

# Home care expenses for the disabled elderly

by Korbin Liu, Kenneth G. Manton, and  
Barbara Marzetta Liu

*This article presents descriptive statistics from the 1982 Long-Term Care Survey on noninstitutionalized elderly Americans with limitations in activities of daily living (ADL) and instrumental activities of daily living (IADL). The focus of this article is on private expenses for home-based care related to ADL and*

*IADL limitations. We describe the amounts of out-of-pocket payments expended relative to the characteristics of the home-based, disabled elderly population. We also discuss several possible implications of the findings for policymakers and further research.*

## Introduction

In the recent past, long-term care expenditures have been practically synonymous with expenditures for nursing home care, but policymakers are now expressing greater interest in home-based long-term care. This orientation toward noninstitutional care for disabled, elderly Americans reflects, in large part, a serious concern that rapidly increasing expenditures for nursing homes cannot be sustained indefinitely. The projected growth of the population over 65 years of age, in general, and of the vulnerable subgroup over 75 years of age, in particular, suggests that the demand for long-term care will only increase (Manton and Liu, 1984). To address the expected increased demand for assistance by the elderly population, both Federal and State policymakers have been fostering home-based care programs in the belief that they may offer a cost-effective alternative to nursing home care. Although home-based care may be a more suitable alternative in many cases, it is currently not clear how much home-based care is required to substitute adequately for nursing home care. Nor is it clear how many disabled elderly could substitute home-based care for nursing home care.

National information has been limited on who provides home care for the disabled elderly, who pays for it, and how much it costs. A number of surveys have explored these issues concerning the institutionalized, long-term care population, but heretofore there have been few sources of data, except for Medicare and Medicaid records, about expenditures for home-based care. Complementary information about out-of-pocket expenditures and about costs covered by third-party insurers is needed. More important, we need to know the relationship between expenditures for home-based care and the characteristics of the disabled elderly.

Recently a national survey was conducted that can help to answer some of these questions. The Department of Health and Human Services (DHHS) sponsored the 1982 Long-Term Care (LTC) Survey to derive information on the characteristics of the disabled elderly residing in the community. In that survey, data on functional status, patterns of informal care, economic and demographic characteristics, and service utilization were collected. Among the

characteristics measured were out-of-pocket expenditures for long-term care services delivered in the home.

## 1982 Long-Term Care Survey

The 1982 LTC Survey was conducted by the Bureau of the Census for DHHS; it was designed to estimate the personal characteristics and use of health-related services by disabled, noninstitutionalized elderly in the United States. The sample for the survey was established by drawing records from the Medicare Health Insurance Skeleton Eligibility Write-Off files (i.e., the files listing all Medicare enrollees). That random sample of approximately 36,000 people was screened by telephone to determine the presence of a limitation in activities of daily living (ADL) or instrumental activities of daily living (IADL) associated with a chronic condition. This procedure produced a sample of 6,393 persons, representing a population of 5.1 million. The sample was then scheduled for intensive interviews on a range of topics related to health status, level of disability, sources of long-term care assistance, personal resources, and family situation. Of the original 6,393 persons, 5,582 possessed at least one of the ADL or IADL limitations described below.<sup>1</sup> This article presents estimates of the characteristics of the disabled elderly population based on the 5,582-persons-sample inflated by their sample weights. The sample represented a total 1982 population of 4.6 million disabled elderly (referred to in this study as the general disabled elderly population) with a specific set of ADL and IADL limitations. As a result of the higher threshold of ADL and IADL limitations that we employed, the disabled population discussed in this article is smaller than the 5.1 million represented by the sample of 6,393 persons. Patterns of ADL and IADL limitations do not differ appreciably between the two populations.<sup>2</sup> Methodological details concerning the 1982 LTC Survey and sampling procedures have been described elsewhere (Macken, 1984; Macken, 1985; Hanley, 1984). Although most of the information presented in this article is self-explanatory, certain

<sup>1</sup>In this article, we employed a specific set of ADL and IADL measures; other researchers (e.g., Macken, 1985) have employed other sets of ADL and IADL measures.

<sup>2</sup>See Macken (1985) for an analysis of the 5.1 million population represented by the 6,393-persons sample.

methodological procedures that we applied require some elaboration.

First, the 1982 LTC Survey was cross-sectional; several of the questions concerning services and costs referred to experiences for specified short periods of time such as week or a month; in some cases, we converted these to annual figures. For example, we multiplied by 12 the reported out-of-pocket costs for assistance in ADL or IADL that had been recorded for a period of 1 month to derive an estimate of annual national expenditures.

Second, the 1982 LTC Survey did not attempt to gather information about costs for home-based care associated with ADL or IADL limitations covered by other sources of payment such as Medicare and Medicaid. We used other sources of information on such expenditures to complement our estimates of out-of-pocket expenditures derived from the 1982 LTC Survey.

Third, in order to present our results as specific to level of disability, we derived an "ADL score" for each respondent by summing the number of different ADL limitations he or she possessed. A person could also have no limitation in ADL, but a limitation in IADL. The ADL indicators that we used were bathing, dressing, eating, getting out of bed, getting around indoors, and toileting. The IADL indicators were managing money, moving about outdoors, shopping, doing heavy housework, meal preparation, making phone calls, and taking medication. People with only IADL limitations generally require less assistance with physical tasks than those with an ADL limitation, and people with higher ADL scores tend to have greater physical resource requirements than those with lower ADL scores.

Fourth, there were substantial gaps in data on payment sources because of inconsistencies in what was reported by the respondent. For example, a respondent might have reported that home care was paid for by a third party, but failed to specify the source. This problem could have been because the respondent did not know who the payer was or, more simply, because of an error in the completion of the interview. We recorded sample respondents as out-of-pocket payers when respondents specified a payment amount. Other payment sources were recorded when specific sources were indicated. Approximately 26 percent of respondents who stated that some paid care was received did not have complete payment source information. (For home health care, the problem of measuring sources of payment from self-reported surveys has been identified by other researchers [Berk and Bernstein, 1985].) We present two distributions of payment amount: (a) as reported, including the 26 percent "unknowns" and (b) "adjusted," where it was assumed that the unknowns were distributed similarly to those with complete information. We recognize that this assumption may not be valid, but it serves to provide relative frequencies for respondents for whom complete data were available.

## Disabled elderly residing in community

In 1982, approximately 4.6 million noninstitutionalized elderly Americans, 18 percent of the total population 65 years of age or older, had ADL or IADL limitations. Two-thirds of them were moderately impaired with 1 or 2 ADL limitations or only IADL limitations (Table 1). At the other extreme, however, about 850,000 elderly people with severe limitations (i.e., ADL, 5 or 6) were residing in the community.

Similar to results from prior research (Soldo, 1983), we found that most of the disabled elderly received personal assistance for ADL or IADL problems from spouses, children, or other informal sources of support (Table 1). Of the 4.6 million disabled elderly, more than 70 percent (3.2 million persons) relied exclusively on nonpaid sources. Almost 1 million received both paid and nonpaid care, and only 240,000 used paid care only. The pattern of sources of care differs according to the person's level of disability. For example, although 81 percent of those with only IADL limitations relied exclusively on unpaid helpers for assistance, 65 percent of their counterparts with 5 or 6 ADL limitations relied exclusively on unpaid helpers. On the other hand, 33 percent of the ADL, 5-6 group received help from both paid and unpaid helpers, in contrast to only 12 percent of those with only IADL limitations. Almost 7 percent of the IADL group used only paid help, and 2.5 percent of the ADL, 5-6 group used only paid help (Table 1).

The results in Table 1 suggest that payment for home-based care has a diversity of roles among the disabled elderly. For example, the relatively high proportion of persons in the ADL, 5-6 group receiving both paid and nonpaid help indicates that paid help may be a necessary complement for unpaid help in the case of the severely disabled elderly. Paid help also appears to serve as a source of assistance for people with mild limitations but who need assistance with chores such as shopping or laundry.

**Table 1**  
Percent of persons with limitations in activity,  
by source of assistance and limitation  
level: United States, 1982

Limitation level	Number of persons in thousands	Source of assistance		
		Paid helpers	Nonpaid helpers	Both paid and nonpaid helpers
		Percent		
Total	4,405	5.5	73.9	20.6
IADL only	1,368	6.8	81.1	12.1
ADL, 1-2	1,506	6.6	74.9	18.5
ADL, 3-4	683	4.0	68.6	27.4
ADL, 5-6	849	2.5	64.7	32.9

NOTE: Total does not equal 4.6 million total disabled elderly because of unknowns. IADL is for instrumental activities of daily living. ADL is for activities of daily living.

**Table 2**

**Percent of disabled persons with all paid helpers and nursing helpers, unadjusted and adjusted for unknown payment source, by payment source: United States, 1982**

Payment source	Persons with nursing helpers		Persons with paid helpers	
	Unadjusted	Adjusted	Unadjusted	Adjusted
	Percent			
Sample person only	40.7	55.0	12.8	16.1
Medicare only	8.4	11.4	30.5	38.5
Medicaid only	6.0	8.1	11.7	14.8
Other organization only	4.8	6.5	5.8	7.3
Sample person and Medicare	2.7	3.6	13.1	13.9
Other private persons	2.1	2.8	( <sup>2</sup> )	( <sup>2</sup> )
Medicare and private insurance	2.0	2.7	5.6	7.1
Sample person and other private persons	1.9	2.6	( <sup>2</sup> )	( <sup>2</sup> )
Sample person and other organization	1.2	1.6	( <sup>2</sup> )	( <sup>2</sup> )
Medicare and Medicaid	11.0	11.4	11.8	12.3
Insurance only	( <sup>2</sup> )	( <sup>2</sup> )	12.4	3.0
All other patterns	3.2	4.3	5.4	6.8
Unknown	26.0	0	20.7	0

<sup>1</sup>Relative standard error greater than 30 percent.

<sup>2</sup>Less than 1 percent.

NOTE: The total number of persons with paid helpers was 1,151,762. The total number of persons with nursing helpers was 290,181.

Although the role of informal sources of assistance for the disabled elderly residing in the community has been widely studied by others (see Doty, 1984, for a review of this literature), we have had less information to date on the sources of payment for the formal care provided to them. In Table 2 the sources of payment are presented for the 1.1 million persons who indicated that they received paid care. Almost 41 percent of these persons specified themselves as the sole payment source for formal care. The next most common sources of payment were Medicare only (8.4 percent) and Medicaid only (6.0 percent). We examined all combinations of payment sources and found that most paid care was paid for by a single source (Table 2). The high proportion of respondents who could not completely specify their payment sources (26 percent) highlights the gap in information discussed above. The adjusted distribution of payment sources gives the relative frequencies of only those cases for which complete information was available (second column in Table 2). The adjustment raises the proportion of each payment source; the "sample person only" payment source increases, for example, to more than one-half the cases.

The large proportion of people who were the only sources of payment for helpers suggests that many disabled elderly were buying assistance for ADL or IADL limitations that would not normally be covered by third-party payers; the assistance they received would not be conventionally described as "nursing." The payment source patterns for those people with paid care who obtained paid assistance from visiting nurses, nurses' aides, and home health aides underlined this phenomenon (last two columns in Table 2). We found that only 290,181 received paid nursing care. These patients composed only 25 percent

of all people for whom any amount of payment was made for home-based care in the community. Medicare only was the most common source of payment (almost 40 percent when adjusted for unknown payment source), and sole out-of-pocket payers accounted for only 16 percent of the adjusted distribution. Overall, the pattern of nursing assistance payment sources indicates that most payments for this level of care were made by third-party payers.

The pattern of sources of payment for different groups of disabled elderly, by their ADL scores, can be found in Table 3. As expected, the proportion of people indicating Medicare, Medicaid, and private insurance as payment sources increases with level of

**Table 3**  
**Percent of individuals with paid care,<sup>1</sup> by payment source and limitation level: United States, 1982**

Limitation level	Payment source <sup>2</sup>				
	Self	Medicare	Medicaid	Insurance	Helping organization
	Percent of persons				
All levels	47.8	15.4	8.5	3.4	6.7
IADL only	54.4	6.2	7.1	1.3	7.3
ADL, 1-2	56.0	9.0	6.4	1.4	6.4
ADL, 3-4	42.0	19.2	8.6	4.2	10.1
ADL, 5-6	35.7	28.7	12.3	7.0	4.0

<sup>1</sup>The distribution of payment sources are based only on those cases in which a clear pattern for a person's payment sources can be determined (i.e., the "unknowns" in Table 2 are not included). Hence, the frequencies of the specific payment sources could be higher than those presented. For example, an estimated 608,000 were self-paying, yet only 550,000 had complete payment source patterns.

<sup>2</sup>These are not mutually exclusive categories, because an individual may have more than one source of payment.

NOTE: IADL is for instrumental activities of daily living. ADL is for activities of daily living.

disability. For example, although 6.2 percent of the IADL-only group mentioned Medicare as a source of payment, almost 29 percent of the ADL, 5-6 group mentioned Medicare. Self-pay, on the other hand, is more prevalent among those with lower levels of disability. The results in Table 3 are consistent with the expectation that home care requirements of the less disabled are generally different from those of their more disabled counterparts. Some of the services required by the former are, generally, not covered by third-party payers, but these services are, at the same time, both demanded and affordable.

## Expenses for home-based care

Total expenses for home-based care for disabilities associated with chronic conditions have been estimated to be approximately \$4.2 billion in 1982 (Cohen et al., 1984). The majority of these expenditures were from public sources. Medicare in 1982 spent \$1.3 billion and Medicaid spent \$495 million (Williams et al., 1984). Other public program expenditures were estimated to be \$950 million in the same year (Cohen et al., 1984).

Although the 1982 LTC Survey did not collect information on the amount of public costs incurred by the survey respondents, it did ask each respondent how much he or she spent out of pocket for assistance because of ADL or IADL limitations. From the LTC, we estimated that 1.1 million people received paid care, 608,000 of whom paid for some part of their home-based care, spending an average of \$164 per month out of pocket. On an annualized basis, this monthly amount implies approximately \$1 billion spent out of pocket by the disabled elderly themselves.<sup>3</sup>

Among the people reporting out-of-pocket payments, some paid considerably more, but most paid less than the monthly average of \$164. Tables 4 and 5 present summary statistics on payment amounts for the total population of 608,000 persons and for subsets of the population who paid out of pocket for nursing services. For the total population, the highly skewed distribution of payment amounts is indicated by the fact that one-half made out-of-pocket payments of \$40 per month or less, and 10 percent reported paying more than \$400 per month (Table 4). Table 4 also presents the distributions of payment amounts by limitation level. As expected, the average monthly payment for ADL increases with the level of limitation, as does the entire distribution of payment amounts. A particularly noticeable difference in payment amount appears to be between the ADL, 5-6 group and others with less than 5 or 6 ADL limitations. For example, the average payment for the

<sup>3</sup>It is important to note, however, that this estimate refers exclusively to payments for personal assistance for disabilities resulting from ADL and IADL limitations and did not include private costs for durable medical equipment. Total national (public and private) expenses for durable medical equipment have been estimated to range from \$840 million to \$1 billion in 1982 (Williams, Gaumer, and Cella, 1984).

**Table 4**  
**Summary statistics on reported out-of-pocket payments for a month for any home care, by limitation level: United States, 1982**

Item	Limitation level				
	All persons	IADL only	ADL, 1-2	ADL, 3-4	ADL, 5-6
Number in thousands					
Persons paying out of pocket	608	150	229	105	124
Average monthly payment					
Average monthly payment	\$164	\$88	\$85	\$117	\$439
<b>Payment at selected percentiles of payers:</b>					
10th	6	6	6	6	15
25th	15	12	12	20	40
50th	40	30	30	50	140
75th	135	70	60	160	450
90th	400	226	209	312	1,260

NOTE: IADL is for instrumental activities of daily living. ADL is for activities of daily living.

ADL, 5-6 group is three to four times greater than that of the ADL, 3-4 group.

Payments by persons who paid for nursing services show a similarly skewed distribution of payment amounts, but the level of payment is considerably higher (Table 5). For example, in contrast to the 75th percentile of all payers who reported payments of \$135, the 75th percentile payers for nursing services reported \$400 for the month. The large difference in the amount of payment for nursing services between the ADL, 5-6 group and those with fewer than 5 ADL's is similar to the distribution of payment amounts for all payers. At the 90th percentile, for example, the ADL, 5-6 group had a payment amount (\$1,922) that was almost five times as great as that of their less disabled counterparts (\$400).

The skewness of the out-of-pocket payment pattern is further highlighted in Table 6. Percentages of the self-payer population by ADL and amount of payment incurred are related to the proportion of the total expenses incurred in a month. The subgroup of individuals who had ADL, 5-6 and paid over \$135 composed only 5.3 percent of the self-payer population, but accounted for almost 44 percent of the total out-of-pocket payments (Table 6). On the other hand, the subgroup of individuals with IADL disabilities, regardless of payment amount, were almost 25 percent of the self-payer population, but accounted for 13 percent of the total out-of-pocket expenditures.

## Personal characteristics of out-of-pocket payers

The personal characteristics and long-term care service use of those who pay out of pocket differ in several important ways from those who do not pay

out of pocket. Moreover, there are differences in the characteristics of private payers associated with the amounts of private monies expended in a month. These differences are presented in Table 7, which provides descriptive statistics on the 4.6 million disabled elderly in the LTC Survey and the subset of private payers by the amount of reported payments in the previous month.

There is a difference of 2 years in age between private payers (78) and all disabled elderly (76). However, there is a 5-year difference between the median age of the disabled elderly and the median age of those spending over \$135 per month. Considerably smaller percentages of private payers are male or married. The absence of a spouse suggests that paid care may be required, to some extent, to offset informal care that might otherwise be provided by spouses. In fact, private payers receive fewer unpaid helper days per week (median = 2) than does the general disabled elderly population (median = 7) (Table 7).

The median family income of private payers is the same as that of the general disabled population. However, the amount of out-of-pocket expenses increases substantially with median family income among the private payers. For example, those with reported payments of less than \$15 per month had a median family income of \$5,500, but those with reported payments of more than \$135 per month had a median family income of \$13,000. The availability of the financial resources appears to be strongly related to the amount of out-of-pocket payments that are made by the disabled elderly. It is clear, however, that the level of assistance needed is also a factor (Table 7).

The average private payer has the same median ADL score (2) as that of the general disabled population (2), yet those who reported paying more than \$135 per month had a median ADL score (3) that was higher. These higher out-of-pocket payers are distinctive because, in contrast to the general disabled population, they are twice as likely to be senile,<sup>4</sup> to need help with meals, and to need help taking medicine. Thus, they seem to have higher levels of cognitive impairments. The average private payer, on the other hand, is very similar to the general disabled population in these areas of need. The use of health services, however, is different between the general disabled elderly population and the average private payer. The private payer had twice the rate of prior nursing home use (15.6 percent versus 7.6 percent); about one-fifth (21.8 percent) of those private payers who paid more than \$135 for home health care had had a prior nursing home stay. Private payers, in general, also had higher prior use of hospitals and adult day care, although their use rate of these other services was not remarkably higher than that of the general disabled elderly population.

<sup>4</sup>Questions about whether the disabled elderly were senile were posed only to proxy respondents; proxy respondents composed about 25 percent of total LTC Survey respondents.

**Table 5**  
Summary statistics on reported out-of-pocket payments for a month for home nursing care, by limitation level: United States, 1982

Item	Limitation level		
	All persons	IADL only and ADL, 1-4	ADL, 5-6
		Number	
Persons paying out of pocket	58,000	30,700	27,394
		Amount	
Average monthly payment	\$424	\$156	\$724
<b>Payment at selected percentiles of payers:</b>			
10th	9	6	24
25th	20	13	40
50th	90	74	100
75th	400	229	807
90th	880	400	1,922

NOTE: IADL is for instrumental activities of daily living. ADL is for activities of daily living.

**Table 6**  
Comparison of percent of subgroups of out-of-pocket payers with percent of total out-of-pocket payments in a month, by payment and limitation level: United States, 1982

Payment and limitation level	Percent of all payers <sup>1</sup>	Percent of all payments <sup>2</sup>
<b>Persons paying less than \$15:</b>		
IADL only	5.5	0.2
ADL, 1-2	8.2	0.3
ADL, 3-4	4.2	0.2
ADL, 5-6	4.2	0.4
<b>Persons paying \$15-135:</b>		
IADL only	12.6	2.5
ADL, 1-2	19.2	3.6
ADL, 3-4	8.7	3.1
ADL, 5-6	11.0	11.6
<b>Persons paying more than \$135:</b>		
IADL only	6.5	10.6
ADL, 1-2	10.4	16.1
ADL, 3-4	4.3	9.3
ADL, 5-6	5.3	43.9

<sup>1</sup>All payers totaled 608,000 persons.

<sup>2</sup>All payments totaled \$99,524,000.

NOTE: IADL is for instrumental activities of daily living. ADL is for activities of daily living.

**Table 7**  
**Profile of disabled elderly, by the amount of**  
**out-of-pocket payments incurred: United States, 1982**

Characteristics	All disabled elderly	Private payers				
		Total	Less than \$15	\$15-39	\$40-135	\$136 or more
Number in thousands	4,400	608	136	146	174	153
Median age	76.0	78.0	77.0	78.0	78.0	81.0
Percent male	34.9	25.1	20.7	28.2	25.4	25.9
Percent married	41.9	31.8	31.0	31.0	36.9	27.5
Median family income	\$8,500	18,500	5,500	7,500	9,500	13,000
Percent on Medicaid	14.9	11.5	15.9	<sup>2</sup> 11.5	<sup>2</sup> 10.4	<sup>2</sup> 8.8
Median ADL <sup>1</sup> score	2.0	2.0	2.0	2.0	2.0	3.0
Percent senile	10.0	9.4	<sup>2</sup> 3.5	<sup>2</sup> 3.6	6.7	23.3
Percent incontinent	24.5	27.8	21.1	26.5	29.1	33.4
Percent needing help with meals	6.8	7.6	<sup>2</sup> 6.6	<sup>2</sup> 4.9	<sup>2</sup> 4.7	14.6
Percent needing help with medicine	27.1	27.2	16.3	15.5	21.7	54.7
Percent ever in nursing home	7.6	15.6	13.4	13.2	13.8	21.8
Percent in hospital in past 12 months	37.6	42.5	40.7	38.0	43.2	47.5
Percent use of adult day care	5.2	5.8	<sup>2</sup> 7.3	7.7	<sup>2</sup> 3.9	<sup>2</sup> 4.9
Percent use of outside sources of meals	4.0	7.3	11.8	<sup>2</sup> 5.6	<sup>2</sup> 3.9	8.6
Percent with payments for home nursing care	6.2	13.9	11.6	8.4	13.3	21.8
Median number of paid helpers per week	0	1	1	1	1	1
Median number of paid helper days per week	0	2	1	1	2	7
Median number of unpaid helpers per week	1	1	1	1	1	1
Median number of unpaid helper days per week	7	2	2	2	3	2

<sup>1</sup>Activities of daily living.

<sup>2</sup>Relative standard error greater than 30 percent.

The average out-of-pocket payer was twice as likely to have made payments for nursing assistance. The more than \$135-per-month payer had three times the rate of payments for nursing assistance. These results are consistent with other statistics (Table 7) that suggest that those with high out-of-pocket payments had higher use of paid helpers and helper days relative to the general population of disabled elderly. On the other hand, the private payers tended to have fewer days of help from informal sources of assistance. These results suggest that there may be some degree of substitution between paid and unpaid assistance. However, further analysis is required to distinguish substitution from "specialization," in which formal and informal caregivers provide complementary care to a disabled, elderly person (Greene, 1983).

In summary, differences exist between private payers for home-based care and the disabled, elderly population in general (Table 7). The most distinctive subgroup includes those who reported paying more than \$135 per month. These high payers had considerably higher levels of disability and prior use of health care.

## Discussion

Public policy deliberations on home-based care as a potentially cost-effective alternative to nursing home care have been constrained, in part, by the dearth of information on the private cost of long-term care for the disabled elderly residing in the community. Although national information has been available on public expenditures for home-based care supported by the Medicare and Medicaid programs, a particularly noticeable gap in knowledge has been private expenses for home-based care. Recently, available data from the 1982 LTC Survey provide new information on the noninstitutionalized disabled elderly, their expenses for home-based care, and the relationships between patient characteristics and out-of-pocket expenses.

Consistent with prior research results (Feller, 1983), we found the noninstitutionalized, disabled, elderly population to be heterogeneous in its level of need. At one extreme, 850,000 (19 percent) had severe ADL limitations (i.e., ADL, 5 or 6). On the other hand, 1.4 million people (31 percent) were only IADL-limited as

a result of minor disabilities associated, for example, with mild arthritis (Manton and Soldo, 1985).

Because of the high proportion of people with mild disabilities, the noninstitutionalized disabled elderly were, on average, less functionally dependent than their counterparts in nursing homes. The 1977 National Nursing Home Survey, for example, revealed that almost all of the elderly nursing home residents had at least one ADL limitation, and that 40 percent had 5 or more ADL limitations (Van Nostrand, Zappolo, Hing et al., 1979). However, because of the large size of the noninstitutionalized disabled population relative to the nursing home population, there were more people who were severely ADL-limited in the community (850,000) than in nursing homes (600,000). It is apparent, therefore, that factors other than functional dependency differentiate disabled elderly in the community from those in nursing homes.

Consistent with the fact that the Medicare home health benefit pays only for medically related home care, we found that a large proportion (two-thirds) of total private expenditures for home-based care went for assistance that was not provided by nurses, nurses' aides, or home health aides. Hence, many disabled elderly residing in the community required assistance that was primarily nonmedical in nature and would not be conventionally covered by either public or private third-party insurers. Private costs for home-based care of noninstitutionalized disabled elderly were incurred for a multiplicity of purposes, ranging from payments for care that might otherwise be provided by informal caregivers to payments for supplementation of care that was provided by family and friends.

Corresponding to the range of purposes and types of paid home-based care received by the disabled elderly, we found large variations in the amount of expenditures incurred. Although most individuals reported monthly payments of less than \$40, some reported spending more than \$880 during a month. Our analysis indicated that the amount of payment is directly related to health status and prior medical service use. We also found that amount of payment is directly related to family income. Hence, the amount of formal care a person used depended, in part, on how much he or she could afford to pay, as well as the level of need and sources of informal assistance. The relative roles of these determinants of paid care, however, are not distinct, and further research is required to clarify their effects.

Our analysis found a strong association between high monthly payments for home care and risk factors associated with institutionalization. We found that the 25 percent of out-of-pocket payers whose reported monthly payment exceeded \$135 had much greater relative rates of such risk factors (e.g., ADL scores, senility, need for assistance in taking medicine, and nursing home stays). Such factors had previously been determined to be good predictors of admission to nursing homes (Weissert, Scanlon, and Unger, 1981; Branch and Jette, 1982; and Doty, 1985). The high

out-of-pocket payers also tended to be older and unmarried. It appears that the private expenses incurred are providing the marginal resources to keep these people out of nursing homes. At the same time, prolonged, high, out-of-pocket expenditures for periods of months may result in a severe economic burden and ultimately become another risk factor for institutionalization. The higher incomes of the high-risk noninstitutionalized elderly relative to other elderly groups may reflect the fact that some of their counterparts, with similar needs for assistance, but lower incomes, have already been institutionalized.

Public policies that aim to divert the disabled elderly from nursing homes need to assess the levels of private payments that are incurred to maintain the high-risk disabled elderly in the community. Further analysis of this subgroup may provide information on the amount of possible public assistance that may be required if private resources are not available.

## References

- Berk, M. L. and Bernstein, A.: Use of home health services: Some findings from the National Medical Care Expenditure Survey. *Home Health Care Services Quarterly*. Vol. 6, No. 1. Spring 1985.
- Branch, G. and Jette, A. M.: A prospective study of long-term care institutionalization among the aged. *Am J Public Health* 72(12):1373-1379, Dec. 1982.
- Cohen, D., Patrizi, P., Wagner, C., and Brunelle, M.: A Planning Study of Alternative Home Health Ventures that Improve Employment Opportunities for the Homemaker/Home Health Aide. Final Report submitted to the Ford Foundation, 1984.
- Doty, P.: Can Home and Community-Based Services Provide Lower Cost Alternatives to Nursing Homes? Unpublished manuscript. Health Care Financing Administration, Office of Legislation and Policy. Washington, D.C., Dec. 1984.
- Feller, B. A.: Americans needing help to function at home. *Advance Data from Vital and Health Statistics*. No. 92. DHHS Pub. No. (PHS) 83-1250. National Center for Health Statistics, Public Health Service. Washington. U.S. Government Printing Office, 1983.
- Greene, V. L.: Substitution between formally and informally provided care for the impaired elderly in the community. *Med Care* 21(6):609-619, June 1983.
- Hanley, R.: Age, ethnicity, and gender differences in daily activity limitations among elderly in the community. Paper presented at the Gerontological Society of America Annual Meeting. San Antonio, Nov. 19, 1984.
- Macken, C. L.: Descriptive Profile of the Functionally Impaired Aged Living in the Community: Findings from the 1982 Long-Term Care Survey. Draft Report. Office of Research and Demonstrations, Health Care Financing Administration. Baltimore, Md., 1985.
- Macken, C. L.: 1982 Long-Term Care Survey, National Estimates of Functional Impairment Among the Elderly Living in the Community. Paper presented at the Gerontological Society of America Annual Meeting. San Antonio, Nov. 19, 1984.

Manton, K. G., and Liu, K.: The Future Growth of the Long-Term Care Population: Projections Based on the 1977 National Nursing Home Survey and the 1982 Long-Term Care Survey. Paper presented at the Hillhaven Foundation's Third National Leadership Conference on Long-Term Care Issues: The Future World of Long-Term Care. Washington. Mar. 7-9, 1984.

Manton, K. G. and Soldo, B.: Dynamic changes in the extreme elderly: New perspective and evidence. *Milbank Memorial Fund Quarterly* 63(2):206-285 1985.

Soldo, B.: The elderly home care population: National prevalence rates, selected characteristics and alternative sources of assistance. Working paper 1466-29. Washington, D.C. The Urban Institute, May 1983.

Van Nostrand, J. F., Zappolo, A., Hing, E., Bloom, B., Hirsch, B., and Foley, D. J.: The National Nursing Home Survey: 1977 Summary for the United States. Vital and Health Statistics. Series 13, No. 43. DHEW Pub. No. (PHS) 79-1794. National Center for Health Statistics, Public Health Service. Washington. U.S. Government Printing Office, July 1979.

Weissert, W., Scanlon, W., and Unger, A.: Estimating the long-term care population: National and state prevalence rates and selected characteristics. Working paper 1466-11. Washington, D.C. The Urban Institute, Dec. 1981.

Williams, J. L., Gaumer, G., and Cella, M. A.: Home health services, An industry in transition. Home Health Agency Prospective Payment Demonstration. Contract No. 500-84-0021-HCFA. Prepared for Health Care Financing Administration. Washington, D.C. Abt Associates, Inc., May 3, 1984.