



Statewide Survey of ADRD Caregivers in VT

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ADRD in Vermont

- ▶ Nationally, it is estimated that approximately 10% of older adults have Alzheimer's disease; this number is expected to rise to 18% by 2020 and 55% by 2025.
 - ▶ It is estimated that nearly 1 in 3 older adults who dies each year has Alzheimer's or another dementia.
- ▶ In Vermont, approximately 12,000 individuals over 65 have Alzheimer's Disease
 - ▶ It is projected that there will be a 41.7% increase in the number of people in Vermont with Alzheimer's disease between 2016 and 2025.
 - ▶ By 2030, it is projected that nearly 25% of Vermont's population will be 65+.
- ▶ It is estimated that there are 2 caregivers per person with dementia, so there are potentially 24,000 ADRD caregivers in Vermont
 - ▶ It is estimated that Vermont's caregivers provided 34 million hours of unpaid care in 2016, worth \$430 million

Study Background

- ▶ Vermont Alliance for Caregivers of Persons with Alzheimer's Disease and Related Dementias
 - ▶ VT Community Foundation Grant Proposal
 - ▶ Alzheimer's Association of Vermont, Champlain Valley Agency on Aging, University of Vermont Center on Aging and Department of Social Work, Vermont Department of Disabilities, Aging and Independent Living, Vermont Governor's Commission on Alzheimer's Disease and Related Dementias
- ▶ Statewide Assessment of ADRD Caregivers
 - ▶ UVM CESS Research Grant
 - ▶ Governor's Commission on ADRD Caregivers

Study Methods

- ▶ Goal: Statewide assessment of ADRD caregiving in Vermont
- ▶ Design: Cross-sectional survey design
- ▶ Sampling and Recruitment
 - ▶ Target sample size of 378; Based on 2014 estimates of 22,000 ADRD caregivers, 95% confidence level, 5% margin of error
- ▶ Data Collection and Analysis
 - ▶ Survey developed based on review of existing statewide assessments (California, Florida) and consultation with key stakeholders
 - ▶ Online and paper distribution between June 2016 and March 2017
 - ▶ SPSS for quantitative data; Content and thematic analysis for qualitative data
 - ▶ Descriptive statistics conducted; inferential statistics can be conducted based on hypotheses

Results

- SAMPLE
- CAREGIVING SITUATION
- IMPACT OF CAREGIVING
- CAREGIVING CAPACITY AND CONCERNS
- CAREGIVER SUPPORT

Sample (N = 227)

- ▶ 84% female, 16% male
- ▶ 96% White, 2% American Indian/Alaskan Native, <1% Asian, <1% Other
 - ▶ 2% Hispanic
 - ▶ 6% speak a language other than English at home or work
- ▶ Range in age 27-96; Average age = 62 (SD = 12)
- ▶ 77% married, 11% divorced or separated, 6% single, 4% partnered, 2% widowed
- ▶ 36% retired, 34% employed full-time
 - ▶ For 32%, employment status changed due to caregiving
- ▶ Income distribution generally flat
 - ▶ 16% over 86,000; 14% under 25,000
- ▶ 29% simultaneously provide care for younger children/grandchildren

Caregiving Situation

- ▶ Care recipients are largely White (95%), female (56%), and either married (51%) or widowed (37%).
 - ▶ They range in age from 61 to 99, with an average age of 81 (SD=9)
- ▶ The majority of caregivers are providing care for a parent (46%) or spouse (34%)
 - ▶ The majority identify as the primary caregiver (68%) and primary decision maker (e.g., power of attorney or guardianship) (76%).
- ▶ The amount of care provided ranges from 0-168 hours/week
 - ▶ On average, caregivers provide 73 hours of care/week
 - ▶ Over one quarter (26%) report providing care 24/7 (168 hours/week)

Caregiving Situation

- ▶ Length of time as ADRD caregiver
 - ▶ The majority (51%) have been providing care for 1-4 years.
- ▶ Living situation
 - ▶ 38% of care recipients lives in the caregiver's home; 18% live in their own home with others, 14% live alone in their own home, 10% in a nursing home, 7% in assisted living, 7% in specialized dementia care facility
- ▶ Care recipient diagnosis
 - ▶ 87% report diagnosis of ADRD
 - ▶ 50% indicate signs of memory or thinking disorder were present 1-2 years prior to diagnosis
 - ▶ 47% report a delay in diagnosis b/c symptoms viewed as part of normal aging
- ▶ Care recipient symptoms/behaviors
 - ▶ Most frequent: forgetfulness, trouble remember recent events, repetitive questions, losing or misplacing things, difficulty concentrating.
 - ▶ Least frequent: threats to hurt oneself or others, destroying property (however, present for 10%)

Impact of Caregiving

▶ Health Status

- ▶ The majority report they are in good (37%) or very good (34%) health
- ▶ While one-third (33%) report no health problems impacting the care they provide, 45% indicated that caregiving has created or worsened their health conditions/problems.

▶ Stress and Strain

- ▶ The majority report they suffer from stress (52%) and feel overwhelmed with caregiving responsibilities.
- ▶ For the majority (66%), providing care is a strain on emotional well-being
 - ▶ To a lesser extent on relationships (45%), physical health (44%) and financial well-being (39%)
- ▶ Nearly half (49%) report feeling isolated as a result of being a caregiver

Caregiving Capacity and Concerns

- ▶ The majority feel knowledgeable about the care their loved one needs (78%) and confident in their ability to provide care (70%).
 - ▶ 68% believe they have developed new skills and abilities since providing care
- ▶ While the majority feel obligated to provide care (73%), it also brings a sense of satisfaction (73%).
- ▶ The top concerns related to caregiving include:
 - ▶ *Preparing for my care recipient's needs*
 - ▶ Balancing work and caregiving responsibilities
 - ▶ Paying for care recipient's needs

Caregiving Capacity and Concerns

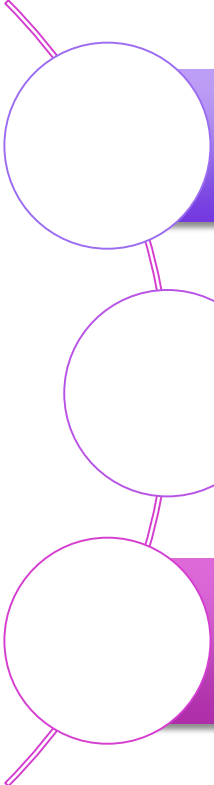
Challenges

- Dealing with ADRD-related Behaviors
- Time and Responsibility of Caregiving
- Feelings of Isolation
- Grief and Loss

Rewards

- Family Responsibility and Connection
- Ability to Keep Loves Ones Home
- Ensuring Safety for Loved One

Caregiver Support



The most common services and supports identified (by over 50% of respondents) as "not needed at this time" were individual and family counseling, support group, and telephone reassurance.

The most common services and supports identified (by over 60% of respondents) as "receive help with this currently" medication management, shopping, and transportation.

The most common services and supports identified as "need more help with this" include companionship (48%), help with household chores (24%) and transportation (24%).

Caregiver Support

- ▶ 1/3 of respondents (33%) report getting unpaid caregiving help from family or friends
- ▶ 66% report they are not receiving caregiving help from social service programs (such as Medicaid or other government or state-funded programs)
 - ▶ While 61% of respondents agreed they are familiar with community resources, a notable 20% neither agreed nor disagreed
- ▶ The main reasons preventing people from receiving services they need but don't have are cost/affordability (32%), care receiver resistance (25%), and lack of knowledge about what is available (25%).

Caregiver Support

Source of Support	% of Respondents
Medical Professional	83%
Family Members or Friends	72%
Area Agency on Aging/ADRC	69%
Home Care/Home Health Agency	50%
Alzheimer's Association	50%

- ▶ In order to continue providing care, caregivers report needing the following services
 - ▶ Respite (48%)
 - ▶ Access to a key contact person for questions and help (42%)
 - ▶ Educational information about disease changes, coping strategies and resources (38%).

Recommendations

AFFORDABILITY OF CARE
AVAILABILITY AND
ACCESSIBILITY OF SUPPORT
EDUCATION AND TRAINING
TRANSLATIONAL RESEARCH

Affordability of Care

- ▶ Issues of affordability were the most common recommendation in terms of what could be done in VT to improve services and programs for individuals with ADRD *AND* their caregivers.
 - ▶ Affordable care needed across the continuum: home care, respite, adult day, assisted living
 - ▶ Expand grant funding (e.g., dementia respite) and program eligibility
 - ▶ Cost analysis: Target funds to services at lower cost with higher impact
- ▶ Addressing affordability of care will likely require advocacy efforts and policy solutions
 - ▶ Consider strategies for involving caregivers in

Availability and Accessibility of Support

- ▶ There were a number of recommendations related to the provision of support – in terms of increasing service availability and quality, but also related to improving awareness of existing services, and streamlining the process for accessing those services.
 - ▶ Need for more respite and emotional support (e.g., isolation, grief & loss)
 - ▶ Older adults and caregivers are often navigating multiple systems; is the point of entry as clear and efficient as possible?
 - ▶ A centralized/organized network to connect those in need of care with those willing to provide care could expand options and, potentially, reduce costs (e.g., some may offer care at low cost or on a volunteer basis).
 - ▶ A statewide public information and information dissemination campaign could establish clarity and increase utilization.

Education and Training

- ▶ Caregivers highlighted a need for education and training for both formal and informal care providers, including themselves.
 - ▶ Formal care providers – from primary care physicians to home health and respite care providers – often lack training in aging and ADRD; often do not have the skills to meet care recipient's needs.
 - ▶ Informal caregivers may benefit from easy access to basic information
 - ▶ Collaborative partnerships with Vermont's educational institutions, AHECs to provide geriatric workforce training and development

Translational Research

- ▶ Over 200 dementia caregiver interventions have been tested and found to be efficacious – however few have been translated for delivery in different service contexts and remain generally inaccessible to ADRD caregivers.
 - ▶ Review of promising practices and models
 - ▶ Consider ‘targeting within universalism’ approach of a statewide implementation with tailored local elements
 - ▶ Build upon Vermont’s history with person-centered care; implementation of person-centered dementia care

Next Steps

HYPOTHESES AND
INFERENCE STATISTICS

REVIEW OF PROMISING
PRACTICES AND MODELS



Questions and Discussion

Thank you!

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