

Appendix B: Topline Results

From a National Survey of Caregivers 18 and Older for National Alliance for Caregiving & AARP January 2003

Interviewing conducted September 5 through December 22, 2003, among N = 1,247 caregivers 18 and older in the United States.

Screening questions, used to identify caregiver respondents at the outset of the interviews for the national study, show the following:

	In the U.S.
Percent of adults who are caregivers	21%
Number of caregivers	44,443,800
Percent of households with caregiver(s)	21%
Number of households with caregiver(s)	22,901,800

Percents may add up to 99% or 101% due to rounding. Data are weighted by gender, age, and race. Margin of sampling error is ± 2.8 percentage points. * indicates less than 1%, and -- indicates zero.

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This survey is part of an important national study conducted by AARP and the National Alliance for Caregiving. We really appreciate your participation. IF HELPFUL, INTERVIEWER MAY TELL RESPONDENT: This is a national survey, and although individual answers are confidential, the results from the overall survey will be published. If you'd like, we could send you a copy of the final report.

1a. Are you <u>currently</u> providing unpaid help to a relative or friend 18 years or older, or, was this something you did in the past 12 months but are no longer doing?	CURRENTLY	66%
	PAST 12 MO.	34
	DK/REF	*

1. How many adults [do you provide this care for? / did you provide this care for in the past 12 months?]	1	69%
	2	22
	3+	8
	DK/REF	1

Mean: 1.7adults

IF ONE PERSON: Now, I'd like to ask you some questions about the adult for whom you [provide/provided] care. IF MORE THAN ONE: Let's focus on the adult for whom you [provide/provided] the most assistance.

1b. What [is/was] this person's relationship to you?	SPOUSE	6%
	MOTHER	28
	FATHER	8
	MOTHER-IN-LAW	7
	FATHER-IN-LAW	2
	SON	3
	DAUGHTER	3
	BROTHER	2
	SISTER	3
	BROTHER-IN-LAW	1
	SISTER-IN-LAW	*
	GRANDMOTHER	9
	GRANDFATHER	3
	GRANDPAR.-IN-LAW	1
	AUNT/UNCLE	5
	OTHER RELATIVE	1
	FRIEND/NEIGHBOR	16
PARTNER	1	
COUSIN	1	
DK/REF	1	

1c&1d. Gender of care recipient. IF NOT KNOWN FROM Q1b RESPONSE: ASK: Would you mind telling me if your () is male or female?	MALE	31%
	FEMALE	65
	DK/REF	4

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2. [Is your (__) currently/ Was your (__)] widowed, married, living with a partner, separated, divorced, or single – that is never been married?	WIDOWED	42%
	MARRIED	27
	PARTNER	2
	SEPARATED	3
	DIVORCED	12
	SINGLE	14
	DK/REF	*
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3. How old [is/was] your (__)? PROMPT: Your best estimate is fine. <i>Mean age is 66.</i>	18-29	8%
	30-49	13
	50-64	16
	65-74	19
	75-84	24
	85-89	11
	90+	9
	DK/REF	1
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4. [Does/Did] your (__) live in your household, within twenty minutes of your home, between 20 minutes and an hour from your home, a one to two hour drive from your home, or more than two hours away?	HOUSEHOLD	24%
	20 MIN AWAY	42
	20 MIN TO 1 HR	19
	1 TO 2 HRS	5
	2 HRS +	10
	DK/REF	*
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5. IF NOT IN HOUSEHOLD, DK, OR REF IN Q4: On average, how often [do/did] you visit your (__)? More than once a week, once a week, few times a month, once a month, few times a year, or less often? <i>Base N = 924</i>	> ONCE A WEEK	56%
	ONCE A WEEK	18
	FEW TIMES A MO	11
	ONCE A MONTH	5
	FEW TIMES A YR	7
	LESS OFTEN	2
	DK/REF	1

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6. IF NOT IN HOUSEHOLD, DK, OR REF IN Q4: [Does/Did] your (___) live in: his or her own home, someone else's home, an independent living or retirement community, in an assisted living facility where some care may be provided, a nursing home or facility, somewhere else? <i>Base N = 924</i>	IN OWN HOME	72%
	OTHERS' HOME	11
	IND. LVNG/ RTRMNT	4
	ASSISTED LVING	6
	NURSING HOME	7
	OTHER	*
	DK/REF	*
7. IF NOT IN HOUSEHOLD, DK, OR REF IN Q4 OR NOT IN NURSING HOME IN Q6: [Does/Did] your (___) live: (MULTIPLE PUNCH OKAY) alone, with her/his spouse, with her/his grown children, with other family members, with friends, with an aid, housekeeper, or other staff, or with someone else? <i>Base N = 869</i>	ALONE	47%
	SPOUSE	26
	CHILDREN	11
	OTHER FAMILY	12
	FRIENDS	3
	AID/ HOUSEKPR	3
	SOMEONE ELSE	1
	DK/REF	*
	8. IF NOT IN HOUSEHOLD IN Q4: [Does/Did] your (___) live in an urban, suburban, or rural area? <i>Base N = 925</i>	URBAN
SUBURBAN		38
RURAL AREA		27
DK/REF		2
9. And do you live in an urban, suburban or rural area?	URBAN	29%
	SUBURBAN	39
	RURAL AREA	29
	DK/REF	3
10. [Is/Was] your (___) frail, sick, disabled, or none of these? MULTIPLE RESPONSE	FRAIL	28%
	SICK	26
	DISABLED	35
	NONE OF THESE	28
	DK/REF	*

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11. What would you say [is/was] the main problem or illness your () [has/had]?
 PRECODED OPEN END: ACCEPT ONE ANSWER IF "DISABLED", PROBE: What kind
 of disability would that be?

AGING	12%
DIABETES	8
CANCER	8
ALZHEIMER'S	6
HEART DISEASE	7
MOBILITY (CAN'T GET AROUND)	5
STROKE	5
ARTHRITIS	4
BLINDNESS/VISION LOSS	3
LUNG DISEASE/EMPHYSEMA	2
PARKINSON'S	1
SURGERY	2
AMPUTEES	1
HIGH BLOOD PRESSURE/HYPERTENSION	1
BROKEN BONES	2
DEAFNESS/HEARING LOSS	*
FEEBLE, UNSTEADY, FALLING	1
MENTAL RETARDATION	1
MENTAL/EMOTIONAL ILLNESS/DEPRESSION	7
OSTEOPOROSIS	1
PARAPLEGIA	1
NEUROLOGICAL PROBLEM/DISORDER	1
MS	1
KIDNEY	1
FINANCES	2
DRUG/ALCOHOL PROBLEMS	1
BACK PROBLEMS	1
AIDS	*
OTHER (SPECIFY)	9
DON'T KNOW/REFUSE	4

12. IF ALZHEIMER'S/ CONFUSION/DEMENTIA <u>NOT</u> MENTIONED: [Does/Did] your () suffer from Alzheimer's or other mental confusion? <i>Combined with "Alzheimer's"</i> <i>responses in Q11.</i>	YES	23%
	NO	76
	DK/REF	1

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13. For how long [have you been providing/did you provide] help to your (___)? PROMPT: Your best estimate is fine. PRE-CODED OPEN END	OCCASION. < 6 MONTHS 6 MOS - 1 YR 1-4 YEARS 5-9 YEARS 10 YEARS+ DK/REF	5% 16 18 31 15 14 1
<i>Mean: 4.3 years</i>		

I'm going to read a list of kinds of help, which might be provided to a person, if the person cannot do this by him or herself. For each, just tell me if you [provide/provided] this kind of help. [Do/Did] you help your (___)....

	YES	NO	DK/REF
14. Get in and out of beds and chairs	36%	64	--
15. Get dressed	29%	71	*
16. Get to and from the toilet	23%	77	--
17. Bathe or shower	26%	74	--
18. Dealing with incontinence or diapers	16%	84	*
19. By feeding him or her	18%	82	--

[Do/Did] you provide help for your (___) with:

	YES	NO	DK/REF
20. Giving medicines, pills, or injections	41%	59	--
21. Managing finances, such as paying bills, or filling out insurance claims	64%	36	--
22. Grocery shopping	75%	25	*
24. Housework, such as doing dishes, laundry, or straightening up	69%	31	--
24b. Preparing meals	59%	42	--
25. Transportation, either by driving him or her, or helping your (___) get transportation	82%	18	*
26. Arranging or supervising services from an agency, such as nurses or aides	30%	70	--

IF NO/DK/REF TO ALL Q14-Q26: TERMINATE

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27. Thinking now of all the kinds of help you [provide/provided] for your (___), about how many hours [do/did] you spend in an average week, doing these things?	<1	4%
	1-8	44
	9-20	23
	21-39	8
	40+	17
	DK/REF	5
28. [Does/Did] your (___) take any prescription medicine?	YES	85%
	NO	12
	DK/REF	2
29. IF YES IN Q28: Would you say your (___) [needs/needed] someone to oversee giving him/her medicine in the right amount and on time, or that he/she [manages/had managed] this well on his/her own? <i>Base N = 1049</i>	NEEDS HELP	45%
	MANAGES	55
	DK/REF	1
30. IF YES IN Q28: Do you feel you [know/knew] as much as you [need/needed] to about the prescription medicine your (___) [takes/took], or that you [need/needed] to know more about it? <i>Base N = 1049</i>	KNOW AS MUCH	76%
	KNOW MORE	22
	DK/REF	2
31. Has anyone else provided <u>unpaid</u> help to your (___) during the last 12 months?	YES	59%
	NO	37
	DK/REF	3

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32a. IF YES IN Q31: What relationship [are/were] they to your (___)?	SPOUSE/FORMER	7%	
	MOTHER	6	
	FATHER	1	
MULTIPLE RESPONSE	MOTHER/FATHER-IN-LAW	*	
	SON	26	
IF "CHILDREN", PROBE: Would that be (___)'s son or daughter or both?	DAUGHTER	42	
	SON/DAUGHTER-IN-LAW	6	
	BROTHER	1	
	SISTER	5	
	BROTHER/SISTER-IN-LAW	*	
	NIECE/NEPHEW	5	
	GRANDSON/GRANDDDGHTR	9	
	OTHER RELATIVE	3	
	ALL FAMILY	4	
	NON-REL./FRIEND/NEIGH.	11	
	VOLUNTEER	1	
	OTHER (SPECIFY)	1	
	DK/REF	1	
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33. IF YES IN Q31: Who would you consider to be the person who [provides/provided] <i>most</i> of the unpaid care for your (___): you yourself, or someone else? <i>Base N = 742</i>	SELF	34%	
	SOMEONE ELSE	55	
	SPLIT 50-50 (VOL.)	10	
	DK/REF	1	
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IF NOT IN NURSING HOME: During the last 12 months, did your (___) receive <u>paid</u> help from any of the following - regardless of who paid for it. First: <i>Base N = 1191</i>			
	YES	NO	DK/REF
34. An aide or nurses hired through an agency or service?	23%	74	3
35. An aide or nurse hired <i>independently</i> - that is not through an agency or service?	7%	90	3
36. A housekeeper hired to clean or cook?	20%	80	*
37. Any other people who are paid to help her/him?	12%	86	2
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38. IF YES TO ANY IN Q34-Q37 ABOVE: Who would you say [provides/provided] more of your (___)'s care: you, other helpers, or paid helpers such as unpaid nurses or aides? <i>Base N = 468</i>	RESPONDENT	44%	
	OTHER UNPAID	34	
	PAID HELPERS	19	
	DK/REF	3	

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39. Now I have a few questions about you.	FULL TIME	48%
Are you currently working full time, working part time, a student, disabled, retired, a homemaker, unemployed and looking for work, or something else?	PART TIME	11
	RETIRED	16
	SOMETHING ELSE	*
	DK/REF	*

40. IF NOT CURRENTLY EMPLOYED OR A PAST CAREGIVER: [Have you been employed at any time since you began helping your (___)? / Were you employed at any time while you were helping your (___)]? <i>Base N = 782</i>	YES	59%
	NO	41
	DK/REF	*

IF WORKING WHILE A CAREGIVER: In your experience as both a worker and a caregiver, did you ever: *Base N = 935*

	YES	NO	DK/REF
41. Have to go in late, leave early, or take time off during the day to provide care	57%	43	*
42. Have to take a leave of absence	17%	83	*
43. Have to go from working full-time to part-time, or taken less demanding job	10%	90	*
44. Have to turn down a promotion	4%	95	1
45. Lose any of your job benefits	5%	95	1
46. Have to give up working entirely	6%	94	--
47. Choose early retirement	3%	97	*

52. IF NOT SPOUSE: How much of your money would you estimate you [spend/spent] in a typical month for groceries, medicines, or other kinds of cash support for your (___)'s care if any? Your best estimate is fine. <i>Base N = 1180</i>	\$0	34%
	\$1-\$50	15
	\$51-\$100	11
	\$101-\$500	25
	\$501+	3
	DK/REF	11

*Mean for those who make financial contributions:
\$200 per month*

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There may have been other ways in which providing care to your (__) has affected your life. As a caregiver,

	YES	NO	DK/REF
53. [Do/Did] you have less time for friends or other family members than before?	51%	48	1
54. [Do/Did] you have to give up vacations, hobbies, or your own social activities?	44%	56	*
55. [Do/Did] you have to get less exercise than before?	26%	74	*
56. Think of a scale from 1 to 5, where 1 is not a strain at all and 5 is very much of a strain. How much of a physical strain would you say that caring for your (__) [is/was] for you?	1 NOT A STRAIN		44%
	2		23
	3		17
	4		8
	5 VERY MUCH		7
	DK/REF		1
57. Using the same scale from 1 to 5, where 1 is not at all stressful and 5 is very stressful, how emotionally stressful would you say that caring for your (__) [is/was] for you?	1 NOT STRESSFUL		27%
	2		17
	3		20
	4		16
	5 VERY STRESSFUL		18
	DK/REF		1
58. Using the same scale from 1 to 5, where 1 is no hardship at all and 5 is a great deal of hardship, how much of a financial hardship would you say that caring for your (__) [is/was] for you?	1 NO HARDSHIP		62%
	2		14
	3		11
	4		5
	5 GREAT DEAL		7
	DK/REF		*
59. We have been talking about the help you [provide/provided] for your (__). Do you feel you had a choice in taking on this responsibility for caring for your (__)?	YES		59%
	NO		39
	DK/REF		1

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I'm going to read a list of ways that caregivers such as yourself have coped with the demands of caregiving. For each one, please tell me whether you have used any of these. [Have/Did] you ever [tried/try] to cope with caregiving stress by:

	YES	NO	DK/REF
60. Talking with or seeking advice from friends or relatives?	61%	39	*
61. Exercising or working out?	41%	59	*
62. Taking any kind of medication	12%	88	*
63. Talking to a professional or spiritual counselor	27%	73	*
65. Praying	73%	27	*
66. Going on the Internet to find information	33%	67	*
67. Reading about caregiving in books or other materials	44%	56	*

IF YES IN Q66: Which of the following things have you looked for on the Internet? *All Base N = 431*

	YES	NO	DK/REF
68. Information about your (___)'s condition and treatment?	88%	11	*
69. Information about services available for people like your (___)?	55%	45	--
70. Support or advice from people with similar caregiving experiences?	39%	61	--

In your experience as a caregiver, [have/did] you ever....

	YES	NO	DK/REF
71. [Requested/Request] information about how to get financial help for your (___)?	25%	75	*
72. [Taken/Take] part in support groups for caregivers?	7%	92	*
73. [Used/Use] a respite service to take care of your (___) to free up your time?	5%	93	3
74. [Helped/Help] enroll your (___) in Adult Day Care?	5%	95	*
75. [Helped/Help] enroll your (___) in a recreation program or camp?	8%	92	*
77. [Had/Have] an outside service such as Meals on Wheels deliver meals to your (___)'s home?	11%	89	*
78. [Had/Have] an outside service provide transportation for your (___) instead of you providing the transportation?	18%	82	*

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Have you done or obtained any of these types of things to make it easier to care for your (___):

	YES	NO	DK/REF
79. Had modifications made in the house or apartment where your (___) [lives/lived] to make things easier for your (___)?	39%	61	*
80. Obtained formal training of some sort about how to care for a person with your (___)'s needs?	18%	81	*
81. Obtained a bathing bench, magnifying lens for reading, or other helpful devices for your (___)?	40%	60	1

As a caregiver, on which of the following do you feel you [need/needed] more help or information:

	YES	NO	DK/REF
82a. Keeping the person I care for safe at home	30%	69	1
82b. Managing challenging behaviors, such as wandering	14%	85	1
82c. Easy activities I can do with the person I care for	27%	73	*
82d. Managing incontinence or toileting problems	11%	89	*
82e. Moving or lifting the person I care for	16%	84	*
82f. Balancing my work and family responsibilities	29%	71	1
82g. Finding time for myself	35%	64	1
82h. Choosing an assisted living facility	13%	87	*
82i. Choosing a nursing home	8%	92	1
82j. Choosing a home care agency	13%	86	*
82k. How to talk with doctors and other healthcare professionals	22%	78	*
82l. Managing my emotional and physical stress	29%	70	1
82m. Making end-of-life decisions	20%	80	1
82n. Finding non-English language educational materials	5%	95	*

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83. If you were looking for information about some aspect of helping take care of your (___), where would you turn? MULTIPLE RESPONSE	INTERNET	29%
	DOCTOR	28
	FAMILY/ FRIEND	15
	HEALTH PROFESSIONALS	10
	BOOKS, MAG., LIBRARY	7
	GOV'T AGENCY	5
	SENIOR CITIZEN'S CENTER	3
	CHURCH/REL. ORG.	3
	AGING ASSOC./GRP/ORG	2
	EMPLOYER	1
	SUPPORT GRPS/PPL LIKE ME	1
	HOSPITAL/CLINIC	1
	OTHER	2
DK/REF	10	

And finally, just a few questions for classification purposes only....

87. How would you describe your own health? Is it excellent, very good, good, fair, or poor?	EXCELLENT	25%
	VERY GOOD	30
	GOOD	28
	FAIR	12
	POOR	5
	DK/REF	*

88. How would you say taking care of your (___) has affected your health? Has made it better, not affected it, or made it worse?	BETTER	9%
	NO EFFECT	74
	WORSE	15
	DK/REF	2

89. Are you currently:	Married	56%
	Living w/ a partner	6
	Widowed	6
	Separated	3
	Divorced	11
	Single, never married	18
	DK/REF	*

91. Did you ever serve on active duty in the US Armed Forces? PROBE: Army, Navy, Air Force, Marines, Coast Guard or Women's Armed Forces	YES	14%
	NO	86
	DK/REF	*

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92. Did your () serve in the US Armed Forces?	YES	17%
	NO	82
	DK/REF	1
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93. Are there any children or grandchildren living in your household under 18 years of age?	YES	37%
	NO	62
	DK/REF	*
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94. What is the last grade of school you completed?	< THAN HS	5%
	HS GRAD	29
	SOME COLL	27
	TECH SCHL	3
	COLL GRAD	22
	GRAD SCHL/ WORK	13
	DK/REF	*
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95. Last year, what was your total annual household income from all sources, before taxes?	< \$15K	8%
	\$15K-\$30K	17
	\$30K-\$50K	26
	\$50K-\$75K	18
	\$75K-\$100K	9
	\$100K+	15
	DK/REF	9
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Gender	MALE	39%
	FEMALE	61
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Race	WHITE	73%
	BLACK	12
	HISPANIC	10
	ASIAN	4
	OTHER	*
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Age	18-24	11%
	25-34	15
	35-44	22
	45-54	23
	55-64	18
	65-74	9
	75+	4
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