

Aging in Place Partnerships: A Training Program for Family Caregivers of Residents Living in Affordable Senior Housing

Alisha Sanders

Robyn Stone

Institute for the Future of Aging Services

Rhoda Meador

Cornell University

Victoria Parker

Boston University School of Medicine

VA Boston Healthcare System

Abstract

This article describes the development and testing of a program to expand the capacity of family caregivers of residents in affordable senior housing properties and enhance the partnerships between family caregivers and the housing properties to help residents meet their needs and “age in place.” A needs assessment revealed that, although family caregivers are providing a great deal of assistance to residents in affordable senior housing properties, they can benefit from expanding their caregiving knowledge and skills. It also revealed that the interaction between family caregivers and housing properties is often minimal. Incorporating input from service coordinators, family caregivers, and residents, a two-part workshop was created and piloted in three affordable senior housing properties. The first part focused on helping the family caregiver understand and build empathy for the challenging tasks that residents and caregivers face; the second focused more specifically on how family caregivers can strengthen their skills and knowledge and partner with housing properties to support aging in place. Participants in the pilot workshops reported being very satisfied with the workshops and more prepared to fulfill their caregiving role. The program team will use the results from the training program to refine the program and explore the potential for dissemination through a “train-the-trainer” approach.

Introduction

This article describes the development and testing of a program that was designed for the family caregivers of residents in affordable senior housing properties. The program's goal was to improve support for and ensure the sustainability of the efforts of these family caregivers by increasing their knowledge, building their skills, and strengthening their partnership with the housing properties' service coordinators. The program had three key objectives:

- Identify the specific needs and knowledge gaps of these family caregivers to inform the development of a training program that would help service coordinators and family caregivers collaborate more effectively in providing support to elderly residents to help them remain in an independent living setting.
- Make housing properties and service coordinators aware that family caregivers can be an integral part of the service network and offer them useful skills on how to train and engage with family caregivers.
- Teach family caregivers about the role of the housing property and service coordinator in helping elderly residents remain safely in their apartments and about how they can establish a partnership to facilitate independent living for their family member.

Background

About two million low-income seniors, most of whom are single women in their mid-70s to early 80s, live in federally subsidized independent rental housing (Wilden and Redfoot, 2002). Research shows that older renters in subsidized housing are twice as likely as older homeowners to be disabled (Heumann, Winter-Nelson, and Anderson, 2001). More than one-half of older renters report limitations in activities such as walking and climbing stairs and one-third report difficulty shopping or going to the doctor. In a 1999 survey, managers of the Section 202 Supportive Housing for the Elderly Program reported that 30 percent of vacancies occurred because of transfers to nursing homes (Heumann, Winter-Nelson, and Anderson, 2001).

The Institute for the Future of Aging Services (IFAS) has spent several years exploring the potential of "affordable housing plus services," a residential care model linking subsidized, multiunit, independent housing for lower income older adults with needed services and supports. The goal is to enable residents to "age in place" as their needs change, rather than having to transfer to a higher and more costly level of care. By doing so, the strategy may provide a means for meeting some of the long-term care needs of lower income seniors who want to remain in an independent living setting as they age.

In one study, IFAS examined how three affordable senior housing communities in Colorado helped residents maintain independent living despite their growing frailty and/or disability (Washko et al., 2007). Each community was committed to helping residents age in place and had developed a strategy to foster independent living and support aging residents in the face of changing needs. Two of the three properties employed formal service coordinators to help elderly individuals obtain needed services. One property offered an extensive array of "inhouse" services.

Each property was embedded in a community with a broad network of aging-service providers. In what was a surprise to IFAS researchers, the study found that residents did not report using many formal services but did rely to a significant extent on family caregivers. Interviews with housing staff buttressed the important role families played in these housing settings. Family support was considered crucial to a resident's general well-being and an essential factor in whether the property was able to help residents maintain their independence. Staff also thought that the availability of informal care was uneven and that, as a result, some residents suffered.

Unpaid family caregivers have traditionally been the primary source of long-term care in the United States, and more than 90 percent of long-term care recipients receive some informal care (Cafferata, Sangl, and Stone, 1987; Houser and Gibson, 2008; Spillman and Black, 2005). Research shows almost all informal caregivers value their caregiving roles and feel appreciated by the care recipient (Donelan et al., 2002; Toseland and Smith, 2001). A substantial body of research, however, also demonstrates that caregivers' physical and mental health can be compromised by caregiving responsibilities (Feinberg, Wolkwitz, and Goldstein, 2006). A recent analysis of national data found caregiver stress as a key variable in the decision to place a family member in a nursing home (Spillman and Long, 2007).

Numerous studies have also examined the efficacy of programs to educate and train caregivers (Knight, Lutzky, and Macofsky-Urban, 1993; Pillemer et al., 2003; Toseland, Smith, and McCallion, 2001; Zarit and Terri, 1992). Most of these studies find that caregiver education and training programs have some effect on (1) increasing knowledge about services and resources, (2) improving caregiver well-being, and (3) improving caregiver problemsolving skills (Toseland and Smith, 2001). Researchers have also documented important differences in the caregiving experiences of African-American, Hispanic, and White families (Janevic and Connell, 2001; Navaie-Waliser et al., 2001; Weiss et al., 2005).

Few studies have addressed the role and effect of caregiving in community residential care settings, such as assisted-living and senior housing. According to data from the National Long-Term Care Survey, approximately 30 percent of children with a parent in a community residential care setting, such as assisted living, provide informal care (Spillman and Black, 2005). Port, et al. (2005) analyzed family involvement with residents with dementia in assisted-living settings and nursing homes and found family caregivers of assisted-living residents more involved in helping with instrumental activities of daily living (IADLs) and monitoring medical status and well-being than caregivers with family members in nursing homes. Caregivers of assisted-living residents also wanted more advice and encouragement from the facility to support their caregiving roles (Port et al., 2005). Another study examined effects of a care management intervention to help family caregivers of adult daycare users develop problemsolving and coping skills and better manage the problem behaviors of their family members. The study found the intervention reduced symptoms of depression, enhanced overall perceived well-being among caregivers, and increased the use of formal services by users of the adult daycare program (Gitlin et al., 2006).

Researchers have paid little attention to the role played by family caregivers in helping maintain independent living of aging residents in publicly subsidized housing. The IFAS study of the three senior housing communities in Colorado described previously is one of the few to actually interview families, residents, and housing staff about informal caregiving and its perceived effect

on care recipients. IFAS researchers and their partners are convinced that strategies to link publicly subsidized rental housing communities to both formal services and informal care offers low- and modest-income seniors a new and important choice about where they can live despite increasing disability and declining health. Most of these seniors will not be able to afford assisted living, which largely remains a high-end product (Wright, 2004). Most older adults want to remain in their own homes as long as possible (AARP Public Policy Institute, 2009).

Methods

The goal of this program was to develop and test a program that would expand the capacity of family caregivers of residents in affordable senior housing properties and enhance the partnerships between family caregivers and the housing properties. The research team identified a purposive sample of four properties in the Washington, D.C. area to participate in the pilot program. To participate, the housing property was required to have at least one service coordinator, at least 100 units, and a diverse resident population to capture any ethnic/cultural issues that might need to be considered for the family caregiver-training program. One site was dropped during the program development phase because the property was unable to participate fully in the required activities.

The three remaining pilot sites were HUD-subsidized properties, including two Section 202 properties and one Section 236 property. Section 202 and Section 236 are programs restricted to low- and very low-income individuals that, through different subsidy mechanisms, offer residents affordable rents generally no higher than 30 percent of their monthly income. The median income of residents in Section 202 properties across the country is \$10,236. In Section 236 and other related HUD-subsidized properties, it is \$10,526 (Haley and Gray, 2008). Two of the pilot sites were located in inner cities and one was in a suburban setting. As exhibit 1 shows, the properties were racially and ethnically diverse.

Exhibit 1

Characteristics of Pilot Sites and Residents*

	Property 1	Property 2	Property 3
Location	Washington, DC	Baltimore, MD	Rockville, MD
Property type	Section 202	Section 202	Section 236
Number of units	140	200	250
Residents' age	Under 75: 42% 75–84: 40% 85 and over: 19%	Under 75: 52% 75–84: 38% 85 and over: 10%	Under 75: 11% 75–84: 31% 85 and over: 58%
Residents' race/ethnicity	Latino: 29% White: 51% Black: 30% Asian: 0% Native Hawaiian: 0% American Indian: 0% Other: 6%	Latino: 4% White: 17% Black: 80% Asian: 2% Native Hawaiian: 1% American Indian: 7% Other: 0%	Latino: 0% White: 96% Black: 2% Asian: 1% Native Hawaiian: 0% American Indian: 0% Other: 1%
Mean time in property (range)	6.9 years (6 months–30 years)	7.2 years (6 months–26 yrs)	4.5 years (6 months–21 years)

* Residents' characteristics represent those residents who participated in the self-administered survey (Property 1, n=53, response rate=35%; Property 2, n=96, response rate=49%; Property 3, n=100, response rate=36%).

Family caregivers of residents in the three pilot sites were recruited through a variety of mechanisms. Invitation letters were distributed to every resident living at the property to pass on to their family members and flyers were posted in prominent areas throughout the properties. In addition, the service coordinators contacted family caregivers to inform them of the program and also provided names of family caregivers to the research team who then contacted the caregivers and invited their participation.

Several activities were conducted on the properties to help inform the development of the program, including interviews with five service coordinators (n=5), focus groups with a total of 30 residents, and focus groups with a total of 25 family caregivers of residents. In addition, self-administered surveys were conducted with residents in the participating housing properties (response rate=35 to 49 percent across the three properties) and with family caregivers recruited to participate in the program (response rate=70 percent). By combining the data gathered during these activities with the research on family caregiving and the program teams' prior experience in developing family caregiver-training programs, a workshop curriculum was developed. The program and the components of the workshop curriculum are detailed later in the article.

Family caregivers of residents in each of the housing sites were recruited (n=56) to participate in the pilot program and were randomly assigned to either an intervention group or a control group. Those in the intervention group subsequently attended the caregiver-training workshop, which was held in each of the three pilot sites.

A post-training survey was sent to all family caregiver participants (both intervention and control group) approximately 6 months after the completion of the caregiver-training workshops to attempt to gauge what effect the workshop may have had on the attendees. The small number of surveys returned for both groups, however, was insufficient to draw meaningful statistical conclusions.

The Need for and Status of Family Caregiving in Affordable Senior Housing Properties

Little is known about the health and functional characteristics of residents of affordable senior housing properties. To better understand the residents' potential support needs and therefore the type and degree of engagement that may be required of a family caregiver, the self-administered resident questionnaire included questions about their physical health and functional status. Because no previous study has examined family caregiving in affordable senior housing properties, the program team also attempted to understand the level and intensity of caregiving that was occurring at the pilot sites.

Resident Health and Functional Needs

Of the residents who answered the questionnaire, 60 percent reported they were in good to excellent health, but 40 percent perceived their health as fair to poor. Residents were asked to self-report specific health conditions or problems they were experiencing. Exhibit 2 shows that the most commonly reported health conditions across the three properties were high blood pressure (65 percent of all respondents), arthritis (51 percent), heart problems (30 percent), and diabetes (26 percent).

Because individuals suffering from multiple health conditions tend to have more complex health and supportive care needs, the program team examined the proportion of residents experiencing multiple conditions. As shown in exhibit 3, nearly one-half of the residents across the three properties reported experiencing three or more of the health conditions listed in exhibit 2.

Residents were also asked about their functional status to help understand the levels and types of disabilities residents are experiencing and the need for assistance to compensate for functional limitations. Exhibit 4 presents the proportion of residents reporting functional limitations. Functional limitations are classified into two categories: limitations in activities of daily living (ADLs), such as eating, bathing, dressing, getting in and out of bed, and using the toilet, and limitations in IADLs, such as preparing meals, managing money, shopping, doing housework, and using a telephone. Across the three properties, slightly more than one-half of the residents reported needing assistance with one or more IADL and one-third need assistance with one or more ADL.

Exhibit 2

Health Conditions Reported by Residents

	Property 1 (%)	Property 2 (%)	Property 3 (%)	Combined (%)
Glaucoma	17.0	16.1	19.8	17.8
Wear hearing aid	7.6	7.5	31.3	16.9
Diabetes	24.5	40.8	12.5	26.0
Cancer	5.7	10.8	15.6	11.6
Lung disease	9.4	6.4	8.3	7.8
Heart problem	30.2	30.9	28.1	29.6
Psychiatric problem	7.5	7.5	10.4	8.6
Arthritis	50.9	51.1	51.0	51.0
High blood pressure	45.3	81.9	57.9	64.5
Chronic pain	18.9	24.5	27.1	24.3

Columns do not total 100 percent because residents may have reported multiple health conditions.

Exhibit 3

Residents Reporting Multiple Health Conditions

	Property 1 (%)	Property 2 (%)	Property 3 (%)	Combined (%)
No health conditions	18.9	3.2	9.4	9.1
1 to 2 conditions	41.5	45.9	39.5	42.4
3 or more conditions	39.6	50.9	51.1	48.5

Columns total 100 percent.

Exhibit 4

Residents Reporting Functional Limitations

	Property 1 (%)	Property 2 (%)	Property 3 (%)	Combined (%)
ADLs				
No limitations	73.6	66.3	62.0	66.5
One limitation	15.1	11.2	19.0	15.3
Two or more limitations	11.3	22.5	19.0	18.2
IADLs				
No limitations	52.8	47.2	47.0	48.4
One limitation	11.3	10.1	7.0	9.1
Two or more limitations	35.9	42.7	46.0	42.5

ADLs = activities of daily living. IADLs = instrumental activities of daily living.

Columns total 100 percent for ADLs and for IADLs.

The residents' health and functional status information suggests a large proportion living in independent housing have chronic conditions and/or functional limitations that put them at risk for falls, increased emergency department use, preventable hospital stays, and nursing home placement. Families and service coordinators face these concerns as they attempt to help elderly residents remain in their apartments and communities. These data also provide insight into the types of interventions that could be achieved through partnerships between the families and properties.

The Level of Family Caregiving Occurring in Affordable Senior Housing Properties

The extent of family caregiving involvement with residents in the housing sites was influenced by how the residents came to reside in the properties. In Property 1, several residents had relocated to the area when they were younger for professional reasons and many did not have family in the area. In Property 2, many residents were native to the community and their families also lived in the area. In Property 3, most residents had relocated to the area late in life to be closer to their children. In the resident self-administered survey, 59 percent of residents in Property 1 reported they had family in the area that could assist them when needed compared with 79 percent in Property 2 and 89 percent in Property 3.

Service coordinators at all three properties reported that they see a range of family member engagement, from those who visit residents regularly and frequently to those who come occasionally and those who never visit. In one property, the service coordinator estimated that one-fourth to one-third of residents have a high level of involvement with their family. In another, the service coordinator estimated approximately 35 percent of residents have families that are actively engaged and consistently at the property every week.

Residents were asked in the survey about the level of interaction they have with their family members and the type of assistance they typically receive from them. As exhibit 5 shows, almost one-half of the resident respondents across the three properties have family members call them daily and 38 percent receive a call weekly. In addition, 18 percent receive daily visits from a family member and 42 percent have a weekly visit.

Exhibit 5

Resident and Family Member Interaction

	Property 1 n=44 (%)	Property 2 n=90 (%)	Property 3 n=97 (%)	Combined n=231 (%)
Call				
Daily	36.4	50.0	50.5	47.6
Weekly	38.6	36.7	38.1	37.7
Monthly	18.2	8.9	9.3	10.8
Less than monthly	2.3	3.3	1.0	2.2
Never call	4.5	1.1	1.0	1.7
Visit				
Daily	19.5	25.0	11.5	18.2
Weekly	29.3	35.2	54.2	42.2
Monthly	17.1	25.0	16.7	20.0
Less than monthly	22.0	11.4	14.6	14.7
Never visit	12.2	3.4	3.1	4.9

Columns total 100 percent for calls and for visits.

Family caregivers who participated in the pilot program were also surveyed about the frequency of assistance they provide their family member living at the participating housing sites. Of those surveyed, 18 percent said they assist daily and 44 percent said they help their family member multiple times each week. Nearly all family caregivers talk with their family member on the phone either daily (49 percent) or multiple times a week (46 percent).

Residents were also asked to describe the intensity of assistance they receive from their family members. As exhibit 6 shows, one-fourth of respondents reported receiving “considerable assistance” from their family members. Almost one-third reported that they “do not need assistance”; however, it should be noted that, later in the survey, many of these residents described the types of assistance their family members provide them. When asked how they felt about the level of assistance they receive from their family members, 80 percent of respondents felt they receive “just the right amount,” but 18 percent wished they received “more assistance.”

Residents reported receiving assistance from their family members in several areas. As exhibit 7 shows, the most frequent areas of assistance included transportation (53 percent), shopping or running errands (49 percent), companionship (37 percent), arranging medical care and communicating with doctors (33 percent), and tracking bills or other financial matters (33 percent). In focus

Exhibit 6

Intensity of Assistance From Family Members

	Property 1 n=45 (%)	Property 2 n=87 (%)	Property 3 n=93 (%)	Combined n=224 (%)
Do not provide assistance	18.2	14.9	8.6	13.0
Limited assistance	11.4	10.3	21.5	15.2
Moderate assistance	13.6	16.1	18.3	16.5
Considerable assistance	13.6	27.6	26.9	24.5
I do not need assistance	43.2	31.0	24.7	30.8

Columns total 100 percent.

Exhibit 7

Areas of Assistance From Family Members

	Property 1 n=40 (%)	Property 2 n=76 (%)	Property 3 n=87 (%)	Combined n=203 (%)
Transportation	26.8	63.2	57.5	53.4
Shopping or running errands	25.0	60.5	49.4	48.8
Housekeeping/laundry	15.0	18.4	13.8	15.8
Preparing meals	12.5	19.7	4.6	11.8
Personal care needs	5.0	10.5	3.4	6.4
Managing medications	5.0	11.8	14.9	11.8
Arranging medical care/communicating with doctors	20.0	26.3	44.8	33.0
Tracking bills or other financial matters	12.5	29.0	46.0	33.0
Financial assistance	22.5	18.4	17.4	18.8
Finding and applying for benefits and services programs	5.0	18.4	18.4	15.8
Companionship	35.0	31.6	43.7	37.4
Social activities	30.0	31.6	24.1	28.1

Columns do not total 100 percent because residents may have reported multiple areas of assistance.

groups with residents, many participants stated they were getting a great deal of assistance from their family members, but some had family who were not as active. Some participants noted that their children were working and caring for their own children, and they appreciated that they did not always have a great deal of time to spend with them.

Family caregivers participating in the program also reported assisting their family members with a variety of activities. More than one-half of respondents said they are assisting their family member with six or more tasks. The most common areas in which family caregivers reported providing assistance include socializing, transportation, running errands, monitoring medical care, and managing bills and other paperwork. Discussion in the focus groups with family caregivers echoed that many are providing their family members with an extensive level of support. Some visit daily or multiple times per week to prepare meals, handle household chores, pick up and monitor medications, handle financial obligations, manage and take their family member to medical appointments, shop for or take their family member shopping, and provide companionship. Some family caregivers' description of their family member and the level of assistance they are providing them illustrate that their family member would likely be unable to remain in "independent" housing without their continued support.

Informing the Development of the Workshop Curriculum

To help inform the content of the family caregiver-training program, the program team gathered information from the surveys completed by the residents and family caregivers and from the interviews and focus groups with service coordinators, family caregivers, and residents. Key findings from the team's analyses are summarized in the following paragraphs.

Issues Experienced in the Caregiving Relationship

Service coordinators in the pilot sites were asked about the nature and magnitude of the issues they see residents and family caregivers experiencing in their interactions with each other. Residents and family caregivers participating in the focus groups were also asked about their experiences in their caregiving relationship. Several dynamics were revealed.

Service coordinators believed family caregivers and residents experience tensions over the evolving roles and boundaries between each other. Some family caregivers, the service coordinators believe, are reluctant to step in and do things for their family member because that is not their traditional role in the relationship. They feel uncomfortable telling their family member how to act and are concerned about violating their privacy; these issues become even more prominent as the resident's abilities decline. The service coordinators also reported that residents and family caregivers experience conflicts between the giving and receiving of care.

Participants in both the resident and family caregiver focus groups echoed these challenges. Parents and children frequently mentioned they are experiencing a role reversal in which the child is now acting as the parent and vice versa. Other caregivers, however, were unable or unwilling to assume any power in the relationship, and were constantly bending to the demands of their family members. Some caregivers spoke of how their older family member may be in denial of or embarrassed by their changing conditions and are unwilling to ask for and/or accept help or change their

habits and practices. Several family caregivers described balancing their desire to preserve their family members' ability to make their own decisions while taking responsibility for their safety and the safety of those around them.

Service coordinators also believed that some family caregivers are in denial of their family member's physical or mental decline and do not understand how their functioning will change as they age. Family caregivers want their family members to continue to act and behave as they always have—getting dressed every day, enjoying cooking, socializing frequently, walking at a reasonable pace, etc. Service coordinators thought that caregivers sometimes believe their family member is “being difficult,” or they may be unwilling or unable to recognize that a change in behavior may be a sign of a health-related problem.

Service coordinators observed that family caregivers often have their own responsibilities that can make it difficult to help their family members, especially those needing a greater level of assistance. Many caregivers are employed and have their own families to care for, making it challenging to find adequate time to assist with their family members' needs.

Service coordinators thought that family caregivers in general had limited knowledge about the services available in the community. The survey of family caregivers participating in the pilot program supported this perception. Although about one-fourth were “mostly” or “very” aware of the resources available in the community that could potentially help meet their family members' needs, 62 percent were only “somewhat aware” and 12 percent were “not at all aware.”

Service coordinators were asked about the areas in which they thought family caregivers needed additional knowledge and skills to enhance their caregiving capacity. Coordinators believed family caregivers need a better understanding of the aging process and how that process would affect their family member's physical and mental health and functional status. Service coordinators thought family caregivers often lose patience with family members who may be experiencing a decline and think the family member is “being difficult” or stubborn. Coordinators thought family caregivers need to understand how these changes would affect their ability and desire to partake in their daily tasks and hobbies. They also need to recognize when a change in behavior may be the sign of a health-related issue that needs to be addressed.

Service coordinators also believed family caregivers need to be taught about handling a resident's transition back to their apartment after a hospital stay. Family caregivers often do not know what to ask of the physicians and discharge planners to ensure their family member is, in fact, ready to return home. Coordinators thought that the elderly relative or the family caregiver do not have the necessary knowledge and resources to successfully manage post-hospitalization care. Service coordinators also believed family caregivers need greater awareness in the area of medication management. They thought some need to have better oversight of the resident's medication regimen and recognize that changes in physical and mental health can be related to complications with medications.

Family Caregivers' Perceptions of Their Caregiving Role and Experience

Family caregivers participating in the pilot program were asked in the survey and in focus groups about their perceived role and experiences as a caregiver. Some family caregivers did not identify themselves as “caregivers.” In fact, during the focus groups, several caregivers asked why the

program team was asking them about the assistance their family members needed or that they provided because their family members lived in “independent” living properties. The resulting perception was that they were therefore not caregivers to their family members.

In addition to asking the family caregivers what types of assistance they provided their family members, the survey also asked caregivers about their use of community services and resources to meet their family members’ needs. When asked how often they or their family members access services from the community, 61 percent said “rarely” or “never.” Among the family caregivers who answered rarely or never, the top reasons given for why they do not access outside services were: “I can take care of my family member’s needs on my own” (48 percent), “my family member won’t let anyone other than me assist them” (33 percent), “we can’t afford to purchase services” (24 percent), and “I’m not aware of available services” (24 percent).

During the focus groups, several family caregivers also spoke of how it was their “duty” to assist their family member. They believed that because their family member had raised them, it was now their obligation to help their family member. Some family caregivers also said they were the only person their family member would allow to assist them; their family member was reluctant to have strangers entering their apartment or knowing the details of their lives. A handful of participants, particularly those who appeared to be newer caregivers, seemed unaware of the community resources that could possibly help their family member.

The survey also asked family caregivers about the effect their caregiving experience has had on them personally (see exhibit 8). In general, the respondents did not feel overwhelmingly stressed or burdened by their caregiving relationship, although a sizable proportion did indicate that they were sometimes strained by their responsibilities.

Several family caregivers participating in the focus groups initially indicated they were not burdened by their caregiver role. As the discussions progressed, however, many began to reveal

Exhibit 8

Feelings About Family Caregiving Experience (n=38)

	Never/Rarely (%)	Sometimes (%)	Frequently/Always (%)
Do you feel that because of the time you spend with your family member that you don’t have enough time for yourself?	55.9	41.2	2.9
Do you feel stressed between caring for your family member and trying to meet other responsibilities for your family or work?	44.2	47.1	8.8
Are you afraid of what the future holds for your family member?	26.6	41.25	32.3
Do you feel strained when you are around your family member?	41.2	47.1	11.7
Do you feel your health has suffered because of your involvement with your family member?	84.85	15.2	0
Do you feel you should be doing more for your family member?	32.4	50.0	17.6
Do you feel burdened by caring for your family member?	58.9	35.29	5.8

the frustrations and challenges they experience in their caregiver relationship. As noted previously, several participants believed it was their duty to care for their family member and may have felt they were not allowed to feel burdened by the role. Most participants had never discussed their experiences before, and the conversation with other family caregivers seemed to provide a comfortable opportunity for them to reveal their thoughts and feelings.

Family caregivers also expressed that, although the rewards of caregiving were obvious when they started assisting their family member, rewards became harder to find over time as the interaction shifted from being predominantly social to more in-depth caretaking. Some respondents noted their fear of the future for both themselves and their family members. About one-third of respondents said they are frequently or always afraid of what the future holds for their family member. They are concerned about how their family member may continue to decline over time and what they, in turn, will have to juggle or drop in their own lives to meet their family member's greater demands and needs. Several caregivers were also very anxious about the possibility of their family member eventually moving to a nursing home; some said they would never allow it. In their opinions, nursing homes were bad places, and it seemed they perceived their family member moving to a nursing facility as a sign of their own failure as a caregiver. In some instances, the family member had told the caregiver they would never go to a nursing home. In other instances, however, the family member had told them they would go to a nursing home when necessary, but the family caregiver could not envision allowing the move to happen.

Interaction Among the Housing Properties, Service Coordinators, and Family Caregivers

The family caregiver survey asked caregivers about their expectations of the housing property concerning their family members' needs for services and supports as they age. As exhibit 9 shows, nearly two-thirds of respondents expect the housing property "to tell my family member or me about services that might help my family member." More than one-fourth of participants, however, said, "I have no expectations of them; this is an independent living property."

About three-fourths of survey respondents are aware of the service coordinator and in an open-ended question described the role as providing information on service and resources, helping arrange and coordinate services, or just generally "helping." Approximately one-fourth of respondents are either not aware of the service coordinator or do not know what they do.

Exhibit 9

Expectations of the Housing Property (n=38)

Expectations of the Housing Property	Caregivers Who Selected the Expectation (%)
I have no expectations of them; this is an independent living property	26.5*
To check on my family member and alert me when there are problems	47.1
To tell my family member or me about services that might help my family member	64.5
To help arrange for the services my family member needs	38.2
To provide my family member the assistance they need	14.7
I don't know	2.9

* Percentages do not total 100 percent because respondents were allowed to select multiple answers.

Of the family caregivers who were asked how often they approach the service coordinator for information or advice regarding their family member, 62 percent said “never” or “rarely” and 32 percent said “sometimes.” Of those respondents who said rarely or never, 59 percent said, “I generally already know how to take care of my family member’s needs” and almost one-fourth said, “I can figure out the answer on my own.” Feedback from the service coordinators concerning their level of interaction with family caregivers reflected the survey responses. Although some family caregivers approach service coordinators frequently, coordinators said many never approach them. Service coordinators believe family caregivers see the properties as apartment complexes and do not expect property staff to assist them with issues related to caring for their family member. Family caregivers confirmed this perspective in the focus groups. Several participants said they do not expect housing property staff to assist them or their family member because it is “independent living.” Service coordinators also said family caregivers often do not approach them until a crisis is occurring and often have had no prior connection with them until the crisis.

When asked how much of a resource they consider the service coordinator to be with respect to helping to meet their family member’s needs, 24 percent of survey respondents find them “somewhat helpful” and 36 percent find them “very helpful.” One-third, however, said they “never” ask the service coordinator for help. Family caregivers gave little indication that it was challenging for them to talk with the service coordinator about their family member’s needs, with only 6 percent saying it is “very” or “somewhat” difficult. When asked if they believe the housing property and/or service coordinator can play a role in helping them meet their family member’s changing needs, approximately one-third reported “definitely” and just less than one-half said “somewhat.”

The Family Caregiver Program and Workshop Curriculum

The program team used the previously described findings, information gleaned from a literature review of family caregiver training programs, and their collective experience in developing and testing family caregiver training programs in other settings to develop the format for the training program and the specific curriculum content.

Assumptions

The program team started with two assumptions about the caregiver-training program. It became evident that both of these assumptions needed to be reexamined. The first assumption was that the workshop curriculum would be adapted from an existing caregiver-training program called Partners in Caregiving (PIC). PIC is a successful program that was initially developed to train nursing home staff and family caregivers about communication techniques and conflict resolution skills and has been adapted for other care settings. As a result of the data gathered from service coordinators, residents, and families, however, it became clear that PIC was not appropriately adaptable for affordable housing communities. This conclusion was based on observed differences in the nature of the settings, the relationships between the housing staff and the family caregivers, and the types of issues experienced in the relationship between residents and their family caregivers. Because housing properties are intended for “independent” living, the property staff’s responsibility for residents, and thus the power relationship between property staff and family caregivers, is quite different from nursing home settings where the staff is responsible for residents’

care. Thus, in an independent living setting, the level of tension and conflict between housing staff and family caregivers is minimal. In addition, family caregivers of housing property residents are in a much more active caregiving role because the housing property is not responsible for caring for the resident. Family caregivers are playing a lead role in ensuring the residents get their needs met. They must be much more knowledgeable about how to assist their family member and how to deal with a variety of issues in their caregiving relationship.

The “independent” nature of the housing properties was a recurring subject of discussion in the service coordinator interviews and the family caregiver focus groups. Service coordinators believed their role is to support the resident in meeting their needs and by doing so become an advocate for the resident. In some instances, they thought the advocate-resident relationship could result in conflict during interactions with family caregivers. They also respect residents’ privacy and, therefore, may know little about the resident and their family caregivers if the caregivers do not seek out the service coordinator. Several family caregivers did not identify themselves as “caregivers” because their family member lived in “independent” housing and many did not expect the housing properties to help support their family member because it was “independent” living. For both groups, however, the goal was to help residents remain in their own apartments and to ensure that residents remained active decisionmakers in their own lives.

It became clear that the program’s focus was not easing tensions between family caregivers and property staff; rather, the focus was building mutual understanding between caregivers and property staff to reinforce residents’ ability to safely age in place. Family caregivers contribute their time and knowledge of the resident while service coordinators contribute their technical expertise of available resources and services.

The second assumption was that the program would use a train-the-trainer model in which the service coordinators in the housing property would be trained to deliver the caregiver-training workshop and then would conduct the workshop with family caregivers. With their expertise on available services and resources and established community relationships, service coordinators play a key role in helping residents meet their needs. Because one goal was to enhance family caregivers’ use of this expertise, the program team thought it logical for service coordinators to conduct the caregiver-training workshops both because of their expertise and to help establish a connection between the two groups. A train-the-trainer curriculum was developed and the service coordinators participating in the program attended a daylong, train-the-trainer workshop.

When the time came to conduct the actual caregiver-training workshops, however, it became apparent that the participating service coordinators did not feel entirely comfortable in this teaching role. Service coordinators may feel uneasy delivering the workshop for multiple reasons. The background and training of service coordinators are quite varied, ranging from those without college degrees to those with master’s degrees. Although they may be knowledgeable about services and perform one-on-one education, many may not have prior experience working with family caregivers or delivering group training. The service coordinators in the pilot program viewed themselves primarily as advocates for the residents and seemed to express a concern that interacting with family caregivers in this way may conflict with this role. Service coordinators are also generally managing a large number of residents and may feel they do not have the time to take on an additional program that is not directly focused on residents. In addition, not all senior housing

properties have service coordinators who could deliver the workshop. Although the family caregivers of residents living in properties without service coordinators could benefit from enhancing their caregiving skills and knowledge, some formal entity would have to be hired or partnered with to deliver a training program such as the one developed for this pilot.

Recognizing the lack of willingness among the three pilot service coordinators to deliver the training, the program team members themselves conducted the workshops in each of the three pilot housing sites. Given the small number of sites in the pilot, it is not clear that all service coordinators would be unwilling to deliver the workshop. Exploring alternative methods for delivery of the workshop, however, will be the next phase in the refinement of the curriculum and delivery process.

The Curriculum

When developing the workshop curriculum, the program team considered all the information that had been gathered through the service coordinator interviews and resident and family caregiver focus groups. The team was also mindful of the family caregivers' time constraints and tried to keep the program length at a span that would not be overwhelming. The final program consists of two 2-hour sessions. The intention is to deliver the sessions on different days; however, it is possible to deliver them in a single, longer session. The sessions are designed to be interactive, asking for input from participants and incorporating role-playing activities to practice the knowledge and techniques being taught.

Session one, entitled *Understanding Aging in Place*, focuses on helping the family caregiver understand and build empathy for the challenging tasks that residents and caregivers face. The session addresses the changes and needs that accompany the aging process, the changing role of the caregiver in relation to those needs, and self-care strategies to help cope with the stress of the caregiving role. Session two, entitled *Helping My Resident Age in Place*, focuses on helping the family caregiver identify specific resources and strengthen specific skills that can help support their family member. The session covers the roles of the service coordinator and housing property and how they can work together with the family caregiver to better understand their family member's needs and the available services and resources to help meet those needs and to improve communication skills to enhance positive interaction with their family member.

Satisfaction With Family Caregiver-Training Workshops

According to results from workshop evaluations, participants were overwhelmingly satisfied with the family caregiver-training workshops. Two-thirds gave them an overall rating of excellent and one-third said they were good. When asked how prepared they now felt to help their family member age in place, nearly all participants said they felt well prepared or very well prepared. One participant felt only somewhat prepared but also noted that he had picked up tools in the workshop that he is ready to try. All participants said they would recommend the workshop to others.

Asked what they liked most about the workshop, several participants said they appreciated that they picked up new ideas and techniques to address some of the challenges they face in assisting their family member. Participants also liked the role-playing exercises, which gave them the

opportunity to practice applying what was taught in the workshop to issues they may face with their family member. Several participants also noted that they appreciated the dialogue with other participants and learning that they share common challenges and concerns and that they are not alone in their caregiver experience.

Discussion

The program team's conversations and surveys conducted with service coordinators, family caregivers, and residents affirmed the need for a training program for family caregivers of affordable senior housing residents. Clearly, both service coordinators and family caregivers are providing a tremendous level of support and assistance to the residents in these settings. Although the health and frailty levels of residents range across the properties, a number of residents need a great deal of assistance and would likely be in nursing homes were it not for the support they are receiving, primarily from family caregivers.

Family caregivers do appear to lack awareness of available services and resources in the community and, sometimes, at the housing property. Although many feel they can take care of their family member's needs on their own, they recognize that a time may come when they need to access outside services. Caregivers may also benefit from beginning to accept that it is permissible for them to accept assistance and that they are not obligated to do everything for their family member. Family caregivers also have to navigate difficult terrain in terms of accepting and adapting to the changes in their family member's condition and abilities, while at the same time helping their family members come to terms with their declining independence. Family caregivers can benefit from additional skills in handling these difficult conversations.

It also appears that, in many cases, family caregivers and services coordinators are not regularly communicating with each other. As a result, they are not sharing their respective knowledge and resources and may not be minimizing burdens on themselves or maximizing the success they could have if they worked more cooperatively. For example, family caregivers sometimes must have difficult conversations with their family member that touch on the resident's loss of independence. Caregivers may have to convince family members to stop a certain behavior, accept assistance in particular areas, or discuss the potential need to move to a higher level of care. Service coordinators participating in the pilot reported they can "play the bad guy" in these discussions and help preserve the relationship between the resident and family caregiver. Service coordinators may also have the expertise to identify behaviors or actions that are actually the result of a medical problem that can be overcome, or they may be aware of resources for additional support that might limit the effect on the family member or forestall a need to move to a higher level of care.

The dynamic interaction between the family caregivers who came together in the program was surprising. It seemed several of the participants did not appreciate that they needed an outlet for talking about their caregiver experiences and challenges before attending the focus groups, but they highly valued the opportunity to share their thoughts and feelings. Many family caregivers assumed natural peer-mentor roles during the focus groups, giving other participants advice on how to deal with their issues. When the focus groups ended, participants asked when the group would meet again and many lingered to talk with each other. None of the family caregivers in the focus

groups had met before and almost all said they did not know other resident family caregivers, aside from seeing people around the building.

In one workshop, the participants noted that they made up a natural support network because of the commonality they share of having a resident in the property and the desire for that resident to remain there. The group could be an opportunity to voice frustrations and challenges and to share information and solutions they have learned that might help each other. Other participants expressed concern for the residents in the properties who did not have family members to help them. Building a family network could possibly bring additional resources to the property assist these residents on occasion or provide other supports to the property.

One challenge in implementing the caregiver-training program is identifying the family caregivers who are less engaged with their family member. An initial goal of the program was to develop a training program that would encourage less active caregivers to increase and enhance the assistance they are currently providing to better meet the needs of their family member. An attempt was made to recruit minimally engaged family caregivers to participate in the pilot program; however, the program team was unsuccessful in this effort. It may require a more targeted appeal from a service coordinator or property staff to entice this type of caregiver. Perhaps the creation of family caregiver peer groups that are active in the property could serve as an avenue for engaging these less engaged family caregivers over time.

Another challenge is identifying the most appropriate trainers to deliver the curriculum. This research found that the service coordinators in the pilot sites were not comfortable in the training role, in part because they were concerned that training families might conflict with their responsibility as advocates for the residents. The coordinators also, however, did not believe they had the skills to conduct the training. As the curriculum development moves from the pilot to the refinement phase, decisions about who should do the training, including whether the curriculum should be delivered by an independent third party, need to be addressed.

Next Steps

Given that nearly 2 million older individuals currently reside in some type of subsidized housing and many are receiving some type of support from family caregivers, this program has the potential to reach a large group of caregivers and elderly residents. The development and dissemination of a successful caregiver-training program could significantly improve the ability of senior housing properties to help their elderly tenants remain in their own homes by minimizing the need for evictions and avoiding more costly transfers to assisted-living facilities or nursing homes. As senior-housing providers experience the aging of their residents and are struggling to meet the needs of an increasingly frail and disabled resident population, supporting family caregivers and strengthening their partnerships with service coordinators may help make “aging in place” a reality for many older adults in communities across the country.

Several next steps have been identified for this program. The program team would like to further refine the caregiver-training workshop curriculum based on the experience of testing the pilot program, feedback from participants, and suggestions from an expert advisory group that was assembled to help guide the dissemination of the program. As part of this process, the team wants

to explore potential community partners for delivery of the training and diffusion of the program. One possibility includes developing a partnership with local area agencies on aging that are already experienced with providing caregiver-training and support programs and with working with senior housing properties. Other potential collaborators include local community groups such as AARP chapters, Red Cross chapters, senior centers, social service organizations, or care managers. These groups represent entities that may already be offering family caregiver-training programs, and partnering with senior housing properties can provide an efficient mechanism for reaching a large group of family caregivers and retaining their participation. After refining the workshop curriculum and exploring different possibilities for disseminating the program, the program team would like to conduct further evaluation to measure the effect of the program on the participating entities.

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Authors

Alisha Sanders is a senior policy research associate at the Institute for the Future of Aging Services, American Association of Homes and Services for the Aging.

Robyn Stone is the executive director of the Institute for the Future of Aging Services and senior vice president for research at the American Association of Homes and Services for the Aging.

Rhoda Meador is the associate director for Extension and Outreach, New York State College of Human Ecology at Cornell University.

Victoria Parker is an associate professor, Boston University School of Public Health, Boston University School of Medicine, and a research scientist at the Center for Organization, Leadership and Management Research, VA Boston Healthcare System.

References

AARP Public Policy Institute. 2009. *Providing More Long-Term Supports and Services at Home: Why It's Critical for Health Reform*. Fact Sheet. Washington, DC: AARP.

Cafferata, Gail Lee, Judith Sangl, and Robyn Stone. 1987. "Caregivers of the Frail Elderly: A National Profile," *The Gerontologist* 25 (4): 352–357.

Donelan, Karen, Craig Hill, Catherine Hoffman, Kimberly Scoles, Penny Hollander Feldman, Carol Levine, and David Gould. 2002. "Challenged To Care: Informal Caregivers in a Changing Health System," *Health Affairs* 21 (4): 222–231.

- Feinberg, Lynn Friss, Kari Wolkwitz, and Cara Goldstein. 2006. *Ahead of the Curve: Emerging Trends and Practices in Family Caregiver Support*. Washington, DC: AARP.
- Gitlin, Laura, Karen Reeve, Marie P. Dennis, Esther Mathieu, and Walter W. Hauck. 2006. "Enhancing Quality of Life of Families Who Use Adult Day Services: Short- and Long-Term Effects of the Adult Day Services Plus Program," *The Gerontologist* 46 (5): 630–639.
- Haley, Barbara A., and Robert W. Gray. 2008. *Section 202 Supportive Housing for the Elderly: Program Status and Performance Measurement*. Washington, DC: U.S. Department of Housing and Urban Development.
- Houser, Ari, and Mary Jo Gibson. 2008. "Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving, 2008 Update." *Insight on the Issues* 13. Washington, DC: AARP Public Policy Institute.
- Huemann, Leonard F., Karen Winter-Nelson, and James R. Anderson. 2001. *The 1999 National Survey of Section 202 Elderly Housing*. Washington, DC: AARP.
- Janevic, Mary R., and Cathleen M. Connell. 2001. "Racial, Ethnic, and Cultural Differences in the Dementia Caregiving Experience: Recent Findings," *The Gerontologist* 41 (3): 334–347.
- Knight, Bob G., Steven M. Lutzky, and Felice Macofsky-Urban. 1993. "A Meta-Analytic Review of Interventions for Caregiver Distress: Recommendations for Future Research," *The Gerontologist* 33 (2): 240–248.
- Navaie-Waliser, Maryam, Penny H. Feldman, David A. Gould, Carol Levine, Alexis N. Kuerbis, and Karen Donelan. 2001. "The Experiences and Challenges of Informal Caregivers: Common Themes and Differences Among Whites, Blacks, and Hispanics," *The Gerontologist* 41 (6): 733–741.
- Pillemer, Karl, Jill Suitor, Charles R. Henderson, Rhoda Meador, Leslie Schultz, Julie Robison, and Carol Hegeman. 2003. "A Cooperative Communication Intervention for Nursing Home Staff and Family Members of Residents," *The Gerontologist* 43 (Special Issue II): 96–106.
- Port, Cynthia L., Sheryl Zimmerman, Christianna S. Williams, Debra Dobbs, John S. Preisser, and Sharon Wallace Williams. 2005. "Families Filling the Gap: Comparing Family Involvement for Assisted Living and Nursing Home Residents With Dementia," *The Gerontologist* 45 (1): 87–95.
- Spillman, Brenda C., and Kirsten J. Black. 2005. *Staying the Course: Trends in Family Caregiving*. Washington, DC: AARP.
- Spillman, Brenda C., and Sharon K. Long. 2007. *Does High Caregiver Stress Lead to Nursing Home Entry?* Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy.
- Toseland, Ronald, and Tamara Smith. 2001. *Supporting Caregivers Through Education and Training*. A technical assistance monograph prepared for the National Family Caregiver Support Program Initiative of the U.S. Administration on Aging.

Toseland, Ronald W., Gregory C. Smith, and Phillip McCallion. 2001. "Helping Family Caregivers." In *Handbook of Social Work Practice With Vulnerable and Resilient Populations*, edited by Alex Gitterman. New York: Columbia University Press: 548–581.

Washko, Michelle, Alisha Sanders, Mary Harahan, Robyn Stone, and Enid Cox. 2007. *Connecting Affordable Senior Housing and Services: A Descriptive Study of Three Colorado Models*. Washington, DC: Institute for the Future of Aging Services.

Weiss, Carlos, Hector M. Gonzalez, Mohammed U. Kabeto, and Kenneth M. Langa. 2005. "Differences in Amount of Informal Care Received by Non-Hispanic Whites and Latinos in a Nationally Representative Sample of Older Americans," *Journal of the American Geriatric Society* 53 (1): 146–151.

Wilden, Robert, and Donald Redfoot. 2002. *Adding Assisted Living Services to Subsidized Housing: Serving Frail Older Persons With Low Incomes*. Washington, DC: AARP.

Wright, Bernadette. 2004. *An Overview of Assisted Living: 2004*. Issue Brief IB 72. Washington, DC: AARP Public Policy Institute.

Zarit, Stephen H., and Linda Teri. 1992. "Interventions and Services for Family Caregivers." In *Annual Review of Gerontology and Geriatrics*, Vol. 11, edited by K. Warner Schaie and M. Powell Lawton. New York: Springer: 287–310.