Mixed Behaviors in Dementia: The Need for a Paradigm Shift

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Abstract:

This research was an examination of two specific types of behaviors, apathy and agitation, that commonly occur in older adults with dementia. In a retrospective analysis of existing data from two intervention projects, the authors explored the times and the types of behaviors occurring in 141 older adults living in the community, assisted living, and nursing home settings. The occurrence of apathetic and agitated behaviors was monitored throughout the day for a 2-week period. The result of the analysis suggests that in all stages and settings, a combination of apathy and agitation is the most common phenomenon, and that the predominant behavior actually fluctuates during the course of the day. The use of individualized interventions based on carefully monitored behavior patterns may provide a more sensitive approach to the overall treatment needs of individuals with dementia in the future.

Article:

During the past few years, the treatment of the behavioral symptoms of dementia has become a specialty. This type of care has been described as best achieved with an interdisciplinary approach, using the best evidence available across the disciplines (Buettner & Fitzsimmons, 2003b). A problem in the treatment of these behaviors has been the attempt to simplify these very complex symptoms by merely prescribing psychoactive medications. Although research has provided detailed analysis of why these symptoms occur, little evidence is available to show practitioners how to proceed through the screening, assessment, and provision of non-pharmacological and pharmacological treatment options and outcomes.

A variety of researchers have evaluated interventions for agitation in older adults with dementia (Cohen-Mansfield, 2001). These approaches include caregiver education, environmental changes to reduce stress, non-pharmacological interventions to improve function or divert attention, detection of delirium, addressing unmet basic needs, and the prescription of psychotropic medications. Apathy has been studied by examining motivation, or the lack thereof (Marin, 1991). Interventions for apathy in dementia are limited in the literature, with some evidence that cholinesterase inhibitors may help in some individuals. Little research has focused on individuals with mixed behaviors, or clients in whom both agitation and apathy occurs throughout the course of the day.

During two recent research projects that tailored recreational therapy interventions for disturbing behaviors, a large percentage of the participants were suspected of having both apathetic and agitated behaviors as observed during their assessment period (Buettner & Fitzsimmons, 2003a; Fitzsimmons & Buettner, 2003). In this retrospective study of assessment data, the authors hypothesized that this mixed behavior type, rather than apathy or agitation alone, is actually the most prevalent form of disturbing behavior in dementia. The purpose of this article is to provide an understanding of the full spectrum of behaviors for clients in various stages of dementia, in an attempt to reveal information that can provide a more sensitive and carefully timed approach to treating clients with dementia-related behaviors. The following research questions guided the analysis and discussion:

- Do older adults with dementia have a primary type of behavior that can be targeted for treatment?

- Do older adults with dementia at different cognitive stages demonstrate different behavior types?
- Do older adults with dementia living in community, assisted living, or nursing home settings demonstrate differing behavior patterns?

TYPES OF BEHAVIORS

An accurate description of a client's behavior is an important first step in the treatment process (Buettner & Fitzsimmons, 2003b). The types of behavioral symptoms that have been identified as disturbing include negative symptoms (i.e., no activity) such as apathy or "just sitting there," and positive symptoms (i.e., activity) such as agitation. Apathy is defined as a lack of motivation that is not attributable to diminished level of consciousness, cognitive impairment, or emotional distress (Marin, 1990). Apathy has several components and includes the lack of initiation and perseverance, lack of emotional expression, and lack of goals. The apathy spectrum also includes decreased interest, motivation, spontaneity, affection, enthusiasm, and emotion (Levy et al., 1998; Marin, 1991).

Agitation may be categorized as physically non-aggressive behavior such as motor-restlessness, repetitive movements, wandering, rummaging, hoarding, hiding things, intrusiveness, spitting, pacing, picking, and rubbing (Buettner & Fitzsimmons, 2003b). Physically aggressive agitation includes spitting, hitting, biting, kicking, pushing, destroying things, and self-injurious behaviors. Verbally non-aggressive behaviors are repetitive vocalizations and questioning, complaining, screaming, weepy, crying, and moaning. Verbally aggressive behaviors include arguing, yelling, threatening, irritability, cursing, and angry outbursts.

Background

A wealth of research has explored the prevalence of behaviors in various care settings. In terms of current epidemiology, a 10-year, population-based longitudinal study indicated that 80% of the participants with Alzheimer's disease exhibited behavioral symptoms (Lyketsos et al., 2002). The most prevalent symptoms in this study were apathy (36%), depression (32%), and agitation (30%). Another cross-sectional population-based study showed 95% of clients with dementia had at least one behavioral symptom (Aarsland, Cummings, & Larsen, 2001). In contrast, Tractenberg, Weiner, and Thal (2002) found 67.5% of community- dwelling elderly individuals with dementia had agitation. Another study of community-dwelling older adults with dementia showed 75% exhibited a neuropsychiatric symptom in the past month, 55% reported 2 or more and 44% reported 3 or more disturbances in the past

TABLE 1

PARTICIPANT DEMOGRAPHICS

	At-Home		Long-Term Care		Combined	
	Frequency or means	Percent or range	Frequency or means	Percent or range	Frequency or means	Percent or range
Total participants	29		112		141	
Age	Mean 81.3	(72 to 90.1)	86.13	(67.5 to 101.9)	85.13	(67.5 to 101.9)
Mini Mental-State Examination (Folstein, Folstein, & McHugh, 1975)	Mean 12.93	(0 to 23)	8.54	(0 to 24)	9.45	(0 to 24)
Global Deteriorization Scale (Reisberg, Ferris, deLeon, Crook, & Haynes, 1987)	Mean 5.28	(4 to 7)	5.41	(2 to 7)	5.38	(2 to 7)
Gender						
Women	19	65.5%	83	74.1%	102	72.3%
Men	10	34.5%	29	25.9%	39	27.7%
Housing						
Community	29	100.0%			29	20.6%
Nursing home			22	19.6%	22	15.6%
Nursing home special care unit			47	42.0%	47	33.3%
Assisted living			11	9.8%	11	7.8%
Assisted living special care unit			32	28.6%	32	22.7%
Dementia Type						
Alzheimer's disease	12	41.4%	43	38.4%	55	39.0%
Vascular	8	27.6%	7	6.3%	15	10.6%
Parkinson's disease	2	6.9%	5	4.5%	7	5.0%
Mixed	3	10.3%	13	11.6%	16	11.3%
Unspecified	4	13.8%	42	37.5%	46	32.6%
Other			2	1.8%	2	1.4%
Daily Medications	Mean 4.31	(1 to 7)	6.67	(0 to 14)	6.18	(0 to 14)
Medication						
None	14	48.3%	48	42.9%	62	44.0%
Antipsychotic	3	10.3%	23	20.5%	26	18.4%
Antianxiety	4	13.8%	12	10.7%	16	11.3%
Sedative	1	3.4%	3	2.7%	4	2.8%
Polypharmacy	7	24.1%	26	23.2%	33	23.4%
Antidepressant medication						
No	15	51.7%	77	68.8%	92	65.2%
Yes	14	48.3%	35	31.3%	49	34.8%

month. The most frequent disturbances were apathy (36%), depression (32%), and agitation/aggression (30%) (Lyketsos et al., 2002).

Apathy has been documented in numerous studies as the first symptom to appear in dementia and is also described as the most prevalent (Derouesne, Piquard, Thibault, Baudouin-Madec, & Lacomblez, 2001; Derouesne et al., 2002, Ready, Ott, Grace, & Cahn-Weiner, 2003;

TABLE 2

BEHAVIORS TIME PERIODS

	6 a.m. to 8 a.m.	8 a.m. to 10 a.m.	10 a.m. to 12 p.m.	12 p.m. to 2 p.m.	2 p.m. to 4 p.m.	4 p.m. to 6 p.m.	6 p.m. to 8 p.m.	8 p.m. to 10 p.m.
Sleeping	121	17	18	38	34	9	12	114
Passive	11	61	53	44	41	49	45	12
Alert and engaged	5	44	42	41	26	40	18	1
Agitated	4	19	28	18	40	43	66	14

TABLE 3

TARGET BEHAVIORS

Target Behavior	Community		Long-Term Care		Combined	
	n	%	*n*	%	*n*	%
Apathy only	5	17.2	35	31.3	40	28.4
Agitation only	3	10.3	11	9.8	14	9.9
Mixed	21	72.4	66	58.9	87	61.7
Total	29		112		141	

Thomas, Clement, Hazif-Thomas, & Leger, 2001). The presence of apathy is linked to alterations in frontal lobe functions (McPherson, Fairbanks, Tiken, Cummings, & Back-Madruga, 2002) and is considered a personality change. Apathy is distinct from dysphoria and depression (McPherson et al., 2002). It correlates with a decline in executive functioning, is a strong predictor for functional decline (Derouesne et al., 2002), and relates to an increased prevalence of verbal aggression (Derouesne et al., 2001).

The level of apathy remains high as dementia progresses, and some studies have found its prevalence to increase as cognition declines (Cummings, 2001). Symptoms of apathy such as withdrawal, loss of motivation, and passive behaviors rather than agitated or mood- related behaviors have a greater detrimental effect on marital relationships (de Vugt et al., 2003) and are the most common complaint of family members (Thomas et al., 2001). No research was found that indicated the percentage of older adults with dementia who had both apathy and agitation at any stage of cognitive impairment.

METHOD

Participants

Data were extracted retrospectively from two intervention research projects aimed at reducing problematic behaviors of older adults with dementia (Buettner & Fitzsimmons, 2003a; Fitzsimmons & Buettner, 2003). These studies included participants living in nursing homes, assisted living centers, and the community. The first study was entitled “therapeutic recreation interventions for need-driven dementia-compromised behaviors in individuals with dementia.” This study included 112 participants from five sites—two assisted living centers and three nursing homes. Of the nursing home sites, one was a regular nursing home unit and two were special care units. Of the assisted living sites, one was a regular assisted living unit and one an assisted living special care unit. The second study was completed in the homes of community-dwelling older adults. This project had 29 participants who lived in the community with a family caregiver. Assessment data from a total of 141 older adult participants were analyzed for this article.

Criteria for inclusion in both studies was:

- 65 years of age or older.
- Diagnosis of dementia in the medical record.
- A score on the Mini-mental State Examination (MMSE) of 24 or less (Folstein, Folstein, & McHugh, 1975).
- Signed consent by guardian.
- Stable on current medications.
- Identified by caregiver as having passive or agitated behaviors.

In the two studies 72.3% (n = 102) of the participants were women and 27.7% (n = 39) were men with a mean age of 85.1 years. Detailed demographic data are listed in Table 1. There were no statistically significant differences between the groups. The breakdown of participation by sites was community-dwelling 20.6% (n = 29), nursing home special care unit 15.6% (n = 22), assisted living special care unit 22.7% (n = 32), skilled nursing care unit 15.6 (n = 22), and traditional assisted living facility 7.8% (n = 11).

RESULTS

To determine the target behaviors of the participants, data were gathered related to what type of

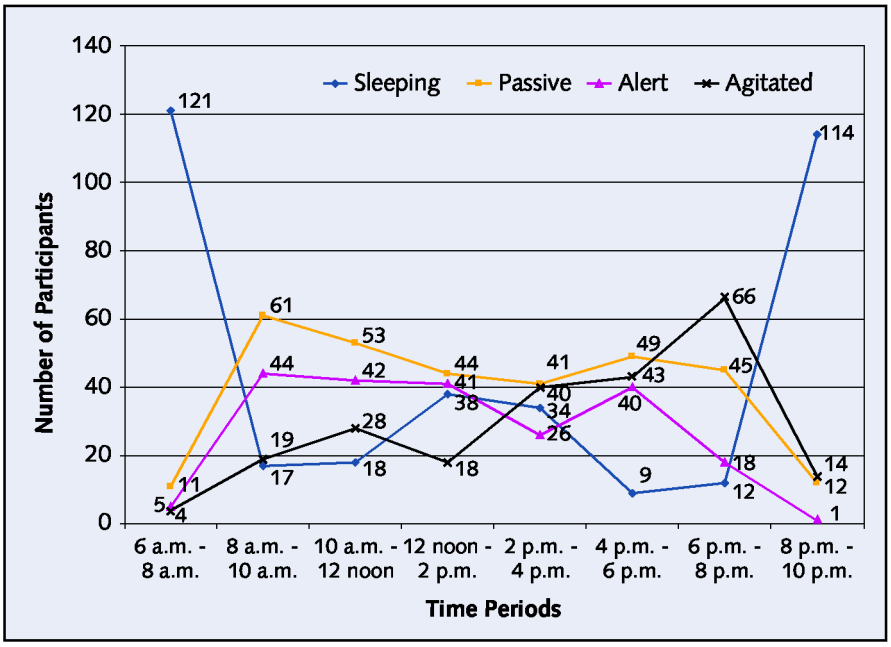

Figure 1. Behavior time graph.

behavior was exhibited during the day. A measurement instrument was designed, with input from field experts in both nursing and recreational therapy disciplines, to operationalize target behavior and thus had high-face validity. Behavior was coded for 8 time periods of 2-hour blocks each starting at 6 a.m. and ending at 10 p.m. for a 2-week period. Primary caregivers coded each time period based on the predominant pattern of activity.

The primary caregivers were trained on using the simple behavior monitoring form provided by the research team. They were then provided with detailed instructions on how to code the various behaviors and took part in practice sessions with the research team. Inter-rater reliabilities between each caregiver and research team member were calculated regularly with correlation coefficients ranging from r = .89 to .97 for family and professional caregivers. Coding for this information was set up as follows:

- 1 = Sleeping, either in bed or elsewhere.
- 2 = Passive, awake and not doing anything.
- 3 = Alert and engaged.
- 4 = Agitated.

Means and ranges for the categories studied include: sleep, 2.55 (0 to 6); apathy, 2.28 (0 to 6); alert, 1.52 (0 to 6); and agitation 1.65 (0 to 8). Table 2 and Figure 1 both display the occurrence of the four primary behavior patterns observed.

Participants were defined as having apathy only if they were coded for at least one time period with passivity and no time periods of agitation. Participants were coded as having agitation only if they had at least one period of agitation and no time periods of passivity. Participants were described as having mixed behaviors if they had at least one time period of passivity and at least one time period of agitation during daytime hours.

Table 3 shows that 72.4% of the participants from the community and 58.9% of the participants from long-term care sites exhibited mixed behaviors. Analysis of the relationship between behavior type and gender, unit type, age, MMSE score, dementia type, depression, psychotropic medications, facility activity participation, total medications, and ambulation resulted in no significant correlations. As research has shown apathy to be one of the earliest and most prevalent symptoms in dementia, MMSE scores were divided into equal mathematical categories (20+, 10 to 19, 0 to 9), as displayed in Table 4, and target behaviors were reexamined by cognitive functioning level. Although apathy alone was much more common than agitation in both the early and late stages, mixed behaviors were again found to be the highest percentage in all three categories of cognitive decline.

The role of medications was also examined for all participants. A medication was categorized as psychoactive if it was an antipsychotic, anti-anxiety, or a sedative. Polypharmacy was coded as the use of more than one of the three categories of psychoactive medications. In analyzing psychoactive medication usage and target behavior, 45% of the participants (n = 63) were on psychoactive medications and still experienced agitated behaviors as illustrated in Figure 2. Additionally, 49% of the participants (n = 69) were on psychoactive medications and had passive behaviors.

LIMITATIONS

Limitations of this study included that the majority of the sample was female; interventions for the behaviors were not included in this analysis; behaviors were not coded for 8 hours during the night; and cholinesterase inhibitor usage was not examined in the participants. This is a limitation because one of the most reliable responses to cholinesterase inhibitors is reduced apathy (Boyle et al., 2003).

DISCUSSION

The results of this analysis suggest that for this sample of individuals with dementia, mixed behaviors (a combination of apathy and agitation) were the most common type of disturbing behaviors and that the primary behavior problem fluctuated during the course of a day. Currently,

TABLE 4

TARGET BEHAVIOR BY MINI MENTAL STATE EXAMINATION (MMSE) SCORE*

MMSE Score*	20 and Higher		10 to 19		0 to 9	
Number of participants	23		46		72	
Mean	21.87		13.87		2.61	
Range	20 to 24		10 to 19		0 to 9	
Target Behavior	***n***	**%**	***n***	**%**	***n***	**%**
Apathy only	8	34.80%	12	26.10%	20	27.80%
Agitation only	1	4.30%	7	15.20%	6	8.30%
Mixed	14	60.90%	27	58.70%	46	63.90%
Total	23	100.00%	46	100.00%	72	100.00%

**Folstein, Folstein, & McHugh (1975).*

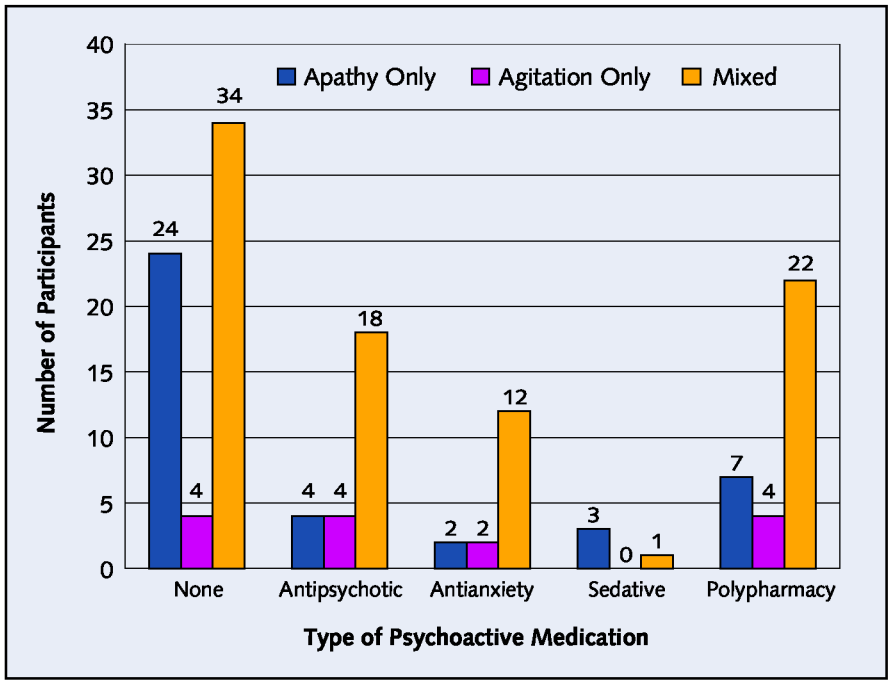

Figure 2. Medication usage and behavior types.

management of behavior problems in clients with dementia primarily focuses on the treatment of agitation, with prescribed medications as the most common treatment approach (Reichman, 2003). There is little evidence in the literature that any consideration is given to the problem of apathy, and the resulting loss of function that occurs, when treating behavior problems. Because sedation, confusion, and lethargy often occur with psychoactive medications, apathy may actually increase as a side effect of the drugs prescribed. This potential consequence has implications for the interdisciplinary treatment plan of older adults with disturbing behaviors.

Apathy is a frequent behavior that is often unrecognized, untreated, misdiagnosed as depression, or not even viewed as a problem (Landes, Sperry, Strauss, & Geldmacher, 2001). Professional caregivers may view their residents with apathy as the "good ones" because they seem to want for nothing. It is rare for a physician or nurse practitioner to be called about a client displaying apathy unless delirium is suspected.

Other studies show that older adults with apathy depend more on caregivers to provide care and are at risk for losses of physical functioning and activities of daily living (ADL) skills (Stout, Wyman, Johnson, Peavy, & Salmon, 2003). In addition, research substantiates the loss of ADL skill as a risk factor for increased behavior

problems (Senanarong et al., 2004). Thus allowing apathy to go untreated may cause loss of function and additional behavioral problems. Sensory stimulating activities have proven beneficial in the treatment of apathy and inactivity (Baker et al., 2001; Buettner, 1999; Orsulic-Jeras, Judge, & Camp, 2000), but the intervention needs to be individualized for the best result. The assessment data analyzed in this article also indicates the timing of the intervention is important.

In this study, 51.7% of the participants living in the community and 57.1 % of those in long-term care settings were receiving daily psychoactive medications. These figures do not include anti-depressant agents. The effectiveness of these medications is questionable because 45% were still experiencing significant periods of agitated behaviors.

A more sophisticated approach is called for in providing stimulation, therapy, and rest for these challenging individuals with complex behaviors. The ability to initiate or sustain meaningful activity is limited in individuals with dementia because of pathological changes associated with cognitive impairment (Mayeux & Sano, 1999). When engaging an older adult in a therapeutic activity, stimulating activities should be provided during the clients' passive periods and calming activities during agitated time periods, and the intervention periods should be short.

Individuals with these mixed behaviors do not necessarily fit into a facility's activities calendar; rather, the schedule should be individualized to the specific client's behavior patterns (Buettner & Fitzsimmons, 2003a). Cohen-Mansfield, Werner, and Marx (1992) found that nursing home staff believed boredom triggered agitated behavior 55% of the time. Buettner (1999) indicated that nursing home residents with dementia often sit for hours with little stimulation or activity. In addition, the more advanced the course of the dementia, the fewer visits individuals have from family and friends. Individuals who are deprived of environmental stimuli or activity are at higher risk for disturbing behaviors (Aubert et al., 2001; Bennett, 2000; Cohen-Mansfield & Werner, 1995; Cohen-Mansfield, Werner, & Marx, 1990; Ragneskeg, Gerdner, Josefsson, & Kihlgren, 1998).

Kovach and Schlidt (2001) found that agitation was significantly higher in the evening and when clients were occupied in the same pursuit for 1.5 hours or longer. Thus, careful timing of the daily routine, including coordination of therapeutic activities and nursing care, based on when residents need stimulation or relaxation should be considered when designing care plans for individuals with dementia.

Both apathy and agitation need to be examined when planning care for clients with dementia. If individuals are provided treatments that cause more apathy, they will be less active, and may actually have more behavior problems as a result. The "use it or lose it" doctrine applies to individuals with and without dementia and all attempts to maintain function are important in older adults. Supporting research has shown the relationship between behavior and function, and that there are effective interventions to improve both areas (Buettner, Lundegren, Lago, Farrell, & Smith, 1996). The vital importance of active engagement, along with physical and cognitive stimulation, is just currently becoming evident as intervention research evolves for individuals with dementia.

NURSING IMPLICATIONS AND INTERDISCIPLINARY ROLES

The authors recommend that both apathy and agitation levels should be assessed by nurses prior to the start of any medication and re-assessed after 60 days to de termine effectiveness of treating agitation and the impact on apathy. Changes in physical and cognitive function should also be assessed at numerous time points during this period. Alternative treatments should be considered if there is an increase in apathy or decline in physical or cognitive functioning.

Nurses should always ask, "Is the client's functioning better with or without the medication?" The answer to this should come from all the members of the interdisciplinary team who care for the client, including family members. Nurses need

to notify other disciplines when medication changes occur to alert them to possible side effects that effect motivation and function.

Social workers can coordinate care plan meetings to discuss the impact of medication side effects. Therapy department staff members need to consider medication influence when they see a negative change in their clients and report these changes. Nurses aides, possibly the workers with the most first-hand information about the client, should be encouraged to report changes in activities of daily living functioning. Family members should be questioned about changes they observe, especially
for clients living in the community. Recreational and activity department members should provide input related to changes in participation levels and engagement. The care team examines this input and a determination is made about the effects of treatment. If warranted, alternative options are explored and the primary health care provider is consulted.

CONCLUSION

This study of 141 individuals with dementia showed that mixed behaviors are the most common type of behavior occurring across all residential settings. Additional studies are needed to test effective treatment approaches that can address both the problems of apathy and agitation with the ultimate goal of shaping a calm, alert, and engaged individual with a preserved quality of life. Simply focusing on agitation alone in our treatment approaches of clients with behavioral issues may add to the problems these individuals face. The concept of mixed behaviors in dementia provides some practical applications important to gerontological nurses and other health care providers and deserves further study. Examination and screening for mixed behaviors could become an important new paradigm for the most sensitive treatment approaches and care of older adults with dementia.

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