Study Protocol

Official Title: Optimizing Care for Patients with Dementia: A Comparison of Two Non-Pharmacological Treatment Approaches

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Scientific Background

More than half of the 1.4 million long-term care nursing home (NH) residents have a diagnosis of Alzheimer's Disease and Related Dementias (ADRD), which we will refer to as dementia throughout this report. [1] Residents living with dementia experience devastating negative effects associated with these progressive, irreversible conditions that result in loss of independence and subsequent long-term institutionalization. As the disease progresses, disruptions in the resident's daily routine, difficulty communicating personal needs, and environmental overstimulation or sensory deprivation often trigger the behavioral and psychological symptoms of dementia (e.g., agitation). [2-4] If untreated, these symptoms result in negative side effects such as self-inflicted pain, limited food/liquid intake, accidental falls, and injuries to self or others (e.g., residents, NH staff), increasing the risk of hospitalization and death. [4]

In the early 2010s, more than 30% of NH residents were taking antipsychotic medication. [5] To reduce this antipsychotic medication use in NH residents, the Centers for Medicare & Medicaid Services (CMS) championed a national initiative to enhance NH dementia care, starting in 2012. This comprehensive program, which had a goal of reducing national NH resident antipsychotic medication use, included NH staff and state surveyor training, established minimum standards for dementia care, and introduced a new quality measure (i.e., the percent of long-stay residents who received an antipsychotic medication) that all CMS certified NHs were mandated to report. [6]

Off-label antipsychotic medications, while commonly used to address the behavioral and psychological symptoms of dementia, have been shown to be ineffective and cause harm to the person living with dementia, [7] including an elevated risk of death. [8] By 2019, approximately 23% of NH residents living with dementia were administered off-label antipsychotics. [5,9] However, these off-label medications have significant negative impacts on the resident's mortality and quality of life, primarily due to inducing withdrawal and lethargy. [10-12]

Given these poor outcomes, families, ADRD and resident advocates, and recent national initiatives have prioritized the reduction of antipsychotic medication use and shifted attention to increased use of non-pharmacological interventions in the NH context. [6,13-15] In particular, CMS has recommended NHs reduce antipsychotic medication use to improve the quality of dementia care. [6] Further, based on our preliminary data, family members and NH providers strongly support the use of non-pharmacological approaches for dementia care.

Common features of such approaches include training staff to understand the disease process of dementia and equip them with strategies to address triggers for negative resident behaviors, such as disruptions in routine or communication difficulties. [15] Given the multi-faceted nature of triggers, evidence suggests that non-pharmacological treatments must incorporate a wide range of NH staff, such as professional healthcare providers and direct care providers. [13,16] First, professional healthcare providers (e.g., include registered nurses, licensed practical nurses, social services, and rehabilitation practitioners/therapists) collaborate to develop a comprehensive, multi-dimensional plan of care to address factors that precipitate

behavioral and psychological symptoms of dementia (e.g., triggers). Second, NH direct care providers (e.g., certified nursing assistants [CNAs], dietary staff, social services, activities department staff), ancillary support staff (e.g., housekeeping), as well as family, are trained by the professional healthcare providers with strategies to support the customized plan of care. [4,17] Collaboration across these individuals ensures maximum support to minimize episodes of extreme behavioral and psychological symptoms of dementia, thereby promoting optimal function, enhancing quality of life for the resident, and improving safety of all individuals.

Two leading approaches (*team- and problem-based*) to dementia care, prioritized by our community-partners, help staff implement non-pharmacological, resident-centered dementia care. Both approaches have randomized control trial (RCT)-level evidence to support efficacy and integration into clinical practice. [4,11,18-23] The NHs using the *team-based (TB) approach to integrated dementia care* provide core training to all professional healthcare providers, direct care providers, ancillary support staff, and administrators, using a common language across disciplines to support continuity and sustainability. Results of randomized trials have indicated that the collaborative TB approach decreases the use of medications as well as the frequency and severity of resident agitation, pacing, and repetitive vocalization, compared to the minimum mandated usual care. [19,24-26] In contrast, the multidisciplinary approach for *problem-based (PB) dementia care* draws on the expertise of the individual professional healthcare providers (e.g., speech language pathology, occupational therapy, nursing) to target issues that arise. For example, when residents have a change in status (e.g., weight loss, accidental fall event, change in self-care or mobility, emergence of behaviors during morning care routine), the nurses request a screen to be conducted by the relevant healthcare providers to determine the need for a resident evaluation by the respective discipline(s), revision to care plan, and treatment to address the emergent issue (i.e., change in status). These providers then train all other staff and family in resident-specific strategies and adjust the care plan as needed. In randomized trials, the PB approach has been found to decrease the frequency and severity of challenging behaviors (including aggression and calling out), as well as reduce the use of antipsychotic medications, when compared to usual care. [25,27]

Despite evidence supporting TB and PB approaches to dementia care, clear gaps in evidence limiting implementation exist. Guided by our community-partners, our team identified the following gaps in evidence and variability in practice patterns that require urgent attention:

First, although efficacy studies support both approaches, [4,11,18-23] the underlying studies have only compared the two approaches to individual, discipline-specific interventions or usual care. [19,24,25,27] These two interventions have not been compared to each other; thus, it is not clear which approach is most effective given the varied resident and NH contexts across the US.

Second, prior studies have been limited by small samples of residents living with dementia (Ns=4 to 250) and use of researchers as opposed to NH personnel for intervention delivery.[17-19] Although supportive of feasibility and general efficacy, previous studies have not provided professional healthcare providers, other NH staff, or NH administrators with the evidence to support widespread implementation, due to the above-noted problems.

Third, there is currently no standardized way in which professional healthcare providers and other NH staff communicate their efforts to ensure that residents living with dementia receive appropriate daily care. Although all NHs provide specialized services (e.g., occupational therapy, recreation therapy, nursing), few NHs support the coordination of care in a predetermined manner, resulting in NH staff often receiving training or information to support their interactions with a resident only after an incident of extreme behavioral and psychological symptoms of dementia occurs.

Although these care approaches are currently used in care delivery, there is significant variability in practical implementation. This variability is primarily due to wide differences in education and dementia-specific training across the numerous NH staff involved in dementia care. Efforts to minimize behavioral and psychological symptoms of dementia through non-pharmacological approaches must better account for the diverse education and training needs of the collective NH staff who all contribute to the care for residents on a day-to-day basis.

The COVID-19 pandemic altered NH care delivery and further exacerbated existing factors that contribute to aggression, agitation, and behavioral and psychological symptoms of dementia among residents. The pandemic policies put in place to minimize viral spread further perpetuated the challenges associated with caring for this vulnerable population. [28-30] This new "normal" created a tension between life safety and an individual's quality of life. For example, NHs had to restrict family visitation per CMS guidance, eliminate all resident group activities and congregate meals, and constrain resident access to limited areas of the NH campus to mitigate spread. [31,32] These examples reflect disruptions in the resident's routine and changes in the environment, all of which contributed to potential exacerbation of behavioral and psychological symptoms associated with dementia. As a result, these COVID-19 policies fostered social isolation and environmental under-stimulation among residents, [32] increasing the likelihood of a resident living with dementia experiencing behavioral and psychological symptoms and expanding the risk of adverse events (e.g., functional decline). These infection control policies had a cascade of negative effects on mood, cognitive status, physical function, and quality of life among NH residents and staff; and were emotionally traumatic for families and others who could not visit their family member living with dementia in person. [32-38] Yet, there is a need to evaluate the best approaches to provide dementia care, given heightened infection control policies.

Despite national initiatives (pre-COVID-19) to reduce off-label medication for these residents, [4,6,11,18-23,39] there is growing concern that the use of off-label antipsychotics may yet again be on the rise to manage behavioral and psychological symptoms of dementia. Strategies that are used in NHs as part of a non-pharmacological comprehensive, multi-dimensional plan (e.g., group activities, consistent routine) may be hindered due to COVID-19-related infection control policies and staffing shortages. Thus, given the multiple challenges NHs face in trying to care for residents, manage behavioral and psychological symptoms among residents living with dementia, and control the spread of COVID-19, NHs may rely more heavily on pharmacological strategies.

Study Objectives

The initial study protocol was designed and initiated prior to the emergence of the COVID-19 pandemic. However, with the emergence of the COVID-19 pandemic, our study was modified to also include looking at the impact of the pandemic. Thus, two questions were addressed by this study: (a) is there a statistically significant difference in resident outcomes among NH residents living with dementia based on the non-pharmacological approach to dementia care? And (b) How did these non-pharmacological approaches compare after the emergence of COVID-19 when residents and staff faced social isolation, infection control policies, and staffing shortages? These questions were addressed via three aims:

Aim 1: Compare the effectiveness of two non-pharmacological approaches for dementia care (*TB and PB) in* reducing the use of antipsychotic medications and behavioral and psychological symptoms in NH residents living with dementia.

Aim 2: Determine the effectiveness of the two non-pharmacological approaches on NH residents living with dementia and staff safety and wellness.

Aim 3: Identify benefits, limitations, barriers, and facilitators of each approach from the perspectives of the NH staff and NH residents' families. This qualitative data will augment the resident-level quantitative data by more fully capturing the impact of the two approaches on resident outcomes; resident-staff, staff-family, and resident-family interactions; and staff job roles before and after the emergence of COVID-19, which will guide future implementation.

Study Design & Methods

The study was initiated in January 2018. As of March 2020, 80 NHs had been recruited, randomized and staff training delivered. The COVID-19 pandemic emerged in early March 2020. Subsequent national lockdown of NHs and leadership requests to not communicate with the NHs as they navigate the early days of the pandemic resulted in a pause on all research related communication between the study team and study sites.

As the pandemic evolved, the study team developed a plan for moving forward, which included assessing the ability for NHs to re-engage in the study. Due to the negative impact of the pandemic, 27 of the 80 NHs were unable to re-engage. The remaining 53 NHs were included in the revised study protocol. This change resulted in the original cluster randomized control trial becoming two sets of exploratory analyses differentiated by the emergence of the COVID-19 pandemic.

Exploratory quantitative analyses were conducted for 53 NHs (TB n=17, PB n=36 NHs). Primary resident-level outcomes included antipsychotic medication use, behavioral symptoms, wandering, and rejection of care, which were extracted from the Minimum Data Set and

electronic medical records. Six-month outcomes were captured prior to the emergence of COVID-19, while 12- and 18-month outcomes were after the start of the pandemic.

As a result of the COVID-19 pandemic and the significant impact it had on the study, the team bolstered the scope of the qualitative interviews from those that were originally planned. Qualitative data was collected via individual interviews with 327 NH staff (TB n=168, PB n=159) and 30 family caregivers (TB n= 13, PB n= 17) to explore their perspective of the two approaches as it relates to resident outcomes and training. Using mixed methods, quantitative and qualitative data were integrated to determine whether these sources confirm each other, provide emergent, or conflicting information.

Eligibility Criteria

Facility-level inclusion criteria required eligible NHs to (a) not have an existing dementia program targeting reduction of off-label antipsychotic medication use, (b) serve an average of >60 long-term care residents living with dementia, (c) be a CMS certified NH (e.g., conduct regularly scheduled resident assessments), and (d) comply with CMS's annual staff dementia care training requirement (i.e., 4 hours). Exclusion criteria included (a) NHs located in states that require more than four hours of dementia-specific training annually were excluded, (b) NHs that had existing dementia care programs which required staff to engage in additional training beyond the CMS minimum training requirements and more than the four hours required by the state.

Eligible NH residents included those that (a) have an existing diagnosis of ADRD or a Cognitive Function Scale score indicating Mild, Moderate, or Severe Cognitive Impairment, (b) are 65 years of age or older, and (c) are long-stay residents (>100 days). Post-acute care patients admitted for a brief stay (<100 days) and respite stay patients were excluded.

Eligible staff were employed by a participating NH and included all staff categories, (a) professional healthcare providers, including licensed staff with professional degrees, such as registered nurses, licensed practical nurses, rehabilitation practitioners (e.g., occupational [OT], physical [PT], speech therapists [SLP]), certified therapeutic recreation specialist, dieticians, (b) direct care providers such as certified nursing assistants [CNA], activities department staff, nutrition services personnel (e.g., dining services/aids); (c) ancillary support staff, including environmental services workers (e.g., maintenance, housekeeping, kitchen staff) and administrative staff (e.g., reception, billing department, medical records); and (d) administrators, including executive directors, directors of nursing.

Eligible family caregivers were the primary contact for a resident living with dementia in a participating NH (e.g., relative, spouse, partner, friend, per neighbor).

Statistical Considerations

Descriptive analyses included calculating appropriate central tendencies (e.g., mean) for each outcome variable. We examined outcomes separately before and after the emergence of COVID-19. To assess validity of randomization, we compared resident characteristics and outcomes and NH characteristics by arm for the six-month baseline period prior to training (December 16, 2018 to June 15, 2019).

We used the intention-to-treat analytic approach to conduct the exploratory quantitative analysis. A difference-in-differences analytic model was used, rather than comparing outcomes across the arms during each six-month period after the training, to account for baseline differences in resident characteristics and outcomes. The estimating equation is as follows:

$$Outcome_{ijt} = \beta_o + post_t\beta_1 + (post_t x TB_i)\beta_2 + X_{ij}\delta + NH_i + u_{ijt}$$

where $Outcome_{ijt}$ is a binary variable of having the outcome measure of interest for resident *j* residing in NH *i* at time *t*. *Post* is an indicator for being in the follow-up period after implementation of approaches, which would be 1 for t=1 and 0 for t=0. *TB* is an indicator for NH *i,* which would be 1 if assigned to team-based approach arm and 0 if assigned to problem-based approach arm. The comparative effectiveness (treatment effect) of the team-based approach relative to the problem-based approach would be estimated with B_2, which is the coefficient estimate of $post_t$ *x* TB_i representing residents in team-based approach NHs during the respective follow-up period while accounting secular time trends ($post_t$) and time invariant characteristics of NH using nursing home fixed effects (NH_i). In addition, the model accounts for a set of individual resident characteristics including age, sex, race/ethnicity, Cognitive Function Scale, number of valid assessments resident had for outcome during period (X_{ij}). Models were analyzed using complete case analysis. Standard errors were clustered at the NH level. Linear probability models were implemented for ease of interpretation; regression coefficients and standard errors are presented in percentage point units. Robustness checks were conducted by implementing logistic regression difference-in-differences models with NH characteristics rather than NH-level fixed-effects to estimate the treatment effect. Marginal effects from the logistic models were computed to complement the linear probability regression models.[40] Finally, stratified analyses were conducted to examine whether treatment effects were different among residents with moderate to severe dementia vs. mild dementia. All analyses were conducted using Stata 14.0 (Stata, College Station, TX).

For resident-level primary and secondary outcomes, we conducted difference-in-differences analyses using baseline data and the first six months of post-implementation data (six-month outcomes; September 15, 2019 to March 14, 2020) to compare outcomes across the two study arms, prior to the emergence of the pandemic. Next, we conducted analyses of resident outcomes after the emergence of pandemic spanning post-implementation months (a) 7-12 (March 15, 2020-September 14, 2020) and (b) 13-18 (September 15, 2020-March 14, 2021) (12-month and 18-month outcomes analyses, respectively). Observations with missing resident covariates were excluded from the analyses.

For staff and resident secondary safety outcomes, we calculated the monthly rate (per 100 residents) of each outcome for each NH that submitted data each month. We averaged the

monthly measures available for each NH and then examined descriptive statistics (e.g., mean) to compare the outcomes across two arms during the first five months of implementation.

Qualitative Analysis

The objectives of the staff analyses were to explore (a) perceived barriers and facilitators surrounding the intervention approach, (b) perspectives on the training modules (e.g., adequacy, acceptability, satisfaction, burden), (c) the quality of resident-staff interactions (i.e., how staff training contributed to patient outcomes) and (d) training program recommendations for modifications (i.e., sustainability, scalability). We used a three-phase team-based rapid qualitative analysis approach. [41,42] In phase one, interview transcripts were reviewed and summarized by domains (based on interview questions) and categories (emerging inductively) into a coding template. Phase two required reviewers to reduce, synthesize, and look for similarities and differences in the data through the use of matrices. In phase three, summary tabulation procedures occurred in which reviewers combined data (e.g., NH cases, care approaches), developing themes. [42] We explored patterns and variations in themes within and across cases and care approaches. [43,44]

We identified themes, patterns, and relationships that emerged from family caregivers that contextualized quantitative and qualitative staff findings. [45] Given the paucity of knowledge regarding the experiences of family caregivers of NH residents living with dementia, we used qualitative analysis, specifically a grounded theory approach, to further analyze caregiver interviews. [46-48] We employed open, axial, and selective coding to understand the perceptions of family caregivers and create a data-driven conceptual model of family caregiver experiences. [41,42,43,44]

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