

Intervention Research

Characteristics of Activities for Persons With Dementia at the Mild, Moderate, and Severe Stages

Natalie G. Regier, PhD,^{1,*} Nancy A. Hodgson, PhD, RN, FAAN^{1,2}, and Laura N. Gitlin, PhD¹

¹Center for Innovative Care in Aging, Johns Hopkins University School of Nursing, Baltimore, Maryland.

²University of Pennsylvania, School of Nursing, Philadelphia, Pennsylvania.

*Address correspondence to Natalie G. Regier, PhD, Center for Innovative Care in Aging, Johns Hopkins University School of Nursing, 525 North Wolfe Street, SON House Room 301, Baltimore, MD 21205. E-mail: nregier1@jhu.edu

Received March 22, 2016; Accepted June 13, 2016

Decision Editor: Suzanne Meeks, PhD

Abstract

Purpose: To understand activity in dementia care, we examine relationships of disease stage with types and characteristics of meaningful activities (cueing needs, help with initiation, and recommended engagement time) provided in a home-based intervention trial designed to reduce behavioral symptoms.

Design and Methods: Data involved 158 activity prescriptions or written documents detailing prescribed activities, cueing needs, and engagement goals designed by occupational therapists for 56 families. Activities were categorized as arts and crafts, exercise/physical, cognitive, music/entertainment, manipulation/sensory/sorting, family/social/ reminiscence, and domestic/homemaking. Bivariate correlations examined relationships of activity categories and characteristics with disease stage (mild, moderate, or severe). Kruskal–Wallis *H* tests examined differences among disease stages and frequency of type of activities prescribed, recommended cues, and engagement time. For significant Kruskal–Wallis tests, pairwise comparisons utilized the Mann–Whitney *U* test.

Results: Activity categories and instructions for set up were significantly related to cognitive and functional levels. Persons with *mild* dementia were most often prescribed complex arts and crafts and cognitive activities. Persons with *moderate* dementia were most often prescribed music/entertainment. Persons with *severe* dementia were most often prescribed simple physical exercises and manipulation/sensory/sorting activities. Average time prescribed for activities was less for those in severe (15 min) versus moderate (24 min) and mild (28 min) stages. The severe group required more assistance with activity initiation and cueing/redirection.

Implications: Type of activity, recommended cueing, and engagement time differed by dementia stage. Findings provide guidance as to how to use and set up activities across the dementia trajectory.

Keywords: Meaningful activity, Tailoring, Nonpharmacological intervention, Caregiver, Dementia, Behaviors

Dementia, a public health crisis, affects 47.5 million people worldwide and is projected to double in prevalence every 20 years (Prince et al., 2013). Nearly all persons affected will manifest behavioral symptoms at some point during the course of the disease regardless of etiology (Gitlin, Kales, & Lyketsos, 2012), and the point prevalence of most behavioral symptoms increases as the disease progresses (Steinberg et al., 2008). Behavioral symptoms, such as

agitation, aggression, and restlessness, are the most difficult, distressing, and burdensome aspects of dementia care and a catalyst for long-term care placement (Lima-Silva et al., 2015; Tun, Murman, Long, Colenda, & von Eye, 2007).

Given the growing prevalence of dementia, the absence of an imminent cure or effective pharmacotherapy, and the profound costs and consequences of behavioral symptoms, it is vital to identify interventions that minimize behavioral

occurrences and improve or sustain the quality of life. It has been suggested that nonpharmacological interventions should be the first approach to treatment for dementia-related behavioral symptoms (Lyketsos et al., 2006). Recent studies have demonstrated that teaching caregivers to administer nonpharmacological interventions can significantly decrease caregiver burden and enable persons with dementia to remain in the community longer (Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010; (McLaren, LaMantia, & Callahan, 2013).

One effective nonpharmacological approach is engagement in meaningful activity, shown to increase positive emotions, improve performance in activities of daily living (ADLs), improve quality of life and well-being, foster positive attitudes toward caregivers, and decrease behavioral symptoms (Barton, Ketelle, Merrilees, & Miller, 2016; Vikström, Josephsson, Stigsdotter-Neely, & Nygård, 2008). A promising activity intervention is the New Ways for Better Days: Tailoring Activities for Persons with Dementia and Caregivers (formerly known as the Tailored Activity Program [TAP]; Gitlin et al., 2008, 2010), which significantly reduced the number of behaviors and frequency of occurrences and objective burden or hours spent in care. Additionally, 86% of caregivers expressed somewhat or very much lower upset with challenging behaviors and 95% expressed feeling somewhat or very much more in control.

Despite the growing evidence of the benefits of activity engagement, there remains a lack of clarity regarding what specific activities are useful and how best to tailor them, given the cognitive and functional declines associated with dementia. Furthermore, little is currently known about what specific characteristics of an activity can enhance an individual's ability to be meaningfully engaged. Utilizing the TAP data, this study examines the clinical practice of prescribing customized activities for persons with dementia in order to derive guidelines for using activities therapeutically in everyday care. Specifically, this study examines the relationships between dementia disease stage (mild, moderate, and severe) and (a) type of activity prescribed and (b) characteristics of activity set up (targeted engagement time, type of cueing/ redirection required, and need for assistance initiating an activity). Understanding what types of activities to implement at each disease stage and how to set them up can inform the incorporation of activities into daily care routines.

Conceptual Frameworks

Several key theories broadly inform engagement in activities and grading to cognitive and functional abilities. According to the activity theory of aging, continued participation in pleasurable activities keeps older adults with and without dementia stimulated, engaged, and of higher well-being throughout the life course (Atchley, 2006; Havighurst & Albrecht, 1953). The unmet needs model suggests that behaviors arise from a decreased ability to communicate one's needs and provide for oneself independently. Not all

behaviors may be a consequence of an unmet need or communication issue, and TAP recognizes the ongoing need for meaningful activity, agency, control, and stimulation throughout the disease course (Roland & Chappell, 2015). The program facilitates participation by developing activities that are customized to performance capabilities and decrease environmental demands, thus addressing heightened vulnerabilities with disease progression.

To understand the specific selection and design of activities, we draw upon the Occupational Therapy Practice Framework (AOTA, 2014). This framework specifies domains to consider in understanding everyday activities, their components and ways to support participation (Thomas, 2015). Domains include, for example, occupations (e.g., ADLs, social participation, and leisure), client factors (e.g., values and beliefs, body functions, and structures), performance skills (e.g., motor, process, and social skills), performance patterns (e.g., habits and routines), and contexts/environments (e.g., cultural, personal, and social; AOTA, 2014), all of which must be considered to achieve a "just-right" fit between an individual and an activity that maximizes engagement.

Methods

This study is a secondary data analysis of activity prescriptions developed by interventionists (occupational therapists [OTs]), for persons with dementia in the TAP trial.

Participants

Participants were Philadelphia-area dementia caregivers and persons with dementia recruited through media announcements and social service mailings. Inclusion criteria for persons with dementia were: English-speaking, physician's diagnosis of dementia or Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975) score <24, and the ability to feed themselves and participate in at least two self-care activities. Exclusion criteria were: a diagnosis of schizophrenia, bipolar disorder, dementia due to head trauma, bed-bound condition, or nonresponsiveness (i.e., unable to respond to short commands). Caregivers were English-speaking, at least 21 years of age, lived with the person with dementia, provided at least 4 hr of daily care, and reported that the person with dementia exhibited boredom, sadness, anxiety, agitation, restlessness, or difficulty focusing on a task. Caregivers involved in another study, seeking nursing home placement, terminally ill, in active cancer treatment, or with three or more hospitalizations in the past year were excluded. Additional recruitment and procedure details are described elsewhere (Gitlin et al., 2008).

Overview of Intervention

TAP is a home-based intervention in which OTs trained in the protocol develop activities tailored to the interests and capabilities of persons with dementia and teach

caregivers to incorporate these activities into daily care routines. Additionally, caregivers receive education about dementia, behaviors, and ways to address their own situational distress. The intervention involved up to eight 90-min home visits over 4 months. Interventionists met with caregivers, introduced intervention goals, used a semi-structured clinical interview and administered performance-based measures. Three domains were assessed: the person with dementia, the caregiver, and the physical home environment. For the persons with dementia, interventionists assessed their previous and current interests using a modification of the Pleasant Event Schedule (Teri & Logsdon, 1991), cognitive abilities using the Dementia Rating Scale-2 (DRS-2; Jurica, Leitten, & Mattis, 2001), their cognitive functioning using Allen's observational craft-based measures (Large Allen Cognitive Level Screen, 5th edition [LACLS-5] and Allen Diagnostic Module, 2nd edition [ADM-2] or Sensory Motor Stimulation Kit I/II; Blue & Allen, 1993; Earhart et al., 2003), their physical balance using the Timed Up-and-Go (TUG) test, and their daily routines through caregiver interview. For the caregiver, interventionists observed dyadic communication, interviewed caregivers as to daily caregiving routines and activities tried and enjoyed, and also the level of readiness to try new strategies (Gitlin & Rose, 2016). As to the home environment, interventionists evaluated features such as clutter, lighting, seating, and wayfinding as they related to activity engagement.

Three activities per person were identified based on the synthesis of interests with preserved cognitive and functional capabilities, as well as caregiver and home environmental assessments. For each activity, interventionists developed a typed document, referred to as an activity prescription (Supplementary Appendix), specifying the person's capabilities, targeted activity (e.g., completing a puzzle form board), engagement goal (e.g., engage in activity 20 min daily after breakfast), and implementation techniques (e.g., help with initiation).

Study Variables

Dementia Disease Stage

In keeping with a commonly used method of global staging (Hughes, Berg, Danziger, Coben, & Martin, 1982; Morris, 1997), we identified three stages of dementia by considering a range of indicators. Specifically, we examined participants' performance on three performance-based tests and two caregiver-reported functional scales: the Large Allen Cognitive Level Screen-5 (LACLS-5; Earhart et al., 2003), administered as a measure of the person with dementia's learning potential, global cognitive processing capacities, and performance abilities; the MMSE (Folstein et al., 1975), a brief cognitive screening tool where scores lower than 24 are suggestive of cognitive impairment (range = 0–30); the Dementia Rating Scale (DRS-2; Jurica et al., 2001), which assessed overall cognitive functioning as well as performance within five cognitive domains (attention, initiation/perseveration, construction, conceptualization, and

memory); level of assistance required on ADLs and instrumental ADLs (IADLs); and frequency/severity of behavioral symptoms as reported by caregivers.

Within our sample, three clear and conceptually cohesive groups were identified based on the collective score profiles from the above measures, reflective of mild, moderate, and severe levels of dementia (Table 1). Specifically, these groups emerged based primarily on a synthesis of the cognitive and functional abilities retained in each of the LACLS-5 ratings, the MMSE score, the DRS-2 subscales, ADL and IADL scores, degree of behavioral symptoms, and information in the literature that helped align participants' scores and abilities with mild, moderate, and severe stages of cognitive impairment (Alzheimer's Association, n.d.; Perneczky et al., 2006; Santabábara et al., 2015).

Functional Capacity

The 15-item Caregiver Assessment of Function and Upset has well-established, psychometrically sound properties corresponding to objective determinations of dependence and assistance required (Gitlin et al., 2005). For each item, caregivers indicated the level of assistance provided on a scale from 1 (*complete help, >75% assistance*) to 7 (*completely independent*). A total mean functional dependence score was derived by summing across items and dividing by the number of items (actual range of means = 1.0–6.3). Lower scores represented greater dependence ($\alpha = .92$). Subscale scores for IADL ($\alpha = .81$) and ADL ($\alpha = .93$) dependence were similarly derived.

Behavioral Symptoms

Caregivers reported behavioral symptoms using the 16-item Agitated Behaviors in Dementia Scale (Logsdon et al., 1999), two items (repetitive questioning and hiding/hoarding) from the Revised Memory and Behavior Problem Checklist (Teri et al., 1992), three items (incontinence, shadowing, and boredom) from previous research identifying these behaviors as common and distressing (Gitlin et al., 2003), and two "other" items identified by caregivers that could not be coded elsewhere. For each behavior, caregivers indicated occurrence (yes/no) and frequency in past month. For this study, we calculated the number of behaviors occurring ($\alpha = 0.86$).

Type of activity

To categorize prescribed activities, a middle-order approach was used, in which some broad distinctions were drawn initially based on common-sense categories or those that have been utilized in previous literature (e.g., Hulme et al., 2010; Treiber et al., 2011). Activities were first carefully reviewed by the principal investigator (PI) of TAP (L. N. Gitlin), the primary author and a research assistant, and categorizations were compared. When there were discrepancies about how an activity should be categorized, the authors and research assistant consulted the literature and discussed activity placement until a consensus was reached.

Table 1. Sociodemographic and Functional Characteristics of Sample

Characteristics	Total sample (<i>n</i> = 56)	Mild stage (<i>n</i> = 21)	Moderate stage (<i>n</i> = 13)	Severe stage (<i>n</i> = 22)	<i>p</i> Value
Care recipient					
Age, Mean (<i>SD</i>)	79.4 (9.28) (<i>R</i> = 56.0–96.2)	77.3 (8.54) (<i>R</i> = 57.6–93.7)	81.9 (9.60) (<i>R</i> = 61.7–96.1)	80.0 (9.76) (<i>R</i> = 56.0–96.2)	
Gender (%)					
Male	53.6	66.7	46.2	45.5	
Female	46.4	33.3	53.8	54.5	
Race (%)					
White	76.8	81.0	84.6	68.2	
African American	21.4	14.3	15.4	31.8	
Other	1.8	4.8	0	0	
Marital status					
Married or partnered	66.1	76.2	46.2	68.2	
Widowed	26.8	19.0	38.5	27.3	
Divorced	5.4	4.8	7.7	4.5	
Single, never married	1.8	0	7.7	0	
Education					
<HS	21.4	19.0	38.5	13.6	
HS	33.9	33.3	30.8	36.4	
Some college	5.4	4.8	7.7	4.5	
College degree	19.6	14.3	23.1	22.7	
Graduate degree	14.3	28.6	0	9.1	
CSDD, Mean (<i>SD</i>)	8.45 (4.71)	8.24 (5.74)	10.0 (4.90)	7.73 (3.31)	
Allen level, Mean (<i>SD</i>), Range	3.63 (0.51), 2.8–4.6	4.22 (.17), 4.0–4.6	3.52 (.17), 3.4–3.8	3.13 (.12), 2.8–3.2	.000
MMSE, Mean (<i>SD</i>)	10.93 (7.95)	16.48 (.74)	10.38 (4.89)	5.95 (6.55)	.000
DRS Attention	6.33 (4.72)	9.95 (3.68)	5.77 (4.46)	3.24 (3.30)	.000
DRS Initiation/Persev.	2.07 (1.11)	2.55 (1.50)	2.00 (.00)	1.67 (.86)	.035
DRS Construction	5.72 (3.86)	8.75 (3.09)	4.85 (2.82)	3.25 (3.08)	.000
DRS Conceptualization	4.28 (3.17)	6.30 (3.47)	4.15 (2.70)	2.35 (1.63)	.000
DRS Memory	2.00 (.91)	2.20 (.95)	2.23 (.83)	1.67 (.86)	.098
Comportment	26.38 (7.07)	28.83 (7.32)	27.08 (4.94)	23.24 (7.34)	.056
IADL, Mean (<i>SD</i>)	2.88 (1.01)	4.00 (.87)	4.30 (.65)	4.54 (.52)	.043
ADL, Mean (<i>SD</i>)	4.28 (0.73)	2.49 (1.14)	2.69 (1.01)	3.21 (.87)	.118
Number of behavioral problems	7.68 (4.10)	6.23 (3.87)	7.38 (2.75)	9.23 (4.48)	.050
Caregiver					
Age, Mean (<i>SD</i>)	64.9 (10.83)	64.8 (9.36)	64.5 (12.48)	65.4 (11.64)	
Relationship to CR, %					
Spouse	59.0	76.2	30.8	59.1	
Daughter	33.9	23.8	53.8	31.8	
Other	5.4	0	15.4	4.5	
Gender (%)					
Male	12.5	9.5	7.7	18.2	
Female	87.5	90.5	92.3	81.8	
Race (%)					
White	76.8	81.0	84.6	68.2	
African American	21.4	14.3	15.4	31.8	
Other	1.8	4.8	0	0	
Marital status					
Married or partnered	78.6	85.7	61.5	81.8	
Widowed	3.6	0	15.4	0	
Divorced	5.4	4.8	7.7	4.5	
Single, never married	12.5	9.5	15.4	13.6	

Table 1. Continued

Characteristics	Total sample (<i>n</i> = 56)	Mild stage (<i>n</i> = 21)	Moderate stage (<i>n</i> = 13)	Severe stage (<i>n</i> = 22)	<i>p</i> Value
Education					
<HS	0	0	0	0	
HS	26.8	42.9	15.4	18.2	
Some college	25	19.0	38.5	22.7	
College degree	28.6	19.0	30.8	36.4	
Graduate degree	17.9	14.3	15.4	22.7	
CESD, Mean (<i>SD</i>)	13.38 (9.47)	12.81 (9.12)	17.46 (11.54)	11.5 (8.08)	
Burden, Mean (<i>SD</i>)	20.76 (8.69)	21.48 (7.70)	22.46 (10.72)	19.0 (8.37)	

Note: One-way ANOVA revealed no between-groups differences in any of the caregiver or care recipient demographic variables. HS = high school; CSDD = Cornell Scale for Depression in Dementia; CES-D = Center for Epidemiologic Studies Depression Scale; MMSE = Mini-Mental State Examination; DRS = Dementia Rating Scale-2; Persev = Perseveration; IADL = instrumental activities of daily living; ADL = basic activities of daily living; ANOVA = analysis of variance; CR = care recipient. Values in boldface indicate statistical significance.

This approach resulted in seven activity categories and a high level of congruence among raters.

Activity Characteristics

To identify specific characteristics of an activity and its set up, activity prescriptions were read for a priori key words (e.g., redirection, initiating, set up, and time) and phrases (e.g., engagement time, assistance with initiation, help initiate/sequence, guide him/her back to activity), including any aspect of the activity prescription instructions that specified how the activity should be set up or performed. The authors then counted the number of times specific instructions or components of activity prescriptions were noted (e.g., “assistance with initiating the activity is needed”) to create units for use in quantitative analyses.

Depression

Depressive symptomatology in persons with dementia was rated using the 19-item Cornell Scale for Depression in Dementia (CSDD; Alexopoulos, Abrams, Young, & Shamoian, 1988). The CSDD was administered independently to persons with dementia and caregivers. Composite scores per item were based on combined ratings (0 = *not present*; 1 = *present*; 2 = *severe*) of caregiver and care recipient. Scores represented the sum of composite scores ($\alpha = 0.76$). Caregiver depression was assessed via the 20-item Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977), with symptoms rated as occurring in the past week (0 = *less than 1 day* to 3 = *5–7 days*). Scores represented summed responses, with higher scores indicating greater symptomatology ($\alpha = 0.91$).

Caregiver Burden

Subjective burden was measured as upset with behaviors (Roth et al., 2003; 0 = *no upset* to 10 = *extreme upset*, with a total target score from 0 to 40 derived by summing across the upset responses for up to four behaviors identified as most distressful), and the 10-item Zarit Burden Interview–Short Form (ZBI-SF; Bedard et al., 2001; 0 = *never* to 4 = *nearly always*), with the sum total used in analyses ($\alpha = 0.89$).

Data Analysis

Sociodemographic characteristics of caregivers and persons with dementia were examined by the type of activity. Bivariate correlations of relevant characteristics of persons with dementia, activity categories, and characteristics of activity set up (cueing needs, help with initiation, and recommended engagement time) were measured with the Pearson product-moment two-tailed correlation coefficient analysis. Differences between disease staging (mild, moderate, or severe) in activity set up and frequency of activity prescription were examined using Kruskal–Wallis *H* tests. For those analyses in which the overall test was significant, pairwise comparisons were completed using the Mann–Whitney *U* test controlling for Type I error across tests with the Bonferroni adjustment.

Results

Sample Characteristics

As shown in Table 1, persons with dementia were predominantly men (53.6%), Caucasian (76.8%), married (66.1%), high school graduates (33.9%), and had a mean age of 79.4 years ($SD = 9.28$). On average, persons with dementia did not meet criteria for major depression on the CSDD (Alexopoulos et al., 1988). Caregivers were primarily women (87.5%), Caucasian (76.8%), married (78.6%), college graduates (28.6%), retired or unemployed (60.7%), and mostly spouses of the person with dementia (42.9%) with a mean age of 64.9 years ($SD = 10.83$). Caregivers had a mean CES-D score of 13.38 ($SD = 9.47$), indicating most did not report depressive symptoms (CES-D; Radloff, 1977). Caregivers reported on average “little-to-no burden” on the ZBI-SF (Table 1).

Cognitive and functional characteristics of persons with dementia are shown in Table 1. Mean Allen level was 3.6, indicating ability to perform self-care activities with supervision and to pay attention to objects in field of view. The mean ADL score of 2.88 suggests a need for mild-to-moderate assistance with basic daily activities, whereas the mean IADL score of 4.28 denotes a need for significant assistance with more complex activities.

Mean MMSE was 10.93, indicative of moderate-to-severe cognitive impairment. Analysis of between-groups differences revealed significant differences in MMSE ($p < .001$), IADL ($p < .05$), DRS-2 attention ($p < .001$), DRS-2 initiation/perseveration ($p < .05$), DRS-2 construction ($p < .001$), DRS-2 conceptualization ($p < .001$), and Allen level ($p < .001$) among the cognitive status groups (Table 1).

Relationships Among Personal Characteristics, Cognition, and Activity

Seven activity types were identified by the authors and an independent reviewer: (a) arts and crafts (e.g., refinishing wood bench and coloring pictures), (b) physical exercise (e.g., pedal pusher exerciser and walking), (c) cognitive (e.g., concentration card game and puzzles), (d) music and entertainment (e.g., watching vintage movies and listening to music), (e) manipulation/sensory/sorting (e.g., activity pillow and sorting jewelry), (f) family/social/reminiscence (e.g., family photo album, reminiscing, and visiting family), and (g) domestic/homemaking (e.g., folding laundry and preparing snacks).

Arts and crafts prescriptions were significantly associated with higher cognitive functioning, per Allen Batteries ($r = .326, p < .05$), and decreased need for ADL assistance ($r = -.312, p < .05$). Cognitive activities were more likely to be prescribed to persons with higher Allen levels ($r = .289, p < .05$), higher MMSE ($r = .356, p < .01$), less need for ADL assistance ($r = -.420, p < .01$), and higher scores on the DRS-2 attention ($r = .288, p < .05$), construction ($r = .304, p < .05$), and conceptualization ($r = .367, p < .01$) subscales. Prescriptions for music/entertainment were significantly associated with lower Allen levels ($r = -.377, p < .01$), lower MMSE ($r = -.323, p < .05$), and lower scores on the DRS-2 attention ($r = -.363, p < .01$), construction ($r = -.383, p < .01$), and conceptualization ($r = -.424, p < .01$) subscales. Manipulation/sensory/sorting activities were significantly correlated with lower Allen level ($r = -.385, p < .01$) and poorer performance on DRS-2 subscales of

initiation/perseveration ($r = -.296, p < .05$) and construction ($r = -.448, p < .01$).

Of note, it appears that cognitive status and functional independence are associated with type of activity versus the number of behaviors (Table 2). No significant relationships were found with cognitive and functional levels and exercise/physical, family/social/reminiscence, and domestic/homemaking categories. Higher Allen levels (better cognitive functioning) were associated with longer minimum ($r = .834, p < .001$) and maximum ($r = .837, p < .001$) time goals for activity engagement and less need for cueing/redirection during activities ($r = -.259, p = .05$) or help initiating an activity ($r = -.616, p < .001$). Controlling for demographic characteristics did not affect these relationships (Table 2).

Differences in Set Up and Activity Specifiers by Cognitive Stage

Cues/Redirection

Regarding set up and activity specifiers, results of Kruskal-Wallis H tests showed a statistically significant difference in need for cues/redirection between the three cognitive stages ($\chi^2(2) = 12.592, p = .002$), with a mean rank score of 18.67 for the mild group, 33.69 for the moderate group, and 34.82 for the severe group (Table 3). Pairwise comparisons indicated a significant difference between mild and severe groups ($U = 121, p = .006$), as well as moderate and severe groups ($U = 40, p < .001$).

Persons with dementia at moderate and severe disease stages were likely to require regular cueing and redirection during activity engagement approximately 78% of the time. Persons functioning at a mild disease stage required regular cueing and redirection 68.3% of the time during activity engagement (Table 3).

Initiation Help

There was a statistically significant difference between the disease stages as to need for help with initiation (Table 3), $\chi^2(2) = 31.827, p < .001$, with a mean rank score of 19.67

Table 2. Correlations of Demographics With Type of Activity

Activity type	Demographics					
	CR age	MMSE	IADL	ADL	Dementia stage	Number of behaviors
Arts and crafts	-.16	.25	-.26	-.31*	.33*	.030
Physical/exercise	.013	-.043	.011	-.037	-.13	.091
Cognitive	-.17	.36**	-.20	-.42**	.29*	-.074
Music/entertainment	.27	-.32*	.21	.14	-.38**	.089
Manipulation/sorting/sensory	.088	-.22	.11	.076	-.39**	.169
Family/social/reminiscence	-.19	.16	-.019	-.005	.15	-.074
Domestic/homemaking	-.01	.050	-.045	.10	-.097	.014

Note: CR = care recipient; MMSE = Mini Mental Status Examination; IADL = instrumental activities of daily living; ADL = basic activities of daily living.

* $p < .05$; ** $p < .01$. Values in boldface indicate statistical significance.

Table 3. Activity Characteristics by Dementia Stage

	Mild (<i>n</i> = 21)	Moderate (<i>n</i> = 13)	Severe (<i>n</i> = 22)	<i>p</i> Value
Activity recommendations				
Engagement time (mean <i>SD</i> , Range)	28.63 (26.75–30.50)	24.11 (22.32–25.89)	15.10 (12.94–17.25)	.000
Cues/redirection	68.3%	77.8%	78.1%	.002
Initiation help	44.4%	50%	65.6%	.000
Type of activity				
Arts and crafts	31.7%	25.0%	9.4%	.000
Exercise/physical	9.5%	13.9%	17.2%	.000
Cognitive	22.2%	11.1%	7.8%	.000
Music/entertainment	12.7%	25.0%	23.4%	.000
Manipulation/Sens/Sort	7.9%	2.8%	25.0%	.000
Family/social/Reminis	9.5%	5.6%	3.1%	.001
Domestic/homemaking	6.3%	16.7%	14.1%	.000

Note: Mild = Allen level 4.0–4.6; Moderate = Allen level 3.4–3.8; Severe = Allen level 2.8–3.2. Sens = Sensory; Sort = Sorting; Reminis = Reminiscence. Values in boldface indicate statistical significance.

for mild, 17.46 for moderate, and 43.55 for severe groups. Pairwise comparisons revealed a statistically significant difference between moderate and severe groups ($U = 43, p < .001$), and mild and severe groups ($U = 0, p < .001$). Per prescriptions, persons with dementia at severe and moderate stages required assistance with initiating activity 50% of the time or more, whereas persons functioning at a mild disease stage appeared to need assistance with initiating activity <50% of the time.

Engagement Time

There was a significant difference among the three cognitive status groups as to the recommended engagement time for activities, $\chi^2(2) = 55.00, p < .001$, (Table 3), with a mean rank score of 45.50 for mild, 28.00 for moderate, and 11.00 min for severe groups. All pairwise comparisons were statistically significant ($U = 0, p < .001$). For persons at the mild stage, activities were prescribed for an average of 28.63 min (range = 27–31 min; Table 2). Persons at a moderate stage were prescribed an average of 24.11 min (range = 22–26 min). Individuals at a severe stage were prescribed an average of 15.10 min (range = 13–17 min).

Differences in Type of Activity by Cognitive Stage

Arts and Crafts

There was a statistically significant difference in the use of arts and craft-type activities across the three cognitive stages, $\chi^2(2) = 31.137, p < .001$, with a mean rank score of 39.60 for mild, 35.62 for moderate, and 13.70 for severe groups (Table 3). Pairwise comparisons showed a statistically significant difference between moderate and severe groups ($U = 12, p < .001$) and mild and severe groups ($U = 36.5, p < .001$). Persons at a mild stage were more frequently prescribed arts and crafts activities of increased complexity than the other two groups.

Exercise/Physical Activities

There was a statistically significant difference in prescribing exercise/physical activities, $\chi^2(2) = 31.326, p < .001$, with a mean rank score of 13.93 for mild, 30.38 for moderate, and 41.30 for severe groups. Pairwise comparisons revealed statistically significant differences between moderate and severe groups ($U = 72, p = .015$), mild and severe groups ($U = 20.5, p < .001$), and moderate and mild groups ($U = 41, p = .001$). Repetitive physical activities were more often offered at a severe disease stage.

Cognitive Activities

There was a statistically significant difference across groups, $\chi^2(2) = 30.198, p < .001$, with a mean rank score of 42.74 for mild, 26.92 for moderate, and 15.84 for severe groups. Pairwise comparisons revealed a statistically significant difference between moderate and severe groups ($U = 54, p = .002$), mild and severe groups ($U = 41.5, p < .001$), and moderate and mild groups ($U = 27, p < .001$). Per the OTs, cognitive activities were prescribed more for persons at the mild versus moderate or severe disease stages.

Music/Entertainment

There was a statistically significant difference across groups, $\chi^2(2) = 30.080, p < .001$, with a mean rank score of 13.93 for mild, 42.69 for moderate, and 34.02 for severe groups. Pairwise comparisons showed a statistically significant difference between moderate and severe groups ($U = 54, p = .002$), mild and severe groups ($U = 20.5, p < .001$), and moderate and mild groups ($U = 41, p < .001$). Persons at a moderate stage were prescribed music/entertainment activities significantly more often than those at mild or severe stages.

Manipulation/Sensory/Sorting Activities

There was a statistically significant difference in the use of manipulation activities across stages, $\chi^2(2) = 41.514,$

$p < .001$, with a mean rank score of 19.69 for mild, 13.96 for moderate, and 45.50 for severe groups. Pairwise comparisons found statistically significant differences between moderate and severe groups ($U = 0$, $p < .001$), and mild and severe groups ($U = 0$, $p < .001$). Persons at a moderate stage were prescribed manipulation/sorting/sensory activities significantly less often than those at mild or severe stages, although those at the severe stage were prescribed these types of activities the most.

Family/Social Reminiscence Activities

There was a statistically significant difference in the number of prescriptions related to family-related/social/remembrance activities across the three cognitive stages, $\chi^2(2) = 13.437$, $p = .001$, with a mean rank score of 36.83 for mild, 30.88 for moderate, and 19.14 for severe groups. Per pairwise comparisons, there was a statistically significant difference between moderate and severe groups ($U = 63$, $p = .005$), and mild and severe groups ($U = 105$, $p = .002$). Individuals at a severe stage of dementia were prescribed family/social/remembrance activities less often than those in mild or moderate stages.

Domestic/Homemaking Activities

Finally, there was a statistically significant difference in prescribing domestic/homemaking activities across the three stages, $\chi^2(2) = 27.272$, $p < .001$, with a mean rank score of 14.52 for mild, 32.15 for moderate, and 39.68 for severe groups. Pairwise comparisons revealed statistically significant differences between the moderate and severe groups ($U = 66$, $p = .008$), mild and severe groups ($U = 62$, $p < .001$), and mild and moderate groups ($U = 12$, $p < .001$). Individuals at a moderate stage were prescribed domestic/homemaking activities more often than those in mild or severe stages.

Discussion

A growing body of research indicates that engagement in tailored, meaningful activities can reduce behavioral symptoms of dementia, as well as caregiver burden and time spent on caregiving "duty" (Gitlin et al., 2008). This study extends our understanding of using activity as a therapeutic modality by examining the relationship of specific types and features of activities judged to be meaningful to persons at different stages of dementia. Analyses of 158 distinct activity prescriptions that were created for 56 persons with dementia enrolled in the TAP study yielded important differences based on disease stage (mild, moderate, and severe). Differences were found concerning the types of activities provided along with instructions for their use such as type and extent of cueing, amount of time to expect engaged in an activity, and whether initiation help was needed.

For this study, we derived global disease stage by examining cognition, physical capabilities, independence levels in basic and complex daily activities, and number of

behavioral symptoms and classified individuals as mild, moderate, or severe. Persons with mild dementia were most often prescribed more complex arts and crafts activities (e.g., sanding and refinishing a table) and cognitive activities requiring multisteps, sequencing, and problem-solving. Persons with moderate dementia were prescribed music/entertainment activities and domestic/homemaking activities most frequently, requiring repetitive actions, one- to two-step directions and which were not necessarily goal oriented. In contrast, persons with severe dementia were prescribed activities that were not goal directed and that involved simple movement (physical exercises) and/or manipulation/sensory/sorting activities more often than other activity types.

Activity set up and characteristics were also significantly related to disease stage. Individuals at a severe disease stage were expected to engage in an activity for shorter periods of time compared with those in moderate or mild stages and to require greater assistance with initiating activity and more cueing/redirection. It appears that persons with more advanced dementia require less complex activities and more cueing to engage successfully in an activity.

To our knowledge, this is the first study to examine whether categories and features of recommended activities are associated with dementia stage. We show that activities were tailored with regard to set up and activity type based on a person's dementia stage that was carefully derived from cognitive and functional status measures as well as knowledge of personal interests, previous habits, and occupations. From an analysis of 158 activity prescriptions, two important points emerge. First, individuals with any level of cognitive status, from mild to severe, can be prescribed an activity to meaningfully engage that person. Second, with disease progression, individuals will require simplifying activities from multisteps (beading using multicolors and patterns), to one to two steps (sorting beads, moving beads from one container to another), and the use of more auditory and tactile cueing to support initiation and sequencing of activity steps. Also, the time expected for activity engagement appears to decrease with disease progression, although for any stage, engagement is still the goal.

The limitations of this study include its small sample size and subsequent small group size for the dementia staging levels. In addition, there is no agreed-upon categorization of activity types. However, as two raters independently coded activities into categories and reached a high level of agreement ($\kappa = .962$, $p < .001$), we believe the categorization scheme is effective for our study purposes. Also, as we show clear differences in the frequency of prescribing each type of activity by disease stage and requirements for setting up activities, we believe we derived meaningful groupings.

Implications for Activity as a Therapeutic Modality

The results of these analyses have important implications for utilizing activity as a therapeutic modality in dementia care.

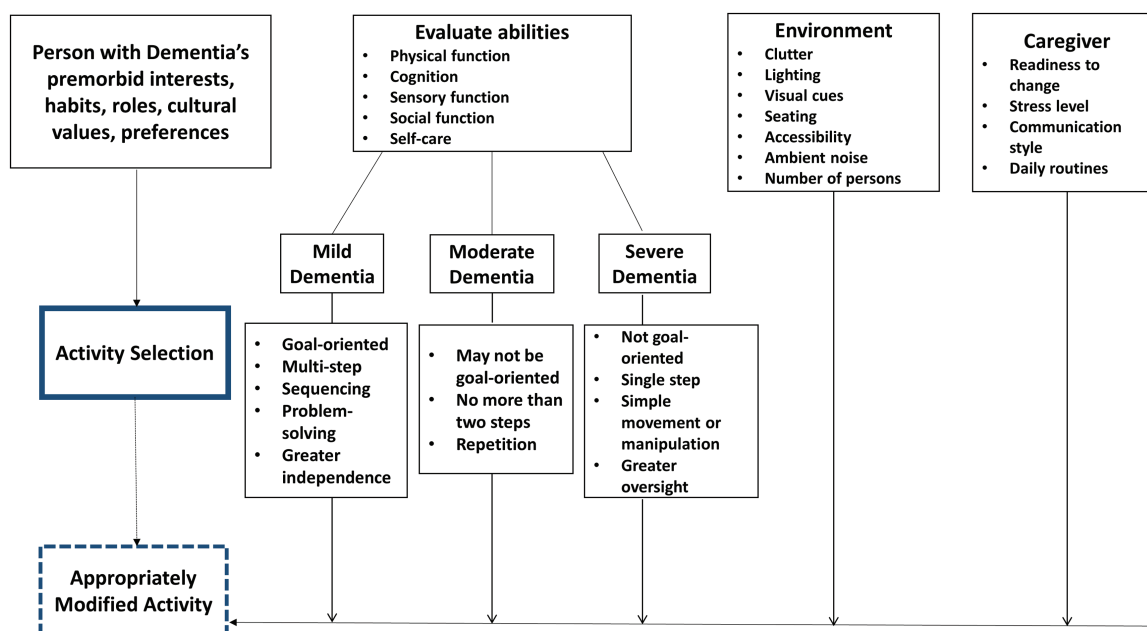


Figure 1. Components of activity selection and modification.

First, although the benefits of meaningful activities for persons with dementia are increasingly well-documented (Cohen-Mansfield, Libin, & Marx, 2007; Gitlin et al., 2008, 2016; Vikström et al., 2008), many caregivers may not know how best to identify and implement activities. The approach used in TAP is to align preserved cognitive and physical functional abilities with interests and environmental characteristics and to design activities that maximize engagement.

Consequently, our findings provide some guidance for choosing an activity and grading it to abilities of persons with dementia (Figure 1). First, identifying previous and current interests may help maintain a sense of self in persons with dementia, even at the severe stages (Cohen-Mansfield, Pappura-Gill, & Golander, 2006; Tappen, Williams, Fishman, & Touhy, 1999). Second, we found that identifying disease stage (mild, moderate, or severe based on interventionists' assessment of cognitive and functional capabilities) is important in choosing an activity and designing its set up. While there is a broader band of activity types to choose from for persons at a mild disease stage, a variety of activity types are still available for individuals at a moderate and severe disease stage that can be used with simplification techniques employed.

Third, caregivers (families and providers) should keep in mind that different cueing techniques and time engaged will vary by cognitive stage. Any amount of time spent in a pleasurable activity, even if for only 10 min as may be the case for persons with severe dementia, may be helpful as evidenced by the previously reported benefits of TAP and how tailoring activities can positively impact mood (Gitlin et al., 2008, 2016).

Additional research is needed to further identify ways to tailor activities based on specific cognitive domains (e.g., executive function, and attention) and caregiver and

environmental characteristics (Cohen-Mansfield et al., 2011). Also, the time of day when activities should be introduced to optimize engagement and well-being (Safi & Hodgson, 2014) needs further consideration. For example, it may be best to offer a more cognitively demanding activity in the late morning, a physical activity in the afternoon, and a low-demand, sensory-based activity such as listening to music at the end of the day.

This study represents an important first step in elucidating the types of activities and their set ups for persons at each stage of dementia. Notably, our study shows that a wide range of meaningful activities with appropriate set up may be useful even for persons in the severe stage of dementia. These findings warrant replication and support moving forward with the development of treatment guidelines for using activity as a therapeutic agent in comprehensive dementia care.

Supplementary Material

Supplementary data are available at *The Gerontologist* online.

Funding

The initial collection of the data analyzed in this article was supported in part by funds from the National Institute of Mental Health (R21 MH069425).

References

- Alexopoulos, G. S., Abrams, R. C., Young, R. C., & Shamoian, C. A. (1988). Cornell Scale for Depression in Dementia. *Biological Psychiatry*, 23, 271–284. doi:10.1037/t20968-000

- Alzheimer's Association. (2015). *Alzheimer's disease facts and figures*. Washington, DC: Alzheimer's Association. Retrieved March 1, 2016, from http://www.alz.org/facts/downloads/facts_figures_2015.pdf
- Alzheimer's Association. (n.d.). *Stages of Alzheimer's*. Washington, DC: Alzheimer's Association. Retrieved March 1, 2015, from http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp
- American Occupational Therapy Association. (2014). Occupational therapy practice framework: Domain and process (3rd ed.). *American Journal of Occupational Therapy*, 68(Suppl. 1), S1–S48. doi:10.5014/ajot.2014.682006
- Atchley, R. C. (2006). Activity theory. In R. Schulz, L. S. Noelker, K. Rookwood, & R. L. Spratt (Eds.), *The Encyclopedia of Aging: A-K* (pp. 9–13). New York, NY: Springer Publishing Company.
- Barton, C., Ketelle, R., Merrilees, J., & Miller, B. (2016). Non-pharmacological management of behavioral symptoms in frontotemporal and other dementias. *Current Neurology and Neuroscience Reports*, 16, 14. doi:10.1007/s11910-015-0618-1
- Bedard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden Interview: A new short version and screening version. *Gerontologist*, 41, 652–657. doi:10.1093/geront/41.5.652
- Blue, T., & Allen, C. K. (1993). *Allen diagnostic module sensory motor stimulation kit II*. Colchester, CT: S&S Worldwide.
- Cohen-Mansfield, J., Libin, A., & Marx, M. S. (2007). Nonpharmacological treatment of agitation: A controlled trial of systematic individualized intervention. *Journal of Gerontology. Series A, Biological Sciences and Medical Sciences*, 62, 908–916. doi:10.1093/gerona/62.8.908
- Cohen-Mansfield, J., Marx, M. S., Freedman, L. S., Murad, H., Regier, N. G., Thein, K., & Dakheel-Ali, M. (2011). The comprehensive process model of engagement. *American Journal of Geriatric Psychiatry*, 19, 859–870. doi:10.1097/jgp.0b013e318202bf5b
- Cohen-Mansfield, J., Parpura-Gill, A., & Golanter, H. (2006). Utilization of self-identity roles for designing interventions for persons with dementia. *Journal of Gerontology: Psychological Sciences*, 61B, 202–212. doi:10.1093/geronb/61.4.p202
- Earhart, C. A., Pollard, D., Allen, C. K., & David, S. (2003). *Large Allen Cognitive Level Screen (LACLS) 2000 test manual*. Colchester, CT: S&S Worldwide.
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-Mental State". A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189–198. doi:10.1016/0022-3956(75)90026-6
- Gitlin, L. N., Kales, H. C., & Lyketsos, C. G. (2012). Nonpharmacologic management of behavioral symptoms in dementia. *Journal of the American Medical Association*, 308, 2020–2029. doi:10.1001/jama.2012.36918
- Gitlin, L. N., Marx, K. A., Alonzi, D., Kvedar, T., Moody, J., Trahan, M., & Van Haitsma, K. (2016). Nonpharmacological care of patients with dementia hospitalized for behavioral symptoms: Feasibility of the Tailored Activity Program for Hospitals (TAP-H). *The Gerontologist*. Advance online publication. doi:10.1093/geront/gnw052
- Gitlin, L. N., & Rose, K. (2016). Impact of caregiver readiness on outcomes of an intervention to address behavioral symptoms in persons with dementia. *International Journal of Geriatric Psychiatry*. Advance online publication. doi:10.1002/gps.4422
- Gitlin, L. N., Roth, D. L., Burgio, L. D., Loewenstein, D. A., Winter, L., Nichols, L., ... Martindale, J. (2005). Caregiver appraisals of functional dependence in individuals with dementia and associated caregiver upset: Psychometric properties of a new scale and response patterns by caregiver and care recipient characteristics. *Journal of Aging and Health*, 17, 148–171. doi:10.1177/0898264304274184
- Gitlin, L. N., Winter, L., Burke, J., Chernett, N., Dennis, M. P., & Hauck, W. W. (2008). Tailored activities to manage neuropsychiatric behaviors in persons with dementia and reduce caregiver burden: a randomized pilot study. *American Journal of Geriatric Psychiatry*, 16, 229–239. doi:10.1097/01.jgp.0000300629.35408.94
- Gitlin, L. N., Winter, L., Corcoran, M., Dennis, M. P., Schinfeld, S., & Hauck, W. W. (2003). Effects of the home environmental skill-building program on the caregiver-care recipient dyad: 6-Month outcomes from the Philadelphia REACH Initiative. *The Gerontologist*, 43, 532–546. doi:10.1093/geront/43.4.532
- Gitlin, L. N., Winter, L., Dennis, M. P., Hodgson, N., & Hauck, W. W. (2010). A biobehavioral home-based intervention and the well-being of patients with dementia and their caregivers: The COPE randomized trial. *Journal of the American Medical Association*, 304, 983–991. doi:10.1001/jama.2010.1253
- Havighurst, R. J., & Albrecht, R. (1953). *Older people*. New York: Longmans, Green.
- Hughes, C. P., Berg, L., Danziger, W. L., Coben, L. A., & Martin, R. L. (1982). A new clinical scale for the staging of dementia. *British Journal of Psychiatry*, 140, 566–572. doi:10.1192/bjp.140.6.566
- Hulme, C., Wright, J., Crocker, T., Oluboyede, Y., & House, A. (2010). Non-pharmacological approaches for dementia that informal carers might try or access: A systematic review. *International Journal of Geriatric Psychiatry*, 25, 756–763. doi:10.1002/gps.2429
- Jurica, S. J., Leitten, C. L., & Mattis, S. (2001). *Dementia Rating Scale: Professional manual*. Odessa, FL: Psychological Assessment Resources.
- Lima-Silva, T. B., Bahia, V. S., Carvalho, V. A., Guimarães, Caramelli, P., ... & Yassuda, M. S. (2015). Neuropsychiatric symptoms, caregiver burden and distress in behavioral-variant frontotemporal dementia and Alzheimer's disease. *Dementia and Geriatric Cognitive Disorders*, 40, 268–275. doi:10.1159/000437351
- Logsdon, R. G., Teri, L., Weiner, M. F., Gibbons, L. E., Raskind, M., Peskind, E., ... Thal, L. J. (1999). Assessment of agitation in Alzheimer's disease: The agitated behavior in dementia scale. Alzheimer's Disease Cooperative Study. *Journal of the American Geriatrics Society*, 47, 1354–1358. doi:10.1111/j.1532-5415.1999.tb07439.x
- Lyketsos, C. G., Colenda, C. C., Beck, C., Blank, K., Doraiswamy, M. P., Kalunian, D. A., ... & Task Force of American Association for Geriatric Psychiatry. (2006). Position statement of the American Association for Geriatric Psychiatry regarding principles of care for patients with dementia resulting from Alzheimer disease. *American Journal of Geriatric Psychiatry*, 14, 561–572. doi:10.1097/01.jgp.0000221334.65330.55

- McLaren, A. N., Lamantia, M. A., & Callahan, C. M. (2013). Systematic review of non-pharmacologic interventions to delay functional decline in community-dwelling patients with dementia. *Aging & Mental Health*, *17*, 655–666. doi:10.1080/13607863.2013.781121
- Morris, J. C. (1997). Clinical Dementia Rating: A reliable and valid diagnostic and staging measure for dementia of the Alzheimer type. *International Psychogeriatrics*, *9*, 173–176. doi:10.1017/s1041610297004870
- Perneczky, R., Wagenpfeil, S., Komossa, K., Grimmer, T., Diehl, J., & Kurz, A. (2006). Mapping scores onto stages: Mini-Mental State Examination and Clinical Dementia Rating. *American Journal of Geriatric Psychiatry*, *14*, 139–144. doi:10.1097/01.jgp.0000192478.82189.a8
- Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., & Ferri, C. P. (2013). The global prevalence of dementia: a systematic review and metaanalysis. *Alzheimers Dementia*, *9*, 63–75. doi:10.1016/j.jalz.2012.11.007
- Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, *1*, 385–401. doi:10.1177/014662167700100306
- Roland, K. P., & Chappell, N. L. (2015). Meaningful activity for persons with dementia: Family caregiver perspectives. *American Journal of Alzheimer's Disease and Other Dementias*, *30*, 559–568. doi:10.1177/15333317515576389
- Roth, D. L., Burgio, L. D., Gitlin, L. N., Gallagher-Thompson, D., Coon, D. W., Belle, S. H., ... & Burns, R. (2003). Psychometric analysis of the Revised Memory and Behavior Problems Checklist: Factor structure of occurrence and reaction ratings. *Psychology and Aging*, *18*, 906–915. doi:10.1037/0882-7974.18.4.906
- Safi, A. J., & Hodgson, N. A. (2014). Timing of activities and their effects on circadian rhythm in the elderly with dementia: A literature review. *Journal of Sleep Disorders & Therapy*, *3*, 176. doi:10.4172/2167-0277.1000176
- Santabárbara, J., Lopez-Anton, R., Gracia-García, P., De-la-Cámara, C., Vaquero-Puyuelo, D., Lobo, E., ... & Lobo, A. (2015). Staging cognitive impairment and incidence of dementia. *Epidemiology and Psychiatric Sciences*. Advance online publication. doi:10.1017/S2045796015000918
- Steinberg, M., Shao, H., Zandi, P., Lyketsos, C. G., Welsh-Bohmer, K. A., ..., & Cache County Investigators. (2008). Point and 5-year prevalence of neuropsychiatric symptoms in dementia: The Cache County Study. *International Journal of Geriatric Psychiatry*, *23*, 170–177. doi:10.1002/gps.1858
- Tappen, R. M., Williams, C., Fishman, S., & Touhy, T. (1999). Persistence of self in advanced Alzheimer's disease. *Image: The Journal of Nursing Scholarship*, *31*, 121–125. doi:10.1111/j.1547-5069.1999.tb00445.x
- Teri, L., & Logsdon, R. G. (1991). Identifying pleasant activities for Alzheimer's disease patients: The Pleasant Events Schedule-AD. *The Gerontologist*, *31*, 124–127. doi:10.1093/geront/31.1.124
- Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S., & Vitaliano, P. P. (1992). Assessment of behavioral problems in dementia: The revised memory and behavior problems checklist. *Psychology and Aging*, *7*, 622–631. doi:10.1037/0882-7974.7.4.622
- Thomas, H. (2015). *Occupation-based activity analysis* (2nd ed.). Thorofare, NJ: SLACK Incorporated.
- Tun, S. M., Murman, D. L., Long, H. L., Colenda, C. C., & von Eye, A. (2007). Predictive validity of neuropsychiatric subgroups on nursing home placement and survival in patients with Alzheimer disease. *American Journal of Geriatric Psychiatry*, *15*, 314–327. doi:10.1097/01.jgp.0000239263.52621.97
- Treiber, K. A., Carlson, M. C., Corcoran, C., Norton, M. C., Breitner, J. C., Piercy, K. W., ... , Tschanz, J. T. (2011). Cognitive stimulation and cognitive and functional decline in Alzheimer's disease: The Cache County Dementia Progression Study. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *66*, 416–425. doi:10.1093/geronb/gbr023
- Vikström, S., Josephsson, S., Stigsdotter-Neely, A., & Nygård, L. (2008). Engagement in activities: Experiences of persons with dementia and their caregiving spouses. *Dementia*, *7*, 251–270. doi:10.1177/1471301208091164