

**A Profile of Family Caregivers:
Results of the 2002 & 2004
California Statewide Survey of Caregivers**

April 27, 2005

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Made possible by a grant from the Archstone Foundation

INTRODUCTION

In the first phase of the study (conducted April through August, 2002), IAR conducted a random sampling of California residents and asked them the following two screening questions in order to identify caregivers of an adult age 50 or over. The first question read: “Do you or does anyone in your household currently provide assistance or support to an adult relative or friend who is ill, disabled, or elderly?”, where the phrase “assistance or support” was defined within the introduction as providing assistance for at least a couple of hours a month with personal needs, household chores, taking care of finances, or arranging for outside services. The second question asked the respondent to indicate the ages and relationships of the people for whom he/she provides care, thus enabling the interviewer to identify the target population: caregivers of adults age 50 or over.

In October 2004, IAR began the second phase of its statewide study of caregivers, the purpose of which was to re-contact the initially interviewed caregivers to determine whether their views about and experiences with caregiving had changed over time. In particular, the follow-up interviews were designed to examine whether caregiver’s needs have changed over time, whether local support programs have met those needs, whether there have been changes in the barriers that inhibit service use or contribute to unmet needs, and whether there have been changes in the physical, mental, and emotional health of the caregivers. The following report details the results of this second phase.

SURVEY METHODS

Questionnaire Construction

Researchers at UC Berkeley reviewed and revised the 2002 survey (hereafter referred to as “time one” survey) and submitted a draft copy of the revised questionnaire (hereafter referred to as the “time two follow up” survey) to IAR for review. This “**follow-up**” **questionnaire** was constructed to elicit information regarding the following:

- the demographic characteristics of caregivers and care recipients;
- care recipient health and functioning;
- level of care provided by the caregiver;
- assistance required by the care recipient;
- services provided to caregivers, and unmet needs of the caregivers; and

- impact of caregiving on work-related issues, emotional health, and physical health

In those instances where the care recipient passed away after September 30, 2003, the wording of the questions changed (from present tense to past tense), however the majority of the questions remained the same for all respondents. The primary difference was that people whose care recipients had recently passed away were asked a few additional questions regarding the cause of death, services received to cope with the death, and the impact of the death on various aspects of the caregiver's life. The instrument used for these caregivers is termed the **“transitional” survey**.

The survey instruments are included as Appendix A.

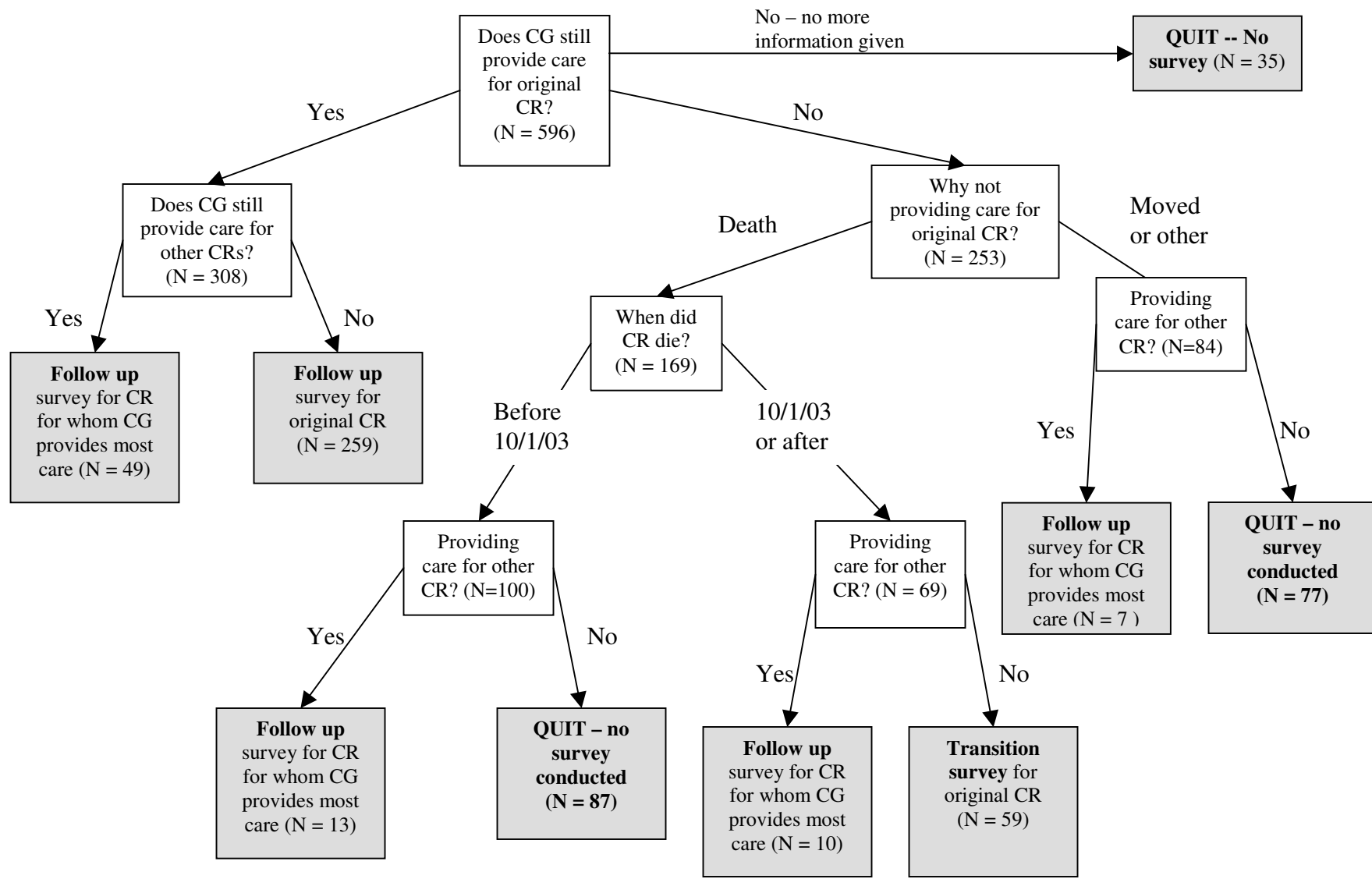
Sampling Methodology

At the conclusion of the time one interviews, respondents were asked if they would agree to being contacted for follow-up in the future. Of the 1,643 respondents who participated in the time one survey, 1,362 of them agreed to be contacted again. In addition, 250 of these caregivers provided names and phone numbers of “reference people” -- individuals that could be contacted if the caregiver could not be reached. All of these 1,362 caregivers were contacted to be included in the 2004 (time two) survey, and are termed the “target population” for the remainder of this report.

In order to begin the time two surveys, a few screening questions were asked of each member of the target population reached to determine whether the respondent should be given the “follow-up” survey or the “transitional” survey. Specifically:

- If the caregiver said he/she was still providing care to the same person and not providing care to anyone else, he/she received the primary **follow-up survey** focusing on both the respondent (caregiver) and the original care recipient.
- If the caregiver said he/she was still providing care to the same person, however he/she was also providing care to someone else (and, in fact, was providing *more* care to that “someone else”); he/she received the primary **follow-up survey** with the care recipient questions referring to the *new* recipient.

- If the caregiver said he/she was no longer caring for the same person because the person passed away after September 30, 2003 and was not providing care to anyone else, he/she received the **transitional survey**.
- If the caregiver said he/she was no longer caring for the original care recipient because the person passed away on September 30, 2003 or earlier, a few questions were asked about the person's death, and then the respondent was asked if he/she is providing care to anyone else age 50 or older. If the answer was "yes," the interview continued using the **follow-up** survey focusing on the new care recipient, and if the answer was "no," the interview was concluded.
- If the caregiver said he/she was no longer caring for the original care recipient for reasons *other* than death of the care recipient, he/she was asked if he/she was caring for anyone else over the age of 50. If the answer was "yes," a **follow-up** survey was conducted focusing on the new care recipient; and if the answer was "no," the interview was concluded.



The following table illustrates the final disposition of all calls conducted during the time-two survey. This final disposition reflects the last known contact made to the caregiver, not the reference person.

Table 1. Final Disposition of Survey Calls

CAREGIVERS REACHED	Count
Follow-up Survey	327
Transitional Survey	57
No Survey / No Longer Caring for Anyone	77
No Survey / Care Recipient Deceased before 10/1/03	87
No Survey / No Longer Caring for Anyone / Reason Unknown	35
Follow-Up Survey / Incomplete	8
Transitional Survey / Incomplete	2
Time-two Survey Only / Follow-Up / Incomplete	3
Total Caregivers Reached	596
CAREGIVERS NOT REACHED	Count
Non-Working / Disconnected Number	194
Unqualified Refusal (Someone other than caregiver refused or hung up on us)	7
Qualified Refusal (Caregiver refused to complete the survey)	87
Unable to Track Down / Moved / Wrong Number	143
Caregiver Deceased	9
Reached Maximum Attempts (At least 3 attempts were made and we kept getting a busy signal, no answer, an answering machine, or they kept asking us to call back)	326
Total caregivers not reached	766

Total Records

1362

In summary, a total of 338 respondents received the follow-up survey (although 11 of those surveys had some questions unanswered), 59 received the transitional survey (although 2 of those surveys had some questions unanswered), and 199 of the respondents with whom contact was made did not receive a survey for the reasons cited above.

Interviewing Procedures

Telephone interviews were conducted from the facilities of CSUSB's Institute of Applied Research and Policy Analysis in San Bernardino using computer assisted telephone interviewing

(CATI) equipment and software. The pre-tests began on October 5, 2004 and data collection was concluded on December 20, 2004. Surveys were conducted during the following shifts: Monday through Friday 9:00 AM – 9:00 PM; Saturday 10:00 AM to 5:00 PM; and Sunday 1:00 PM – 7:00 PM. To ensure the quality and reliability of the interviews, an Institute Staff Research Assistant was present for all interviews conducted from phones at CSUSB.

If the interviewer reached an answering-machine, a message was left informing the caregiver about the reason for the call, and asking the respondent to call IAR back. The message also indicated that when the respondent returned the call, IAR would call them back immediately so that the caregiver did not have to bear the costs of the call. If the caregiver did not respond to the message left on their answering machine, two more callbacks were made before the interviewer called the first reference person. The same protocol was conducted for each reference person on the list. After this protocol was complete, IAR called non-responding caregivers an additional three or four times. These included caregivers whom we still had not contacted and were classified as “no answer”, “busy”, “answering machine”, and those who had asked us to call back but who remained unavailable when the call back was made. In the event that the caregiver called did not answer the phone and there was no answering machine in place, two more callbacks were made (on different days and times) before the interviewer called the first reference person. The protocol then proceeded as described above.

Analysis of Survey Data

Data gathered from the interviews were edited, coded and entered into the computer for analysis. Each caregiver was matched to his or her 2002 data in SPSS using their initial respondent number so that changes over time could be analyzed. The computerized data were analyzed using SPSS (Statistical Package for the Social Sciences).

In reading this report and reviewing the data display, it should be noted that some respondents failed to answer some questions due to lack of information or lack of interest or unwillingness. The table totals associated with individual items, therefore, often differ. The reader is encouraged to review the full array of findings available in Appendix _____.

SURVEY FINDINGS

This section of the report focuses on the findings for the 2004 follow-up survey of California caregivers. The sample size in the tables at times differs from the total sample size of 397 (338 follow-up and 59 transitional) since (1) some respondents chose not to answer some questions, and (2) some questions were only asked of a subset of the caregiver population.

In each of the following sections, the 2004 data for both the follow-up and transitional populations are presented alongside the 2002 data, and where possible comments are made about changes between 2002 findings and the 2004 findings. It is worth noting that in 2002, all respondents were current caregivers, whereas in the 2004 group some surveys (the transitional surveys) were conducted with people who were formerly caregivers but who were not caregivers at the time of the 2004 survey due to the death of the care recipient. The basic approach for analysis, therefore, will be to first look at changes over time between the 2002 respondents and the 2004 follow-up subset (i.e.; comparable groups), then the transitional group will be examined where appropriate. Regarding this latter point: the sample size of the transitional group (59 respondents) is obviously too small to generalize to the larger population/cohort under study with much confidence, however in this report we treat the findings for this sub-cohort as providing interesting initial insights which should be followed up in future studies of caregivers whose recipients die.

ARE THE CAREGIVERS STILL PROVIDING CARE?

A notable percentage of caregivers no longer provide assistance to a recipient. One should expect therefore that the rate of caregiving in California and nationally is likely a dynamic phenomenon. For example, among the 596 respondents who were contacted in this follow-up study, 258 responding caregivers (43%) indicated that they no longer provide care or assistance. Of the respondents providing reasons for no longer providing assistance, 58% indicated that the death of the recipients was the reason for the ending of assistance. Whether this is a typical rate among the larger population is not something that can be determined from this study.

DESCRIPTION OF THE CAREGIVERS AND CARE RECIPIENTS

Table 2 summarizes key social and demographic traits among the caregivers who responded to the 2002 and 2004 surveys in order to determine whether the 2004 survey cohort is

composed of a population that is generally representative of the 2002 project. It should be noted, that most of the caregivers, in the earlier and later studies, are between 35 and 64 years old, married, and do not have children under the age of 18 living at home. The findings for both periods differ some, but the differences are minor and the overall patterns are remarkably similar. Insofar as there are any differences, the “transitional group” of respondents whose care-recipients died, are somewhat older than the other groups. An overwhelming number of the caregivers are women in the 2004 survey, as was the case in the earlier study. In addition, the caregivers remain predominantly White/Caucasian, with much smaller proportions indicating that they are Hispanic/ Latino background, Black/African American, or Asian/Pacific Islanders. Most caregivers in both periods were born in the US, with much smaller proportions reporting Mexico as their country of origin. A smattering of respondents in both the earlier and later study are from such places and areas as Canada, Europe, Asia, or Central America. Further, most have incomes over \$30,000, and a significant number report incomes over \$50,000.

Table 3 summarizes the key social and demographic traits among the care recipients (as reported by the caregivers) for both study periods. In both instances, half of the care-recipients are widowed. The largest groups of care-recipients continue to be living either with the caregiver or alone in their own home. Most of the care-recipients in both studies are in their 80’s or 70’s and most are female. Although there are some differences between the two periods with regard to race and ethnicity, the overall pattern seems very similar.

By far, most of the care-recipients were born in the United States (78% in both periods), with the highest number of non-U.S. born group being those born in Mexico. Perhaps the most notable characteristic is that insofar as the caregiver respondents are able to provide an estimate of the recipient’s income, it is clear that care receivers have lower household incomes than the caregivers, with the vast majority having household incomes under \$30,000 (and many having household incomes below \$10,000). It is possible, then, that one major cause of care giving provided by the respondents is the inability of the care receivers to afford professional care.

There are a number of key observations regarding the caregivers (respondents) and care recipients, as shown in Table 4. First, it is clear that by far most care recipients are parents of the caregivers. Additionally, the vast majority of the respondents care for only one recipient in both periods. Finally, the data from both periods under study show that the majority of caregivers live less than 30 minutes from the care recipients.

TABLE 2.
CAREGIVER SOCIAL AND DEMOGRAPHIC CHARACTERISTICS

Age	% in 2002 Sample (N=1,597)	% in 2004 Follow-up (N=331)	% in 2004 Transitional Survey (N=59)	Current Marital Status	% in 2002 Sample (N = 1,499)	% in 2004 Follow-up (N= 325)	% in 2004 Transitional Survey (N=57)
Under 35	14.1%	3.9%	5.1%	Married	60.4%	62.8%	66.7%
35 - 49	32.5%	25.1%	13.6%	Living with partner	2.0%	1.5%	NA
50 - 64	34.4%	43.2%	32.2%	Separated	2.1%	3.1%	1.8%
65 or older	19.0%	27.86%	49.2%	Divorced	12.3%	10.8%	7.0%
Mean age	50.87 yrs	56.56yrs	61.71 yrs	Widowed	6.8%	9.2%	12.3%
Modal age	50 yrs	57 yrs	66yrs	Never Married	16.4%	12.6%	12.3%
Gender	% in 2002 Sample (N = 1,635)	% in 2004 Follow-up (N= 332)	% in 2004 Transitional Survey (N= 59)	Children <18 yrs old in household	% in 2002 Sample (N=1,630)	% in 2004 Follow-up (N= 325)	% in 2004 Transitional Survey (N=57)
Female	74.9%	74.1%	79.7%	Yes	31.3%	21.2%	10.5%
Male	25.1%	25.9%	20.3%	No	68.7%	78.8%	89.5%
Highest Level of Schooling	% in 2002 Sample (N= 1,625)	% in 2004 Follow-up (N= 291)	% in 2004 Transitional Survey (N=59)	Race/Ethnicity	% in 2002 Sample (N = 1,614)	% in 2004 Follow-up (N= 329)	% in 2004 Transitional Survey (N=59)
< High School grad	10.6%	10.7%	10.2%	White (non-Hisp)	61.3%	67.1%	84.7%
High School grad	20.6%	18.6%	20.3%	Black (non-Hisp)	6.0%	6.1%	3.4%
Post HS training	33.4%	27.5%	30.5%	Hispanic/Latino	24.7%	20.4%	10.2%
College graduate	23.6%	33.0%	18.6%	Asian	4.5%	2.7%	3.4%
Post-graduate degree	11.7%	10.3%	20.3%	American Indian/ Alaska Native	1.1%	1.2%	1.7%
				Hawaiian/ Pacific Islander	0.2%	0.3%	0.0%
				Mixed	1.5%	1.2%	NA
				Other	0.7%	0.9%	NA

**TABLE 2, continued,
CAREGIVER SOCIAL AND DEMOGRAPHIC CHARACTERISTICS**

Household Income	% in 2002 Sample (N=1,419)	% in 2004 Follow-up (N= 299)	Transitional Survey (N=51)	Country of Origin	% in 2002 Sample (N= 1,380)	% in 2004 Follow-up (N = 293)	Transitional Survey (N=59)
Under \$10,000	9.0%	5.7%	7.8%	United States	85.6%	88.4%	94.9%
\$10,000 - \$20,000	15.9%	16.1%	17.6%	Mexico	6.3%	6.1%	1.7%
\$20,001 - \$30,000	13.3%	13.0%	13.7%	Asian/Pacific Island	2.4%	0.7%	NA
< \$30,000 (unspecified)	1.8%	2.0%	0.0%	Central America	1.7%	0.3%	NA
\$30,001 - \$39,999	10.7%	10.0%	3.9%	Europe	1.6%	0.7%	NA
\$40,000 - \$50,000	12.3%	15.1%	17.6%	Canada	0.5%	0.3%	NA
\$50,001 - \$80,000	17.2%	15.7%	19.6%	Other	1.9%	1.6%	3.4%
Over \$80,000	17.0%	19.1%	17.6%				
> \$30,000 (unspecified)	2.9%	3.3%	2.0%				

TABLE 3. SOCIAL AND DEMOGRAPHIC CHARACTERISTICS OF CARE RECIPIENTS (REPORTED BY CAREGIVERS)

Age	% in 2002 Sample (N=1,620)	% in 2004 Follow-Up (N=324)		Current Marital Status	% in 2002 Sample (N= 1,384)	% in 2004 Follow-Up (N=328)	Transitional Survey (N=59)
50 – 59 yrs old	11.8%	9.5%		Married	31.6%	31.7%	28.8%
60 – 69 yrs old	13.2%	12.8%		Living with partner	0.2%	NA	1.7%
70 – 79 yrs old	28.7%	25.0%		Separated	3.0%	2.1%	NA
80 – 89 yrs old	34.4%	36.0%		Divorced	10.5%	11.3%	6.8%
90 yrs old or older	11.7 %	16.2%		Widowed	49.5%	50.0%	62.7%
Mean age	76.81 yrs	77.77 yrs		Never Married	5.1%	4.9%	NA
Median age	78 yrs	80 yrs					
Modal age	80 yrs	82 yrs					
Gender	% in Sample (N =1,386)	% in 2004 Follow-Up (N= 337)	Transitional Survey (N=58)	Current living arrangement	% in 2002 Sample (N= 1,641)	% in 2004 Follow-Up (N= 334)	Transitional Survey (N=57)
Female	69.6%	72.4	62.1%	Alone in home or apt.	33.8%	27.2%	15.8%
Male	30.4%	27.6%	37.9%	With caregiver	34.6%	45.8%	35.1%
				With spouse or partner	9.4%	5.4%	NA
				With family or friend	9.6%	6.6%	5.3%
				Retirement community	3.9%	3.3%	1.8%
				Board/care home/Assisted living	5.9%	7.2%	22.8%
				Nursing home/elsewhere	2.7%	4.5%	9.3%

TABLE 3. (continued)
SOCIAL AND DEMOGRAPHIC CHARACTERISTICS OF CARE RECIPIENTS (REPORTED BY CAREGIVERS)

Highest Level of Schooling (n = 1,275)	% in 2002 Sample (N= 1,275)	% in 2004 Follow-Up (N=317)	Transitional Survey (N=56)	Race/Ethnicity	% in 2002 Sample (N=1,371)	% in 2004 Follow-Up (N=316)	Transitional Survey (N=57)
< High School grad	32.2%	32.2%	39.3%	White (non-Hisp)	64.8%	68.7%	87.7%
High School grad	32.5%	31.2%	32.1%	Black (non-Hisp)	5.9%	7.0%	NA
Post HS training	15.1%	17.4%	7.1%	Hispanic/Latino	22.3%	19.9%	8.8%
College graduate	14.4%	14.5%	16.1%	Asian	4.5%	3.2%	3.5%
Post-graduate degree	5.7%	4.7%	5.4%	American Indian/ Alaska Native	0.7%	0.3%	NA
				Hawaiian/Pacific Islander	0.2%	NA	NA
				Mixed	1.2%	NA	NA
				Other	0.4%	0.9%	NA
Household Income for 2001	% in 2002 Sample (N= 1,087)	% in 2004 Follow-Up	Transitional Survey (N=59)	Country of Origin	% in 2002 Sample (N= 1,372)	% in 2004 Follow-Up (N= 332)	Transitional Survey (N=55)
Under \$10,000	36.4%	28.3%	17.1%	United States	78.1%	78.0%	87.3%
\$10,000 - \$20,000	27.3%	34.2%	34.1%	Mexico	9.0%	9.9%	3.6%
\$20,001 - \$30,000	11.0%	9.6%	22.0%	Asian/Pacific Island	3.8%	2.4%	NA
< \$30,000 (unspecified)	4.6%	1.3%	0.0%	Central America	1.6%	0.3%	NA
\$30,001 - \$39,999	4.5%	5.4%	7.3%	Europe	3.7%	3.6%	1.8%
\$40,000 - \$50,000	6.0%	6.3%	4.9%	Canada	1.4%	0.9%	3.6%
\$50,001 - \$80,000	3.8%	5.0%	4.9%	Other	2.3%	4.8%	3.6%
Over \$80,000	4.2%	2.1%	0.0%				
> \$30,000 (unspecified)	2.1%	1.3%	0.0%				
Same as Caregiver / Live Together		6.7%	9.8%				

**TABLE 4.
OTHER INFORMATION ABOUT RECIPIENT
OF CARE AND CAREGIVER**

Who Is Caregiver Assisting?	% in 2002 Sample (N = 1,635)	% in 2004 Follow-Up (N=329)	Transitional Survey (N=59)
Parent	48.8%	48.0%	54.2%
Spouse/Significant Other	12.3%	17.0%	16.9%
Friend	11.5%	9.4%	3.4%
In-Law Parent	8.3%	10.9%	10.2%
Grandparent	7.5%	2.4%	5.1%
Other Extended Family Member	5.2%	5.5%	3.4%
Sibling	3.2%	4.3%	NA
Neighbor	3.1%	2.4%	3.4%
Travel Time (One Way) Between Caregiver and Care Recipient	% in 2002 Sample (N = 1,441)	% in 2004 Follow-Up (N= 175)	Transitional Survey (N=36)
0 (live together)	39.4%	NA	NA
Less than 15 minutes	33.1%	54.9%	55.6%
15 to 30 minutes	14.1%	21.1%	19.4%
30 minutes to an hour	6.6%	12.6%	2.8%
More than an hour	6.8%	11.4%	22.2%
Number of People For Whom Caregiver Provides Care	% in 2002 Sample (N = 1,641)	% in 2004 Follow-Up (N=332)	
1	86.2%	72.6%	
2	11.9%	23.8%	
3	1.7%	3.0%	
4	0.2%	0.6%	

CARE RECIPIENT HEALTH AND FUNCTIONING

The care recipients suffer from a variety of illnesses and the following table (Table 5) reports the distribution of ailments as reported by the caregivers. Caregivers were first offered a “check list” of illnesses and health conditions, and then the respondent was asked if there are any other conditions to report.

Again the patterns for the two periods are very similar. By far cardiovascular issues and arthritis continue to be the most prevalent health problems suffered by the care recipients. This is followed by severe memory problems/dementia, and mental health or emotional problems. The only real difference in the rankings of the ailments suffered involves hearing impairment, which seems a bit more prevalent and serious among the 2004 respondents. Less than 1% of the respondents in both periods indicated that the care recipients were suffering from HIV/AIDS.

**TABLE 5.
CARE RECIPIENT ILLNESSES AND HEALTH CONDITIONS REPORTED
BY CAREGIVER RESPONDENT**

ILLNESS/HEALTH PROBLEM	PERCENT YES (2002)	% YES FOLLOW-UP (2004)	% YES TRANSITIONAL (2004)
Heart Disease or High Blood Pressure	997 (61.8%)	226 (70.4%)	31 (56.4%)
Arthritis	966 (60.1%)	202 (62.9%)	31 (56.4%)
Severe Memory Problems or Dementia	591 (36.4%)	126 (39.3%)	33 (60.0%)
Mental Health Problems/Emotional Problems	578 (35.6%)	117 (36.4%)	22 (40.0%)
Severe Hearing Impairment	465 (28.5%)	104 (32.4%)	22 (40.0%)
Blindness or Severe Visual Impairment	470 (28.9%)	95 (29.6%)	13 (23.6%)
Diabetes	423 (26.1%)	89 (27.7%)	6 (10.9%)
Behavior Problems	392 (24.1%)	84 (26.2%)	20 (36.4%)
Stroke or Paralysis	407 (25.0%)	71 (22.1%)	16 (29.1%)
Lung Disease or Emphysema	249 (15.5%)	46 (14.3%)	8 (14.5%)
Cancer	217 (13.4%)	39 (12.1%)	10 (18.2%)
HIV/AIDS	5 (0.3%)	1 (0.3%)	0 (0.0%)

In the 2002 study, 92% of the respondents reported more than one condition experienced by the care recipient. Similarly, among the follow-up respondents in 2004 (N=201), 92% reported more than one of the listed health conditions. In fact, the median number of listed conditions was 3. In addition, a number of people mentioned “other” health problems. Those conditions with at least five combined mentions as additional conditions are listed in the following table. The transitional group is quite similar, but since we know that their recipients died, we also expect that several of the problems the recipients suffered would be worse, such as memory and dementia and behavior problems, likely a consequence of the former.

Table 6. “Other” Health Conditions Suffered by Care Recipients, 2002 and 2004 Surveys

ILLNESS/HEALTH PROBLEM	Number of Mentions, 2002	Number of Mentions, 2004
Bone problems/broken bones/osteoporosis	129	30
GI/Liver/Reproductive disorders	62	22
Nervous system disorders	97	20
Renal disease	44	14
Muscle pain or muscle disorders	42	10
Blood/Circulation Disorders	25	5
Acute Disorders	28	
Skin Problems	10	

As in the report based on the 2002 study, the key point is that many caregivers are dealing with care recipients who are experiencing multiple health problems, not simply the primary health condition.

CARE PROVIDED BY THE CAREGIVER (AND OTHERS)

Respondents were also asked in both 2002 and 2004 what sorts of services were provided to the care recipients. The following table reports that “going shopping or getting to the doctor’s office” are the most frequently cited services provided in both periods. Indeed, nearly 86% (2002) and 88% (2004) of the follow-up care recipients received this category of assistance. The next most frequently provided assistance in both periods is preparing meals, doing laundry, or cleaning house. Care recipients required the least assistance in dressing, eating, bathing, or getting to the bathroom.

**TABLE 7.
ACTIVITIES FOR WHICH CARE-RECEIVER NEEDS ASSISTANCE, AND WHO PROVIDES THE HELP**

ACTIVITY FOR WHICH CARE-RECEIVER REQUIRES ASSISTANCE	2002 SURVEY: WHO PROVIDES THE HELP FOR ACTIVITY				2004 FOLLOW-UP SURVEYS: CR NEEDS FOR ASSISTANCE, AND PEOPLE WHO PROVIDE THE HELP				2004 TRANSITIONAL SURVEYS: CR NEEDS FOR ASSISTANCE, AND PEOPLE WHO PROVIDE THE HELP			
	Needs Help	CG	Fam./ Fr/ Neigh	Paid Prov.	Needs Help	CG	Fam./ Fr/ Neigh	Paid Prov.	Needs Help	CG	Fam./ Fr/ Neigh	Paid Prov.
Going shopping or getting to the doctor's office	85.7%	85.0%	36.3%	11.8%	87.6%	81.3%	31.1%	14.9%	89.5%	64.7%	21.6%	41.2%
Preparing meals, doing laundry, or cleaning house	74.6%	73.5%	32.5%	25.7%	77.1%	69.5%	26.6%	28.5%	91.2%	55.8%	17.3%	59.6%
Keeping track of bills, writing checks, or other financial matters	64.2%	76.0%	35.9%	4.4%	67.8%	79.4%	27.4%	5.8%	84.2%	79.2%	27.1%	16.7%
Arranging for care or services	54.4%	81.5%	35.0%	8.3%	55.3%	82.4%	28.6%	13.2%	77.2%	77.3%	36.4%	15.9%
Medical needs, e.g., taking medicine or changing bandages	49.8%	74.1%	29.9%	25.0%	55.6%	67.9%	24.5%	26.1%	80.7%	52.2%	13.0%	63.0%
Dressing, eating, bathing or getting to the bathroom	41.5%	69.3%	33.5%	32.5%								
Bathing					43.1%	57.3%	18.9%	42.0%	82.5%	42.6%	12.8%	66.0%
Dressing					37.8%	60.0%	23.2%	38.4%	70.2%	50.0%	15.0%	57.5%
Eating					13.9%	58.7%	19.6%	47.8%	47.4%	63.0%	22.2%	59.3%
Toileting					26.5%	61.4%	25.0%	45.5%	64.9%	45.9%	16.2%	59.5%
Transferring					32.8%	69.7%	29.4%	35.8%	59.6%	52.9%	23.5%	52.9%

As the above table aptly demonstrates, care recipients have a variety of needs, and these needs are met by more than one person, including the caregiver being interviewed as well as family, friends, neighbors, and occasionally paid providers. The major burden of caregiving, however, falls on the caregiver themselves, as is evident by the answer to the explicit question asking who is the person who provides *the most* care to the care recipient? The majority of follow-up respondents (61.2%) said that they themselves provide most of the care.

Further, in the follow-up population (as in the 2002 survey), family members and friends/neighbors were the most frequently mentioned as “others” providing assistance for each of the listed activities. The respondents also acknowledged the role of paid providers, particularly in the areas of dressing, eating, bathing, and getting to the bathroom. It is noteworthy that the *transitional group showed a different pattern*, with paid caregivers assuming a more important role than family/friends/neighbors in most categories, and even more than the respondents themselves in a few categories. While these findings are based on small numbers of respondents, they are supported by an intuitive understanding that paid caregivers may become increasingly necessary as the care recipients become increasingly ill in the period immediately before they pass away.

Next, a question was posed regarding the number of hours caregivers (and others) spend per week providing help. In 2002, the median number of hours spent was reported as 14 (that is, half the people spent more than 14 hours and half spent less) and the median time spent by other family and friends was 10. Sixteen percent of the 2002 respondents reported that they provide virtually “constant” care throughout the week. For the 2004 follow-up respondents, the results indicated that the median number of hours spent on caregiving in an average week was 20 hours, the median number of hours spent by other family and friends was 10, and nearly 19% of the respondents reported providing virtually constant care.

Respondents were also asked “If you were unable to help your care recipient, is there someone else who would do the things you do?” In 2002, most of the respondents who answered the question (70%) indicated that there was someone else, while 65% of the 2004 interviewees indicated that there was someone else.

In 2002 respondents were presented with a list of three community services and asked whether in the past month (at the time of the interview) the care receiver used any of them. In these earlier interviews, twenty-five percent (25%) of respondents indicated that the recipient had used *at least* one of the listed community services. More specifically, 8% received home-

delivered meals (such as meals on wheels), 7% had received adult day services, 9% had received mental health counseling, and 14% had received some “other” community service. Among these “other” community services mentioned most frequently were: transportation services (49 people), medical/nutritional rehabilitation (30 people), and home care services (28 people).

A larger list of services was used in the 2004 survey. Following is the care recipient usage of those services in 2004.

Table 8. Percent of Care Givers Reporting Care Recipient Use of Services

	2004 Follow-up Surveys (n = 331)	2004 Transitional Surveys (n = 57)
Transportation and delivery services	14.8%	12.3%
Home care	12.7%	26.3%
Institutional care	8.8%	38.6%
Senior center	8.2%	5.3%
Financial assistance	6.6%	10.5%
Recreational services	5.4%	5.3%
Adult day services	4.8%	1.8%
Food service and home delivered meals	4.2%	8.8%
Mental health and counseling services	2.7%	1.8%
Legal assistance	2.7%	5.3%

It is interesting to note that the transitional care givers report much more usage of institutional care and home care for their care recipients than did those caregivers completing the follow-up surveys.

Follow-up caregivers report that service providers other than family or friends spend a mean of 58 hours and a median of 24.5 hours per week assisting the care recipients. This is apparently in addition to the median of 20 hours spent by the respondents and 10 hours spent by other family and friends.

CAREGIVER SERVICES AND SUPPORT

Assistance Received

The 2004 caregiver respondents were asked a series of questions regarding the kinds of assistance they may have received for themselves within the past 2 years to help them provide

care or handle the challenges of providing care. The following table summarizes the results regarding these items.

TABLE 9. ASSISTANCE RECEIVED BY CAREGIVERS, 2002, 2004 FOLLOW-UP, AND 2004 TRANSITION GROUP

	2002		2004 FOLLOW-UP		2004 TRANSITION	
	%	N	%	N	%	N
ASSISTANCE TO CAREGIVER						
Help in taking care of care recipient	38.3	1616	40.3	320	45.6	57
Information about community services	30.1	1624	38.1	328	42.1	57
Education or training on assisting care recipient	31.5	1639	30.2	328	28.1	57
Gotten information about legal rights and obligations	26.1	1627	26.5	328	47.4	57
Talked with a group of other people in similar situation	24.7	1641	25.8	329	31.6	57
Financial information or advice to help planning to care for care recipient	20.5	1617	19.3	326	16.1	56
Advice or counseling from a clergy person	19.4	1637	19.2	328	22.8	57
Having care recipient stay overnight away from home	13.0	1612	17.4	321	12.3	57
Help in getting or using community services	12.5	1613	14.5	325	19.3	57
Professional counseling	14.6	1633	14.1	327	15.8	57
Bringing care recipient to a center during the day	12.6	1613	13.6	324	19.3	57

The data indicate that the 2002 and 2004 follow-up interviews produce very similar findings. Help in taking care of care recipients (in home respite) and getting general information about community services were among the most frequently reported kinds of assistance. On the other hand, the transitional group (those whose care recipients have died) seem a bit different. A much higher proportion of this group sought information about rights and obligations.

Respondents were also asked who provided the services listed above. In the 2002 report, it was noted that family and friends generally are second in importance to more “formal” sources (e.g. an agency). At that time, there were three exceptions: helping with the care receiver in the home, being part of a group of other people in similar situations (e.g. a support group), and providing overnight respite care. In all other instances, “formal” services providers (other people or agencies) were cited as primary providers of the information or service. As noted in Table 10

below, these 2002 findings were reaffirmed by the 2004 follow-up findings (the transitional group was too small for any meaningful findings here).

Further, Table 11 details the survey findings relative to: *satisfaction with services* (that is, whether or not the caregivers' needs were met), perceptions among those who didn't receive the service as to whether it *would have been helpful*, and *knowledge of where to get the service* among those who did not receive the service but indicated that it might be helpful. These findings generally mimic those from the 2002 survey which indicated that satisfaction with all services is uniformly high (where satisfaction is defined as the respondents' statement that their needs have been met). It also mimics the finding that many of the caregivers who did not utilize a service still perceived that it might be helpful. This is especially the case with "information" services (about community services, about legal rights/obligations, and about finances). But knowledge about how to get the service appears to have remained stable or dropped slightly for most services when the 2004 survey is compared with the 2002 results.

TABLE 10. SOURCES OF ASSISTANCE RECEIVED BY CAREGIVERS AND SATISFACTION WITH ASSISTANCE (2004 FOLLOW-UP)

ASSISTANCE TO CAREGIVER	Number receiving the service	1*	2	3	4	5	6	7	8	9	10
Help in taking care of care recipient	129	58.9	20.9	na	na	10.1	2.3	4.7	1.6	0.0	4.7
Information about community services	125	4.0	6.4	19.2	4.8	18.4	3.2	14.4	9.6	1.6	1.6
Education or training on assisting care recipient	99	8.1	2.0	na	na	25.3	0.0	7.1	7.1	4.0	1.0
Got information about legal rights and obligations	87	8.0	2.3	na	na	14.9	1.1	8.0	13.8	1.1	4.6
Talked with a group of other people in similar situation	85	10.6	40.0	na	na	9.4	3.5	10.6	3.5	4.7	1.2
Financial information or advice to help planning to care for care recipient	63	6.3	3.2	4.8	1.6	12.7	1.6	12.7	11.1	1.6	4.8
Advice or counseling from a clergy person	63	na	na	na	na	7.9	63.5	0.0	0.0	0.0	0.0
Having care recipient stay overnight away from home	56	75.0	5.4	na	na	7.1	0.0	1.8	0.0	0.0	5.4
Help in getting or using community services	47	6.4	10.6	na	na	14.9	2.1	21.3	10.6	0.0	0.0
Professional counseling	46	na	na	na	na	32.6	2.2	2.2	13.0	0.0	10.9
Bringing care recipient to a center during the day	44	6.8	6.8	na	na	9.1	6.8	22.7	4.5	0.0	2.3

1 = Family, 2 = Friends, 3 = Written materials/mail/radio/TV, 4 = Internet, 5 = Health care provider, 6 = Religious cultural organization, 7 = Community Agency, 8 = Government program, 9 = At work, 10 = Independent provider, 11 = "other"

TABLE 11. HAVE NEEDS BEEN MET? (2004 FOLLOW-UP)

ASSISTANCE TO CAREGIVER	RECEIVED SERVICE		DID NOT RECEIVE SERVICE (OR DON'T KNOW)	
	Number receiving the service	Number whose needs have been met (i.e. satisfaction)	Perceived Helpfulness	Know where to get the service?
Help in taking care of care recipient in home	129	86.0% (111 of 129)	42.2% (81 of 192)	38.5% (30 of 78)
Information about community services	125	81.5% (97 of 119)	59.5% (113 of 190)	29.6% (32 of 108)
Education or training on assisting care recipient	99	90.7% (88 of 97)	46.0% (103 of 224)	31.7% (32 of 101)
Gotten information about legal rights and obligations	87	93.0% (80 of 86)	65.4% (149 of 228)	23.8% (35 of 147)
Talked with a group of other people in similar situation	85	88.0% (73 of 83)	41.4% (95 of 231)	39.1% (36 of 92)
Financial information or advice to help planning to care for care recipient	63	88.9% (56 of 63)	58.1% (151 of 260)	24.7% (36 of 146)
Advice or counseling from a clergy person	63	98.4% (60 of 61)	24.1% (60 of 249)	73.3% (44 of 60)
Having care recipient stay overnight away from home	56	89.3% (50 of 56)	28.2% (73 of 259)	32.4% (23 of 71)
Help in getting or using community services	47	89.1% (41 of 46)	54.5% (145 of 266)	41.3% (59 of 143)
Professional counseling	46	82.6% (38 of 46)	34.7% (93 of 268)	49.5% (46 of 93)
Bringing care recipient to a center during the day	44	72.1% (31 of 43)	31.4% (86 of 274)	51.9% (42 of 81)

Reasons for Not Receiving More Outside Help

The final question in the series of items regarding caregiver support is one designed to determine why the caregiver has not received more outside help. The following table summarizes the results of the question posing a list of items that might account for the lack of more outside help to the respondent.

TABLE 12. REASONS GIVEN BY CAREGIVERS FOR NOT GETTING MORE OUTSIDE HELP FOR CARE RECIPIENTS, 2002 AND 2004 RESPONDENTS

Reasons Why Services Not Sought/Gotten	2002	2004	Transitional
Already have all help needed	70.8% (1365)	56.6% (318)	66.1% (56)
It is your duty to provide care	NA	79.3% (324)	82.1% (56)
Raised to believe family should provide care	NA	78.3% (322)	73.2% (56)
Family expects you to provide care	NA	61.2% (309)	60.4% (53)
Care recipient doesn't want care	44.2% (475)	37.2% (304)	37.0% (54)
Services cost too much	56.4% (431)	37.3% (279)	36.0% (50)
Didn't know where to obtain services	NA	34.1% (320)	25.9% (54)
No time to get help for myself	26.1% (487)	21.2% (307)	16.7% (54)
Service quality is poor	36.0% (386)	20.6% (248)	22.9% (48)
Services not offered by people like you	25.2% (420)	19.9% (251)	18.8% (48)
Services not available	41.4% (411)	19.8% (262)	28.6% (49)
Services not available at times when needed	32.0% (422)	17.6% (261)	22.4% (49)
Transportation is not available	24.8% (484)	15.7% (313)	19.2% (52)
No one to stay with care recipient	27.5% (483)	15.2% (315)	14.5% (55)
Providers don't speak your language	16.7% (462)	12.5% (288)	10.2% (49)

The data indicate that a significant number of respondents indicate that they did not receive more outside help in their caregiving activities was because they simply “already have all

the help” they need. In fact, 56.6% of the 2004 follow-up respondents, 66.1% of the 2004 Transitional respondents, and 70.8% of those interviewed only in 2002 assert that they already have all the help that they need.

Reasons offered for not receiving more outside help were generally consistent for the two time frames under consideration. The most-often mentioned reason is that caregivers seem to believe that they are largely responsible for taking care of their friends, family, or neighbors. Further, about ¾ of follow-up and transitional cohorts indicate that they were raised to believe that the family should be the primary source of care. These individuals, apparently, believe there is no need or justification for seeking or demanding additional services. In fact, approximately 6 out of every 10 caregivers indicate that their family expects them to provide care.

There were two areas of significant change between the 2002 and 2004 surveys. The first involves cost of service. In the 2002 survey, 56.4% of respondents reported that they didn’t receive more outside help because services were too costly, whereas among the 2004 respondents that figure dropped by about 20%. The other notable difference involved services not available. In 2002, 41.4% indicated that they believed services were not available, whereas in 2004 only 19.8% of the follow-up and 28.6% of the transitional respondents indicated that belief. Although this finding may be an artifact of the methodology (and the specific caregivers that agreed to be re-interviewed), it is also possible that there has been a major improvement in information dissemination (including information about the costs involved) of available services.

IMPACT OF CARE GIVING

Work and Employment Effects:

A number of items were included which permitted the examination of possible changes in workplace burdens and sacrifices made by caregivers. In the 2002 report, for example, it was reported that one of the more important findings was that the vast majority of respondents reported that they have *not* experienced significant additional workplace burdens and sacrifices as a result of their care giving activities. Although this general pattern has continued, there is some modest evidence that changes have occurred with respect to the employment and workplace situation of the caregivers. For example, among those respondents who were interviewed in 2002, 49.1% were employed at the time; whereas in 2004, 40.4% of the follow-up respondents (and 33.3% of the transitional) indicated that they were currently employed. About 49% of 2002 non-working respondents indicated that the unemployment was due to retirement,

whereas 59.7% of the unemployed follow-up respondents (and 71.1% of unemployed transitional) in 2004 are retired. These changes in employment figures are not unexpected given that the caregivers have aged roughly two years.

The 2004 follow-up respondents continued to report that their work situation had *not changed* over the past two years because of helping the caregiver. Indeed, 78.5% of 2004 follow-up respondents saw no change in job status, virtually the same as the 76.8% of respondents in the 2002 survey. Interestingly, 86.0% of 2004 transitional respondents reported no change in work status (perhaps because of the increasing need to utilizing more paid providers).

However some respondents did report some change in their work situation in terms of work hours reduced or days of work missed. For example, in the 2002 survey we noted that 13% of respondents had reported reducing the number of work hours, whereas that figure dropped to approximately 8% in the 2004 follow-up survey group. When the employed respondents were asked if they had missed any work in the past two weeks because of helping their relationship, approximately 80% of the 2002 respondents and 90% of the 2004 follow-up respondents said “no.” Clearly these figures support our earlier statement that overall, from the point of view of the caregiver, their jobs have not been adversely affected by the experiencing of caregiving.

Other Hardship Effects:

Many of the follow-up respondents expressed feelings of stress and strain regarding the caregiving experience. For example:

- 47.3% of respondents feel “sometimes” or “quite frequently” that they don’t have enough time for themselves because of the time they spend with the care recipient.
- 58.5% of respondents feel “sometimes” or “quite frequently” that they feel stress between caring for the recipient and trying to meet other responsibilities.
- 45.0% of respondents feel “sometimes” or “quite frequently” that they feel strained when they are around the care recipient.
- 43.5% of respondents feel “sometimes” or “quite frequently” that they feel uncertain about what to do about the recipient.

That notwithstanding, as described in the 2002 survey report and confirmed in this 2004 report (see tables below), the majority of respondents indicate that they do not experience

significant financial hardship or significant physical strain as a result of their caregiving activities.

Table 13. Financial Hardship of Caring for Care Recipient

Level of Hardship	2002 Survey	2004 Follow-up Survey	2004 Transitional Survey
1. No hardship at all	56.3%	53.8%	56.1%
2.	15.1%	20.3%	8.8%
3.	14.1%	13.2%	17.5%
4.	5.5%	6.5%	8.8%
5. A great deal of hardship	9.0%	6.2%	8.8%

Table 14. Physical Strain of Caring for Care Recipient

Level of Physical Strain	2002 Survey	2004 Follow-up Survey	2004 Transitional Survey
1. Not much of a strain	44.5%	47.9%	33.3%
2.	20.9%	19.8%	10.5%
3.	16.9%	16.8%	26.3%
4.	8.2%	8.5%	15.8%
5. Very much of a strain	9.5%	7.0%	14.0%

As seen in the above tables, nearly identical proportions of 2002 and 2004 follow-up respondents indicated that their care-giving responsibilities were not a significant financial hardship or a physical strain. On the other hand, the transitional group reported a bit more strain which is perhaps understandable given that they have experienced the death of a loved one or friend.

Table 15. Emotional Stress of Caring for Care Recipient

Level of Emotional Stress	2002 Survey	2004 Follow-up Survey	2004 Transitional Survey
1. Not at all stressful	28.1%	27.9%	14.3%
2.	19.4%	23.2%	7.1%
3.	19.7%	23.5%	25.0%
4.	15.7%	13.0%	26.8%
5. Very stressful	17.1%	12.4%	26.8%

Emotional stress, of course, is another matter. In the 2002 report we stated that “it is emotional stress that is most often reported, with nearly 33% reporting the experience to be quite stressful (rating of “4” or “5”).” In the 2004 follow-up group, this figure dropped to 25.4%. Emotional stress still appears to be more notable and widespread among the caregivers than either financial hardship or physical stress. The transitional respondents are again clustered more towards the “stressful” side, potentially reinforcing the notion that caregivers whose recipients have died may still be experiencing a period of mourning which may be intensifying their memories of the stress of caregiving. In addition, some caregivers may feel a sense of relief that they no longer have the responsibility of caregiving, but this sense of relief may in itself produce an inner guilt that they have these feelings. This combination of guilt and relief may actually intensify caregivers’ recognition of how emotionally stressed they felt while providing care. And of course, a more mundane explanation is that transitional respondents were simply dealing with care recipients who were more ill, thus increasing the level of stress at that time.

As noted in our 2002 report, despite the stresses reported by caregivers surveyed at that time, many respondents viewed caregiving as a very positive experience. This appears to be confirmed by the 2004 survey findings in that:

- 46.4% of follow-up respondents and 61.4% of transitional felt that the caregiving situation brought the family closer together either “very much” or “somewhat”;
- only 28.3% of follow-up respondents and 24.6% of transitional agreed “very much” or “somewhat” that the situation had created conflict or disagreement in the family; and
- 38.6% of both follow-up and transitional respondents agreed “very much” or “somewhat” that the situation had been a hardship on the family.

Although there has been a slight erosion in these figures since the 2002 report, there is still a substantial number of caregivers who apparently believe that caregiving has contributed to the family’s “well-being.” Nevertheless, in both the 2002 and 2004 surveys about a quarter of the respondents report suffering physical and/or emotional problems as a result of their caregiving activity. Additionally, approximately a quarter of the caregivers indicate that they have had their sleep interrupted during the week prior to their interview. Further, when positive comments of any type are combined and compared with negative comments of any type, the results are consistent for both the 2002 and 2004 interviewees; the *positive comments far outweigh the negative.*

CAREGIVER HEALTH AND FUNCTIONING

Respondents were asked to indicate whether “In general, compared to other people your age, would you say your health is excellent, very good, good, fair, or poor?” The distribution of answers from the 2002 and 2004 follow-up surveys are as follows:

**TABLE 16.
REPORTED COMPARISON OF HEALTH COMPARED
TO OTHERS OF RESPONDENT’S AGE, 2002 AND 2004**

	2002 Survey	2004 Follow-up Survey	2004 Transitional Survey
Poor	5%	6%	3%
Fair	21%	19%	21%
Good	34%	35%	37%
Very good	24%	26%	23%
Excellent	16%	13%	16%

The preceding data indicate that the vast majority of caregivers in both periods evaluate their own health as good to excellent. But the flip side of this continues to be that about a quarter of the respondents in both periods indicate that their health is fair to poor, indicating that many of the respondents are struggling with their own health problems even as they act as caregivers. In fact when asked directly whether respondents have any illnesses or emotional challenges that make it difficult to provide assistance or support to the care recipient, 28% of the 2002

respondents, 33% of 2004 follow-up respondents, and 32% of 2004 transitional respondents indicated that they did.

Many caregivers, however, report being connected to various support systems to help them deal with the stresses of caregiving (confirming the 2002 findings). Approximately 83% of follow-up respondents and 88% of transitional indicate that there is a friend or family member whom they can go to for support and understanding. The large number of respondents report attending religious services, meetings, and activities at least once a week (39% of 2004 follow-up and 54% of transitional). Further, more than three-quarters of 2004 respondents (both follow-up and transitional) report praying or meditating on their own at least once a week.

THE BOTTOM LINE

The 2002 report concluded with the following statements: “Family caregiving, in an earlier age, was expected. As the industrial age developed and families dispersed geographically, it became increasingly important to rely on paid professionals to supply the needed care. Yet some of the caregivers in this study appear not to be a product of the industrial 21st century...rather they look like a modern-day version of another time and place in which they, too, somehow, are able to balance the rigors of caregiving with a sense of accomplishment and contribution.”

These statements appear to be no less true in 2004. Indeed, the bottom line is that there have been relatively few changes over the 2 intervening years. But this may be simply an artifact of the short period of time between surveys rather than a finding of overall stability in caregivers’ lives and activities.