

Do Interventions Bringing Current Self-care Practices Into Greater Correspondence With Those Performed Premorbidly Benefit the Person With Dementia? A Pilot Study

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This article assessed whether bringing current self-care practices into greater correspondence with those performed before the onset of dementia benefits the dementia patient. Participants were 20 nursing home residents with dementia, their spouses, and nursing assistants. Past and current self-care routines were determined by proxy responses of spouses and nursing assistants, respectively, using the Self-maintenance Habits and Preferences in Elderly questionnaire. Interventions were proposed based on current practices that were

inconsistent with those practiced in the past and that had been important to residents. Residents showed engagement with the interventions, as these resulted in significantly more positive than negative or neutral responses. There was no effect on agitation. Incorporating prior preferences into care routines can contribute to the quality of life of dementia patients.

Keywords: dementia; self-care; preferences; nonpharmacological interventions

There is interest in nonpharmacological methods for controlling problem behaviors in dementia, such as aggression, and in promoting positive behaviors, such as engagement. One method that has been proposed to accomplish this involves individualizing programs of care by incorporating previous habits and preferences of the individual. The few investigations that have looked at the effects of individualized interventions in dementia have produced encouraging results. For example, individualized activities for persons with dementia based on the sense of identity of participants were found to result in significant

improvement in positive affect and reduction of agitated behaviors.¹ Other work tested the effects of individualized music on the behavior of confused and agitated older patients.² Findings here suggested that individualized music may decrease agitation in persons with dementia. The effect, however, may be dependent on the importance of the intervention to the person, as the response was greatest for the individual for whom music had played a highly significant role in prior life.

Self-care activities form a substantial part of the daily regimen for people with dementia, who possess a lifelong set of routines, preferences, and habits regarding performance of these. Continuity with customary patterns can provide a sense of familiarity that is both reassuring and reinforcing^{3,4} and that can help maintain or maximize the functional abilities that remain.⁵ This can be expected to benefit even the severely impaired patient.

Several studies have proposed individualized interventions related to specific self-care activities. Miller,⁶ for example, has suggested taking into account prior preferences regarding type and time of bathing and using familiar objects, such as a favorite bathrobe or

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Table 1. Participant Demographics and Medical, Cognitive, and Functional Status

	Men	Women
Number	8	12
Age, y		
Mean (\pm SD)	79 (\pm 3.81)	84 (\pm 5.24)
Range	71-84	76-91
Occupation*		
Managerial/professional specialty	5 (62.5%)	4 (33.3%)
Technical, sales, and administrative support	2 (25%)	4 (33.3%)
Other	1 (12.5%)	1 (8.3%)
Unemployed	0 (0%)	3 (25%)
Education		
High school incomplete	1 (12.5%)	1 (8.3%)
High school complete	1 (12.5%)	9 (75%)
Bachelor's degree	1 (12.5%)	1 (8.3%)
Graduate degree	5 (62.5%)	1 (8.3%)
Race		
Caucasian	7 (87.5%)	12 (100%)
Black	1 (12.5%)	0 (0%)
Length of stay in nursing home, mo		
Mean (\pm SD)	12 (\pm 8.98)	33 (\pm 28.85)
Range	2-26	1-104
Number of medical diagnoses	7.63 (\pm 1.85)	7.67 (\pm 2.39)
Number of medications	7.12 (\pm 2.85)	6.75 (\pm 4.52)
On cognitive enhancers	5 (62.5%)	2 (16.7%)
On antidepressants	5 (62.5%)	4 (33.3%)
Activities of daily living (PSMS) [†]	3.52 (\pm 0.77)	4.30 (\pm 1.17)
Cognitive level (BCRS) [‡]	6.00 (\pm 0.83)	6.44 (\pm 0.79)
Depression (RDS) [§]	2.04 (\pm 0.70)	1.64 (\pm 0.72)

PSMS = Physical Self-maintenance Scale; BCRS = Brief Cognitive Rating Scale; RDS = Raskin Depression Scale.

*Occupational categories were taken from the Current Population Survey conducted by the Bureau of the Census, No. 637. Employed Civilians, by Occupation, Sex, Race, 1983 and 1995.

[†]Scores range from 1 (*needs no assistance*) to 5 (*needs complete assistance*).

[‡]Scores range from 1 (*normal ability*) to 7 (*total loss of ability*).

[§]Scores range from 1 (*not at all*) to 4 (*very much*).

powder, to manage disruptive responses associated with bathing in cognitively impaired older persons. Similarly, Vogelpohl et al⁷ advocate establishing a routine for dressing that incorporates an individual's premorbid habits to slow the decline in dressing independence that frequently occurs in dementia. However, although the use of individualized interventions related to self-care has been proposed, the utility of doing so has not been assessed.

This article looks at whether interventions that bring current self-care routines into greater correspondence with those practiced premorbidly will affect the behavior of nursing home residents with dementia. Individualization of the interventions is accomplished by utilizing items that had previously been important to each patient.

Individualized interventions have generally been employed in situations in which there is a need to reduce problematic behaviors. Little has been done

to investigate whether they also can promote positive behaviors. Thus, in looking at the effects of individualizing self-care interventions, we hypothesized that a greater congruence with past self-care practices would result in diverse positive reactions, including engagement with the object or activity, positive affect, or verbal response, in nursing home residents with dementia.

Methods

Participants

Participants were 20 nursing home residents with dementia, their spouses, and the nursing assistants with primary responsibility for each resident during the 7 AM to 3 PM and 3 PM to 11 PM shifts. Details of resident demographics and cognitive, functional, and medical status are presented in Table 1.

Table 2. List of Proposed Interventions

Personal Item	Environmental Modification	Personal Product	Activity	Personal Care
Wallet	Adjust lighting	Mouthwash	Magazine	Brush teeth
Watch	Alarm clock	Soap	Television	Hair care
Keychain	Extra or special pillow	Shampoo	Radio	Extra time in bed
Jewelry	Mirror	Toothpaste	Book	Snacks/ice cream
Purse	Towel	Floss	Crossword puzzle	
Handkerchief	Untuck sheets	Shower cap		
	Tissues near bed			
	Adjust blinds			
	Extra blanket			
	Wall clock			

Assessment of Self-care Practices

This study used the Self-maintenance Habits and Preferences in Elderly (SHAPE) questionnaire to assess customary practices pertaining to self-care routines. SHAPE is composed of close-ended items covering the areas of sleep, eating, dressing and grooming, and hygiene. Each content question is accompanied by a paired question that asks for the importance of that habit on a 4-point Likert-type scale ranging from 1 (*not important*) to 4 (*very important*), with the additional response possibility of "I do not know." Responses for each of the 4 sections obtained from an initial sample of community-dwelling senior respondents are summarized in separate reports.⁸⁻¹⁰ Test-retest percentage agreement for the content items on SHAPE was 73% for exact matches and 93% when including close or partial agreement. For the importance ratings, the mean intraclass correlation coefficient was 0.72.¹¹

Interventions

The interventions used are listed in Table 2. These fall into 5 categories (personal items, environmental modifications, personal products, activities, and personal care) and include such items as providing the resident with a watch, wallet, or jewelry to wear or carry during the day; providing an extra blanket or pillow, or a special type of pillow; playing the television or radio during meals or before bed; using a special brand of soap or shampoo; untucking the top sheet; closing blinds or brushing teeth at bedtime; and using a mirror during dressing. Interventions were presented to the residents daily for 1 week. Five to 11 interventions were proposed for each resident.

Not all potential interventions were proposed, and of those that were proposed, not all were actually provided. Reasons for interventions not being used include the disease state of the patient (the patient could not use floss because he could not grip anything), inflexibility of the nursing home (regarding time for meals, frequency of bathing), residence in a nursing home (patient no longer eats dinner with spouse), expense (providing a personal television), refusal or unwillingness of spouse (spouse would not bring personal items from home), safety or security issues (bathroom door cannot be closed, bedroom cannot be completely dark), or failure of the nursing assistants to present the interventions (because of time constraints for dealing with each patient or staff resistance).

Interventions involving personal items were proposed most frequently (the 7 items in this category were proposed an average of 7.83 times), with a wallet being proposed in 14 and a watch in 12 cases. This was followed by activities (mean = 4.60) and environmental modifications (mean = 4.20). Personal care and personal product items were proposed in an average of 3.50 and 3.33 of cases, respectively.

Background Measures

Data regarding resident age, gender, race, education, and lifetime occupation were collected from the charts, as was information regarding medical diagnoses, diagnosis of dementia, and number of medications. Activity of daily living functioning of the residents was assessed using the Physical Self-maintenance Scale (PSMS),¹² cognitive status was assessed with the Brief Cognitive Rating Scale (BCRS),¹³ and depression was assessed by the Raskin Depression Scale (RDS).¹⁴

Dependent Measures

Engagement was measured by the nursing assistants, who recorded positive, negative, and neutral responses to each intervention. A positive response was recorded if the resident seemed pleased by the intervention, looked at the item or seemed interested in it, or used the item. A neutral response was scored if the resident ignored the item. A negative response was scored if the resident seemed bothered by the intervention or moved the item away. This measure was chosen because other measures were not considered sufficiently sensitive to capture responses to the interventions.

The Cohen-Mansfield Agitation Inventory (CMAI–Short Form) was used to measure agitated behaviors in the residents. The CMAI–Short Form uses informant ratings to measure the frequency of occurrence of 14 agitated behaviors that are rated on a 5-point scale, with 1 indicating that the individual never engages in the specific behavior and 5 indicating that the individual manifests the behavior on the average of several times an hour. Interrater agreement rates were 0.82 for exact agreement and 0.93 for agreement within 1 point. Further details regarding the CMAI–Short Form are provided in Werner et al.¹⁵

Procedures

Informed consent was obtained for all participants. Due to the severe memory problems of the residents, spouses were asked to complete the SHAPE questionnaire in a one-on-one interview with a trained research assistant. Spouses were instructed to answer in accord with resident self-care practices at a time when the resident was able to care for himself or herself fully. This would be a time prior to the onset of dementia symptoms. The nursing assistants were asked to describe on SHAPE the self-care practices of each participant that were relevant to their shift (either morning/early afternoon or late afternoon/evening). In addition, the daytime nursing assistant completed the BCRS, RDS, and PSMS.

Patient self-care habits that were rated by the spouse as very important, important, or somewhat important for the patient premorbidly were identified. Spouse and nurse questionnaires were compared for these items to determine the habits for which current practices were inconsistent with practices in the past. A meeting was held between the investigator, research assistant, and charge nurse and nursing assistant(s) to formulate an intervention plan to increase the

correspondence of these current self-care practices with the way they were performed in the past. For example, if a female resident wore jewelry in the past, jewelry might be provided for that resident.

The study was a staggered control design in which all of the participants received treatment. One half of the participants received the interventions immediately for 1 week; the other half were monitored for 1 week prior to receiving treatment. Intervention items were pointed out or presented to the residents daily. Assessments of agitation (CMAI) were made at the beginning and end of each week. The immediate intervention group thus had 2 agitation assessments, whereas the delayed intervention group had 3. Positive, negative, and neutral responses were recorded by the certified nursing assistants after each intervention was presented.

The number of positive, negative, and neutral responses to each intervention item were determined. Paired *t* tests were used to compare types of responses and pretreatment versus posttreatment levels of agitated behaviors.

Results

The interventions produced more positive responses ($\bar{x} \pm SD = 3.85 \pm 1.95$) than they did negative (0.35 ± 0.59 , $t[19] = 7.400$, $P < .001$) or neutral (1.95 ± 1.47 , $t[19] = 2.948$, $P = .008$) responses. There were also more neutral responses than negative responses ($t[19] = 4.376$, $P < .001$). The interventions did not affect agitation, however, as the mean CMAI scores after treatment (24.38 ± 6.07) were basically identical to those obtained before treatment (24.65 ± 7.84).

Table 3 presents the percentage of positive, negative, and neutral responses obtained for each of the 5 intervention categories. The greatest percentages of positive responses were obtained for the personal products (84%) and personal items (76%) categories. Personal products and environmental modifications resulted in the lowest percentages of negative responses: 0% and 1%, respectively.

Discussion

This article presents initial evidence that bringing current self-care practices that had been important to the person into closer correspondence with those practiced premorbidly may benefit the person with

Table 3. Mean Percentage Positive, Negative, and Neutral Responses for the Intervention Categories

	% Positive Responses	% Negative Responses	% Neutral Responses
Personal items	76	10	14
Activities	65	10	25
Environmental modifications	65	1	34
Personal products	84	0	16
Personal care	58	8	25

dementia. Residents showed engagement, interest, and/or pleasure in the interventions in that they produced more positive than negative or neutral responses. One patient, for example, had enjoyed doing crossword puzzles at night and during her free time pre-morbidly. After she was given a crossword puzzle book, one of the nurses noted a decrease in complaints and in requests for continence care. Another resident, who had made her own jewelry in the past, appeared to enjoy wearing the jewelry she was given as an intervention. Residents were allowed to keep the items they were given as interventions, and a number of them continued to use the items past the intervention period.

The interventions appeared to have no effect, however, on agitation. Agitation was measured after 1 week, at the end of the intervention period, rather than during the interventions themselves. In addition, measurement of agitation was based on informant ratings, which may not have been sensitive enough to detect changes under the conditions of this research. It is possible that direct observation techniques would have produced positive results.

Alternately, the lack of effect on agitation could be attributed to the small sample size or to a low level of agitation at baseline. Participants were not selected by their initial level of agitation and may therefore have manifested a floor effect.

A notable aspect of this study is the advanced level of dementia of these residents. To qualify for the study, nursing home residents had to have a spouse who could provide information about the resident's pre-morbid self-care activities. However, for a married person to be in a nursing home, that person is likely to be in an advanced stage of dementia. Accordingly, the sample in this study was composed of residents with an average BCRS score of 6.3 (of a possible 7), indicating that they were in the very last stages of the disease. This group may be the least likely to benefit from personalized interventions, and their reduced

level of responsiveness to the environment may have limited their response to the interventions in this study. They may also be the hardest to assess, as existing instruments may not be adequate or appropriate for people at this level. Alternately, a married person with less severe dementia in a nursing home is often an indication that the spouse is physically or mentally incapacitated himself or herself and thus is no longer able to care for the patient. This calls into question the adequacy of the spouse as a provider of proxy information about the resident's prior self-care activities.

Long-term memory has been differentiated into explicit and implicit memory, with explicit memory being lost earlier in the dementia process. It is the more preserved implicit memory that is presumed to be active in dealing with familiar items and habits,^{5,16} such as might be involved in self-care. It would be expected, however, that at some point, the cognitive and memory deficits of dementia would increase to such an extent as to preclude response to any intervention, and it has indeed been noted that many treatments do not affect behavior in the late stages of the disease.¹⁷ However, it is important to note that patients with advanced disease are still able to respond to interventions that reflect their past preferences, such as those presented here. It has been shown that even the severely impaired retain the ability to perform some well-practiced actions with objects that are familiar to them.¹⁸⁻²⁰ It appears that patients demonstrate higher levels of awareness than previously expected, even at very low levels of cognitive functioning, and they can become engaged in situations in which objects are meaningful to them and reflect their prior preferences and interests.²¹ Future research needs to ascertain which types of activities and implicit memories are indeed retained until the late stages of the disease and when and for whom they are not.

Many of the interventions presented were relatively simple (eg, providing the patient with a wallet or a watch, using a special shampoo), requiring little extra in caregiver time and effort. Many were personal items brought in by the spouse from home. Yet they produced positive behaviors in these persons with dementia. Interventions were selected on the basis of their past importance to each individual patient. Some of these items (eg, personal items carried daily) are assigned high importance, in general, by community-dwelling seniors⁵; others are considered to be of low importance (eg, use of a special shampoo or conditioner⁷). But even these items can serve as effective interventions to those people for whom they had been important.

Yet perhaps even more could have been accomplished were nursing staff able or willing to undertake more involved interventions. Staff was willing to make elementary changes, such as providing the resident with familiar items or changing the type of pillow. However, institutional demands or inflexibility, or even resistance on the part of the staff members themselves, prevented them from implementing other, more complex, alterations. There was little flexibility, for example, regarding time for meals, time of awakening in the morning or allowing the resident extra time in bed, or evening baths. It is possible that bringing such routines into greater correspondence with those practiced in the past could have resulted in even more benefit for the residents.

Given the importance people attribute to their self-care preferences,⁸⁻¹⁰ self-care items that are important to an individual can be indicated pre-morbidly or in the early stages of dementia in an advance directive for personal care. This would provide caregivers with information needed to adjust elements of the older person's daily routine so that they correspond with residents' prior habits and preferences.

This research has shown that incorporating prior preferences related to self-care into care routines can increase positive behaviors in persons with dementia, thereby improving their quality of life. Future research needs to examine this effect in people in earlier stages of dementia, with larger sample sizes and with additional assessments.

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