistance, and if so, whether the person was a paid, or formal, helper; an unpaid, or informal, unrelated helper; or a relative. Relatives were not asked whether they were paid, so all are by default considered unpaid, informal caregivers in this study. We used this full file of household members, nonresident children, and helpers to identify whether each elderly sampled person was receiving informal care only, formal care only, or both.

Checks were performed to verify and reconcile data across the rosters of household members and nonresident children and also the disability and helper segments of the survey. Logical editing could be used to correct most inconsistent or incomplete reporting. The small number of remaining missing values due to item nonresponse, primarily information on spouses and children of institutionalized persons, were imputed, based on the weighted, sequential hot-decking statistical procedure developed by Iannacchione (1982).

From this full caregiver sample, we drew the subsample of spouses and children of disabled elderly persons that is the focus of our caregiver-level analysis. The focus on spouses and children, as opposed to all potential caregivers, which is necessary because of data limitations, is nonetheless valid from an analytic and policy perspective. Information on other relatives or nonrelatives is collected only if they were providing care to, or living with, the disabled elder. However, whereas the universe of potential caregivers is theoretically, and often in reality, much larger than the immediate family of spouses and children, these nearest kin have the most direct social, and sometimes legal, responsibility. Spouses and children are the majority of active informal caregivers to disabled elders. Three-fifths of the 7.3 million active informal caregivers in 1984 were spouses or children of the care recipient (Stone and Kemper 1989). That proportion had increased to two-thirds by 1994 (Spector, Fleishman, Pezzin, et al. 1998). Spouses and children also form the group of informal caregivers most likely to be affected by public policy, such as family leave policies, tax incentives, and caregiver allowance programs.

Analytic Methods

We examine changes in disability and type of care received among chronically disabled elderly persons and then profile their potential family caregivers (spouses and children) with respect to demographic characteristics, living arrangements, distance from the care recipient, and the level of disability of the care recipient. Living arrangement was classified according to five mutually exclusive categories based on relationship and whether the caregiver lived with the care recipient: resident spouse, applicable only to community-dwelling, disabled elderly persons; nonresident spouses of institutionalized elderly persons; resident children living with a community-dwelling disabled parent; nonresident children with a disabled parent in the community; and nonresident children with a disabled parent in an institution. Distance was measured as the time it would take the caregiver to get to the care recipient.

Although we can identify spouses and children of the full community and institutional sample, the NLTCS did not collect information on whether any informal care was provided to institutional residents. Therefore, our estimates of active caregivers pertain only to chronically disabled persons living in the community, and any increase in institutional care by definition results in a decline in the percent of potential caregivers actively providing care. We also further classified active caregivers as primary or secondary.

A helper's status as primary caregiver was defined as follows: Among those actively caring for elderly persons with ADL limitations, primary status was assigned to the caregiver identified by the respondent as helping the most with ADLs. Among active caregivers of disabled persons with only IADL limitations, primary status was assigned to the caregiver who helped with the largest number of IADLs. The small number of ties among caregivers providing help with the same number of IADLs was resolved by assigning primary status hierarchically according to the number of days per week; the tasks assumed to require more frequent help, such as medication management and meal preparation; and the caregiver's relationship in the order of spouse, daughter, or son of the disabled person.

The chronically disabled were categorized into three disability levels: those who received help with only IADL limitations, those who received help with one to two ADLs, and those receiving help with three to six ADLs. IADL disability was not ascertained for institutional residents. We classified institutional residents who were not reported to be receiving human help with ADLs as receiving help with IADLs only.

Estimates were weighted based on the 1984 and 1994 cross-sectional sampling weights to represent the U.S. population aged 65 and older in each year. We have further adjusted these weights to be consistent with the Census Bureau definitions of institutional residence. Differences in our 1984 estimates relative to similar estimates appearing in Stone and Kemper (1989) are the result of slightly different weighting. We re-estimated all 1984 numbers to ensure consistent methodology across the two years.

Standard errors were calculated based on the generalized variance function method described in the Bureau of the Census "Source and Accuracy Statement" for both years. Unless otherwise noted, only differences that are statistically significant at the 5 percent level are discussed in the text. Estimates that may be unreliable because of high sampling variability (relative standard errors greater than 30 percent) are also noted in the tables.

Results

Prevalence of Chronic Disability

Consistent with findings for a more broadly defined disabled population, the prevalence of chronic disability requiring human assistance among the elderly declined from 19.7 percent in 1984 to 16.7 percent

TABLE 1
Prevalence of Chronic Disability among the Elderly, 1984 and 1994

	All		Community residents		Institutional residents	
	1984	1994	1984	1994	1984	1994
Number of chronically disabled (thousands)	5,504	5,537	4,095	3,900**	1,409	1,638**
	Percent of all elderly					
All chronically disabled	19.7	16.7**	14.6	11.8**	5.0	4.9
Receiving help with[a]:						
IADLs only	7.7	5.0**	7.3	4.6**	0.4	0.4
1–2 ADLs	5.0	4.6*	3.8	3.7	1.2	0.9**
3–6 ADLs	7.0	7.2	3.6	3.5	3.4	3.7
	Distribution by disability level					
IADL only	39.2	29.8**	49.7	38.9**	8.6	8.1
1–2 ADLs	25.4	27.3**	25.7	31.2**	24.5	18.0**
3–6 ADLs	35.4	42.9**	24.6	29.9**	66.9	73.9**

[a] The ADLs included are bathing, dressing, toileting, transferring, getting around inside, and eating. IADLs include meal preparation, grocery shopping, light housework, financial management, taking medication, telephoning, and outside mobility.
*Significantly different from the 1984 estimate at the 10 percent level of significance.
**Significantly different from the 1984 estimate at the 5 percent level of significance.

in 1994 (table 1). Although the population over 65 increased from about 28 million to 33.1 million in 1994, the number of chronically disabled persons remained about 5.5 million. The prevalence of institutional use was about 5 percent of the elderly population in both years. (We also examined a broader definition of disability, which included reports of those who used ADL equipment but no human help in 1984 and 1994. Because this group is growing, the decline in total disability would have been 1.8 percentage points, rather than the three-point decline we found in disability requiring human assistance.)

The decline in prevalence of chronic disability occurred primarily among the least disabled. The prevalence of IADL-only limitations dropped from 7.7 percent to 5 percent, while the prevalence of any ADL limitation was about 12 percent in both years. The prevalence of ADL limitation was stable for both community and institutional residents: In 1994, 7.2 percent of the elderly were receiving ADL help in the community, which was not statistically different from 7.4 percent in 1984, and 4.6 percent were receiving ADL help in institutions in both years.

The decline in prevalence of IADL-only disability, combined with no decline in prevalence of ADL disability, implies a higher level of disability among those who receive help. This can be seen in the lower panel of table 1. In 1994, about 30 percent of the chronically disabled elderly received only IADL help, down from 39 percent in 1984. Conversely, about 43 percent received help with three to six ADLs in 1994, compared with about 35 percent in 1984. In the community, IADL assistance fell 10.8 percentage points, and help with one to two ADLs and three to six ADLs each rose just over 5 percentage points. In the institution, the percent receiving help with one to two ADLs declined, and the percent receiving help with three to six ADLs increased from about two-thirds to nearly three-quarters, perhaps reflecting a trend toward community care for all but the most severely disabled.

Prevalence of Informal Care

Coincident with the shift upward in the level of disability among chronically disabled persons, there was a decline in the percent receiving any informal care and an increase in the proportion using any formal or institutional care (table 2). Disabled persons are classified in the upper panel of table 2 according to whether they received each type of care. In the lower panel, they are classified into mutually exclusive categories according to type of care and from whom it was received.

The percent receiving any informal care declined from 70.5 percent in 1984 to 65.8 percent in 1994, while the percent receiving any formal or institutional care rose from 48.7 percent in 1984 to 59.9 percent in 1994 as a result of increases in formal care in the community and in institutional care. In the lower panel, it can be seen that more than half the 11-point increase in formal care reflects greater use of both formal and informal care in the community. That is, a larger proportion who received any informal care—including informal care from spouses or children—were also using some formal care in 1994. More than half the chronically disabled elderly relied solely on informal care in 1984, and about 19 percent used both formal and informal care. In 1994 sole reliance on informal care had dropped to about 40 percent, while the use

TABLE 2
Family Availability and Type of Care Received by Chronically Disabled Elderly Persons, 1984 and 1994

	All		Those with spouse or children	
	1984	1994	1984	1994
Number of persons (thousands)	5,504	5,537	4,418	4,537**
Percent using:				
Any informal care	70.6	65.8**	78.7	71.9**
Any formal or institutional care	48.7	59.9**	41.9	55.3**
Any care from spouse or child	56.8	52.6**	70.7	64.2**
	Distribution by type and source of care			
Informal care only:	51.3	40.1**	59.3	44.8**
From spouse or child	43.4	33.5**	54.0	40.9**
From other relative	5.9	5.0	3.1	2.7
From other nonrelative	2.0	1.6	2.2	1.2
Informal care with formal care:	19.3	25.7**	19.4	27.1**
From spouse or child	13.4	19.1**	16.7	23.3**
From other relative	3.7	4.2	1.7	2.1
From other nonrelative	2.2	2.3	1.1	1.6**
Formal care only	3.8	4.6**	2.7	3.4**
Institutional	25.6	29.6**	19.8	24.8**

*Significantly different from the 1984 estimate at the 10 percent level of significance.
**Significantly different from the 1984 estimate at the 5 percent level of significance.

of both types of care rose to just over a quarter. The rest of the increase in formal care is accounted for by a nearly one-point increase in the percentage of persons receiving only formal care in the community and a four-point increase in the percentage in institutions, from 25.6 percent in 1984 to 29.6 percent in 1994.

This pattern of declining informal care and rising formal care also pertains to the subset of the chronically disabled with spouses or children who could act as family caregivers. The proportion who had potential family caregivers rose slightly to 82 percent of the disabled elderly in 1994, up from 80 percent in 1984, and the percent who had children rose from 75 percent to 78 percent (not shown). As would be expected, among those with potential family caregivers, the proportion receiving informal care is higher, and the proportions receiving only formal or institutional care are lower than among all disabled elderly persons in both years. Nevertheless, this group had a larger decline in the percent receiving any informal care and a larger increase in the percent receiving both informal and formal care. The percent of those with spouses or children receiving any informal care fell from 78.7 percent in 1984 to 71.9 percent in 1994, while the percent receiving both informal and formal care rose from 19.4 percent to 27.1 percent. Receipt of any care from a spouse or child also decreased to 64.2 percent among those who had a spouse or child in 1994, down from 70.7 percent in 1984. The use of institutional care among the group with spouses or children rose by five points, from 19.8 percent to 24.8 percent in 1994.

We examined the possibility that this trend toward less informal and more formal care was due to changes among the new cohorts turning 65 in the decade between the surveys. To do this, we compared persons aged 65 to 74 in 1984 with those in the same age bracket in 1994, all of whom turned 65 after the 1984 survey, and those aged 75 or older in each year (table 3). We found that the pattern of declining informal care and rising formal care holds for both age groups. In both 1984 and 1994, those under age 75 were far more likely to receive any informal care and to receive care from spouses or children and less likely to receive formal care than the older group. This is consistent with the idea that, as age and disability increase, it becomes more difficult to rely on only informal sources of care (Stoller and Cutler 1993). Among those who had spouses or children, the percent of those under age 75 who received any informal care and any care specifically from spouses or children each fell by about six points. For those 75 or older who had spouses or children, the declines were 4.5 and 5.5 points, respectively.

An important qualifier to the decline in informal care is that it depends in part on the increase in institutional care, which may reflect the greater level of disability among the chronically disabled in 1994 as well as any decline in family commitment to caregiving. However, even among community residents, family caregiving has declined. Among those under age 75 who had spouses or children, 95.4 percent were receiving any informal care in 1994, 2.4 percentage points less than in 1984, and 86.2 percent were receiving informal care from spouses or children, down from 89.5 percent in 1984. Among those aged 75 or older with spouses or children, there was no decline in the percent receiving any informal care (about 96 percent in both years), but the percent receiving care from spouses or children dropped from 87.4 percent in 1984 to 85 percent in 1994.

TABLE 3
Family Availability and Type of Care Received by Age of Elderly Care Recipients, 1984 and 1994

	All		Those with spouse or children	
	1984	1994	1984	1994
	Age less than 75			
Percent of chronically disabled	32.1	27.0**	33.4	28.2**
All persons, percent using:				
Any informal care	81.8	79.0*	88.8	83.1**
Any formal or institutional care	36.3	45.5**	29.0	41.3**
Any care from spouse or child	67.9	64.2**	81.2	75.1**
Community residents, percent using:				
Any informal care	96.4	94.4**	97.8	95.4**
Any formal care	24.9	34.9**	21.7	32.6**
Any care from spouse or child	80.1	76.7*	89.5	86.2**
	Age 75 or older			
Percent of chronically disabled	67.9	73.0**	66.6	71.8**
All persons, percent using:				
Any informal care	65.3	60.9**	71.9	67.4**
Any formal or institutional care	54.7	65.1**	48.4	60.7**
Any care from spouse or child	51.5	48.3**	65.4	60.0**
Community residents, percent using:				
Any informal care	94.0	93.0	96.1	95.6
Any formal care	34.8	46.8**	31.0	44.3**
Any care from spouse or child	74.1	73.8	87.4	85.0*

*Significantly different from the 1984 estimate at the 10 percent level of significance.
**Significantly different from the 1984 estimate at the 5 percent level of significance.

Trends in the Demographic Profile of Potential and Active Caregivers

These trends toward less informal and more formal care among those who have spouses and children can also be seen in the numbers and characteristics of their potential and active family caregivers (table 4). The number of spouses and children *at risk* for informal caregiving increased slightly over the ten-year period, from 13.9 million to 14.6 million, maintaining a ratio of 3.1 potential family caregivers per disabled elderly person. The number of spouses and children actively providing

TABLE 4
Characteristics of Potential and Active Family Caregivers: Spouses and Children of Chronically Disabled Elderly Persons, 1984 and 1994

			Active caregivers[a]			
	Potential caregivers		Primary		Secondary	
	1984	1994	1984	1994	1984	1994
Number of persons (000s)	13,901	14,582**	2,648	2,674	1,719	1,130**
Percent of the U.S. population	7.5	7.2	1.4	1.3	0.9	0.5
	Distribution by characteristics					
Age						
14–34	9.0	6.4**	3.7	2.2**	11.6	6.2**
35–44	22.2	21.9	8.5	9.5	24.1	25.6
45–54	28.6	31.2**	13.7	18.2**	29.8	36.0**
55–64	23.4	21.3**	23.7	19.0**	23.6	21.1
65–74	11.1	12.2**	32.3	27.3**	7.1	8.5
75–84	4.5	5.6**	16.0	19.8**	2.6	1.7
85+	1.1	1.4**	2.1	4.0**	1.1	0.9+
Relationship						
Wife	7.6	6.8**	33.9	28.6**	2.3	2.1
Husband	5.7	5.5	20.7	20.9	3.8	2.5*
Daughter	44.3	44.8	34.7	35.2	51.6	55.3
Son	42.4	43.0	10.7	15.3**	42.3	40.1
Marital status						
Married	79.0	89.9**	80.8	82.0	73.9	83.6**
Unmarried[b]	21.0	10.1**	19.2	18.0	26.1	16.4**
Race						
White or other	87.2	87.3	88.5	88.4	87.7	86.0
Black	12.8	12.7	11.5	11.6	12.3	14.0
Living arrangement						
Resident spouse	12.2	10.7**	54.6	49.5**	6.1	4.6
Resident child	7.9	7.6	24.0	24.1	18.4	21.4
Nonresident spouse	1.1	1.6**	0.0	0.0	0.0	0.0
Nonresident child	78.7	80.2	21.4	26.4	75.4	74.0
Parent in community	66.0	62.1**	21.4	26.4**	75.4	74.0
Parent in nursing home	12.7	18.1**	0.0	0.0	0.0	0.0

(*continued*)

TABLE 4 *continued*

	Potential caregivers		Active caregivers[a] Primary		Active caregivers[a] Secondary	
	1984	1994	1984	1994	1984	1994
Distance from care recipient						
Resident or within 10 minutes	37.2	37.6	89.5	86.2**	55.7	61.3**
11 to 30 minutes	19.8	19.9	7.2	8.1	26.8	22.8**
30 to 60 minutes	10.0	10.8**	1.6	2.8**	10.3	9.2
60 minutes to 24 hours	21.3	21.7	1.4	2.6**	6.4	6.5
More than 24 hours	11.7	10.0**	0.2	0.3	0.8	0.3

[a] The NLTCS collects no information on informal caregiving for institutionalized persons. Hence, the analysis of active caregiving is effectively restricted to spouses and children who provide care to community residents.
[b] The "unmarried" category includes persons who are widowed, divorced, separated, or never married.
*Significantly different from the 1984 estimate at the 10 percent level of significance.
**Significantly different from the 1984 estimate at the 5 percent level of significance.
+Relative standard greater than 30 percent.

care, however, declined 13 percent, from 4.3 million in 1984 to 3.8 million in 1994. This decline reflects, in part, the decline from 3.5 million to 3.4 million in community residence among the chronically disabled with spouses and children. Nonetheless, the ratio of active family caregivers per community-dwelling disabled person with a spouse or child also fell, from 1.23 in 1984 to 1.11 in 1994, consistent with a reduction in family caregiving even among community-dwelling disabled elderly persons. None of this reduction, however, occurred among primary caregivers, whose numbers remained constant at 2.6 million, despite the decline in the number of community-care recipients. Combined with the results in table 2, this indicates that although a smaller proportion of community residents with a spouse or child were receiving any care from them in 1994, a larger proportion were receiving their primary care from these family caregivers (78.3 percent in 1994, up from 74.7 percent in 1984). The reduction in total active caregivers was entirely due to a decline from 1.7 to 1.1 million persons in the number of family caregivers serving a secondary role. Given the increase in formal care, it seems plausible that paid helpers are filling this secondary role for more recipients.

To put the magnitude of family caregiving in a national perspective, spouses and children with potential family caregiving responsibilities made up slightly over 7 percent of all persons aged 15 or older in the United States in 1994, similar to the 1984 percentage. Spouses and children actively providing ADL or IADL care to disabled elderly persons were less than 2 percent of the U.S. population aged 15 or older in 1994, down a half percentage point from the 1984 level of 2.3 percent.

With the exception of a marked increase in the proportion of married persons, there were no striking changes in the demographic profile of potential caregivers. The vast majority are adult children (12.0 million and 12.8 million in 1984 and 1994, respectively), with roughly equal numbers of daughters and sons in both survey years. The age distribution was largely unchanged, although there was a shift toward older ages, with a slight increase in the proportion of middle-aged (45 to 54 years old) spouses or children and in the proportion of potential caregivers aged 65 or older.

Among active primary caregivers, spouses and children aged 65 to 74 continued to be the largest group of primary active caregivers (32.3 percent in 1984 and 27.3 percent in 1994), but there was a significant increase in the proportion of primary caregivers who were themselves quite old. Nearly one-quarter of all active primary caregivers in 1994—636,000 persons—were aged 75 and older, up from 18 percent in 1984. There was also a significant increase in the proportion of middle-aged active caregivers, with slightly above 18 percent of primary caregivers and more than one in three secondary caregivers between ages 45 and 54, an age group that also is more likely to have competing demands from market work and child-rearing.

Overall, children far outnumbered spouses as active caregivers, reflecting both the high rates of widowhood among the elderly population and the fact that multiple siblings sometimes share the responsibility of caring for a disabled parent. Contrary to past trends, however, about as many children as spouses were *primary* active caregivers in 1994. This was due largely to a significant decrease (from 33.9 percent in 1984 to 28.6 percent in 1994) in the proportion of primary caregivers who were wives and a corresponding increase in the proportion who were sons. Spouses, nonetheless, continued to bear a large share of primary caregiving, representing only 12 percent of potential caregivers, but 49.5 percent of all primary active caregivers in 1994.

Despite the decrease in active caregiving by wives, they continue to be more likely to provide care than husbands, and daughters remain more likely to provide care than sons. Among children who are primary active caregivers, daughters still outnumber sons by more than two to one. Participation of sons as primary caregivers increased by 50 percent between 1984 and 1994, but they still accounted for only 15 percent of primary caregivers in 1994.

Finally, there was an increase, from 12.7 percent in 1984 to 18.1 percent in 1994, in the potential caregivers who were children with institutionalized parents. Among active caregivers, the proportion of active primary caregiver children who did not live with their disabled elderly parent increased five percentage points in 1994.

Although there were some significant differences in the distance of caregivers from the care recipient, the differences were small. Just over two-thirds of potential caregivers lived within an hour of the care recipient in both years. Not surprisingly, active caregivers were far more likely to be nearby. In 1994, 97 percent of primary caregivers and 93 percent of secondary caregivers were within an hour of the care recipient. Interestingly, there was a small decline (3.3 points) in the percent of primary caregivers living with or within 10 minutes of the care recipient, and a slightly larger increase (5.6 points) in the percent of resident secondary caregivers.

Trends in Caregiving by Disability Levels

Consistent with the relative decline in the prevalence of IADL-only disability among elderly persons receiving human help, both potential and active family caregivers were faced with higher disability levels among care recipients in 1994. Nearly 5.7 million persons—40 percent of all spouses and children of disabled elderly persons—had an elderly spouse or parent who needed help with three or more ADLs. This is a 23 percent increase in the number of potential caregivers with severely disabled elderly spouses or parents and a similar decrease in the percent of potential caregivers for those with only IADL disability (not shown). As shown in table 5, this pattern holds for wives, husbands, daughters, and sons with a disabled spouse or parent, and generally for active caregivers as well.

The exception is wives, who declined in overall numbers and in the number and percent acting as primary active caregivers. Wives who were primary caregivers were not significantly more likely to be caring for a

TABLE 5

Potential and Active Family Caregivers by Relationship and Disability Level of Spouse or Parent, 1984 and 1994

	Wives		Husbands		Daughters		Sons	
	1984	1994	1984	1994	1984	1994	1984	1994
	Potential caregivers							
Persons (thousands)	1,054	982	797	799	6,152	6,527**	5,897	6,274**
	Distribution by recipient's disability level							
IADL only	40.3	36.4*	39.7	27.1**	42.8	32.1**	43.0	33.9**
1–2 ADLs[a]	26.1	24.9	27.2	30.9**	25.6	28.5**	25.7	27.7**
3–6 ADLs	33.6	38.7**	33.1	41.9**	31.6	39.3**	31.2	38.3**
	Primary active caregivers[b]							
Persons (thousands)	898	764**	547	560	919	941	284	408**
	Distribution by recipient's disability level							
IADL only	42.0	39.1	41.7	23.6**	50.8	34.9**	60.4	42.1**
1–2 ADLs	26.7	28.7	28.6	35.2**	25.8	31.2**	19.7	31.5*
3–6 ADLs	31.3	32.2	29.7	41.2**	23.4	33.9**	19.9	26.4**

[a] The ADLs considered are bathing, dressing, toileting, transferring, getting around inside, and eating. IADLs include meal preparation, grocery shopping, light housework, financial management, taking medication, telephoning, and outside mobility.

[b] The analysis of active caregiving is effectively restricted to spouses and children providing care to disabled persons living in the community. The NLTCS does not collect information on informal caregiving for institutional residents.

*Significantly different from the 1984 estimate at the 10 percent level of significance.

**Significantly different from the 1984 estimate at the 5 percent level of significance.

moderately or severely disabled spouse in 1994. In contrast, more than three-quarters of husbands who were primary caregivers were caring for a spouse with an ADL limitation in 1994, up from less than three in five in 1984. Both daughters and sons also were significantly more likely to be providing care to parents with moderate or severe disability and significantly less likely to be providing care to parents with only IADL limitations in 1994 than in 1984. Among children who were primary active caregivers, over three in five daughters and nearly three in five sons were caring for a parent with ADL limitations in 1994, compared with half of daughters and 40 percent of sons in 1984.

Secondary caregivers also were caring for spouses or parents with higher levels of disability in 1994 than in 1984, but the patterns varied substantially, depending on the caregiver's relationship to the disabled person (not shown). The shift among secondary caregivers toward caring for more severely disabled persons was driven primarily by daughters: nearly seven out of ten daughters who were secondary caregivers in 1994 provided help to an ADL-disabled parent, an 11 percentage point increase relative to 1984. Secondary-caregiver sons were less likely to provide care to an ADL-disabled parent in 1994 but more likely to be caring for more severely disabled parents (three to six ADLs). Conversely, there was a marked trend toward lighter care among the small number of spouses who were secondary caregivers in 1994.

The Sandwich Generation and Competing Demands

Table 6 examines patterns of caregiving among those who have both a disabled parent or spouse and the competing demands of child care or full-time work. In 1994, nearly 3.5 million persons were in the so-called sandwich generation, facing the potentially dual responsibility of caring for an elderly person and a minor child. They were about 24 percent of all potential caregivers, about 8 percent of primary caregivers, and about 24 percent of secondary caregivers.

In 1994, approximately 1.7 million women—5.2 percent of all women with children under the age of 15—in the United States had at least one child under the age of 15 and a disabled elderly spouse or parent. Of those potential caregivers, 322,000 were actively providing care to a disabled elderly spouse or parent, and nearly half were primary caregivers. Women with dependent children were about 22 percent of all women who were

TABLE 6
Competing Demands for Potential and Active Family Caregivers, 1984 and 1994

	Potential caregivers		Active caregivers			
			Primary		Secondary	
	1984	1994	1984	1994	1984	1994
	With children less than age 15					
Total						
Number (thousands)	3,810	3,449**	205	211	504	267**
Percent[a]	27.4	23.7**	7.7	7.9	29.3	23.7**
Women						
Number (thousands)	1,842	1,682**	170	156	290	166**
Percent[b]	25.6	22.4**	9.4	9.1	31.3	25.5**
Men						
Number (thousands)	1,968	1,767**	35	54*	215	102**
Percent[c]	29.4	25.0**	4.2	5.6	27.1	21.1**
	Working 30 or more hours per week					
Total						
Number (thousands)	7,786	8,127**	588	728**	1,004	665**
Percent[a]	56.0	55.7	22.2	27.2**	58.4	58.9
Women						
Number (thousands)	3,122	3,582**	417	469	456	363**
Percent[b]	43.3	47.7**	23.0	27.5**	49.2	56.0**
Men						
Number (thousands)	4,664	4,545**	171	259**	549	302**
Percent[c]	69.7	64.3**	20.6	26.7**	69.2	62.7*

[a] Percent of all potential, active primary, or active secondary caregivers, respectively.
[b] Percent of all female potential, active primary, or active secondary caregivers, respectively.
[c] Percent of all male potential, active primary, or active secondary caregivers, respectively.
*Significantly different from the 1984 estimate at the 10 percent level of significance.
**Significantly different from the 1984 estimate at the 5 percent level of significance.

potential caregivers but only about 9 percent of women who were primary caregivers in both years.

Roughly 1.8 million men—one-quarter of all men with a disabled elderly spouse or parent in 1994—were also part of the sandwich generation. Although men are less likely to bear primary responsibility for child care, they also continue to be far less likely than women to be active caregivers if they also have children. Less than 6 percent of men who were primary caregivers had dependent children in 1994.

A much larger group of both men and women faces the competing demands of potential caregiving responsibility and full-time work, and workers make up an increasing proportion of primary active caregivers. The lower panel of table 6 presents the number and proportion of potential and active caregivers who were full-time workers in 1984 and 1994, by gender. About eight million persons, 56 percent of all spouses and children of disabled elderly persons, worked 30 hours or more per week in 1994, the same proportion as in 1984. These potential caregivers were 8.1 percent of the U.S. population employed full time in 1994, a slight decrease from 9 percent in 1984 (not shown). They accounted for 27 percent of primary caregivers in 1994, up from 22 percent in 1984. Although fewer workers were secondary caregivers in 1994, they represented 58.9 percent of that group, about the same proportion as in 1984.

Consistent with the steady rise in female labor-force participation over the ten-year period, there was a 4.4 percentage point increase, from 43.3 percent in 1984 to 47.7 percent in 1994, in the proportion of full-time workers among wives and daughters who had a disabled elderly spouse or parent. Full-time workers also composed a larger proportion of women who were active caregivers. In 1994, 27.5 percent of women who were primary caregivers were also full-time workers, up from 23 percent in 1984, and the percent of full-time workers among women who were secondary caregivers rose to 56 percent in 1994, up from just under half in 1984. Interestingly, since the absolute number of working women who were secondary caregivers fell, their increased representation suggests that the number of nonworking, female secondary caregivers must have fallen even more. The estimates also indicate the increased participation of full-time working men as primary caregivers. The proportion of primary caregiving men who were full-time workers increased from 20.6 percent in 1984 to 26.7 percent in 1994. Contrary to the results for women, however, the proportion of workers among male secondary caregivers fell from 69.2 percent in 1984 to 62.7 percent in 1994.

These results for workers are consistent with the overall trends for potential caregivers, whereby there is less caregiving because of reduced secondary roles. For both women and men, and for workers of both genders, the total percent of potential caregivers actively giving care fell between 1984 and 1994; the largest decreases occurred for secondary caregiving. Interestingly, however, working potential caregivers of both genders maintained or increased their participation as primary caregivers. Among potential caregivers, 13 percent of working women in both years were primary caregivers, whereas working men increased their participation as primary caregivers from 3.7 percent in 1984 to 5.7 percent in 1994 (not shown). These increases in the proportion of workers undertaking primary-care responsibility may help to explain the increased use of formal care.

Discussion

Our results present a mixed picture of declines in the number of family caregivers but a potential increase in the intensity of caregiving provided by spouses and children. Between 1984 and 1994, the percent of the elderly receiving help with ADLs or IADLs decreased significantly, but, because the decline was almost exclusively at the lowest level of disability, those receiving care were more disabled. This increase in disability level was accompanied by a significant increase in receipt of formal care, whether measured over all disabled elderly persons or over only those living in the community. However, it also was accompanied by a decrease in receipt of informal care, specifically care from spouses and children. In fact, the prevalence of informal care decreased more among those who had these potential family caregivers. The decrease in the prevalence of informal care and the greater prevalence of formal care held for both younger and older cohorts. There was a similar mixed finding at the caregiver level, with potential family caregivers less likely to be active caregivers but more likely to be the primary caregiver if they were providing care. A constant 2.6 million persons were primary caregivers to disabled spouses or parents in both years; the decline in caregiving occurred only among secondary caregivers.

Our results suggest a far lower level of caregiving than was reflected in estimates from a recent survey that found that 23 percent of U.S. households had at least one member who had provided care to a relative or friend in the prior 12 months (National Alliance for Caregiving 1997). Aside from being a household-level estimate, there are several reasons why it is not comparable to ours. The estimate includes those caring for any relative or friend at any time during the year, and care recipients could be as young as 50 and potentially free of chronic disability. Also, sampling at the caregiver level does not link caregivers to any well-defined population of recipients. Although differences in method make it difficult to compare our results, if every *potential* caregiver in our sample lived in a different household, our household count would be 14.6 million, only about two-thirds of the 1997 study's estimate of 21 million households with *active* caregivers.

We found no striking changes in the characteristics of potential caregivers, although they were more likely to be married and were slightly older, which may contribute to the increased use of formal care. There also was a significant increase in the proportion of both primary and secondary caregiving among those aged 45 to 54, a group likely to have competing demands from work and child care. Those with minor children who were full-time workers maintained or increased their participation as primary caregivers, although they generally showed the same reduced secondary participation as did caregivers as a whole. This factor also could be contributing to increased use of formal care as a way to manage competing responsibilities.

The increase in community formal care use reflects in part changes in the availability of long-term Medicare home health benefits. Changes in access to the benefit, beginning with removal of the requirement of a prior hospitalization in 1980, resulted in about a fivefold increase in spending between 1984 and 1994, from about $2 billion to over $10 billion (Letsch, Lazenby, Levit, et al. 1992; Welch, Wennberg, and Welch 1996; Braden, Cowan, Lazenby, et al. 1998). Half the spending increase reflected higher average visits per recipient, but more than a third reflected an increased proportion of beneficiaries using the service (Komisar and Feder 1998). The percent of disabled elderly persons with formal caregivers who reported Medicare as a payment source rose from 16 percent in 1982 to more than a quarter in 1994 (Liu, Manton, and Aragon 2000). Medicaid programs over the same period have also greatly increased spending on community long-term care as an alternative to nursing-home care. Although the rate of increase in Medicare home health spending has ameliorated, and the benefit will be further affected by the prospective payment system now under development, spending increases were not limited to public dollars. Out-of-pocket payments for home health care, which does not include all the largely unmeasured, less skilled services most likely to substitute for informal care, also increased rapidly, from about $500 million in 1984 to $6 billion in 1994 (Letsch, Lazenby, Levit, et al. 1992; Braden, Cowan, Lazenby, et al. 1998).

These trends in formal care spending are consistent with factors we observed that are likely to promote use of formal providers: higher disability levels among those receiving human help; increased age of caregivers; and increased primary caregiving among those who work 30 hours or more a week. The modest increases in the number of men serving as primary caregivers also may work in the direction of increased use of formal care, based on evidence that male caregivers are more likely to incorporate formal care (Stoller and Cutler 1993).

Preferences and rising incomes among the elderly also may intensify both the increase in formal care and the decrease in secondary caregiving that we observed. For example, Stoller and Cutler (1993) found that both higher income and higher disability increased the likelihood of paid care being used for ADL services. The probability of relying on paid care was similar among those who had nearby children and those who did not. They concluded that those who can afford formal care may prefer to hire help rather than depending on children, especially for high-intensity personal care tasks. This may prove to be even more true as the Baby Boom generation progresses into old age, bringing with them a history of incorporating more formal care into their own caregiving than was the norm for earlier generations and of having fewer children than current cohorts of elderly.

It is important to note that the decline in informal caregiving shown here reflects entirely changes in caregiving behavior rather than a decline in the number of children and spouses available to give care. The percent of the disabled elderly with potential family caregivers actually rose from 80 percent in 1984 to 82 percent in 1994, and the percent with children rose from 75 percent to 78 percent. The lower fertility of the Baby Boom cohort implies that, in the next 20 to 30 years, there will also be fewer children per recipient potentially to provide care and, very likely, a greater proportion called on to serve as primary caregivers, with or without formal support. Moreover, with increased longevity, the Baby Boom, which is the sandwich generation of today, may itself face continued informal caregiving responsibility for parents and new responsibility for spouses who are aging into frailty.

Our results raise a number of issues for policy. President Clinton's proposal for a modest tax credit for severely disabled persons and their caregivers, combined with federal grants to states for information and respite services (Komisar and Feder 1999), is a recognition that there is a public interest in the burden long-term care places on families.

The demographic changes projected for the coming decades are likely to increase this burden.

There is substantial concern about a shrinking labor pool as the Baby Boom generation moves out of the labor force, leaving behind smaller cohorts of workers (Kotlikoff 1992; U.S. General Accounting Office 1997). Employers and policy makers, faced with a decreasing ratio of workers to elderly retirees, may be called upon to address their own competing demands to promote increased labor-force participation and potentially later retirement while supporting an informal caregiving system that provides the majority of long-term care. Shortages of formal care workers could interfere with labor-force participation by informal caregivers and also work against efforts to encourage later retirement by the Baby Boom generation. Employers may need to build more flexibility into the workplace through such measures as flex time and flex place, which are already increasing. Employers may also find more direct self-interest in sponsoring long-term-care benefits for workers and dependents. The federal government currently is formulating such a program, which may serve as an impetus and model for private employers (Komisar and Feder 1999). If the current policy environment, which deemphasizes large expansions of public benefits and stresses private-sector solutions, continues, policy makers may be pressed to consider changes in the tax status of such benefits to put them on an equal footing with other benefits, such as acute-oriented health insurance.

An inadequate supply of formal care workers also could drive long-term-care toward a more institutional, or quasi-institutional, form. This trend is already occurring with the growth of residential care alternatives to nursing homes, such as assisted-living facilities and personal care homes, where formal services are part of the living arrangement (Bishop 1999). Some of these settings are in our institutional sample and others are in the community sample, but we cannot distinguish well enough between types of institutional or community residence to examine this issue. It is likely, however, some of the increase in both community formal care and institutional use reflects this growth, and much more needs to be discovered about the potential for such settings.

Reductions in the availability of Medicare home health, intended to prevent the acute care–oriented program from becoming a de facto long-term-care program as well, may also have the unintended consequence of removing one source of support for informal providers. The impact would be most important for lower-income recipients and caregivers.

Some shifting of home care costs to the Medicaid program, and thus partially to state budgets, can be expected. Limitations on that program, and especially on waiver services suggest, however, that there may be a significant number of lower-income caregivers and recipients who will not have access to this means of supporting informal caregiving efforts, with unknown consequences for labor-force participation, quality of life for caregivers and recipients, and, potentially, quality of care for the recipient.

Another issue of importance is the potential role of special equipment in supporting informal caregiving. For analytic and methodological reasons, we excluded from our analysis of caregiving those who used special ADL-related equipment but received no human assistance. More research is needed into the potential for equipment to improve the quality of life for recipients and caregivers and to support the ability of caregivers to manage competing demands. In a recent study, Agree and Freedman (2000) found that equipment use was more prevalent among those receiving informal ADL assistance and most prevalent among those receiving formal care. It may be that the growth in use of special equipment partly reflects the greater knowledge of its availability and access that has resulted from the increased contact with formal providers we observed. It may be prudent public policy to examine further whether equipment reduces the intensity of dependence on formal and informal providers.

Our results highlight the complexities of devising policies that can support family caregiving while promoting labor-market participation and solvency of public programs. The results also indicate issues where much remains to be learned and suggest several avenues for future research. The finding of a stable participation among primary caregivers, despite more competing demands, and a decline in the efforts of secondary caregivers, for example, suggests a need to understand better the process by which families come to share the effort of caring for their frail elderly members. Although a number of studies have addressed the trade-offs between market work and informal caregiving (Doty, Jackson, and Crown 1998; Pezzin and Schone 1999; Johnson and Lo Sasso 2000), they were individual-level, cross-sectional analyses based on static models. It would be worthwhile to take a dynamic approach and to treat the family, rather than the individual potential caregiver, as the relevant unit of analysis. Future research that takes advantage of the family-wide, longitudinal aspect of the data and recognizes the macro-implications of evolving incentives and constraints faced by potential caregivers would be useful. Our finding of increased participation of men, particularly adult sons, in the care of a disabled spouse or parent, also suggests the value of further exploring the effect of caregiver gender in the interactions between formal care, informal care, and labor supply as a natural extension to the present work.

A better understanding of how demographic trends are changing the caregiving landscape, and how families are responding to these changes, is essential to formulating policy initiatives that enhance the welfare of caregivers and care recipients while recognizing the trade-offs with other policy aims and public budgets. The results presented here provide a useful context for framing the discussion.

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