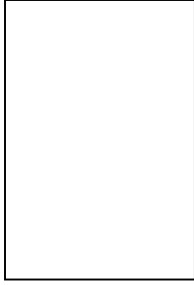


# **“PICKING UP THE TAB”: FAMILIES DISCUSS THE FINANCIAL IMPACT OF CAREGIVING**

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**September 2003**

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## **Executive Summary**

This pilot study analyzed the stories and circumstances of family caregivers to older adults regarding the often-overlooked financial dimension of caregiver burden. The findings suggest that the negative financial impact of caregiving is costly in terms of dollars and cents and in its toll on caregiving families. Themes explored in the interviews include: the timing of the caregiving episode, planning for long-term care needs, relationships within the family, the process and effects of decisions and choices, legal issues, work issues, caregiving and non-caregiving expenses, and non-financial costs related to caregiving. As was expected, many of the themes overlapped and interacted with the others. Also, many of the themes related to financial impact were similar to themes identified in other research on caregiver burden. Program and policy implications include the addition of financial management skills to caregiver training programs, strengthening of family leave policies to better assist working caregivers, and tax incentives for long-term care insurance purchases.

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## Introduction & Background

Most people who need long-term care live at home or in the community (Agency for Healthcare Research and Quality, 2000). Nearly 25% of households in the United States give care to an older family member (National Caregiver Alliance and AARP, 1997). As the number of older adults rises over the next several decades, families will increasingly be called on to care for their older members. “Over the next 10 years, the total number of employed caregivers in the United States is expected to increase to between 11 and 15.6 million working Americans - roughly one in ten employed workers” (Mature Market Institute, 1999, p. 2). The changing nature of families also influences the caregiving situation. Divorced and unmarried people do not have spouses to serve as caregivers. Smaller families also mean fewer children as potential caregivers. As a result, fewer caregivers will be available, and those who are available may have a wider variety of responsibilities than in the past.

Family caregivers often provide 24-hours a day, 7 days a week, 365 days a year care, and are known to experience burden and burnout because of caregiving. Caregiver burden is defined as “the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired

older adults,” (George and Gwyther, 1986, p. 253). Some burden or stress comes directly from caregiving activities, some from negotiating responsibilities with other family members, employers, and health care and long-term care providers. Other stressors may have existed before caregiving, and may have been worsened by caregiving. Even though caregiver burden has been studied and many interventions designed to alleviate burden, the financial consequences of caregiving have not been studied extensively.

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### ***Financial impact influences and is influenced by many aspects of caregiving.***

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Financial impact of caregiving (FIC) is complex. It influences and is influenced by many aspects of caregiving. The complexity of financial burden can be illustrated by looking at the typical family caregiver. According to the National Alliance for Caregiving (1997), the “average” caregiver is a 46-year-old, employed, married woman with a median household income of \$35,000, who spends approximately 18 hours per week giving care, about \$171 per month on out-of-pocket caregiving expenses, probably has at least one child under 18 living in the home and has made formal or informal adjustments to her work schedule to accommodate caregiving activities. If this caregiver is also “average” in her financial situation, she has a credit card balance of approximately \$7,500 (Lawson, 2000), in addition to other debts and daily living expenses.



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The financial impact of giving care can also affect the caregiver long after caregiving ends. Lost job assignments, transfers and promotions, training and networking opportunities may not be available again. These opportunities are more difficult to make up as a worker ages since future possibilities usually come through taking advantage of present opportunities. Similarly, debt often takes years to pay down. Income used to pay debt cannot be used for retirement savings and cannot accumulate interest. Neglected health due to caregiving activities or limited resources may result in the care provider needing care or assistance before it otherwise would have been expected.

This research study focuses on the negative financial impact experienced by caregivers during and after caregiving. FIC was explored in some detail and the themes that emerged from the interviews with caregivers are identified and discussed. This qualitative study used a combination of structured and unstructured interviewing, and the caregivers discussed the issues and events that were most salient to them and their personal situations.

## Methodology

### Sample

Fourteen interviews were completed: nine with caregivers or

caregiver couples currently giving care to an older family member, and five with former caregivers or caregiver couples who had ended caregiving within the last two years. Caregiver couples refers to a husband and wife who care or cared for an older family member and who were interviewed together. Caregivers were recruited through several avenues. Most received home and community-based services through a county levy-funded program. Additional participants were recruited by the researcher at a caregiver support conference in southwestern Ohio and through referrals from other caregivers. Caregivers were contacted by telephone, questions about the study were answered, and an interview scheduled if the caregiver was willing to participate.

### Procedures

The in-person interviews included both structured questions with closed and open-ended responses, and topics for reflective discussion. Structured questions included the amount and type of disability of the care recipient; timing and length of caregiving; assistance and social support with caregiving from family members, friends, and paid professionals; work and employment issues; home modification and caregiving expenses; the care recipient's long-term care (LTC) planning; and planning for the caregiver's LTC needs. Topics for unstructured discussion included caregiver and care recipient LTC and retirement planning issues, adjustments to household and personal spending during caregiving, family financial obligations, and debt and credit issues.

A written, self-administered survey to be completed and returned by mail was given to the participants upon completion of the interview. The survey contained questions about household size and composition; amount and source of income; amount and type of debt before, during, and after (where appropriate) the caregiving period; use of credit cards to pay for everyday expenses; amount of concern about debt; and advice sought about debt. The survey also included the Financial Impact Scale (FIS) (Todtman and Gustafson, 1991). The FIS did not include an item regarding debt, so an item (“I felt that caregiving sometimes made it difficult to manage my debt.”) was added for a total of 22 items. The scale used a 5-point Likert scale, with 1 being “strongly agree,” 3 being “undecided”, and 5 being “strongly disagree.”

## **Findings**

In addition to completing the in-person interviews, all 14 caregivers and caregiver couples returned the pencil and paper survey. For caregiving couples, the family member is listed as the 1<sup>st</sup> caregiver (e.g. son); the 2<sup>nd</sup> caregiver is the spouse of the 1<sup>st</sup> caregiver (daughter-in-law). This distinction is for clarification in reporting only; it is not meant to describe the amount of care given by a specific caregiver. Table 1 reports the demographics of the caregivers; the demographics for the care recipients are in Table 2.

**Table 1. Caregiver Characteristics**

<b>Average Age of First Caregiver</b>	<b>60.9 (12.4)</b>
49 or younger	12%
50 – 59	30%
60 – 69	36%
70 – 79	10%
80 or older	12%
<b>Average Age of Second Caregiver</b>	<b>57.8 (9.86)</b>
49 or younger	40%
50 – 59	0%
60 – 69	60%
70 – 79	0%
80 or older	0%
<b>Gender of Caregivers*</b>	
Men	25%
Women	75%
<b>Ethnicity</b>	
Anglo American	86%
African American	14%
<b>Marital Status of Caregiver</b>	
Currently Married	82%
Currently Single	18%
Caregiver couples	2
<b># of Adults in Caregiver Household</b>	
1-2	79%
3-4	21%
<b># of Children in Caregiver Household</b>	
0	86%
1	0%
2	7%
3	7%
Caregiver to Multiple Recipients	21%
<b>Living Arrangements –Spouses</b>	
Caregiver’s home	80%
Facility	20%
<b>Living Arrangements – Non-Spouses</b>	
Caregiver’s home	50%
Care Recipient’s home	42%
Facility	8%
<b>Average Length of Time Caregiving in Years</b>	<b>7.6 (8.22)</b>

\* Includes gender of primary & secondary caregivers

**Table 2. Care Recipient Characteristics**

<b>Care Recipient</b>	
<b>Average Age</b>	
<b>82.6 (12.66)</b>	
49 or younger	0%
50 – 59	0%
60 – 69	20%
70 – 79	0%
80 or older	80%
<b>Female Care Recipients</b>	<b>70.6%</b>
<b>Relationship to Caregiver</b>	
Spouse	29%
Parent/parent-in-law	53%
Sibling	6%
Other	12%
<b>Had Some Form of Dementia</b>	<b>41.2%</b>

Caregivers reported receiving hands-on help with caregiving from the following sources: privately paid workers (56.3%; mean # of hours per week = 57.33, sd = 34.84), unpaid family members (50%; mean # of hours per week = 4.75, sd = 1.89), other paid workers (50%; mean # of hours per week = 4, sd = 1.73), unpaid friends (37.5%; mean # of hours per week = 1, sd = 0), Medicare workers (18.8%; mean # of hours per week = 8.5, sd = 9.19), and Medicaid workers (6.3%; mean # of hours per week = 10, sd=0). Seventeen percent of privately paid workers were paid for by the caregiver. Forty-three percent of caregivers made modification to a home to facilitate caregiving, and 83.5% of care recipients had received a formal care assessment some time during caregiving. Although 58.8% of caregivers/care recipients had

applied for some form of financial assistance with caregiving, 25% had been denied assistance for a variety of reasons. Most caregivers were working when caregiving began (76.5%) and over half of those caregivers stopped working at some point during caregiving (52.9%). Of working caregivers, 29.4% reported using vacation or sick leave for caregiving, 23.5% reduced the number of hours or shifts worked, 11.8% switched jobs, 23.5% quit a job or retired due to caregiving, and 17.6% felt unable to take a job due to caregiving. Only 11.8% of caregivers reported cashing out a retirement or savings account during the time of caregiving.

The results of the pencil and paper survey are displayed in Table 3. There was no significant difference in the mean household income between the time caregiving began and the time of the interview for current caregivers, nor between the time caregiving began and the time it ended for former caregivers. Debt stayed the same for current and former caregivers between the time caregiving began and the interview.

On the FI scale, “1” indicates high FIC and “5” indicates low FIC. The median value for all caregivers of 2.33 showed some financial impact. There was no significant difference between current and former caregivers (current x = 2.68, sd = .91; former x = 2.7, sd = 1.2). Although reliability analysis with this sample resulted in a high alpha of .96, the scale could be improved by elimination of several items (see table 4).

**Table 3. Survey Summary**

	<b>All Caregivers - When Caregiving Began</b>	<b>Current Caregivers – At Time of Interview</b>	<b>Former Caregivers – When Caregiving Ended</b>
<b>Household income</b>			
> \$20,000	8.3%	0%	14.3%
\$20-29,999	25.0%	20.0%	0%
\$30-39,999	16.7%	20.0%	28.6%
\$40-49,999	8.3%	20.0%	28.6%
\$50-59,999	25.0%	40.0%	14.3%
\$60,000 +	16.7%	0%	14.3%
<b>Estimate of debt</b>			
> \$5,000	0%	0%	0%
\$5-9,999	18.2%	25.0%	0%
\$10-24,999	27.3%	25.0%	33.3%
\$25-49,999	18.2%	0%	33.3%
\$50-99,999	9.1%	15.0%	0%
\$100-149,999	9.1%	0%	16.7%
\$150-249,999	18.2%	0%	16.7%
\$250,000 +	0%	0%	0%
<b>Type of Debt</b>			
Mortgages	61.5%	38.5%	60.0%
Credit cards	61.5%	38.5%	80.0%
Car loans	46.2%	30.8%	40.0%
Medical bills	30.8%	20.0%	20.0%
Personal loans	23.1%	15.4%	0%
Dental bills	23.1%	25.0%	20.0%
Taxes/fines	15.4%	12.5%	20.0%
Other debts	15.4%	15.4%	0%
No debt	7.1%	21.4%	7.1%
<b>Concerned about debt</b>	<b>28.6%</b>	<b>46.2%</b>	<b>40.0%</b>
<b>Debt as a Result of Caregiving</b>			
Mortgages		28.6%	
Personal loans		14.3%	
Medical/dental		14.3%	
Credit cards		14.3%	
Car loans		14.3%	
Other debts		14.3%	
<b>Used debt counselor</b>		<b>15.4%</b>	

**Table 4. Financial Impact Scale Reliability Item-Total Statistics**

	<b>Corrected Item-Total Correlation</b>	<b><math>\alpha</math> if Item Deleted</b>
Afford to remodel home	0.3047	0.9621
Have to change jobs	0.8125	0.9572
Argued more about \$\$	0.6192	0.9594
Had to go to Dr. more	0.4575	0.9624
Save \$ for own future	0.8901	0.9565
Afford vacation	0.7047	0.9585
Others help pay	0.5201	0.9607
Had to pay for food	0.8468	0.9568
Nursing home too expensive	0.2224	0.9631
Pay for travel due to caregiving	0.9249	0.9558
Financial burden	0.9748	0.9552
Cut down on own expenses	0.6772	0.9590
Unable to leave an estate	0.9818	0.9548
Could not pay bill on time	0.8448	0.9575
Unable to buy clothing	0.9721	0.9556
Strained family/social life	0.8592	0.9566
Worried about caregiving costs	0.9726	0.9559
Financial drain on family	0.9720	0.9556
Pay for CR medical bills	0.5412	0.9604
Pay for CR major living expenses	0.5640	0.9600
Nursing home use up my savings	0.1041	0.9652
Difficult to manage debt	0.9747	0.9554
$\alpha = 0.9603$ Standardized item $\alpha = 0.9607$		

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The in-person interviews underscored the limitations of the traditional survey included in this study. Although there was limited evidence of financial impact in the survey, the stories of the caregivers strongly suggest otherwise. Themes explored in the interviews included: the timing of the caregiving episode, planning for long-term care needs, relationships within the family, the process and effects of decisions and choices, legal issues, work issues, caregiving and non-caregiving expenses, and non-financial costs related to caregiving. As was expected, many of the themes overlapped and interacted with the others. Also, many of the themes related to financial impact were similar to themes identified in other research on caregiver burden.

### **Timing of the Caregiving Episode**

The timing of the caregiving episode was an important contributor to the financial impact felt by caregivers. Several of these caregivers had teenage children living in the home during the time they cared for their relative while others had young adult children in college, getting married, or having children during this time. Caregivers in this situation are often referred to as the “sandwich” generation, placed between the needs of their aging parents and their maturing children. These caregivers have many competing demands on their time, money and other resources.

*My biggest concern was about the care of him (my husband) since I had to continue to work*

*to keep income coming in. I had one child in high school yet and two in college. (Wife)*

*I was either dealing with children when they were home from school or I was dealing with the things that needed to be taken care of with his mother. (Daughter-in-law)*

### **Planning for Long-term Care Needs**

Another factor in the effect of the timing of caregiving is whether and how well the care recipient planned for their own care needs. Some care recipients had planned financially for their own care while others had been unable or chose not to do so.

*My parents planned well and so financially we had no expenses. (Daughter)*

*We wouldn't have had any problem having enough money as long as we live. I still don't think we will, but I mean... it eats it up pretty fast. (Husband)*

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### ***The problem often arose of the cost of formal care outstripping the ability to pay for it.***

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For some, planning included using a family member as the primary source of care, at least until care needs outstripped the caregiver's abilities. Once this happened, the problem arose of the cost of formal care outstripping the ability to pay for it.

*I think he still has enough funds left that he could even go into a nursing home for maybe a year with what his out-of-pocket would have to be, but after that I don't know what we would do. (Daughter)*

*I've been the sole care of my mother for forever, but the last maybe five years have been the worst. Where she's needed more care, physically or financially. (Daughter)*

*I've been trying to warn my three sisters that in about 2003-2004, mother is going to run out of money. (Son)*

Some of these care recipients put money in savings or purchased LTC insurance because they anticipated needing professional long-term care. However, only two care recipients in this study were able to pay for all their long-term care needs; the others had little or no ability to save money or purchase insurance during their lifetime and were dependent physically and financially upon their caregivers.

*She has her retirement from the university plus Social Security, which is not a lot really. That's all she has. She had no savings or anything. Nothing. (Daughter)*

*My mother has no assets. She had no savings. Nothing. I really doubt if my mother has enough money to bury herself. (Daughter)*

*She couldn't think about it because she never had the money to think about it with. (Daughter)*

*I just know that if there's a serious problem, she can't pay for it and I will pay for it. That's just the way it is. (Son)*

Some caregivers in this study anticipated becoming a caregiver and this gave them the opportunity to prepare to make adjustments to employment, housing, finances, and other areas that they expected to be affected by caregiving. Other families were not able to plan because caregiving began suddenly and without warning, or because other family members abdicated the care responsibilities that were expected of them.

*We could have slapped it off on somebody else, but we were just in the best position to do it, I guess. (Son)*

*My mother feels it is a child's duty to take care of their parents. That's my responsibility. (Daughter)*

*She (my sister) was the primary caregiver. She left in April of '93; it evolved to us. Everybody else was kind of missing in action. (Son)*

Some caregivers and their families were very adept at planning for the care recipient's needs while others had a much more difficult time dealing with the challenges of caregiving. Many caregivers were resourceful people who



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tried very hard to anticipate future needs and ways to deal with them. This preparation worked for some but for others, a sudden stroke or fall brought a change in the needs of the care recipient that presented the caregivers with a new set of challenges.

*My husband's eyesight failed and then things just got worse so I never went back to work. Until fall of 2000, I had not worked since 1985. (Wife)*

*She had three major surgeries in a year and one morning about four o'clock, she fell and broke her hip. (Daughter)*

*She had one of her accidents here a couple of years ago; we had to put her in the nursing home. We had to pay for it because Medicare wouldn't pay. (Daughter)*

*There was not much of a decision to make about going in the nursing home because when she fell, she broke her hip. (Husband)*

## **Relationships Within the Caregiving Family**

Families often make decisions about who will provide care and under what circumstances. For some families, the choices are limited. The spouse or only child is the caregiver by default; there is no one else. Divorce and remarriage also affect who is available to give care and what financial resources exist for that caregiver. In some families, the caregiver is chosen

by mutual agreement, but in still other families, the "designated" caregiver is unable or unwilling to provide care. Such family situations can result in limited social and instrumental support for the care recipient, the caregiver, and other family members, such as children.

*I had a nephew that was a nurse and he would come in. We could get help from our family if we asked, if we needed it. We were really lucky. (Daughter)*

*She (my daughter) came over. That was the only help we got. (Husband)*

*Because of the stress at home, my husband of 22 years has now left us. I have two younger sisters and their husbands and their children who have estranged us. (Daughter)*

Such circumstances and decisions can have enormous impact on the relationships and financial situations within families. When the pool of caregivers is limited, the financial, emotional, physical, and psychological burdens cannot readily be shared. Also, the impact of caregiving is not limited to those providing the hands-on care. Parents often use limited resources to meet the immediate needs of their children and the care recipient rather than their own future needs related to retirement and long-term care. This postponement of planning and resource gathering can trickle-down to affect subsequent generations. For example, a parent who is a caregiver and is unable to save sufficiently for retirement or long-term care many need to rely

financially on his or her children in later life.

*They never once offered a dime toward her care. So everything has fallen to us. (Daughter & son-in-law)*

*Oh, we know they are not going to pitch in a dime. It'll come down to us. We'll go into debt. (Son)*

### **Process and Effects of Decisions and Choices**

The impact of specific choices related to caregiving also emerged during interviews. Decisions about living arrangements had a tremendous impact on the caregiving situation, including FIC. In many of the families, where the care recipient would live was one of the first decisions made. Although the decision for non-spousal care recipients to move into the caregiver's home is the norm, for some families the choice was made for caregivers to move into the care recipient's home.

*We sold our home and then moved in to live with my daughter and her husband so she could do anything when I was at work. (Wife)*

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***Maintaining two households in a caregiving situation can be expensive in terms of money and extra time.***

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Other care recipients remained in their own homes. While allowing the care recipients and non-spousal caregivers to retain separate and independent lives to some extent, maintaining two households in a caregiving situation can be expensive both in terms of money and in the extra time needed to give care.

*I've had a lady to stay with her at different times at night when she had been very ill in the hospital or she had fallen. We paid for that privately. (Daughter)*

*My husband bought into the house that they (his parents) were in at that time and we made two house payments for four years. That's why our big night out was McDonald's. (Daughter-in-law)*

*It wasn't cheap when she came out of the nursing home and for a few weeks having someone come and stay with her at night. Boy, that added up. But you couldn't do that forever. (Daughter)*

Several caregivers talked about the impact of specific choices they made that may seem extravagant, unnecessary, or unwise to others. One daughter remodeled a bedroom with a large picture window so that her bedridden mother could have more sunlight and could view something besides the walls and television. While admitting that the window was probably unnecessary from a practical perspective, this caregiver felt that it enhanced both her mother's and her

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own quality of life. Decisions about employment were also made and had both positive and negative consequences.

*The needs are so great with my mom and dad that probably affected that decision to just sit tight and not try to find just a part time job. (Daughter)*

*I had taken off work to work with him. Then things just got worse so I never went back to work. (Wife)*

*I realized that mom should really not be left by herself so I haven't gone back to work. (Daughter)*

It was apparent from some stories that more abundant financial resources gave some caregivers a wider range of choices in how to give care as well as decreasing FIC. More abundant resources also allowed the caregiver(s) to shift some of the hands-on care to formal care providers, freeing them to give more emotional and psychological care, as well as allowing them time to attend to other responsibilities in the household.

*Medicare paid for the home health aide. But eventually that was no longer allowed and we paid for it ourselves. (Wife)*

*We hire somebody about 14 hours a day. That's what really costs the most money because it's \$10 an hour. (Husband)*

Those caregivers with limited financial resources used their resources

of time and energy to provide care, which resulted in less time and energy to attend to other responsibilities, such as childcare and employment. Caregivers also had to use their limited financial resources to pay for expenses, such as car repairs, that could only be purchased with money. Some caregivers were unable to cut back expenses while caregiving because resources were already limited and there were few optional expenses to eliminate from the family budget.

*We really couldn't cut back on anything because we didn't live extravagantly. (Wife)*

*I watched when I spent. I used coupons to buy briefs, anything I could do to make ends meet. I wasn't going to spend money just because it was there. (Wife)*

*I kept the house sitting at 40 degrees for a while, except our bedroom. That was turned up so it would stay warm in there. But January and February were tough months. (Daughter)*

## **Legal Issues**

Legal issues centered on the control of the care recipient's financial assets and resources. For several caregivers, the responsibility was an undesirable one, necessitated by the cognitive or physical impairment of their family member. For most caregivers, their control was informal, meaning they did not have legal control, such as a power of attorney arrangement. The caregivers were simply acknowledged by businesses and agencies as the

person with whom arrangements and agreements would be made.

Some caregivers had sought legal agreements when advised to do so by the care recipient’s attorney or by a caseworker. A power of attorney agreement was the most commonly used mechanism, although some caregivers investigated other ways, such as declaring the care recipient as a dependent for tax purposes. However, for recipients receiving assistance for low-income persons, this solution would mean that the caregiver’s income would be considered when determining eligibility and would most often result in a loss of benefits.

*My sister has power of attorney over such matters, but only rarely does she (mother) ask my sister for help with such matters, but you can tell that time is drawing near. (Daughter)*

*I’m the number one daughter. I’m the Power of Attorney. (Daughter)*

*We cannot declare her as a dependent because then her Medicaid would go. The money we save wouldn’t buy two month’s medicine. (Son)*

Caregivers often expressed concern about their responsibility to be fiscally prudent with their family member’s resources, to make them last as long as possible before applying for financial assistance such as Medicaid. More than one caregiver expressed awareness of a family member’s

reluctance to apply for government assistance.

*My uncle had to do that with my grandmother. For a while, he paid for a kind of short-term policy for nursing home care, but he eventually had to apply for Medicaid. (Daughter)*

## **Work Issues**

As was expected, most non-spousal caregivers and several spousal caregivers worked during caregiving. Some managed to maintain their employment by juggling responsibilities, often through informal agreements with their employer or because they had flexible working schedules.

*I took weeks off when my dad went into hospice. I was going to take off whatever it took. (Daughter)*

*I worked the night shift for a long time. I changed from twelve hour shifts to five eight hour shifts. (Wife)*

*After my retirement, I attempted to work as an independent and I was having problems trying to do that because she required more and more care. I don’t think I lasted like that for a year, not even for a year. (Husband)*

*When it (the stroke) first happened I did take some time off that wasn’t really sick time and I just didn’t get paid for it. (Daughter)*

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*With both of them (our mothers) being 83, it was getting to be too much. So it was a big part of my decision to stop working there and just work with my husband so we would both be free to cover bases. (Daughter)*

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***Some caregivers quit work, changed jobs or hours worked, some became self-employed, or postponed a new job.***

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Many caregivers made adjustments or decisions about employment. Some caregivers quit work, others changed jobs or changed the hours worked, some became self-employed, and still others postponed starting a new job. The adjustment provided time for caregiving while decreasing the financial resources that may have been needed.

*I was actually doing two jobs. So then I quit \_\_\_\_\_ Elementary just to work with him [her husband] and that way I have a lot more flexibility. (Daughter-in-law)*

*I've often thought about it but it was like, what happens if I'm at a job and I have to go because my mother's on the phone instantly wanting me there. (Daughter)*

Even caregivers who felt no immediate FIC experienced work-related adjustments that could have long-term consequences. A caregiver who is unemployed does not pay Social

Security tax, which could limit the monthly benefit he or she will be eligible to receive. Similarly, a caregiver may not have the resources to contribute to a private pension plan during that time. If the caregiving is protracted, caregivers could find themselves “playing catch-up” to provide for their own retirement and long-term care needs.

*But knowing I was losing all these work years, I was going to have to do something for a better retirement for myself. I've been doing what I can. (Wife)*

*As far as retirement goes, we always say we're going to save toward retirement. But we've always got extra expenses that take it. (Daughter)*

*You asked if caregiving meant I didn't get to work and yes. That's going to have a long-term impact because I gave up fifteen years of work. Fifteen years toward retirement. (Wife)*

Another work-related issue is the cost of lost opportunities. Most research on the impact of caregiving on employment issues has focused on the effects on caregivers with more traditional work situations such as salaried or hourly employees. Several caregivers in this study were self-employed. Each of them talked about the effect that caregiving had on their ability or opportunity to work at their business. One such caregiver also pointed out that other family members felt that he and his wife were the ideal caregivers because of the perceived flexibility self-employment gave him and his wife.

*Every hour you spend up there (at mother’s house) meant one hour you could not be in the studio creating something to sell. It was lost opportunity income. Basically, I could work at night. But I lost a lot of hours. (Daughter-in-law)*

*I just would work [on bookkeeping] at night after they were asleep. (Daughter)*

*along with the co-pay and other deductibles. (Husband)*

*We’ve purchased the bedside commode, canes, elevated toilet seats, shower chairs, shower benches, walkers, and a lift chair. (Daughter)*

*It was a financial impact when we had to remodel the bathroom. (Husband)*

## **Caregiving and Non-Caregiving Expenses**

Not only can caregiving affect employment, additional expenses can also increase the negative FIC. Care recipients often need prescription drugs, incontinent supplies, mobility devices and other home medical equipment, and home modifications for safety. Most caregivers in this study had made home modifications to increase safety, mobility and ease of caregiving. Some modifications were common and relatively inexpensive while others were costly renovations. Even with assistance from local agencies, Medicare, and/or Medicaid, there is often a cost to the caregiver or care recipient.

*But Medicare didn’t pay for prescriptions. She got like \$600 a month (Social Security) and it took every dime of that for her medication and her Depends. We didn’t have anything left. (Daughter-in-law)*

*Every time she went to (the hospital), there was a deductible up front of about seven hundred and fifty bucks,*

Although a few care recipients in this study qualified for services from means-tested programs, most did not. Many paid out-of-pocket for services such as adult day care and in-home personal care. This is demonstrated by the high percentage of caregivers using privately paid care workers (56.3%) and in the average number of hours of care purchased by care recipients and their families (mean # of hours per week = 57.3, sd=34.84).

*We had a way of just being slightly over the cutoff line financially so we never made a formal application. We were told not to bother. (Daughter)*

*We finally got on PASSPORT (Medicaid) the month before she died. (Daughter)*

In addition to long-term care services and caregiving supplies, caregivers often purchased items and services that make caregiving easier or less stressful. Some examples are transportation, convenience foods, adjustable beds, televisions and other electronic entertainment equipment, special clothing that is easy to put on, and vehicles that accommodate

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wheelchairs. Caregivers often adjusted their spending patterns to accommodate additional expenses related to caregiving. Caregiving meant living more frugally. Things like vacations and recreation were considered luxuries, in terms of money, time, and responsibility.

*If we could have got help with hearing aides... Mom wore her mother's because she couldn't afford to buy one. (Daughter-in-law)*

*I just went for the things that she absolutely had to have. (Daughter)*

*I bought one of the electric chairs that he could raise himself up. It was an \$800 chair and \$200 was paid for by Medicare. I had to get a lightweight wheelchair which they only paid part of it too. (Wife)*

*Medicare doesn't cover everything. And we carry insurance. It's up above \$2,000 a year for each one of us now. (Husband)*

*This time of year we'd like to go away but I can't do it. It's hard to go away for two weeks because she (mother) just emotionally can't handle it. She wants me here all the time. (Daughter)*

Increased expenses sometimes required "creative financing" from the caregiver. At a time when income seldom increases to meet the increase in expenses, some caregivers found

alternative ways to obtain things that were useful or needed.

*I got on some kind of a panel through Proctor and Gamble and was able to get some free briefs at some point so that was a big help. (Wife)*

*I wanted something for a handicap (in the bathroom) so, I had to make a deal with the landlord on the rent and paying stuff like that. (Husband)*

Several caregivers reported "borrowing" money from retirement, insurance, and other accounts and returning the money when tax refunds or insurance payments came through. Others took out personal loans for large expenses such as home modifications. Still others used the old standby, the credit card, to meet both day-to-day expenses and emergency needs.

*I was always going a little bit on the credit card more than I wanted to. I would draw out a lump sum and pay that off if I got anymore behind than that. (Wife)*

*I didn't cash out (my retirement). I borrowed on it and had to pay it back. (Husband)*

*I maxed out four credit cards and I just had to open another one because my car needed repair. (Daughter)*

*We were always a month behind in our paying for things because we would charge them. (Daughter)*

Just as caregivers have competing and compounding demands on their time and energy, there are competing and compounding demands on their financial resources. There is the very real possibility that for some caregivers and their family members, the caregiving period will outlast the financial resources available. “Human” resources can be depleted as well, meaning that caregivers burnout emotionally, physically, and mentally.

*Mom has paid around \$20,000 last year out of pocket just for caregiving and then I get \$18,000 a year. So that right there is \$38,000 just for her to be able to live and be cared for. (Daughter)*

*If she did not have it (Social Security), we could not afford the medication and neither could she. It’s as simple as that. (Son)*

*I was concerned that if I kept using the IRA, if he lived a long time, we would have a hard time. (Wife)*

*I never thought at eighty-two I’d be looking for a job but could be that I might find something to plug up the holes a little bit. (Husband)*

*If my mother would have to permanently go into a nursing home, all that would be on my husband and I. (Daughter)*

Even for those care recipients who had seemingly planned well, the very real possibility of out-living their

resources frightened caregivers. This is especially true when caregivers themselves can no longer provide the level of care the family member needs.

*I just planned on using his IRA account. If we used it up, we used it up. I have to take care of him so we used quite a bit of that to live on. (Wife)*

*She was a private patient that whole year. I don’t know that I could do that again. (Daughter)*

### **Non-Financial “Costs” of Caregiving**

It is well documented that caregivers often experience physical and emotional health problems related to caregiving. Increased health problems often mean increased health care costs, including out-of-pocket medical expenses and the need to temporarily replace informal care with formal, paid care. Some caregivers in this study reported ignoring their own health care because they did not have the financial resources to pay for it. This can have detrimental effects on a caregiver’s ability to provide care as well as on their health, disability status, and long-term care needs. When caregiving limits the opportunity to work, a caregiver’s health care benefits are also jeopardized.

*I broke one foot from moving my husband. (Wife)*

The emotional costs of dealing with agencies, programs, and long-term care providers also took their toll. Problems such as unreliable service



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providers and home care workers, and program and policy requirements (red-tape) consume time, and physical and emotional energy that are needed for caregiving, and create problems for working caregivers.

*One time we had people from \_\_\_\_\_ for a while. They used to call me about the time somebody was supposed to come in for their shift and say they couldn't come. It's too late to get somebody else, you know. (Husband)*

*I would say the stress of it is probably worse to me especially, than the financial aspect of it. (Daughter)*

## Conclusions

The findings from this study suggest that the negative financial impact of caregiving is costly in terms of dollars and cents and in its toll on caregiving families. The large number of themes that emerged from the personal interviews illustrates the complexity of FIC. Some of the themes related to financial impact are the same as those found in other research on caregiver burden (e.g., independence, responsibility, conflicting priorities, limited resources). There were striking similarities between financial impact and the other dimensions of caregiver burden. However, the previous research

on FIC has been limited and narrow in scope.

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***Some caregivers seemed unaware of or unable to acknowledge the long-term financial consequences of caregiving for themselves and their families.***

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Many of the issues discussed by the caregivers in this study were not merely financial in nature, but affected the quality of life for care recipients, caregivers, and their families. Caregivers appeared resourceful, but it was just as apparent that resources, such as money, time, physical energy, and emotional strength, were finite. Caregivers in this study, as in other studies of caregiver burden, struggled to balance the many aspects of care. The impact of unmet needs of everyone in a caregiving family was substantial and very real and there was an on-going struggle to achieve balance between competing needs. In many cases this balance was never achieved, often at the expense of the caregiver and sometimes the family. In other words, when decisions were made, many times the caregiver did what he or she felt was best for the care recipient, even when it had a negative impact on the caregiver, his or her immediate family, and future circumstances. These sacrifices were often done willingly. Other caregivers seemed unaware of or unable to acknowledge the long-term financial consequences of caregiving for themselves and their families, which could have significant impact on personal and family resources in the future.

*Although it is a huge burden, I do it because I love them and I wouldn't step away from this for anything. I mean, I'm in here for the long haul. (Daughter)*

*My finances were secure while my husband was alive and receiving my care, and I did not “worry” then about the present and not too much about the future. But the choices I made then, that made me a good caregiver, have their impact now in reduced financial circumstances. (Wife)*

An obvious, immediate effect of caregiving was an increase in expenses related directly to caregiving. Household expenses as well as health and long-term care expenses increased when caregiving began, and tended to escalate over the course of the caregiving episode. There was also the psychological and emotional stress of negative FIC and other dimensions of caregiver stress. For at least a few, there was an accumulation of and inability to pay financial obligations, including credit card and other types of debt. Caregivers postponed their own health care, home and car maintenance, and retirement and long-term care savings. Furthermore, financial impact did not necessarily end when caregiving ended, and could have far-reaching effects on a caregiver's ability to plan for retirement and long-term care needs.

## **Policy Implications**

Because negative FIC is a very tangible dimension of caregiver burden or stress, it should be included in any

program for assisting caregivers. Its importance has been largely ignored in research and policy. If caregivers at risk of significant negative FIC can be identified earlier in their caregiving careers, financial impact and other types of caregiver burden related to it could be reduced. Reducing burden helps caregivers to provide care longer. Reducing FIC can also help caregivers to plan for their own retirement and long-term care needs. Earlier identification of caregivers at risk for FIC is also important for professionals who work with caregivers. Financial impact is a complex issue, often involving at least two generations, and the effects of FIC have the potential to be passed along to subsequent generations as well.

One way to assist caregivers is through training in financial management. Caregivers act as advisors and managers for care recipients, making financial decisions and endeavoring to responsibly manage both their own and the care recipient's resources. Financial management skills are not intuitive, and so need to be taught just as do other caregiving skills. Also, when resources of any kind are limited, the conservation of those resources takes on greater importance. Therefore, financial management skills are an important component of a caregiver training or assistance program. The financial management skills of caregivers need to be assessed and improved as part of any intervention to help them with the demands of caregiving.

Educational efforts should also address the misconceptions of Americans about the costs of long-term

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care services and the sources of payment for those services. A study by AARP (2001) suggests that as few as 15% of those surveyed could provide an estimate of the national average cost of a month of nursing home care and only 27% could estimate the cost of assisted living care. This same survey found that 31% of respondents reported having long-term care coverage although the Health Insurance Association of America estimates that only 6% have actually purchased long-term care insurance. The researchers suggest that respondents are confusing health and long-term care insurance, or believe that their health policy provides LTC coverage when it does not.

Educational efforts in this area may also become more effective if the contributions of family caregivers are emphasized by including the value of informal caregiving when describing sources of payment. Including the value of unpaid care demonstrates at least some of the financial impact that caregiving can have on caregiving families. For example, in 1999 in Ohio, informal caregivers provided 50% of all the long-term care, with an estimated value of almost \$5 million. Care recipients or their families paid an additional \$1.98 million in out-of-pocket expenses (20%), for a total of 70% of all long-term care costs (Mehdzadeh & Murdoch, 2003). Inclusion of the financial contributions of informal caregivers de-emphasizes public funding. By providing a more realistic picture of who pays for long-term care and how much it costs, people may be encouraged to better plan for their care needs, and policy-makers may be encouraged to provide additional assistance for the enormous

contributions made by families giving care.

Caregivers must often act as a source of income for a care recipient, resulting in emotional, physical, and financial strain within the family. There are several ways in which policies and programs can assist with this situation:

- Expanded family and medical leave policies and legislation can assist caregivers in managing both caregiving duties and employment without removing the caregiver from the workforce or decreasing productivity.
- A prescription drug benefit under Medicare would reduce out-of-pocket expenses for whomever is paying for the medication, whether it be the care recipient or a family member.
- Tax incentives to encourage the purchase of long-term care insurance should also be strongly considered. Such tax reform would encourage greater personal and family responsibility in planning for long-term care needs and has proven successful in increasing private pension savings.
- The use of reverse mortgages to pay for long-term care expenses or for long-term care insurance premiums may make LTC insurance affordable, par-

ticularly for those whose only asset is their home.

- Consumer-directed care (CDC) allows care recipients to hire and pay their own workers using Medicaid funds. Expanding CDC could help families replace some of the income lost when a caregiver quits working or reduces the number of hours worked to provide care.

This study was pilot research designed to hear the stories and circumstances of family caregivers to older adults regarding the often-overlooked financial dimension of caregiver burden. Interviews revealed that caregiving does have a negative financial effect on caregivers and their families, although it is difficult to quantify it. This study and future research can serve to inform policy development and as the basis for designing more sensitive and appropriate evaluation and measurement tools for use with caregiving families. Educational programs should include a financial management component and more persuasively encourage personal financial planning and responsibility as it relates to long-term care. Legislative and policy reform should seek to assist the most important providers in the long-term care system – informal caregivers.

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## References

Agency for Healthcare Research and Quality. (2000). Long-term Care Users Range in Age and Most Do Not Live in Nursing Homes: Research Alert. Rockville, MD: Agency for Healthcare Research and Quality.

George, L.K., & Gwyther, L.P. (1986). Caregiver well-being: A multi-dimensional examination of family caregivers of demented adults. The Gerontologist, 26, 253-259.

Lawson, B. (2000). Mismanagement of Credit Cards Primary Cause of Bankruptcy. Huntsville Times. Huntsville, AL. October 2, 2000.

Mature Market Institute. (1999). The MetLife Juggling Act study: Balancing caregiving with work and the costs involved. Westport, CT: The MetLife Mature Market Institute.

Mehdizadeh, S.A., & Murdoch, L.D. (2003). The Value of Long-term Care in Ohio: Public Dollars and Private Dedications. Oxford, OH: Scripps Gerontology Center, Miami University.

National Alliance for Caregiving, & AARP. (1997). Family Caregiving in the U.S.: Findings From a National Survey. Bethesda, MD: National Alliance for Caregiving.

Todtman, K., & Gustafson, A. W. (1991). The Financial Impact Scale: An instrument for assessing informal long-term caregivers. Journal of Gerontological Social Work, 18, 135-150.