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Activity Engagement: Perspectives from Nursing Home Residents with Dementia

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Abstract

Engagement in social and leisure activities is an indicator of quality of life and well-being in nursing homes. There are few studies in which nursing home residents with dementia self-reported their experiences in activity engagement. This qualitative study describes types of current activity involvement and barriers to activities as perceived by nursing home residents with dementia. Thirty-one residents participated in short, open-ended interviews and six in in-depth interviews. Thematic content analysis showed that participants primarily depended on activities organized by their nursing homes. Few participants engaged in self-directed activities such as walking, visiting other residents and family members, and attending in church services. Many residents felt they had limited opportunities and motivation for activities. They missed past hobbies greatly but could not continue them due to lack of accommodation and limitation in physical function. Environmental factors, along with fixed activity schedule, further prevented them from engaging in activities. Residents with dementia should be invited to participate in activity planning and have necessary assistance and accommodation in order to engage in activities that matter to them. Based on the findings, a checklist for individualizing and evaluating activities for persons with dementia is detailed.

Engagement in activities beyond routine primary care is an important indicator of quality of life in nursing homes. Having “choice of activities” and “activities that amount to something” is important for improving a sense of independence and positive self-image in nursing home residents (Allen, 2011). Activities can provide a sense of purpose when residents produce something, use skills from former work, or make a contribution.

The more cognitively and functionally dependent elders are, the more activities become critical to their lives. Activities most missed by elders with disability are often leisure activities (Mann, 2005). Nursing home residents with dementia are particularly limited in continuing their favorite leisure activities as a result of their cognitive and functional limitations and their institutionalized environment. Almost half of nursing home residents have dementia (Hebert, Scherr, Bienias, Bennett, & Evans, 2003; Magaziner et al., 2000). Further, nearly 50% of the population have difficulty in 3–6 activities of daily living (Jones, Dwyer, Bercovitz, & Strahan, 2009). Excessive unoccupied time among nursing home residents is evident in studies that have found that they “do nothing” 65% of the time (Harper-Ice, 2002) and can spend 17 hours a day in bed (Bates-Jensen et al., 2004) when awake or not receiving treatment or primary care.

Nursing home residents with dementia express positive affect much more often during times of activity than during unoccupied time (Schreiner, Yamamoto, & Shiotani, 2005). Making activities continuously available and appropriate to individuals is emphasized in the activity regulations and guidelines by the Department of Health and Human Services (DHHS) Center for Medicare and Medicaid Services (Allen, 2011). In the guidelines, nursing homes are required to provide a sufficient and ongoing activity program that accommodates individual residents' interests and enhances their physical, mental, and psychosocial well-being.

Activities can be frustrating and uninteresting unless they fit the individual competencies and skills of persons with dementia (Kolanowski, Litaker, & Buettner, 2005; Marshall & Hutchinson, 2001). Persons with dementia may feel threatened when activities require excessive memory retrieval or cognitive skills (Buettner, 1999). Attention to individual interests and functional competencies in selecting activities is critical to increasing participation and positive experience in persons with dementia (Buettner & Fitzsimmons, 2003; Kolanowski, Buettner, Costa, & Litaker, 2001). However, little is known about the experiences in activity engagement from the perspectives of nursing home residents with dementia. Activities are often planned without considering residents’ point of view. It is largely because of the assumption that they do not have the ability to self-report due to their cognitive limitations. Yet evidence suggests that people with mild to moderate dementia can make a self-report, articulate feelings, and provide reliable evaluations (Buckles et al., 2003; Trigg, Jones, & Skevington, 2007). Therefore, the purpose of this qualitative study is to describe types of current activity involvement and barriers to activities reported by nursing home residents with dementia.

Methods

This qualitative study utilized content analysis within an ethnographic framework as described by Morse and Field (1995) and Spradley (1979). The ethnographic approach enables researchers to view phenomena of day-to-day activities in the context in which they occur, thus facilitating better understanding of behaviors in a group of individuals. Such information is critical to the provision of care that is beneficial to the recipients. The concept of culture, when defined in a broad sense, is useful to examination of day-to-day activity

behaviors of groups of individuals experiencing a common illness such as dementia. The researchers had no a priori theory or preconceived conclusions prior to the study.

Participants

A convenience sample of 37 residents was recruited from nursing homes in a southern state: 31 participated in short, open-ended interviews and six completed in-depth interviews. To be included in the study, a resident had to be 60 years or older, have an MMSE score of 10–26, and must have lived in a nursing home for at least 2 months. All participants had an Elements of Informed Consent (EIC) (Buckles, et al., 2003) score of 8–10 at screening of the ability to understand informed consent information, communicate, and make a verbal self-report. On average, participants were 84.6 (*SD* = 5.8, range 72–97) years of age with a Mini Mental State Exam score of 16.4 (*SD* = 4.9, range 10–26), indicating moderate dementia. They were not depressed (Geriatric Depression Score: mean = 3.1, *SD* = 2.7, range 0–11). The majority of the participants were women (67%) and Caucasians (94%).

Procedures

With an approval of institutional review board, facility nursing staff assisted to identify potential study participants and obtained verbal or written permission from each participant prior to contact from the research team. Upon their permission, the research team contacted and screened participants for the ability to consent using the EIC form, if the residents were interested in participating in the study. Residents who met the eligibility criteria and consented to participate in the study took part in semi-structured interviews that focused on their current activity engagement, their level of activity involvement, and barriers and motivators to attending activities. For example, questions included the following: “What kind of activities do you do?” “What kind of activities is important to you?” “Tell me any problems you have in doing activities,” or “Tell me what motivates you to engage in an activity.” The interviews took approximately 15–30 minutes and were audio-taped and transcribed. The transcripts were checked for accuracy in comparison to the audiotapes.

Data Analysis

Descriptive content analysis within an ethnographic framework (Morse & Field, 1995; Spradley, 1979) was conducted to examine the interview data on current activity engagement, level of activity involvement, and barriers and motivators reported by nursing home residents with dementia. The interview data were analyzed for recurring themes, using a two-step approach described by Morse and Field (1995) and Appleton (1995). First, interview information was sorted into categories by questions in the interview guide. Transcribed interview sections for each question were compared among participants so that an initial category framework and descriptive codes were produced (Burns & Grove, 2005). The categories were then refined or reorganized based on new information from the analysis of subsequent transcripts (Dye, Schatz, Rosenberg, & Coleman, 2000). In the second step, interpretive codes were developed through the analysis of the categorized data (Burns & Grove, 2005). The three coders were involved with coding and thematic analysis; the first and second coder analyzed the interview transcripts and created code summaries independently, which were then discussed and modified based on the input from the third

coder. Review of the category data yielded themes and subthemes that described the experience of activity engagement. The codes were revised by grouping and collapsing them when commonalities were apparent. Meaning and relationships of the words and phrases were examined. The analysis progressed from description to interpretation within or across categories. Detailed record keeping was made for an audit trail that provided the evidence and consistency in analysis processes. Dedoose (Dedoose.com) and QRS NUD*IST Vivo (qsrinternational.com) computer programs were used for analysis of qualitative data and organization of the interview data.

Results

Study participants held various interests, skills, experiences. Their previous occupations included teacher/school personnel; secretary; military service; farmer; manager; administrator; business owner; social worker; waitress; seamstress; stenographer; and sales/staff personnel in stores, agencies and organizations. Some residents continued with the skills and hobbies from prior to coming to the nursing home. Yet many respondents missed past favorite hobbies they enjoyed before they moved to the nursing facility. Table 1 illustrates various hobbies and favorite activities that study participants wished to continue.

Study participants primarily depended on activities organized by the nursing homes. Bingo, card games, and religious gatherings were the most cited types of activities in that they involved. The reasons for them to participate in bingo or card games varied. To some residents, bingo was the most appealing of activities offered in nursing homes. Yet others did not like to play them at all and preferred to watch television rather than to participate in the activities. Interestingly, residents played bingo to meet people and expand social opportunities. One resident remarked, *"Yeah. I play bingo, but I'm not crazy about that, but I do play just to mix and mingle, you know."* Another respondent stated, *"I love to mingle with my friends. And I've made some nice friends here, and I don't think sitting in your room is going to make you get acquainted, so I mingle. Each time they have an affair, I'm there."* For those who were new to the community, participation in religious activities also helped them to connect with other residents. Nevertheless, attendance in bible study, devotionals, and other church services were life-long religious practice in many study participants.

Other activities such as live music were popular in residents. They enjoyed activities around entertainment (e.g., singing, music, and dance). Programs featuring live entertainment frequently occurred around the time of the holiday season or special occasions. Occasionally, groups from the community came and provided live entertainment. One respondent said, *"I like, you know, any kind—any musical. And I just love it when they have something musical come in. Any kind of—just any kind of entertainment like that . . . . That's my favorite thing."* Another respondent stated that *"I like the entertainment they have. I like it when they have a group coming in to sing. I like to dance."*

Walking inside and outside of the facility on a daily basis was an important individual activity to residents. A respondent stated that she likes to maintain healthy exercise behaviors. In other cases, walking is simply a preferred activity they like to do. One respondent stated that she "*walks around all day long."* Regular visits of their family

members were a vital component integrated into the lives of residents. One respondent remarked that *"I have a son who lives here in town—him and his wife—so I do things with them . . . . Every week we try to do something together. Sometimes my son brings it up, and sometimes we are just talking, and something just comes up. I would say [he visits me] once a week . . . ."*

It was important for them to maintain both facility's organized or self-directed activities. Most residents participated in activities at least once a week, while a few attended activities several times a week or even every day. One resident noted that *"I really don't do any activities . . . . I enjoyed everything they had, but here lately, I just—I don't have the desire to do that stuff . . . ."* Motivation to engage in activities stemmed from *"a general desire to have something to do;"* as another resident remarked, "*feeling rested*" helped bring the desire back to a resident who did not have a good night sleep. One of the study participants crocheted baby clothes to donate to hospitals: *"It gives me a lot of purpose in my life to share with the hospitals."* In some cases, a spirit of competition can be a motivator for activity participation as one man mentioned, "*Well, I like to compete. I like to play cards; and you know, I like to be with the people*." A respondent believed trying something new or doing things differently could produce excitement and motivation to participate in activities. She shared her experience saying, *". . . we talk, and we talk, and we get . . . 'til that gets boring. And the other day, I just thought, 'Why don't you say, 'Let's sing.'?' And it was kind of like a get-together, you know, thing. And we've done it twice now. They're starting to do . . . . It was a pretty good room full of us, and we just sit there, never said a word, never talked, we never done nothing. And I thought, 'Why don't we sing anything? Just sing something? Some old song or some new song if anybody knows one.' And you know . . . and they never did. We just sat there, quiet as a mouse."*

Major barriers to getting involved in activities included limited activity choices, impairment in physical functioning, and lack of accommodation in schedule, resources and transportation. First of all, having few activities to choose was a concern by the residents. *"We just—we don't do any—we absolutely don't do anything, and I don't think that's good . . . . I would like to do more of anything,"* said a respondent. Another respondent corroborated this, stating, *"Well, there's nothing to—really to do,"* Residents with dementia found that most of the activities offered by nursing homes did not interest them. One respondent stated that she instead opted to read newspapers or other reading materials. *"I wish we had something more interesting to do, at least once or twice a week. . . . . We don't have any excitement. No excitement . . . ."* They perceived that activities were limited or did not align with their hobbies or interests. One respondent explained that although she liked to paint, there was not a designated space in which she could paint alone. Instead, she attended arts and crafts classes among activities provided by nursing home facility.

Physical limitations that prevented them from active participating in activities included "trouble" with hands, fingers, feet, and knees, back problems, limited eyesight, and hearing difficulty. A male respondent was limited in participating in *"game things,"* as he *"[does] have a problem with that, but that's just part of my Parkinson's."* Another respondent listed the activities that she could do because *"that's all I can do anymore."* Activities also proved to be physically demanding—as one respondent noted that he/she would *"get tired of*

sitting," which hindered long-term participation. A female respondent gave up an idea of continuing cooking-related activities due to her physical difficulties: *"I doubt if I could even —you have to stand up. You just have to. And I can stand up a little bit, but I have to hold onto something. And so, see, I'm just—you know, I sit."* Many residents relied on staff assistance in order to attend in activities. Use of a wheelchair or walker is often necessary to move around the facility. Yet the residents tried as much as possible not to rely on staff as noted in wheelchair-bound respondents' statement. *"All I need is somebody to take me there and bring me back." "No, I do not need someone to take me. I can roll the chair. I hate to be a burden to them. . . ."*

Although the majority of respondents remarked that the current schedule for activities was acceptable, there were exceptions in which a fixed activity schedule did not fit to residents' preferences. A respondent noted that the schedule for devotionals was not convenient for him and that this activity often did not start on time; he commented that *"There's one going on right now, and I didn't go. It's almost 12:00 . . . . They don't always get there on time."* Another respondent stated that late afternoon was a good time for activities, saying, "*Sometimes I get a nap when I'm dressed. But I don't really feel like doing anything until the afternoon and I don't attend many of the activities...*" In addition, the need for a higher frequency of activities was also suggested. *"We could have [bingo] in the morning, then the evening, too."* In addition, residents had different preferences in the set-up of the activity room, including lightening and noise level. One respondent remarked that *". . . it's a lot of noise that doesn't seem to belong in there."* Another respondent stated, *"I like it quiet if I'm trying to learn something."*

Lack of accommodation in resources and transportation were also mentioned. They wished the facility would be accommodating and, *"encouraging anything we wanted to do in the hobby department . . . ."* Transportation to activities offered outside of the facility was a limiting factor, as many respondents did not have a proper means of transportation at their convenience and had to rely on others to get from place to place. One respondent who attended dancing classes outside the facility remarked, *"I have a friend that lives not too far from here that can pick me up. I don't know what's happened to my car, but I just don't know what the future holds."*

Discussion

The findings suggest that residents want a variety of activities that are "interesting" or "desirable". Previous studies suggest that activities can be meaningful and interesting if they stimulate thinking, are gender-specific, produce something useful, are related to previous work of residents, allow for socializing with visitors and participating in community events, or are physically active (Allen, 2011; Kolanowski, et al., 2001; Marshall & Hutchinson, 2001). It is evident that no single activity can meet the needs of all residents. For example, bingo games were a favorite activity for some residents but a dislike for others. Some enjoyed walking and others could not walk due to physical disabilities. Similarly, residents are not satisfied with participation in only one particular activity. Residents engaged in many different activities at different times of the day or week (e.g., walking every morning, going to bingo twice a week, and interacting with other residents and family members

occasionally). In particular, they used to engage in many different activities and hobbies prior to institutionalization. It was understandable that residents in this study found that few activities offered by facilities were interesting or desirable. Thus, nursing homes have a great challenge to expand the availability of various, sufficient, and ongoing activities for residents whose interests and needs vary while meeting the guidelines by DHHS Center for Medicare and Medicaid Services.

Residents with dementia did not want to participate in an activity in order to just make themselves keep busy (Allen, 2011). Unless activities were relevant and meaningful to their lives, they preferred to watch TV or do nothing rather than attend activity sessions. They walked daily as exercise, enjoyed competition of card games, and spent time with others and family members because these activities were meaningful and important for the residents. It is important to help the residents to continue past hobbies even after institutionalization. A growing body of literature suggests that past interests in music, art, and pets affects current selection of an activity that reflects those interests (Cohen-Mansfield, Marx, Thein, & Dakheel-Ali, 2010; Cohen-Mansfield, Thein, Dakheel-Ali, & Marx, 2010). Activities relating to occupation or family role can promote involvement. In particular, provision of resources (e.g., transportation, space, or supplies) is important to help them continue their past hobbies because current physical disability and functional limitation affect residents' participation in the activities. Modification of activities and assistance from staff is also imperative to improve residents' activity experience. Activities should be consistent with resident preferences and functional capacity and tailored to individuals' needs. Attention to personal interests and functional competencies are emphasized in Buettner's (1999) Simple Pleasures project and the Kolanowski et al. (2005) activity intervention. Previous studies found that nursing home residents with Alzheimer's disease showed significantly increased positive affect and decreased agitated behaviors when activities were tailored to their skill level and style of interest (Kolanowski, et al., 2001; Kolanowski, et al., 2005; Kolanowski, Litaker, & Baumann, 2002). Activities that are appropriate to residents' competencies, needs and preferences promote their sense of purpose, self-esteem, pleasure, comfort, education, creativity, success, and/or independence (Allen, 2011).

Connecting with the community via outings to places of worship, visits from volunteer groups, or involvement in athletic and education programs (e.g., learning computer or Internet for emails and games) may enrich activity experiences of residents. Nursing homes should promote the connection with community and organize activities in an appropriate format—including a combination of large and small group, one-to-one, and self-directed activities. The findings in this study indicate that nursing homes should involve residents in planning and scheduling of activities so that they can attend in activities of their choice. For example, altering schedules may mean completing a therapy session or having a bath/shower before residents participate in a preferred activity. Another example can be that residents are allowed to have a late breakfast after they attend religious services when these events occur at the same time. Tailoring activities appropriate to an individual resident requires all relevant departments in nursing homes to collaborate and communicate during the development of an activity plan for each resident. A recent movement of culture change puts emphasis on eliminating a traditional activities calendar and instead empowering residents to

choose and lead their own ongoing and spontaneous activities and chores (Doty, Koren, & Sturla, 2008).

The environment in the nursing home should optimize engagement in persons with dementia (Cohen-Mansfield, Marx, et al., 2010). Adjustment of noise levels and lighting is necessary when they bother residents during an activity session. Previous studies suggest that study participants were engaged more often with moderate levels of sound and in the presence of a small group of people (Cohen-Mansfield, Dakheel-Ali, & Marx, 2009; Cohen-Mansfield, Thein, et al., 2010). Residents with physical and cognitive limitations need additional assistance to attend in activities. Whenever needed, staff's assistance should be available for residents with physical disability (e.g., wheelchair-bound). Further, it is helpful to demonstrate how to play a game or do an activity, in particular, for severely cognitively impaired residents. Repeated presentations or reminder of the same activity can be beneficial for both the severely impaired and the moderately cognitively impaired.

Implications for Practice

It is important that residents' activity engagement patterns are periodically evaluated in order to identify limitations, concerns, or problems affecting their engagement in activities. A checklist can serve a useful tool to individualize and evaluate activity engagement in nursing home residents with dementia (see Table 2). Evaluations can include types of activities, frequencies and attendance, tailoring an activity that matches residents' abilities, level of attention and engagement during the activity, and satisfaction with the activity—expressed verbally or non-verbally. In addition, residents' involvement should be emphasized in the development of activity plans and then throughout the activity engagement process. As an individual needs are continuously changing, activity plans have to be changeable and revised as often as necessary. Keeping residents in the center of the activity planning and decision-making will improve engagement in relevant and meaningful activities.

Conclusions

Nursing home residents with dementia previously enjoyed a variety of hobbies and activities before they moved to nursing homes. Yet their current activities in nursing home settings were very limited and uninteresting. Activities should be expanded and tailored to their needs and interests. Flexible schedule and provision of resources and accommodation is also imperative to engage them in their preferred activities despite limited functioning.

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Table 1

Past hobbies and favorite activities of study participants (N=37)

Outdoor/physical activities	Playing sports (e.g., swimming, golf, baseball, basketball, horseback riding)
	Fishing/ camping/ hiking
	Traveling/ driving
	Yard work/ gardening
	Dancing/ walking
	Shopping
Arts and crafts	Sewing/ knitting/ crocheting/ clothes design/ crafts (e.g., making necklaces and headbands)
	Painting/ drawing
	Photography
	Collecting things (e.g., postcards, articles, stamps, pens, old magazines)
	Making scrapbooks
Watching, listening, and reading Games	Watching movie, star, bird, university athletics games, or TV
	Listening to Music/ playing piano
	Reading/ writing (e.g., prose and poetry)
	Playing board games, cards, chess or bridge
	Solving arithmetic problems
Service	Volunteering (e.g., helping children, serving at church for youth group) Teaching
Socialization	Hang out with friends
	Making friends from other countries via mails
Cooking	Baking/ making candies/ cooking for entertaining guests
Other	No hobbies
	Politics

Table 2

A checklist for individualizing and evaluating activity engagement

Items	Checklist
Current activity engagement	• What types of activities is resident currently involved? (List activities in terms of organized, individual, one-to-one, and self-directed) • To what extent does resident involve for each activity? (e.g., once, 2~3 times, daily per week) • What is the level of attention and engagement during activities? (e.g., dozing, not focused and distracted, passively engaged, actively engaged in the steps of the activity)
Tailoring activity	• What functional needs (e.g., cognitive, health status, physiological, and psychosocial) are affecting his/her engagement in activities? • What is required to address functional needs of resident in order to participate in preferred activities? (e.g., accessories, assistive devices, supplies, or modification of activity) • What assistance does resident need in activities? (e.g., staff assistance to go to activity room, repeated instructions/reminders)
Activity schedule	• Do resident have activities in a regular basis? (e.g., daily, weekly, and monthly) • When is resident's preferred time of day for an organized activity offered by the facility in general? (e.g., morning, afternoon, evening, no preference) • Is a change in his/her daily routines necessary in order to attend an activity? If the resident prefers not to change his/her routines, can the facility offer an alternative? • What is the preferred duration for an activity? (e.g., half an hour, one hour, more than one hour)
Room set-up	• Does resident have a preference in the size of an activity? (e.g., small group, large group, one-to-one, no preference) • Does resident have preference in the place of activity? (e.g., own room, facility activity room/ indoor, outdoor, no preference) • Is an adjustment of sound necessary during an activity? (e.g., making sound louder for a resident with hearing difficulty) • Is an adjustment of lighting required? (e.g., more light for a resident with a vision problem)
Activity satisfaction	• Does the resident express positive emotion and satisfaction verbally or nonverbally during an activity? • What is the most preferred activity of resident? • What is the least preferred activity of resident? • What concerns do resident have in participating in activities?
Expanding activities	• Does resident express interests in continuing hobbies and activities that he/she previously enjoyed? • What motivates resident's interests in doing activities? • Has resident tried a new activity recently and how does he/she like?
Special accommodation	• Does resident need a transportation arrangement to attend a regular activity outside the facility? • What resources from the facility are required in order for resident to