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What are the barriers to performing nonpharmacological interventions for Behavioral symptoms in the nursing home?

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Abstract

OBJECTIVE—Behavioral symptoms are common in persons with dementia, and nonpharmacological interventions are recommended as the first line of therapy. We describe barriers to conducting nonpharmacological interventions for behavioral symptoms.

DESIGN—A descriptive study of barriers to intervention delivery in a controlled trial.

SETTINGS—The study was conducted in 6 nursing homes in Maryland.

PARTICIPANTS—89 agitated nursing home residents with dementia.

INTERVENTION—Personalized interventions were developed using the TREA decision tree protocol. Trained research assistants prepared and delivered the interventions. Feasibility of the interventions was determined.

MEASUREMENTS—Barriers to Intervention Delivery Assessment (BIDA), ADL, cognitive functioning, depressed affect, pain, observed agitation, and observed affect.

RESULTS—Barriers were observed for the categories of *resident barriers* (specifically, unwillingness to participate; resident attributes, such as unresponsive), *barriers related to resident unavailability* (resident asleep or eating), and for *external barriers* (staff-related barriers, family-related barriers, environmental barriers, and system process variables). Interventions pertaining to food/drink and to 1-on-1 socializing were found to have the fewest barriers, while higher numbers of barriers occurred with puzzles/board games and arts and crafts activities. Moreover, when successful interventions were presented to participants after the feasibility period, we noted fewer barriers, presumably because barrier identification had been used to better tailor interventions to each participant and to the environment.

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CONCLUSION—Knowledge of barriers provides a tool by which to tailor interventions so as to anticipate or circumvent barriers, thereby maximizing intervention delivery.

Keywords

agitation; dementia; nonpharmacological; barriers; interventions

Managing the behavioral expressions (BE) seen with dementia is one of the most difficult challenges a clinician must face¹, and the inability to successfully meet this challenge often results in increased burden on family and professional caregivers², use of physical restraints, or pharmacologic interventions (PIs)³. Concern about the ethics, utility, and adverse effects of restraints and PI has led to the use of nonpharmacologic interventions (NPIs) for inappropriate behaviors and adoption of NPIs as the first line of treatment in multiple clinical guidelines⁴. Indeed, guidelines state that PI should be used only when NPI fails to adequately control behavioral disruption⁵.

Research has demonstrated that BEs often arise from incongruence between a person's needs (e.g., pain/discomfort^{6,7}, loneliness/isolation⁸, boredom^{9,10}, sensory deprivation^{11,12}) and the degree to which the environment fulfills these needs^{13,14}. Consequently, BEs may indicate unmet needs, an inadequate attempt to fill those needs, or a desire for help.

Although NPIs for dementia-related BEs have proven effective^{15,16,17,18}, address underlying psychosocial/environmental reasons for behavior, and avoid the adverse effects of PIs, the reality is that PIs prevail^{19,20}. While the provision of PI is reimbursed, funding for NPI is rarely reimbursed. The underlying structure for PI delivery is in place with regard to the roles of physicians, medicine aides, pharmacies, monitoring, and quality control. Providing NPIs, however, is a work in progress as there is no designated person to systematically determine the etiology of BEs and plan NPIs. Even with this person, implementation would be trying, as nursing home (NH) staff is already overworked. Finally, there is a misconception that those with dementia cannot be helped²¹. This situation is due to negative stereotypes and insufficient funding for NPI treatment²¹ and research, including topics such as barriers to the NPI delivery process.

While we found no studies of NPI delivery barriers for BEs in NHs, others have identified NH barriers pertaining to technology use²², implementation of an activities-based intervention for depression²³, care in general²¹, feeding and incontinence care^{24,25}, and pain medication administration²⁶. Reported barriers include: lack of staff time^{23,24,25}, lack of support from staff or family²⁶, monetary issues (limited resources/lack of cost-effectiveness information/lack of reimbursement)^{21,22,23,24,25}, lack of standards to facilitate integration²², and discouragement of innovation by the regulatory environment²⁰.

For this study, we define a barrier as any cause that hinders delivery of a scheduled NPI, and conceptualize these categories: 1) external barriers, comprised of staff-related, family-related, environmental, and system process barriers; 2) resident barriers including unwillingness to participate and resident attribute barriers; and 3) barriers of resident unavailability. This study was conducted to delineate barriers to administration of NPIs for dementia-related BEs. Also explored were relationships of barriers with resident, behavior, and NPI characteristics.

METHODS

This research was conducted within the context of the treatment arm of a randomized placebo-controlled repeated measures design of NPIs for BEs in persons with dementia²⁷.

Participants

Participants were 89 residents from six Maryland NHs. The mean age was 85.9 years, 73% were female, 81% were White, and the mean MMSE score was 7.6. Participants received a mean of nine medications; 100% received analgesics (Table 1).

Assessments—The following data were obtained from NH charts: background data (age, gender, marital status, ethnicity, education); medical data pertaining to prescribed medications (including pain relievers and psychotropics) and diagnoses (including a dementia diagnosis confirmed by a physician); and, Minimum Data Set (MDS)²⁸ data (pain, vision, hearing, speech, and ADL).

Cognitive status was assessed via the Mini-Mental Status Examination (MMSE)²⁹. Participants' relatives completed the *Self-Identity Questionnaire*³⁰. *Pain and depressed affect* were obtained by interview of each resident's primary staff caregiver using the Pain Assessment In Elderly Persons (PAINE)^{26,31} and Raskin Depression Scale (RDS)³². Direct observations of *agitation* were recorded via the Agitation Behavior Mapping Instrument³³. The ABMI includes 14 items describing physical and verbal agitation; inter-rater reliabilities of behaviors averaged 96% with intra-class correlation (ICC) of 0.90²⁷. Direct observations of *affect* were recorded using Lawton's Modified Behavior Stream³⁴, which includes five modes: pleasure, interest, anger, anxiety, and sadness. Due to low frequencies of occurrence, a mean was calculated for anger, anxiety and sadness to yield a score of negative affect. Inter-rater agreement averaged 88% per mode (range: 70–99%) with mean ICC of 0.91.

The *Barriers to Intervention Delivery Assessment*, an outgrowth of discussions of our experiences on the units and extensive literature review, categorizes reasons for NPI delivery failure as: *staff-related barriers* (e.g., refusal to remove restraints); *family-related barriers* (e.g., failure to provide family photos for a NPI); *environmental barriers* (e.g., noise); *system process barriers* (e.g., insufficient funds for NPIs); *resident barriers* (e.g., unwillingness to participate, resident attributes such as unresponsive); *resident not available* (e.g., eating). Barriers were noted in close-ended items, along with an 'other' category to capture unanticipated barriers. As to reliability, the BIDA was completed independently by 3 research assistants for 11 residents and agreement rate averaged 94%.

Procedure—The study protocol received approval from the CESLC IRB. Inclusion criteria were: the resident had been at the NH three weeks, had been identified by nursing staff as agitated at least several times a day, and had a diagnosis of dementia. Exclusion criteria were: life expectancy < 3 months, a bipolar or schizophrenia diagnosis; and MMSE 25. Once informed consent was obtained from relatives/other responsible parties³⁵, research assistants observed baseline agitation for 3 days using the ABMI. Four consecutive hours of peak agitation, as well as type of agitation (i.e., verbal or physical), were identified for each resident. The Treatment Routes for Exploring Agitation (TREA) decision tree protocol³⁶ was used to uncover possible reasons for each participant's agitation. TREA incorporates data from participants, relatives, nursing staff, and physicians that are obtained through direct observations, interviews, questionnaires, and chart review. Based on the decision tree, we hypothesized an unmet need, identified a corresponding treatment category, and designed a personalized NPI to best fit the resident's past identity and preferences as well as sensory, mobility, and cognitive abilities. Many NPIs were used, such as sensory stimulation (e.g., music, perfume), simulated social stimuli (e.g., family videos/pictures); 1-on-1 socializing with a research assistant; activities (e.g. sorting cards, arts & crafts); care-related activities (e.g., responding to a request for toileting); and others – see Table 3. For each resident, several NPIs were proposed and delivered during a 3-week feasibility period where

both intervention feasibility and resident responses were assessed. The BIDA was filled out after each NPI presentation by the research assistant who conducted the NPI.

To assess the efficacy of the TREA decision tree protocol, we selected those NPIs identified as most successful and presented these after completion of the feasibility period, making sure that NPI administration took place during each resident's peak agitation hours (determined during baseline). Again, the BIDA was completed after each NPI presentation.

Analytic Approach

In order to examine the data from more than one perspective, barriers to NPI delivery were quantified as: occurring for % of participants and occurring during % of sessions. For barriers encountered for >10 participants, relationships between barriers and resident, behavior, and affect characteristics at baseline (i.e., not influenced by NPI) were calculated using chi-square (for nominal level variables) and t-tests (for ordinal and interval level variables). Due to the chance of a type 1 error with multiple comparisons, findings are presented only when $p \leq .01$ or when consistent with other findings.

RESULTS

As to *external barriers*, the staff-related barrier reported most often (for 24% of participants) was the physician concluding that the resident had no pain, despite the detection of pain through formal assessment or observation (Table 2). Barriers arising from general staff refusal or interruptions were reported for 10% of participants. Family-related barriers were noted for 17% of participants. Environmental barriers did occur but were rare. System process issues created barriers for 34.8% of participants. In the *resident barriers category*, both explicit and passive refusal occurred for over half of the participants (for 12.7% and 6.9% of sessions). Willingness to participate occurred for 84.3% of residents, accounting for 20.5% of sessions. The most noted resident attribute barriers were communication problems and unresponsiveness, each seen for about 20% of residents. The barrier of *resident unavailability* was most often due to sleeping, noted for 40% of participants yet accounting for only 2.7% of sessions.

Relationship of barriers with participant characteristics

Participants for whom staff barriers were noted ($n=31$) had more pain than did those without staff barriers ($n=58$) (MDS: $t_{(31,9)}=3.095$, $p=.004$; PAIN: $t_{(46,3)}=3.98$, $p<.001$). For *resident barriers*, when explicit refusal was noted ($n=53$), residents tended to be older, unmarried, and had higher cognitive functioning than those who did not manifest explicit refusal ($n=36$) ($t_{(87)}=2.56$, $p=.012$; $X^2=10.96$, $p=.001$; $t_{(87)}=3.60$, $p=.001$, respectively). Those for whom the resident attributes barrier occurred ($n=44$) had greater cognitive impairment than did those without this barrier ($n=45$) ($t_{(87)}=4.26$, $p<.001$); a closer look revealed that the individual barriers of communication and unresponsiveness were strongly related to greater cognitive impairment ($t_{(36,2)}=4.82$, $p<.001$; $t_{(42,11)}=6.12$, $p<.001$; respectively). The *resident not available* barrier ($n=41$) was linked with more speech problems than was the case when this barrier did not occur ($n=48$) ($t_{(55,3)}=2.63$, $p=.01$).

Relationship of barriers with observed behavior and affect (from baseline)

From the *resident barriers category*, unwillingness to participate ($n=75$) was related to comparatively less agitation than that of the 14 residents for whom this barrier was not noted ($t_{(87)}=2.72$, $p=.008$). Alternately, the resident attributes barrier ($n=44$) was related to more agitation ($t_{(68)}=3.59$, $p=.001$; comparison group: $n=45$), as was the individual barrier of communication problems ($n=18$) ($t_{(87)}=2.819$, $p=.006$; comparison group: $n=71$). More barriers correlated with less pleasure ($r=-.28$, $p=.008$; $n=89$). Less pleasure and also less

interest were linked with the unresponsiveness barrier ($n=17$) when compared to those without this barrier ($n=72$) ($t_{(76,8)}=3.98$, $p<.001$; $t_{(87)}=3.08$, $p=.003$, respectively). *Resident unavailability* ($n=41$) was related to less interest ($t_{(87)}=3.66$, $p<.001$; comparison group: $n=48$), and being asleep ($n=36$) was linked with less interest and pleasure ($t_{(87)}=4.40$, $p<.001$; $t_{(81,2)}=3.31$, $p=.02$; comparison group: $n=53$).

Relationship of barriers with treatment characteristics

The NPI of providing food had the least barriers, followed by 1-on-1 socializing (Table 3). NPIs with the most barriers were puzzles/board games, arts & crafts, books, physical activity, and provision of care. Explicit refusal rates were lowest for care activities and movies/DVDs.

Following the completion of the feasibility period, NPIs were presented to residents during their hours of peak agitation. We found that the occurrence of barriers during the post-feasibility period was less frequent than that seen during the feasibility period (these data are available upon request). Specifically, the mean percentage of barrier-free NPI presentations at the post-feasibility period was 91%, as compared to 72% during the feasibility period (Table 3). The corresponding rates for explicit refusal are 7% and 12% and for passive refusal 1% and 8%, for the post-feasibility and feasibility periods, respectively.

DISCUSSION

The results demonstrate the presence of many barriers to NPI delivery, which are consistent with the conceptualized categories of external barriers, resident barriers, and resident unavailability barriers. Our analyses enable us to consider barriers that need improvement or change, barriers that need to be accommodated (as these can't be changed), and barriers that signify positive processes which could be strengthened. Barriers that need improvement include staff- and relative-based barriers. For example, the barrier pertaining to a physician's denial of resident pain, despite evidence to the contrary, must be improved. As to relative-related barriers, family is often the only source of in-depth understanding of the resident, and their lack of cooperation can curtail a NPI. What is needed is improved education of physicians and communication with them and methods to educate family members and to entice them to collaborate in the NPI process. Staff-related barriers were minimized as NPIs were handled by research staff. Therefore, this study did not capture data that can speak to nursing staff improvement/change.

Environmental barriers, such as too much noise or locating a DVD player, can also be changed as these present obstacles with workable solutions. We noted a low occurrence of these, partly because our team provided the majority of NPI items/activities. Yet, the research design did not always allow us to obtain intervention items, as when a NPI exceeded budget (e.g., purchase of a hearing aid) or when more than the allocated time was needed to locate a specialized NPI (e.g., a translator or an item from a hard-to-reach relative). Such design issues can be improved in future studies.

Resident attribute barriers most often cannot be changed and must be accommodated. Specifically, a resident's level of function must be accommodated, particularly for those with significant communication problems or unresponsiveness in late stages of dementia. While our TREA NPIs are tailored for this, as in a massage intervention requiring little resident input, these barriers still occurred. Finally, we saw positive reasons for resident unavailability barriers; such as when residents were involved in engaging activities (e.g., movies/reading/music; group activities) that were not our NPIs. While inconvenient for research, planned activities facilitated by NH staff are needed to prevent BEs and should be encouraged.

We found a decrease in barriers when successful NPIs were presented following the feasibility period. We see this as support for the efficacy of the TREA methodology, i.e., barriers identified during the feasibility period serve to fine-tune NPIs to the resident and environment. Systematic examination of the utility of different NPIs and the accompanying barriers is recommended for regular practice in nursing homes.

Relationships found between barriers and resident characteristics validate the nature of barriers and illuminate related processes. For example, our finding that staff-related barriers were linked with two (independent) pain measures is consistent with the most frequent staff-related barrier that the physician thinks there is no pain. Similarly, the link of the resident attributes barrier with greater cognitive impairment is consistent with the most frequent resident attributes barriers being communication problems and unresponsiveness. The finding that those with higher cognitive function were more likely to refuse NPIs agrees with a previous study that reported a link between cognitive function and stimulus refusal³⁷.

Relationships between barriers and NPI characteristics are noteworthy. First, the fewest barriers were seen with the intervention of food or drink, possibly because this NPI served as a response to a direct need. It would be interesting to examine other food-related interventions, such as cooking and dining NPIs, in future studies. Second, we saw that 1-on-1 socializing was relatively barrier-free, concurring with prior research that found less refusal and more engagement with live 1-on-1 social contact³⁸. Third, NPIs not needing active participation by the resident (e.g., movies) were linked with fewer barriers than those requiring active participation (e.g., puzzles). We believe that, despite differing levels of barriers, an abundant NPI toolkit is needed for optimal utilization of NPIs, for personalizing NPIs and for allowing NPIs to be alternated and continually utilized.

Because our protocol called for research staff to conduct NPIs, the results do not represent the full scope of barriers to NPI delivery in traditional (non-research) nursing home care. Indeed, many other barriers exist, including organizational barriers, social factors, lack of knowledge, legal and regulatory factors, physical setting, and economic factors³⁹. Future studies should examine barriers to NPI implementation created by specific departments in nursing homes (e.g., nursing, medical, activities) within their delivery of NPIs.

CONCLUSION

This is the first study to systematically examine NPI barriers and their rates of occurrence in nursing home residents with dementia. Also provided is an initial methodology for categorizing barriers. Analysis of barriers is an important step in establishing much-needed NPI programs in nursing homes. We suggest that NHs consider systems for education and mentoring of staff and family members that will serve to reduce staff-related and family-related barriers.

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Table 1

Participant characteristics and baseline levels of behavior and affect

Characteristics	n= 89
<i>Demographic</i>	M(SD) or %
Age	85.9 (8.62)
Gender	
Female	73.0%
Male	27.0%
Ethnicity	
White	80.9%
African American	12.4%
Asian/Pacific Islander	3.4%
Hispanic/Latino	2.3%
Other	1.1%
Marital status	
Widowed	60.7%
Married	28.1%
Separated/Divorced	9.0%
Never married	2.2%
Education	
High school or less	57.3%
College/Technical school	23.2%
Graduate degree	19.5%
<i>Functional</i>	
Cognitive status (MMSE)	7.6 (6.33)
ADL (MDS)	2.72 (0.84)
Depression (Raskin Depression Scale)	1.54 (0.78)
Vision (MDS)	0.64 (1.07)
Hearing (MDS)	0.40 (0.72)
Speech (MDS)	0.17 (0.41)
Pain frequency (MDS)	1.12 (0.36)
<i>Diagnoses and medication</i>	
Diagnosis index	5.3 (1.47)
Total # of medications per study participant	8.8 (2.11)
% administered sedatives	9.0%
% administered antipsychotics	60.7%
% administered antidepressants	70.8%
% administered anti-anxiety medications	42.7%
% administered analgesics	100%
<i>Baseline value of behavior and affect</i>	n=89
Overall agitation (ABMI)	8.76 (5.61)
Pleasure	1.06 (0.13)

Characteristics	n= 89
Interest	3.20 (0.78)
Negative affect	1.06 (0.10)

Notes: Ranges for scales are: Mini-Mental State Examination (MMSE) – higher scores indicate higher cognitive function; Raskin Depression Scale, from 1 (not at all depressed) to 5 (very much depressed); From Minimum Data Set (MDS) – Activities of Daily Living (ADL), from 0 (independent) to 4 (total dependence); Vision, 0 (adequate) to 4 (severely impaired); Hearing, 0 (hears adequately) to 3 (highly impaired); Speech, 0 (clear speech) to 2 (no speech); Pain frequency, 1 (no pain) to 3 (pain daily).

Diagnosis index = count of 11 categories: cardiovascular disease, respiratory disease, neurological diseases, musculoskeletal diseases, genitourinary disease, diseases of the digestive system, endocrine system diseases, blood diseases, diagnosis of dementia, other psychiatric and major affective disorders, and other (including cancer, allergies, skin conditions)

ABMI = Agitation Behavior Mapping Instrument

Table 2

Barriers to nonpharmacologic intervention delivery, presented as frequency of participants and frequency of sessions

	Frequency/% (participants)		Frequency/% (sessions)	
	<i>n</i> =89		<i>n</i> =1553	
	Frequency	%	Frequency	%
External barriers				
Staff				
Physician does not think there is pain	21	23.6	Not applicable	
General staff refusal/interruptions	9	10.1		
Physician not accessible *	4	4.5		
<i>Overall staff</i>	<i>31</i>	<i>34.8</i>		
Family				
Lack of family availability or cooperation	15	16.9		
Environmental				
Too cold/hot outside	3	3.4	3	0.2
Too much noise	1	1.1	1	0.1
Other resident interference *	0	0	0	0
Other environmental ^a	6	6.7	8	0.5
<i>Overall environmental</i>	<i>10</i>	<i>11.2</i>	<i>12</i>	<i>0.8</i>
System process				
Not enough time or money * to get materials	14	15.7	Not applicable	
Inappropriate intervention *	18	20.2		
<i>Overall system process</i>	<i>31</i>	<i>34.8</i>		
Resident barriers				
Unwillingness to participate				
Explicit refusal	53	59.6	198	12.7
Passive refusal *	47	52.8	107	6.9
Need of coaxing	22	24.7	25	1.6
Fears (e.g., fear of failure)	6	6.7	6	0.4
“Imagined” fears (e.g., fear that research assistant will request payment)	1	1.1	1	0.1
<i>Overall unwillingness to participate</i>	<i>75</i>	<i>84.3</i>	<i>336</i>	<i>21.6</i>
Resident attributes				
Communication (language & cognitive)	18	20.2	20	1.3
Unresponsive	17	19.1	29	1.9
Physical concerns/needs	10	11.2	11	0.7
Hearing	8	9	8	0.5
Vision	5	5.6	6	0.4
Very distressed at start of intervention *	3	3.4	3	0.2
<i>Overall resident attributes</i>	<i>44</i>	<i>49.4</i>	<i>77</i>	<i>5</i>
Resident not available				

	Frequency/% (participants)		Frequency/% (sessions)	
	<i>n</i> =89		<i>n</i> =1553	
	Frequency	%	Frequency	%
Asleep	36	40.4	42	2.7
Eating *	8	9	5	0.5
With family/socializing/phone	5	5.6	5	0.3
In shower	4	4.5	4	0.3
At beauty parlor/physical therapy	3	3.4	3	0.2
Off unit	2	2.2	2	0.1
Involved in a structured or a group activity *	2	2.2	2	0.1
ADL with nurse/bathroom/taking medication *	2	2.2	2	0.1
In room with the door closed *	0	0	0	0
Watching TV/movie—reading—listening to music *	0	0	0	0
<i>Overall resident not available</i>	<i>41</i>	<i>46.1</i>	<i>68</i>	<i>4.4</i>

* designates categories not anticipated during BIDA development but observed during intervention delivery attempts. These may therefore represent an underestimate of their occurrence.

^aOther environmental contains these barriers: no TV/VCR/DVD to present movie, netted bed or restraint, not enough activity in the unit for a group activity, unable to move resident to another unit as it was under renovation, toddlers didn't show up for the intervention.

Note: Session frequencies may be underestimates, as research assistants did not always note recurring barriers

Table 3

Percentages of No Barriers, Explicit Refusal, and Passive Refusal by type of Individualized Nonpharmacologic Intervention

Intervention	<i>n</i>	No barriers encountered %	Explicit refusal %	Passive refusal %
Food or drink	14	92.86	7.14	
1-on-1 socializing	98	88.78	6.12	1.02
Movies/DVDs	60	81.67	3.33	5
Olfactory & tactile sensory stimulation	47	80.85	10.64	
Sorting (cards or envelopes)	29	79.31	10.34	6.9
Music	95	76.84	11.58	5.26
Work-related	75	72.00	13.33	9.33
Simulated social	378	70.37	12.96	6.88
Group activity	50	68.00	18	6
Care-related	133	64.66	1.5	
Physical activity	188	64.36	15.43	10.11
Magazines/reading/books on tape	132	62.12	17.42	9.85
Arts & crafts	136	61.76	16.91	11.76
Puzzles & board games	88	56.82	19.32	12.5
Mean (across NPIs)		72	12	8

Note: the sum of percentages for no barriers, explicit refusal, and passive refusal is not 100% for each intervention as other barriers that occurred (e.g., family or staff barriers) are not included in this table.