

THE CAREGIVING BOOM: BABY BOOMER WOMEN GIVING CARE

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KEY FINDINGS

In the spring of 1998, the National Alliance for Caregiving, with funding from the Equitable Foundation, conducted a national survey of Baby Boomer women caregivers to find out how the experience of caregiving changed their own planning for long term care. They were asked questions about caregiving information they had sought and would have liked and financial and services planning for their own long term care. These 267 women, ages 33 to 51, had previously identified themselves as caregivers during a national random digit dial telephone survey, reported as “Family Caregiving in the US,” by the Alliance and AARP.

CAREGIVING SITUATION

- Only half of the respondents are still providing care to an elderly person, approximately 18 months after this group of caregivers had been previously surveyed. Referring to the last twelve months in which they provided care, respondents report spending an average of 22 hours per week giving care, although four in ten provide ten hours or less.
- Among current caregivers, a third finds the situation easier than it was a year ago, and a third finds it more difficult. One-half of the past caregivers feel the situation became more difficult during the last twelve months of the caregiving relationship.
- Caregivers say that half of the care recipients use paid services. These services are usually paid for by the care recipient’s own funds, through Medicare or Medicaid, or by private health insurance.
- One-half of the respondents do not feel any financial hardship as a result of providing care to an elderly person, but one in five feels a strong financial hardship.

INFORMATION SOUGHT: SOURCES AND CONTENT

- The large majority of respondents report seeking information from at least one source in the past year, and nearly half says they contacted three or more sources.
- More respondents report seeking information from health professionals such as doctors and nurses than any other source, but many also say they contacted friends, relatives or other caregivers for information. More than half of the respondents report contacting each of these types of sources.
- Although significantly fewer caregivers contact other sources, several sources including hospital discharge planners, libraries or bookstores, social service organizations and organizations dealing with specific diseases are tapped by at least one in six caregivers.
- The respondents say they find health-related information to be most valuable, including what to expect with a particular disease or how to administer medical treatments. They also value information on how to provide basic care.

HELPFULNESS OF INFORMATION

- Three-quarters of caregivers report that information about how to deal with the stress of giving care or how to balance caregiving with work and family would be very helpful. Nearly as many would also consider information about facilitating caregiving to be helpful, including evaluating services for in-home health or daily living.

INFORMATION CHANNELS

- More caregivers say they would like to receive important information about caregiving by reading than any other information channel. Nevertheless, over half would like to receive information by television or videotape, and similar proportions would like to get information in a phone conversation or in a face-to-face meeting or presentation.

CAREGIVER'S FUTURE

- Over half of the caregivers feel relatively unprepared for their own possible long term care. That is, they feel only *a little* or *not at all* prepared. Only six percent feel *very well* prepared, and 42 percent feel *somewhat* prepared.
- Caregivers report thinking more about saving money to meet their needs as a result of their caregiving experience. They also think about the adequacy of their insurance and the need to plan.
- Over one-third of the caregivers say they have taken some specific actions to plan for their own possible long term care, mostly by increasing their investments or by obtaining more insurance.
- Thinking ahead to the information they will need about long term care, more respondents name a health professional as the most valuable source than any other.
- Although only three percent say a financial advisor would be the most valuable source of information, one-quarter says financial information would be the most valuable type of information to help them prepare for their own possible long term care.
- The respondents believe that their own long term care will be paid by private insurance, savings and investments or government insurance such as Medicare or Medicaid.

INTRODUCTION

In Spring 1998, the National Alliance for Caregiving, a nonprofit organization focused on support for family caregivers of the elderly, received a major grant from the Equitable Foundation to survey Baby Boomer women who are caring for elderly relatives or friends. The objectives of the survey were to learn about the types and sources of information that would be useful to these caregivers and to determine how the experience of caregiving influences planning for one's own long term care. The survey results will be the basis for developing an educational tool that will be disseminated through women's organizations and employer human resource groups.

The women caregivers surveyed in this study are a subset of participants in the National Caregiver Survey conducted 17 months ago. The results from that survey were published by the National Alliance for Caregiving and the American Association of Retired Persons in a 1997 report entitled "Family Caregiving in the U.S.: Findings from a National Survey." The sample for this study included all the prior study participants who are female, Baby Boomers between the ages of 33 and 51, currently serve as caregivers or did so within a year of the earlier survey, and expressed a willingness to participate in future caregiving research.

Of the 438 women who met these criteria, 267 completed interviews for this study. Only 39 did not wish to participate, and several others participated in a survey pre-test. For most of the rest, the phone numbers were no longer valid, and there were some numbers where no one could be reached.

The study was designed by project consultants Dr. Neal Cutler and Dr. John Migliaccio, and Gail Hunt of the National Alliance for Caregiving, with assistance from Matthew Greenwald and Associates and conducted by Mathew Greenwald & Associates. Information was gathered through ten-minute telephone interviews conducted by trained professional telephone interviewers in January 1998.

The margin of error for this study (at the 95% confidence level) is plus or minus approximately eight percentage points. Responses for particular subgroups will have larger margins of error, depending on the size of the subgroups. All differences between subgroups that appear in this report are statistically significant.

* * *

The National Alliance for Caregiving is a new non-profit consortium of 14 national groups focused on support to family caregivers of the elderly. The Alliance conducts research, develops national programs and works to increase public awareness of family caregiving issues.

The Equitable Foundation, Inc., is the philanthropic arm of The Equitable Life Assurance Society of the United States, New York, NY 10019. Support for this study is part of The Foundation's ongoing commitment to address social issues affecting Equitable's clients, investors, employees, and agents, as well as the general public. As a provider of insurance products and asset management for financial security and retirement savings, Equitable helps people plan for the future, maximize the quality of their lives and manage their responsibilities toward those who depend on them.

PROFILE OF SURVEY RESPONDENTS

As expected, the profile of this study's respondents closely mirrors the profile of all Baby-Boomer female caregivers in the prior study.

More respondents are caring for their mother or mother-in-law than any other family relation or acquaintance; one-third names their mother as the care recipient (35%) and an additional 10 percent name their mother-in-law. Fourteen percent name their father or father-in-law as the care recipient, another fourth cares for some other relative (25%) and the rest take care of someone who is not a relative (16%).

About four in ten respondents have a high school education or less (39%), one-quarter has some college (26%), two in ten have graduated from college (21%) and another one in ten (9%) has gone to graduate school. A small proportion has attended technical school or some other type of school (4%).

The respondents' household incomes are evenly distributed across a moderate range, with two-tenths having household incomes under \$20,000 (21%), about a third reporting a household income ranging from \$20,000 to \$39,999 (31%), another third reporting between \$40,000 and \$75,000 (33%) and nearly one in ten reporting \$75,000 or more in household income (8%).

Two-thirds of the respondents are married (68%), twenty percent are separated, divorced or widowed, and one-tenth have never been married (11%).

About one-third of the caregivers are 33 to 39 years of age (33%), slightly fewer are between the ages of 40 and 44 (29%), and the remaining 37 percent are between the ages of 45 and 51.

Four in ten are non-Hispanic whites (39%), three in ten are non-Hispanic blacks (29%), two in ten are Hispanic (21%) and one in ten is Asian (12%). The relatively balanced racial/ethnic composition of the respondent group is due to the use of quotas to ensure racial and ethnic representation in the prior study.

Table 1: Profile of Survey Respondents Compared to All Baby Boomer Female Caregivers in Prior Study

	1998 Respondents (n=267)	1996 Baby Boomer\ Female Caregivers (n=524)
Relationship of Care Recipient to Caregiver		
Mother	35%	38%
Non-relative/friend	16	15
Father	11	11
Grandmother	10	10
Mother-in-law	10	11
Aunt/Uncle	7	6
Father-in-law	3	3
Spouse	2	2
Other relative	6	4
Education:		
Less than high school graduate	8%	7%
High school graduate	31	32
Some college	26	25
Graduated college	21	23
Graduate school	9	9
Technical school/other	4	3
Refused	2	1
Household Income:		
Less than \$10,000	6%	8%
\$10,000 - \$19,999	15	15
\$20,000 - \$29,999	16	16
\$30,000 - \$39,999	15	14
\$40,000 - \$49,999	12	10
\$50,000 - \$74,999	21	17
\$75,000 or more	8	12
Don't know/refused	7	8
Marital Status:		
Married	68%	69%
Separated, Divorced, Widowed	20	20
Single, Never Married	11	11
Age:		
33 to 39 years	33%	34%
40 to 44 years	29	30
45 to 51 years	37	36
Race/Ethnicity:		
White Non-Hispanic	39%	42%
Black Non-Hispanic	29	24
Hispanic	21	20
Asian	12	15

DETAILED FINDINGS

CAREGIVING SITUATION

Current Caregiving Status

Seventeen months after the first survey of caregivers was conducted, over half of the caregivers are no longer providing care to an elderly person (53%). These respondents were asked to refer to their last twelve months of caregiving during the interview, while those who were still giving care were asked to refer to the immediate past twelve months. Of those who were no longer caregivers, one-quarter had cared for someone for less than a year (24%), half had given care for at least one year but less than five (50%), while a quarter gave care for five years or more (26%).

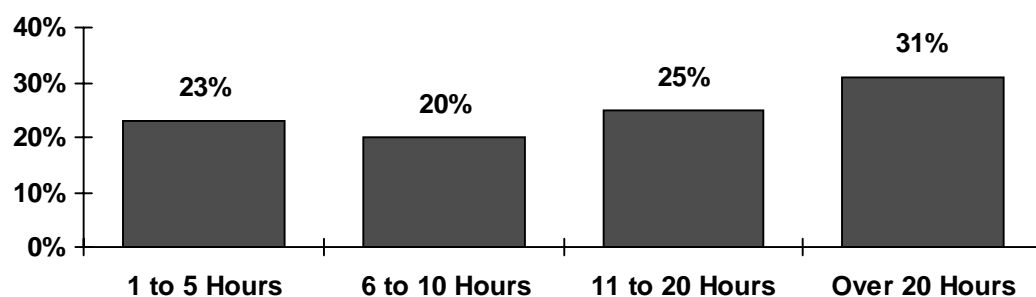
Time Spent Giving Care

Overall, respondents report spending an average of 22 hours per week providing care to their elderly relatives or friends, although there is quite a bit of variation in the amount of time spent. As Figure A shows, about one-fifth spends between one and five hours per week (23%) and a similar proportion spends between six and ten hours per week (20%). One-quarter spends between eleven and twenty hours per week giving care (25%) while three in ten spend over twenty hours per week (31%).

Figure A: Time Spent Giving Care

On average over the past year, how many hours per week did you spend giving care?

(n=267)



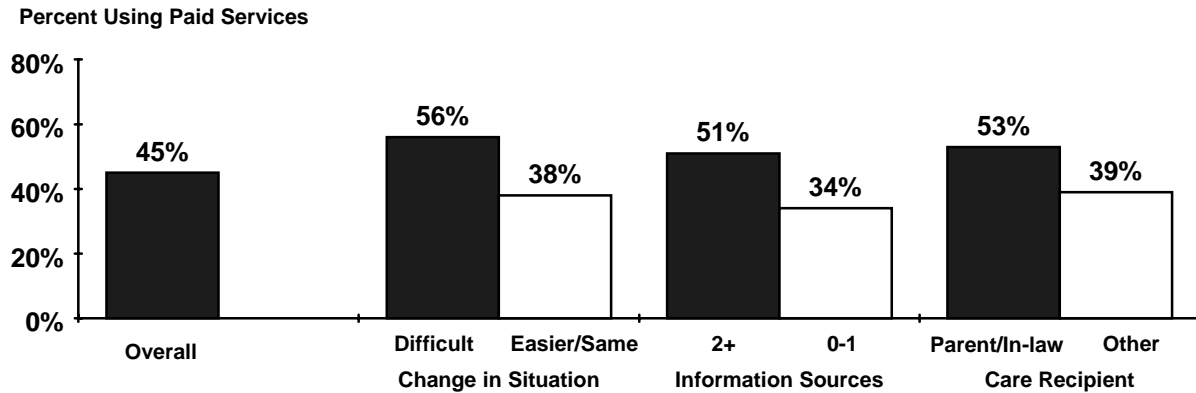
As one might expect, the respondents who say their caregiving is easier than it was twelve months ago are more likely to report spending one to five hours giving care, while those whose caregiving is more difficult are more likely to report spending over twenty hours giving care. Similarly, the caregivers who do not feel any financial hardship report spending less time giving care than those who do feel financial hardship (an average of 17 hours vs. 27 hours). The respondents who do not name themselves as one of the people most involved in making decisions about the recipient's care also spend less time giving care compared to those who do name themselves as a key decision maker (an average of 15 hours vs. 28 hours).

Change in Caregiving Situation

When asked how the caregiving situation has changed in the last twelve months of their caregiving, the responses of those who are currently providing care are different from those who are no longer providing care. [See Figure B.] About three in ten respondents among both current and past caregivers say the situation is *much* or *somewhat easier* (33% vs. 30%), but current caregivers are much more likely than past caregivers to say the situation is *about the same* (37% vs. 20%) and they are less likely to say that the situation is *more* or *much more difficult* (30% vs. 50%). Those who are no longer giving care are especially likely to say that the last twelve months were *much more* difficult. This may reflect a worsening of the condition of care recipients, leading to the end of the caregiving relationship—perhaps due to a move to a specialized facility or the death of the care recipient.

Figure C: Use of Paid Services

Did the care recipient use any paid services during the last 12 months? (n=267)



The most important sources of funds used for paying for these services are the care recipient's own personal funds (34%), Medicare (30%), Medicaid (13%) and private health insurance (10%). A very small percentage mentions Veteran's administration benefits, the caregiver's personal funds or the funds of other friends and relatives (3% each).

One-half of the respondents say that providing care for an elderly person has not caused them any financial hardship (51%). About a third reports a moderate level of hardship indicated by ratings of two to three on a five-point scale (32%) and the remaining 17 percent report a high level of hardship (a rating of four to five).

The respondents who provide care for ten hours or less and those whose caregiving situation has become easier in the past year are more likely to report feeling no financial hardship. So are those who do not name themselves as involved in important decisions regarding the care and those people who sought information at less than two sources.

Comparing this survey's findings on financial hardship to results from an identical question asked in the survey 17 months ago, one-third feels an increased financial hardship (34%), half feels no change (50%) and thirteen percent feel less. Caregivers who spend eleven or more hours a week giving care and people who sought information from two or more sources are more likely to report an increased level of hardship.

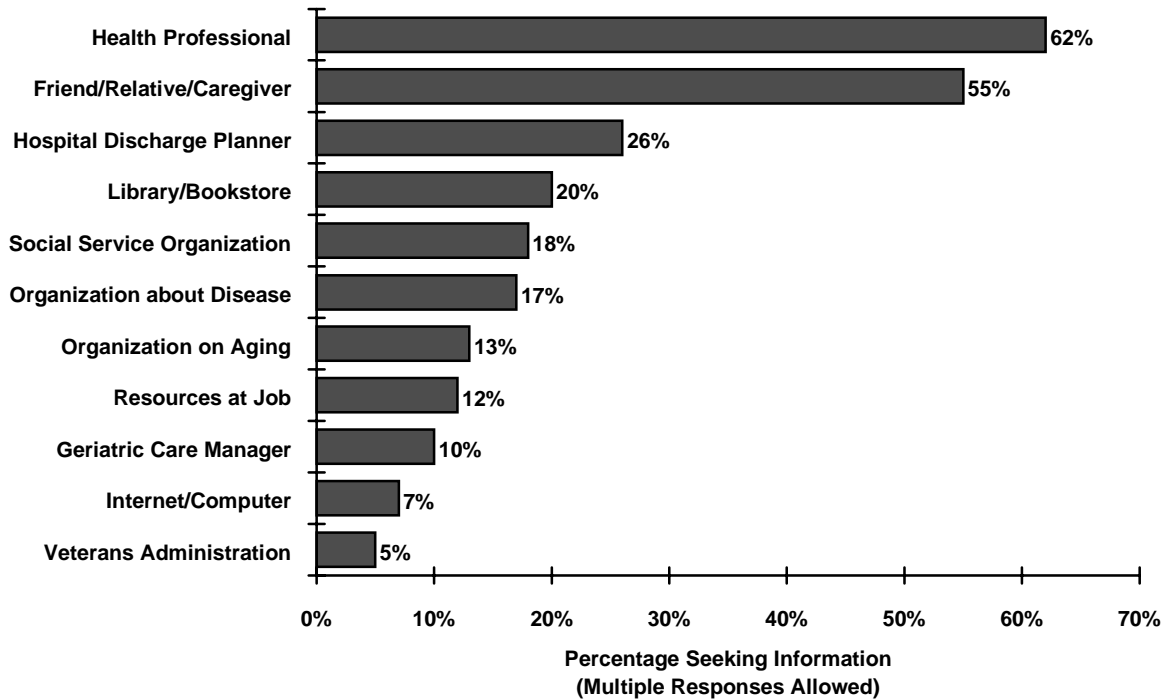
INFORMATION SOUGHT: SOURCES AND CONTENT

Through a series of questions, respondents were asked whether or not they sought information on caregiving during the past year from any of eleven specific sources including health professionals, health or social services organizations, and other organizations or individuals. On average, respondents report seeking information from two to three sources. The large majority reports seeking information from at least one of the sources (82%), with one-third seeking information from one or two sources (34%), another third contacting three or four sources (33%) and 14 percent contacting five or more sources.

As Figure D illustrates, more respondents report seeking information from a health professional such as a doctor or nurse (62%) than any other source of information. Many care providers also say they sought information from a friend, relative or other caregiver, with over half reporting that they had done so in the past year (55%). Respondents do not contact any of the other information sources to nearly the same degree. One-quarter says they sought information from a hospital discharge planner (26%) and roughly one-fifth each reports looking for information in a library or bookstore (20%), a social service organization (18%) and an organization that specializes in a particular disease (17%).

Figure D: Information Sources Contacted

Over the past year, did you seek out any information about caregiving from ... (n=267)



Past caregivers are more likely than current caregivers to have contacted health professionals while there is no such difference for any other information source. This may signal that the care recipient’s health became an issue prior to the end of the caregiving relationship. Respondents who provide eleven or more hours of care per week, those who use paid services and those who feel some degree of financial hardship are also more likely to have sought information from a health professional.

Ironically, respondents whose caregiving situation is *about the same* as a year ago report seeking information from fewer sources than those whose situations are either *easier* or *more difficult*.

The respondents who have taken some specific actions to plan for their own possible long term care report seeking information from a greater number of sources than those who have not. In particular, they are more likely to have sought information from a health professional, a library or bookstore, resources at their job, the internet or a computer program and the veterans administration.

Respondents who use paid services for the care recipient report seeking information from particular sources more often than those who do not use paid services. Specifically, those who use paid services are more likely to have sought information from a health professional (71% vs. 55%), a social service organization (26% vs. 12%), an organization dealing with a specific disease (22% vs. 12%), an organization on aging (19% vs. 8%) and a geriatric care manager (15% vs. 6%).

When asked what the most valuable piece of information they obtained is, many caregivers cite information about a disease, such as what to expect, the stages of the disease, how to care for someone with the disease and so on; one-quarter says this type of information is the most valuable (27%). About half as many respondents say information about basic care is the most valuable, including information on feeding or bathing care recipients, keeping them comfortable or helping them move around (13%). Seven percent each cite information about medication, in-home services and how the caregiver can act. [See Table 2.]

Table 2: Most Valuable Information

What was the most valuable piece of information you obtained? (n=218)

Most Frequent Responses:

Information about disease: Stages of disease, care, treatment	27%
Basic care: Feeding, bathing, moving around, keeping comfortable, safety	13
Medication: Drug interaction, how to administer, use of IVs or oxygen	7
In-home services: Someone to come in during the day, full-time care	7
How caregiver should act: patience, understanding, managing my own time	7
Understanding the patient: what they are going through, depression	5
Financial and health benefit information	5
Support and information for caregiver	5

Consistent with other results, the respondents who are not currently providing care are more likely to find information about a disease most valuable. Younger respondents, age 33 to 41, are also more likely to value this type of information. Those who say the caregiving situation has become more difficult in the past year are more likely to say information on in-home care was the most valuable.

Since so many respondents cite information related to health or medical treatment as the most valuable, it is not surprising that nearly one-half also say that the most valuable information came from a doctor, nurse or hospital (45%). More than one in ten says that it came from a friend, relative or caregiver (14%) or a health/human services organization (12%). Small numbers also cite a person or organization that provides caregiving services (8%), a book or library (6%) or a government organization (6%) as valuable information sources. All other sources are named by no more than two percent of the respondents.

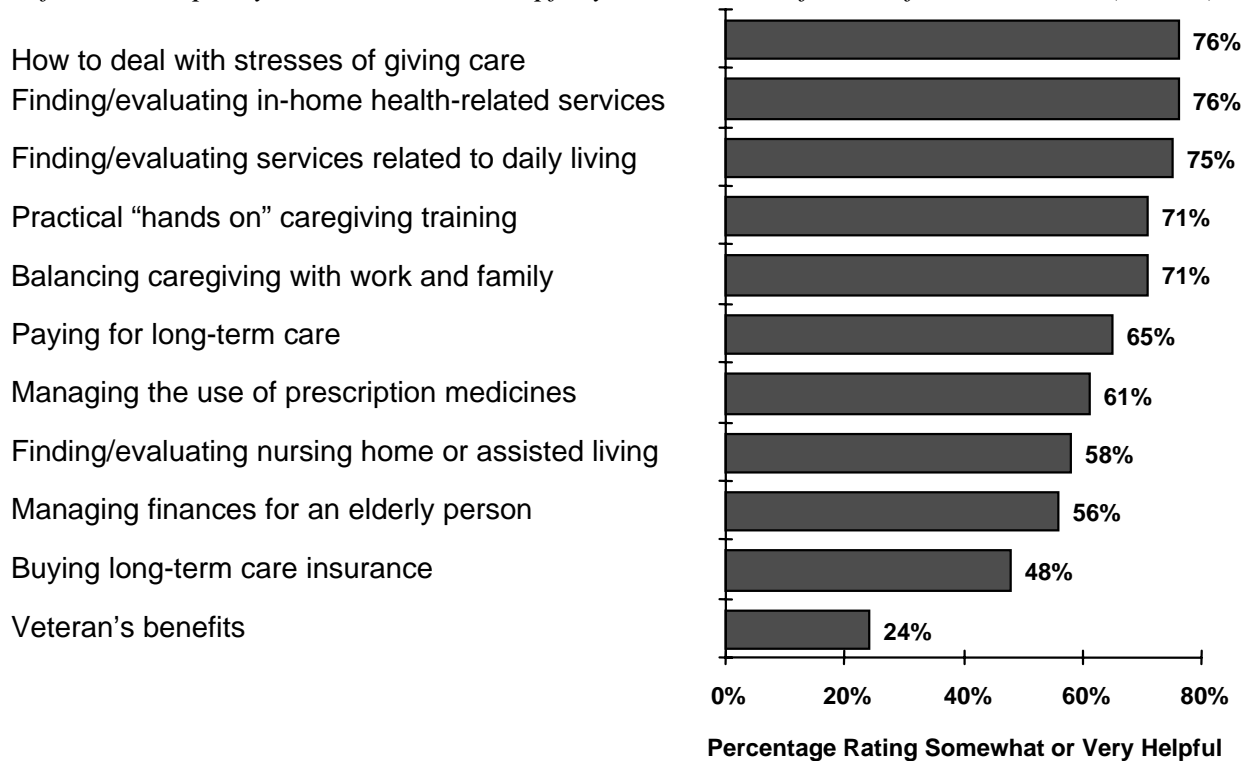
HELPFULNESS OF INFORMATION

Another section of the questionnaire asked respondents how helpful they would have found information on each of eleven topics during the past year. The five topics they rate as most helpful all relate to facilitating caregiving in the home or reducing stress related to it; seven in ten respondents rate each of five topics as *somewhat* or *very helpful*. Relating to stress reduction, they would find information about how to deal with the stress of giving care helpful (76%) as well as information on balancing caregiving with work and family (71%). Relating to facilitating caregiving, they would like to know how to find and evaluate both in-home health-related services (76%) and services related to daily living (75%), or have information about practical “hands on” caregiving training (71%). [See Figure E.]

Several other types of information about which they were asked would also be helpful to caregivers. Over six in ten say that information on paying for long term care or managing prescription medicines would be helpful to them (65% and 61% respectively). Over half say information on finding and evaluating nursing homes or assisted living facilities would be helpful (58%), as would information about managing finances for an elderly person (56%). Nearly half would like information on buying long term care insurance (48%). About one-quarter is interested in information on veteran’s benefits (24%).

Figure E: Helpfulness of Information

Reflect on the past year and rate how helpful you would have found information on... (n=267)



In general, three subgroups of respondents are more likely to say that the various types of information would be helpful to them: (1) those who report seeking information from two or more sources in the past year, (2) those who feel some financial hardship in their caregiving relationship and (3) those who use paid caregiving services.

One-fourth of the respondents also think information on some other subject would be helpful (25%). The topics they mention most often are transportation or meal services for the elderly (17%), finances such as social security benefits, pensions and funeral costs (14%) and information about diseases (12%).

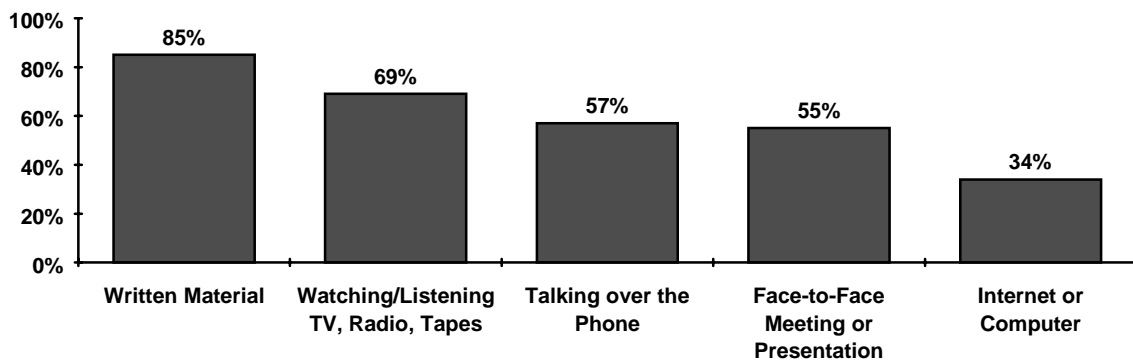
INFORMATION CHANNELS

The large majority of caregivers say they would like to receive important information about caregiving by reading some kind of written material (85%). Over two-thirds would like to receive it by watching or listening to television, radio or tapes (69%). Over half would like their information in a phone conversation (57%) or a face-to-face meeting or presentation (55%). Only one-third says they want to receive information on the internet or using the computer (34%). [See Figure F.]

Not surprisingly, younger caregivers are more likely than older ones to say they like receiving information on the Internet or the computer. Users of paid caregiving services are more responsive to face-to-face and telephone communications than those who do not use paid services.

Figure F: Preferred Information Channels

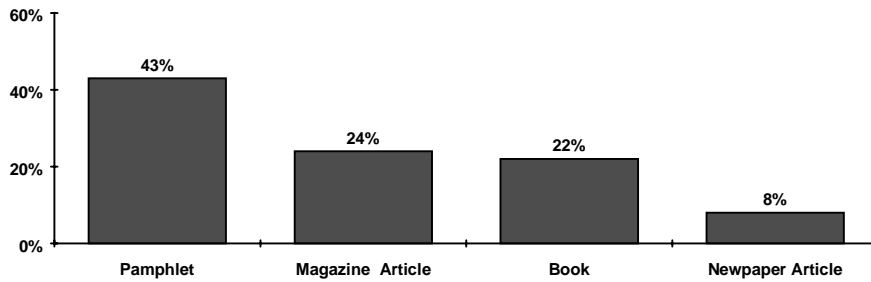
In which of the following ways would you like to receive important information about caregiving?
(n=267)



Among caregivers who would be responsive to written communications, most prefer reading a pamphlet (43%), followed by a magazine article (24%), a book (22%) and a newspaper article (8%). [See Figure G.]

Figure G: Preferred Written Materials

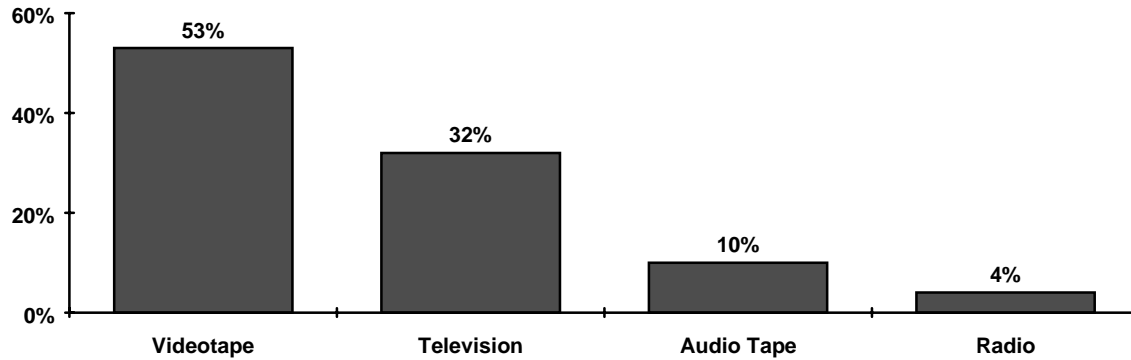
Would you most prefer getting important information from a pamphlet, a book, a magazine article, or a newspaper article? [Asked only of respondents preferring written materials] (n=227)



Among those who prefer getting information by watching or listening, half prefers a videotape (53%), a third prefers getting the information by watching television (32%) and smaller proportions prefer an audio tape (10%) or listening to the radio (4%). [See Figure H.]

Figure H: Preferred Watching/Listening Channels

*Would you most prefer getting important information from TV, radio, a videotape or an audio tape?
[Asked only of respondents preferring watching/listening] (n=183)*



CAREGIVER'S FUTURE

Thinking and Actions About Caregiver's Future

When caregivers are asked how their thinking about their future has been influenced by the caregiving experience, one-fifth says they think about saving more money and how much they will need (21%). About one-tenth each thinks about the adequacy of their insurance coverage or simply the need to plan (12% and 11% respectively). Smaller proportions contemplate not wanting to be a burden to anyone (7%), taking care of their health (6%) or who might eventually take care of them (5%), while a few simply think about the future more often (5%). [See Table 3.]

Table 3: Influence of Caregiving on Thinking about Future

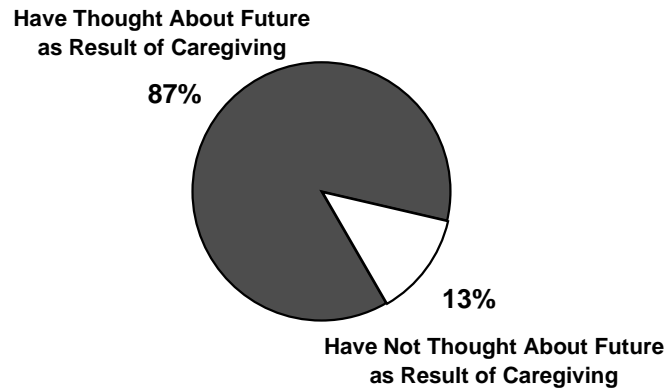
How has your thinking about your future been influenced by your caregiving experience? (n=267)

Most Frequent Topics of Thought:	
Savings needed	21%
Adequacy of insurance	12
The need to plan	11
Desire not to be a burden to others	7
Taking care of physical health—nutrition and exercise	6
Who might take care of me	5
The future	5

A vast majority of caregivers, 87% of the respondents, have thought about their future long-term care needs as a result of their caregiving experience, although more than one-tenth say they have not thought about the future (13%). [See Figure I.] Caregivers with a high school diploma or less education are less likely than those with a college degree to say they have thought about it (5% vs. 17%). Respondents who have not taken any actions to plan for their own long term care are also more likely to report not thinking about the future (and vice versa). Those who have taken some actions to plan for their own long term care are more likely to report thinking about savings and the adequacy of their insurance. This may be a hidden benefit of caregiving—it helps motivate consideration of future personal care needs among current caregivers.

Figure I: Influence of Caregiving on Thinking about Future

How has your thinking about your future been influenced by your caregiving experience? (n=267)

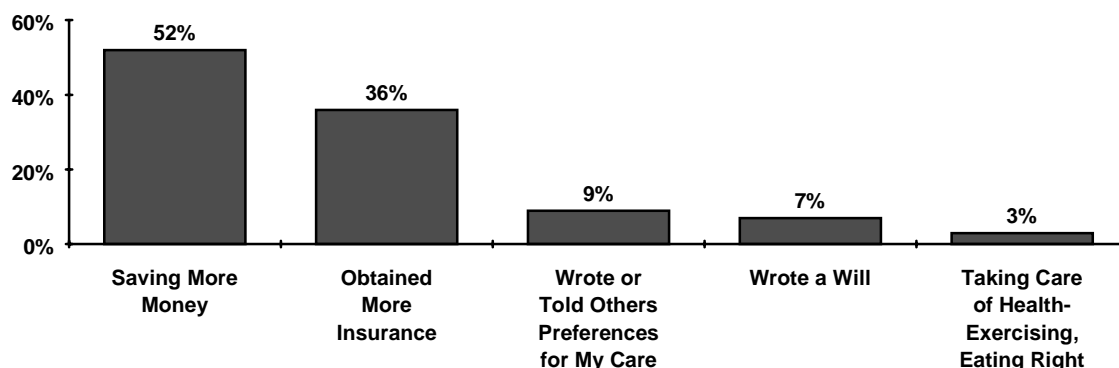


Over one-third of caregivers claim they have taken some specific actions to plan for their own possible future long term care as a result of their experience caring for someone (37%). As Figure J. illustrates, their actions reflect the issues they think about. Half says they are saving more money through increased investments or contributions to retirement accounts (52%), while one-third reports obtaining more insurance including health, life or long term care policies (36%). One in ten has either written out a living will or communicated preferences for their care to others (9%). Smaller percentages report writing a will (7%), taking care of their health (3%) or researching and reading more about their choices (1%).

These results suggest another more important hidden benefit of caregiving in that significant numbers of caregivers increase savings and obtain additional insurance for their future care needs. They also suggest that while caregiving per se is not sufficient to motivate or create specific areas of consideration for future long-term care needs for the majority of caregivers, it undoubtedly creates a widespread awareness that the global issue of their long-term care needs must be considered.

Figure J: Actions Taken to Plan for Own Long Term Care Needs

What actions have you taken to plan for your own possible future long term care needs as a result of your caregiving experience? (n=100)



The younger Baby Boomer caregivers are more likely to report increasing their savings than older caregivers (62% vs. 42%), but they are less likely to obtain more insurance (26% vs. 46%). Caregivers whose situation is about the same as last year are much more likely to increase their savings (74%) than those whose situations are either easier (46%) or harder (42%).

Information Sources and Needs

As they think ahead to the person or organization that would be their most valuable source of information about their own future long term care, more respondents mention a health professional such as a doctor or nurse than any other information source (21%). Small percentages name a social worker, geriatric care manager or hospital discharge planner (7%), an organization for the aging (7%), other caregivers or friends (5%), another social service organization (4%), resources at one's job (4%), a financial advisor (3%), a health care organization (3%) or a home health organization or nursing home (3%). No other source is named by more than two percent of the respondents.

When asked what one specific piece of information they would like to help prepare for their own possible long term care needs, one-third of the caregivers do not know (33%). Over one-quarter of the respondents, however, mention financial information (28%). Specifically, about one-tenth says they would like financial planning information (10%) and information on the related topic of determining how much their care and general living needs will cost (8%). Caregivers would also like information on long term care insurance (4%), government assistance (4%) or investments (2%).

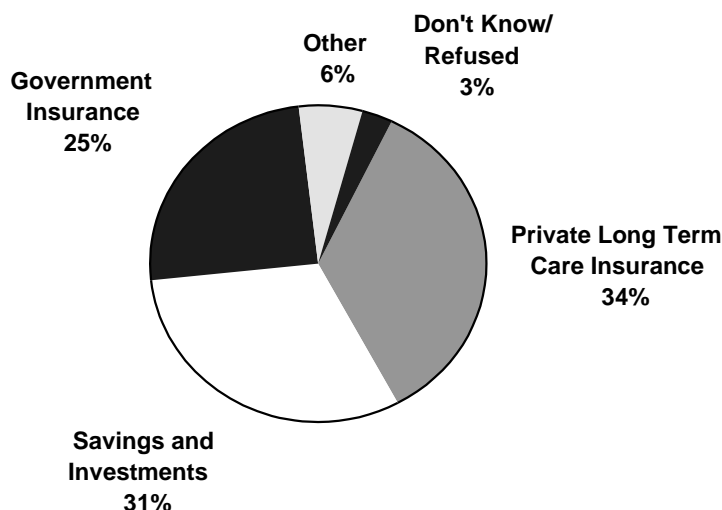
Other topics in which the caregivers express interest include what resources are available to them (6%), general information (6%), types of care facilities (4%), home health care (3%), quality of care (3%), residential care (3%) and how to stay healthy (3%).

Financing Own Long Term Care

Nearly all of the respondents believe that their own future long term care will be paid for by one of three means—private long term care insurance that the respondent purchases (34%), savings and investments (31%) or government insurance such as Medicare or Medicaid (25%). [See Figure K.] The belief, among some respondents, that Medicare or Medicaid will pay for future long term care may reflect a lack of knowledge about the financial and medical conditions that must be met to qualify for government insurance coverage of long term care.

Figure K: Expected Ways to Pay for Future Long Term Care

What is the one way you think most of your own future long term care needs will be paid for? (n=267)



Respondents who name themselves as involved in important care decisions are more likely than those who say others are most involved to believe that their long term care costs will be paid by private long term care insurance (41% vs. 27%). Those who take care of parents or in-laws are also more likely to think such insurance will pay most of the costs than those who care for other relatives or friends (40% vs. 26%). Those who care for someone other than a parent or in-law are more likely to say their own savings and investments will cover the costs of care (40% vs. 26%).

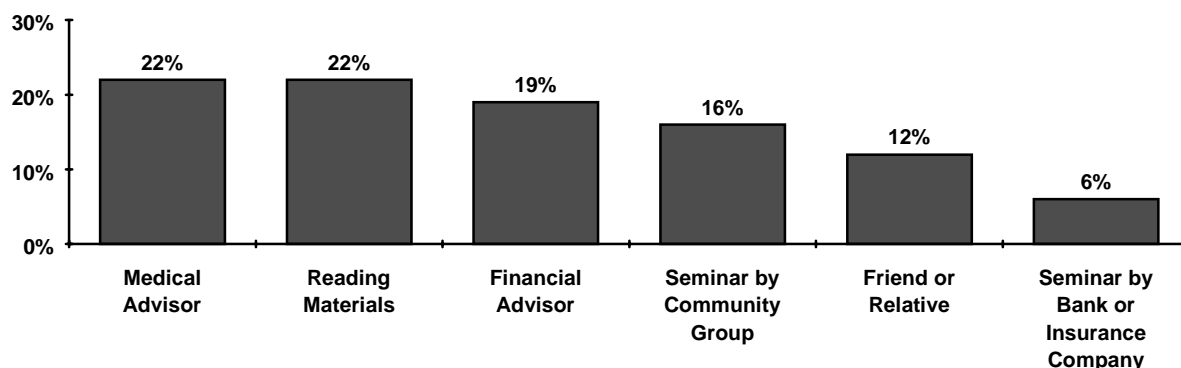
Caregivers who have taken action to plan for their own long term care mention their own savings and investments as the main way to pay for costs more often than those who have not taken action (39% vs. 27%). Those who have *not* taken such action are more likely to mention relying on government insurance such as Medicare or Medicaid (30% vs. 19%). Taken together, these results suggest that caregivers are more realistic in their understanding of the limitations of Medicare and other governmental programs in paying for the typical services needed in long-term care, and understand the likely role that insurance and their own resources will play in funding their own caregiving services.

When they are read a list of six sources of financial information on long term care and asked which they would be most likely to go to, respondents are divided. About one-fifth each says they would be most likely to speak with a medical advisor (22%), to read a brochure, financial magazine or library resource (22%) or to speak with a financial advisor (19%).

Sixteen percent prefer to attend a seminar sponsored by a community group and twelve percent prefer speaking with a relative or a friend, while significantly fewer would be most likely to attend a seminar sponsored by a bank or insurance company (6%). [See Figure L.]

Figure L: Sources of Financial Information about Long Term Care

Which one of the following sources would you be most likely to go to for financial information on long term care? (n=267)



Two subgroups of respondents are more likely than their counterparts to speak with a medical advisor about financial information—those with household income less than \$40,000 and those with only a high school diploma or less education. By contrast, households with incomes of 40,000 or more are more likely to prefer reading materials. Several subgroups are more likely to go to a financial advisor—higher income households, college graduates, those involved in important care decisions and younger respondents.

The specific pieces of *financial* information that caregivers report they would like include costs of long term care (15%), investment strategies (12%), insurance policy information (10%), how to save enough money (9%) and estimations of the amount of money they will need (7%).

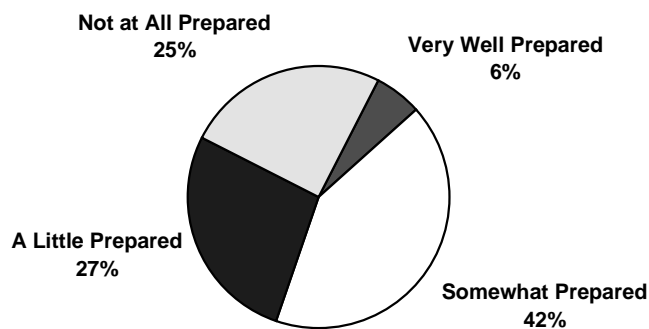
Those who spend one to ten hours a week giving care and those who sought information from less than two sources are more likely to say investment strategies would be helpful. Caregivers who feel financial hardship are more likely to want information on insurance policies. Those with household incomes over \$40,000 are more likely to value information about how much money they will need to meet their needs.

Preparation for Own Long Term Care

Few respondents feel they are *very well* prepared for their own possible long term care (6%) but four in ten feel *somewhat* prepared (42%). Over half reports feeling only *a little* or *not at all* prepared (27% and 25% respectively). [See Figure M.]

Figure M: Perceived Preparation for Future Long Term Care Needs

How well prepared do you feel you are for your own possible long term care? (n=267)



Interestingly, the caregivers who feel no financial hardship are much more likely to feel *not at all* prepared than those who feel some level of hardship (30% vs. 19%). Not surprisingly, those who have not taken any specific action to plan for their long term care also feel unprepared compared to those who have taken action (37% *not at all* vs. 6%). Older respondents are more likely to feel unprepared than younger ones (31% vs. 18%).

Comparing Financial Consequences of Caregiving

An especially unique characteristic of this survey is the ability to examine changes over approximately a year's time (from August 1996 to January 1998) in some of the financial consequences of caregiving. This, in turn, gives us the ability to address two inter-related questions— How much change has taken place? and What is the impact of this change on caregivers' preferences for information and support?

The question was asked – How much of a financial hardship would you say that caring for “X” is for you? [where “X” is the specific person identified earlier in the interview] — using the same wording in both interviews. While Financial Hardship was not seen as a problem by a majority in either survey, the change between the the first and second survey was substantial. [See Table 4] In 1996 only 27% of the sample said that caregiving is of some financial hardship; a year later almost half of these same Baby Boomer women caregivers (49%) said that caregiving comes with financial hardship.

Table 4: Financial Hardship Caused by your Caregiving, 1996 and 1998

	<u>1996</u>	<u>1998</u>
Some to Great Deal of Hardship	27%	49%
No Hardship at all	73	51

N=262 in both surveys

Despite the clear direction of this change not all caregivers share this burden of increasing financial hardship. The longitudinal two-survey design of this project allows us to distinguish among women in terms of their then-and-now pattern of financial hardship.

As Table 5 shows, 44% of all the women surveyed were in the fortunate situation of being able to say that they experienced no financial hardship at all, either then or now. The remaining 56%, however, either did or does perceive such a hardship, although this number includes 7% who changed from some financial hardship then to no hardship in 1998. For almost half (49%) the sample, however, there is either a continuing financial hardship (21%) or worse, a move to some hardship from a previous situation of none (28%).

This project was not designed to study in depth the reasons for the increased (or decreased) financial hardships associated with caregiving shown in Table 5. On the other hand, information and educational services designed to support caregivers should take into account differences in how they perceive their financial burden, and the project does indeed support this important task.

Table 5: Changes in Financial Hardship, 1996 and 1998

Financial Hardship 1996 vs. 1998	<u>%</u>	<u>N</u>
None then & none now	44%	116
Some then & none now	7%	18
Some then & some now	21%	54
None then & some now	28%	73
	100%	261

“none” = no hardship at all

“some” = from some hardship to a great deal of hardship

The 1998 survey asked women to reflect on the previous year of caregiving, and to estimate how helpful different kinds of information would have been (very helpful, somewhat helpful, a little helpful, not at all helpful). The list of kinds of information ranges from financial information (e.g., long-term care insurance) to veterans’ benefit information to help in administering medicines to guidance in locating and evaluating assisted living facilities. In other words, the range includes more immediate day-to-day caregiving tasks to future planning- oriented caregiver responsibilities.

Table 6 indicates the differential information preferences of these women caregivers, in terms of how their financial hardship has changed or not changed. While we are concerned with helping all caregivers, of special interest here are those women whose financial burdens have gotten more difficult (column 1).

Table 6: Changes in Financial Hardship and Helpful Information

How are changes in financial hardship related to differential information preferences?

(percentages = % Helpful)

<u>Information Preferences</u>	Financial Hardship Change, 1996 to 1998			<u>Total Sample</u>
	1 <u>None to Some</u>	2 <u>Some to Some</u>	3 <u>Some/none to None</u>	
Stress of giving care	90%	80%	69%	77%
Balance care with work/family	82	74	65	72
In-home ADL services	82	81	68	75
In-Home Health services	77	87	72	76
How to Pay for long-term care	77	70	56	65
Practical Hands-on training	77	76	66	71
Evaluate living arrangements	68	64	52	59
Manage Elder’s finances	58	60	54	56
Manage use of prescriptions	57	62	65	61
Buying LTC insurance	52	42	67	50
Veteran’s Benefits	20	26	25	24

NB: information questions asked in 1998 survey;

“Helpful” = Very + Somewhat helpful (in contrast to A little helpful + Not at all helpful)

Using the first row as an example the percentages in this table are read as follows. Of the women who said “no” financial hardship in 1996 but changed to “some” financial hardship a year later (28% of the sample as indicated in Table 5), 90% of them said that information about how to deal with the stresses of caregiving would be helpful (very or somewhat helpful).

By contrast, the women (in column 2) who said they experienced financial burdens both before and now divided 80%/20% on the helpfulness of information about how to handle stress. And only 69% of caregivers who said that they did not experience financial hardship in either survey would find the stress-oriented information helpful.

There are a number of such “stories” that can be created out of the interesting data in Table 6, not all of which are as “logical” as we might have thought. For example, those women who did not mention financial hardship in either survey are more interested in information on how to buy long-term care insurance (67%) than either of the two financial hardship groups (52% and 42%).

But more of the “stories” are consistent with what we might have anticipated. Quite understandably, for example, women who are experiencing increases in their financial hardship are more enthusiastic about receiving information about how to balance work and family with their caregiving responsibilities.

At the same time, the texture of Table 6 reminds us not to forget those women who said that they experienced financial hardship both times the question was asked. We have “scored” them here as “no change” but because the survey did not probe their financial burdens in detail, for many of the women in column 2 their financial situation may well have gone from bad to worse. These women (especially in contrast to those without financial hardship) are very interested in information about handling everyday caregiver stress, and in how to plan for the future in terms of evaluating in-home health services and in-home daily assistance services.

The profiles in Table 6 offer us a template for understanding the differential information preferences of caregivers. While such differences are not rooted exclusively in money, certainly a significant component of their challenges are in the financial burden they shoulder and in the changes in that financial burden that they may experience. The development and distribution of appropriate caregiver support will be much improved as we more fully understand both the pattern and the sources of these differential preferences.

Recommendations For Project's Next Steps

Based on the results of this survey, The National Alliance for Caregiving will be developing an educational package for Baby Boomer Caergivers. The following recommendations for this package reflrect the information needs of the caregivers surveyed.

1. NAC should undertake a public education campaign which would disseminate caregiving information consistent with the expressed needs and preferences of the survey respondents. The suggested components of the campaign should include:

- A two-part booklet of information appropriate to middle-aged female caregivers. Part A of the booklet would include information on

Caregiver / care recipient issues:

- caregiving skills
- disease-specific information
- national caregiver resource organizations
- local caregiver resource organizations (see Recommendation 2 below)
- selection and evaluation criteria for formal in-home health and ADL caregiving services
- public benefits/entitlements

Part B of the booklet would include information on

Caregiver personal and planning issues:

- stress reduction/coping skills
- long term care planning
- long term care insurance planning
- personal financial planning
- balancing work and family in the context of aging

2. As part of these booklets, NAC should incorporate a special template (Computer diskette) for use by local/regional dissemination partners to incorporate local information and resources into the booklets. The Guidebook should implement the strategy of "Understand nationally. Act locally."
3. NAC should engage the participation/partnership of national women's organizations, aging groups and employer groups to disseminate the booklets and template developed.
4. NAC should develop prototype materials and dissemination processes and test these with the appropriate local and regional "consumers" of those materials and processes prior to dissemination of the final product.

5. NAC should include as much already existing materials from its prior activities and those of its partner organizations as possible to maximize efficiency.
6. NAC should consider implementing a national Baby Boomer focused public awareness campaign tested in selected areas through inserts in regional newspaper media (e.g., Sunday Supplement or women's magazines, etc.) to alert the public about the availability of its national/local booklets.
7. NAC should undertake evaluation research of its dissemination efforts to further refine its booklets and template, modify it for special constituencies (e.g., minority/ethnic constituents, etc.), and expand the dissemination process.
8. NAC should undertake additional survey research on this area, and continue to create baseline data and benchmark data. There remains a host of research questions of special importance to middle-aged boomers who will be increasingly called upon to care for longer-lived elderly parents. Examples include caregiving issues and personal planning on the part of caregivers for their own future. This is especially true for their preferred sources of information and the ability of those sources to deliver planning information effectively. Particularly relevant to the intergenerational financial/family issues are questions about financial planning, insurance, and health and health services consumer areas.

Appendix A

QUESTIONNAIRE SHOWING SURVEY RESULT