

# Palliative Care Through a Dementia Lens

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## Introduction

Seventy-five percent of those with dementia will spend time in a nursing home, most typically in the moderate and advanced stages. Alzheimer's is a progressive, terminal disease; the average time between diagnosis and death is 8 to 10 years, but it is extremely variable and can last up to 20 years or more; typically, about 40% of this time is spent in the advanced stages. Someone who reaches the age of 80 and does not have dementia has an approximately 5% chance of spending time in a nursing home, whereas someone who reaches the age of 80 and has dementia has an approximately 80% chance of spending time in a nursing home. (Arrighi, HM; Neumann, PJ; Lieberburg, IM; Townsend, RJ. "Lethality of Alzheimer's disease and its impact on nursing home placement." *Alzheimer Disease & Associated Disorders* 2010; 24(1):(90–95).

Sadly, while palliative care has much to offer people with advanced dementia, unless there are specific modifications in how palliation is offered to them, there is a strong possibility that it will be ineffective...and far too often, palliation isn't even considered as an option for people with dementia. As an individual's dementia advances, his/her actions, rather than words are most likely to communicate distress. Unfortunately, all too often these behavioral expressions are not understood as distress; rather they are often assumed to be the inevitable consequences of the dementia itself. Palliation cannot occur if the reason or triggers for distress are not known or understood. Anti-psychotic, anti-anxiety and sedative medications do not take away pain, nor do they comfort if someone living with dementia is hungry, cold, too warm, tired, lonely, or frightened by noises or activity in their environment.

Dementia-capable palliative care applies dementia-specific practices and tools to evaluate and to respond appropriately to people with advanced dementia, including (1) use of a behavior-based pain assessment tool; (2) use of regularly-scheduled rather than PRN orders for pain medications; (3) offering food in small portions, especially finger foods, round-the-clock (and elimination of supplement use); (4) essential flexibility for rising, eating, bedtime and other routines; (5) attention to the person with dementia's needs for a delicate balance of stimulation and rest throughout the day.

In 2012, the Alzheimer's Association, New York City Chapter undertook a special project with three NYC nursing homes to adapt the groundbreaking model developed by the Beatitudes Campus, Phoenix, Arizona (with their partner, Hospice of the Valley), which has invested considerable research and training into expanding knowledge and practice in the area of residentially-based care for people with advanced dementia. The nursing homes participating in this project are:

Cobble Hill Health Center, Inc.  
Isabella Geriatric Center  
The New Jewish Home, Manhattan

## Phase I

The first phase of the project, "Palliative Care for Advanced Dementia: Training and Implementation" (7/1/12 through 12/31/14) focused on pilot units in each of the facilities as they worked to begin implementation of the practices promoted by the Beatitudes. The goal during all of first phase was to identify the organizational adaptations that would be needed to sustain these practice improvements, and spread them throughout their facilities. The first year of this phase was extensively evaluated, and addressed resident outcomes, staff knowledge and attitudes, cost, pharmacologic usage patterns, and programmatic design.

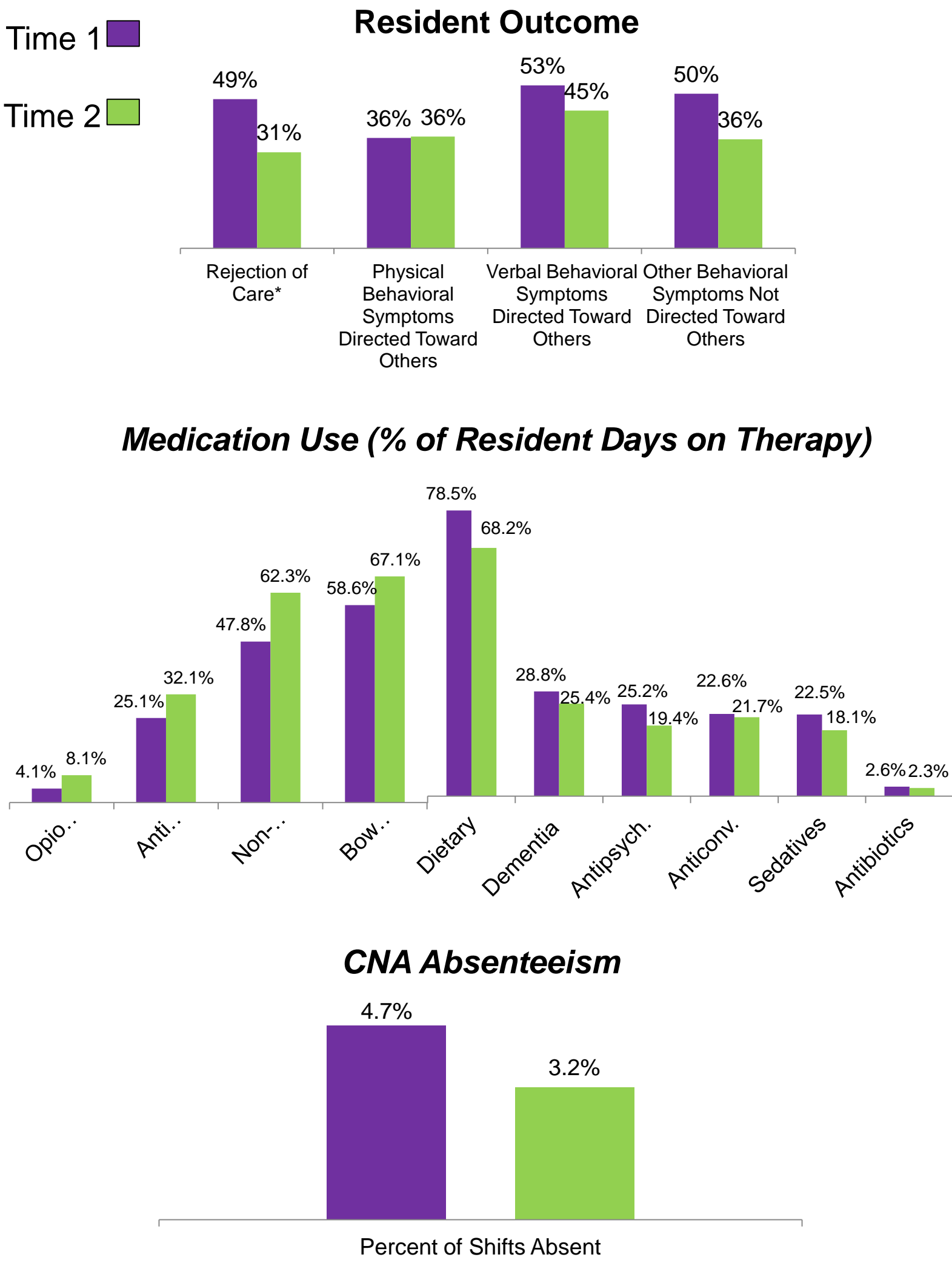
### Phase I: Procedures

1. Preparatory orientation and education
2. 12-month implementation:
  - Specific palliative care practices as chosen by the facilities varied by site and included attention to pain, weight loss, sleep-wake cycles, care planning, the physical environment, anticipation of need and meaningful engagement
  - Additional training as needed/requested
  - Weekly on-unit interdisciplinary meetings
  - Facilities encouraged to spread successful pilot unit interventions through their nursing home
3. Evaluation using pre- and post-project measure (first year only)

### Phase I: Measures

1. *Artifacts of Culture Change for Dementia Care: Focus on Advanced Dementia*©
  - 42 stand-alone items
2. *Questionnaire of Palliative Care for Advanced Dementia (qPAD)*©
  - 23 items related to knowledge of advanced dementia care (Knowledge Test).
  - 12 questions related to beliefs, perceptions, and attitudes related to palliative and end-of-life care (Attitude Scale).
3. *Minimum Data Set 3.0 (MDS)*, including...
  - Physical behavioral symptoms directed towards others
  - Verbal behavioral symptoms directed towards others
  - Other behavioral symptoms not directed towards others
  - Rejection of Care
4. *Medication Administration Records (MARs)*
5. *Service Cost and Utilization survey*
  - Developed for the project by LeadingAge Center for Applied Research

### Phase I: Select Results



## Phase II

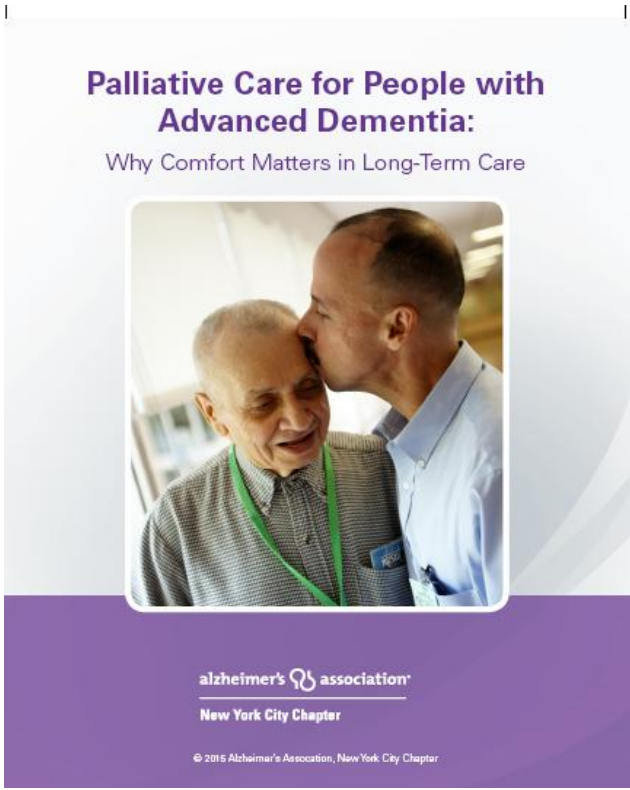
For the second phase of the project, "Advancing the Practice of Dementia Capable Palliative Care," (6/1/15 through 11/30/16) all three homes are continuing their efforts in dementia-capable palliation by working to achieve accreditation for their pilot units in *Comfort Matters*.™ *Comfort Matters*™ accreditation (developed by the Beatitudes) is granted to organizations that adopt *Comfort Matters*™ principles and demonstrates program fidelity, and assesses:

- Environmental factors which promote comfort for people with dementia
- Comfort practices
- Emergency department and hospitalization utilization
- Pain management
- Medication Management
- Dementia-related behavior such as rejection of care
- Weight trends and supplement use

## Findings To-Date

- Pilot units made significant progress: adoption of PAINAD; elimination of PRN orders for residents with dementia; flexible wake/sleep routines; liberalized diets; more meaningful engagement in activities, enhanced physical environments
- No evidence that the changes made were at an additional cost to the facilities
- The evaluation process helped highlight and reinforce the value of looking at dementia from a palliative perspective
- Weekly on-unit interdisciplinary meetings continue and are now considered essential for successful care planning

Implementation Guidelines



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