



Caregivers to older adults

*How they connect to services
and how connections can be
encouraged and strengthened*

J U N E 2 0 1 3

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Summary

Background

Title III-E of the Older Americans Act, the National Family Caregiver Support Program, provides assistance to family and informal caregivers who care for individuals aged 60 and older, or individuals of any age with Alzheimer's disease or related disorders. Program funds are intended primarily to assist older caregivers (60 and over) and those caring for older individuals with the greatest social and economic need who are not eligible for assistance through Elderly Waiver or Alternative Care programs.

The Metropolitan Area Agency on Aging (MAAA) administers Title III-E funds in the seven-county Twin Cities metropolitan area, providing funding to six types of caregiver services:

- 1) counseling and coaching
- 2) respite care
- 3) assistance accessing services
- 4) group education
- 5) information services
- 6) supplemental services on a limited basis (e.g. chore or transportation assistance)

In 2012, MAAA contracted with Wilder Research to conduct a study of informal caregivers in the Twin Cities metropolitan area to learn what kinds of support and services caregivers find most helpful and to identify ways in which caregivers might be better served through available resources, particularly those currently offered through the National Family Caregiver Support Program.

Study approach and data sources

Data for this report come from three main sources:

- Thirteen focus groups with 104 metropolitan-area caregivers, held between March 5 and May 10, 2013. With the direction of MAAA staff, Wilder Research worked with members of the Metropolitan Caregiver Service Collaborative and Title III-E Caregiver Support Service Providers Group, who helped establish the configuration of each

group and identify potential participants. Three of the thirteen groups were conducted on the telephone via conference call.

- A review of research literature, completed to learn more about caregivers' needs and supports.
- Data from MAAA program records provided by MAAA staff to show current Title III-E funding and services.

Focus group participants

All focus group participants were caregivers living in the seven-county Twin Cities area. They included spouses, adult children, and non-relative caregivers, both in and out of the work force. Groups were held with caregivers who used formal services such as coaching or respite, as well as those who received no formal services. Culturally specific groups were composed of African American, Hmong, Latino, and Somali caregivers. In addition, one group was made up of caregivers who had recently experienced the loss of the person they were caring for.

Eighty percent of focus group participants were female. The average age of participants was 62; 43 percent were age 65 or older. Four of five participants were caring for a family member and almost half (48%) shared a home with the care receiver. Forty-three percent of participants were employed full or part-time.

Just over half (52%) of focus group participants had been providing care for six or more years, and about one-third (32%) reported they spend 40 or more hours per week helping their care recipient. Almost three-quarters (71%) said they had used at least one formal service to help with their caregiving tasks. A majority of these (53%) had used a support group and approximately one-third had used respite services, transportation assistance, a group class, or a website with caregiving information.

Findings

Characteristics

Although there was much diversity represented in terms of cultural and caregiving circumstances among the 104 caregivers who participated in focus groups, these caregivers, nonetheless, shared many characteristics.

Help from family, friends, and other individuals was their most important source of social, emotional, and (often) instrumental support.

Focus group participants felt a deep sense of responsibility for their care recipients' welfare, and frequently made significant personal sacrifices of their own time and resources to ensure that care recipients' needs were met.

Many focus group participants, particularly spouses and those in African American, Hmong, and Latino groups, assumed the role of caregiver as a matter of course – as a part of their role as a partner or family member.

Most participants described similar caregiving experiences, and many shared stories about the anxiety and stress engendered by their caregiving responsibilities. It was often the case that the care recipient's health deteriorated gradually, and focus group participants found themselves devoting more and more time to care without fully realizing the effect it was having on their health and other aspects of their lives.

Barriers to service use

Lack of awareness of services

Focus group discussions revealed that a lack of awareness of services is one of the most common barriers. Few caregivers are aware that services exist to help those who are caring for family or friends. Even fewer participants appeared to be aware that some services are available at little or no cost. This was particularly evident in the Hmong group.

Need for supports that meet cultural needs and expectations

For the four non-White groups, in particular, a barrier to accessing services was reflected in their observations about the lack of culturally appropriate support resources and, for Hmong, Somali and Latino immigrant groups, services in their native languages.

Concerns about the quality of services

In-home services such as respite and help with household tasks and personal care are services that almost all focus group participants felt would be of great help to them. Yet, for some, there was resistance to using these services because of their misgivings about having unfamiliar people come into their homes, and concerns about the quality of care. Likewise, out-of-home respite also raised concerns among some caregivers because of the need to provide or arrange transportation to another site.

Care receiver's resistance to using services

The care receiver's reluctance and, in many cases, outright refusal to accept any kind of outside services was cited as a major barrier to service use by many focus group participants. Focus group participants in some cases reported that care recipients were resistant to having any other caregivers involved and, especially in cases of dementia, anxious about having other people come to their home.

Cost of services

For many focus group participants, concern about the cost of services, particularly costs associated with respite, home health, housekeeping, and transportation services is a major barrier to service use.

Reliance on informal support from family, friends, and non-relatives

Participants generally take on the caregiving role gradually as their care recipients become less able to accomplish daily living tasks on their own. When care receivers' needs increase, many look primarily for assistance from family and friends, and often do not plan to use additional formal supportive services until they see no other option.

Hmong, Latino, and Somali focus group participants, in particular, clearly view caregiving as something that family members simply do for each other across the lifespan and do not usually see caregiving as a distinct or separate role or function.

Failure to recognize the need for help

Many focus group participants acknowledged that they became so immersed in their caregiving responsibilities and handling things on their own that they were unable to see that they needed help. Recognition of such needs sometimes occurred following comments from a trusted friend or family member, or a personal health crisis.

Difficulty finding sources of useful information

Focus group participants sometimes found it difficult to find information about services and caregiver resources available in their immediate communities. Not surprisingly, younger caregivers, who may be more tech savvy, were more likely than older caregivers to use on-line information source to find this information.

How and why caregivers become connected with supportive services

Most participants initially learned about services from trusted informal sources, such as family or friends, or acquaintances. For most it appeared to be a somewhat random process of gathering information wherever it was available and to be driven in large part by their specific needs at the time. In a few cases, a health care provider attending to the care recipient, would also inquire about the well-being and needs of the caregiver, and suggest resources that the caregiver might find useful.

Many caregivers waited to seek supportive services until their care recipient's health had deteriorated to the point that caregiving required a great deal of time and/or became so difficult that outside help was required to adequately meet the care recipient's needs. A suggestion by an adult child or other family member convinced some that it was time to get formal help.

Very few caregivers indicated they had used any systematic strategies for locating or arranging formal services. Many indicated that they had no idea where to start or what to ask. However, once they were connected to a service, they frequently used it as a pathway for getting information about and connections to additional assistance.

Opportunities for engaging and supporting caregivers

Focus group participants were quite clear about their needs for support. According to participants, caregivers will benefit from:

1. Easy access to information about caregiving services and supports including:
 - Accurate information in accessible form
 - Information early in the caregiving experience
 - Information about what to expect as part of the caregiving journey and how to anticipate future needs
 - Specific information about local services
 - Information available on demand, as problems are experienced and when aspects of the situation may feel out of control
 - Direct, one-on-one assistance, both in-person and by phone

2. Opportunities to connect with others for support and education including:
 - Support groups or one-on-one contact with other caregivers
 - Informal gatherings or discussion groups
 - Education sessions focused on caregiving
3. In-home and community-based services that are:
 - Flexible
 - Trustworthy and reliable
 - Consistent in staffing
 - Affordable
4. More formal and informal services that offer:
 - Daytime and overnight respite care
 - Transportation assistance
5. Workplace supports that include:
 - Policies that help caregivers balance work and caregiving
 - Employee education and presentations
 - Training about caregiving for employers
6. Services for African American, Hmong, Latino, and Somali communities that are:
 - Relevant to their cultural norms and practices
 - Available in their native languages
 - Provided in their own communities

Recommendations

The focus group results presented here, along with findings from many similar studies of caregivers suggest some ways to approach the challenge of getting caregivers the help they need when they need it.

1. Begin with the assumption that every first door should be the right door for a caregiver to begin accessing support.

Over and over again we learned that the caregiving journey often starts gradually and, before one knows it, it has become a fait accompli. As this journey begins there are many opportunities for interaction with health care providers; friends and family; members of a church, synagogue or mosque; as well as those whose jobs are intended to provide help, guidance, access, and support to family caregivers. If we are to be successful in being in the right place at the right time for caregivers, then we have to look at each of these potential interactions as an opportunity for information to be exchanged, needs to be assessed, and plans to be made.

2. Create opportunities for contact with experienced caregivers.

Participants across multiple focus groups reported on the benefits they derived from talking with experienced caregivers. In fact, the focus groups themselves were a source of satisfaction and support, as evidenced by the fact that groups often concluded by a participant asking when they could all meet again.

In the *Caregiving in Context* study, multiple respondents 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.

3. Take advantage of the fact that caregivers put their care recipient first.

Since most caregivers first begin thinking about the needs of their care recipient rather than themselves, it makes sense to encourage clinics and primary care settings, home care agencies, chronic disease associations and related services designed to support those with acute and chronic illness to also prepare and orient themselves to identify the family caregiver and consider the needs of a caregiver alongside the needs of the individual whose disease or functional distress is being treated. Protocols designed to identify and assess caregiver needs, if used routinely as part of health care visits, would likely lead to the earlier identification of problems and a more timely response to challenging caregiving circumstances.

4. Provide caregiver education to middle-aged (and older) adults in multiple settings.

Since adult children are often the key to service connections and are less reluctant than spouses to make such connections, educating adult children about the ways in which caregiving can affect life circumstances and health can produce multiple benefits. Respondents from several focus groups reported that they benefited from various group educational experiences including information about benefits eligibility, legal issues, and advanced care planning. Such discussions could and probably should be promoted more aggressively in diverse settings, including health care settings where potential health impacts can be assessed and addressed.

5. Make workplace education and attention to the needs of caregivers the norm and not the exception.

By all accounts, employed caregivers make up a significant number of those who provide care to older adults. However, focus group participants provided mixed reviews on how well their employers were able to accommodate their needs as a caregiver. Many opportunities exist for caregiver education in the workplace, including lunchtime presentations and discussion sessions, and the dissemination of caregiver resources. While it is not reasonable to expect that one presentation at one time in a workplace would provide all of the resources an emerging caregiver might need, over time, and with multiple exposures, the information is likely to sink in and be acted upon.

6. Make early identification of needs and opportunities for joint caregiver/care recipient participation a focus of services to caregivers serving those with memory loss.

Nearly half of all focus group participants in this study were providing care to someone with Alzheimer's disease or another impairment resulting in memory loss.

Earlier diagnosis and efforts to reduce stigma associated with memory loss can help in the support of these caregivers. In addition, many can also benefit from: a) the early identification of caregiver needs, b) coaching regarding how the caregiver role might unfold during the course of such a disease, and c) support – especially in the early stages – to engage in activities that caregivers and care recipients can do together. Several focus group participants noted the value derived from being able to do activities with their care recipient in the early stages of memory loss and the emotional benefit that both could derive from such activities. This is also likely to be a time when peer coaching, if made available through a trusted connection, could be of immense help to those who are wondering what will come next.

7. Consider the application of evidence-based programs that use behavioral activation as a strategy for reducing depression and stress among caregivers.

Walking and other forms of light exercise were frequently mentioned as methods by which caregivers cleared their heads, refreshed their energy, and prepared themselves for whatever might come next on their caregiving journey. Moreover, in the professional literature, such exercise and activity is widely recognized as a deliberate strategy – often referred to as behavioral activation – for reducing stress, depression and related problems. It is clear from the study findings that caregivers benefit from such activity and it is possible that more vigorous attempts to promote and make space for such activities could be of benefit to a wider circle of caregivers.

Introduction

Following a competitive bid process, Wilder Research was selected by the Metropolitan Area Agency on Aging (MAAA) to conduct a focus group study of caregivers serving older adults in the Twin Cities metropolitan area. The study was designed to develop a portrait of the caregiving experience, learn about the ways in which caregivers find support and encouragement for their work, and identify ways in which caregivers might be better served and supported through available resources, especially those funded under the Older Americans Act—National Family Caregiver Support Program. The study was designed to provide a rich and textured portrait of caregiving for older adults and to stimulate ideas about how best to engage caregivers and configure services in ways that can allow them to derive the maximum benefit from the range of caregiver supports available now, and in the future.

Through focused conversations with diverse groups of caregivers, the study seeks to get beneath the surface of the caregiving experience and learn how caregivers manage to get through the daily work of caregiving and find the help they need when they need it. Through the eyes of experienced caregivers, we are able to learn what they have learned over the course of their caregiving journeys, what kinds of help are most appreciated, where service and support connections can be most easily formed, and how service professionals can interact with caregivers in ways that relieve stress, reduce burden, and provide an “on ramp” to needed help.

In order to make well-informed funding decisions and best support caregivers, MAAA leaders are interested in exploring the following main questions:

- Why do caregivers not take advantage of existing caregiver support services?
- To what extent does the current array of caregiver support services represent a “good fit” with the actual needs and conditions of caregivers?

The study begins with a brief review of the current funding and service configurations offered through the Metropolitan Area Agency on Aging, and a summary of research literature on caregiver needs and supports. Both are intended to provide support and background to the focus group results which follow.

Current service funding

The Older Americans Act states that Title III-E funding is available to caregivers who provide in-home or community care to older individuals, aged 60 years or older or to individuals of any age with Alzheimer's disease and related disorders. Title III-E funding is intended to target caregivers who are older individuals (60+), or caring for care recipients who are older individuals, with the greatest social and economic need who are not yet eligible for the Elderly Waiver and Alternative Care programs, with particular attention to low-income minorities.

The National Family Caregiver Support Program provides grants to fund information, support and assistance for informal caregivers. In the MAAA program service area, Title III-E funds six service categories:

- Counseling and Coaching

Counseling or coaching involves a trained professional who provides assistance to caregivers in making decisions and solving problems related to their caregiver role. Assistance may include: identification of needs and preferences, development of individualized approaches and plans, and assistance.

- Respite Care

Respite services provide temporary, substitute care and supervision to older adults, to allow the caregiver a brief period of relief or rest. This is provided by trained volunteers or licensed professionals, and can be provided both in-home and out-of-home.

- Supplemental Services

Supplemental services are provided to caregivers on a limited basis to help ease the burden of care or to complement the care provided by caregivers. Examples of supplemental services include personal care, chore help or transportation assistance.

- Access Assistance

Access assistance offers caregivers help in accessing services and resources in their communities, and includes linking individuals directly to the service provider, when possible. The Senior LinkAge Line[®] is Minnesota's statewide telephone access assistance program funded by the Minnesota Board of Aging, but it is not the only form of access assistance available to caregivers.

- Group Education

Group education is designed to help caregivers provide, manage, or cope with caring for an older adult, while preserving their own health and well-being.

- Information Services

Information services provide the public and individuals with information about available caregiver resources and services statewide. Service units are for activities directed at large audiences of current or potential caregivers.

With a total of \$635,399 in federal funding, MAAA distributed funds in 2012 for a total of 10 programs (not including the Senior LinkAge Line[®]) in the following way:

MAAA Title III-E Funds Distribution for 2012

Type of Service	Amount	Number of People Served	Units of Service
Counseling and Coaching	\$240,416	691	5,899
Respite	\$188,723	256	14,731
Access Assistance	\$133,673	152	3,446
Supplemental Services	\$34,459	705	7,563
Group Education	\$32,198	4,243*	113
Self-Directed	\$5,930	6	462
TOTAL	\$635,399	1072**	32,214

* Includes participants in web-based training at the county level

** Unduplicated count without group education (with education the figure is 5,315)

The figure shows that nearly 68 percent of all current dollars are being spent on counseling, coaching or respite care. An additional 21 percent is used to support access assistance, with supplemental services, group education and self-directed support receiving the remaining 11% of funds.

MAAA program records show that 1072 caregivers received support from Title III-E funding during 2012, a relatively small proportion of the overall caregiving population, which is estimated to be 386,746 in the metro area (Spuit, 2012, p.27).

Background

The imminent exponential growth in the number of older adults, the current and future economic landscape facing Social Security and Medicare, as well as the increased longevity associated with the improved management of a wide range of chronic diseases, have all made the support of informal caregivers an imperative in any thoughtful response to the needs of older adults. Over the last decade, a wide range of services has emerged, some supported by the Older Americans Act—National Family Caregivers Support Program, to provide resources to caregivers that include coaching, counseling, respite, access assistance, and related supports.

The importance of resources for caregivers is clear given this nexus of the following realities:

- Approximately 43.5 million Americans provided part-time or full-time care for another adult aged 50 or over in 2009. (National Alliance for Caregiving, 2009).
- In 2010, 42 percent of employed Americans had provided care to an older adult in the last five years. This figure is expected to increase by 2015 to half of employed Americans providing care for older adults. (Feinberg & Choula, 2012)
- The economic value of unpaid, informal caregiving in MN was estimated to be \$8.9 billion in 2011. (Caregiving in MN 2013 Policy Brief) In the United States in 2009, that value was estimated to be about \$450 billion. (Feinberg & Reamy, 2011)

Recent research on caregiving completed by Wilder Research in *Caregiving in Context*¹ serves to enhance the understanding of the caregiving experience in the Twin Cities metropolitan area. Several issues emerged, including:

- Caregivers' most valued source of support is the informal assistance they receive from family and friends.
- Informal services are often combined with formal services that include practical assistance such as transportation, respite, meals and household chores.
- Caregivers with weaker support networks report poor health, increased distress, and long hours devoted to caregiving.

¹ This survey explored sources of support and key challenges for informal caregivers. The survey was conducted in 2011 as part of the Wilder Foundations' Capacity to Care Initiative, working to develop strategies for helping caregivers build strong informal support networks. Random sampling strategy yielded surveys with 212 informal caregivers living in 7 Saint Paul neighborhoods. Methodology and post-study comparisons to other surveys give researchers confidence that the findings are generalizable to caregivers in many settings.

The stress on caregivers and the effects of caregiving on their health and well-being are well documented anecdotally and in research. The strain of caregiving also costs employers in productivity losses. According to findings from the *Caregiving in Context* study, caregivers could benefit from:

- Improved access to accurate information about financial assistance and support services that would help them navigate their roles as caregivers
- Coaching and problem-solving related to caregiving challenges
- Help in understanding which support services for caregivers and care recipients are of the highest quality
- Help in locating other caregivers to talk with and opportunities to connect for support and education
- Respite care
- More help with basic needs like transportation and chores

In fact, services often appear to be unknown or underutilized, inadequately suited to the actual needs of caregivers, or simply not seen as viable options when considered in the light of a caregiver's resources or circumstances. This is true despite recent efforts to increase caregiver awareness and to expand service offerings and increase opportunities for access. The question is not whether caregiving stress ought to be reduced, but rather how to get caregivers to seek and accept help.

Another study, completed for The Family Caregivers Self-Awareness and Empowerment Project in 2001, considered the factors that support reaching caregivers. Due to caregivers' reluctance to self-identify, communicating with caregivers can be complex and difficult. The researchers suggested being careful about using the caregiver label because of associated negative connotations and perceptions. Two other main points emerged. First, "caregivers feel strongly that the most legitimate and compelling messengers are other caregivers" (Lake Snell Perry & Associates, 2001, p. 30). Second, the study confirmed that, in order to be effective, messages to caregivers need to be strategically crafted and directed through a variety of sources. This strategy is summarized in the following way:

Communications strategies should take advantage of the fact that many caregivers are interested or open to support, advice and information most often if it is about doing a better job caregiving. Giving such advice and support may bring caregivers into contact with organizations or resource centers, and once they are in the fold they can be approached about their own needs as caregivers. (Lake et al, 2001, p. 24)

Several studies have taken a more in-depth look at the conditions or factors that affect service use. One study which examined the use of respite services among minority and rural caregivers identified knowledge, access, and intent as factors that are “amenable to intervention by service providers, either by manipulating the manner in which services are offered and advertised, or through programs designed to change the attitudes and beliefs held by clients” (Montoro-Rodriguez, Kosloski & Montgomery, 2003, p. 917). These factors can be influenced by culture and language. Other conditions, largely out of the sphere of influence of service providers, include the relationship between the caregiver and care recipient, the level of confidence and trust in the service, perceptions about the service outcomes, and the trajectory of the disease or condition of the care recipient.

Caregiving is increasingly recognized as a dynamic situation, requiring interventions that respond to current conditions. Samia, Hepburn & Nichols (2012) note that group training allows participants to learn from each other and validate their unique experiences, while planning and preparing for the future. As such, caregivers receive insider knowledge about strategies and resources, learning which questions to ask and where to find the answers in a variety of stages. In this way, caregivers can avoid unnecessary trial and error, as their “changing roles call for varied and multiple interventions across the caregiving career” (Samia et al, 2012, p. 607).

Finally, the National Association of Area Agencies on Aging (2011) identified benefits to caregivers from partnerships that integrate services, established under Title III-E, in order to better support caregivers. Partnerships allow for an expanded reach and enhanced services, by combining resources with other agencies. Better access to programs, better information about resources, better coordination of service, and coordinated training programs were among the most common benefits identified.

Methodology

Introduction

The focus group methods and results which follow represent the individual and collective voices of diverse caregivers in the Minneapolis and St. Paul seven county metropolitan area. In these discussions, held in person and by phone, caregivers had an opportunity to describe their own journeys and hear about the journeys of others, express sources of frustration and joy, identify the forms of help and support that have made a difference in their lives, and suggest ways in which they and other caregivers could be supported in future.

Focus group guidelines

Between March 5 and May 10, 2013, Wilder Research completed 13 focus groups with a total of 104 caregivers living in the Minneapolis and St. Paul seven county metropolitan area.

Under the direction of MAAA, the following guidelines were established for focus group configurations:

- Representative of entire 7-county metro area
- Racial and ethnic diversity
- Employed/not employed
- Family vs. non-family
- Use of coaching or respite services
- Use of any services vs. no use of services

Researchers consulted with a number of agencies in order to determine the best use of resources for reaching representative groups of caregivers. Members of the Metropolitan Caregiver Service Collaborative and Title III-E Caregiver Support Service Providers Group helped to focus and refine the emphasis of each group.

Recruitment

The recruitment of participants for the focus groups was managed in one of two ways. For participants who were using or had used services, host agencies reached out to individuals already associated with their particular organizations. Researchers used newsletters and personal contacts to recruit potential participants who were not associated with agencies or services. Once individuals were identified as interested or available to participate, they called a researcher at Wilder to be screened, in order to determine suitability for participation in specific groups. Once participants were assigned to groups, they received follow-up emails or phone calls to remind them of the date, time and location for their focus groups. Alternatively, agency liaisons confirmed the focus group date, time and location with the participants that they had recruited.

Agency liaisons who assisted with direct recruitment or hosted focus groups at their facilities received stipends to reimburse costs for food and for their agencies' time.

Focus group format and protocol

In order to accommodate participants' schedules and caregiving responsibilities, focus groups were held at a variety of times during the day. Five were held in the morning, two were held in the afternoon, and six were held in the evening. Four focus groups were completed on the telephone via conference call. This format proved useful in accommodating participants' responsibilities and schedules as caregivers.

Focus group hosts provided refreshments for the participants. Participants were also offered an incentive to increase the likelihood of cooperation. Upon completion of the focus group, each participant received a \$20 Target gift card to compensate them for their time and effort. Gift cards were mailed to participants who phoned in for the focus groups.

At the beginning of each focus group, the facilitator described the purpose of the study and explained that the participants' comments would be kept confidential. With the permission of the participants, each focus group was recorded in order to guarantee that the full range of comments and opinions were captured by the researchers. Each focus group was also facilitated by one staff person from Wilder Research, while at least one staff person took notes. The focus group with Somali caregivers was the exception to this format. The Somali facilitator transcribed the notes after the focus group, while an additional researcher observed the group.

Table 1 provides information on the types and locations of the 13 focus groups.

1. Focus group configurations

Group Definition	Number attended	Host or recruiting agency	Agency service location
Adult children	10	West 7 th Community Center	St. Paul
African American, receiving services	11	VOA of Minnesota	Hennepin County
Caregivers not using services*	8	Phone interviews	Multiple locations
Hmong	9	Wilder Southeast Asian Services	St. Paul
Latino	5	CLUES	Minneapolis
Non-Relatives (program volunteers)	11	Lyngblomsten—The Gathering	Ramsey County
Receiving/received coaching	9	Family Caregiver Connection	Anoka County
Receiving/received respite	5	Family Means	Washington County
Recent loss*	6	Senior Community Services	Multiple locations
Somali	11	Brian Coyle Community Center	Minneapolis
Spousal caregivers*	8	Senior Community Services	Multiple locations
Working, not using services	5	Hennepin County, State of MN	Multiple locations
Working, receiving services	6	DARTS	Dakota County
TOTAL	104		

*Completed via telephone.

Before the group discussions commenced, researchers asked participants to complete a brief one page survey of personal background information, including age, gender, residence, employment status, type and history of caregiving, and use of caregiving supports. Providing this information was voluntary and some focus group formats may have reduced the amount of background information collected. Background characteristics and caregiving profile of the focus group participants are presented in Tables 2 and 3.

2. Characteristics of focus group participants*

Characteristics

Gender (N=104)

Male	20%
Female	80%

Race (N=95)

White	64%
African American	15%
Somali	12%
Hmong	10%

Hispanic/Latino Origin (N=95) (can be of any race)

	6%
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Age (N=90)

Under age 65	57%
65 and older	43%
Average Age	62 years

Employment (N=93)

Employed	43%
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*Some percentages may add up to >100% due to rounding.

3. Caregiving profile of focus group participants

Caregiving profile

Caregiving information (N= 99)

Care for family member	79%
Care for non-relative	21%
Share home with care recipient	48%

Hours per week (N=66)

Fewer than 10 hours	30%
10-39 hours	38%
40 or more hours	32%
Average hours per week	48.6 hours

Years of caregiving (N=74)*

Fewer than 3 years	18%
3-5 years	31%
6-8 years	26%
9 or more	26%
Average years of caregiving	6.2 years

Reported services ever used (N=74)**

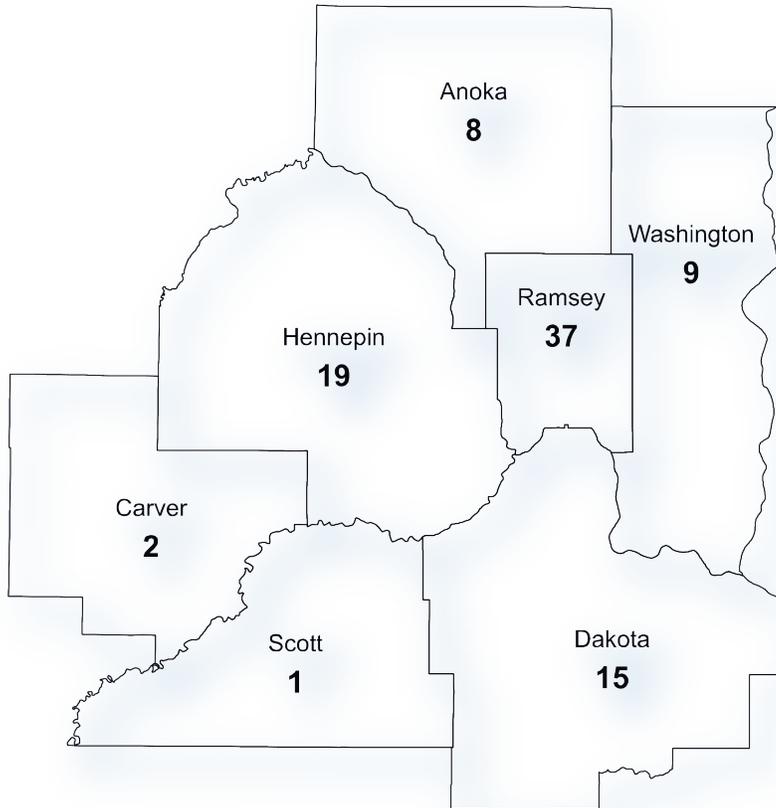
Support group	53%
Website with information	35%
Respite	30%
Help with transportation	30%
Group class	30%
Help with chores	26%
Coaching	23%
Counseling	20%
Hotline about services (unspecified)	14%

*Percentage adds up to >100% due to rounding.

**Percentage adds up to >100 % due to multiple responses.

Figure 4 below provides a map with the numbers of focus group participants by county.

4. County of Residence for Focus Group Participants (N=91)



Findings

In order to look more carefully at caregiving for older adults across a diverse range of experiences, focus groups were organized to reflect the unique and specific experiences of each of the following groups:

1. Spouses
2. Adult children
3. Non-family caregivers
4. Culturally specific groups (Hmong, Latino, African-American, and Somali)
5. Employed caregivers
6. Caregivers already connected to some form of caregiver support service
7. Caregivers who were not connected to caregiver support services

Of course, caregivers often have a variety of characteristics that would make them appropriate participants in several different groups, but for purposes of this report, the authors have attempted to focus on the unique elements and defining characteristics of the groupings listed above.

Caregivers who have experienced a recent loss, along with those who provide support and care to persons with Alzheimer's or related dementias, are included in the discussions as they are represented across the seven categories described above.

Six of 104 (6%) of participants were recruited specifically for the group focused on recent loss. Five participants were spousal caregivers and one was a caregiver for a parent. Their responses are included in the findings for spouses and adult children. Fifty out of 104 (48%) of focus group participants were explicit about caregiving related to Alzheimer's disease or memory loss. Hmong, Latino, and Somali respondents did not discuss Alzheimer's disease or memory loss.

Each section that follows describes:

- the needs and circumstances of each specific group
- barriers to service use
- how and why caregivers became connected with supportive services
- opportunities for engaging and supporting this specific group of caregivers

Wherever appropriate and useful, the authors have incorporated information from other sources into the discussion of each group including Wilder's recent survey of 212 metro area caregivers (Caregiving in Context, 2012), other recent national surveys of caregivers, and any other studies deemed relevant to the support of caregivers that are available through professional or research literature.

Spouses

Unique needs and circumstances

Both national and local surveys of caregivers have shown that spouses represent about one-quarter of all primary caregivers serving older adults. Spouses, in comparison to other caregivers, are most likely to accept without question the expectation that the responsibility of caring for their partner falls squarely on their shoulders. Spouses are also more likely than other caregivers to be living with the person they are caring for and to persist in the caregiving role even when it becomes difficult and represents a clear threat to their own health or well-being.

In fact, spousal caregivers can be at risk for the highest levels of caregiver distress or burden due to a number of factors (Pinquart & Sorensen, 2011):

- Generally spouses are older adults themselves, and 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.
- Caregiving in the home 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 the adults they are caring for, and the impending loss of their partner is significantly stressful.

Characteristics

As noted, spousal caregivers are typically much older than other caregiver groups. In Wilder's recent survey of friend and family caregivers in St. Paul, 72 percent of spousal caregivers were over age 65. Since men typically have shorter life expectancies than women, the ratio of female to male spousal caregivers is around four to one (Caregiving in Context, 2012).

Barriers to service use

Focus group results show that spouses, like many other caregivers, take on the caregiving role gradually as their partners' conditions deteriorate. It is often only in hindsight that a spouse recognizes how narrowly focused his or her life has become as a result of caregiving demands. Because these demands progress or change gradually, there is often no specific demarcation of what might be an appropriate point at which to seek support. As one husband reported:

My wife lost her memory over a period of many years. It happened gradually and it was hard to admit what was happening. By the time I did see how it was affecting me it seemed like I didn't have enough time to do anything but look after my wife.

A significant barrier that spouses often encounter in considering formal service use is the fact that caregiving demands make it difficult for them to leave the care recipient for any length of time. Related to this is the fact that many spouses report that their care recipient does not really want anyone else involved in their care or coming to their home. This may mean a reluctance to attend an adult day health program or use any other type of respite service or in-home support. Overcoming this type of barrier can be difficult, and the focus group results show that it is often subtle and more stealth engagement strategies that successfully relieve a caregivers' burden. Engagement in the home appeared to occur most often when some type of prior relationship existed with the family. A spouse in one focus group described how her husband's involvement in an exercise program at the local community center helped put her in contact with the center's social worker who soon became a trusted confidant and a source of both information and support. Another focus group respondent described how a local tai chi class gave both her and her husband an opportunity to participate in exercises together and softened his resistance to participating in other activities outside of the home, including adult day care.

How and why caregivers become engaged with supportive services

The Caregiving in Context study showed that less than half (48%) of spouses had formal services in place to support their caregiving responsibilities. Nursing care provided by aides, transportation assistance, personal care provided by aides, and help with heavy chores were the services most likely to be used by spouses in the month preceding the survey. 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.

Focus group results, however, show another important aspect of how connections to other sources of support may occur. For example, a husband described how his caregiving responsibilities for his spouse with memory loss were eased when the next-door neighbor, an experienced caregiver and health aide herself, began to assist with weekly bathing. Another talked about occasional meals that were brought by or a short respite visit by a friend that allowed the caregiver to take a walk or drive. Such informal connections occurred frequently when neighbors, church members, or other friends informally learned about the circumstances and difficulties of people they cared about. Such offers of help were most common for those who had more developed social networks. This suggests that early identification and outreach to caregivers and the establishment of a relationship of trust and confidence prior to the occurrence of a crisis, may be the best opportunity to overcome barriers that prevent families from accepting help in their homes. It also suggests that it is important to cast a wider net in preparing individuals to support caregivers, since virtually anyone may be in a position to lend such support if they are aware of the need and are in some ways equipped to respond.

When spouses made contact with health care professionals at clinics or home care agencies or day care programs, they often learned of other supports that could be helpful. Focus group results show that this most often occurred when a health care worker took the time to sit down with the caregiver and ask about their circumstances and needs.

Spousal caregivers were most often distressed about their own feelings of isolation, concerns about the medical management of the person they were caring for, or feelings of frustration or inadequacy in dealing with the dramatic changes in life's circumstances as a caregiver for a spouse with a serious illness.

Opportunities for engaging and supporting spousal caregivers

Focus group participants made it clear that what one needs depends on where one is in the caregiving journey. Early on, often coincident with a life-limiting diagnosis such as Alzheimer's disease, related dementia or stroke, spousal caregivers benefit from accurate information, sensitively relayed, that tells them what to expect as the disease progresses. As one respondent commented:

If more could have been done when we got the diagnosis--if there was someone who could just sit down with people after the diagnosis and tell you what to expect.

Or as another said:

You're in shock after the diagnosis. But my clinic made an appointment for us with a geriatrician. It helped us to know what we could do. There should be more encouragement for this.

Spouses also reported learning new information at transition points, often information that could have been useful earlier. As one husband noted:

After four years I tried day care. It made a big difference for me. I suppose I could've used this sooner.

But often it is only as a result of a nudge by an adult child or a trusted friend that the spousal caregiver will take a seemingly risky step, go beyond their comfort zone, and try something that can potentially relieve their caregiving burden. As one spouse reported,

It was hard for me to admit what was happening. It was my daughter that convinced me to get some help. Because I used the [home care] agency, it opened the door for me. Talking to a nurse manager was helpful. I stopped worrying about all of the medical decisions.

Spouses reported that time away for simple things was a huge relief, as the following comments suggest:

I was able to call my brother and take a short trip.

I only needed an hour or so for a walk. But that makes a world of difference for me. Walking raises my spirits.

We have a program where we can do tai chi together. I can't emphasize enough how much that has helped.

Finally, spouses reported that it is important to find out what one qualifies for, and what services are available based on need and income. Some focus group participants use the Internet, often with mixed reviews. (The *Caregiving in Context* study showed that 35 percent of all caregivers, but only about 20 percent of spousal caregivers, used the internet as a caregiving resource.) Some took advantage of an opportunity to talk with an elder law attorney during a group presentation or discussion sponsored by a local agency. Three of the thirteen caregivers contacted the Senior LinkAge Line[®] for information. According to spouses, there are lots of information sources but it is often difficult to know where to start, and they are not equally accessible or satisfactory for all people to use.

Adult children

Unique needs and circumstances

Multiple studies have found that adult children caregivers make up the single largest group of informal caregivers in the United States. The National Alliance for Caregiving in the U.S. and AARP study (2009) reported that 44 percent of caregivers care for a parent, step-parent, mother- or father-in-law.

Adult children caregivers are often caught up with a myriad of family and career responsibilities while at the same time caring for an aging parent. Recent studies provide information about their unique circumstances and suggest that many of the services available to caregivers may be of particular benefit to this group.

- Age of caregiver. Most individuals caring for a parent are middle-aged. A 2010 study (Wagner and Takagi, 2010) found that 70 percent of those who care for their parents are between the ages of 50 and 64.
- Multiple caregiving responsibilities. Thirty-nine percent of adult children caregivers interviewed in the Wilder *Caregiving in Context* study reported that as well as caring for one or more parents, they had additional caregiving responsibilities, including care for a child under 18, an adult child with a disability, or another family member, friend, or neighbor. Research by the National Alliance for Caregiving (APA, 2013) suggests that nationally about one-fifth of the estimated 65 million caregivers in the U.S have caregiving responsibilities for both an adult and a child.
- Advanced age of care recipient. Adult children are most likely to provide care for their parents or grandparents, who are generally among the “old-old” or “oldest old,” whose needs for assistance can create a heavy burden for caregivers. In a Gallup survey (Mendes, 2011), two-thirds (67%) of caregivers reported that they were caring for someone age 75 or older. The percentage of all caregivers caring for individuals over the age of 85 has increased across all three of the most recent national surveys (1977, 2004, and 2009) of informal caregivers conducted by the National Alliance for Caregiving in the U.S. and AARP.
- Employment. Most adult child caregivers are employed. The Wilder *Caregiving in Context* study found that a majority (63%) of adult child caregivers were employed either full or part time. This is very similar to results of a nationwide survey conducted in 2009 that found that 61 percent of Americans providing care for a family member age 50 or older were employed. (Feinberg & Choula, 2012)

Characteristics

Caregivers in the focus group with eleven adult children ranged in age from 44 to 67. The youngest care receiver was 75 and the oldest was 97, with an average age of 85 years. Seven of these caregivers had been providing care to their parents for five or more years.

The primary caregiving issues experienced by this group of caregivers were feelings of stress and anxiety. The caregivers explained that the constant concern and distractions of caregiving are stressful, and that the close emotional ties with their parents add to the stress. They also expressed frustration with being tied to a schedule and having to plan

everything in advance. Most said their greatest needs were to have some freedom to do things on their own and find ways to relieve their stress.

Examples of their comments include the following:

Stressors are a constant. Finding ways to de-stress is a challenge.

It is hard to be tied to a schedule. I miss freedom. It's like when the kids were little and you had to do everything during preschool or get a babysitter.

Barriers to service use

Focus group participants described the main barrier to using services as simply not knowing where to begin or what questions to ask. Arranging for services is time consuming, and caregivers grow weary of having to jump through too many hoops to get answers. Participants are also put off by impersonal service from help lines where they have to tell and re-tell their stories. Examples of their comments include the following:

We need neighborhood-based assistance. The help line doesn't know your neighborhood or your situation. We need local assistance that is present in the community.

The main job is figuring out what someone needs. Where do I start? I need a person who can listen carefully and help figure out both the questions and the needs.

I want to know what is available and where to find it.

I don't even know what to do or what to ask for. I just want to tell someone.

How and why caregivers become engaged with supportive services

Most caregivers in this group said that support from their siblings has helped them the most in caring for their parent. Others indicated that their most important source of support came from their grown children. Caregivers said both siblings and grown children provide moral support, as well as help with everyday tasks.

Formal services and supports mentioned by caregivers as most helpful include the programs and resources at a local community center. A range of supports are available, including outreach, health and wellness programs, homemaking and care management. Initially, a number of caregivers became connected to services through the exercise program and other activities at the center. Additionally, caregivers mentioned the value of the block nurse program, home health services, home delivered meals, and activities at the care recipient's residence in supporting their caregiving.

Opportunities for engaging and supporting adult children caregivers

Caregivers in this group had several ideas about the kinds of services that would be effective in engaging and supporting caregivers in similar situations. In general they recommended services that are easy to access and provide personal assistance from a familiar, trusted source.

Specifically, focus group participants felt that programs such as those at their local community center, which provide assistance and resources at the neighborhood level, are of great value. Caregivers appreciate the effectiveness of the model for supporting caregivers through building relationships between staff and caregivers. They also praised the center for its convenient and high quality services, and knowledgeable and caring staff. One caregiver described the program in this way:

(It is) a unique community and a best kept secret. It's like a mini social services agency.

All focus group participants felt strongly that increased and improved publicity about assistance and resources is needed. They noted that people need to be aware that there are services for caregivers, and, most importantly, what is available to them locally. One participant suggested a website for caregivers with simple directions and answers about where different types of help are available. Caregiver coaching or consultation were also acknowledged as services that could benefit caregivers. Participants envisioned this as assistance that could provide caregivers with someone to talk to, who would take time to listen and address individual needs, including in a crisis situation. This type of service would have added value to them if they could also receive technical advice on things such as long-term care insurance and legal matters.

Examples of focus group participants' comments include the following:

People need help in the heat of the moment and have no time to search on the Internet for help. It is difficult to access services. People have very individualized needs. Coaching is a huge opportunity.

I would like a caregiver sponsor, like in Alcoholics Anonymous. I want to share my stories, laugh, and feel better.

Coaching and skillful people for advice sounds good.

Caregivers are so tired. They want to talk to a person and do not want a menu on the phone.

Non-family caregivers participating as volunteers in a day respite program

Unique needs

The National Alliance for Caregiving and AARP (2009) reported that 14 percent of caregivers are unrelated to their care recipient. In Wilder's *Caregiving In Context* report, friends and neighbors represented 18 percent of caregivers surveyed. Older adults who are cared for by friends, neighbors or other acquaintances often have few or no other family connections nearby who are available to them for support. Non-relatives who are caregivers more often serve as secondary caregivers, in roles that support primary family member caregivers. Caregivers in this category often help family members with specific tasks like transportation, meals or errands, and were often a source of service information, emotional support, or both.

In the present study, a group of caregivers who volunteer in a day respite program offered a unique perspective on the value of respite and the path to using it. Many have become deeply connected to the families in the program and identified ways in which they see that the respite care benefits caregivers and care recipients alike.

Characteristics

The nine focus group participants described in this section are connected as volunteer caregivers through a group respite program. Respite care in five hour blocks of time is provided for caregivers whose care recipients have early to mid-stage memory loss.

Five of the nine focus group participants said they had previous experience as informal caregivers before becoming volunteers. They listed a number of motivations for volunteering, ranging from personal faith to seeking meaningful volunteer work to understanding the critical need for full-time caregivers to have respite. Examples of their comments include the following:

I know the desperation of caregivers. I wanted to do something that treats people with respect.

My mom lived out of state and people there helped her a lot. I wanted to give back and pay it forward in Minnesota.

My husband's brother was a caregiver for my mother-in-law and so I knew the stress of caregiving. I am recently retired and I was looking for something meaningful.

Barriers to service use

These focus group participants provided a perspective on respite care both from their personal experience with caregiving and as volunteers who see caregivers struggling with the burden of caregiving. They identified two main barriers to caregivers using respite care—admitting that they need help and feelings about using in-home respite services. According to the volunteers, even when caregivers recognize the importance of getting a break, they may feel reluctant to make a change and let go of control. This group of volunteers unanimously agreed that the first step of admitting the need for assistance and getting to the site is difficult. Examples of their comments include the following:

...Caregivers need permission to let go of control.

Both the care recipient and caregiver can be reluctant. This is a change, something new. The caregivers can wait around a little to make sure all is well. It's reassuring.

...They are admitting a need by coming to [group respite program], and this makes it difficult and a big hurdle.

Respite care in the home has its own issues, including awkward boundaries and trust. The respite care volunteers expressed their perspective about the experience in this way:

In-home care feels like babysitting. Caregivers feel like they have to clean up their homes before someone from the outside comes in to provide respite.

Caregivers don't feel like they are in charge when someone is in their home. They think, "I know how to do it best."

How and why caregivers become connected with supportive services

According to program staff, the group respite program is highly sought after and always seems to have a waiting list. The small and individualized setting and volunteer staffing, coupled with professional medical staff, volunteer training, and quality programming, make this an attractive model for families.

Focus group participants believe that other services could be valuable for caregivers, too. In addition to respite care, they think coaching could be valuable in helping caregivers feel empowered and see the value in support groups to augment the benefits of respite care.

Volunteers reported their experience with seeing firsthand the benefits of caregivers receiving respite care. Examples of their comments include the following:

This is the first time many caregivers have accepted help. They do it for the care recipient and then realize the benefits for them.

Caregivers need to have their guilt lifted—their guilt over not being able to do this alone...Coming into this program eases that burden.

You can see the difference in the caregiver right after respite. Even something like skin color improves after the five hours away.

Opportunities for engaging and supporting non-family volunteer caregivers

Focus group participants had only positive comments about their volunteer work and the benefits of group respite care. While they did not feel any need for additional support themselves, they could see a value in replicating respite programs like this so that more people could be served. For example, they were not aware of similar programs operating on weekends, or programs with more intensive staff support that would be able to serve higher-need clients or families.

Participants did feel, however, that there was important payback for volunteers who served in such programs. They described a range of benefits that are bestowed on volunteers when they enter into such reciprocal relationships, saying that sometimes they felt guilty because, as one participant put it:

We get so much more out of the program than we put in. It is a gift to be part of this experience.

This suggests that volunteer activities like this are extremely effective in educating individuals about the needs of caregivers and sensitizing them to both the demands and the benefits that caregiving can bring to the life of a caregiver.

Culturally specific groups

Unique needs

The needs of non-White caregivers are uniquely influenced by a myriad of conditions, including an older population that is becoming more racially and ethnically diverse (Reinhard and Choula, 2012). In 2009, three-quarters of family caregivers were white, one in ten was Hispanic and one in nine was African American (Reinhard and Choula, 2012). The Census Bureau predicts that in 2060, 44 percent of elders over the age of 65 will be non-White (U.S. Census Bureau, 2012).

The literature also indicates that non-White caregivers face unique conditions that influence their access to formal supportive services. While the background conditions and context are complex, and generalizing to entire populations is, at best, risky, one study in particular provides insight into these unique challenges. In their pivotal study, *Cultural Attitudes and*

Caregiver Use: Lessons from Focus Groups with Racially and Ethnically Diverse Family Caregivers, the authors (2006) suggest that three main factors exist to affect low service use:

- Familism
- Group identity
- Service barriers

Familism, or the cultural traditions surrounding family obligations, requires that members of many communities of color care for their elders. It is often a fundamental expectation and one that is fulfilled without question. Caregiving is also influenced by group identity, which can be expressed as a desire to keep the community intact. This can be especially desirable for those who have experienced discrimination or other hardships (Scharlach et al, 2006, p. 141) as part of the non-dominant culture. Finally, members of racially or ethnically diverse communities may experience barriers to formal services due to a lack of full information about what is available, mistrust of established (dominant culture) systems, and a lack of services that address language and cultural needs. In addition, many ethnically or racially diverse caregivers are more likely to rely on informal networks of support, thereby reducing their need for more formal services (Scharlach et al, 2006,p. 143).

Characteristics

Through four focus groups, researchers spoke to a total of 36 caregivers from racial or cultural groups who identify as non-White. Eleven identify as African American, 11 identify as Somali, 9 identify as Hmong and 5 identify as Latino. Nine of the 11 Somali caregivers are employed as personal care assistants (PCA). Two have caregiving responsibilities with a parent. Caregiving responsibilities and gender for these participants are presented in Table 5 below.

5. Caregiving responsibilities and gender

Group	Caregiving for:				Gender	
	Parent	Spouse	Child	Non-relative	Male	Female
African American (N=11)	7	5	0	0	0	11
Somali (N=11)	2	0	0	9	2	9
Hmong (N=9)*		1	2	0	1	8
Latino (N=5)	3	2	0	0	1	4
Total					4	32

*Caregiving status unknown for 6 of 9 caregivers.

Due to the paid PCA roles of the Somali caregivers, the discussion of findings for that focus group will be discussed separately.

Barriers to service use—Hmong, Latino, African American

Cultural differences influence the experiences of the participants in these focus groups, and create the context for different needs. These differences are evident through participants' comments about language, cultural expectations for caregiving, and perceptions about the kinds of assistance they expect or want.

Participants from the recent immigrant groups—Hmong and Latino—have a common barrier in language, as non-native speakers. They seem more comfortable with connections that occur within their ethnic communities, and in their native languages, in particular.

The Hmong and Latino caregivers spoke of the need for help with interpreting and paperwork:

Since I arrived in America, a Hmong woman helps me coordinate services and helps with translation.

The program would have been more useful if the materials had been translated into Hmong and had included visuals.

The social worker helps me out with transportation and with paperwork. (Latino)

Participants from the group of African American caregivers are keenly aware of different cultural needs, even though language is not an issue. One participant expressed her experience of caregiving and connection to a support group in the following way:

Though the experience of caregiving is the same, it is experienced differently [in the African American community]...[These are] services for White people. The approach and assumptions are that we [caregivers] are all the same. [In this support group], culturally we have things in common.

Another African American caregiver commented on the importance of culturally relevant materials:

I received a packet of information with games and activities you can do. Well, those aren't the things that African Americans do in their homes. Culturally, that's not what we do. You can't approach it all the same way.

Social workers with the sponsoring organization reported that the Hmong caregivers do not typically perceive themselves as caregivers. In fact, the participants in this group said it was helpful to know these caregiving strategies, presented through Powerful Tools for

Caregivers, so that they could use them in the future when they might have caregiving responsibilities.

How and why caregivers become connected with supportive services—Hmong, Latino, African American

In general, caregivers' comments about the ways in which they either became or work as caregivers demonstrates the firm belief in familism. Examples of their comments include the following:

We do it because we love them. That's just how it is supposed to be. (Latino)

I learned from my mom about how to take care, because she took care of her own mother. (African American)

In contrast, both the ways in which caregivers in each of these three groups became connected with supportive services and the actual connections vary considerably.

African American. The African American focus group participants were savvy and connected, reporting that they made connections to services in a variety of ways. Particularly helpful were the connections gained through the Alzheimer's Association and Veterans Administration, which allowed them to access a wide range of services, including day care, as well as doctors who connected them with hospice care. One caregiver noted that the book *The 36 Hour Day* was extremely helpful in gaining an understanding of the progression and nature of Alzheimer's disease. Another spoke of the Meeting of the Minds conference as a good, early resource. These caregivers also spoke highly of the support received in the racially-specific support group. In this group, they also shared valuable information with each other, as their caregiving duties became more stressful.

Hmong. Because many Hmong do not think of the caregiving role as distinct from simply being a member of a family, with the responsibilities that entails, they do not tend to seek connections to supportive services or resources designated specifically for caregivers. Even in this study where focus group members were recruited following their participation in a social support group, it was not clear that the training associated with Powerful Tools for Caregivers, was seen as immediately relevant to their needs. One additional complication in interpreting the results from this focus group, relates to the fact that the materials distributed to participants were not translated into Hmong, and therefore were not accessible to participants following the meetings.

Latino. The participants in the Latino focus group spoke about their work as caregivers as an expected and fulfilling duty. To cope with the stress of the caregiving, they rely greatly on their personal faith. Examples of comments include the following:

I ask God to give me strength.

I ask God that we are healthy and can provide care. If we aren't good or can't get out of bed, then we can't take care of them.

Their connections at a culturally-specific agency provide an important link to government aid and other assistance such as transportation and respite care. One caregiver mentioned training through Powerful Tools for Caregivers:

We had Powerful Tools training and lots of caregivers were able to receive it. They learned how to take care of themselves so that they can be a good caregiver.

Opportunities for engaging and supporting Hmong, Latino, and African American caregivers

The study by Scharlach et al (2006) identified several potential ways for overcoming service barriers. Suggestions include building services that emphasize a family-centered approach to caregiving, with care providers of a similar cultural background, as well as building community partnerships in order to strengthen “the capacity of...existing communal organizations and institutions” (Scharlach et al, 2006, p. 152).

While not representative of all non-White caregivers, the responses and experiences of these caregivers shed light on ways in which their diverse needs may be better met.

African American. African American caregivers discussed a wide range of ideas for supports. Culturally specific supports and services were thought to be particularly important, including support groups with other African American caregivers, where they may approach topics and resources in culturally familiar ways.

African American caregivers also spoke of the need for respite care, and prefer care out of their homes, along with flexible times and days. They would like a list of services or newsletters with information about supports. Additionally, they understand the importance of stress relief, and mentioned massage and exercise. Having a personal contact proved important, too. Caregivers appreciated the connections to physicians and social workers, who were able to give them personal guidance. Finally, this group of caregivers expressed many concerns about the affordability of services and discussed the importance of sliding-fee-scales to improve access.

Hmong. The Hmong caregivers are reluctant to think of themselves as caregivers. They recognize that a positive attitude is essential in being able help their family member, and understand the importance of relaxation. They also perceive a lack of available culturally relevant and sensitive information in Hmong for the Hmong community, and would like more help with paperwork and translations. Caregivers were somewhat aware of services that are available. Specific assistance they mentioned includes help with home health, universal design and accessibility, additional education or group training, and services that would support the caregiver.

Latino. The Latino caregivers talked about the need for more funding to provide services for others in the Latino community. One caregiver said:

There are a lot of people in the community who don't have (Medical Assistance). Sometimes it is their legal status, but...the government changed the criteria of the people who qualified for the program. They tend to have more problems with mobility...and that makes it harder for them to come to the programs.

Somali caregivers

Somali caregivers' comments about language, cultural expectations for caregiving, and perceptions about the kinds of assistance they seek provide insight into the ways in which they experience the role of caregiver. For the most part, it appears that Somali caregivers perceive their own needs primarily in relation to the needs of the elders for whom they care, and that the resolution of a care recipient's needs is essentially the same as the resolution of their own needs as caregivers.

While two Somali focus group participants cared for elderly parents, and nine others provide care through employment as PCAs, they all spoke of feeling responsible for elders in their community, simply because of their cultural ties and traditions related to family obligations. A number of Somali PCA caregivers reported that they spend far more hours caregiving than they actually get paid for, simply out of a sense of duty. Examples of their comments include the following:

It is difficult, but we understand the person is in great need and hurting... We are Somali. We help our neighbors like they are our family.

We are Muslim and we are to help others. It is a must. These people need help and as long as we are healthy, we can help. (Somali)

Somali caregivers discussed the emotional and mental health needs of isolated elders.

We take them to the home care places, where they get to talk to people, there is a gym and there is a place they can read the Quran or it is read to them. They focus on other things so they don't think too much.

Many of who we care for are old and would like the person that would be caring for them to be Somali and speak their language. This would help them the most.

These caregivers also spoke of the frustrations of figuring out transportation and housing, and of working with PCA agency staff who focus on assistance that is paid for by the agencies, but is less helpful to the Somali elders. One PCA stated it in this way:

(The agencies) only give us hours for things like cleaning [brushing teeth, bathing], but they need to focus on the memory and mental issues.

The Somali caregivers were very clear about the needs of their care recipients. They spoke of the importance of supports that are tied to the specific cultural needs of Somali elders, and especially of services that reduce their isolation. A number of caregivers spoke highly of respite care in community locations with other elders where care recipients get meals, and exercise and companionship. They would like to have classes on topics including mental illness, financial needs, and legal issues. Home health care is currently limited in hours and the range of supports available, and would benefit elders by being both expanded and reconfigured to meet their actual needs. One caregiver said:

Here is a community center that has helped me and has helped a lot of people...Look at the people who need care and see if it is possible for the people we care for to come to this center. I want the Area Agency on Aging services to be [in] the Somali community.

Employed caregivers

Needs and characteristics

Participants in the employed caregivers group share many characteristics with adult children caregivers: They are mostly middle-aged, caring for an aging parent while working and, in several cases, carrying additional caregiving responsibilities.

Eleven caregivers participated in two focus groups of employed caregivers.² One group used formal services to augment informal care; caregivers in the other group were not using formal services. Half of the caregivers who used services were caring for parents living in assisted living or skilled nursing facilities. Caregivers in the group that did not use formal services were also caring for family members, mostly parents or parents-in-law who live in their own homes in the community.

Caregivers in these two groups worked an average of 38 hours a week. They ranged in age from 22 to 65.

² One participant was a full time college student who was not employed.

Barriers to service use

Focus group participants said a major barrier to using services has been their care recipient's resistance to accepting help. One participant said:

Mom doesn't want outside help – people she doesn't know.

Another participant related that when her parents were living in the community, they would “chase away home care with brooms.”

Caregivers also expressed their own reservations about respite care services, although most indicated respite care is something they feel is valuable and would welcome for themselves. Examples of their comments follow:

You don't know how reliable they are. A care worker came into a friend's, and things would be missing. Or even to be able to find someone who will do things properly.

[It's about finding someone] that you can trust and be comfortable with.

...I don't know if home health care would put up with the abuse [from care recipient].

Caregivers also spoke of challenges they had encountered when seeking services. They felt mainly that information available to them was often too general and did not provide enough information about local services. Other challenges mentioned included long waits to talk with Senior LinkAge Line[®] specialists, lack of guidance from professionals, and the cost of services.

How and why caregivers become connected with supportive services

Like many caregivers, most focus group participants first became connected with supportive services when they began seeking help for a family member who was starting to have problems living independently.

Caregivers in both the “services” and “no services” groups have used workplace resources, such as their employee assistance and wellness programs, and educational presentations to learn more about caregiving and supportive services available to them. They said they have found these resources useful.

Some participants stated that the most important support they have received - support that enables them continue to care for their family member at home - has come from their employer, through policies that allow them to use sick time, work flexible hours, and take advantage of telecommuting options. Examples of their comments follow:

My employer lets me telecommute. They are very supportive. I can take what I am doing – it makes me even more committed at work.

They have been very supportive. I can use my sick time and do not have to use my vacation.

They are supportive. I work four days a week.

Not all participants have found their workplaces to be supportive of their needs. They spoke of instances when employers refused their requests for flexible work schedules or reduced hours, or times when they feared that asking their employer for any kind of accommodation would lead to being targeted as a problem employee.

Focus group participants also said they have found valuable support and resources for their caregiving through family and friends, individual coaching, support groups, and health club programs. Family members are a particularly important source of assistance to the caregivers who do not currently use formal services.

Opportunities for engaging and supporting employed caregivers

Focus group participants expressed frustration about the lack of time they have to devote to their own needs and interests. Their comments indicate that they place high value on services that are flexible and easy to access. They are comfortable with technology and appear open to the idea of using on-line or telephone support services and Web-based services that can provide specific information tailored to their needs.

In addition, employed caregivers clearly feel a need for services that provide respite of some kind. Examples of their comments follow:

A little more freedom – to do what you want. If I take off a week, she [care recipient] has a fit.

I would like to go to exercise. I would like to take a class, but they are 55 minutes. I don't feel I can.

[A service so that] caregivers could go to baseball games – fun things just to get away. Somebody who would like my mom and just talk with her.

Just myself, alone with my thoughts. I would do things just for me and not think about it.

Readjusting – I used to like to travel just for myself. Now it has to be so planful and has to be close...I would like to be spontaneous.

Finally, the discussion with employed caregivers shows that they believe that offering workplace supports can offer significant benefits to both employees and employers. They appreciate information and about public and private resources available to caregivers, support groups and education about caregiving, and options for alternative work schedules. There were also suggestions for ways that employers could strengthen their support for working caregivers including:

- Providing case management services to caregiving employees
- Offering training to supervisory staff about the caregiving experience
- Educating human resource personnel about the caregiver's rights in the workplace

Caregivers connected to services

Unique needs

While caregivers' most important supports will likely continue to be from informal sources, the *Caregiving in Context* study found that formal support services can actually help caregivers strengthen their personal networks. The study also found that formal service providers may help reduce and simplify caregivers' interactions within their systems, which may contribute to less stress and burden for these caregivers.

The 2011 study completed by Minnesota Department of Human Services (DHS) on supporting family caregivers asked care managers and Long Term Care Counseling assessors about their perspectives on barriers to families' use of respite and caregiver training. Barriers they frequently identified for both types of care include:

- Reluctance to accept this help
- Needs for which no services are available
- Lack of awareness of the services or of the benefits of respite care or training

Respondents for the DHS study mentioned two other barriers for respite care, including preferring to get paid to provide the care themselves and concerns about the older adult disliking respite care. They also mentioned a lack of interest in caregiver training, no time to attend the training, and a lack of transportation to attend.

Characteristics

In 2012, MAAA funded counseling and respite services with just over two-thirds of the available Title III-E funding.

Of the 74 focus group participants who completed background information forms, 30 percent said they had used respite services. Twenty-three percent said they had used coaching, while 20 percent said they had used counseling.

A total of 14 caregivers participated in the two focus groups about connections to respite and coaching services. Participants were recruited based on:

- Their contact with staff in Anoka County who provided needs assessment and coaching services
- Their past or current use of respite care in Washington County, or their status as a respite care volunteer

Barriers to service use

For this study, focus group participants discussed a variety of issues that keep them from fully accessing assistance. Consistent across both groups were mentions of cost of services and concerns about trust in providers.

Comments about cost include:

We don't travel for more than a week now...[I am concerned about] the expense for an extended time.

One thing is the cost—the money has to last.

Comments about trust include:

Having someone come into your home [is a concern]. The trust factor. We've had things disappear and we've had a bad experience or two. They are so vulnerable and so many things can happen. My anxiety level on having someone come in is so high.

There is more and more fraud against seniors our age.

Other barriers that respondents mentioned were simply being aware of the need and not knowing the questions to ask or where to start. Examples of comments include:

[There is an issue with] recognition on the part of the caregivers that they need respite or help. You get used to it and don't realize it.

People are in denial about needing services.

If you are not asking the right questions, they don't address the right need.

How and why caregivers become connected with supportive services

Caregivers who were involved with respite care came to be connected in a variety of ways. In large part, it was the stress of caregiving or the realization that they couldn't leave the care recipient alone that finally pushed the caregivers to do something. Another focus group participant enlisted help so that she did not have to visit her mother every day. Examples of their comments include the following:

We hire someone to do dishes and empty the commode each day....This assistance is my respite, so I don't have to go every day.

Caring for my husband was exhausting and disturbed my sleep. I would take him to [ADH] to get a break.

I need respite when my patience runs thin and I start hollering and I have to catch myself. I can only leave my wife alone for about an hour. But...it's not really respite because I just worry.

Caregivers who were involved with coaching also came to be connected in a variety of ways. Some connected through their churches or the county social worker, but most found out through a friend or acquaintance.

Caregivers in both groups receive their information from a wide variety of sources, and their best source depends upon the specifics of their need at that time. However, word-of-mouth was most commonly mentioned as the most important source. Examples of their comments include the following:

Especially when finding a service to trust, word-of-mouth is good.

I like having a referral from someone.

Word-of-mouth for information is powerful and helpful.

Other sources of information they mentioned include peers in the same or similar situation, health care providers, elder law attorneys, funeral home staff, county workers, faith community, the Internet, Veterans Administration, adult children in health care professions, and Senior Expos or conferences. Once they were connected to primary services, caregivers also spoke about getting more information as they needed it from those sources. For example, while involved in respite care, they learned the value of support groups or connections with peers.

Opportunities for engaging and supporting caregivers connected to services

Participants in these focus groups were very clear about the fact that no one size fits all in terms of meeting the needs of caregivers, but that finding something is critically important, due to the negative consequences of stress and the hard work of caregiving. They were also very clear about what they think they need and how others may benefit, as well as where and how these connections can happen.

According to this group of 14 focus group participants, caregivers need to start somewhere, since a preliminary connection can open pathways to other assistance. They also believe that caregivers generally need the following:

- A block of time that allows them to recuperate and clear their heads
- Peers who can provide advice, perspective and camaraderie

- The option of flexible and/or spontaneous help

Suggestions for the best ways to get information include:

- Print media, such as brochures, newsletters and mass mailings in a variety of public locations
- Electronic media, such as webinars, TV or radio advertisements
- Expert professionals, such as health care providers or elder law attorneys
- Peers

Caregivers not connected to services

Characteristics and needs

In another attempt to refine our understanding of caregiver needs and service use, researchers sought to identify caregivers who had not received any type of formal caregiver support service, such as those funded by MAAA and described at the beginning of this report. This turned out to be somewhat of a challenge. It appears that, over the course of most caregiving journeys, it is unusual for caregivers, even those who felt that they had not used such services to be, in fact, truly isolated from a similar range of supports. For example, it was unusual for caregivers in this group to have not received some sort of respite through a day health program or to have not sought some type of caregiver resource through the library or Internet. The book *The 36 Hour Day* was mentioned by several.

Similarly, caregivers in this group frequently had received some type of encouragement or uplift through friends, family, or church members when feeling low, and this sometimes led to learning about programs like group respite. Some had tried to use MinnesotaHelp.info to learn about service eligibility or made contact with organizations through the Senior LinkAge Line[®]. In one way or another, many of these so-called disconnected caregivers were in fact linked to a service or support of some kind, although they were seldom served directly by the Title III-E programs.

Barriers to service use

Those not using formal caregiver support services appeared less likely to have found a caregiver "on ramp" early in their caregiving journey. Most had never heard of the Senior LinkAge Line[®], many were likely to mention feelings of isolation or loneliness, and many in this group relied heavily on family or friends. This was true for both employed and retired caregivers who were not using caregiver support services.

One important barrier to service use, described multiple times by those not using caregiver support services, but certainly not unique to this group, was the concern about strangers coming to the home as one participant stated:

Mother doesn't want people around the house unless it is spotless. She is leery of strangers. She has become more paranoid.

Or as another reported:

Mom doesn't want outside help—people she doesn't know. Now with me it is a changed relationship because of my frustration. The way she has been with dementia. I hoped she would have a happy, peaceful, dignified old age... But she guilts me out. The role reversal is frustrating. Outside help would be a relief.

Another barrier to service use appears to be the desire not to seek help or services unless absolutely needed, partly to avoid the expense, and partly as a result of stubbornness or simple resistance to change. As one respondent described it:

I had my husband at home for 4 1/2 years. I have nursing background so I assumed I could do it alone. I would rethink that now! We finally got respite care through a home health care agency in January 2012. This opened the door to have the social worker come talk to me. We had no idea about Elderly Waiver or anything like that. Once a nurse manager was assigned to the case it relieved me from being the sole decision-maker for all the health issues.

How and why caregivers become connected with supportive services

One of the triggers, especially for spousal caregivers, to explore service possibilities, is the presence of an adult child, often a daughter, who insists that mom or dad get some help. As one focus group participant reported,

Without my daughter available, I would have hesitated to go or use the service. I had to weigh the economy of everything. I wanted to wait until she needed more care. But I wish I had this support earlier.

In addition, changes in the health status of the care recipient often represent a turning point on the caregiving journey. For one respondent, it was the initial use of an adult day health center when care became overly burdensome that opened the door to facility-based respite care and allowed the caregiver to take a much-needed four-day holiday. As she described it,

It was the social worker in the Veterans' adult day care program who told me about this. We now get transportation assistance and some help with cleaning. This has made a big difference.

When family is available, this also represents a significant form of support, but does not necessarily lead to other service use. As one respondent describes it:

My sister comes to help give baths. And my brother helps with some meals. But my connection to the exercise program at the West Seventh Community Center was what made it possible to receive some housecleaning help from one of the other program staff.

In general it appears that access to funded services may occur more by chance, as a result of knowing someone who has knowledge about a service or program, and not necessarily as a result of the caregiver reaching out in seeking a specific service through his or her own efforts. Nonetheless, once supports become available, participants express gratitude for the relief they provide. At this point, caregivers may be more open to other forms of support as long as they are seen to fit within the particular circumstances and the willingness of both the caregiver and the care receiver to fit within their circumstances.

Opportunities for engaging and supporting caregivers not connected to services

Focus group results suggest that health related contacts that initially focus on the needs of the care recipient may be one of the best potential connection points for caregivers as well. It is often through such health related contacts the caregivers are introduced to supports that can reduce burden and improve the likelihood of sustaining their work as caregivers.

In addition, earlier diagnosis of disease, accompanied by a specific inquiry into what changes may occur over time, appears to be another good opportunity for getting caregiver supports in place earlier on the journey. Two recent developments may serve to support the work.

First, ACT on Alzheimer's, the statewide collaboration preparing Minnesota for the impacts of Alzheimer's disease and related dementias, has established a goal of early detection and diagnosis of the disease. The identification of the family caregiver at diagnosis could result in earlier attention to caregiver needs. Education on what to expect throughout the course of the disease accompanied by information on caregiver support services could also be provided at diagnosis.

Second, and in a related way, the move to establish health care homes in Minnesota, as more holistic and patient centered approaches to care that are more fully integrated into a range of community supports and resources, may also be a boon for caregivers. As more and more primary care models move toward embodying the policies and principles of health care homes, there is a greater likelihood that useful community-based resources could be identified earlier. In turn, these resources could be considered as part of a continuum of supports that can strengthen the caregiver's hand and be considered more

easily in conjunction with the usual health care resources that help to meet the medical needs of the person being cared for.

In short, any service connection, especially those that are health related, can become a point at which caregiver needs are directly and consciously addressed. But this can only happen when the needs of caregivers are seen as central to the goal of providing good patient care and when care in the home is recognized as a major component for maintaining health and well-being.

Focus group results show that caregivers who are not connected to funded caregiver supports are themselves remarkably resourceful, but often stumble across the services that they later come to value. Further, caregivers' needs for relief are often quite simple, such as getting time away for a walk, visiting with a friend, going to a church group, out to dinner, or even shopping. Interestingly, those not connected to services often like the idea of peer-to-peer coaching or phone connections to other caregivers. These services were not seen as invasive, and caregivers could easily envision accessing these services without a major change in circumstance.

Conclusions and recommendations

The focus group results presented here, along with findings from many similar studies of caregivers, suggest an important but seemingly contradictory conclusion:

On the one hand, all caregiver journeys are unique, influenced in specific and innumerable ways by the course of an illness, the circumstances of care, the resourcefulness of the individuals involved, the availability of friends and family to help, specialized knowledge of resources, who one knows, the type of residence one lives in, the nature of the community in which one resides, along with dozens of other factors both personal and contextual.

On the other hand, caregiver experiences are woven with many common threads including necessary interactions with health care professionals, a desire to be helpful and caring toward loved ones, inevitable changes in health and functioning, access to a myriad of life-extending technology (more widely available than ever before), a need for equilibrium and balance in a person's life, and the need to satisfy universal daily needs including nourishment, safety, and shelter.

In this tapestry of unique journeys and common threads, how does one best ensure that caregivers will get the help they need at the time they need it? The stories derived from these focus group conversations suggest a few key directions.

1. Begin with the assumption that every first door should be the right door for a caregiver to begin accessing support.

Over and over again we learn that the caregiving journey often starts gradually and, before one knows it, it has become a fait accompli. As this journey begins there are many opportunities for interaction with health care providers; friends and family; members of a church, synagogue or mosque; as well as those whose jobs are intended to provide help, guidance, access, and support to family caregivers. If we are to be successful in being in the right place at the right time for caregivers, given the wide range of pathways into caregiving, then we have to look at each of these potential interactions as an opportunity for information to be exchanged, needs to be assessed, and plans to be made.

Earlier results from Wilder's survey of St. Paul caregivers, reported in *Caregiving in Context*, showed that caregivers would like to have the option of contacting someone directly when they have specific questions, need advice, or just want to talk to someone about caring for their care recipient. Some expressed the desire for a "hotline" with a live person they could call when needed for tips and advice about everyday caregiving problems and issues.

The focus group results are more nuanced, however, and show that caregivers do best at walking through the doors that are already open. Trusted friends, a health care professional, a service worker at a local community center, all may provide a gateway to service and support if they understand who caregivers are, common tasks caregivers assist with, and potential needs they may have. This suggests that education efforts need to be broadly based rather than narrowly focused, and that people who are not professionals, including family members and the general public, can benefit from this knowledge as much as those whose formal role it is to provide health care or social support.

2. Create opportunities for contact with experienced caregivers.

Participants across multiple focus groups reported on the benefits they derived from talking with experienced caregivers. In fact, the focus groups themselves were a source of satisfaction and support, as evidenced by the fact that groups often concluded by a participant asking when they could all meet again.

In the *Caregiving in Context* study, multiple respondents 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.

MAAA's decision to experiment with a new form of focus group also resulted in some useful observations. In particular, it was interesting to watch social relationships develop, however briefly, in the focus groups that were conducted via telephone conference call. In three of the four calls there was at least one example of advice giving by one participant to another among caregivers who had never met face-to-face. When the conversations were concluded and the facilitator asked what participants thought of this new type of focus group format, there was a general recognition that the format was both useful and uplifting. One participant expressed the view that if such services were offered on a routine basis, caregivers who were more isolated by situation or circumstance could take time to join a regularly scheduled call and learn about what is helping others and, if desired, share with others what has been useful to them.

3. Take advantage of the fact that caregivers put their care recipient first.

Most caregivers think first about the needs of their care recipient before thinking of their own needs. Therefore, it makes sense to encourage clinics and primary care settings, home care agencies, chronic disease associations and related services designed to support those with acute and chronic illness to also prepare and orient themselves to

identify the family caregiver and consider the needs of a caregiver alongside the needs of the individual whose disease or functional distress is being treated. Protocols designed to identify and assess caregiver needs, if used routinely as part of health care visits, would likely lead to the earlier identification of problems and a more timely response to challenging caregiving circumstances.

As noted earlier, new legislation creating health care homes has already begun to do this job. In order to qualify as a health care home, one has to demonstrate the capacity for team planning around care needs, the ability to marshal community resources on behalf of the patient and family, and attentiveness to the needs of the entire family when developing care plans. Health care homes also emphasize the need to have adequate supports in place in order to prevent unnecessary hospitalizations, emergency visits or medical treatment.

In addition to the work of health care homes, we are also in the midst of a statewide initiative to improve community capacity for responding to Alzheimer's disease. The *ACT on Alzheimer's* collaboration seeks to encourage early detection and diagnosis of the disease, increase awareness and sustain caregivers in their role. Many of the focus group participants who cared for family members with dementia noted that the delay in diagnoses ran parallel to a delay in gaining support for their caregiving role.

It is likely that we can encourage greater support for caregivers by building more deliberate and routine attention to the needs of caregivers into any health care visit that involves an older adult affected by acute or chronic disease.

4. Provide caregiver education to middle-aged (and older) adults in multiple settings.

Since adult children are often the key to service connections and are less reluctant than spouses to make such connections, educating adult children about the ways in which caregiving can affect life circumstances and health can produce multiple benefits. Respondents from several focus groups reported that they benefited from various group educational experiences focusing on information about benefits eligibility, legal issues, and advanced care planning. Such discussions could and probably should be promoted more aggressively in diverse settings, including health care settings where potential health impacts can be assessed and addressed.

In the AARP Public policy publication, *A Call to Action: What Experts Say Needs to Be Done to Meet the Challenges of Family Caregiving* (Reinhard, Feinberg & Choula, 2012), the authors promote the idea of greater public education and awareness. They suggest a greater emphasis on Medicare education; caregiver storytelling, including tips about practical tools and resources; and national discussions about advanced care

planning. They also suggest engaging communities and faith-based organizations in these educational efforts.

While it is not possible to derive a prescription like this strictly from focus group findings, such a call to action makes sense in light of the seemingly haphazard way in which many of our study participants came to acquire the knowledge they needed to respond effectively to their caregiving challenges.

5. Make workplace education and attention to the needs of caregivers the norm and not the exception.

By all accounts, employed caregivers make up a significant number of those who provide care to older adults. However, focus group participants provided mixed reviews on how well their employers were able to accommodate their needs as a caregiver. In fact, Wilder's *Caregiving in Context* study found that over half (52%) of primary caregivers said they were employed full or part time, and about one in five reported that they did not receive any support from their employer. Among the four out of five who did receive support from their employer, support was most likely to come in the form of a flexible work schedule, which allowed them to be with their care recipient at critical times.

Some employers are now taking an interest in how the work of an employed caregiver might be affected by caregiving responsibilities and are taking steps to learn more about the issue. One way employers are doing this is by administering on-line surveys to employees. However, some employers undoubtedly see caregiving as a potential distraction to work and employed caregivers have at times reported that it does not feel safe to talk about caregiving with one's employer if it might cause them to be seen as a worker with divided loyalties (Caregiver Policy Forum, 2013)

Nonetheless, many opportunities exist for caregiver education in the workplace, including lunchtime presentations and discussion sessions, and the dissemination of caregiver resources. While it is not reasonable to expect that a single presentation in the workplace would provide all of the resources an emerging caregiver might need, the more opportunities caregivers and potential caregivers have to gain relevant information, the greater the likelihood that information will make its way to them and be useful. The work place may be one key location for this broader dissemination and may also serve to help employers see the potential benefits of addressing these issues more directly.

6. Make early identification of needs and opportunities for joint caregiver/care recipient participation a focus of services to caregivers serving those with memory loss.

Nearly half of all focus group participants in this study were providing care to someone with Alzheimer's disease or another impairment resulting in memory loss. They have reported that the role of a caregiver in such cases often begins gradually. In fact, many focus group participants noted that they had become caregivers almost before they knew it had happened. As noted in recommendation 3 (above), earlier diagnosis and efforts to reduce stigma associated with memory loss can help in the support of these caregivers. In addition, many can also benefit from, a) the early identification of *caregiver* needs, b) coaching regarding how the caregiver role might unfold during the course of such a disease, and c) support, especially in the early stages, to engage in activities that caregivers and care recipients can do together. Several focus group participants noted the value derived from being able to do activities with their care recipient in the early stages of memory loss and the emotional benefit that both could derive from such activities. This is also likely to be a time when peer coaching, if made available through a trusted connection, could be of immense help to those who are wondering what will come next.

7. Consider the application of evidence-based programs that use behavioral activation as a strategy for reducing depression and stress among caregivers.

Walking and other forms of light exercise were frequently mentioned as methods by which caregivers cleared their heads, refreshed their energy, and prepared themselves for whatever might come next on their caregiving journey. Moreover, in the professional literature, exercise and activity is widely recognized as a deliberate strategy – often referred to as behavioral activation – for reducing depression, anxiety, and related problems (Spates, Pagoto & Kalata, 2006). In one example, behavioral activation was used successfully with dementia patients, after training caregivers in the principles of activity scheduling. This produced benefits for the caregivers as well (Logsdon, 1990). Similarly, the Healthy Ideas Program, developed by Baylor College of Medicine, uses behavioral activation as part of a depression self-management program and includes an educational component for both clients and family caregivers (Casado, et.al. 2008).

It is clear from this study and other professional literature that caregivers benefit from various forms of activity and it is possible that more vigorous attempts to promote such activities, and make such activities possible through respite support, could be of benefit to a wider circle of caregivers.

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