

# MemoryCare: Caregiver Involvement in an Out-Patient, Community-Based Dementia Care Program

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## Abstract

### Background and Objectives

Absent a cure or effective disease modifying treatment for dementia, developing cost-effective models of care that address needs of caregivers alongside medical management of the disease is necessary to maximize quality of care, address safety issues, and enhance patient/caregiver experience. MemoryCare is a community-based non-profit organization providing integrated medical and care management services to older adults with dementia and their families. With a comprehensive, inter-professional approach engaging patient and caregiver, needs are identified and formally addressed over time. MemoryCare supplements primary care services to facilitate highest quality, affordable dementia care.

### Methods

The program collects basic socio-demographic and clinical data on all patients and caregivers served. We conducted an outcomes survey of randomly selected primary caregivers, compiled results and compared to prior years. Quality evaluation efforts included internal chart audits to assess program fidelity across providers and site of service delivery and to verify provider compliance with Physician Quality Reporting Systems dementia measures group. Hospitalization rates were examined retrospectively for the subset of patients who had been enrolled a minimum of two years at the end of 2014 to allow a minimum of one year exposure to the program. By reviewing an online database of our local hospital system we identified all MemoryCare patients with any admission in 2014 requiring an overnight stay and compared findings with published hospitalization rates for those with dementia and with data from the local hospital system regarding length of stay, readmission rates, and costs.

### Results

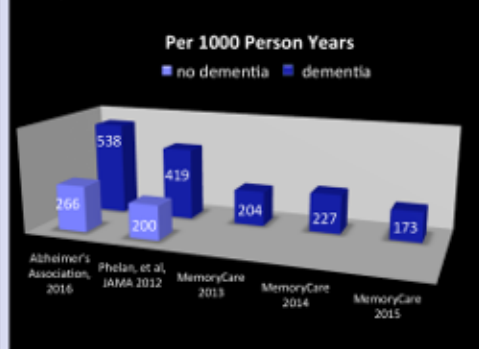
Observational data on 944 patients and 3276 caregivers served by MemoryCare in 2014 reveal high levels of satisfaction, increased dementia-specific knowledge, improved ability to manage challenging behavioral aspects of dementia and lengthened time in the home setting. Data suggest lower hospitalization rates, reduced length of stay and readmission rates for those who are admitted, and related cost savings.

### Conclusions

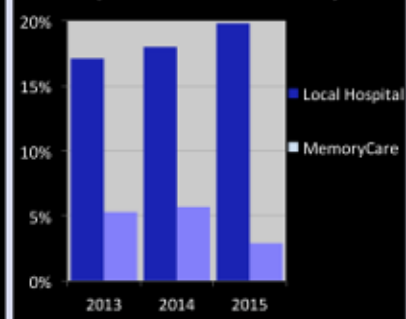
MemoryCare offers a high-quality, cost-effective means of managing one of the greatest healthcare challenges of our time. Data suggests that the inclusion of caregivers in the medical model of care for those with dementia may improve overall outcomes and warrants further study of broader integration of caregivers into clinical care models.

## Results

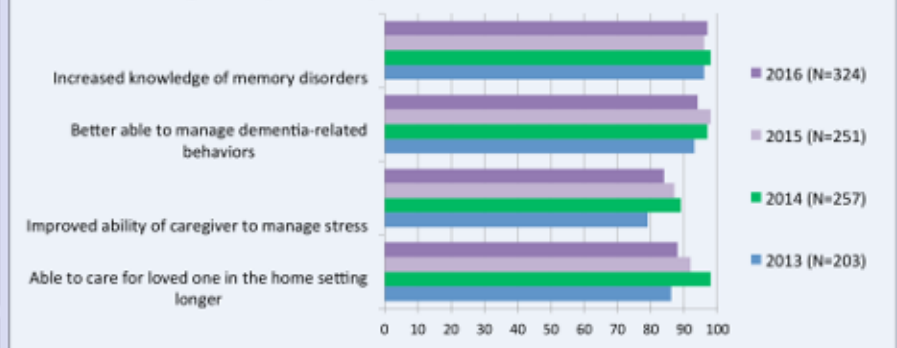
### Hospitalization



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



### Caregiver Impact Survey: Results Over a 4 Year Period



## Discussion

### Background

MemoryCare is a community based non-profit organization founded in 2000 as an alternative to the traditional medical approach to dementia care. Through our physician and care manager (nurse or social worker) teams, we incorporate caregiver education, counseling, and support into the evaluation and medical management of the patient. Currently 14.1% of the population in the United States is over age 65 while over 20% is over 65 in the western North Carolina. Because of these demographics, the prevalence of individuals with cognitive disorders in our region is high. In North Carolina in 2014, there were 448,000 dementia caregivers providing over 510 million hours of unpaid care valued at over \$6.2 billion dollars. At MemoryCare 86% of patients are cared for in the home setting by family members as compared to 70% of those with cognitive impairment in the United States. Families need support and education in order to continue this care.

### Model of Care

With MemoryCare's model, we invite all caregivers to participate at every visit and engage on average three caregivers for each cognitively impaired person enrolled. After the initial evaluation, families and referring physicians receive a written care plan that is amended over time as the patient's disease progresses. They have full access to our resource library, workshops, "Caregiver College" and staff for educational materials and support. MemoryCare staff train caregivers to monitor their loved one's health and safety, provide needed supervision for activities of daily living and manage challenging behaviors due to the dementia while managing their own added caregiver related stress. Through our integrated process, MemoryCare physicians develop personalized care plans that are shared with all caregivers and medical providers to facilitate care coordination. The teams coordinate diagnostic work-up, disease management planning, caregiver training, counseling and support for each enrolled family. They also provide guidance and medical assistance in managing difficult dementia-related behaviors. Our staff help coordinate available community resources, assist low income elderly in applying for medication assistance, guide through transitions in care, and counsel families regarding end of life decision making. With education about dementia, patients and caregivers develop realistic goals which helps reduce inappropriate use of hospitals, improve communication when there, and minimize risk of readmission due to an understanding of the need for their involvement with any care plan.

### Methods

This descriptive of our program is based on observational data on client characteristics, caregiver impact surveys 2013-2016 for comparison, and outcomes regarding utilization of the hospital system. We conduct an annual caregiver impact survey to a random sample of caregivers who respond anonymously and track hospitalization and re-hospitalization rates for all MemoryCare patients who have been enrolled for at least one year to ensure time for program impact. Hospitalization rates were compared with published data and hospitalization rates for those with dementia in our local hospital.

### Conclusion

MemoryCare offers a high-quality, cost-effective means of managing one of the greatest healthcare challenges of our time. We focus on protecting vulnerable, cognitively impaired adults from medication errors, malnutrition and other safety risks that often lead to unnecessary admissions. By including caregivers from the outset, we are able to conclude that MemoryCare patients have fewer hospitalizations overall. This impacts costs and overall quality of care. As dementia progresses, goals of care often change. MemoryCare's focus on educating and training caregivers about dementia stage, prognosis, and the risk/benefits of medical interventions allows them to be strong advocates and to navigate the health care system with better success at achieving patient-centered goals of care.

## Patient/Caregiver

	2014	2015
Number of Patients Enrolled	944	1,054
Mean Patient Age	80 (52-101)	80 (53 - 103)
Patient Gender	37% male 63% female	37% male 63% female
Number of Caregivers Enrolled	3,276	3,478
Caregiver : Patient Ratio	3.2:1	3.3:1
Primary Caregiver Relationship	Spouse 48% Child 45% Other Family 7%	Spouse 48.5% Child 44.5% Other Family 7%
Percent Low Income by Federal Poverty Standards	49%	48%
Percent Living at Home/Assisted Living/Skilled Nursing Facility	84%/11%/5%	86%/11%/3%
Dependency in ≥ 2 Basic ADLs- (% that qualify for nursing home level of care)	48%	49%