



The Open Journal of Occupational Therapy

Volume 3
Issue 1 *Winter 2015*

Article 3

1-1-2015

An Exploration of Volition: Caregiver Perceptions of Persons with Dementia

Christine Raber

Shawnee State University, craber@shawnee.edu

Mikel Stone

Shawnee State University, mstone@shawnee.edu

Follow this and additional works at: <https://scholarworks.wmich.edu/ojot>

 Part of the [Occupational Therapy Commons](#)

Recommended Citation

Raber, C., & Stone, M. (2015). An Exploration of Volition: Caregiver Perceptions of Persons with Dementia. *The Open Journal of Occupational Therapy*, 3(1). <https://doi.org/10.15453/2168-6408.1075>

This document has been accepted for inclusion in The Open Journal of Occupational Therapy by the editors. Free, open access is provided by ScholarWorks at WMU. For more information, please contact wmu-scholarworks@wmich.edu.

An Exploration of Volition: Caregiver Perceptions of Persons with Dementia

Abstract

The purpose of this study was to understand what formal caregivers know about the volition of older adults with moderate dementia. A qualitative approach was used at one assisted living facility. Semi-structured interviews were conducted with formal caregivers to gain their perceptions of residents' volition or motivation for occupation. Volition of resident participants was assessed using the Volitional Questionnaire (VQ). Caregiver interviews and resident VQ's were analyzed using van Manen's phenomenological approach to examine their congruence with regard to the volitional abilities of residents. Thematic analysis yielded two broad themes: (a) Caregivers possess varying layers of insight regarding the volitional abilities of the older adults with dementia, and (b) caregivers develop a script regarding the volitional abilities of the older adults with dementia. Caregivers possess knowledge about volitional abilities of older adults with dementia. Further research is needed to understand how these perceptions affect their care-giving behaviors.

Keywords

motivation, dementia, caregivers, occupational therapy

Cover Page Footnote

The authors express their deepest gratitude to all of the participants involved in the study, and for the gift of exceptional mentorship, particularly from Dr. Gary Kielhofner. The contributions of Sally Abbott-Dennis are also gratefully acknowledged.

Credentials Display

Christine Raber, PhD, OTR/L

Mikel Stone, MOT, OTR/L

Copyright transfer agreements are not obtained by The Open Journal of Occupational Therapy (OJOT). Reprint permission for this Applied Research should be obtained from the corresponding author(s). Click [here](#) to view our open access statement regarding user rights and distribution of this Applied Research.
DOI: 10.15453/2168-6408.1075

Background

Currently, an estimated 5.2 million Americans are living with Alzheimer's disease (Alzheimer's Association, 2013), and the rate of Alzheimer's disease and related dementias (ADRD) is growing, with an estimated 34 million people having some form of dementia in 2009 (Wimo, Winblad, & Jönsson, 2010). ADRD is defined as a condition characterized by a wide range of cognitive deficits, marked by memory impairment accompanied by language disturbance; difficulty with motor performance; inability to recognize or identify objects; and/or problems with planning, organizing, or sequencing (American Psychological Association, 2000). Given the projected growth of the older adult population to 71.5 million by 2030 (*Older Americans*, 2012), the prevalence of ADRD will also increase.

Individuals with ADRD experience challenges, such as cognitive decline and a decreased ability to engage independently in valued occupations (Warchol, 2006). People living with dementia become progressively restricted in their performance of daily activities, leading to the need for increased assistance from others in response to their functional losses (Holst & Hallberg, 2003). The progressive nature of ADRD often places increased demands on the family members of the care recipient (Lewis, Hepburn, Narayan, & Kirk, 2005), such as assistance with activities of daily living (ADLs), increased need for supervision, and provision of a safe environment. Because of these increased care demands, residential care is often the only option for many families, and assisted living facilities (ALFs) are a popular choice (Zimmerman

et al., 2005a). Estimates indicate that individuals diagnosed with dementia account for 34% to 68% of ALF residents (Kang, Smith, Buckwalter, Ellingrod, & Schultz, 2010). In ALFs, residents typically have their own apartment and formal caregivers provide support and assistance in self-care, instrumental activities of daily living, leisure, and productive occupations.

Since individuals with ADRD rely on others to support their engagement in occupation, details regarding their life stories are critical for planning and providing daily care (Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010; McKeown, Clarke, & Repper, 2006). Investigation into formal caregivers' perceptions of the abilities of persons with dementia is limited, but since the experience of dementia is different for each individual, individualized care that is attentive to each person's unique experience is recommended. Older adults with ADRD often experience feelings of loss and frustration because of decreased opportunities to engage in preferred occupations, and caregivers' actions may either enhance or detract from the individual's participation in daily activities (Holst & Hallberg, 2003).

Dementia also creates declines in communication skills that often affect the ability to make choices regarding engagement in preferred occupations. Breakdowns in communication affect the relationship between the caregiver and the person with dementia, leaving the caregiver to make assumptions about the person's choices (Small, Geldart, & Gutman, 2000). Caregivers' assumptions about choice have the potential to significantly impact, positively and negatively,

occupational engagement. Individuals with ADRD often experience a compromised ability to independently engage in activities of their own choosing (Kolanowski, Buettner, Litaker, & Yu, 2006). Many formal caregivers may unintentionally promote disengagement by “doing for” the person, and at times, may exclude individuals with dementia from activities due to behaviors perceived as problematic (Kolanowski et al., 2006). Individually designed activities, however, can help decrease challenging behaviors and agitation. When activities were specifically designed to meet three factors—interests, cognitive abilities, and physical abilities—nursing home residents with dementia demonstrated positive affect, greater engagement, and greater ability in the activities (Kolanowski, Buettner, & Moeller, 2006), illustrating the caregivers’ potential positive impact in supporting occupational participation.

Accuracy of caregivers’ judgment of the abilities of persons with dementia may be questionable, creating potential concerns about strategies that support engagement in occupation. It has been suggested that caregivers of persons with ADRD may misjudge the functional abilities of those in their care (Argüelles, Loewenstein, Eisdorfer, & Argüelles, 2001). For example, performance assessments of community-dwelling individuals with ADRD and their primary caregivers indicated that caregivers often overestimated the abilities of the person in functional tasks, such as telling time, money-related tasks, brushing teeth, and eating with utensils.

In dementia care, there is a growing trend toward use of a person-centered care (PCC) approach (Brooker, 2007), which focuses on supporting personhood by enabling the person’s abilities rather than focusing on the disability caused by dementia. Caregiver approaches and skill sets are essential to effective use of PCC, and rely on caregivers’ understanding of the intrinsic qualities of personhood, such as the person’s history, prior occupations, interests, and values. Gitlin et al. (2010) highlighted the influence of the care environment, along with the caregiver-client relationship, on the ability of community-dwelling older adults with ADRD to perform in a goal-directed manner and to engage in occupations. In addition, a study by McKeown, Clarke, Ingleton, Ryan, & Repper (2010) demonstrated that an understanding of the life story of individuals with dementia is a central tenet of dementia care. PCC approaches underscore the important dynamic that exists between a caregiver’s understanding of a person’s abilities and preferences, and the environmental and social contexts that support the fullest capabilities of people with dementia.

A significant aspect of personhood in dementia care is volition, or motivation for occupation (Raber, Teitelman, Watts, & Kielhofner, 2010). Volition, a Model of Human Occupation construct (Kielhofner, 2008), refers to one’s unique values, interests, and personal causation that elicit motivational responses for meaningful occupation. Choice and preference in daily occupations are aspects of volition and are critical to successful

occupational engagement at all levels (Kielhofner, 2008). Values include intrinsic thoughts and feelings about what is important to the person (Kielhofner, 2008). Interests are defined as aspects of life that one finds enjoyable or fulfilling and include individual preferences, while personal causation includes the person's perception of his or her abilities and effectiveness in using those abilities (Kielhofner, 2008). Cognitive dysfunction affects expression of volition, since "volition is an ongoing process and is determined by what has been learned from past experiences" (de las Heras, Llerena, & Kielhofner, 2003, p. 9). Volition involves making interpretations and judgments about the environment and acting on them. Those with cognitive impairments will make volitional judgments and interpretations and act on the environment based on their current abilities (de las Heras et al., 2003).

The experience of ADRD plays a large role in volitional behavior, since the disease process changes the ability to communicate likes, dislikes, and interests, as well as the ability to process environmental cues and stimuli, leaving others in the person's world to recognize and interpret volitional behavior (Raber et al., 2010). Therefore, the social environment exerts a significant impact on volitional expression. Since ADRD results in decreased communication skills, decreased initiation of activities, and decreased processing of cues from the environment, caregivers need to be especially in tune with the volitional behavior of persons with dementia (Teitelman, Raber, & Watts,

2010). Caregiver behaviors that can support volition include noticing volitional behavior, interpreting what the person may be trying to communicate through behavior, and responding appropriately and effectively. Expressions of volition are seen in an individual's preferences and are often exhibited behaviorally more frequently than verbally in people with dementia (Raber et al., 2010).

It is apparent that caregivers have a significant charge in the provision of care and support for older adults with ADRD. Providing support for people with ADRD involves more than simply doing for the person, and encompasses promoting engagement in everyday occupations. Practice Guidelines from the Alzheimer's Association (Tilly & Reed, 2006) promote the use of a person-centered approach in dementia care, in which life stories are understood and paired with knowledge of the person's preferences and their functional ability, and represent the standard of practice for which caregivers and dementia care programs should strive. One challenge that persons with dementia face in formal care environments, such as assisted living, is staff perceptions of residents' functional abilities, their capacity to make choices, and their ability to express preferences about their everyday activities. The area of caregivers' perceptions about residents' preferences and abilities has not been adequately explored and described, and limited research exists about caregivers' understanding and knowledge of motivation of persons with dementia.

Therefore, the purpose of this qualitative study was to gain insight into the experiences of ALF formal caregivers regarding their understanding of the volitional abilities of persons with ADRD for whom they provide care. Since formal caregivers play an intrinsic role in supporting abilities and choices for persons living with dementia, investigating the lived experiences of caregivers provides information about their understanding of the volitional abilities of individuals with dementia. The guiding research question was: What insights do formal caregivers have about the volitional abilities of individuals with ADRD in the assisted living environment?

Method

Van Manen's phenomenological approach (van Manen, 1990) guided development of the research question, sampling, data collection, and data analysis, and was selected to facilitate understanding of the subjective, lived experience of the formal caregivers providing care for ALF residents with ADRD. This phenomenological approach is considered a type of hermeneutic, or interpretative, approach (Finlay, 2009), and as such, the phenomenon was explored through reflection, journaling, and thematic analysis of collected data (van Manen, 1990).

Participants

Ethical approval for the study was provided by Shawnee State University's Institutional Review Board. The administration of a memory support ALF in the Midwestern United States approved the study and provided access to the potential

participants. Staff members and legally authorized representatives (LAR) of residents provided consent to participate in the study and residents assented to participation.

Purposive sampling (Creswell, 2003) was used to recruit all participants. Inclusion criteria for staff participants were employment in the memory care unit for a minimum of four months and willingness to participate. For resident participants to be included in the study, they were required to have a diagnosis of some form of dementia in the moderate stage, as well as to be a resident of the facility for at least four months. Moderate dementia was defined using criteria from the Global Deterioration Scale (Reisberg, Ferris, de Leon, & Crook, 1982), which includes major difficulty in initiating, persisting, and completing ADLs, IADLs, social participation, and leisure interests due to the progression of dementia. Investigators collaborated with the program manager to identify staff and resident participants who met the inclusion criteria.

During the study period, there were 19 residents living in the facility, and 10 met the inclusion criteria. The ALF was part of a continuing care retirement community and 18 staff members worked in this area at the time of the study. Of the 10 residents who met the inclusion criteria, the program manager identified seven potential residents for the study, and investigators approached their family members about the study. Three LARs provided consent for their family member to participate. Ten day and evening shift staff members met inclusion criteria and were

approached to participate. Seven of these staff members agreed to join the study. The program manager's role was limited to identifying potential participants and approaching them (staff member or the LAR of residents) using an Institutional Review Board-approved script to seek permission to provide their contact information to the investigators. After receiving permission to contact potential participants, investigators conducted the recruitment process without program manager input. Staff participant consent forms contained specific language protecting the participants' information from disclosure to the employer in any form, including choice to participate in the study.

IRB-approved assent forms were used with resident participants after their LARs provided

consent, and investigators also gained verbal assent during each encounter with the resident participants. Three resident participants, two men and one woman, were included in the study. ALF staff participants included one activity director, four resident helpers, two nurses, and an activity director from a local adult day program, which one resident participant attended daily. His participation in the day program was identified and the activity director from this day program was invited to participate in the study as investigators decided her experiences would provide an additional perspective. Table 1 offers selected information about resident participants, and Table 2 provides general information about staff participants. Pseudonyms are used for all participants.

Table 1

Resident Participant Information

Resident participant *pseudonym	Demographic information	Selected preferences and background information	Number of observations rated using VQ, and number of raters
Jane	Never married, no children	Liked playing the piano Nurse Teacher Always wore skirts/dresses Routinely had her hair done Banged walker on floor when upset	4 (2 raters for all sessions)
John	Married, with children	Spouse in same facility, but not in ALF section Upset when unable to speak to wife on phone due to her illness Attended vespers and made a point of speaking to minister before and after service Liked specific chair in living room	6 (one rater)
Jack	Married, with children	Attended adult day program daily Soda jerk as a young man Liked specific dress on a daily basis	6 (4 at ALF, 2 at adult day program; one rater for all sessions)

Table 2*Staff Participants' Educational and Work Experience*

Staff participant *pseudonym	Work role	Educational experiences	Years of work experience in Dementia Care
Lisa	Adult day care coordinator	High school degree; associate's degree	15 years
Denise	LPN	High school degree; LPN program graduate	9 years
Rhonda	Resident helper	High school degree	6 months
Joyce	Resident helper	High school degree; some college	5 years
Heather	Resident helper	High school degree	14 years
Cassy	Resident helper	High school degree	19 years
Carla	Activities director	High school degree	31 years
Paula	LPN	High school degree; LPN program graduate	14.5 years

Instrumentation

Three data collection methods were used: background interviews with the activity director about resident participants; administration of the Volitional Questionnaire with resident participants; and interviews with staff participants that explored the ways in which their experience of working with resident participants related to their perceptions of resident participants' volition. Instrumentation used was the Volitional Questionnaire (VQ) (de las Heras, Geist, Kielhofner, & Li, 2007) and the semi-structured interviews with the activity director and staff participants. To provide information to guide documentation of VQ observations, one interview for each resident participant was conducted with the activity director prior to completing the VQ and staff participant interviews. These three interviews yielded background information about each

resident's likes, dislikes, and interests. Following completion of the VQ, interviews were conducted with each staff participant, which focused on their experiences with and perceptions of resident participants' volition.

The VQ is an observational assessment that rates motivation for occupation and the impact of the environment on motivation (de las Heras et al., 2007). Fourteen items are scored using a four-point scale with ratings of passive, hesitant, involved, and spontaneous. Rating items reflect the individual's volitional behavior, versus the individual's success with the task at hand, and individuals are rated during typical daily activities selected by the therapist in three to five sessions (de las Heras et al., 2007). The VQ assesses volition in people who have significant limitations in cognition, verbal or physical abilities, and have difficulty in articulating

what motivates them (de las Heras et al., 2007). It is a valid measure of the construct of volition across a variety of environments (Chern, Kielhofner, de las Heras, & Magalhaes, 1996), and has demonstrated acceptable inter-rater reliability (Li & Kielhofner, 2004).

To facilitate consistency between investigators during interviewing, two interview guides were developed for each type of interview (background interviews with the activity director to guide VQ observations and interviews with staff participants). Concepts of volition and examples of behaviors indicative of volition were used in staff participant questions in order to facilitate expression of their experience of perceiving residents' volition while working with them. Table 3 provides sample

interview questions. Guided questioning was chosen as a method of obtaining information, as it allowed formal caregiver participants the opportunity to discuss their lived experience in the role of caring for participants with dementia, and afforded investigators the opportunity to probe for further information. Before use in this study, investigators piloted the activity director interview guide at a nursing facility with its activity staff and the formal caregiver interview guide was piloted at a separate ALF with its staff. Both interview guides were then revised using feedback from each pilot site. Investigators were trained in interviewing strategies prior to conducting interviews with participants.

Table 3
Sample Questions

Background interviews with activity director	Interviews with staff participants
<p>What do you feel (resident) is interested in? What does (resident) like or enjoy?</p>	<p>In your experience with (resident), how does s/he show curiosity? In what ways have you experienced (resident) expressing pleasure and enjoyment during his/her day?</p>

The activity director script allowed investigators to glean basic information about each resident participant in order to plan VQ observations. These background interviews were focused on eliciting descriptions of resident participants' general daily routines and their likes,

dislikes, and interests. The activity director also identified times of day for both optimal engagement and ability, and times that were more challenging for each resident participant. Investigators then arranged observation sessions to complete the VQ with each resident participant. Resident

participants' VQ ratings were completed prior to interviewing staff participants. Information about the number of investigators completing the VQ, in addition to the number of sessions observed, is included in Table 1. The VQ provided a snapshot of resident participants' volition at the time of the study. Investigators observed resident participants as they were involved in daily activities; VQ observations did not include private activities, such as bathing, dressing, and toileting. Investigators were trained by the principal investigator to administer the VQ accurately and consistently, which involved the learning process outlined in the VQ manual, supervised practice, and competency check-offs prior to VQ use in the field.

The interview guide for the staff participant interviews was grounded in the 14 VQ items, reflecting the volitional continuum of exploration, competency, and achievement (de las Heras et al., 2003). Exploration is the most basic demonstration of volition, indicating that one desires to interact with the environment by showing curiosity or interest in his or her surroundings, followed by competency, which demonstrates one's attempt to act on the environment (de las Heras et al., 2003). The highest level of volitional behavior is achievement, in which there is an attempt to master a skill and respond to challenges presented by the environment (de las Heras et al., 2003). The primary focus of staff participants' interviews was to elicit information about their experiences with and perceptions of resident participants' volition. All interviews were recorded and transcribed by a

transcriptionist, who signed a confidentiality agreement. Finally, each investigator wrote field notes after every contact with all participants during data collection. Investigators were trained in the process of writing field notes using practice sessions with feedback from the principal investigator prior to entering the field, and field notes were discussed during peer debriefing sessions.

Data Analysis

To ensure authenticity, rigor was addressed through the use of field notes (written immediately following each resident participant and staff participant contact), member checks of interviews, regular peer debriefing, and triangulation of data. Consistent with qualitative inquiry procedures, field notes were collected to describe contextual data that occurred during the VQ and interview contacts. Member checks consisted of providing interview transcripts to staff participants for their review to verify accuracy of the transcript and provide the opportunity to add any additional thoughts. Three of the eight staff participants offered additional input to their interviews. Face-to-face discussions of data collection occurred weekly with all researchers throughout the data collection process. The reflexive process of recording field notes, reviewing member checks, and conducting peer debriefing (Creswell, 2003) allowed investigators to document overall impressions of staff participant interviews and resident participant contacts. The reflexive process was also used to bracket investigators' previous experiences and assumptions

and identify their impact on the analysis, as well as aiding investigators in refining interviewing techniques during the study.

Three interviews with the activity director, the resident VQ data, and eight staff interviews were analyzed using van Manen's methods (1990). Thematic analysis was undertaken, which van Manen refers to as the process of reflective inquiry, in order to "interpret the aspects of meaning or meaningfulness that are associated with this phenomenon" (van Manen, 2011, Methods and Procedures section, para. 2). Reflective inquiry focused on identifiable patterns of behaviors that expressed the phenomenon, namely perceptions of resident participants' volition. HyperResearch software (2009) enabled researchers to code, retrieve, and build themes based on gathered data. Codes were established that identified staff participants' experiences and perceptions of resident participants' past and current interests and preferences. Analysis of the codes and patterns that emerged was used to develop the themes that portrayed the phenomenon of caregiver insight into the volitional abilities of resident participants. Data saturation was reached when no new information was found.

The process of coding was iterative and guided by van Manen's (1990) analytic process of isolating thematic statements in which three approaches can be used: holistic, selective, and detailed. In the coding layer of analysis, the researchers chose to use the selective approach, in which the reading of the text focuses on the

question, "What statement(s) or phrase(s) seem particularly essential or revealing about the phenomenon or experience being described?" (van Manen, 1990, p. 93). This question was used as an anchor to guide coding and thematic analysis. Writing and rewriting the themes, also advocated by van Manen, assisted in shaping and articulating the major themes that reflected the experience of understanding resident participants' volition.

Results

Two major themes emerged from the data analysis and revealed variations in staff participants' insights and their articulation of the volitional abilities of the resident participants. Patterns of these variations were then consolidated into the study themes, which are presented below.

Theme one: Varying layers of insight. The first theme was identified as: Staff participants possess varying layers of insight regarding the volitional abilities of the older adults with ADRD for whom they care. During interviews, the staff participants shared experiences and reflections focused on the ways in which knowledge about volitional ability is formed from daily observations, the resident's history, and what other staff members say about the resident. Interviews with staff participants yielded high frequencies of caregiver knowledge about resident preferences, residents' expression of emotions, and residents' daily routines. Each of these areas of knowledge represents key aspects of volition as they contribute to, or support, a person's self-efficacy and values. Varying layers of insight, therefore, were defined as the range of experiences

caregivers shared about their understanding of resident participants' volition, which is represented in the following descriptions.

In regards to knowledge of preferences, staff participants articulated information about what the resident participants liked to eat, how and where they liked to spend their time, with whom they enjoyed spending time, and their overall preferences about their daily routines, which was often consistent with the activity director's brief narratives about each resident participant. Staff participants often commented on experiences, things, and situations the resident participants disliked. One staff participant discussed the clothing that Jack preferred, while another staff member discussed how Jane liked to wear her hair and the clothing she liked to wear. Cassy stated, "You always see her in a dress. I've never seen her in slacks."

Staff participants were especially articulate when discussing the emotions of resident participants. Staff participants stated they recognized and understood resident participants' emotions by focusing in on facial expressions and gestures. Heather reported that she could tell how John was feeling by watching his facial expressions. He would become mad at other residents when they sat in a chair in the living room that he perceived was his, and his facial expression reflected this emotion. Likewise, Denise reported that when Jane banged her walker on the floor, she was communicating that she was angry. Carla also said of Jane, "When she goes to the beauty shop on

Tuesdays, she comes back, she just kind of struts and feels better about herself." Heather shared that when John talked with his wife, "he sits ram rod straight when he gets on the phone . . . he's very attentive to everything she has to say." Heather commented that John's mood after speaking with his wife "was almost thoughtful. Kind of like lost in his own thoughts."

Staff participants frequently expressed insight regarding resident participants' daily routines. Daily routine in this assisted living environment was typically consistent, as seen in regular meal and activity schedules, but Cassy identified various minute aspects of John's daily routine:

While we're getting his stuff ready for his teeth and stuff, and then he just about knows about the time we get done (getting ready). Then he gets up and starts walking toward the bathroom. So we can give him his bath (or) whatever we're doing for him. And . . . it's his teeth first . . . and then he knows when it's time to get back up.

She later stated that she was unsure if other staff followed the same routine with John.

Heather stated, "John talks on the phone to his wife after dinner every day." When discussing a situation in which John could not speak to his wife on the phone due to her illness, causing an interruption of his daily routine, Heather said, "He

was very upset that whole evening after that.” She reported that he asked about his wife twice that evening, which he did not typically do when they had their regular phone conversation. In addition, Heather discussed that John frequently attends the vespers activity and initiates interactions with the minister stating, “he always makes sure to talk to him (the minister) before and after the service.”

Educational differences among staff participants appeared to play a role in the varying levels of knowledge each possessed about resident participants. Five staff participants in the study did not have formal education beyond high school. The highest level of education received by one of the eight staff participants was an associate’s degree. However, all staff participants received continuing education through their employer and/or were credentialed in their respective fields. Staff participants’ educational backgrounds were reviewed to examine patterns between education and staff participants understanding of volition in the resident participants. For example, Lisa appeared to articulate an understanding of Jack’s volition with fewer prompts to express these insights. The main difference investigators found with Lisa in comparison to the other staff participants was her reported ability to incorporate and adapt meaningful occupations into Jack’s daily routine.

While Lisa finished a two-year degree, her total years of experience with the population was fewer than other staff participants in the study. In addition, she worked at an adult day program and

not at the ALF. According to Lisa, the philosophy of the adult day program emphasized front-loading their program with family interviews to gain insight into the values of the older adults in the program. She was able to identify changes in Jack’s abilities and environmental influences on his behavior. For instance, when asked for her perceptions about Jack’s apparent frustration with bingo, Lisa shared:

When he first came, he would play bingo some, you know. Um, and what we do . . . anyone that needs assistance we’ve put them by the caller . . . or we have a couple clients that like to help each other and they’re very good at it. Um, but it got to be where he, um, he . . . wanted to kinda do it his own way . . . which we don’t mind but we have other confused clients that um, or one with short term loss, who felt like she needed to remind him how to play. . . . And the two of them ride the bus together and she is kind of bossy . . . anyhow, and, so if anybody down here was going to uh, trigger a behavior, you know, so . . . we try not to put him by her.

Another prominent difference between Lisa and the other staff participants in this study was her ability to articulate past roles of the person, such as Jack’s role as a soda jerk and his former worker role, whereas the other staff participants reported

knowing little about his past roles. This knowledge illustrates possible differences between the two facilities in the processes used for sharing background stories of participants.

Participants expressed varying levels of knowledge about volition and all interviews reflected a range of sources from which they gained their understanding about the resident's volitional abilities, which included observation, the resident's family, and other staff. During interviews, staff participants often made statements about a resident participant's volitional abilities, but they often said it was difficult to expand upon the information and explicitly identify the source of their knowledge. For instance, Joyce knew that Jane was from out of state, but she did not know from what state she had moved. Investigators also observed that staff participants had varied understandings about resident participants' life stories. When investigators probed Joyce about how she came to understand certain aspects of Jane's self-care routine, she reported, "It's just what I've been told . . . because that's what the day shift girl told me."

Staff participants also expressed a range of perceptions about the resident participants' abilities and often overestimated what the person could do during daily living tasks in the assisted living environment. The importance of deciphering where and how this knowledge is obtained can assist caregivers in assessing the accuracy of their knowledge. In most interviews, staff participants did not identify that their knowledge of the resident's volition was consistently from a single

source, such as a supervisor, their observations of daily routine, or history gathered from family or other staff members. Staff participants frequently said they used different resources to gain information about the resident participants. For instance, Lisa obtained a majority of information from an interview with family, whereas Carla identified information coming from observation and her history of working with Jack for six years.

Investigators noted that staff participants had differing levels of understanding about resident participants' life stories. For instance, Heather stated that John "was in the Armed Forces but I'm not sure which branch . . . I think it was Army." Cassy was also unsure of Jack's previous work life: "I don't know if he was an engineer or a plumber or electrician but he's always, 'I've gotta get this done for the guys before we can go for another job,' so he may have been something to do with contracting." Last, Carla stated, "I'm actually not sure what he done for a living but um . . . it seems like to me it had something to do with accounting or something." Despite the ALF staff participants' seemingly vague understanding of resident participants' past roles and life stories, they were often able to describe the immediate needs of the residents.

Theme two: Using scripts. Theme two was framed as: Staff participants develop and use scripts about the older adults with ADRD for whom they care. Staff participants frequently used a type of sharing that investigators identified as "scripts" in descriptions of their experiences with and knowledge of resident participants. Scripts were

defined by investigators as the oral narratives used regularly by staff participants when talking about their experience of knowing the person in their care. These oral narratives summarized the daily routines, preferences, and emotions of resident participants, typically in a brief fashion. Use of scripts, or oral narratives, provided staff participants with a means of articulating the volitional abilities of resident participants and supported ease of communication between staff participants. This phenomenon is further explored in two particular aspects of participants' use of scripts: 1) Staff participants' culture of care supports the development of scripts, and 2) scripts can lead to a unidimensional perspective about resident participants.

While staff participants were able to provide insights about the resident participants, their knowledge often appeared to be static, or unchanging in relation to the disease process, and was typically shared using a brief, repeated set of statements about the person. Scripts often included statements about preferences (i.e., likes and dislikes of resident) in addition to interpretations of behaviors, such as, "she always bangs her walker when she's mad." In this ALF's culture of care, regular sharing of information is expected among formal caregivers and scripts enable caregivers to pass information on to each other in a condensed fashion. This practice is also common in hospital environments, as seen during shift change when staff members arrive for the next shift and are provided with a quick oral exchange of how each patient was doing during the previous shift. While

not formalized as a practice in this work environment, staff participants' training in the medical model sustained this skill, as noted in staff participants' communication style. To illustrate, Joyce offered this script:

He will sit out in the lobby area and he likes to do activities, such as the ball playing, and he'll do some word games, balloon badminton, and he will join in simple word games. He likes a snack after activities. Um . . . he likes music activities. He really enjoys kids coming in. Um . . . In the summer time and spring, he likes to sit on the patio.

Joyce shared that she told other staff this same information, which offers one example of using an oral script to communicate resident preferences to other team members. Common scripts were used across staff participants to describe resident participants. For example, all staff participants consistently described Jane as a "helper," John was described as "territorial," while Jack was labeled a "wanderer." The use of single words or labels to describe the resident was a common feature of scripts used by staff participants in this study.

The phenomenon of scripting was noted with staff participants using narrative-like responses when discussing resident participants' preferences. Scripts often had a unidimensional perspective, as the scripts frequently focused on one facet of the person. Unidimensional is defined as "possessing only one dimension, presenting or perceiving only

the most superficial aspects of something” (“Unidimensional,” 2008). This definition resonated with the majority of staff participants’ narratives regarding resident participants’ volitional abilities, including resident interests, preferences, and staff beliefs about residents’ abilities. Staff participants using a unidimensional perspective tended to focus on one area of past interest or skill, and frequently did not observe possible changes in interests or how to support past interests in a new way. For example, Jane enjoyed playing the piano and she was known for her piano skills. All staff participants interviewed regarding Jane discussed how they encouraged her to play the piano. VQ ratings revealed that this resident became nervous while playing the piano and this anxiety appeared related to her declining ability to perform at her previous skill level. In all VQ situations, investigators noted a behavioral change that reflected subtle distress and decreased volition when she faced a challenging task. This change of behavior, however, was not observed nor explored by staff participants. Another example of a unidimensional staff perspective was observed when staff labeled Jack as someone who tended to wander and that he was often seen going in and out of rooms. Carla stated, “He tends to wander more and you have a harder time getting him away from the door.” This was considered unidimensional since staff could not offer an explanation for this behavior; rather, only acknowledged the behavior as a problem that staff needed to address.

Discussion

Understanding caregivers’ perceptions of volitional abilities of persons with ADRD is important for occupational therapy practitioners working in dementia care and providing ancillary support to staff members. Findings from this study illustrated staff participants’ understanding of resident participants’ daily routines, preferences, and emotions. To share this information, staff participants typically developed an oral script or a short narrative that outlined a person’s likes and dislikes. Data for scripts came from different sources and varied in the manner in which they were communicated among staff. While staff participants shared information amongst one another about resident participants’ volitional abilities, scripts were frequently developed and expressed by staff participants using a unidimensional perspective of resident participants. VQ observations of resident participants revealed subtleties of volitional behavior that was rarely noted by staff participants. However, staff participants typically were able to state general interests of resident participants and their preferences about objects in the environment. In addition, this study noted gaps and discrepancies in staff participants’ knowledge of resident participants’ past roles and life stories, thereby potentially resulting in missed opportunities for engagement in meaningful occupations.

Holst and Hallberg (2003) discuss that the person with ADRD has difficulty reaching out to others as well as difficulty maintaining a sense of

self. The use of life story resources for caregiver reference and reflection with the person with dementia may prove to increase the caregivers' understanding of past life roles, preferences and interests, as well as dislikes. Understanding routines and preferences influence caregivers' insight into the person's lived experience, which can be used to support volition. The critical role of others in validating personhood and personal causation has been observed as an essential volitional support (Raber et al., 2010). Findings of the current study highlight gaps between caregivers' insights and reported support of volition, which emphasizes a need to create more effective bridges between caregiver perceptions and caregiver actions.

Clinical Implications

Zimmerman et al. (2005a) emphasized that specialized dementia care training should include all domains of dementia care. Specialized staff training to understand the nuances of volition communicated through behavior is an important factor to add to these domains. Memory care facilities should consider training workers in methods that encourage activity participation as it relates to change in the resident's abilities (Tilley & Reed, 2006; Zimmerman, et al., 2005b). Several staff participants of the study expressed that they are unsure about how to support the volitional abilities of Jane in regards to progression of the disease. While Jane previously identified strongly with playing the piano, the disease process was affecting her ability to play at her previous skill

level. Staff continued to encourage Jane's playing of the piano, even though her skill level had diminished, as the perception of the staff interviewed was that playing the piano was still an important activity to Jane. VQ observations revealed Jane's apprehension about playing the piano and her uncertainty about engagement in this previously important occupation.

Since ADRD creates declining and noticeable differences in the abilities of persons with dementia, recognizing motivation for occupation, or volition, is often challenging. Caregivers may focus more on lack of ability, rather than a person's desire to engage in occupations. Person-centered care tenets posit that all behavior is communication for persons with ADRD, and many behaviors are often a major challenge for any caregiver (Teitelman et al., 2010). The findings of this study suggest that caregiver scripts are often focused on a static conceptualization of resident abilities and interests, which may limit understanding of the dynamics of volition for persons with dementia. Openness to a dynamic, changing perspective of the person living with dementia can more effectively support volition, and therefore, engagement in meaningful occupations (Raber et al., 2010). As abilities diminish, caregivers need to provide an alternate means for the person with dementia to pursue interests. For example, as Jane's experience in this study illustrates, instead of continued support of her past interest of playing the piano, it may have been more beneficial for her to be supported in engaging in this

occupation using modifications, such as conversations about playing the piano, listening to classical music, looking at past photos of herself while playing the piano, or having her sit with and assist someone who was playing the piano.

In this study, varying levels of education had minimal influence on the caregivers' expressions of their insights into residents' volitional abilities. However, Lisa, the staff participant with the most formal education, expressed Jack's volitional abilities in a clearer and more concise manner, and she explicitly articulated the importance of understanding the person's past in order to better understand what motivates them. In addition, without prompting, Lisa shared specific examples about ways to create an environment that minimized challenging behaviors. Across all staff participants, individual variations in communication skills and style were illustrated, which may have a potential impact on the way in which information is being shared among team members. Identifying communication styles among team members could support sharing of life stories with more depth and include each team members' nuanced view.

Limitations

Limitations of this study include the small sample size, limited range of staff participants, and the use of only one memory care facility. A larger sample of formal caregivers in a range of memory care facilities would contribute to increased representativeness of findings. Additionally, observations of caregiving actions and behaviors would add further depth and address the gap

between staff reports and caregiving actions, which would also provide the opportunity to better target training needs. Finally, time constraints for conducting interviews could have limited the amount of data obtained, and follow-up interviews may have provided further insights from staff participants regarding their understanding of resident participants' volition.

Recommendations for Further Research

To further explore the findings of this study, future research should be undertaken focusing on caregivers' use of person-centered care approaches that support volition and the use of strategies to increase engagement in meaningful occupations. Studies that integrate specific aspects of volition into life story work as a key component of caregiver education could expand understanding about how caregivers use information about likes, dislikes, preferences, daily routines, and past and current life roles, in their care approaches. Another possible avenue of investigation may be to specifically examine the types and quality of scripting that caregivers use and observe the ways in which these scripts impact caregiver behavior. Each of these approaches could further advance knowledge about the optimal volitional supports necessary to promote meaningful engagement in occupations for persons with dementia.

Conclusion

Findings from this study illustrate the ways staff participants expressed understanding of resident participants' daily routines, preferences, and emotions. Staff participants' expression of their

understanding of volition through the use of scripts supports some aspects of the life story of people with dementia. Results reflect a potential gap in caregiving practices and highlight the importance of a multidimensional approach to providing care that supports the life story, and therefore volition, of people with dementia. Occupational therapy interventions that support a person's volition may facilitate increased use of remaining abilities, which

underscores the need to incorporate information about volition into caregiver training. Training that focuses on sharing volitional and life story information to support a multidimensional approach to developing and using dynamic caregiving scripts has the potential to positively impact engagement in daily activities and quality of life for people living with dementia.

References

- Alzheimer's Association. (2013). 2013 Alzheimer's disease facts & figures. *Alzheimer's & Dementia*, 9(2), 1-68. Retrieved from http://www.alz.org/downloads/facts_figures_2013.pdf
- American Psychological Association. (2000). *Diagnostic and statistical manual of mental disorders* (Rev. 4th ed.) Washington, DC: American Psychological Association.
- Argüelles, S., Loewenstein, D. A., Eisdorfer, C., & Argüelles, T. (2001). Caregivers' judgments of the functional abilities of the Alzheimer's disease patient: Impact of caregivers' depression and perceived burden. *Journal of Geriatric Psychiatry and Neurology*, 14(2), 91-98. <http://dx.doi.org/10.1177/089198870101400209>
- Brooker, D. (2007). *Person-centered dementia care: Making services better*. London: Jessica Kingsley Publishers.
- Chern, J., Kielhofner, G., de las Heras, C. G., & Magalhaes, L. C. (1996). The volitional questionnaire: Psychometric development and practical use. *American Journal of Occupational Therapy*, 50(7), 516-525. <http://dx.doi.org/10.5014/ajot.50.7.516>
- Creswell, J. W. (2003). *Research design: Qualitative, quantitative and mixed methods approaches*. (2nd Ed.). Thousand Oaks, CA: Sage.
- de las Heras, C. G., Geist, R., Kielhofner, G., & Li, Y. (2007). *User's manual for the volitional questionnaire*. Chicago, IL: The Model of Human Occupation Clearinghouse, Department of Occupational Therapy, College of Applied Health Sciences, University of Illinois at Chicago.
- de las Heras, C. G., Llerena, V., & Kielhofner, G. (2003). *User's manual for remotivation process: Progressive intervention for individuals with severe volitional challenges*. Chicago, IL: The Model of Human Occupation Clearinghouse, Department of Occupational Therapy, College of Applied Health Sciences, University of Illinois at Chicago.
- Finlay, L. (2009). Exploring lived experience: Principles and practice of phenomenological research. *International Journal of Therapy and Rehabilitation*, 16(9), 474-481. <http://dx.doi.org/10.12968/ijtr.2009.16.9.43765>
- Gitlin, L. N., Winter, L., Dennis, M. P., Hodgson, N., & Hauck, W. W. (2010). Targeting and managing behavioral symptoms in individuals with dementia: A randomized trial of a

- nonpharmacological intervention. *Journal of the American Geriatrics Society*, 58(8), 1465-1474. <http://dx.doi.org/10.1111/j.1532-5415.2010.02971.x>
- Holst, G., & Hallberg, I. R. (2003). Exploring the meaning of everyday life, for those suffering from dementia. *American Journal of Alzheimer's Disease & Other Dementias*, 18(6), 359-365. <http://dx.doi.org/10.1177/153331750301800605>
- HyperRESEARCH (2009). HyperRESEARCH (2.8.3) [Computer software]. Randolph, MA: ResearchWare, Inc.
- Kang, H., Smith, M., Buckwalter, K. C., Ellingrod, V., & Schultz, S. K. (2010). Anxiety, depression, and cognitive impairment in dementia-specific and traditional assisted living. *Journal of Gerontological Nursing*, 36(1), 18-30. <http://dx.doi.org/10.3928/00989134-20091204-01>
- Kielhofner, G. (2008). *Model of human occupation: Theory and application* (4th ed.). Baltimore: Lippincott Williams & Wilkins.
- Kolanowski, A., Buettner, L., Litaker, M., & Yu, F. (2006). Factors that relate to activity engagement in nursing home residents. *American Journal of Alzheimer's Disease & Other Dementias*, 21(1), 15-22. <http://dx.doi.org/10.1177/153331750602100109>
- Kolanowski, A., Buettner, L., & Moeller, J. (2006). Treatment fidelity plan for an activity intervention designed for persons with dementia. *American Journal of Alzheimer's Disease & Other Dementias*, 21(5), 326-332. <http://dx.doi.org/10.1177/1533317506291074>
- Lewis, M. L., Hepburn, K., Narayan, S., & Kirk, L. N. (2005). Relationship matters in dementia caregiving. *American Journal of Alzheimer's Disease & Other Dementias*, 20(6), 341-347. <http://dx.doi.org/10.1177/153331750502000609>
- Li, Y., & Kielhofner, G. (2004). Psychometric properties of the volitional questionnaire. *The Israel Journal of Occupational Therapy*, 13, E85-E98.
- McKeown, J., Clarke, A., Ingleton, C., Ryan, T., & Repper, J. (2010). The use of life story work with people with dementia to enhance person-centred care. *International Journal of Older People Nursing*, 5(2), 148-158. <http://dx.doi.org/10.1111/j.1748-3743.2010.00219.x>
- McKeown, J., Clarke, A., & Repper, J. (2006). Life story work in health and social care:

- Systematic literature review. *Journal of Advanced Nursing*, 55(2), 237-247.
<http://dx.doi.org/10.1111/j.1365-2648.2006.03897.x>
- Older Americans 2012: Key indicators of well-being. (2012). Retrieved from
http://www.agingstats.gov/agingstatsdotnet/main_site/default.aspx
- Raber, C., Teitelman, J., Watts, J. H., & Kielhofner, G. (2010). A phenomenological study of volition in everyday occupations of older people with dementia. *The British Journal of Occupational Therapy*, 73(11), 498-506.
<http://dx.doi.org/10.4276/030802210X12892992239116>
- Reisberg, B., Ferris, S. H., de Leon, M. J., & Crook, T. (1982). The Global Deterioration Scale for assessment of primary degenerative dementia. *American Journal of Psychiatry*, 139(9), 1136-1139.
- Small, J. A., Geldart, K., & Gutman, G. (2000). Communication between individuals with dementia and their caregivers during activities of daily living. *American Journal of Alzheimer's Disease and Other Dementias*, 15(5), 291-295.
<http://dx.doi.org/10.1177/153331750001500511>
- Teitelman, J., Raber, C., & Watts, J. H. (2010). The power of the social environment in motivating persons with dementia to engage in occupation: Qualitative findings. *Physical and Occupational Therapy in Geriatrics*, 28(4), 321-333.
<http://dx.doi.org/10.3109/02703181.2010.532582>
- Tilly, J., & Reed, P. (2006). *Dementia care practice recommendations for assisted living residences and nursing homes*. Washington, DC: Alzheimer's Association.
- Unidimensional. (2008). In Merriam-Webster online dictionary. Retrieved from
<http://www.merriam-webster.com/dictionary/unidimensional>
- van Manen, M. (1990). *Researching the lived experience: Human science for an action sensitive pedagogy*. Albany, NY: State University of New York.
- van Manen, M. (2011). Thematic reflection. Retrieved from
<http://www.phenomenologyonline.com/inquiry/methods-procedures/>
- Warchol, K. (2006). Facilitating functional and quality-of-life potential: Strength-based assessment and treatment for all stages of dementia. *Topics in Geriatric Rehabilitation*, 22(3), 213-227. <http://dx.doi.org/10.1097/00013614-200607000-00004>
- Wimo, A., Winblad, B., & Jönsson, L. (2010). The worldwide societal costs of dementia:

Estimates for 2009. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 6(2), 98-103. <http://dx.doi.org/10.1016/j.jalz.2010.01.010>

Zimmerman, S., Sloane, P. D., Williams, C. S., Reed, P. S., Preisser, J. S., Eckert, J. K., . . .

Dobbs, D. (2005a). Dementia care and quality of life in assisted living and nursing homes. *The Gerontologist*, 45, 133-146. http://dx.doi.org/10.1093/geront/45.suppl_1.133

Zimmerman, S., Williams, C. S., Reed, P. S., Boustani, M., Preisser, J. S., Heck, E., & Sloane, P. D. (2005b). Attitudes, stress, and satisfaction of staff who care for residents with dementia. *The Gerontologist*, 45, 96-105. http://dx.doi.org/10.1093/geront/45.suppl_1.96