

FACT SHEET: Side-by-Side Comparison of Family Caregiver Prevalence Studies

The following table provides a side-by-side comparison of the most commonly referenced caregiver prevalence studies. Differences in definitions and data sources are included. The last section of the table also includes a brief list of additional published reports and studies that use the same data or build on the original study cited in the table.

Study	The Characteristics of Long-Term Care Users ¹	Family Caregiving in the U.S.: Findings From a National Survey ²	The Economic Value of Informal Caregiving ³	The Economic Value of Informal Caregiving ⁴	Informal Caregiving: Compassion in Action, Part I ⁵	Informal Caregiving: Compassion in Action, Part II ⁶	Characteristics of Caregivers Based on the SIPP ⁷
Estimated # of Caregivers	5.9 million caregivers	22.4 million households (5 million of which provide care to someone with dementia)	24 million caregivers	27.6 million caregivers	52 million caregivers	7 million caregivers	9.4 million caregivers
Definition of Caregiver/Care Recipient	Family or friend providing help to a disabled elder (65+) living in the community with a need that has lasted or is expected to last 3+ months.	Someone 18 or older currently providing care or who had at some point in the past 12 months to a relative or friend who is aged 50 or older to help them take care of themselves. "[M]ay include help with personal needs or household chores. It might be taking care of a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person does not need to live with you."	Anyone aged 15+ needed or provided assistance with everyday activities due to a condition that lasted or was expected to last 3+ months.	Need for or provision of personal assistance due to disability or chronic illness, Aged 18+ .	Aged 20+ providing "informal care" to a family member or friend of any age who is ill or disabled.	Provided care to an elder (65+) who needed assistance with everyday activities.	"Unpaid care or assistance to someone [of any age] with a long-term illness or a disability during the past month."

¹ Spector, W. D. et al. (September, 2000). *The Characteristics of Long-Term Care Users* (AHRQ Publication No. 00-0049). Agency for Healthcare Research and Policy, Rockville, MD

² National Alliance for Caregiving and AARP (June, 1997). *Family Caregiving in the U.S.: Findings From a National Survey*, National Alliance for Caregiving, Bethesda, MD and AARP, Washington, DC

³ Arno, P. S., Levine, C. and Memmott, M. M. (1999). The Economic Value of Informal Caregiving. *Health Affairs*, Vol. 18, No. 2, pp. 182-188

⁴ Arno, P. S., Levine, C. and Memmott, M. M. (1999). The Economic Value of Informal Caregiving. *Health Affairs*, Vol. 18, No. 2, pp. 182-188

⁵ Health and Human Services (June, 1998). *Informal Caregiving: Compassion in Action*. Department of Health and Human Services, Washington, DC

⁶ Health and Human Services (June, 1998). *Informal Caregiving: Compassion in Action*. Department of Health and Human Services, Washington, DC

⁷ Alexchih, L. M. B., Zeruid, S. and Olearczyk, B. (2001). *Characteristics of Caregivers Based on the Survey of Income and Program Participation*. The Lewin Group, Falls Church, VA. [National Family Caregiver Support Program: Selected Issue Briefs.]

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Data Source	1994 National Long-Term Care Survey: LTC Users aged 65+.	1,509 telephone interviews with caregivers conducted in 1996.	1986 Survey on Income and Program Participation (SIPP) [19,100 respondents] Used data from <i>Family Caregiving in the U.S.: Findings From a National Survey</i> , to determine number of caregiving hours.	1987/1988 National Survey of Families and Households (NSFH) [13,017 respondents]. [Note: In their study, Arno, Levine and Memmott used the average (25.8 million caregivers) of the SIPP and NSFH prevalence data.]	1987 and 1992 National Survey of Families and Households (NSFH).	1982 and 1994 National Long-Term Care Survey and the Informal Caregiver Supplement to the 1989 National Long-Term Care Survey.	1996 Survey on Income and Program Participation (SIPP) [Data collected from 1996 – 2000.]
Average Age of Caregiver	NA	46	NA	NA	43	60+	NA
Ratio of Female Caregivers to Male	Female 63.1% Male 35.1%	Female 72.5% Male 27.5%	NA	Female 59.0% Male 41.0%	NA	Female 75.0% Male 25.0% (approx.)	Female 65.0% Male 35.0%
Age Breakdown of Caregivers	14 – 34 5.3% 35 – 44 10.7% 45 – 54 16.9% 55 – 64 15.2% 65 – 74 15.8% 75 – 84 10.5% 85+ 2.3% Missing 23.5%	18 – 34 22.3% 35 – 49 39.4% 50 – 64 26.0% 65+ 12.4%	NA	NA	NA	NA	15 – 24 7.0% 25 – 44 30.0% 45 – 54 25.0% 55 – 64 18.0% 65 – 74 12.0% 75+ 8.0%

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Relationship of Caregiver to Care Recipient	Wife 13.4% Husband 10.0% Daughter 26.6% Son 14.7% Other Female Relative 17.5% Other Male Relative 8.6% Other Female Non-Relative 5.7% Other Male Non-Relative 1.8%	Relative 85.0% Friend/Neighbor 15.0%	NA	NA	Relative 71% Friend 29%	NA	Spouse 15.0% Child 16.0% Other Relative 21.0% Parent 25.0% Non-Relative 8.0% Relationship not identified 15.0%
Average # of Hours of Care per Week	NA	17.9 hours	NA	NA	NA	20 hours (18 hours for employed caregivers)	24 hours
% Caregivers Employed	NA	64.2% full- or part-time 51.8% full-time	NA	NA	64%	31%	50.6%
Other Reports Using Same Data Set (s)	Health and Human Services (June, 1998). <i>Informal Caregiving: Compassion in Action</i> . Department of Health and Human Services, Washington, DC.	Metlife Mature Market Group and National Alliance for Caregiving (June, 1997). <i>The MetLife Study of Employer Costs for Working Caregivers</i> . Metlife Mature Market Group, Westport, CT and National Alliance for Caregiving, Bethesda, MD.	Health and Human Services (June, 1998). <i>Informal Caregiving: Compassion in Action</i> . Department of Health and Human Services, Washington, DC.	NA	Arno, P. S., Levine, C. and Memmott, M. M. (1999). <i>The Economic Value of Informal Caregiving. Health Affairs, Vol. 18, No. 2, pp. 182-188.</i>	Spector, W. D. et al. (September, 2000). <i>The Characteristics of Long-Term Care Users (AHRQ Publication No. 00-0049)</i> . Agency for Healthcare Research and Policy, Rockville, MD.	

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<p>Other Reports Using Same Data Set (s)</p>		<p>Alzheimer's Association and National Alliance for Caregiving (1999). <i>Who Cares: Families Caring for Persons with Alzheimer's Disease</i>. Alzheimer's Association, Washington, DC and National Alliance for Caregiving, Bethesda, MD.</p> <p>Wagner, D. L. (June, 1997). <i>Comparative Analysis of Caregiver Data for Caregivers to the Elderly 1987 and 1997</i>. National Alliance for Caregiving, Bethesda, MD.</p> <p>Arno, P. S., Levine, C. and Memmott, M. M. (1999). The Economic Value of Informal Caregiving. <i>Health Affairs</i>, Vol. 18, No. 2, pp. 182-188.</p> <p>Ory, M. G. et al. (1999). Prevalence and Impact of Caregiving: A Detailed Comparison Between Dementia and Nondementia Caregivers. <i>The Gerontologist</i>, Vo. 39, No. 2, pp. 177-185.</p>					
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