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## Information Needs and Challenges Faced by Adult Child Financial Caregivers of Aging Parents

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## Information Needs and Challenges Faced by Adult Child Financial Caregivers of Aging Parents

### Abstract

The exploratory study reported here examined needs and challenges faced by "financial caregivers" for aging parents. Focus group interviews revealed how caregivers (N=22) assisted their parent(s) and financial information needed. Findings indicated most caregivers needed information about later life financial products and processes, and some needed basic financial literacy skills. Caregiver challenges included concerns about adequacy of parents' resources, difficulty communicating about finances, finding/organizing parents' records, accessing parents' accounts, and selecting/financing long-term care. The author concludes caregivers need and could benefit from financial education. She recommends segmenting the caregiver population and targeting subgroups with appropriate methods and messages.

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## Introduction

Extension is "strategically directed" and "uniquely positioned" to address the many challenges of an aging population (Gerrior & Crocoll, 2008; Marsden, 1990). Among the Extension efforts aimed at improving the quality of life for older adults, a growing number have recognized the importance of family caregivers and identified them as a target audience for research, education, and outreach (Bailey & Paul, 2008; Cheang, Yancura, Kutara, & Greenwood, 2011; eXtension, 2011; Marsden, 1990).

## Importance of Caregiving

Eighty percent (80%) of elders who live in the community rely *exclusively* on unpaid assistance from family and friends to meet all their care needs (National Clearinghouse for Long Term Care Information, 2011). In the future, as government programs continue to move from emphasizing facility-based care to focus on home- and community-based care, family caregivers will play an

increasingly important role in the nation's caregiving "system."

## Prevalence of Caregiving

Almost 20% of U.S. adults—an estimated 43.5 million—provide unpaid care to a family member or friend who is age 50 or older (Caregiving & AARP, 2009; Newhouse, Ellis, & Halpert, 1988). Over the next 25 years, the percentage of elders needing care is likely to increase, which means that the proportion and number of family caregivers in the population can also be expected to increase (Caregiving & AARP, 2009; Carter, 2008).

## Definition of Caregiving

A "caregiver" is operationally defined as any individual (age 18+) who identifies himself or herself as a caregiver and assists a person with at least one *activity of daily living* or one *instrumental activity of daily living* (Caregiving & AARP, 2009). The activities of daily living (ADLs) include:

- Getting in and out of beds and chairs
- Getting dressed
- Bathing or showering
- Getting to and from the toilet
- Feeding
- Dealing with incontinence or diapers

The instrumental activities of daily living (IADLs) are:

- Transportation
- Housework
- Grocery shopping
- Managing finances
- Arranging or supervising paid services

## Financial Caregiving

The study reported here examined the information needs of family caregivers who assisted an elderly parent(s) with one IADL: managing their finances. (They may have assisted with other IADLs or ADLs as well.) Almost two-thirds (63%) of family caregivers help a loved one manage their finances (Caregiving & AARP, 2009).

## Need for the Study

Previous studies have found that *financial caregivers* often lack the knowledge, training, skills, or confidence to be successful in their financial responsibilities (Aumann, Galinsky, Sakai, Brown, & Bond, 2008; Bailey & Paul, 2008; Jones & Field, 2005), and frequently have to make decisions about financial matters they have little, if any, life experience with (Caring to Help Others: A Training Manual for Preparing Volunteers to Assist Caregivers of Older Adults, 2000) such as:

- Managing retirement income
- Dealing with benefits from Social Security, Medicare, or Medicaid
- Financing long-term care
- Selling a family home

Financial mistakes are particularly problematic for elders and their families because there may not be sufficient time or income to make up for losses. For example, poor investment decisions could deplete a care recipient's assets, resulting in a reduced standard of living for the remainder of his or her life, and cause family conflicts or even lawsuits (Financial Caregiving, 1997; Financial caregiving, 2003).

## Aim and Purpose of the Study

The exploratory study aimed to understand the information needs of adult children who were helping an older parent(s) manage their finances. The purpose was to develop a needs-based financial education tool for Extension educators, a Financial Caregiving Series for Adult Children of Aging Parents <<http://ucanr.org/freepubs/freepubsub.cfm?cat=36&subcat=38>> (Wooten Swanson, Schindler, & Tran, 2009), to inform and empower financial caregivers to provide needed care and thus improve the quality of life for their aging and infirm parents. The findings reported here were part of a larger project that also included interviews with caregiving professionals.

## Procedures

Project staff recruited potential focus group participants and screened volunteers for eligibility using a scripted telephone survey. Prior to focus group meetings, subjects completed a Financial Caregiver Intake Form with demographic data about themselves and their care recipients.

Researchers conducted five 1½-hour focus groups using an interview protocol approved by the Human Subject Committee at the University of California, Davis. Open-ended questions addressed three aspects of financial caregiving:

1. How are you assisting your parent(s) with their finances?
2. What challenges are you facing or have you faced as a financial caregiver?

3. What financial knowledge, information, or skills do you/did you need to provide the best possible care for your parent(s)?

Focus group sessions were audio-recorded and professionally transcribed, then coded and analyzed using NVivo, qualitative analysis software. Subjects received \$30 gift cards in appreciation for their participation.

## Findings

### 1. Demographics

Subjects (N=22) were predominantly white (77%), female (77%), and age 50-65 years old. All but one had completed some postsecondary education, and seven had graduate degrees. Seventy-five percent (75%) had household incomes of \$50,000 or more. All participants described themselves as "financial caregivers."

Two subjects identified themselves as long-distance caregivers, with their care recipients living in Chicago and Los Angeles, respectively. One caregiver reported an elderly parent lived with them, and no caregivers reported moving into a loved one's residence to provide care.

### 2. How Financial Caregivers Assist Their Parent(s)

Like financial caregivers described elsewhere; (Financial Caregiving, 1997; Financial Caregiving, 2003; Fiscal Fitness, 2005; For Financial Caregivers, 2008), focus group participants performed a range of financial management tasks, including banking, bill paying, making saving and investment decisions, managing health insurance reimbursements, securing adult day care services or supportive housing (such as assisted living), financing long-term care, and tax preparation. Some caregivers bought and sold real estate or managed rental property for their parents.

- ***Money Management***

Caregivers managed parents' income from many sources, including Social Security, military retirement, pensions (one from a foreign government), "numerous high value certificates of deposit (CDs)," retirement accounts such as 401(k) plans and individual retirement accounts (IRAs), annuities, and individual investments in stocks, bonds, or real estate.

- ***Financial Planning***

Caregivers also reported financial planning responsibilities. One described planning for long-term care by forecasting income and expenses for 10 years out, based on increasing amounts and costs of care over time. A few managed their parents' investment portfolios, while others had consulted or planned to consult a financial professional(s) for assistance with investments. Many sought professional assistance for estate planning, including wills, trusts, financial and health care powers-of-attorney, and end-of-life planning.

- ***Other Financial Responsibilities***

One or more caregivers reported performing other tasks such as gifting to family members, managing trusts, cleaning out a parent's house and disposing of "50 years' worth of accumulated personal property," getting a parent's house ready to sell, serving as a parent's conservator, or being executor of a parent's estate.

### 3. Challenges Faced by Financial Caregivers

Although each situation was unique, caregivers faced common challenges, including some or all of the following.

- ***Fear of Inadequate Financial Resources***

Caregivers saw expenses increasing without an end in sight and worried whether their parents had enough money or other resources to last until the end of their lives.

- ***Communicating with Parents About Finances***

Caregivers often reported difficulty in talking with parents about finances. While some parents were reportedly very open, others refused to reveal any details about their finances or even where they kept their financial and legal records. Communication problems related to the following issues:

- *Caregiver's attitudes*, such as reluctance to bring up difficult financial matters out of respect for their parent's privacy, or not wanting to talk about later life financial issues because of the potential sadness and loss it represented
- *Parent(s)' attitudes*, such as an unwillingness to talk about sensitive matters like potential long-term care needs or not wanting to "worry" their children
- *Inadequate communication skills*, such as not knowing how to approach emotionally-laden topics like wills
- *Conflict avoidance*

- ***Finding and Organizing Financial Records***

A major challenge for many caregivers was finding and organizing their parents' financial records. Some had to "start from scratch" to figure out their parents' income, expenses, and assets. Others had to dig through "piles of papers" or "organize years of records that were stashed all over the house." One caregiver said, "...when I was there for three weeks, I went through all of her financial stuff and re-organized it. I shredded checks from probably 1980. It was a huge task and I [finally] got it all organized."

- ***Gaining Access to Parents' Accounts***

Some caregivers had difficulty accessing their parents' bank and brokerage account(s). They lacked knowledge of the various alternatives available to facilitate this process.

- ***Lack of Relevant Financial Knowledge or Skills***

Many felt unprepared for their financial caregiving responsibilities. One caregiver indicated she had almost no personal financial experience. Another explained, "... we are trying to stay on top of the...financial issues. I am uncertain about many, many things."

A caregiver who was the trustee with full responsibility for her parent's investment portfolio described herself as a "novice" in managing investments and said it was difficult trying to decide whether to save or invest her parent's money, and if investing, figuring out the best way to do it—short-term or long-term.

- ***Selecting and Financing Long-Term Care***

Caregivers had limited understanding of long-term care services and options. Individual caregivers:

- Were confused Medicare and Medicaid (called Medi-Cal in California)
- Thought Medicare would pay for long-term care (it does not)
- Did not know how to select supportive housing, such as assisted living
- Were unaware that care facilities generally limit the number of Medicaid rooms
- Did not understand long-term care insurance (One caregiver tried to purchase long-term care insurance for her mother after she had a stroke and went into a nursing home---unaware that such a policy could only be purchased when the insured was healthy and did not need care.)
- Failed to realize it might be necessary to re-visit long-term care decisions and possibly even relocate a parent several times as their needs changed

- ***Protecting Parents Against Financial Fraud and Abuse***

Subjects identified incidences of elder fraud by scammers using high-pressures sales techniques and time-worn schemes, such as "free" offers, bogus charities, magazine sweepstakes, and being sold products that were inappropriate for their age (such as a new roof with a 30 year warranty "that's going to outlast their grandchildren").

Caregivers also recounted financial abuse (misuse of an elder's money, personal belongings, or assets) perpetrated by family members and a paid caregiver. For example, one caregiver said that whenever her brother visited their mother, he took her to the bank so she could withdraw "thousands of dollars in cash" for him and "...it's not a very good situation." Another reported his sister managed to be appointed as trustee of their parent's estate, and then (without approval

from other family members) paid herself \$11,400 in trustee fees and rented the deceased parents' house for her own profit.

## Discussion

### Financial Caregivers Are Diverse

Financial caregivers differed in many ways and cared for elders in diverse health and financial circumstances. For example, caregivers differed in financial knowledge and experience, communication styles and capabilities, confidence in their financial abilities, and quality of relationships with their parents. Some were long-distance caregivers, while others lived with the care recipient. This diversity has been observed in large nationally representative samples of caregivers who were helping a parent(s) manage their finances (National Alliance for Caregiving & AARP, 2004; National Alliance for Caregiving & AARP, 2009).

### Financial Caregivers' Responsibilities Change Over Time

Although the need for and duration of caregiving varies widely among individual elders, experts estimate that someone who is 65 years old today will need some type of long-term care and support for 3 to 5 years at the end of life (National Clearinghouse for Long Term Care, 2011).

As care recipients age and their physical and/or mental health declines, financial caregiver responsibilities typically change and intensify. Accordingly, caregiver responsibilities change over time leading to changing financial education and information needs.

### Financial Caregivers Need Specialized Information

Most caregivers in the study reported here needed information about financial issues, programs, products, and/or services relevant to the later stages of life, including:

- **Communication:** How to initiate and manage difficult conversations, problem-solving techniques, family consensus building, and strategies for communicating with health and legal professionals.
- **Social Security:** How to estimate retirement benefits, how and when to apply for benefits, types of benefits available (retirement, disability, survivors and Supplemental Security Income (SSI), how spousal benefits are determined, and how to become a representative payee.
- **Medicare and Medicaid:** The purpose and coverage provided by each program, the interface of the two systems, and how to qualify for Medicaid.
- **Long-term care:** Information about service options available at home, in the community, and in facilities; how to access free or low-cost services; how to estimate lifetime costs of care; and strategies families use to finance care, including long-term care insurance.
- **Estate planning:** Goals and tools for estate planning, including legally designating someone to

make health and financial decisions, and end-of-life care.

## Financial Caregivers May Need Basic Financial Education

Caregivers in the study reported here had a broad range of financial experience and capability. Some described themselves as having little financial "know-how," while a few had relevant professional experience, such as in accounting.

Caregivers also indicated a lack of financial knowledge by what they did not do. For example, although participants commonly expressed fears that their parents might run out of money, only one reported using a written budget, which is widely recognized as a key to financial success at every stage of life.

Given these findings and the results of a national financial capability study which concluded that many American adults are financially illiterate (Lusardi, 2010), it is reasonable to assume that at least some Extension clients who respond to financial caregiving programs may need to learn basic financial skills and concepts to be effective in their financial caregiving responsibilities.

### Implications

1. As indicated, Extension is "strategically directed" to address the needs of America's aging population. One way to accomplish this is to offer financial education programs for some of the 43.5+ million family caregivers to the elderly, two-thirds of whom are financial caregivers.
2. Family financial caregivers play an important role in assuring the health and well-being of their care recipients. Extension educators who do not currently provide programs for this audience might consider it, since they need and could benefit from unbiased information and education relevant to later life financial issues, which, if acted upon, have the potential to improve the quality of life for the elders in their care.
3. Given the diversity of financial caregivers, financial caregiving circumstances, the changing nature of roles and responsibilities over the duration of financial caregiving, and caregiver financial experience and literacy, "one size" Extension programming does not fit all potential clients.
4. Extension programs for financial caregivers should segment the population and target specific subgroups, such as those who anticipate becoming caregivers and want to plan ahead or those who have recently taken on financial caregiving responsibilities. Alternatively, financial caregivers might be segmented by socioeconomic status (since adequacy of resources influences options), by the age and health status of care recipients, or the age of the caregiver, which may be related to financial knowledge and experience, as well as preferences for using technology as an instructional medium.
5. As with all Extension programs, it is important to select the appropriate outreach and educational methods and modify content for the target audience.
6. Finally, financial caregiving programs offered by Extension may need to include basic financial

literacy skills because clients can only make behavioral changes if they know how to perform the related tasks. For example, clients might need to learn how to create and use a budget, apply the investment principles of risk and return, or acquire knowledge about financial tools such as an online retirement benefits calculator or how to pay down credit card debt efficiently using a tool such as [PowerPay](#).

## Limitations

The exploratory study reported here relied on a small, convenience sample with limited ethnic and socioeconomic diversity. While useful for understanding financial caregiving, findings may not be generalizable. Also, data were collected prior to the 2008 economic downturn, which would have likely affected the income and asset values of current care recipients and thus the knowledge and skills needed by their financial caregivers.

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