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Research Article

Assisted Living Residents With Dementia: Being Out in the World and Negotiating Connections

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Abstract

Background and Objectives: Persons living with dementia, including long-term care residents, and their care partners emphasize the importance of meaningful engagement and stress the need for activity and opportunities to go outdoors or offsite. Yet, little is known about getting out in this population. Here, our objectives are to (a) identify residents' opportunities for, and experiences with, getting out; (b) understand the significance of getting out; and (c) explain influential factors.

Research Design and Methods: Guided by grounded theory methods, we analyzed qualitative data collected over a 1-year period in 4 diverse assisted living communities. We followed 33 residents with dementia and their care partners. Data include detailed fieldnotes capturing 1,560 observation hours, 114 interviews with residents (where possible), assisted living staff, family members, and other visitors, and record review.

Results: We identified the centrality of “being out in the world and negotiating connections,” which characterizes residents' experiences with the outside world as a process of “working out” engagement with nature, others, and the community. Being out in the world was consequential to well-being and quality of life. Most residents got out at least occasionally; some lacked opportunities. Among residents who got out, most benefitted from ensuing connections. Yet, not all experiences were positive. Being out in the world varied over time and by individual-, care convoy-, assisted living community-, and neighborhood-level factors.

Discussion and Implications: We discuss the implications of our findings for research and practice surrounding meaningful engagement among persons with dementia, including during crises such as the pandemic.

Keywords: Alzheimer's disease, Engagement, Long-term care, Outings, Qualitative research

Meaningful engagement is essential to quality of life and influences individual well-being, including for persons living with dementia (Fazio et al., 2018). As with most people, including this heterogeneous population, engaging in personally meaningful activities can bring enjoyment, promote a sense of self, and facilitate connection to others (Phinney et al., 2007). For these reasons, recent care models and practice recommendations promoted by the Alzheimer's Association (Fazio et al.,

2018), the Dementia Action Alliance (2016) and other advocates, emphasize the centrality of meaningful engagement. Yet, persons with dementia frequently report having little to do and, along with family members, identify lack of meaningful activity as a persistent and critical unmet care need whether living at home (Maranda et al., 2014) or in residential care settings (Hancock et al., 2006; Wood et al., 2009), including assisted living (AL).

In the United States, like many nations, AL communities are increasingly popular residential long-term care options, especially for persons with dementia (Zimmerman et al., 2020). As with others needing support, AL residents are situated within individualized care convoys, or networks, comprised of dynamic constellations of potential care partners including, for example, staff, family members and friends, volunteers, medical practitioners, therapists, and other external providers (Kemp et al., 2013, 2018). Network members contribute to residents' daily lives and care, including engagement opportunities (Kemp et al., 2021). Informal care partners, especially family members, are key engagement partners, but vary in their availability and involvement in residents' lives (Kemp et al., 2018).

Most AL communities have regular activity programming (Harris-Kojetin et al., 2016). Although residents with lower cognitive and physical function participate less relative to those with greater function (Bender et al., 2021; Sandhu et al., 2013), a small, but growing body of research examines the therapeutic value of engagement among residents with dementia occurring inside the care environment (Jones et al., 2020), including music activities (McDermott et al., 2014), animal therapies (Olsen et al., 2019), or social interactions (Theurer et al., 2015). However, limited research exists on the opportunities and experiences that long-term care, especially AL, residents with dementia have for meaningful engagement outside the care setting, including time spent outdoors or offsite.

What little is known about long-term care residents with dementia and time spent in onsite, outdoor spaces, for example, purpose-built gardens, indicates positive outcomes (Marcus & Sachs, 2013). These associations include better quality sleep (Connell et al., 2007), reduced agitation (Edwards et al., 2013), greater orientation to time (Hernandez & Newcomer, 2007; Liao et al., 2018), and decreased usage of pro re nata (PRN) medications (Detweiler et al., 2008). Yet, multiple factors can restrict residents' use of outdoor spaces, such as low staffing levels/availability, poor weather, and a lack of comfortable, convenient seating (Dahlkvist et al., 2014). Furthermore, locked doors intended to provide safety and security can prevent residents from accessing outdoor spaces specifically designed for their use and benefit (Dahlkvist et al., 2014; Hernandez & Newcomer, 2007; Liao et al., 2018).

Using national survey data from residential care communities in the United States, Sengupta et al. (2019) examined activity engagement, including, but not limited to, staff-initiated activities and those occurring within the care setting and offsite. They considered three domains: (a) outings (e.g., dining out, movies, and shopping), (b) leisure activities (e.g., games, arts and crafts, listening to music, exercise, and religious activities), and (c) talking with family and friends. The survey assessed whether residents engaged in these types of activities at least twice monthly. Cognitive status was significantly related to outings. Residents with severe cognitive impairment had 70% lower odds of leaving

the community relative to others and were less likely to talk with family and friends.

A U.K. study investigating what matters most to care home residents with dementia and their family members identified "the need for activities and outings" as "the most prevalent theme overall" (Popham & Orrell, 2012, p. 184). Being unable to leave the care environment can negatively influence a resident's ability to maintain connections with their families (Stadnyk et al., 2013) and surrounding community (Perkins et al., 2012) through participation in meaningful traditions, gatherings, and events. Participation in these community-based activities and relationships is a key component of citizenship (Kontos et al., 2017), yet as research demonstrates, it often is restricted for persons living with dementia, especially long-term care residents.

Despite potential implications for meaningful engagement, quality of life, well-being, and inclusion, little is known about "getting out," which we define as going outdoors or offsite, among AL residents with dementia. We address this significant knowledge gap using data from the 5-year study, "Meaningful Engagement and Quality of Life among Assisted Living Residents with Dementia." Our aims were to (a) identify residents' opportunities for, and experiences with, getting out; (b) understand the significance of getting out; and (c) explain factors that influence getting out.

Design and Methods

We present an analysis of qualitative data from our grounded theory study, which seeks to identify best care practices aimed at recognizing, creating, and maintaining optimal meaningful engagement opportunities for persons with dementia that enhance their quality of life. Institutional Review Board approvals derive from Advarra: Pro00029867, Georgia State University: H19198, and Emory University: IRB00108144. We assign pseudonyms to sites and participants for anonymity.

The research team consisted of 19 gerontologists with training in anthropology, exercise science, human services, nursing, psychology, social work, and sociology. All had training in collecting and analyzing qualitative data, working with people living with dementia, and conducting AL research. Comprised of male and female researchers, the team included undergraduate and graduate students, staff, and faculty researchers.

Study Setting and Participants

We collected data in four diverse AL communities (Table 1) that varied in size, location, resources, and other characteristics that we believed would influence resident engagement. Across sites, we began purposively selecting residents living with dementia, seeking maximum variation in characteristics, including age, race, levels of cognitive and physical function, and health conditions.

Table 1. Select Study Setting Characteristics by Site

Characteristic/Site	Rosie's Place	The Gardens	Holly House	Parkview Manor
Resident capacity	6	36	52	100+
Ownership	Private	Corporate	Private	Corporate
Location	Urban residential area	Large suburban area	Small town setting	Large suburban area
Outdoor access	Unrestricted	Access with alarm code	Access with alarm code	Access with alarm code
Onsite outdoor amenities	Outdoor seating Gazebo Back deck	Outdoor seating Garden area Courtyard Walking paths Gathering place All memory	Outdoor seating Garden area Courtyard Front porch	Outdoor seating Garden area Courtyard Fish pond Walking paths
Memory care unit(s)	No		Yes	Yes
Monthly fees (US\$)	2,250–3,000	5,050–6,175	3,450–4,850	3,500–6,550
Engagement staff and formal programming	No	Yes	Yes	Yes
Onsite transportation/wheelchair accessible	No	Yes/Yes	Yes/No	Yes/Yes

As data collection progressed, we used theoretical sampling (Corbin & Strauss, 2015) to identify and recruit additional residents who provided information into different engagement scenarios. For example, we learned that differences in residents' care needs and partners' abilities created differences in engagement opportunities, including patterns of getting out. Table 2 provides select care needs and health characteristics of the 33 resident participants. We selected 100 care partners purposively based on their knowledge of and involvement in residents' daily life and care, and through theoretical sampling to optimize perspectives and understand engagement-related concepts we were identifying in the field. Care partners included 48 AL administrators and staff, 36 family members and friends of resident participants, 12

Table 2. Resident Participants' Select Care Needs and Health Conditions ($N = 33$)

	<i>n</i> (%)	<i>M</i> (<i>SD</i>)
<i>Resident care needs</i>		
Incontinent/accidents (bowel or bladder)	20 (61)	
Unable or needs help using the toilet	22 (67)	
Unable or needs help eating	14 (42)	
Unable or needs help transferring	19 (58)	
Unable or needs help climbing stairs	19 (58)	
Unable to ambulate	8 (24)	
<i>Assistive devices</i>		
Uses a walker	16 (48)	
Uses a wheelchair	15 (45)	
<i>External care use</i>		
Receives hospice	13 (40)	
Assistance from private care aides	3 (9)	
<i>Health conditions</i>		
<i>Comorbidities ($n = 31$)^a</i>		
High blood pressure	16 (52)	
Heart disease	5 (16)	
Depression	10 (32)	
Osteoarthritis	5 (16)	
Diabetes	5 (16)	
Emphysema, chronic bronchitis, COPD	1 (3)	
Cancer	1 (3)	
<i>Dementia diagnosis</i>		
Alzheimer's disease	11 (33)	
Lewy body	1 (3)	
Vascular	2 (6)	
Unspecified	19 (58)	
MoCA ^b ($n = 14$; range = 1–19)		10 (4.7)

Note: COPD = chronic obstructive pulmonary disease; MoCA = Montreal Cognitive Assessment.

^aTwo residents passed away before the chart abstraction process and are excluded from this table.

^bTotal possible scores range from 0 to 30. Score interpretation is as followed: severe cognitive impairment, <10; moderate cognitive impairment, 10–17; mild cognitive impairment, 18–25.

^c14 of 33 residents were able to complete the MoCA.

external workers, and four volunteers (see Table 3 for participants' select characteristics).

Data Collection

Our 1-year data collection period occurred between 2018 and 2019. We used participant observation, semistructured qualitative interviews, and review of resident participants' AL records. Record review provided details about, for example, residents' social and medical histories, diagnoses, medications, and care needs. We used these data to describe the sample and for contextual information relevant to understanding engagement patterns. Overall, we made 502 site visits, representing 1,560 hours of participant observation, recorded in detailed field notes. To understand the ebb and flow of daily life, we varied site visits by day of the week, time, and locations within the community, including outdoor areas, and joined recreational outings organized by care communities. We conducted 114 formal interviews focused on resident history, daily life, care routines, connections with others, and engagement patterns, including opportunities and experiences associated with going outside or offsite. Fourteen of

our 33 resident participants had the physical/cognitive capacity to participate in semistructured interviews. We spoke with and observed all residents during our year of data collection, which enhanced familiarity and knowledge. Following grounded theory's iterative approach to data collection and analysis (Corbin & Strauss, 2015), we modified interview and observation guides based on ongoing analysis. For example, in the first weeks of participant observation, we recognized the need to examine "getting out" as a dimension of engagement, including understanding its significance, influential factors, and outcomes, and modified our data collection accordingly to add relevant questions and observations (Table 4).

After extending invitations to participate, researchers explained the study, procedures, risks, and participants' rights. We obtained written permission from administrators to enter sites and written informed consent prior to in-depth interviews with care partners. For resident participants, we obtained proxy consent from a legally authorized representative. We sought verbal assent before formally interviewing residents and on an ongoing basis before speaking with all participants and others in the setting.

Table 3. Select Participant Characteristics by Participant Type

Participant demographics	Residents (N = 33)	Informal care partners (N = 40)	Formal care partners (N = 60)
Mean age, years (SD)	86 (7)	65 (13)	47 (14) ^a
Gender, <i>n</i> (%)			
Female	8 (85)	25 (63)	56 (93)
Male	4 (12)	15 (38)	4 (7)
Transgender	1 (3)	—	—
Race, <i>n</i> (%)			
Asian or Asian American	—	1 (3)	1 (2)
Black or African American	7 (21)	7 (18)	38 (63)
Mixed or multiple races	—	—	2 (3)
White or European American	26 (79)	32 (80)	16 (27)
Other	—	—	2 (3)
Refused	—	—	1 (2)
Marital status, <i>n</i> (%)			
Married	6 (18)	34 (85)	26 (43)
Widowed	21 (64)	2 (5)	3 (5)
Divorced/separated	4 (12)	2 (5)	7 (12)
Never married	2 (6)	1 (3)	19 (32)
Cohabiting or other	—	1 (3)	2 (3)
Refused	—	—	3 (5)
Education, <i>n</i> (%)			
Less than high school	1 (3)	—	1 (2)
High school diploma	10 (30)	2 (5)	11 (18)
Some college	8 (24)	9 (23)	16 (27)
College	9 (27)	12 (30)	19 (32)
Postgraduate	4 (12)	17 (43)	12 (20)
Unknown or refused	1 (3)	—	1 (2)

^aFive formal care partners refused age questions.

Table 4. Sample Interview Questions and Observation Guide Topics

Main question	Topics for probes (not exhaustive)	Associated Guide
1. When and where do most activities take place?	Areas within the community; outside the community; seasonal variation	Activity Director/Engagement Coordinator Guide Administrator Guide
2. Can you please talk about the role outings play in the activity/engagement programming?	Frequency; participants; nature of outing; transportation	Activity Director/Engagement Coordinator Guide Administrator Guide
3. What activities or situations do you think residents with dementia find most meaningful or valuable?	Kinds of activities; social interactions; sitting outside; variations in gender, age, race, religion, socioeconomic situation, health; variations in types of dementia and levels of impairment	Activity Director/Engagement Coordinator Guide
4. How would you characterize the involvement of residents' family members and friends in their daily lives, care, and engagement?	Typical caregiver; frequency of visits/contact; activities; variability; role in outings; impact of dementia in interactions	Administrator Guide
5. What kinds of activities do residents do together?	Activity types; participants; location	Direct Care Worker Guide
6. How does the physical layout of the home influence residents' interactions with other residents?		Direct Care Worker Guide
7. Do you ever take your [family member/friend] out of the home? If no, what are the barriers? If yes (see probes).	Destination; type of activities; importance; variability by season or holidays	Informal Care Partner Guide
8. What are your attitudes toward community activities and outings?	Informal Care Partner Guide	Informal Care Partner Guide
9. Do you go places outside of [Name of the community]?	Importance; destination; participants	Resident Guide
10. Is there an outside "communal" area for residents (e.g., patio, deck, open courtyard, gazebo, garden, or lawn area)? If so, describe the area.	Inviting; safe; condition; seating; tables; utilization (residents or nonresidents)	Observation Guide
11. Is there an area of sidewalks, paths, or other walkways where residents can take a walk? If so, describe the area.	Seating for rest; safe for mobility (wide, smooth, easy to navigate, stepless)	Observation Guide
12. Is resident access to outside restricted? Yes/No.		Observation Guide
13. Describe the activity taking place.	Sequence of events; location; participants; interactions; outcomes; variation in outcomes	Observation Guide

Data Analysis

We used the qualitative data analysis program NVivo 12 (QSR International) to store our data and facilitate coding and analyses. We began coding during data collection using a set of codes derived from our research questions, the literature, and field observations. Codes included, for example, "outside," "offsite," and "residents' behaviors/responses to engagement." These codes allowed us to sort the data into broad categories and facilitated the higher-order coding reported here and that followed the data collection.

Following the grounded theory method (Corbin & Strauss, 2015), we engaged in a three-pronged coding

process analyzing data relevant to getting out. We began with initial coding, reviewing data segments relevant to residents leaving the care environment. Initial codes included, for example, "joyride," "connecting with nature," "connecting with others," "family-initiated outing," and "community event." Next, during axial coding, we linked initial codes to one another and to categories designating context, including influential factors. For example, we found that residents' physical and cognitive function, care partner beliefs and resources, and care community size, location, and staffing influenced getting out. Finally, we engaged in selective

coding; we integrated our findings across residents and sites over time, refining and organizing our concepts around the core category, “being out in the world and negotiating connections.”

Consistent with the grounded theory method, we revisited the literature with our results. Han et al.’s (2016, p. 118) meta-ethnographic analysis of qualitative research involving persons with dementia identified “being connected” to “self,” “the environment,” and “others” as underlying motivations for participating in activities. Although focused on “getting out,” our analysis also identifies “connection” as an overarching explanatory narrative. Our core category, “being out in the world and negotiating connections,” expands the work of Han et al. by viewing getting out among residents with dementia as a dynamic process involving negotiation between residents and engagement partners that *creates, maintains, or diminishes* residents’ personhood, social participation, and relationships with others and the physical world beyond the care setting and has implications for inclusion, exclusion, and, hence, quality of life. Connection or connecting is essential to understanding the significance of getting out or not doing so.

Findings

Being Out in the World and Negotiating Connections

Patterns of getting out, including opportunities and accompanying experiences, revealed much about resident engagement. As illustrated in Figure 1, our core category conceptualizes getting out among residents with dementia as a process that involves being present in and engaging with the world beyond the immediate care setting and their dementia diagnosis in consequential ways. Being out in the world involved residents observing, experiencing and sensing, or participating and consequently, negotiating (i.e., navigating or working out) connections with nature and the outdoors, other people, including their family, friends, fellow residents, and others they encounter, and wider community spaces/events/settings (e.g., religious, spiritual, and cultural). In family members’ words, being out in the world as “regular people” doing “normal things” could reinforce residents’ personhood and identity and represented opportunities to connect with the past and present and enhance social, physical, spiritual, and emotional engagement beyond the care context. Yet, getting out sometimes led to distress and disruption that alienated residents from social and physical environments, and meaningful connections were not successfully negotiated, which left certain residents marginalized or excluded from participating or connecting. Experiences associated with being out in the world and negotiating connections, including both positive and negative ones, varied by community, care partner, resident, and over time and were influenced by a host of intersecting factors at multiple levels.

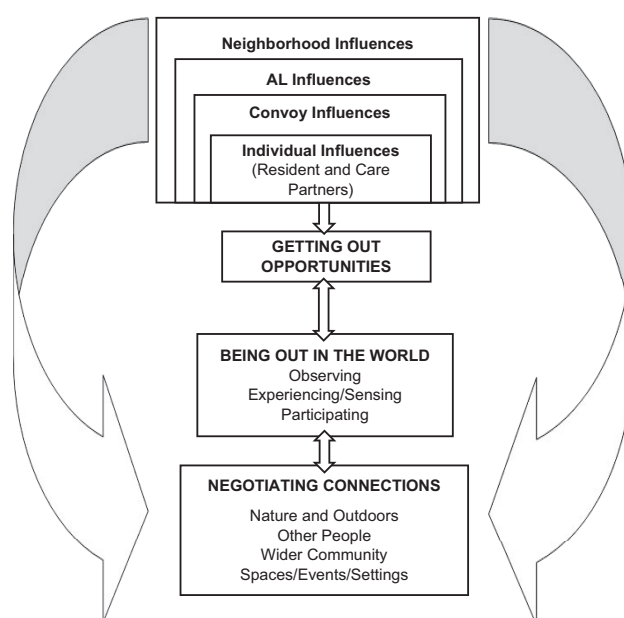


Figure 1. Being out in the world and negotiating connections. AL = assisted living.

Getting Out Opportunities

Most residents with dementia went out to some extent, including 20 participants. Of this group, 12 had regular and frequent opportunities to go outside or offsite with staff and family members, four relied almost exclusively on AL staff because family members were not local or found it too difficult to transport the resident or manage behaviors, and four were excluded from most AL outings because of care needs and mobility challenges, which family members were willing to navigate without staff assistance. Certain residents, including 13 participants, rarely or never went offsite or outside. All were on hospice and/or had a private care aide and were perceived by care partners as too difficult to take out. Most were physically frail and unable to ambulate independently, including seven residents who died during the study.

Going Outside and Negotiating Connections

Among residents who went out in the world, being outdoors was common. Residents accessed onsite outdoor areas (Table 1) for a variety of activities, including independent and group activities, self-directed activities, and those facilitated by staff, family members, and, in rare instances, other residents. Being outside was valued by residents because of the pleasant sensory experiences, including sights, sounds, smells, feeling the sun or breeze, and connecting with nature, which frequently had a calming influence. This field note excerpt illustrates one Gardens’ resident’s experience:

Sarah was trying to open the door and asked me [a researcher] if I knew how to get out. I told her there was

a code and said I would go ask a staff member if I could take her out. I asked [LPN] and she said I could as long as I brought her back in. I took her out and she immediately began to be very excited about being out. She said, "This is so exciting. I want to be out at least one hour." We [went] around looking at the flowers. She commented several times about the bees. She wanted to sit in the sun, saying, "I love to sit in the sun."

Gladys, a Rosie's Place resident, similarly explained, "There's nothing like getting some good fresh air and sun" rather than being "cooped up" indoors.

Community surroundings, including neighborhood and parking lot activity, the sky, airplanes overhead, the weather, and flora and fauna were of interest to residents and sparked discussions with those around them. Getting outside buoyed residents' spirits and enhanced their quality of life, offering new sights, sounds, experiences, and faces. A Holly House care worker elaborated:

It's just like me and you. You start to feel down and depressed and closed in if you're always in the same environment, always inside. Even taking them out on the porch is an activity for them because they're getting fresh air. They're getting out of the building. They don't feel closed in. Then being around different people they haven't seen before is a means of engagement too. Talking to somebody that doesn't know that you have dementia is probably different for them too.

Being outside offered opportunities to reconnect with the world and people beyond residents' dementia diagnoses.

Opportunities to get out onsite varied by characteristics of individuals and care settings. Because it was not a locked community, Rosie's Place residents had the most regular and frequent opportunities to be outside compared to other communities. Here, weather-permitting, sitting outside was the primary activity for residents. Outdoor areas were used the least at The Gardens, in part because staff needed to facilitate entry/exit and often were unavailable.

Parkview and Holly House regularly used outdoor areas for activities and events; The Gardens did so occasionally. Activities involved resident programming such as exercises or games, snack time, or just sitting talking or listening to music, which encouraged further connection with the outdoors and between fellow residents, staff, and visitors. Seasonally, there were several large-scale events for family members to attend, including ice cream socials, cookouts, and festivals, frequently with live music. A researcher described an annual Holly House food-truck event: "It was a lively day on the patio and there was a lot of movement and activity Everyone really seemed to be enjoying themselves and the usual signs of anxiety (i.e., looking for keys, trying to get home, etc.) were not apparent." Despite seeming mundane, the often taken-for-granted experiences of being outside to engage in conversation, activities, or

events were highly meaningful for residents and allowed them to enjoy the moment and connect with their social and physical environment.

Being Offsite and Negotiating Connections

Across settings, many residents welcomed opportunities to go offsite. These opportunities included organized community activities and informal outings with family members, ranging from simple joyrides to museum trips or personal appointments. Maria, who went on most Parkview trips, said she was always ready "to get the hell out."

"Riding" in a car or bus was an accessible way for residents to be out in the world, and such rides occurred at all four study communities. The three largest communities offered joyrides on the bus for small groups of residents as part of activity programming. These rides served as literal windows to the world and involved taking in the local sights, for example, architecture, seasonal decorations, or scenic landscapes. The Gardens' engagement director explained:

They need to see the world. They need to not be stuck inside ... even the ones who are lower-functioning, I still try to do a scenic tour. I still try to at least bring them in the bus and drive them around places. Because they still need that. They may not can say much, but they can still see and look at the nice trees.

Riding was meaningful to residents and care partners. When the study began, Parkview resident Pat joined AL outings accompanied by his private care aid who noted, "I like getting away from here. He does too and it does him good. He enjoys the bus ride. We'll be singing on the bus and engaging with other residents. He likes that." As the study progressed, Parkview staff cited mobility issues, including his bulky wheelchair and large stature, for excluding Pat from trips. Despite challenges, Pat's ex-wife continued taking him out, explaining, "I like to take him out because in a car, he's normal. When we're sitting in the car, it's like regular people."

Riding could involve stopping to engage with the environment. For example, drives to local parks occasionally resulted in feeding ducks or admiring the foliage. Rides also might include stops to wash the vehicle, check a tire, or have a coffee or snack. One Holly House activity staff member described joyrides saying, "We stop and we go get ice cream. [It's] the little things like that just improve their mood and it's fun." She said of residents who routinely expressed desires to go home, "when we go out on the outings, [residents] never think that, 'Oh, we need to go home,' because they're just out like a regular day." Meanwhile, the son of Alice, a Rosie's Place resident, noted:

I took her to the grocery store with me the other day, and she loved it, just going grocery shopping. Just those

kinds of things that they used to do. Just normal everyday things. It doesn't have to be anything exotic. ... I had to stop at the gas station, and she loved that.

Being out in the world doing everyday things restored a sense of normalcy for residents who otherwise spent most of their time indoors in the same environment.

Across communities, we observed residents going out with staff and family members to health and beauty appointments, church services, restaurants, and on shopping trips. Some outings were oriented around entertainment or special events, like visiting cultural venues, including art galleries or gardens, attending performances, or participating in holiday celebrations. Fieldnote data described The Gardens' residents' reactions to a choir concert:

Penny said the concert was "just wonderful" and that she "just loved every minute of it." Lisa, who rarely speaks, nodded her head enthusiastically in agreement and smiled. Regina also said it was "lovely" and that she recognized many of the songs.

The Gardens and Parkview offered restaurant outings at least monthly and family members also took residents out for meals. Most residents appreciated the chance to eat different foods and enjoyed conversations with coresidents, servers, and patrons.

Negotiating Connection and Disconnection

Sometimes getting out included multiple activities involving familiar and unfamiliar people, places, and scenarios. Depending on the purpose, residents typically left for a few hours or parts of the day. Leaving the community was not always pleasant and sometimes created a disconnect between residents and their surroundings. Alice's son observed this variability when taking her to his house: "She doesn't look as relaxed as she does if we're just going out to lunch or going somewhere where it's a temporary short thing." "If," he continued, "we're having a barbeque or something like that there's times where she seems to get withdrawn."

A Parkview activity staff member emphasized needing to "do things where [residents] feel comfortable, they feel confident going, and they get something out of the outing." Yet, doing so could be challenging. At times, researchers observed resident discomfort during AL outings. This excerpt, for example, describes a Gardens' outing to a bustling café:

Ella became a little confused and anxious and kept asking me what she was supposed to be doing. ... Bess [was] now attempting to stand up in her wheelchair and walk off. ... Sally was very irritated by this and yelled at Bess to "sit down."

This scenario highlights the importance of appropriate venue selection and resident/care partner ratios when planning outings to maximize benefits and anticipate challenges.

Even with prior planning, reactions to going offsite were sometimes unpredictable. Several family members reported distressing experiences, including accounts of residents becoming "disoriented" or "impossible to manage" or worse. Shortly after moving to Parkview, Stuart's daughter, for instance, took him out for coffee as they always had done, but she explained, "he got confused of where he was and he started yelling. He couldn't breathe." Stuart was hospitalized for two days following this panic attack and was never taken out again.

For residents who did not go out, we observed efforts to bring in the outside world. Some families, for instance, brought food from favorite restaurants or shared photos of people and events. And, in the larger communities, students from local schools visited as part of activity programming. The food truck event at Holly House exemplifies another creative strategy.

Variability in Getting Out

Experiences with being out in the world and negotiating connections were dynamic and varied across settings, by resident and care partner, and over time. To further highlight variability, dynamism, and influential factors, we present two illustrative cases.

Margaret

In her late 90s, Margaret, a petite White woman, moved to Rosie's Place following a dementia diagnosis. Margaret was mobile with a walker but needed oversight and assistance with activities of daily living and had difficulty expressing herself verbally. Her only child, Sam, and his wife, Renee, lived nearby and along with staff, were Margaret's primary care partners.

Margaret, a homemaker, had occasionally worked part-time retail jobs. She enjoyed being around people and was a lifelong member and elder of her church community. Sam selected Rosie's Place because of its intimate environment and proximity to him and the church. When asked about her quality of life, Sam said it was necessary "to have some activity in her life, some deviation rather than just sitting there." Sam and Renee knew Rosie's Place had no outings and thus remained committed to taking Margaret out.

Each Sunday Sam took Margaret to church followed by breakfast with a group. Margaret was well known, had "quite a group of friends," and had become a "focal point of interest." Sam explained:

She really isn't able to carry on conversation, but she has the respect of the community. ... Though she doesn't have an easy time recalling things, she really lights up when she's in the community because people know her

and they talk to her and say, “Oh, how are you, and what’s going on?”. ... That’s really something that she responds to.

Margaret got out during the week with Sam and Renee just to go out for “a drive or for coffee.” They liked to take her to restaurants because, in addition to enjoying a Coke and fries, he explained, “She really enjoys watching people. She goes crazy over little kids ... The kids typically respond, which is pretty funny.”

Sam communicated with staff about outings and Margaret was always ready. Renee explained that Margaret was “really happy” and eager when they arrived, saying, “Let’s go.” Staff said that Margaret returned “happy,” with “a big smile on her face” and “chatty.” So as not to be “cumbersome or uncomfortable,” Sam and Renee planned weekday outings when it was not “too cold” or “raining.”

At Rosie’s Place, Margaret frequently spent time sitting or using her walker in outdoor spaces. Time outside was restorative, relaxing her and giving her conversation topics. Fieldnote data illustrate, “Margaret seemed so happy to be outside ... she was like a whole different person. She was much chattier, attempting to be a part of the conversation Margaret chuckled every time the wind would dishevel her hair.”

Edith

Edith, an African American woman in her 90s, had a diagnosis of vascular dementia and lived in Holly House’s memory care unit. Edith was confused about time and place, but loved to talk. She was physically mobile and ambulatory without a walker. She had bouts of depression, but was always pleasant to staff, fellow residents, and others. Her daughter, Doris, lived nearby and was involved with Edith’s care.

Edith had frequent opportunities to get out. A retired executive who traveled often during her working life, Edith was accustomed to dining out and socializing. She appreciated the arts, loved people, especially children, and was religiously devout. Getting out was important to her quality of life, facilitating continuity with her past and meaningful connections to people, places, and things. Doris selected Holly House because “they go places” and “take them out.” Doris also appreciated the front porch, noting, “We like sitting outside with her.”

Edith’s interest in getting out, alongside what staff labeled her “appropriateness” for outings (e.g., mobility, pleasant demeanor, continence, and minimal elopement risk) meant regular inclusion. Joyrides were her favorite. Edith explained, “Seeing all the beautiful trees that God created and the blue sky” during rides “is just about the most meaningful thing in the world to me.” Edith was a regular attendee of a monthly luncheon at a local church. Describing a recent luncheon, a volunteer explained that the residents “usually have a good time,” especially Edith:

As soon as the music starts playing, Edith’s outta her chair She went straight to the front up there with the guy, the musician. She was hugging on him. He took it good The lady that was in church ... she went and got Edith, and she brought her up, and they sang “Happy Birthday” together, and Edith was up there. Yeah, that made her day.

Edith also attended a local outdoor concert series. We observed Edith dancing, smiling, chatting, and laughing at this community event.

Edith went out regularly with family members. Doris noted, “Sundays, if we’re doing something at the house, if I’m not working, she’ll come over and just hang out.” Edith attended most family celebrations. Yet, Doris commented, “There are good days and there are bad days,” which influenced getting out. Occasionally, Edith was depressed and declined invitations. And, sometimes Edith made public outings challenging if she made sexual advances or tried hugging strangers or kissing babies. Some care partners were deterred by residents’ bad days, but Doris remained dedicated to giving Edith opportunities to get out, always hoping for a “good day,” but ending outings prematurely on “bad” ones.

Influential Factors

Our analysis identified key multilevel factors that shaped residents’ experiences of being out in the world (Figure 1). At the individual level, resident factors such as demeanor, disposition, and behavior; levels of cognitive and physical function; care needs and arrangements; personal interests and preferences, including the desire to get out; health status; and how they were feeling on a given day exerted influence. Alongside past experiences, care partners weighed these factors when making decisions about going out. Meanwhile, care role and relationship history, availability, willingness, resources, including time, money, and transportation, capacity for getting residents out, dementia training and knowledge, attitudes, and beliefs about care and approach, were key care partner influences. A resident’s convoy (i.e., network), including the availability and involvement of family, communication between AL staff and family members, and overall resources were influential.

Influential AL community factors included size, ownership, and organizational structure; staffing levels, configuration, and training; resources, including the availability and nature of onsite transportation and activity budgets for programming; the accessibility, configuration, comfort, and use of outdoor spaces; care schedules and routines; family and volunteer involvement; and permeability between the AL and surrounding community. AL location influenced the availability and accessibility of surrounding community resources and venues. Finally, the weather and seasonal variations influenced getting out.

Discussion

With a goal of understanding the opportunities for, and experiences with, getting out and the factors that influence opportunities, the present analysis fills a significant knowledge gap and has implications for policy, practice, and future research. Our core category and conceptual model, developed from our analysis, highlight the multilevel factors that influence how and when residents get out and how they negotiate connections, either by making them or not, during solitary, family-led, or community-led outings.

Our core category, being out in the world and negotiating connections, resonates with existing research that shows persons living with dementia participate in activities for purposes of continuity and well-being, social connectedness, and connections to the physical world (Han et al., 2016). Yet, as Kontos et al. (2017) argue, persons living with dementia frequently encounter barriers to participating in society, including as citizens, that stem from dominant assumptions about loss of self and autonomy. Proposing an alternative approach, their “relational citizenship” model emphasizes “interdependence,” “reciprocity,” “relationship-centered care,” and “embodiment,” which considers lived bodily experiences such as expression and movement. Our findings demonstrate that experiences associated with getting out of the care setting or not are intimately connected to issues of embodiment and social constructs of normative behaviors. Getting out reinforced citizenship for some as was the case for Margaret and Edith. In other instances, citizenship was withheld, as was Stuart’s experience.

Our findings reinforce the research and practice recommendations that emphasize the importance of meaningful engagement, inclusion, and participation. The Dementia Action Alliance (2016, p. 15) highlights the need for approaches to care that involve “Enabling opportunities for continuation of normalcy and growth of self; and enhancing individual purpose, meaning, enjoyment, and belonging.” Opportunities for getting out, being out, and negotiating connections allow for this engagement, yet activity planning often overlooks the importance of relatively simple outings and experiences, including access to outdoor spaces (Dahlkvist et al., 2014; Hernandez & Newcomer, 2007; Liao et al., 2018).

This research confirms the generally positive experiences associated with time spent outdoors among people living with dementia (Connell et al., 2007; Edwards et al., 2013; Liao et al., 2018; Marcus & Sachs, 2013). Yet, not all residents had pleasant experiences going on outings. Rather, we found that doing so could provoke anxiety and confusion, leading staff and care partners to conclude that benefits did not always outweigh the challenges or negative outcomes. We found a combination of staff and informal care partner participation in helping residents get out was necessary to maximize opportunities and maintain continuity over time. Of special importance was how all care partners utilized

the four strategies we previously identified as key to promoting meaningful engagement: (a) knowing the resident, (b) connecting and meeting people where they are, (c) being in the moment, and (d) viewing all encounters as meaningful (Kemp et al., 2021). For example, Alice and Edith’s children were attentive to their mothers’ responses and able to pivot and improvise as needed.

Findings confirm that the frequency, availability, and quality of activity programming, including getting outdoors and offsite, were influenced by the resources invested, including staffing levels, training, and care philosophy (Bender et al., 2021; Kemp et al., 2019). We found that opportunities for engagement with the larger world varied, from facilitating simple pleasures such as sitting on a patio and smelling flowers, to more complex outings such as community events. The use of low-resource, simple opportunities is ideal for smaller communities that lack transportation or staffing to go beyond the community, and these opportunities should not be overlooked as meaningful to residents.

Getting out and negotiating connections also relied heavily on the support of informal care partners, as was highlighted by the experiences of Margaret and Edith. As previous work shows (Ball et al., 2005), informal care partner support of resident autonomy and meaningful engagement also is important. However, we also confirmed that informal care partners often have competing demands, their own health concerns, or concerns about their ability to support their family member without help, which can influence involvement (Kemp et al., 2018). Thus, some residents lacked the opportunity to go out; some lacked the desire. For those who did not get out, their daily lives and engagement partners were limited to the space around them. Most, but not all, residents who remained exclusively in the care setting were on hospice, including several at end of life, which confirms research about shrinking social and physical worlds at the end of life (Vandenberg et al., 2018) and challenges leaving the community even for basic health care (Kemp et al., 2019).

Overall, these findings reinforce the importance of engagement with the larger world beyond the AL community for most persons with dementia. Our data collection concluded as coronavirus disease 2019 emerged as a pandemic and the public health context created barriers to getting out and being in the world. Safety protocols involved limiting or banning engagement partners in long-term care settings, including most family, friends, and community members, and restricting group activities and outings. Such bans affect residents’ quality of life (Kemp, 2021) and mental health, potentially hastening cognitive and physical deterioration among long-term care residents with dementia (Simard & Volicer, 2020; Suarez-Gonzalez et al., 2020). Limited informal care contributions place the burden on direct care workers, who already experience heavy workloads (Ball et al.,

2010; Kemp, 2021), and reduce opportunities and collaborations for getting out among residents. Yet, as our pre-pandemic observations demonstrate, there are creative ways to bring the outside world in that can be continued despite safety protocols; for example, bringing in favorite restaurant food, optimizing outdoor spaces, and attending virtual church services or community events.

Our research is not without limitations. First, we collected data at four AL communities in one state. Although these sites were diverse, this approach limits our ability to generalize and account for differences across all care communities and by location. Second, we could not be present at all hours and days or attend every outing. Future research might consider focusing specifically on all aspects of outings, including experiences in the broader community with family members and other scenarios that we were unable to observe directly.

Our research also has many strengths such as our in-depth, longitudinal approach to data collection and analysis and the inclusion of residents as well as an array of care partners. With a focus on getting out, our work affirms the significance and highlights the variability of meaningful engagement among persons living with dementia. Under optimal conditions, going outside or offsite can contribute in meaningful ways to the quality of life and care for most AL residents living with dementia and should be a priority in care planning.

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Conflict of Interest

None declared.

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References

- Ball, M. M., Perkins, M. M., Hollingsworth, C., & Kemp, C. L. (Eds.). (2010). *Frontline workers in assisted living*. Johns Hopkins University Press.
- Ball, M. M., Perkins, M. M., Whittington, F. J., Combs, B. L., Hollingsworth, C., & King, S. V. (2005). *Communities of care: Assisted living for African American elders*. Johns Hopkins University Press.
- Bender, A. A., Halpin, S. N., Kemp, C. L., & Perkins, M. M. (2021). Barriers and facilitators to exercise participation among frail older African American assisted living residents. *Journal of Applied Gerontology*, 40(3), 268–277. doi:10.1177/0733464819893923
- Connell, B. R., Sanford, J. A., & Lewis, D. (2007). Therapeutic effects of an outdoor activity program on nursing home residents with dementia. *Journal of Housing for the Elderly*, 21(3–4), 194–209. doi:10.1300/J081v21n03_10
- Corbin, J., & Strauss, A. (2015). *Basics of qualitative research: Techniques and procedures for developing grounded theory (4th ed.)*. SAGE Publications.
- Dahlkvist, E., Nilsson, A., Skovdahl, K., & Engström, M. (2014). Is there a caring perspective in garden/patio design in elderly care? A description and a comparison of residents' and staff members' perceptions of these outdoor spaces. *Journal of Housing for the Elderly*, 28(1), 85–106. doi:10.1080/02763893.2013.858094
- Dementia Action Alliance. (2016). *Living with dementia: Changing the status quo*. https://daanow.org/wp-content/uploads/2016/04/Living_Fully_With_Dementia_White-Paper_040316.pdf
- Detweiler, M. B., Murphy, P. F., Myers, L. C., & Kim, K. Y. (2008). Does a wander garden influence inappropriate behaviors in dementia residents? *American Journal of Alzheimer's Disease & Other Dementias*, 23(1), 31–45. doi:10.1177/1533317507309799
- Edwards, C., McDonnell, C., & Merl, H. (2013). An evaluation of a therapeutic garden's influence on the quality of life of aged care residents with dementia. *Dementia*, 12, 494–510. doi:10.1177/1471301211435188
- Fazio, S., Pace, D., Flinner, J., & Kallmyer, B. (2018). The fundamentals of person-centered care for individuals with dementia. *The Gerontologist*, 58(Suppl. 1), S10–S19. doi:10.1093/geront/gnx122
- Han, A., Radel, J., McDowd, J. M., & Sabata, D. (2016). Perspectives of people with dementia about meaningful activities: A synthesis. *American Journal of Alzheimer's Disease & Other Dementias*, 31(2), 115–123. doi:10.1177/1533317515598857
- Hancock, G. A., Woods, B., Challis, D., & Orrell, M. (2006). The needs of older people with dementia in residential care. *International Journal of Geriatric Psychiatry*, 21(1), 43–49. doi:10.1002/gps.1421
- Harris-Kojetin, L., Sengupta, M., Park-Lee, E., Valverde, R., Caffrey, C., Rome, V., & Lendon, J. (2016). Long-term care providers and services users in the United States: Data from the National Study of Long-Term Care Providers, 2013–2014. National Center for Health Statistics. *Vital Health Statistics*, 3(38).
- Hernandez, M., & Newcomer, R. (2007). Assisted living and special populations: What do we know about differences in use and potential access barriers? *The Gerontologist*, 47(Suppl. 1), 110–117. doi:10.1093/geront/47.Supplement_1.110
- Jones, C., Liu, F., Murfield, J., & Moyle, W. (2020). Effects of non-facilitated meaningful activities for people with dementia in long-term care facilities: A systematic review. *Geriatric Nursing*, 41(6), 863–871. doi:10.1016/j.gerinurse.2020.06.001
- Kemp, C. L. (2021). # MoreThanAVisitor: Families as “essential” care partners during COVID-19. *The Gerontologist*, 61(2), 145–151. doi:10.1093/geront/gnaa161

- Kemp, C. L., Ball, M. M., Morgan, J. C., Doyle, P. J., Burgess, E. O., & Perkins, M. M. (2018). Maneuvering together, apart, and at odds: Residents' care convoys in assisted living. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 73(4), 13–23. doi:10.1093/geronb/gbx184
- Kemp, C. L., Ball, M. M., & Perkins, M. M. (2013). Convoys of care: Theorizing intersections of formal and informal care. *Journal of Aging Studies*, 27, 15–29. doi:10.1016/j.jaging.2012.10.002
- Kemp, C. L., Ball, M. M., & Perkins, M. M. (2019). Individualization and the health care mosaic in assisted living. *The Gerontologist*, 59(4), 644–654. doi:10.1093/geront/gny065
- Kemp, C. L., Bender, A. A., Ciofi, J., Craft Morgan, J., Burgess, E. O., Duong, S., Epps, F., Hill, A. M., Manley, P., Sease, J., & Perkins, M. M. (2021). Meaningful engagement among assisted living residents with dementia: Successful approaches. *Journal of Applied Gerontology*, doi:10.1177/0733464821996866
- Kontos, P., Miller, K. L., & Kontos, A. P. (2017). Relational citizenship: Supporting embodied selfhood and relationality in dementia care. *Sociology of Health & Illness*, 39(2), 182–198. doi:10.1111/1467-9566.12453
- Liao, M.-L., Ou, S.-J., Heng H. C., Li, Z., & Ko, C.-C. (2018). Effects of garden visits on people with dementia: A pilot study. *Dementia*, 19(4), 1009–1028. doi:10.1177/1471301218793319
- Maranda, A. T., Julie, K., Michelle, C. C., & Laura, N. G. (2014). A systematic review of strategies to foster activity engagement in persons with dementia. *Health Education & Behavior*, 41(1_Suppl), 70S–83S. doi:10.1177/1090198114531782
- Marcus, C. C., & Sachs, N. A. (2013). *Therapeutic landscapes: An evidence-based approach to designing healing gardens and restorative outdoor spaces*. John Wiley & Sons.
- McDermott, O., Orrell, M., & Ridder, H. M. (2014). The importance of music for people with dementia: The perspectives of people with dementia, family carers, staff and music therapists. *Aging & Mental Health*, 18(6), 706–716. doi:10.1080/13607863.2013.875124
- Olsen, C., Pedersen, I., Bergland, A., Enders-Slegers, M. J., & Ihlebæk, C. (2019). Engagement in elderly persons with dementia attending animal-assisted group activity. *Dementia*, 18(1), 245–261. doi:10.1177/1471301216667320
- Perkins, M. M., Ball, M. M., Whittington, F. J., & Hollingsworth, C. (2012). Relational autonomy in assisted living: A focus on diverse care settings for older adults. *Journal of Aging Studies*, 26(2), 214–225. doi:10.1016/j.jaging.2012.01.001
- Phinney, A., Chaudhury, H., & O'Connor, D. (2007). Doing as much as I can: Meaningful activity for people with dementia. *Journal of Aging and Mental Health*, 11(4), 384–293. doi:10.1080/13607860601086470
- Popham, C., & Orrell, M. (2012). What matters for people with dementia in care homes? *Aging & Mental Health*, 16(2), 181–188. doi:10.1080/13607863.2011.628972
- Sandhu, N. K., Kemp, C. L., Ball, M. M., Burgess, E. O., & Perkins, M. M. (2013). Coming together and pulling apart: Exploring the influence of functional status on co-resident relationships in assisted living. *Journal of Aging Studies*, 27(4), 317–329. doi:10.1016/j.jaging.2013.07.001
- Sengupta, M., Zimmerman, S., & Harris-Kojetin, L. (2019). Activity engagement in residential care settings: Findings from the National Survey of Residential Care Facilities. *Journal of Housing for the Elderly*, 33(2), 120–139. doi:10.1080/02763893.2018.1534178
- Simard, J., & Volicer, L. (2020). Loneliness and isolation in long-term care and the COVID-19 pandemic. *Journal of the American Medical Directors Association*, 21(7), 966–967. doi:10.1016/j.jamda.2020.05.006
- Stadnyk, R. L., Jurczak, S. C., Johnson, V., Augustine, H., & Sampson, R. D. (2013). Effects of the physical and social environment on resident-family member activities in assisted living facilities for persons with dementia. *Seniors Housing & Care Journal*, 21(1), 36–52.
- Suárez-González, A., Livingston, G., Low, L. F., Cahill, S., Hennesly, N., Dawson, W. D., Weidner, W., Bocchetta, M., Ferri, C. P., Matias-Guiu, J. A., Alladi, S., Musyimi, C. W., & Comas-Herrera, A. (2020). *Impact and mortality of COVID-19 on people living with dementia: Cross-country report*. International Long-Term Care Policy Network, CPECLSE.
- Theurer, K., Mortenson, W. B., Stone, R., Suto, M., Timonen, V., & Rozanova, J. (2015). The need for a social revolution in residential care. *Journal of Aging Studies*, 35(Suppl. C), 201–210. doi:10.1016/j.jaging.2015.08.011
- Vandenberg, A. E., Ball, M. M., Kemp, C. L., Doyle, P. J., Fritz, M., Halpin, S., Hundley, L., & Perkins, M. M. (2018). Contours of “here”: Phenomenology of space for assisted living residents approaching end of life. *Journal of Aging Studies*, 47, 72–83. doi:10.1016/j.jaging.2018.03.001
- Wood, W., Womack, J., & Hooper, B. (2009). Dying of boredom: An exploratory case study of time use, apparent affect, and routine activity situations on two Alzheimer's special care units. *American Journal of Occupational Therapy*, 63, 337–350. doi:10.5014/ajot.63.3.337
- Zimmerman, S., Sloane, P. D., Katz, P. R., Kunze, M., O'Neil, K., & Resnick, B. (2020). The need to include assisted living in responding to the COVID-19 pandemic. *Journal of the American Medical Directors Association*, 21(5), 572–575. doi:10.1016/j.jamda.2020.03.024