

# Caregiver Perspectives on Transitions to Assisted Living and Memory Care

Susan G. Kelsey, MS, PhD,<sup>1</sup> Sarah B. Laditka, PhD,<sup>1</sup> and James N. Laditka, DA, PhD<sup>1</sup>

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## Abstract

This study describes family caregivers' experiences moving relatives with Alzheimer's disease or related disorders (ADRD) from their homes to assisted living facilities (ALFs) and subsequently to memory care units (MCUs). We also examined how these experiences differed between caregiver dyad types, such as adult children caring for parents. In-depth interviews with 15 caregivers were transcribed verbatim. Grounded theory identified themes. Constant comparative analysis compared experiences of caregiver dyads. Most caregivers recognized the likely need for future specialized care at the time of the move to the ALF, but did not recall receiving information about transfer policies. The ALF move was harder for spouses, the MCU move for adult children. Assisted living facilities can improve support for caregivers facing a relative's MCU transition through education about advantages of MCU placement and information about transfer policies. Support needs during transitions may differ between adult children and spouses.

## Keywords

Alzheimer's disease, assisted living, caregiving, dementia, memory care

About 5 million people have Alzheimer's disease (AD), with 7.7 million expected by 2030<sup>1</sup> and 11 to 16 million by 2050.<sup>1,2</sup> Nearly 75% are cared for by a family member at home.<sup>3</sup> Caring for someone with Alzheimer's disease or a related disorder (ADRD) can impair the caregiver's health and emotional well-being.<sup>4</sup> Often, the caregiver is an older spouse who may also have impaired health. At other times, adult children provide the care while juggling family needs and employment. Living arrangement transitions are difficult, especially for older adults.<sup>5</sup> Thus, older adults and their families often resist a move to an assisted living facility (ALF). However, the physical and psychological effects of providing care to family members with ADRD often lead to ALF placement. Residents of ALFs with ADRD and their families also often resist a later transition to a specialized memory care unit (MCU), which may be required by the ALF when physical, behavioral, and/or cognitive effects of ADRD make continued ALF residence inadvisable or not feasible.

Memory care units are specialized supportive environments for persons with ADRD. They can be free-standing facilities or located within an ALF, part of the continuum of care in a continuing care retirement community (CCRC), or affiliated with a skilled nursing facility (SNF). According to Mollica,<sup>6</sup> approximately 30% of ALFs have either a separate ADRD unit or are free-standing ALFs dedicated exclusively to residents with ADRD. In South Carolina, where this study was conducted, there are 480 ALFs, of which 80 have separate MCUs; 18 CCRCs that have MCUs with more than 15 beds;

and 185 SNFs, of which 18 have MCUs.<sup>7-9</sup> Features of MCUs in all facility types include higher staff-to-resident ratios, meaningful activities for persons with ADRD, specially trained staff, support groups for family members, a secure or locked unit to prevent elopement (leaving the building or premises without anyone's knowledge), and extra room for wandering.<sup>10</sup>

Little research has examined transitions to ALFs and MCUs from the perspective of family caregivers. The purpose of this study is to describe the decision to move a family member with ADRD from the community to an ALF and from there to an MCU, from the perspective of the primary caregiver. A secondary objective is to begin to understand how caregivers who are spouses or adult children may differ in their experience of these transitions and also how women and men may experience these moves differently.

## Background

Assisted living facilities joined the long-term care continuum in the mid-1980s, as an option for older adults needing help

<sup>1</sup>Department of Public Health Sciences, University of North Carolina at Charlotte, Charlotte, SC, USA

## Corresponding Author:

Susan G. Kelsey, 5 Whistling Swan Road, Hilton Head Island, SC 29928, USA.  
Email: skelsey@hargray.com

with activities of daily living (ADLs) because of cognitive and/or physical decline. By 2001, there were 36 399 licensed facilities, with a capacity for 910 486 residents.<sup>11,12</sup> Between 23% and 42% of ALF residents have moderate or severe dementia.<sup>13</sup>

An appeal of assisted living is its philosophy of adjusting care to meet changing needs, avoiding premature nursing home placement. This expectation to “age in place” may lead caregivers to believe that their family member can remain in the ALF despite declining health and function.<sup>14,15</sup> However, Hawes and Phillips<sup>15</sup> found that 45% of ALF administrators reported that they would not retain residents with behavioral changes such as wandering or difficulty socializing. Thus, aging in place may not apply to ALF residents with moderate-to-severe cognitive decline.

Researchers have examined preventing or delaying transfer of cognitively impaired adults to nursing homes with caregiver interventions<sup>16</sup>; circumstances and behaviors that increase nursing home placement<sup>17</sup>; reasons for transferring a resident from an ALF to a nursing home<sup>18</sup>; and time from MCU entry to SNF placement.<sup>10</sup> Studies have also examined perspectives of residents who transitioned to different levels of care (ALF or SNF) within a CCRC,<sup>19</sup> stress experienced by family caregivers associated with the transfer of a relative to a long-term care facility,<sup>20</sup> and risk factors associated with the ALF to SNF transition.<sup>21</sup> Seven qualitative research studies have examined transitions from ALFs. They have used face-to-face interviews or interviews in combination with observation, discussion, and participation in resident activities. Of the 7 studies,<sup>19,22-27</sup> only 2 included family caregivers.<sup>22,24</sup> A recent qualitative study explored the decision making of married couples when relocating from the community to an ALF.<sup>28</sup> No research has examined caregivers' experiences with dual transitions: from home to an ALF, and then from an ALF to an MCU. Findings from 2 recent studies suggested that family caregivers' perspectives may help inform improvements in this difficult transition.<sup>29,30</sup>

## Methods

### *Conceptual Model*

The conceptual model guiding this research is based on a typology developed by Nolan and Dellasega,<sup>31</sup> emphasizing perceptions and processes that interact to form 4 distinct types of long-term care admission experiences. This model provides a framework for assessing the success of the decision-making process used when admitting older adults to long-term care facilities from the perspectives of family caregivers and care receivers. This model has been applied to evaluate satisfaction with nursing home placement in the United States and the United Kingdom.<sup>31</sup> In this study, we apply this framework to examine transitions from ALFs to MCUs. This framework consists of 4 processes: anticipation, participation, exploration, and information. Anticipation refers to proactive planning of a move to a long-term care facility before the need arises. In this study, anticipation represents communication between family members and ALF administrators prior to the transfer,

including how the ALF manages physical and behavioral changes for residents admitted with a diagnosis of ADRD. Participation represents the degree of input family members and residents have in the admission process. In our study, the decision to transition from the ALF to the MCU rests largely with family members, as residents have moderate-to-severe cognitive impairment. The extent to which family members perceive they can participate in the decision-making process is likely to affect their satisfaction with the transfer. Participation may vary depending on the role of the family member, most commonly adult child or spouse. Exploration includes 3 components: (1) determining whether there are other feasible options; (2) recognizing feelings of family members and residents; and (3) locating and visiting facilities for comparison. Information represents information family members have to make an informed decision about the transfer. Information sources include ALF administrators or staff, brochures, and written transfer policies. Additional information sources include support groups, educational programs, physicians, social workers, nurses, geriatric care managers, and other professionals who specialize in ADRD.

### **Sample**

To be eligible for inclusion, we required that participants had experienced the transition of a family member from the community to an ALF and subsequently from the ALF to an MCU. Fifteen caregivers who shared this important set of life experiences comprise the study sample. Participants were recruited through referrals from ADRD support group leaders and through a recruitment notice placed in the South Carolina Alzheimer's Association (SCAA) newsletter and Website. Support group leaders from both rural and urban areas were contacted, to attempt as much as possible to secure a diverse sample. A total of 21 support group leaders were contacted. Of these, 5 were in rural areas and 16 in urban (metropolitan statistical) areas.<sup>32</sup> The first author made 6 in-person recruitment presentations to support groups. In all other instances, the group leader discussed the study with the group members.

### *Interview Procedures*

The authors developed an in-depth interview script. To ensure the questions were clear and appropriately sequenced, the interview script was pretested with 1 health care professional and 1 former caregiver; both had experienced the transition of a family member from the community to an ALF and subsequently from the ALF to an MCU. The interview script consisted of openended and semistructured questions that encouraged caregivers to speak at length about topics related to the ALF and MCU transitions; it is summarized in Table 1. The interview script included several questions about participants' characteristics. All interviews were audiorecorded, with the participants' permission. The study was approved by the Institutional Review Board at the University of South Carolina.

**Table 1.** Caregiver Perspectives on Moves to Assisted Living and Memory Care: Caregiver Discussion Guide

1. Tell me how you decided to move your [spouse/parent/loved one] into an assisted living facility.
2. Why did you select that particular assisted living facility?
3. When your [spouse/parent/loved one] was first admitted to the assisted living facility, did you think they might someday need specialized care for dementia?
4. When your [spouse/parent/loved one] was first admitted, what did the assisted living facility tell you about their policy about moving residents with dementia?
5. Tell me how you were informed that your [spouse/parent/loved one] would have to move from the assisted living facility to a memory care unit.
6. Tell me about your reaction when you heard that your [spouse/parent/loved one] needed to be moved from the assisted living facility.
7. How did your expectations about memory care units compare with your [spouse's/parent's/loved one's] actual experience there?
8. If you were talking with a family who was admitting a loved one with dementia to an assisted living facility, what suggestions would you give them?
9. If you were talking with a family with a loved one who is moving from an assisted living facility to a memory care unit, what suggestions would you give them?

The first 7 interviews were in person. The remaining 8 interviews, which were conducted at considerable distance (>50 miles), were conducted by telephone. The first author conducted all interviews. To help ensure that the 2 interview modes did not influence the results, we used a consistent interview script, including introductory comments and an interviewer debriefing evaluation immediately after the interview was conducted. Within 2 to 3 days following each of the first 3 phone interviews, the first and second authors reviewed the interview content and participant responses, comparing the content and participant responses with those of participants in the in-person interviews. There was no evidence of differences in the qualities of interactions between the in-person and telephone interviews or in the results in terms of themes.

### Analytic Procedures

Descriptive statistics summarized demographic information about the caregivers and family members. Recordings were transcribed verbatim into Microsoft Word. To ensure accuracy, transcripts were then compared to the recordings word-for-word. Analysis of the interview transcripts used grounded theory.<sup>33</sup> The transcripts were read and coded for thematic analysis, initially by the first author.<sup>34</sup> This involved an iterative process of reviewing each transcript for major ideas mentioned by the participants, linking these ideas by category within each transcript, and then analyzing these data for common attributes or themes. A codebook, developed from the interview content, categorized and organized concepts. The “axial coding” process<sup>33</sup> was performed to connect code categories and to look for relationships that could reasonably be taken to represent common themes. To identify and examine the distribution and relationships of themes by caregiver dyad type, the authors developed conceptual matrices<sup>35</sup> in which content was organized across 3 dyad types of caregivers and care recipients: spouses, women–men (and men–women), and parent–adult child. The constant-comparative method<sup>36</sup> identified similarities and differences across 3 dyad types of caregivers and care recipients. Triangulation was used to limit bias,<sup>37</sup> with both the first and second authors independently analyzing the qualitative data. To reduce potential researcher

bias and subjectivity, we used a standardized codebook and regular reviews by another reviewer.<sup>38</sup>

## Results

### Characteristics of Caregivers

Caregivers’ characteristics are shown in Table 2. Of the 15 caregivers, 11 were women; 2 were spouses, 1 was a sibling, and 8 were daughters. Of the 4 men, 2 were spouses and 2 were sons. Spouses and adult children averaged ages 84.0 and 58.1, respectively. Most caregivers were highly educated. The sample was drawn from 2 broad geographic areas of South Carolina: the western portion of the state (the “Upstate,”  $n = 5$ ) and the coastal area (the “Low Country,”  $n = 10$ ). Ten participants were recruited through support group leaders, 5 through the Alzheimer’s Association.

Table 3 shows additional details about the caregiver dyads: 7 care receivers were deceased by the time of the interview, while 8 remained in MCUs. Of the 10 parent–child pairs, there was 1 father–daughter dyad, 2 with mothers–sons, and 7 with mothers–daughters. Of the 4 spousal pairs, 2 of those with ADRD were wives and 2 were husbands. One wife and 1 husband were in MCUs at the time of the interview; the other 2 were deceased. On average, the care receivers had been in ALFs for 22 months and in MCUs for 24 months.

### Thematic Analysis

The sections that follow describe themes identified by the analysis and similarities and differences among caregiver dyad types.

### Reasons for the ALF Move and Experiences With It

Most women as well as most children said that the family member with ADRD was moved to an ALF because it was a better or safer place. Adult children were concerned with their parents’ safety regarding medication management, bill paying, and meal preparation, as well as their anxiety, forgetfulness, confusion, and wandering. One daughter said, “I think it became safety and health-related as to why I needed to move

**Table 2.** Caregiver Perspectives on Moves to Assisted Living and Memory Care: Characteristics of Caregivers<sup>a</sup>

Characteristics	N
Gender	
Female	11
Male	4
Caregiver's relationship to person with ADRD <sup>b</sup>	
Husband	2
Wife	2
Son	2
Daughter	8
Sibling	1
Age	
Average age of spouse (range) N = 4	84.0 (78-89)
Average age of adult child (range) N = 10	58.1 (50-67)
Age of sibling	63
Region of state	
Coastal/low country	10
Upstate	5
Education	
Doctoral degree	2
Master's degree	4
Bachelor's degree	6
Two years undergraduate	1
High school graduate	2
Referral source	
Support group leader	10
South Carolina Alzheimer's Association	5
Type of interview	
In-person	7
Telephone	8

<sup>a</sup> Source: interviews conducted with caregivers, 2008 (N = 15).

<sup>b</sup> Alzheimer's disease and related disorders.

her." Another said, "We weren't comfortable with her giving herself her meds and cooking for herself." All parents were living independently at home at the time of placement, excepting the parent of 1 adult child caregiver. Many adult children did not live in the same city as their parents, making oversight difficult. An adult child commented:

I hired a home assistant liaison person to come a couple of days a week, check on my mom, check on her pill medication, check to make sure that she was eating . . . and got feedback from them that she needed more and more care.

Spouses spoke of increased burden leading to the ALF move. One husband and one wife each made the decision due to health-related issues. The husband noted that he "ended up in the hospital with a stress-related heart condition." The wife had an elective surgical procedure and made arrangements in advance to place her husband in an ALF while she was hospitalized. Another husband made the decision to place his wife in an ALF due to cognitive decline: "I could see that her mind was not working properly and that she was getting confused about a lot of things."

**Table 3.** Caregiver Perspectives on Moves to Assisted Living and Memory Care: Characteristics of Caregiver Dyads<sup>a</sup>

Characteristics	N
Gender of caregiver (interviewee)	
Female	11
Male	4
Gender of care receiver	
Female	11
Male	4
Type of caregiver dyad (care receiver-caregiver)	
Husband-wife	2
Wife-husband	2
Parent-adult child	10
Mother-daughter	7
Mother-son	2
Father-daughter	1
Brother-sister	1
Number of participants in each dyad analyzed	
Husbands-wives	2-2
Adult children-spouses	10-4
Men-women	4-11
Status of care receiver	
Alive, living in memory care unit	8
Deceased	7
Length of time residing in assisted living facility (months)	
Mean	22
Median	24
Range	2.5-60
Length of time residing in memory care unit (months)	
Mean	24
Median	13
Range	4-84

<sup>a</sup> Source: interviews conducted with caregivers, 2008 (N = 15).

Over a third of the adult children mentioned that their parents moved into ALFs voluntarily. One stated, "And then the second time we took her back [to the ALF] for just a tour, we were walking out and she said then that she was ready to move in." Other reasons mentioned for moving into an ALF included self-neglect and sudden crisis.

Only a few adult children mentioned that moving their parents into ALFs was extremely difficult for them. However, all of the spouses said that the move was very emotional for them. A husband commented:

It's a traumatic experience to take your wife, and she's lived with you for over a half a century, and you're going to put her in a facility . . . Mother, son or daughter is different than husband and wife. Husband and wife's a totally different relationship.

### Reasons for Selecting a Particular ALF

Two themes were identified. The majority chose the ALF because they liked the facility or because of its proximity to

their home. “When we walked in, it was bright. It was sunny. There were activities. It was a happy place.” Comments regarding convenient location included: “I could go over there in five minutes and take care of him. Convenience was very important.” These same 2 reasons for selecting the ALF were given by at least a third of the female caregivers and half of the male caregivers. Half of the spouses chose the ALF because it was part of the CCRC where they lived.

### *Recognized Need for Future Dementia Care on Admission to ALF*

Most caregivers said that they had recognized there might be a future need for specialized dementia care when they admitted their family member to the ALF. However, half of the caregivers had expected their relative to remain in the ALF, even when specialized care might be needed; 1 spouse did not even know about MCUs at the time of the ALF admission. As 1 wife stated:

But it came as a shock when they told me that he really needed to leave and needed to be in a facility that could handle Alzheimer’s. He was no longer appropriate for that unit. And I had the option of putting him in skilled nursing, but I knew that was not appropriate.

Other spouses concurred. “I just thought ‘she’ll be here and when she needs more help, they’ll provide it for her here.’” “Well, I knew he needed specialized care, but I didn’t know there was a place . . . until the social worker [at the ALF] took me aside one day and she said, ‘Did you know that there are places you could take your husband where they care for Alzheimer and dementia people exclusively?’ And I said, ‘No, I didn’t know that.’”

Although the majority of the adult children recognized the potential need for specialized dementia care in the future, only a few selected an ALF with an attached MCU specifically for that reason. One daughter commented, “But it came down to, I think, for me, number one, knowing that I would move her one place and if there was an option that she needed to go into more care that it would be available.”

### *Transfer Policy From ALF Described on Admission*

A majority of caregivers said they were not informed at the time of the ALF admission about the policy for transferring residents with advancing dementia nor were they given written information about the transfer policy. This included most of the spouses. A spouse put it this way: “There wasn’t that clear connect between where I placed her and what the next step would entail . . . Maybe somebody mentioned it, but it certainly wasn’t clear to me.” Some spouses and adult children could not remember whether a discussion was held or written information provided. Most men said they did not receive verbal information and could not remember whether they were given written information.

### *Informing Caregivers of the Need for the MCU Move*

There were no differences in the ways that adult children or the 1 sibling were informed of the need for the MCU. Assisted living facilities staff members initiated the conversation. An adult child described the process:

They talked to me about it, but I ultimately decided to move her mainly for her own safety, because she was getting dressed in the middle of the night and thinking she had to go to work . . . and trying to get out of the building. So it was for her own safety, but it was at the initiation mostly from the staff.

Spouses reported that they were informed by a single staff member, by a physician, or in a formal conference with the ALF staff.

### *Caregiver Reaction to Transitioning From ALF to MCU*

About half of the women and men said that the thought of moving their family member from the ALF to the MCU was traumatic. Almost all of these respondents were adult children. Many adult children also said they experienced denial and anger. One daughter said, “It was like somebody slapped me in the face, okay? Because I had not really projected [the move into an MCU].” Another daughter commented:

No, I didn’t want it to happen, and . . . I had not even been in that facility [the MCU wing]. I went back there and took a look at it and said, ‘Oh, my Mom’s not ready for this.’ It really is like I wasn’t ready for this.

A few caregivers said it was necessary to have a neutral person validate the move. As one adult child explained:

I hired [name of person] to go in and tell me it wasn’t true. ‘My Mom really doesn’t need to be in there.’ That’s what I really wanted to hear . . . to help me make the decision before we actually let go of her . . . I felt like I needed another person that was not a staff person to tell me.

The spouse caregivers had diverse reactions to being told the MCU move was needed. However, most commented that this transition was not as traumatic as the move into the ALF. A husband said, “Well, I agreed, because I was aware, I observed, and saw the actions that were going on [with my wife].” A wife expressed gratitude at knowing that her husband was going to a place that was more suitable for his needs: “Made me feel good to know there was another place where he might be happier.” Regarding the move into assisted living for her husband, she said, “I was not prepared at all,” but then said about the move to an MCU, “that was good news for me.” The remaining wife had a negative reaction to the MCU move, commenting, “I had some anger about it with [ALF name]. But I guess deep down in my heart I knew it was going to happen anyway.”

### *Expectations of Transitioning to MCUs*

Caregivers reported their expectations about the MCU move and compared these expectations to their actual experiences. Three themes characterize responses of all caregiver dyad types. In the first, the majority of respondents said they were satisfied with care provided by the MCU's. A spouse said: "I'd say they even surpassed my expectations. I thought they did a wonderful job . . . one special nurse that took care of him was such a loving, caring young woman. She was wonderful." A son stated: "They've met or exceeded the expectations that I had."

In the second theme, the majority of caregivers retrospectively recognized that the MCU move was the correct decision. A daughter commented, "Once we were there for a short time, . . . and he was settled in and I was emotionally . . . settled in, I began to see that he was probably right where he ought to be." Another daughter said:

I know my mother did so much better. She was just the queen bee when she moved into [the MCU], because she was . . . the top of the totem pole. And she could help other people and she was happy again.

In the third theme, most caregivers reported that the family member adjusted well. Comments highlighting this included: "It was early on . . . a difficult transition for my mother. But it really didn't take very long for her to adapt." "I guess my mother handled it better than I thought she would." "Initially I felt that my mom shouldn't have been there. But that was because I had to accept it. It was really all about me accepting it, and I can look back now and see that."

### *Suggestions for Moving a Family Member With ADRD Into an ALF*

About a third of women and a third of adult children said there was an advantage to ALFs with attached MCUs, because of the ease of transitioning to an MCU in the same building. Some had determined this before the ALF admission; others understood this retrospectively. A daughter commented:

I'm really so grateful that they were one building. The trauma of having to think about picking my mom up and moving her to another whole facility . . . I think would be so hard and so overwhelming. And so, if at all possible, that's exactly how I would do it again.

The benefit of moving into an ALF with an MCU was echoed by a wife who commented that she would advise people who had a relative with dementia, "that they go to an ALF that also ran a dementia unit or Alzheimer's unit, so that it could be a step-thing."

Some caregivers suggested that before moving their relative with ADRD into an ALF, among other things, the caregiver should talk with the spouses or adult children of current residents to learn about the facility. A daughter commented:

You go and visit . . . You ask if you could talk to some other people that have lived there for a while . . . You would talk to other family members . . . Go and sit and observe. See what activities they have for them.

A spouse suggested having a neutral party accompany the caregiver to the ALF, to assure that all information is absorbed at this highly emotional time.

If I had to do it over again, with what I know now, I would make sure I have somebody with me. I would talk to [name of support group leader] . . . I'm sure she would have [accompanied me].

### *Concern About Greater Costs of MCUs*

Of the 4 men in the sample, 3 expressed concern about the extra cost of placing their family member in an MCU compared to ALF cost. Two were spouses and 1 was an adult child. One of the spouses explained his thoughts as he was talking with the MCU administrator:

I think you're pretty well focused on housekeeping and, of course, you're also focused on cost. You know, what's your own financial wherewithal? You're thinking of that, too. "Boy, this is costing me a lot of money and will we go through our entire, what we saved for our entire lives, and all that sort of stuff."

The other spouse mentioned the high cost of care for his wife in the MCU, saying: "My wife's expenses here are [number] bucks a month, and it's no small matter." Only two women mentioned financial considerations.

### *Suggestions to Improve the Move From ALF to MCU*

Three themes were identified regarding ways to improve the ALF to MCU transition. About a third of the participants said that ALFs need to prepare, support, and educate caregivers about the stages of ADRD, by offering or referring caregivers to support groups. Although spouses in our sample had all attended support groups at some time, only adult children mentioned their importance. Comments included: "She started that support group [at the ALF], almost right at that time. For me it . . . fell together and I would really highly recommend that they get the family caregivers into some sort of, really push them into a support group of some sort or have it available." One adult child said:

I've been going to an Alzheimer's support group that's sponsored through the state and the local association, and I think that's extremely valuable for people . . . support groups are really helpful because they prepare you for the next step.

Comments in 2 of the 3 themes included important features of the MCU. A majority of spouses and adult children said that a caring staff was very important when selecting an MCU.

Comments included, “I guess number one there is the care. By the time they reach that point, I believe the care is number one and a staff that really is trained and understands Alzheimer’s.”

Another feature of the MCU that was important to caregivers was the presence of meaningful and stimulating activities. Some respondents described a lack of appropriate activities. An adult child said:

Look at the staffing and what type of training they have received. . . . Have they dumbed down the social activities too much? Are they still doing things that are engaging with the person?

## Discussion

Although substantially more people will experience caring for a family member with ADRD as the US population ages,<sup>1</sup> no previous research has examined the transition from home to an ALF and from there to an MCU, from the perspective of family caregivers. This study provided insight about these transitions from individuals who are uniquely qualified to understand ALF and MCU transitions. A secondary objective was to begin to understand how transitions may differ by caregiver dyad type.

A number of findings were common among all caregivers. When family members were admitted to the ALFs, caregivers recognized the likely need for future specialized care. Most did not recall receiving information about the ALF’s transfer policy. A recent study found that most ALF administrators discussed the possibility of transfer orally with family members during the admission process. Only a few ALF administrators reported providing written information on transfer policies to families when admitting a new resident.<sup>30</sup> In another area, caregivers found that family members adjusted well to the MCU. This finding is consistent with perspectives of ALF administrators.<sup>30</sup> They were also satisfied with the MCU care. Retrospectively, caregivers recognized that the MCU move was in the best interest of their family members. Caregivers emphasized that caring staff and meaningful activities were important MCU features. These findings are consistent with a study of ALFs and SNFs, where residents had better quality of life when staff were trained in ADRD care and actively encouraged participation in activities.<sup>39</sup>

There were a number of differences among caregiver types. Spouses, who in this study had been married for many years, said the ALF transition was particularly difficult. This finding is consistent with previous research on spouse caregivers and long-term care placement outside the home.<sup>40</sup> Spouses did not report negative emotions or guilt associated with the MCU transition. They may have made their decision to relinquish living with their life partner, passing what has been called the “vigilance” stage of caregiving,<sup>41</sup> at the time of the move to the ALF. It is possible that they had accepted separation from their spouses in the time since the ALF transition, and now simply wanted the best care, although they did not comment specifically about this aspect of the transition.

Compared with spouses, adult children did not report the same degree of trauma about the ALF transition and found the transition to be satisfactory. The majority of adult children urged their parents to move into the ALFs due to safety issues and need for more oversight. None of the adult children reported resistance from their parents about the ALF move. In contrast to spouses, adult children found the ALF-MCU transition to be considerably more traumatic. Many reported anger or denial, consistent with the grief process that commonly occurs with major adverse life changes. Looking back on the MCU move, all dyad types were surprised that their family member adjusted so easily and viewed the MCU as an appropriate care setting.

Consistent with previous research on benefits of support groups for caregivers of individuals with ADRD,<sup>42</sup> adult children reported that support groups helped them adjust to the MCU move. Adult children also stressed the need for more information about ADRD progression. Spouse caregivers did not mention that support groups were important to them. Experiences of the ALF and MCU moves were more related to family roles, spouse or adult child, than to gender. However, men were more likely than women to emphasize financial concerns regarding the cost of long-term care and MCUs. This could be related to the lifetime roles of men and women who participated in this study. The limited gender differences observed in this study may result from the limited sample of men.

Returning to the conceptual model that guided this research, findings from the current study suggest that all 4 processes—anticipation, participation, exploration, and information—are involved in the ALF to MCU transition process and influence the degree to which family members are satisfied with the transition.<sup>43</sup> Most family members recognized the need for possible future specialized dementia care (or anticipation); however, most said that written or verbal policies regarding transfer criteria from the ALF were not discussed on admission. Because of this lack of information, when the time came for transfer to the MCU, many felt they were not sufficiently prepared. Another aspect of information that was mentioned by one third of family members was the need for knowledge about the progression of ADRD. Many participants said that they would have been better prepared for the transition with more education. Many indicated that support groups play an important role in acquiring this information.

The initial transition to the ALF appeared to be less traumatic for adult children than for spouses. Among the child–parent dyads, often both were involved in the decision. In the spousal dyads, decision making excluded the spouse with ADRD. The reverse occurred during the final decision making for the transfer from ALF to MCU, when adult children found the transition to be more traumatic than did spouses, and felt that their participation in decision-making was limited. All participants were informed of the need for the move by ALF administrators, staff, or physicians. Most indicated that their participation was limited to agreeing to the date or method of transitioning. Greater communication between caregivers and

ALF administrative staff prior to the move may reduce resistance to transitioning.<sup>30</sup> Only a few family members mentioned discussing the transition timing with administrative staff far in advance of the transition; others mentioned administrators who offered to gradually initiate the transfer. This exploration phase for the caregivers was available only in ALFs with MCUs; a few caregivers suggested that the structure of the ALFs with MCUs eased the transition.<sup>30</sup> One caregiver only learned of the MCU option from a social worker at the ALF, who suggested this as an alternative to an SNF. Caregivers whose family members were at free-standing ALFs, or at CCRCs with ALFs but not MCUs, more commonly said that the exploration phase of the transition was difficult. They cited the time pressure to find an alternative residence for their family member as a reason for the difficulty. Most caregivers in this study did not fully benefit from the 4 processes described by Nolan and Dellasega.<sup>13</sup> Some elements were absent from the experiences of most caregivers. Ensuring that all elements are addressed may help reduce stress associated with transitioning from an ALF to MCU.

Several factors should be considered when evaluating these results. All study participants experienced moving a family member from a community setting to an ALF and subsequently to an MCU. These individuals are uniquely qualified to provide insights into ALF and MCU transitions. There are no standard methods to determine adequate sample size for qualitative research. Instead, a key consideration is whether the findings are sufficiently supported so that additional data collection would be unlikely to produce different findings, a phenomenon commonly called saturation.<sup>44</sup> Given the consistency of the findings regarding each type of move for each dyad type, the data appear to have reached saturation. However, we acknowledge that it would be useful to confirm the results of this study through additional research with larger dyad samples of caregivers and care receivers.

We also acknowledge that the sample was recruited through Alzheimer's support group leaders. Results may not characterize caregivers who do not participate in support groups. Another consideration is that caregivers lived in 1 relatively small, rural, Southeastern state. Only about a quarter of caregivers were from metropolitan areas. Options for long-term care in small communities may be limited compared to those in major metropolitan areas. This may explain why some family members were unfamiliar with MCUs and why proximity of the ALF to the adult child's home influenced ALF selection. The average participating caregiver was much more highly educated than the typical South Carolinian. However, ALFs and MCUs are costly, most often requiring private pay. Thus, families using ALFs or MCUs typically have considerably higher socioeconomic status than the general population, including education and income.

Findings of this study have practice implications. Caregivers are often confused and overwhelmed by the options and decisions involved when moving their family member to an ALF or MCU. Hiring a qualified professional, such as a social worker or geriatric care manager, can provide needed

guidance.<sup>45</sup> In another area, the initial choice of ALF could help ease the MCU transition. If the care receiver has ADRD when entering an ALF, family members may want to consider an ALF with an MCU. Respondents suggested that this makes the physical transition easier and avoids the stress of later finding an MCU.<sup>30</sup>

Findings suggest implications for the timing of support given to spouse caregivers and adult child caregivers. Spouses may have more difficulty making the initial decision to place their husbands or wives in ALFs. They may benefit from information and guidance while they are still living with their family member. Adult child caregivers may require more support while their parents are in ALFs, to prepare for possible MCU moves. An adult child may also benefit from seeking a support group before the parent is admitted to an ALF. When ADRD is diagnosed, referral to a support group may be beneficial for most caregivers. As the diagnosis is typically made by a family physician or neurologist, physicians can be instrumental in referring caregivers to support groups. Assisted living facility administrators have an opportunity to provide more information to adult children through support groups and educational programming, to better prepare them for the MCU transition. Doing so may help the adult children better understand the benefits of MCU care. Finally, almost all children and spouses in this study looked back on the transition as the right decision, one that helped their family member. Communicating this knowledge to caregivers who face the MCU transition may give them useful information and comfort.

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