



Aging and
Retirement

Life Journey Study

A Report on an Online Survey of 602 Adult Children
of Recently Deceased Parents



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Executive Summary

The Society of Actuaries' (SOA) *Life Journey Study* provides insights into how the retirement experience unfolds in the later years of life, surveying the children of recently deceased parents or those who provided support for other relatives who survived beyond age 85.

This survey is part of the SOA's Aging and Retirement Strategic Research Program. The program includes the SOA Committee of Post-Retirement Needs and Risks, which for more than 20 years has focused on the issues facing middle-income Americans, with the objective of improving retirement and retirement risk management.

This report focuses on the quantitative portion of the research that involved an online survey of 602 children of deceased parents and were not married at the time of their death and did not have financial assets of over \$400K. While the results of the qualitative research—in-depth interviews with 40 children that met these criteria—were presented in an earlier report, parallels are drawn throughout this report between the findings of the current quantitative undertaking and the qualitative study. This research studies the last phase of retirement, right up to end of life using children as proxies to describe how events unfolded.

The purpose of this research is to gain the insights from those who have completed the full life cycle and how they deal with decline and death. One focus of this research is to study variety of different family types and how each works together to deal with these end-of-life issues.

Overall, many of the study's findings contribute to a better understanding of the financial and health issues faced by the elderly. Some of the most significant findings are as follows:

- **Children's Retrospective on How Well They Cared for Parents.** Children gave themselves high grades when it came to caring for their parents, grades that may be inflated by the sampling process that screened for those involved enough with the care to participate in the survey. Over half gave themselves an "A" on both the care they provided and the planning they did for this care. Most of the remaining participants gave themselves a "B". Findings suggest that the area that challenged them the most was handling changes in their parents' health. When asked what the one thing is they could have done better in the care of their parents, the most common response was to spend more time with them. These grades somewhat contradict the lack of planning that earlier research suggest children actually do when it comes to preparing for the aging of their parents.
- **Life Journeys.** As found in the in-depth interviews, the decline in health that occurred among parents varied a great deal. The most common condition having a major impact on parents' health and viability, affecting close to half, was unsteadiness walking. Over one-third had an injury due to a fall. Well over one-third cited that cognitive decline had a major impact on their parents. This is a critical issue because cognitive decline occurs more gradually and often results in the need for extensive long-term care. Conditions most often first showed up in the parents' 80s, although vision problems often began earlier. Only a small percentage of parents needed assistance from their children prior to age 80. A large majority of children cited that their parents were able to drive and maintain their residences prior to this, and 5% or fewer required assistance with Activities of Daily Living (ADLs) of long-term care prior to age 80. These findings suggest that there is a great deal of unpredictability in planning for each situation.

- **Impact of Spousal Financial Role.** Over half of the mostly female deceased were not primary breadwinners during their working years while married. However, over six in ten claimed their parents were in charge of or had an equal role in finances. We suspect, based on in-depth interviews in both this study and the 85+ study, that the financial role of the female spouse in these traditional marriages was making decisions about purchases rather than actual money management. As found in qualitative work, most respondents reported that the death of the parent's spouse did not have an impact on their parent's finances, but one-third felt that it had a negative impact on financial security and the ability to manage finances. While the shock of death or divorce disrupts retirement finances, the qualitative research here suggests that, in the very later years of life, they may do so less. Spouses no longer have the same financial impact on each other later in life.
- **Finances.** Most reported that their parents' finances before death were the same or better than they were at age 65. However, among the remaining sample, one quarter said they were much worse. While qualitative work suggested that parents were able to balance spending and income, care expenses could quickly eat into savings, and half in this study reported that nursing care, at home or in a facility, had a major negative impact on their parents' finances. One of the threats to finances is that so many of the elderly have a delicate balance between income and expenses before they need care, making them vulnerable to the expense that care involves.
- **Financial management support.** Most children did take over their parents' finances, and nearly two-thirds that did so managed the money for at least five years. Children were less involved in investment management, consistent with qualitative work which suggested that some parents did not have investments or relied on advisors. Six in ten times, the need for any financial management support was caused by cognitive decline, and over four in ten reported it was due to the parent's difficulty with technology. It may be instructional for families to know how common it is for them to have to step in some day.
- **Housing.** Close to half reported that their parents moved during retirement, with one in five moving more than once. Close to half who moved did so to find a place more accommodating to their limitations and almost four in ten moved to be close to family. Two-thirds cited that their parents resided alone after their parent's spouse died, but one in five lived with one or more of their children. Research suggests that there are clearly different paths that people take later in life.
- **Role of Family.** A large majority reported that they or other family members played various roles for their parents at some point relating to emotional support, managing finances, providing transportation, and managing the house. Two-thirds provided support with activities of daily living at some point. The most common role for family was to provide emotional support and almost two-thirds did so for over five years. Across a variety of roles, respondents were involved two-thirds of the time, while the same proportion of respondents' spouses, brothers, and sisters often kept the parent company, performed chores, and were involved in the decision to place parents in assisted living or nursing homes. In one in five cases, non-relatives played a role. Findings support that in the asset range where families may not be able to fully fund care, the family role is critical.
- **Family Dynamics.** Results of this research confirm the qualitative finding that most families gave themselves high grades when it came to caring for their elderly parents. Half or more in this study gave themselves an "A" when it came to families agreeing on things and each person doing what they were best at. Most of the rest gave themselves a "B." Most rate the family as very effective in financial planning and managing care.

As seen in the qualitative research, the area which families do the worst is having everyone "pull their weight." Four in ten gave the family a grade of "C" or lower on this dimension and three in ten did so on tolerance for other members who did less because of distance or family obligations. We saw instances in the qualitative research where those providing support understood why other family members did not pull their weight but were not happy about it.

- **Fraud.** Over one in ten reported that their parent did experience a fraudulent incident. Over six in ten times, the fraud was committed by someone their parent knew, most often another family member. About one-sixth reported having a dispute with a family member over their parent's money or property. Fraud correlates with the incidence of other financial challenges in retirement. We do not know if fraud causes these problems or those susceptible to fraud do not manage other issues as well.
- **Assisted Living.** Eight in ten reported that their parents' need for support evolved gradually, suggesting that most of the time there is an opportunity to prepare for the decision to provide assisted living. When support was provided at home, eight times out of ten it was provided completely or mostly by family members. Factors most often involved in the decision to provide assisted living included general frailty, providing a better quality of life, cognitive decline, and, somewhat less often, a medical event. Three quarters of the time, the parent had at least some involvement in the decision, and only one quarter of the time did they put up strong resistance to it. These findings suggest that there are various reasons to transition into assisted living, and that the parent often plays a collaborative role. The research suggests that it may be beneficial for families to work with parents to discuss ahead of time the scenarios where assisted living may be a good decision.
- **Nursing Home Decision.** The most common factor that precipitated moving to a nursing home was a medical event, which occurred over half the time. As with the need for assisted living, close to half the time, general frailty and cognitive decline were causes. About four in ten times, the recommendation of a professional led to the decision to enter a nursing home. As might be expected, it was less common for the parent to participate in the decision than they did with assisted living, but they still did so to at least some extent, about half the time. About one quarter reported that their parents strongly resisted moving to a nursing home. As found in qualitative work, families have to be reminded that sometimes the trajectory to needing nursing care is gradual and predictable, and sometimes it is not.
- **Paying for Nursing Homes.** The most common source contributing to funding for nursing homes, occurring over six in ten times, was Social Security. Qualitative research suggested that the nursing home often requests that Social Security income be turned over to them as a means of paying for care. This research does not address how much of the costs Social Security covers. Close to half the time, care was paid for with assets. Over one-third of the time Medicaid was used, and half of these instances involved spending down assets. Again, the sampling criteria for this study eliminated those at higher asset levels and those whose parents did not have a partner at the time of death, so findings should not be projected to the entire population.
- **Impact of COVID-19.** COVID-19 has created additional challenges to providing this care. Among the small percentage who had parents who were alive during the pandemic, the biggest challenge was isolation and loneliness. Half reported that they were unable to see their parents for some period of time before they died.

These findings, along with those from the qualitative research, tell a compelling and consistent story of the financial views of parents' late life journey and provides an important road map to understanding and supporting a segment of the population that has been little examined in prior research.

The following sections examine the study's implications, introduce the research, explain the methodology and present an overview of the survey findings. The report concludes with the full report of findings.

Implications and Perspectives

For many years, financial experts have warned about the implications of an American public that is inadequately prepared for retirement. Experts have cautioned that with growing life expectancies, Americans run the risk of depleting their assets over their retirement years. Studying the financial experiences of individuals ages 85 and over provides key insights into how people successfully manage the key risks of retirement from inflation to long-term care.

However, this research, along with prior qualitative and quantitative research of retirees over age 85, suggests that the way Americans prepare for retirement does not consider how non-linear and unpredictable a progression retirement is. The common model for determining retirement preparedness is to accumulate a nest egg, and then determine if the income produced by the nest egg is sustainable over a lifetime. These income needs are often calculated based on lifestyle at retirement.

However, the general approach to retirement planning often does not consider common changes that occur during retirement as well as preferences expressed by many retirees during consumer research and what happens later in life. Because activity levels decline past age 85, the amount of money needed to simply maintain one's desired lifestyle declines, until care and support is needed. Also, the likelihood of some financial shocks becomes rarer as divorce is highly unlikely, most no longer have cars to maintain, and some have moved to residences that do not require maintenance. In most cases, Medicare and Medigap policies cover acute health crises well.

Although all parents of the children in this study had lost spouses, the financial impact on them was not that great. While some parents lost income, they were only supporting one person instead of two. In addition, if the parent's spouse was sick for a long time, the need to provide and/or finance care ended at death, improving finances.

While the reduced impact of living expenses and shocks can make finances more sustainable for many, this is not the case if care is required by the parent for a long period of time. A parent requiring assisted living or long-term care with the asset cap screened for in this study can easily run out of money if having to pay for those expenses. Except for those who passed suddenly, this research suggests that most parents need care at some point in their lives, but the length of time that is required varies greatly. Those experiencing cognitive decline often require the longest period of care, and children who had parents experiencing this represented over two-thirds of the sample.

The other factor that determines the financial impact is the role that the family plays. The progression to needing assistance in the activities of daily living tends to be gradual, and family can fill in the gaps part or all the way in that progression. This research shows that when parents are living at home, family does provide most of the care needed.

The qualitative portion of this study suggests that the extent to which the family provides care and support varies greatly based on the family's willingness and ability to do so. The support provided generally included emotional support, help with day-to-day tasks such as transportation and housekeeping, personal care, and financial management, but not much financial support.

There are several factors in the ability to provide care including the number of children and their spouses, their geographic location, and whether or not they have the time to do so, without job or child rearing responsibilities interfering. It is important to note that because this study screened for those involved in their parents' care, this study may not accurately measure the level of care provided across the whole population.

Given that caution, this study shows that most respondents gave themselves high grades when it came to the care they provided to their parents and to how they coordinated among family including planning and coordinating care and providing financial support. They were less sanguine about everyone pulling their weight, even though different family members did not have the same ability to do so.

Another important finding is that the majority of adult children helped their parents with various aspects of financial management. This study does not indicate whether the help started when the parent was alone or before their spouse died. Most children provided help with all of their parent's finances, and of those who helped, the majority provided help for five years or more. The children were also most likely involved with planning, but this study does not explicitly define how much of the planning they took over or how they collaborated with their parents on planning.

Findings offer important insights for actuaries, the professional retirement community, the public, and caregivers:

- Those with assets below a certain threshold face wide ranging scenarios as they reach their mid-80s and beyond driven by their health and aging process. The need for assets can range from minimalistic to overwhelming based on the amount of care required and family support provided. On the other hand, the impact of the variation in other life expenses is less of a factor.
- For those who are not wealthy, retirement planning needs to be about more than just managing accumulated money. There are health and vitality uncertainties that need to be addressed that assets alone will not cover, and the impact of these uncertainties is highly driven by the role and participation of family.
- Families need to be prepared for the role of money management because most families will play this role at some point, and many will do so for a long period of time. The preparation does not require sophisticated financial training because most tasks required are routine, but families should prepare themselves for the dynamics and issues involved.
- In this research, we see the potential for discrepancies in how families grade themselves and how well they may do in caring for their parents. Respondents give themselves very high grades on various components of caring for parents. Qualitative work suggests that, while there are not many situations where families have serious problems coordinating care, there is often room for improvement. Since family involvement has such a profound impact on the well-being and the finances of the elderly, this gap needs to be explored further.
- As found in earlier studies, families provide other types of support, often for years. This research continues to suggest that it is important for families to approach this lack of attention by focusing on intergenerational family discussions. Perhaps in this context more realistic planning can occur as both the elderly and their family confront plans together.
- The most common support provided by children is emotional support and the most common regret children have looking back is not spending more time with their parents. In discussions about planning and family dynamics, it may be important to address the emotional connection with their parents and how important it is to focus on it.
- Planning for care is important. Most families give themselves high grades on working together, but qualitative research suggests that there are a number of instance where this does not happen. The one area where there could be room for improvement is to discuss the capabilities of family members to provide this care, especially if they do not reside nearby or have other obligations. Families sometimes resent the unequal roles played and perhaps this is a matter that can be discussed further.
- More broadly, families should evaluate the resources they have available to provide support for elderly parents, particularly the ability to provide care. Resources include the number of children in the mix and the availability they have to provide care. This is a part of the planning process that needs to be addressed. Data here suggests that children in the asset range of this study often provide the care or piece it together with outside support.
- Another useful strategy for planners to consider is a care road map with milestones. At what point will parents need their children's support, will additional support be needed, and will a nursing home be needed? The likelihood of these events is particularly salient when cognitive issues are involved. For each step, there needs to be a consideration for what family resources are available, how much financial readiness is there, and what defines the need to move to the next level?

Part of the planning process that families should consider is that the parents' Social Security will often be redirected to the nursing home. In qualitative research, we found that some nursing homes, who otherwise would not, will take Medicaid if the parents come in with assets. While there are details that parents will find out when they research homes, it would be good for consumers to be educated about them in advance. The retirement planning process can be improved by considering how long-term care can be paid for if needed and having a plan to develop the resources to pay for it. About one-third of the sample in this study were in assisted living or a nursing home.

This research again shows that morbidity is a major risk. The cost of a substantial period of paid long-term care can be a financial disaster. Long-term care seems more likely to lead to running out of money than a long life as retirees generally seem to manage their finances reasonably well unless they experience a period of paid long-term care.

In interpreting these results, it is important to understand the sample we studied a little more. This is a study focusing on people who died after age 85 and who did not have a partner at death. The respondents are people who cared for them and knew about their situation, mostly adult children, but some nieces, nephews, and neighbors. Ninety percent of the respondents are adult children or children of former partners.

There were more female than male parents represented in this study which is not surprising since there are many more women who are alone at death at ages over 85, because women live longer and are less likely to remarry if they lose a spouse. Adult children (and sometimes others) play an important role in assisting and caring for parents, often over a period of five years or more. The study offers no indication of how often such help is needed and the sample did not include children who had low involvement in their parents' care.

Note that the children were biological children and in-laws, with virtually no representation of blended families. The study shows that stepchildren are less likely to offer such support for five years or longer. More work is needed with larger samples.

There is a lot of variation in life paths and in the need for help, including the type of help needed and amount of time that help is needed. This study provides some data on these areas from the viewpoint of the helper.

AREAS FOR FURTHER RESEARCH

Family Resources Study. One area that could provide useful information is a study among families with parents in their 70s and 80s to assess the availability of family resources to care for parents. Across the population, what proportion have one versus multiple potential caregivers in the future, including those who are in the area and are available for support? How does this vary by socioeconomics and what proportion of those with inadequate support have the financial resources to supplement? How does it vary for elderly couples based on whether or not both need help? Based on this research, we can estimate the proportion of families prepared for future caretaking.

Nursing Home and Assisted Living Funding Gap Study. In the past, there have been numerous studies done on retirement readiness and the gap between needed and actual resources. Similar work has been done to measure the adequacy of life insurance. One type of thought leadership study that can draw more attention to the challenge of providing nursing care is a similar study with nursing home care. For those with parents ages 75-85, what resources are available to produce income for nursing care? The research can then be compared against nursing home costs and determine how much coverage the average family has for nursing homes based on average cost per state. We could calculate average coverage per month to determine the gap between this and how long a stay the respondent would like to be able to cover. Medicaid should also be factored in.

Pathways Through Retirement. The study shows us how different the lives of those at ages 85 and over are from those who are 20 years younger, and it also shows many individual differences among them. Further work is needed to understand the changes people undergo as they age and how they cope with them.

Family Segmentation Study. When it comes to planning for and providing care to parents, what types of family structures and plans are there, and which are most effective? This research can address the types of family dynamics that work in planning for care. What are the variables that define success whether they be advanced planning, family communication, a good diversity of roles and talents, family structure, and dedication/commitment? Are there certain types of professional backgrounds that work better? Does more parity in financial situations help? We suggest a qualitative study where a segmentation analysis would be conducted as well as measuring correlates of success. This research would also include blended families, solo agers, and couples needing help.

A “He Said/She Said” Family Dynamics Gap Study. In this study, there would be an exploration of the extent to which families have a false sense of confidence in how well they are doing in caregiving by talking with different family members in the same family as well as exploring these issues with gerontologists and social workers involved with the elderly. Knowing these gaps will be instructional in improving care. This research concept is triggered by the high grades families give themselves for communicating with each other and providing care, which we suspect may not reflect reality.

COVID-19 Follow-up Study. Given the impact that COVID-19 has had on the isolation felt by parents in institutional settings, research in the coming year could examine what impact it has had on assisted living and long-term care facilities. Will there be more reluctance to use such settings and what have been the lessons learned when it comes to caring for parents and the attention that they need?

Background and Methodology

BACKGROUND

For more than 20 years, the Society of Actuaries (SOA) has been actively involved in understanding the approach pre-retirees and retirees take risk management, financial planning and decision-making surrounding retirement and retirement-related issues. This work started in 2001¹ with the Risks and Process of Retirement Survey, a survey of people ages 45 to 80, which has been conducted biennially since its creation. The surveys have been supplemented by a series of studies that tracked what people were doing throughout retirement.

The SOA also conducted a series of focus groups in 2013² with people who (1) chose to retire, meaning they were not forced to retire due to ill health, disability, or job loss; and (2) had only a modest amount of assets and income. All the people in the study had retired within the previous 10 years. The study found that even though the individuals had retired voluntarily, most had been pushed into retirement by job or personal circumstances. Few of them retired to meet their dreams. The study also found that there were substantial gaps in retirement planning including at the time of retirement. Often people were focusing on short term cash flows, and some said they would deal with risks when they happened. However, the study also found that most participants were resilient and modified their spending as their major financial management approach.

In 2015, the SOA extended its research by conducting focus groups and in-depth interviews in the U.S. and Canada with people who retired at least 15 years before³. The goals of this study were to understand whether the strategies found in the 2013 study persisted and were working out, and to understand what shocks retirees were facing and how the retirees were dealing with shocks.

The study found that the most common shocks cited were home repairs and dental expenses. As before, the retirees used short-term cash flow strategies and dealt with risks when events happened rather than planning for them in advance. While the retirees were still resilient, they were not able to deal well with major long-term care events requiring paid care, divorce in retirement, or adult children needing help over a long period. This study found a very mixed situation, Americans and Canadians were able to absorb many of the shocks of retirement, but multiple shocks were much more difficult.

In 2017, the SOA studied those 85 years and older to further discover how retirement finances played out in the later years of life and what help they needed⁴. A big underlying question was whether things would fall apart for retirees at this late stage of life. Based on in-depth interviews with those over age 85 and their adult children, this study found that older Americans had mastered the art of balancing income and spending by being frugal and having less active lifestyles. Financial shocks were not a major issue, especially because Medicare and the Canadian system made health care costs more predictable. In this study, interviewees reported that family support was an important factor as health and independence declined, and being able to offer driving, cooking, and housekeeping services helped the elderly's finances and lives. Furthermore, participants were not well prepared for the potential of needing paid assisted living and long-term care, and most had not done adequate planning for these eventualities. It is important to remember that the sample for this study did not include those at higher asset levels.

Based on this previous research, it was felt that it was important to examine further how families coped with the final years of life by interviewing the children of recently deceased parents. This report represents the second phase

1 Greenwald & Associates, 2001. Society of Actuaries Report, Risk and the Process of Retirement Survey, Report of Findings

2 Greenwald & Associate, 2013. Society of Actuaries, Focus Group Report on Decision to Retire

3 Greenwald & Associates, 2015. Society of Actuaries Report, The Process of Retirement and Retirement Risk

4 Greenwald & Associates, 2017. Society of Actuaries Report, Post-Retirement Experiences of Individuals 85+ Years Old

of a two-phase research effort being conducted on these issues. The first part of this research, completed in 2019, included in-depth interviews with 40 of these respondents that focused on how they managed the progression from having relatively healthy parents to their parents' eventual death in the United States and Canada. The interviews probed the aspects of support the families provided as parents became more dependent.

The study found that end-of-life scenarios that children described with their elderly parents varied greatly depending on the progression of illness and cognitive decline, and the resources that the parent and the family had to use to handle the aging and eventual death of their parents. Despite the fact that children almost always eventually took over their parents' finances, there was very little planning in advance. In most cases, the physical and emotional toll that care required was far greater than children expected.

The ability to care for parents was also driven by the nature of family dynamics and how well families coordinates care. Placing a parent in a nursing home is a difficult decision, although one more easily made when there is cognitive decline. Cognitive decline is often less sudden and the need for care more apparent. Some families provided care at home with a combination of family support and outside aides. When looking back, children remembered the emotional toll more than the financial.

This next phase of the research is an online survey that further explores these issues. This is important because the results of qualitative research reflect a relatively small number of interviews and contains anecdotal information. The survey sheds light on the prevalence of these findings among this population.

METHODOLOGY

To achieve its goals for the quantitative portion of this study, the SOA commissioned a 20-minute online survey with 602 children of recently deceased parents. The survey was administered in January of 2021. Participants consisted of 55- to 75-year-old adults with deceased elderly parents, stepparents, in-laws, aunts or uncles, friends, or neighbors whom they cared for at least to some extent. If multiple relatives met the criteria, the respondent was asked for the most recent deceased, however quotas were set to prioritize subjects of the research who were in-laws, stepparents, were over 90, and needed long-term care. For the purposes of the study, the deceased parent or other relative met these conditions:

- Passed away in the last 5 years and were 85 or older when they did.
- Did not have a spouse or partner at the time of death.
- Had no more than \$400,000 in financial assets at the time of death.

The specific sample breakdown, regarding the relationship of the deceased subject of the interview to the interviewee is shown in Table 1.

Table 1
PARTICIPANTS RELATIONSHIP TO THE DECEASED

Relationship	Percent of Participants
Deceased was a biological female parent	57%
Deceased was a biological male parent	17
Deceased was a female in-law	13
Deceased was a male in-law	2
Deceased was a stepparent	<.5%
Deceased was an aunt or uncle or other relative	7
Deceased was a neighbor or friend	3

It is not surprising that there are more female than male parents in the sample since women tend to live longer and are more likely to be widowed than men.

Because the overwhelming majority of participants referred to parents or in-laws, for purposes of this study we will refer to the deceased subject of the study as “parent.”

The questionnaire for this study appears in the Appendix.

The deceased parents of participants had a variety of final living arrangements: in their own residences, with family, or in continuing care retirement communities (CCRCs), assisted-living facilities, or nursing homes.

CONSIDERATIONS RELATING TO THE SAMPLE

As in any study, the characteristics of the sample have an impact on the results. The interview sample includes people from varied cultural backgrounds, family relationships, and social situations. The parents of the older respondents in this study were born in the 1920s and 1930s and thus:

- Many of the elderly couples and widows spent their adult years in households where women did not work full-time outside of the household and often were not responsible for handling the finances.
- Many were children in the Great Depression or had parents who imparted a lifestyle based on experiences of the Great Depression. As a result, they may generally have lower financial expectations than baby boomers.

It is also important to realize that the sample does not completely represent the elderly population of the country. The deceased parents only included the last to die in a household. Respondents could not have a parent who died with over \$400,000 in assets. This does impact the responses to a number of questions. The non-wealthy elderly may be more likely to receive care from family than from paid assistants. Adding to this tendency, respondents were screened for having some role in caring for their parents, thus eliminating a sample where parents did not have children involved in their care. Given these factors, children in this study had more contact with their elderly parents than found in the general population.

Overview of Survey Findings

HEALTH ISSUES THAT OCCURRED WITH AGING

A majority of respondents' parents were coping with some type of health issue such as cognitive decline, cardiovascular events, skeletal or joint problems, hearing loss, or balance and/or visual issues, some of this was driven by the selection of the sample that were alone and needed support for children.

As found in the in-depth interviews, the risk of falling was the biggest factor affecting health and vitality, and injury due to fall was common as well. This study also found that over one-third cited cognitive decline as a major factor, and another third cited it as a minor factor on their parents' health and vitality. As seen in the qualitative work, cognitive decline has major implications on care later in life. These issues commonly began when parents hit their 80s. Vision problems, chronic disease, and depression were the problems most likely to start before this age, although still only a minority of the time.

Cognitive decline was slightly more likely to first occur before care was provided as did general slowdown. These conditions, which often occur gradually, may not require care at first or may go unnoticed. The inability to walk tended to first occur far more often when care was already being provided than before.

IMPACT OF COVID-19 ON DECEASED PARENTS

One in five had parents who were alive after the COVID-19 pandemic began and fewer than one in five of these parents died from complications of the virus. Over half reported that their parents were more isolated due to the pandemic and close to half reported that they were unable to visit their parents for some period before they died, not necessarily from COVID-19.

IMPACT OF LOSS OF SPOUSE

Nine in ten of the deceased parents were widowed at the time they passed. Fewer than one in ten were divorced. Not surprisingly, close to half of the aunts and uncles who were cared for by respondents in this study were never married.

One factor that affects the role children play is the level of responsibility that the parent had for finances during the marriage. More than half of the time, the deceased parent had or shared this responsibility, with most of the deceased sample being female in what were often traditional households. Less than half of the time the spouse was a primary or equal breadwinner. The qualitative work suggests that some financial tasks performed by the widowed females were more purchase decision focused rather than money management related.

For the most part, the death of the spouse did not have a major impact on the deceased subject's ability to manage their lives. This is not surprising given that qualitative interviews suggested that the spouse was elderly as well and could not provide support, and in many cases required support as well. Similar results were found when it came to managing household finances.

HOW FINANCES CHANGED DURING AGING

About one-quarter felt that their parents' finances were much worse, but a majority felt that their finances were the same or better before they died compared to the time that they were 65 years old. Needing nursing care or long-term care was the event that had the most impact on making their parents' finances worse, having a major impact on half. Needing assisted living or help at home had an impact on many as well. Over four in ten said that the death of a spouse had a major negative impact on their parents' finances, although in a different question, far fewer felt it affected their overall financial security.

In contrast, day-to-day expenses throughout life had less of an impact, with fewer claiming that overspending on non-essentials affected their parent's finances in a major way. In fact, most confirmed that spending less on non-essentials had at least a minor impact on helping their parents' finances. Qualitative work concurred that older Americans spend very little in their later years, driven by a decrease in activity, assuming they don't need paid care. Supporting family also affected few of the parents financially although we saw a few instances of it in the qualitative work.

Only one in five claimed that medical expenses had a major impact on their parents' finances, which confirms what we heard in the qualitative research, where respondents claimed that Medicare and Medigap coverage does fairly well. While the death of a spouse had some negative impact on the finances of most parents, this event also had at least minor positive effects on many who no longer had a spouse to support, often with a medical condition.

FINANCIAL MANAGEMENT SUPPORT PROVIDED BY CHILDREN

As found in the qualitative research, most respondents reported that at some point they took over their parents' finances, most commonly managing daily activities including paying bills and balancing the checkbook. Children were less likely to get involved in financial management such as budgeting and investment management, although significant minorities did. Qualitative research supported this because in some instances there were either no investments to manage or an advisor was doing it. When children did manage finance, most of the time it was for more than five years.

The most common cause for needing to take over their parents' finances was cognitive decline, with a majority citing it. As discussed earlier, children most of the time reported that their parents had declined cognitively before they required care. Our qualitative interviews cited instances of children taking over finances for parents who were declining cognitively but did not necessarily have extensive dementia. Rather, in these instances, the decision was often made based on judgments of the competence of parents to manage daily finances and was sometimes triggered by mistakes they were making or difficulties they were having with technology or visiting their bank.

HOUSING DURING RETIREMENT

Almost half say that their parent moved during retirement, with one in five reporting that their parent moved more than once. Common reasons parents had for moving related to being able to better manage their residence, but almost as many moved to downsize. Close to four in ten moved to be close to family. Most of the parents who resided in their home were there alone, but a small percentage resided with children and a very small percent with a caregiver.

TASKS PERFORMED BY FAMILY

Close to two-thirds of respondents or their families aided in the activities of daily living at some point, with one in five doing so for over five years. Qualitative research suggested that the range of support provided varies a great deal from a small amount to full-fledged nursing care.

Most children provided emotional support for their parents, with most doing so for five years or more. About half of parents received support when they still had semi-active lives, being taken places including shopping and to the doctor. A large majority reported that they or another family member provided assistance with finances, acted as Power of Attorney, or acted as Health Care Power of Attorney.

Respondents were asked which relatives were responsible for various tasks. A large majority of the time, the respondents themselves were involved in various responsibilities including making decisions about nursing homes or assisted living, providing company, performing tasks and chores, money management, being named on a medical directive, and having Power of Attorney. Some of this outcome may have been a function of who qualified based on screening questions.

However, spouses, brothers, and sisters were also involved in these responsibilities, and when combined, provided roughly the same level of participation in most areas except for money management, where they were far less involved. While not being involved nearly as often, it was not uncommon for nonpaid non-relatives to care for the parents, playing a major or critical role for one in five parents.

FAMILY DYNAMICS

A large majority of respondents reported that the financial planning and physical care provided to their parents was very or somewhat effective. For the most part, respondents gave themselves and their families high grades when it came to caring for the deceased parent. When asked to grade themselves and their families on various criteria related to the care they provided to the parent, respondents gave high grades, with between half to three-quarters giving themselves an “A” and close to nine in ten giving themselves an “A” or a “B”.

Respondents gave the family dynamic the highest grade on agreement on medical decisions, but also graded themselves and their family relatively highly on each doing what they were best at, planning, communicating well, and agreeing on roles. The area where respondents themselves reported the lowest grades was on everyone pulling their weight, with close to one quarter grading the family with a “D” or “F” on this dimension. We heard complaints about this in the qualitative work. Also, about one in six reported that they had a dispute with a family member over money, something we saw in the qualitative research.

IMPACT OF FRAUD

Fraud is a common problem facing the elderly and even a small percentage of fraud represents significant financial loss. In this study, 12% of children said that their parents were victims of fraud. Most of the time it was perpetuated by someone they knew, most likely a family member but also likely was a non-family member they knew. Less often it was by their financial advisors or care providers. The qualitative research found several instances where fraud by financial advisors was reported.

ASSISTED LIVING

A large percentage of respondents reported that their parents’ need for support occurred gradually. A very small percentage needed assisted living or long-term care before age 80 but most eventually needed it. The most common need prior to this age was to be driven places, applying to one quarter of this population.

Roughly half of the respondents’ parents first needed support in their 80s with household chores, being driven places, and assistance with walking.

The qualitative study suggests that care begins in the home. Research from this study suggests that a large majority of the time this care was provided completely or mostly by family members, with paid support rarely having most of the responsibility. Qualitative work suggests that parents often had lost friends and that the companionship of family was important.

The most common factors that led to placing the parent in an assisted living facility, with close to half citing them, were general frailty, cognitive decline, or a medical event. Close to half also did so to provide their parent with a better quality of life. It was less common for parents to be placed in assisted living because they could not provide the care at home or based on the recommendation of a doctor, social worker, or other professional.

About half the time, the parent was a participant in the decision to move to an assisted living facility. Among those who did not participate in the decision, only about one quarter put up strong resistance to going into assisted living.

NURSING HOME DECISION

Most of the events that led to the decision to place a parent in a nursing home were similar to the ones that led to assisted living. Roughly half the time these included a medical event, cognitive decline, and general frailty. In the in-depth interviews, the decision was more urgent when it was due to cognitive decline. More often than with assisted living, the decision to place a parent in a nursing home was based on a recommendation by a doctor, social worker, or other professional. More than a quarter of the time the decision was made because at-home care was too physically and emotionally taxing or because housing was not suitable to care for the parent. Although not tested here, qualitative work suggests that this decision is very stressful.

Not surprisingly, the parent was less involved in the decision to go to a nursing home than they were with assisted living, but still played an active role about one-third of the time. Parents not involved in the decision resisted about half the time, more often than with assisted living.

PAYING FOR LONG-TERM CARE

Retirees have a variety of income sources, with Social Security being the only income source available to nearly all of them. Social Security was far more often used as a source of funding to pay for long-term care than any other. This was consistent with what we heard in the qualitative research, where nursing homes often insisted that Social Security payments be redirected to them as a condition of admission. More than one-third of the time the parents' pensions played a major role in funding long-term care while personal assets, outside the sale of the home, were used about half the time.

Over one-third of the time Medicaid played a major role, and half of parents who financed their long-term care with Medicaid needed to spend down assets to qualify. As we have seen in other research, the incidence of long-term care policies is low and only one in six say it plays a major role in paying for long-term care including combo life insurance policies. Qualitative research suggests that children do not often provide financial support for their parents, and few paid for nursing homes.

OVERALL EVALUATION

Respondents gave themselves and their families high grades across a variety of areas when it came to caring for their parents in their final years. Majorities graded themselves with an "A" when it came to preparing for funerals and final expenses, financial management, making correct medical decisions, taking care of the parents, providing emotional support, planning for final years, and the amount of time spent with the parent. The only area where fewer than half gave themselves an "A" was preparing for medical changes.

When asked what the one thing they could have done better, by far the most common response given was spending more time with their parents. Qualitative research suggested that spending time with the parent was the most important thing children could have done. Only a small percentage of children had regrets in other areas such as getting involved in finances earlier or planning sooner.

Survey Findings

HEALTH ISSUES THAT OCCURRED WITH AGING

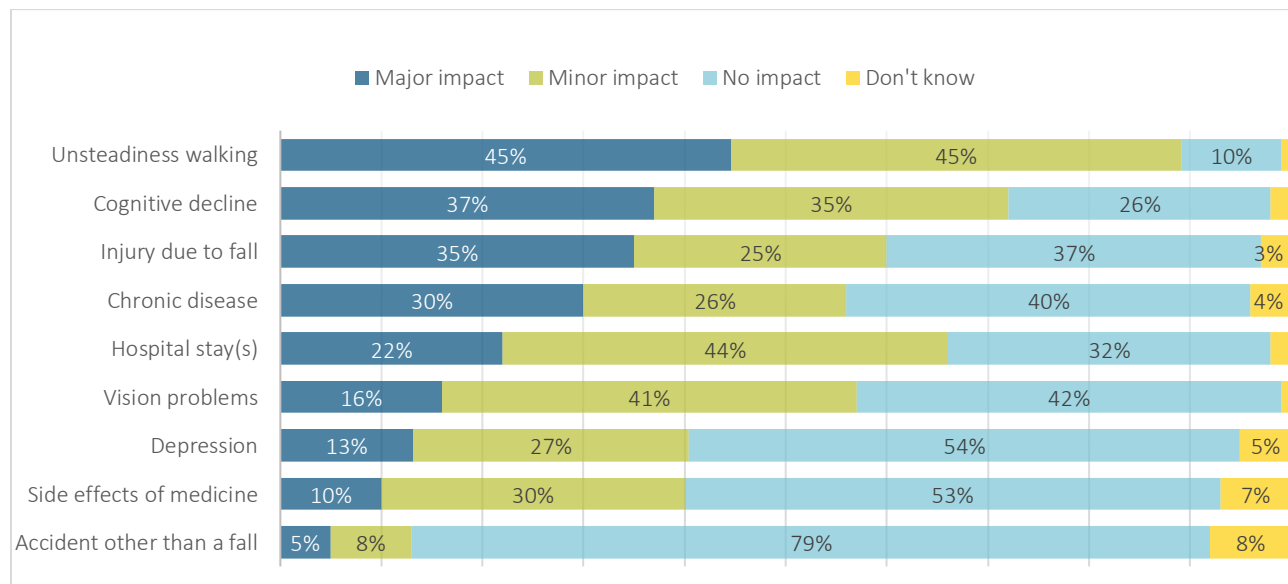
As found in the qualitative research, children indicated that almost all their parents over age 85 were coping with some type of health issue such as cognitive decline, cardiovascular events, skeletal or joint problems, hearing loss, or balance and/or visual issues. However, the rapidity of onset and severity of these maladies varied greatly, making the timing of future needs hard to predict.

Respondents were asked to rate the impact that cognitive and physical conditions had on their parents’ health and vitality. As found in the in-depth interviews, a major factor for almost half of parents (45%) was unsteadiness walking – the risk of a fall rather than falling itself. This risk is not unfounded, with close to one-third citing injury due to a fall as having a major impact. This study also found that over one-third (37%) cited cognitive decline as a major factor, and another third cited it as a minor factor (35%) on their parents’ health. This is important because, as discussed later, cognitive decline has unique consequences on care later in life. The next most common factor experienced by three in ten parents was chronic disease.

She fell five times, I think, and out of the five times, three times we had to take her to the hospital. —Toronto

Figure 1

Q6. OVER THE YEARS, HOW MUCH IMPACT DID EACH OF THE FOLLOWING HAVE ON YOUR [RELATIVE]’S HEALTH AND VITALITY. TOTAL (N=602)



Parents experiencing cognitive decline and depression were more apt to be victims of fraud. Parents experiencing cognitive decline were also more likely to experience depression. Male parents were more likely to be affected by chronic disease than female parents.

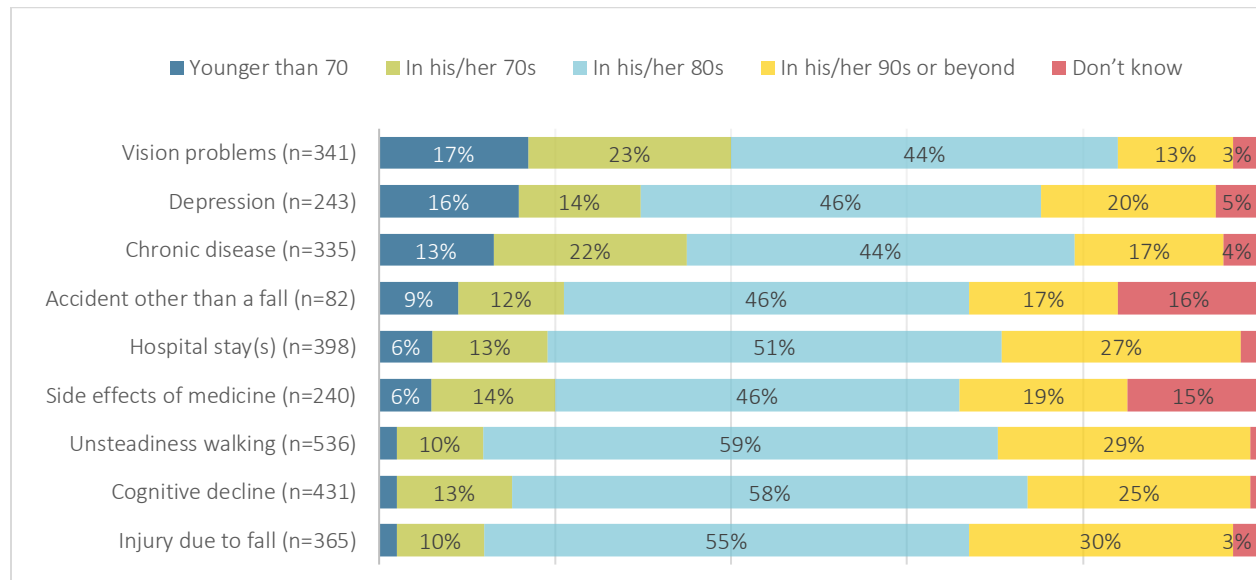
Respondents were also asked the age of onset for various conditions that affected their parents’ health and vitality. The most common age period for onset for conditions discussed above was in the parents’ 80s with over half citing that unsteadiness walking (59%), injury due to fall (55%), and cognitive decline (58%) occurred at these ages. It is important to note that these numbers incorporate the fact that 40% of parents did not survive into their 90s. Children reported that the most common issue which manifested earlier in their parent’s life was vision problems.

Of the 57% respondents whose parents had at least minor vision problems, 40% reported that they occurred before age 80. Among the 30% of parents who experienced chronic disease, 35% experienced it before age 80 and the same percent of those who experienced depression, did so before this age.

Figure 2

Q7. ROUGHLY HOW OLD WAS YOUR [RELATIVE] WHEN THESE ISSUES FIRST AFFECTED HIM/HER?

RELATIVE IMPACTED BY CONDITION/INJURY



The tendency of these health events to occur before or during care varied based on the nature of the parent’s condition. The inability to walk tended to first occur far more often after care was provided (43%) than before (9%) as did unsteadiness walking (37% before and 51% after). Cognitive decline first occurred fairly evenly before care was provided (37%) and after (33%) as did general slowdown (51% before and 45% after). However, hearing and vision problems were far more apt to occur before care was provided than after, perhaps because these problems tended to start earlier in life.

[My father] could not live by himself after my mother passed. He had macular degeneration in his eyes and hearing aids in both of his ears, and we didn't think it was a good idea for him to be by himself, so he moved in half of the week at my brother's and half of the week at my house. —Deerfield

She needed two caregivers. It was too much. It was not set up as assisted living for her needs. ... She couldn't walk or do things for herself, I guess. —Deerfield

We had just a family meeting to let them know that mom is declining. [This was] two years [ago]. She wasn't mobilizing like she normally did, moving around the house, cooking and doing all that. —Memphis

Male parents were more apt to experience hearing problems than females and those showing cognitive decline were more apt to need long-term care through an assisted living facility or nursing home and be cared for more than five years by their children. Also, respondents who cared for deceased non-parent subjects, were less likely to report that they knew about the person experiencing vision problems or depression.

Figure 3

Q3. WHEN DID YOUR [RELATIVE] FIRST EXPERIENCE THE FOLLOWING, IF AT ALL?
 DECEASED MALE (N=126); DECEASED FEMALE (446)

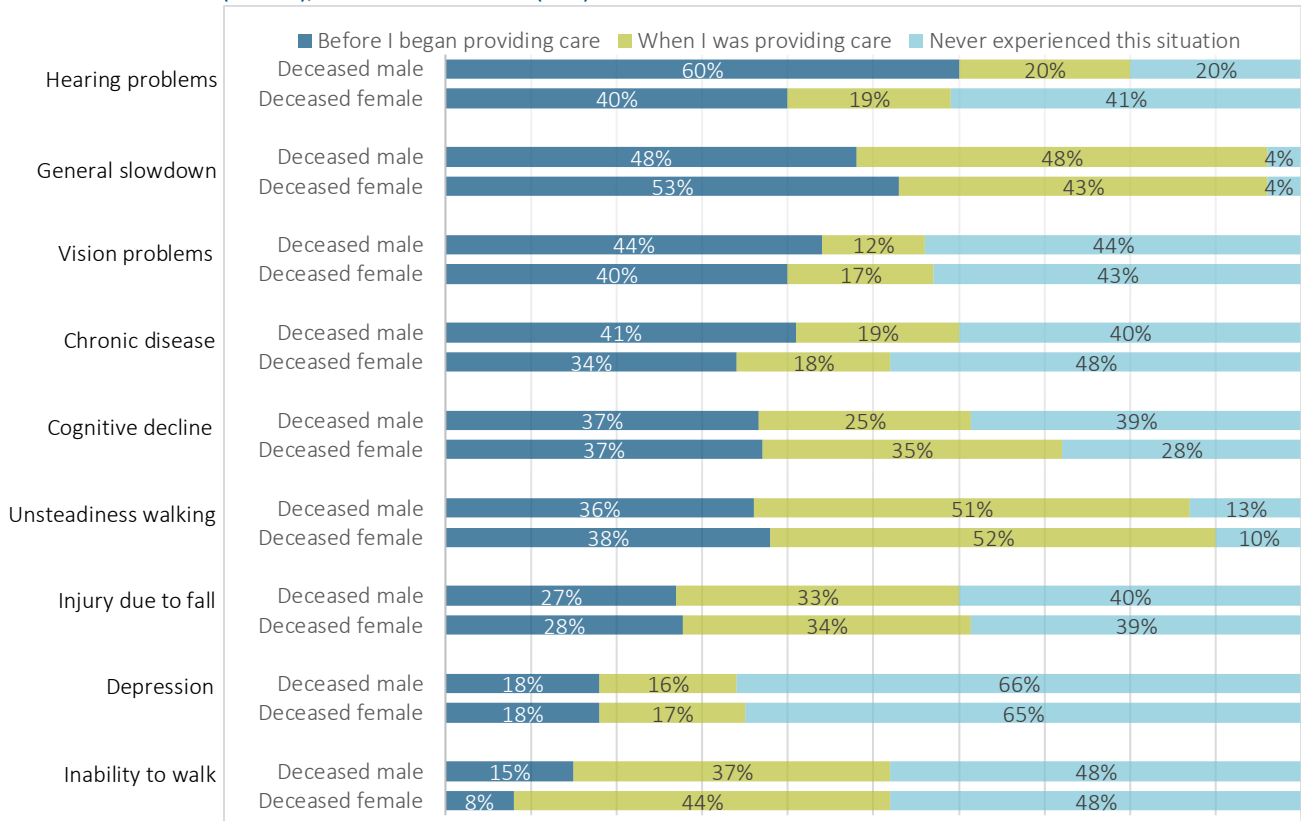


Figure 4

Q3. WHEN DID YOUR [RELATIVE] FIRST EXPERIENCE THE FOLLOWING, IF AT ALL?
LONG TERM CARE (N=316); NO LONG-TERM CARE (286)

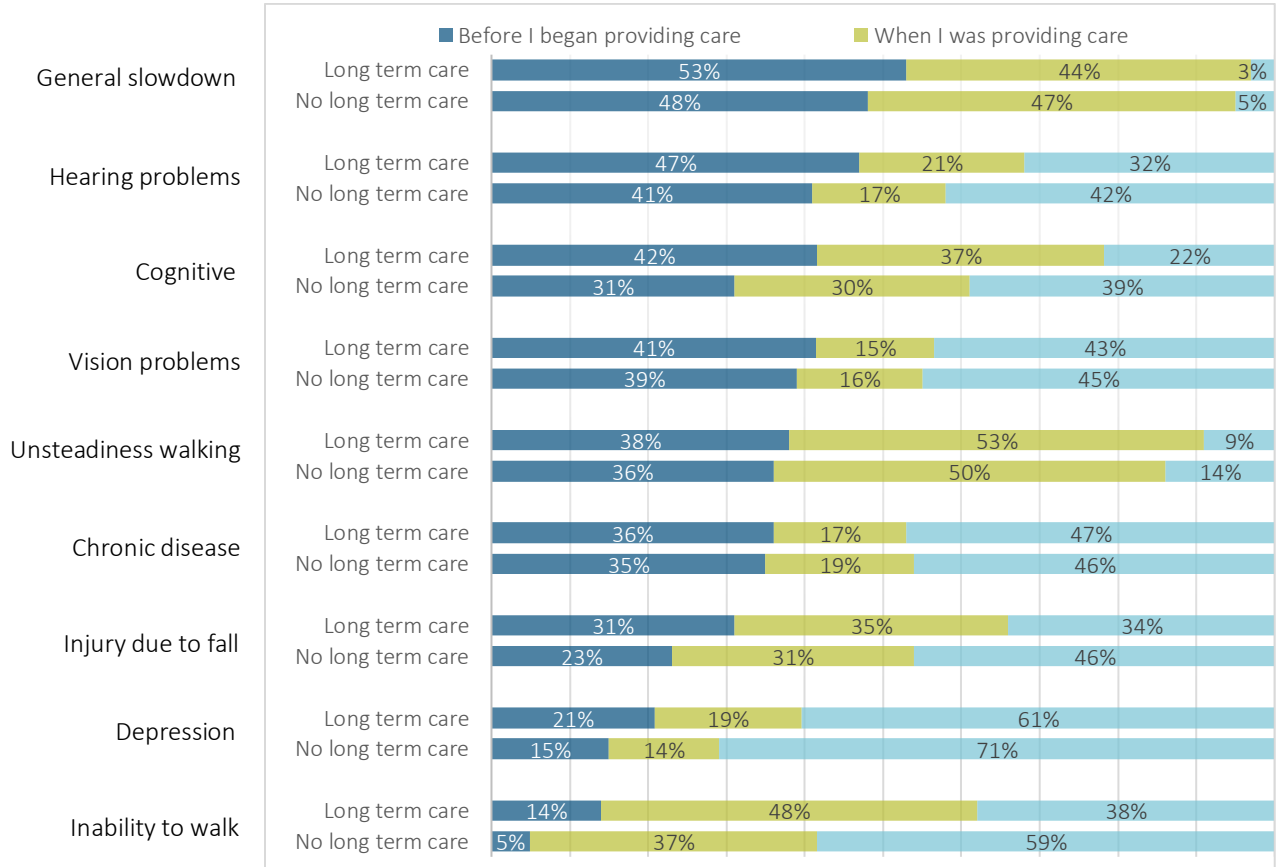


Figure 5

Q3. WHEN DID YOUR [RELATIVE] FIRST EXPERIENCE THE FOLLOWING, IF AT ALL?
 COGNITIVE DECLINE (N=422); NO COGNITIVE DECLINE (180)

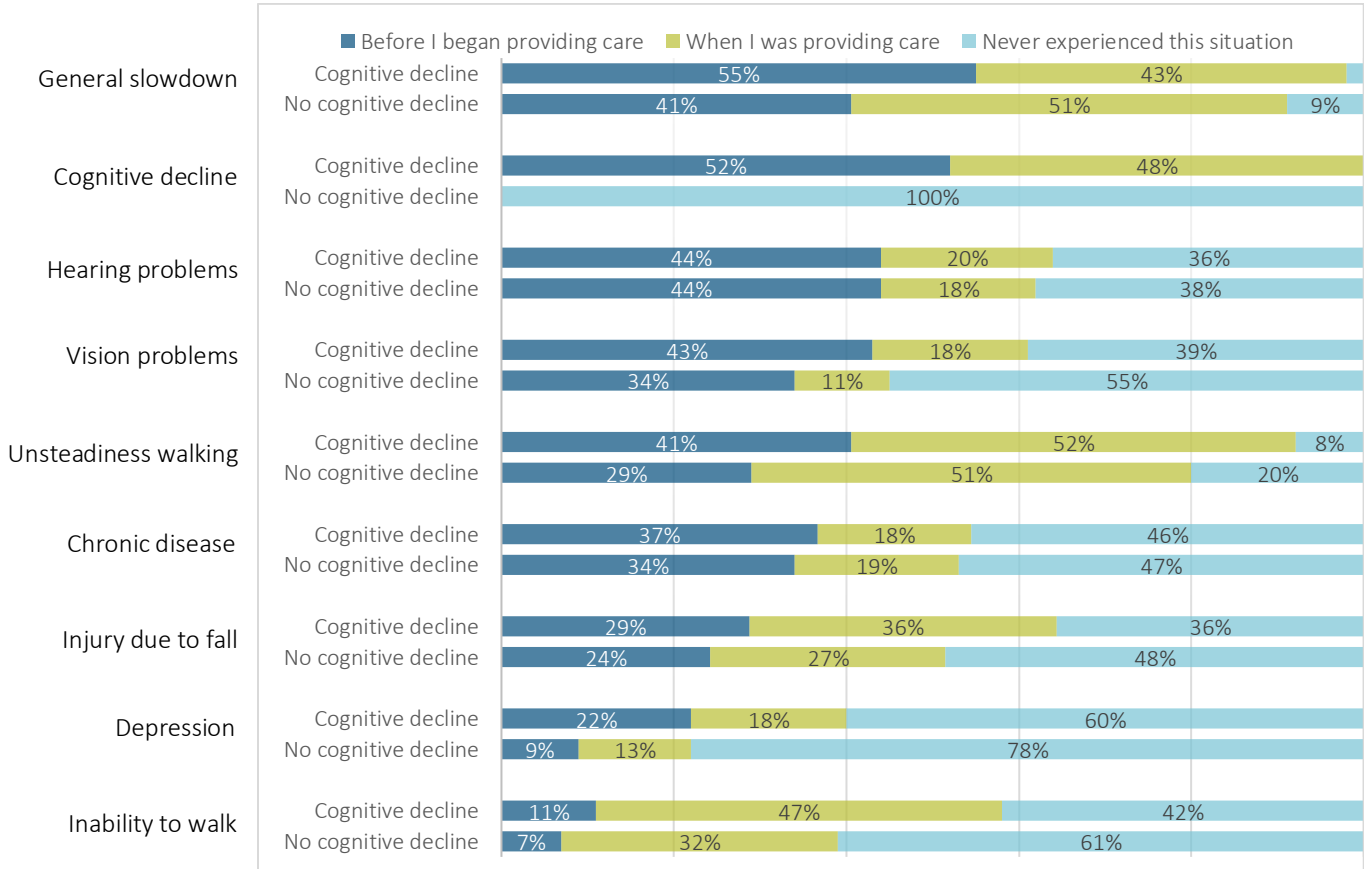
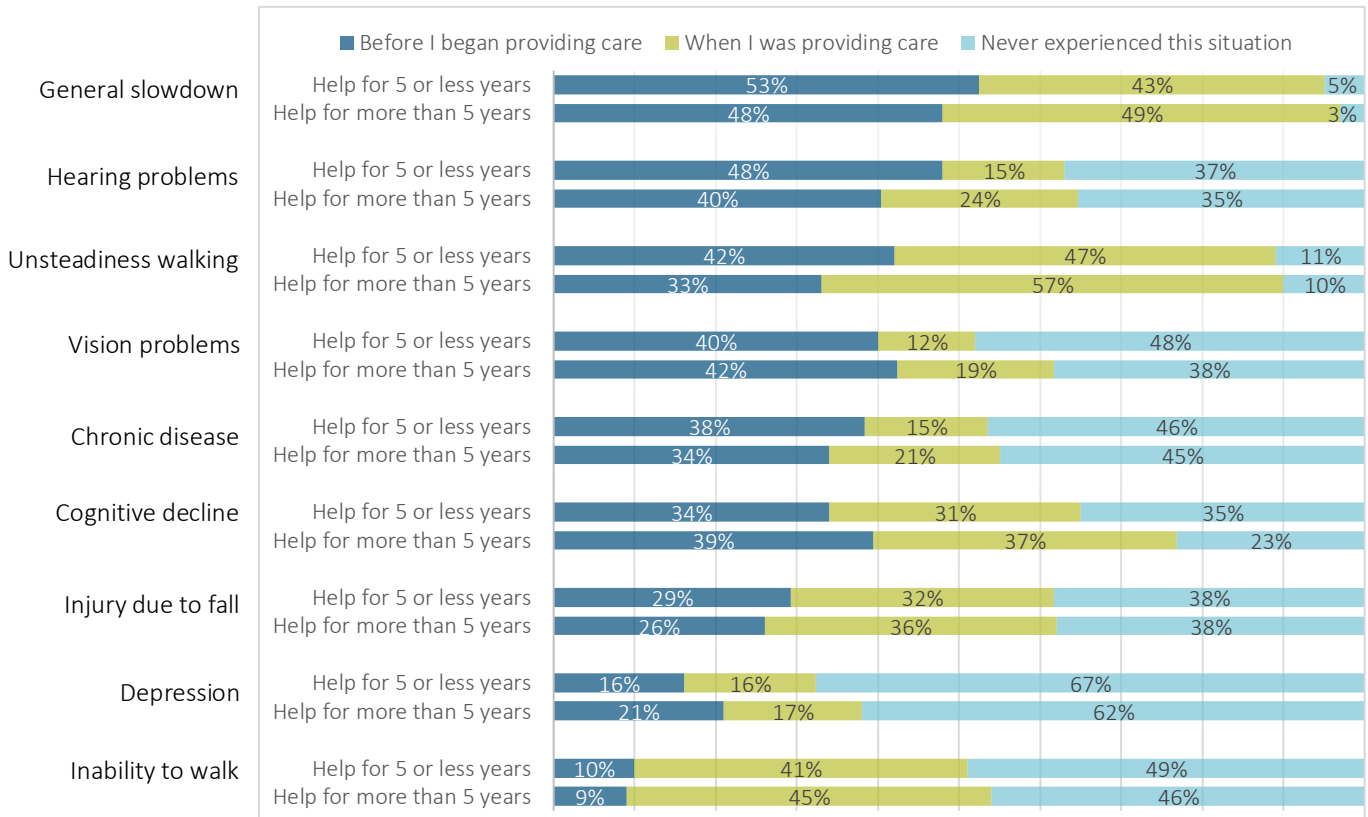


Figure 6

Q3. WHEN DID YOUR [RELATIVE] FIRST EXPERIENCE THE FOLLOWING, IF AT ALL?
 HELP FOR 5 OR LESS YEARS (N=285); HELP FOR MORE THAN 5 YEARS (286)



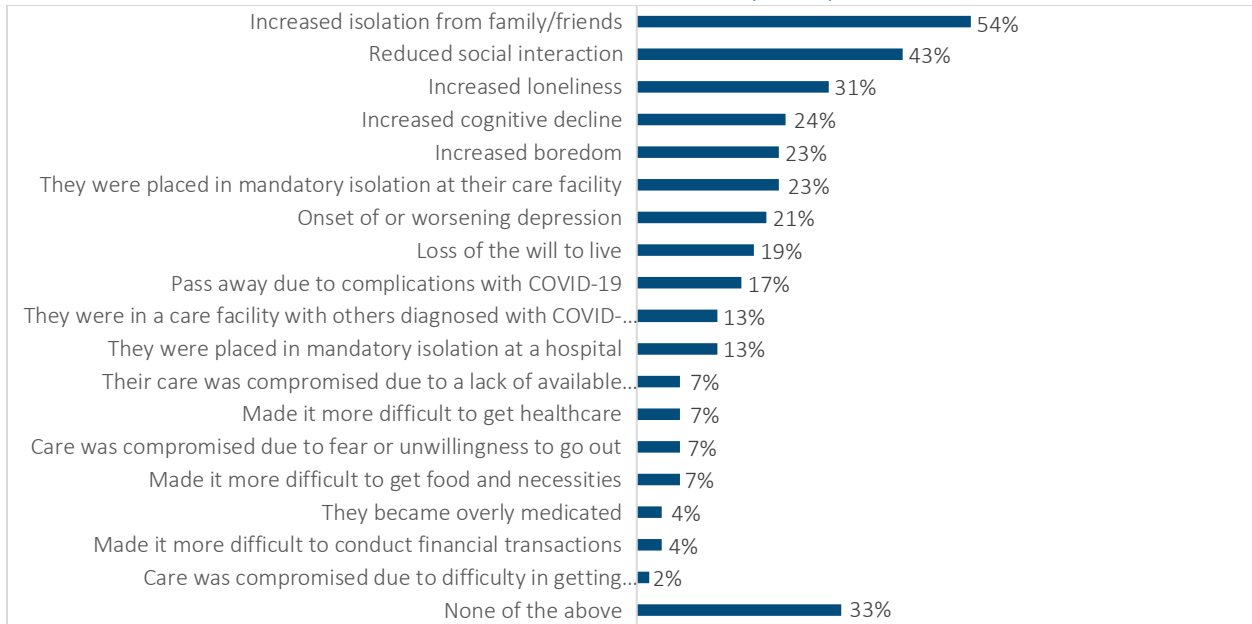
IMPACT OF COVID-19 ON DECEASED PARENTS

Because this study covered any parent who passed away in the past five years, only 20% of the sample had living parents during the COVID-19 crisis, and 17% of these parents passed away due to COVID-19.

Figure 7

Q39 AND Q40. DID THE COVID-19 PANDEMIC IMPACT YOUR [RELATIVE] IN THE FOLLOWING WAYS? PLEASE SELECT ALL THAT APPLY.

RELATIVE PASSED AWAY DURING OR AFTER FEBRUARY 2020: TOTAL (N=123)



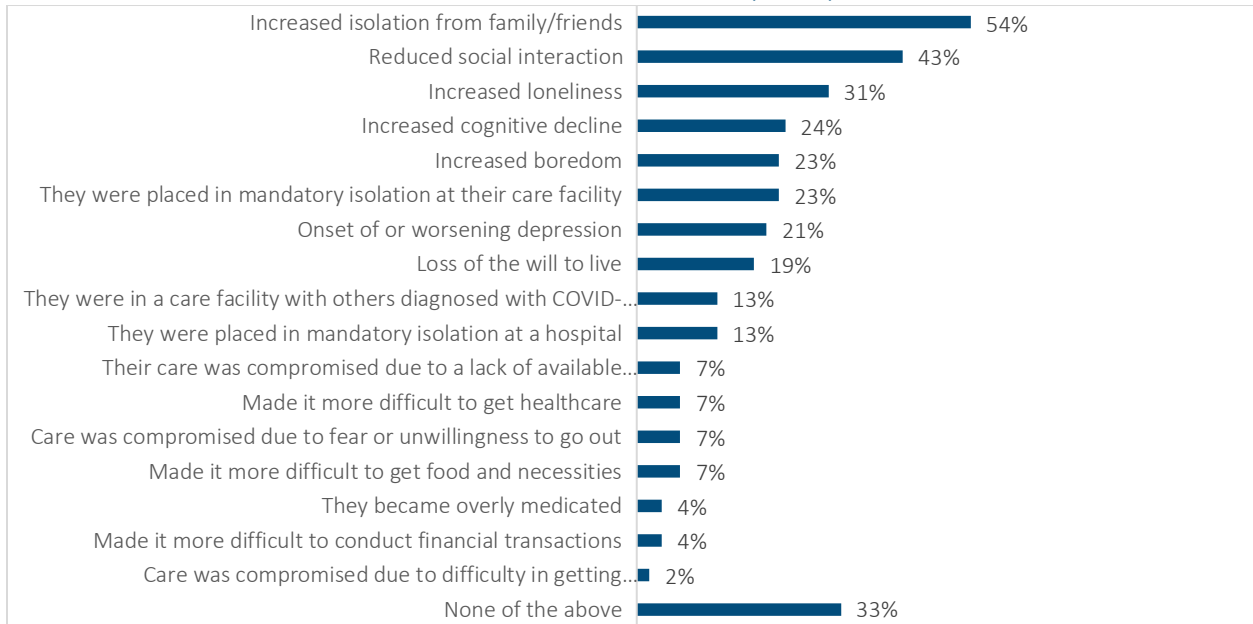
When asked how COVID-19 affected their parents, the biggest impacts were social effects, increased isolation from family and friends (54%), and reduced social interaction (43%). Smaller numbers report that their parents experienced loneliness (31%) and boredom (23%).

One critical finding in this research was that for a significant minority of parents, the COVID-19 crisis had an impact on cognitive and psychological decline. Almost one-quarter (24%) reported that the virus caused increased cognitive decline for their parent. Another fifth (21%) reported that it brought on or worsened depression for their parent and resulted in the loss of the will to live (19%).

Figure 9

Q40. DID THE COVID-19 PANDEMIC IMPACT YOUR [RELATIVE] IN THE FOLLOWING WAYS? PLEASE SELECT ALL THAT APPLY.

RELATIVE PASSED AWAY DURING OR AFTER FEBRUARY 2020: TOTAL (N=123)

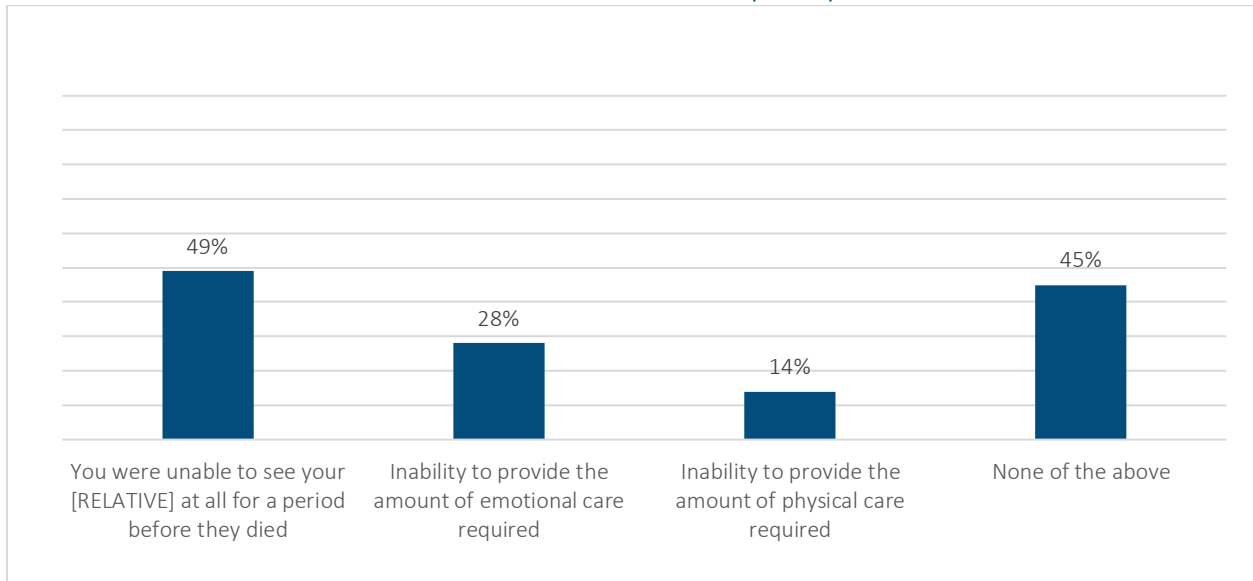


In addition to these various affects, half of those (49%) who lost a parent after February 2020 reported that they were not able to visit their parent for a period before they died because of the pandemic, and over one quarter (28%) reported being unable to provide the emotional care needed.

Figure 10

Q41. DID THE COVID-19 PANDEMIC IMPACT YOUR ABILITY TO CARE FOR YOUR [RELATIVE] IN THE FOLLOWING WAYS? PLEASE SELECT ALL THAT APPLY

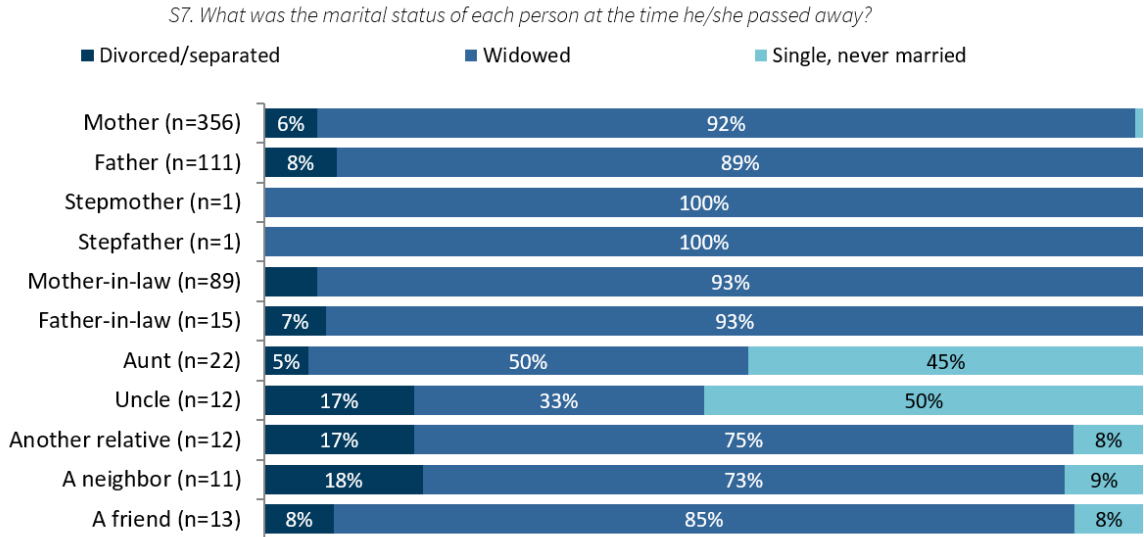
RELATIVE PASSED AWAY DURING OR AFTER FEBRUARY 2020: TOTAL (N=123)



IMPACT OF LOSS OF SPOUSE

Nine in ten of the deceased parents were widowed at the time they passed away. Fewer than one in ten were divorced. Not surprisingly, close to half of the 34 deceased aunts and uncles who were cared for by respondents in this study were never married.

Figure 11

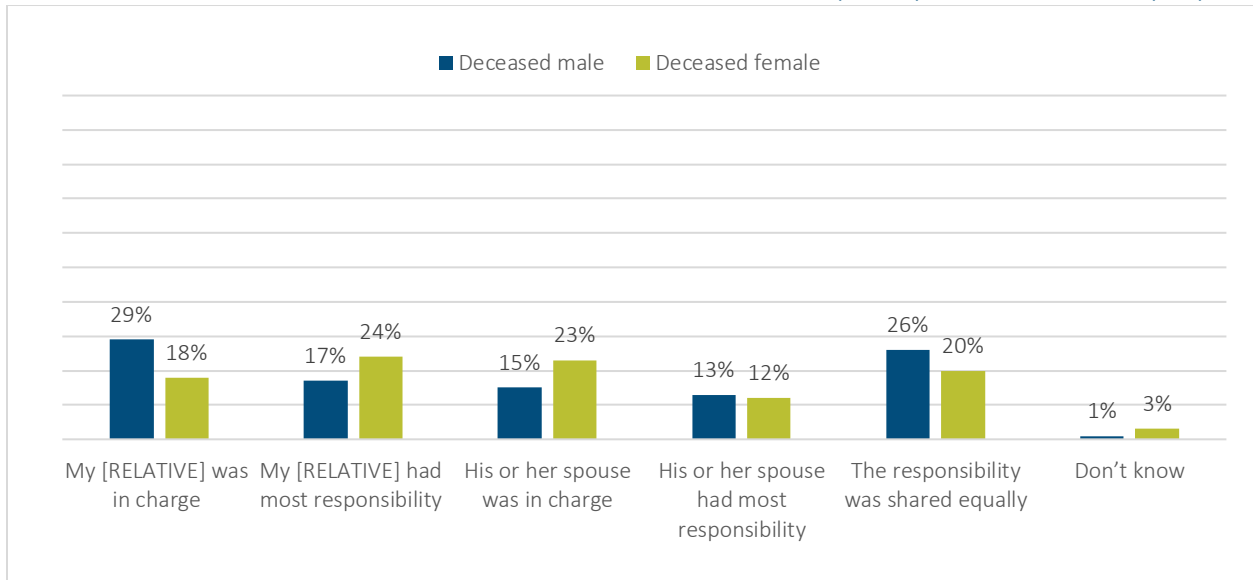


Respondents were asked about the role their parents played in managing their household finances when they were married. Over four in ten (43%) said that their parent was in charge or had most of the responsibility while one-third (33%) said that their parent’s spouse did. Another one-fifth (21%) said that the responsibility was shared equally. Children were more apt to say that their parent was completely in charge if their parent was male (29%) than if they were female (18%), not surprising given these households were more likely to have traditional marriages.

Figure 12

Q2. DURING YOUR [RELATIVE]’S MARRIAGE, WHICH BEST DESCRIBES THEIR ROLE IN MANAGING THE HOUSEHOLD’S FINANCES?

THE RELATIVE WAS WIDOWED OR DIVORCED/SEPARATED: DECEASED MALE (N=121); DECEASED FEMALE (433)



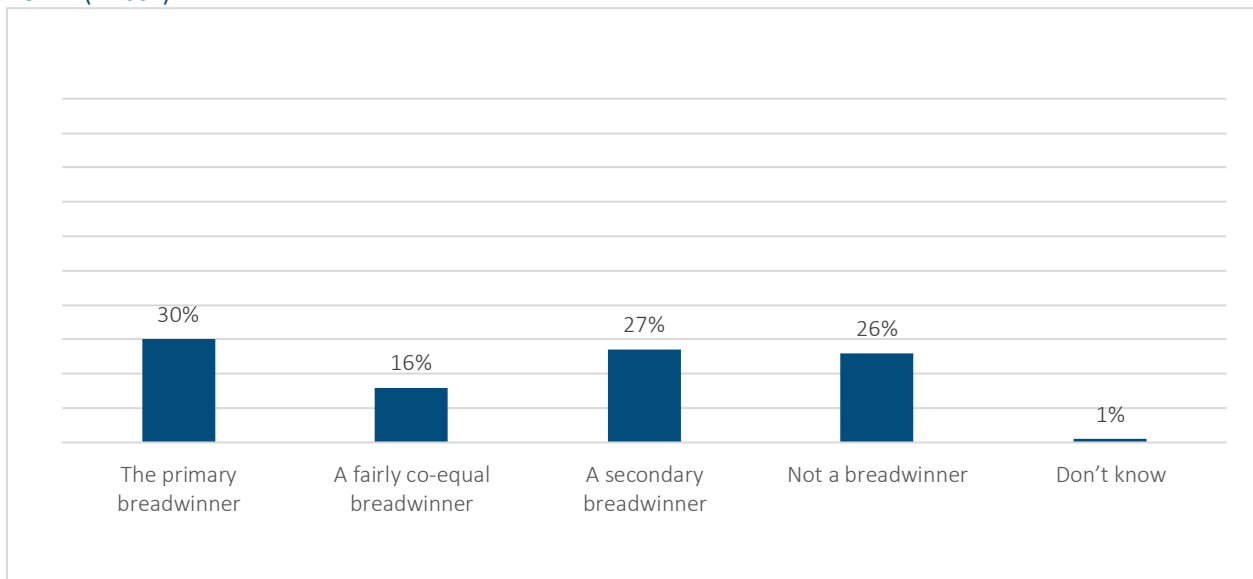
Respondents were also asked if their parent was the breadwinner. Three in ten said that the deceased parent was the primary breadwinner, but over half (54%) claimed that their parent was either a secondary breadwinner or not a breadwinner. This is also not surprising given that over seven in ten of the parents discussed in the study were female, and females were less likely to be primary or secondary breadwinners (29%) than males (98%).

[When father died] it didn't affect [mother] at all [financially]. She was the one that saved all their money and they were living on whatever she would get monthly in Social Security. So she lived the same. —Deerfield

Figure 13

Q1. DURING HIS OR HER ADULT WORKING YEARS WAS YOUR [RELATIVE]...?

TOTAL (N=602)



For the most part, the death of a spouse did not have a major impact on deceased subjects’ ability to manage their lives. This is not surprising given that qualitative interviews suggested that spouses were elderly as well and could not provide support, and in many cases required support as well. Only 14% of children claimed that their parents’ spouses’ death had a major negative impact on their parents’ overall financial security and another 20% claimed it had a minor negative impact. Over half claimed that it had no impact (38%) or a positive impact (14%) on their parents’ financial security. Similar results were found when it came to managing household finances, transportation, or health management. Not surprisingly given the traditional roles of these parents, the death of the female spouse was more likely to have a negative impact on the surviving spouse’s meal preparation and the death of a male spouse negatively affected the ability of the female spouse to secure transportation. Qualitative research suggested that not all of the women of this generation drove.

[When she died] it didn’t have any impact on him financially. Emotionally, of course, it did. ... He got sick ... he ended up in a wheelchair, so I think he was probably ... affected. —Deerfield

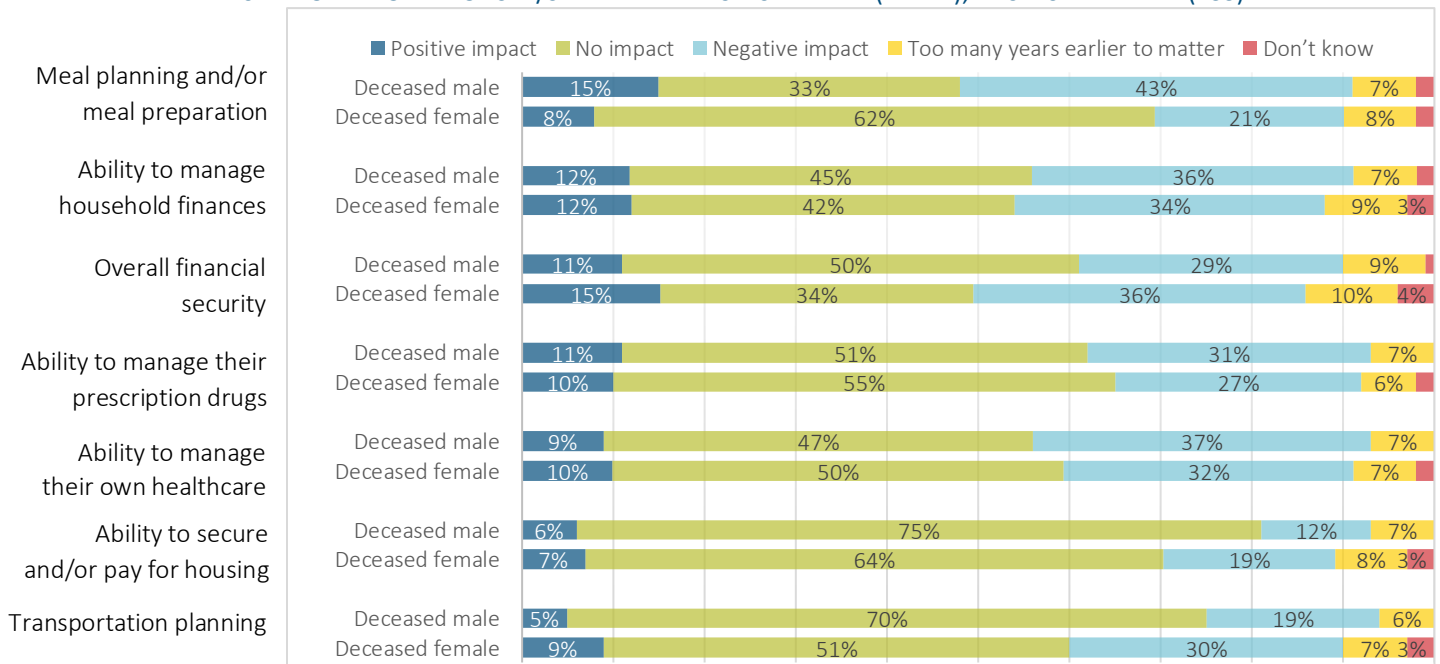
[After my father’s death,] financially there was not an issue. We are not wealthy people by any sense of the word, but financially mom was not really affected. ... She had income of her own and she also had some money through an investment. They had money through an investment that mom was the beneficiary [of]. —Memphis

Emotionally ... he was lost. My mother was in charge of social activities, so he was lost. My mother was a rare bird. She cooked three meals a day for my dad, probably five days a week. —Deerfield

Figure 14

Q4. WHAT IMPACT DID YOUR [RELATIVE]’S SPOUSE’S DEATH [(MOST RECENT IF MORE THAN ONE) DIVORCE/SEPARATION] HAVE ON HIS OR HER...?

RELATIVE WAS WIDOWED OR DIVORCED/SEPARATED: DECEASED MALE (N=121); DECEASED FEMALE (433)



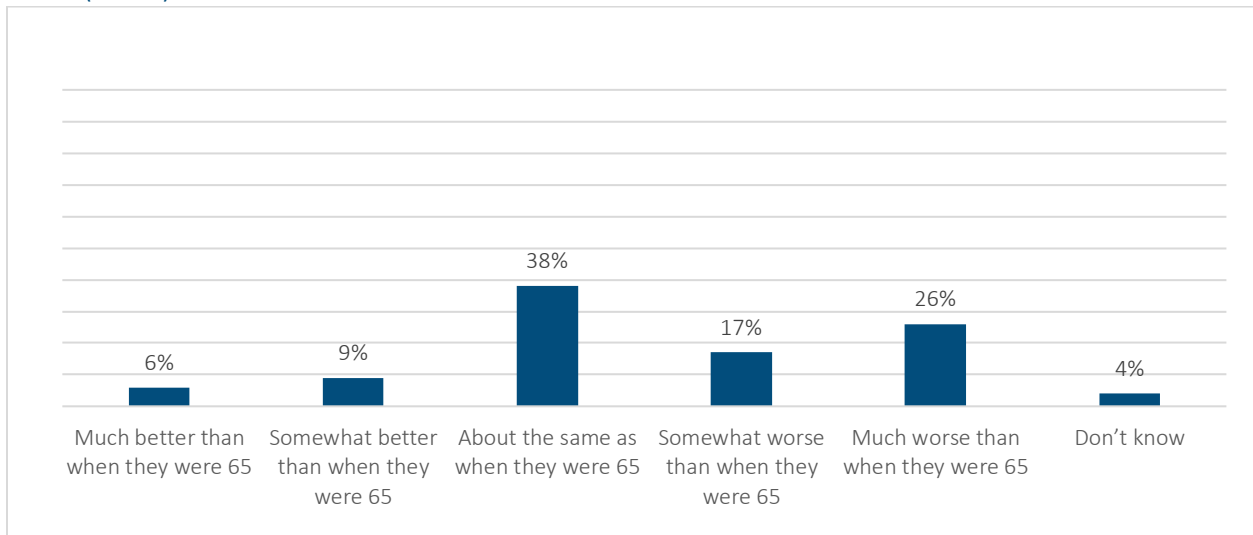
HOW FINANCES CHANGED DURING AGING

Respondents were asked how their deceased parents' financial condition changed from the time they were 65 years old to one year before they died. About one-quarter (26%) felt that their parents' finances were much worse, but a majority felt that their finances were the same (38%) or, in some cases, better (15%). This paralleled what we heard in the qualitative research, that in many cases, the retired parent did not spend down a significant percent of their assets. It was more common for this to happen when the parent required long-term care. Fifty-three percent of respondents whose parents required long-term care claimed that their parent's situation had gotten worse, compared to 33% who did not require long-term care.

She didn't have that many because the house was paid for, the car was paid for. She didn't have to pay utilities any longer. She paid her insurance. That was one of her bills she paid and her cell phone. She had a cell phone. — Memphis

Figure 15

Q8. COMPARING WHEN YOUR [RELATIVE] WAS 65 YEARS OLD UNTIL ONE YEAR BEFORE THEY PASSED AWAY, WOULD YOU SAY THAT THEIR FINANCIAL CONDITION ONE YEAR BEFORE THEY PASSED AWAY WAS...? TOTAL (N=602)



When asked about the impact of a variety of events on their parents' finances, as expected, needing nursing care or long-term care was the event that had the most impact, with half (49%) citing it as having a major impact on making their parents' finances worse. It was more common among female parents (70%) than male parents (49%) for long-term care to have at least a minor impact on finances. Four in ten (39%) children cited their parents needing assisted living or help at home as having a major impact, also more common among female parents. Over four in ten said that the death of their parent's spouse had a major negative impact on their parent's finances, although, far fewer in an earlier question felt it affected their parent's overall financial security. It was more common for the death of a spouse to have a major impact on female parents (48%) than male parents (30%).

Maybe after three years [of being in assisted living, his personal financial resources ran out]. The independent care was very expensive so of course we put money in for that. —Deerfield

She probably had somewhere around \$150,000 maybe. Maybe \$200,000. So maybe it [the aides] was \$30,000 or \$40,000 a year. ... It worked. I remember us saying we just about drained her money. —Deerfield

However, what was also striking about the data was how few respondents claimed that other occurrences had a major impact on their parents’ finances. Very few claimed that overspending on non-essentials (7%), had a major impact on their parents’ financial situation, consistent with the qualitative research that suggests that older Americans spend very little in their later years driven by a decrease in activity. The qualitative research identified a few whose finances were affected by spending on children and grandchildren and that was the case here. Small percentages claimed that gifting to children and grandchildren (7%), supporting an adult child (6%), or supporting a grandchild (5%) had a major impact on their parents’ finances.

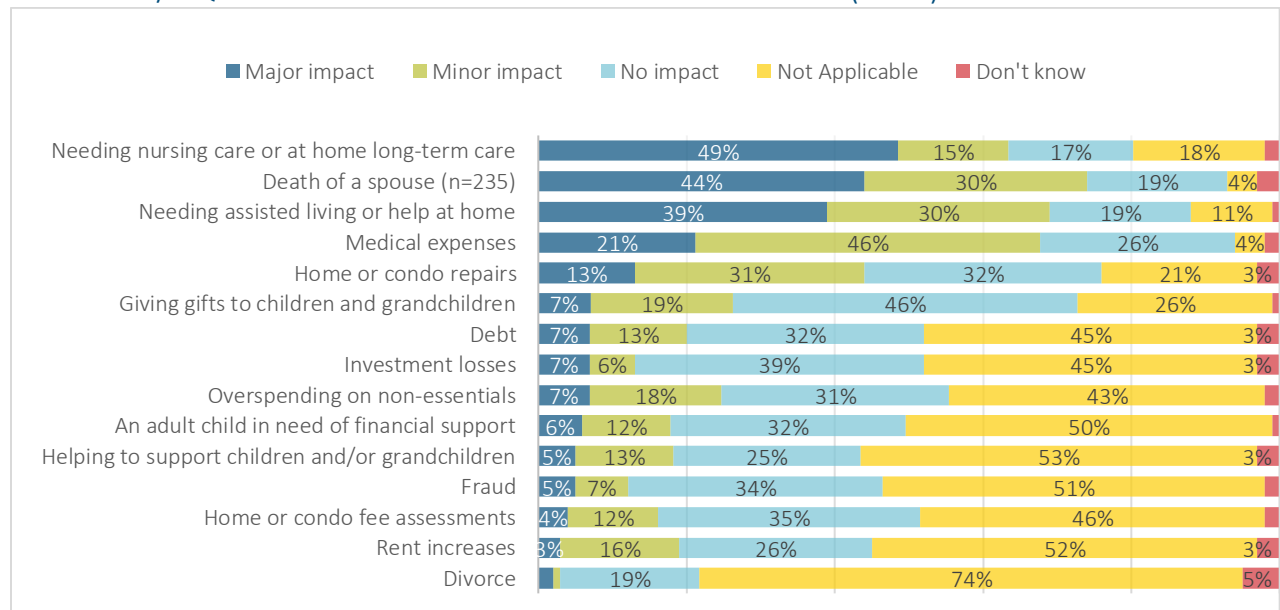
One finding we have seen throughout the research program, including in the qualitative research, is that medical expenses do not have a major impact on a large majority of the elderly because of Medicare and Medigap coverage. In this study, that was the case as well, with only 21% claiming that these expenses had a major impact on their parents’ finances. We suspect that this number may be a little inflated because some conflate long-term care with medical expenses.

Fraud had a major impact on 5% of the deceased parent sample, and a minor impact of another 7%.

One compelling finding is that parents who experienced fraud were more apt to have their financial condition worsened by various factors such as needing assisted living or long-term care, giving gifts to children, investment loss, debt, or children needing support. It is unclear whether fraud was involved in these issues or if those who were victims of fraud were more vulnerable to other issues.

Figure 16

**Q9. HOW BIG AN IMPACT DID EACH OF THE FOLLOWING HAVE ON MAKING YOUR [RELATIVE]’S FINANCES WORSE AFTER RETIREMENT?
IF RELATIVE’S/ACQUAINTANCE’S FINANCIAL CONDITION WAS WORSE: TOTAL (N=259)**



Participants were also asked about what events had a positive impact on their parents’ finances. As expected, close to two-thirds cited their parents having access to government benefits such as Social Security, Medicare, and Medicaid (66%) as having at least a minor impact and over one-third (35%) cited the sale of property as having at least a minor impact. One-third (34%) also cited investment gains as having at least a minor positive impact on their parents’ finances.

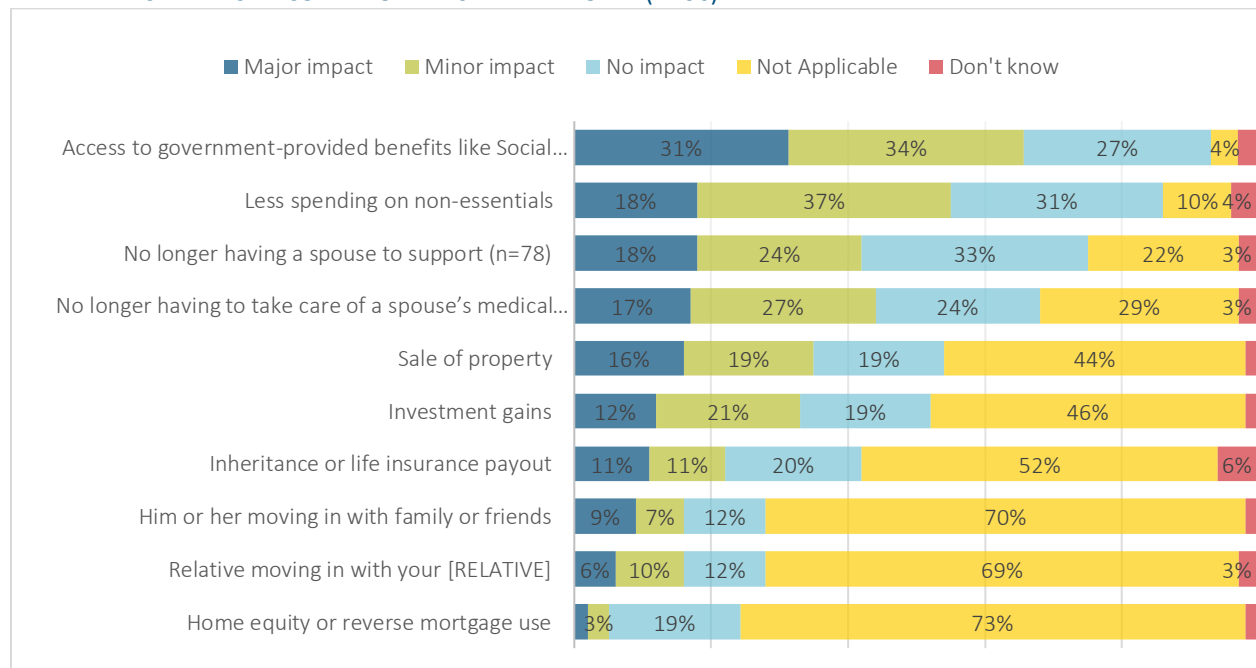
She had Social Security. She had a pension from the painters’ union, which my father put her in years ago as a secretary and she was getting paid just like \$100 a month or something. Then she had her investment stuff and if there was more money needed, something would get sold and it would go into her checking account. —Deerfield

Throughout this research study, we have found that a key way the elderly managed their finances is by reducing their spending. In the qualitative portion of this study, children of deceased parents often described their parents’ non- health or care-related expenses as minimalistic. In this research, well over half (54%) confirmed that spending less on non-essentials had at least a minor positive impact on their parents’ finances.

Frugal. She was born in 1930. ... Until they retired in town, they basically lived from year to year and when they retired to town, they started getting rental money from the farm and then they got their retirement pensions, and then they had more money. —Edmonton

While the death of a spouse had some negative impact on the finances of most parents, this event was cited by respondents to have at least minor positive effects on over four in ten parents, in that they no longer had a spouse to support (42%) and no longer had the spouse’s medical needs to support (44%).

Figure 17
Q10. HOW BIG AN IMPACT DID EACH OF THE FOLLOWING HAVE ON MAKING YOUR [RELATIVE] FINANCES BETTER AFTER RETIREMENT?
IF RELATIVE'S FINANCIAL CONDITION WAS BETTER: TOTAL (N=90)



FINANCIAL MANAGEMENT SUPPORT PROVIDED BY CHILDREN

During the qualitative research, we found that it was common for children to eventually take over their parents’ finances later in life and quantitative data supports these observations. A majority of respondents reported that at some point they took over all of their parents’ finances (58%), provided support for paying bills (63%), and helped balance their parents’ checkbook (57%). Fewer reported communicating with a bank manager (48%) or budgeting (38%). Far fewer got involved in investment management (30%) for their parents’ assets. This is not surprising given that qualitative research suggested that parents sometimes did not have enough money to manage, or they were

using an advisor. For each of these various tasks, more than six in ten reported managing the task for five or more years.

She had just gotten the girl [an aide]. I think she was still writing some checks when she first got into the hospital bed. ... Yeah, so for the first year and then she didn't write anymore. —Deerfield

For many of those years I would do it at her kitchen table because she wanted to be there and know how things were going and then I got a little bit wiser and I would collect them and bring them back home. —Deerfield

As might be expected, parents experiencing cognitive decline were much more apt to be supported by their children than parents who did not experience cognitive decline, with tasks such as finances in general (68% with cognitive decline vs. 34% without), bill paying (72% with cognitive decline vs. 44% without), balancing a checkbook (66% with cognitive decline vs. 37% without), budgeting (45% with cognitive decline vs. 21% without), and investment management (34% with cognitive decline vs. 19% without).

Figure 18

Q11. DID YOUR [RELATIVE] EVER NEED SUPPORT FOR THE FOLLOWING IN THE YEARS AFTER THEIR RETIREMENT? TOTAL (N=602)

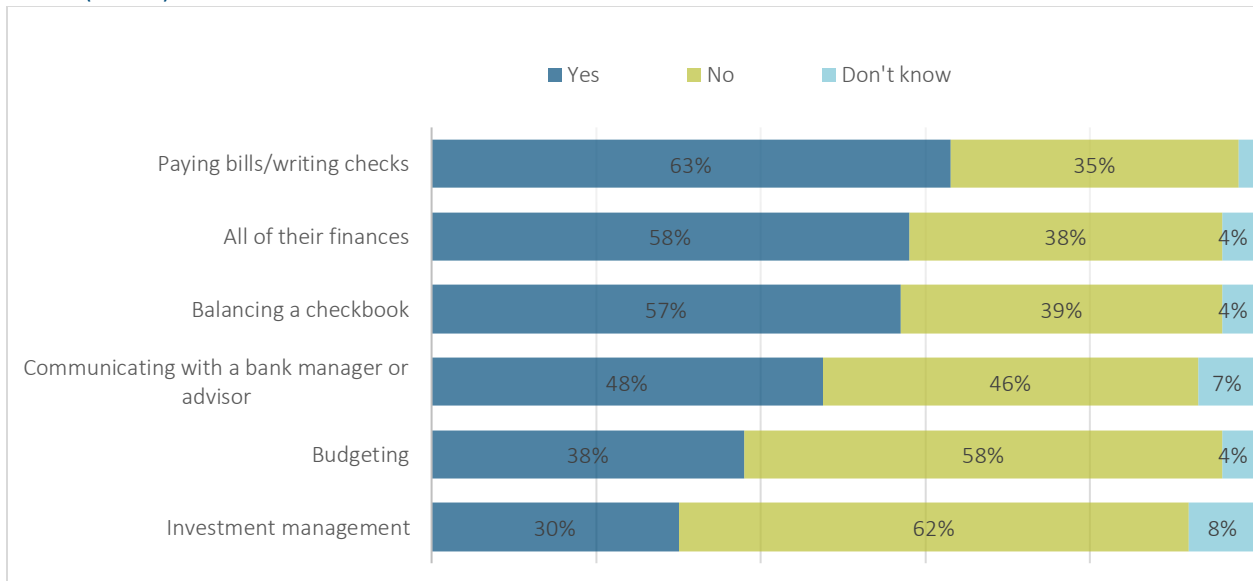
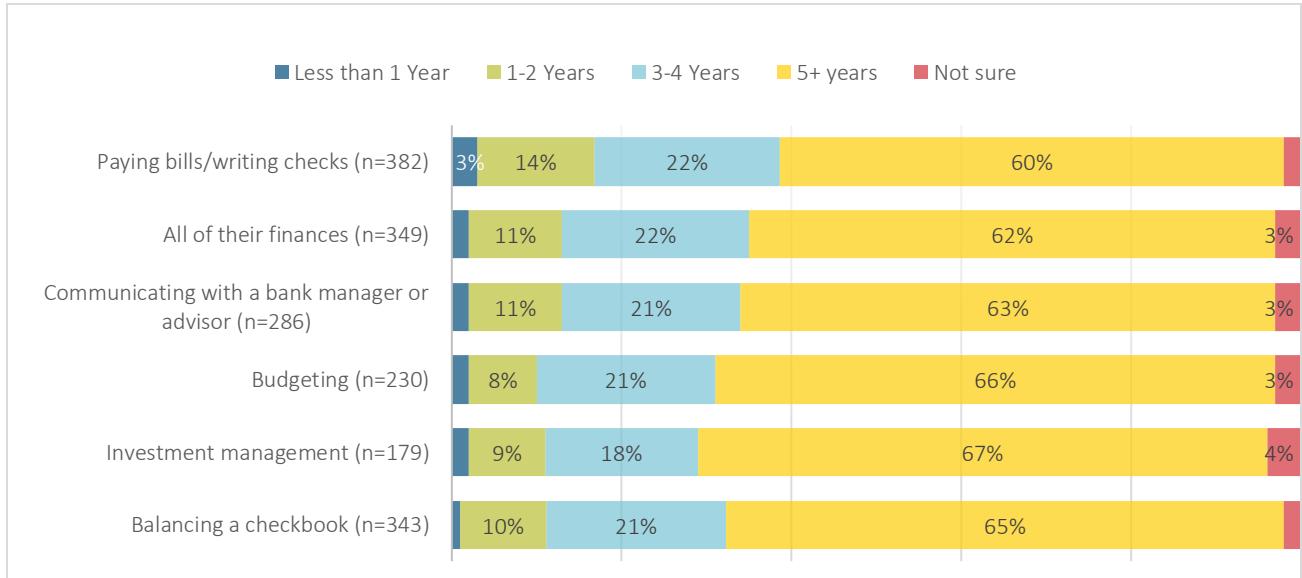


Figure 19

Q12. FOR ABOUT HOW MANY YEARS WAS THIS SUPPORT PROVIDED?
BASED ON THOSE WHOSE RELATIVE NEEDED THE SUPPORT IN RETIREMENT



Respondents were asked what events played a role in their need to take over their parents' finances. By far the most often cited source was cognitive decline (62%). Given the broad definition of cognitive decline, this category covered more than dementia. In our qualitative interviews, we saw instances of children taking over finances for parents who were declining cognitively but did not necessarily have dementia. Relating to this issue over one-third (36%) took over finances because of obvious mistakes parents were making. In our qualitative research, these mistakes were taken as a signal of cognitive decline affecting the ability to manage their finances. Parents having difficulty with technology (44%) and being unable to go the bank (38%) were also reasons that a significant number of children took over their parents' finances.

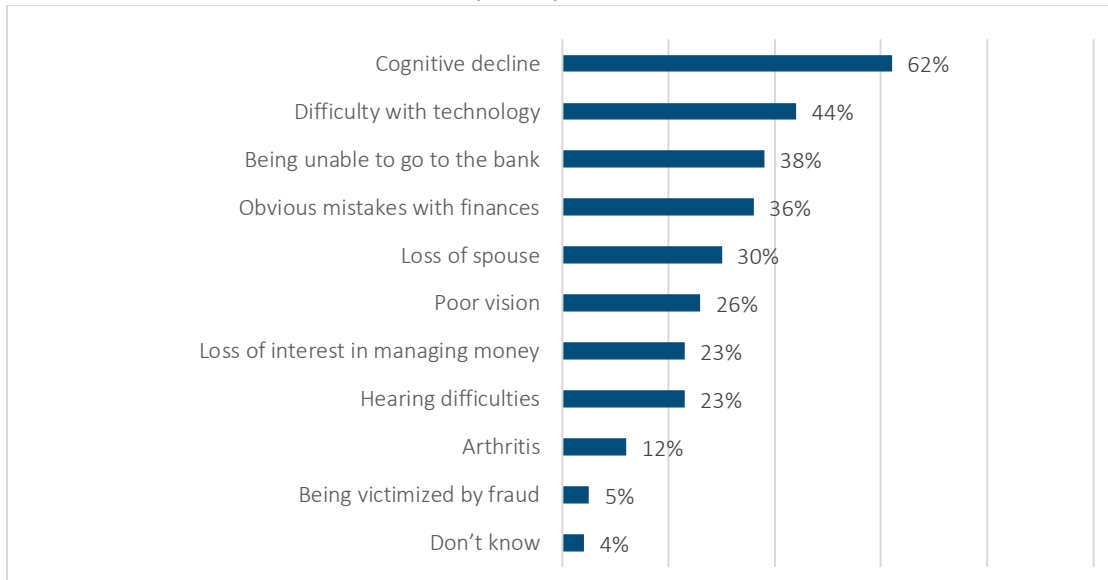
I would watch the checking account. Toward the end, she became, not even toward the end, for a few years she didn't realize the value of money and she kept saying to pay the caretaker from my check, let's go buy groceries. She had no concept of how much money was coming in and what was going out. —Deerfield

Parents who were victims of fraud (59%) were cited by respondents to be far more apt to make mistakes with finances than those who were not (31%).

Figure 20

Q13. WHICH OF THE FOLLOWING EVENTS PLAYED A ROLE IN YOUR [RELATIVE] NEEDING SUPPORT WITH FINANCIAL MANAGEMENT? PLEASE SELECT ALL THAT APPLY.

RELATIVE NEEDED SOME SUPPORT: TOTAL (N=445)



HOUSING DURING RETIREMENT

Close to half of the sample (46%) reported that their parent moved after retirement with one in five reporting that their parent moved more than once. The most common reasons parents had for moving related to wanting a more convenient residence, as close to half (48%) moved to a place that was more accommodating or to a residence that was easier to manage (40%). Children with assets over \$50,000 (54%) were more apt to have parents move to a more accommodating place than those with assets under \$50,000 (38%). Over another third of parents (36%) moved to downsize. Close to four in ten (38%) moved to be close to family.

My mother-in-law left the house and went into an apartment. She died in 2008. She was probably in the apartment 20 years. Like '88. She couldn't maintain the house for a single day, and at that time she would have been in her 70s. —Deerfield

Very close to the area that she lived there was a new senior's building come up, a big building. So we convinced her, although she didn't want to leave this house, it was too big for her with a big yard, and she couldn't manage it anymore. —Edmonton

Figure 21

Q14. SINCE THE TIME OF YOUR [RELATIVE]'S RETIREMENT, [AND BEFORE NEEDING CARE], DID THEY MOVE TO A DIFFERENT RESIDENCE?

TOTAL (N=602)

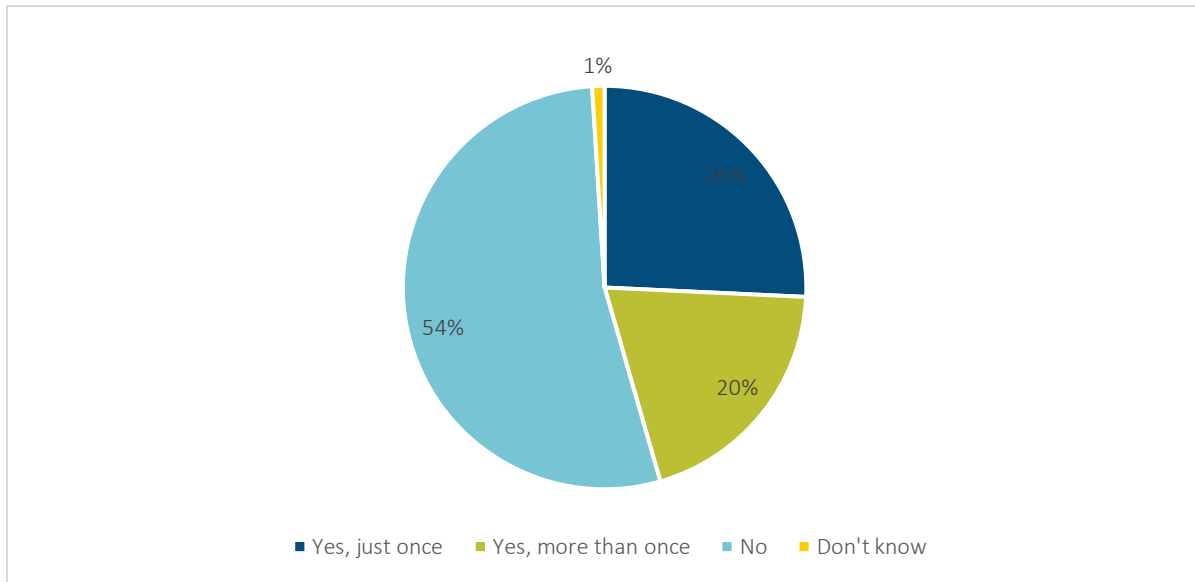
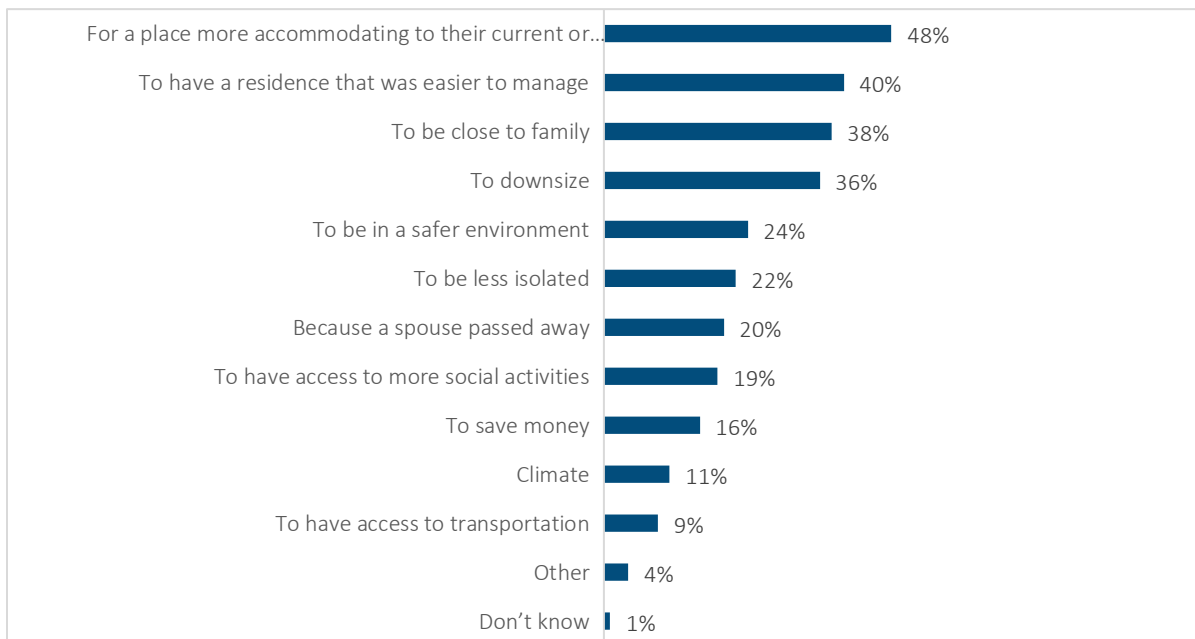


Figure 22

Q15. WHY DID YOUR [RELATIVE] MOVE IN RETIREMENT? [PLEASE CONSIDER THE MOST RECENT TIME THAT YOUR [RELATIVE] MOVED. PLEASE SELECT ALL THAT APPLY.]

RELATIVE MOVED AT LEAST ONCE AFTER RETIRING: TOTAL (N=274)



Two-thirds (66%) of children reported that their parents resided alone. Of remaining parents, over one in five (22%) resided with their children. Far fewer resided with a paid caregiver (7%).

TASKS PERFORMED BY FAMILY

Respondents were asked the length of time that they or some other relative was involved in performing various tasks for their parents including providing financial and emotional support, assisting in daily activities, and acting as general and health care Power of Attorney.

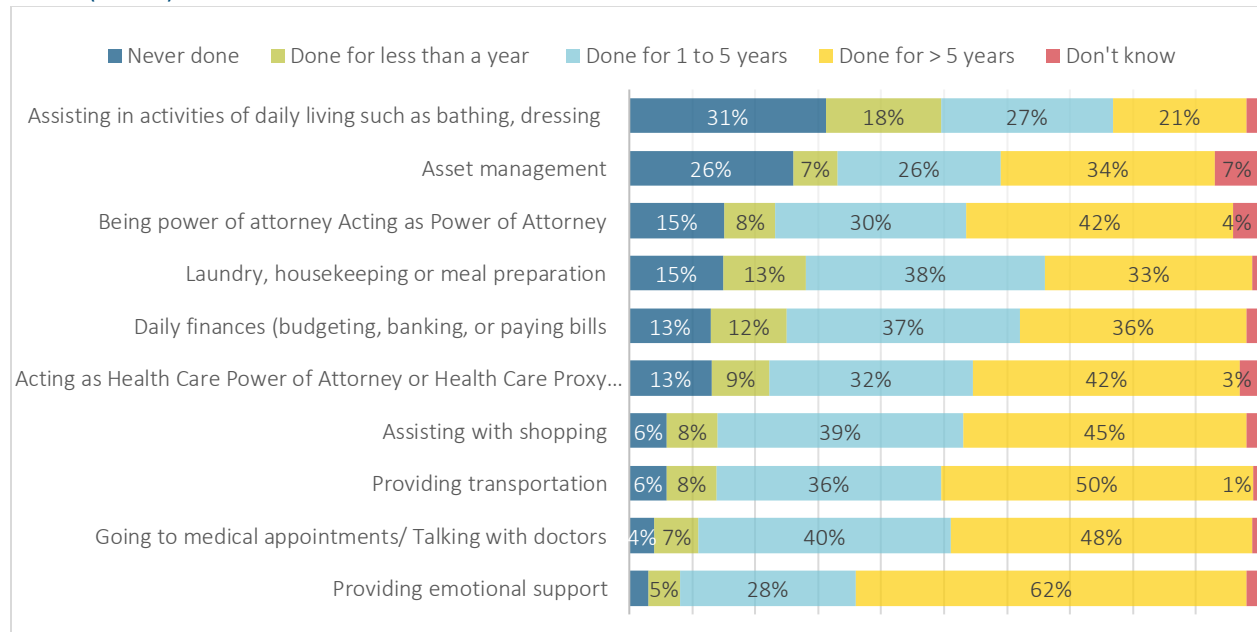
One key finding was that close to two-thirds of families aided in the activities of daily living at some point with one in five doing so for over five years. However, this question was asked in a general sense and the support may have been provided in concert with hired aides. Also, it was not clear from the question the extent to which the support was required. Qualitative research suggested that the range of support provided varies a great deal from a small amount to full-fledged nursing care.

The most common role that children played was to provide emotional support for their parents with six in ten doing so for five years or more. Close to half of respondents helped their parents travel to locations for a period of over five years, including offering transportation in general (50%), taking their parents to doctors’ appointments (48%), and assisting with shopping (45%). Eighty-five percent reported that someone provided assistance with finances and two-thirds (67%) were involved with asset management at some point, although earlier data suggests that, for many, this did not involve investment management. Non-family members were less apt than others to provide various types of support for more than 5 years.

Well over eight in ten reported that they or another family member acted as Power of Attorney (81%) or Health Care Power of Attorney (84%). Caretakers who were not children of the deceased were less likely to have these powers. Parents with cognitive decline were more apt to get this care.

I always ran everything by their [general practitioner] ... and he was the one who said this needs to be done. You need to try this because my dad, his bones were getting more brittle from the prednisone. The rheumatologist was probably the only second opinion we had. —Deerfield

Figure 23
Q17. FOR WHAT LENGTH OF TIME WERE YOU OR SOMEONE ELSE INVOLVED IN DOING EACH OF THE FOLLOWING IN THE CARE OF YOUR [RELATIVE]?
TOTAL (N=602)

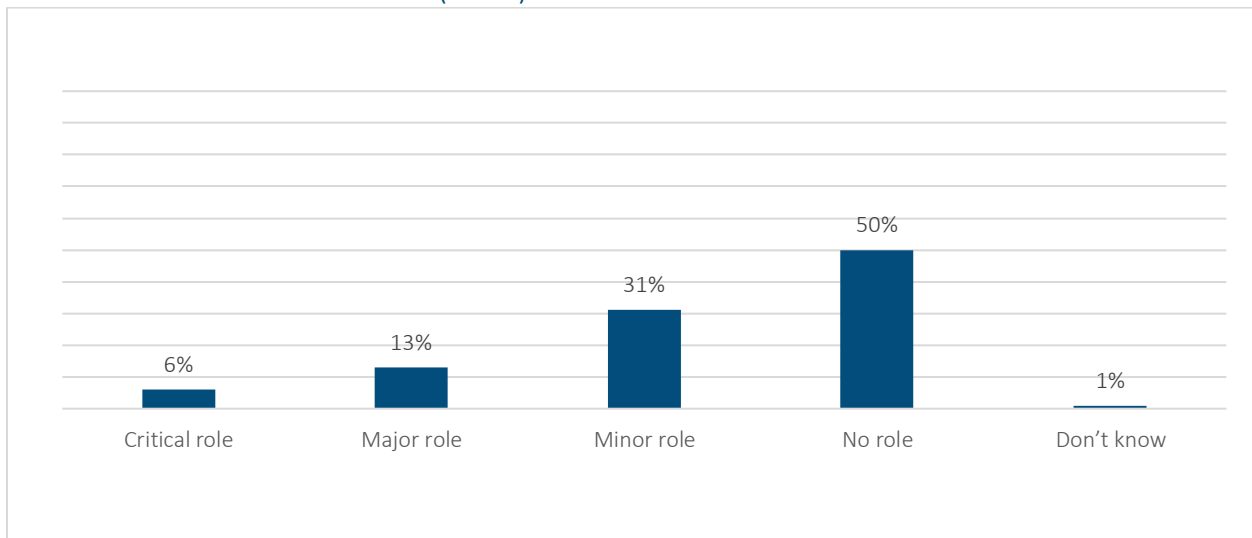


It was not uncommon for nonpaid non-relatives to play an important role in caring for the parent. Close to one in five (19%) reported that non-relatives played a major or critical role and close to an additional third (31%) reported that they played a minor role.

They would clean the apartment. They would fix him a meal. ... They would give him a bath, change the bed, sweep the floor. The aides would help out for two hours a day. —Memphis

Figure 24

Q18. HOW BIG A ROLE DID NON-RELATIVES PLAY IN CARING FOR YOUR [RELATIVE]? PLEASE CONSIDER FRIENDS AND NEIGHBORS RATHER THAN THOSE PAID TO PROVIDE CARE.
RELATIVE IS A FAMILY MEMBER: TOTAL (N=583)



Respondents were asked which relatives were responsible for various tasks. The respondent themselves performed each of the various tasks a majority of the time, including making decisions about nursing homes or assisted living (80%), providing company (79%), performing tasks and chores (79%), managing money (71%), being named on a medical directive (68%), and having Power of Attorney (67%). Some of these outcomes may have been a function of who qualified based on screening questions.

The most common other relatives to provide these services were respondents' spouses, brothers, and sisters, each providing roughly the same level of participation as each other. However, when combining brothers and sisters, siblings were about twice as likely to provide support compared to spouses.

Roughly one quarter of each kept the parent company and performed tasks and chores for the parent. When the respondent was not a child of the deceased parent, they were far more likely to report that nieces and nephews also kept the parent company.

Spouses were slightly more likely (30%) than brothers (26%) or sisters (22%) to make decisions regarding nursing home or assisted living when those situations arose. It was less common for the respondents' spouses (13%), brothers (18%), or sisters (14%) to be involved in money management, and roughly one in seven to one in six of each had Power of Attorney or were named on a medical directive. This data is somewhat hard to compare since we do not know how many had brothers and sisters.

Figure 25

Q19. WHO WAS SIGNIFICANTLY RESPONSIBLE FOR YOUR [RELATIVE] IN THE FOLLOWING AREAS?
RELATIVE IS A FAMILY MEMBER

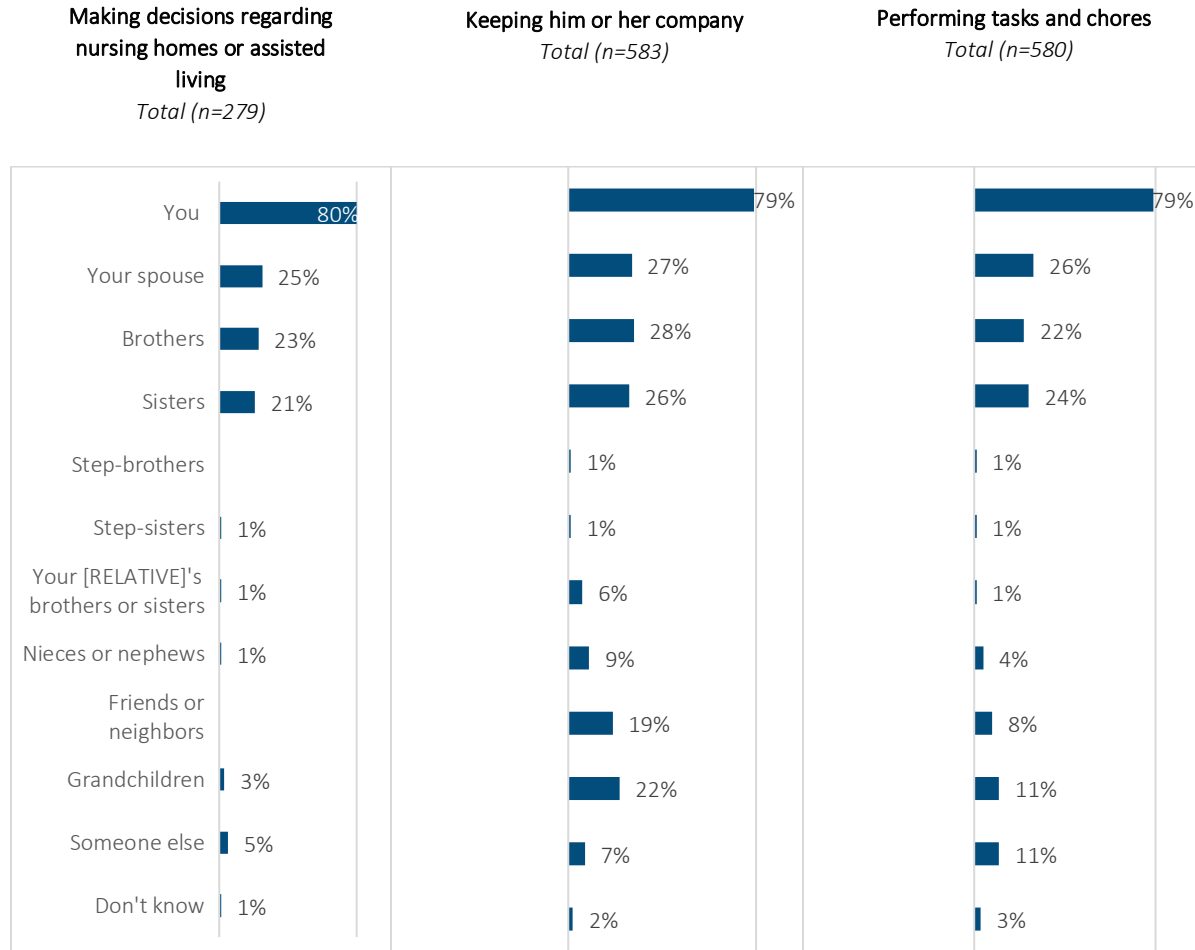
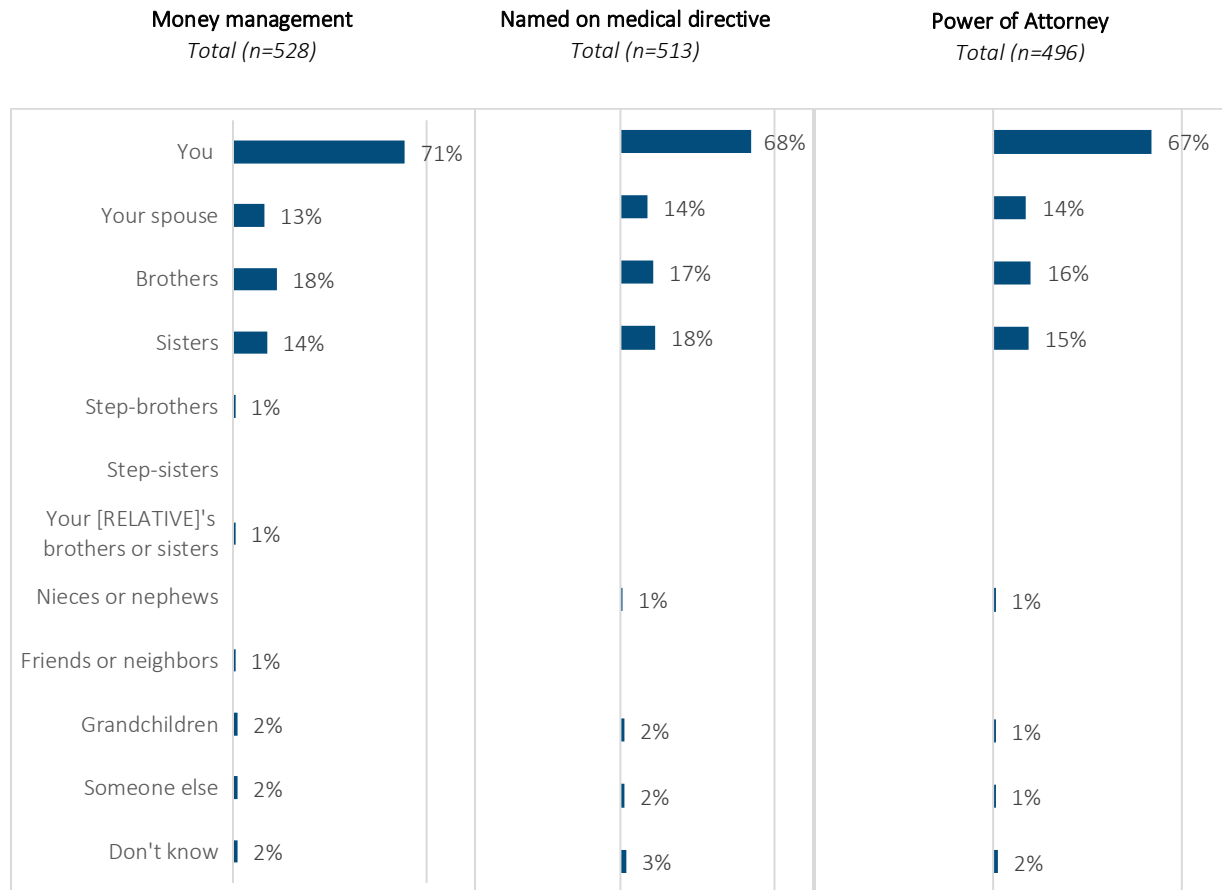


Figure 25 (cont.)

Q19. WHO WAS SIGNIFICANTLY RESPONSIBLE FOR YOUR [RELATIVE] IN THE FOLLOWING AREAS? (CONT.)
RELATIVE IS A FAMILY MEMBER



FAMILY DYNAMICS

In the qualitative research, it was more common for families to get along at least fairly well and to understand the roles that each would play based on skills and availability. However, there were some instances of tension between relatives, due to feeling that some were not doing their share. This study reflected those results. When asked to grade themselves and their families on various criteria related to the care they provided to the parent, between one-third and two-thirds gave themselves an “A” and over half to close to nine in ten gave themselves an “A” or a “B”.

We kind of consulted. I didn't try to say, "I think you ought to do this," or ... I didn't make the financial decision. We would sit down and talk about what the options were and then the family would make a decision. —Memphis

My sister was in charge of that [medical directives, power of attorney] because she worked at the hospital. She's not a doctor but she worked with all the doctors and everything and so she just, they just asked, they gave it to her. —Deerfield

My other brother, the one down from me, he lived close to her and he was there a lot. He would fix things that went haywire. Leaky faucets, the toilet or things like that. The building is 50 something years old. —Deerfield

Respondents gave their family dynamics the highest grades on agreeing upon medical decisions, with well over eight in ten giving the family dynamic either an “A” (62%) or a “B” (22%) and working out finances (58% “A” and 24% “B”). The respondents graded themselves and their family somewhat lower but still relatively high on each doing what they were best at (50% “A” and 31% “B”), planning together (45% “A” and 34% “B”), communicating well with each other (48% “A” and 26% “B”), and agreeing on the roles that each would play (48% “A” and 24% “B”).

My sister came up with the plan and said, “This is it.” She said, “It doesn’t matter how much money is left, he has to get into a place.” So she, I have to say, had the foresight and said we’re going to put him on a list. —Deerfield

We had just a family meeting to let them know that mom is declining. [This was] two years [ago]. She wasn’t mobilizing like she normally did, moving around the house, cooking and doing all that. —Memphis

When she was first diagnosed with lung cancer, she was still pretty healthy and then she had a couple of surgeries and she deteriorated, so once her diagnosis was lung cancer, we sat down and decided who was going to do what. —Deerfield

While giving themselves fairly high grades on designating and planning for roles, grades were somewhat lower on the roles actually played. Only slightly more than half graded their family with an “A” (33%) or “B” (24%) on feeling that everyone was pulling their weight and close to one quarter (22%) graded the family with a “D” or “F” on this dimension, far more than for any other dimension.

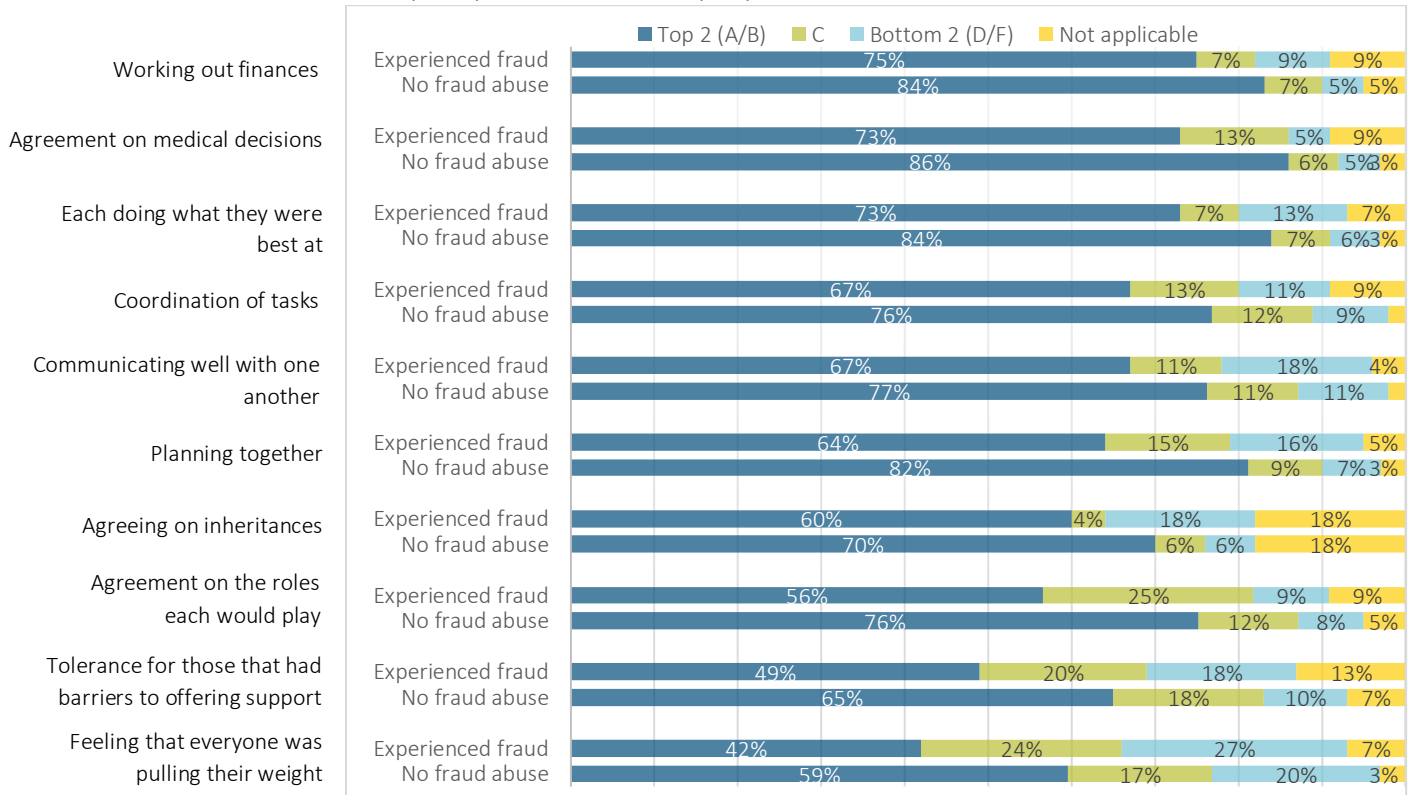
The girls were more [involved in taking her shopping] than the brothers ... a lot more. Probably 70/30. ... Probably [there was tension]. When somebody was dead tired on their feet and they couldn’t get the brother to go do something, probably. —Memphis

Those whose parents were not victims of fraud were far more apt to give themselves an “A” on planning together (48%) and communicating with each other (52%) than those whose parents were victims of fraud (27% and 29%, respectively). They were also more apt to give themselves an “A” on working out finances (63% vs. 38%). When the elderly were non-biological parents, stepparents, or non-parents of the respondents, the respondents were more apt to give themselves high grades on planning together.

Figure 26

Q20. USING AN A-F SCALE LIKE YOU WOULD IN SCHOOL, WHAT GRADE WOULD YOU GIVE YOURSELF AND YOUR FAMILY WHEN IT CAME TO THE FOLLOWING ASPECTS OF YOUR RELATIONSHIPS WHEN CARING FOR YOUR [RELATIVE]?

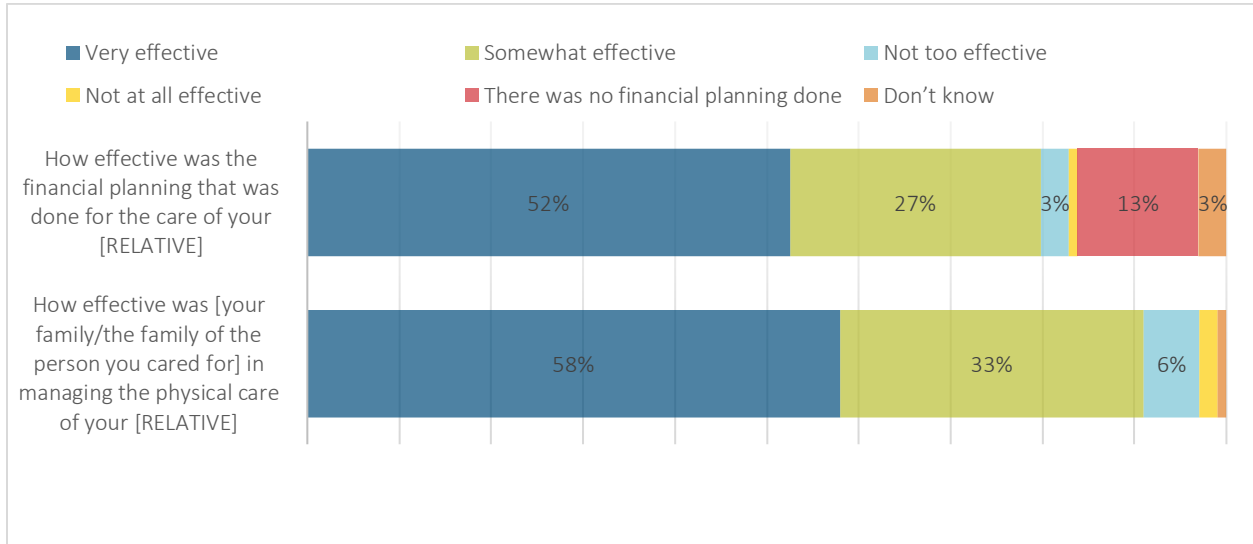
RESPONDENT AND ONE OTHER PERSON IS RESPONSIBLE FOR PROVIDING CARE AND RELATIVE IS A FAMILY MEMBER: EXPERIENCED FRAUD (N=55); NO FRAUD ABUSE (376)



A large majority (89%) of respondents reported that the financial planning done for their parents was very (52%) or somewhat effective (27%), and an even larger majority reported that the physical care provided was very (58%) or somewhat effective (33%). Those whose parents were not victims of fraud (56%) were more likely to say that financial planning was very effective than those who were not (36%). Children with over \$200,000 in assets (61%) were more apt to say that financial planning was very effective than those who had under \$200,000 in assets (48%).

Figure 27

Q21 AND Q22. HOW EFFECTIVE WAS THE FINANCIAL AND PHYSICAL PLANNING THAT WAS DONE FOR THE CARE OF YOUR [RELATIVE]? TOTAL (N=602)

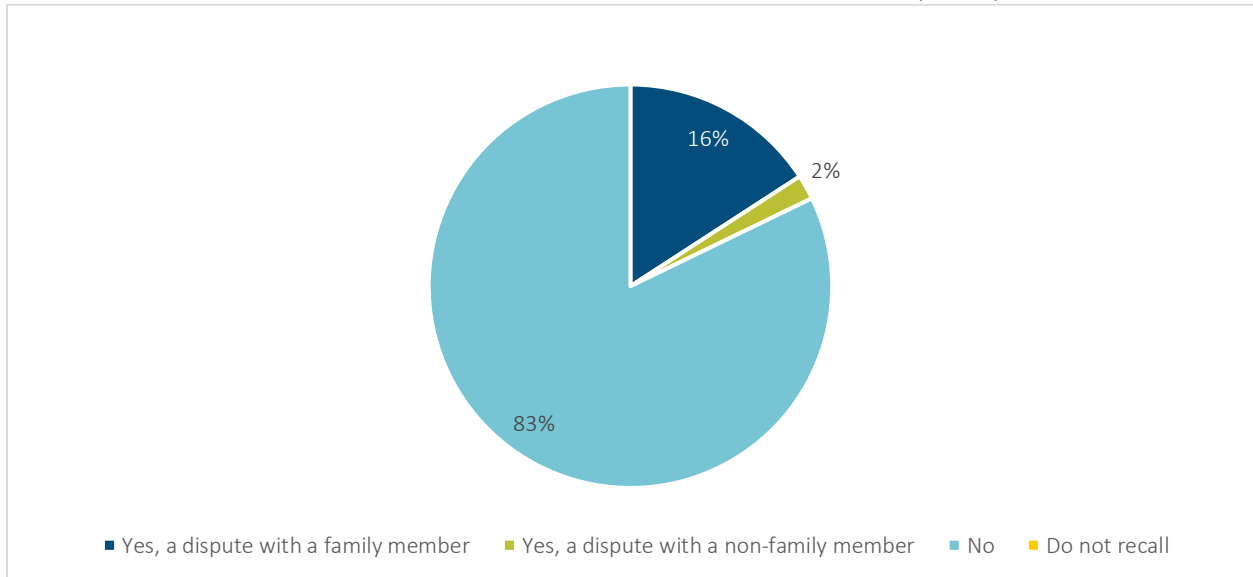


IMPACT OF FRAUD

Also, about one in six (16%) reported having a dispute with a family member over money, something we saw instances of in the qualitative research. Over one-third (35%) of those who reported their parents experienced fraud, had such a dispute.

Figure 28

Q25. DID YOU EVER HAVE A DISPUTE WITH ANOTHER PERSON OVER DECISIONS THAT YOU MADE ABOUT YOUR [RELATIVE]'S MONEY OR PROPERTY? RESPONDENT IS RESPONSIBLE FOR THE RELATIVE'S MONEY MANAGEMENT: TOTAL (N=373)



Fraud is a common problem facing the elderly and even a small percentage of fraud represents significant financial loss. In this study, 12% of children said that their parents were victims of fraud. Over six out of ten times (63%), the fraud was perpetrated by someone they knew, most often a family member (29%) but also non-family member they knew (16%), their parent’s financial advisor (10%), or care provider (8%). The qualitative research found several instances of fraud by financial advisors.

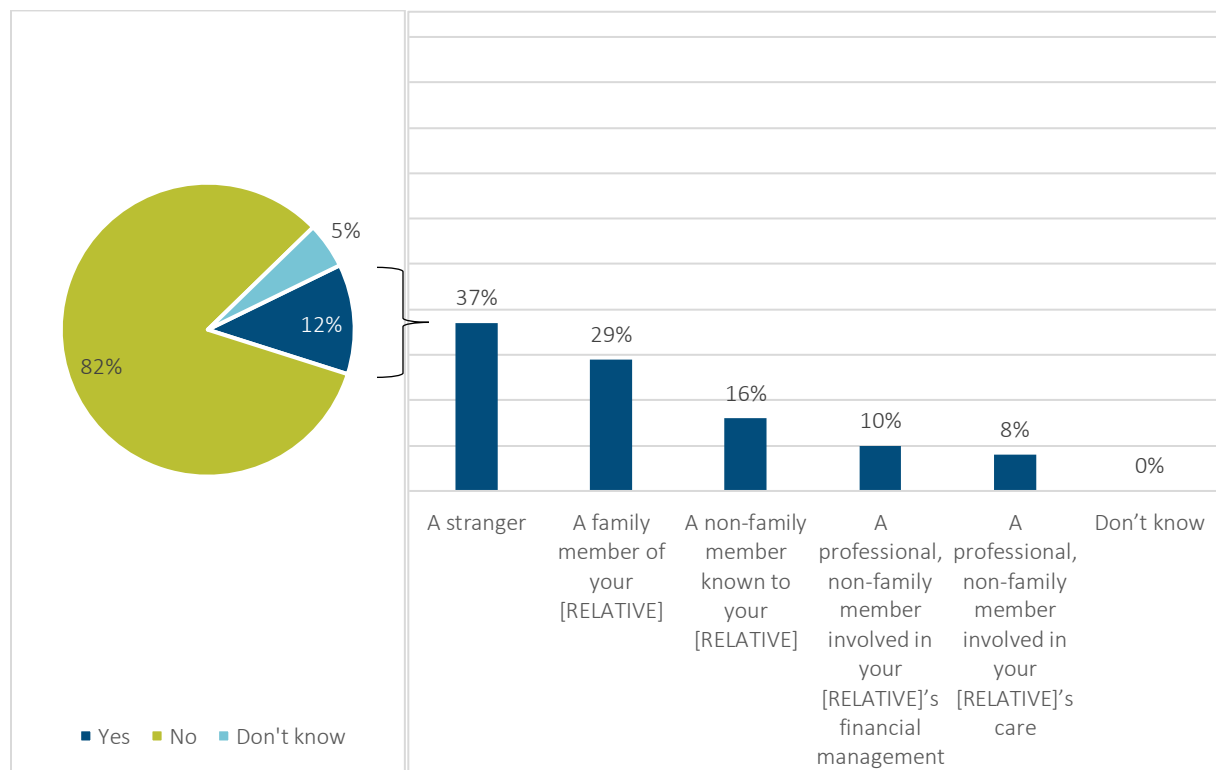
Mother’s son spent all her money. While she lived with him, they would use her Social Security. They would all go to the casino. —Deerfield

My uncle decided that they would give my uncle’s son power of attorney since they lived in the same town. ... He spent over a quarter of a million dollars and so we had to go through all of that. I guess it was closer to half a million. It had been going on for two years before we realized, if it had not been for her broker realizing, that something was wrong. —Memphis

Figure 29

Q23. In the years following their retirement, was there ever an instance of fraud, a scam, or financial abuse perpetrated on your [RELATIVE]? Total (n=602)

Q24. Was this incident of fraud or abuse perpetrated by...? Relative/acquaintance was a victim of fraud in retirement: Total (n=73)



ASSISTED LIVING

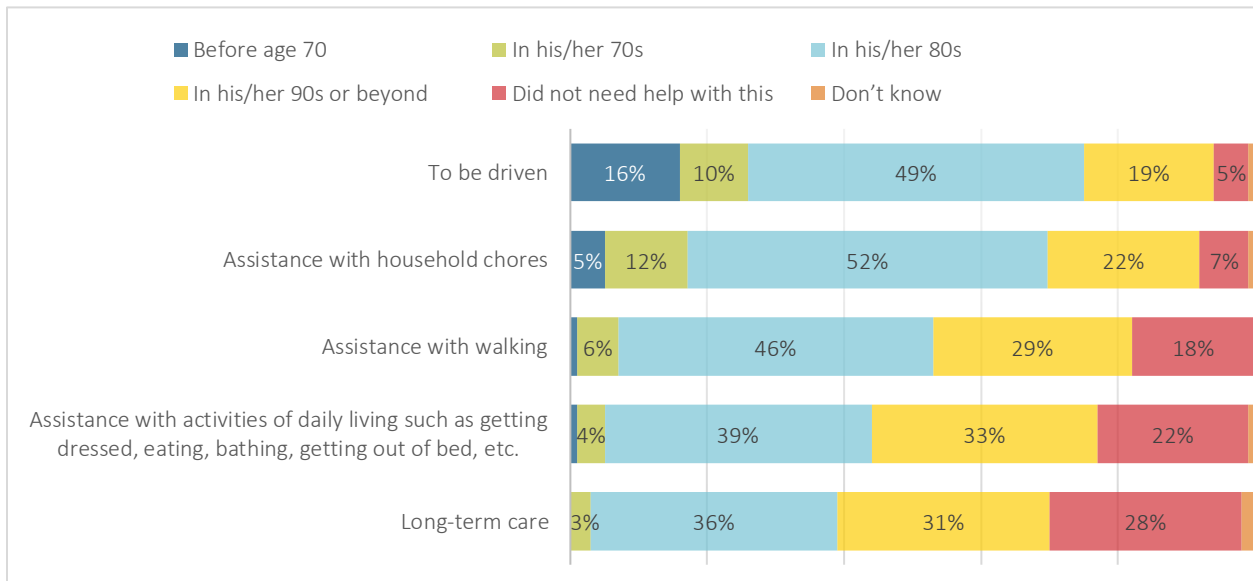
Respondents were asked at what age their parents needed various types of assistance with their life, ranging from needing support with transportation to full-fledged long-term care. For the most part, none of these needs occurred before age 80. However, only a small minority of parents went through life without the need of some type of

support. It is important to remember that we only sampled children with parents who survived past age 85. The most common need prior to age 80 was to be driven places, applying to one quarter (26%) of this population. However, the qualitative research suggests that this number may be a little inflated because some in this generation never drove a car, especially the females who comprise a majority of the deceased parent sample.

Roughly half of the deceased sample first needed support in their 80s with household chores (52%), being driven places (49%), and assistance with walking (46%). The majority of first occurrences for needing assistance with daily living occurred in parents' 80s (39%) and 90s (33%) as did the need for long-term care (36% in their 80s and 31% in their 90s).

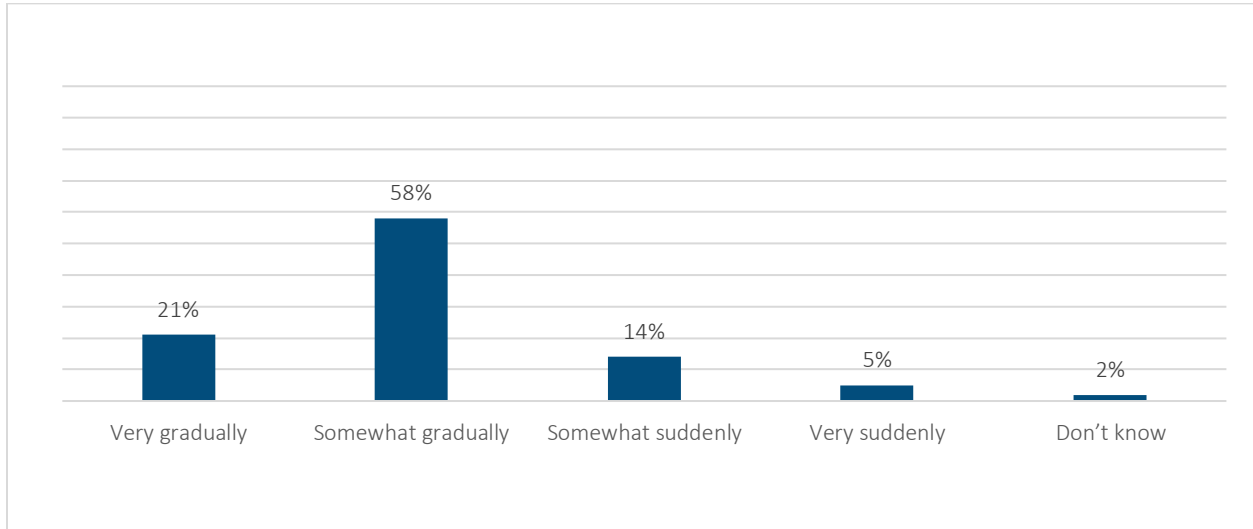
She could clean her house and, occasionally, we'd have a cleaning lady come in. ... It was very small, it was a one-bedroom condo, small, and at a point where I was shopping for her, I was getting a lot of prepared foods for her. — Deerfield

Figure 30
Q5. WHICH OF THE FOLLOWING DID YOUR [RELATIVE] EVER NEED AND IF SO, AT ABOUT WHAT AGE DID THEY START NEEDING HELP?
TOTAL (N=602)



For the most part, parents’ need for support occurred somewhat (58%) or very gradually (21%).

Figure 31
Q26. BROADLY SPEAKING, DID YOUR [RELATIVE] NEED FOR SUPPORT HAPPEN...?
TOTAL (N=602)

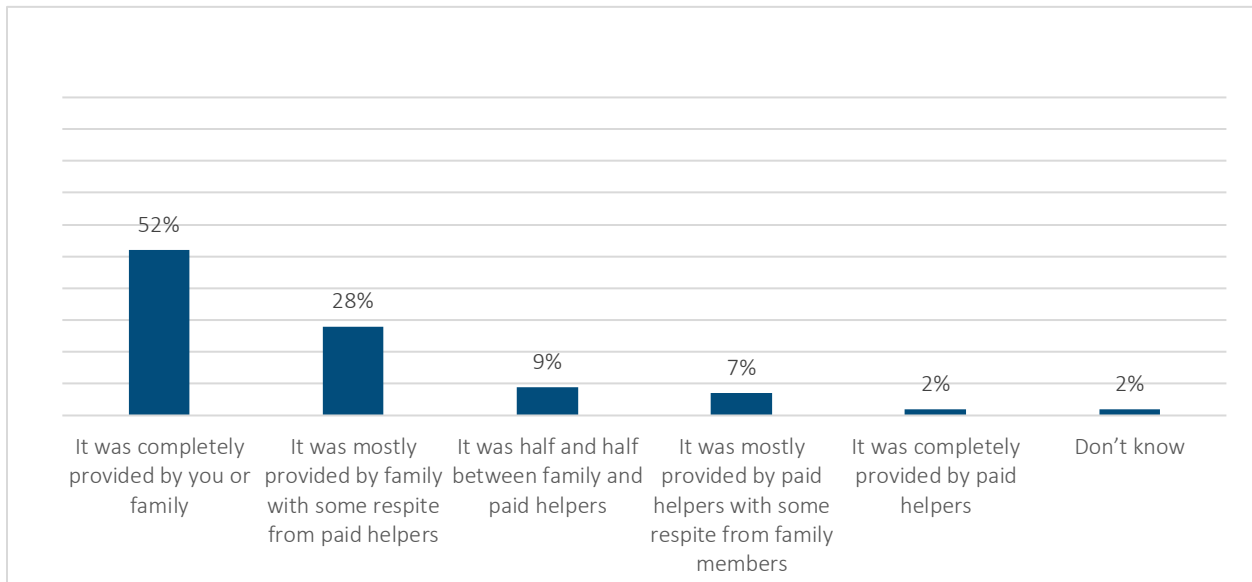


The qualitative study suggests that care begins in the home and may or may not require a decision to use a facility later. When asked how support at home was provided over time, over half the time (52%) it was completely provided by the respondent or his/her family, and another quarter of the time (28%) it was provided mostly by the family with some assistance by paid helpers. Such care was rarely provided (2%) completely by paid helpers. The tendency for care to be provided by family, may have somewhat elevated by the fact that we eliminated those whose parents had more than \$400,000 in financial assets at the time of death and may have had more wealth to hire outside support.

When we couldn't help out there were times that they [the attendant and my father] would just go grocery shopping. They lived near a big grocery store so they would just walk over and get what they needed and then walk back or drive over and drive back. —Deerfield

Figure 32

Q27. THINKING ABOUT THE SUPPORT YOUR [RELATIVE] RECEIVED AT HOME OVER TIME, WOULD YOU SAY THAT...? TOTAL (N=602)



When asked what factors led to the decision to place the parent in an assisted living facility, the most common reasons given were general frailty (46%), to provide a better quality of life (46%), and cognitive decline (45%). Almost just as common reasons were a medical event (39%) or housing no longer being suitable (38%) which perhaps relates to offering a better quality of life. General frailty was given as a reason far more often for parents who experienced cognitive decline (50%) than for those who did not (32%).

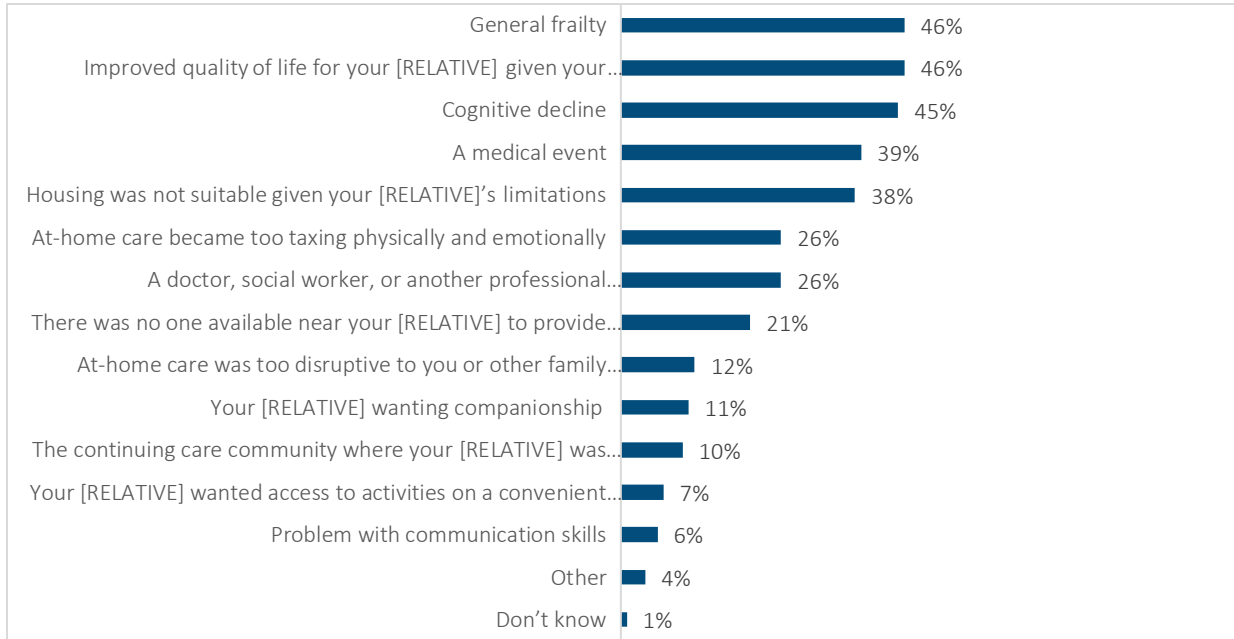
Fewer respondents (26%) placed parents in assisted living because they could not provide the care or because there was no one available to do so (21%). A similar number placed their parents in assisted living because a doctor, social worker, or other professional recommended it (26%), suggesting that there are a number of instances where the decision is not done in concert with the recommendation of a professional.

We were worried that she would burn herself or start a fire in the co-op. ... She cooked. They never ate in restaurants. They were kosher and she cooked, and she had the stove burning overnight sometimes without turning it off. — Deerfield

Figure 33

Q28. WHAT OF THE FOLLOWING LED TO MOVING YOUR [RELATIVE] TO AN ASSISTED LIVING FACILITY? PLEASE SELECT ALL THAT APPLY.

RELATIVE SPENT MORE THAN 6 MONTHS IN AN ASSISTED LIVING FACILITY: TOTAL (N=203)

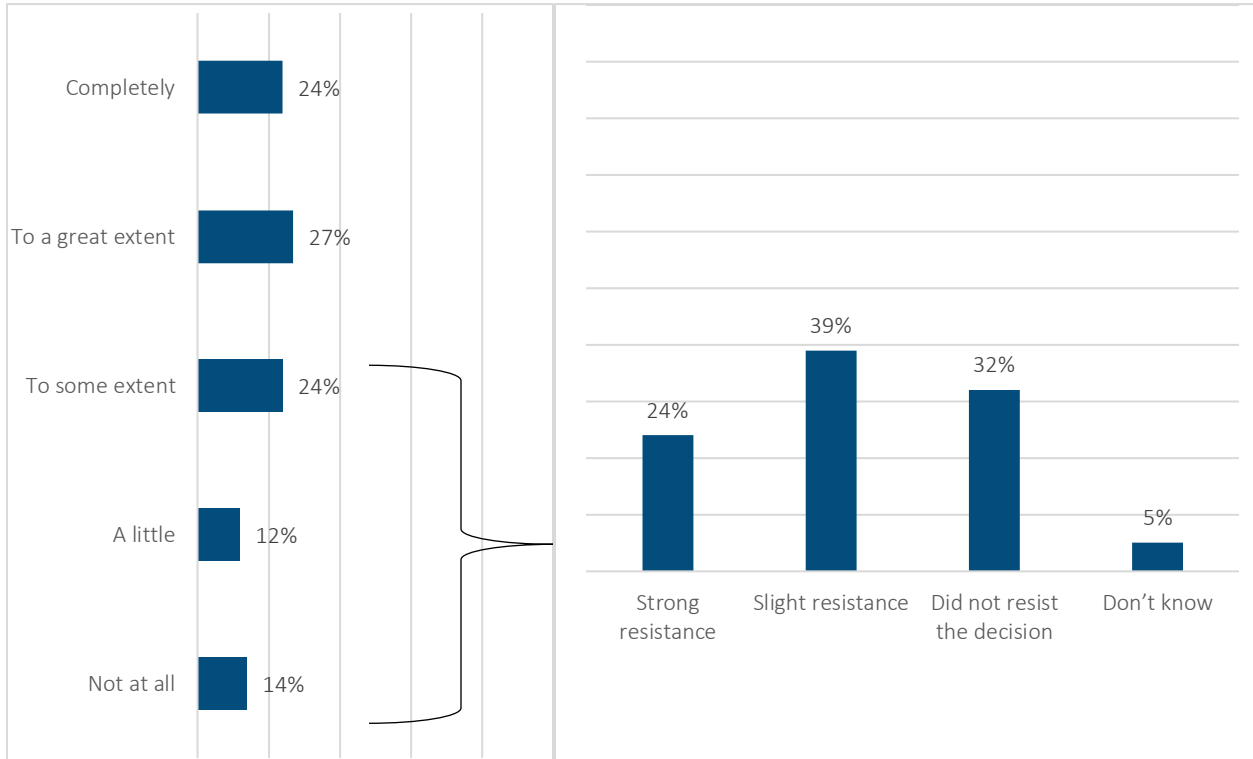


About half the time (51%) when deciding to place a parent in assisted living, the parent participated in the decision completely (24%) or to a great extent (27%). If the parent experienced cognitive decline, they are less likely to be involved in the decision (40% with cognitive decline vs. 85% without). Only one quarter of the time (26%) did parents have little (12%) or no (14%) involvement in the decision. Among parents who did not participate in the decision, only about one quarter (24%) put up strong resistance against going into assisted living.

Figure 34

Q29. To what extent did your [RELATIVE] participate in the decision to have assisted living?
Relative spent more than 6 months in an assisted living facility: Total (n=203)

Q30. Did your [RELATIVE] resist the decision to enter assisted living?
Relative was in assisted living facility and was only involved to some extent or less in the decision: Total (n=100)



NURSING HOME DECISION

Of parents who required long-term care, whether in an assisted living facility or a nursing home, 66% spent more than six months in a nursing home. Respondents were asked what event led to the parent needing to be placed in a long-term care facility. Over half the time (54%) the cause of the need was a medical event, and as with the need for assisted living, other common reasons were cognitive decline (48%) and general frailty (47%). More often than with assisted living, the decision to place a parent in long-term care was based on a recommendation by a doctor, social worker, or other professional (39%). About a quarter or more of the time (26%) the decision was made because at-home care was too physically and emotionally taxing or because housing was not suitable to care for the parent (30%).

Well, we found a doctor, a geriatric doctor that said to me, "It's time for you to really seriously think of what's going to be the safest thing for your mom." And so that doctor helped. —Deerfield

Figure 35

Q31. WHAT OF THE FOLLOWING LED TO MOVING YOUR [RELATIVE] TO A NURSING HOME? PLEASE SELECT ALL THAT APPLY.

RELATIVE SPENT MORE THAN 6 MONTHS IN A NURSING HOME: TOTAL (N=209)



The extent to which the parent participated in the decision to move to a nursing home varied. Close to one-third of the time (31%), the respondent reported that their parent participated completely or to a great extent, but close to half the time (49%) parents participated little or not at all in the decision. Children cited only a quarter of their parents who experienced cognitive decline (27%) participated in the decision completely or to a great extent. A smaller percent was involved in this decision than in the decision to pursue assisted living, perhaps because outside professionals played more of a role in determining the need for long-term care. About half (51%) of respondents reported that their parents put up resistance to being put into a nursing home, with about one in five putting up strong resistance.

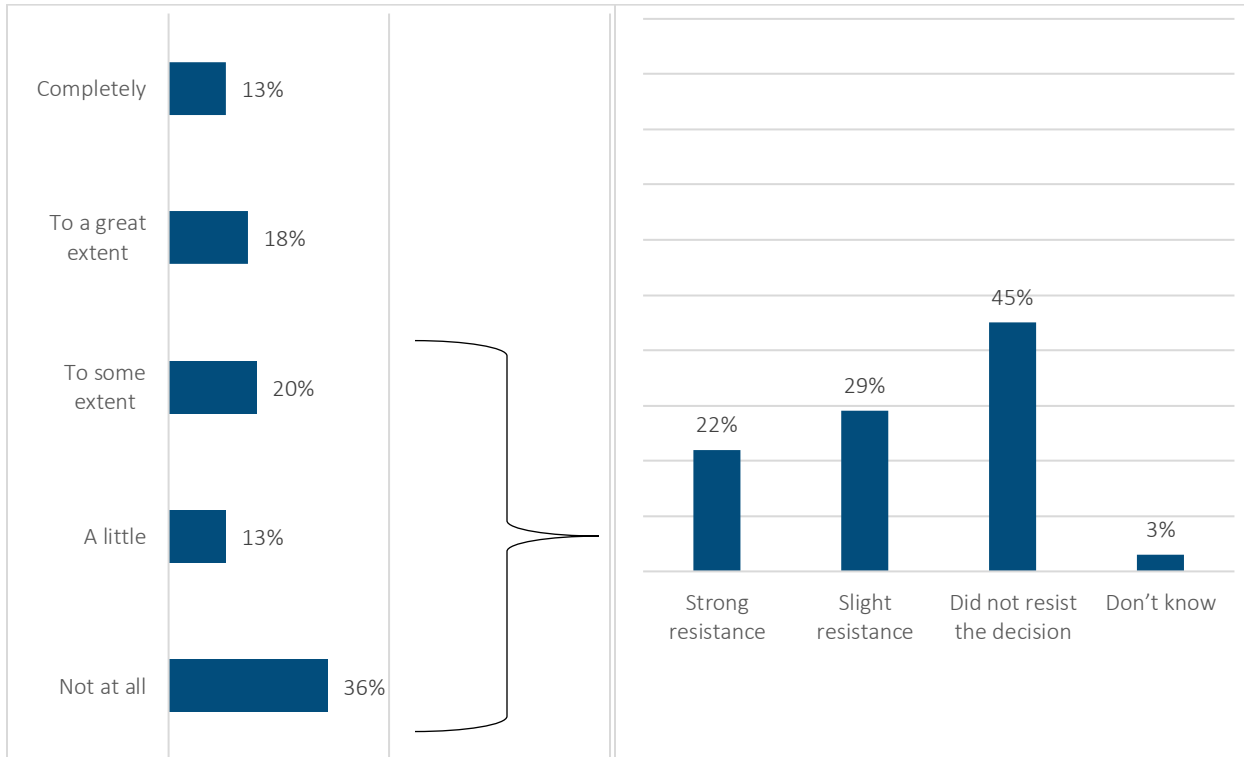
When we finally put her in there, she didn't really realize where she was. She really didn't realize it and we ended up in two or three different places, because I wasn't happy with them. I'd sneak visits and I wasn't happy. So finally, not that long before her death, we got a great place. —Memphis

She needed two caregivers. It was too much. It was not set up as assisted living for her needs. ... She couldn't walk or do things for herself, I guess. —Deerfield

Figure 36

Q32. To what extent did your [RELATIVE] participate in the decision to move to a nursing home?
 Relative spent more than 6 months in a nursing home: Total (n=209)

Q33. Did your [RELATIVE] resist the decision to enter a nursing home?
 Relative/acquaintance was in a nursing home and only involved to some extent or less in the decision: Total (n=144)



PAYING FOR LONG-TERM CARE

When asked what sources played a major or minor role in paying for long-term care, by far the most common fund playing a major role was Social Security, with 63% claiming that it played this role. The next most common source playing a major role were the parents’ personal assets not including the sale of the home (47%). Medicaid (37%) and pension income (35%) were the next most common in playing a major role. As we have seen in other research, the incidence of long-term care policies is low and only one in six (16%) say it plays a major role in paying for long-term care including combo life insurance policies. It is also uncommon for family members to pay for long-term care and this funding source plays a major role only 11% of the time. Among families using Medicaid, roughly half (51%) had to spend down the parents’ assets to be able to claim it.

Male children (46%) were far more likely to use their or their family’s assets than female children were (27%).

She didn't have any money. Remember, it was running down, and she hadn't been accepted to Medicaid yet, it was pending, that's what it was called, Medicaid pending, and they [nursing home] took her in Medicaid pending as long as I gave the \$25,000 [deposit]. —Deerfield

[He had] Medicaid. He went on public assistance. They took his Social Security check and his pension check and gave him enough spending money for odds and ends, took the rest of it and public aid paid the rest. —Deerfield

Figure 37

Q34. HOW BIG A ROLE DID EACH OF THE FOLLOWING PLAY IN COVERING THE COSTS OF LONG-TERM CARE? RELATIVE SPENT MORE THAN 6 MONTHS IN AN ASSISTED LIVING FACILITY OR NURSING HOME: TOTAL (N=316)

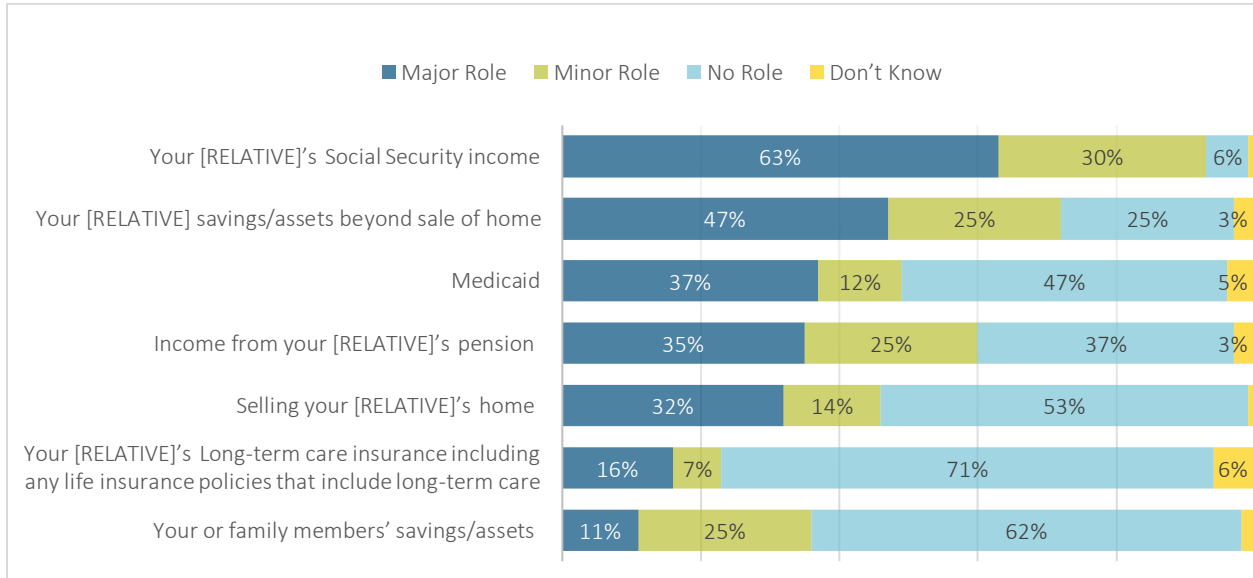
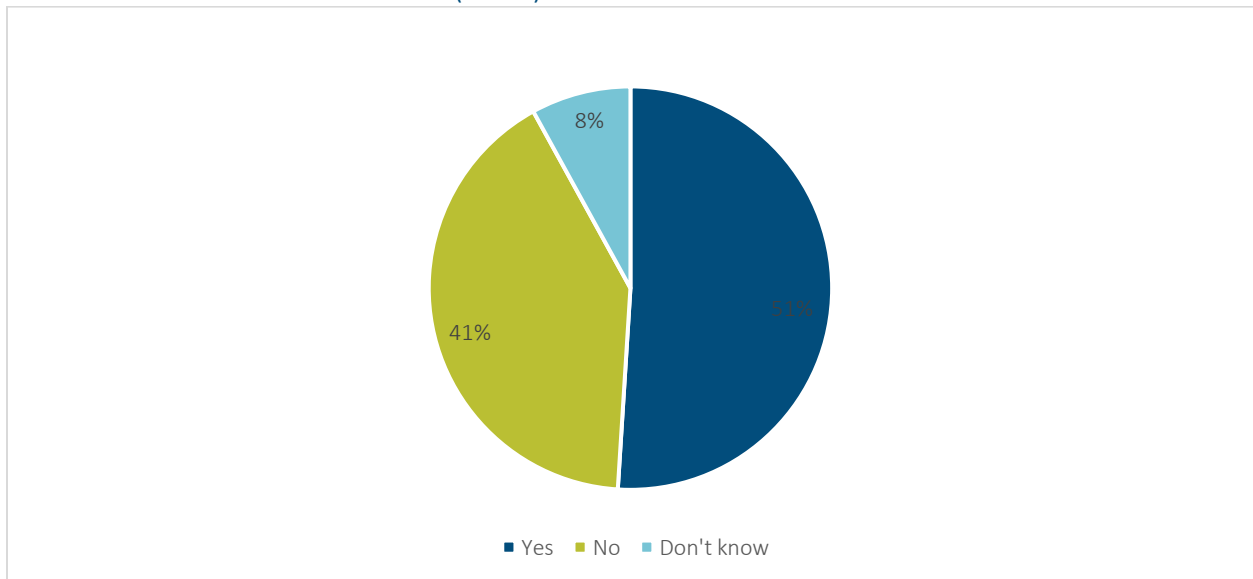


Figure 38

Q35. YOU SAID THAT MEDICAID PAID FOR SOME OF THE CARE. DID YOUR [RELATIVE] HAVE TO SPENDDOWN ASSETS IN ORDER TO QUALIFY FOR MEDICAID? RELATIVE WAS IN AN ASSISTED LIVING FACILITY OR NURSING HOME AND MEDICAID PLAYED A ROLE IN COVERING THE COSTS OF LONG-TERM CARE: TOTAL (N=154)



OVERALL EVALUATION

When asked to evaluate how their family did in taking care of their deceased parent, respondents gave themselves and their families high grades across a variety of areas. As seen in the qualitative research, three quarters (74%) gave themselves an “A” when it came to preparing for funerals and final expenses, the highest grade achieved.

My mom and my dad had planned [for their funeral], they had bought plots ... they paid for it. It was all done. ... [In terms of the actual funeral] I'm not sure, I think so, yeah. I know he had set aside money for that. —Deerfield

However, majorities also gave themselves an “A” in other areas as well including financial management (68%), making correct medical decisions (65%), taking care of the parents (64%), providing emotional support (61%), planning for final years (55%), and the amount of time spent with the parent (55%). The only area receiving fewer than half “As” was preparing for changes in health (47%), although this still achieved high grades as well.

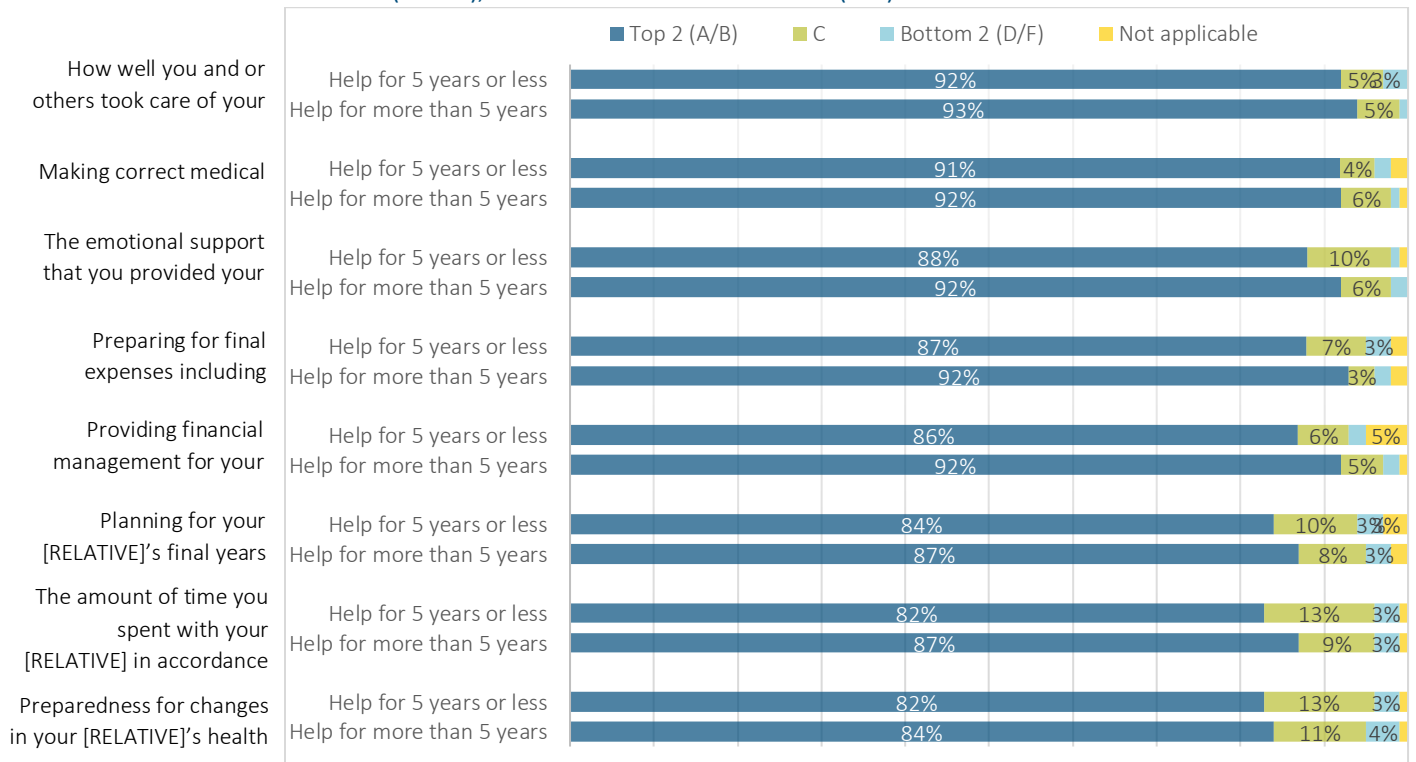
It brought us closer together, yeah. My dad was such an independent person and it was so sad to see that he needed all of us. But we were always a close family. ... My niece would go there after school every day to visit him. ... Yeah, we were very close. ... It didn't divide us; if anything, it united us more. —Deerfield

As might be expected, those who spent more than five years caring for their parents were more apt to give themselves an “A” on various dimensions than those who did not.

Figure 39

Q36. USING AN A-F SCALE LIKE YOU WOULD IN SCHOOL, WHAT GRADE WOULD YOU GIVE YOU AND [YOUR FAMILY/ THE PEOPLE YOU COLLABORATED WITH] WHEN IT CAME TO THE SUCCESS OF CARING FOR YOUR [RELATIVE] IN EACH OF THE FOLLOWING AREAS?

HELP FOR 5 OR LESS YEARS (N=285); HELP FOR MORE THAN 5 YEARS (286)



When asked what the one thing they could have done better, by far the most common response given was spending more time with their parents (29%), more commonly expressed by children who had parents who did not experience cognitive decline (36%). At the same time, qualitative research suggests that spending such time can be very stressful. Far fewer mentioned other aspects of care including getting involved in finances earlier (9%) or planning sooner (9%).

His health [was the biggest stress in my life] ... like when he would be in the hospital. I guess that sometimes we'd worry about whether or not he was going to make it. —Deerfield

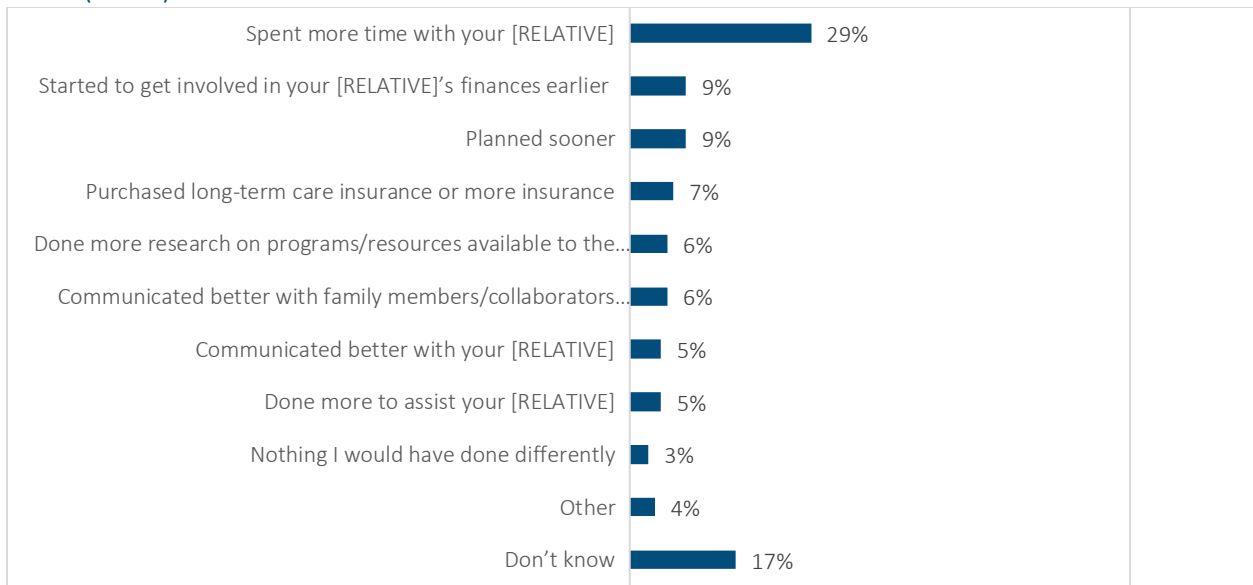
It was more of an emotional stress than a physical one. Because looking at a person that is fairly healthy and you see them decline, it was very emotionally stressful because you actually kind of prepare yourself for their death. And that was hard. —Memphis

Everyone is so different and their needs and what they want and that kind of thing. Just spending as much time with them as you can. I know she really enjoyed when we came there and were able to spend some time with her. —Edmonton

Figure 40

Q37. IF YOU OR [YOUR FAMILY/ THE PEOPLE YOU COLLABORATED WITH] COULD HAVE DONE ONE THING BETTER IN THE CARE OF YOUR [RELATIVE], WHAT WOULD IT HAVE BEEN? PLEASE ONLY SELECT ONE.

TOTAL (N=602)



Profile of Survey Respondents

	Total (n=602)
Age	
55–59	7%
60–64	20
65–69	39
70–75	34
Gender	
Female	57%
Male	43
Marital status	
Married	67%
Divorced/ Separated	14
Single, never married	10
Widowed	6
Living with a partner	4
Employment status	
Employed full time	14%
Employed part time	7
Not working	6
Retired from your primary occupation	70
Unemployed in the past 6 months	1
Unemployed for longer than 6 months	1
Education	
High school graduate or less	13%
Some college/technical school	29
Bachelor's degree	27

Post graduate work	4
Graduate or professional degree	26
Savings and investments	
Less than \$25,000	14%
\$25,000–\$49,999	18
\$50,000–\$99,999	19
\$100,000–\$199,999	13
\$200,000–\$299,999	6
\$300,000–\$499,999	7
\$500,000–\$999,999	8
\$1,000,000 or more	12
Relationship to deceased	
Your mother	57%
Your father	17
Your stepmother	*
Your stepfather	*
Your mother-in-law	13
Your father-in-law	2
Your aunt	3
Your uncle	1
Another relative	2
A neighbor	1
A friend	2
Reimbursement for care	
Yes, I was reimbursed for out-of-pocket expenses	5%
I was provided gifts, but these were not contingent upon providing care	7
No	88
Relative in long-term care	
An assisted living facility or adult foster care	

Yes	34%
No	66
A nursing home	
Yes	35%
No	65
Stepsiblings/half-siblings	
Yes	11%
No	89

APPENDIX: Questionnaire

SOCIETY OF ACTUARIES

2020 LIFE JOURNEY RETIREMENT SURVEY

January 2021

Welcome to this survey! This survey will be focused on your experiences providing care and support to someone who passed away after living well into old age. For the purposes of this survey, support could include tasks such as providing companionship, transportation, managing medication, assisting with finances, helping with personal daily activities, or planning for nursing care whether through aides or a nursing home for more than a year

Screening Questions

S1. In what year were you born? **[TERMINATE IF UNDER 55 OR OLDER THAN 75]**

	Total	(n=602)
55–59	7%	
60–64	20	
65–69	39	
70–75	34	

S2. What is your marital status?

	Total	(n=602)
Married	67%	
Living with a partner	4	
Divorced/Separated	14	
Widowed	6	
Single, never married	10	

S3. Have any of the following people in your life passed away in the past five years after having spent at least the last three years of their lives without a spouse or partner? *Please select all that apply.*

	Total	(n=602)
Mother	62%	
Father	20%	
Stepmother	1%	

Stepfather *

[If S2=1 or 2] Mother-in-law 19%

[If S2=1 or 2] Father-in-law 4%

Aunt 15%

Uncle 8%

Another relative 11%

A neighbor 8%

A friend 15%

None of the above passed away in the past 5 years after
 living three or more years without a spouse/partner [TERMINATE] --

S4. Please select those that you provided support, planning, and/or care for in the past 5 years.

If you provided support for multiple people in one relationship category, please only think of the person who passed away most recently.

[ONLY SHOW RESPONSE OPTIONS SELECTED IN S3]

	Total	(n=602)
Mother	60%	
Father	19%	
Stepmother	*	
Stepfather	*	
Mother-in-law	15%	
Father-in-law	2%	
Aunt	5%	
Uncle	2%	
Another relative	3%	
A neighbor	2%	
A friend	4%	
I did not provide support for any of the above in the past 5 years [TERMINATE] --		

S5. How extensively were you involved in providing assistance, support, care, financial guidance, or planning for each person? Support could include tasks such as providing transportation, managing medication, taking over finances, helping with personal daily activities, or planning for nursing care whether through aides or a nursing home for more than a year.

[ONLY SHOW ITEMS SELECTED IN S4]

		A great deal	To some extent	A little	Not at all
a.	Mother (n=362)	69%	30	1	--
b.	Father (n=113)	69%	30	1	--
c.	Stepmother (n=1)	100%	--	--	--
d.	Stepfather (n=1)	100%	--	--	--
e.	Mother-in-law (n=92)	50%	47	3	--
f.	Father-in-law (n=15)	40%	60	--	--
g.	Aunt (n=28)	54%	32	11	4
h.	Uncle (n=12)	58%	42	--	--
i.	Another relative (n=18)	39%	56	--	6
j.	A neighbor (n=13)	15%	85%	--	--
k.	A friend (n=22)	41%	50	9	--

[TERMINATE IF ALL IN S5<3]

S6. How old were the following people when they passed away?

If multiple people in one relationship category passed away, please only think of the person who passed away most recently.

[ONLY SHOW ITEMS WHERE S5=3 OR 4]

		Younger than 85	85-90	Older than 90	Prefer not to say
a.	Mother (n=360)	1%	43	56	--
b.	Father (n=112)	1%	34	65	--
c.	Stepmother (n=1)	--	--	100%	--
d.	Stepfather (n=1)	--	100%	--	--
e.	Mother-in-law (n=89)	--	40%	60	--
f.	Father-in-law (n=15)	--	47%	53	--
g.	Aunt (n=24)	8%	29	63	--
h.	Uncle (n=12)	--	58%	42	--
i.	Another relative (n=17)	29%	35	35	--
j.	A neighbor (n=13)	15%	54	31	--
k.	A friend (n=20)	35%	35	30	--

[TERMINATE IF ALL IN S6=1 or 4]

S7. What was the marital status of each person at the time he/she passed away?

If multiple people in one relationship category passed away, please only think of the person who passed away most recently.

[ONLY SHOW ITEMS WHERE S6=2 OR 3]

		Married/living with partner	Divorced/separated	Widowed	Single, never married
a.	Mother (n=356)	--	6%	92	1
b.	Father (n=111)	3%	8	89	--
c.	Stepmother (n=1)	--	--	100%	--
d.	Stepfather (n=1)	--	--	100%	--

e.	Mother-in-law (n=89)	1%	6	93	--
f.	Father-in-law (n=15)	--	7%	93	--
g.	Aunt (n=22)	--	5%	50	45
h.	Uncle (n=12)	17%	--	33	50
i.	Another relative (n=12)	--	17%	75	8
j.	A neighbor (n=11)	--	18%	73	9
k.	A friend (n=13)	--	8%	85	8

[TERMINATE IF ALL S7=1]

S8. To the best of your knowledge, did the following people have more than \$400,000 in financial assets at the time of their death, not counting any equity in their primary residence?

If multiple people in one relationship category passed away, please only think of the person who passed away most recently.

[ONLY SHOW ITEMS WHERE S7>1]

		Yes	No
a.	Mother (n=356)	1%	99
b.	Father (n=108)	3%	97
c.	Stepmother (n=1)	--	100%
d.	Stepfather (n=1)	--	100%
e.	Mother-in-law (n=88)	2%	98
f.	Father-in-law (n=15)	7%	93
g.	Aunt (n=22)	18%	82
h.	Uncle (n=10)	30%	70
i.	Another relative (n=12)	42%	58
j.	A neighbor (n=11)	36%	64

		Yes	No
k.	A friend (n=13)	38%	62

[TERMINATE IF ALL S8a-S8f=1 and no answer for S8g-S8I]

S9. Please select the person who passed away most recently.

If multiple people in one relationship category passed away, please only think of the person who passed away most recently.

[SHOW ONLY MULTIPLE PEOPLE=4 or MULTIPLE PEOPLE=3 and no 4 ON S5]

Note: this prioritizes those who provided more extensive care, with recency as a tiebreaker

[AUTOPUNCH IF ONLY 1 RESPONSE OPTION WOULD SHOW]

	Total	(n=602)
[IF S8a=2] Your mother	57%	
[IF S8b=2] Your father	17	
[IF S8c=2] Your stepmother	*	
[IF S8d=2] Your stepfather	*	
[IF S8e=2] Your mother-in-law	13	
[IF S8f=2] Your father-in-law	2	
[IF S7g>1] Your aunt	3	
[IF S7h>1] Your uncle	1	
[IF S7i>1] Another relative	2	
[IF S7j>1] A neighbor	1	
[IF S7k>1] A friend	2	

S10. Were you paid or reimbursed for the care that you provided for your [PIPE IN ANSWER FROM S9]?

	Total	(n=602)
Yes, I was paid an hourly rate or salary for providing care	[TERMINATE]	--
Yes, I was reimbursed for out-of-pocket expenses	5%	
I was provided gifts, but these were not contingent upon providing care	7	

No 88

S11. Did your [PIPE ANSWER FROM S9] spend more than 6 months in...?

	Total (n=602)	Yes	No
a.	An assisted living facility or adult foster care (for people who are mostly independent but require some assistance with day-to-day living)	34%	66
b.	A nursing home (for seniors who require 24-hour medical care and can no longer live independently)	35%	65

S12. Do you have any stepbrothers, stepsisters, half-brothers or half-sisters from your [PIPE IN S9 ANSWER]'s previous marriages or relationships that you or your [PIPE IN S9 ANSWER] have/had a relationship with?

	Total	(n=602)
Yes	11%	
No	89	

QUOTAS

Name	Logic	Quota
Stepparents	S5=3 or 4	At least n=25
In-laws	S5=5 or 6	Maximum n=200
Non-parent	S5=7-11	N=50
90+	S6=3	At least n=200
LTC	S11a=1 OR S11b=1	At least n=200

Marriage

1. During his or her adult working years was your [PIPE IN S9 ANSWER]...?

	Total	(n=602)
The primary breadwinner	30%	
A fairly co-equal breadwinner	16	

A secondary breadwinner 27

Not a breadwinner 26

Don't know 1

2. [IF S7 NE 4] During your [PIPE IN S9 ANSWER]'s marriage, which best describes their role in managing the household's finances?

	Total	(n=581)
My [PIPE IN S9 ANSWER] was in charge	20%	
My [PIPE IN S9 ANSWER] had most responsibility		23
His or her spouse was in charge	21	
His or her spouse had most responsibility	12	
The responsibility was shared equally	21	
Don't know		3

3. When did your [PIPE IN S9 ANSWER] first experience the following, if at all?

	Total (n=602)	Before I began providing care	When I was providing care	Never experienced this situation
a.	Cognitive decline	37%	33	30
b.	Vision problems	40%	16	44
c.	Hearing problems	44%	19	37
d.	Unsteadiness walking	37%	51	11
e.	Injury due to fall	27%	33	39
f.	Chronic disease	36%	18	46
g.	Depression	18%	17	65
h.	Inability to walk	9%	43	48
i.	General slowdown	51%	45	4

4. [IF WIDOWED, S7=3] What impact did your [PIPE IN S9 ANSWER]'s spouse's death have on his or her...?

[IF DIVORCED/SEPARATED, S7=2] What impact did your [PIPE IN S9 ANSWER]'s spouse's (most recent if more than one) divorce/separation have on his or her...?

		Major positive impact	Minor positive impact	No impact	Minor negative impact	Major negative impact	Too many years earlier to matter	Don't know
	Total (n=581)							
a.	Overall financial security	8%	6	38	20	14	10	4
b.	Ability to manage household finances	7%	6	42	20	14	8	3
c.	Ability to secure and/or pay for housing	3%	3	66	9	8	7	3
d.	Transportation planning	4%	4	55	13	15	7	3
e.	Meal planning and/or meal preparation	5%	5	55	16	10	7	2
f.	Ability to manage their own healthcare (doctor's appointments, insurance, etc.)	5%	4	49	18	15	7	2
g.	Ability to manage their prescription drugs	5%	5	54	17	10	6	2

Health

5. Which of the following did your [PIPE IN S9 ANSWER] ever need the following and if so, at about what age did they start needing help?

	Total (n=602)	Before age 70	In his/her 70s	In his/her 80s	[Do not show if passed away before 90] In his/her 90s or beyond	Did not need help with this	Don't know
a.	Assistance with household chores	5%	12	52	22	7	1
b.	To be driven	16%	10	49	19	5	1
c.	Assistance with walking	1%	6	46	29	18	*
d.	Assistance with activities of daily living such as getting dressed, eating, bathing, getting out of bed, etc.	1%	4	39	33	22	1
e.	Long-term care	*	3%	36	31	28	2

6. Over the years, how much impact did each of the following have on your [PIPE IN S9 ANSWER]'s health and vitality:

	Total (n=602)	Major impact	Minor Impact	No impact	Don't know
a.	Cognitive decline	37%	35	26	2
b.	Vision problems	16%	41	42	1
c.	Unsteadiness walking	45%	45	10	1
d.	Injury due to fall	35%	25	37	3
e.	Chronic disease	30%	26	40	4
f.	Accident other than a fall	5%	8	79	8
g.	Depression	13%	27	54	5

	Total (n=602)	Major impact	Minor Impact	No impact	Don't know
h.	Hospital stay(s)	22%	44	32	2
i.	Side effects of medicine	10%	30	53	7

7. [IF ANY IMPACT IN Q6=2,3] Roughly how old was your [PIPE IN S9 ANSWER] when these issues first affected him/her?

		Younger than 70	In his/her 70s	In his/her 80s	[Do not show if passed away before 90] In his/her 90s or beyond	Don't know
a.	Cognitive decline (n=431)	2%	13	58	25	1
b.	Vision problems (n=341)	17%	23	44	13	3
c.	Unsteadiness walking (n=536)	2%	10	59	29	1
d.	Injury due to fall (n=365)	2%	10	55	30	3
e.	Chronic disease (n=335)	13%	22	44	17	4
f.	Accident other than a fall (n=82)	9%	12	46	17	16
g.	Depression (n=243)	16%	14	46	20	5
h.	Hospital stay(s) (n=398)	6%	13	51	27	2
i.	Side effects of medicine (n=240)	6%	14	46	19	15

Finances

8. Comparing when your [PIPE IN S9 ANSWER] was 65 years old until one year before they passed away, would you say that their financial condition one year before they passed away was...?

Total (n=602)

Much better than when they were 65 6%

Somewhat better than when they were 65 9

About the same as when they were 65 38
 Somewhat worse than when they were 65 17
 Much worse than when they were 65 26
 Don't know 4

9. **[IF FINANCES GOT WORSE, Q8 =1,2]** How big an impact did each of the following have on making your **[PIPE IN S9 ANSWER]**'s finances worse after retirement?

	Total (n=259)	Major impact	Minor Impact	No impact	Not Applicable	Don't know
a.	Home or condo repairs	13%	31	32	21	3
b.	Home or condo fee assessments	4%	12	35	46	2
c.	Medical expenses	21%	46	26	4	2
d.	[IF S7=3] Death of a spouse (n=235)	44%	30	19	4	3
e.	An adult child in need of financial support	6%	12	32	50	1
f.	Needing assisted living or help at home	39%	30	19	11	1
g.	Giving gifts to children and grandchildren	7%	19	46	26	1
h.	Fraud	5%	7	34	51	2
i.	Investment losses	7%	6	39	45	3
j.	Needing nursing care or at home long-term care	49%	15	17	18	2
k.	Divorce	2%	1	19	74	5
l.	Overspending on non-essentials	7%	18	31	43	2
m.	Debt	7%	13	32	45	3
n.	Rent increases	3%	16	26	52	3
o.	Helping to support children and/or grandchildren	5%	13	25	53	3

10. **[FINANCES GOT BETTER, IF Q8 =4,5]** How big an impact did each of the following have on making your **[PIPE IN S9 ANSWER]** finances better after retirement?

	Total (n=90)	Major impact	Minor Impact	No impact	Not Applicable	Don't know
a.	Sale of property	16%	19	19	44	2
b.	Access to government-provided benefits like Social Security, Medicare, or Medicaid	31%	34	27	4	3
c.	Less spending on non-essentials	18%	37	31	10	4
d.	Home equity or reverse mortgage use	2%	3	19	73	2
e.	Investment gains	12%	21	19	46	2
f.	Relative moving in with your [PIPE IN S9 ANSWER]	6%	10	12	69	3
g.	Him or her moving in with family or friends	9%	7	12	70	2
h.	Inheritance or life insurance payout	11%	11	20	52	6
i.	[IF WIDOWED] No longer having a spouse to support (n=78)	18%	24	33	22	3
j.	[IF WIDOWED] No longer having to take care of a spouse's medical needs (n=78)	17%	27	24	29	3

11. Did your [PIPE IN S9 ANSWER] ever need support for the following in the years after their retirement?

	Total (n=602)	Yes	No	Don't know
a.	Investment management	30%	62	8
b.	Balancing a checkbook	57%	39	4
c.	Paying bills/writing checks	63%	35	2
d.	Communicating with a bank manager or advisor	48%	46	7
e.	All of their finances	58%	38	4
f.	Budgeting	38%	58	4

12. [IF YES, Q11=1] For about how many years was this support provided?

		Less than 1 Year	1-2 Years	3-4 Years	5+ years	Not sure
a.	Investment management (n=179)	2%	9	18	67	4

		Less than 1 Year	1-2 Years	3-4 Years	5+ years	Not sure
b.	Balancing a checkbook (n=343)	1%	10	21	65	2
c.	Paying bills/writing checks (n=382)	3%	14	22	60	2
d.	Communicating with a bank manager or advisor (n=286)	2%	11	21	63	3
e.	All of their finances (n=349)	2%	11	22	62	3
f.	Budgeting (n=230)	2%	8	21	66	3

13. [IF ANY Q11=1] Which of the following events played a role in your [PIPE IN S9 ANSWER] needing support with financial management? Please select all that apply.

Total (n=445)

- Cognitive decline 62%
- Difficulty with technology 44%
- Being unable to go to the bank 38%
- Obvious mistakes with finances 36%
- [IF S7=3] Loss of spouse 30%
- Poor vision 26%
- Loss of interest in managing money 23%
- Hearing difficulties 23%
- Arthritis 12%
- Being victimized by fraud 5%
- Don't know 4%

Housing Timeline

14. Since the time of your [PIPE IN S9 ANSWER]'s retirement, [IF ANY S11=1 and before needing care], did they move to a different residence?

Total (n=602)

- Yes, just once 26%
- Yes, more than once 20

No 54
 Don't know 1

15. **[IF Q14 < 3]** Why did your **[PIPE IN S9 ANSWER]** move in retirement? **[IF Q14=2]**: Please consider the most recent time that your **[PIPE IN S9 ANSWER]** moved. *Please select all that apply.*

Total	(n=274)
For a place more accommodating to their current or expected limitations	48%
To have a residence that was easier to manage	40%
To be close to family	38%
To downsize	36%
To be in a safer environment	24%
To be less isolated	22%
Because a spouse passed away	20%
To have access to more social activities	19%
To save money	16%
Climate	11%
To have access to transportation	9%
Other [SPECIFY]	4%
Don't know	1%

16. When residing independently, did any of the following live with your **[PIPE IN S9 ANSWER]** **[IF S7=3 after their spouse passed away]**? **[MULTIPLE RESPONSE ACCEPTED]**

Total	(n=602)
One or more of their children	22%
A paid caregiver	7%
One or more of their grandchildren	4%
Someone else who is not related to him/her/them	2%
Another relative	2%
No one did	66%
Don't know	1%

Role of Family

17. For what length of time were you or someone else involved in doing each of the following in the care of your [PIPE IN S9 ANSWER]?

		Never done	Done for less than a year	Done for 1 to 5 years	Done for more than 5 years	Don't know
	Total (n=602)					
a.	Asset management	26%	7	26	34	7
	Daily finances (budgeting, banking, or paying bills)	13%	12	37	36	2
c.	Providing emotional support	3%	5	28	62	2
d.	Being power of Attorney/Acting as Power of Attorney	15%	8	30	42	4
e.	Acting as Health Care Power of Attorney or Health Care Proxy (i.e., in charge of making healthcare decisions)	13%	9	32	42	3
f.	Going to medical appointments/ Talking with doctors	4%	7	40	48	1
g.	Providing transportation	6%	8	36	50	1
h.	Assisting with shopping	6%	8	39	45	2
i.	Laundry, housekeeping or meal preparation	15%	13	38	33	1
j.	Assisting in activities of daily living such as bathing, dressing	31%	18	27	21	2

18. [IF FAMILY MEMBER S9=1-9] How big a role did non-relatives play in caring for your [PIPE IN S9 ANSWER]?
Please consider friends and neighbors rather than those paid to provide care.

	Total	(n=583)
Critical role	6%	
Major role	13	
Minor role	31	
No role	50	
Don't know	1	

19. **[IF FAMILY MEMBER S9=1-9]** Who was significantly responsible for your **[PIPE IN S9 ANSWER]** in the following areas? **[MULTIPLE RESPONSES ALLOWED]**

	You	Your Spouse	Brothers	Sisters	Step-Brothers	Step-sisters	Your [PIPE IN S9 ANSWER] brothers or sisters	Nieces or nephews	Friends or neighbors	Grandchildren	Someone else SPECIFY:	Don't know
a. Money management (n=528)	71%	13%	18%	14%	1%	*	1%	*	1%	2%	2%	2%
b. Keeping him or her company (n=583)	79%	27%	28%	26%	1%	1%	6%	9%	19%	22%	7%	2%
c. Performing tasks and chores (n=580)	79%	26%	22%	24%	1%	1%	1%	4%	8%	11%	11%	3%
d. Making decisions regarding nursing homes or assisted living (n=279)	80%	25%	23%	21%	--	1%	1%	1%	*	3%	5%	1%
e. Power of Attorney (n=496)	67%	14%	16%	15%	*	--	--	1%	*	1%	1%	2%
f. Named on medical directive (n=513)	68%	14%	17%	18%	*	*	--	1%	*	2%	2%	3%

Family Dynamics

20. [IF RESPONDENT AND AT LEAST ONE OTHER PERSON INVOLVED IN Q19, IF FAMILY MEMBER S9=1-9] Using an A-F scale like you would in school, what grade would you give yourself and your family when it came to the following aspects of your relationships when caring for your [PIPE IN S9 ANSWER]?

	Total (n=454)	A	B	C	D	F	Not Applicable
a.	Planning together	44%	34	10	6	3	3
b.	Each doing what they were best at	50%	31	7	4	3	4
c.	Agreement on the roles each would play	48%	24	14	5	4	5
d.	Feeling that everyone was pulling their weight	33%	24	17	13	9	4
e.	Tolerance for those that had barriers to offering support – distance, family obligations career	35%	28	17	8	4	8
f.	Coordination of tasks	44%	30	13	6	4	4
g.	Agreement on medical decisions	62%	22	7	2	4	4
h.	Working out finances	58%	24	7	3	3	6
i.	Agreeing on inheritances	55%	13	5	3	5	19
j.	Communicating well with one another	48%	26	11	6	6	2

21. How effective was the financial planning that was done for the care of your [PIPE IN S9 ANSWER]

	Total	(n=602)
Very effective	52%	
Somewhat effective	27	
Not too effective	3	
Not at all effective	1	
There was no financial planning done	13	
Don't know	3	

22. How effective was [IF S9=1-9: your family/ IF S9=10-11: the family of the person you cared for] in managing the physical care of your [PIPE IN S9 ANSWER]

	Total	(n=602)
Very effective	58%	
Somewhat effective	33	

Not too effective 6
 Not at all effective 2
 Don't know 1

23. In the years following their retirement, was there ever an instance of fraud, a scam, or financial abuse perpetrated on your [PIPE IN S9 ANSWER]?

	Total	(n=602)
Yes	12%	
No	82	
Don't know	5	

24. [IF FRAUD, Q23=1] Was this incident of fraud or abuse perpetrated by...?

	Total	(n=73)
A stranger	37%	
A family member of your [PIPE IN S9 ANSWER]	29	
A non-family member known to your [PIPE IN S9 ANSWER]	16	
A professional, non-family member involved in your [PIPE IN S9 ANSWER]'s financial management	10	
A professional, non-family member involved in your [PIPE IN S9 ANSWER]'s care	8	
Don't know	--	

25. [If responsible for money mgmt., Q19a=1] Did you ever have a dispute with another person over decisions that you made about your [PIPE IN S9 ANSWER]'s money or property?

	Total	(n=373)
Yes, a dispute with a family member	16%	
Yes, a dispute with a non-family member	2	
No	83	
Do not recall	*	

Assisted Living and Long-Term Care

26. Broadly speaking, did your [PIPE IN S9 ANSWER] need for support happen...?

	Total	(n=602)
Very gradually	21%	
Somewhat gradually	58	
Somewhat suddenly	14	
Very suddenly	5	
Don't know	2	

Support at Home

27. Thinking about the support your [PIPE IN S9 ANSWER] received at home over time, would you say that...?

	Total	(n=602)
It was completely provided by you or family	52%	
It was mostly provided by family with some respite from paid helpers	28	
It was half and half between family and paid helpers	9	
It was mostly provided by paid helpers with some respite from family members	7	
It was completely provided by paid helpers	2	
Don't know	2	

Assisted Living

28. [IF Assisted Living Facility, S11a=1] What of the following led to moving your [PIPE IN S9 ANSWER] to an assisted living facility? *Please select all that apply.* [RANDOMIZE]

	Total	(n=203)
General frailty	46%	
Improved quality of life for your [PIPE IN S9 ANSWER] given your [PIPE IN S9 ANSWER]'s limitations	46%	
Cognitive decline	45%	

- A medical event 39%
- Housing was not suitable given your [PIPE IN S9 ANSWER]'s limitations 38%
- At-home care became too taxing physically and emotionally 26%
- A doctor, social worker, or another professional recommended it 26%
- There was no one available near your [PIPE IN S9 ANSWER]
to provide the help that was required 21%
- At-home care was too disruptive to you or other family members 12%
- Your [PIPE IN S9 ANSWER] wanting companionship 11%
- The continuing care community where your [PIPE IN S9 ANSWER]
was staying recommended it 10%
- Your [PIPE IN S9 ANSWER] wanted access to activities on a convenient basis 7%
- Problem with communication skills 6%
- Other [SPECIFY] 4%
- Don't know 1%

29. [IF Assisted Living Facility,S11a=1] To what extent did your [PIPE IN S9 ANSWER] participate in the decision to have assisted living?

	Total	(n=203)
Completely	24%	
To a great extent	27	
To some extent	24	
A little	12	
Not at all	14	

30. [IF Q29 = 1-3] Did your [PIPE IN S9 ANSWER] resist the decision to enter assisted living?

	Total	(n=100)
Strong resistance	24%	
Slight resistance	39	
Did not resist the decision	32	
Don't know	5	

Nursing Home

31. **[IF Nursing Home Care, S11b=1]** What of the following led to moving your **[PIPE IN S9 ANSWER]** to a nursing home? Please select all that apply. **[RANDOMIZE]**

Total	(n=209)
A medical event	54%
Cognitive decline	48%
General frailty	47%
A doctor, social worker, or other professional recommended it	39%
Housing was not suitable given your [PIPE IN S9 ANSWER] 's limitations	30%
At-home care became too taxing physically and emotionally	26%
The assisted living or continuing care community place where your parent was staying recommended it	18%
At-home care was too disruptive to you or other family members	12%
There was no one available near your [PIPE IN S9 ANSWER] to provide the help that was required	12%
Other [SPECIFY]	7%
Don't know	1%

32. **[IF Nursing Home Care, S11b=1]** To what extent did your **[PIPE IN S9 ANSWER]** participate in the decision to move to a nursing home?

Total	(n=209)
Completely	13%
To a great extent	18
To some extent	20
A little	13
Not at all	36

33. **[IF Q32=1-3]** Did your **[PIPE IN S9 ANSWER]** resist the decision to enter a nursing home?

Total	(n=144)
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Strong resistance 22%

Slight resistance 29

Did not resist the decision 45

Don't know 3

Paying for Long-Term Care

34. [IF NURSING HOME AND/OR ASSISTED LIVING, IF ANY S11=1] How big a role did each of the following play in covering the costs of long-term care? [RANDOMIZE]

	Total (n=316)	Major Role	Minor Role	No Role	Don't Know
a.	Your [PIPE IN S9 ANSWER]'s Long-term care insurance including any life insurance policies that include long-term care	16%	7	71	6
b.	Your or family members' savings/assets	11%	25	62	2
c.	Income from your [PIPE IN S9 ANSWER]'s pension	35%	25	37	3
d.	Your [PIPE IN S9 ANSWER]'s Social Security income	63%	30	6	1
e.	Selling your [PIPE IN S9 ANSWER]'s home	32%	14	53	2
f.	Medicaid	37%	12	47	5
g.	Your [PIPE IN S9 ANSWER] savings/assets beyond sale of home	47%	25	25	3

35. [IF MEDICAID PLAYED AT LEAST MINOR ROLE IN COVERING COSTS, Q34f<3] You said that Medicaid paid for some of the care. Did your [PIPE IN S9 ANSWER] have to spenddown assets in order to qualify for Medicaid?

Total (n=154)

Yes 51%

No 41

Don't know 8

Overall Evaluation

36. Using an A-F scale like you would in school, what grade would you give you and [IF S9=1-9: your family/ IF S9=10-11: the people you collaborated with] when it came to the success of caring for your [PIPE IN S9 ANSWER] in each of the following areas?

	Total (n=602)	A	B	C	D	F	Don't know
a.	Making correct medical decisions	65%	25	6	1	*	2
b.	How well you and or others took care of your [PIPE IN S9 ANSWER]	64%	28	5	1	1	*
c.	Preparing for final expenses including funeral expenses	74%	16	5	1	1	3
d.	Preparedness for changes in your [PIPE IN S9 ANSWER]'s health	47%	36	12	3	*	1
e.	The emotional support that you provided your [PIPE IN S9 ANSWER]	61%	29	8	1	*	1
f.	Providing financial management for your [PIPE IN S9 ANSWER]	68%	20	6	2	1	4
g.	Planning for your [PIPE IN S9 ANSWER]'s final years	55%	29	9	2	1	3
h.	The amount of time you spent with your [PIPE IN S9 ANSWER] in accordance with his or her wishes	55%	30	11	2	1	1

37. If you or IF S9=1-9: your family/ IF S9=10-11: the people you collaborated with] could have done one thing better in the care of your [PIPE IN S9 ANSWER], what would it have been? *Please only select one.*
[RANDOMIZE]

	Total	(n=602)
Spent more time with your [PIPE IN S9 ANSWER]	29%	
Started to get involved in your [PIPE IN S9 ANSWER]'s finances earlier	9	
Planned sooner	9	
Purchased long-term care insurance or more insurance	7	
Done more research on programs/resources available to the aging	6	
Communicated better with family members/collaborators other than your [PIPE IN S9 ANSWER]	6	
Communicated better with your [PIPE IN S9 ANSWER]	5	
Done more to assist your [PIPE IN S9 ANSWER]	5	

Nothing I would have done differently 3
 Other [SPECIFY] 4
 Don't know 17

COVID-19

38. Did your [PIPE IN S9 ANSWER] pass away...?

	Total	(n=602)
Before February 2020	80%	
During or after February 2020	20	

39. [IF PASSED AWAY AFTER February 2020] Did your [PIPE IN S9 ANSWER] pass away due to complications with COVID-19?

	Total	(n=123)
Yes	17%	
No	83	

40. [IF PASSED AWAY AFTER Feb 2020] Did the COVID-19 pandemic impact your [PIPE IN S9 ANSWER] in the following ways? Please select all that apply. **RANDOMIZE**

	Total	(n=123)
Increased isolation from family/friends	54%	
Reduced social interaction	43%	
Increased loneliness	31%	
Increased cognitive decline	24%	
Increased boredom	23%	
[IF LTC] They were placed in mandatory isolation at their care facility	23%	
Onset of or worsening depression	21%	
Loss of the will to live	19%	
[IF LTC] They were in a care facility with others diagnosed with COVID-19	13%	
They were placed in mandatory isolation at a hospital	13%	

Their care was compromised due to a lack of available healthcare resources	7%
Made it more difficult to get healthcare	7%
Care was compromised due to fear or unwillingness to go out	7%
Made it more difficult to get food and necessities	7%
They became overly medicated	4%
Made it more difficult to conduct financial transactions	4%
Care was compromised due to difficulty in getting transportation	2%
None of the above	33%

41. **[IF PASSED AWAY AFTER Feb 2020]** Did the COVID-19 pandemic impact your ability to care for your **[PIPE IN S9 ANSWER]** in the following ways? Please select all that apply. **RANDOMIZE**

Total	(n=123)
You were unable to see your [S9 ANSWER] at all for a period before they died	49%
Inability to provide the amount of emotional care required	28%
Inability to provide the amount of physical care required	14%
None of the above	45%

Now just a few more questions about you for statistical purposes ...

42. Are you...?

Total	(n=602)
Male	43%
Female	57%

43. What is the highest level of education you completed?

Total	(n=602)
High school graduate or less	13%
Some college/technical school	29%
Bachelor's degree	27%
Post graduate work	4%
Graduate or professional degree	26%

44. Are you currently...?

	Total	(n=602)
Employed full time	14%	
Employed part time	7	
Not working	6	
Retired from your primary occupation		70
Unemployed in the past 6 months	1	
Unemployed for longer than 6 months		1

45. What is the total amount your household has in savings and investments, not counting the equity in your home?

	Total	(n=602)
Less than \$25,000	14%	
\$25,000 to \$49,999	18	
\$50,000 to \$99,999	19	
\$100,000 to \$199,999	13	
\$200,000 to \$299,999	6	
\$300,000 to \$499,999	7	
\$500,000 to \$999,999	8	
\$1,000,000 or more	12	

Thank you very much for completing this survey!

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