

**THE CENTER FOR STATE HEALTH POLICY**

**Evaluation of New Jersey's  
"Caring for You, Caring for Me" Course**

Mina Silberberg, Ph.D.

Submitted to the  
New Jersey Department of Health and Senior Services

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A Publication of The Center for State Health Policy  
Institute for Health, Health Care Policy, and Aging Research  
Rutgers, The State University of New Jersey



## ACKNOWLEDGMENTS

We gratefully acknowledge the assistance of the New Jersey Department of Health and Senior Services in facilitating this project. We wish particularly to recognize the efforts of Kristina Rosenheim, former Caregiver Education Specialist, whose idea it was to conduct this evaluation, and who assembled the Department's data and documentation. Peri Nearon, Administrator of the Statewide Respite Care Program, was instrumental in the project's completion. The report was reviewed by (and improved by the contributions of) Barbara Fuller, Program Manager, NJEASE, Caregiver Support and Housing; and Jack Ryan, Supervisor, Training and Research, Office of Senior Affairs. At the Center for State Health Policy, Paul Hamborg was central to the project, carrying out the data analysis with assistance from Herle Werner. Susan Brownlee played a key role in the design of the follow-up survey and in data entry. Data entry and coding were carried out by Dawn Harris and Felicity Tsikiwa, and survey tracking by Carrie Bogert. Daniel Caruso provided research assistance in the project's early stages. We also thank Lori Glickman for formatting, editing, and publication of the report. Finally, we thank David Haigler of the Rosalynn Carter Institute for Human Development for his insights into the course and issues in its evaluation.



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# EVALUATION OF NEW JERSEY'S "CARING FOR YOU, CARING FOR ME" COURSE

## EXECUTIVE SUMMARY

### INTRODUCTION

Since November of 1999, the New Jersey Department of Health and Senior Services (DHSS) has offered the "Caring for You, Caring for Me" course to caregivers of the disabled and frail elderly. The goal of the course is to improve the lives of caregivers and extend caregiving by increasing participants' capacity for self-help and their ability to access resources for caregiving and caregiving support. The course's five topics are: 1. What it means to be a caregiver. 2. Taking care of yourself while caregiving. 3. Building cooperative relationships with other caregivers. 4. Preventing and solving problems while caregiving. 5. Accessing and developing caregiving resources. This report presents the findings of an evaluation of the course for the period November 1999 to August 2000. The evaluation was carried out by the Rutgers' Center for State Health Policy (CSHP) between November 2000 and July 2001.

### EVALUATION QUESTIONS AND METHODS

The evaluation addresses the following questions:

1. Who takes the course and how do they find out about it?
2. What do participants think of the course?
3. How do course participants perceive and use course content after the course has ended?
4. How do participants' feelings about being a caregiver and self-perceived knowledge of caregiving change from the beginning to the end of the course? How do they change after participants have been away from the course for awhile?

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These questions were answered using four data sources:

1. The Caregiver Skills Training Participant Questionnaire: Contains descriptive information on course participants and the individuals for whom they care, the nature of their caregiving relationships, and the caregiver's work responsibilities and the impact of caregiving on their work. Three hundred and fifty-five of these surveys were completed.
2. The Course Participant Evaluation: Gathers participants' opinions on the course at the course's end; 299 individuals completed this survey.
3. The Survey of Caregivers: Measures respondents' feelings about and self-perceived knowledge of caregiving by asking them to "strongly agree, agree, disagree, or strongly disagree" with a series of statements. This survey is administered both at the beginning of the course and at the end; 252 individuals completed the pre-test and 214 the post-test.

4. Follow-Up Survey: Mailed to respondents in the winter of 2001, this repeats the items used in the Survey of Caregivers, as well as asking respondents about what they learned in the class, how much they remember, what they've used, and how useful they found it. 157 individuals completed this survey, including 60 who had also completed both the pre- and post-course Survey of Caregivers.

## **FINDINGS**

Course participants were generally in intensive caregiving situations. By every indicator, the course was highly valued by participants. Furthermore, course participation appears to be associated with increased confidence in knowledge about caregiving and a decreased sense of isolation. There were no consistent concerns about the course among any sizable group of respondents. However, the course was designed to be part of a larger strategy of caregiver support; this approach of coupling the course with other supports is also suggested by the data.

### ***Course Participants***

- Course participants from November of 1999 to August 2000 were primarily non-elderly, and were caring for a relative. Most were female, and the vast majority were White; minorities appear underrepresented in the program. Working caregivers were a sizable part of the population.
- Care recipients were by-and-large elderly, mostly female, and predominantly White. Most were living with the caregiver, but many of the oldest-old were on their own. The most prevalent diagnoses for care recipients were arthritis, Alzheimer's disease/dementia, and heart disease.
- Caregiving relationships were highly intensive, with half of course participants assisting with six Activities of Daily Living or Instrumental Activities of Daily Living (I/ADLs) or more. Most caregivers had been providing care for one to five years, and seven out of ten provided care around-the-clock or more than once a day. However, most respondents had the assistance of paid resources, family or friends, or both.
- More than three-quarters of those who were working experienced conflicts between caregiving and their job "sometimes" or more often. In fact, 7.4% of respondents had stopped working because of caregiving. One-in-four respondents said that when or if they were at work, the care recipient would be without assistance. Information and referral services were the only employer caregiving benefit that was perceived as useful by a significant number of people.
- At the beginning of the course, caregivers felt extreme physical, emotional, and time demands from caregiving. They wished to improve both their lives as caregivers and the quality of care they were providing. They saw key strategies for improving their lives and their caregiving as including learning more about formal support services, getting support from peers (in the class and in support groups), and learning more about the diseases/disabilities of the care recipients.
- Most respondents had learned about the course through newspapers and personal networks.



## ***Participant Opinions of the Course***

- The course was highly regarded by participants both at the end of the course and the time of the follow-up, and only small numbers of respondents found any of the topics not to be helpful.
- “Accessing and Developing Resources” and “Taking Care of Yourself” were considered to be the most helpful topics both immediately following the course and at the time of the follow-up, although they switched places, with “Taking Care of Yourself” commonly seen as the most helpful topic at the time of follow-up.

## ***Course Impact: Contact with Others, Feelings of Isolation as a Caregiver, and Ability to Express Feelings***

- Feelings of isolation as a caregiver were reported to have diminished as a result of taking the class. This did not apparently require ongoing contact with fellow caregivers or the teacher.
- Although in theory respondents thought contact could be of help, they were unlikely to have had much, usually because of a lack of time or energy.
- Respondents believed they felt more comfortable expressing their feelings as a result of taking the course.

## ***Course Impact: Use of Course Materials***

- For all course content areas there was a similar pattern in use of materials. Respondents felt that they had learned a lot about the designated topic and that what they had learned was helpful. Average scores went down a little for remembering what they had learned, and a little more for actually using it. Average scores for how much respondents had used the course content ranged from more than “a little” to “some,” despite the fact that lack of time and energy were considered barriers to employing what caregivers had learned.

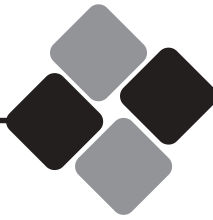
## ***Course Outcomes***

- Statistically significant gains were shown from the beginning to the end of the course for all of the knowledge questions in the “Survey of Caregivers” scales except one (sense of preparation for caregiving). There was a statistically insignificant, but consistent, pattern towards some reversal of gain at the time of follow-up. However, progress was maintained at a statistically significant level and sense of preparation for caregiving continued to improve, achieving a statistically significant gain.
- In contrast, emotional gains were not statistically significant, although this may be a result of sample size. While comfort talking with others about caregiving improved from before the course to immediately after, and while caregivers felt that the course had improved their comfort levels, the gain was reversed and significance lost at follow-up.

## **RECOMMENDATIONS**

The following steps are recommended:

- Examine reasons for underrepresentation of racial/ethnic minorities. Consider additional newspapers, provider networks, places of worship, etc. for inclusion in outreach, with attention to outlets most suited for reaching underrepresented groups.
- Develop resources to help sustain cognitive gains, e.g., employer information and referral services, email distribution lists, support groups. Enhance awareness and accessibility of NJ EASE.
- Provide complementary support to the cognitive training offered through this course:
  - Build into this course, or another, information on the progression of prevalent diseases/disabilities, or provide caregivers with more advice on how to obtain this information.
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The evaluation addresses the following questions:

1. Who takes the course? What types of caregivers are they? What is their demographic profile? For whom are they caring? What is the nature of the caregiving relationship? What are the caregivers' work responsibilities, and how have these been affected by caregiving? What are the needs and expectations of caregivers before starting the course? What are their feelings about caregiving and their preparation for it? How do they find out about the course?
2. What do participants think of the course, including content, format, quality of instruction, and ancillary aspects (e.g., facility where offered)?
3. How do course participants perceive and use course content after the course has ended?
4. How do the feelings of participants about being a caregiver change from the beginning to the end of the course? How do they change after they have been away from the course for awhile?

## BACKGROUND

"Caring for You, Caring for Me" has been offered by DHSS since November of 1999. It is one of two courses offered by the Department to caregivers of the frail elderly and disabled. "Caring for You, Caring for Me" is a classroom-based course designed to improve the knowledge base of caregivers. The other course offered by DHSS is an in-home training.

"Caring for You, Caring for Me" was designed by the Rosalyn Carter Institute of Georgia Southwestern State University. The goals of the course are to provide caregivers with knowledge, cognitive skills, and support that will help them to: 1. reduce the adverse emotional effects of caregiving, 2. increase their caregiving capabilities and self-confidence, 3. increase their gain from caregiving, and 4. avoid premature institutionalization of the care recipient. A goal of the course as originally designed by the Carter Institute was to enhance relations between informal and formal caregivers by having both types of caregivers in the class. While providing instruction on building relationships with different types of caregivers, New Jersey has seen the greatest need for the course among informal caregivers and has not emphasized bringing formal caregivers into the class; in fact, only a small number participate.

The course is offered through local agencies that contract with the state. These agencies include health care and long-term care providers, non-profits, and local government agencies. DHSS has trained over 160 individuals specifically for the purpose of teaching “Caring for You/ Caring for Me,” and it is from among these individuals that instructors have been hired. The instructor is employed by the agency and must have expertise in group process, interpersonal skills, and gerontology, as well as course-specific training.

Over a five-week period, the class meets once per week for two hours. Each session is designed to cover a distinct topic. The five topics are:

- What it means to be a caregiver
- Taking care of yourself while caregiving
- Building cooperative relationships with other caregivers
- Preventing and solving problems while caregiving
- Accessing and developing caregiving resources

The course is offered simultaneously in multiple locations around the state. (It is not currently offered in every community in the state.) It is given on a rolling basis; after one course ends, the next begins.

## EVALUATION METHODS

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The course evaluation utilized data on course participants for the period November 1999 to August 2000. Four sources of data were used: 1. The Caregiver Skills Training Participant Questionnaire. 2. The Course Participant Evaluation. 3. The Survey of Caregivers. 4. The Follow-Up Survey. [See Appendix A.]

The first three instruments were administered by DHSS, which provided the data to CSHP. The content of these three datasets was as follows:<sup>1</sup>

1. The Caregiver Skills Training Participant Questionnaire: A written survey designed by DHSS and administered to participants at the beginning of the course. The survey contains descriptive information on: course participants and the individuals for whom they care, the nature of their caregiving relationships, and the caregiver’s work responsibilities and the impact of caregiving on their work. Three hundred and fifty-five of these surveys were completed.
2. The Course Participant Evaluation: An instrument designed by the Rosalyn Carter Institute for the purpose of gathering participants’ opinions on the course. It is administered at the end of the course. This survey was completed by 299 individuals. There were no identifiers on either the Participant Questionnaire or the Participant Evaluation.
3. The Survey of Caregivers: Also designed by the Carter Institute, an instrument that measures respondents’ feelings about caregiving by asking them to “strongly agree, agree, disagree, or strongly disagree” with a series of statements. This survey is administered both at the beginning of the first day of the course and at the end of the last day. Respondents are asked to provide specific information (e.g., first letter of mother’s first name) that creates a confidential identifier, allowing linking of the “pre” and “post” responses; 252 individuals completed the pre-test and 214 the post-test.

Following a review of these instruments and the course curriculum, as well as conversations with the course administrator at DHSS and a representative of the Rosalyn Carter Institute, the Center for State Health Policy designed and administered a Follow-Up Survey. This Follow-Up Survey utilized the same system for creating confidential identifiers that was used in the pre- and post-course Survey of Caregivers, allowing for respondent anonymity and for linking of individuals' responses on the three surveys. The Follow-Up has four main purposes. First, the survey replicates questions from the Course Participant Evaluation about respondents' perceptions of the course; this was done because perspectives may change after one has been away from the course for awhile and had time to learn what one has used. Second, in order to see if there is any change in feelings about and perceived knowledge of caregiving after participants have been out of the course for awhile, the Follow-Up Survey contains the scales for feelings and knowledge used in the Survey of Caregivers. Third, in discussing the course with a staff member from the Rosalynn Carter Institute (RCI), we discovered that a major purpose of the course was to reduce caregivers' feelings of isolation. In addition, our RCI contact suggested that the course might make caregivers feel more comfortable expressing their feelings about caregiving – potentially, in fact, leading them to express more negative feelings about caregiving *after* taking the course! We therefore included in the Follow-Up Survey several items on these topics. Finally, our RCI contact noted that the course's primary intent is to enhance the knowledge base of the participants. The goal is not to solve participant problems in five weeks, but to provide caregivers with new ideas about how to begin to address problems and enhance their quality of life. We recognized that the existing evaluation materials had very little focus on the use of course content (which logically could not be studied without a follow-up survey). Therefore we included several items to assess whether skills and knowledge imparted in the course were remembered, used, and found helpful.

DHSS provided us with the names of 333 individuals who had taken the course during the study period, unfortunately fewer than the 355 who had completed the Participant Questionnaire in that time.<sup>2</sup> We did not have and were unable to obtain addresses for 41 of these 333 people, and Follow-Up Surveys were mailed out to the remaining 292. A reminder letter was sent out and two telephone calls made to increase return. Ultimately, 157 individuals completed the Follow-Up Survey, a 47% rate of response from the original pool of 333. Respondents had finished the course anywhere from two months to two years before completing the Follow-Up Survey, with a median time since course completion of ten months.

Table 1a shows those characteristics of respondents that were collected in comparable ways on the Participant Questionnaire and the Follow-Up Survey, allowing us to get some sense of the representativeness of our follow-up respondents. An age difference (respondents were somewhat older than the original group) was the only notable discrepancy.

The Follow-Up Survey revealed a great deal of change in the lives of course participants since the course had ended. Seventy percent of those responding to the follow-up survey were currently caregiving. However, 18.5% had had to admit a care recipient to a nursing home or similar facility, and 18.5% reported a care recipient passing away. The majority – 61.1% — reported that a care recipient's condition had declined, and only 2.5% that it had improved. Since the time of the course, 8.3% had changed caregiver type, e.g., from being a volunteer to being paid.

The lack of a control group is the primary limitation in this evaluation. Whatever changes in caregiver feelings occur over the span of the course or after cannot necessarily be attributed to the course, but could in fact be a result of the passage of time. However, we have used a cross-sectional analysis of our own sample to test the association between length of time caregiving and feelings about caregiving. Although this approach is limited because of self-selection into the sample, it provides some insight. This issue will be addressed further in the discussion of findings.<sup>3</sup>



**Table 1a: Comparison of Participant Questionnaire and Follow-Up Survey Respondents**

		Participant Questionnaire Respondent Characteristics (n=355)		Follow-Up Survey Respondent Characteristics (n=157)	
		Number	Percent	Number	Percent
<b>Caregiver Type</b>	Informal <sup>1</sup>	294	93.0%	139	89.1%
	Other <sup>2</sup>	22	7.0	17	10.9
<b>Gender</b>	Female	305	86.6	131	86.2
	Male	47	13.4	21	13.8
<b>Age</b>	Under 40	15	4.4	3	2.0
	40 to 64	206	59.9	77	51.0
	65 to 74	74	21.5	42	27.8
	75 to 84	46	13.4	27	17.9
	85 or older	3	0.9	2	1.3
<b>Race/Ethnicity</b>	White	312	89.1	141	93.4
	Black	22	6.3	6	4.0
	Hispanic	9	2.6	3	2.0
	Asian/Other	7	2.0	1	0.7

<sup>1</sup> Could be informal and some other category as well.

<sup>2</sup> Respondents were allowed to designate more than one caregiver type on the Follow-Up Survey. “Other” signifies a respondent who did not check the option for informal. However, as noted in the text, some of these were future or past caregivers who otherwise did not designate type at all.

## **FINDINGS**

### ***Who Are Course Participants?***

#### **Participant and Care Recipient Characteristics**

Information on course participants is taken from the Participant Questionnaire, which provided descriptive information about participants and their caregiving, and which was completed by 355 individuals.

Tables 1a and 1b provide a profile of course participants. They were primarily non-elderly, but more than one-third were over 65. Mirroring the dominance of women as caregivers, the majority were female. The vast majority of participants —89.1%—were White, non-Hispanic, and 6.3% were African-American/Black, non-Hispanic. While we have no statistics on the racial composition of caregivers in the state, we do know that only 68.4% of the general population is White, non-Hispanic, suggesting that, as is common in public programs, minorities have been underrepresented; in particular, 14.7% of the state is African-American.

The working caregiver is an important target population for the program. Again we do not know the percentage of caregivers in the state that work. However, we do know that the program



**Table 1b: Employment Status of Course Participants**

Employment Status (n=324)	Number	Percent
Retired	122	37.7
Full time	99	30.6
Part time	53	16.4
Left due to caregiving	24	7.4
Unemployed	16	4.9
Other	10	3.1

has served a large number of working caregivers. While over one-third of the group is retired and 4.9% are unemployed, 47% are working, two-thirds of these full-time. Notably, 7.4% had to stop working because of caregiving. Caregivers were asked their current or former occupations through an open-ended question. Occupations were, of course, extremely diverse; however, there were concentrations in the positions of educator, administrative assistance, clerk, and nurse (reflecting in part the predominance of females).

Some course participants were taking care of more than one individual. The most common scenarios were informal caregivers assisting two relatives and formal caregivers working with many care recipients. In the former case, our analysis of care recipients reports on the primary (or first-listed) care recipient; in the latter case, we have not reported on any care recipient information.

The majority of course participants were taking care of a relative [See Table 2a.] Half were taking care of their parents and almost 30% were taking care of a spouse. Informal caregivers also took the form of friends or neighbors, who made up 2.5% of participants. While the course was primarily targeted at informal caregivers, 5.1% of survey respondents were professional caregivers and 1.9% were volunteers.

Care recipients were by-in-large elderly, with only 8.1 percent under 65. To a lesser extent than caregivers, they were primarily female. Their racial makeup mirrored that of the caregivers. Half were widowed and most of the remainder married. Most (56.8%) were living with the caregiver, but 7.1% resided in a nursing home, and 29.8% were in their own home or apartment. Interestingly, the number living with the caregiver rises as we move from the middle-aged group to the young elderly, but declines again as we move into the older-old and oldest-old categories, reaching its lowest point (45.3%) for those 85 and older [See Table 2b]. It may be that many who once lived with spouses had lost their spouses at these older ages. This decline in living with the caregiver is not primarily made up by an increase in nursing home use. More than one-third of the oldest-old were living on their own.

Most of the care recipients had one or two diagnoses noted on the Participant Questionnaire [See Table 3]. The most prevalent diagnoses were Alzheimer's disease/senile dementia, arthritis, and heart disease, each of which occurred in about a quarter of the care recipient group. Sensory impairment and stroke were each noted for approximately one-fifth of the cases. Two-thirds of care recipients were reported not to be homebound, although the definition of homebound likely varies from one individual to another.

**Table 2a Comparison of Participant Questionnaire and Follow-Up Survey Respondents**

		Number	Percentage
<b>Relationship of Care Recipient to Care Provider (n=316)</b>	Parent	160	50.6
	Husband	76	24.1
	Wife	17	5.4
	Client (Caregiver is Professional)	16	5.1
	Mother/Father in-law	11	3.5
	Friend/Neighbor	8	2.5
	Other relative <sup>1</sup>	8	2.5
	Sister/Brother	7	2.2
	Client (Caregiver is Volunteer)	6	1.9
	Daughter/Son	5	1.6
	Grandparent	2	0.6
<b>Age (n=321)</b>	Under 40	4	1.2
	40 to 64	22	6.9
	65 to 74	45	14.0
	75 to 84	119	37.1
	85 or older	131	40.8
<b>Gender (n=320)</b>	Female	200	62.5
	Male	120	37.5
Race/Ethnicity (n=318)	White	285	89.6
	Black	19	6.0
	Hispanic	7	2.2
	Asian/Other	7	2.2
<b>Marital Status (n=322)</b>	Widowed	159	49.4
	Married	135	41.9
	Divorced/ Separated	15	4.7
	Never married	13	4.0
<b>Living Situation (n=322)</b>	In caregiver's home/apartment	183	56.8
	In own home/apartment	96	29.8
	In a nursing home	23	7.1
	Other <sup>2</sup>	20	6.2

<sup>1</sup> Other relatives included aunt, uncle, stepparent, sister-in-law, ex-husband, and significant other.

<sup>2</sup> Six individuals were in assisted living. Other places of residence included adult home, hospice, rehabilitation facility, senior residence, in the home of another sibling. One person resided both at the caregiver's home and that of a sibling.

**Table 2b: Care Recipients' Living Situation by Age (n=314)**

	Age									
	Under 40 (n=4)		40-46 (n=21)		65-74 (n=44)		75-84 (n=117)		85 or Over (n=128)	
	N	%	N	%	N	%	N	%	N	%
<b>Residence</b>										
In caregiver's home/apartment	3	75.0	19	90.5	25	56.8	75	64.1	58	45.3
In own home/apartment	1	25.0	1	4.8	10	22.7	32	27.4	50	39.1
In a nursing home	0	0.0	0	0.0	8	18.2	4	3.4	11	8.6
Other	0	0.0	1	4.8	1	2.3	6	5.1	9	7.0

**Table 3: Care Recipients' Diagnoses and Mobility**

		Number	Percent
<b>Number of Diagnoses (n=355)</b>	Zero	33	9.3
	One	111	31.3
	Two	102	28.7
	Three	53	14.9
	Four or more	56	15.8
<b>Prevalence of Diagnosis<sup>1</sup> (n=355)</b>	Alzheimer's disease/dementia	134	37.7
	Heart disease	103	29.0
	Arthritis	98	27.6
	Sensory impairment	80	22.5
	Stroke	70	19.7
	Diabetes	53	14.9
	Parkinson's disease	39	11.0
	Cancer	30	8.5
	Lung disease	20	5.6
	Age	10	2.8
	Developmental disability	9	2.5
	Multiple Sclerosis	8	2.3
	Frailty/decreased endurance	8	2.3
	Mobility problems	8	2.3
	Depression	10	2.8
Other <sup>2</sup>	96	28.0	
<b>Is the Care Recipient Homebound? (n=304)</b>	Yes	102	33.
	No	202	66.4

<sup>1</sup> Will total to more than 100% as respondents could cite more than one.

<sup>2</sup> The most common "other" conditions – age, frailty, mobility problems, and depression – have been added into the table. Others cited by three or more respondents included amputation, hip break/fracture, kidney problems/disease, and osteoporosis.

## **Nature of Caregiving**

Course participants were asked a variety of questions about their caregiving [See Table 4]. Overall, these caregiving relationships were highly intensive. Most respondents were assisting care recipients with a significant number of Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs), the median number being six. Assistance with IADLs was more common than assistance with ADLs. Over half of caregivers assisted with each of the following: transportation, grocery shopping, finances, medications, cooking, and housework. At least one-quarter assisted with every other specified activity.

The length of time respondents had been caregiving varied greatly, with 15.6% caregiving for less than one year, and 8.5% caregiving for more than ten years. Six out of ten had been caregiving for one to five years. Strikingly, 44.0% reported that they provided around-the-clock care and another 26.7% provided care more than once in a day. Only 5.5% provided care less than once a week.

However, most respondents were not entirely alone in their caregiving. Seven out of ten used some sort of paid resources, and almost that same number provided care together with, or with assistance from, other family or friends. In addition to help from family and friends (received by 46.5% and 20.3% of the group respectively), the most commonly used resources were adult day care (15.8%), homemaker/health aides (12.4%), and chore/cleaning services (11.5%).

## **Balancing Caregiving and Work**

8 Table 5 shows the extent to which caregiving interfered with employment activities for informal caregivers, 44.4% of whom were working full-time or part-time. Most drastically, another 7.4% had stopped working because of caregiving. Of those for whom the question was applicable, a quarter reported experiencing conflicts between caregiving and their job very often, and slightly over half reported sometimes experiencing such conflicts. Only 1.0% had never had this experience. Most had missed some work during the previous year because of caregiving, although generally 5 days or less. However, close to four in ten had missed six days or more, and two in ten had missed eleven days or more. Other common forms of employment interference included changing one's work schedule or using leave, vacation, or sick time for caregiving. Respondents were also asked who was assisting or would assist the care recipient while the respondent was at work. About four in ten said a professional would be employed (or the care recipient placed in a community-based or institutional setting) and another third said a family member or friend would step in. However, a striking 23.2% said that the client would have to fend for him or herself.

Informal caregiver respondents were about evenly divided in their awareness of their employer's Family Leave Policy. Fewer than one-in-five, and sometimes far fewer, perceived each of the employer benefits listed on the survey as helpful. The notable exception was information and referral services, which were perceived as helpful by 39.5%. Overall, three-quarters stated that they would be willing to pay something towards such employer benefits.

## **Participants' Needs and Expectations**

There are a number of sources of information about the caregivers' needs and expectations at the beginning the course. In the Participant Questionnaire, caregivers were asked what aspects of caregiving they found most difficult, what would help to make their caregiving more manageable, and why they had enrolled in the course. Respondents were also asked in the Survey of Caregivers to address their feelings about and knowledge of caregiving.

**Table 4: Caregiver Involvement**

		<b>Number</b>	<b>Percent</b>
<b>Number of Activities Caregiver Assists With (n=355)</b>	Zero	34	9.6
	One to three	61	17.2
	Four to six	90	25.4
	Seven to ten	104	29.3
	Eleven or more	66	18.6
<b>Assists with Specific Activities (n=355)</b>	Transportation	246	69.3
	Grocery Shopping	234	65.9
	Finances	228	64.2
	Medications	210	59.2
	Cooking	209	58.9
	Housework	190	53.5
	Supervision	174	49.0
	Grooming	140	39.4
	Dressing	138	38.9
	Bathing	126	35.5
	Walking	124	34.9
	Eating	100	28.2
	Toileting	96	27.0
	Other <sup>1</sup>	42	11.8
<b>Duration of Caregiving (n=295)</b>	Less than one year	46	15.6
	One to two years	78	26.4
	Three to five years	99	33.6
	Six to ten years	47	15.9
	More than ten years	25	8.5
<b>Frequency of Caregiving (n=307)</b>	Around the clock	135	44.0
	At least once per day	82	26.7
	Several times per week	49	16.0
	Twice per week	24	7.8
	Less than once per week	17	5.5
<b>Use of Community Resources (n=355)</b>	Any Paid Resources	275	77.5
	Any Informal Resources	238	67.0
	Family	165	46.5
	Friends	73	20.6
	Adult day care	57	16.1
	Homemaker/Home health aide	46	13.0
	Chore/Cleaning	41	11.5
	Visiting nurse service	29	8.2
	Respite	19	5.4
	Home delivered meals	17	4.8
	Companion	16	4.5
	Paid 24-hour live-in	11	3.1
	Mental health	9	2.5
	Private duty nursing	8	2.3
Other <sup>2</sup>	22	6.2	

<sup>1</sup> Several individuals mentioned assisting with medical/health maintenance, and several with companionship/talking/support. A number of other forms of assistance were mentioned as well.

<sup>2</sup> Hospice and nursing home were the most common "other resources," cited by 6 respondents each.

**Table 5: Employment Interference for Informal Caregivers Who were Employed Full Time or Part Time, or Who Left Work Due to Caregiving (n=147)**

	Number	Percent
<b>Conflicts between caregiving and job (n=118)</b>		
Very often	22	18.6
Sometimes	52	44.1
Rarely	21	17.8
Never	23	19.5
<b>Days of missed work (n=112)</b>		
5 or less	69	56.6
6 to 10	21	17.2
11 or more	22	18.0
<b>Other Employment Interference (n=147)</b>		
Called in sick	32	21.8
Taken personal leave	42	28.6
Changed work schedule	54	36.7
Taken vacation time	40	27.2
Changed hours with employer	14	9.5
Other <sup>1</sup>	7	4.8
<b>Awareness of Family Leave Policy (n=111)</b>		
Yes	58	52.3
No	53	47.7
<b>Perceived Helpfulness of Work Benefits (n=147)</b>		
Reduced hours without loss of benefits	20	13.6
Flexible benefits plan	9	6.1
Flextime	24	16.3
On-site elder daycare center	24	16.3
Job sharing	7	4.8
Info and referral service	58	39.5
<b>Willingness to Pay for Benefits (n=77)</b>		
Yes	59	76.6
No	18	23.4

When asked what aspects of caregiving they found most difficult, respondents most commonly talked about the ways in which caregiving consumed their lives, placing large emotional, physical and time demands on them, and making it difficult for them to attend to other things, including their own needs. Many also described deficiencies in their coping skills, the difficulties of watching the care recipient deteriorate, and the challenges of communicating with the care recipient.

As seen in Table 6, a particular interest of caregivers was in getting information about programs and services. Large numbers were also interested in support groups or in obtaining information about the disability or illness of the person they were caring for and what to expect as it

**Table 6: What caregivers need to make caregiving more manageable (n=355)**

	Number	Percent
Information about disability/illness	140	39.4
Information about programs/services	213	60.0
Caregiver support group	171	48.2
Help negotiating employment issues	22	6.2
Other <sup>1</sup>	54	15.2

<sup>1</sup> The most commonly cited other needs were space/time for one's self, understanding on the part of the care recipient, and another caregiver.

progressed. A number said that they needed more time for themselves and/or the assistance of another caregiver.

Finally, when asked why they had enrolled in the course, about one-third—the largest group—said it was to learn to be a better caregiver, e.g., to understand the care recipients' particular needs. Other common responses included wanting information about resources, having the chance to share with peers, and getting some relief from the emotional stress of caregiving. Formal caregivers were likely to cite their professional development as a motivation.

At the beginning and end of the course, respondents were asked in the Survey of Caregivers to address their feelings about and knowledge of caregiving (and these scales were then repeated in the Follow-Up Survey). Respondents stated whether they “strongly disagree(d), disagree(d), agree(d), or strongly agree(d)” with a series of 13 statements about caregiving. Some of these statements dealt with knowledge about caregiving (e.g., “I know where to find help with problems related to caregiving”) and others with emotions generated by caregiving (e.g., “I find caregiving rewarding”). Some were phrased as positive statements (e.g., “I am comfortable being a caregiver”) and some as negative statements (e.g., “I am ‘burned out’ as a caregiver”). Strong agreement was scored as a 4, agreement as a 3, and so on to 1 for strong disagreement.

Before the course, average ratings for the positive and negative statements among all respondents tended to be around 2.5—between agreement nor disagreement. The lowest score (most disagreement) for a positive statement was 2.28 for familiarity with programs/resources. The highest was 2.91 for “People appreciate my caregiving.” The three negative statements did not range much, with a low average of 2.45 (“I am not well-prepared for caregiving duties”) and a high average of 2.58 (“Caregiving is hard for me”).

In sum, the Participant Questionnaire creates a picture of caregivers who feel overwhelmed by the demands of caregiving, and who want to improve their lives as caregivers and the quality of care they are providing. They see key strategies for doing so as including learning about formal support services, getting support from peers, and learning more about the diseases/disabilities of the care recipients.

### **How Did Participants Find Out About the Course?**

The largest number of respondents (40.6%) found out about the course through a newspaper. Word-of-mouth was also a good vehicle for advising people about the course. Three-tenths of respondents were recommended to the course by somebody, most often a formal caregiver, and 15.9% of the total sample were recommended by somebody who'd taken the course.



## Participant Opinions of the Course

At the last session, participants were asked to rate various aspects of the course in the Participant Evaluation [See Table 7]. These course dimensions received high ratings, with over 90% of participants rating most aspects as excellent or good. The aspect of the course receiving the lowest, but still high ratings, was the number of sessions (rated as excellent or good by 77.9%). Virtually all respondents rated the course overall as excellent or good. As seen in Table 7, there were no notable differences in the views of informal caregivers, formal caregivers, and volunteers.

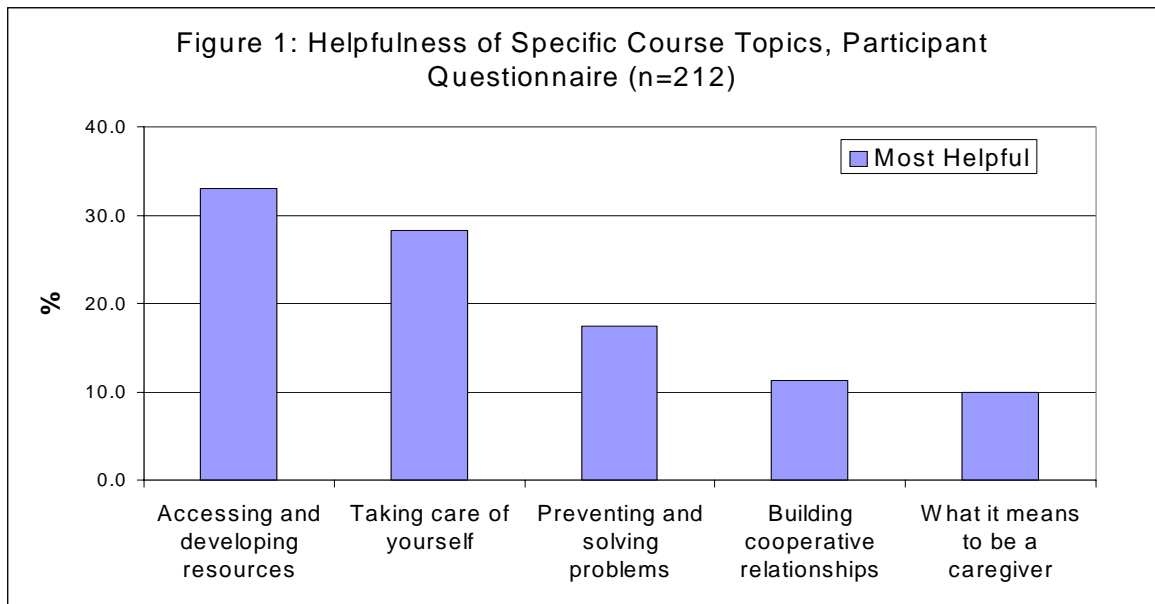
**Table 7: Course Evaluation Rating**

	Caregiver Type							
	All (n=299)		Informal (n=198)		Formal (n=38)		Volunteer (n=26)	
	Excellent/ Good	Percent	Excellent/ Good	Percent	Excellent/ Good	Percent	Excellent/ Good	Percent
Quality of instruction	294	98.3	194	98.0	38	100.0	26	100.0
Material/information presented	291	97.3	190	96.0	38	100.0	25	96.2
Number of sessions	233	77.9	149	75.3	28	73.7	19	73.1
Length of each session	256	85.6	166	83.8	30	78.9	19	73.1
Topics covered	286	95.7	187	94.4	35	92.1	25	96.2
Organization of topics	283	94.6	187	94.4	35	92.1	23	88.5
Facilities	290	97.0	193	97.5	36	94.7	26	100.0
Breaks/refreshments	264	88.3	174	87.9	34	89.5	22	84.6
Convenience of sessions <sup>1</sup>	275	92.0	176	88.9	34	89.5	25	96.2
Overall rating	295	98.7	196	99.0	38	100.0	26	100.0

Figure 1 shows which of the five course topics participants found most helpful in the original Participant Evaluation. “Accessing and Developing Resources” and “Taking Care of Yourself” were the topics deemed most helpful by the greatest number of respondents. Both items correspond to interests and concerns expressed in the pre-course Participant Questionnaire. Only a small number found any of the topics to be “not helpful.” [See Table 8.]

Figure 2 shows which of the five course topics respondents found most helpful at the time of the Follow-Up Survey. Precise comparison of the results from the Participant Evaluation and the Follow-Up are not appropriate, as these do not represent the same group of people. However, a rough comparison highlights an interesting result. While “Accessing and Developing Resources” and “Taking Care of Yourself” are still deemed the most helpful topics, they have switched places rather dramatically, with “Taking Care of Yourself” now considered to be the most helpful topic by the largest number of people—41.5%. It is not surprising that concrete information on community resources would seem most helpful at the time of the course, while techniques for self-care would “prove themselves” when participants had had a chance to use them. The proportions of people finding the topics not to be helpful are not dramatically different in the Follow-Up Survey than in the original Participant Evaluation [see Table 6c]; the biggest changes are for those topics that were rarely selected in the first survey, but the resulting percentages are still small.



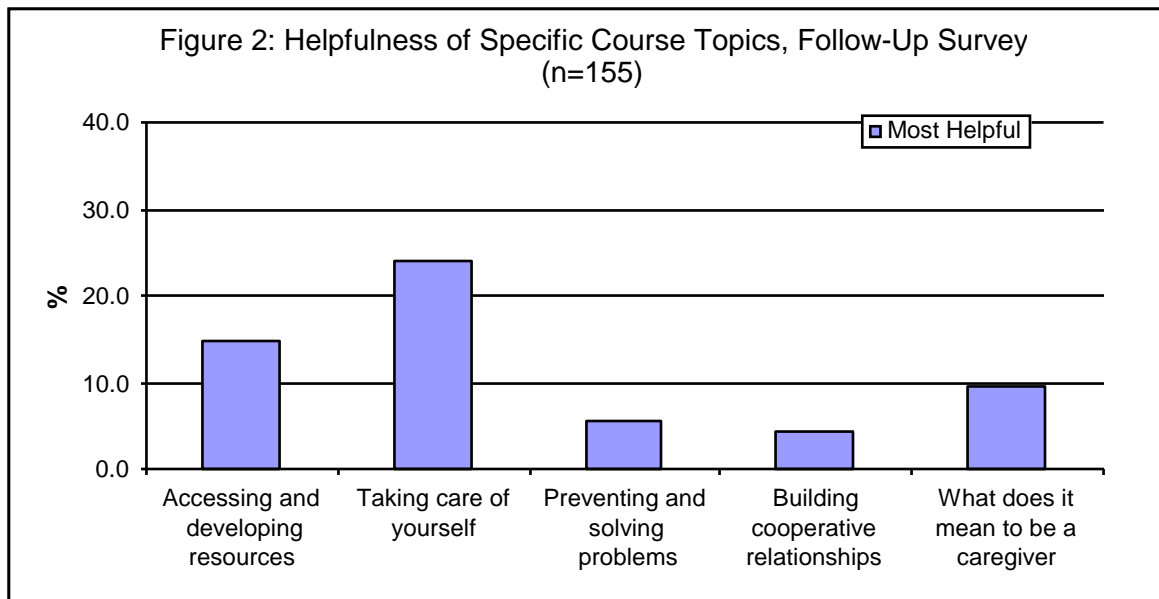


Respondents were also asked to rate the course overall at the time of the Follow-Up Survey<sup>4</sup>. With hindsight, eight out of ten respondents still rated the course as excellent or very good, and another 16.4% rated it as good. None rated it as poor. Additionally, 98.7% of respondents to the Follow-Up Survey said they would recommend the course to a friend. Open-ended questions inviting comment on the course solicited positive comments, as well as disparate suggestions for the course (e.g., more time on specific subjects), none of which showed any dominant patterns.

Another measure of participant interest in the course is attendance, which we inquired about in the Follow-Up Survey. Seven out of ten respondents reported attending all of the sessions, and another one in ten attended four. This is probably an overestimate of course attendance overall, as those willing and able to fill out the survey were also probably those most willing and able to attend class. Nonetheless, it is a strong showing for caregivers whose time is constrained. Not surprisingly, judging by the classes attended by the respondents, attendance was strongest at the beginning of the five-week session, dropped off in the middle, then rose again towards the end.

**Table 8: Topic found to be “not helpful”**

	Participant Evaluation (n=200) Not Helpful		Follow-up Survey (n=157) Not Helpful	
	Number	Percent	Number	Percent
What it means to be a caregiver	21	7.0	12	7.6
Taking care of yourself	8	2.7	11	7.0
Building cooperative relationships	16	5.4	10	6.4
Preventing and solving problems	7	2.3	10	6.4
Accessing and developing resources	5	1.7	5	3.2



### ***Course Impact: Contact with Others, Feelings of Isolation as a Caregiver, and Ability to Express Feelings***

In the Follow-Up Survey, caregivers were asked to indicate their level of agreement with statements about feeling less isolated as a result of the course and feeling more comfortable expressing feelings, also as a result of the course. A score of 1 indicated strong disagreement while a score of 4 indicated strong agreement. Respondents were also asked a number of additional questions about these topics, again on a four-point scale. This time, a score of 1 indicated “Not at all” and a score of 4 indicated “A lot.”

As Tables 9a and 9b show, caregivers on average felt that the course had made them feel less isolated as caregivers and more comfortable expressing their feelings. Interestingly, feeling less isolated did not seem to require continued contact with others from the course or the instructor. On average, respondents reported having only a small amount of ongoing contact with fellow caregivers or the teacher, although in theory they thought it could be of some help. Yet feelings of isolation were reported to have diminished. Not surprisingly, a lack of time or energy was strongly cited as a reason for not maintaining contact (much more so than distance). Another key reason included not having established a connection with anybody in the course or not having much in common with other participants.

### ***Course Impact: Use of Course Materials***

After the introductory session, the course addressed four specific content areas: taking care of yourself, building cooperative relationships with other caregivers, preventing and solving problems, and accessing and developing caregiving resources. For each of these content areas, the Follow-Up Survey asked respondents a number of questions designed to elicit information about how much they believed they had learned at the time of the course, how much they remembered, how much they had used of what they learned, how helpful they perceived the course content to be, and any reasons that they might not have used what they had learned.

Tables 10-13 show that for all content areas, there is a similar pattern, with some small differences of degree. Respondents felt that they had learned a lot about the designated topic and felt that what they had learned was helpful. Average scores went down a little for remembering what they had learned, and a little more for actually using it. This is predictable for short-term

**Table 9a: Feelings of Isolation and Ability to Express Feelings**

Questions/Statements	Mean	SD
As a result of taking the course, I've felt less isolated as a caregiver. (n=153)	3.190	0.582
As a result of taking the course, I've felt more comfortable expressing my feelings about being a caregiver. (n=153)	3.150	0.582

**Scale:** 1 =Strongly Agree 2 =Disagree 3 =Agree 4 =Strongly Agree

**Table 9b: Contact with Others**

Questions/Statements	Mean	SD
Since the course, how much contact have you had with other participants from the class? (n=153)	1.730	0.900
How helpful do you think it is to remain in contact with other class participants? (n=151)	2.720	0.970
Since the course, how much contact have you had with the instructor from the class? (n=150)	1.830	0.990
How helpful do you think it is to remain in contact with the instructor? (n=151)	2.750	0.970
How much does a lack of time or energy make it difficult for you to remain in contact with people from the class? (n=151)	2.970	1.070
How difficult is it for you to remain in contact with people from the class because you live too far away from them? (n=151)	2.190	1.180

**Scale:** 1 =Not at All 2 =A Little 3 =Somewhat 4 = A Lot

instruction. More importantly, the average scores for having actually used what they learned ranged from 2.33 out of 4 (more than “a little”) to 2.92 (“some”). The lowest score was for using techniques to overcoming barriers to accessing resources. The highest was for using self-help techniques. This substantiates the finding that, at the time of follow-up, self-care was commonly perceived as the most helpful topic, and accessing resources had slipped to second place. For all techniques, the data show a lack of time and energy making it difficult for people to employ what they learned, although on average they did so to varying degrees nonetheless.

**Table 10: Taking Care of Yourself while Caregiving**

Questions	Mean	SD
How much did the course teach you about the importance of taking care of yourself? (n=154)	3.61	0.62
How much did the course teach you about how to identify ways that you were and were not taking care of yourself? (n=155)	3.32	0.76
How much did the course teach you about how to take better care of yourself? (n=155)	3.39	0.66
How much do you remember of the techniques you learned in the class for identifying ways in which you are and are not taking care of yourself? (n=149)	2.97	0.85
How much have you used these techniques? (n=153)	2.85	0.79
How helpful do you think these techniques are? (n=153)	3.40	0.73
How much does a lack of time and energy make it difficult for you to use these techniques? (n=151)	3.01	0.91
How much do you remember of the techniques you learned for taking better care of yourself? (n=152)	3.07	0.78
How much have you used these techniques? (n=151)	2.92	0.78
How helpful do you think these techniques are? (n=152)	3.37	0.69
How much does a lack of time and energy make it difficult for you to use these techniques? (n=148)	2.97	0.92

**Scale:** 1 =Not at All 2 =A Little 3 =Somewhat 4 = A Lot

Course instructors were given discretion as to which resources they emphasized in the session on accessing resources. According to the results of the Follow-Up Survey, support groups, books about caregiving, and respite care were the three resources most often presented in respondents' classes. Books and support groups were also the resources that had been used by the most respondents, followed by videos, and then respite. In general there was a gap between the numbers of people seeing a resource as helpful and the number who had used it. This was particularly true in the case of respite; the number perceiving respite as useful was double the number who had used it. All resources were perceived as useful by most respondents with the exception of NJ EASE, which was presented to only half of the respondents, had been used by only one fifth and was perceived as helpful by only one third.<sup>5</sup>

**Table 11: Building Cooperative Relationships with Other Caregivers**

Questions	Mean	SD
How much did the course teach you about the importance of cooperative relationships between different types of caregivers? (n=148)	3.28	0.83
How much did the course teach you about how to build and maintain better relationships between different types of caregivers? (n=148)	3.11	0.87
How much did the course teach you about how to build and maintain better relationships with fellow caregivers like yourself (e.g., if you are an informal caregiver, with other friends and family caring for the same individual)? (n=147)	3.10	0.90
Since the course, how much do you remember of the techniques you learned for improving caregiver relationships? (n=145)	2.95	0.78
How much have you used these techniques to improve your relationships with fellow caregivers like yourself (e.g., informal if you are informal)? (n=145)	2.49	0.99
How much have you used these techniques to improve your relationships with caregivers of different types (e.g., formal if you are informal)? (n=143)	2.48	1.02
How helpful do you think these techniques are? (n=144)	3.23	0.86
How much does a lack of time and energy make it difficult for you to use these techniques? (n=145)	2.81	1.00

**Scale:** 1 =Not at All 2 =A Little 3 =Somewhat 4 = A Lot

***Course Outcomes: Changes Over the Span of the Course and After***

Table 14 shows the average scores on the feeling and knowledge scales before the course, immediately after the course, and at the time of the follow-up survey. Average scores are shown for all respondents at each moment of testing and for the “matched group,” i.e. the individuals who responded all three times. There were sixty of these. Table 15 tests for significant average differences among the scores of the individuals in the matched group for three pairs of moments: pre/post, post/follow-up, and pre/follow-up.<sup>6</sup> Taken together, these point-in-time comparisons allow us to see whether there was a significant change from before the course to after and —if so — whether it was increased, sustained, or reversed by the time of the follow-up.

Three points stand out from Tables 14 and 15. The first is that statistically significant gains were shown from the beginning to the end of the course for all of the knowledge questions except one (“I am not well-prepared for caregiving duties.”) Although there was consistently a small drop

**Table 12: Preventing and Solving Problems while Caregiving**

Questions	Mean	SD
How much did the course teach you about common problems faced by caregivers? (n=150)	3.73	0.53
How much did the course teach you about the importance of using problem solving techniques? (n=151)	3.52	0.65
How much did the course teach you about specific problem solving techniques? (n=150)	3.33	0.77
Since the course, how much do you remember of the techniques you learned for problem solving? (n=148)	2.99	0.79
How much have you used these techniques? (n=149)	2.81	0.86
How helpful do you think these techniques are? (n=146)	3.32	0.81
How much does a lack of time and energy make it difficult for you to use these techniques? (n=145)	2.84	0.94

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**Scale:** 1 =Not at All 2 =A Little 3 =Somewhat 4 = A Lot

in mean scores at the time of follow-up (not surprisingly), statistically significant gain was maintained on all of these dimensions. In fact, respondents' sense of preparation for caregiving duties continued to improve from immediately after the course to the time of follow-up, and the pre/follow-up difference was significant. Thus, the course's main purpose—to change caregivers' knowledge base—seems to have been achieved. Although it is possible that with more time, cognitive gains may have been further reversed, it is equally possible that this is not the case.

Second, in contrast to the perceived changes in cognition, only one significant change was seen from before the course to after in responses to feeling statements. This change, in respondents' comfort in talking about their feelings about caregiving, was not sustained at the time of follow-up. Thus, although respondents elsewhere reported feeling more comfortable talking about caregiving as a result of the course, their objective comfort scores do not show a sustained impact. It seems unlikely that comfort expressing oneself would be fully reversed; this data may instead reflect a more general sense of emotional taxation.

Third, the patterns noted among the matched group are mirrored by the responses of the larger respondent groups, suggesting that these patterns do not reflect anything unique about those who completed all three surveys.

Three possible caveats must be considered to the finding that there is no gain on feeling statements: sample size and the effect of the course on expression of feelings. While a larger sample might show some significant gains in caregiver emotions, it is striking that self-perceived cognition gains are achieved and sustained with the existing sample, while emotional gains are not. One possibility is that actual emotional gains are offset by increased comfort in expressing feelings; in other words, respondents are doing better emotionally than before, but also feel more

**Table 13: Accessing and Developing Caregiving Resources**

How much did the course teach you about community resources you didn't know about? (n=152)	3.45	0.80
How much did the course teach you about how to overcome barriers to using resources? (n=151)	3.26	0.78
How much did the course teach you about how to identify and use your own personal support network? (n=149)	3.17	0.78
How much do you remember about the community resources presented in the course? (n=149)	3.03	0.85
How much have you used these resources? (n=149)	2.45	1.04
How helpful do you think these resources are? (n=145)	3.36	0.89
How much does a lack of time or energy make it difficult for you to use these resources? (n=144)	2.73	1.03
How much do you remember of the techniques you learned for overcoming barriers to using these resources? (n=137)	2.65	0.82
How much have you used these techniques? (n=135)	2.33	0.95
How helpful do you think these techniques are? (n=130)	3.05	0.87
How much does a lack of time and energy make it difficult for you to use these techniques? (n=129)	2.75	1.05
How much do you remember of the techniques you learned for identifying and using your own personal support network? (n=140)	2.82	0.83
How much have you used these techniques? (n=140)	2.56	0.85
How helpful do you think these techniques are? (n=137)	3.13	0.86
How much does a lack of time and energy make it difficult for you to use these techniques? (n=134)	2.75	1.01

**Scale:** 1 =Not at All 2 =A Little 3 =Somewhat 4 = A Lot

**Table 14: Feelings About and Knowledge of Caregiving at Three Points in Time\***

	Mean					
	Pre-Test		Post-Test		Follow-Up	
	Matched Group (n=60)	All (n=252)	Matched Group (n=60)	All (n=214)	Matched Group (n=60)	All (n=150)
I am comfortable being a caregiver.	3.04	2.75	3.10	2.98	2.86	2.80
I know where to find help with problems related to my caregiving.	2.60	2.54	3.14	3.10	3.05	3.09
I am able to solve problems related to my caregiving.	2.68	2.60	3.06	2.96	3.02	3.00
I find my caregiving to be rewarding.	2.85	2.70	2.97	2.88	2.72	2.69
I am not well prepared for my caregiving duties.	2.50	2.45	2.28	2.18	2.19	2.21
I know how to get other people to help me with my caregiving.	2.44	2.35	2.93	2.82	2.83	2.76
I am familiar with programs/ resources to help me with caregiving.	2.33	2.28	3.09	2.99	3.03	3.01
I am “burned out” as a caregiver.	2.45	2.49	2.29	2.31	2.22	2.33
I know where to get information about the problems my family has (or the problems my clients have).	2.33	2.39	3.01	2.98	2.97	2.91
People appreciate my caregiving.	3.10	2.91	3.22	3.09	3.08	3.07
Caregiving is hard for me.	2.54	2.58	2.47	2.51	2.57	2.66
I know how to take care of myself as I care for someone else.	2.65	2.57	3.07	2.97	3.07	2.88
I am comfortable talking with others about my caregiving.	2.97	2.90	3.27	3.19	3.18	3.09

\*N's represent the maximum possible sample. Because of item non-response, n's for specific items will vary. For the matched group, n's range from 53 to 60. For the complete pre-test sample, they range from 242 to 251. For the post-test complete sample, they range from 209 to 213. For the complete follow-up sample, they range from 140 to 151.

**Scale**

1 =Strongly Agree      2 =Disagree      3 =Agree      4 = Strongly Agree



**Table 15: Test of Average Differences From Before Course to Immediately After to Follow-Up**

	Group Differences (Post-hoc Procedures)		
	Pre/Post Difference	Post/Follow-Up Difference	Pre/Follow-Up Difference
<b>Knowledge-Based Statements</b>			
<b>Positively-worded statements</b>			
I am familiar with programs/ resources to help me with caregiving (n=57)	0.76 *	- 0.06	0.70 *
I know where to get information regarding problems (n=54)	0.68 *	- 0.04	0.64 *
I know where to find help with problems related to caregiving (n=57)	0.54 *	- 0.09	0.45 *
I know how to get people to help me with caregiving (n=58)	0.49 *	- 0.10	0.39 *
I know how to take care of myself while caregiving (n=59)	0.42 *	0.00	0.42 *
I am able to solve problems related to caregiving (n=57)	0.38 *	- 0.04	0.34 *
<b>Negatively-worded statements</b>			
I am not well prepared for caregiving duties (n=56)	- 0.22	- 0.09	- 0.31
<b>Feelings-Based Statements</b>			
<b>Positively-worded statements</b>			
I am comfortable talking with others about caregiving (n=60)	0.30 *	- 0.09	0.21
I find caregiving rewarding (n=59)	0.12	- 0.25 -	0.13
People appreciate my caregiving (n=60)	0.12	- 0.14 -	0.02
I am comfortable being a caregiver (n=56)	0.06	- 0.24 *	- 0.18
<b>Negatively-worded statements</b>			
Caregiving is hard for me (n=60)	- 0.07	0.10	0.03
I am "burned out" as a caregiver (n=53)	- 0.16	- 0.07	- 0.23

\* indicates significance at the .05 level

comfortable expressing things that bother them. However, it seems unlikely that this would affect only the feeling statements and not the self-perceived knowledge statements. A third possible caveat is that without the course, emotional well-being might have declined, i.e., that the lack of a decline is itself a gain. Unfortunately, it is difficult to know whether this is the case. The literature on caregiving interventions shows variation among control groups in the trajectory of their well-being (with well-being usually static or declining). Studies also vary in the tools used, time periods involved, and baseline levels of emotional difficulties.

A related concern for the analysis overall was whether changes in feelings or self-perceived knowledge might be due simply to the passage of time or length of time caregiving, rather than to the intervention of a course. To test this proposition, we conducted a cross-sectional analysis of the original respondents to the Survey of Caregivers, testing for an association between the length of time they had been caregiving and their responses to the scales. Two items showed an association with length of time caregiving. “I am comfortable being a caregiver” was positively associated with length of time caregiving, and “Caregiving is hard for me” was negatively associated with length of time caregiving. In both cases, the correlation coefficients suggested only a small effect of time on response to these items, and these items showed no different pattern on the point-in-time comparisons than the others. Self-selection makes the cross-sectional analysis less than ideal. However, the consistent pattern of the evaluation findings (cognitive not emotional gains) and their conformity to course content suggests that the gains are likely attributable to the intervention.

An additional concern was whether former course participants might lose increasingly more of their gain with more time away from the course. If this were true, a later survey might find a significant drop in gain for respondents overall. To examine this possibility, we tested for a correlation between length of time out of the course and the change in scores from post-course testing to testing at time of follow-up. We did not find a statistically significant relationship between time out and the post/follow-up score change for any of the scale items. In all but one case, however, there was a trend in the expected direction. It is possible, therefore, that with a larger sample or longer times out of the course, we may have found a significant correlation. In sum, the data suggest that there *may* be greater loss of gain the longer that caregivers are away from the program, but we cannot at this point provide real evidence to that effect.

## CONCLUSIONS AND RECOMMENDATIONS

The course evaluation paints a very positive picture of the “Caring for You, Caring for Me” course. Course participants were generally in intensive caregiving situations. By every indicator, the course was highly valued by participants. Furthermore, course participation appears to be associated with increased confidence in knowledge about caregiving and a decreased sense of isolation. There were no consistent concerns about the course among any sizable group of respondents. However, the course was designed to be part of a larger strategy of caregiver support, and this approach is supported by the data.

### ***Course Participants***

Course participants were primarily non-elderly, although one-third were over 65. Most were caring for a relative. Most were female, and the vast majority were White; minorities appear underrepresented in the program. Working caregivers were a sizable part of the population.

Care recipients were by-in-large elderly, mostly female, and predominantly White. Most were living with the caregiver, but many oldest-old were on their own. The most prevalent diagnoses for care recipients were arthritis, Alzheimer’s Disease/senile dementia, and heart disease.

Caregiving relationships were highly intensive, with half of course participants assisting with six I/ADLs or more. Most caregivers had been providing care for one to five years, and seven out of ten provided care around-the-clock or more than once a day. However, most respondents had the assistance of paid resources, family or friends, or both.

More than three-quarters of those who were working experienced conflicts between caregiving and their job “sometimes” or more often, with 7.4% of respondents having stopped working because of caregiving. One-in-four respondents said that when or if they were at work, the care recipient would be without assistance. Information and referral services were the only employer caregiving benefit that was perceived as useful by a significant number of people.

Caregivers felt extreme physical, emotional, and time demands from caregiving. They wished to improve their lives as caregivers and the quality of care they were providing. They saw key strategies for doing so as including learning more about formal support services, getting support from peers (in the class and in support groups), and learning more about the diseases/disabilities of the care recipients.

### ***Participant Opinions of the Course***

The course was highly regarded by participants and none of the topics were deemed “not helpful” by any sizable number of respondents. “Accessing and Developing Resources” and “Taking Care of Yourself” were considered to be the most helpful topics both immediately following the course and at the time of the follow-up, although they had switched places, with “Accessing and Developing Resources” dropping to second place rather dramatically. This change was substantiated by the data on use of course materials. This may reflect the fact that concrete information may be immediately valued while tools will only be valued once applied.

### ***Course Impact: Contact with Others, Feelings of Isolation as a Caregiver, and Ability to Express Feelings***

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Feelings of isolation as a caregiver were reported to have diminished as a result of taking the class. This did not apparently require ongoing contact with fellow caregivers or the teacher. Although in theory respondents thought contact could be of help, they were unlikely to have had much, usually because of a lack of time or energy. Respondents also believed they felt more comfortable expressing their feelings as a result of taking the course.

### ***Course Impact: Use of Course Materials***

For all course content areas there was a similar pattern in use of course materials. Respondents felt that they had learned a lot about the designated topic and that what they had learned was helpful. Average scores went down a little for remembering what they had learned, and a little more for actually using it. Average scores for how much respondents had used the course content ranged from more than a little to some, despite the fact that lack of time and energy were considered barriers to employing what they had learned. Techniques for overcoming barriers to accessing resources had been used least and self-help had been used most. This conforms to the fact that at the time of follow-up, self-help was perceived as the most helpful of the course topics, whereas at the course’s end it had been accessing resources.

### ***Course Outcomes***

Statistically significant gains were shown from the beginning to the end of the course for all of the knowledge questions in the “Survey of Caregivers” scales except one (sense of preparation for caregiving). Despite some movement towards reversal by the time of follow-up, progress was maintained at a statistically significant level for all items. In fact, sense of preparation for caregiv-

ing duties continued to improve from immediately after the course to the time of follow-up, achieving a statistically significant improvement relative to the pre-course testing.

In contrast, emotional gains were not registered at statistically significant levels. While comfort talking with others about caregiving improved from before the course to immediately after, and while caregivers felt that the course had improved their comfort levels, the gain was reversed and significance lost at the time of follow-up.

### ***Recommendations***

- Examine reasons for underrepresentation of racial/ethnic minorities in the course. Newspapers and personal networks have thus far been the best vehicles for bringing people to the course. Consider additional newspapers, provider networks, places of worship, etc. for inclusion in outreach, with attention to those outlets most likely to reach underrepresented groups.
- Develop resources to help sustain cognitive gains, e.g., employer information and referral services, email distribution lists, support groups. Enhance awareness and accessibility of NJ EASE.
- Provide complementary support to the cognitive training offered through this course:
  - Build into this course, or another, information on the progression of prevalent diseases/disabilities, or provide caregivers with more advice on how to obtain this information.
  - Expand resources to address the emotional needs of caregivers, such as: 1) respite care and 2) mechanisms of peer support, e.g., support groups and email discussion groups.

## ENDNOTES

- <sup>1</sup> Differences in sample size for the first three surveys may be attributed to course attrition, course absences, administrative problems, or other factors.
- <sup>2</sup> A possible explanation is that some individuals quickly withdrew from the course.
- <sup>3</sup> The literature on this topic shows mixed results.
- <sup>4</sup> This rating was on a five-point scale (excellent, very good, good, fair, poor), rather than a four-point scale.
- <sup>5</sup> There were a large number of missing responses to the questions about NJ EASE, perhaps reflecting a lack of familiarity with the name. Percentages are reported with missing excluded from the denominator.
- <sup>6</sup> The statistical test employed here is based on the differences from one testing point to the next for the scores of each individual respondent.



## **APPENDIX A**

### **SURVEY INSTRUMENTS**