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Meaningful Engagement among Assisted Living Residents with Dementia: Successful Approaches

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Abstract

Meaningful engagement is an important dimension of quality of life and care for persons living with dementia, including the growing number who reside in assisted living communities. This report presents preliminary findings from an ongoing qualitative study aimed at identifying best care practices to create and maintain meaningful engagement among persons with dementia. Over a one-year period, we conducted interviews, residents' record review, and participant observations in four diverse care communities. Our analysis identified four approaches that successfully promote meaningful engagement: 1) knowing the person; 2) connecting with and meeting people where they are; 3) being in the moment; and 4) viewing all encounters as opportunity. Incorporation of these approaches in care routines and adoption by all care partners can promote meaningful engagement, including during crises such as COVID-19.

Background

Meaningful engagement is a critical dimension of quality of life and quality of care for persons living with dementia (Dementia Action Alliance, 2016; Fazio et al., 2018). Engagement refers to “the act of being occupied or involved in an external stimulus” (Cohen-Mansfield et al., 2009, p.2) and has implications for well-being, mental health, and cognitive and physical function (Theurer et al., 2015). Meaningful engagement

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shows promise as a non-pharmacological strategy for addressing anxiety, depression, and behavioral expressions (Mansbach et al., 2017).

For residents in assisted living (AL), an increasingly popular care setting for persons with dementia (Zimmerman et al., 2020), meaningful engagement is neither universally nor consistently available, especially for those with dementia (Sandhu et al., 2013). AL communities typically offer activity programming (Harris-Kojetin et al., 2016), which elicits limited participation among persons with dementia (Theurer et al., 2015). AL residents are embedded in care convoys (i.e., networks) comprised of formal and informal care partners who support their daily activities (Kemp et al., 2013). AL care staff have the most frequent yet consistently overlooked opportunities for meaningful resident engagement (Wood et al., 2009). Meanwhile, as we are learning, informal caregivers of persons living with dementia in AL are critical to meaningful engagement, but some have difficulty interacting; others avoid visiting altogether. Therefore, evidence points to the importance of meaningful engagement for persons living with dementia, but also to challenges.

In this brief report, we share preliminary findings from our ongoing study, “Meaningful Engagement and Quality of Life among Assisted Living Residents with Dementia,” which seeks to identify care practices that recognize, create, and maintain optimal meaningful engagement for persons living with dementia. Our aims are to: 1) outline the range of opportunities for and experiences with meaningful engagement among AL residents with dementia; and 2) identify successful engagement partner approaches.

Method

In 2019, an interdisciplinary team of trained researchers began collecting data for our five-year qualitative Grounded Theory study. The research is guided by the Convoys of Care model, which places residents at the center of their care networks and highlights the contributions made by an evolving collection of care partners such as family, friends, AL staff, external care workers, volunteers, and community members (Kemp et al., 2013). We completed one year of data collection in four diverse AL communities that varied by characteristics apt to influence resident engagement, including size, location, ownership, fees, and availability of a memory care unit (see Table 1). Prior to entry, we obtained written consent from owners/administrators. Consent for individual participants involved written consent, proxy consent for residents unable to consent, and routine assent procedures with each encounter. Institutional Review Board approval derives from Advarra (Pro00029867). We use pseudonyms for individuals and communities.

We followed 33 residents, purposively selected from those diagnosed with dementia and chosen to maximize diversity in age, gender, health conditions, levels of physical and cognitive function, and backgrounds (see Table 2). Researchers conducted 114 semi-structured interviews, including 14 of the 33 resident participants who could participate in formal interviews and their care partners (n=100). Care partners included AL staff (n=48), external workers (n=12), volunteers (n=4), and at least one family member/friend per resident participant (n=36) (see Table 3). Interviews covered residents’ daily lives and routines, including engagement opportunities and experiences. We made 502 visits, which

included resident record review and 1,560 hours of participant observation documented in fieldnotes. Over the one-year period, researchers spoke with and observed individuals in the setting, including resident participants we could not formally interview for cognitive or physical reasons (see Table 4). Fieldnotes document residents' activities, interactions, and accompanying verbal and non-verbal responses indicating, for example, pleasure and displeasure.

We used NVivo12 (QSR International) to store and manage our qualitative data, including interviews and field notes, and to facilitate analyses. Researchers coded data using a codebook derived from our research questions, the literature, and the data. Drawing on these coded segments, we created analysis charts for each resident to capture their opportunities for and experiences with meaningful engagement, including influential factors such as their cognitive and physical abilities, care needs, and personal history and interests. We also analyzed care partners' strategies, including approaches to engagement and associated resident outcomes. Table 4 provides additional methodological details. Below, we present findings beginning with an overview of engagement opportunities and experiences.

Findings

Engagement Opportunities and Experiences

Residents' opportunities for and experiences with engagement varied within and across AL communities and amongst residents over time. Three of the largest communities had formal engagement programming, providing regular opportunities for physical, social, intellectual, and religious activities, including special events and off-site outings (see Table 5). Engagement partners included AL administrative, engagement, care, dietary, housekeeping, maintenance, and transportation staff, volunteers, and co-residents, who were especially significant partners during mealtimes and group activities. We observed meaningful visits from external non-health care workers, including hairdressers, manicurists, and music and pet therapists, and from family members and friends. These visits, especially from family and friends, enhanced resident quality of life (e.g., observed or expressed satisfaction, enjoyment, pleasure, or state of general well-being, including residents' and care partners' views regarding what is important and meaningful) and were pivotal in all settings, especially in the smallest community, which offered few planned activities, limited outings, and few events. Moreover, one worker performed all tasks, which limited engagement partners and opportunities.

Residents with higher physical and cognitive function, compared to residents with more limited function, typically were more engaged. Some participated in self-directed activities such as walking, reading, conversing with others, listening to music, or watching television. Most residents, particularly those with lower physical or cognitive function, required assistance with engagement. Without concerted effort, some lacked any engagement opportunities. A resident's son explained:

It bothers me that [staff] put some residents in the back of the room. That bothers me as an educator. We were always taught that you teach a variety of styles to engage a variety of learning, whatever, and I know that when we come we always

bring Mom to the front so that she's close to the action and even if she's not singing she's pulsing. Even if her eyes are closed, she's engaged. I think they could engage her a lot more.

Successful Engagement Approaches

Rather than focusing on activities, scenarios, and contexts, we found that certain approaches successfully promoted meaningful engagement across all levels of resident functioning. These strategies were used by a variety of engagement partners (e.g., staff, family, volunteers). Those who used one or a combination of these approaches tended to receive more positive resident responses—expressed verbally or non-verbally (e.g., laughter, smiles, concentration)—and fewer negative expressions (e.g., displays of anxiety, frustration, anger), relative to those who did not. Successful engagement approaches began with inclusivity and individualization. Residents' responses manifested differently based on needs, abilities, and contexts. Facilitating positive engagement experiences among residents with dementia required observation, attentiveness, and person- and relationship-centered approaches. These approaches included: 1) knowing the person; 2) connecting with the person and meeting them where they are; 3) being in the moment; and 4) viewing all encounters as opportunity. Below, we present each approach with supporting data; additional data appear in the Supplementary Data Table.

Knowing the person.—Getting to know the resident as a person was foundational. An activity director noted, “I really look at their life stories and see what they like and also what they dislike...we're all about being personalized.” This process involved asking questions, taking an interest in residents' lives, and collaborating to empower residents to do things for themselves or to do activities that were apt to elicit positive responses. It also meant being observant of individual behaviors and responses. One activity staff member explained, “When Emily's about to get really fretful about something, she'll sit there biting her nails... Then she's looking out the window. Then she wants to get your attention.” Collaboration with residents and sharing information among convoy members facilitated knowing the person and making connections in the moment.

Connecting and meeting people where they are.—Actively listening and observing verbal and non-verbal cues were keys to connecting and meeting residents on their own terms. An aesthetician shared, “I have some people who cannot communicate through speaking. I [taught] myself to communicate with them by sound or expression or a way that I do things or just really always [looking] in their eyes and just communicating how they understand.” Engagement partners who met residents “where they were” in terms of orientation to time and place also tended to have greater success than those who did not. A care worker explained, “Join them wherever they're at, and whatever thinking or whatever they're goin' through, because we don't know what they're goin' through, and they're confused, as well. My philosophy is just don't argue. Don't try to correct. Just join them.” Legitimizing residents' experiences and treating them “like people” were critical. One resident explained, “I treat people the way I want to be treated.” A daughter noted, “Just treat Mom like she's a person.” Strength-based and personalized approaches also were essential. An activity director explained:

Marta really needs a lot of structure and a lot of reminding and a lot of breaking down things into very small steps to feel successful. She's one that can very easily almost get lost if you're not careful because she's looking to see what other people are doing and following along, but she's not able. You wanna make sure you capture her too.

Residents reinforced the importance of meeting them on their terms. One resident commented, "If I see where I can do it successfully, I'll do it. If I see I can't do it successfully, I'll just turn it down." Meeting residents where they were promoted inclusion, showed empathy, and reinforced dignity and respect.

Being in the moment.—An extension of meeting residents where they are, being in the moment demanded attentiveness and adaptability to ongoing change. Frequently, doing so meant adjusting expectations and interactions, including when a resident's memory, abilities, responses, or interests changed; the past was not always a reliable resource or guide. An activity director explained, "I really try to guide families by saying, 'Just engage in a different way... Just come to our exercise and just be with her as somebody that she may not know but that's somebody who she probably knows loves her.'" Being in the moment was enacted successfully through flexibility and improvisation. A daughter explained, "You do and try to see whatever works. Sometimes one thing works, and it may not work the next time." And, a son advised, "Come with some things to talk about and be flexible. Be quick on your feet. Just pivot and shift, depending on where mom is and how she's doing and what she wants to do." Residents discussed this dynamism, including one who said, "I like to have company. Now, there's sometimes where you wanna be quiet by yourself." Approaches that accommodated residents' in-the-moment needs and abilities were critical for promoting meaningful engagement.

Viewing all encounters as opportunity.—Residents had more frequent and positive outcomes when all interaction partners viewed each encounter as a potential for meaningful engagement. Even small encounters held potential. An activity director noted, "Like I tell [care staff] here, part of daily living is engagement ... you don't get residents dressed and feed them and do all that, and don't interact with them." Care interactions, although routine, represented especially important and oft-overlooked meaningful engagement opportunities. Encounters with non-activity personnel, including kitchen, housekeeping, other staff, and visitors also presented opportunities (see also Supplementary Data Table).

Discussion

This research confirms the importance of engagement and identifies successful approaches to engaging persons living with dementia in meaningful ways. Our work makes a unique contribution by involving multiple care partners and residents with dementia and collecting qualitative data longitudinally. Since collecting these data, COVID-19 introduced challenges to meaningful engagement. In most regions, including ours, the response includes banning key engagement partners in long-term care settings, including most family, friends, and community members, and restricting dining and group activities. The pandemic, including accompanying bans, represents a threat to resident quality of life (Kemp, 2020) and is

associated with increasing anxiety, depression, and isolation, and hastening cognitive and physical deterioration among long-term care residents with dementia (Simard & Volicer, 2020; Suarez-Gonzalez, 2020).

Meaningful engagement holds promise for offsetting the negative effects of social distancing for residents and for reducing care partner strain. The successful approaches we identified include: 1) knowing the person; 2) connecting with the person and meeting them where they are; 3) being in the moment; and 4) viewing all encounters as opportunity. These approaches extend other recommendations, including calls to place persons and relationships at the center of care (Fazio et al., 2018). They can be used on an ongoing basis, including during COVID-19 and future emergencies.

Although collected prior to the pandemic, our data speak to the importance of resident engagement and the involvement of a variety of care partners. Family members should continue to be involved in AL residents' lives (Zimmerman et al., 2020), including engagement. Involvement could be virtual via phone or video calls or in-person distance visiting or consist of exchanging information with staff about residents, including sharing details between care partners that facilitate knowing the resident and identifying the best ways to connect. Collaborations between family and AL staff are essential as staff attempt to fill pandemic-related voids while performing their already physically- and emotionally-demanding jobs (Kemp, 2020).

We recommend that staff and other care partners receive hands-on, competency-based training on these simple, yet successful approaches with emphasis on maintaining and enhancing relationships with all care partners to support improved quality of life for people living with dementia. Thoughtfully incorporating these approaches into daily life and care routines and adoption by all care partners in resident encounters are ways to maintain and promote meaningful engagement. Whether individual, one-on-one, or group-based engagement experiences, person-centered and relationship-based approaches are foundational to promoting meaningful engagement and improving the quality of life for persons living with dementia in both ordinary and extraordinary times.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Select Characteristics by Study Home

	Rosie's Place	The Gardens	Holly House	Parkview Manor
Resident Capacity	6	36	52	100+
Ownership	Private	Corporate	Private	Corporate
Location	Urban	Large Suburban	Small Town	Large Suburban
Memory Care Unit	No	All memory	Yes	Yes
Monthly Fees (US\$)	1,850 – 3,000	5,050 – 6,175	2,850 – 4,850	3,500 – 6,800

Table 2.

Select Resident Participant Characteristics

Resident Characteristic (N=33)		
	Range	Mean (SD)
Age (years)	66–97	86 (6.8)
Gender	n (%)	
Female	28 (85)	
Male	4 (12)	
Transgender	1 (3)	
Marital Status		
Married	6 (18)	
Widowed	21 (64)	
Divorced/Separated	4 (12)	
Never married	2 (6)	
Race		
White	26 (79)	
Black	7 (21)	
Education		
Less than high school	1 (3)	
High school diploma	10 (30)	
Some College	8 (24)	
College	9 (27)	
Post Graduate	4 (12)	
Unknown	1 (3)	
Care Needs and Health Conditions	Range	Mean (SD)
Barthel Index ^a	0–20	11 (7.4)
MoCA ^b	1–19	10 (4.7)
Co-morbidities	1–6	2.61 (1.1)
Mobility	n (%)	
Uses a walker	16 (48)	
Uses a wheelchair	15 (45)	
Health Conditions (n=31)^c		
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)	

^aTotal possible scores for the Barthel Index range from 0 – 20, with a lower score indicating more assistance needed in performing activities of daily living.

^bMontreal Cognitive Assessment. Total possible scores for the MoCA range from 0 – 30. Score interpretation is as followed: severe cognitive impairment <10; moderate cognitive impairment, 10–17; mild cognitive impairment, 18–25. Figures are based on the 14 residents who were able to complete the assessment.

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

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Table 3.

Care Partner Participants by Type

Participant type	N=100
Formal Convoy Members^a (n=60)	
AL workers (n=48)	
Executive directors	5
Resident care director	3
Medication technicians	10
Direct care workers	17
Activity personnel	11
Kitchen and dietary staff	1
On-site therapists	1
External workers (n=12)	
Hospice personnel	3
Music therapists	1
Musician	1
Private care aides	3
Hair stylists and nail technicians	3
Social worker	1
Informal Care Partners^b (n=40)	
Current spouse	6
Former spouse	1
Daughter	12
Daughter-in-law	4
Son	8
Sibling	2
Sister-in-law	1
Niece	1
Friend	1
Volunteers	4

^aIncludes 3 Registered Nurses (1 Executive Director, 1 Resident Care Director, and 1 Hospice Nurse)

^bWe interviewed at least one family member or friend associated with each of the 33 resident participants.

Table 4.

Select Information on the Research Team and Methods

Research Domain	Description
Research Team and Reflexivity	
Size and Composition	The research team consists of 19 researchers, both female and male, with backgrounds in gerontology, anthropology, sociology, psychology, nursing, exercise science, human services, and social work. The team includes undergraduate and graduate, staff, postdoctoral, and faculty researchers. All researchers are trained in qualitative methods, working with persons with dementia, and doing research in assisted living communities. Of the authors, CLK, AAB, JMC, AMH, SD, and PRM collected data.
Participant-Researcher Relationships	Researchers were divided into four teams, each assigned to one of the four study sites. They collected data over a one-year period, built rapport, and familiarized participants with the study's purpose and procedures on an ongoing basis.
Study Design Features	
Interview Details	Most interviews were conducted face-to-face in one sitting and lasted an average of just over one hour in length. A few interviews took place over the phone and in multiple sittings. All interviews were digitally recorded and transcribed verbatim.
Ethnographic Observations	Researchers recorded ethnographic observations in detailed field notes using an observation guide designed for the project as a sensitizing tool to help identify aspects of the physical and social environment (e.g. interactions, body language, facial expressions, how people situate themselves in social space) salient to meaningful engagement and residents' quality of life and quality of care. Our one-year observation period also facilitated the identification of continuity and change over time.
Recruitment, Refusals, and Retention	Participants were recruited in-person and also via telephone or email. We had 10 individuals refuse to participate. No one dropped out of the study, but 1 resident relocated and six passed away during the study.
Member Checking	The one-year duration in the field allowed us to member check interviews and preliminary findings through subsequent interactions.
Analysis	
Coding Team	Fourteen researchers participated in the initial coding of the data and a subset participated in the higher order coding presented in the manuscript.
Coding Processes	The project codebook includes codes pertaining to different types of activities, resident, care partner, and setting influences, and resident responses.

Table 5:

Activity Categories by Site and Frequency

Activity Categories*	Regularly Offered (>2 times/ week)	Sometimes Offered (2 to 4 times/ month)	Infrequent or Seasonal (once every 1–2 months)	Rarely/Never (once every 7–12 months or not a all)
Exercise/Physical	◀■●	★		
Games/Mental Stimulation	◀■●★			
Arts & Crafts	◀■●★			
Music- Live or Therapy	◀■●	★		
Music- Ambient	◀■●★			
Cooking or Baking	◀		■	●★
Conversations or Reminiscing	◀■●★			
Outdoor Activities (Seasonal)	■★		◀●	
Parties and Holiday Events		■	◀●★	
Animal Activities		◀■		●★
Religious or Spiritual	◀■●★			
Television and Movies	◀■●★			
Outings (Recreational)		◀■●		★
Hair, Nails, and Spa Activities	◀■●★			

*Categories are not always mutually exclusive

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