



Aging and Retirement

Life Journey Study

A Report on 40 In-Depth Interviews in the
United States and Canada With Adult Children
of Recently Deceased Parents





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Section 1: Executive Summary

1.1 BACKGROUND

For more than 15 years, the Society of Actuaries (SOA) has been actively involved in understanding the approach pre-retirees and retirees take to 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 that time. In 2005, the SOA conducted a series of focus groups with retirees to investigate the level of financial and other planning that led to the decision to retire.

The 2005 study² found that many did little financial planning or analysis prior to deciding to retire. Few made any effort to project or estimate if they had enough money to maintain financial security throughout their retirement. To better understand the lack of planning and its consequences, the SOA conducted a series of focus groups in 2013 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. This study validated the results of the 200 research by again finding a notable lack of planning. However, the study found that most people adjusted well to their financial circumstances and modified their spending as their major financial planning tool.

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 voluntarily at least 15 years before³. The goal was to examine the common financial strategies used by retirees. These tended to include short-term cash flow strategies and dealing with risk when events happened rather than planning for them in advance. This study generally found that despite inadequate planning, Americans and Canadians were able to absorb many of the shocks of retirement. Not surprisingly, Americans were more exposed to health care costs than Canadians, but participants in both countries were concerned about the impact of needing long-term care and were generally not prepared for it.

In 2017, the SOA studied those 85 years and older to further discover how retirement finances played out in the later years of life⁴. 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. This study also found that family support was an important factor as health and independence declined, and the elderly whose families could offer driving, cooking and housekeeping services fared much better than those whose families could not provide this assistance.

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

² Greenwald & Associates, 2005. Society of Actuaries Report, Risk and the Process of Retirement Survey, Report of Findings

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

However, 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.

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. The interviews described in this research report focused on how children managed the progression from having relatively healthy parents to their parents’ eventual death. Furthermore, the interviews probed the aspects of support the families provided as parents became more dependent. The earlier research suggested that children did not plan well for this stage in life. This report examines the consequences of this and how well a small number of families adapted as the parents aged.

This report represents the first phase of a two-phase research effort being conducted on these issues. The second phase will be an online survey further exploring the issues. The information gathered from these interviews will be used to help structure the questionnaire for the second phase, scheduled for later in 2019. It is important to remember that the results in this report reflect a relatively small number of interviews and contain anecdotal information.

1.2 METHODOLOGY

To achieve its goals for the interview portion of this study, the SOA commissioned 24 one-hour in-depth interviews in the United States and 16 in Canada. The interviews were conducted in November 2018 in Memphis, Tennessee, and Deerfield, Illinois, in the United States; and Toronto, Ontario, and Edmonton, Alberta, in Canada. Interviewees were recruited by local facilities in each area using their respondent lists.

Interviewees consisted of 55- to 75-year-old adults with deceased elderly parents, in-laws, aunts or uncles whom they cared for at least to some extent. For the purposes of the study, the deceased parent or other relative met these conditions:

- Passed away in the last 10 years and were older than 85 when they did,
- Survived a spouse by at least two years, and
- Had no more than \$400,000 in financial assets at the time of death.

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. Individuals who cared for stepparents in blended families were also recruited.

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

Table 1
PARTICIPANTS RELATIONSHIP TO THE DECEASED

Relationship*	U.S.	Canada
Deceased was a biological female parent	13	12
Deceased was a biological male parent	4	2
Deceased was a female in-law	7	0
Deceased was a male in-law	0	1
Deceased was a stepparent	0	1
Deceased was an aunt or uncle	5	0
Deceased was a neighbor	0	1

**Numbers add up to more than 40 because there were several respondents interviewed regarding multiple roles.*

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

This phase of the research is qualitative. The participants were not drawn from a representative sample of the retiree population, and the number of people involved was not large. Thus, we cannot draw statistically significant conclusions as compared to the general population.

However, qualitative research can provide important insights and identify issues worthy of further quantitative research. In this vein, this report helps inform the quantitative questions for the second phase of this research.

The guide for the interviews reported on here appears in the Appendix.

1.3 IMPORTANT CONSIDERATIONS RELATED TO THE SAMPLE

In addition to the small size of 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 needs than baby boomers.

Because we screened for those involved in their parents’ care, our sample is somewhat skewed against situations where adult children did not take that much responsibility or where there were no children. For obvious reasons, those less involved would have had far less to discuss in an interview.

The interviews also excluded people without children or nieces or nephews who acted as children, with one exception of a neighbor who was cared for by a participant. The interviews also excluded people for whom a court-appointed guardian took control of the situation. There are likely different issues in such situations.

1.4 KEY FINDINGS

This section summarizes some themes that surfaced in the course of the interviews but does not provide any information about how common these occurrences are in the general population. The second phase of this research will provide more insights on these outcomes.

1.4.1 LIFE PROGRESSION AND PLANNING

1.4.1.1 End-of-Life Journey Discussions Differed Concerning Care and Expense

The end-of-life scenarios the children in this study described for 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.

In a few of the interviews, parents were relatively healthy until death and only required a brief period of intensive support, but more of them indicated there was an extended period for which some level of support was required.

When adult children managed their parents' condition at the end of life, some dealt with physical decline, some with cognitive decline and some with both:

- **Cognitive decline.** Parents experiencing cognitive decline usually required a longer period of care, were more dependent and had less say in decisions. Cognitive decline often happened gradually, and aging parents often hid signs of impairment initially. Children did not always recognize the severity of the decline, and by the time it was dealt with, it was often quite significant.
- **Physical decline.** Parents often had a triggering event that led to sudden physical decline such as a fall, a stroke or heart attack, but sometimes the decline was gradual, caused by factors such as arthritis or macular degeneration. Sometimes there were a series of incidents where parents might decline and then get better for a while. In some cases, children absorbed the need for more help and in other cases, the parent needed to move to a new type of support arrangement.

1.4.1.2 Adult Children Did Very Little Advanced Planning

As discussed above, some health changes happened suddenly and some gradually. Generally, the adult children tended to react to their parents' changing needs rather than plan for them. This tendency surfaced in some interviews among siblings who did not have strong relationships with each other; this may have exacerbated a lack of planning. The researchers observed that these children may be the most in need of planning since coordination among them could be a struggle.

The interviews indicated a variety of events or functional decline that led adult children to increasingly take responsibility for their parents' care including widowhood (especially when the deceased parent managed the finances); loss of the ability to drive or get around on public transportation; loss of the ability to physically maintain a residence, cook or clean; and mobility issues or other issues that required long-term care. One specific triggering event was the inability of the parent to remember to take medications. Irrespective of family dynamics, one of the factors that precluded planning was that, until they experienced it, adult children often didn't understand the toll caring for a parent would take on them.

1.4.1.3 Adult Children Most Often Did Not Question Doctor's Advice

Adult children often helped take their parent to doctor's appointments and consult with the doctor. In this research, it was most common for the adult children to follow the doctor's advice without question and play an active role in making sure it was followed. However, several did get second opinions or seek geriatricians, and a few questioned the doctor's decision later.

1.4.1.4 Most Adult Children Took Over Their Parent's Finances Eventually

One key responsibility that the adult children took over was managing their parents' finances, but some respondents only did it for a short period while others managed them for a very long time. This sometimes happened when the parental spouse who handled finances died first. At times, when children took over responsibility for driving, they took their parent to the bank and began to meet with bank staff.

One pattern cited was that children acquired joint management of checking accounts and took over bill paying. Sometimes the children wrote the checks due to the parent's physical or vision issues, as online banking was almost unheard of in this generation. Children also took over investment management; however, in the wealth

band tested in this study, there may have been few assets to manage, and most often those assets were in a bank and not in an investment portfolio.

Furthermore, the interviews indicated that another event which led children to managing finances was when the parent began to need care. The need for care often changed the ability of parents to cover their needs with their financial resources. As found in the 85+ Post-Retirement Experiences study, most elderly, even those with minimal wealth, were able to balance inflows and outflows. Often Social Security or a Canada Pension Plan (CPP) was the primary or only source of income, which made the management easier.

The need for care was also often accompanied by less ability and/or desire to manage finances. If the parent required a nursing care facility, the children often directed the income to the nursing care facility and the parent had no responsibility except for handling a small amount of spending money.

There was some evidence of children taking advantage of their parents for financial gain either on their own or with the support of advisers. We did not come across instances of fraudulent activity from an unknown person contacting the parent.

COMMENTS FROM THE SOA

Who managed finances when help was needed. In reviewing the interviews and the relationship of the children to their parents' finances, it should be remembered that the method of selecting people to interview would tend toward significant involvement in those tasks. It is likely that many people eventually need help managing finances but the study did not explore situations where there were no family members, or where family had virtually no involvement. An area for future research is further options for managing finances.

Fraud and financial exploitation. These interviews offered limited information about fraud and financial exploitation, but other evidence indicates that this can be a significant problem. However, there is a major problem of under-reporting in these situations. Also, this sample consisted of children who were heavily involved with their parents' affairs; this might have reduced the incidence of fraud. There are a wide variety of different types of fraud and financial exploitation. The Stanford Center on Longevity and Financial Industry Regulatory Agency (FINRA) have done substantial work on fraud and the methods of combatting it.

1.4.2 THE NEED FOR CARE

1.4.2.1 *Need for Paid Outside Help Varied by Circumstance*

The extent and nature of the role that those providing outside support played was driven by the parents' needs, the extent to which family intervened and provided the support, and whether the family was committed to the parent aging in place or eventually moving to a facility. If a parent had a sudden incident that required the transition to care, the children often needed to scramble to find support. In Canada, the provinces provided free nursing support, with visits ranging from several times a week to daily, to provide personal care such as bathing. These nursing support aides sometimes supplemented efforts of the children and at times filled the gap in care needs.

These interviews indicated that in some cases, outside help was hired to come to assisted living facilities to give the parent more support and attention than the facility provided. Some facilities resisted this since they may have charged "a la carte" for certain types of support like bringing medicine, and the private aides supplanted this function, impacting facility revenue.

Aides were often found through word of mouth or other connections: In these interviews, the family used word-of-mouth recommendations to find aides more often than using the services of an agency. In Canada, home care aides were not chosen by the family but rather assigned by the province with very little decision-making on the part of the family. The services these aides provided were limited so the family still sometimes hired their own helpers to supplement the care.

1.4.2.2 Hardest Decision Was Putting Parent in Nursing Home

The families had different values, resources and intentions when it came to the decision to have a parent age in place or put them in a nursing home. The decision was driven by how willing the parent was to enter a nursing home, the quality of the network of care and support that existed to provide home care, and the financial resources available.

Finding care often involved a difficult decision. If a family had to turn to Medicaid to afford care, then a nursing home was usually the option. In cases where families wanted to avoid a nursing home, home care could be provided by aides, a combination of family and aides, rotating family members where there were multiple siblings or by a family member that chose to live with the parent. Again, in Canada, the province did offer some part-time aides free of charge that may have supplemented the care schedule. However, as the 85+ Post-Retirement Experiences study showed, even in Canada, parents often ended up using a nursing home when care became overwhelming.

One key element of the progression toward deciding on nursing care was whether the primary concern was physical or cognitive. The decision to move the parent to a residential facility was often more urgent with cognitive decline. Some interviews indicated that children didn't have a real sense of how serious the situation had become until the decline had advanced quite a bit. At this point there may have been a concern about leaving the parent alone. Sometimes, the move to a nursing home followed a time in assisted living. In this situation, the facility made the decision to recommend a nursing home because the parent could no longer function in assisted living or had become belligerent.

COMMENTS FROM THE SOA

This study assumes nursing facilities handle memory care although researchers did not query the incidence of facilities having a separate unit.

With physical decline, sometimes the issue was more complicated because the parent may still have had cognitive capabilities and was more apt to participate in the decision. Some physical conditions happened suddenly, such as a fall or a stroke, and some were more gradual. While a person with significant diminished cognitive capability could require around-the-clock attention, a person with physical limitations could as well if there was a risk of a life-threatening fall, for example.

There were a couple of instances, in a similar fashion to what adult children did, where a person aging without a spouse or children needed a nursing home and nephews or nieces took responsibility.

The interviewed families typically did not plan far in advance for the possibility of nursing home care and usually made the decision at the time the parent needed it. More often, the nursing home was selected without much shopping around, and the decision was based on either a religious affiliation, proximity, a newly constructed facility or word of mouth. In the U.S., the need to rely on Medicaid factored into the decision-making for some, while others had the resources to pay for their care. Families were limited by facilities that fell within their means and, if applicable, whether they accepted Medicaid.

Unlike the U.S., in Canada there were substantially subsidized facilities, but these were subject to availability and often required sharing rooms with one or more residents. Families were able to submit preferences for three facilities, but the province would select the facility the parent entered based on availability.

1.4.3 FAMILY DYNAMICS AND STRESS

1.4.3.1 Parents' Quality of Care Depended Largely on Family Dynamics

Within the interviewed population, family dynamics played a huge role in the emotional and financial experiences of elderly parents. The willingness and ability of children to provide or get parents the support needed was critical to their finances and quality of life. Prior to needing care, children may have taken care of transportation and financial management. When care was needed, children arranged for and/or provided it and financially managed it; they sometimes also chose to supervise the care and serve as advocates.

Children also provided key emotional support as elderly parents lost friends and companions. However, as discussed earlier, children often did not plan well for their parents' future needs and the functionality of family relationships was a critical factor in how well children adapted to their parents' changing situation.

The interactions of families interviewed in this study ranged from unanimity to dysfunctional. In most cases, when there were multiple children or children-in-law, they played different roles including financial management, health care coordination and companionship. In cases where parents were still at home, some children were handier than others in cooking or fixing things and this influenced how responsibilities were divided. Males were more likely to take financial responsibility and less likely to play other roles.

There was seldom an advanced discussion of who should play which role, but in functional families, siblings seemed to understand intuitively who should play various roles and didn't argue about it. They knew each other's strengths, as well as each other's ability to provide support. The availability to provide support and the type of care could have been driven by geographic proximity, the siblings' other family or career responsibilities, emotional relationship with the parent, health and personality.

In families that did not interact well, there was often resentment that one or more siblings was not doing enough. On the other hand, those doing less sometimes thought one or more siblings took the role without approval or permission. In almost no family did siblings contribute the exact same amount of time and effort; members of dysfunctional families reacted negatively to this inequity more strongly than functional ones did.

Often the caregiving relationship dynamic was not really understood until the parent's health and abilities started to fail and family relationships were stressed by this event. In functional families, siblings were generally tolerant and accepting of the different challenges and abilities that other siblings had, while in dysfunctional families they were not.

In cohesive families, caring for a parent brought close families even closer together. In the few instances where there was an aunt or uncle aging without spouse or children, there was less controversy because nieces and nephews provided support out of a sense of concern rather than obligation.

There were a couple of instances of stepchildren caring for stepparents in blended families and there did not appear to be substantial differences in the issues they faced. It seemed as if the dynamics of care were driven by the personalities and abilities of the children rather than how they were related to the older person—although this is based on the relatively small number of interviews. There was one interesting case where the child took care of a stepmother who married her father late in life. Her reason for doing so was her sense of gratitude that this woman had done so much for her father.

1.4.3.2 *Caring for Aging Parents Was Extremely Stressful*

With only a few exceptions, participants in this study found the care of their aging parent to be extremely stressful. The greatest source of stress was simply watching the parent decline. In addition to the decline, the adult children often spent a lot of time and energy in providing care, sometimes putting parts of their lives on hold. The responsibilities involved in handling the situation, particularly decisions about placement in a nursing home, were also stressful. Additionally, sometimes the children reported significant stress if they were dealing with parents who were depressed or angry or had other mental health issues.

1.4.4 FINAL DAYS AND RETROSPECTIVE

1.4.4.1 *Most Interviewees Managed Parents' End-of-Life, Funeral Plans*

While families struggled with decisions regarding aides and nursing care, in most cases a parents' final days were well managed and pain-free. This occurred because palliative care was available without the ongoing expense involved in providing care and because many died in hospitals where they were well medicated.

Most of the families interviewed made plans for funerals. These plans included decisions such as family plots, cremation arrangements, affiliations with religious institutions and choices made by the parents. While long-term care insurance was rare, some had burial insurance to help with expenses. In a few cases, the children had to do the planning.

Given the asset range screened for this study, few left much of an inheritance. In many cases, all or part of the nest egg was depleted with care costs.

1.4.4.2 *Looking Back, Children Focused on Emotional, not Financial, Aspects*

When asked to evaluate the experience of dealing with their dying parents, most of the adult children interviewed felt that they did what they could to help them and are glad they did. The most common advice they gave was to spend as much time as you can with your parents and listen to their needs. Some wished they had put their parent in a nursing home sooner, despite the conflict involved in the decision at the time.

A few expressed some financial concerns and wished they had the money to take care of their parents at home or place them in a better nursing home, but this was not that prevalent among those interviewed.

When asked what advice they would give or what they would do differently for themselves, several suggested the importance of having discussions with their children in advance to avoid the stress and conflict that comes from not being prepared.

1.5 THEMES IDENTIFIED: DEFINING ISSUES FOR THE QUANTITATIVE STUDY

The 85+ Post-Retirement Experiences study, along with other SOA research, provided a comprehensive story about how retirees' lives change as they live beyond age 85. The 85+ Post-Retirement Experiences study found that most of those over age 85 who are healthy have learned to balance their finances, including medical costs. The interviews discussed in this report focused on what happened to parents and aunts or uncles as their health failed and they approached the end of their lives. One focus of the interviews was on how finances changed as these parents needed aides or extensive care.

It was observed in the course of the interviews that those who survived beyond age 85 had a wide variety of health conditions, capabilities and activity levels. It was also noticed that as the parents approached the end of life, this variation seemed to increase even more. The results of the interviews provide a further picture of different situations that people encountered as they approached the end of life and suggest areas of exploration for the quantitative research. The research will next quantitatively explore the planning process and decisions that are necessitated at the end of life.

COMMENTS FROM THE SOA

The interviews did not include any mention of care managers and other professionals who assist families in managing care for those who need it. The SOA expert panel pointed to the availability of such professionals.

1.6 NEXT STEPS

This qualitative research represents the first step of the study. The next step is to examine these issues through quantitative research with adult children who have recently lost parents, with similar specifications to the populations used in this research.

In addition, the qualitative findings here suggest there are compelling issues to examine in the future, including a more in-depth study of the impact of family structure on the care that families provide. Research here suggests this care is pivotal.

Section 2: Detailed Findings

2.1 THE VARIETY OF LIFE JOURNEYS

Children interviewed 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 issues 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.

2.1.1 LIFE EVENTS PRIOR TO AGING

The first set of questions asked respondents to discuss their parents' journey up to the point of old age. This included how long they were married, when they lost their spouse and how long they had lived in their home.

COMMENTS FROM THE SOA

This study further elaborates on the prior 85+ research in describing the various life journeys that are taken based on the health and vitality of the elderly parent. While it is hard to discern the prevalence of various factors (e.g., physical versus cognitive decline) from a small number of interviews, the quantitative survey in Phase 2 of this research will attempt to do so.

As we would expect, the length of time that parents were widowed or divorced ran the gamut from those who were widowed and divorced for decades to parents who lost a spouse only a few years before they themselves died. Some of those who lost a spouse more recently were affected emotionally by it and for those dealing with a more recent loss, the emotional impact may have hastened their decline

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

[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

Loneliness. She was very, very lonely. She would call me. She lived in Vegreville. Do you know where Vegreville is? It is 50 miles east of Edmonton. A town, not a city. ... And she would phone me every day. —Edmonton

On the other hand, as found in the prior research, financial consequences were less apparent, especially among those who lost a spouse only shortly before they died. The decline in income due to lower pension or Social Security benefits was often offset by only having one person to support.

If a spouse had medical or care issues, sometimes their death improved the survivor's financial situation. Among lower asset and income individuals, death of one spouse sometimes did not have much impact if government benefits continued. The spouse seldom had any income besides these sources.

[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

[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

Financially, she was fine. She kept the pension. I think everything stayed the same. Of course, she lost my dad's CPP and all of that. She was very strong. —Toronto

It [her husband's death] didn't really impact her because they did not sell the farm when they retired to town so she still got rent from the farm. The only thing is her old age security and stuff was less. That was the only impact. —Edmonton

Some of those who lost a spouse many years earlier suffered some financial consequences by not having that spouse's income or, in some cases, financial management. Sometimes, divorce earlier in life could have an effect throughout the other spouse's lifetime.

[After the divorce, things were] kind of bad because it was not a happy divorce situation, and my father-in-law did not leave [it so that] she would get Social Security from him or part of his retirement. He did not give her any of that. —Memphis

Their pension was cut in half [when her husband died], but they are of the generation where you save because when you have lighting, there is power. They are not of the generation where you have credit cards and you just spend on your credit cards. They had cash or you don't buy. —Toronto

Most parents of those interviewed in this survey had been living in their house for many years and then might have transitioned to senior or assisted living, sometimes due to health and sometimes because they could not manage a house anymore.

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

They moved into an assisted living facility. They had a condo for 17 years. They moved there after retirement. —Memphis

They lived in an apartment. While they were married [for] 11 years and then [my mother] stayed on in the apartment for one year after my dad had passed away. Then she decided that she wanted to go and move to a senior's residence. My mom and dad sold the family home quite a few years, maybe 10 years, before. —Toronto

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

In some cases, a widowed parent moved into a smaller residence after their spouse died. There were a few who downsized or relocated in the few years leading up to moving into an assisted living facility. There were also a couple of elderly parents who stayed in their homes along with an adult child who moved in with them.

They stayed in their home. She passed away in her home. My dad too. —Toronto

Another issue that surfaced in a few situations was that parents outlived some of their children.

I have one brother who lives in Florida and I have one sister. I had another brother, but he passed away in his 50s from leukemia. —Deerfield

I had one sister and I had five brothers, big family. One of my brothers passed a couple of years ago from lung cancer and my sister died 14 years ago. —Memphis

I have two older sisters, an older brother that passed, and a younger sister and a twin brother. —Edmonton

2.1.2 END-OF-LIFE SCENARIOS

The end-of-life scenarios that children of elderly parents described for their parents varied greatly depending on the progression of illness, cognitive decline, and the resources that the parent and the family had to handle the aging and ultimate death of their parents.

In some cases, parents were relatively healthy until the end and only required a brief period of intensive support. However, even in these cases, mobility and the ability to live completely independently diminished.

Yes, [father was doing OK three years before his death]. Even though he had gallbladder surgery and all of these things, yes. ... He was playing tennis five days a week. By the way, he was playing tennis five days a week a year and a half before his death and beating everyone. —Deerfield

She took no medications. She had no complications. She was considered a healthy lady. At one point in her life, she did have one of her kidneys removed, but after that, she still didn't have to be on medications, just for a short time, and then after that she never had to take anything. —Memphis

No. She was very healthy other than that. She always looked out for herself, and she was a very active person. She was always on the go. She could look after herself with no problem at all. —Toronto

In most cases, the elderly had a period of time when they needed some type of assistance. In a few cases, the parent suffered from cognitive decline, either from Alzheimer's or other organic causes such as a stroke. In these cases, the parent lost touch with other sources of companionship and became dependent on caregivers.

It turns out she wasn't well, and she didn't want anyone to see her. She needed teeth. She lost a lot of her eyesight, but we didn't know how bad things were until we had to put her in a nursing home. —Deerfield

Eight to 10 [years], somewhere around there [she was diagnosed with Alzheimer's and couldn't take care of herself at all]. ... The last four years she didn't know anybody. ... It was fast. —Memphis

She started deteriorating because in a couple years she had full-blown dementia. —Toronto

She was too independent. She had this huge house, huge yard, and I think it was just too much. ... She told us [she] fell on ice and hit her head. She didn't tell us this until afterwards. I think it started a dementia thing going on because then she started to lose her memory and she wasn't eating well. —Edmonton

The most common type of decline we found was associated with some health condition. With these conditions, the parent was still mentally capable, although sometimes there were signs of a decline in mental capacity during the later years. Sometimes a stroke, heart attack or cancer was involved.

Basically, he was a diabetic since he was 60 years old. So, he suffered from migraines, he had an ulcer, he had knee problems, arthritis and diabetes, cholesterol, and I forget what other. ... A ton of medical stuff going on. —Memphis

Then she had a stroke and I would say she had the stroke about 88 and that was a heartbreaker and she had to go back onto the road for. —Toronto

She was just getting older. She'd had cancer at that time, I think, twice or three times. So, it just sort of knocked her back a little bit each time she got it. Yeah, she beat it four times. Eye cancer, sinus cancer, skin cancer ... just the radiation. When she had breast cancer, we had to go for 31 days every day, and she was 86 at that time or something like that. —Edmonton

Other common health issues related to some type of muscular/skeletal condition such as arthritis or a broken or fractured bone. Often some of these conditions were precipitated by a fall. While many of these conditions could have been repaired with surgery, such as knee or hip replacement, the elderly parent often had a hard time recovering from the surgery. Other issues that signaled the need for care were vision and hearing loss.

[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

At age 98.8, a woman in the walker caught the tip of her shoe and my mother tried to move not knowing it was in there and she went down on her knees, which meant you can't get up. It was about

two weeks later, she went in the hospital because now she is not moving around and moving the blood and all that other stuff. In the hospital, seven weeks [later] she is gone. —Deerfield

[In the last four or five years she lived with us] she would try to walk, but she always had to have a walker. She stayed in the house a lot. —Memphis

I have arthritis very badly, and it was to the point where I had to physically basically get her to the bathroom and things like that, and I just couldn't do it anymore. —Toronto

2.2 PLANNING FOR PARENTS' FINAL YEARS

In the interviewed households, despite the critical role that children played, there was very little advance planning for the financial and care management that would most likely be needed. Rather, children commonly tended to react to events after they happened. The need to pay for a nursing aide, assisted living or long-term care can easily throw formerly well-balanced finances out of balance. Some of this was driven by the unpredictability of these occasions.

2.2.1 AMOUNT OF PRE-PLANNING DONE

These varied life journeys often required different plans and actions when adult children became involved in care. There were a variety of events that precipitated the need for resources and support.

- At the time of widowhood, some were not able to manage their finances with the spouse gone, requiring an adult child to take over the finances or teach the elderly survivor how to manage their money.
- The parent became unable to drive or use public transportation. In some cases, the person never learned to drive and relied on public transportation, which became too difficult to use. In other cases, they were no longer able to drive. Adult children often provided transportation or ran errands for them.
- The parent lost the energy or physical ability to maintain their residence, requiring action on the part of the adult child to help maintain the residence or move them to a more suitable dwelling.
- The parent became less capable of doing everyday tasks such as cooking or cleaning and the adult child needed to provide this support, hire help or find a new residence where support was provided.
- The elderly person became less mobile, often due to problems that could have been caused by a variety of conditions such as skeletal issues after a fall, arthritis or just physical weakness. The adult child needed to provide support, hire assistance or seek a residence that offered this backing.
- One particularly disconcerting event was when the parent forgot to take medication.
- The parent required full-fledged nursing care. While the children could sometimes provide this care, hiring aides or placing the parent in a nursing home was far more common.

COMMENTS FROM THE SOA

The prior 85+ study highlighted the lack of planning that occurs in families. The current research confirms these findings and further elaborates on the various scenarios that can occur.

Even though these various events required actions on the part of adult children, there was virtually **no advance planning** for any of them; some were unpredictable, and adult children were often unprepared for them.

No, I don't think they planned. I used to say to them, let's plan, let's put money away, let's do this for them. No, no, no. It's too late. Which is surprising because my husband is in the insurance business. — 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

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

No [planning for assisted living], not at the beginning. It was all haphazard reactionary stuff. I didn't know what the difference was between continuing care or assisted living, dementia care, nursing home, hospice care. I didn't have any idea of any of that stuff. —Edmonton

Sometimes, changes in a parent's needs were caused by an acute event such as a fall or a stroke. Once the event occurred, or once parents had new needs, children often did extensive research and planning. Sometimes planning involved how to spend down assets to qualify for Medicaid.

My wife started looking around for places where she could go because it was really important that we find something. She didn't want her to go into just any place. And then I took the ball of doing everything to get my mother-in-law on Medicaid. I did all the paperwork; I called all the people. — Deerfield

What made me have to really step in then was he wasn't eating breakfast. I said, "Come on. Eat some breakfast." He said, "I don't feel like eating." —Memphis

Well, we tried to plan the original, initial entrance into the seniors housing, the independent living. So we went through that with her because her sister was actually living in that unit as well and so she wanted to move into the same unit as her sister. —Edmonton

Those with multiple family members involved in a cohesive way seemed best able to handle these changes, but even these families did not plan.

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 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

Well, here's the thing, you have so many family members but the ones that have the financial clout are actually the ones that are going to make the decisions at the end. —Toronto

When families had any type of issues in their relationships it became challenging for them to do any type of planning since the planning often exacerbated tension.

No [planning, it happened all of a sudden]. We knew we couldn't get any help from the [sister-in-law] in Arizona. I mean she would come for a visit, and she would stay at my mother-in-law's apartment when she did come in, but it was more or less a week and that was it, and then she would go back home. —Deerfield

I don't know. They [the brothers] just wouldn't do it. They depended on me to do it and they just wouldn't do it. —Memphis

There were only a couple of exceptions to the lack of planning. When the parent received a diagnosis with a predictable path such as cancer or congestive heart failure, it did trigger planning. From an insurance product planning perspective, a few parents had a long-term care policy.

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

Adult children, similar to findings from the recent 85+ research, didn't have a sense of the physical and emotional toll that these changes could have on them.

2.3 PARENTS' FINANCES

Among the families interviewed, at some point in their parents' lives, children commonly took over the management of their parents' finances. Sometimes children took control for the surviving parent when one parent died and had this control for years. Another key trigger point for taking control was when the parent went to assisted living or a nursing home. In other cases, it occurred shortly before death. With multiple siblings, usually one sibling assumed the role and had power of attorney over finances, although another might be the health care proxy.

Findings in the current study confirm those in the recent 85+ Post-Retirement Experiences study. While finances varied greatly prior to needing care, most of the parents in the current study were maintaining sufficient resources. By the time they reached their 80s, most were not spending very much and were able to balance their income and spending quite well. This was true even among those who were relying mostly on Social Security or CPP. Most of the parents discussed in this report were frugal.

We eventually filed for [Veterans Affairs] benefits for her because my father-in-law was a veteran and that was an easy process. ... It helped. It gave her an extra \$3,000 a month or something. —Deerfield

She has a government retirement, she had a small investment that paid her monthly and then she has her long-term care health insurance. ... [Her nursing is covered.] ... We don't have to worry financially about her. —Memphis

The way he structured his pension, if he died first ... she ended up getting about 75%. He did the right things and set her up, so she was fine as far as a pension. It covered everything she needed. —Edmonton

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

My dad had saved really, really well. They had the Canada Pension Plan and social security and stuff, but apart from that, there was no private pension like I have. —Toronto

A significant minority had other sources of income such as work or military pensions and some also had assets from the sale of a house. In various instances, the deceased spouse had provided income for the survivor through pensions or Social Security or the Canadian pension. It was uncommon for the parents to complain about money, although on occasion children did subsidize their parents when they needed care.

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

She had \$1,500 a month from a pension. She had that and that was it. She had the house and stuff like that, so I had to supplement. She probably would [have worried/complained] if she didn't have me to depend on. I handled the money and I gave my sisters money to go take her to do what she needed to do and all that. But as far as her having money, she had lost her ability to handle it. —Memphis

I think it [her pension] was like \$500 ... and then she got my dad's CPP too. ... I would say about \$100. I just know the combination was about \$600 or \$700 a month. —Edmonton

The sample was restricted to people with investable assets of \$400,000 or less, and the level of wealth varied from practically no assets to assets that approached the limit. While most maintained their assets while they were relatively healthy, a significant number spent all or most of their assets on care.

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

She was there for almost nine years so I would say by around after five years they [her funds] were getting depleted. —Toronto

2.3.1 FINANCIAL MANAGEMENT

The married couples in this study almost always managed their own finances while they were both alive and before the end of life neared. Toward the end of life, children almost always took over their parents' finances. Sometimes children took over the finances because of the parent's inability to manage money and sometimes because of the parent's lack of interest.

COMMENTS FROM THE SOA

The prior 85+ research found that children often take over the finances of their parents as they age. The current study sheds more light on the role that family dynamics and the parent's aging progression can play. This can provide an important roadmap for better family financial planning.

The extent to which and age at which the parent ceded responsibility varied greatly.

At one extreme, it was common for children to take over financial management as soon as the first parent died. It was often the female survivor who needed financial support because the husband did the financial management. While this was customary for this generation, there were a few instances of role reversal.

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 far as being in charge of it, no. Like paying her bills. She kept very aware of her money. We just paid her bills [for two years]. 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

Managed her finances, took care of paying the bills eventually. Kept an eye on investments. Money was sitting in a bank account. Mother didn't have credit cards. —Toronto

The next trigger point for financial takeover was when the parent could no longer drive. This generation was used to brick-and-mortar banking and when the parent could no longer go to the bank alone, children took over the driving as well as the banking. There were also instances where the parent could no longer sign checks clearly.

We did [contribute]. Every now and then [my husband] would put \$100 in her little fund. She got \$50 out of the \$4,000 for her fund, but my husband probably every two months would put another \$100 in there [for spending money]. —Memphis

What was I doing? Nothing. She was looking after herself. I would go down to the bank with her and explain what she was doing, like you've got to pay this, and you've got to pay this. I would go wait along with her, because I didn't want to take any of that away from her. I wanted her to realize exactly ... as if she was still in control of it. —Toronto

If this did not happen, adult children tended to take over financial control when the parents needed some type of at-home care. The need for aides could greatly change finances for an elderly parent who had been used to balancing inflows and outflows in the past.

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

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

Yes, he was [doing it himself before his surgery]. Then ... I would be saying to him, "Would you sign this check, so I can pay Bell Canada," and I realized his signature was failing. —Toronto

The children almost always took over when the parent moved to an institutional setting (assisted living or long-term care). Occasionally, the children may have taken over even when parents moved to an independent living facility. There were two triggers that led to this:

- The parent lacked the ability to manage their own finances.
- When the parent was in a facility, most of the money (income) was going to the facility directly and there were no other regular bills to pay. The parent received a small amount for incidentals.

Then I had her checkbook and was paying any bills that came up. ... I'm trying to think what kind of bills there even were then, not much. When she was in that home, we were paying them, and I don't think any other. —Deerfield

The only thing that they had to pay for was their telephone, which was like \$25 a month or something, their landline. I said don't worry, if you move in there and I give you \$100 and my sister gives you \$100

[you will have enough money to pay for everything]. But every time mom needed groceries, or her prescriptions picked up, whoever did all that, we all just paid for it. —Edmonton

Finally, there were some instances, often where the parent did not have cognitive decline and did not need to move to an institutional setting until the very end of life, where the parent maintained control of the finances.

My dad was pretty active until probably six months before his death ... he was sharp as a tack. He would watch the stock market. We would talk every day. —Deerfield

Financially, my mom did all the bookkeeping and all the accounting. She was the only child in her family, there were 12 kids, that went to school. —Edmonton

The one area where the elderly parent sometimes wanted to stay involved was in giving gifts to children and grandchildren, sometimes in the form of checks. There were occasions where surviving spouses had not managed money before and the children taught them to do so.

She managed [the money she was given]. She'd give the grandchildren and great-grandchildren money for their birthdays out of that. ... Or if she wanted a new pair of shoes, we'd go out and get her a new pair of shoes with that money. —Edmonton

There were several components that children took over as the parent aged such as paying bills, managing bank accounts and managing investments. When adult children paid bills, they tended to also take over balancing the checkbook or to have a joint account with the parent. Some adult children took over the relationship with banks entirely; others went to the bank with the parent or worked with them. Adult children sometimes moved their parents' finances to online banking.

Yes [during these six months]. He had two credit cards [that he could use during any time, and my sister would just take care of paying the bills]. —Deerfield

Her adopted daughter pretty much kind of oversaw her finances. —Memphis

I did have a joint account [before the surgery] ... not terribly long before. He had had a joint account with his sister, who moved to Poland and died, his older sister, and he put me on the account with him instead of her so then it was a joint account with him, and I used that, but I did have power of attorney, as well, so I could then sign. —Toronto

When she could no longer drive and go to the bank herself ... we went with her to the bank. We signed a power of attorney. ... We took her to the bank. She signed a power of attorney so that she would not have to go personally to the bank. —Edmonton

The children played a limited role in managing investments because the parent's assets were too small to manage or because the parent had an adviser. Sometimes children assisted in putting a limited amount of money into a safe investment, often with a bank. On a few occasions, children worked with the adviser.

No financial advisers. My husband is very much into investing. Even when he managed money for his uncle, he invested for him. He invested in mutual funds and things for him. —Deerfield

I helped her. That was my thing because I made her put money into tax-free savings to take down her taxes because the interest, she was having to pay taxes on, and it affected her. She was so worried. She said, "Are you sure it's good?" I said, "Mother, believe me." —Edmonton

He [my brother] did things on his own a little more than I would have liked. ... Made decisions and stuff ... Just the financial stuff, the investments and that sort of thing. ... He had power of attorney [and medical directive]. ... He had pretty much all the power. —Edmonton

When there were multiple children, one child usually took over the financial management; this child had either been the closest to the parent’s finances or had the most knowledge of financial management through personal interest or career. Usually, that person also had the financial power of attorney.

My brother actually contributed more, my sister did the medical and I contributed and gave him money for grocery shopping and for expenses. His rent was paid for on his own and basically, we, my brother and I, shared the attendant’s salary. —Deerfield

There was one period during this 30-year period that I turned guardianship over to another sister, and everything got in a mess. Her house, they didn’t pay the taxes. Her house taxes were \$5,000 in arrears. This is after I paid off the house, I turned it over. I paid off the house early ... probably 10 [years before death]. —Memphis

I was power of attorney and we had joint accounts. Just mostly looking after the bills. I would take her to the bank when her [Registered Retirement Savings Plans] were due. She had like an investment in the RRSP. You renew them. We would go over and talk to Tina at the bank and she would advise us. Usually we would renew them. —Toronto

My sister looked after her finances. I never looked after her finances. She paid me \$500 a month. They gave her \$200 a month. ... When she moved into my house, they took over her finances. I didn’t know nothing about her finances. —Edmonton

The research uncovered instances of the respondents reporting that their elderly parents were taken advantage of by another sibling or a financial adviser affiliated with the sibling. There were also several situations where children of the elderly took advantage of the parent when they were living with the parent. While these situations were not always outright fraud, the children were spending money that belonged to their parents and not to them.

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

Here’s what happened. Eventually when we realized that the guy was screwing around with us, my sister was happy with where she was banking at Chase and she liked this young guy who took care of them and she brought everything that was left over to him, and he put it into some conservative things. —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

2.4 INTERACTING WITH DOCTORS

One of the critical roles that children played was to attend doctor’s visits and make sure that the doctor’s advice was followed. In a few instances, they questioned that advice.

Adult children were almost always involved in working with their parents' doctors. When they consulted with doctors, they seldom questioned the doctor's judgment or got a second opinion. There were some instances where the doctor had the psychological impact of making the elderly patient feel better.

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

She had a terrific doctor that took very good care of her. He was also my doctor. Either my brother or I were there for every doctor's appointment. We were kept very informed about what was going on and what we needed to expect. —Memphis

This is more psychological, but my mother, when she went to the doctor, always felt better. It's like the old placebo, go to the doctor, he's like the priest or the rabbi or whatever, you go to him, you talk to him, and all of a sudden you feel better. —Toronto

A few adult children realized that conventional doctors may not be well versed enough to handle the elderly and sought geriatric doctors. The most common area of discussion was whether the elderly patient would be able to survive a surgery.

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

When the doctors mentioned that she was going to have to have a mastectomy done, then I went with her to the doctor, to the cardiologist, and I interacted with him and asked him what was his opinion about her being able to go through with a major surgery. —Memphis

In a few cases, families had negative experiences with doctors and medical staff. Some adult children expressed regret that they had not done more about it at the time. The biggest area of contention was related to the care and attention their parents got when they were in the hospital.

Well, I wasn't very happy with the hospital, not walking her, and I wasn't very happy with the doctor that put her there because she didn't want to do any testing on her... She wouldn't give her antibiotics, I wanted her just to give her antibiotics because obviously she had a [urinary tract infection] and she wouldn't give it to her. —Toronto

He was in the hospital and we had given them all of his data. It was not the hospital where he had the surgery. We discovered that he was receiving insulin, but everything else they were not giving him. —Edmonton

Family dynamics regarding medical issues played out similarly to the financial issues. One person often had the most responsibility—taking their parent to doctor's visits and filling prescriptions and often had medical power of attorney or "do not resuscitate" orders. However, it was more common for medical power of attorney to be shared; major medical decisions were also more likely to be made jointly. Key moments included moving a parent to assisted living or a nursing home or deciding when to put the parent on palliative care.

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

They'd [anyone interacting with my mother would] go to doctors [with my mother]. ... One sister in particular did more than anybody, because mother stayed with her a lot more than she did anybody else. —Memphis

My mother made me the power of attorney for her health, so I'm the one that kind of had to see over it. —Toronto

Finally in the end, when they wanted to put mom on comfort care, they came to me and asked. I said we will have to. ... They wanted to have a meeting with the whole family and explain this is what we are going to be doing with your mom now. —Edmonton

2.5 SEEKING NURSING SUPPORT

The current study showed the importance of the family role increased significantly as parents required more daily care. Parents may have lacked the ability to make care choices and to arrange for themselves as they aged, so the intervention of children was helpful in choosing care alternatives that met parents' needs. Interviews suggested that the skill and effort of children to find the right care had major emotional and financial consequences. The extent of support was driven by the parent's health and the availability of children to step in and provide care.

One of the interim steps in providing care for parents or other relatives is to arrange for nursing support as their health declines. The role these aides played varied in function and extent depending on the health and needs of the parent, the nature of their living arrangement and the support received from family.

COMMENTS FROM THE SOA

The prior 85+ research found families often don't plan well for the possibility of an elderly parent needing nursing home care, and some families avoid planning altogether. However, the current research suggests the struggles involved in supporting a parent who needs assistance can begin well before nursing care is needed. This research shows the financial and emotional toll that supporting parents outside of an institutional setting can take.

Occasionally, there were round-the-clock caregivers or caregivers who spent each night or each day in the parent's residence. In these cases, families hired multiple aides to rotate the help provided, or, if there were multiple siblings, each child took turns caring for the parent with the help of an aide present. In some instances, a relative, often a child or occasionally another younger relative, moved in with the parent. In some cases, the child moved in to care for the parent while in other instances the child was there to live rent-free. Sometimes several siblings traded off taking care of the elderly parent on a rotating schedule, sometimes with an aide supplementing their care.

In Canada, they could get part-time support from an aide for no charge. As will be discussed later, the logistics of coordinating multiple caregivers was complicated and benefited from a solid family relationship.

At one point at the end we had two caregivers. One would work four days a week and one would work three days a week. She had to have seven days. —Deerfield

When I got off work, I would go and spend the night with her. The home health care people would be there before I left. —Memphis

She (the aide) wasn't there in the evening. She was only 25 to 26, and she had her friends and everything... It was just the fact that I knew that she would come home at night and she would be there overnight. —Toronto

However, in most cases, families needed minimal but specific help that only required a few hours every day for tasks such as dispensing pills and/or making meals and feeding the elderly parent. In Canada, the provinces provided free aides that visited from a couple times a week to daily. They provided personal care such as bathing; this care could supplement efforts of the children.

[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 need and then walk back or drive over and drive back. —Deerfield

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

They would just get her dressed so that's it. Half an hour at the most. ... The reason we called home care is she said it took her two hours to get dressed every morning and then by the time she was dressed, she was exhausted. This way with home care, they would come and get her dressed. —Edmonton

It was just until 6:00, until she was going to have her dinner and finish up and then they were gone. —Toronto

Aides were also hired for parents in facilities either with independent status or in assisted living. The aides were hired because children were concerned the staff at the facilities didn't come often enough to meet their parents' needs. Having an independently hired aide helped ensure the facility would take better care of the parent, although some facilities charged a la carte for care and didn't like when someone had a private aide.

When he was in the assisted living, we had our own private aides there because you know what, assisted living you go from therapy and they put you in your room. I didn't quite get this, but the problem was then he was alone, and we didn't want him to fall. —Deerfield

It caused me a lot of hassle because the unit she was in ... they considered as a senior apartment so she would have home care come in, and she had her panic button, but they weren't too happy about doing anything else, and she was just getting progressively worse. —Edmonton

Aides were found in different ways. Sometimes the family got together and did research to find someone, including interviewing one or more candidates. This might have included contacting various agencies. More often aides were found by word of mouth through friends and family who may have used the aide (or aide service) themselves or knew someone who had.

In Canada, home care aides were not chosen by the family but rather assigned by the province with very little decision-making on the part of the family. The aides could change depending on availability and their services could be limited. The family could sometimes request not to have a particular aide but could not choose one.

We talked to other ladies in the community and said we were looking for someone. ... I did that because I was in charge of like my mother, I was in charge of the social talking to people. —Deerfield

I had a former parent who had worked for home health care. ... She came in my classroom one day and said, "I don't know where you are with your mom, but I want to recommend a home health care company for you." —Memphis

When we arranged for her to go into [the facility], what we really liked about it and what she really liked about it is they have different levels of care in that complex. It was a huge complex, and they absolutely assured her and absolutely promised her, and I was there, and I heard it, that when she needed more care, it would just be a matter of her moving to a different unit in the building. —Edmonton

A personal care worker ... from social services, my dad's a veteran so he had ... I guess veterans kicked in. Yeah, it was covered, it was covered, and they actually found ... my father's English wasn't the greatest, so they actually found a Polish woman. —Toronto

2.6 NURSING HOMES AND ASSISTED LIVING

Among the families interviewed, a number tried to keep the parent in their own home, if possible, through a combination of personally providing care and/or getting aides to assist. Some children lived with parents; in other cases, multiple children alternated visits. Sometimes, these arrangements fell apart when the parent needed round-the-clock care and attention. Usually, there was not a lot of advanced planning.

The decision on whether to use a nursing home or age in place was also based on the parent's preference, although for aging in place to be an option, this preference often must be strong since it required a great deal of resources to implement. Parents who first went to an assisted living or progressive care facility eventually ended up in a nursing home if long-term care was needed. The extent to which family shopped for homes varied, with proximity and religious affiliation often playing a role in the choice.

Some interviews indicated that parents were placed in a nursing home against their wishes, and others indicated that children delayed the decision to honor their parent's wishes to not go into a nursing home. Looking back, most interviewees with parents who protested felt that placing the parent in the nursing home was the right decision.

COMMENTS FROM THE SOA

While the 85+ study examined how families dealt with the need for nursing homes, the current study elaborates on the decision-making process far more extensively. Furthermore, because the study addresses deceased parents, the respondents have a better perspective on the wisdom of the decision to put their parents in long-term care facilities.

2.6.1 HOME VERSUS INSTITUTIONAL CARE

As a parent needed more assistance in daily living, it was likely they would be placed in a nursing or assisted living facility after some time. In many cases, the family preferred to keep the parents in place, and sometimes they had the resources to allow it to happen. In other cases, there was conflict between the parent and child on whether to stay in place or move to a nursing home—some children confronted the issue and forced the parent to move and some didn't. A few had parents who simply did not care.

For many, the decision came down to financial issues. If the elderly individual did not have the money, sometimes the family couldn't afford aides and needed to place the parent in a nursing home where Medicaid

would pay for care. In the end, most parents adjusted to the new residence. When there was cognitive decline, the parent was not that attentive to the change in surroundings.

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

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 wouldn't hear of that. I said to her at one point to say a prayer that I live to take care of you to the end. I don't know what's going to happen if something happens to me and her comment was, "I'm staying here in my house." —Toronto

2.6.2 DECISION TRIGGERS AND TIMING

The main triggers for considering nursing home care stemmed from either physical or cognitive decline.

With cognitive decline, the need for nursing care evolved over time. Those suffering cognitive decline often disguised it for a period. Often loved ones didn't have a real sense of how serious the decline had become until it had advanced quite a bit. With cognitive decline, there was a concern about leaving the person unattended and the consequence of this person perhaps hurting himself or herself.

One concern was having the elderly person unattended near a stove, creating the potential of starting a fire or getting burnt. Eventually the person usually needed 24/7 supervision and could not simply be left alone with care from rotating family members or part-time aides or even in a facility without round-the-clock care.

Another common factor was when the relative had difficulty interacting with others. In some cases, that person could be hostile or belligerent. This behavior was not as great a trigger when the person was cared for at home, because family could be more tolerant of the behavior. There were some instances of elderly parents being "kicked out" of assisted living and sent to nursing care because of their behavior.

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

They had a facility right next door that is part of them and ... it was the Alzheimer's dementia wing. ... And she had total supervision. —Deerfield

The physical decline among the parents led to somewhat different scenarios. Such decline could be sudden, often after a stroke or a fall, but could also occur gradually. One issue with physical decline was that the individual often remained capable of interaction with others so it could be depressing to be put in a facility shared with those experiencing cognitive decline. Some facilities had cognitive care units and some didn't.

The specific nature of physical needs could have an impact on caregiver requirements. One of the biggest issues that the elderly faced was the risk of falling. In some instances, dizziness or skeletal problems could increase this risk greatly, but in other cases it could simply be caused by frailty. A fall could have life-threatening consequences and the elderly person could require constant monitoring and attention. In some instances, physical conditions could require lifting the elderly person and the caregiver relative could have trouble doing this, creating a strain for them.

There were several instances in this study where nephews and nieces took responsibility for those aging without spouse or children and the decision-making process was fairly similar.

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

From what we understand and from the times we visited him, he was pretty much on his own and he was fine. They did have nurses on duty and in fact the place he was living had a nursing care wing. If you require constant nursing care, you're moving. —Edmonton

2.6.3 CHOOSING A HOME

The process of selecting a nursing home varied among respondents. Although a few individuals had long-term care insurance, in most cases there was not a lot of advance planning for future long-term care needs.

In Canada, those seeking subsidized homes put their name on a list. They could choose up to any three facilities they wanted, but the determination of where the parent went was based on availability, and there could be a long wait for the desired facility. This led to a choice down the road when the preferable option became available. However, once the parent was settled, they usually stayed put.

Often the search for a nursing home began when it became apparent the parent needed one. Some families shopped around and interviewed several homes before deciding. They often visited the home, sometimes tasted the food and walked around. The nursing homes were checked for cleanliness and lack of odor.

Before moving her there, I went to visit. I knew people liked it. A lot of people had parents there or relatives; they were very happy. We went and we ate the food; the food was very good. I ate a lot of meals with my mom there and the family. —Deerfield

The person who met with us, she was really lovely. She was very sincere, very positive, very interested in [stepmother]. The thing that impressed me the most, she turned to [stepmother] and said, "Tell me about yourself." —Toronto

That was a relatively easy process. We were given a choice. We had to select ... three locations where they could send her and, fingers crossed, you get the one you want. We did each time. We were lucky to get the right one. —Edmonton

Others relied more heavily on word-of-mouth and recommendations from a friend or family member who had experienced the home themselves.

We pretty much took care of it. My best friend's daughter was a hospice nurse who had taken care of my mother so if I had any questions about things, I would give them a call. —Deerfield

My cousin's wife was very, very knowledgeable about this stuff because she had gone through it with her mother. So she knew the offices, she knew the doctors, she knew who to talk to, where to go. She sent me to the most strategic places. —Memphis

My aunt had been in this old part of this building one time. I knew that they were building a new part, and one day I just thought, I'm going to go over there and see what is going on, if they built that new section yet, because it's three different sections that they built. —Edmonton

For some families, location was the most important factor, as proximity made it easier for the children to visit and care for their parent. A few were fortunate to have new homes being built in the area as they searched.

I found her a nursing home not far from my house, about 20 minutes from my house. I wanted something light and bright so that I wouldn't hate going there. —Deerfield

The long-term care they put her in was exactly halfway between where I live ... and where my sister lives ... so every day my sister would go in the morning, and my husband would drop me off in the afternoon so my mom was never left by herself until the end. —Edmonton

The need for a nursing home that catered to religious viewpoints and caretaking, such as Jewish homes that provide kosher meals, was a common factor in nursing home searches. The religiously oriented nursing homes were implicitly trusted by those applying for them.

The synagogue was, sort of, once they placed him, they didn't really consult with his sister, my mother, at all. They just took it upon themselves to place him and I guess we had no argument with it. —Deerfield

It was a kosher; it was a Jewish place. That was a familiar criterion, yes. I knew they'd be familiar with the foods, they'd be familiar with the holidays, the parties, they would have a familiarity about it. One, they would take him. From the place, the other places I've seen, this was the nicer one. [We looked at] maybe eight to 10. —Memphis

We have two Greek nursing homes and there is a long waiting list there, and people want it because their parents speak Greek, so they want like a Greek facility to be in; however, it's a long waiting list. —Toronto

Affordability was often a factor and could limit choices. In Canada, nursing homes were subsidized and when the pension was transferred to the home, it covered a great deal of the costs. In both countries, Social Security and other income sources were usually turned over to the nursing home, and sometimes the elderly patient received a small stipend for daily spending.

[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

Maybe if you have a lot of money and you could afford to pay \$7,000 a month or whatever it is, you can have a choice. But you've got to take what's open sometimes, but then you can stay on. ... [I looked at] what was available and look up their ratings. You can go online to look at reviews. —Memphis

2.7 FAMILY DYNAMICS IN TAKING CARE OF AN ELDERLY PARENT

In some interviews, the key, sometimes hidden, variable in the success of caring for parents was the dynamic among the children. Caring for a parent enhanced the bonds of functional families and further tore apart dysfunctional ones; the coordination among children had an impact on how well parents' care was executed.

The researchers also observed that different children played different roles and handled the allocation of these roles in distinct ways. Major roles included financial management, care coordination and emotional support. In some of the families interviewed, these roles were in place before parents' needs grew but often they were not. In functional families, the assumption of these roles by different children could be seamless but in other families there could be disagreement and resentment surrounding them.

While the sample was limited, we did see instances of nieces or nephews taking care of aunts or uncles who had no spouses or children, although how common this is cannot be ascertained. Taking care of aunts or uncles seemed to be more of a choice than an obligation, which may explain why we saw less evidence of family conflict and disagreement among these caregivers than among other families.

For most adult children, assisting a dying parent was stressful. But also causing stress was the fact that many were not prepared for the time and effort required and the disruption which occurred when a parent was dying. For some, family dynamics were also a source of stress. Although no firm conclusions can be drawn, in the interviews, women seemed to be more affected emotionally by the event than men did.

2.7.1 IMPORTANCE OF FAMILY

As found in the 85+ Post-Retirement Experiences study, family dynamics played a huge role in the emotional and financial experiences of elderly parents. While children did not usually provide much financial support to parents, they offered additional help that contributed to parents' well-being. In the prior 85+ Post-Retirement Experiences study, research focused on the role that children played in providing transportation and support in maintaining residences. As parents needed more assistance, the role of children became even more critical. Again, it is important to point out that the sample of interviewees was screened for respondents that were involved with their parents' finances and/or care so the sample may have been somewhat skewed to those more involved than average.

There were three broad roles that children played when it came to elderly parents—financial manager, coordinator of health care and companion. When there were fewer children, or only one child, caregivers took on multiple responsibilities. When there were multiple children, these three roles tended to be taken on by different people who had the desire or the background to play them well. The role could also be played by spouses of children and grandchildren. In cases where parents were still at home, some children were handier than others in cooking or fixing things. Also, men were more apt to play financial roles, rather than serve as health care coordinators or companions.

With the natural progression, we took it as it came, and it just made sense. He was able to help her financially, and I was able to help her otherwise. —Deerfield

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

[My brother and I] did communicate and work together well, but there were things that just weren't appropriate for him. He was very willing to help, but he would do things for her. He would buy things that she needed, but like the care, the cooking and the personal care, was me. —Edmonton

There was seldom an advanced discussion of who should play which role, but in functional families sometimes the roles were taken on naturally, with each party understanding why the role played was appropriate. Sometimes there was discussion. In families that didn't get along, there could be resentment and a sense that one sibling took the role they thought they would play. One of the main issues that divided families was the division of responsibility.

We were co-executors my parents' whole life, and I found out in May of 2017 my sister went with my dad and changed it where she was the sole executor of my dad's trust, not my mother's, my dad's. I

was very upset about it so when my dad died, she was like co-trustee with my dad. I was very upset about that. I took it very personally. —Deerfield

In the beginning it tore us apart because my brother, being a doctor and a scientist, “We’ve got to know why, we have to figure out why.” So we have to test to figure out what’s going on before we can make a decision. And my thing was, “You know what? Let him be comfortable. Why put him through unnecessary tests?” —Memphis

As parents approached the age where they needed care for their daily activities and eventually round-the-clock care, they depended on children at various stages. When a parent needed part-time care, children either provided it themselves or hired aides, both finding and arranging for them. When aides were used, children were engaged in supervising them, making sure that they were adequate, and filling in the gaps when aides were not available.

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

She still could dress herself. She still could put a bra on. She dressed herself and still loved to put her makeup on, but at the end, I would like to help her put her makeup on because she didn’t want to go out without her powder and her lipstick on. She would go shopping. I would take her, most of the time. —Memphis

At the beginning, she was fine and then I would help her get in and out of the stall shower on her chair, wash her back and she would do the rest of her body, help her out, help her dry and put cream on her back. —Toronto

As discussed earlier, parents often needed assistance with financial management, and this was almost always provided by children. Without this support, parents would have a far greater chance of being in financial peril.

In many families, children provided key emotional support. The parents lost a lot of their friends either to death or cognitive or physical decline, and the companionship of adult children was critical. The parents were also less able to transport themselves and engage in a variety of activities so having the companionship of family made a difference emotionally, especially when the parent was depressed.

I had to talk to him three times a day and see what he was doing today. ... My mother was the love of his life and this just traumatized him. He didn’t know what to do. —Deerfield

They’d go and visit her and talk and that social contact was really important. Our family, we would have family get-togethers at her residence and people would come by and say, “Boy, you’re so lucky, you have all the family.” Nine of us would show up ... and grandchildren too. —Toronto

Children were also heavily involved in finding nursing homes and in making financial decisions regarding the affordability of these homes and how payments would be arranged. Importantly, when a parent or aunt or uncle was in a nursing home or hospital, there was no guarantee that they would get effective care, both in the quality of the care and the extent of supervision. Having children as advocates and at the parents’ side made a big difference in the quality of care parents got.

Yeah, and then when she moved into the nursing home, which was 2013, so for three years, the first year we went up every day. So I was there for lunch and my sister was there at supper; for a year we did that. And then after a year we switched, so we went up every other day. —Edmonton

Confirming the results of the 85+ Post-Retirement Experiences study, the efforts of children were important in the emotional and financial lives of the parents. Yet, as discussed earlier, parents and children often didn't discuss the future or plan for it but rather tended to react to events.

2.7.2 FAMILY DYNAMICS

While the role that children played was important, the family dynamics among adult children affected the kind of care parents received. There was a range of family dynamics, from complete love and harmony to complete dysfunction and everything in between. Not only did family dynamics impact care, but the experience of caring for a parent sometimes brought children closer together or tore them apart. Sometimes there was tension, but all was forgiven later; sometimes not. Of course, family dynamics played far less of a role when there was only one child or no children.

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

The sisters, it may have brought them closer. The brothers, I don't know. ... Well, we started having real problems with mother. She didn't realize we were here ... but it brought the family closer, I think.
—Memphis

I am the middle child, and my sister and father always fought. This was one of the times that he didn't have anything to do ... I don't know. Then he was hearing things about my mom that he didn't like.
—Toronto

It got testy. Primarily because ... the sister-in-law, she is a control freak. Primarily because of her education and work that she does, and it became evident to us kind of late in the game because you read between the lines the response and conversations you are having with the hospital staff.
—Edmonton

COMMENTS FROM THE SOA

The prior 85+ research found that family plays a critical role in the financial and emotional well-being of the elderly and that accounting for this is critical in any type of financial planning. The current research greatly expands on the nature of the roles family play and the factors that need to be taken into account in assessing the effectiveness of these positions. Along with the coming quantitative study, this research is intended to provide valuable information on family dynamics and its impact.

In almost no family did siblings contribute the exact same amount of time and effort. There were several reasons why there are differences:

- **Proximity to the elderly parent.** Those that lived closer found it easier to visit. In some cases, children were out of town, but even for those in the area, being a half hour or hour away could make a difference.

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

Every once in a while, we would get in a cleaning crew that helped with the housework. But on a regular basis, it would be between me. My sister would come down that one weekend or something. Basically the bottom line was me. I was the one that was over there every day, because I lived in the area. —Toronto

- **Competing factors in the lives of the children.** Some children had more active lives that cut into the time they had available. Some had jobs and children or grandchildren while others didn't. Some led very active lives, which included social engagements and travel. While siblings tended to be tolerant of the family and career obligations of other siblings, they tended to be less tolerant of the leisure activities.

They worked full-time and they had jobs where they were paid, I don't know if it was hourly or not, but they couldn't leave and weren't as flexible. My husband and I were both in sales, so we had more flexible timing. —Deerfield

Well, we were five siblings, and all had different viewpoints and there was a lot of, "I do more, and you don't do enough." Well, she [my sister] doesn't have any kids, didn't have a spouse, so she had more free time to spend. —Toronto

When she fell and needed more help, I wanted them to come and clean her room or just to help me. I had my work. They always felt because I was working from home, I didn't have any work to do. —Edmonton

- **Relationship between child and parent.** Some children simply had a better relationship with the parent and wanted to be there, and in some cases, the parent could feel the same way. Also, there were some activities, such as bathing or toileting, where if the children were assisting, gender was important.

You can be close with your sibling and still disagree. My view was more emotional and his was more rational apparently. In retrospect, I realized that. —Deerfield

I was there. I was retired. I lived in the same building, and the oldest daughter always ... it has always been my role to take care of people. I just seemed to have spent my life taking care of people. —Toronto

- **Other traumatic family events.** Sometimes other family dynamics or events interfered with the ability to be emotionally available, such as divorce or health issues or special needs.

Kind of everything fell on me and my little sister. ... The youngest daughter, daughter no. 5, her problem was she went through a messy divorce. Let's just leave it at that, and she suffers from depression and could not handle my dad. Even though they were close, they were very close, she could not handle him. —Deerfield

I have a twin brother, but he has never been married. He would sit and visit with my mom. But when she was in the hospital, he said, "I don't like seeing mom like this." I said, "Do you think I do? She is wasting away to nothing. Somebody has to sit here." —Edmonton

- **Personality of the elderly parent.** Some parents were pleasant to be around, and some were not. The demeanor of the parent was important in determining how emotionally easy or hard it was to care for them and how children got along. Cognitive decline could make the parent more passive or belligerent.

My mother-in-law made us, when she was getting on and it was getting close, she would always talk to us all and say, “You have to promise me that you will stay close.” She said that. We always keep in touch because of that. We promised her and we would not go back on our word to that. —Deerfield

We talked about what was going to be needed. We looked at her present condition and what the doctors had told her to expect, that she was going to decline and that as the disease progressed, she was not going to be able to do for herself. So in our discussions we talked about someone who would be comfortable giving her a bath and do it with dignity. —Memphis

Family dynamics were often not understood until the parent’s health and abilities started to fail. The relationships that existed prior to a parent’s aging were tested in ways they never had been before as the parent approached their final days. Sometimes the relationships stood up to the test and sometimes the failing health of a parent exacerbated issues in the relationship.

In functional families, siblings were tolerant of the pressures that others face, while in dysfunctional families they were not. One of the things that brought close families even closer was that the care of a parent gave them something significant to work on and talk about over and above the mundane. Sometimes, certain children felt that they were unfairly doing more than others but accepted it and focused on keeping the relationship with their siblings. However, other times, the lack of attention that a sibling paid to a parent could be a source of resentment.

The sister-in-law from Arizona just came to visit. [The other one] helped a little bit here and there, but I would say that my husband and I were doing more. Sometimes you have to say to yourself some people are capable of just so much and you take over when you know you have to. I think that’s how it is in most families. —Deerfield

In the few instances where there was an aunt or uncle with no spouse or children, there was less controversy because nieces and nephews provided support out of a sense of concern rather than obligation.

My aunt, she had a sister, she had a sister and a brother. My aunt didn’t have any children. The other sister didn’t have any children, and the brother only had a son. So it was like between her sister and me and another niece. We just kind of huddled together. —Memphis

2.7.3 ROLE OF STRESS

One of the biggest challenges of caring for a parent was the amount of stress that it caused. There were two major sources of stress:

- The emotions of having to deal with the decline and death of a parent.
- The effort and energy required to take care of a parent while juggling other responsibilities. In addition to the time and disruption involved, there was a great deal of pressure trying to coordinate care and share responsibilities with other family members. There could also be physical stress in overextending oneself.

Emotionally, stress was exacerbated by having to make care decisions that the parent might not be happy with, particularly when it came to placing them in a nursing home or dealing with an irrational parent that might not have always appreciated the effort taken to care for him or her. Another source of stress was a sense that one was never doing enough to take care of a parent because no matter how much one did, it could not prevent the inevitable.

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

It was hard to watch someone who did so much in their lives and was so active to become so less active and forgetful. —Toronto

And then probably the moving from the hospital to a nursing home, every decision is always difficult. So same thing, moving her upstairs to the Alzheimer's unit, "Should we do this? Is this a good idea? Is this going to help?" —Edmonton

The effort and energy required was driven by having the responsibility to be sure the parent got the coverage he or she needed. Sometimes this put a strain on one's marriage when it interfered with the time one could spend with a spouse. There was also financial stress, which varied a great deal depending on how equipped the family was financially to care for the parent. Finances also caused stress among family members as to who would take responsibility.

[If we didn't have the money to take care of him, it would] probably [be more stressful], but like I said, we would have made different choices. We would have sold his home, or the townhome, and he would have moved in with one of us. We would have probably taken turns taking care of him and maybe I wouldn't have been working. —Deerfield

It [the biggest source of stress] was probably having to go away and I didn't like the area. It just wasn't home. It never was. I never lived in that area. When they moved, I was already ... just too out of sorts. —Memphis

The only stress would be my mom, like saying "Come stay with me for two weeks or something," so my husband would say, "OK, you can go stay for three or four days, but I'm not staying here by myself." —Edmonton

With only a couple of exceptions, everyone interviewed found the experience of watching their parent decline and eventually die highly stressful. Women were far more emotional when recalling events than were men.

2.7.4 CHANGING SOCIAL LIFE

One of the challenges adult children faced was that as parents aged, they started to lose their friends and become more reliant on their children for social support. The connections parents had with close friends fell apart for several reasons, including death, diminished cognitive capacity and simple physical separation as the friend or parent moved to a facility. Sometimes even short distances apart made it hard for friends to stay in physical contact. Furthermore, the parent might not have the energy or cognitive capacity to maintain friendships. The 85+ Post-Retirement Experiences study also showed the dramatic decline in friendships as parents aged. Once a parent was in a nursing home, it became even rarer for him or her to have friends. Some parents also lost brothers or sisters to whom they were close and might have depended on for care.

His best friend was fighting kidney cancer and going through dialysis, and that took a toll on my dad. He missed him. —Deerfield

During that period of time [after she had spinal surgery], she really did get sad because she would say, “I won’t ever get to go to Selmer again.” It was very strange because she and her sisters and brother were always so close and the last two years, I guess the last 18 months, they did not come to see her. —Memphis

She didn’t see [her friends there] as much, of course. She made not as many friends because some of them weren’t really, kind of, as well cognitively, like they didn’t want to talk or they didn’t want to really interact, so she missed that aspect. —Toronto

They were in the same place, they could get up and see each other but by that time, again, her memory was kind of bad so she couldn’t remember how to get to her sister. —Edmonton

Sometimes the parents met new friends when they entered a progressive or assisted living facility, and a few did have friends until the end. In addition, one of the most enduring types of friendship was one that resulted from common affiliation, such as with a religious or charitable organization. Sometimes these organizations encouraged the continuation of friendships and even provided transportation to get people together. In addition, sometimes parents kept in touch with friends by phone.

In the room next door to her was a man who was younger than her, and there wasn’t anything the man did. He was a guy in a wheelchair ... he befriended my mother, and he was constantly talking to her all the time. —Deerfield

Several friends had died, but she did still have friends because her church would still call and check on her. She had a couple of friends who would call and check on her, but because we didn’t live in the city of Memphis, we lived in the suburbs, a lot of the older friends that would come by her house to see her, they could not find their way out there. —Memphis

We talked to the pastor at the church, and he arranged for, they have parishioners that visit people who are homebound so there was a lady who would come out and visit mom. —Edmonton

2.8 END-OF-LIFE PLANNING AND PALLIATIVE CARE

Most of the parents of those interviewed died peacefully with hospice care and/or in a hospital and were given adequate medication to cope with pain. Most had arranged funeral plans through a religious institution, family legacy or privately.

2.8.1 FUNERAL PLANNING AND EXPENSES

Most families in the study had funeral plans set in place, or at the very least had purchased or inherited a plot. Most of those plans involved pre-paid measures by the parents themselves, though some chose to earmark money or leave life insurance policies to cover the expenses.

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

She had a [life insurance] policy. She already had told us who she wanted to be in the care of as far as funeral home so that was it. We had the policy, so we didn’t really have to do any planning on that because the money was there for her funeral services. —Memphis

Everything had been sorted out all before, yeah. The funeral and the whole thing, yeah, that was all organized in advance. Yeah, it was all taken care of some years before. —Toronto

For others, the parents relayed the final arrangements they wanted—cremation or burial—but it was up to the child to execute those plans and pay the expenses. In some cases, the families had help from religious organizations that assisted with both planning and paying for the expenses.

We prepaid her funeral and that was probably the smartest thing that we did. —Deerfield

No, but we had found some money in her house, not a lot, but had found some money and we had put that up for her funeral. —Memphis

So we had the plots and then my sister and I had gone a few years earlier, I don't really know why, and arranged her casket and paid for a bunch of that. —Edmonton

In our community we have a burial fund and you contribute to that and one for all and all for one. So when a death happens, we have members of this burial committee come and take over. —Toronto

When parents planned their funeral and expenses, it was often years in advance. When the burden fell to the children, plans were usually put into place about a year to six months in advance.

My dad and mother arranged that [funeral arrangements] probably 15 years ago. ... They gave us instructions. Everything was paid for. I had the card and I had all the documents. —Deerfield

We didn't [have burial plans]. We had the plot because when dad passed, we bought enough for mom and me. We have an extra plot for somebody, but that was it. We didn't make any arrangements. We made them like the next day after she passed. —Toronto

She had prearranged in 2007 because her husband had been cremated and his ashes put in an urn, and they were buried at the [cemetery]. She paid for the portion of the urn and the burial. —Toronto

2.8.2 PARENTS' END OF LIFE

For most, but not all, of the children, their parent or aunt/uncle died peacefully in their sleep—often able to say a last goodbye. A few spent their final days in the hospital after a major event such as a fall or a heart attack. Those who suffered from long-term illnesses such as cancer generally also had palliative care toward the end. The most common cause of death was simply “old age” or “loss of appetite” where the parent would stop eating—a strong sign that they were ready to go.

She just died peacefully. She was already in hospice, because she didn't have any disease, I think her heart just was giving up, her heart was weakening and ... we just got a call ... she wasn't doing well and, like asleep all the time, and that's when we called in hospice and then they start giving people morphine. ... [She died] peacefully. —Deerfield

She was up and she wasn't hurting the night before she died. She just said, “Baby, I just don't know how.” I said, “Mom, how are you feeling?” She knew. She said, “I'm not going to be here much longer.” But she wasn't really hurting or suffering, and she was smiling. We kissed. She went to bed. I checked on her. It must have happened sometime in the middle of the night. —Memphis

Yes [she went peacefully from her cancer]. The one morphine did it. It was only a couple of hours after the morphine. —Toronto

I'm thinking it was the cancer, and her heart was starting to go. When the ambulance came for the last time when they took her from [the nursing home], they said it was her heart. Her heart was just giving out. —Edmonton

2.8.3 INHERITANCE AND FINANCIAL LEGACY

A handful of children were lucky enough to be left inheritances, not always money, but sometimes a house, jewelry or other assets. While a few parents strived to leave an inheritance, many simply did not consider the option. In a few cases, money was left behind when there was money earmarked for health care costs that ended up not being used. In contrast, some parents aimed to leave behind some money, but ended up running out or spending it all to support themselves while they were alive.

I think that probably at one point he did [have an inheritance for us kids] but the older he got and so he probably used his savings, he and my mother. ... Probably [they spent our inheritance] but that's OK. —Deerfield

She would make remarks that she had all this money put up in her lockbox, which there was enough for her funeral, but that's all. She would tell us like there was \$75,000 in her lockbox. There wasn't. —Memphis

We sold their condo and there was a little bit there and yes, we split it three ways. —Edmonton

2.9 RETROSPECTIVE ON CARING FOR PARENT

Most participants focused on the importance of being there for their parents rather than on financial issues, although finances drove the kind of care they were able to offer. A few wish they had planned sooner.

Participants were asked to summarize their experience of caring for their deceased parent or in-laws. For the most part, the most common issues that came up were emotional ones. The sample of adult children include those who felt they had done all that they could for their parents or other older relatives and those who wished they had done more. Some felt guilt while the parent was alive but realized later there was not much more they could have done to help the parent—some things are just inevitable. The adult children offered the advice to future generations on how to care for parents:

- Spend as much time as you can with them.
- Listen to your parents to understand their needs.
- Be patient and also take time for yourself.

Enjoy every minute you have with her. That is hard to do. ... I have heard people say that before someone gets too old, you take some of their assets and move it out of their name. That wasn't something my husband and her sisters wanted to do. —Deerfield

Ask for someone to come in if you want to assist. Make time for yourself, even if it's like an hour going for a walk, just kind of distancing yourself a little bit just for your own peace of mind. —Toronto

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

COMMENTS FROM THE SOA

The current study provides a perspective not available in prior research and is instructive in guiding others who are currently managing aging parents.

A few raised financial issues as one of the regrets that they have. In these cases, the children thought the lack of money limited their choices and that they want to have more money than their parents did. For those who wanted their parents to age in place, it was a financial strain—especially in the United States, where the government does not provide funding for care. Those who put their parents in an assisted living or a nursing home felt their choices were severely constrained by how much money they had.

In Canada, relying on a publicly subsidized option can mean waiting lists to get parents in the desired facility. Sometimes this is a problem. The parent may also be forced to share a room.

There weren't too many choices for my mother because she didn't have the money. I would have preferred putting her at home and having somebody live with her, but she didn't have the money, and I couldn't do it. It would cost a fortune. —Deerfield

If there is somebody without a pension and they have absolutely no income coming in, you're in trouble. You can still get into any of the nursing homes, any of them. They can't deny you. You would be four in a room or whatever, and they would have to treat you the same way as everybody else in the nursing home. —Toronto

When looking back at the experience with their parents, some participants observed that they don't want to put financial strain on their own children. A couple mentioned the importance of getting long-term care insurance, but burial insurance was more commonly owned. There was also some concern about who was managing the money, which led to the suggestion to be careful about it.

I do think that with financial planners and the market there's a need for saving now, in our generation, because there are people that are living longer. I think that there's a need for people in their, let's say, 40s, 50s, 60s to start planning for their parents, not only for their children. —Deerfield

I think people should have long-term care insurance. I don't have long-term care insurance, but I did buy a burial plan. One of the things was they didn't have burial plans; my parents didn't prepare for that. —Memphis

Some also wished that they had planned more to avoid the stress of scrambling to figure everything out when their parents needed support. Some felt it would be a good thing to discuss their affairs with their children so that there is more planning done for their own futures. One suggestion was to have children agree who will oversee things ahead of time so that there is no squabbling when they need to step in.

I should be planning more. I guess I'm thinking I'm going to be like my father and mother and be pretty much independent as long as possible and then just pass away. I find myself wishing I had a daughter in addition to my sons because I find the daughters take more responsibility. —Deerfield

Have the discussion while you are healthy. As a matter of fact, maybe the first discussion when you're 50 or even 60. When your mind is [clear] and [you know] what your thoughts are and what you want done. —Memphis

A few also wished that they had gotten their parents into a facility sooner, even if it was against their wishes. In some cases, with cognitive decline, they realized in retrospect the dementia had started sooner than they discovered. A few just had general feelings of regret and frustration, not having been able to do more for their parents while they were alive.

Back then I felt terribly guilty. I still do to some extent that why would she end up there? She deserved a better ending. She had a terrible life and deserved a better ending, and we should have done more to help her out rather than just throwing her in a nursing home. But now that I think about it, we didn't really have a choice. —Deerfield

Our fault at that began when we agreed to let my cousin have [power of attorney]. I would say keep a very sharp eye on finances. Who is holding the money? The POA. It is a terrible thing to think ... I voiced my opinion that I was concerned. —Memphis

I don't feel like we have any regrets because we did as much as we could. —Edmonton

APPENDIX: Interview Guide

Interviewer Guide: Adult Children

Society of Actuaries Life Journey In-Depth Interview Questions

(ROTATE TOPICS AS NEEDED)

I. Introduction (5 minutes)

- A. Purpose of the interview: Study the experience you had with your aging parent later in life and what you learned from it.
- B. Rules of interviews
 1. Observers, taping
 2. No wrong answers
 3. No follow-up, research only
- C. Background
 1. Your current family and employment situation, including brothers, sisters, nieces, nephews, stepsiblings, etc.
 - (IF BLENDED FAMILY) How long the parent was connected to the stepchildren?
 2. Number of loved ones who resided in proximity to the parent?
 3. How long ago did your last surviving parent pass away? What was the role you played in providing support to him or her?
 4. How long since that parent had a partner?
 5. Did the parent move during retirement? How many times did they move? Why?
 - To be near family
 - To get care and help
 - To downsize

II. Discussion of last surviving parent's final years (5 minutes)

- A. Journey to widowhood or single status
 1. How long married?
 2. Widowed or divorced and when?
 3. Nature and amount of care provided to spouse or partner?
 4. Impact of care on finances?
 5. How surviving parent changed because of situation?
 - Emotionally
 - Financially
- B. The final years of your parent's life

1. How long did he or she live?
2. When did his or her capability and/or health start to decline?
3. What health issues did he or she face and when?
4. What kind of support and care did he or she require as he or she declined?
5. Specifically focus on any mental decline.

C. Timetable (PROBE FOR: Gradual versus sudden changes)

1. Fully capable post-retirement years?
2. Years of widowhood?
3. Years requiring help with shopping, cleaning, etc.?
4. Years requiring some assistance in getting around?
5. Years requiring help with day-to-day financial management?
6. Years of diminished capacity or illness? Continuous or on and off?
7. Physical versus cognitive challenges?
8. Years requiring full-time long-term care?
9. Years requiring a combination of some paid help and family care? Describe situation.
10. Years with home health aide versus only family care? Describe situation.
11. Years in own home versus senior housing and/or community setting that offered some kind of care to residents?
12. Additional changes after going to community setting?
13. Years living with family in their home?

D. Defining transitions (HIGH IMPORTANCE: Seek life-changing events)

1. How did you define when your parent went from one stage of care to another? What defined the stages for you?
2. What were the triggers that led to your parent moving from one living arrangement to another? (PROBE FOR: Physical versus mental decline.)
3. Do you consider yourself old now? At what age did you consider your parents old?

III. Planning for your parent's final years (15 minutes)

A. When did you first begin planning for how you would handle your parent's aging?

1. When did you start preparing emotionally?
2. When did you start planning financially?
 - How far in advance did you plan?
 - Was there a triggering event that led to the planning?
 - Were outside advisers involved, such as financial advisers or social workers?

- B. How much did you account for the impact on them and the impact on you? (IF ON YOU) What did you account for?
1. Was parent amenable or resistant to support and care?
- C. Before your parent started aging, how much thought and planning did you do to prepare for it?
1. What types of issues did you discuss?
 2. Did your ability to discuss with your parent change as they aged and how did discussions change?
 3. How did the planning evolve over time?
 4. Who was involved in that planning with you?
 - How much did you discuss with the parent?
 - Spouse?
 - Siblings?
 - Stepsiblings/blended family?
 - Who played the lead role in the discussion?
 - Were there any disagreements or conflicts?
- D. As your parent aged, what interactions did you have with medical staff during your parent's incapacity?
1. What role did you play in medical care and decisions?
 - Did you make appointments for doctors' visits, go to doctors' visits, manage medications (ordering, making sure your parent took them)?
 - If you did not play such a role, did someone else? Who? What determined who played such a role?
 - If you went on doctor's visits, how active a role did you play with the doctor?
 2. How well did medical staff understand your parent's condition as they aged?
 3. Did you or another sibling have a health care power of attorney?
 4. Did your parent have an advance directive? Was it helpful?
- E. (WHERE APPROPRIATE) Tell me about the process of getting any type of paid person providing support for your parent.
1. Was there a progression in the amount of time the paid helper spent with your parent? Can you describe it?
 - How much was due to declining health versus adult children's inability to spend the time?
 2. How much research did you do?
 3. What resources did you use in the search—agency versus personal contact versus other?
 4. Paid versus volunteer support?
 5. Describe the process.
 - Who paid for it, you or your parent? Was there a conflict with this?
 - How did you know when to act?
 - Do you feel like you acted soon enough?

- Was it an emergency?
 - Did you have any Medicare coverage in the beginning for this person (e.g., a period of care following a hospital visit)?
 - Did you stick with the aide you first hired? How often did you change?
 - Did you price shop?
 - Between you and your siblings, who made the decision and how was it discussed?
 - What did you do to preserve dignity and independence?
- F. (WHERE APPROPRIATE) Tell me about the process of placing your parent in an assisted living or nursing home (or residential facility with support).
1. Did the need evolve over time?
 2. How was the decision made that this type of care/support would be needed?
 - At what point was it decided that the parent could no longer stay at home and what led to that decision?
 3. Who paid for it, you or your parent? Was there a conflict with this?
 - Did your parents have the money?
 - Was there an upfront payment involved?
 - How was it financed?
 - Was the sale of your parent's house involved? What was your or a sibling's role in that?
 4. How much research did you do? What resources did you use in the search? What specific work did you do to decide if it was a good deal?
 5. Describe the process.
 - How did you know when to act?
 - Did you feel like you acted soon enough?
 - Was it an emergency?
 - Did you stick with the first home you placed your parent in?
 - Did you price shop?
 - Did you consider the willingness of the home to accept Medicaid?
 - Between you and your siblings, who made the decision and how was it discussed?
 6. How did it work out?
 - Were you able to get a home you were confident would provide good care or were you constrained in your options by availability of space or money? Describe the trade-off.
 - What worked well and what did not work well?
 - Were you satisfied with the choice?
 - What is the one thing about the environment that bothered you the most?
 - What did you do to preserve dignity and independence?
- G. (IF BLENDED FAMILY) Discuss role and responsibilities of children versus stepchildren. (IF ELDER ORPHAN/NO CHILDREN TO CARE FOR THEM) Discuss role of nieces and nephews.
- H. Looking back at your parent's experience, were there instances where you got welcome and valuable assistance from others? Who offered this help and what did they provide?
- I. What impact did the experience have on your sibling relationships then and now?

IV. Parent's financial situation (10 minutes)

- A. How would you evaluate your parent's financial situation as they aged?
1. How would you describe your parent's standard of living in retirement?
 - Level of income and assets?
 - Extent to which they balanced income and spending while they were healthy?
 - How parent felt about finances when healthy?
 - Level of spending or frugality when they were healthy and when they started aging?
 - If applicable, was there a significant change when one parent died?
 2. What were his or her primary sources of income as he or she aged? (ASK OPEN ENDED QUESTIONS AND THEN PROBE FOR ROLE OF:)
 - Social Security
 - Pensions
 - Retirement accounts
 - Investment income (PROBE IF from inheritance or life insurance)
 - Rental income
 - Annuities
 3. What was the Medicare coverage—A, B, D, supplemental, advantage?
- B. How was financial management handled?
1. (IF MARRIED IN RETIREMENT) Was your parent the one responsible for managing money when still married?
 - If not, who took over the finances when the spouse died?
 2. Did someone manage your parent's finances as they aged?
 - Which child was responsible—you or relation to you?
 - Was the same person or a different person primarily responsible for taking care of your parent physically and emotionally?
 3. Were there any issues with fraud or scams as they aged, whether outright fraud or bad decisions (e.g., poor advisers, being overly generous to solicitors)?
 4. Describe the progression of taking control of financial management.
 - Was it sudden or gradual? Did your parent lose track of:
 - Paying bills?
 - Their assets and accounts?
 - Being able to manage their checkbook?
 - Investment strategies?
 - The ability to access online information?
 - How much they were gifting?
 - Did you work with advisers? Your or your parent's?
 - How much control did you or a sibling have—bank accounts, credit cards, spending, etc.?
 5. How did your parent feel about having someone take over his or her finances? Were they willing or not?
 6. Was there a trust and if so, how did that help?

7. Was there an adviser involved and what was his or her role?
 - Did they use an adviser(s) before they started aging? What type?
 - Was the adviser involved in helping as they aged? What did the adviser do?
 - Was there help with tasks such as bill paying, balancing the checkbook?
 - Did the helpers interact with the adviser?
 - How smooth was the transition? Did you keep your parent’s adviser?
 - What role did the adviser play after the transition?
- D. Did your parent ever go on Medicaid?
 1. Describe when and how that happened.
- E. Did you or other family members provide financial support? Which ones and to what extent?

V. Family dynamics and emotions (15 minutes)

- A. Review roles and relationships as parent aged.
 1. Cooking, cleaning, driving, coordinating services, caregiving?
 2. What role did you and siblings play?
- B. Who took responsibility and how well did family coordinate?
 1. How many siblings were there and how well did family work together?
 - Did there tend to be cooperation or conflict? Can you describe either or both?
 - What roles did they play?
 - Did they have access to information?
 - (IF BLENDED FAMILY) Describe the relationships and roles of biological versus stepchildren.
 - (IF ELDER ORPHAN) Describe role of nieces and nephews and how it was different
 3. Did the experience bring the family closer together or pull them apart—explain more of the relationship dynamics
 4. (IF BLENDED FAMILY) Describe this experience and how it differed for biological and stepchildren.
 5. (IF ELDER ORPHAN) Describe the impact on nieces and nephews or others who became family helpers.
- C. How much stress was involved for you and your family in handling the situation?
 1. Tell me more about the nature and cause of the stress.
 2. During what periods of your parent’s life was the stress strongest and when was it less?
 3. What impact did caregiver stress have on your personal and professional life?
 4. Did your parent experience the stress as well?
 5. Did you take any measures to cope with the stress? What strategies did you use?
- D. How did your parent’s social life and support system change as they aged?
 1. How did friendships change?
 - Friends dying or losing cognitive capability?
 - Parent not able to get around to see friends?

- Loss of cognitive ability?
- 2. (IF LOST SPOUSE) How has the loss of his or her spouse affected the level of social interaction he or she had?
- 3. Did they become more dependent on you or other family as this happened?

VI. Final days (5 minutes)

- A. All things considered, did your parent have the kind of death that you hoped for? Why or why not? Had they communicated their wishes?
- B. How prepared was your parent for funeral and final expenses? Tell me about what was planned.
 - 1. If unprepared, how and when did things fall apart?
 - 2. Did your parent leave money to children or grandchildren or some other place, such as a charity?
 - 3. Was it a substantial or relatively modest amount?
 - 4. What was his or her philosophy and intention when it came to leaving money?
 - 5. How does the amount he or she left compare to what he or she started with in retirement? How does it compare to five years before death?
 - 6. Did your parent leave as much as he or she intended to?

VII. Retrospective (5 minutes)

- A. Thinking back now, what do you wish you had done differently when it came to you and your sibling(s) preparing for your parent’s aging? Is there anything you wished your parent had done differently?
 - 1. Given what you learned with your parents, how proactive will you be in getting your children prepared for your aging?
- B. What lessons have you learned from the experience and how will you apply it when you age? (IF BLENDED FAMILY) Discuss for children versus stepchildren. (IF ELDER ORPHAN) Discuss for nieces and nephews.
 - 1. How should your children act as you are going from one care stage to another?
 - 2. Should they act sooner than you did with your parent?
 - 3. What can you tell them about how to treat you based on your experience with your parent?
 - 4. What discussions have you or will you have with them and when?
 - 5. What have you learned about managing conflict in family and will it be similar or different with your children?

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The Society of Actuaries (SOA), formed in 1949, is one of the largest actuarial professional organizations in the world dedicated to serving 32,000 actuarial members and the public in the United States, Canada and worldwide. In line with the SOA Vision Statement, actuaries act as business leaders who develop and use mathematical models to measure and manage risk in support of financial security for individuals, organizations and the public.

The SOA supports actuaries and advances knowledge through research and education. As part of its work, the SOA seeks to inform public policy development and public understanding through research. The SOA aspires to be a trusted source of objective, data-driven research and analysis with an actuarial perspective for its members, industry, policymakers and the public. This distinct perspective comes from the SOA as an association of actuaries, who have a rigorous formal education and direct experience as practitioners as they perform applied research. The SOA also welcomes the opportunity to partner with other organizations in our work where appropriate.

The SOA has a history of working with public policy makers and regulators in developing historical experience studies and projection techniques as well as individual reports on health care, retirement and other topics. The SOA's research is intended to aid the work of policymakers and regulators and follow certain core principles:

Objectivity: The SOA's research informs and provides analysis that can be relied upon by other individuals or organizations involved in public policy discussions. The SOA does not take advocacy positions or lobby specific policy proposals.

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