Non-Pharmacological Approaches to Address Behaviors

Understanding Behavioral and Psychological Symptoms of Dementia

'Dementia behaviors' are referred to and thought of in many different ways, which can be confusing to providers and family members caring for persons living with dementia. Behavioral and Psychological Symptoms of Dementia (BPSD) refer to non-cognitive symptoms that occur commonly among persons with dementia. These behaviors have been referred to as problematic, disturbing, difficult, inappropriate and challenging. Such language actually reflects the perspective of the observer rather than that of the person living with dementia. BPSD are now widely viewed as a form of communication that is meaningful (rather than a problem) and is an individual's best attempt to communicate any variety of unmet needs. In recent years, providers and researchers have shifted away from using this negative terminology and have adopted more person-centered terminology, such as 'behavioral symptoms' and 'responsive behaviors' to recognize the experience of the person with dementia exhibiting the behaviors. Throughout the guide we will refer to these as Behavioral and Psychological Symptoms of Dementia (BPSD), realizing other terminology exists.

The etiology (or underlying cause) of BPSD is multi-factorial. Behaviors may result from any combination of: neurodegenerative damage associated with the disease itself; unmet physical needs such as pain or discomfort; and unmet psychosocial needs, such as the need for meaningful human contact or fear. BPSD also commonly co-occur or occur in "clusters."

Examples of BPSD include:

- Aggression
- Abnormal/repetitive vocalizations
- Sleep disturbances
- Wandering
- Agitation, and/or restlessness
- Screaming
- Repetitive motor activity
- Anxiety
- Depression
- Psychosis (delusions and hallucinations)

Some important things to know about BPSD:

- Antipsychotic and atypical-antipsychotic medications are only moderately effective for most BPSD and should be trialed as the last resort. The only BPSD that may be responsive to or appropriate for antipsychotic treatment are aggression, agitation, or psychotic symptoms that pose an immediate risk for harm. However, not all psychotic symptoms necessarily require pharmacologic treatment, i.e., hallucinations that do not distress the person with dementia.
- Most BPSD are responsive to NPA. The approach should be based on an assessment of predisposing and precipitating factors (see Clinical Decision Support below) and individualized to the person’s abilities and physical/emotional/social needs.
- It is important to consider other social, psychological and physical needs that a person might have that may result in BPSD, especially pain, which is highly prevalent among older persons.

Practical Guidance for Nursing Home Providers

In addition to being effective, NPA should also be feasible. Nursing homes have multiple barriers to implementing practice change. To assist nursing home providers in choosing which NPA to implement, Table 2 lists specific NPA identified during a review of extant evidence and includes those approaches that demonstrated both efficacy and feasibility. An approach was considered to be more feasible if it required
fewer resources, lower-cost supplies, less complex activities, minimal staff training, and less need for additional or specialized personnel. In most nursing home settings, feasibility is centrally important for the sustainability of a given approach.

Critical considerations in implementing non pharmacologic approaches: Lessons from our focus groups with direct care providers

Regardless of the specific NPA selected for use in addressing the resident’s BPSD and distress, several considerations should be kept in mind.

1) Human behaviors are a dynamic, moving target.

All of us have good days and bad days. Fluctuations in mood and behavior are a normal part of human functioning. For persons living with dementia, these fluctuations can be even more exaggerated. In our focus groups direct care providers eloquently expressed their awareness of these fluctuations in acknowledging that sometimes it is really hard to pinpoint what may “set someone off” on any given day. If you follow all the guidance and direction provided by this toolkit, you may still be stymied on what is causing a given resident’s distress in a specific moment in time. There is no magic bullet.

2) It’s all about trial and error.

There is no magic bullet. Selecting a given approach to trial with a given resident with BPSD is only the beginning of the process. Though this toolkit has delineated the best and most feasible evidence based approaches for you, keep in mind that any given approach follows the “one-third” rule. A given approach may work for about a third of persons immediately; while with another third it will be only moderately successful, and the final third will not respond at all. To make things even more complex, as the direct care providers noted in our discussions, an approach that works today, may not work tomorrow, or, even an hour from now. Furthermore, some approaches that are effective when implemented by one direct caregiver may not work when implemented by another. These realities have several implications:

- Foster a mind set of “let’s try this and see what happens”
- Always have a backup approach if a given approach is not successful
- One trial of an approach may not be sufficient. Try again another day.
- Interview and observe what a “successful” direct provider is doing and saying. Within his or her success lies important information that can be shared with others.

3) Individualizing the approach to a given person is critical to success.

Many research reviews have stressed that the more individualized or tailored an approach is, the more likely it will be that it will succeed. Direct care providers describe the process of getting to know an individual’s preferences as the secret to success in preventing or ameliorating the distress of BPSD. They also articulate feeling hampered by knowing very little about an individual new to a facility. The flow of information from family member to direct care staff is often not a linear process, hampering the direct care workers ability to provide person centered care.

Effective evidence-based tools are designed to help facilitate collecting and sharing this information. The first is collected upon admission via the 16 items from the MDS 3.0 Section F Customary Routine. Collecting and sharing this information with direct care staff within the first 24 to 48 hours of admission can be an effective way of closing the individualized knowledge gap. The second tool is the Preferences for Everyday Living Inventory (PELI) (see System Integration section of Toolkit).

The PELI is designed to provide a comprehensive overview of the daily preferences, providing more detail beyond the items included in the MDS 3.0 Section F. Recently, the MDS Section F items have been incorporated into an Advancing Excellence Campaign Person Centered Care (PCC) quality improvement tool that allows providers to track whether or not a given resident’s preferences are being honored to his or her satisfaction. This PCC tool allows providers to see “at a glance” which resident preferences are not being met. Targeting these unmet preferences is one strategy for selecting a particular approach to address that individual’s distress in experiencing BPSD.
4) Involve the direct care worker in the interdisciplinary care planning team.

Interdisciplinary teams are the optimal venue for selecting a particular approach for a given resident. Too often these teams do not include the direct care worker. While logistical difficulties abound in facilitating participation by direct care workers, interdisciplinary teams ignore this critical team member to their peril. The direct care workers we talked with believed that the team was missing critical information by excluding them. They also believed that the care plan did not adequately reflect approaches that were useful to them in their daily care activities. Reflecting the centrality of including the direct care giver in the care planning team meetings, Advancing Excellence included this metric in their Person-Centered Care Quality indicator.\[10\]

5) There is a need for specific approaches to acute episodes of a given behavior.

In addition to knowing the individual preferences of each resident, direct care staff requested information on how to initially respond to acute episodes of behaviors such as hitting, spitting, or screaming. Specifically, they requested information on “what to say” and “how to react” in the moment. For this reason a section was added on individual behaviors that lists approaches for initial responses that help de-escalate the behavior (see Specific Behaviors in the Toolkit). Staff also indicated that the best method for staff education is live demonstration or videos that depict successful approaches vs. unsuccessful approaches. They did not feel that written information or the internet were viable options for continuing education. The Education and Leadership section of the Toolkit highlights in red those educational programs that include demonstrations and videos on how to respond to acute episodes of behavior.

Review of the Evidence for Non-pharmacologic Approaches

Several different types of non-pharmacologic approaches are reflective of theoretical frameworks about the predisposing/precipitating factors and meaning of behaviors. Among these are: sensory stimulation, environmental modification, behavioral therapy, cognitive/emotion-oriented approaches, social contact (real or simulated), caregiver training/development (see Education and Leadership Development section of the Toolkit), structured activities, clinically-oriented approaches, individualized/person-centered care, and clinical decision support approaches. Findings from systematic reviews that have evaluated the evidence for these approaches are inconsistent, due in part to reviews having different criteria for inclusion of studies. A summary of the evidence for specific non-pharmacological approaches is presented in Table 1. In addition to systematic reviews, articles related to clinical-decision support were retrieved separately. Across systematic reviews the following points were highlighted:

- All systematic reviews underscored the need for more rigorous evidence and recognized several methodological limitations of the existing evidence-base, including the small sample sizes, variability in definitions and measurement scales, and limited measurement of different components of the approaches such as social contact.\[11-13\]
- The effects of most NPA for BPSD are small to moderate and have only been demonstrated to last for short durations of time. However, these effects are comparable to or greater than pharmacological approaches.
- The type of approaches most consistently found to be effective were sensory stimulation approaches, including: aromatherapy, hand massage, thermal baths, and calming or preferred music.
- There are inconsistent results regarding the benefits of behavior management approaches, in which caregivers are trained to redirect problematic behavior and reward socially acceptable behavior.\[14,15\]
- Only one review evaluated the interventions using two criteria: efficacy and feasibility. The investigators concluded that approaches with the greatest efficacy, such as consultation from geriatric mental health clinicians, often lacked feasibility given limited resources in nursing homes.\[21\] Approaches with modest evidence of efficacy but low cost, such as music therapy and sensory stimulation, were deemed more feasible.
- Across studies, an individualized approach to implementation of NPA is recommended.\[14\] Additionally, approaches that were tailored to individual symptoms and/or client needs were consistently the most effective.\[12\] Individualized approaches should include assessment for possible needs being communicated via BPSD, including for relief of pain, fatigue, hunger, thirst, and boredom or overstimulation.\[14\]
- The most recent advance in individualized NPA is the development and testing of clinical decision-support approaches, which were not included in many of the systematic reviews (likely in part because some reviews targeted specific BPSD while clinical decision-support approaches are generally intended to assist providers in responding to a range of BPSD). The evidence-base for these approaches was reviewed separately and is outlined in Table 2.
Clinical Decision Support Approaches

Recently, approaches have been developed and tested that provide staff with clinical decision support algorithms to facilitate appropriate assessment and approach in response to BPSD in an individualized manner. Two approaches tested in randomized trials include the Serial Trial Intervention and Treatment Routes for Exploring Agitation (TREA). Both are briefly described here. Both can be supplemented by guidance provided in the Assessment document and the Specific Behaviors document. A third clinical decision tool is the Describe, Investigate, Create and Evaluate (DICE) model developed by Kales, Gitlin and Lyketsos.

**Serial Trial Intervention.** The Serial Trial Intervention is a 9-step decision support tool for long-term care staff to follow with the goals of improving comfort and reducing agitation in persons with advanced dementia (see also Assessment document). The care provider moves from step 1 to step 9 based on whether or not each approach results in decreased agitation:

1. A physical needs assessment and subsequent approaches as indicated.
2. An affective needs assessment and subsequent approaches as indicated.
3. A trial of non-pharmacologic comfort treatment(s) tailored to the individual.
5. Consultation with other disciplines
6. Schedule dosing of effective (non-pharmacologic and analgesic) treatments for continued use if one time treatment is effective.
7. Stop ineffective treatments (based on daily tracking forms)
8. Add adjunctive and preventative treatments.

**Treatment Routes for Exploring Agitation (TREA).** TREA is a systematic methodology for individualizing various non-pharmacologic approaches to decrease agitation in older persons with dementia. The premise of TREA is that agitation has different etiologies at different times and as such requires different treatment based on the individual’s needs, past identify/roles, preferences and abilities. TREA guides staff in identifying unmet needs underlying agitation through formal and informal data collection including: gathering information from staff and family caregivers and observations of the individual experiencing agitation focusing on behavior and environment. Using this information staff suggest personalized approaches based on systematic algorithms. TREA has demonstrated reductions in physical nonaggressive and verbal agitation as well as increases in pleasure and interest among persons with dementia (see also Assessment document)

**Describe, Investigate, Create and Evaluate (DICE).** DICE is a model that starts with a description of the behavior followed by an investigation of possible causes, the formulation of a tailored treatment plan using non-pharmacological approaches and ongoing evaluation of outcomes. Greater detail on all steps is provided in the publication.
References


