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# Therapeutic recreation interventions for need-driven dementia-compromised behaviors in community-dwelling elders

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## Abstract

*This study describes a clinical trial of at-home recreational therapy for community dwelling older adults with dementia and disturbing behaviors. After two weeks of daily, individualized recreational therapy interventions (TRIs), results indicated a significant decrease in levels of both passivity and agitation. Biograph data collection was useful in identifying the physiological changes that occurred with each intervention technique. Specific information is included on the time of day each behavior occurred and the most effective interventions, as well as implications for service delivery.*

*Key words: community-based care, dementia, recreational therapy, behavioral interventions*

## Introduction

Alzheimer's disease is a significant quality-of-care challenge for our society. The goal of preserving an individual's personal control, dignity, and quality of life is an enormous and important task. In addition to the severe physical and emotional demands placed on patients and their caregivers, the financial costs of the disease are alarmingly high. As the prevalence of Alzheimer's disease and related disorders is predicted to continue rising due to our aging population, this burden will surely become greater in years to come.

Social interactions and pleasurable recreational experiences are ways of offering the elderly opportunities to

attain happiness, purpose, a state of well-being, and an improved quality of life. Recreational therapy experiences have been shown to relieve stress, improve physical function, reduce depression, and change behavior in nursing home residents with dementia.<sup>7</sup> Adults with dementia and disturbing behaviors frequently encounter barriers to community-based recreation and leisure, in the form of multiple chronic health conditions, as well as cognitive, behavioral, and mobility impairments.<sup>5</sup> Another common barrier is that these individuals may not want to leave their homes for services. Helping them to get ready and transporting them is often seen as an additional burden on the caregiver. For individuals with these complex problems, the specialized services of a therapist often are required and may be best delivered in the home setting.

A small number of at-home recreational therapy services currently exist for older adults with dementia. However, there is little or no research that demonstrates the effectiveness of such therapy in dealing with disturbing behaviors. This research project selected individuals with disturbing behaviors and provided them with a clinical trial of at-home recreational therapy three to five times per week for two weeks. The purpose of this paper is to describe the at-home therapeutic recreation therapy intervention (TRI) program that was recently completed in Southwest Florida for 30 families living with and coping with dementia and disturbing behaviors.

## Literature review

Dementia is now considered a chronic disease that leads to functional disabilities over a period of many years.<sup>8</sup> Nearly one-quarter (22.9 percent) of all people aged 65 and over in this country are functionally disabled or currently in need of some form of long-term

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care.<sup>9-11</sup> According to NAC/AARP data, 22 percent of caregivers report that their care recipients suffer from dementia.<sup>12</sup> As would be expected when compared with caregivers of nondementia persons, dementia caregivers provide more hours of care (19.0 vs. 12.5 hours), more types of care, and are more likely to assist care recipients with personal activities of daily living (ADLs).<sup>13</sup> Many of the most difficult challenges faced by caregivers are related to the secondary behavioral symptoms of these diseases. These secondary symptoms often lead to a poor quality of life for the entire family,<sup>14</sup> substantially increased financial costs,<sup>15</sup> and premature and increased rates of institutionalization for the individual with dementia.<sup>16-20</sup>

## Behavioral challenges of dementia

The behavioral problems that arise in dementia may be as distressing to caregivers as the cognitive disturbances that characterize the diseases. Recent analytical models have shown this to be true.<sup>21,22</sup> Findings indicate that caregiver burden is not overly influenced by either the disability status or the amount and type of care needed; however, the manifestations of disturbing behaviors (wandering, hitting, disrobing) associated with dementia have been consistently related to greater caregiver burden. Colling<sup>1</sup> suggests that passive behaviors, seen as diminished emotional, interactive, and psychomotor activities, also cause substantial caregiver concern. In addition, caregivers who reported this type of role overload were also more likely to be depressed.<sup>22</sup> Healthcare providers and family caregivers have become increasingly interested in discovering ways to mediate caregiver distress caused by disturbing behaviors.

Numerous nursing home studies have shown that TRIs are effective in maintaining function, improving mood state, and preventing or reducing disturbing behavior for individuals with dementia. Individuals with impaired physical functioning<sup>23-25</sup> and with dementia and depression<sup>20,26</sup> are at high risk for disturbing behaviors; thus, there is a need to maximize functioning and reduce depression when attempting to address disturbing behaviors. Research indicates that TRIs of a physical nature, that are designed to meet the specific needs of individuals, can improve physical functioning,<sup>23,27,28</sup> and decrease agitated behaviors.<sup>29-32</sup> Adventure programs, such as wheelchair biking, were successfully used in three research projects to reduce symptoms of depression, increase psychosocial opportunities with peers, and to reduce passivity.<sup>33-36</sup> This program consistently brought depressed, inactive individuals to a new level of active engagement and significantly reduced symptoms of depression. Art therapy was examined in a 10-week

study and was found to significantly improve depression, decrease passivity, and offer opportunities for expression.<sup>37-40</sup> Interventions that are based on cognitive stimulation have also been found to decrease agitation<sup>5,41,42</sup> and reduce passivity.<sup>43,44</sup>

Sensory stimulation interventions have been found to reduce passive behaviors,<sup>45</sup> provide more constructive engagement and pleasure,<sup>42,46</sup> and improve behaviors.<sup>47-49</sup> Reminiscence-based sensory motor stimulation<sup>50</sup> was used successfully in clinical practice as a behavioral alternative to medication or restraint in long-term care clients. Interventions designed to promote relaxation have also been used to reduce agitation and anxiety and to increase socialization.<sup>51-53</sup> The results of relaxation studies have showed a trend in agitation reduction,<sup>54</sup> a decrease in wandering and agitation,<sup>55</sup> a significant decrease in fidgeting,<sup>56</sup> significant effects on agitation,<sup>54,56,57</sup> a calming effect, and reduced resistance to care.<sup>58</sup>

Musical interventions have been successfully used in dancing, movement, and singing sessions. A meta-analysis of 21 empirical studies with a total of 336 subjects found the overall effect of music to be highly significant for maintaining and improving active involvement, social, emotional and cognitive skills, and for decreasing negative behaviors.<sup>59</sup> Interventions with animals also significantly reduce agitation and loneliness.<sup>60</sup> Horticultural interventions been found to stimulate a sense of fascination, hold attention,<sup>61</sup> reduce stress levels, and decrease agitation.<sup>62,63</sup>

In summary, the literature shows that many types of recreational interventions in long-term care settings help with the secondary symptoms of dementia. The question remains whether they would be equally helpful for the disturbing behaviors so problematic to caregivers in the home setting. The impetus for this study was a comparison of the effectiveness of recreational therapy interventions in a nursing home setting with the lack of available services of this type for community dwelling individuals with dementia.

## TRI study framework

The TRI project used individualized recreational therapy interventions for calming agitated individuals and/or alerting cognitively-impaired passive individuals who exhibited disturbing behaviors. The conceptual framework for understanding the behaviors was the Need-Driven Dementia-Compromised Behavior (NDB) model.<sup>64</sup>

The NDB model is a middle-range theory, which has challenged the prevailing view that disturbing behaviors are simply part of the disease process. It changes the

view of dementia-related behaviors from “disruptive” to “stating an understandable need.”<sup>2</sup> The NDB model focuses on the interaction of relatively stable individual characteristics (background factors) and current situational variables (proximal factors) to produce disruptive behaviors.<sup>81</sup> If these needs are responded to appropriately, quality of life will be enhanced.<sup>2</sup> The model, described by Kolanowski,<sup>2</sup> explained need-driven dementia-compromised behavior as the result of moderately constant individual characteristics combined with inconsistent environmental factors, which together trigger the behavior. *Need-driven behaviors as expressed by cognitively-impaired individuals are the most meaningful, integrated responses they can communicate, given the restrictions of the disease, the cognitive functioning that is still intact, and other supportive or restrictive factors in the environment.*<sup>2</sup> In spite of cognitive losses, older adults with dementia retain basic human needs to belong, to have an identity, and to feel capable and useful. This project attempted to fulfill those needs with opportunities for meaningful involvement in their environment through activities based on functioning level, past interests, and current skills. The ultimate goal was to engage individuals with dementia in carefully planned recreational activities in their own homes, resulting in a positive impact on disturbing behaviors.

### *Research questions and hypothesis*

This research was designed to address three basic areas. First, we examined the impact of at-home recreation therapy on the level of disturbing behaviors observed in older adults living in the community. Second, we explored the efficacy of specific interventions in calming agitated individuals and engaging passive individuals. Third, we documented the types of behavior problems occurring in the community setting and the times of day in which they occurred. The following hypothesis was developed to guide the study: older adults who participate in an at-home recreation therapy program will have lower levels of disturbing behaviors than those who do not participate in an at-home recreation therapy program.

### *Program objectives*

The research project was designed to assist older adults living in the community by providing TRIs for individuals with need-driven dementia-compromised behaviors. In addition, the project was designed to determine whether prescribed TRIs had an effect on physiological processes, as measured by biofeedback, and to examine the relationship between physiological measures

and levels of agitation and/or passivity. Time of day for the service, consumer satisfaction, and cost of the service were also measured, with the hope of improving community-based service delivery in the future.

### *Setting*

The project took place in Charlotte County, Florida, which has a population of approximately 134,000 people, 35 percent of whom are over the age of 65. Charlotte County has one of the oldest populations in the nation, with a median age of 51.8.<sup>65</sup> Interventions took place in each subject’s home, which were mostly single-family houses in residential neighborhoods.

### *Design*

This study used a pre-test/post-test experimental design with biofeedback measures of physiological effects occurring during the interventions. Each subject served as his or her own control for this study due to variability in physiological measures. Caregivers and research staff evaluated each subject prior to a baseline period, and two weeks later subjects were re-evaluated. A specially trained recreation therapist introduced the treatment period. Finally, post-test data was collected at the end of the two-week intervention period. Blood pulse volume (BPV) and heart rate (HR) were measured and compared to baseline/intervention and intervention/control results; coded videotaped data was recorded three times during the actual intervention period. Statistical analysis included paired t-tests, and correlations. An alpha of .05 was used to determine significance.

An intervention group and a delayed intervention control group were randomly assigned following the collection of baseline data on days 1 through 5. Subjects were involved six at a time, with three in each group. The intervention group received individually prescribed therapeutic recreation three to five days a week for 1.5 hours per day for two weeks. The delayed intervention group received usual homecare for two weeks, followed by the individually prescribed therapeutic recreation program for two weeks.

### *Sample*

Inclusion criteria specified that each subject: 1) be 65 years of age or older; 2) be living at home; 3) have a medical diagnosis of dementia in the medical record; 4) have a score of 24 or less on the Mini-Mental State Examination (MMSE); 5) have a signed consent by guardian; and 6) be stable on current medications. The target population was community-dwelling older adults

**Table 1. Subject demographics**

		Frequency or means	Percent or range
Gender	Female	19	65.5
	Male	10	34.5
Total subjects		29	
Age		mean = 81.3	range 72 – 90.1
Marital status	Married	23	79.3
	Widow/widower	3	10.3
	Never married	1	3.4
	Divorced	2	6.9
Housing	Own home	23	79.3
	Senior apartment	3	10.3
	CCRC apartment	2	3.4
	Other	1	6.9
Hours subject may be left alone at a time		mean = 0.76	range 0 – 4
Ambulation status	Self	14	48.3
	Self with device	11	37.9
	With 1 assist	3	10.3
	Nonambulatory	1	3.4
Ambulation distance	None	1	3.4
	Across a room	4	13.8
	Short (< 300 feet)	11	37.9
	Long (> 300 feet)	13	44.8
Depression	No	15	51.7
	Yes	14	48.3
Dementia type	Alzheimer's	12	41.4
	Vascular	8	27.6
	Parkinson's	2	6.9
	Mixed	3	10.3
	Unspecified	4	13.8
Antidepressant	No	15	51.7
	Yes	14	48.3
Daily medications		mean = 4.31	range 1 – 7
Psychotropic	None	14	48.3
	Antipsychotic	3	10.3
	Antianxiety	4	13.8
	Sedative	1	3.4
	Poly-pharmacy	7	24.1
Psychiatric	None	25	86.2
	Bipolar	3	10.3
	Schizophrenia	1	3.4
Mini-Mental State		mean = 12.93	range 0 – 23
Global Deterioration Scale		mean = 5.28	range 4 – 7
Geriatric Depression Scale		mean = 5.1	range 0 – 12
Target behavior	Passivity	8	27.6
	Disturbing	2	6.9
	Mixed	19	65.5

with a diagnosis of dementia. Thirty subjects were recruited through the Southwest Florida Alzheimer's Association, and 29 completed the study (one subject was too paranoid to allow the research team into the home). All of the subjects lived with family caregivers, most of them their spouses.

### *Characteristics of participants*

Table 1 presents detailed demographic information for the subjects. The participants in this study consisted of 34.5 percent males ( $n = 10$ ) and 65.5 percent females ( $n = 19$ ), with a mean age of 81.2 years. Dementia types included Alzheimer's disease, Parkinson's dementia, dementia due to encephalitis, and mixed dementias. The subjects' mean cognitive score was 12.93, which indicated moderate to severe cognitive impairment, as measured by the MMSE. There are some significant facts regarding the low levels of cognitive functioning in some of the subjects in the sample. Although all of the subjects lived in the community, most with a spouse caregiver, eight of the subjects had an MMSE score of seven or less, and among them four subjects had a score of zero. In addition to the dementia diagnoses, the participants had numerous other health problems, which limited physical functioning. Four of the subjects also had current and long histories of mental illness, including three that had diagnoses of bipolar disorder and one with schizophrenia. Fourteen of the subjects were on daily psychotropic medications for behaviors. Eight of the subjects had passive behaviors only, two had agitated behaviors only, and nineteen displayed both. Twenty-three of the subjects were married, three were widowed, one never married, and two were divorced.

Table 2 presents detailed demographic information for the caregivers. The caregivers' mean age was 74.6; 55.2 percent of them ( $n = 16$ ) were female and 44.8 percent ( $n = 13$ ) were male. The mean caregiving time in years was 3.95 ( $r = 0.5-12$ ), and the mean amount of time the caregivers reported they could leave the subjects alone was 0.76 hours ( $r = 0-4$ ).

### *Instrumentation*

The at-home caregivers measured 10-hour-behavior patterns using the Behavior Flow Sheet to determine the time of day that behavior patterns occurred. These data were collected on days 1 through 5 of the baseline period. The at-home caregiver assessed frequency of agitated behaviors using the Cohen-Mansfield Agitation Inventory (CMAI)<sup>68</sup> and passivity with portions of the Passivity in Dementia Scale<sup>69</sup> on day 5 of baseline and day 14 of the intervention. The CMAI is a 29-item caregiver-rating

questionnaire for the assessment of agitation in elderly persons. It includes descriptions of 29 agitated behaviors, each rated on a seven-point scale of frequency. Inter-rater agreement rates ranged between .88 and .92 in the literature. Inter-rater reliability for this study was .90. A second version of the CMAI was used to code videotapes of all recorded sessions. The behaviors were observed by a trained research assistant and recorded on the observational version of the CMAI for comparison with the Biograph readings.

Passivity was measured using four questions from Colling's<sup>1</sup> nursing home version of the Passivity in Dementia Scale. Although the scale is still undergoing final testing, the creator of the scale allowed us to use it in our study. The areas examined were (1) initiative, (2) interaction with surroundings, (3) involvement with others, and (4) busy during the day. The responses were graded from "a little," "somewhat," "quite a bit," "very much," to "don't know." These questions were completed by the family caregiver at pretest and post-test time points.

Calming and alerting effects of interventions were measured during the recreation therapy sessions using a biograph device attached to a laptop. Blood volume pulse (BVP) and HR were recorded for later analysis. These readings are unique for each individual and needed to be compared only to their own baseline data. The biograph system is a battery operated fiberoptic biofeedback unit that directly records an intervention session on a laptop computer placed in the same room. Light-emitting diode (LED) transmission to the biograph measures the amount of light that bounces off tiny blood vessels in the finger of the nondominant hand. Blood volume in the finger increases with each heartbeat and decreases between heartbeats. When stressed, the blood flow stays in the body core, allowing a large amount of light to go through the finger, recording a high BVP. As an individual becomes relaxed and engaged in a therapeutic activity, blood flow to the finger increases, causing a lower BVP. To determine whether therapeutic interventions had an impact on the physiology of each subject, we correlated the change in BVP with the change in behavior on the observation version of the CMAI.

The desired outcome is that BVP increase and HR decrease if the therapist is attempting a calming intervention, indicating engagement in therapeutic activity and reduction of stress. When attempting an alerting intervention, the desired outcome is that BVP decreases and HR increases, thus there is a need to measure changes in the reading and compare them to changes in each individual's behavior. Readings were taken during three sessions for each subject after a trusting relationship had been formed and the subject was comfortable

**Table 2. Caregiver demographics**

		Frequency or mean	Percent or range
Gender	Female	16	55.2
	Male	13	44.8
Age of caregiver		mean = 74.61	range 52.5 – 89.1
Caregivers	Husband	12	41.4
	Wife	9	31.0
	Son	1	3.4
	Daughter	2	6.9
	Sister	1	6.9
	Friend	1	3.4
	In-law	2	6.9
How long caring for subject, in years		mean = 3.95	range .5 – 12
Observed subject hygiene		mean = 8.16	range 3 – 10
Caregiver satisfaction		mean = 9.14	range 5 – 10
Caregiver observed			
Anxiety towards subject	No	20	69.0
	Yes	9	31.0
Calm/friendly towards subject	No	3	10.3
	Yes	26	89.7
Overbearing/overcompensating towards subject	No	18	62.1
	Yes	11	37.9
Hurtful towards subject	No	21	72.4
	Yes	8	27.6
Negatively interacting	No	17	58.6
	Yes	8	27.6
	Frequently	4	13.8
Verbal and/or physical affection	No	10	34.5
	Yes	14	48.3
	Frequently	5	17.2
Behavior helped or hindered sessions		mean = 8.66	range 4 – 10
Interest in learning		mean = 7.45	range 1 – 10

around the interventionist. The procedure was to attach the monitoring device to the finger of the subject's non-dominant hand, wait two minutes, take a baseline reading at two minutes, introduce the intervention, and take another reading 10 minutes into the intervention followed by a third reading during the recovery period. In addition, staff recorded the following information from each intervention introduced at each session: time spent on the intervention, subject's engagement percentage with intervention, active or passive participation, encouragement needed, mood, and restlessness/agitation. The session was recorded on video. Research assistants using the observational version of the CMAI for the three corresponding time points coded each video recording.

A client satisfaction instrument was created to collect data on overall satisfaction with this service. The scale was a Likert scale with 10 being extremely satisfied and 1 extremely dissatisfied. A comment area was included to encourage suggestions. This was used at the end of the two-week intervention period only.

### *Procedure*

The most successful activities for individuals with dementia utilized strengths from current functioning, past interests, and current needs.<sup>5</sup> Each subject was assessed using the Global Deterioration Scale<sup>70</sup> for functioning level and the Farrington Leisure Assessment<sup>5</sup> for leisure interests. The principal investigator (LB) prescribed the therapeutic program of activities based on the data from these assessments. These assessments involved interviews with subjects and family members, as well as observation of subjects' behavior. The ultimate goal for each individual in the project was to attain a state of calm active engagement in a meaningful activity. This was true whether the subject was passive, agitated, or presented a mix of both. The ideal outcome was the same for all.

The interventions involved the subjects in prescribed therapeutic recreation activities tailored to their functioning level, strengths, interests, and needs for one to two hours three to five times per week for two weeks. A total of 73 different interventions were used, with a total of 750 intervention attempts. Examples of some of these interventions include therapeutic cooking, art/craft therapy, animal assisted therapy (AAT), wheelchair biking, relaxation, and exercise. The most effective interventions were different for each subject but we were able to prescribe a recreational therapy intervention program that was successful for all but two participants.

## Results

The hypothesis that older adults who participate in an

at-home recreation therapy program will have lower levels of disturbing behaviors than those who do not participate in an at-home recreation therapy program was tested, by comparing the differences in post-test levels of the CMAI and Passivity in Dementia Scale with the treatment phase and control phase. Table 3 presents a statistical summary for all paired t-tests.

The caregivers completed the pretest and post-test CMAIs. The CMAI scores were analyzed using paired t-tests, with a two-tailed significance accepted at the  $\alpha = .05$  level, as shown in Table 3. The pretest mean of 1.87 decreased at the post-test to 1.76, indicating a significant improvement in levels of agitation. The analysis of this variable determined that the difference in mean CMAI was significant at the  $p < 0.01$  level.

The passivity scores were also analyzed for behavior changes using four select questions from the Passivity in Dementia Scale, with a two-tailed significance at the  $\alpha = .05$  level, as shown in Table 3. The pretest mean of 1.63 increased at the post-test to 1.97, indicating a significant improvement in passive behaviors.

Behaviors according to the time of day they occurred are presented in Figure 1. Behavior was graphed as sleeping, none (meaning calm, alert, and engaged in something), passive (sitting doing nothing), or agitated (as defined by Cohen-Mansfield). Agitated behaviors gradually increased throughout the day, with a peak between 4 p.m. and 8 p.m. Passive behaviors peaked in late morning (10 a.m. to 12 noon) and then again in the late afternoon (4 p.m. to 6 p.m.). Interesting to note was the relationship between sleeping and passivity, which had very similar patterns but in opposite directions.

Biograph readings during the interventions recorded the subjects' physiological responses to the interventions. Biograph readings during selected intervention sessions found that change in BPV is significantly correlated with change in observed passive behavior. As BPV increased, active engagement increased ( $p < .001$ ). Change in HR, measured as pulse, significantly correlated with change in observed agitated behavior. As HR decreased, agitation decreased ( $p < .05$ ). These correlations are presented in Table 4. These readings were always consistent with staff observations of subject responses. It is important to emphasize that the interpretation of these readings is specific to subject target behaviors, not to specific interventions. An intervention, such as painting, might alert a passive subject, while for an agitated subject the same intervention was calming. This highlights the importance of matching interventions to client functioning ability and interest, in order to induce the target behavior. These new methods of determining target effects are helpful to determine what works for individuals in the later stages of dementia.

**Table 3. Statistical summary**

			<b>n</b>	<b>Mean</b>	<b>SD</b>	<b>Significance</b>
Cohen-Mansfield Agitation Inventory (CMAI)	Pretest	Treatment	29	1.89	0.47	
		Control	30	1.86	0.48	
	Post-test	Treatment	29	1.64	0.35	0.029
		Control	30	1.88	0.47	
Passivity	Pretest	Treatment	29	1.58	0.75	
		Control	30	1.68	0.78	
	Post-test	Treatment	29	2.37	0.82	0.000
		Control	30	1.59	0.73	
Clinging to caregiver	Pretest	Treatment	29	1.10	1.11	
		Control	30	1.07	1.20	
	Post-test	Treatment	29	0.59	0.98	0.041
		Control	30	1.17	1.15	
Accusing behaviors	Pretest	Treatment	29	1.14	0.99	
		Control	30	0.97	1.07	
	Post-test	Treatment	29	0.86	0.95	0.360
		Control	30	1.10	1.03	
Waking up at night	Pretest	Treatment	29	0.97	1.12	
		Control	30	0.87	1.04	
	Post-test	Treatment	29	0.79	0.94	0.590
		Control	30	0.93	1.05	
Sad, crying	Pretest	Treatment	29	1.14	1.13	
		Control	30	1.03	1.13	
	Post-test	Treatment	29	0.83	1.04	0.480
		Control	30	1.03	1.16	
Hallucinations	Pretest	Treatment	29	0.86	1.19	
		Control	30	0.83	1.23	
	Post-test	Treatment	29	0.62	0.94	0.330
		Control	30	0.90	1.24	
Getting into unsafe situations	Pretest	Treatment	29	0.79	1.01	
		Control	30	0.70	0.99	
	Post-test	Treatment	29	0.52	0.69	0.410
		Control	30	0.70	0.99	



**Table 4. Correlation of Biograph™ readings and change in behaviors (N = 28)**

Behavior	Biograph reading	r	p
Passivity	Blood volume pulse (BVP)	.462	.013*
Agitation	Heart rate (HR)	.445	.018*

\* Correlation is significant at the .05 level (2-tailed).

One intervention, aromatherapy, was not found to be effective as either a calming or an alerting agent. Each aromatherapy session was measured using the same biograph protocol as the other interventions, with no other stimulus being introduced, nor were clients notified of its use. Six different aromas were tested, three with claims of calming effects and three with stimulating effects, for a total of 34 sessions. With the exception of three sessions, none of the aromatherapy sessions had any impact on physiological response nor did research staff observe any changes in behavior. Of those three exceptions, one subject developed respiratory irritation and the intervention had to stop. The remaining two became agitated with the introduction of the aroma, one from lavender, which is reported to calm, and one from peppermint, which is reported to alert. This agitation was noted by observation and confirmed on the biograph readings.

The average time engaged in a therapeutic activity was 27 minutes; however, multiple interventions were performed at each session. Table 5 presents a summary of the interventions. A significant relationship was found between time engaged, MMSE, and encouragement required (the lower the MMSE score, the less the time engaged and the more encouragement needed to remain engaged).

Cost estimation was based on a 1.5-hour visit at \$30 per hour for staff and \$10 per week per subject for supplies, for a total of \$235 per week or \$470 per two-week period. Two caregivers reported that the interventions delayed nursing home placement. These individuals remain in their homes one year later. The average cost of nursing home placement in Southwest Florida is \$4,500 per month. The at-home therapeutic interventions were most successful for families nearing the placement point, and represented about one-tenth of the cost of one month in a skilled nursing facility.

### Study limitations

Scheduling of home visits was somewhat problematic, as sessions needed to be planned for the time of day

that the behaviors most often occur. Scheduling around meals, nap times, personal care, and numerous medical appointments for either the caregiver or receiver, made this a challenge. This occasionally led to not being able to schedule a visit at the times when behavior problems were most significant.

The study was limited to the ethnic mix of respondents in the Charlotte County area of Florida. Recruitment came from referrals from the Alzheimer's Association, a local news story, and from announcements at various support meetings and conferences. Six percent of the subjects were of Caribbean descent and 94 percent were white non-Hispanic, limiting the ability to generalize results to other populations. Many variables influence the types of behaviors in this population; this study explored one variable.

The sample included older adults on various types of medications that were not controlled in the study; however, families agreed to not change, eliminate, or add any behavior-affecting medication during the study. In addition, the study was for a short duration, two weeks, with no further testing to determine carry-over effects.

### Discussion

The results of this study demonstrated a positive effect on behaviors through the use of individualized prescribed recreational therapy interventions. Disturbing behavior was defined as passive (no motivation, initiative), agitated (physically or verbally aggressive, repetitive motor, wandering) or mixed (both passive and agitated). We did not anticipate that so few subjects would have agitated behaviors only, as agitation is usually reported as the most difficult problem for caregivers. The breakdown was 65.5 percent with mixed behaviors, 27.6 percent with passivity only, and 6.9 percent with agitation only. Although this meant that 72.4 percent had agitated behaviors, most of them were also passive during the same day.

Eighty-eight percent of the caregivers reported that keeping their family member active was one of their major concerns. During each session, research staff

**Table 5. Summary of interventions**

Intervention	Number of times	Male	Female	Age	MMSE mean	MMSE range	Time (minutes)	Engagement (percent)	Enc.*
Ambulation	37	3	34	79	8	0–20	16.6	97.3	0.16
Aromatherapy	34	12	22	78.9	15	0–22	14	51	1.40
Automobiles	7	7	0	87.5	0	0–0	18.6	56.4	1.14
Beadwork (adapted)	5	0	5	78.5	12	0–22	19	52	0.80
Bird activities	24	5	19	81.4	19	7–23	27.2	86.3	0.48
Books	19	6	13	82.1	10	0–23	16.1	80	0.42
Cards (adapted)	20	10	10	78.9	15	0–20	35.8	95.5	0.35
Checkers	6	4	2	81.9	16	12–20	14.2	72.5	0.80
Clay/pottery	2	1	1	81.3	6	0–12	52.5	85	1.00
Cognitive games	17	7	10	81.7	9	0–18	21.8	91.8	0.59
Community outings	16	5	11	79.9	15	5–23	82	97	0.43
Cooking	16	2	14	79.4	10	0–18	36.9	81.9	0.86
Construction crafts	12	8	4	82.3	15	7–20	31.5	86.5	0.70
Current events	6	1	5	81.3	18	5–23	23.3	87.5	0.33
Dominoes	32	20	12	80.5	14	0–22	22.3	79.4	0.65
Exercise	25	20	5	82.2	11	0–20	18.2	82.2	0.78
Feelings/discussion	38	8	30	82.2	14	0–23	31	88	0.46
Fine motor/sorting	13	10	3	83.3	13	0–18	25	85.8	0.15
Flower arranging	2	0	2	81.9	16	13–18	15	90	0.00
Gardening	7	1	6	80.9	15	0–20	22.9	92.1	0.57
Golf (adapted)	17	9	8	80.9	17	6–22	45.6	98.3	0.06
Hint book	7	0	7	81.5	13	13	26.9	91.1	0.71
Home decorating	10	1	9	81	3	0–20	18	76.5	0.80
Instrument playing	12	0	12	76.1	2	0–13	25.4	85.4	1.30
Interior design	12	1	11	83.5	11	6–20	57.5	86.7	0.17
Jewelry box	12	0	12	80.4	6	0–18	24.9	81.3	0.67
Massage	5	4	1	86.3	13	7–18	12	86	0.00
Memory book	8	1	7	79.9	8	0–20	25	100	0.13

\* Encouragement required: 0 = normal; 1 = some; 2 = much; 3 = constant or refused to participate.

**Table 5. Summary of interventions (continued)**

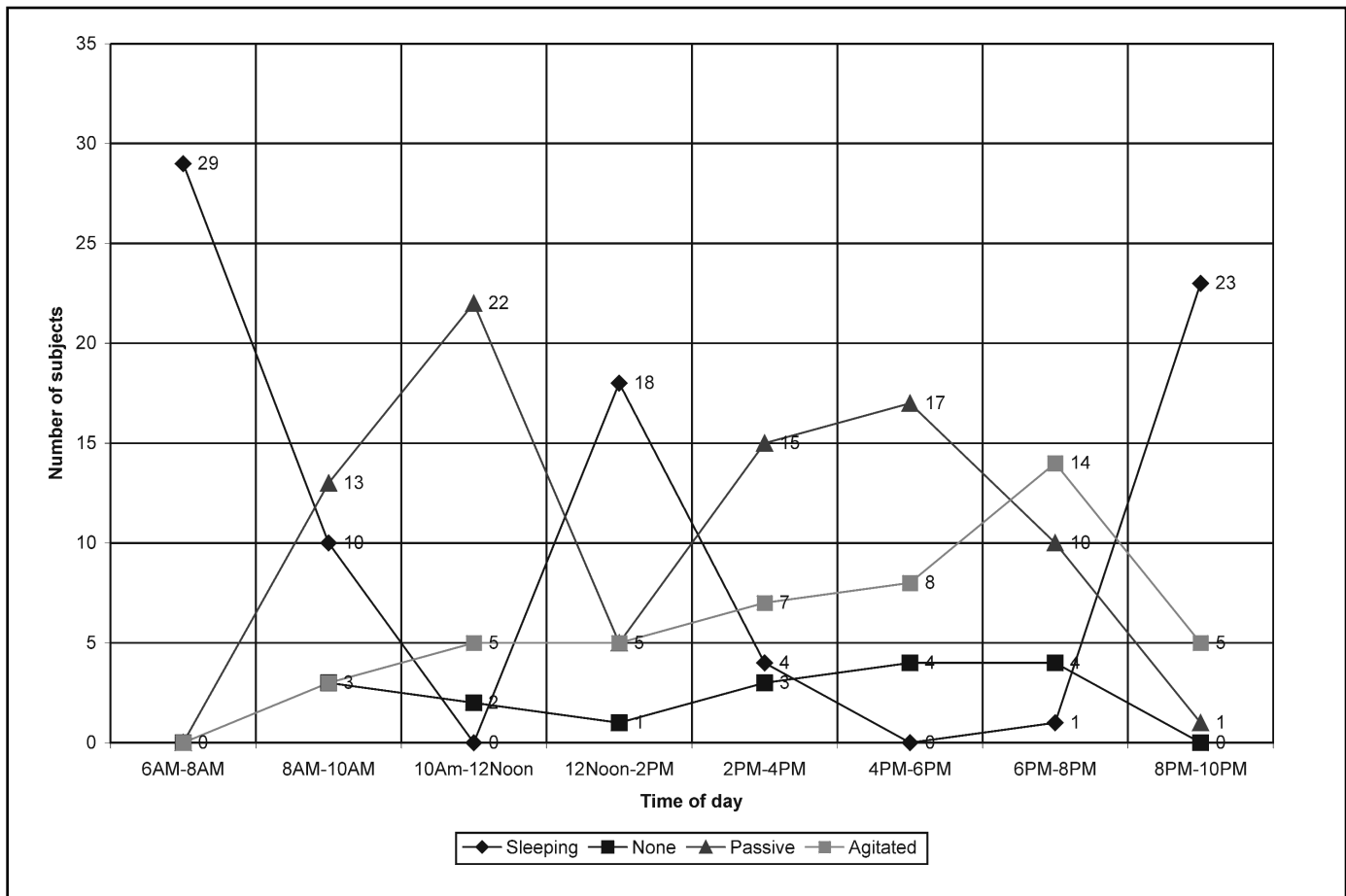
Intervention	Number of times	Male	Female	Age	MMSE mean	MMSE range	Time (minutes)	Engagement (percent)	Enc.*
Memory tea	5	0	5	81.7	16	13 – 23	25	85	0.60
Message magnets	3	2	1	82.7	5	0 – 16	15.7	83.3	1.00
Music (adapted)	7	5	2	77.9	11	0 – 20	18.6	80	0.43
Nurturing dolls	7	0	7	78.1	5	0 – 13	19.3	78.6	0.71
Painting/drawing	74	35	39	80.5	16	0 – 23	36.2	88.1	0.35
Pet therapy	8	3	5	80.5	16	12 – 23	20.6	72.5	0.38
Photography	11	3	8	83	13	6 – 20	29.1	85.4	0.46
Poetry/riddles	16	2	14	82.4	16	7 – 18	23.1	66.6	0.94
Postcards	17	5	12	81.1	13	0 – 23	25.3	70	0.94
Puzzles	10	6	4	81.4	9	0 – 20	14.5	88	0.70
Reminiscing	25	8	17	85.3	14	5 – 23	27.2	95.6	0.04
Sand/shells	12	7	5	84.4	10	0 – 22	20.4	62.1	1.40
Sensory fish	6	0	6	80.4	7	0 – 13	8	83.3	0.33
Sensory stimulation	5	3	2	83.3	0	0 – 0	19	39	1.60
Sewing (adapted)	19	0	19	83.6	13	5 – 18	20.9	75.2	0.95
Singing	7	5	2	86.5	13	7 – 18	22.9	82.1	0.00
Sports	8	1	7	85.9	14	7 – 18	11.5	77.5	0.50
Tether ball	16	7	9	82.8	5	0 – 18	12.6	66.3	1.13
Travel box	8	1	7	79.6	2	0 – 13	24.4	75.6	0.88
Wheelchair biking	15	1	14	76.8	9	0 – 20	27.3	84	0.47
Woodworking	23	18	5	78.3	16	6 – 20	35.7	85.9	0.87

\* Encouragement required: 0 = normal; 1 = some; 2 = much; 3 = constant or refused to participate.

encouraged the caregivers to do the personal things he or she previously could not due to the burden of caregiving. This provided the caregivers with 1.5 hours of respite per day. Although some caregivers stayed to watch the session, many reported they were able to work in the yard, run errands, relax, or have lunch with a friend.

Several caregivers expressed need for a longer respite period. The caregivers themselves were extremely needy and the research interventionists spent a considerable amount of time addressing their educational, resource, communication, and emotional needs. Most of the

caregivers had a good understanding of dementia, but could not get beyond intellectual knowledge of the symptoms and adjust their interactions and responses. The role modeling provided by the research interventionists was somewhat helpful for this problem. We believe that in the future interventionists should not work with a care receiver without having a plan for the needs of the caregiver. In addition, a maintenance period of one to two sessions per week should be included in future programs of this type, possibly run by trained volunteers or college students for service-learning credit.



**Figure 1. Behavior times.**

Most of the caregivers expressed sorrow over the sessions ending, despite the fact that we connected them with community day programs and other services.

During this project we worked with each subject three to five times per week for a two-week period. We learned that the subjects with comorbid mental illnesses required more time to develop a trusting relationship and to change their behavior patterns. Subjects with a predementia history of schizophrenia, bipolar disease, depression, anxiety, and paranoia especially needed to have their behaviors addressed. In the future more consideration should be given to subjects with dual diagnoses.

Many of our interventions were custom designed, and an understanding of individualization and adaptation is essential to successful behavior management with therapeutic activities. A recreational therapist has the essential skills to accomplish this and to monitor the intervention's effectiveness during the two-week period. One female subject had enjoyed sewing quilts in the past but was unable to see well enough or coordinate her motor function for the exquisite hand stitching required. Volunteers crocheted quilting squares, and with yarn and

a large plastic needle the subject was once again able to make quilts by sewing them together. Adaptation is the key, but often the specific activity had to be altered in different ways for different subjects. Several of our subjects had been accomplished artists, but all were frustrated and disappointed with their decline in skills and had abandoned their art activities.

In one intervention, a large foam board with broad lines and spaces enabled the subject to paint in the areas and create beautiful abstracts. Another subject had been an illustrator of texts and journals who now rummaged in his studio, confused and slightly agitated over not knowing how or what to do. We photocopied illustrations that he chose from art books and from his own works, and by taping tracing paper over the copy, he was able to draw once again. With the use of a digital camera, we were also able to provide photos of his home and family members for him to trace. For another, using sponges dipped in paint to decorate a clay pot, then adding soil and a plant, was a way of combining her two lifelong passions, gardening and painting. For one very passive subject who refused to do anything with us for days, we finally

found the key. Knowing she was from Pennsylvania, we showed her a book on Pennsylvania Dutch hex signs, which piqued her interest. The next day she was painting hex signs on foam board, on which we had penciled the design. Still another subject, who had painted in oils, now enjoyed viewing art and was passionate about colors, but no amount of adaptation could offer her a way to paint. Focusing on her love of colors, we provided her with sample books of wallpaper fabric and paint. Immediately she was engrossed, discussing which swatches of color would go together, and how they could work in a room. Using a jewelry box filled with costume jewelry, scarves and fabric samples also proved to engage and animate this subject. In all cases, the family member continued the activities after the project ended.

Cognitive activities and games were surprisingly successful with the subjects in this study. It was anticipated that these types of interventions would lead to frustration and withdrawal, but the opposite actually occurred. Not only did the subjects enjoy cognitive stimulation, but also they stayed involved and seemed to benefit from it. For one, it meant the development of a "hint book," a small notebook to refer to when she could not remember a specific word or name. Together we made a page each for family members, stores, doctors, food items, and other categories. Her husband assisted by adding to the book whenever a new word came up that she could not remember. She keeps the book close by her, frequently reading and reinforcing the word, and feels empowered rather than frustrated.

Other successful interventions included various projects from the Simple Pleasures Rural Partnership program.<sup>71</sup> The projects in this program are simple enough to not overwhelm an individual with dementia, *i.e.*, interesting and familiar, yet producing results in which they could take pride. During the study the participants completed many sewing and wood-working projects, such as planters, puzzles, birdhouses, and quilts, which upon completion, were donated to others in nursing homes. In this way the participants felt pride over being a community volunteer.

Flexibility and always having a backup plan available was critical to making a program like this a success. When working with older adults with dementia in their homes, it was important to plan ahead for the next visit. We found it necessary to have several extra activities as a backup in the event the subject did not wish to do the planned intervention. Something that worked well one day may not be effective the next day.

## Implications

Demographic data repeatedly warns healthcare providers of the continually growing number of older adults with dementia. This population shift will give rise to an

increase in informal caregivers in communities across the world. This rise in numbers will also bring an increase in the number of older adults with cognitive impairments and disturbing behaviors. Research indicates that up to 70 percent of older adults with dementia have disturbing behaviors, and one of the consequences of this is further disability, leading to greater disturbing behaviors, greater caregiver burden, and finally nursing home placement. Very little research has been aimed at providing individualized at-home therapy. As we strive to prevent residential placement, both from a quality-of-life and a financial standpoint, we must continue to find innovative methods of assisting caregivers in their task and addressing the unmet needs of the person with dementia. Providing the cognitively impaired individual with a much-needed opportunity for socialization, increased independence, cognitive and physical challenges, and sense of self-worth helps to fulfill these needs. This need is often left unmet, as adult day care programs are attended by only 2 percent of this population. It is time to rethink the timing, location, and delivery approaches used for providing therapeutic activities for this population. It is also clear from this study that timing interventions for behaviors is a helpful new approach to individualized care and that physiological markers can be helpful to determine exactly what works.

Heart rate is a good simple indicator of the calming effects of specific interventions. Observed change on the CMAI correlated well with physiological measures. These findings indicate that monitoring heart rate and behaviors on this observational tool are effective and inexpensive ways to evaluate the behavioral outcomes of therapy services. The knowledge that therapeutic recreation interventions can be effective in changing behavioral outcomes should lead to new types of dementia-related programs and services.

## Conclusion

This community project supports earlier nursing home studies that show that recreational therapy helps reduce the disturbing behaviors so often seen in dementia. More advanced studies are needed to examine the most efficient way to prescribe specific recreational interventions and at what stage they are most effective. Further studies are also necessary to examine the full impact of this community-based intervention model. Research with specific populations, such as minorities, rural populations, and impoverished individuals could provide greater insights on populations that could benefit the most from TRIs, and at what point in the disease. The impact of long-term caregiver burden and stress levels on the informal caregivers is an additional area open to investigation. Examination of

variables other than behaviors is also recommended, such as depression, sleep, socialization, and quality of life. The addition of a maintenance or follow-up period of one or two sessions a week for several months would serve to further assist the families and provide insights into how improvements could best be maintained over time. For example, an effective follow-up to this model is the idea of a "mobile recreational therapy unit" stationed outside the local grocery store, as shopping was seen as a difficult situation for most caregivers. The recreational therapy unit would allow caregivers to shop in a more relaxed manner, with weekly follow-up sessions being provided for the individual with dementia at the same time. We hope that as families gain more control over services provided with "client directed care" models, they will be able to select at-home recreational therapy as an option.

## Note

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