CAREGIVING in context

Understanding Caregivers' Networks of Support

October 2012

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Caregiving in Context

Understanding Caregivers' Networks of Support

October 2012

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Foreword

We find ourselves today at a time in which the old outnumber the young. As a daughter of baby boomers, I believe caregiving will shape my generation's experience of adulthood. Our parents are likely to live longer than our grandparents did; they will be more technologically connected, will retire later, and may or may not have Social Security and Medicare. Even those of us who don't actively provide care will be impacted by the financial cost of supporting the aging members of our communities.

The baby boomer "age wave" will be accompanied by a "caregiver groundswell." Our approaches to caregiving must adapt and evolve to meet these changes. For those working in service systems, it is easy to adopt a service-design approach to problem solving, but *Caregiving in Context* sought to think outside that paradigm.

Caregiving in Context was designed to increase our understanding of the informal support—the family, friends, and neighbors—that surround caregivers. We wanted to better understand this support for a number of reasons:

- Our hypothesis was that it is the most important support caregivers receive—and we wanted to know if they were getting enough of it.
- Formal sources of support will be unable to meet future demands—making it all the more essential for caregivers to have in place strong informal networks.
- The most effective solutions often involve building on the natural networks that exist in people's lives—knowing the strengths and weaknesses of these networks is the first step.

As aging and caregiving evolve, health care and social service systems are growing ever more complex. Navigating these systems has become a daunting task, one that saps caregivers of time and energy. Those of us working in government, health care, and social service systems need to ask ourselves new questions:

"How can we encourage, support, and build the capacity of caregivers to seek support from those in their lives?"

"What if we shift our focus from the burden of caregiving to the burden of system navigation?"

This report is a challenge for all of us—families and friends, social service and health care providers, neighborhoods, and faith communities—to think in new ways about the support we offer to caregivers. I hope it provides you new insights and ideas. Working together we can create communities that value people as they age and support those who provide the majority of care.

Kirsten Johnson
Community Leadership Manager

History and context

With more than 78 million baby boomers reaching retirement age over the next decade and the cost of health care and related services rising faster than virtually all other sectors of the American economy, the support and care provided by family members and friends is drawing increasing scrutiny, interest, and importance. Consider these facts:

- Approximately 43.5 million Americans provide part-time or full-time care for another adult age 50 or over (National Alliance for Caregiving, 2009).

- Informal caregiving will likely continue to be the largest source of direct care as the baby boomer generation retires, with estimates of informal caregivers rising from 20 million in 2000 to 37 million in 2050, an increase of 85 percent. (U.S. Department of Health and Human Services, 2010).

- Conservative estimates predict the nationwide economic value of unpaid, informal care provided by family and friends will be $306 billion per year (Arno, 2004).

- 17% of American workers (and 22% over age 50) are caregivers. The estimated cost of lost productivity due to absenteeism among caregivers working full time is more than $25 billion annually (Gallup, 2011).

- Among female caregivers over 50 who are employed outside the home, 20% report fair or poor health, more than double the percentage reported by non-caregivers in the workforce of similar age (MetLife Mature Market Institute and National Alliance for Caregiving, 2010).

- Caregivers who hire paid help can still expect to spend an average of 24 hours each week providing actual care (National Alliance for Caregiving and Evercare, 2007).

- The burden of family caregiving increases substantially as cognitive impairment worsens. Elders with mild dementia receive 8.5 more hours of care per week than those with normal cognitive function, who receive only 4.6 hours of care per week. Those with severe dementia received 41.5 more hours of help per week than elders with normal cognition (K. M. Langa, 2001).

Both national and statewide initiatives are already focused on how best to encourage and support caregiving in the home by family and friends, broaden the range of community-based resources for caregivers, and increase the utilization of less costly community-based services. While these initiatives work to develop new approaches, there is widespread recognition that formal systems of support will not adequately meet the needs of future populations of caregivers and older adults. Informal systems of support, including networks of friends, families, faith communities, neighbors, and other naturally occurring communities and associations, will be asked to fill this gap.

The times call for new strategies for expanding community-based care, new methods for engaging older adults in the consideration of care choices at an earlier time when more options exist, and new models for strengthening both formal and informal supports available to friend and family caregivers. This report represents the Wilder Foundation's effort to build on existing research on the role of friend and family caregivers, examine how caregivers are supported in their efforts, and consider what might be done to strengthen these support networks in the future.

Background

In 2011, the Amherst H. Wilder Foundation launched a series of Community Initiatives designed to address complex community challenges. These projects were intended to integrate Wilder’s expertise in research, direct service, and community engagement. The Capacity to Care project was developed by an interdisciplinary team of Wilder staff, volunteers, and collaborative partners. The goals of the initiative were to:

- Increase community awareness and understanding of the strengths and challenges faced by family, friends, and community caregivers
- Build the capacity of informal caregivers to offer older adults high quality support
- Foster connections and collaborations among family, friends, and community caregivers
- Create stronger connections between informal caregivers and formal care systems
- Influence policymakers through education on what supports are needed to ensure the success of informal caregivers

Wilder's first step in launching Capacity to Care was to conduct a geographically-focused pilot project, which included:

- Forming a community-based Caregiver Advisory Group
- Reviewing caregiving literature
- Having conversations with city, county, and state aging service planners
- Examining the demographic profiles for selected neighborhoods
- Developing a strategy for collecting information from a representative sample of both primary and secondary caregivers living within the geographic focus area

The all-volunteer Caregiver Advisory Group served as both a sounding board and reviewer for the study presented here. With their advice, program and research staff from Wilder developed a survey instrument to learn more about the networks of support currently in place for family, friends, and community caregivers. It included questions about caregivers' connections with both formal and informal supports, the sources and means of getting information related to their needs, as well as the events and circumstances that shaped their caregiving experience. This report describes the results of the survey.

Methods

Between September 14 and December 8, 2011, Wilder Research conducted telephone interviews with 212 informal caregivers of older adults living in seven St. Paul neighborhoods.

Survey development

The survey was developed as part of the Capacity to Care initiative by an integrated team of staff from Wilder Research, Wilder Center for Communities (WCC), Wilder Caregiver Services, members of the volunteer Caregiver Advisory Group, and community caregivers. Planning began early in 2011, and the final survey instrument was approved in August 2011. The following is an overview of the steps in the survey planning and development process:

1. Wilder Research and WCC project staff met with the volunteer Caregiver Advisory Group to discuss their experiences and needs as caregivers, share the goals of the survey, and solicit feedback on the proposed survey design.

2. WCC project staff conducted two focus groups with caregivers from the St. Paul community to learn more about caregivers. The results of these groups were used to help shape the survey, which was designed to elicit information about caregivers' experiences, their social and community connections, and the formal and informal supports on which they rely.

3. Throughout the survey development process, the volunteer Caregiver Advisory Group and the Wilder Caregiver Services staff provided suggestions for survey questions and assisted with review of the survey instrument drafts.

4. Wilder Research conducted pre-tests of the survey instrument with members of the volunteer Caregiver Advisory Group.

Sample

The Wilder Foundation has approached this initiative with the assumption that the East Metro area is home to many caregivers who both support others and who are in need of support themselves. The survey employed a random sample of listed telephone numbers (landlines only) from seven neighborhoods in the city of St. Paul: Greater East Side, West Side, Payne-Phalen, Thomas-Dale, Summit-University, Macalester-Groveland, and Highland.

The size and demographic make-up of the older adult population in each neighborhood was a primary consideration in determining which to select for the sample. The neighborhoods selected included those that had large numbers of adults age 65 and older and were made up mostly of middle- and lower-income households. In addition, an attempt was made to select neighborhoods that, taken together, included sizable numbers of older adults from the major racial and ethnic groups that live in St. Paul. The figure below shows the neighborhoods in the city of St. Paul and the locations (shaded) of the neighborhoods selected for this survey.

1. Sampled neighborhoods in St. Paul

Survey respondents

Survey participants were adults (age 18 or older) living in one of the sampled St. Paul neighborhoods who regularly provide care for someone age 50 or older who, because of illness or disability, requires assistance to meet their daily needs. Eligibility was limited to informal (unpaid) caregivers.

Also included in this survey were people who were caregivers for an older adult living in a long-term care facility or other institutional setting where daily care is provided by paid staff.

Eligible participants were divided into two groups for the survey: primary and secondary caregivers.

- **A primary caregiver** was defined as the person who is mainly responsible for an older adult's care or the decisions regarding that care.
- **A secondary caregiver** was defined as a person who assists in caring for or supporting an older adult, but who does not have the primary responsibility for the day-to-day care or the decisions regarding that care.

Both primary and secondary caregivers were included to provide a more complete picture of caregiving. Secondary caregivers are often a critical part of the network of support for primary caregivers, providing emergency backup, emotional support, and substantial amount of help with many of the regular tasks that primary caregivers perform.

Caregivers who completed an interview received a $10 gift card to thank them for their time. On average, interviews with primary caregivers lasted 46 minutes, while secondary caregiver interviews lasted 20 minutes.

Sample results

Interviews were completed with a total of 212 caregivers in the selected neighborhoods; 141 of those were completed by primary caregivers (at least 20 from each sample neighborhood) and 71 with secondary caregivers (at least 10 from each sample neighborhood).

All interviews were completed by the professional interviewing staff at Wilder Research, using Computer Assisted Telephone Interviewing (CATI) technology. Open-ended responses were coded for descriptive and statistical analysis.

In comparing these results to other caregiver surveys, it appears that the respondents from the selected St. Paul neighborhoods may have longer tenure in their communities and perhaps a stronger sense of connectedness to their neighbors. However, in most other ways, the respondents in this sample appear very similar to those represented in other studies, giving researchers confidence that the findings can be reasonably generalized to caregivers in other communities.

Introduction

Caregivers are everywhere in our communities. They are diverse in age and background, support both relatives and friends, and perform a wide range of tasks and services as their skills and time allow. As this report illustrates, there are many different vantage points from which to view the 212 participant caregivers. These vantage points are influenced by the level of responsibility caregivers have, the level of assistance they receive from others, and their relationship with the adult in their care.

Significant research has been conducted both locally and nationally documenting the tasks completed by caregivers, the impact of caregiving on health and well-being, and the economic value of this tremendous informal source of support for older adults. Our analysis attempts to build on this existing knowledge with a primary focus on the informal support that surrounds caregivers.

The ultimate goal of this initiative is to strengthen the fabric of support for family, friends, and community caregivers, and to do so in ways that are compatible with the values and needs of community residents.

As part of this initiative, Wilder has sought to answer the following key research questions:

- How do caregivers come to take on their role?
- To what extent are caregivers using home-based services?
- What are the characteristics of caregivers' informal support networks? How and in what ways does this informal support help caregivers in their role?
- How does caregiving differ based on one's relationship with the person receiving care?
- What opportunities exist to strengthen support for caregivers and ensure that this critical resource cannot only endure, but thrive within our community?

First, this report provides an overview of the processes by which one assumes the role of caregiver, the time commitment and responsibilities involved, and the challenges that arise when providing care to a family member, friend, or neighbor. Distinctions between primary and secondary caregivers (i.e., whether or not the caregiver is mainly responsible for the care of the older adult) are discussed whenever relevant.

Next, the report will present general findings about the support surrounding caregivers including their use of home-based services, employer-based supports, and informal support.

Lastly, we'll explore caregivers' experiences and levels of informal support through several frameworks:

1. **"Informal support networks"** describes a measure developed by Wilder Research to understand the overall strength of informal support in the lives of caregivers.

2. **"Who assists caregivers?"** looks specifically at who provides informal support and the extent to which different configurations of family members, friends, neighbors, and others were present in our sample.

3. Lastly, **"Caregiving within relationships"** presents profiles based on how the caregiver relates to the older adult in their care—a spouse, son or daughter, or a friend or neighbor—and how and in what ways those relationships contextualize caregiving.

Though each of these lenses, comparisons between groups of caregivers are highlighted, especially concerning variations in signs of distress and presence of informal support. In each case, we seek to identify areas where strengthening informal support networks may be especially beneficial to caregivers.

Characteristics

Caregiving in Context interviewed 212 caregivers and discovered a diverse group of men and women providing care to older adults:

- The average age is 57
- One in four (25%) caregivers are persons of color
- More than half (54%) are employed
- Over a quarter (28%) are low-income households
- Less than half (42%) are married or partnered
- 18 percent are parents of minor children

Caregivers were deeply rooted in their communities: On average they have lived in their neighborhood for 20 years, and the vast majority felt connected to their neighbors.

Characteristics

Phone interviews were conducted with adults who identified themselves as either primary or secondary caregivers to a family member, friend, or neighbor age 50 or older who, because of illness or disability, requires assistance to meet their daily needs. The survey included those who provided care to individuals living in a long-term care facility or other institutional setting where daily care is provided by paid staff.

- A primary caregiver was defined as the person who is mainly responsible for an older adult's care or the decisions regarding that care.
- A secondary caregiver was defined as a person who assists in caring for or supporting an older adult, but who does not have the primary responsibility for the day-to-day care or the decisions regarding that care.

Caregivers' demographics

Respondents interviewed in this study were reasonably well-aligned with the demographic trends seen in recent national studies (National Alliance for Caregiving, 2009).

In this study, the largest group of caregivers was female and age 50 through 64 years old, most often the daughter of the older adult receiving care. However, *Caregiving in Context* reached a notable number of male caregivers (31%) as well as caregivers of different ages. Overall, 60 percent of caregivers were under age 60, and the average age of caregivers was 57 years (Figure 2).

A quarter of the sample was persons of color: 15 percent were African American, 7 percent were Hispanic, and 3 percent were of another race. Demographic information was missing for two caregivers interviewed.

2. Gender, age, and race/ethnicity

	Primary caregivers (N=140)	Secondary caregivers (N=70)	All caregivers (N=210)
Male	34%	24%	31%
Female	66%	76%	69%
Under 50 years old	21%	28%	24%
50 to 59	36%	38%	37%
60 to 64	14%	10%	13%
65 to 74	15%	21%	17%
75 or older	14%	3%	10%
Average age	59 years old	55 years old	57 years old
White	76%	73%	75%
Persons of color	24%	27%	25%

Note: Percentages may not equal 100% due to rounding.

The level of educational attainment of caregivers was high: 72 percent had schooling or training beyond high school. Over a third (35%) had at least a bachelor's degree, and 17 percent reported taking graduate classes or completing a graduate degree (Figure 3).

3. Educational attainment

	Primary caregivers (N=141)	Secondary caregivers (N=71)	All caregivers (N=212)
Less than high school degree	4%	4%	4%
High school diploma or GED	23%	25%	24%
Some college or technical training	37%	38%	37%
College graduate	20%	16%	18%
Post-baccalaureate	16%	17%	17%

Note: Percentages may not equal 100% due to rounding.

More than half (54%) of caregivers were employed full (32%) or part time (22%) at the time of the interview. Another third (33%) were no longer in the labor force due to retirement or disability, and 14 percent were not working or were unemployed (Figure 4). Primary caregivers were slightly less likely to be employed full time and more likely to be retired compared to secondary caregivers.

4. Employment status

	Primary caregivers (N=141)	Secondary caregivers (N=71)	All caregivers (N=212)
Employed	52%	58%	54%
Full time	30%	35%	32%
Part time	22%	23%	22%
Retired or no longer in the labor force	36%	27%	33%
Unemployed	13%	16%	14%

Note: Percentages may not equal 100% due to rounding.

According to the U.S. Census Bureau, the median income for the city overall was $44,265 in 2010; the caregivers interviewed in this study show a similar overall distribution in that just over half (51%) reported incomes under $50,000 (Figure 5). One in five caregivers (20%) reported their household income as less than $25,000, including 13 percent earning less than $15,000. Another 31 percent said their household income was between $25,000 and $50,000, and 36 percent said their income was $50,000 or more. Thirteen percent of caregivers did not provide information about their income.

Taking a closer look at household income and the number of persons that income supports, Wilder Research was able to identify low-income households, i.e., households that fall at or below 200% of the 2010 federal poverty threshold. Over a quarter (28%) of the sample overall were low-income households by this definition. A slightly higher proportion of primary caregivers (29%) were low income, compared to 25 percent of secondary caregivers.

5. Household income

	Primary caregivers (N=141)	Secondary caregivers (N=71)	All caregivers (N=212)
Less than $25,000	21%	18%	20%
$25,000 to under $50,000	33%	27%	31%
$50,000 to under $80,000	17%	14%	16%
$80,000 and over	18%	25%	20%
Did not disclose income	12%	16%	13%
Low-income households[a]	29%	25%	28%

Note: Percentages may not equal 100% due to rounding.

(a) Households that fell clearly below 200% of the 2010 federal poverty threshold as defined by the U.S. Department of Health and Human Services. Because income was reported in ranges, not all low-income households may have been identified. This should be considered a conservative estimate.

Overall, an equal number of caregivers in our sample were married or partnered (42%) and unpartnered (41%), e.g., divorced, separated, single, or widowed (Figure 6). Notably, fewer primary caregivers were married or partnered compared to secondary caregivers. Males were twice as likely to be divorced or separated as females (30% versus 16%). Female caregivers were more often widowed than their male counterparts (7% and 2%, respectively).

Nearly one in five (18%) caregivers was also parenting at least one child under age 18 at the time of the interview. A higher proportion of secondary caregivers were parents of a minor child; 26 percent of parents to minor children were men, and 74 percent were women. The average household size across the sample was 2.5 persons.

6. Family structures

	Primary caregivers (N=141)	Secondary caregivers (N=71)	All caregivers (N=212)
Married or living with a partner	35%	55%	42%
Divorced or separated	15%	20%	17%
Single (never married)	23%	16%	20%
Widowed	4%	6%	5%
Did not disclose marital status	23%	4%	17%
Parent of a minor child	14%	27%	18%
Average household size	2.5 persons	2.4 persons	2.5 persons

Note: Percentages may not equal 100% due to rounding.

As seen in Figures 2 through 6, the overall sample of caregivers interviewed was diverse considering:

- The wide range of ages
- One in four caregivers are persons of color
- A mix of employed, retired, and unemployed caregivers
- A sizeable number of low-income households
- Various family structures

Caregivers' connections to community

In addition to questions concerning demographics, the survey also asked caregivers how long they've lived at their current residence and how they feel about their neighbors and neighborhoods at large.

The majority of caregivers (78%) live in a single family home, and 5 percent described their housing as a duplex or triplex. Seventeen percent live in an apartment, condo, or townhome, including 4 percent who said their housing was specifically for seniors.

On average, caregivers reported living at their current residence for 20 years, and nearly half (48%) reported living in their community even longer (Figure 7). One in five caregivers (20%), however, said they had moved to their current community more recently—within the last five years. All but two who had recently moved came from other areas within St. Paul or the Twin Cities metro region.

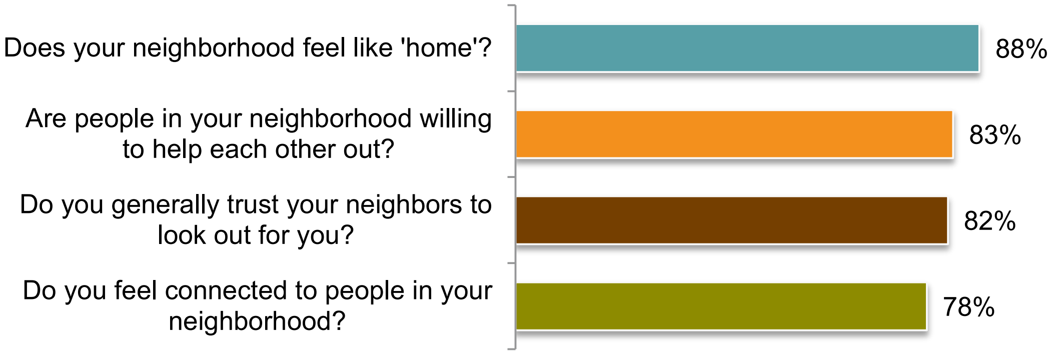
7. Length of time at current residence

	Primary caregivers (N=141)	Secondary caregivers (N=71)	All caregivers (N=212)
Less than 5 years	20%	20%	20%
6 to 10 years	10%	14%	11%
11 to 19 years	20%	24%	21%
20 years or longer	50%	42%	48%
Average time at current residence	21 years	18 years	20 years

Note: Percentages may not equal 100% due to rounding.

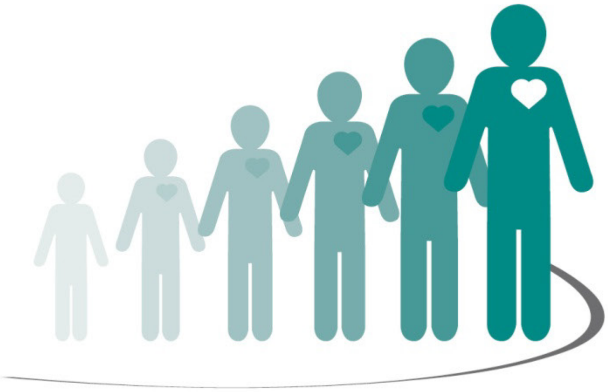
Beyond years, caregivers indicated a strong sense of cohesion within their communities and with their neighbors, shown in Figure 8. The majority of caregivers said their neighborhood felt like "home" (88%), that their neighbors are willing to help each other out (83%), that their neighbors were trustworthy (82%), and that they felt connected to others in their neighborhood (78%).

8. Feelings about neighbors and community (N=212)



Caregivers feel particularly rooted in their homes and within their neighborhoods, which is important to keep in mind while reading the following sections of the report, as they focus on the caregiving experience itself.

Becoming a caregiver



The vast majority of caregivers are relatives of the older adult they care for; they are their spouses and partners, daughters and sons, and other family members. A small number of primary caregivers—and a significant proportion of secondary caregivers—are friends, neighbors, or members of the same faith community as the older adult receiving care.

Caregivers described how they transitioned from these primary roles of spouses, children, and friends to caregivers. Several themes emerged from their stories:

- Few respondents (21%) said they planned in advance to become caregivers.
- Many caregivers feel their role was expected of them. At the same time, many felt a sense of responsibility and acceptance of their role.
- Physical proximity to the older adult and specific skill sets or available time also played a role in becoming a caregiver.

section 2

Becoming a Caregiver

"One person caring about another represents life's greatest value." - Jim Rohn

Relationships with care recipients

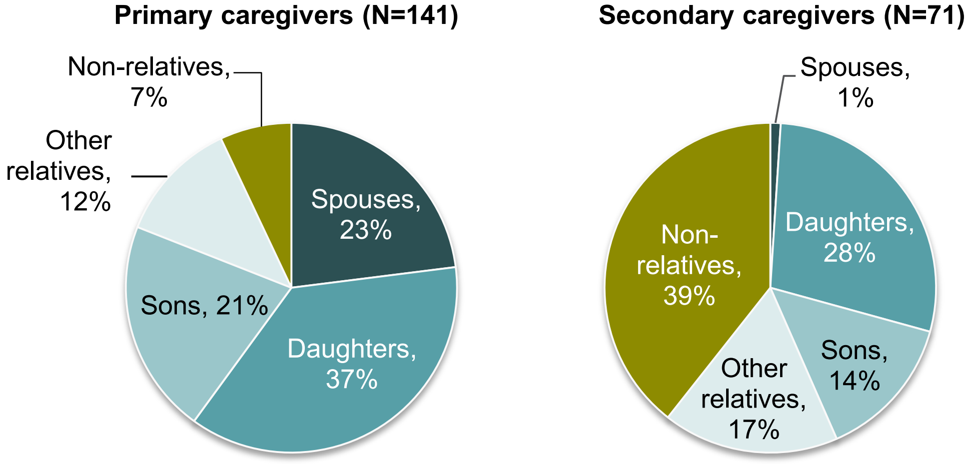
The first question asked in the *Caregiving in Context* survey asked caregivers to describe their relationship to the older adult in their care.

The majority (83%) of caregivers were related to the person they care for; most frequently, caregivers were adult children (53%), spouses/partners (16%), and other relatives (14%) such as daughters- or sons-in-law, grandchildren, nieces or nephews, or adult siblings of the care recipient. However, not all caregivers were family members of older adults: One in six (17%) was a friend, neighbor, or other individual known to the care recipient.

Figure 9 breaks down primary and secondary caregivers by how they are related to their care recipient. The most notable differences are:

- Spouses are almost always primary caregivers. They represent 23 percent of primary caregivers overall (and of spouses, 97 percent identified themselves as primary caregivers).
- Friends and neighbors (non-relative caregivers) are more likely to be secondary caregivers.

9. Caregiver's relationship to their care recipient



Respondents who were identified as secondary caregivers (N=71) were asked who was "mainly responsible" for the older adult's care. Twenty percent said the primary caregiver was a relative of the older adult (a spouse, adult child, or other relative), and 7 percent described other non-relatives such as nursing home staff, case managers, doctors, or Personal Care Attendants (PCA). Four percent said the older adult they provide care to could care for themselves and did not have another caregiver.

How the relationship between caregivers and older adults contextualizes the caregiving experience, as well as comparisons of the caregiving role based on these groups, is explored in much more depth in a later section of this report (see *"Caregiving within relationships").*

Pathways to caregiving

Primary caregivers (N=141) were asked to describe how they assumed their role. Their responses showed that the process of becoming a caregiver often involved a complex set of personal values, family dynamics, and life circumstances. Despite the wide-range of narratives shared, some common themes emerged:

- **Over half (53%) of primary caregivers expressed a sense of responsibility or duty as part of the process in assuming the role of caregiver to their family member, friend, or neighbor.** Nearly all (97%) who described innate feelings of responsibility and voluntary acceptance of their caregiving role were related to the older adult in their care, a subtext seen in the representative responses below:

  It is my responsibility to take care of my parents, my family.

  It was my choice. I took it on voluntarily.

  There was nothing decided about it: I'm his wife and he would do the same for me...we've been married 56 years.

  She is my mother—it was never an issue; it's something you do.

These feelings were not exclusive to family caregivers, however. Eight primary caregivers who were friends or neighbors of their care recipient shared similar sentiments:

> *When you have an 80-something-year-old guy who was just struggling; he had no one to help out...I do for him what I would want someone to do for my father if he needed it.*

> *We have known her since we were teenagers, and her and her husband have always been close friends. He passed away, and we were then willing to do whatever was needed to help her.*

- **Over a third (36%) of primary caregivers said their physical proximity to the older adult in need of help played a role in becoming their caregiver.** Although closeness to the care recipient was a common part of the caregiving process, it was more often than not one of several factors described by respondents.

  > *I live closer than my sister, who lives 600 miles away (I'm about 45 miles away). I assumed the role because it was logical—I'm closer.*

  > *My family came to the U.S. with four people total. My father became disabled, my mother went to work. They don't speak English or drive. I am the only child in the state and take care of them.*

  > *Part of it is distance: I'm the second closest [child], I'm retired, I don't have a family, and I'm the oldest.*

Other responses less frequently mentioned but still shared by a sizable number of caregivers included:

- 15 percent of caregivers explained they were well-positioned to take on the role based on 1) their availability, e.g., they were retired or had a flexible work schedule, or 2) they had a particular skill set, such as a nursing or medical background, or language skills.

- 12 percent said becoming the caregiver prevented placement in a nursing home or long-term care facility or was the result of a crisis situation.

- 10 percent stated their role as a caregiver was because no other family members or friends were willing or able to take on the role.

Some of the common experiences described above imply a certain degree of preparation for the caregiving role, while others became caregivers without a deliberate plan. In a separate analysis, responses that specifically mentioned a planning process, such as a family discussion or personal request to become the caregiver, were flagged. Not every response spoke to this point; in 53 percent of cases, the presence of a plan was unable to be determined. However, of remaining responses, it was determined that:

- **Compared to secondary caregivers, a slightly higher proportion of primary caregivers did not plan to become a caregiver (26% versus 21%).** The absence of a formal plan or discussion did not necessarily mean the assumption of their role was a response to crisis, more often it was described as an organic occurrence or series of events that resulted in their position as caregiver. For example:

> *I don't know if it was 'decided,' it just happened.*

> *I don't know how it came about that I am here, but I'm glad I am.*

For others, however, it was clear their role was born out of a sudden change in health status or circumstances:

> *The phone rang; emergency room calls, and that started the ball rolling. Then I started caring for him.*

- **About one in five primary caregivers (21%) had explicitly discussed their role as caregiver and care arrangements with other family members or the care recipients themselves.**

> *My sister and I provide the caregiving/support to my mother jointly. We met as a family and talked about how we were going to deal with the challenges.*

> *My husband and I decided that I would be the caregiver. I keep him home, comfortable, and happy.*

Another question later in the survey asked all caregivers (N=212), "Do you feel the expectation of playing a caregiver role for your family member, friend, or neighbor fell solely on you?" and 62 percent said "yes." As the statements from primary caregivers below illustrate, the expectation was often associated with the respondent's position in the family, such as being an only child or the oldest child, or an adult child who did not have their own family responsibilities. In several cases, caregivers explained that their parent lost their spouse or partner, making them the next closest family member.

> *I'm her daughter and the only child. She designated me as the person in charge of her health care.*

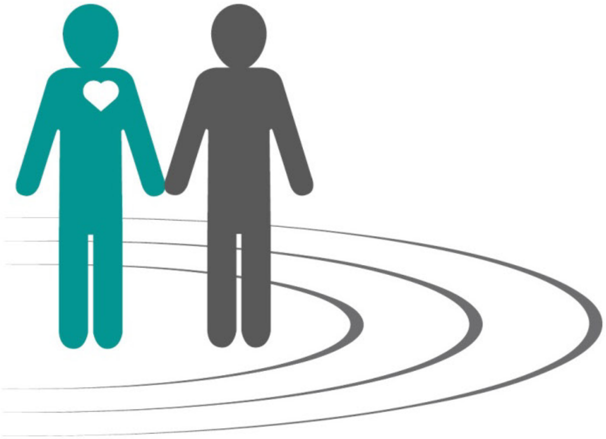
> *Because I'm the oldest, and it's what I've done.*

> *My father remarried after my mom died, and his second wife died in March 2010. At that point, my father decided that he wanted me to become his primary caregiver.*

> *She called me for help. She's been pretty independent until the last couple of years.*

These results show that there are many paths by which someone becomes a caregiver. The next section will explore what being a caregiver actually means in practice.

Being a caregiver



Caregivers we spoke with were experienced in their role: 86 percent had spent at least a year providing care, including 30 percent who had been caregivers for six years or longer.

The caregiver role differed between primary and secondary caregivers in two key ways:

- On average, primary caregivers spent 37 hours per week in their role, and secondary caregivers spent about 9 hours per week.
- Over half (56%) of primary caregivers lived with their care recipient, compared to only 8 percent of secondary caregivers.

The tasks all caregivers helped with most often included companionship (93%), help with shopping or errands (86%), and transportation (84%). Primary caregivers were more likely to help with more intimate tasks, such as personal or nursing care and managing finances, than secondary caregivers.

section 3

Being a Caregiver

The experience of caregiving is as diverse as the individuals involved and the circumstances in which they find themselves.

To learn more about this, those interviewed were asked to provide details about how much time they spend providing care, how long they've been a caregiver, what tasks are involved in their caregiving, and where they seek information about assistance.

Time spent providing care

At the time of the survey, caregivers already had many years of experience in their role. Overall, 86 percent of caregivers reported being in their role for at least a year, including 30 percent who said they've provided care for six years or longer (Figure 10). One in seven respondents (14%) could be considered relatively recent caregivers in that they've spent less than a year in their role.

The primary caregivers were more likely to report providing long-term care (6 years or more) than secondary caregivers (38% compared to 14%, respectively). Still, the majority (82%) of secondary caregivers had served in their role for more than one year at the time of the survey.

10. Number of years as a caregiver

	Primary caregivers (N=141)	Secondary caregivers (N=71)	All caregivers (N=212)
Less than a year	12%	18%	14%
1-5 years	50%	68%	56%
6-10 years	21%	10%	17%
More than 10 years	17%	4%	13%

Note: Percentages may not equal 100% due to rounding.

Caregivers spent a significant amount of their time providing care: On average, caregivers spent 27 hours per week in their role (Figure 11). One in every six caregivers interviewed (18%) were essentially "full time," spending 40 or more hours per week providing care; nearly all (94%) of these caregivers were living in the same home as their care recipient.

Although many secondary caregivers described long-term caregiving arrangements with older adults, their weekly time commitment was not as intense as primary caregivers. Eight percent of secondary caregivers spent over 20 hours per week providing care (compared to 51% of primary caregivers), and on average, primary caregivers reported four times as many hours per week as secondary caregivers.

11. Hours per week providing care

	Primary caregivers (N=141)	Secondary caregivers (N=71)	All caregivers (N=212)
Less than 10 hours	31%	76%	47%
10 to 19 hours	17%	16%	17%
20 to 39 hours	28%	3%	19%
40 hours or more	24%	6%	18%
Average time spent per week	36.5 hours	8.7 hours	26.9 hours

Note: Percentages may not equal 100% due to rounding.

Proximity to care recipients

Four in ten (40%) caregivers interviewed—mainly primary caregivers—share a home with their care recipient (Figure 12). Another 43 percent of caregivers live within 20 minutes of their care recipient, and the remaining 12 percent are slightly farther away (20 minutes or more). Few primary caregivers lived more than an hour from their care recipient (3%).

12. Distance from care recipients

	Primary caregivers (N=141)	Secondary caregivers (N=71)	All caregivers (N=212)
Caregiver and care recipient share a home	56%	8%	40%
Lives less than 10 minutes away	17%	30%	21%
Lives between 10 and 20 minutes away	17%	31%	22%
Lives between 20 minutes and 1 hour away	6%	8%	7%
More than 1 hour away	3%	8%	5%
No information	1%	14%	5%

Note: Percentages may not equal 100% due to rounding.

Over a quarter (26%) of all caregivers said the older adult they care for lives alone in a private residence in the community (Figure 13). Over half (55%) of caregivers said their care recipient shares a home with others—most frequently, caregivers said they shared a home with their care recipient and other family members or friends. In almost every case

(97%), these are relative caregivers who either moved in with their older family member or their older family member moved in with them.

Secondary caregivers were more often caring for older adults living independently (41%) or with other family members (28%) compared to primary caregivers. A sizable number of both primary and secondary caregivers were caring for older adults living in a long-term care facility such as a nursing home, group home, or assisted living center.

13. Living arrangements of care recipients

	Primary caregivers (N=141)	Secondary caregivers (N=71)	All caregivers (N=212)
Care recipient lives with caregiver and other family members or friends	52%	8%	37%
Lives alone in a private residence	19%	41%	26%
Lives alone in a long-term care facility	16%	23%	18%
Lives with family members or friends (but not their caregiver)	9%	28%	15%
Shares a home with their caregiver (only)	4%	0%	3%

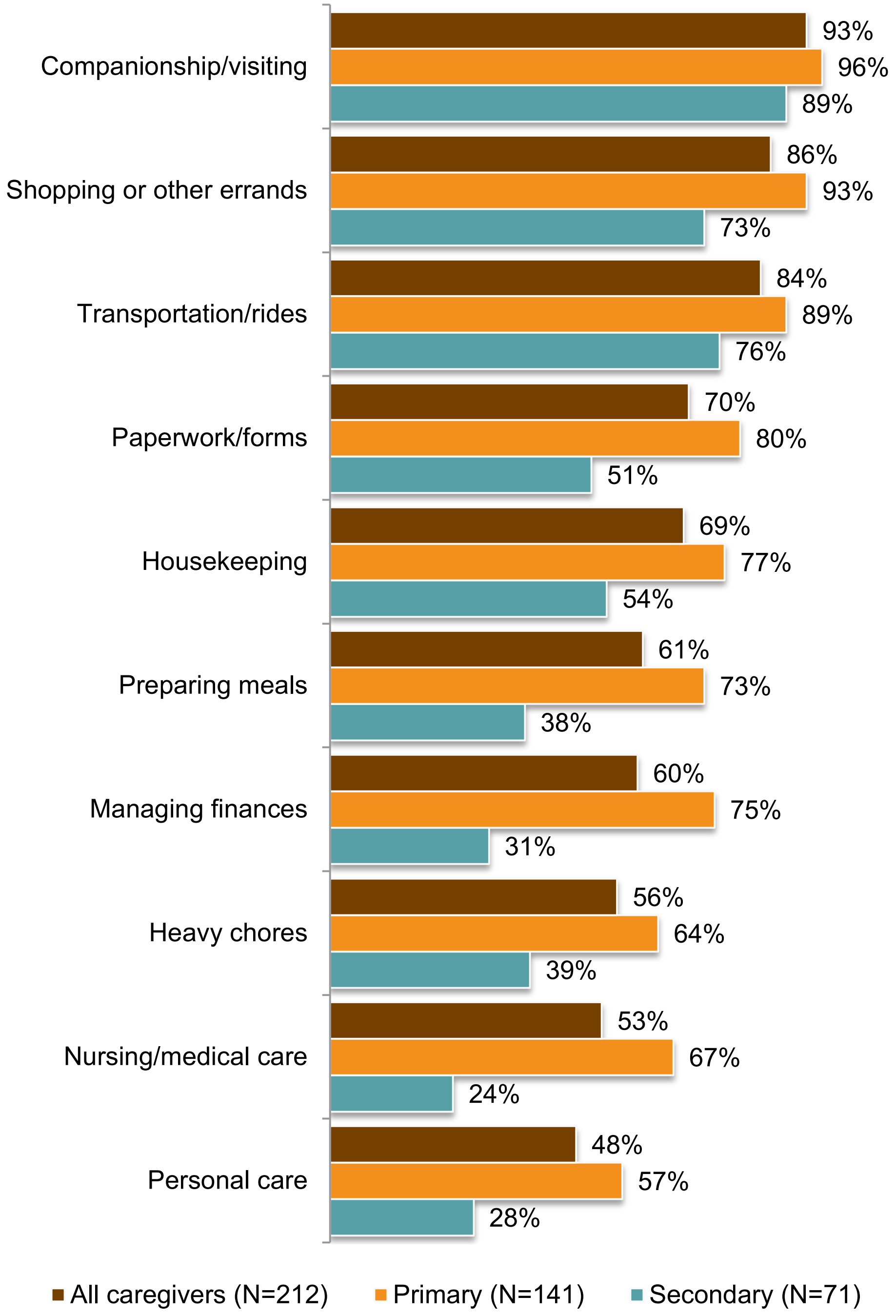
Note: Percentages may not equal 100% due to rounding.

How caregivers help

Caregivers assist older adults with a wide range of tasks. Companionship (93%), help with shopping or errands (86%), and providing transportation (84%) were the top three types of assistance mentioned by caregivers overall (Figure 14).

Primary caregivers were more likely than secondary caregivers to help their care recipient with tasks that are more intimate, such as personal care and nursing care, or tasks that deal with sensitive personal information, like managing finances or other paperwork (Figure 14).

14. Types of assistance provided by caregivers



Ninety-one percent of primary caregivers and 59 percent of secondary caregivers help their care recipients with at least five tasks listed above. Nearly one in five caregivers (19%)—mostly primary caregivers—said they routinely assist their care recipient with all of the tasks listed in Figure 14, indicating the significant role that caregivers play in helping older adults remain in their current living arrangements.

Finding information

In their own words, primary caregivers (N=141) described where they would look for information for themselves or to find services for their care recipient, and their responses are summarized in Figure 15. The sources of information most frequently included in their responses were medical sources (26%), the Internet or websites (25%), and case managers or social workers (16%).

Fourteen percent of primary caregivers said they would turn to community-based organizations for information. The senior block nurse program, Little Sisters of the Poor, Keystone, First Call for Help, United Way, and Disabled Vets were mentioned by name. Wilder Foundation was mentioned specifically by seven respondents.

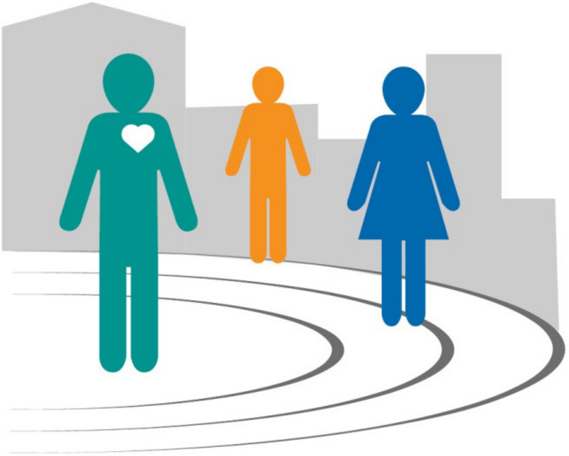
15. "Where would you look for information?"

	Primary caregivers (N=141)
Medical sources (e.g., doctors, nurses, hospice care, etc.)	26%
Internet or websites	25%
Case manager or social worker	16%
County or state social services	14%
Community-based organizations	14%
Family members or friends	10%
Senior LinkAge Line/MAAA	6%
Staff at a nursing home or residential facility	5%
Other	18%

Note: Open-ended responses were coded for themes; responses are not mutually exclusive.

"Other" sources of information included caregivers' faith community or church; media sources such as radio, television, newspaper ads, magazines, direct mail, and brochures; public libraries; financial advisors or banks; and Medicare, Medicaid or Social Security resources.

Support surrounding caregivers



Caregivers most frequently described the support from their family members and friends as the most important resource they have in place that supports them as a caregiver.

This informal support takes several forms:

- 85 percent of caregivers receive help from someone else. However, 45 percent of these caregivers only receive help from one other person, usually a family member.
- 69 percent receive emotional support through frequent contact with someone close to them.
- Over half (56%) received help with a specific caregiving task from a family member or friend.

Caregivers also receive support from home-based services and, if employed, from their employers.

Support surrounding caregivers

The focus of the *Caregiving in Context* survey was to better understand how caregivers are supported, what that support looks like, and where opportunities exist to strengthen support with the intention of reducing caregivers' distress.

Resources important to caregivers

Primary caregivers were asked to describe the most important resources they had in place at the time of the survey, and their responses are summarized in Figure 16. Support from other family members and friends was explicitly mentioned by over six in ten (62%) primary caregivers, followed by health care or medical resources (48%), and home-based services (15%).

16. "What is the most important resource you currently have in place to support your role as a caregiver?"

	Primary caregivers (N=141)
Support from family members, friends, and others	62%
Health care resources (e.g., health care providers, nursing or assisted living staff, and home health aides)	48%
Home-based services (e.g., Meals on Wheels, chore help, transportation assistance)	15%
Community-based resources (i.e., community service organizations, referrals for services, or advice)	8%
Faith-based resources	6%
Personal resources (i.e., hobbies, flexible job, caregiving experience, social activities)	6%
Professional services (i.e., social worker, case managers, or mental health professionals)	4%
No resources in place	5%

Note: Open-ended responses were coded for themes; responses are not mutually exclusive.

Prior research has shown, and caregivers interviewed in this survey confirmed, informal support—that is, help from their family members, friends, or neighbors—plays a key role in the lives of caregivers. However, as Figure 16 demonstrates, the health care system, home- and community-based services, employers, and faith communities are also part of the fabric of support surrounding caregivers. The rest of the section focuses on top-level findings related to these sources of support.

Use of home-based services

Primary caregivers were asked whether they received assistance with specific tasks in the past month and, if so, who provided this assistance—an individual (family member, friend, or neighbor) or an organization or business. Figure 17 summarizes the assistance provided by the latter.

Over half (54%) of primary caregivers who care for older adults living in the community[1] reported use of at least one home-based service in the past month (Figure 17). The five services most frequently used included nursing care provided by a home health aide (25%), transportation assistance (17%), personal care provided by a home health aide (16%), home delivered meals (15%), and help with housekeeping (15%). Few caregivers reported using daytime or overnight respite care, and no one reported the use of home-based services to help manage household finances.

17. Home-based services used in the past month

	Primary caregivers (N=117)
Any assistance from an organization or business	54%
Nursing care from a home health aide (i.e., changing dressing or giving medicine)	25%
Transportation or rides	17%
Personal care from a home health aide (e.g., bathing, dressing, grooming, eating, etc.)	16%
Home-delivered meals	15%
Housekeeping help	15%
Heavy chores (i.e., mowing grass, shoveling snow, heavy housecleaning)	7%
Shopping help (including home delivery)	5%
Adult Day program	5%
Preparing meals	4%
Correspondence or paperwork (i.e., filling out forms for insurance, Medicare, or other services)	3%
Respite care (daytime or overnight)	3%
Managing finances (e.g., keeping track of bills, writing checks, etc.)	0%
Other	2%

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[1] Detailed information about informal support is presented for primary caregivers of older adults who live in a non-institutional setting (N=117). Primary caregivers to older adults in an assisted living center, nursing home, or other long-term care facility (N=24) more closely resembled secondary caregivers in terms of the amount of time spent providing care and were not included in this analysis.

Of the caregivers who utilized at least one home-based service in the past month (N=63), 59 percent said the service involved fees. Caregivers paid for services in a variety of ways, most commonly they reported their care recipient paid out of pocket (N=19), the service was covered by Medicare (N=10), other family members paid out of pocket (N=6), or county or state assistance was used, such as elderly waivers (N=6).

Support from employers

Over half (52%) of primary caregivers said they were employed full or part time at the time of the survey; those who were employed were asked in what ways their employer supports them in their role as a caregiver.

Most employed caregivers (82%) said they were able to leave work as needed to address caregiving responsibilities. More specifically, caregivers described flexible scheduling, unplanned time off for emergencies, or allowing longer-term absences as the way their employer supports their care responsibilities. For example:

> *I can get time for my mom's doctor's appointments or just to care for her if I really need to.*
>
> *They are very understanding. I've never been given any negative anything when I've had to go to care for my mother or step-father.*
>
> *It was OK to cut back on hours.*
>
> *They are very supportive. They know everything that is going on with my spouse. If I ever need time off or someone to talk to, they are always there for me.*
>
> *She knows that if my mother calls or needs me they allow me to take time to take off from work and take care of her needs or emergency situation.*
>
> *They let me take whatever time I need to do those things.*

At least five employed caregivers referred to specific programs like the Family and Medical Leave Act (FMLA) and Employee Assistance Program (EAP) as being an employer-based support.

Caregivers' responses also indicated some support from employers, but with limitations:

> *They acknowledge and understand the need for caregiving, and if I need to be away for caregiving. But, while they understand, they are still demanding. But I do feel supported.*

> *I can take off early if I need to as long as I let them know what is going on. But, I have to use my vacation to do that.*

About one in five (21%) employed caregivers (N=61) said they did not receive any support from their employer, though it was unclear if caregivers made employers aware of their situation:

> *They don't because she is a cousin, and not immediate family.*
>
> *I don't see or hear from them at all about this topic.*
>
> *They are not involved. No support in this role.*

Eight employed caregivers (13%) said they were self-employed, which proved to be an asset in balancing work and caregiving responsibilities:

> *It is a help being self-employed. I can be flexible and do what I need to do and help my friend and my sister.*
>
> *I'm self-employed which allows me to be flexible with my hours.*

Informal support

As stated earlier, support from family members and friends was most often described as caregivers' most important resource; this informal support was the primary focus of *Caregiving in Context*. This section describes general findings about informal support used by caregivers. First, the direct, tangible support provided by others is presented.

HELP FROM OTHERS

A key measure of informal support is whether or not family members or other (unrelated) individuals help caregivers with their responsibilities. Because the survey captured rich, detailed information about the number of others helping caregivers and how they're associated with the caregiver, this area of informal support is addressed more fully in a later section of this report, *"Who Assists Caregivers?"*

For now, however, consider the following:

- 85 percent of caregivers had at least one other person currently assisting them in their role as a caregiver, including 20 percent who had three or more individuals aiding them.

- Most commonly, caregivers' family members, such as siblings, spouses, or other relatives, were involved. However, non-family members such as friends and neighbors also provided support to caregivers, albeit less frequently.
- 15 percent of caregivers said no one helped them.

HELP WITH SPECIFIC TASKS

Over half (56%) of primary caregivers said a family member, friend, or neighbor helped them with a specific task related to caregiving in the past month (Figure 18). Help with heavy chores (31%), transportation or rides (19%), housekeeping (16%), and help with paperwork (14%) were mentioned most often.

18. Help from others in the past month

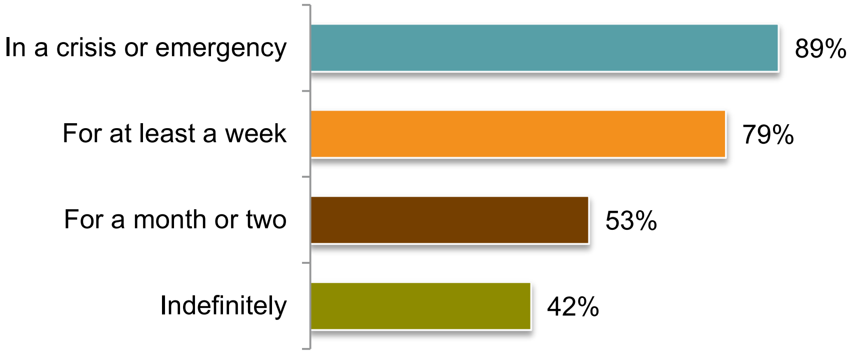
	Primary caregivers (N=117)
Any assistance from family members, friends, or neighbors	56%
Heavy chores (i.e., mowing grass, shoveling snow, heavy housecleaning)	31%
Transportation or rides	19%
Housekeeping help	16%
Correspondence or paperwork (i.e., filling out forms for insurance, Medicare, or other services)	14%
Shopping help (including home delivery)	13%
Managing finances (keeping track of bills, writing checks, etc.)	11%
Preparing meals	9%
Nursing care from a home health aide (i.e., changing dressing or giving medicine)	4%
Daytime respite care	3%
Overnight respite care	3%
Personal care from a home health aide (e.g., bathing, dressing, grooming, eating, etc.)	2%
Home delivered meals	2%

One in six caregivers (16%) said others helped them with at least three of the tasks listed in Figure 18.

THE AVAILABILITY OF BACK UP SUPPORT

The vast majority of primary caregivers (89%) felt a friend or family member would be able to take over their caregiving responsibilities in the event of a crisis or emergency (Figure 19). However, as the need for back-up support increased, fewer caregivers felt it would be available. Just over half (53%) of caregivers said others could fill in for a month or two, and 42 percent of caregivers said other family members or friends could provide help for an indefinite time period if needed.

19. Length of time assistance is available in the absence of caregiver (N=117)



Given the varied demands associated with caregiving, leveraging existing relationships with others and enlisting their help, using community activities as sources of support, and gathering information are vital skills for caregivers. The following findings related to informal support examine the extent to which caregivers are reaching out for help.

COMMUNITY ACTIVITIES AS CAREGIVING RESOURCES

Figure 20 shows the community activities caregivers attended in the last three months and which, if any, they said they used as a resource to support them in their role as a caregiver. The vast majority of primary caregivers (84%) said they attended at least one community activity in the past three months, most frequently religious services (59%), visiting a public library (53%), or community events (47%) such as block group events.

Despite this arguably high level of community engagement, only 44 percent of caregivers said they used a community activity as a resource in support of their caregiving responsibilities. Religious services, visits to a public library, and community social groups were the community activities most often used as resources by caregivers. This finding should be interpreted with caution, however, as not every community activity may have lent itself to be used as a resource related to caregiving.

20. Community activities attended and used as resources (N=117)

	Attended by caregivers in past 3 months...	Attended and used as a resource in caregiving...
Any community activity	**84%**	**44%**
Religious services	59%	28%
Public Library	53%	16%
Community events (such as school or library events or block group events)	47%	9%
Community social group (such as a local senior's club or community center)	17%	12%
Civic group meetings (VFW, Lion's Club, Kiwanis)	17%	7%
Planning District or City Council meetings	10%	3%
Other community activity	20%	6%

Overall, nearly one in five (19%) caregivers had effectively utilized two or more community activities as resources in support of their role as a caregiver.

ENLISTING THE HELP OF OTHERS

Seventy-six percent of caregivers asked for help from those around them—including family members, neighbors, friends, a member of their faith community, or a coworker—for help with caregiving (Figure 21). Outreach was most successful (meaning those who were asked to help began assisting the caregiver) with other family members. Surprisingly, only half of the caregivers who had reached out to members of their faith community said they were currently receiving assistance from them.

21. Outreach to others for help (N=117)

	Asked by caregivers to help...	Currently helping in caregiving role...
Any outreach	**76%**	**61%**
Family members	65%	55%
Neighbors	21%	15%
Friends	18%	10%
Members of faith community	15%	7%
Co-workers	4%	2%

Almost one in three caregivers (30%) felt there were other family members who could be helping with caregiving responsibilities but were not currently doing so. When asked to explain why they felt this way, their responses described an array of family and personal circumstances:

> *It's a tough one. Part of it is distance, and they have their own issues. We have strained relationships. They don't recognize the need.*
>
> *They have their own families to deal with. They have spouses and children, so they focus on that.*
>
> *I believe I could reach out to others such as my wife. I don't feel it's her responsibility; someone needs to take care of our children.*
>
> *Some people I know they do not do things right, I do not trust anyone.*
>
> *I think my sister-in-law might be able to provide a little more direct support. We have not yet sat down as a sibling group to sort out the details of that.*
>
> *My sister could step in a bit more...but can't do it emotionally...and I accept that. My brother would help but he does not live in Minnesota.*

GATHERING INFORMATION

Caregivers used information about assistance for themselves or their care recipient from a wide variety of sources (Figure 22); friends and family (65%) and insurance or health care providers (47%) were the sources most frequently mentioned.

22. Sources of information used by caregivers

	Primary caregivers (N=117)
Family members or friends	65%
Insurance or health care providers	47%
Newspaper articles or ads	36%
Internet or websites	35%
County or state social services	33%
Direct mail or brochures	31%
Neighbors	21%
Radio or television	21%
Community-based organizations	21%
Faith community or church	19%
Senior LinkAge Line	15%
Chronic care organization	13%

Seventy percent of caregivers identified at least two sources, and 29 percent said they've used information from five or more sources over the course of their caregiving experience.

Emotional support

More than two-thirds (69%) of primary caregivers engage in frequent contact with a close friend or family member about their caregiving role (Figure 23). This contact takes place primarily through phone conversations (60%), personal visits (40%), and, to a lesser extent, email (15%).

23. Weekly contact with family or close friends

	Primary Caregivers (N=117)
Any of the below	**69%**
Phone contact	60%
Personal visits	40%
Email exchange	15%

Caregivers were also asked about their use of social media. Over a quarter (27%) said they were connecting with friends and family members through Facebook or other such platforms. Twelve percent said their social media connections served as a support in their caregiving role.

Clearly, caregivers receive informal support from various sources. Some use home-based services and, for employed caregivers, support from employers in the form of flexible work schedules. The support they most frequently identified as most important, however, was the help of their family members and friends. This informal support took the form of help with caregiving tasks, supportive phone calls or visits, and back-up support. This support is the foundation caregivers stand on when facing the challenges and distress of their role. The most difficult aspects of caregiving, and the extent to which signs of distress are visible, is discussed in the next section.

Challenges of caregiving

Though *Caregiving in Context* acknowledges the positive experiences of providing care to an older adult, it shows—as many studies on caregiving have—that caregivers experience distress as a result of their role. For example:

- Caregivers indicated the overall level of commitment required to carry out their responsibilities was challenging. They also mentioned the loss of the person in their care and maintaining positive relationships as challenges.
- Almost half (49%) of caregivers recently experienced symptoms of depression or anxiety.
- Over half (57%) described their caregiving role as “somewhat” or “very” stressful.

These signs of distress underscore the importance of strengthening support available to caregivers.

The Challenges of Caregiving

Research on caregiving tends to focus on the stress and burden experienced by caregivers and its subsequent effect on their mental and physical health. This unilateral view on caregiving—while important for understanding the challenges faced by caregivers and opportunities to enhance support— can overlook the positive experiences or rewards of providing care to a family member, friend, or neighbor (Lin, 2012). Caring for frail, older adults can generate feelings of usefulness (Raschick & Ingersoll-Dayton, 2004), personal satisfaction from fulfilling caregiving expectations within families (Lin, 2012), and a sense of reciprocity for the care given to them at earlier stages in their life (Henretta et.al, 1997).

With this in mind, community residents and members (N=6) of the Caregiver Advisory Group who participated in a focus group that preceded the survey were asked, "What has been the most rewarding thing for you in taking care of your loved one?" They offered the following:

> *Whenever my mother has a good day, when she is lucid and times when she can recall moments from her past.*
>
> *Reminiscing about family history with my great aunt.*
>
> *Caregiving brings you closer together.*
>
> *It makes you appreciate every day.*
>
> *The one-on-one connection it creates.*
>
> *Any kind of indication that I made any difference – this is huge.*

Although our survey at large did not ask caregivers to describe the positive experiences in their role, understanding that providing care involves rewards, as well as challenges and burden, is important to keep in mind. The following section presents the challenges caregivers face in providing care to older adults.

Most difficult aspects of caregiving

All caregivers (N=212) were asked to describe what they found most challenging about their caregiving responsibilities. The responses were analyzed for key themes and coded into non-mutually exclusive categories.

A considerable percentage of caregivers (13%) said they did not find anything difficult about caregiving. Common comments were that the recipient was easy to care for, the caregiving felt natural, or there were no challenges.

Many others, however, described a wide range of challenges, which appear to reflect the uniqueness of their individual caregiving experiences and the ways in which they perceive the demands of their caregiving roles. The following summary of major challenges includes a sample of representative responses from both primary and secondary caregivers.

- **The overall time commitment required to be a caregiver, i.e., finding time to perform caregiving responsibilities while also attending to their own needs and responsibilities, was the challenge most frequently mentioned by caregivers (14%).** Within this theme, caregivers expressed frustration with trying to balance their role as a caregiver with work and family responsibilities, for example:

  Giving up personal time —I mean, the extra time I had to do things, like visit friends, I don't do anymore because I spend time with my parents.

  Sometimes things are scheduled that I can't really control such as doctor's appointments. I have to do that at that point in time.

  Time —the time it takes to do it right and I feel guilty if it (all the caregiving) is not done right.

  I guess the ability to prioritize my time so that I am available for everyone when I'm needed. When you are a caregiver you let things in your own life go.

  Balancing my work hours, the care I need to give my mother, and personal care needs can be really rough—sometimes I end up only getting a few hours of sleep because of the care time I have committed to my mother.

  I think it's just making enough time for my own kids and my family. I have four kids and have a job and also go to college.

- **Many caregivers (13%) described the most difficult aspect of caregiving as the overall burden of their responsibilities.** These caregivers said they felt that their caregiving has required significant personal sacrifices including considerable strain related to making decisions for another person, learning new skills, and having no personal flexibility (being continually tied down).

It never stops. He always needs me because he can't do it himself. Don't get me wrong, I get home and can do the lawn and cook dinner...but taking time to rest when I need that rest is challenging because he is up all the time and he always needs me. He has a breathing machine and he might need a glass of water. It is challenging every day.

Giving too much and getting nothing in return.

The responsibility and not having my own life; the sacrifice I need to make gets to be kind of hard.

Everything. Time, no time for myself. Having patience. My mother has dementia so it takes her longer to answer and she is not the same anymore. Trying to get her to do something that she's unable to do. Patience with myself, so that I know that it's okay not to get everything right all the time; it's just okay to be tired – you know – miss a beat, be human. Your time is not yours anymore, you lose track of your flexibility.

- **A sizable proportion of caregivers (12%) reported their biggest challenge was dealing with the loss of the care recipient.** This included watching their loved one's health and abilities decline, experiencing the loss of their companionship, and coming to the realization of what the future held.

  It's hard to see the decline in her memory as she ages. Seeing that she is not able to do what she normally would be able to do. Seeing her frustration with this.

  The loss of my wife's companionship and seeing her deteriorate.

  Just seeing her the way she is, her disabilities. She has lung cancer and her condition is progressing, and that makes me feel very sad.

  Watching my mother change and not being able to do anything about it other than just being there for her.

- **Maintaining a positive attitude and good relationship with the care recipient was mentioned as the biggest challenge by 11 percent of caregivers.** Some related the difficulties they had remaining patient, attentive, compassionate, and respectful of care recipients who were not grateful for their help or who had been abusive to them. Others (sons and daughters, especially) reported challenges they had experienced with role reversals.

  A little bit of anxiety because of this role reversal, because I'm caring for the man that cared for me, and I don't know how he feels about that.

Just being attentive and compassionate with her needs.

I'm caregiving for someone who didn't take good care of me. I'm an adult survivor of childhood abuse. I try to stay pleasant, but it is really hard.

Respecting my father's need—his desire to be independent and have some type of —you know, he gets embarrassed and frustrated. Awareness of personal space, awareness of personal choice.

Switching roles—being the one to make or encourage him to make a decision—it's hard for me to take that parent role with my dad, encouraging him to make decisions.

Trying to understand the importance of patience. There's not always a sense of gratitude on my mother's part, but she's not in a place to understand that. I need to keep that in my mind and I understand the need to be patient.

Knowing when help is wanted or needed. How do you approach them without making them feel too dependent? She wants to feel or be independent. She lives alone and she's 93.

- **Ten percent of caregivers cited the difficulty of communicating with and caring for others with mental or hearing impairments as a significant challenge.** They reported that dementia, confusion, hearing loss, and other care recipient's deficits often make it hard for them to make themselves understood or to gain the cooperation of the care recipient.

I would say communication on the phone, because she can't hear me. She hangs up the phone on me because she states that she can't hear me, but she does hear my husband, her son.

Well, I think because she has dementia it is hard to communicate with her because she is always a little confused, so that is difficult.

She has aphasia so her language is almost completely gone; so communication is the most difficult.

Getting him to cooperate—sometimes he will not comply. After he thinks about it, then he agrees to do what's needed.

That I have to watch and keep an eye on my wife. She has Alzheimer's and goes the other way and wants to get into the wrong car. It's like dealing with a drunk person.

> *It is hard because we don't always think the same. When they are older they think that things should go their way and it is hard to work with them when they are trying to be independent without creating a safety problem for their own well-being.*

Many other themes about what is difficult about being a caregiver were also heard in a smaller percentage of respondents (<10%).

A slightly smaller proportion of caregivers (9%), said that the most difficult thing about caregiving was making sure that all of the care recipient's needs were met. This included making sure that care recipients were taking medications as prescribed, monitoring medical needs, arranging for care, and overseeing formal services.

> *Just being here all the time - her medical care – her IV care - has to happen every day - the nursing challenges of it.*
>
> *Just being able to keep her comfortable – be sure she is not in pain. She cannot communicate so I have to sense if she is okay.*

Eight percent of caregivers said that stress, worry, or anxiety about their loved one or their caregiving responsibilities were the most significant challenges for them.

> *Decision making, in some instances: Is she safe, should she be in a higher level of care? Leaving her and wondering if she is going to be okay; you always have it in your mind.*
>
> *My anxiety and worrying about him that he would die. He had a stroke about three years ago and had brain surgery like five years ago.*

Four percent of caregivers said that their own physical health limitations or problems were what made caregiving most difficult for them.

> *I learned to slow it down and get healing for myself. I had a few surgeries myself and I need some time to heal.*
>
> *Just getting out to see her, because of my own physical problems.*
>
> *My aging, I am getting older.*

Financial problems, e.g., lack of money for basic needs or finding the resources to pay the care recipient's bills, were mentioned as a challenge by 4 percent of caregivers.

> *The money, we are on Social Security – sometimes there just isn't enough to go around.*

> *The hardest part is trying to figure out what to do when the money runs out. I've got just another year before that runs out. The main thing is she's got to do that spend-down of any money she has left before Medicaid kicks in.*
>
> *The financial part. When I'm caregiving I'm not working and not bringing any money into the home.*

Three percent or fewer caregivers named the following aspects of caregiving as most difficult for them:

- Physical care for care recipient, such as bathing, dressing *(6 caregivers)*
- Lack of supports, e.g., lack of back-up, respite care *(5 caregivers)*
- Living too far from care recipient *(5 caregivers)*
- Dealing with emergencies, unforeseen events *(3 caregivers)*
- Issues with family dynamics; family conflicts *(2 caregivers)*
- Legal forms; matters requiring an attorney *(2 caregivers)*
- Housekeeping, grocery shopping, meal preparation *(2 caregivers)*
- Lack of a car; caregiver does not drive *(2 caregivers)*

CAREGIVERS' WORRIES

In addition to what is difficult about caregiving, all primary caregivers (N=141) were asked what they worried about the most in their role as a caregiver. Not surprisingly, their main concerns were about the health and well-being of those for whom they are caring and how to ensure that they are well cared for. Their concerns are summarized below.

Caregivers reported a variety of concerns about their own ability to meet both the short and long-term needs of the family member, friend, or neighbor:

- What will happen to the care recipient if they get sick and are not able to provide care or they die before the care recipient (16%)

  > *I am always afraid that I will get sick or get injured. If I get sick it would really change our lives.*
  >
  > *Getting sick myself and no one available to care for him the way I would.*

That something will happen to me and who will care for her then.

That if I should die before her, I just want to make sure she is well taken care of before her death. I need to get off my butt and get it taken care of.

- Worries that their care recipient is receiving the right level of care or that they are able to manage or provide adequate care (17%)

  I worry that I'm giving her the level of care that she needs and deserves without comprising her integrity.

  My biggest concern is whether she gets the help and care that she needs.

  Being able to keep up with the level of care she is currently receiving.

- Inadequate finances; how to pay the bills when the money runs out (6%)

  Money is always an issue, and that she may live longer than me.

  Paying the bills, the rest of the stuff I can handle.

- How to deal with emergencies and unforeseen events related to caregiving responsibilities; no back-up plan in place (3%)

  That emergency situation – just having a back-up.

  That I get into a situation that I can't handle and would not know what to do next. It's a scary thing.

Caregivers voiced many concerns about the health and safety of the care recipient. They include:

- The care recipient will fall or sustain an injury (17%)

  I guess probably falls really scare me, if he would take a fall, and then also that the memory loss is getting worse. He can be very, very sharp at times, great personality, but it is borderline.

  She is just too stubborn. She has a Life Line but doesn't push it because she doesn't want paramedics to come. My fear is she will fall.

  She goes upstairs and I worry that she will fall down the stairs, I got her to quit taking the basement stairs.

- The failing health of the care recipient and their ability to remain living in the community (10%)

  It's that my father will not remain mobile so he can stay there and not go into a nursing home.

  Her being able to continue to be independent and to afford to stay where she is.

  What's going to happen to my mom in the near future. She's 80 and she might not be able to get around by herself anymore.

- The care recipient is still driving (2%)

  At her age she is still working and she is still driving. If she needs something and no one is here to get it for her, she will drive and get it herself.

Lastly, many caregivers described the worry and anxiety they experience as a major concern. They include:

- Anxiety about leaving the care recipient alone and worries that the caregiver will not be present if something happens (12%)

  My biggest concern is that she would die alone - that something would happen so fast that we would not be able to get there.

  I worry during work (4 am to 1 pm I am at work), and I worry when I am gone.

  The distance, and being able to respond in a timely fashion (250 miles).

- Stress and strain of commitment to caregiving activities taking an overall toll on caregiver's physical and emotional reserves (10%)

  I don't know how much longer I can keep doing it.

  Not being able to do everything that needs to be done...feeling kind of overwhelmed.

  Trying to take care of her and keep my health. My health is going down because of my caregiver role. I have high blood pressure and diabetes; there is a lot of stress, given my health issues.

- Feeling anxiety or dread about the deterioration of the care recipient's health and the inevitable loss they are facing (10%)

  It has gone through stages. Now it is how I am going to handle it when she passes away, the planning and the emotional.

> *How to deal with what is to come-I have no clue how to deal with that.-It may be coming sooner than I think.*
>
> *That one of us is going to be alone when the other goes.*
>
> *My mother dying. It's just a day-to-day thing, and the last few days are not so good.*

- Worries that they are not doing enough for the care recipient, or that they will make a mistake when providing care (10%)

> *Things falling through the cracks, missing things. You go and do a safety check. You just want to make sure that nothing falls through the cracks, I call every day.*
>
> *Not doing a good job. Primarily you second guess yourself to death I guess.*

Five primary caregivers said they had no worries or concerns related to their caregiving roles.

Signs of distress

The distress or burden (here used interchangeably) experienced by those providing care to a family member, friend, or neighbor is well-documented. A wide range of psychometric tools are available to assess stress and strain of caregivers, yet the literature agrees that burden is a complex, multidimensional experience that does not easily lend itself to common—let alone global —measurement (Savundranayagam, 2010; Pinquart & Sorensen, 2011). While some definitions of burden strictly consider the level of care provided to care recipients as measured by the number of activities of daily living (ADL) or the amount of time spent in the caregiving role, others examine the specific ways providing care affects caregiver's daily routines, or the physical and emotional strain experienced by caregivers (Lin, 2012; Savundranayagam, 2010). Furthermore, several research studies have examined specific types of caregivers and found notable variation in what predicts distress when the gender of the caregiver and relationship to the care recipient is considered (Lin, 2012; Kang, 2006; Pinquart & Sorensen, 2011)—the findings of which are discussed in greater detail later in this report *(see "Caregiving in Context: Relationship to Care Recipient")*.

Caregivers interviewed were asked questions about their health status, whether they recently experienced depression or anxiety, the level of stress they typically experience, and whether or not caregiving has affected time spent on providing care to other family members (including minor children), employment, or other activities such as volunteerism or involvement in community activities. Taken together, these outcomes represent many frequently explored and decidedly important indicators of caregiver distress or burden.

PHYSICAL HEALTH

Caregivers were asked to rate their health "in general" as part of the interview; the results are shown in Figure 24. Overall, 50 percent of caregivers rated their health as "excellent" or "very good," another 32 percent described their health as "good," and 19 percent said their health was "fair" or "poor."

Secondary caregivers were slightly more likely to describe their health as "excellent" or "very good" (58% compared with 46%). This finding is consistent with other research that shows intensive caregiving responsibilities (i.e., spending more hours per week and longer periods of time providing care) can affect a caregiver's perception of their physical and mental health (Pinquart & Sorensen, 2003).

24. Caregivers' self-reported health

	Primary caregivers (N=117)	Secondary caregivers (N=75)	All caregivers (N=172)
Excellent	15%	36%	22%
Very good	31%	22%	28%
Good	31%	33%	32%
Fair	20%	6%	15%
Poor	3%	4%	4%

Note: Percentages may not equal 100% due to rounding.

Over a quarter (27%) of caregivers said they had a health problem that "interfered with their daily activities or made it difficult to provide care" to their family member, friend, or neighbor (Figure 25). Of the 46 caregivers who reported health problems that affected their daily life or role as a caregiver, over half (52%) still rated their health as "very good" or "good," indicating that even with these difficulties, caregivers did not view their health as "poor." As shown in Figure 25, the most common health issues were described as chronic conditions such as joint or bone issues (like arthritis), back problems, or chronic pain.

Severe health issues like neurological problems, cardiovascular disease, kidney disease, and autoimmune disorders were less frequently mentioned (three or less respondents).

25. Top 5 health problems reported by caregivers

	Primary caregivers with a health issue (N=46)
Joint or bone issues (e.g., osteoporosis, arthritis)	35%
Back problems	20%
Chronic pain/neuralgia	15%
Mental health issues	13%
Lung problems	9%
Diabetes	9%

Note: Multiple responses selected, total will not equal 100%.

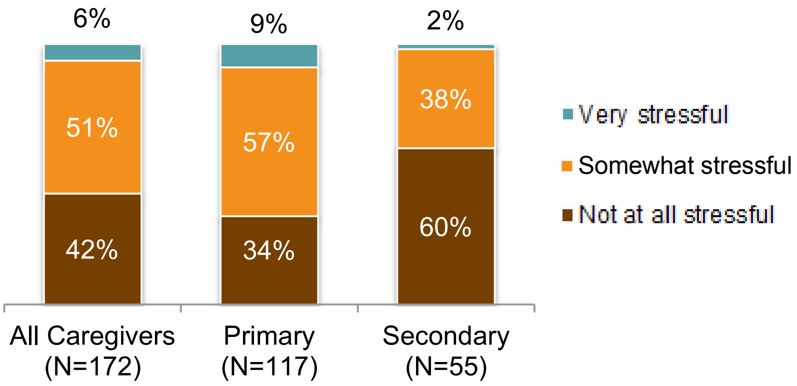
MENTAL HEALTH AND STRESS

Depression and anxiety are well-established indicators of distress and are often included in more complex scales of burden. In fact, research suggests psychological distress can compromise the physical health of caregivers (Savundranayagam, 2010; Pinquart & Sorensen, 2007).

Primary caregivers were asked whether they had experienced depression or anxiety in the past six months, and nearly half (49%) said "yes." Of those who reported recent depression or anxiety (N=57), 35 percent sought professional help or counseling services. Caregivers who did not seek treatment for their symptoms were asked why they chose not to. Mostly, caregivers felt their depression or anxiety was not serious enough to seek professional services, that their feelings would pass in time, or that they simply "didn't need it." Several others said they did not have time, or that they relied on other family members, friends, or members of their faith community to help them.

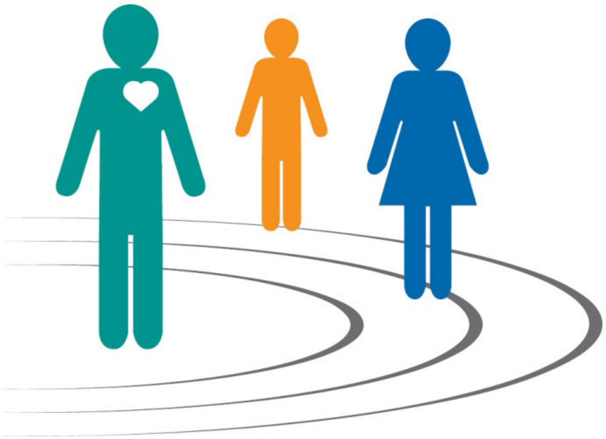
Over half (57%) of caregivers said caring for their family member, friend, or neighbor was at least "somewhat stressful." Not surprisingly, primary caregivers expressed higher levels of stress than secondary caregivers (Figure 26). For example, 57 percent of primary caregivers found caregiving to be "somewhat stressful" compared to 38 percent of secondary caregivers. That said, 42 percent of caregivers overall said their role as a caregiver was "not at all stressful."

26. Stress level associated with providing care



With challenges come opportunities: The next section provides insight on how and in what ways caregivers can be better supported, and what resources and services interest them.

Informal support networks



Wilder Reseach developed a measure that looks at the strength of caregivers' informal support networks, i.e., how all the help they receive from family members and friends works together to provide support. We found:

- About one-third (32%) of caregivers had a low score on our network scale, indicating low levels of informal support.
- By contrast, 25 percent had the highest scores, suggesting their informal support networks had considerable strength.

We found caregivers with strong informal support networks in our sample:

- Had better self-reported health
- Less frequently described their role as "very stressful"

section 6

Informal support networks

Understanding how and in what ways informal support eases caregivers' distress or negative experiences is a complex process with sometimes confounding results. As Miller et al. (2001) explains, "Some stressors may affect stress directly, whereas others have primarily indirect effects, depending on the mobilization of support and other resources" (p. 250). That said, several research studies suggest the importance and positive effects of informal support, for example:

- The availability of others to periodically take over caregiving tasks, or lack of support from family or friends, is associated with depression (Lin, 2012).
- Caregivers with less emotional support experience higher levels of distress (Miller et al., 2001).
- Support from friends or relatives was determined to be the most important factor in predicting positive caregiving experiences for daughter and wife caregivers (Lin, 2012).

In order to understand how the many aspects of informal support— specifically, instrumental support, resourcefulness, and emotional support—may have a collective impact on caregivers' distress or burden, or simply be another way in which to characterize and explore caregivers and their experience, a cumulative measure was developed.

Items used to assess network "strength"

An overall score (ranging from 0 to 14) was assigned to all primary caregivers caring for a family member, friend, or neighbor living in the community (N=117). Eight items were used to measure three domains of informal support, and are defined in the following sections.

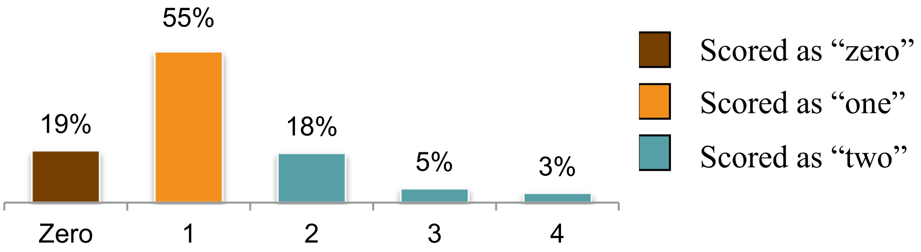
HELP WITH CAREGIVING TASKS (4 ITEMS)

These four variables are used to assess the help that caregivers receive in doing tasks:

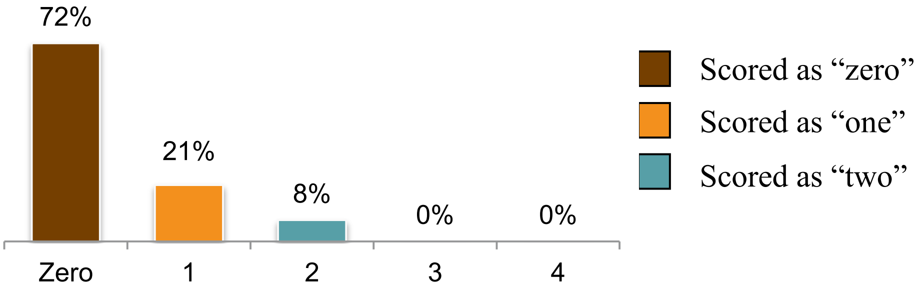
- The number of family members (of the caregiver, care recipient, or both) who currently assist the caregiver
- The number of non-family members (e.g., members of faith community, other friends or neighbors, or co-workers) who currently assist the caregiver
- The number of specific tasks caregivers have received help with in the past month
- Whether or not someone could take over in the long-term absence of the caregiver

27. Help with caregiving tasks (N=117)

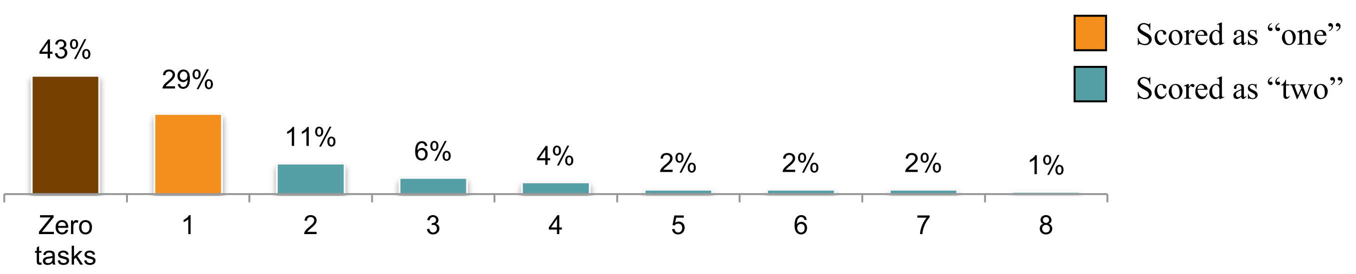
Number of family members helping caregivers



Number of non-family members helping caregivers



Number of specific tasks others helped with in past month



Access to long-term help with caregiving in the absence of caregiver

As seen in Figure 27, 81 percent of caregivers scored at least “one” in the area of family assistance— where informal support was strong. Over half (57%) scored at least a “one” by receiving help with a specific task in the past month. About half of all caregivers (53%) reported that they would have access to long-term assistance in their absence.

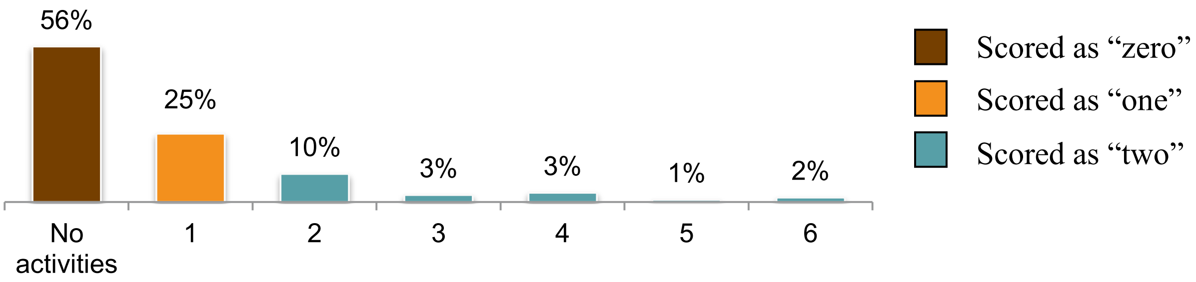
REACHING OUT FOR HELP (3 ITEMS)

These items were selected to describe networks of informal support in terms of how caregivers have reached out for help:

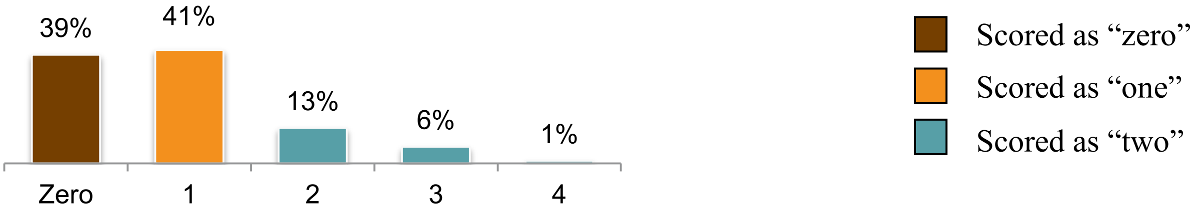
- The number of community activities respondents have used as a resource in support of their role as a caregiver
- The number of family members, friends, or others caregivers enlisted to support their caregiving
- The number of different sources of information about their role as a caregiver or resources for their care recipient

28. Strength of informal support network: Reaching out for help

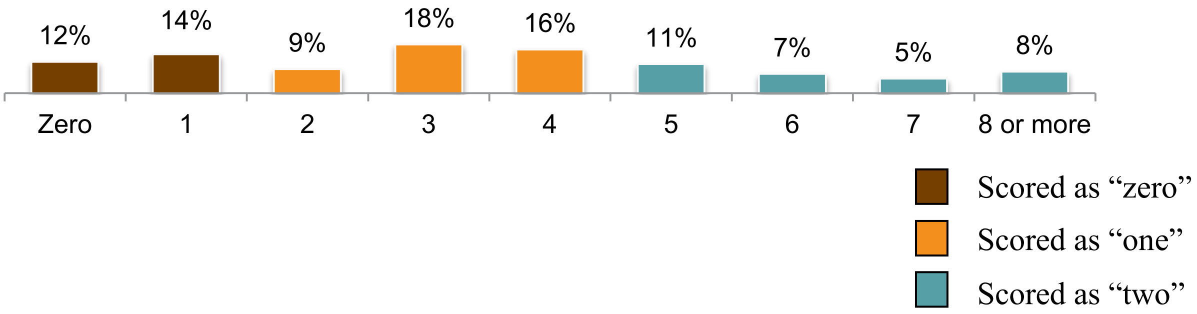
Number of community activities used as resources in caregiving (N=117)



Number of people caregivers enlisted to help with caregiving (N=117)



Number of sources of information caregivers sought or received by caregivers (N=117)

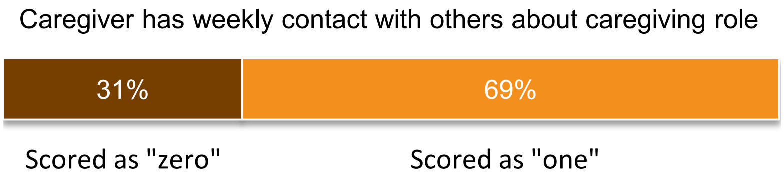


Overall, caregivers were particularly adept at seeking or receiving information in support of their caregiving role from a variety of sources, and enlisting the help of others (Figure 28). Of the three measures, leveraging their community activities as resources was less frequent.

EMOTIONAL SUPPORT (1 ITEM)

Caregivers who reported that they have someone to talk with about their caregiving role on, at least, a weekly basis (face-to-face, over the phone, or via email) received a score of "1" on this measure of emotional support.

29. Strength of informal support network: Emotional support (N=117)



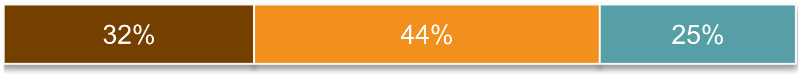
The majority of caregivers (69%) were in frequent contact with close friends or family members (Figure 29).

OVERALL STRENGTH OF INFORMAL SUPPORT NETWORKS

Figure 30 shows categories of the summed scores across the eight measures described.

Overall, strength of informal support networks varied across primary caregivers. A quarter (25%) were considered well-supported on the "strong network" scale. Nearly half (44%) showed moderate strength of informal support networks, and one-third (32%) were characterized as having a weaker network of informal support.

30. Overall strength of informal support networks (N=117)



- 🟫 Lower score (0 to 4) indicates the caregiver has less informal support overall
- 🟧 Moderate score (5 to 7) indicates the caregiver has a range of informal supports in
- 🟦 Higher score (8 to 14) indicates the caregiver is well-supported and has a large network of informal resources

Relating informal support to caregiver distress

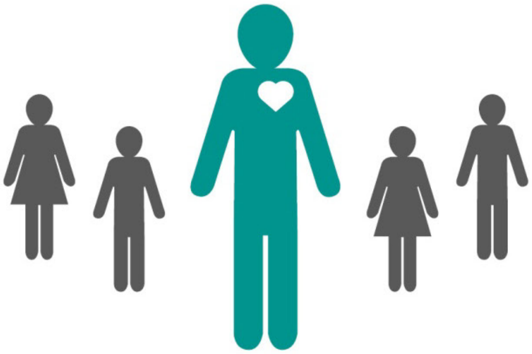
Analysis shows that the strength of a primary caregiver's informal support network is related to distress or burden in the following, statistically significant ($p < .05$), ways:

- Caregivers with less informal support, i.e., weaker networks of informal support, were more likely to rate their health as "fair" or "poor."
- Caregivers with less informal support were more likely to say their caregiving role is "somewhat" or "very" stressful compared to caregivers who had moderate or strong networks of informal support.
- Caregivers who said a health problem interfered with their daily activities, including caregiving, were also less likely to have moderate or strong systems of informal support.

No relationship was noted between feelings of depression or anxiety in the past six months and the strength of informal support systems.

These findings suggest what other research efforts have shown: Overall, caregivers lacking informal support are more likely to experience distress and burden (Pinquart & Sorensen 2011; Savundranayagam 2010).

Who assists caregivers?



Eighty-five percent of primary caregivers who were assisting someone living at home were supported by at least one other person. However, caregivers without such support were more likely to:

- Be a spouse of the care recipient
- Be older than other caregivers
- Help with more daily tasks
- Report their health status as “fair” or “poor”

Caregivers whose networks of support include family and friends were more likely to:

- Report better health status
- Use formal services
- Report fewer hours per week required for caregiving

section 7

Who Assists Caregivers?

As mentioned earlier in this report, the availability of others to assist caregivers in their responsibilities is a frequently used and important measure of caregivers' informal support (Pinquart & Sorensen, 2011). The presence of others to aid in caring for older adults has the potential to increase respite opportunities for primary caregivers, decrease daily demands by helping with concrete tasks, and overall lessen the negative experiences associated with caregiving (Miller et.al, 2001; Lin, 2012).

That said, however, prior studies have also acknowledged that having others involved in caregiving—which is largely beneficial for the reasons stated above—may also introduce new stressors, confounding the ability to measure how and in what ways this type of instrumental support mitigates caregivers' distress (Miller et.al, 2001).

Among primary caregivers caring for someone in the community, 85 percent said they received assistance from at least one other person. This compares favorably with a recent national study in which only 70 percent of caregivers reported unpaid help with caregiving responsibilities (National Alliance for Caregiving, 2009).

This section provides a detailed, side-by-side view of caregivers grouped by who they identified as assisting them in their role (see Figure 31 below). Their characteristics, time commitment and responsibilities, informal supports, and signs of distress are presented.

Group definitions

Primary caregivers providing home-based care (N=117) were grouped in the following ways:

- Family-based assistance includes caregivers with one or more family members providing help with their caregiving responsibilities, but who are without aid from friends, neighbors, or others outside their family. Fifteen percent, or 66 caregivers, are included in this category. In most cases, it is one other family member who is involved (N=50), but several caregivers (N=16) have two or more family members aiding them in their role.

- Extended support refers to caregivers who reported a combination of family and non-family members (such as a friend, neighbor, co-worker, or member of their faith community) providing assistance with their caregiving responsibilities at the time of the survey. The total number of others assisting caregivers ranged from two persons up to five. Twenty nine caregivers (25%) fell into this category.

- Solitary caregivers are those who indicated no one helps them in their role as a caregiver. This group included 18 caregivers (15%).
- Friend or neighbor assistance is a small but distinct group of caregivers who do not receive help from family members but do have friends or neighbors who help them in providing care. Only four caregivers (3%) are represented in this group.

Summary

FAMILY-BASED ASSISTANCE COMPARED TO EXTENDED SUPPORT

At first-glance, caregivers who are aided solely by other family members look similar to caregivers with extended support: They are primarily adult children, of similar age, and a significant portion of both have additional caregiving roles such as caring for minor children, an adult child with a disability, or another care recipient. Although family-assisted caregivers were slightly younger (an average age of 56 years compared to 60 years, respectively), those with extended support were more often employed in full- or part-time positions.

Differences begin to emerge as specifics about their caregiving roles are identified. For example, caregivers with extended support (both family members and friends) have been in their role longer, yet spend fewer hours per week providing care, and are not as frequently depended on for a full array of daily tasks. This could be due, in part, to fewer caregivers with extended support sharing a home with their care recipient compared to caregivers assisted exclusively by family members. However, a larger proportion of caregivers with extended support used formal services to supplement their caregiving responsibilities and, by definition, have more help from family members and others. Combined, it seems caregivers with extended support have leveraged both formal services and informal supports to balance their caregiving role with other responsibilities.

Both family-assisted caregivers and those with extended support exhibit strength in sources of informal support. Family-assisted caregivers fared better in the areas of instrumental support, namely that others are available to take over their role if needed. Those with extended support showed greater resourcefulness and more emotional support—perhaps the result of more experience in their role.

Signs of distress, specifically in the area of mental health and stress, are markedly similar, despite the differences in their responsibilities and supports described above. Levels of stress and incidence of depression or anxiety are nearly equal. Worth noting, however, is that caregivers assisted only by other family members more often reported their health as “fair” or “poor” compared to those with extended support.

SOLITARY CAREGIVERS

Solitary caregivers were unlike those with family-based assistance or extended support. This group, which includes a higher proportion of spouses, is slightly older, more likely to be retired, and less likely to have additional caregiving responsibilities. They reported the most hours per week providing care, and often helped care recipients with most of their daily tasks. Half had used formal services in the past month to aid in their caregiving responsibilities.

Caregivers without the assistance of others did show some strength in specific areas of informal support, such as the availability of help in a crisis or emergency, emotional support, and exposure to a wide range of informational sources in support of their caregiving role. Resourcefulness, that is, leveraging community activities or reaching out to others for help was lacking for most caregivers in this group. This could be the effect of a caregiving role with high demands and long hours and, therefore, less opportunity to proactively seek additional informal support.

As one might expect, solitary caregivers reported higher levels of stress in their role as a caregiver. Moreover, they were also more likely to report their health as "fair" or "poor," and to describe a health problem that interfered with daily activities, including caregiving. Although solitary caregivers were no more likely to have experienced recent depression or anxiety than other groups, they sought professional help less frequently.

SUPPORT FROM OUTSIDE FAMILIES

The four caregivers who received help only from non-family members, that is, a friend or neighbor, seemed evenly divided between two individuals who were well-supported and showed less signs of distress, and two others who resembled solitary caregivers in that they had less informal support and more signs of distress.

31. Summary of primary caregivers providing home-based care grouped by others who assist them (N=117)

	Family-based assistance only (N=66)	**Extended (family & non-family) support** (N=29)	**Solitary caregivers** (N=15)	**Friend or neighbor assistance only** (N=4)
WHO ARE THESE CAREGIVERS?	All but one caregiver in this category is caring for a family member: ■ 60% are the adult child of care recipient ■ 27% are spouses or partners ■ 12% are other relatives ■ 1 friend (non-relative) Two-thirds (66%) are female, and their average age is 56 years old. Over half (52%) are currently employed, and 33 percent are retired or no longer in labor force. Ten are unemployed. Two out of five (40%) report other caregiving responsibilities such as caring for a minor child, disabled adult child, or another care recipient.	Nearly all (93%) are relative caregivers, including: ■ 66% are the adult child of care recipient ■ 17% are spouses or partners ■ 3 caregivers are other relatives ■ 2 caregivers are non-relatives—a friend and a neighbor Seventy percent are female, and their average age is 60 years old. Over two-thirds (69%) are currently employed, and 28 percent are retired or no longer in the labor force. One is unemployed. About a third (31%) report other caregiving responsibilities such as caring for a minor child, disabled adult child, or another care recipient.	Eighty-three percent of those providing care unaided are related to the care recipient: ■ 39% are the adult child of care recipient (more often a son) ■ 33% are the spouse or partner of the care recipient ■ 2 caregivers are other relatives ■ 2 friends and 1 neighbor Just over half (56%) are female, and their average age is 63 years old. Half (50%) are retired or no longer in the labor force, five are employed, and four are unemployed. Three caregivers (17%) report other caregiving responsibilities such as caring for a minor child, disabled adult child, or another care recipient.	A small but distinct group of caregivers: ■ 2 caregivers are the adult child of the care recipient ■ 2 are friends of the care recipient Three are female, and their average age is 57 years old. Two caregivers are employed, another was retired, and the other is unemployed. None of these caregivers reported other caregiving responsibilities.

31. Summary of primary caregivers providing home-based care grouped by others who assist them (N=117) (continued)

	Family-based assistance only (N=66)	**Extended (family & non-family) support** (N=29)	**Solitary caregivers** (N=15)	**Friend or neighbor assistance only** (N=4)
THEIR ROLE AS A CAREGIVER	Two-thirds (67%) have provided care for 5 years or less, and spend 41 hours per week in their caregiving role on average. Seventy-six percent share a home with the care recipient. Over one-third (36%) assist care recipients with <u>all</u> tasks listed in Figure 14. Just under half (46%) had used formal services in the past month. The services mentioned most frequently include: ■ Nursing care provided by home health aides (21%) ■ Home delivered meals (15%) ■ Personal care provided by home health aides (15%) ■ Transportation assistance (14%)	Over half (55%) have provided care for 6 years or more, and spend 36 hours per week in their caregiver role on average. Slightly less than half (46%) share a home with the care recipient. A quarter (25%) assists care recipients with <u>all</u> of the daily tasks listed in Figure 14. More than two-thirds (69%) had used formal services in the past month. The services mentioned most frequently include: ■ Nursing care provided by home health aides (31%) ■ Housekeeping help (24%) ■ Home delivered meals (21%) ■ Personal care provided by home health aides (21%) ■ Transportation assistance (21%)	The vast majority (72%) have provided care for 5 years or less, and spend 58 hours per week in their caregiving role on average. Seventy-two percent share a home with the care recipient. Half (50%) assist care recipients with <u>all</u> of the daily tasks listed in Figure 14. Half (50%) had used formal services in the past month. The services mentioned most frequently include: ■ Nursing care provided by home health aides (22%) ■ Transportation assistance (22%) ■ Personal care provided by home health aides (11%)	Three of the four caregivers have provided care 5 years or less, and spend 33 hours per week in their caregiving role on average. Two (50%) share a home with the care recipient. None of the caregivers help with <u>all</u> tasks listed in Figure 14. All four caregivers had used formal services in the past month. The services mentioned most frequently include: ■ Heavy chores and personal care provided by home health aides were mentioned by two caregivers (50%) ■ Other services used include help with shopping, transportation, housekeeping, and personal care provided by home health aides

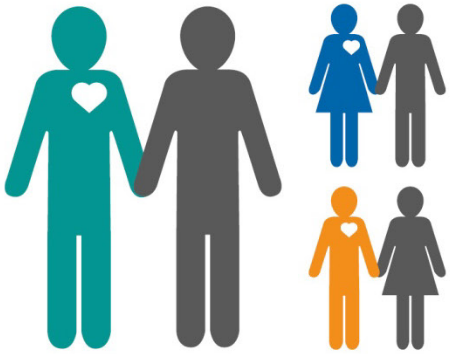
31. Summary of primary caregivers providing home-based care grouped by others who assist them (N=117) (continued)

	Family-based assistance only (N=66)	**Extended (family & non-family) support** (N=29)	**Solitary caregivers** (N=15)	**Friend or neighbor assistance only** (N=4)
INFORMAL SUPPORT	Instrumental support: ■ 91% said a family member or friend could help with caregiving responsibilities in a crisis or emergency ■ 56% have access to indefinite help with their caregiving responsibilities if they became sick or disabled Resourcefulness: ■ 44% used at least one community activity attended in the past three months as a resource in their role as a caregiver, including 20% who used two or more ■ 74% had reached out to at least one other family member, friend, or neighbor for help with caregiving ■ 64% of caregivers have sought or received information from at least two different sources Emotional support: 65% are in frequent contact with friends or family members about their caregiving role	Instrumental support: ■ All (100%) have access to immediate help with caregiving responsibilities in a crisis or emergency ■ 33% have access to indefinite help with their caregiving responsibilities if they became sick or disabled Resourcefulness: ■ 48% used at least one community activity attended in the past three months as a resource in their role as a caregiver, including 28% who used two or more ■ All (100%) had reached out to at least one other family member, friend, or neighbor for help with caregiving ■ 90% of caregivers have sought or received information from at least two different sources Emotional support: 83% are in frequent contact with friends or family members about their caregiving role	Instrumental support: ■ 72% have access to immediate help with caregiving responsibilities in a crisis or emergency ■ Only one caregiver reported access to indefinite help with their caregiving responsibilities if they became sick or disabled Resourcefulness: ■ 33% used at least one community activity attended in the past three months as a resource in their role as a caregiver, including 6% who used two or more ■ 39% had reached out to at least one other family member, friend, or neighbor for help with caregiving ■ 72% of caregivers have sought or received information from at least two different sources Emotional support: 67% are in frequent contact with friends or family members about their caregiving role	Instrumental support: 50% have access to immediate help with caregiving in a crisis or emergency or access to indefinite help if they became sick or disabled Resourcefulness: ■ Two caregivers had not used any community activities as a caregiving resource; the other two caregivers had used one ■ All four caregivers said they reached out to another family member, friend, or neighbor for help with caregiving ■ Two caregivers had sought or received very little information (one source at most) while the other two had used 5 or more Emotional support: Two caregivers (50%) are in frequent contact about their caregiving role

31. Summary of primary caregivers providing home-based care grouped by others who assist them (N=117) (continued)

	Family-based assistance only (N=66)	Extended (family & non-family) support (N=29)	Solitary caregivers (N=15)	Friend or neighbor assistance only (N=4)
SIGNS OF DISTRESS	Their top three biggest challenges include: ■ 14% said the time commitment (i.e., balancing demands of caregiving with own needs) ■ Another 14% said they had no challenges, or that caregiving felt natural and therefore did not pose challenges ■ 12% said the relationship with their care recipient (i.e., staying patient, role reversal, etc.) Physical health: A quarter (25%) described their health as "fair" or "poor," and 26% reported a health issue that interfered with daily activities, including caregiving. Mental health and stress: Over half (62%) said providing care was "somewhat" or "very" stressful. Half (N=32) experienced depression or anxiety in the past six months; of those, 11 sought professional help. About a third (31%) said they would like additional help with caregiving role.	Their top three biggest challenges include: ■ 17% said meeting the needs of their care recipient (i.e., monitoring care, medical needs, schedule, etc.) ■ Another 17% said the time commitment (i.e., balancing demands of caregiving with own needs) ■ Each of the following were cited by 14%: loss of their care recipient, issues with life balance, the overall burden of caregiving, and maintaining their mental health. Physical health: 10% described their health as "fair" or "poor," and 24% reported a health issue that interfered with daily activities. Mental health and stress: Over half (62%) said providing care was "somewhat" or "very" stressful. Almost half (N=14) experienced depression or anxiety in the past six months; of those, 6 sought professional help. Over a quarter (27%) said they would like additional help with caregiving role.	Their top three biggest challenges include: ■ 28% said communication with care recipients was difficult (due to their physical or mental capacity) ■ 22% said the overall burden of caregiving (i.e., strain, sacrifice, or high level of dependency of their care recipient) ■ Both loss of care recipient and (difficult) relationships with their care recipient were mentioned by 17% of caregivers Physical health: Over a quarter (28%) described their health as "fair" or "poor," and 39% reported a health issue that interfered with daily activities. Mental health and stress: Most (89%) said providing care was "somewhat" or "very" stressful. Almost half (N=9) experienced depression or anxiety in the past six months; of those, 3 sought professional help. Over a quarter (29%) said they would like additional help.	This small group of caregivers mentioned the following as biggest challenges: ■ No down time (i.e., caregiving constant, little flexibility, no vacation) ■ Relationship with their care recipient (i.e., staying patient, role reversal, etc.) ■ Dealing with difficult behaviors of care recipient (i.e., reluctant to make decisions, excessive demands, gaining cooperation, etc.) ■ Meeting the needs of their care recipient (i.e., monitoring care, medical needs, schedule, etc.) Physical health: One caregiver described their health as "very good," and the other three said it was "fair." Two had health problems that affected daily activities. Mental health and stress: Two caregivers said providing care was "somewhat" stressful, and the other two said it was "not at all stressful." Two caregivers experienced depression or anxiety in the past six months; neither sought help. One caregiver said they would like additional help.

Caregiving within relationships



Caregiving experiences vary, in part, based on who is providing care.

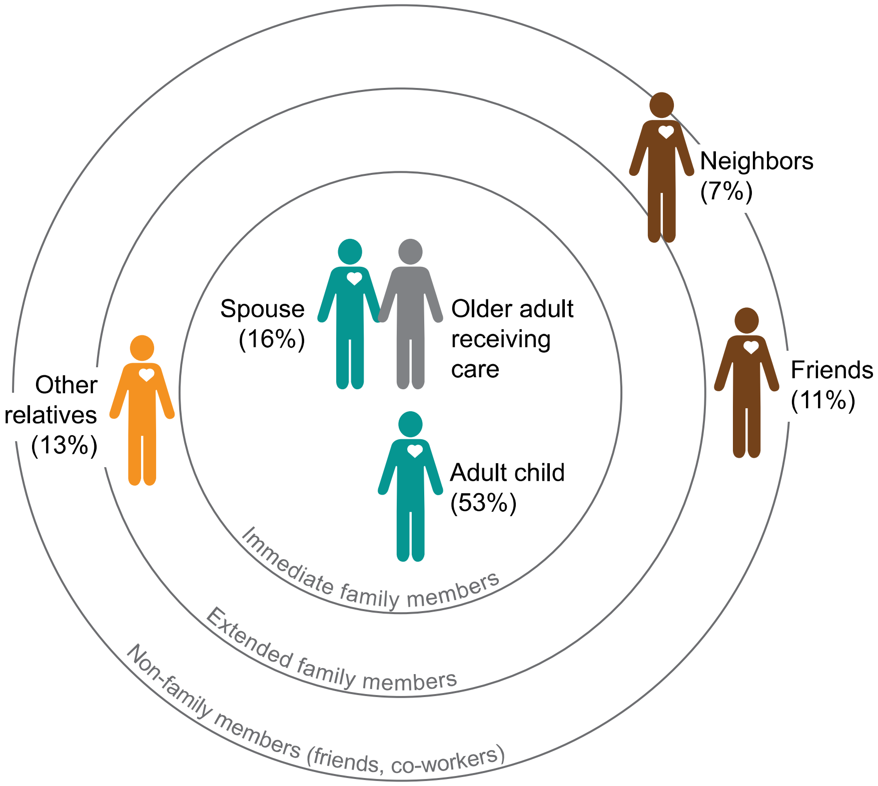
- Spouses were generally older, provided many hours of assistance, and were often stressed by both the burden of care and the threatened loss of their life partner.
- Daughters were generally younger, employed, and often felt that the expectation to become a caregiver fell solely on them.
- Sons were more likely than daughters to reside with the care recipient and provided help with a wider range of tasks, but were less likely to have support outside of the family.
- Friends and neighbors were more likely to be secondary caregivers and seldom lived with the care recipient. However, they provided significant levels of instrumental support.

Caregiving within relationships

This report has explored varied experiences of caregiving based on whether or not respondents served as a primary or secondary caregiver to an older adult, the extent to which caregivers are receiving help from others, and the strength of their networks of informal support. Another, and perhaps more fundamental, way in which to understand caregivers' experiences is within the context of their relationship to their care recipient.

- In the sections that follow we look at how each of these groups is both unique and similar by comparing characteristics, examining their networks of informal support and formal service use, and discussing what distress or burden they experience. Again, we chose to focus exclusively on primary caregivers providing care in home-based environments, thus excluding 24 primary caregivers from the analysis overall.
- The largest group of primary caregivers are the adult children of their care recipient (53%), followed by spouses/partners (16%), other relatives (13%), and lastly non-family members (18%) such as friends and neighbors (Figure 32).

32. Primary caregivers' relationship to older adults (N=117)



Spouses as Caregivers

Caring for a spouse or partner is the focus of many studies on caregiving. Usually first in line to provide care to their partner, spousal caregivers can be at-risk for the highest levels of caregiver distress or burden due to a number of factors (Pinquart & Sorensen, 2011), namely:

- Generally older adults themselves, spousal caregivers are more likely to have physical limitations or chronic health conditions that can impede their ability to provide care, which may, in turn, increase perceptions of distress or burden.
- Home-based caregiving means spouses provide many hours of care and assist their partner with more daily tasks than other caregivers.
- Spouses are considered to be the most important attachment figure for adults, and the impending loss of their partner is significantly stressful.

As mentioned earlier, not only is caregiving unique to the relationship between caregivers and care recipients, it is also affected by gender. For example, one study found reciprocal help (i.e., care recipients are able to pitch in to some extent), having others provide assistance with caregiving responsibilities, and lower levels of family conflict were more helpful for wife caregivers' than husbands (Lin, 2012). Thus, distinctions between husband and wife caregivers are made as needed.

Characteristics

Although spouses and partners represent only 16 percent of all caregivers in our sample overall, they are almost always (97%) the primary caregiver to their spouse or partner. Of the 33 caregivers identified as spouses, three were providing care to a partner living in a long-term care facility such as an assisted living center or nursing home. These three caregivers are excluded from the results presented here.

Spouses were much older than other caregiver groups: Their average age was 71 compared to primary caregivers providing home-based care overall (58 years) as seen in Figure 33. Seventy-two percent of spousal caregivers were over age 65. Most spouses interviewed were female (72%), but eight males are also represented. About one in five (21%) spousal caregivers were persons of color, specifically African-American (N=6), Latino (N=2), and African native (N=1).

33. Gender, age, and race/ethnicity of spouses compared to all primary caregivers

	Spousal caregivers (N=29)	All primary caregivers (N=117)
Male	28%	34%
Female	72%	66%
Under 50 years old	7%	25%
50 to 59	14%	35%
60 to 64	7%	12%
65 to 74	31%	15%
75 or older	41%	14%
Average age	71 years	58 years
White	79%	74%
Persons of color	21%	26%

Note: Percentages may not equal 100% due to rounding.

Most spouse-caregivers (69%) were retired, and several indicated they are no longer in the labor force due to disability—this is double the proportion of primary caregivers overall (Figure 34).

Over a quarter (28%) of spouses reported their annual household income as under $25,000, a higher percentage than seen in the overall sample.

34. Employment status and household income of spouses compared to all primary caregivers

	Spousal caregivers (N=29)	All primary caregivers (N=117)
Employed full time	17%	31%
Employed part time	7%	21%
Retired or not in the labor force	69%	34%
Not working	7%	14%
Less than $25,000	28%	23%
$25,000 to under $50,000	28%	33%
$50,000 to under $100,000	24%	26%
$100,000 and over	0%	5%
No information	21%	12%

Note: Percentages may not equal 100% due to rounding.

Naturally, all spousal caregivers lived in the same home with the partner in their care; most (93%) also had other family members present in their home—such an adult child or other relative (Figure 35). The majority of spouses (79%), like most primary caregivers, live in a single family home. The average length of time at their current residence is 30 years (compared to 21 years for all primary caregivers), making this one of the least mobile groups of caregivers.

35. Living arrangements of spouses compared to all primary caregivers

	Spousal caregivers (N=29)	All primary caregivers (N=117)
Care recipient lives with caregiver (only)	7%	4%
Care recipient lives with caregiver and others	93%	62%
Care recipient lives alone	0%	23%
Care recipient lives with others (but not their caregiver)	0%	10%
Single family home	79%	77%
Other housing (i.e., apartment, condo, duplex, etc.)	21%	23%
Average time at current residence	30 years	21 years

Note: Percentages may not equal 100% due to rounding.

From spouse to caregiver

ASSUMING THE ROLE

Seventy-two percent of spousal caregivers said the expectation to be their partner's caregiver fell solely on them—which is not surprising considering caregiving is often seen as the natural role within a partnered relationship. A sense of responsibility to become a caregiver, described by 86 percent of spouses, may even lessen distress of taking on the role compared to adult children who are more often motivated by duty or obligation (Pinquart & Sorensen, 2011). The following comments provided by spouses illustrate this point further:

> *You marry for better and worse, and that is the card I got dealt. I would not want to see him in a home. I will keep him as long as I can.*
>
> *I think it is natural to begin to take care of him.*

> *I tried a nursing home for a while but she did not get the kind of care I wanted so I made up my mind to do it myself. I just wanted her to be comfortable ...just felt the only way I could be sure of this was to do it myself.*
>
> *There was very little decision. I am the husband and I'm going to help her.*

Five spousal caregivers also mentioned proximity to the care recipient (all share the same household), and four said becoming the caregiver prevented a nursing home placement.

TIME COMMITMENT, WHAT SPOUSES HELP WITH, AND THE USE OF FORMAL SERVICES

As other research has shown—and caregivers interviewed in this survey confirmed—, spouses spend many hours providing care and assist their partner with a wide array of tasks on a daily basis (Figure 36).

All spouses (100%) said they provide help with meals and transportation or rides. Other top responses include companionship and/or arranging for appointments and activities outside the home (97%), help with shopping and errands (97%), housework (93%), managing finances (86%), and paperwork such as insurance forms (86%).

36. Time and tasks involved in caregiving, spouses compared to other caregivers

	Spousal caregivers (N=29)	All primary caregivers (N=117)
In caregiving role for 5 years or less	76%	62%
In caregiving role for 6 years or more	24%	38%
1 to 4 daily tasks (of 10)	0%	7%
5 to 7 daily tasks	34%	26%
8 or more daily tasks	66%	67%
Average hours per week providing care	62 hours	42 hours

Note: Percentages may not equal 100% due to rounding.

Furthermore, spouses are not just providing care to their partner, 21 percent have additional caregiving responsibilities, such as caring for a minor child (N=1), an adult child with a disability (N=2), or another care recipient, i.e., a family member, friend, or neighbor (N=3).

Less than half (48%) of spouses had formal services in place to support their caregiving responsibilities. Nursing care provided by aides (N=8), transportation assistance (N=5), personal care provided by aides (N=2), and help with heavy chores (N=2) were the formal services used in the past month by spouses.

When asked where they would look for information about the kinds of assistance available to them as caregivers, or how to obtain services for their partner, 31 percent of spouses described medical sources (from doctors, nurses, and other health care providers or staff), followed by community-based organizations (21%), and county or state social services.

Informal support

Given the potential physical limitations and lack of formal service use, one might expect spousal caregivers to rely on informal support as much as possible. Though some measures of informal support were quite strong—such as other family members providing routine assistance or help with specific tasks and frequent contact with others about their caregiving role—other areas showed a lack of informal support.

INSTRUMENTAL SUPPORT

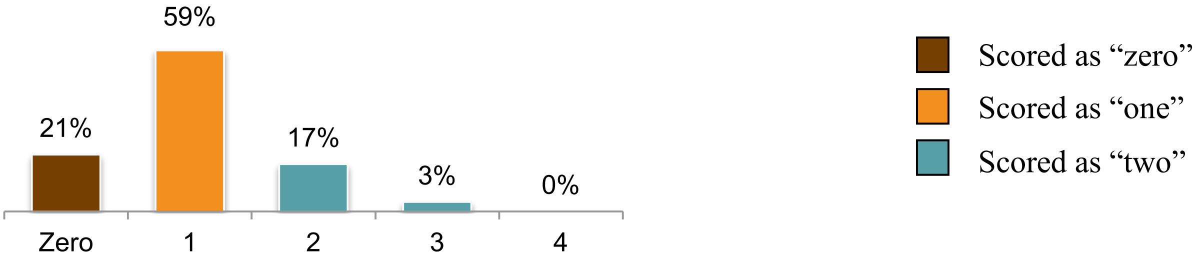
Spouses showed particular strength in the number of other family members assisting them; 79 percent had at least one other family member providing help with caring, including 20 percent who said two or more family members provided help (Figure 37).

Spouses were also well-supported when it came to recent help with specific tasks from others. Thirty-eight percent received help with one task, and 31 percent said others helped them with two or more tasks.

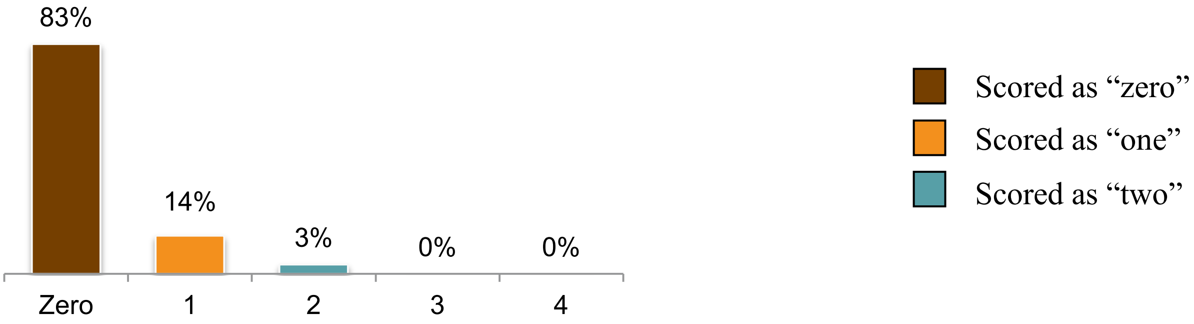
Spouses were less supported in the areas of long-term help in their absence (only 38% felt this would be available to them), and in assistance from non-family members such as friends or neighbors (17% received help from someone other than a family member).

37. Instrumental support of spouses (N=29)

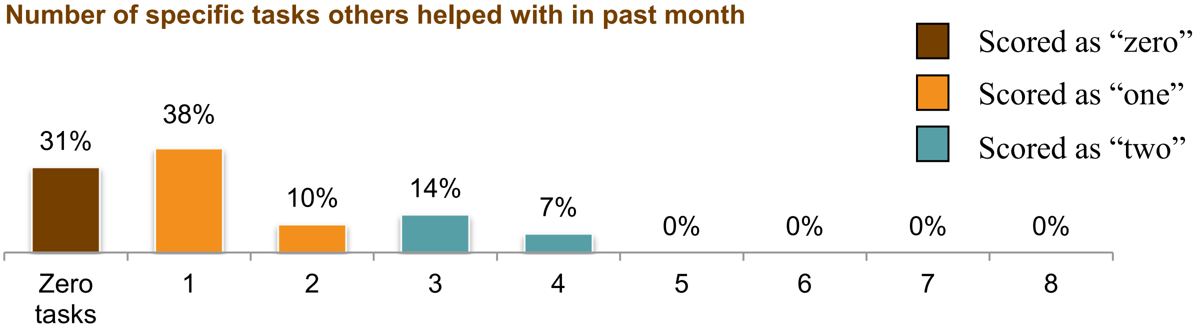
Number of family members helping spouses



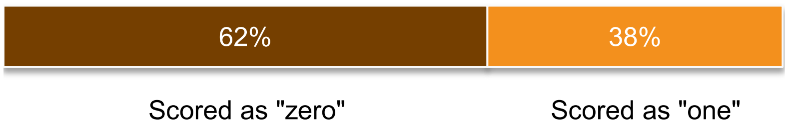
Number of non-family members helping spouses



Number of specific tasks others helped with in past month



Access to long-term help with caregiving in the absence of spouse

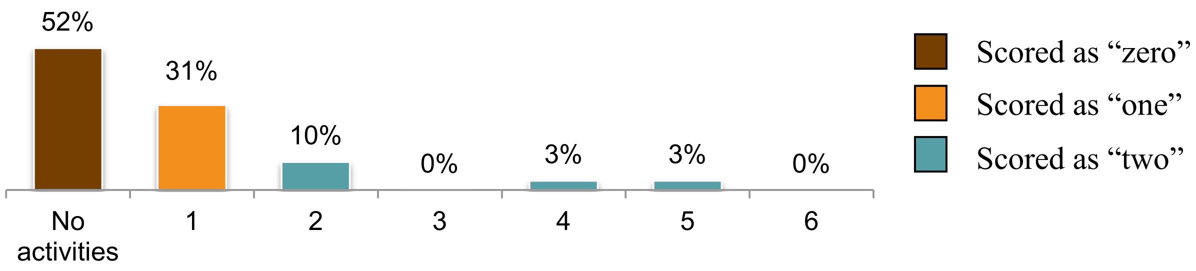


RESOURCEFULNESS

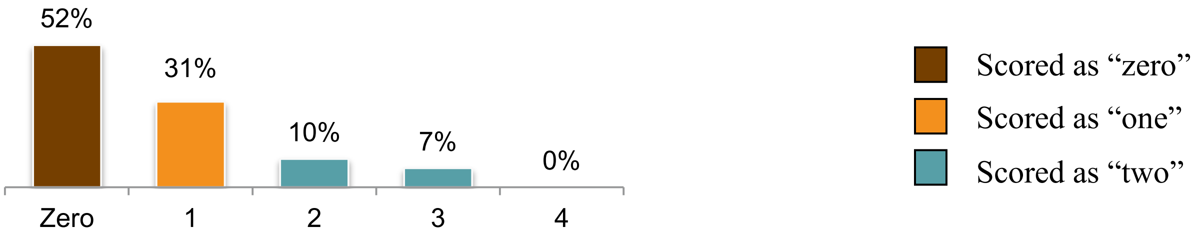
Seventy-eight percent of spouses had sought or received information related to caregiving assistance for themselves or their partner from two or more sources; and about a third (33%) specified five or more sources (Figure 38). Though seemingly well-versed in gathering information, spouses did not exhibit strengths in other areas of resourcefulness. When it came to leveraging existing relationships or community activities, less than half (48%) of spousal caregivers had been successful in receiving help from others or had used a community activity as a resource in the past 3 months.

38. Resourcefulness of spouses (N=29)

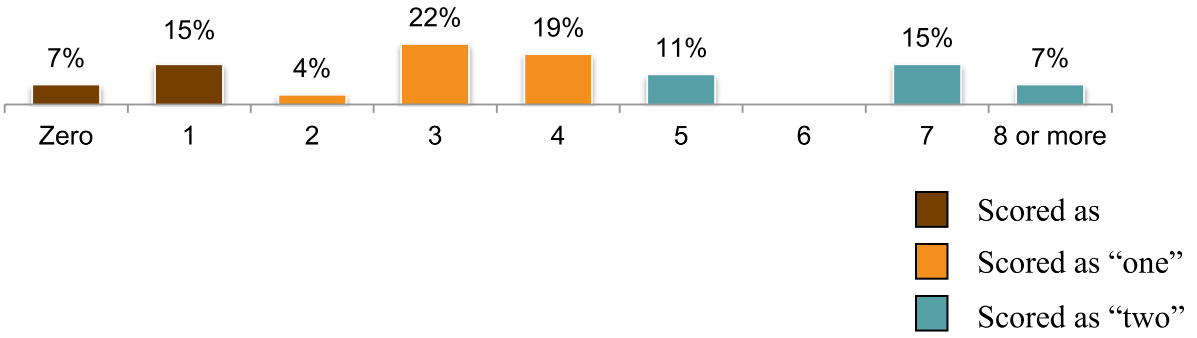
Number of community activities used as resources in caregiving



Number of people spouses enlisted to help with caregiving



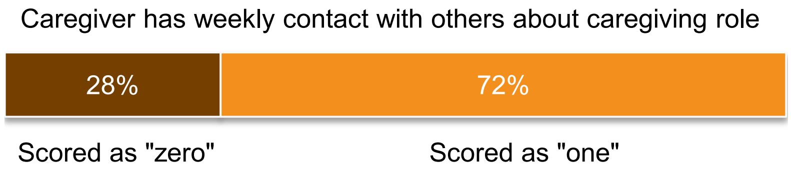
Number of sources spouses sought or received by caregivers



EMOTIONAL SUPPORT

Seventy-two percent of spouses were in frequent contact with a close friend or family member about their role as a caregiver (Figure 39). Frequent contact was defined as weekly visits or phone calls and/or monthly email exchanges with close friends or family members about their role as a caregiver.

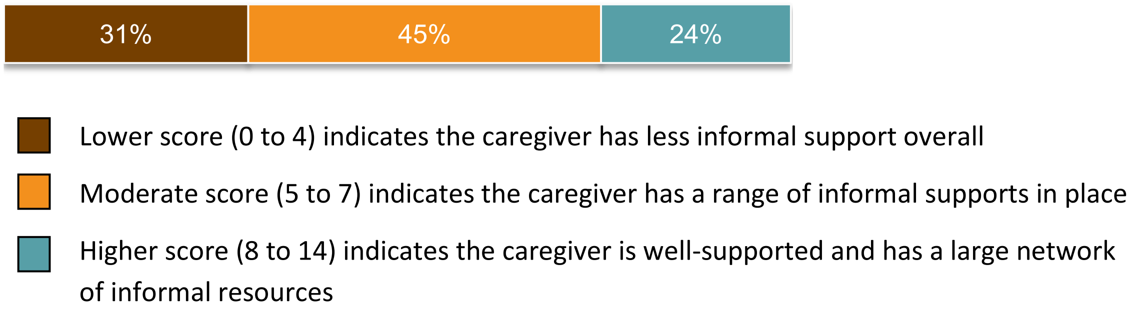
39. Emotional support of spouses (N=29)



NETWORKS OF SUPPORT

When looking at instrumental support, resourcefulness, and emotional support of spouses as a whole, the majority (69%) show either "strong" or "moderate" strength in their informal support networks—which closely aligns with primary caregivers overall (Figure 40).

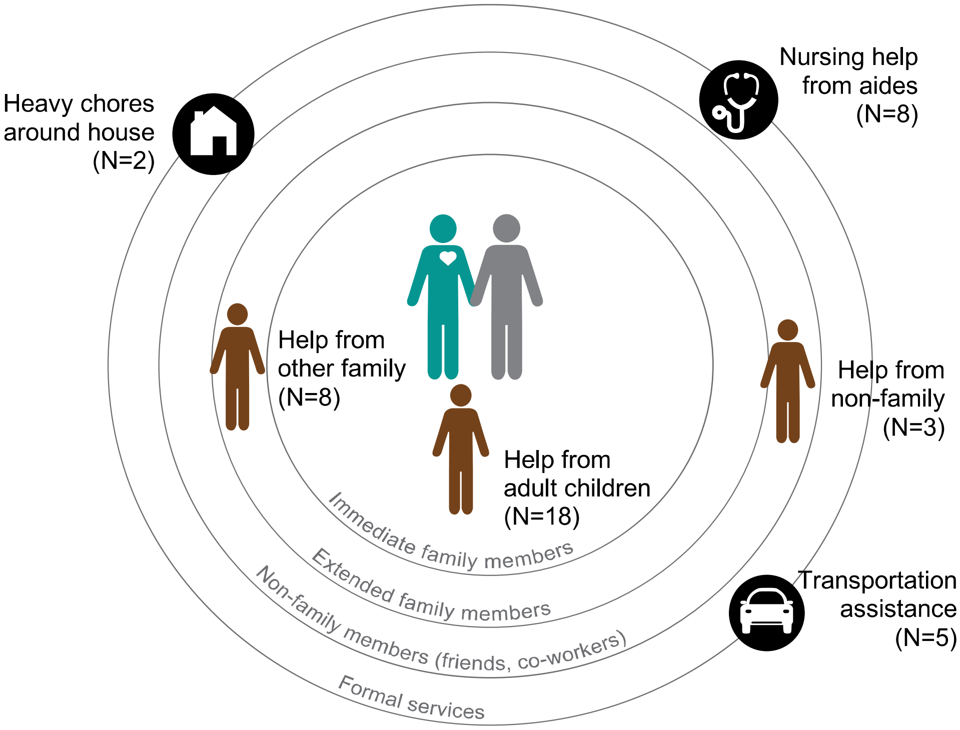
40. Strength of informal support networks for spousal caregivers (N=29)



That said, however, it seems wives receive stronger informal support than husbands. Over a quarter (29%) of wives were characterized as having a "strong" network of informal support compared to 13 percent of husbands. Given the small number of husbands in our sample, this finding—though supported by research on spousal caregivers—should be interpreted with caution.

It's important to point out that sometimes those lacking informal support may be relying on formal services to supplement their caregiving responsibilities. In fact, 44 percent of the spouses characterized as having a "weak" network of support had used a formal service in the past month (this is a higher proportion than those with "moderate" or "strong" networks). An overall picture of informal support (specifically instrumental support) and formal services of spouses is depicted below (Figure 41).

41. Sources of formal and informal support of spousal caregivers (N=29)



Distress experienced by spouses

Two-thirds (66%) report feeling anxious or depressed during the past six months and over half (55%) report that their work as a caregiver "always or sometimes" prevents them from engaging in activities in their community. In fact, more than one third (37%) say they have stopped engaging in one or more volunteer activities as a result of their caregiving role.

That said, 79 percent of spousal caregivers reported their health as "excellent," "very good," or "good," though nine spouses reported health issues that interfere with daily activities.

Daughters as Caregivers

Daughters are a frequently studied and discussed group of caregivers, perhaps because they represent the majority of caregivers to older adults. Our study is no exception, as just over one-third (34%) of all the caregivers interviewed for the survey identified themselves as daughters caring for an aging parent.

Characteristics

Almost three-quarters (72%) of daughters served as primary caregivers, and 28 percent were identified as secondary caregivers. Ten daughters (specifically primary caregivers) said their parent was living in an assisted living center, group home, or nursing home and were therefore excluded from this profile.

Daughters were younger than other caregivers interviewed as seen in Figure 42. Seventy-one percent of daughters were under age 60 (compared to 60% of all primary caregivers) and their average age was 55 years (versus 58 years).

Eighty percent of daughters describe their race or ethnicity as white or Caucasian, and women of color (21%) included African-American (N=6) caregivers and Latinas (N=2).

42. Age and race/ethnicity of daughters compared to other caregivers

	Daughter caregivers (N=42)	All primary caregivers (N=117)
Under 50 years old	26%	25%
50 to 59	45%	35%
60 to 64	12%	12%
65 to 74	17%	15%
75 or older	0%	14%
Average age	55 years	58 years
White	80%	74%
Persons of color	21%	26%

Note: Percentages may not equal 100% due to rounding.

Just over two-thirds of daughter caregivers (69%) were employed full or part time which, by comparison to all home-based primary caregivers interviewed, was more frequent (Figure 43). Fewer daughters, likely due to their younger age, were retired. Nearly two in ten daughters (17%) reported their annual household income as less than $25,000 per year, and a considerable proportion (14%) reported high household incomes ($100,000 or more).

43. Employment status and household income of daughters compared to all primary caregivers

	Daughter caregivers (N=42)	All primary caregivers (N=117)
Employed full time	38%	31%
Employed part time	31%	21%
Retired or not in the labor force	24%	34%
Not working	7%	14%
Less than $25,000	17%	23%
$25,000 to under $50,000	36%	33%
$50,000 to under $100,000	24%	26%
$100,000 and over	14%	5%
No information	10%	12%

Note: Percentages may not equal 100% due to rounding.

Figure 44 shows just under half (48%) of daughters shared a home with the parent in their care, which has implications for the amount of time they spend and number of daily tasks they perform. About one-third (31%) provided care to parents who live alone in the community. One in five (21%) daughters were taking care of a parent who lived with others. Daughters had lived at their current residence, on average, for 20 years at the time of the survey, on par with primary caregivers overall.

44. Living arrangements of daughters compared to other caregivers

	Daughter caregivers (N=42)	All primary caregivers (N=117)
Care recipient lives with caregiver (only)	5%	4%
Care recipient lives with caregiver and others	43%	62%
Care recipient lives alone	31%	23%
Care recipient lives with others (but not their caregiver)	21%	10%
Single family home	83%	77%
Other housing (i.e., apartment, condo, duplex, etc.)	17%	23%
Average time at current residence	20 years	21 years

Note: Percentages may not equal 100% due to rounding.

From daughter to caregiver

ASSUMING THE ROLE

The majority of daughters (64%) said they felt the expectation of becoming a caregiver to their parent fell solely on them. When asked to describe the process of how they assumed the role in more detail, two factors were commonly mentioned:

- Over half (55%) of daughters said their proximity to their parent in need of care played a role in becoming a caregiver.

  I am the only daughter in the family, I'm a nurse, and I'm the closest.

  My sister lives in Florida, so it had to be me.

- About one-third (31%) of daughters expressed a sense of responsibility or duty in assuming their role as caregiver for their parent.

  It's automatic. You just do it—[they're] your parents.

  I am that type of person and my sister is not.

Four caregivers specifically mentioned their position "as a daughter" played a role in them becoming a caregiver.

TIME COMMITMENT, WHAT DAUGHTERS HELP WITH, AND THE USE OF FORMAL SERVICES

Sixty-two percent of daughters had been caregivers for five years or less at the time of the survey and, on average, spent 31 hours per week providing care to their parent (Figure 45). As noted above, 48 percent of daughters live with the parent they care for and, therefore, help with many daily tasks (55% routinely provide 8 of the 10 tasks listed in Figure 14 of this report).

45. Length of time as caregiver, help with tasks, and hours per week providing care

	Daughter caregivers (N=42)	All primary caregivers (N=117)
In caregiving role for 5 years or less	62%	62%
In caregiving role for 6 years or more	38%	38%
1 to 4 daily tasks (of 10)	14%	7%
5 to 7 daily tasks	31%	26%
8 or more daily tasks	55%	67%
Average hours per week providing care	31 hours	42 hours

Note: Percentages may not equal 100% due to rounding.

The caregiving tasks most frequently provided by daughters include companionship (89%); help with transportation (89%); help with shopping (85%); help with light housework (76%); and help with correspondence, paper work, or insurance (74%). Other common caregiver activities performed in this group include help with nursing care (51%) and help with personal care (43%).

Forty-three percent of daughters reported additional caregiving responsibilities, including caring for a child under 18, an adult child with a disability, or another care recipient, i.e., another family member, friend, or neighbor.

Nearly six in ten (57%) daughters had used a formal service in the past month to aid them in their caregiving responsibilities. The services mentioned most often included help with housekeeping (19%), home delivered meals (17%), nursing care provided by a home health aide (17%), and assistance with transportation (14%).

When asked where they would look for information about assistance available for themselves as a caregiver, or for services available for their care recipient, daughters most frequently mentioned using the Internet and websites (31%); followed by medical resources, such as doctors, nurses, and other health providers (24%); community-based organizations (17%); and county or state social services (12%).

Informal support

Overall daughters' informal support networks showed strength in involving other family members in caregiving responsibilities (instrumental support), connecting with others about their role as a caregiver (emotional support), and in the number of successful outreach efforts and sources of information used in support of their caregiving (resourcefulness).

INSTRUMENTAL SUPPORT

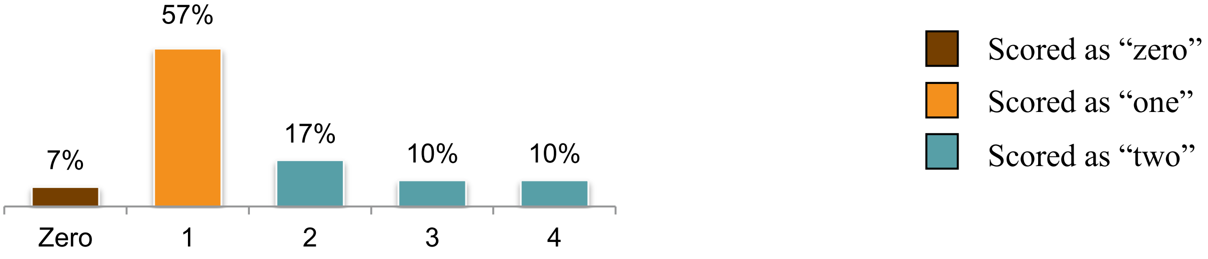
Daughters appear to have relatively high levels of instrumental support. For example, almost all (91%) said they have friends or family they could call to provide care to their parent in a crisis or emergency. Sixty-two percent said if they became sick or disabled a family member or friend could take over the caring for their parent for a month or two in their absence (Figure 46).

In addition, daughters have assistance with their caregiving responsibilities: 93 percent of daughter caregivers have at least one family member currently helping them, including 36 percent who have two or more family members involved. Furthermore, one-third (33%) have at least one non-family member, i.e. a friend, neighbor, co-worker, or a member of their family community, who helps them provide care to their parent.

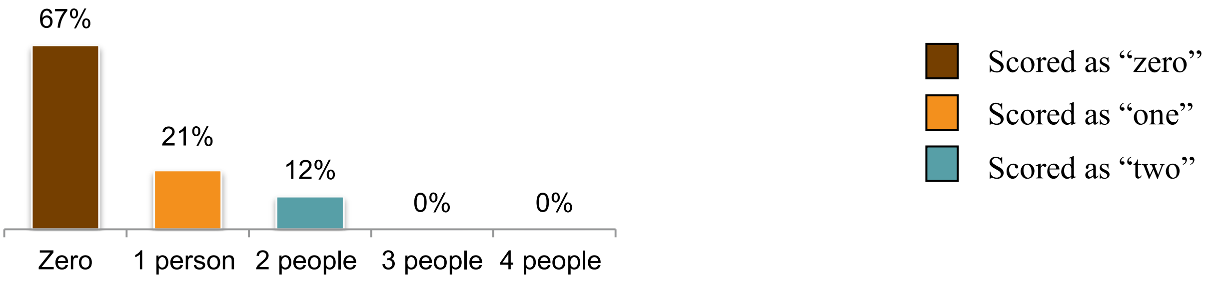
Nearly six in ten (57%) daughters said a family member, friend, or neighbor helped them with a specific task related to their caregiving responsibilities in the past month, and about a quarter identified two or more tasks others had helped with recently.

46. Instrumental support of daughters (N=42)

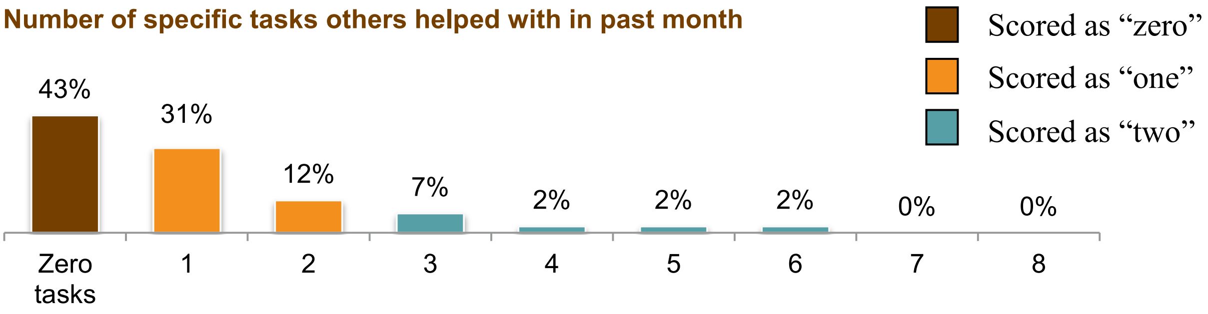
Number of family members helping daughters



Number of non-family members helping daughters



Number of specific tasks others helped with in past month



Access to long-term help with caregiving in the absence of daughter

RESOURCEFULNESS

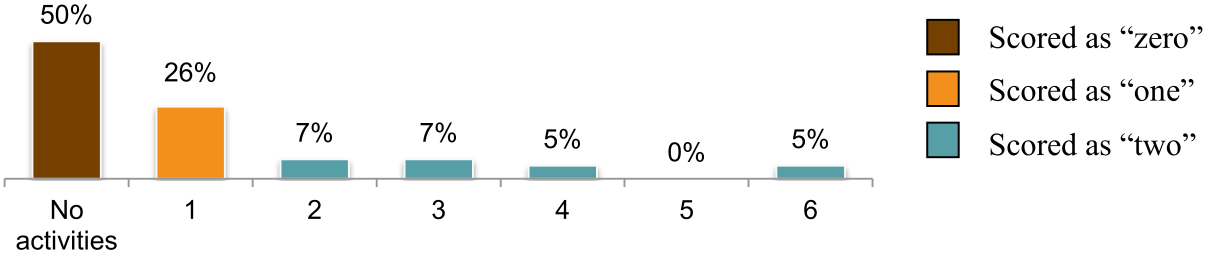
Half (50%) of daughter caregivers have used at least one community activity as a resource in their caregiving (Figure 47), including 10 daughters (24%) who said they've attended more than one event. Top activities used as caregiving resources were religious services (N=14); public libraries (N=10); community events such as block parties, school or library events (N=6); and/or community social groups (N=6).

Daughter caregivers were also very adept at reaching out for help and engaging others in caregiving responsibilities: 72 percent reported at least one successful outreach effort.

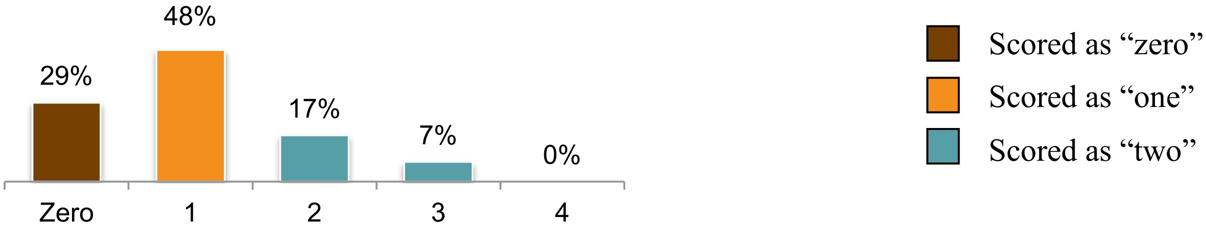
Lastly, over a third (36%) of daughter caregivers have sought or received information about their caregiving role or about services for the parent in their care from a wide range of sources (more than 5) since they've been a caregiver.

47. Resourcefulness of daughters (N=42)

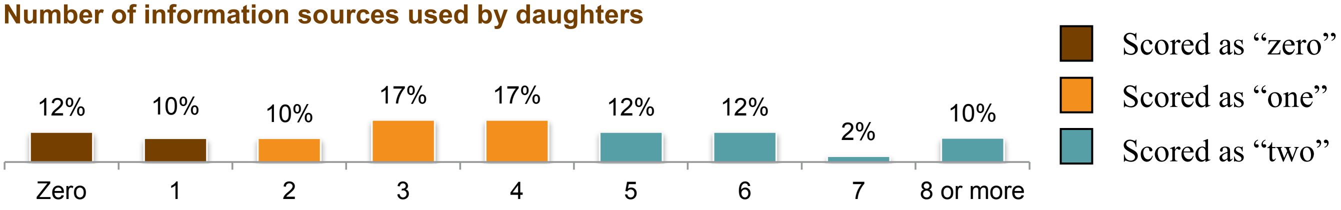
Number of community activities used as resources in caregiving



Number of people daughters enlisted to help with caregiving



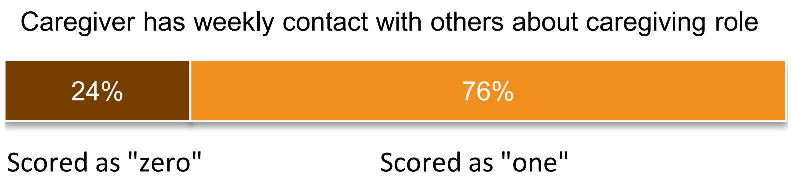
Number of information sources used by daughters



EMOTIONAL SUPPORT

As seen in Figure 48, daughters are in frequent contact with friends or family members, a key area in terms of social support. Seventy-six percent said they have weekly contact via phone or personal visits, or at least a monthly email exchange in support of their caregiving role.

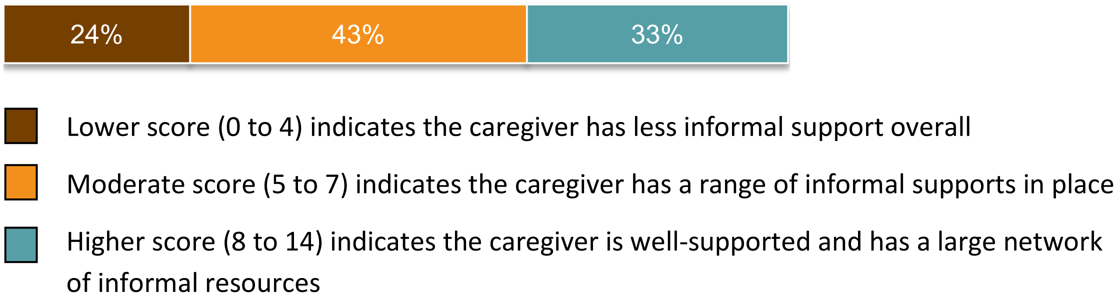
48. Emotional support of daughters (N=42)



NETWORKS OF SUPPORT

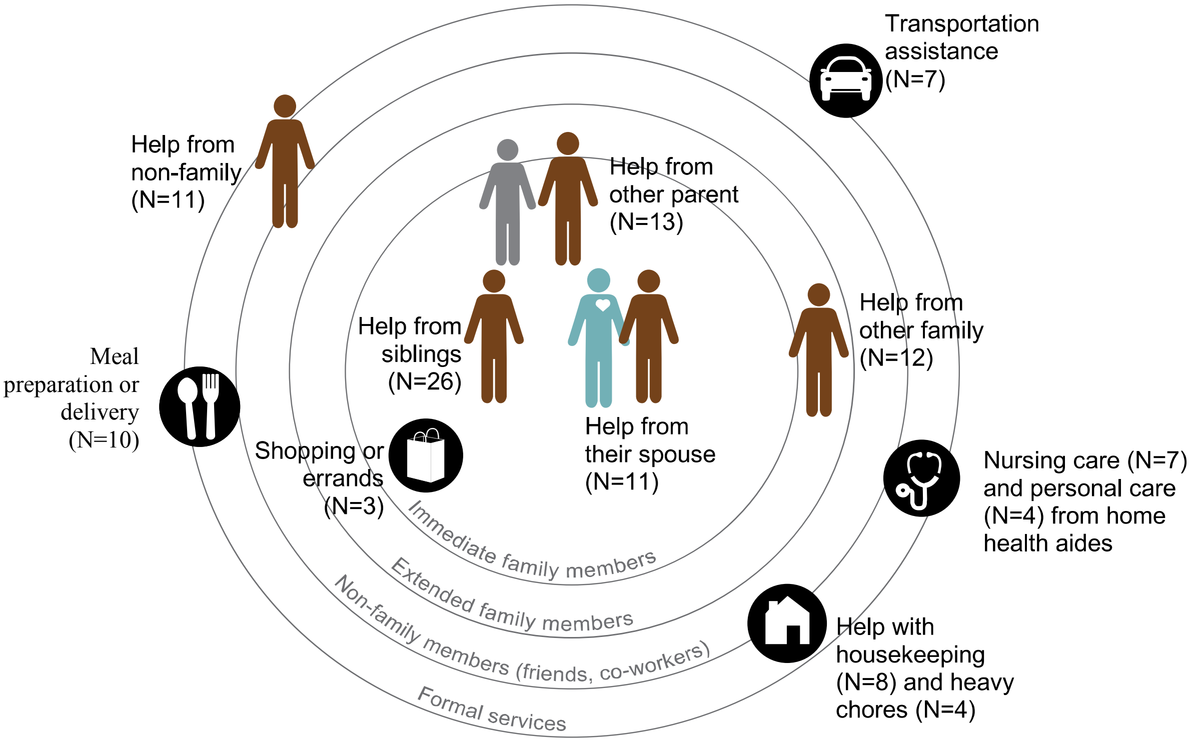
Daughter caregivers showed strong networks of informal support. Overall, 76 percent of daughters were characterized as having "moderate" or "strong" networks of informal support, a greater proportion than primary caregivers overall (69%). Just under a quarter (24%) had "weak" networks, which also compared favorably against caregivers as a whole (Figure 49).

49. Strength of informal support networks for daughters (N=42)



The use of formal services to supplement informal support and aid in caregiving responsibilities was evenly distributed across daughters with "strong," "moderate," and "weak" networks of informal support, perhaps suggesting that motives to use formal services are not based in the absence of informal support. Research outside of this report indicates balancing caregiving with other responsibilities, such as parenting or work, or the level of dependency of care recipients are common stressors that may play a role in seeking other support (Lin, 2012; Miller et.al, 2001; Pinquart & Sorensen, 2011). Figure 50 presents an overview of who helps daughters, and the types of formal support they used recently to support their caregiving.

50. Sources of formal and informal support of daughter caregivers (N=42)



Distress experienced by daughters

Eighty-five percent of all daughter caregivers rated their overall health as "good," "very good," or "excellent." Yet nearly a quarter (21%) mentioned they have health problems that interfere with their daily activities or make it difficult to accomplish their caregiving responsibilities. Moreover, two-thirds (68%) indicated that their caregiving is "somewhat" or "very" stressful and one-half (48%) report that they had felt depressed or anxious at some time during the last six months. Of those who reported having anxiety or stress, just over one-third (35%) said they had sought professional help or counseling.

Sons as Caregivers

Sons and daughters are often grouped together and studied as simply ‘adult child caregivers.’ However, several studies that look at both gender and relationship differences have shown sons’ experiences providing care to aging parents are unique in their own right. Though sons can be at-risk for distress and strain because they’re not socialized to caregiving in the same way as their female counterparts (Lin, 2012), prior research has acknowledged the resilience of son caregivers; even if stressed, sons tend to have more positive caregiving experiences and enjoy more personal satisfaction from providing reciprocal caregiving to their frail parents (Pinquart & Sorenson, 2007). The sons interviewed in this study are described below.

Characteristics

Forty of the caregivers in our sample overall (19%) are sons of the care recipient. The majority of these respondents (75%) are primary caregivers and one-quarter are secondary caregivers. The vast majority of sons (83%) care for parents who live in the community rather than a nursing home or assisted living facility. The seven primary caregivers providing care to a parent in a long-term care facility were excluded from this profile.

The vast majority (84%) of son caregivers were under age 60, making them a considerably younger cohort when compared to primary caregivers overall (Figure 51). Sons, though mostly white (68%) were comprised of a slightly higher proportion of persons of color, including caregivers who identified themselves as African-American (N=5), Asian (N=2), Latino (N=1), and American Indian (N=1).

51. Age and race/ethnicity of sons compared to all primary caregivers

	Son caregivers (N=25)	All primary caregivers (N=117)
Under 50 years old	36%	25%
50 to 59	48%	35%
60 to 64	16%	12%
65 to 74	0%	15%
75 or older	0%	14%
Average age	52 years	58 years
White	68%	74%
Persons of color	32%	26%

Note: Percentages may not equal 100% due to rounding.

Unlike other groups, nearly half (40%) of these respondents were employed full time; an additional 12 percent were employed part time (Figure 52). Only five son caregivers said they were retired, proportionally far less than in the primary caregiver sample overall (20% versus 34%, respectively). The household income reported by sons aligned closely with our sample of primary caregivers overall.

52. Employment status and household income of sons compared to all primary caregivers

	Son caregivers (N=25)	All primary caregivers (N=117)
Employed full time	40%	31%
Employed part time	12%	21%
Retired or not in the labor force	20%	34%
Not working	28%	14%
Less than $25,000	24%	23%
$25,000 to under $50,000	32%	33%
$50,000 to under $100,000	32%	26%
$100,000 and over	0%	5%
No information	12%	12%

Note: Percentages may not equal 100% due to rounding.

Most sons (76%) live in a single-family home and with the parent they care for (72%), a much higher proportion than observed in daughter caregivers (Figure 53). Seven sons were providing care to a parent they did not live with, and four of those care recipients were living alone in the community. On average, sons had spent 16 years at their current residence, less than primary caregivers overall and, as presented earlier, both spouses and daughter caregivers, making sons the most mobile group of caregivers.

53. Living arrangements of sons compared to all primary caregivers

	Son caregivers (N=25)	All primary caregivers (N=117)
Care recipient lives with caregiver (only)	4%	4%
Care recipient lives with caregiver and others	68%	62%
Care recipient lives alone	16%	23%
Care recipient lives with others (but not their caregiver)	12%	10%
Single family home	76%	77%
Other housing (i.e., apartment, condo, duplex, etc.)	24%	23%
Average time at current residence	16 years	21 years

Note: Percentages may not equal 100% due to rounding.

From son to caregiver

ASSUMING THE ROLE

Among sons who provide care to their parents living in the community, just over half (52%) report that the expectation to serve as their parents' caregiver felt solely on them. Forty percent agreed that they played this role because of their proximity to the care recipient:

> *It wasn't consciously decided. My sisters live far away, and our families have unresolved conflicts so it just fell upon me. I had some cousins here who helped sometimes, but they moved away.*
>
> *I was the best fit. He moved into my home, I am the closest by location and a single son. Other siblings help out but I am the main caregiver.*

Nonetheless, 36 percent report that they felt that it was their responsibility to do so, as heard in the comments below:

> *I was here when he got sick - it was the natural thing for me to do.*
>
> *Being the oldest sibling, I felt it was my responsibility.*
>
> *Sometimes they try to carry something and when they get older they can't carry, not strong enough. Even walking they are tired. It is my responsibility to take care of my parents, my family.*

Only 12 percent report that they were the only person available to take them and 9 percent indicate that the decision was specifically intended to help prevent a nursing home placement. Only five of the sons said there was a planned process by which they became caregiver.

TIME COMMITMENT, WHAT SONS HELP WITH, AND THE USE OF FORMAL SERVICES

Over half (52%) of sons have been providing care to their parent for six years or longer, and spend an average of 36 hours per week providing care (Figure 54). Given that the majority of sons live with their aging parent, it's not surprising that they provide help with many daily tasks (84% assist with 8 or more tasks listed in Figure 14 of this report). Although the weekly time commitment is similar to that of daughter caregivers, it seems sons may provide more assistance in terms of tasks.

More specifically, son caregivers said they helped their parents with transportation or rides (92%), light housekeeping (92%), preparing meals (88%), nursing care (84%), heavy chores or cleaning (84%), and managing finances or helping with paperwork such as insurance forms (76%).

54. Length of time as caregiver, help with tasks, and hours per week providing care

	Son caregivers (N=25)	All primary caregivers (N=117)
In caregiving role for 5 years or less	48%	62%
In caregiving role for 6 years or more	52%	38%
1 to 4 daily tasks (of 10 possible)	0%	7%
5 to 7 daily tasks	16%	26%
8 or more daily tasks	84%	67%
Average hours per week providing care	36 hours	42 hours

Note: Percentages may not equal 100% due to rounding

Eight of the 25 sons profiled here reported additional caregiving responsibilities, including caring for their minor child (N=4) and providing care to another care recipient, i.e., a family member, friend, or neighbor (N=6).

Over half (56%) of sons reported use of a formal service in the past month to aid them in providing care to their parent. They most frequently mentioned personal care services (40%) and help with nursing care (36%) provided by home health aides, help with housekeeping (24%), and home delivered meals (16%). More so than other caregiving groups, sons utilized programs such as daytime respite (N=2), adult day health programs (N=2), and overnight respite (N=1) programs.

When asked where they would look for information about assistance available for themselves as a caregiver, or for services available for their care recipient, sons closely resembled daughters in saying they would use medical resources, such as doctors, nurses, and other health providers (36%); the Internet and websites (28%); county or state social services (16%); and community-based organizations (12%).

Informal support

Gathering information and reaching out to others for help (both measures of resourcefulness) and involving other family members in caregiving responsibilities (instrumental support) were the main strengths of sons' informal support networks.

INSTRUMENTAL SUPPORT

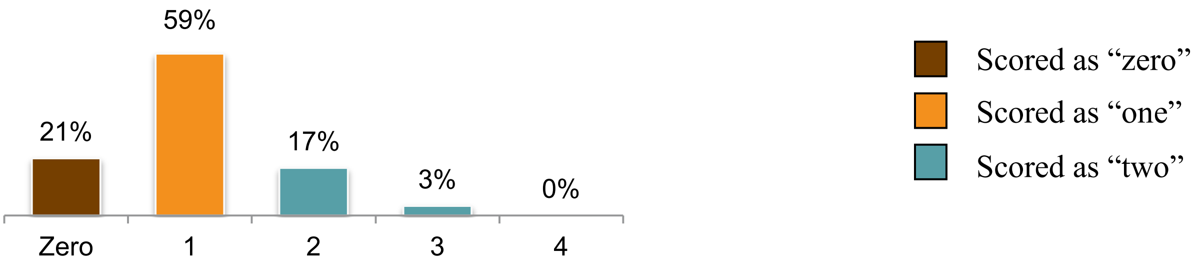
The vast majority of sons (84%) felt other family members or friends could provide care to their parent in a crisis or emergency, however, just over half (52%) said the same help could be available for a longer period of time (several months).

Even though sons felt longer-term assistance was limited, 79 percent said they had at least one other family member currently helping them with their caregiving responsibilities, including 20 percent who had at least two family members involved in care provision (Figure 55). Help from non-family members, i.e., friends, neighbors, coworkers, or members of their faith community, were not as involved: Just 17 percent, or seven sons, reported help from help outside their family.

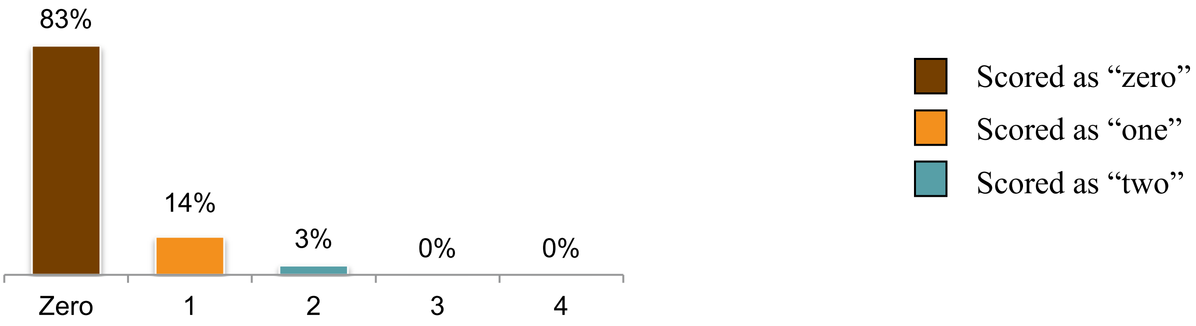
Despite the presence of other informal caregivers, namely family members, less than half (31%) of sons said they received help with at least two specific tasks related to their caregiving role, indicating the help they receive from others may not be as tangible as help with meals or shopping errands.

55. Instrumental support of sons (N=25)

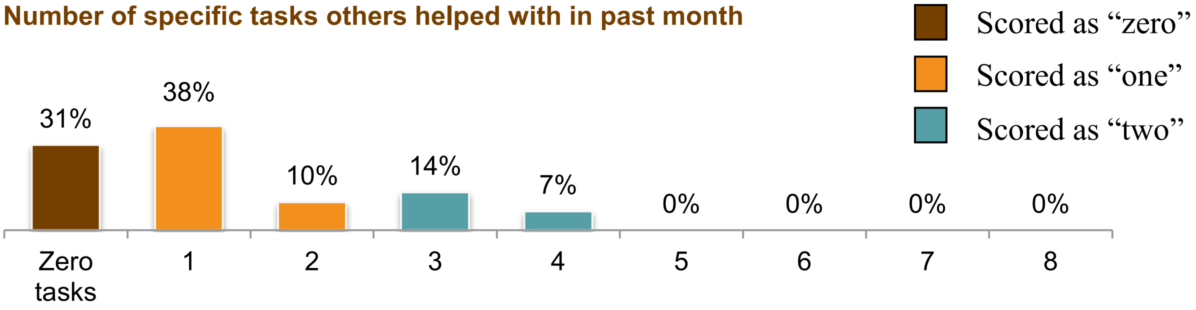
Number of family members helping sons



Number of non-family members helping caregivers



Number of specific tasks others helped with in past month



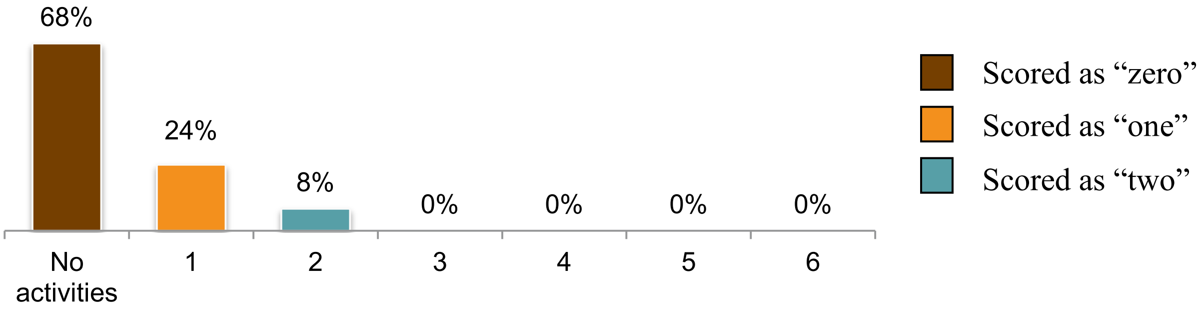
Access to long-term help with caregiving in the absence of son

RESOURCEFULNESS

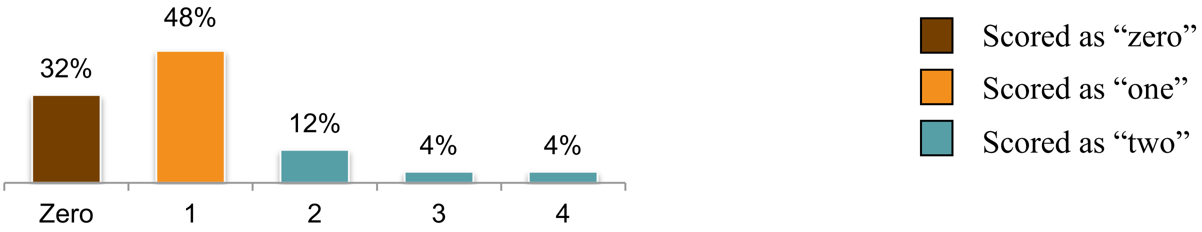
As mentioned earlier, sons were especially skilled in two of the three measures of resourcefulness used in this study: exposure to a wide range of information (26% identified 5 or more sources) and successfully reaching out to others for help (68% reported at least successful effort) as seen in Figure 56.

56. Resourcefulness of sons (N=25)

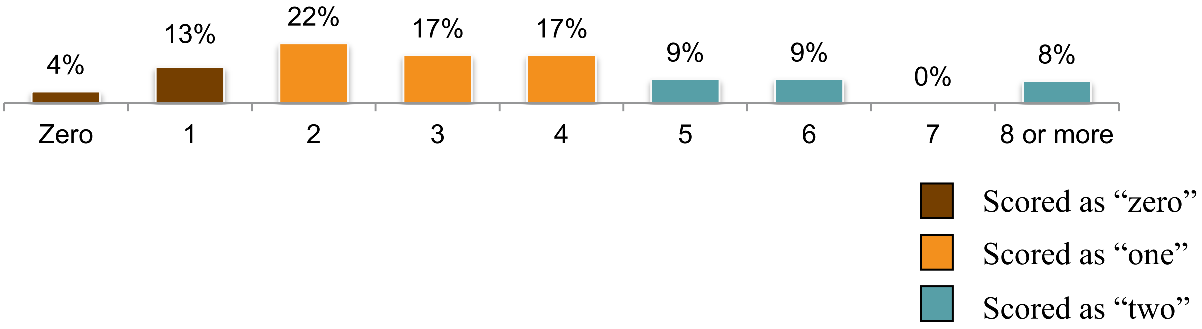
Number of community activities used as resources in caregiving



Number of people sons enlisted to help with caregiving



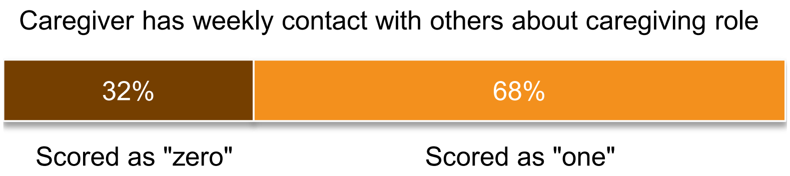
Number of information sources sons sought or received by caregivers



EMOTIONAL SUPPORT

Sons get support in a wide variety of ways, including weekly personal contact with friends or family members about their role as caregiver (33%), weekly telephone conversations about their caregiving role (46%), or email exchanges with others (12%). Taken as a whole, 68 percent of son caregivers were in frequent contact with others about their role as a caregiver, and therefore were considered to have strong emotional support (Figure 57).

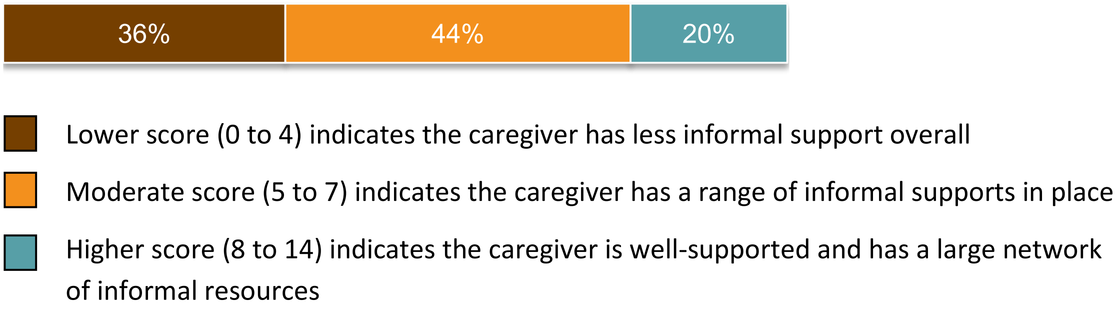
57. Emotional support of sons (N=25)



NETWORKS OF SUPPORT

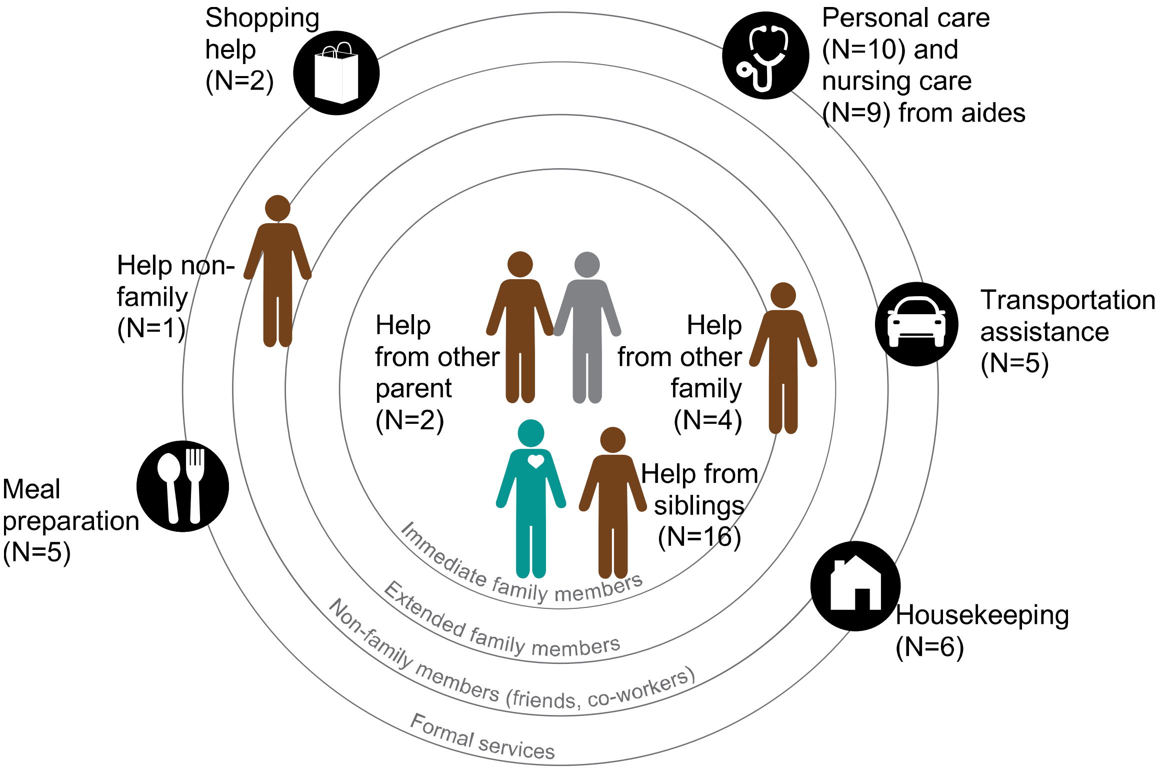
Son caregivers show slightly weaker informal support networks. As Figure 58 shows, 20 percent of son caregivers were characterized as having “strong” networks (compared with 25% of all primary caregivers) and a slightly higher proportion of decidedly “weak” informal support networks (36% versus 31%). Most sons, however, were best described as having “moderate” informal support in place overall, which mimics that of the larger sample of primary caregivers considered here.

58. Strength of informal support networks for son caregivers (N=25)



When both informal support networks and the use of formal services are viewed as a whole, it's clear sons do have a diverse range of resources in place to support their caregiving responsibilities (Figure 59).

59. Sources of formal and informal support of sons (N=25)



Distress experienced by sons

Seventy-nine percent of sons in our sample rate their overall health as "good," "very good," or "excellent." However, a full 36 percent report that they have health problems of their own that interfere with their daily activities or make it difficult to provide care to their parent. Moreover, nearly two-thirds (64%) report that serving as a caregiver is "very" or "somewhat" stressful and just over half (52%) report that they have felt depressed or anxious during the past six months. Twelve percent of these respondents have seen a professional counselor or psychologist to deal with stress and depression.

Non-Family Members as Caregivers

Thirty-eight respondents (or 18%) interviewed were not related to the older adult in their care; rather, they were a friend, a neighbor, another acquaintance, such as a member of the same faith community, or a volunteer. The prevalence of caregivers unrelated to their care recipient was slightly higher in our study than a recent national study of caregivers to older adults (MetLife Mature Market Institute and National Alliance for Caregiving, 2010) perhaps reflecting strong connections to community reported by our sample (discussed earlier in this report in “Respondent Characteristics”). This group, though small, is decidedly distinct from relative caregivers.

Characteristics

Friends, neighbors, and others interviewed in our study more often served as secondary caregivers to older adults. Of the 38 non-family members interviewed, 74 percent were secondary caregivers, and 26 percent said they were mainly responsible for their care recipient. Generally, the primary caregivers were friends of the care recipient (N=8), and were providing home-based care, with the exception of two respondents (who are subsequently excluded here).

This is a very small group (N=8) and comparisons to primary caregivers as a whole must be interpreted with caution given the sample size.

Non-family caregivers were similar in age and gender to primary caregivers overall (Figure 60). In both groups, the highest percentage of respondents was between age 50 and 59, and average age was fairly close. Three non-family caregivers were male, and five were female.

Most of the friend and neighbor caregivers were white (5 of 8) and the persons of color included two African-American respondents and one Latino.

60. Age and race/ethnicity of non-family caregivers compared to all primary caregivers

	Non-family caregivers (N=8)	All primary caregivers (N=117)
Male	38%	34%
Female	63%	66%
Under 50 years old	13%	25%
50 to 59	50%	35%
60 to 64	13%	12%
65 to 74	0%	15%
75 or older	25%	14%
Average age	62 years	58 years
White	63%	74%
Persons of color	37%	26%

Note: Percentages may not equal 100% due to rounding.

Five of the eight friend and neighbor caregivers were employed full or part time at the time of the survey (Figure 61).

61. Employment status and household income of non-family caregivers compared to all primary caregivers

	Non-family caregivers (N=8)	All primary caregivers (N=117)
Employed full time	25%	31%
Employed part time	38%	21%
Retired or not in the labor force	13%	34%
Not working	25%	14%
Less than $25,000	38%	23%
$25,000 to under $50,000	25%	33%
$50,000 to under $100,000	38%	26%
$100,000 and over	0%	5%
No information	0%	12%

Note: Percentages may not equal 100% due to rounding.

All but one friend or neighbor providing care lived apart from their care recipient (Figure 62), which is markedly different than the other caregiver groups discussed in this section. However, all of these seven caregivers said they lived within 20 minutes of their care recipient. Non-family caregivers had spent 15 years at their current residence, on average.

62. Living arrangements of non-family caregivers compared to all primary caregivers

	Non-family caregivers (N=8)	All primary caregivers (N=117)
Care recipient lives with caregiver (only)	0%	4%
Care recipient lives with caregiver and others	25%	62%
Care recipient lives alone	75%	23%
Care recipient lives with others (but not their caregiver)	0%	10%
Single family home	75%	77%
Other housing (i.e., apartment, condo, duplex, etc.)	25%	23%
Average time at current residence	15 years	21 years

From friend or neighbor to caregiver

ASSUMING THE ROLE

Friends and neighbors described a diverse range of circumstances that contributed to the process of becoming a caregiver to the older adult in their care:

> *[My friend] called me to take him to the hospital. They wouldn't let him go. He told me to make all the arrangements for his home and communication with his relative. He calls me his Block Nurse.*
>
> *When your friend is sick with cancer you take care of them. I just assumed...I thought that was the thing to do.*
>
> *He has been a neighbor since 1979 and in 2004 he had health issues and needed my help. I am the caretaker of his building. I went to see him in the hospital and have taken care of him since.*
>
> *I don't think it was decided. He had no help at all, so I just stepped up. You have an 80-something-year-old guy and he was just struggling and he had no one to help out. What I do for him I would want someone to do for my father if he needed it. He is an old war vet and has a lot of stories to tell.*
>
> *She just started to visit us and became part of the family. I have no other idea how I became her caregiver.*

> *We were friends for so many years, and his mother needed help at one time and he asked me to help her. I did...then I kept on with him. He worked nights and I used to go over and make sure the mother had food. When he got sick and after he retired he had a heart attack...it just happened.*

TIME COMMITMENT, WHAT FRIENDS AND NEIGHBORS HELP WITH, AND THE USE OF FORMAL SERVICES

Even though most non-family caregivers did not live with their care recipient, their time commitment and the number of daily tasks was consistent with primary caregivers overall, as shown in Figure 63.

All (100%) friend and neighbors said companionship and visiting was part of their caregiving. They also said they assist their care recipient with shopping help or errands (88%), transportation assistance (88%), managing finances (88%), preparing meals (75%), attending to their personal or nursing care needs (75%), and housekeeping (75%).

63. Length of time as caregiver, help with tasks, and hours per week providing care

	Non-family caregivers (N=8)	All primary caregivers (N=117)
In caregiving role for 5 years or less	63%	62%
In caregiving role for 6 years or more	38%	38%
1 to 4 daily tasks (of 10 possible)	13%	7%
5 to 7 daily tasks	25%	26%
8 or more daily tasks	50%	67%
Average hours per week providing care	37 hours	42 hours

Three non-family caregivers reported additional caregiving responsibilities. One was the parent of a minor child, and the other two had additional care recipients in their charge.

Five of the eight non-family caregivers said their care recipient had received assistance from a formal service in the past month. The most common service, mentioned by three caregivers, was nursing care provided by home health aides. None of the non-family members identified daytime or overnight respite services or an adult day health program.

Half (50%) of non-family caregivers said they would ask case managers or social workers of their care recipient for information about assistance available for themselves or about services available to their care recipient. Another two (25%) said they would turn to medical resources, such as doctors, nurses, or other health care providers.

Informal support

Half (50%) of friends and neighbors providing care to older adults living in the community were considered to have “moderate” networks of informal support, as defined by our scale, and the other half, “weak” networks. In so far as there were strengths within networks, they were in the following measures:

- Five caregivers said they received help with a specific task related to their caregiving from a family member, friend, or neighbor in the past month (instrumental support).
- Four of the eight non-family members had at least one other friend, neighbor, co-worker, or member of their faith community helping out with their caregiving responsibilities (instrumental support).
- Four non-family caregivers had used at least one community activity as a resource in support of their caregiving role in the past three months (resourcefulness).

Distress experienced by non-family caregivers

Despite having fewer sources of informal support than other caregiving groups, friend or neighbor caregivers were less likely to feel stressed by their role. None of the eight non-family caregivers found their caregiving responsibilities to be “very stressful” (though four said it was “somewhat" stressful). Five said their health was “excellent,” “good,” or “very good,” and the other three said their health was “fair.” Two reported feeling depressed or anxious within the past six months, and one sought professional help to address this issue.

Most (7 of the 8) said they get enough time off from their caregiving responsibilities to do other things, and only one non-family respondent said they’d like additional help in their role as a caregiver.

Strengthening informal support

Caregivers need support in many areas. This section shows that caregivers could use additional help with:

- Accessing information about services and financial assistance
- Coaching and problem solving related to caregiving challenges
- Understanding which services are of the highest quality
- Finding other caregivers to talk with and places to connect for support and education
- Respite care
- Help with basic needs like transportation, financial support, and care

section 9

Opportunities to strengthen support

In their own words

To learn more about specific needs for support, primary caregivers were asked to describe in their own words the kind of support service they would design to meet their needs as a caregiver.

"Support service" was defined for respondents as a service that would provide information about services and help them navigate their role as a caregiver. One hundred twenty primary caregivers responded with ideas about a support service; nineteen caregivers said they didn't know what they would design; and two declined to answer, saying they had no need or interest in formal support services of any kind.

Although caregivers' responses to this question varied widely and were unique to individual caregiving situations, many expressed definite ideas about what a support service should offer and several themes clearly emerged from their comments.

- Caregivers want a support service that has a broad range of information about all resources related to caregiving and is easy to access, whether by telephone or on the internet. Most indicated their wish to have a number to call; a few said they would like to be able to explore information through a website or Facebook page before initiating any other kind of contact.

- Caregivers would like to have the option to contact someone directly when they have specific questions, need advice, or just want to talk to someone about caring for their care recipient. Many expressed the desire for a "hot-line" that they could call when needed for tips and advice about everyday caregiving problems and issues. Some caregivers said they would like to be able to bring their questions and concerns to someone in person. A few suggested training sessions for caregivers to improve their skills. Several clearly stated that it is important to them that these aspects of a support service be provided by caring, engaged professionals – social workers or counselors with particular knowledge about the needs of older adults and the issues encountered in caring for those suffering from Alzheimer's or other cognitive impairments.

- Caregivers want access to comprehensive information about quality services and in some instances want help making arrangements for them. Several caregivers said that they would like the ability to request the support services and to make arrangements for various kinds of direct services on an "as-needed" basis. Some caregivers mentioned that it would be particularly helpful if these direct services were vetted by the support service. Services mentioned include:

- Day care activities for the care recipient
- Transportation assistance
- In-home services (housekeeping, home maintenance, home-delivered meals, nursing, physical therapy, and PCA services for assistance with personal care)
- Care coordination, including scheduling appointments and ensuring that all needed services were provided every day
- Respite care
- A daily check-up on care recipient

- Caregivers expressed a need for specialized or technical information related to their caregiving responsibilities. Many indicated that it was important to be able to talk with someone who was professional and trustworthy, and could provide information that was clear and easy to understand. Commonly mentioned were needs for information about:

- Medicare, Medicaid, and other government programs
- Financial or legal issues such as taxes, financial assistance, real estate transactions, investments, and long-term health insurance
- Medications and medical issues

- Some caregivers indicated that the best kind of support service for them would include the ability to spend time with other caregivers, in support groups or other informal settings, where they could share their stories, learn how others are handling their caregiving responsibilities, and have a little lighthearted conversation.

- Several caregivers described their ideal support service as a physical space or a center that provided information and services for both caregivers and care recipients. Some offered details about the services they would like to see offered in such a place. These included day-care programs; medical, dental, and physical therapy services; and access to indoor exercise facilities. Also mentioned were opportunities for caregivers to participate in caregiver education sessions, meet with caregiver staff, and socialize with other caregivers.

Valued support for caregivers in need

Forty-three percent of primary caregivers said they would like additional support with their caregiving responsibilities. To better understand what kinds of support needs these caregivers were referring to, the survey asked them to describe what kind of help would be of most value to them. Forty-nine primary caregivers provided answers (and two others said they didn't know); themes were identified from their responses and are presented below:

- Caregivers would value additional, on-site help to provide occasional respite from their responsibilities. Many caregivers said they could use additional people to support them in their caregiving role. They described several ways in which others could support them, including:

— Someone who could come in and take over all the things they do for their care recipient, allowing caregivers to take time off or to serve as an additional resource in an emergency (N=12)

— Someone to take their care recipient out into the community for things like lunch, ball games, recreation, or exercise activities (N=7)

— Someone to visit with the care recipient (N=3)

- A sizable number of caregivers said that they need help with specific in-home services including:

— Housekeeping and laundry (N=4)

— General household chores and yard work (N=3)

— PCA assistance with personal care (N=3)

— Meal preparation and grocery delivery (N=3)

- **Other caregivers said they would like social and emotional support, such as:**

— Support group for caregivers *(N=3)*

— Someone available to talk to – an empathetic person who understands the problems faced by caregivers *(N=2)*

— More involvement from family members to help with decision-making or other support needs (N=2)

- **Lastly, caregivers in need of additional support provided specifics on what could help them in their role:**

— Transportation assistance (N=6)

— Person to provide overall care coordination or oversight of services for care recipient (N=3)

— Assistance in finding appropriate resources for needs such as psychiatric care, Assisted Living facilities, or housing in the community for caregiver and care recipient (N=3)

— Help with financial needs including gas money (N=3)

— Availability of community resources for care recipient such as employment, community work, or activities (N=3)

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