

Executive Summary

Boomer Women's Long-Term Care Planning: Barriers And Levers

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Data Collected by Knowledge Networks, Inc.

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INTRODUCTION

Background

This report presents findings of a survey of 2,895 Boomer women that examined attitudes, opinions, and behavior regarding planning for their own possible needs for long term care (LTC). In this research, "long-term care" refers to care provided on a regular basis for three months or more for age-related or other chronic conditions. Examples include:

- Someone comes to your home for a few hours each day to help with daily activities or personal care tasks such as: using the telephone, paying bills, shopping, driving, doing housework, preparing meals, bathing, dressing, using the toilet, getting in or out of a bed or chair, walking, or eating.
- Home visits from a nurse, physical therapist, or other health professional that provide skilled services such as physical rehabilitation and blood pressure monitoring.
- Living in an assisted living facility where aides are available to help you with some personal care tasks or with medications.
- Living in a nursing home where aides and nurses take care of you, as do other health professionals who provide skilled services such as physical rehabilitation.

There is an abundance of research and information on the role of adult children assisting their aging parents to plan for their LTC needs, on the importance for people of all ages to have forms that convey one's desires if incapacitated and cannot make medical treatment decisions, and on the myriad of problems of the long-term care system and delivery of services. However, only a paucity of research exists that has focused on understanding attitudes, opinions, and behaviors in relation to Boomer women planning for their own LTC needs.

Research has shown that, in the past, getting people to make LTC plans is a challenge, and this may be particularly the case for Boomers. A common belief is that with the aging of the Boomers, society will witness a metamorphosis of the landscape of older America into a silver haired version of the Sixties, with working, laughing, dating, and skiing Boomers who are not driving their father's "Oldsmobile," nor living their parents' retirements. Experiencing better living through pharmaceutical chemistry, they will be the new and different American seniors. They will live in a society in which prevailing attitudes, demography, economics, and medical advances have made the prospect of growing old in America one which contains previously un-dreamt-of choices of managing chronic illnesses and in remaining active and involved in life. Since, on the one hand, Boomers are aging in an era of extraordinary rapid medical and technological advancements, their attitude may be that the time is approaching when individuals die suddenly from a short illness after living a long and healthy life. This mindset could lead them to believe that, most likely, they will never have a need for LTC, and thus LTC planning is not relevant.

On the other hand, Boomers are viewed as self directed, fiercely independent, insistent on controlling their own destiny, changing the rules, and raised to expect more than their parents. Some characterized them as having relatively little confidence and trust in some of society's major institutions, such as government, corporations, and churches. They are described as instinctively, would rather burn out than fade away. These characteristics may indicate Boomers will be receptive to planning for their LTC so that they can feel that they will be able to maintain control of their destiny in late life.

The Baby Boom Generation is about 77 million Americans, or roughly 28 percent of the current U.S. population (AARP, 2008). In less than 10 years, the entire Baby Boom generation will be over 50. The National Maturity Institute (NMI, 2008) found nearly one fourth (22%) of Boomers indicate they have a disability, handicap, or chronic disease that keep them from participating fully in activities. With aging, it can be expected that this percentage will increase. For example, according to the Centers for Disease Control and Prevention (CDC) the number of U.S. adults reporting a disability is increasing. In 2005, more than one-third of the 47.5 million adults who reported a disability are aging baby Boomers (CDC, 2009). Thus, even though Boomers have broken the norms at previous life stages, there is some evidence that indicates a swell in the population who are likely to need LTC services as they age. Considering the size of the Boomer population, this is critically important given that currently, as noted by US. Department of Health and Human Services Secretary (HSS) Kathleen Sebelius, \$232 billion is being spent on long-term care annually (Sebelius, 2009).

It has been noted that without a LTC plan, when many older adults seek LTC services– whether for in their homes, in residential settings, or in institutions such as a nursing home–their search for information and resources about their options most likely will be very confusing. Most people are in crises when they seek help, do not know where to turn for aid, and are not prepared to navigate the non-system LTC choices. Trying to navigate such systems at a time of crises for many means they will not have time to find quality providers, spend too much money on the wrong system, or end up in a nursing home when their needs could possibly have been met with community services.

The two primary purposes of the research were to:

- 1. Understand the influences or influencers that impact Boomer women regarding planning for their LTC needs.
- 2. Determine if Boomer women can be segmented into subgroups regarding LTC planning based on attributes, including attitudinal, behavioral, motivational, and demographic characteristics.

The report is organized into two sections. Section 1 examines attitudes, opinions, and experiences, including behaviors of Boomer women age 50 to 62 years as barriers or levers in regard to planning their own LTC. Section 1 addresses the following questions:

- 1.What are the attitudes beliefs, opinions, and behaviors regarding planning for their own LTC?
- 2. What experience have they had with caregiving?
- 3. What steps, if any, have they taken to plan their own LTC?
- 4. What are the attributes or characteristics of Boomer women with regard to LTC planning?

Section 2 of the research examines whether Boomer women can be segmented into subgroups based on attributes with regard to LTC planning identified in analysis reported in Section 1 of the study. The goal is to gain an understanding of the differences among Boomer women and the factors that are motivators or barriers to subgroups planning for their LTC needs.

METHODOLOGY

Questionnaire Development

A questionnaire was developed based on review of literature on opinions and experience with LTC and Boomer characteristics. This included barriers and levers to LTC planning, social and demographic characteristics of Boomers, and perceived steps and stages that people take in planning LTC. A total of 212 variables were identified in the literature review. In order to keep the survey a reasonable length, 96 questions plus demographic variables were developed to use for an online survey.

Online Survey

In late September, 2008, AARP contracted Knowledge Networks, Inc. to conduct an online survey with a nationally representative panel of 2,898 Boomer Women age 50 to 62 years old. The panel included oversamples of African American and Hispanic Boomer Women.

Data Analyses

Data analyses of the included tabulation of the frequency of the responses for all of the items, cross-tabulations of the survey items to identify relationships, factor and cluster analyses to identify groupings and to uncover underlying constructs of groups of questions, and a segmentation of Boomer women into smaller LTC subgroups.

KEY FINDINGS

- More than half (53%) of the Boomer women have not had any experience with caregiving. Just over a third (36%) have provided care or are currently providing for an aging relative. Those who have been caregivers are twice as likely to have some kind of LTC plan (16%) than those who have not (8%).
- Most of the women (56%) indicated that they did not have any type of plan when asked to check if they had a family, legal, or financial plan for their LTC needs. However, those who have made at least one kind of plan are more likely to have made additional plans.
- Most often, the trusted source of information Boomer women turn to in order to plan and/or make decisions on their health and/or financial security falls in the category of family and friends (83%). Factor analysis revealed that 12 sources of information listed in the survey group into four categories:
 - 1. Media
 - 2. Government agencies and community organizations
 - 3. Internet and groups or associations they belong to
 - 4. Family and religious organizations
- When respondents were asked to rank the following factors in terms of what has most influenced you or would most influence you to make and implement a long-term care plan, those ranked number 1 most often are:
 - 31% Observing the long-term care experience/treatment of a friend and/or family member
 - 24% Understanding clearly available options
 - 21% Fearing what will happen if I do not take action
 - 12% Receiving support/encouragement from friends and/or family
 - 3% Feeling momentum to continue after evaluating available options
- There are three things Boomer women indicate they are most often currently doing or have done relating to long-term care:
 - 1. Had heard or read stories about LTC (43%)
 - 2. Discussed their LTC needs with their family or friends (27%)
 - 3. Prepared and executed advance directive forms that reflect their choices about their own care (26%)
- Two-thirds of Boomer women (65%) indicated they cannot afford the cost associated with LTC planning right now.
- Unaware that Medicare does not cover LTC, over a quarter of the Boomer women (29%) are counting on Medicare to pay for their LTC service needs.

♦ Virtually none of the respondents (2%) indicated volunteering for the issue of LTC.

The survey included 19 variables that a large body of literature suggests are barriers to planning for LTC needs. Using a five-point scale where "5" was *Strongly Agree* and "1" was *Strongly Disagree*, most of the barrier variables asked the respondents to indicate their level of agreement or disagreement with attitudes, behaviors, and opinions perceived to impede Boomer women from dealing with the issue of LTC.

- Of the 19 variables, more than half or more of the women *strongly* or *somewhat agree* with the following:
- 67% I am hesitant to rely in the existing health system to meet my LTC needs
- 65% I can not afford the cost associated with planning for LTC now
- 62% I do not have enough retirement saving or other assets to meet my LTC needs
- 57% I am not comfortable giving up control to someone else
- 55% I don't think a plan will ensure getting the care I expect

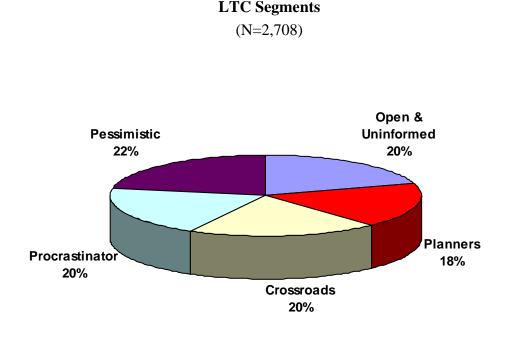
The majority of the respondents do not *agree* with most of the variables, indicating that they are either *neutral* towards them, *strongly disagree*, or *somewhat disagree* with the statements. This suggests that rather than barriers, many of the items could be leverages for LTC planning.

- Factor analysis reveals the following seven themes underlie the 19 barrier items:
- 1. Do not know what to do
- 2. No need to plan LTC now
- 3. Cost perceived prohibitive
- 4. Lack faith in the health care system and concern with giving up control
- 5. Lack satisfaction with and interest in volunteerism
- 6. Activists for other issues
- 7. Depending on family for LTC

A total of 23 questions were developed based on literature of characteristics or attributes related to Boomer women's LTC planning. Respondents indicated their level of *agreement* with the questions on a five-point scale where "5" means *Strongly Agree* and "1" means *Strongly Disagree*. They also rated their health status on a five-point scale where "5" means *excellent health* and "1" *poor health*. In addition, there were five items for respondents to indicate their experience with the issue of long-term care with a *Yes* or *No* response.

- ✤ There are four statements that represent Boomer attributes for which as a total group, nearly half or more *strongly* or *somewhat agree*. These statements refer to finances (63%), awareness from experience the need to plan for their own possible need for LTC (50%), and although respondents did not want to think about the possibility of needing LTC (50%) they realize the possibility that they may need it (49%). On the other hand, Boomer women were least likely to *agree* that they probably won't need LTC because they are healthy now (9%) and that it is too late to plan for their LTC (8%).
- Scores obtained for each respondent in a factor analysis of the attribute variables were used in a segmentation analysis to gain a better understanding of subgroups of Boomer women regarding LTC issues. The percentages and broad summary of the women for the five segments are below.

Percentage of Respondents in the Five



Source: Boomer Women's Long-Term Care Planning: Barriers And Levers

22% Pessimistic

The poorest and least educated segment, these older Boomer women are least likely to rate their health as excellent or very good and are more likely to believe it is too late and too expensive to plan for LTC.

Boomer women in this segment are most likely to think they can rely on Medicare to support their LTC needs, and are more pessimistic about their situation – they think

that they will likely end up alone in a nursing home, regardless of the plans they make.

20% Open and Uninformed

More often single, working, and without children, these younger Boomer women don't know where to turn for information, what questions to ask, or what should go in a LTC plan.

While most have not yet made any plans, they see the need for planning and are willing to explore their options.

20% Procrastinators

More likely to be married, working, and with children, these younger Boomer women are putting off planning due to being busy, lack of information about what goes into a plan, and their perception they cannot afford to plan. They will deal with LTC when they have to.

20% Crossroads

These healthy, older Boomer women are most likely to have taken none of the LTC continuum steps, and are least likely to have any experience providing care.

However, this group is becoming more aware and motivated about planning due to the observations of others' experiences and is beginning to fear what will happen if they do not take action.

18% Planners

The wealthiest and most educated segment, these healthier, older Boomer women are most likely to have experience providing care, have spoken with family and friends about their plans, and have made at least one type of LTC plan.

DISCUSSION AND CONCLUSIONS

The findings for this research have implications for increasing the percentage of Boomers who have made plans for their own possible LTC needs and for future research on this issue.

The finding that over half of the respondents for this research indicated they do not have any type of plan when asked to check if they had a family, legal, or financial plan for their LTC needs confirms the need to target this population for initiatives designed to increase the percentage of Boomer women who have a LTC plan in place. This need is reinforced by the finding that most of the women do not know what to ask or what to do regarding LTC planning. This also suggests the need to convey at the exposure or awareness stage that there is step by step assistance to help navigate the LTC planning process. The research found those who have at least one kind of plan are more likely to have made additional plans and that at least a quarter have prepared and executed advance-directive forms. This result suggests that LTC planning could increase if introduced when individuals are completing advance directives.

Two results indicate that Boomer women who have experience with family members needing LTC may be receptive to planning their possible need LTC. Although not consistent with previous AARP research, Boomer women in this study who have experience with caregiving were twice as likely to have had a LTC plan as those who have not. Although not the same as caregiving, the somewhat related finding that seeing what has happened to a family member or friend was a factor respondents ranked high that would motivate them to make a LTC plan suggests that just observing a situation for which LTC is needed may result in Boomer women wanting to use readily accessible LTC planning materials. This group may be the low-hanging fruit. Thus, finding opportunities to work with Boomer women to prepare their own plan when caregiving may captivate on what in education circles is known as "a 'teachable moment."

The finding that 4 in 10 of the respondents have heard or read or seen something about LTC, but a much smaller percentage have taken any other steps suggests that "exposure to or awareness" alone will not necessarily lead Boomer women to take a next step to having a LTC plan. Since exposure to the need to plan LTC needs appears not to be a strong enough motivator, exposure will need to address levers that facilitate planning or dispel indicated barriers.

The finding that a barrier is Boomer women may think in terms of LTC planning as ceding control to someone else indicates that this concept needs to be turned on its head so that the messages emphasize that planning for one's own possible LTC needs can help maintain control.

The finding that nearly two-thirds of the respondents believe they can not afford the cost associated with planning for LTC right now suggests that Boomer women need to know that LTC planning is not limited to finances. Too much focus on insurance may be a barrier to any kind of LTC planning and probably should not be used as an introduction but rather, included as one option among other alternatives in LTC planning. This is related to the finding that nearly a quarter of the respondents say clearly understanding available options would provide momentum for planning and further supports the importance for Boomer women to know LTC alternatives. Also, since nearly two-thirds feel they do not have enough retirement saving or other assets to meet their LTC needs, it may be useful to include information such as reverse mortgages to help pay for LTC services as an alternative if they are financially strapped homeowners. However, since nearly a third are erroneously counting on Medicare to pay for their LTC service needs, the financial dimensions of LTC should not be ignored.

The finding that virtually none of the respondents indicated volunteering on the issue of LTC, that two-thirds say they lack confidence in the health care system, and more than half say they don't think a plan will ensure getting the care they expect suggest Boomer women probably are not good candidates for advocating for LTC services at this time.

The healthy mature generation may be more interested in being activists for this issue as they observe what their family, friends, or peers are experiencing.

Segmentation results revealed that Boomer women as a group should not be viewed as homogeneous regarding the issue of LTC and planning for their own needs. Thus, a one approach fits all may well not work for addressing the barriers and for using leverages for Boomer women to plan for their own possible LTC needs.

The findings for this study also have implications for future research. The results of the factor analyses suggest that fewer questions can capture much of the information obtained in the lengthy survey used for this study. For example, instead of twelve items on trusted resources, one question that includes four choices could be used and seven items in place of 19 barrier items. A shorter questionnaire is important for questionnaire completion, response rate, and cost. Also, a shorter questionnaire may enable different data collection modes, such as a telephone survey.

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