COMPARATIVE ANALYSIS OF CAREGIVER DATA FOR CAREGIVERS TO THE ELDERLY 1987 and 1997

Prepared By:
Donna L. Wagner, Ph.D.
Towson State University, MD

June, 1997

NATIONAL ALLIANCE FOR CAREGIVING
4720 Montgomery Lane · Suite 642 · Bethesda, Maryland 20814 Phone: 301 · 718 · 8444 · Fax: 301 · 652 · 7711

INTRODUCTION

In 1987, the American Association of Retired Persons (AARP) in collaboration with The Travelers Foundation, undertook a study of caregivers to the elderly. The study, a phone interview, provided data on informal caregivers to the elderly as well as data on those who are receiving help from the caregivers. In 1997, the National Alliance for Caregiving and AARP, with funding from Glaxo Wellcome Inc. and additional support from the Archstone Foundation, Manor-Care Health Services and Metropolitan Life Insurance Company, conducted a telephone survey of caregivers designed to both update and expand the 1987 data collected on informal caregiving to elders in America. This document compares both sets of data in order to examine trends in caregiving which are likely to persist into the next ten-year period—through 2007.

Definitions.

In 1987, a sample of caregivers was screened using the following operational definition:

An adult individual who reports that he or she is now providing, or has provided within the past 12 months, assistance with at least two (2) or more Instrumental Activities of Daily Living (IADL) or at least one (1) Activity of Daily Living (ADL)* to someone over the age of 50 years.

A probability sample was drawn in order that estimates derived were no more than +/- 5% and in a way which allowed projections to be made to the caregiver population at large. There were 754 individual caregivers included in the final sample.

In 1997, the sample was screened using a more generally-defined operational definition: Providing unpaid care to a relative or friend who is aged 50 or over to help them take care of themselves. Screening included the question: Have you or anyone in your household provided such care to an older relative or friend in the past 12 months?

The study population is therefore defined as representative of US households with one or more caregivers, with the base sample of 754 interviews being accurate to within +/- 3.58% at the 95% confidence interval.

The 1997 survey also included a supplemental sample of 755 households to represent Blacks, Hispanics, Asians and other nonwhite households for a total sample size of 1509. This was done in order to address a lack of minority caregiver data. The data were weighted to reflect the true frequency of each group based upon the US Census Data.

In all, the total sample consists of:

Whites (non-Hispanic)	623
Blacks (non-Hispanic)	306
Hispanics	307
Asians	264
Other	9

Limitations of Trend Comparison Analysis

The obvious limitations associated with both telephone survey methodologies and self-identification of respondents as caregiver apply to the comparison described in this document. In addition, there were several variables which were measured differently on the two surveys, limiting the scope of the comparison. But the most serious limiting factor in this comparison was the unavailability of raw data from the 1987 survey. Thus, the comparison must be based only on aggregate percentages, and the number of variables upon which the comparisons are based are likewise limited to those which are described and detailed in the printed report of the 1987 survey and which can confidently be compared to the 1997 survey findings.

And, finally, we are limited due to the measures used to assess the effects of caregiving as reported by respondents. Only three comparable indicators existed. Similarly, there are indicators on the 1997 which were not present on the 1987 survey—most importantly, a measure of the number of caregivers who were caring for an elder more than an hour distant from them (long-distance caregivers).

Despite the limitations of the comparison, we believe that there are interesting trends present which speak to future trends around family caregiving and ways in which we can better support family caregivers.

PREVALENCE MEASURES

In 1987, the estimated prevalence of caregiving for an elder was 7.8%, or approximately 7 million households involved in caregiving activities.

In 1997, the estimated prevalence is 22% (using the 1987 operational definition of providing a minimum of 2+ IADLs or 1 ADL) or more than 21 million households.

During this same ten-year period, the population 65 and older increased from approximately 28 million to approximately 34 million. This increase in elderly population is roughly 21%. However, according to the surveys, during this same time period there was an increase in caregiving households equivalent to 278%. Based upon this increase, by the year 2007 we would expect to see an increase in caregiving households to a number which would significantly exceed the estimated number of elderly projected—approximately 39 million!

In 1987, the Agency for Health Care Policy and Research estimated that there were 5.4 million elderly who required assistance with at least one IADL. This number obviously is exceeded by the estimated prevalence rate of caregiving households (7 million).

The increase in caregiving households and the contrast between numbers of elderly who need assistance suggests that many Americans are involved in providing help to an elder, but are doing so either with the assistance of another sibling or relative or by helping another sibling or relative. The comparative analysis of the caregiving situation of respondents in both surveys supports the notion that, in America, caregiving truly is a family affair and one which involves an increasing number of younger Americans sharing the care rather than the identification of a single family caregiver who is managing care basically on their own.

PROFILE OF CAREGIVERS

The comparison of caregiver profiles, in the aggregate, show striking similarities between 1987 and 1997. The average age of caregivers is 45 years for both samples, and the majority of caregivers are women (75% in 1987 and 72% in 1997). Both samples

---

* Activities of Daily Living (ADLs) are those that are usually performed in the course of a normal day. They generally include bathing, dressing and undressing, grooming, eating, transferring from bed and chair, and toileting. Instrumental Activities of Daily Living (IADLs) are activities that may not necessarily be done daily, but which are important to independent living. They generally include preparing meals, doing housework, doing laundry, shopping, using transportation, managing money, using the telephone and doing home maintenance.

were most likely to report providing care for a parent and the average length of time they had been helping the elder was 5 years in 1987 and 4.5 years in 1988.

However, when we look at employment status of the caregiver groups, we do see a higher percentage employed in 1997 (64%) than 1987 (55%).

The caregiving situation is also a bit different between the two samples. There were a larger number of "primary" caregivers in the 1987 sample (63%) than the 1997 sample (41%), which may account for differences in the caregiving situation. Later in this report, we will discuss the differences between primary caregivers in each sample.

In the aggregate, the 1987 caregivers appear to be spending more time in caregiving activities than the 1997 caregivers. For example, one-fourth of the 1987 sample reported that they were providing 21+ hours of care a week to the care recipient, while only 14% reported doing so in the 1997 sample. Similarly, there were more caregivers providing help with ADLs in the 1987 sample than the 1997 sample. Only 32% of the 1987 sample reported that they did not help with ADLs at all, while nearly half (49%) of the 1997 reported they provided no help with ADLs.

Despite the seemingly lower levels of care provided by the 1997 sample, more respondents in this group of caregivers reported a change in their family life as a result of caregiving (43%) than did the 1987 sample (34%).

A comparison of the services used by caregivers and their care recipients was limited by the comparable measures in the two surveys. There were more caregivers in 1997 reporting the use of personal care services than in 1987 (38% compared to 22%), and less reporting they attended support groups for caregivers (7% compared to 12%).

COMPARISON OF WORKING CAREGIVERS

A comparison of working caregivers in both samples shows an increase in distinct differences over the ten-year period. The first difference is decrease in the number of respondents who reported they were primary caregivers. In the 1987 survey, 59% of the working caregivers reported being the primary caregiver as compared with 35% in 1997. While the length of time caring was the same (4.7 years in 1987, 4.5 years in 1997), the number of hours spent in caregiving per week was significantly less among the 1997 employed caregiver group. In 1987, 36% of the working caregivers reported spending 8 hours or less; in 1997, 52% reported this level of activity. Almost one-third of the 1987 working caregivers (32%) reported spending between 9 and 20 hours weekly caring for an elder while only 24% of the 1997 group reported this level of activity. More than one-fourth of the 1987 working caregivers (26%) reported they spend 21 hours or more a week providing care, while only 11% of the 1997 group reported that level of care. Interestingly, the percentages who reported that they were providing "constant" care was similar—6% for 1987 and 8% for 1997.

The 1997 employed caregiver group was also much less likely than the 1987 group to be helping with an ADL—53% reported no ADL assistance compared with only 35% in 1987.

One of the most striking differences between these two groups is the percentage reporting co-residence with the older person. In 1987, 32% of the working caregivers were living with the elder for whom they provided assistance. In 1997, only 17% reported co-residence. There were also more caregivers living a distance of more than 20 minutes in 1997—34% as compared with 14%. The co-residency differences were also present in both aggregate samples as well—in 1987 37% of all the respondents reported co-residence compared with 21% in 1997.

The effects of caregiving on work were, paradoxically, more likely to be reported by the 1997 group than the 1987 group. More than half of the employed caregivers (52%) in 1997 reported that they were required to leave work early, arrive late or take time off as a result of caregiving while only 34% of the 1987 group reported this interference. There were a similar number of people reporting that they took a leave of absence to provide care—9% in 1987 and 10% in 1997.

COMPARISON OF PRIMARY CAREGIVERS

When we compare primary caregivers in the 1987 sample to 1997 primary caregivers, we also see similar trends in the intensity of caregiving as was described in the sample as a whole and among the working caregivers. For example, the median hours spent in caregiving activities per week were 18 hours for the primary caregiver group in 1987 and 10 hours in 1997. Only 20% of the 1987 group reported spending 8 hours per week or less on caregiving activities, while a full third of the 1997 reported this level of activity. Similarly, almost a third (30%) of the 1987 primary caregiver group reported spending 21 or more hours weekly on caregiving while only 19% of the 1997 group reported this level of care. Almost one-half (48%) of the primary caregivers in 1997 reported that they provided no ADL assistance while only a third of the 1987 group reported no ADL assistance.

There were fewer men in the primary caregiver group in 1997 than 1987—19% compared to 23%. However, more of the primary caregivers were working in 1997 than in 1987 (55% compared to 40%). And, there were fewer of these caregivers reporting co-residence with their care recipient in 1997 than in 1987 (36% compared with 50%). This number is higher among primary caregivers than the other two groups, however. In the aggregate caregiver comparison, 37% in 1987 and 21% in 1997 reported co-residence; in the working caregiver group it was 32% in 1987 and only 17% in 1997. Again we see higher numbers of people in 1997 reported changes in family life as a result of caregiving than in 1987—51% compared with 38%.

Among the primary caregivers, as in the other two caregiver groups, the types of IADL assistance provided was similar between the two survey populations.

IMPLICATIONS AND TRENDS

1. *Caregiving for an elder has become a "normative" experience for US families—an experience that is touching more households today than in the past.*

It is difficult to estimate how many families are likely to be involved in caregiving in the future based upon the two surveys. Confounding our understanding of the dramatic increase in prevalence rates over the past ten years is an increased awareness on the part of individuals about caregiving and, lacking more information about the factors involved in nominating oneself as a caregiver, an incidence estimate is not possible.

However, it appears, from the comparison of the two surveys, that, although more households are reporting involvement in caregiving, the intensity and levels of caregiving are lower than ten years ago. This can be a function of more people defining themselves as caregivers as a result of increased awareness of caregiving in general, or a function of more older people in supportive community options (such as assisted living)—which means caregivers are providing less intense caregiving for their elders, or both. The decrease in the intensity of caregiving may also be related to the fact that the caregiving responsibilities are being spread among more family members. Of course, it could also be related to relatively higher levels of functioning on the part of the elderly population over the ten-year period as well.

2. *In the future, based upon comparison of the two surveys, we can expect to see more caregivers in the workforce.*

Between 1987 and 1997, the percentage of working caregivers rose from 55% to 64%—an increase of 9%. The estimate of working caregivers in the US for the 1997 survey is between 10 and 14 million, which is nearly consistent with a three-year old GAO estimate of a potential 8 million employees who were or may have been called upon to provide caregiving in 1994.

If the 1997 range increases an additional 9% in the next 10 years, there will be between 11 and 15.6 million employed caregivers in the US.

3. *Workplace issues for employed caregivers are likely to increase in the future.*

With an increase in the number of employed caregivers, some employers have begun programs in the workplace to assist employees with eldercare responsibilities. There were, however, increases in the number of employed caregivers who reported negative workplace impacts as a result of caregiving over the ten-year period. The percentage of employed caregivers reporting impacts on work increased 17%—from 34% to 52%. It is impossible to determine whether this increase was due to greater availability of workplace policies such as flex-time and telecommuting, which may allow employees to be more open about their caregiving situations, or due to greater difficulties with balancing work and family in general. The increase may also be due to workers feeling more at ease in speaking to their bosses about their caregiving problems.

It is clear, however, that the workplace will likely need to accommodate the schedules and situations of increasing numbers of caregiving employees in the future.

4. *As more employed persons become involved in caregiving, we may see an increase in male caregivers over time.*

When we examine the characteristics of employed caregivers, both in the 1987 and 1997 samples, we see a higher percentage of men reporting caregiver involvement than in the general caregiving population. More research is needed to understand the underlying factors involved in this difference. If men are more likely to be providing care when their wives are also working, we may see an increase in men in the caregiving role.

5. *Based upon the trends observed, we can anticipate a reduction in co-residence households in the future.*

Living together with the care recipient can be a strategy for the caregiver to help balance work and family life. There was a 16% reduction in reported co-residence households in the ten-year period, however. This suggests that, based upon an estimated number of co-residence households of 4.6 million, by 2007 we may see only 3.8 million such households. Co-residence may be decreasing in part because of the growth of alternative services, such as home health care, that allow the older person to remain in his or her own home.

6. *Based upon the ten-year decrease in numbers of caregivers providing assistance with an ADL, caregivers may generally be less involved in ADL assistance in the future.*

The number of caregivers reporting that they did not help with any ADL assistance increased by 17% in the ten-year period. Because of the measurement indices used in both surveys, it is impossible to tell whether this was due to alternative sources of assistance with ADLs available to the elders (e.g., assistive devices or paid care) or a diminished capacity to provide ADLs on the part of caregivers. This is an area which merits further research in order to assure that options are available to the increasing numbers of older people who need ADL assistance.

7. *As the prevalence of caregiving increases, more households will be involved in long-distance caregiving in the future.*

Although it was impossible to assess precisely the increase in long-distance caregivers over the ten-year period because long-distance caregiving was not measured in 1987; there was an observable increase in the numbers of respondents who reported that their care recipient lived more than 20 minutes away—16% in 1987 and 24% in 1997. For the employed caregivers, the increase was from 14% in 1987 to 34% in 1997.

A recent study by The National Council on the Aging estimates the prevalence of long-distance caregiving to be approximately 7 million Americans—the same prevalence number as was estimated for all caregiving in 1987. With this estimate and the trends observed in the two surveys compared in this document, it is likely that, not only will there be an increase in long-distance caregivers in the future, but these caregivers will more likely be employed caregivers. This also is an area that merits more research and certainly attention when policies to support caregivers are developed or considered.

NATIONAL SURVEYS OF CAREGIVERS
1987 AND 1997

COMPARATIVE TABLES	1987 (N=754)	1997 (N=1509)
Caregiver Gender:		
Male	25%	28%
Female	75	72
Median Age of Caregivers	45 years	45 years
Caregiver Marital Status:		
Married	66%	62%
Not married	34	38
Children in Household	39%	41%
Relationship to Care Recipient:		
Mother	28%	31%
Father	12	9
Parent In-Law	13	12
Spouse	10	5
Grandparent	16	15
Other relative	10	9
Non-relative	15	15
Distance from Caregiver:		
Lives with caregiver	37%	21%
Within 20 minutes	47	55
20 minutes away +	16	24
Living Arrangements of Recipient:		
With Caregiver	37%	21%
Independently	50	54
Nursing Home	5	6
Condition Type:		
Short-term/Acute	16%	12%
Long-term/Chronic	70	71
Both	5	11
Age of Recipient:		
Median	77 years	78 years
50-64	13%	12%
65-74	26	23
75-84	36	40
85+	24	24
Length of Time Caregiving:		
Average	5 years	4.5 years
Primary Caregivers:	63%	41%
Hours Spent per Week:		
8 hours or less	28%	48%
9-20 hours	26	21
21+	25	14
Constant Care	11	11

	1987	1997
Types of IADL Help Provided:		
Transportation	79%	79%
Grocery Shopping	82	77
Housework	75	74
Meal Preparation	68	60
Managing Finances	65	56
Medication Administration	45	37
Types of ADL Help Provided:		
Walking–Transferring	46%	37%
Dressing	41	31
Bathing	38	27
Toileting	29	26
Feeding	27	20
None	32	49
Number of ADLs Provided:		
None	32%	49%
1	19	14
2	15	9
3+	33	28
Employment Status of Caregivers:		
Full-time	42%	52%
Part-time	13	12
Retired	16	16
Not employed	27	20
Reported Changes As A Result of Caregiving:		
Changes in family life	34%	43%
Leisure time changes	51	43
None	28	45
Financial Assistance Provided:		
No financial help given	48%	45%
Median Monthly Amount*	$117	$100
Median Percent of Monthly Income*	7%	3%
* Excludes those who provided no financial help.		
Services Used:		
Personal care/nursing	22%**	38%
Home modification	N/A	28
Meal Service	14	16
Transportation	N/A	15
Housework	22	16
Adult Day Care/Sr. Cntrs.	N/A	10
Support group	12	7
Financial Info. Service	N/A	16

** 1987 survey assessed numbers of caregivers using home health aides.

COMPARISON OF EMPLOYED CAREGIVERS
1987 AND 1997

	1987	1997
Gender:		
Male	32%	32%
Female	68	68
Caregiver Age:		
LT 35 years	35%	27
35-49	36	47
50-64	26	24
64+	2	2
Marital Status:		
Married	64%	63%
Not married	36	37
Children in Household	N/A	47%
Responsibility:		
Primary caregiver	59%	35%
Helping/Secondary caregiver	41	65
Average Length of Time Caring	4.7 years	4.5 years
Number hours caring per week:		
8 or less	36%	52%
9-20	32	24
21+	26	11
Constant	6	8
Assistance with ADLs:		
Walking - transferring	46%	35
Dressing	35	28
Bathing	34	24
Toileting	30	24
Feeding	24	20
None	35	53
Number of ADLs Provided:		
None	35%	53%
1	21	13
2	14	8
3+	30	26
Assistance with IADLS:		
Grocery Shopping	81%	76%
Transportation	80	78
Housework	74	74
Meal preparation	65	58
Managing finances	64	57
Administering medication	41	35
Relationship of Care Recipient:		
Mother	28%	32%
Father	13	11
In-laws	12	13
Spouse	4	2
Grandparent	19	17

	1987	1997
Relationship of Care Recipient (continued):		
Other relative	10	13
Non-relative	14	12
Age of Care Recipient:		
50-64 years	12%	13%
64-74	28	26
75-84	38	34
85+	22	22
Median Age	77 years	77 years
Distance from Care Recipient:		
Same household	32%	17%
Within 20 minutes	54	59
More than 20 minutes	14	34
Services Used:		
Personal care/nursing*	26%	36%
Housework help	23	15
Support groups	12	5
Meal service	16	15
*Home Health Aides use assessed in 1987 survey.		
Condition Type:		
Short-term/Acute	17%	13%
Long-term/chronic	68	70
Both	5	11
Reported Changes as a Result of Caregiving:		
Changes in Leisure time	49%	42%
Changes in time with family	32	46
None	N/A	44
Work Effects:		
Late arrivals, early departures, days off	34%	52%
Leaves of absence to care	9	10
Reduction of work hours	7	6
Loss of benefits	14	4
Turn down promotion	3	3

COMPARISON OF PRIMARY CAREGIVERS
1987 AND 1997

	1987	1997
Gender:		
Male	23%	19%
Female	77	81
Median Age of Caregivers	49 years	49 years
Caregiver Marital Status		
Married	66%	58%
Not married	34	42
Employed	40%	55%
Distance from Caregiver:		
Lives with caregiver	50%	36%
Within 20 minutes	36	48
20 minutes away +	14	16
Length of Time Caregiving		
Average	5 years	4.6 years
Hours spent per week:		
8 hours or less	20%	33%
9- 20 hours	25	21
21+	30	19
Constant care	16	21
Median hours per week	18 hours	10 hours
Types of IADL Help Provided:		
Transportation	82%	87%
Grocery Shopping	87	87
Housework	78	78
Meal Preparation	74	67
Managing Finances	73	69
Medication Administration	50	45
Types of ADL Help Provided:		
Walking - Transferring	44%	34%
Dressing	45	37
Bathing	44	32
Toileting	31	26
Feeding	26	17
None	33	48
Number of ADLs Provided:		
None	33%	48%
1	17	13
2	14	10
3+	36	30
Reported Changes as a Result of Caregiving:		
Changes in Family Life	38%	51%
Leisure Time Changes	58	51
None	21	37