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## Special Article

# What Is Really Needed to Provide Effective, Person-Centered Care for Behavioral Expressions of Dementia? Guidance from The Alzheimer's Association Dementia Care Provider Roundtable



Sam Fazio PhD<sup>a,\*</sup>, Sheryl Zimmerman PhD<sup>b</sup>, Patrick J. Doyle PhD<sup>c</sup>, Emily Shubeck<sup>a</sup>, Molly Carpenter<sup>d</sup>, Pauline Coram<sup>e</sup>, Juliet Holt Klinger<sup>f</sup>, Letitia Jackson<sup>g</sup>, Douglas Pace<sup>a</sup>, Beth Kallmyer<sup>a</sup>, Joanne Pike DrPH<sup>a</sup>, and members of the Alzheimer's Association Dementia Care Provider Roundtable<sup>†</sup>

<sup>a</sup> Alzheimer's Association, Chicago, IL, USA

<sup>b</sup> University of North Carolina at Chapel Hill School of Social Work, NC, USA

<sup>c</sup> Brightview Senior Living Center, Baltimore, MD, USA

<sup>d</sup> Home Instead Senior Care, Omaha, NE, USA

<sup>e</sup> HCR ManorCare, Toledo, OH, USA

<sup>f</sup> Brookdale Senior Living, Brentwood, TN, USA

<sup>g</sup> Senior Star, Tulsa, OK, USA

## A B S T R A C T

## Keywords:

Person-centered care  
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In April, 2019, the Alzheimer's Association Dementia Care Provider Roundtable convened to discuss common challenges faced when implementing person-centered, non-pharmacological practices in long-term care and other settings that provide care and programs for persons living with dementia, and to develop relevant, specific guidance from the perspective of administrative leaders from 23 long-term and community-based care provider organizations (representing home, community-based, and residential care). Guidance related to 5 practice areas emerged from the facilitated discussion: having a foundational person-centered culture, conceptualizing behaviors as expressions and focusing on behavioral support, identifying antecedents and placing person-centeredness before protocols, modifying training to promote person-centered culture, and valuing implementation flexibility. In developing the practice guidance, a related list of priority areas for research and policy were also identified.

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Since the 1980s, there has been a gradual shift in dementia care away from the traditional biomedical model, with its prioritization of custodial, task-oriented processes and schedules, toward a person-centered approach emphasizing building and nurturing authentic relationships and providing opportunities for meaningful engagement and individualized care in the home or in community and residential settings that have a homelike environment.<sup>1,2</sup> But although making changes to physical environments is relatively straightforward, altering the extant culture of care within those walls can prove more

difficult. Nowhere is this more evident than in relation to one of the most challenging aspects of care provision for persons with dementia: addressing behaviors that indicate distress with the social or physical environment.

Historically referred to as behavioral and psychological symptoms of dementia (BPSD), and now conceptualized as behavioral expressions (reactions, dementia-related behaviors, or other terms), almost all persons with dementia eventually exhibit 1 or more forms.<sup>3</sup> Apathy, depression, anxiety, delusions, hallucinations, sexual or social disinhibition, sleep disturbance, aggression, agitation, and other similar behaviors fall under this clinical presentation.<sup>4</sup> These behaviors are now understood as reactions or responses to the physical and social environment rather than “symptoms of dementia,” as they arise from environmental demands, coping challenges, and expressions of need.<sup>5</sup> In addition to being some of the most challenging sequelae of Alzheimer's disease and related dementias, they also account for an

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\* Address correspondence to Sam Fazio, PhD, Alzheimer's Association, 225 N Michigan Ave, Floor 17, Chicago, IL 60601.

E-mail address: [sfazio@alz.org](mailto:sfazio@alz.org) (S. Fazio).

<sup>†</sup> The names and affiliations of the members of the Alzheimer's Association Dementia Care Provider Roundtable are listed in Table 1.

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estimated 30% of the cost of caring for individuals with dementia.<sup>6</sup> Left unaddressed, they are associated with more rapid progression of disease.<sup>7</sup> Effective prevention and response may, therefore, lower the overall costs of dementia care and improve quality of life.

Behavioral expressions are often regarded “purely as medication targets,” despite both a lack of evidence of the effectiveness of psychotropics for this purpose and at the same time evidence of medication-related serious side-effects and adverse events.<sup>8</sup> Psychotropic medications, and antipsychotics in particular, are associated with adverse events such as falls and fractures,<sup>9</sup> cardiovascular events,<sup>10,11</sup> mortality,<sup>12</sup> and poor risk-benefit ratios overall in this population.<sup>13–15</sup> They can even cause new behavioral expressions.<sup>16</sup> Although pain management can be an important part of successful treatment, and medications that address cognitive symptoms of dementia may be useful, to date, no medications have been approved for the direct treatment of behavioral expressions, thus, pharmacologic intervention for this purpose represents off-label prescribing.<sup>16–19</sup>

Fortunately, the use of these medications is avoidable. An anti-prescribing and education intervention in 23 nursing homes found a nearly 82% reduction in antipsychotic use over the 1-year follow-up with no increases in symptoms or other adverse outcomes.<sup>20</sup> Relatedly, the Centers for Medicare and Medicaid Services (CMS) issued a series of initiatives and established regulations to ensure that antipsychotic medications are considered only after thorough investigation of the causes of the behaviors, and only when the behaviors present a danger.<sup>19,21</sup> Although prescribing of antipsychotic medications in skilled care has decreased, prescriptions of other sedating psychotropics have increased,<sup>19</sup> a situation causing alarm as there is even less evidence of support for their efficacy and more support for potential risks.<sup>22</sup> Alternatives to medications are needed to improve the treatment and safety of individuals with dementia and to achieve the goals of person-centered care.<sup>1,2,5</sup>

Many expert groups recommend nonpharmacologic approaches as the preferred first-line intervention to reduce the distress that underlies behavioral expressions.<sup>16,17,23–25</sup> Also known as behavioral support approaches or well-being support approaches, examples include sensory stimulation practices (eg, aromatherapy, massage/touch therapy, bright light therapy, sensory garden, and acupressure), psychosocial practices (eg, music/dance therapy, pet therapy, validation therapy, and reminiscence therapy), structured care protocols (eg, mouth care and bathing), and environment-based interventions.<sup>5,26</sup> A recent literature review<sup>5</sup> found many can be implemented with “minimal to moderate investment,” but, because of their breadth and heterogeneity, empirical evidence of their effectiveness is limited.<sup>18,26</sup> The strongest support is found for home-based behavioral management approaches, caregiver/staff training to increase person-centered and communication-based skills, and music therapy to alleviate agitation and anxiety.<sup>26,27</sup>

Despite this, behavioral support approaches are not yet integrated into routine clinical and care practice.<sup>28,29</sup> There is emerging concern that they are not well understood by intended users, and that “person-centered” practices are not always as person-centered as intended. In response, the Alzheimer’s Association devoted their in-person inaugural, April 2019 meeting of the Dementia Care Provider Roundtable to the challenges underlying wider implementation of behavioral support and person-centered approaches.

## Methods

The Alzheimer’s Association Dementia Care Provider Roundtable is a group of 23 administrative leaders and expert providers representing long-term and community-based care settings. After a presentation that reviewed current research, practices, and emerging issues, the Roundtable members spent an afternoon identifying change areas and offering practical solutions to address the unmet needs of

individuals living with dementia through organizational and direct care practices that employ a person-centered approach. The material was summarized in narrative form, followed by a series of electronic communications among Roundtable members. The resulting material was discussed at the in-person September 2019 meeting, and consensus was achieved regarding the resulting practice guidance. Recommendations were also proposed related to research and policy. The literature was then reviewed and compiled in order to place the material in context, and all members approved the final product.

## Practice Guidance

Five practice areas of guidance arose: having a foundational person-centered culture, conceptualizing behaviors as expressions and focusing on behavioral support, identifying antecedents and placing person-centeredness above protocols, insuring training promotes person-centered culture, and valuing implementation flexibility.

### *Having a Foundational Person-Centered Culture*

Research and expert discussion on the implementation of behavioral support approaches often refer to the difficulties of maintaining fidelity and sustainability over time. An approach may be offered in a consistent and effective manner initially, yet fade or be dropped after the training period has ended. Heavy workloads, provider turnover, broken equipment, lack of buy-in from key stakeholders, or a failure to promote and maintain regular use of a new practice are common reasons for the abandonment or gradual discontinuation of a practice. Although these challenges are very real, the core issue may be that there is not a consistent person-centered culture within the organization.<sup>27</sup>

Person-centered practice should not be an “add on” that new long-term and community-based care providers “buy into.” The culture permeates every activity within the organization, from language to mentoring to resource allocation, and envelops every staff member from their initial interview to their final day at the job. It is critical, therefore, that the foundation of person-centered care begins with leadership. The care recipient and family members are enveloped also, as equal partners. They especially contribute to person-centered assessment, including systemic methods for capturing and sharing life history to identify and support unique elements of personhood. Interdisciplinary team processes must be in place to support the ongoing use of observation, clinical assessment, and person-centered information to develop creative and individualized plans that proactively address care recipient needs.<sup>30</sup> The members of an organization actively employing a person-centered philosophy will apply their knowledge about the individual to every interaction, evaluating the environment and anticipating care needs to the greatest extent possible.

A telling example that a person-centered culture may not yet be foundational within an organization is the practice of referring to “the new admission” or “the new client.” Common phrases, they signify lack of person-centeredness because they reduce a person to a series of tasks to be completed. Some have suggested that a new language may be needed to truly change the culture, such as “Shahbazim” to refer to direct care workers and, as per the Green House model of nursing home care, “elders” instead of “residents.”<sup>31</sup> Regardless of the specific changes indicated, the crux of person-centered care is that it be standard care.

### *Conceptualizing Behaviors as Expressions and Focusing on Behavioral Support*

Persons living with dementia commonly experience communication difficulties that interfere with expressing feelings, frustrations, or

symptoms.<sup>16</sup> Comorbidities, such as visual impairment or illness-related frailty or weakness, can lead to further limitations.<sup>16,32</sup> Harried care providers can contribute to poor communications. Thus, although the common “disruptive” or “unpleasant” behaviors and responses are often positioned as clinical symptoms of a disease, they are better understood as coping and/or communication strategies (eg, expressions) of a person whose ability to think, remember, communicate, and control their body has changed and may be lost.

Framed as expressions, the behaviors are clues to the internal state of a person who is no longer able to communicate an issue through other means. In person-centered culture, the goal of the care partner is to ask, “What is this person expressing, what is causing this reaction, and how can we respond to reduce their distress?” rather than, “How do we manage this behavior?” Anticipating the aspects of a situation that may lead to distress for a given individual may prevent their occurrence in the first place (see third practice guidance, below) but, once an expression is occurring, discerning its cause and meaning is the first step to selecting an intervention to reduce its future need or intensity<sup>8,17,30</sup>—not because the expression causes distress, but because the expression is a sign that the person exhibiting the behavior is already in distress.

Replacing the disease-focused perspective of clinical symptoms with a person-centered one also leads naturally to a more person-centered understanding of treatments.<sup>33</sup> Nonmedical approaches, such as touch or joining the person in their reality, can be more than just “nonpharmacologic.” Implemented correctly, they are active, individualized attempts at supporting a person’s changing ability to communicate a need—also known as behavioral support approaches. Indeed, the concept of behavioral (or well-being) support can be extended to all interactions with a person living with dementia. A recent randomized controlled trial in 11 nursing homes found that an intervention to simply increase person-centered communication led to a nearly 23% decrease of antipsychotic prescribing over 6 months of follow-up.<sup>34</sup>

#### *Identifying Antecedents and Placing Person-Centeredness before Protocols*

Behavioral support can too often become restricted through the “process-oriented” lens of daily care routines, but understanding the concepts of person-centered care must come first in order to recognize how routines may be causing a behavioral expression to occur in the first place. For example, forcing a life-long “night owl” to get up early for the staff’s convenience or the family’s wishes might encourage an otherwise avoidable behavioral expression. Without considerations for individual uniqueness (eg, personal values, beliefs, interests, and physical and cognitive limitations), the likelihood of the behavioral support approach being offered in an effective manner is compromised. For 1 person with dementia, agitation may be secondary to pain, although for another, it may be associated with fear, confusion, or inadequate sleep.<sup>16</sup> Observational skills training should extend to facets of the environment that may be triggering or exacerbating a behavioral expression,<sup>5</sup> such as increased activity, sound, or other modifiable factors. Environmental triggers are central to *Bathing without a Battle*, a person-centered practice that sensitizes caregivers to the sometimes impersonal bathing environment and how it can be modified.<sup>35</sup>

A true person-centered approach may reduce or prevent the need for an intervention in the first place. Teaching care providers, family, and friends about common unmet needs and how to identify changes in cognition or mood can help them recognize signs of unmet need prior to escalation.<sup>36</sup> Identifying components of the physical or social environment that elicit behavioral expressions, such as increased activity or sounds—the antecedents for behavioral expressions—is necessary for proactively minimizing them. Early information about

the context in which a behavior occurs, as well as whether a disturbance represents a continuation or worsening of a previously observed behavior, can usually be discerned by those who spend the most time with the person with dementia.<sup>16</sup> In this manner, nonclinical providers and family members can be critical in terms of bringing a new issue to the attention of others, or noting when a current approach becomes less effective or is even inappropriate. Although some supervisors or administrators may balk at time being spent on preventing behaviors rather than addressing activities of daily living, prevention offers overall time, health, and cost savings.<sup>6,7</sup>

#### *Insuring Training Promotes a Person-Centered Culture*

The methods by which long-term and community-based care providers are trained in applying a specific person-centered approach to address dementia-related expressions can themselves reinforce the person-centered values of an organization. Curriculum can be designed such that learners experience the related activities from the perspective of the person living with dementia, an important practical and philosophical component of person-centered care.<sup>1</sup> For example, when staff receive in-service training in providing person-centered mouth care using *Mouth Care Without a Battle*,<sup>37</sup> they are asked to brush each other’s teeth using the recommended approaches. Typically, at least 1 trainee balks at brushing the teeth of a colleague, or at having their own teeth brushed, which in and of itself sensitizes them to the personal nature of tooth-brushing. Similarly, the Namaste Care program training takes place within the prepared sensory space, and trainees are recipients of the multisensory, spa-like experience as they learn its purpose and techniques. Encouraging long-term and community-based care providers to think about which persons within their care might benefit from an activity as they are receiving training is another way training and its outcomes can be more person-centered. In a recent implementation of Namaste Care, staff were empowered when the persons they had recommended for participation responded positively to the intervention. Informal tracking found a reduction in the number of urinary tract infections, a reduction in the use of some medications, and improved nourishment, communication, and skin integrity over 6 months.

#### *Valuing Implementation Flexibility*

As stressed above, a rigid, one-size-fits-all implementation cannot be considered person-centered and may interfere with the sustainability of a new practice. Translating a one-size-fits-all program into person-centered culture might begin with conducting a full review of each person’s favorite soothers and stressors, as gleaned from the person with dementia and their caregivers. Making sure that the person with late stage dementia is completely surrounded by the things that they love the most—a favorite pillow, blanket, aroma, or music—can make the difference in the success of the effort. Each care recipient’s sensory and other physical capabilities must also be considered. A systematic review of 64 clinical trials of behavioral support interventions in nursing homes found that 28 did not consider the capabilities of the person with dementia.<sup>38</sup> A care recipient’s preferences and capabilities should be made available to all associates providing the program, preferably in a manner that is easy to use and refine as providers become versed in how to best support each care recipient.

Flexibility extends beyond the initial “fit” with a care recipient’s needs, however. The chronic neurodegenerative nature of dementia means that person-centered care must be responsive to continually changing needs and abilities.<sup>16</sup> More research is needed in understanding how the preferences and needs of persons with dementia change over time.<sup>39</sup> Flexibility may also be needed to respond to the needs or limitations of the family, staff, or organization. For example,

in some settings, implementation of behavioral support approaches may prove successful when there are staff “champions,” whereas in others, such arrangements can cause staff to feel that “someone else will do it.” Similarly, some family members may be more able and amenable to participating in such efforts than others.

Although flexibility is desirable, one must find the balance between tailoring of care plans and modifications so extensive that the protocol can no longer be considered evidence-based. Modifications of evidence-based practices should therefore only be undertaken to ensure practices are truly person-centered and a good fit for the organization's operational system. Modified approaches should also be monitored to assure they are having the intended effect.

### Implications for Practice, Policy, and Research

Throughout the Roundtable discussions, numerous areas for additional research and change in policy were identified.

#### *Research is needed that will:*

- Develop and evaluate detailed, evidence-based protocols for the implementation of behavioral support approaches designed to prevent or address behavioral expressions, including their training practices.<sup>29</sup>
- Examine the effects of modifying components in the administration of supportive approaches (eg, variations in the length of exposure to light therapy or aromatherapy, or the repetition of therapeutic activities) if modifications are necessary for feasible and sustainable implementation.
- Develop and promulgate the use of consistently defined terms, concepts, measurement domains, and measures (common data measurement structures) in order to improve the interpretation, data sharing, and replicability of studies within the field of person-centered care.<sup>40</sup>
- Validate systematic algorithmic approaches to addressing behavioral expressions so as to establish sequential and iterative steps for integrating pharmacological and behavioral support approaches in a person-centered manner, which may lead to their greater use.<sup>6</sup> An example of such an approach is the DICE model which, in addition to integrating pharmacological and behavioral support approaches, empowers and engages providers and others as key partners in “problem solving, brainstorming, identifying triggers, and implementing person-centered care strategies.”<sup>22</sup>
- Incorporate more person-centered outcomes, such as pain, cognitive function, and activities of daily living, in clinical medication trials.<sup>41,42</sup>
- Develop better tools for comparing pharmacologic interventions with behavioral support approaches.

#### *Policy changes are needed that will:*

- Lead to a reorganization of the way dementia care providers and organizations are incentivized, in order to provide adequate compensation for the time and expertise required to understand, identify, and address behavioral expressions.<sup>22</sup>
- Require regular/continuous input from the field, such as through advisory panels, care recipient stakeholder groups, and expert roundtables. This will require funding for behavioral consultation and intervention, and access to the research evidence base.
- Encourage greater understanding of person-centered practice in dementia care, including from informal caregivers (family members), formal caregivers, (physicians, nurses, non-medical

**Table 1**

Alzheimer's Association Dementia Care Provider Roundtable Members

Providers	Contributors
AccentCare	Dave I. Davis RN-BC, ACRN Randall Billingsley
Acts Retirement-Life Communities	Kelly O'Shea Carney PhD, ABPP, CMC
Affinity Living Group	Julie Cook-Walker MLS, CADDCT, CMDCP, NCALA
Artis Senior Living	Mary Underwood CDP, CADDCT
Bayada Home Health Care	Kristin Kingery MSW LSW Joseph Zazworsky
Brandywine Living	Maria Nadelstump MA, CDAL Carole Proce RN, C-AL, MS
Brightview Senior Living	Patrick J. Doyle PhD
Brookdale Senior Living	Juliet Holt Klinger MA
Care One	Joan Di Paola RN
Five Star Senior Living	Laura Warnecke RN
Genesis HealthCare	Felicia Chew MS, OTR/L, FAOTA Garry Pezzano EMBA, MS/CCC-SLP, FNAP
HCR ManorCare: Arden Courts	Pauline Coram
Memory Care Communities	Terri Lalonde CTRS
Home Instead Senior Care	Lakelyn Hogan MA, MBA Molly Carpenter MA, MA Stacy Scott Terrell LNHA, MBA, MDiv
Kendall	Antonio Galvan Jr
Life Care Services	Mattia J. Gilmartin PhD, RN, FAAN
Nurses Improving Care for Healthsystem Elders (NICHE)	Jennifer Pettis MS, RN, CNE, WCC
NYU Rory Meyers College of Nursing	
Presbyterian Homes & Services	Jess Drecktrah MHA, MN, RN Nancy Schwartz CTRS
Right at Home	Debbie Friedman
Seniorlink	Katherine Tardiff MSN, RN, GNP-BC William McIvor
Senior Star	Letitia Jackson
Silverado	Kim Butrum
Sunrise Senior Living	Rita Altman MSN, RN, CVT Lisa M. Gill DNP, CRNP
Van Dyk Healthcare	Suzanne Gramuglia CALA, CDP

staff members, and administrators) and entities involved in the licensing, monitoring, and regulation of care settings.

It is hoped that the 5 areas of guidance promoted in this article—having a foundational person-centered culture, conceptualizing behaviors as expressions and focusing on behavioral support, identifying antecedents and placing person-centeredness above protocols, insuring training promotes person-centered culture, and valuing implementation flexibility, along with progress in research and policy, will ultimately lead to real provision of effective, person-centered care for behavioral expressions of dementia, regardless of the setting in which care is provided.

For a full glossary of terms please see [Supplementary Material Glossary of Terms](#).

### Acknowledgments

The Alzheimer's Association acknowledges the provide member organizations of the Dementia Care Provider Roundtable.

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**Supplementary Material. Glossary of Terms**

**Behavioral Expression:** Any action, vocalization, or response from the individual living with dementia to internal or external stimulation. These expressions signal stress, coping, and/or the existence of an unmet need or desire.

**Behavioral Support Approaches (Well-Being Approaches):** Nonpharmacologic care approaches that aim to reduce the frequency and severity of behavioral expressions of individuals living

with dementia, such as sensory stimulation or psychosocial practices.

**Foundational Person-Centered Culture:** Core principles and practices embedded within an organization that recognize and support the identity and unique needs of individuals living with dementia.

**Antecedents for Behavioral Expressions:** Components of the physical or social environment that elicit behavioral expressions, such as increased activity or sounds. These components should be identified and modified.