Change in the Number of Informal Helpers of Frail Older Persons

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Synopsis

Little is known of the extent to which helper networks of frail older persons change over time and what factors are associated with change. Few national estimates of the scope of change exist to aid policy planners.

This study provides national estimates of changes in the size of the informal helping network of frail elderly by sociodemographic and functional status subgroups of this segment of the population. The data are drawn from the 1982–84 National Long Term Care Survey, which included longitudinal followup of 4,530 respondents living in the community at both times. Bivariate patterns of change over 2 years in the number of informal helpers were analyzed. Sociodemographic factors (sex, age group, and race) of the frail elderly may be more important influences on change in the number of helpers than functional status expressed in terms of their limitations in activities of daily living.

The purpose of this brief report is to compare changes in the number of informal (that is, family, relatives, friends, and neighbors) helpers assisting the frail elderly with activity of daily living (ADL) and instrumental ADL (IADL) tasks by sociodemographic and functional status subgroups. Approximately 80–90 percent of community-based long-term care comes from informal networks of family or friends (*1*), and approximately 60–70 percent of frail older persons have two or more helpers (*2,3*).

The number of informal helpers in the assistance network may represent the social network configuration of the dependent elder (*3,4*) or an increased need for help by persons with higher levels of dependency. Yet, little is known of the extent to which the size of helper networks changes over time, and what factors are associated with change. Few national estimates of the scope of change exist.

In this report, national estimates were made of the 2-year changes in helper network size, risk of death, and risk of institutionalization according to functional status, sex, age, and race. These estimates allow for the assessment of the contribution of selected sociodemographic and functional status variables to the stability of sources of community care of frail older persons.

Methods

The data are drawn from the 1982–84 National Long Term Care Survey (NLTCS) (*5,6*). The NLTCS investigated the demographic characteristics, health and functioning, and patterns of assistance of a national sample of noninstitutionalized persons 65 years of age or older. A random sample of approximately 36,000 persons drawn from Medicare enrollment files was screened to identify persons with functional limitations, defined as the inability to perform at least one activity of personal care or management of daily affairs for a period of 3 months or more. In 1982, more than 6,400 persons were identified and 6,393 persons were interviewed. The 1984 survey included longitudinal followup of 4,530 respondents living in the community and also identified those institutionalized and deceased.

All results are weighted and thus are representative of the total U.S. frail elder population 65 years of age and older residing in the community. Software developed by the Research Triangle Institute was used to generate the appropriate variance estimates which incorporate the complex sample design of the NLTCS (*7,8*). All differences discussed were statistically significant at the $P<.05$ level.

Informal helpers included all persons identified by the dependent elder who assisted with at least one ADL, at least one IADL, or both, in the week preceding the interview. Such helpers included spouses, adult children, other relatives, friends, and neighbors. Helpers from formal organizations or paid helpers were not included as part of the informal

Table 1. Percent of frail persons ages 65 and older using only informal helpers in 1982, United States

Sex, race, age, and ADL [1] status	Number of frail elderly (thousands)	Number of informal helpers in 1982		
		1	2	3 or more
Sex:				
Male	1,313	65.0	21.7	13.3
Female	1,917	45.0	30.4	24.6
Race:				
White	2,770	54.5	26.2	19.3
All other races	460	45.3	30.4	24.3
Age:				
65–74 years	1,426	61.7	21.8	16.5
75–84 years	1,237	49.7	28.9	21.5
85 years or older	567	39.3	35.2	25.5
ADL limitations[1]:				
None	2,128	56.9	25.7	17.4
1	516	47.5	29.1	23.4
2	225	52.7	24.6	22.7
3-5	361	39.5	31.7	28.8
Total	3,230	53.1	26.8	20.0

[1]ADL = activity of daily living; includes the following ADLs: bathing, dressing, transferring, toileting, eating.
NOTE: Row percents may not add to 100 percent because of rounding.

helper network. Functional limitations are measured by the number of ADL's the older person received help with—eating, dressing, bathing, bed transfers, and toileting. No data are provided for those limited in IADL only.

Results

In the 1982 baseline sample, women, all other races, persons ages 85 years or older, and persons receiving help with three to five ADLs were significantly more likely to have more than one helper than were males, whites, elderly persons in younger age groups, and elderly persons with less ADL dependency (table 1). The change or stability in the number of helpers over time varied by size of the network at baseline (table 2). One-helper networks were more stable than multiple-helper networks. Overall, 45 percent of the sample who had one helper in 1982 had one helper in 1984. Twenty-nine percent of those with two helpers in 1982 and also those with three or more helpers in 1982 had the same number of helpers in 1984.

Patterns of informal network size for the 2-year period varied by selected sociodemographic factors. Men showed more stability in having one helper than women, 49 percent versus 41 percent, but there was no difference in stability of helper networks for men and women with two, three, or more helpers. There was no sex difference in the shift from one helper to no helpers. However, women were more likely to shift from one informal helper to two (17 percent) than were men (12 percent). With respect to race, whites with one helper in 1982 were more likely to still have one helper in 1984 (46 percent) than were all other races (35 percent). Whites were less likely than all other races to change from one helper in 1982 to no helpers in 1984 (8 percent compared with 13 percent) and to show an increase to two helpers (14 percent compared with 20 percent).

Younger age groups were more likely to continue to receive assistance from one helper than were older age groups. Fifty-one percent of those 65 to 74 years with one helper in 1982 had one helper in 1984 in comparison to 42 percent and 33 percent for those 75 to 84 and 85 and older, respectively. Frail elders ages 65 to 74 years were more likely than those 75 to 84 to decrease the size of their helper network from 1 to 0. No age differences were evident in the increase in number of informal helpers for the 2-year period.

The association between ADL limitations and stability or change in number of helpers was minimal. Frail elders who had no ADL limitations but who had one helper (for IADLs) in 1982 were more likely to still have one helper in 1984 than those with three to five ADLs (47 percent versus 35 percent). There were no shifts to larger size networks among those with three to five ADLs. Rather, this ADL group was more likely to be deceased in 1984 than those with no ADLs. Frail elders who had one ADL in 1982 were less likely to shift from one helper to no helpers in 1984 than were those who had no ADLs. There were no other meaningful differences in increases or decreases in network size associated with ADL limitations.

Discussion

Based on bivariate patterns of association, sociodemographic factors may be more important influences than functional status on shifts in the number of informal helpers over 2 years. Age, race, and sex influenced selected shifts in number of helpers, whereas the effect of functional status was not evident.

Marital patterns may account for the sex difference seen. It has been noted elsewhere that a person is more likely to have multiple helpers when the primary caregiver is not a spouse (*3,4*). Because older men are more likely to be married than older women, female spouses are more available to care for dependent men. Dependent women are more likely to be widowed, divorced, or never married and cared for by adult children (*2*).

Limitations of this study include the lack of

Table 2. Percent of frail persons 65 years of age and older using only informal helpers in 1982 by their use in 1984, United States

Demographic factors, ADLs, number of helpers in 1982	Number of frail elderly (thousands)	Number of informal helpers or status in 1984					
		0	1	2	3 or more	Institutionalized	Decreased
Total							
1	1,717	8.2	45.0	14.4	8.6	5.8	18.1
2	867	3.9	18.5	29.1	17.0	9.0	22.4
3 and more	646	3.3	15.2	19.5	28.9	7.9	25.1
Sex							
Male:							
1	853	7.6	48.8	11.7	7.1	3.9	20.9
2	286	[1]2.2	17.0	26.7	14.8	8.2	31.2
3 and more	174	[1]1.9	17.8	11.6	23.9	[1]4.5	40.2
Female:							
1	863	8.9	41.2	17.1	10.0	7.6	15.2
2	582	4.8	19.3	30.3	18.1	9.4	18.1
3 and more	472	3.8	14.3	22.4	30.8	9.2	19.5
Race							
White:							
1	1,508	7.6	46.4	13.6	8.2	6.2	18.1
2	727	3.8	18.8	29.9	16.3	9.9	21.4
3 and more	534	3.6	14.8	18.8	28.9	8.7	25.3
All other:							
1	208	12.7	34.5	20.4	11.5	[1]3.2	17.7
2	140	[1]4.6	17.5	25.2	20.7	[1]4.2	27.9
3 and more	112	[1]2.1	17.4	22.8	29.1	[1]4.3	24.4
Age							
65–74 years:							
1	880	11.4	50.5	13.6	8.1	3.3	13.2
2	310	4.5	23.9	29.0	20.2	5.6	16.9
3 and more	236	5.3	20.2	19.8	28.6	5.6	20.5
75–84 years:							
1	615	6.0	41.5	15.4	8.4	7.3	21.4
2	357	4.5	16.9	29.1	13.3	10.7	25.5
3 and more	266	[1]2.5	16.1	19.6	31.6	7.6	22.5
85 years and older:							
1	222	[1]1.9	32.6	14.9	11.0	11.7	28.0
2	200	[1]2.0	13.2	29.4	18.6	11.2	25.6
3 and more	145	1.5	5.4	18.7	24.5	12.4	37.5
ADL limitations[2]							
None:							
1	1,211	10.3	47.0	15.4	7.9	5.2	14.3
2	547	5.1	20.1	31.6	17.6	7.7	17.9
3	370	4.2	17.7	22.6	29.9	5.7	19.8
1 limitation:							
1	245	4.9	45.0	12.4	9.2	7.3	21.3
2	150	[1]1.7	14.9	28.4	17.9	12.5	24.7
3 and more	121	[1]3.2	11.5	18.7	34.1	[1]8.0	24.6
2 limitations:							
1	119	[1]1.6	36.0	13.6	8.0	[1]8.5	32.3
2	55	[1]6.5	18.3	17.2	13.7	[1]11.8	32.5
3 and more	51	...	[1]14.3	15.4	26.9	[1]15.3	28.2
3–5 limitations:							
1	142	[1]2.3	34.8	10.3	13.7	[1]6.3	32.5
2	114	...	16.0	23.9	14.5	9.2	36.4
3 and more	104	[1]1.7	11.2	11.4	20.4	12.2	43.1

[1]Relative standard error 30 percent.

[2]ADL = activity of daily living; includes the following ADL's: bathing, dressing, transferring, toileting, eating. Data are based on personal interviews of the functionally impaired Medicare eligibles living in the community.

NOTE: Row percents may not add to 100 percent because of rounding.

SOURCE: National Long Term Care Survey, 1982–84.

knowledge about the number of helper shifts that may have occurred during the two data collection points. In addition, it was not known if the same persons remained in the helper network over time, or if replacements had occurred. From a followup sampling perspective, we also note that the number of informal helpers a frail elder had at baseline was associated with subsequent mortality and institutionalization (table 2). Furthermore, because those who are more functionally dependent at baseline have more helpers, there is less opportunity for change or increase in help. Thus, those remaining in the community at followup are more likely to be less functionally disabled.

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PUBLIC HEALTH PROGRAMS AND PRACTICES

Drug Use Occupies Emergency Rooms, Public Opinion Polls

As drug-related hospital emergency room admissions for the first half of 1993 rose 9 percent overall compared with the first half of 1992 (232,800 vs. 214,600), public opinion on drugs ranged from youthful acceptance to a desired shift from law and order emphasis to treatment.

Drug Abuse Warning Network data showed that heroin-related emergencies increased by 44 percent, accounting for more than half the total increase, with the number of cases rising in all adult age groups and among all major racial-ethnic categories. Overall, cocaine-related emergencies showed little change from the 1992 reporting period. PCP-related admissions were up by 45 percent; methamphetamine/speed-related emergencies showed a 61-percent increase; and marijuana-related emergencies increased by 19 percent.

Although these figures reflect large percentage changes, drug-related cases represent only 0.5 percent of total use of emergency rooms nationwide, the report by the Substance Abuse and Mental Health Services Administration (SAMHSA) indicates.

At the same time, SAMHSA's 1992 Household Survey on Drug Abuse showed that substantial numbers of Americans, notably young people, believe that using drugs is not harmful.

According to the study, only 54 percent of 12–17-year-olds in 1992 believed that there is great risk associated with trying cocaine once or twice. Only about half (49 percent) of those youths reported that smoking a pack or more of cigarettes per day is associated with great risk of harm. In both cases, youth see less harm associated with drug use than the rest of the population.

Meanwhile, another new national opinion survey found that 7 in 10 Americans see drug abuse as worse than 5 years ago, that government leaders are not doing enough, and that money spent on overseas and border interdiction efforts would be better spent on direct aid to American communities.

The survey of 1,001 randomly selected adults also found most Americans want major changes in the government's "war on drugs," with more spent on prevention and treatment, and less on jails and overseas programs.

These new findings are the result of the most recent poll of attitudes towards drug policy. Responses throughout the survey reflect a loss of support for the government's past "supply side" approach focusing on law enforcement, drug seizures, and crop eradication overseas, and movement towards "demand side" prevention and treatment efforts focused in communities with the greatest drug problems.

The poll was commissioned by Drug Strategies, a nonprofit organization seeking the most effective approaches to drug abuse, and was conducted by Peter D. Hart Research Associates on February 2 and 3, 1994. Drug Strategies is funded by the Carnegie Corporation of New York, the Soros Foundations, and the Edna McConnell Clark Foundation.

Analysis of the new SAMHSA survey data shows that

- among all Americans ages 12 years and older fewer than half (45 percent) reported believing that occasional marijuana use was associated with great risk of harm. This is a decrease from the 50-percent level in 1988.
- 68 percent of Americans reported that trying cocaine once or twice was associated with great risk of harm, down from the 71 percent in 1988.
- 75 percent of Americans reported that trying heroin once or twice was associated with great risk of harm,