MAKING THE MOST OF THE DAY: QUALITY OF LIFE AND MEANINGFUL ACTIVITY

Factors Influencing Participation in Activities in Dementia Care Settings

BY DANIEL KUHN, MSW, BRADLEY R. FULTON, MA, AND PERRY EDELMAN, PhD

The influence of cognitive impairment, functional impairment, and care setting on participation in activities has not been examined. To better understand these relationships, data were collected for 166 persons with dementia in 3 types of care settings. Residents of nursing homes and those with highest levels of cognitive and functional impairment had the lowest level of participation in staff-led activities and the greatest frequency of sleeping. In contrast, persons with mild dementia and those attending adult day centers had the highest level of participation in staff-led activities and the lowest frequency of sleeping. Implications for practice are discussed.

Key words: activities, adult day centers, assisted living facilities, dementia, nursing homes, participation

In his remarkable account of living with Alzheimer’s disease, Davis makes known his personal wish that may well represent a universal need: "I want to participate in life to my utmost limit." Whether living in one’s own home or in a care facility, persons with dementia retain a human desire for activity that is personally meaningful. Engagement in meaningful activities by persons living in residential care facilities is important for maintaining quality of life and preserving dignity.
care facilities has long been recognized as an important factor in their quality of life. However, persons with dementia often lack the initiative to begin or sustain activities because of cognitive impairment and diminished self-care skills. If meaningful activities are not structured for them, they may face ‘the three plagues of helplessness, boredom, and loneliness.’ In formal care settings, staff-led activities are critical for maximizing the quality of life of persons with dementia. Thus far, there has been little effort to document factors influencing participation in activities among persons with dementia.

Activities comprise the ‘stuff’ of everyday life. According to the dictionary, an activity is ‘the quality or state of being active’ or ‘a pursuit in which a person is active or a form of organized, supervised, often extracurricular recreation.’ In most formal care settings, activities usually refer to a structured program of staff-led events such as physical exercise, music and singing, games, handicrafts, and a host of other leisure and creative experiences. In guidelines for client-centered practice, the Canadian Association of Occupational Therapists defines a meaningful lifestyle in terms of 3 spheres of activity: self-care, productivity, and recreation. Others like Hellen, Sifton, and Zgola take a broader view and argue that staff members can use virtually every encounter to engage persons with dementia in cognitive, physical, psychosocial, or spiritual activities. However, observational studies reveal that nursing home residents with dementia often have nothing to do, prompting challenging behaviors such as agitation.

The importance of activities for nursing home residents in the United States is highlighted by government regulations that require activity departments to be directed by ‘a qualified professional.’ The National Certification Council for Activity Professionals and the American Therapeutic Recreation Association set standards for such professionals. The Alzheimer’s Association recognizes activity programming as a key element to good care and a major contributor to life satisfaction.

In recent years, several studies have used proxy and self-reports to examine quality of life among people with dementia in residential care and outpatient clinic settings. Several observational studies to assess quality of life have also been conducted in nursing homes, assisted living facilities (ALFs), and adult day centers (ADCs). The most widely used outcome measure in these observational studies has been Dementia Care Mapping (DCM). DCM was initially developed in the early 1990s under the leadership of the late Tom Kitwood, a social psychologist and head of the Bradford Dementia Group in England. DCM stems from Kitwood’s humanistic philosophy of person-centered care aimed at improving the care of people with dementia through engagement in a positive social environment. Kitwood assumed that well-being for people with dementia occurs within the interaction of relationships. He included participation in meaningful activities or ‘occupation’ as central to personal well-being: ‘If people are deprived of occupation their abilities begin to atrophy, and self-esteem drains away.’ In the course of extensive observational work, Kitwood and colleagues identified indicators of well-being and ill-being that were then operationalized into DCM. It is primarily intended to measure and improve the quality of care provided by staff in formal care settings but can also be used to assess quality of life. DCM involves making detailed observations of 24 behaviors and activities (Behavior Category Codes [BCCs]) and 6 states of well-being/ill-being (WIB scores).

THE PRESENT STUDY

Data reported in this article were obtained from a larger study comparing different measures of quality of life through direct interviews, staff proxy reports, and observation. The present study examined the relationships between participation in activities, cognitive impairment, functional impairment, and care setting. Persons with dementia were assessed in 3 types of dementia-specific care settings including 2 special care facilities (SCFs) that were licensed nursing homes, 5 ALFs, and 5 community-based, ADCs. Staff-led activities were led at all sites by staff members trained in activities geared primarily to persons with dementia.

The following research questions are addressed here: What types of activities, both staff-led and others, take place in these care settings? Is the type of care setting related to participation in activities? Are cognitive impairment and activities of daily living (ADL) dependency related to participation in activities?

METHODS

Participants

A convenience sample of 8 care sites in the Chicago area was recruited. All sites had dementia-specific programs and staff trained in the care of people with Alzheimer’s disease or related dementias. Written consent was obtained from key family members or legal representatives on behalf of 184 persons with dementia participating in the study. In addition, consent was obtained directly from...
Participants with Mini-Mental State Examination (MMSE) scores greater than 9. Other researchers have found that people with dementia with an MMSE score greater than 9 are able to respond appropriately during an interview.\(^1\)\(^7\) Complete data for the 6 quality of life measures used in the larger study were obtained for 166 individuals (90% of those who consented). The sample size included 62 residents of SCFs, 49 residents of ALFs, and 55 clients of ADCs.

**Measures**

DCM involves making detailed observations of 6 to 8 persons during each 5-minute period for up to 6 continuous hours. This process is simply referred to as mapping. Observations take place in congregate care settings, but in public areas only such as living rooms, dining rooms, or activity areas—bedrooms and bathrooms are excluded. DCM data collection involves 2 main “coding frames.” The first coding frame, called Behavior Category Coding, describes each person’s behavior or activity during every 5-minute period. Each behavior is recorded or “mapped” by assigning a letter representing 1 of 24 BCCs such as exercising, playing a game, eating and drinking, sleeping, and walking. The second coding frame consists of an index of well-being/ill-being (WIB score) with 6 numerical values ranging from 1 (exceptional well-being) to 5 (extremes of apathy, withdrawal, or despair). WIB scores are actual average scores, calculated by dividing the sum of all numerical values by the total number of time frames during the observation period. Individual WIB scores for each person observed or mapped can be calculated WIB scores for a group or site, referred to as Group WIB scores, can also be calculated. Because there is no generally accepted method of computing internal consistency reliability for BCCs or WIB scores, none is reported here.

In DCM’s current seventh edition,\(^2\) the 24 BCCs are grouped into 4 types: (1) Type 1 includes 15 BCCs that primarily promote well-being, (2) Type 2 includes 6 BCCs that primarily promote ill-being, including passive social involvement (code B), being withdrawn (code C), being distressed (code D), being unresponded to (code U), engaged in repetition (code B), and being withdrawn (code C), (3) Walking (code K), and (4) Sleeping (code N). For the purpose of this study, Type 1 BCCs were subdivided into (a) 8 staffed activities including self-expression through music, art, and dance (code E), exercise (code J), games (codes I & G), handicrafts (code H), religious practices (code R), sensory stimulation (code T), and work or work-like activity (code L) and (b) 7 other activities generally independent of initiative by staff including social interaction (code A), watching media (code M), receiving personal care (code P), sexual behaviors (codes S), and eating or drinking (code F).

Information was collected regarding each person’s age, gender, race, length of stay, depression, comorbid conditions, cognitive impairment, and dependency with respect to personal ADLs. Cognitive impairment was assessed with the MMSE that employs a 30-point scale with a score of 0 at the lowest end of the scale indicating profound dementia.\(^1\)\(^3\) The 6-item Activities of Daily Living Scale was used to measure participants’ functional impairment (eg, toileting, bathing, dressing).\(^1\)\(^5\) Responses to the 5-point ADL Scale define different levels of independence/dependence: Scale scores were computed as a count of the total number of dependent ADLs. Missing items were assumed absent and not added to the count.

**Procedure**

Mapping was conducted by 2 highly trained and experienced mappers who achieved a high level of interrater reliability (>95% exact agreement for BCCs and WIB scores). Each of the 166 participants was observed continuously on a weekday, typically between 9:00 AM and 3:00 PM for an average of 5.8 hours or 70 time frames. Per DCM guidelines, observations were not made when participants were situated in a private area such as a bedroom or bathroom. Consequently, staff time spent assisting participants with intimate ADLs such as dressing, grooming, bathing, and toileting was usually not documented. Thus, the average number of usable observations per participant was actually 4.7 hours or 57 time frames. The total number of usable observations for the entire sample was 9503. A research assistant assessed each participant’s cognitive impairment using the MMSE and a nurse collected the remaining information.

**Analysis**

All data were analyzed using SPSS computer software.\(^3\)\(^5\) Based on a review of MMSE categories used by other researchers and clinicians to delineate severity of cognitive impairment,\(^1\)\(^9\)\(^-\)\(^1\)\(^5\) MMSE scores were recoded into 4 categories: 0 points = profound, 1 to 9 = severe, 10 to 19 = moderate, and 20+ = mild. Three levels of ADL dependency were identified by examining frequency distributions: persons with 4 to 6 ADL dependencies had the highest level of need, persons with 1 to 3 ADL dependencies had a moderate level of need, and persons with no ADL dependencies had no need of assistance.

Demographics and other characteristics were examined across the total sample as well as by care setting using the

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**Participation in Activities in Dementia Care**

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Pearson chi-square statistic and analysis of variance (ANOVA) because ADL categories were constructed based on the current data set, post hoc analyses (Tukey's HSD) rather than planned comparisons were used in the relevant ANOVAs. However, the MMSE categories were constructed based on previous research, allowing a priori hypotheses. Thus, planned comparisons were used in the relevant ANOVAs.

Five types of BCCs were examined across care settings, across categories of MMSE scores, and across levels of ADL dependency. An ANOVA was conducted to examine differences in mean WIB score by care setting. Mean quality of life scores per type of care setting were computed as the average of the Individual WIB scores for participants in each of the 5 types of care settings (ie, SCFs, ALFs, and ADCs). Although this method of computing the WIB score for the care setting varies slightly from the typical manner in which Group WIB score is computed, computing the WIB using both of these methods showed that the mean of individual scores by site was nearly identical to site Group WIB scores calculated the traditional way. Comparing these 2 methods, the difference in mean WIB scores was 0.03 or less for each of the 3 care settings.

RESULTS

Demographics and other characteristics

Table 1 summarizes the demographic information and other characteristics of study participants across the 3 types of care settings. The mean age of the 166 participants was 83.5 and women accounted for 75% of the sample. An ANOVA identified a significant difference in the mean age by care setting, $F(2, 163) = 9.752$, $P < 0.0005$, $\eta^2 = 0.107$. Specifically, post hoc analyses identified differences between the mean age of ADC participants (80.8) and the mean age of ALF residents (85.6, $P < 0.0005$) and SCF residents (84.3, $P = 0.004$). A Pearson chi-square identified significant differences in the proportion of males/females by care setting, $\chi^2(2) = 8.175$, $P = 0.017$. The mean length of time spent in a care setting was 724 days or almost 2 years. Nearly all (96%) participants were Caucasian.

The mean number of dependent ADLs was 2.4 (out of 6 possible), and the overall mean MMSE score was 10.6, just above the designated cutoff score of severe dementia (1–9 points). ANOVAs identified significant differences in both mean MMSE scores, $F(2, 163) = 6.610$, $P = 0.002$, $\eta^2 = 0.075$, and ADL dependency scores, $F(2, 163) = 4.085$, $P = 0.019$, $\eta^2 = 0.048$, among care settings. Planned comparisons indicated a significant difference in mean MMSE scores between SCFs and ADCs ($P = 0.005$). Differences in the proportions of participants in the 4 MMSE categories reflected these findings. For example, 23% of SCF residents were profoundly impaired, compared to 4% of ALF residents and 7% of ADC clients. Post hoc comparisons (Tukey’s HSD) indicated that people living in SCFs ($P = 0.001$) and ALFs ($P = 0.055$) were the most impaired with respect to ADLs compared to those in ADCs. The mean individual WIB score was 1.4; an ANOVA identified a significant difference, $F(2, 163) = 19.841$, $P < 0.0005$, $\eta^2 = 0.196$. 

### Table 1.

#### Demographic Profile and Other Characteristics by Care Setting*

<table>
<thead>
<tr>
<th></th>
<th>Total sample (n = 166)</th>
<th>SCFs (n = 62)</th>
<th>ALFs (n = 49)</th>
<th>ADCs (n = 55)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>83.5 (6.1)</td>
<td>84.3 (5.6)</td>
<td>85.6 (5.2)</td>
<td>80.8 (6.4)</td>
</tr>
<tr>
<td>% Female</td>
<td>75%</td>
<td>81%</td>
<td>84%</td>
<td>82%</td>
</tr>
<tr>
<td>% Caucasian</td>
<td>96%</td>
<td>97%</td>
<td>98%</td>
<td>95%</td>
</tr>
<tr>
<td>Length of stay, d</td>
<td>724 (645)</td>
<td>793 (710)</td>
<td>702 (567)</td>
<td>668 (638)</td>
</tr>
<tr>
<td>ADL dependency (0–6)</td>
<td>2.4 (2.2)</td>
<td>3.0 (2.3)</td>
<td>2.6 (2.0)</td>
<td>1.6 (1.8)</td>
</tr>
<tr>
<td>MMSE score†</td>
<td>10.6 (7.1)</td>
<td>8.8 (7.1)</td>
<td>10.8 (6.9)</td>
<td>12.5 (7.2)</td>
</tr>
<tr>
<td>Individual WIB score†</td>
<td>1.4 (0.5)</td>
<td>1.1 (0.4)</td>
<td>1.5 (0.5)</td>
<td>1.6 (0.4)</td>
</tr>
</tbody>
</table>

*SCFs indicates special care facilities; ALFs assisted living facilities; ADCs, Adult day centers; ADL, activity of daily living; MMSE, Mini-mental State Examination; WIB, well-being/ill-being.

†$P = 0.005$

‡$P = 0.017$

§$P = 0.002$

‖$P = 0.019$
Planned comparisons identified differences between the mean score at SCFs (1.1) and the other 2 types of care settings, ALFs (1.5, P < .0005) and ADCs (1.6, P < .0005). Thus, persons living at SCFs were judged to have considerably lower well-being scores than did persons living in ALFs or attending ADCs.

Activities and behavior category codes

The 24 BCCs were divided among 5 types. Table 2 illustrates the percentage of these types across the 3 types of care settings. Type 1 BCCs generally promote well-being and were divided between staff-led activities and other activities that generally do not require staff initiation. Differences were seen across care settings in terms of time spent participating in staff-led activities: 11.3% in SCFs, 17.8% in ALFs, and 22.2% in ADCs. Also, participants in ADCs spent the least amount of time sleeping (5.6%) compared to participants in ALFs (9.4%) and SCFs (10.8%). No other major differences in types of BCCs were noted.

BCCs were examined to determine the relationship between cognitive impairment and the types of interactions or activities in which people with dementia participate. Table 3 shows the relationship between the 5 types of BCCs and the 4 MMSE categories. The first column includes observations for the total sample, and the remaining columns represent observations by MMSE category. The proportion of observations accounted for by each type of BCC within MMSE category is shown. Thus the columns sum to 100%.

Among the highlights in Table 3, persons with profound cognitive impairment were observed participating in staff-led activities only 6.3% of the time, a much lower frequency compared to persons with severe, moderate, and mild dementia. Sleeping was observed most frequently among participants with profound cognitive impairment (19.7%). On average, persons with profound cognitive impairment spent less than 20 minutes involved in staff-led activities and spent 60 minutes sleeping during 5, peak daytime hours. Time observed in other Type 1 behaviors was fairly similar across all categories of cognitive impairment.

Functional impairment may also influence the types of interactions or activities in which people with dementia participate. Table 4 shows the relationship between the 5 types of BCCs and the 3 levels of ADL dependency. Individuals with the highest level of dependency were observed to have the lowest frequency of participation in staff-led activities (9.5%) compared to those with a moderate level of dependency (19.1%) and no dependency.

Table 2.

<table>
<thead>
<tr>
<th>BCC types</th>
<th>Total sample</th>
<th>SCFs</th>
<th>ALFs</th>
<th>ADCs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff-led</td>
<td>16.8</td>
<td>11.3</td>
<td>17.8</td>
<td>22.2</td>
</tr>
<tr>
<td>Other</td>
<td>36.3</td>
<td>39.4</td>
<td>33.6</td>
<td>35.1</td>
</tr>
<tr>
<td>Type 2</td>
<td>26.1</td>
<td>25.5</td>
<td>25.6</td>
<td>27.2</td>
</tr>
<tr>
<td>Walking</td>
<td>12.1</td>
<td>12.9</td>
<td>13.6</td>
<td>9.8</td>
</tr>
<tr>
<td>Sleeping</td>
<td>8.7</td>
<td>10.8</td>
<td>9.4</td>
<td>5.6</td>
</tr>
</tbody>
</table>

*BCC indicates Behavior Category Code; SCFs, special care facilities; ALFs, assisted living facilities; ADCs, adult day centers.

Table 3.

<table>
<thead>
<tr>
<th>BCC types</th>
<th>Total sample</th>
<th>MMSE: 0 (Profound; n = 20)</th>
<th>MMSE: 1–9 (Severe; n = 52)</th>
<th>MMSE: 10–19 (Moderate; n = 75)</th>
<th>MMSE: 20+ (Mild; n = 19)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Staff-led</td>
<td>16.8</td>
<td>6.3</td>
<td>15.9</td>
<td>19.1</td>
<td>21.4</td>
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<tr>
<td>Other</td>
<td>36.3</td>
<td>38.3</td>
<td>37.1</td>
<td>35</td>
<td>36.7</td>
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<tr>
<td>Type 2</td>
<td>26.1</td>
<td>30.1</td>
<td>26.5</td>
<td>24.7</td>
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<tr>
<td>Walking</td>
<td>12.1</td>
<td>5.5</td>
<td>13.3</td>
<td>12.8</td>
<td>13</td>
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<td>Sleeping</td>
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</table>

*BCC indicates Behavior Category Code, MMSE, Mini-Mental State Examination.
Individuals with the greatest level of dependency were observed to have the highest frequency of sleeping (12.7%) compared to those with a moderate level of dependency (7.8%) and no dependency (4.6%). Time observed in other Type 1 behaviors was fairly similar across all levels of dependency.

DISCUSSION

There are a number of limitations to this study. First, the number of sites and participants in the study was relatively small. The population was largely female and predominately Caucasian so that results are not generalizable. Second, per DCM scoring guidelines, observations were conducted in public areas only and one-to-one interactions between staff and participants in ADLs such as dressing, grooming, bathing, and toileting were usually not recorded. The potential for experiencing positive well-being in these important activities cannot be overlooked. Third, the method of separating Type 1 staff-led activities from other Type 1 activities has not yet been validated, although it has face validity. Any positive interaction, whether it is staffed or initiated by residents/clients or others, may be equally important to persons with dementia. Like any observational measure, DCM estimates the experience of others; it would be helpful to get feedback directly from persons with dementia. The larger study from which these data are drawn will be helpful in addressing some of these limitations. By comparing direct interviews, staff proxy reports, and observational data, it is hoped that a synthesized approach to assessing dementia-specific quality of life can be developed that will take into account these multiple perspectives.

In this study, care setting was associated with activities. Staff-led activities were observed least frequently in SCFs, and sleeping was observed most frequently in SCFs. SCFs included the most impaired individuals in terms of dementia severity and ADL dependency. Not surprisingly, the lowest quality of life (as indicated by WIB scores) was observed in SCFs. Although the causal relationship among activities, participants’ characteristics, and care setting remains to be determined, maximizing participation in activities is a reasonable goal for improving the quality of life of persons living in SCFs.

Cognitive impairment and ADL dependency were important factors associated with participation in staff-led activities. People with profound dementia seldom participated in staff-led activities and spent a disproportionate amount of time sleeping compared to individuals with severe, moderate, and mild dementia. Reasons for low participation in staff-led activities and excessive daytime sleep, including psychotropic drug use, require further exploration.

The results of this study suggest that people with the highest levels of cognitive impairment or ADL dependency infrequently participate in staff-led activities. Because persons with profound impairment also spent a disproportionate amount of time sleeping compared to individuals with severe, moderate, and mild dementia, reasons for low participation in staff-led activities and excessive daytime sleep, including psychotropic drug use, require further exploration.

The results of this study suggest that people with the highest levels of cognitive impairment or ADL dependency infrequently participate in staff-led activities. Because persons with profound impairment also spent a disproportionate amount of time sleeping, they were often unable to engage in any activities. Profoundly impaired persons have a limited capacity to engage in activities on their own and need considerable prompting and coaching. Engaging them may not be easy, but they can participate in certain activities under the right conditions. Staff may require extra time, better training in activity programming, and other resources necessary to enhance engagement in activities among individuals with the highest levels of impairment. Factors such as staffing can also influence engagement in activities. Policy makers, administrators, and others involved in funding services need to understand that good care is costly, especially among the frailest population.

Table 4.

<table>
<thead>
<tr>
<th>BCC types</th>
<th>Total sample (n = 166)</th>
<th>High dependency (4–6 ADLs; n = 61)</th>
<th>Moderate dependency (1–3 ADLs; n = 56)</th>
<th>No dependency (0 ADLs; n = 49)</th>
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<tbody>
<tr>
<td>Type 1</td>
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*BCC indicates Behavior Category Code; ADL, activity of daily living.

(23.3%). Individuals with the greatest level of dependency were observed to have the highest frequency of sleeping (12.7%) compared to those with a moderate level of dependency (7.8%) and no dependency (4.6%). Time observed in other Type 1 behaviors was fairly similar across all levels of dependency.
Results of this study support the concept promoted by Fazio et al. of “clustering” people with dementia into groups of similar needs and abilities. It is clearly difficult for people with the highest levels of impairment to be engaged in meaningful activities. They can be characterized as an “at risk” subgroup compared to less impaired individuals who generally respond much better to activity programs. Staff-led activities often appear geared primarily to individuals who are most responsive and most likely to benefit. Therefore, those at risk persons with dementia require different interventions that take into account their special needs.

Activities must be tailored to suit the needs and abilities of persons at different levels of impairment. Brooker and Duce found that group reminiscence was more engaging among persons with mild to moderate dementia than either goal-directed crafts and games or unstructured time. Kovach and Magliocco found that persons with profound dementia responded well to various therapeutic activities involving many senses, although for short periods of time. The present study underscores the need for careful assessment of needs and abilities of persons with dementia in order to plan and implement effective group and individual activities. Otherwise, it seems clear that persons with profound dementia are easily overlooked.

Persons in the late stages of dementia are not likely to respond to large group activities, and require one-to-one and small group approaches to promote engagement and maximize their quality of life. Perrin argues that goal-oriented and cooperative activities may be counterproductive so that “mothering is an appropriate model for maintaining being and well-being in late dementia.” In describing dementia in terms of a “journey from doing to being,” she draws upon the work of developmental theorists and the love of mothers for their disabled children to better understand and meet the needs of persons with advanced dementia.

Other approaches such as Montessori-based activities and music have been found to be effective among persons in the middle and late stages of dementia. A review of 63 studies involving a variety of psychosocial interventions employed among persons at different levels of dementia concluded that most interventions resulted in clinically significant behavioral changes. Moreover, most interventions were relatively simple to implement and of little to no cost. Although large-scale studies have not been conducted on the effects of multisensory rooms, their growing popularity attests to the desire to engage persons with dementia in ways that suit their needs. It remains to be seen if such expensive interventions or technological innovations can increase participation in meaningful activities and enhance the quality of life of persons with dementia.

Understanding the disabling effects of dementia in terms of cognitive and functional impairment as well as the residual skills and abilities of individuals are important for promoting engagement in appropriate activities. The human resources needed to put ingenuity and skill into practice are also a critical factor in ensuring that the diverse needs and abilities of persons with dementia are addressed.

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REFERENCES


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QUERIES TO THE AUTHOR

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TITLE: Factors Influencing Participation in Activities in Dementia Care Settings

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QA2: Kindly provide the page range.