A critique of research on the use of activities with persons with Alzheimer’s disease: a systematic literature review

Melody J. Marshall PhD ARNP
Associate Professor, College of Nursing, University of Florida Health Science Center, Gainesville, Florida, USA

and Sally A. Hutchinson PhD RN FAAN
Professor, College of Nursing, University of Florida Health Science Center – Jacksonville, Jacksonville, Florida, USA

Submitted for publication 12 September 2000
Accepted for publication 9 May 2001

Correspondence:
Melody Marshall,
College of Nursing,
University of Florida Health Science Center,
1935 NW 22nd Street,
Gainesville,
FL 32605,
USA.
E-mail: marshmj@ufl.edu

35(4), 488–496
A critique of research on the use of activities with persons with Alzheimer’s disease: a systematic literature review

Topic. The topic of this paper concerns the use of therapeutic activities with persons with Alzheimer’s disease (AD).

Purpose. The purpose is to present a critique of the research on these activities, with an emphasis on methodology.

Organizing construct and scope. Nursing literature identifies a number of purposes for activities for persons with AD. Activities should be therapeutic, enhance quality of life, arrest mental decline, and generate and maintain self-esteem. Other purposes of activities for this population are to create immediate pleasure, re-establish dignity, provide meaningful tasks, restore roles, and enable friendships. Activities may be more important to the psychological state of well-being of persons with dementia than the general physical and social environments in which they live.

Sources. The literature reviewed was identified with the use of computer data bases (Medline – 1991–March 2001; Cumulative Index of Nursing and Allied Health Literature (CINAHL) – 1991–March 2001; and PsychLit – 1988–March 1999). In addition, data bases of Science Citation Index and Social Science Citation Indexes as they appear in the computer base, Web of Science, were searched for 1992–2001. The time period for each search was determined by the manner in which the literature was grouped for inclusion in the particular database. Hand searches of 11 selected journals included the years 1993–2001. The search dates were selected to reflect the time period when the largest number of studies on activities and AD have appeared in the professional literature. We critique a total of 33 studies.

Conclusions. While researchers have demonstrated interest in the use of activities with persons with AD, theoretical and methodological difficulties, unclear findings and gaps exist, including a lack of emphasis on gender, ethnic, racial or cultural differences. Sampling issues involving diagnosis and staging complicate the research on individuals with AD. Case studies, single subject experimental designs, and tightly controlled quasi-experimental and experimental designs are needed to advance knowledge in this important area.

Keywords: Alzheimer’s disease, activities, elderly, music, exercise, art therapy, games, reminiscence, movement, rhythm, systematic review, literature
Introduction

Alzheimer’s disease (AD) is a progressive, debilitating neurological disease that presents an escalating social and public health problem. By 2047, the number of people with AD in the United States of America (USA) is expected to rise by a factor of 3 to between 4.37 and 15.4 million. The number of new cases of AD diagnosed annually is expected to triple to 11.4 million cases (Brookmayer et al. 1998). How to structure the days for AD clients and how to be ‘therapeutic’ are problems that confront both professional and family caregivers.


For the elderly, satisfaction with leisure activities is one of the best predictors of overall life satisfaction (Campbell et al. 1976).

Nursing literature suggests that activities for the person with AD should be therapeutic, enhance quality of life (Hitch 1994), arrest mental decline (Pulsford 1997), and generate and maintain self-esteem (Rentz 1995). In their literature review relating exercise to quality of life in elders, Ellingsson and Conn (2000) include four dimensions to quality of life: well-being, functional status, socioeconomic status, and self-esteem.

In addition to creating immediate pleasure, Mace (1987) asserts that the goals of activities for the person with AD are to re-establish dignity, provide meaningful tasks, restore roles, and enable friendships. Activities may be more important to the psychological state of well-being of persons with dementia than the general physical and social environments in which they live (Perrin 1997). That long-term results from therapeutic activities have not been demonstrated should not deter their use with this population (Pulsford 1997). In fact, failure to provide opportunities for such activities is tantamount to abuse of persons with dementia (Crump 1991). To date the knowledge, we have about the use of activities with persons with AD is minimal and fragmented. However, researchers and clinicians alike emphasize the benefits of activities with this vulnerable population.

In this paper, we present a critical review of research on the use of activities with individuals with AD, with an emphasis on methodology. Articles were reviewed that included physical or cognitive activities planned by others for individuals with AD. We reviewed national and international journals in the English language only. Computer data bases included Medline (1991–March 2001), Cumulative Index of Nursing and Allied Health Literature (CINAHL – 1991–March 2001), and PsychLit (1988–March 1999). In addition, databases of Science Citation Index and Social Science Citation Indexes as they appear in the computer base, Web of Science, were searched for 1992–2001. The time period for each search was determined by the manner in which the literature was grouped for inclusion in the particular database. The broad subject category ‘dementia’, along with narrower subordinate terms, such as ‘Alzheimer’s disease’, were combined with subject descriptors such as ‘music therapy’ and ‘art therapy’ and additional key or text-words such as ‘games’ and ‘reminiscence’, truncated for various word endings to elicit appropriate citations. Hand searches of selected journals included the years 1993–2001. Journals included Image: The Journal of Nursing Scholarship, Journal of Advanced Nursing, Journal of Gerontological Nursing, Geriatric Nursing, Journal of Music Therapy, Gerontology and Geriatrics Education, The Gerontologist, Physical and Occupational Therapy in Geriatrics, Journal of The American Geriatrics Society, Activities, Adaptation and Ageing (1995–1999), and The American Journal of Art Therapy (1993–1995). The search dates were selected to reflect the time period when the largest number of studies on activities and AD have appeared in the professional literature. We critique a total of 33 studies, the total that we identified in our search that met our criteria of the use of therapeutic exercise with persons with AD. Characteristics of these studies were assembled in tabular form in which authors, method of diagnosis and staging, theory used, type of study methodology (for example, case study, quasi-experimental, experimental, or qualitative), and findings were outlined.

We validated our analysis in discussions between the two authors of this article and, when questions arose, with two research professors at a Health Science Center of a major south-eastern university. The framework for our evaluation was taken from well-known nursing research textbooks (Wilson & Hutchinson, 1996, Polit & Hungler 1999) and essentially followed the research process.

The state of knowledge: a critical evaluation

Conceptual framework

Conceptual framework should guide quantitative research or be generated by qualitative research. However, in the
reviewed literature, many researchers did not identify a theoretical framework that influenced their decisions about choice of an activity, and how they used the activity. Rather, researchers alluded to a theoretical rationale or embryonic framework. A few researchers, however, chose theories that emphasized the importance of the environment for people with AD. Gerdner and Swanson (1993) used the progressively lowered stress threshold (PLST) model (Hall & Buckwalter 1987) to support their use of music, while Hansen et al. (1996), used the PLST and the person-environment fit model (PE fit) (Roberts & Algase 1988) as a basis for the use of music including movement, rhythm and singing. Thomas et al. (1997) used the PE Fit to evaluate the effect of music on bathing co-operation.

Sterritt and Pokorny (1994) used flow theory (Csikszentmihalyi 1990) that involves joy, creativity and the process of total involvement and Watson’s (1994) theory of human care as a theoretical rationale for their study. Jensen (1997) used Ackerman’s (1990) theory of sensory integration – music, art, and movement – to stimulate emotional and affective recall and reminiscence, strengthening a sense of identity and recognition in nursing home residents with AD. Rentz (1995), in her case study of three, used Kovach’s model of reminiscence (Kovach 1991) to construct her study and Lawton’s theory of well-being (Lawton 1983) to explain the results. Theoretical models did not guide the majority of studies reviewed and were used with varying degrees of clarity and integration. Theory was never tested in the research, but was used to provide a theoretical perspective.

Methodological issues

The studies cited in this critique, while pointing in a number of important directions, tend to have certain methodological problems in common. These include sampling (unclear selection criteria, small sample sizes, diagnostic difficulties), design and measurement (lack of rigor, unclear measurement and the use of instruments without reporting reliability and validity in this population), and interventions and outcomes (inadequate description and measurement).

Sampling

In many cases, researchers used a particular setting for their sample, without choosing individuals based on specific inclusion or exclusion criteria; this convenience sampling prevents generalization. The majority of the research took place in nursing home settings and adult day care centres and focused on the patients’ responses to activities. Some researchers put patients from different settings together (Sterritt & Pokorny 1994, Greiner et al. 1997, Arkin 1999). The co-mingling of individuals, which probably increases the heterogeneity of the sample, can confuse the outcomes. Patients’ feelings about their own comfort and safety because of the new people or a new environment may have affected their response to the activities.

Sample sizes were generally small (32 or less), with the exception of two studies that used 51 (Hanson et al. 1996) and 60 (Lord & Garner 1993) persons. Researchers often did not describe how they selected subjects. Some were selected by staff or were chosen because of the presence or absence of specific behaviours, for example, aggressive behaviour (Clark et al. 1998), wandering (Groene 1993), resistance to bathing (Thomas et al. 1997), nonparticipation in activities (Christie 1995), and patient activity preferences (Christie 1992). In one study (Smith-Marchese 1994), orientation to the environment and communication functioning were used as selection criteria. Staff identified the subjects in the study by Groene et al. (1998) as having a tentative diagnosis of probable Alzheimer’s type or related criteria. In Arkin’s (1999) study staff from various facilities, family members, and physicians referred subjects. The subject’s physician had to agree to his or her participation and identify any exercise limitations or precautions.

The difficulty of diagnosis and staging or profiling of AD affected the quality of the samples. A definitive diagnosis of AD is only possible with autopsy or with a rarely conducted brain biopsy. However, health care professionals use a variety of screening instruments in order to diagnose ‘probable’ AD. Some researchers have staged AD (Reisman 1983), suggesting that symptoms progress in a logical downward trajectory, while others have identified different profiles of cognitive impairment (Martin et al. 1986). Both of these theoretical propositions suggest that patients present with different clinical pictures at different times during the course of their disease; certainty about staging or profiling is difficult at best.

In the research on AD and activities, the majority (n = 25) of the researchers identified the sample of patients as ‘diagnosed’, while others mentioned specific tools used for diagnosis such as the Diagnostic and Statistical Manual III-R (DSM III-R) (Groene 1993), the NINCDS–ADRDA (National Institute of Neurological and Communicable Diseases and Stroke – Alzheimer’s Disease and Related Disorders Association) (Friedman & Tappen 1991, Namazi & Haynes 1994, Namazi et al. 1995, Greiner et al. 1997, Teri et al. 1998), and the Consortium to Establish a Registry for AD (Arkin 1999). In one study health care professionals used combinations of clinical history, neurological and
psychiatric evaluations and laboratory test results to determine diagnosis (Beatty et al. 1994). Additional concerns relevant to diagnosis include the fact that premorbid and comorbid conditions were not specified. Individuals with metabolic illnesses, such as diabetes and depression, can exhibit the same symptoms as dementia, including AD. Hearing and vision problems, and pain and anxiety medication (Casby & Holm 1994) can also interfere with individuals' responses to the environment. In the majority of the studies, researchers did not indicate they took these variables into account.

Researchers used a variety of methods to select a sample. Clair et al. (1995) Rentz (1995), and Thomas et al. (1997) used the Global Deterioration Scale (GDS); Friedman and Tappen (1991), Gerdtner and Swanson (1993) and Tabourne (1995) used the Mini-Mental Status Exam (MMSE) while Silber and Hes (1995) used the Gottfries–Brane–Steen Scale (GBS). Staff and therapists selected participants in the Gibb et al. (1997) study, whereas researcher developed criteria facilitated selection of individuals with early AD in Carruth’s (1997) research. Francese et al. (1997) used the physician identified stages listed in the patient’s chart.


Lack of clarity about diagnosis and level of cognitive impairment of the sample prevents credible generalization of results. Thus the success or failure of activities with this population is not predictable. Bach et al. (1995) acknowledged the importance of staging or describing cognitive impairment in selecting the sample. They questioned whether improved cognitive performance as a result of activity participation occurs only in selected instances in individuals with AD, that is, the early stage, or whether it occurs regardless of stage, but the client is unable to demonstrate the improvement. Likewise, Rentz (1995) questioned whether reminiscence is a helpful activity for persons in all stages of AD and whether the lack of verbal skills affects the reminiscence process. Therefore, the staging of subjects is of paramount importance.

Design and measurement

Research included four studies identified as case studies by the authors; three descriptive studies; 22 quasi-experimental studies that involved control or comparison groups and interventions but not random sampling; one experimental study with random sampling, a control group and an intervention; one experimental study with total sampling, random group assignment, and an intervention; and one qualitative study based on textual data. Our understanding of activities is affected by the methods used. With each method, we view activities differently which is reflected in the following analysis.

Case studies

Case studies included one to eight subjects. Fitzgerald-Cloutier (1993) examined music and reading and its effect on agitation (measured by the amount of time the patient stayed seated) in a single subject with AD. The patient experienced less agitation with music than when read to by a therapist; however, the method of selection of music and reading was not described. Gerdtner and Swanson (1993) described the positive effects of music on agitation in five participants, three of whom had AD. They used the modified Cohen-Mansfield inventory before, during and after individualized music therapy but did not address reliability and validity of the instrument. Rentz (1995), in a descriptive case study of three persons with AD, used reminiscence with the use of subject’s photo albums and concluded from her observations that reminiscence may be supported for AD patients who have a loss of self recognition. Jensen’s (1997) descriptive case study discussed the use of music, art, and movement activity with two nursing home residents with AD or related disorder, concluding that these activities facilitated remote memory and activity level.

Beatty et al. (1994) in a case study of five individuals with AD chose activities that they did in the past and were still able to do, determining that some complex skills are retained. Although the individuals’ illness was unstaged, they underwent physical and neurological screening for study selection. Sterritt and Pokorny (1994) observed and interviewed patients diagnosed with AD, multi-infarct dementia, Parkinson’s disease, and schizophrenia. They suggest that participation in art therapy encouraged expression of feelings and increased interaction but did not mention how they observed or measured the behaviours.
These case studies are limited in application to a broader population of persons with AD. However, good case studies with experimental designs or rich, descriptive detail raise important questions, for example, the necessity to stage patients, the potential importance of a specific intervention, for example, photo reminiscence, that can be addressed in future studies with more rigorous designs. Although not present in this literature review, case studies can be used to illustrate the usefulness of a particular theory in studying this population and activities.

Descriptive studies
Sterritt and Pokorny (1994), using art therapy as the group study intervention, described an increased occurrence of reminiscence, expression of feelings, and interaction among eight attendees at a senior day program at a psychiatric hospital. Some of the subjects lived at home, others lived at a nursing home; diagnoses of persons in the study included AD, multi-infarct dementia, Parkinson’s disease, and schizophrenia.

Two descriptive studies by Christie (1992, 1995) are included in this review. In one study, Christie (1992) engaged 21 elderly residents [an individual with AD, an AD group, a mixed diagnosis (progressive dementia, stroke, glaucoma, and Parkinson’s disease) group, and a bell choir group] in music therapy during a 10-week period. The subjects with AD were noted to be at different stages of the disease based on their behaviours. How they were selected for the study was not discussed. The goal for the music interventions for all subjects was to increase quality of life, defined operationally as increased attending skills; an additional goal for the bell choir group was to play bells more musically in a group. Although all interventions were implemented over a 10-week period, those for the individual and two small groups, and the larger bell choir group, were implemented for different time intervals.

Christie (1995) also reported on a study to investigate whether adding a highly participatory peer to an activity group was associated with motivating group behaviours of lower functioning persons with AD and related dementias. Eight residents of a facility specifically for persons with AD and related dementias, and a resident of the same unit as the group members but who had better verbal skills and was responsive to music than did the other eight persons and who enjoyed singing, were engaged in music therapy twice weekly for 30 minutes for 42 sessions. The subjects were selected because they did not participate in regular activities on the unit.

In all three studies, there was co-mingling of subjects with a diagnosis of AD with subjects with other diagnoses, confounding the study results. The subjects in Sterritt and Pokorny’s (1994) study were drawn from two different types of residences, home and a nursing home, further confounding the study results. In addition, Christie (1992) identified the general subject behaviours to be measured for attending and group participation without validation from the literature or reliability testing prior to beginning the studies. The study interventions were not described in a way that would permit replication.

Quasi-experimental studies
Weaknesses in the methodology of several quasi-experimental studies concerned use of the study instruments with individuals with AD. Tabourne (1995), in examining the effects of a life review programme on 16 nursing home veteran and novice participants of such a programme with AD, used. The Self-Esteem Questionnaire that had not been previously tested on persons with AD. Other researchers did not address construction or reliability and validity determinations of study instruments (Smith-Marchese 1994, Christie 1995, Francese et al. 1997, Clark et al. 1998). Namazi and Haynes (1994) and Tabourne (1995), used MMSE (Mini-Mental State Exam) scores as an outcome variable with an intervention of reminiscence and life review, respectively. The MMSE’s sensitivity for measuring subtle changes in cognition is undetermined.

Although Thomas et al. (1997) reported determining inter-rater reliability for the data collectors in their study of familiar music and resistance to bathing by 14 nursing home residents with AD, they did not provide these statistics. Researchers failed to report any inter-rater reliability testing in four studies (Namazi & Haynes 1994, Namazi et al. 1995, Sambandham & Schirm 1995, Tabloski et al. 1995, Arkin 1999). Carruth (1997) conducted inter-rater reliability determinations when a graduate student sat in on selected singing and social visit sessions engaged in by seven female nursing home residents, but did not report how the sessions were selected for these determinations or the results of the reliability checks.

Namazi et al. (1995) used nursing staff to keep the sleep logs of their 22 nursing home resident subjects with AD, but did not report if or how staff were trained. Trained college students worked as data collectors during exercise sessions for the subjects but, although the content of the exercise sessions was described, information was lacking on what data they collected. Instead, the researchers referenced a prior article with their detailed protocol. Sambandham and Schirm (1995) reported percentages but did not report statistical P-values when reporting their study results, although they used ANOVA and Tukey’s Honestly Significant Difference tests. Teri et al. (1998), in their study of 30 individuals with AD, reported standard deviations and
ranges but not statistical $P$-values. One study (Carruth 1997), identified as experimental by the researcher, did not include random selection of the subjects. Researchers in three reviewed studies (Clair et al. 1995, Tabourne 1995, Carruth 1997) included subjects with cognitive diagnoses other than AD in their studies. Francese et al. (1997) called their study experimental but did not randomly select their sample. Francese et al. (1997) did not address reliability and validity scores on their instrument used to measure the effects of regular exercise on muscle strength and functional ability in 11 nursing home residents with AD. Flaws in the quasi-experimental studies limit their generalizability and raise questions of scientific rigor.

Experimental studies

Lord and Garner (1993) used an experimental study with repeated measures to assess the effects of music, puzzle exercises, and recreational activities of drawing and painting on mood, mental state, and social interaction and collaboration on 60 residents of an AD nursing home unit. They found that those in the music group were more alert, happier, and had higher recall of past personal history. However, they did not indicate that they assessed the reliability and validity of the researcher designed instrument used to assess outcomes.

Qualitative designs

Gibb et al. (1997) described reminiscence following Tai Chi sessions in persons with AD and multi-infarct dementia. They stated that ‘structured reminiscence with Tai Chi facilitated thinking that was focused and insightful, beyond the level normally manifested for this group of participants’ (p. 198) yet did not provide any explanation of how they evaluated this change. This ‘qualitative’ study produced textual data but was structured like a quantitative intervention study. Silber and Hes (1995) reported their anecdotal results as a description of AD patients’ song and poetry writing, singing, and behaviours. It is not clear how they evaluated the patients and came up with both their detailed and global conclusions.

Interventions and outcomes

Researchers used a wide range of activities for interventions including music, art, reminiscence, physical activity, life review, reading and games. Music was used alone in 16 studies and was combined with other activities in seven studies, making it, by far, the activity of choice.

Researchers used activities for different purposes and provided varying levels of description. For example, music was used to stimulate cognition, emotional response, and to encourage movement. Some investigators were extremely detailed in their description (Groene 1993, Lord & Garner 1993, Groene et al. 1998) and thus their studies were replicable. Most others did not adequately describe the activity.

Outcome variables included both negative behaviours – agitation such as wandering and disruptive vocalizations, and aggression, and positive behaviours – participation in group activity, social interaction, naming, social skills, reality orientation, reminiscence, and feeling expression. Some outcome variables were cognitive, such as remote memory, orientation, and complex cognitive skills revealed in games such as dominoes and musical instruments. Sleep behaviours and muscle strength were tested in other studies. Rationale for the selection of outcome variables was sometimes based on the aim of improving quality of life. However, it is not clear how study participants would evaluate their life quality were they able and given the opportunity to do so. In other cases, less conceptual and more pragmatic concerns such as disruptive bath time behaviours inspired the choice of outcome variables. Outcome variables were sometimes measured more subjectively than objectively. Some researchers (Sterritt & Pokorny 1994, Jensen 1997) did not identify predetermined outcome variables for their studies in which they described subjects’ responses to an undirected art activity. Jensen (1997) discussed subjects’ responses to these activities in relation to self-esteem and preservation of individual uniqueness; neither outcome was measured.

Gaps in knowledge

Doing research with individuals with AD is extremely difficult. We commend investigators who have initiated research with this population and offer our critique in the hope that we can build on the existing body of knowledge. Several problems surfaced in this critical literature review. To date, lack of theoretical frameworks to guide the studies, convenience samples of captive audiences without systematic diagnosis and staging or profiling, and problems with design and measurement directly affect our lack of knowledge about activities and individuals with AD.

The influence of gender on activity participation was not a consideration for any of the researchers although several research teams included subjects of only one gender in their studies (Fitzgerald-Cloutier 1993, Gerdner & Swanson 1993, Namazi & Haynes 1994, Brotons & Pickett-Cooper 1994, Carruth 1997). This was not apparently purposive but may have to do with the availability of subjects. The relationship among gender preferences, prior socialization, vocational patterns, and activity participation needs to be considered.


493
when planning research relating to activity and AD. Studies that focus on particular ethnic and cultural groups are needed to assess the relevance of that variable in various contexts.

Research directions for the future
Clinical practice and research indicates the value that health care professionals and researchers place on activities for individuals with AD. Theoretical and methodological problems and gaps in knowledge identified in this critical literature review suggest important research directions. Although it is extremely difficult to do methodologically sound research with this population, researchers should aim for rigor, including theoretical specificity and conceptual clarity. A clear theoretical framework should assist researchers in the identification of critical variables.

The importance of design cannot be overemphasized. In order to obtain a homogeneous sample, researchers should select patients diagnosed by similar criteria. Inclusion and exclusion criteria are necessary. Staging or profiling patients, or having a clear definition of patient behaviours, will help increase rigor, as will random sampling and selection, and control groups. Along with research focused on patient behaviour, research collaboration by nurse researchers and neuropsychologists can focus on cognitive responses to activities, adding to the rigor of the research by determining homogeneous samples. Stage, behavioural, cognitive, and gender specific interventions can be evaluated. The intervention can focus on patient symptoms such as agitation or social withdrawal that have outcomes that can be measured with reliable and valid instruments. If such instruments are not available, pilot testing and methodological studies can provide a valuable first step, as can qualitative observational research that can provide the basis for instrument development.

Case studies that use experimental designs that examine one treatment at a time contribute to knowledge development; replication studies with larger samples can follow. Case studies are especially useful for extreme, unusual cases, to raise questions, and to permit experimentation with a variety of approaches.

Because two-thirds of patients remain at home, home based research is mandatory for understanding activities in the home setting. We need to attempt to understand and describe subjective behaviours with a dual focus on the patient and the professional or family care provider.

Kovach and Henschel (1996) noted that the dynamics of participation in therapeutic activities have not been studied except anecdotally.

Triangulation of quantitative and qualitative methods for evaluation of process and outcomes is important. All of these strategies aimed toward the generation of quality research are critical to advancing nursing knowledge.

Acknowledgements
This critical literature review evolved from research funded by The Miami Jewish Home and Hospital for the Aged. Sally Hutchinson, PI; Melody Marshall, CO-PI.

References
Integrative literature reviews and meta-analyses


