

# Community-Based Dementia Care: Integrating Medical & Caregiver Support

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## BACKGROUND

MemoryCare, a community-based, non-profit organization, has 19 years of experience delivering an outpatient medical and care management model for persons with Alzheimer's disease and other types of dementia. Absent a cure or effective disease modifying treatment, developing cost-effective models of care that address the needs of caregivers alongside the medical management of the disease has potential to maximize quality of care, address safety issues, and enhance the patient/caregiver experience.

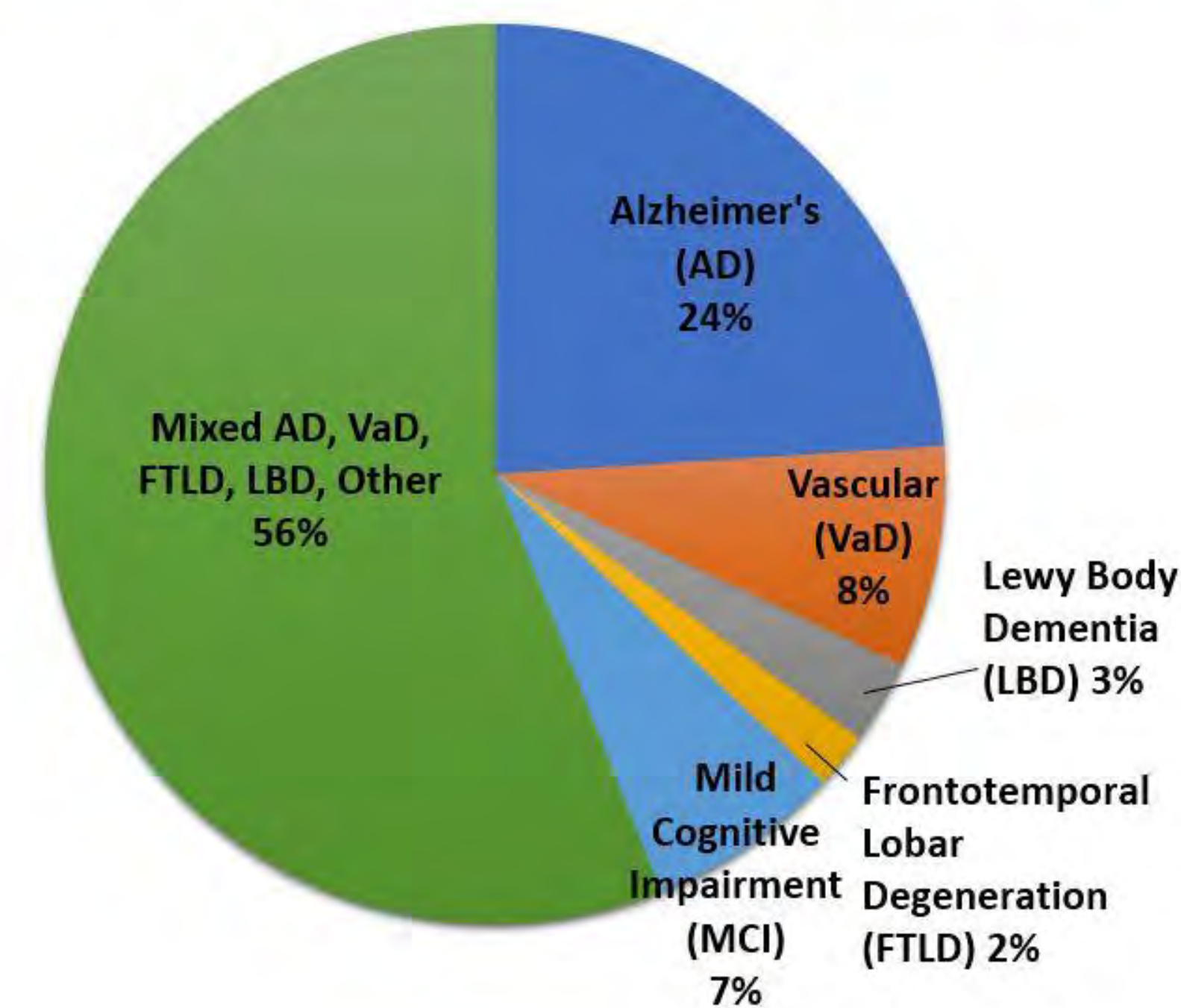
This study reports three years (2015-17) of the program's data on acute care utilization by patients as well as caregiver surveys on program impact and satisfaction.

## METHODS

Physician and care manager (nurse or social worker) teams incorporate caregiver education, training and support into the evaluation and medical management of the patient. After the initial evaluation, families and referring physicians receive a written care plan that is amended over time as the patient's dementia progresses. All components of the dementia care planning CPT code, 99483, are addressed within an annual cycle. Caregivers have full access to a resource library, workshops, and staff for educational materials and support. Families average four clinical visits and 14 phone or email contacts a year.

The program collects basic socio-demographic and clinical data on all patients and caregivers served and conducts an annual impact survey to primary caregivers. Hospitalization, readmission, and emergency department utilization rates are collected annually through the health system database for the subset of patients residing in the primary service county who have been enrolled a minimum of one year.

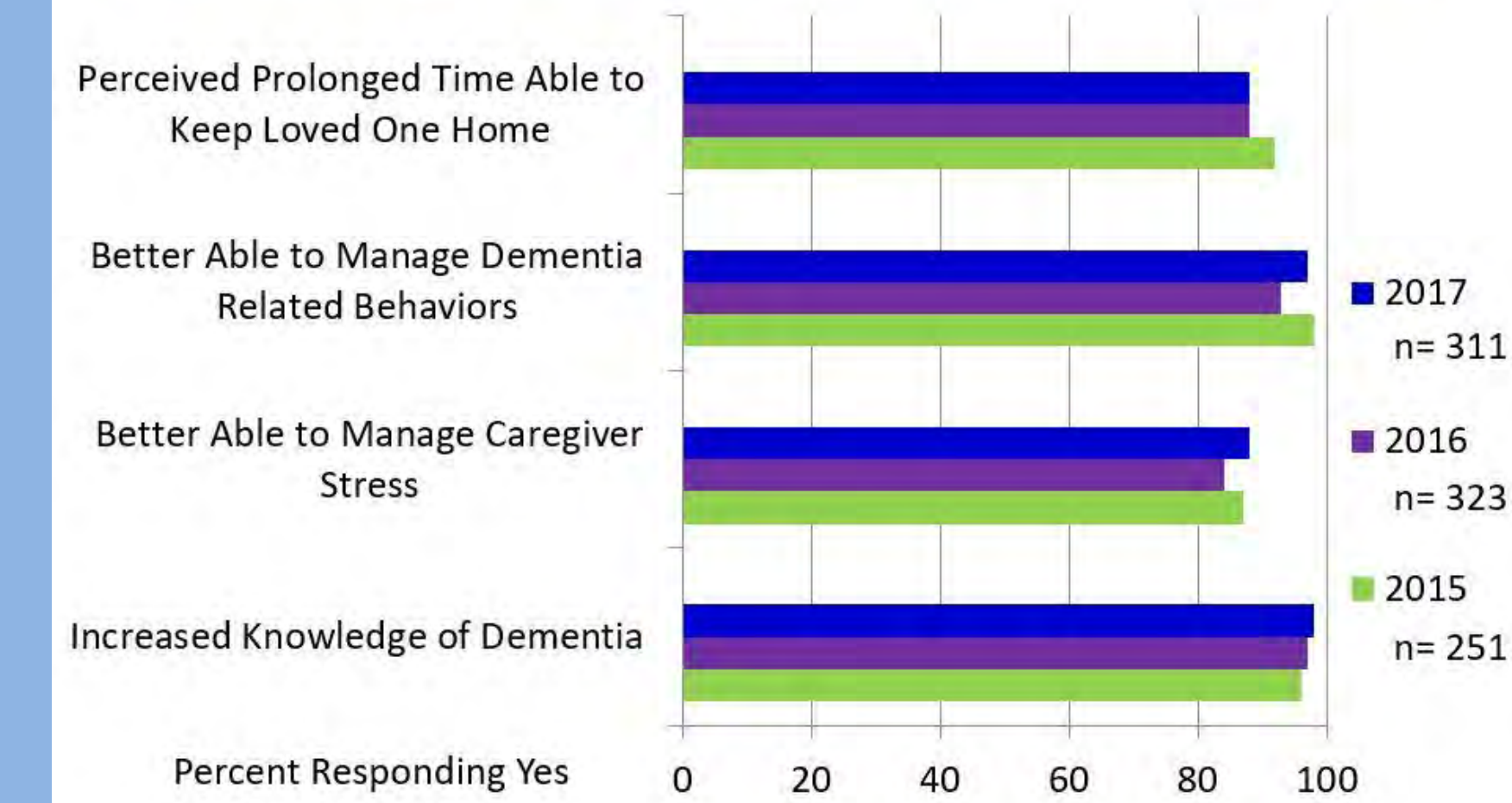
## Primary Clinical Diagnosis



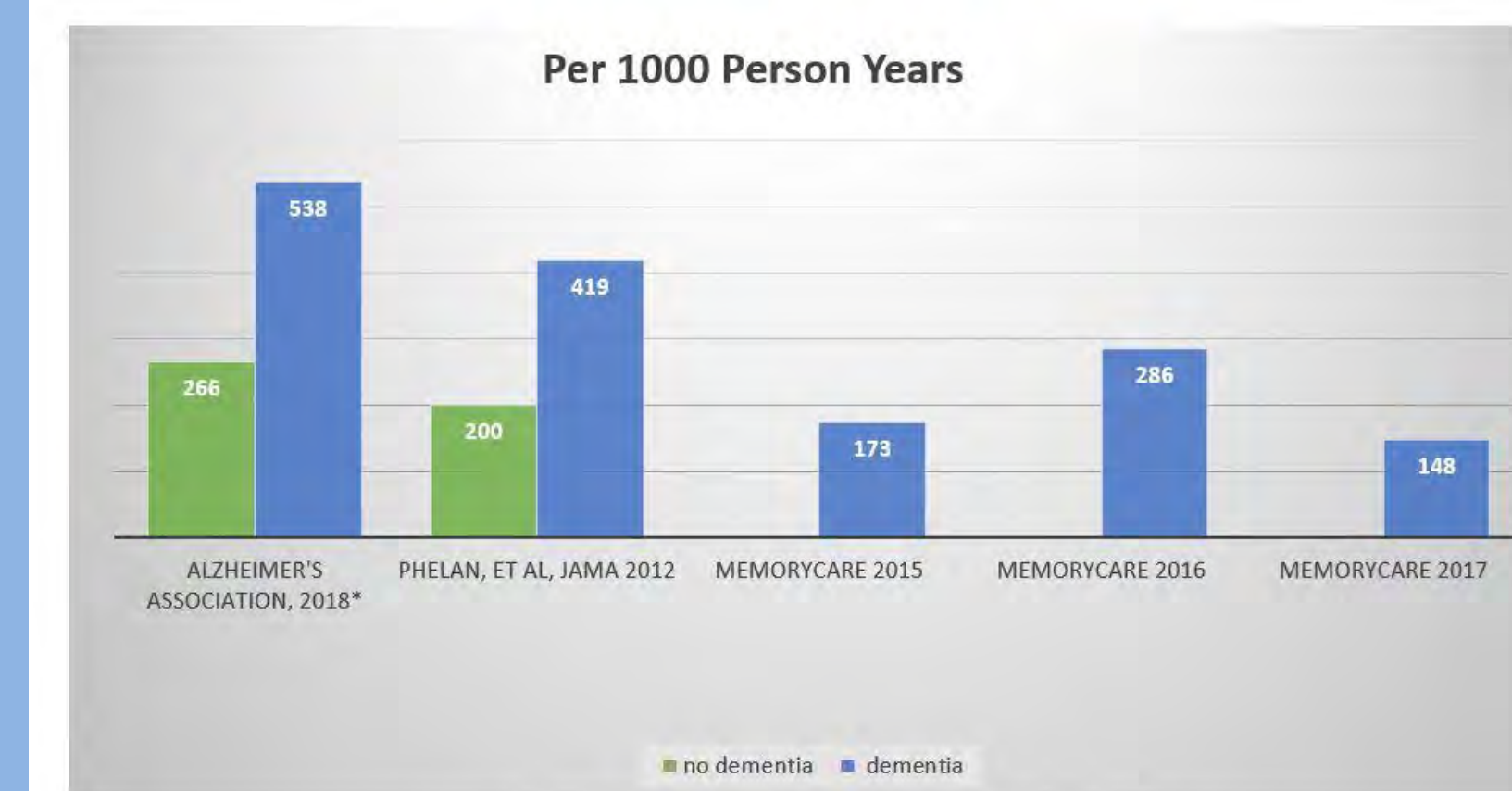
## Whom MemoryCare Serves

Average Number of Families Enrolled Per Year	1053 persons with dementia; 3513 caregivers
Caregiver : patient ratio	3.35 : 1
Mean Patient Age	80 years; range 49-102
Patient Gender	37% male; 63% female
County	54% Buncombe; remainder 19 other counties in western North Carolina served by Buncombe and two more rural satellite clinics
Percent Low Income per HHS	41%
Primary Caregiver Relationship	Spouse 43% Child 50% Other Family 5% Non-family 1% Paid Caregiver 1%
Percent Living at Home/ALF/SNF	87%/ 9%/ 4%
Dependency in ≥ 2 Basic ADLs	48% (% that qualify for nursing home level of care)
Severity of dementia stage	Ranges from mild to severe with average patient in the moderately severe stage

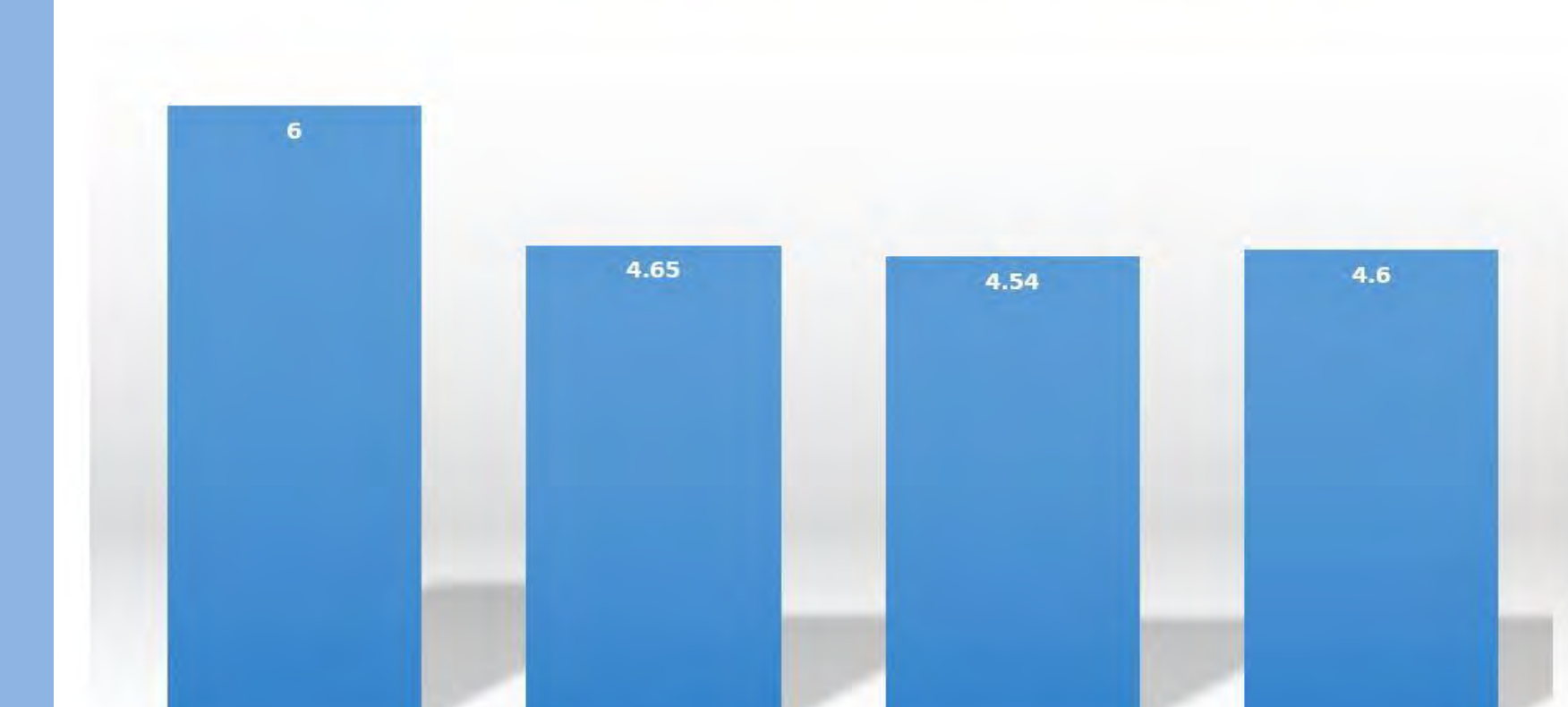
## MemoryCare Caregiver Impact Survey



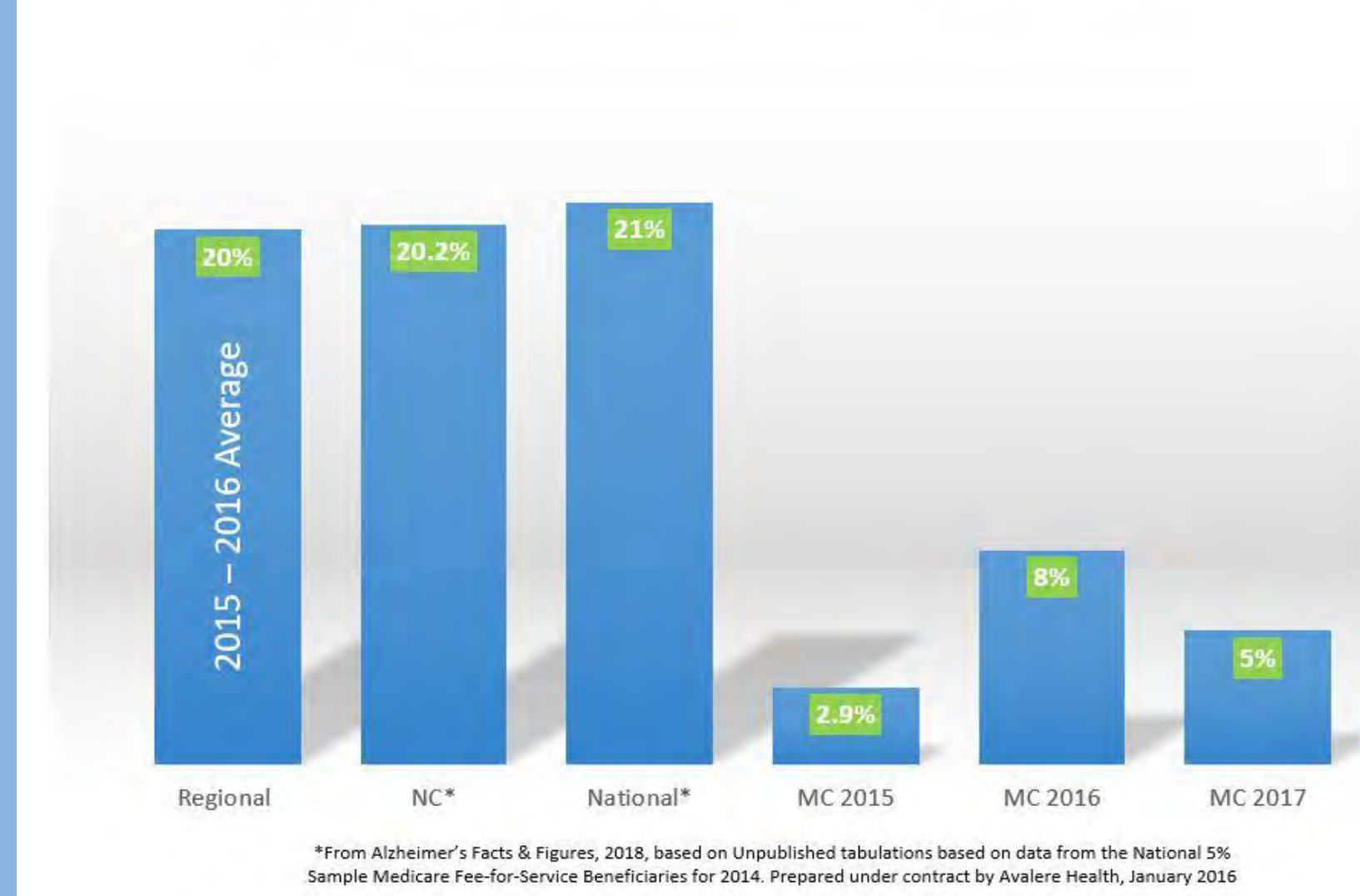
## Hospitalization Rates



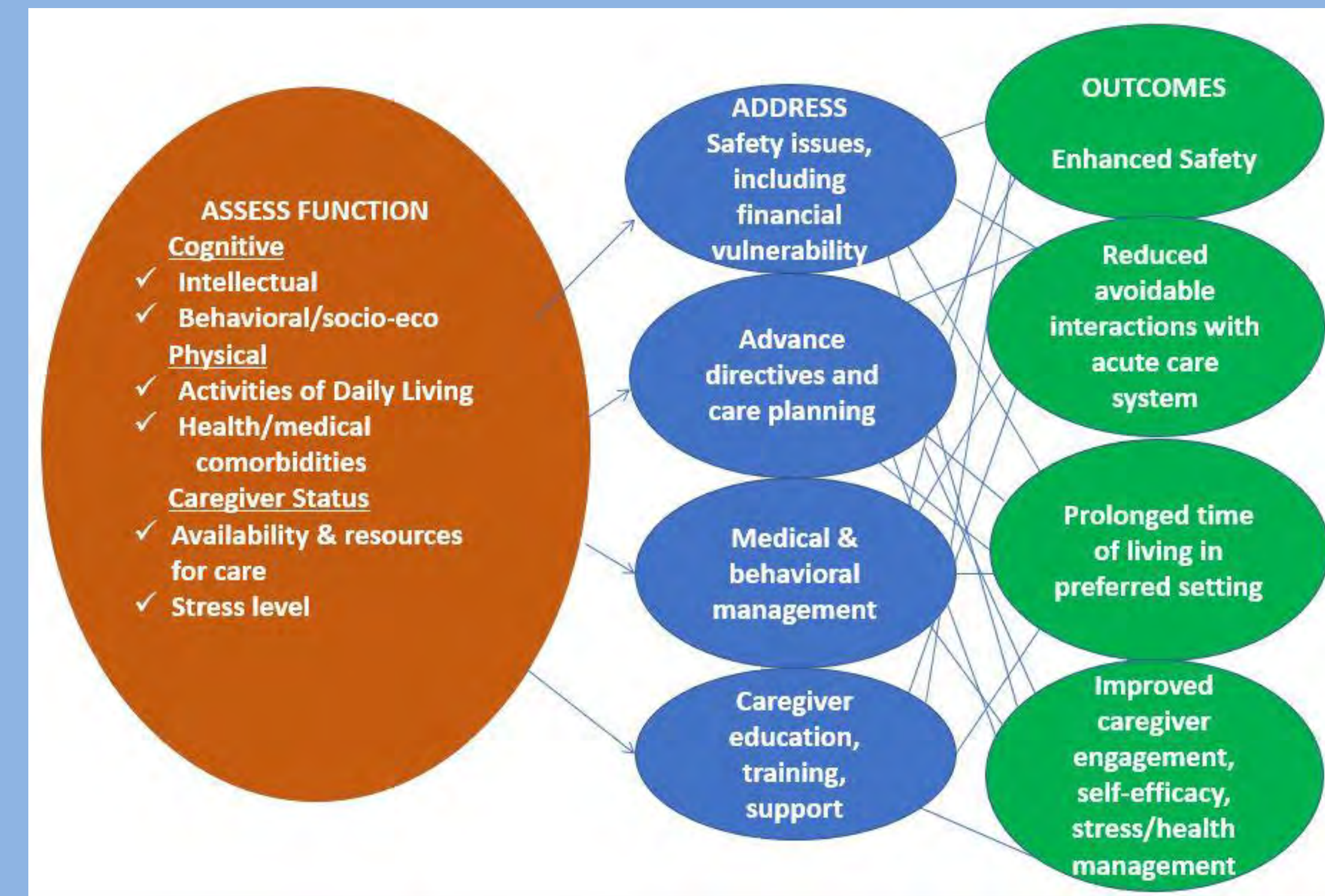
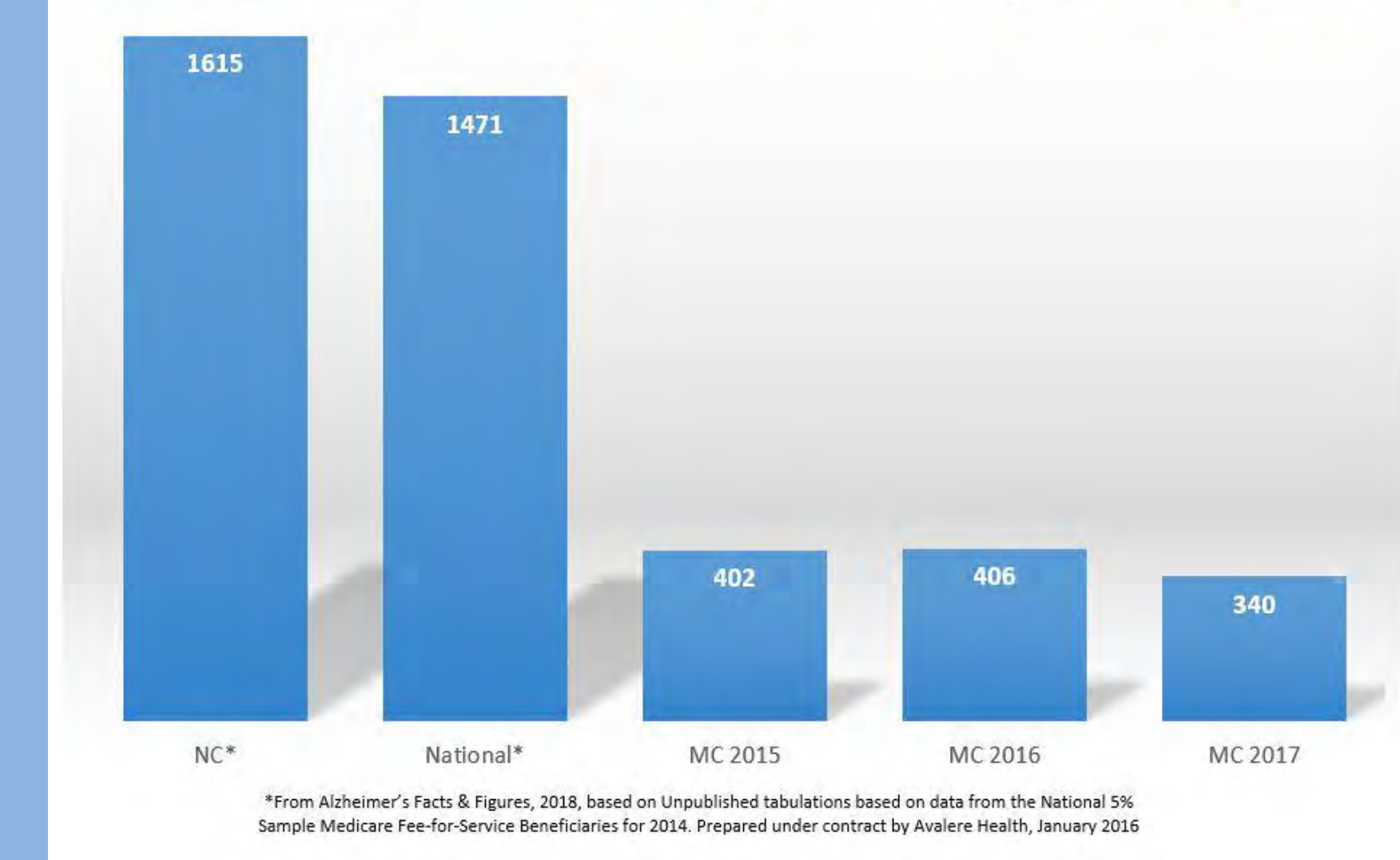
## Average Length of Stay (# days) for Admitted Patients with Dementia Diagnosis



## Percent of Persons with Dementia Re-Hospitalized Within 30 Days



## Number of Emergency Department Visits for Persons with Dementia per 1000 person years



## MemoryCare Process Model

## DISCUSSION

MemoryCare was founded as a community-based, non-profit organization in 2000 as an alternative to the traditional medical approach to dementia care. For 19 years, MemoryCare has fully implemented and delivered a community-based program in predominantly rural western North Carolina that applies best practice dementia care. MemoryCare is designed to address the most common concerns of caregivers who interface with the medical system as advocates for persons living with dementia: the lack of recognition that a memory disorder is present and the lack of communication between medical provider and caregiver on how to best assist the person living with dementia. MemoryCare's goal is to enhance basic community services with a program that helps older adults and their families have the best possible quality of life in the face of a progressive memory disorder.

Observational data reported here from 2015 through 2017 reveal high levels of caregiver satisfaction and increased dementia specific knowledge, ability to manage behaviors and caregiver stress, as well as perceived ability to prolong the period of time that they can provide care in a home setting. While limitations in observational data are inherent, families enrolled at MemoryCare exhibit reductions in hospitalization rates, length of stay, 30 day re-hospitalization, and emergency department utilization compared with published benchmarks and unpublished regional health system data.

Recognizing the role of caregivers in chronic disease management is likely to have multiple benefits that impact these observational findings, including the management of other co-morbid conditions, medication compliance, nutritional oversight, prompt recognition of changes in health status, advance care planning and attention to multiple other safety issues that can prevent injuries. While the provision of a reimbursed CPT code for assessment and care planning of patients with cognitive impairment will further advance improved standards of dementia care, additional public policy changes in health care reimbursement are needed before programs that co-address the needs of dementia caregivers can exist on a national scale.

Of all age-related, chronic progressive diseases, dementia has great potential to exhaust human and health care resources given its high prevalence, prolonged course of increasing functional dependency and lack of effective treatments on the near horizon. These findings support promotion of integrated care models in addressing the needs of the person with dementia while recognizing, valuing, and integrating the essential role of the caregiver(s).

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