



A Statewide Survey

CARING FOR ADRD CAREGIVERS IN VT

It is estimated that every 67 seconds,
someone in the United States develops Alzheimer's disease.

As the population ages, the incidence of Alzheimer's disease and related dementias (ADRD) is expected to increase significantly. In Vermont, it is projected that nearly 25% of the population will be over age 65 by 2030 (U.S. Census Bureau, 2005).

Given that our health care system depends on families to assume caregiving responsibilities, it is incumbent upon us to understand and respond to their needs in order to assure safety and quality of life for those with ADRD and their caregivers.

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CARING FOR THOSE WITH ADRD

Over 5 million Americans are living with Alzheimer's and it is estimated that as many as 16 million will have the disease in 2050 (Alzheimer's Association, 2014). This irreversible, progressive brain disease slowly damages and eventually destroys brain cells, leading to memory loss and changes in brain functions. In most cases, symptoms first appear after age 65. Currently, approximately 10% of older adults have Alzheimer's disease, and this number is expected to rise to 18% by 2020 and 55% by 2025. By 2050, the proportion of people suffering from the most severe phase of the degenerative disease will increase to almost half, or 6.5 million people, of those who are projected to develop the disease.

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In Vermont, approximately 12,000 individuals over 65 have the disease (Alzheimer's Association, 2017) and it is projected that there will be a 41.7% increase in the number of people with Alzheimer's between 2016 and 2025 (to 17,000 individuals) (Weuve, Hebert, Scherr, & Evans, 2015). It is estimated that nearly one in every three older adults who dies each year has Alzheimer's or another dementia; there were 266 deaths attributed to ADRD in 2016 (Alzheimer's Association, 2017). While Alzheimer's disease is the most common type of dementia, accounting for 50-80% of cases, this study will focus on those with Alzheimer's disease and related dementias (ADRD) and their caregivers. Other types of dementia include vascular dementia, frontotemporal dementia, dementia with Lewy Bodies (DLB), Parkinson's disease, Huntington's disease, and mixed dementia. Dementia involves a decline in cognitive functioning and impacts a person's ability to perform everyday activities.

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Nationally, the cost of caring for those with ADRD was estimated at \$259 billion in 2016, excluding the value of unpaid care provided by caregivers. It is estimated that 15.9 million Americans provided 18.2 billion hours of unpaid care to those with ADRD in 2016. In Vermont, it is estimated that caregivers provided 34 million hours of unpaid care in 2016, worth \$430 million (Alzheimer's Association, 2017). Caregiving tasks range from assistance with daily tasks such as feeding and bathing, transportation and accompaniment to health visits, care coordination, and end-of-life care (Reinhard, Samis, & Levine, 2014). While families often take on a caregiving role willingly and as a source of satisfaction, it can exact a high cost in terms of increased health risks, emotional strain, employment challenges and economic burdens (Feinberg, Newman, Gray, & Kolb, 2004). As a result of the physical and emotional stress of caregiving, ADRD

caregivers had an estimated \$11 billion in additional health care costs of their own in 2016 (Alzheimer's Association, 2017).

Over the past 25 years, research has shown that support services can effectively reduce burden, strain and depression among caregivers (Mittelman, Roth, Haley, & Zarit, 2004; Montgomery & Borgatta, 1989; Ostwald, Hepburn, Caron, Burns, & Mantell, 1999; Zarit, Stephens, Townsend, & Greene, 1998), allow family caregivers to remain in the workforce (Wagner, 2001), and may even delay institutionalization (Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996). Over the past 30+ years, "more than 200 dementia caregiver interventions have been tested in randomized clinical trials and found to be efficacious" (Gitlin, Marx, Stanley, & Hodgson, 2015, p. 1). Caregiving interventions have been summarized in 7 meta-analyses and 17 systematic reviews, suggesting a strong evidence base (Gitlin & Hodgson, 2015). However, few have been translated for delivery in different service contexts and they remain generally inaccessible to ADRD caregivers. It is essential that the needs and resources of ADRD caregivers in Vermont inform future translational efforts.

While over 200 dementia caregiver interventions have been tested and found to be efficacious, few have been translated for delivery in different service contexts and they remain generally inaccessible to ADRD caregivers.

Efforts are underway across the nation and throughout the world to prevent and treat ADRD, and researchers are actively engaged in developing effective ways to care for those with ADRD and support their families and caregivers. In collaboration with the Governor's Commission on ADRD, Vermont's Department of Disabilities, Aging and Independent Living (DAIL) is actively working to raise awareness and create opportunities to improve systems of care for peoples with dementia and their caregivers, with a goal to "excel at the provision of state of the art dementia care, policies and programs" (DAIL, 2009, p. 17). Enriching our dementia care infrastructure requires a comprehensive assessment of the needs and resources of Vermont's ADRD caregivers.

Conducting community needs assessments of the older adult population has been at the core of the Area Agency on Aging planning process since the early 1980s. Information about ADRD caregivers and their needs, examined in the context of existing services, enables the identification of service gaps and priority areas for change. In this way, the needs assessment process can assist in the allocation of limited resources in the most effective and efficient manner possible. As Scharlach and colleagues (2002) note, "data regarding caregivers' needs and the effectiveness of existing services for meeting those needs can be a powerful tool in providing a basis for assuring that resources are targeted where they are most needed, that services are provided in an effective and equitable manner, and that caregivers receive the support they need" (p. 66). The global health

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challenge of ADRD demands a sense of urgency and innovation, informed by the perspectives of those most intimately involved.

A STATEWIDE SURVEY OF VERMONT'S ADRD CAREGIVERS

This study utilized a cross-sectional survey design for gathering information about the needs of and resources for caregivers of persons with Alzheimer's disease and related dementias in Vermont. This study included a statewide survey of ADRD caregivers in an effort to describe the current population of ADRD caregivers in Vermont and determine their existing and unmet needs

METHODOLOGY

SAMPLING AND RECRUITMENT

At the start of the study, it was estimated that there were 11,000 persons with dementia in Vermont, based on estimates of 132,000 persons over 60 and 8.3% of the over 65 population with a cognitive disability. It was also estimated there are 2 caregivers per person with dementia, so it was estimated that there are approximately 22,000 ADRD caregivers in Vermont. At a 95% confidence level with a 5% margin of error, the target sample size was 378.

Participants were recruited from across Vermont through major providers/programs such as the VT Dementia Respite Program, the Alzheimer's Association, and the Area Agencies on Aging (AAA). A weblink to the online survey was distributed by multiple providers and posted on social media sites such as facebook and twitter. Paper copies of the survey were distributed as requested, largely via AAA case managers and caregiver support programs.

DATA COLLECTION AND ANALYSIS

The survey instrument was developed by the researcher in consultation with community partners such as DAIL and Alzheimer's Association staff, and members of the Governor's Commission on ADRD. Existing statewide surveys of caregivers (e.g., California, Florida) as well as a number of well-established caregiver assessment measures were reviewed to inform the development of the survey instrument used in Vermont.

The survey instrument collected information on:

- Demographic characteristics of caregivers and care recipients;
- Care recipient health and functioning;
- Level of assistance required by the care recipient;
- Level of care provided by the caregiver;

- Services provided to caregivers, and unmet needs of the caregivers; and
- Impact of caregiving on work-related issues, emotional health, and physical health

Data was collected between June 2016 – March 2017, using print and online distribution. The researcher analyzed survey data using SPSS. Raw data was entered imported from SurveyMonkey or entered directly into SPSS for analysis. Descriptive statistics are reported here and future inferential statistics will be conducted according to stakeholder interests (i.e., comparison of different age groups, types of care provided, etc.). Qualitative data was analyzed using content and thematic analysis.

RESULTS

SAMPLE

The study consisted of 227 participants. This sample results in a 6% margin of error – well within the acceptable margin of error between 4% and 8% at the 95% confidence interval. Therefore, the results of this survey are accurate at the 95% confidence level plus or minus 6 percentage points.

Of the 227 respondents, 84% identified as female and 16% as male. Respondents ranged in age from 27-96, with an average age of 62 (SD = 12) (median=62, mode=64). The vast majority (77%) identified as married, with the remainder divorced or separated (11%), single (6%), partnered (4%) or widowed (2%). In terms of race, 96% identified as White, 2% as American Indian or Alaska Native, less than 1% Asian and less than 1% other, while the remaining 1% declined to state. In terms of ethnicity, 2% identified as Hispanic. 6% of respondents speak a language other than English at work or home. Languages identified include Abenaki, French, Spanish, Polish, Dutch, and Tagalog.

In terms of education, only 3.5% of respondents reported having less than a high school education. 18% identified their highest level of education as high school, 30% as college graduates, and over one quarter (26%) with post-graduate education. The majority of respondents identified as retired (36%) or employed full-time (34%). 13% reported “other” employment, including self-employment or being a full-time caregiver. For 32% of respondents, their employment status changed because of caregiving duties. The income distribution of participants was almost flat, with the greatest numbers making either over \$86,000 (16%) or under \$25,000 (14%). In addition to providing care for an individual with ADRD, 29% of respondents currently provide care for younger children or grandchildren.

CAREGIVING SITUATION

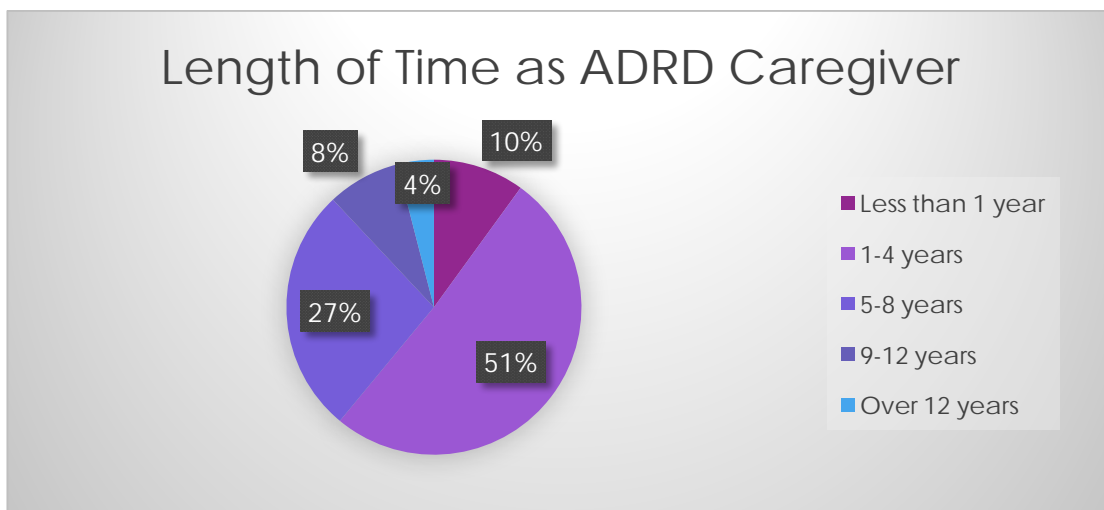
The vast majority of respondents reported providing care for a parent (46%) or spouse (34%). Interestingly, while the survey was intended for informal caregivers, 7% reported that they were caregivers for clients/residents. The remaining 13% of respondents were

caring for an aunt/uncle (1%), friend (3%), adult child (0.5%), in-law relation (1%), grandparent (2%), sibling (1%), partner (2%), or other person (4%). 68% of respondents

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indicated they are primary caregivers, while 76% identified as the primary decision maker (having power of attorney or guardianship). Caregivers report providing an average of 73 hours of care per week, with responses ranging from 0 to 168. Over one quarter of respondents (26%) report providing care 24/7 (168 hours/week).

While 10% of respondents have been providing care for an ADRD individual for less than 1 year, the majority (51%) indicated that they have cared for the individual between 1 and 4 years. 30% have been providing care for 5-8 years, 8% have been providing care for 9-12 years, and 4% have provided care for over 12 years.



The majority of care recipients are 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) (median = 82, mode = 81).

In terms of living situation, 38% of respondents indicated the person receiving their care lives in the respondent/caregiver's home. The remainder live in their own home with others (18%), alone in their own home (14%), in a nursing home (10%), in an assisted living facility (7%), in a specialized care facility for persons with dementia (7%), in a retirement community (3%), in the home of another family member (1%), or some other, unspecified location (2%). Among those who do not live in the same home with the person receiving their care, only 8% report living more than an hour away.

When asked to describe the condition of their person receiving their care, nearly half (47%) of caregivers reported that the person has more problems with memory, language, short attention span, trouble with the daily routine of fixing meals, dressing, bathing, and needs help to complete tasks. 26% reported that the person has problems with memory, conversation, mood and being lost. The remainder identified that the person has a

complete loss of memory and language, sleep problems, is clumsy using hands or walking, and needs constant help to do personal care (15%) or has ongoing memory problems but no other problems with thinking (12%).

When asked how long the person receiving care has shown signs of a memory or thinking disorder, the most common response was 5-10 years (40%), followed by 3-4 years (28%) and 1-2 years (20%). Few caregivers report signs such as forgetting things, losing items or being unable to speak well for less than 1 year (6%) or greater than 10 years (6%).

50% of respondents indicated that the care recipient showed signs of a memory or thinking disorder for 1-2 years before a diagnosis was made.

The vast majority of respondents (87%) report that the person receiving their care has received a medical diagnosis of Alzheimer's disease or a related disorder. Less than 5% are unsure about diagnostic status. The most common types of dementia or memory disorders that have been diagnosed include Alzheimer's disease (54%), mild cognitive impairment (14%), vascular dementia (11%), and mixed dementia (11%). Most often, the diagnosis was provided by the Memory Disorder Center (30%), a family doctor/primary care physician (27%) or neurologist (27%). Notably, 50% of respondents indicated that the person receiving their care showed signs of a memory or thinking disorder (such as forgetfulness or disorientation), for 1-2 years before a diagnosis was made. An additional 22% indicated signs were visible for 3-4 years prior to diagnosis and 13% felt that signs were showing as many as 5-10 years before a formal diagnosis was made. When asked to identify any potential causes for a delayed diagnosis, 33% indicated that they did not think there was a delay. However, 47% reported a delay because the symptoms were viewed as a part of normal aging.

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Respondents identified the most frequent behaviors exhibited as forgetfulness, trouble remembering recent events, repetitive questions, losing or misplacing things, and difficulty concentrating. While dangerous behaviors such as threats to hurt oneself or others, or destroying property were identified least frequently, it is important to note that 10% of respondents reported occurrence of these behaviors.

IMPACT OF CAREGIVING

When asked about their health status, the majority of respondents reported they are in good (37%) or very good (34%) health. The remainder identified as being in fair (16%), excellent (10%), or poor (3%) health. Respondents were asked to identify specific health conditions/problems that impact the kind or amount of care they provide. A majority of respondents (52%) reported that they suffer from stress. Other common health problems impacting the care respondents provide include back problems and other joint issues

(33%), heart problems (23%), and mental health problems (18%). Notably, 33% of respondents reported no health problems impacting the care they provide. When asked if their caregiving responsibilities created or worsened their health conditions/problems, 45% of respondents indicated yes, 41% indicated no, and 14% were unsure.

Perhaps not surprisingly, the majority of caregivers (57%) report feeling overwhelmed with their caregiving responsibilities. For two-thirds of respondents (66%), providing care has been a strain on their emotional well-being. To a lesser extent, caregiving has also strained their physical health (44%) and the financial situation (39%). The impact of caregiving on familial relationships appears quite varied. Half of respondents (51%) neither agree nor disagree that relationships with family have improved since they began providing care, while 28% disagreed and 21% agreed. For 45% of respondents, providing care to their loved one has been a strain on relationships. Nearly half of respondents (49%) report they often feel isolated as a result of providing care to their loved one.

CAREGIVING CAPACITY AND CONCERNS

Overall, the majority of respondents feel knowledgeable about the care their loved one needs (78%) and confident in their ability to provide care (70%). Further, while the majority of respondents feel obligated to provide care (73%), it also brings a sense of satisfaction (73%). The majority of respondents (68%) believe they have developed new skills and abilities since they began providing care, however a sizeable number (24%) neither agreed nor disagreed with this statement.

Overall, the majority of respondents feel knowledgeable about the care their loved one needs (78%) and confident in their ability to provide care (70%).

When asked about their top three areas of concern related to caregiving, the most frequently identified areas were 1) preparing for my care recipient's needs, 2) help balancing my work and caregiving responsibilities, and 3) help with paying for my care recipient's needs.



The most frequently identified top area of concern was “preparing for my care recipient’s needs.” This was ranked as the top concern most frequently and as a concern by 107 respondents. The next most frequent concern, help with balancing work and caregiving responsibilities, was identified by 68 respondents.

CHALLENGES OF CAREGIVING

When asked to identify the most challenging aspect of being a caregiver, responses fell into four major categories related to 1) dealing with behaviors related to ADRD, 2) time and responsibility of caregiving, 3) feelings of isolation, and 4) grief and loss.

Challenges related to dealing with ADRD related behaviors were articulated in statements such as:

- “Not knowing if I am saying or doing the right thing when I am faced with his emotional swings/fears.”
- “Not knowing how his day is going to go behavior wise. It varies day to day.”
- “Not taking things personally when she is rude or short-tempered.”
- “Repeating, getting her to do or not do things. The thing that bothers me the most is having to shower my mother... this is probably humiliating for her.”

Challenges related to the time and responsibility of caregiving were expressed in quotes such as:

- “Constant, non-stop”
- “Having to drop work to help her and her needs during the day.”
- “Balancing the time it takes, with a full-time job, finding time for my own family, and for me to have time for myself.”
- “Time for myself. I’m exhausted.”

Feelings of isolation were identified as challenging – sometimes in relation to time, but often as a distinct challenge, as indicated by quotes such as:

- “Isolation, not able to come and go as I please.”
- “Not being able to just ‘go’ anywhere, anytime, without having to consider my mom’s care.”
- “Not having interaction with friends and others who don’t have cognitive impairment.”
- “Being alone without support.”

Feelings of grief were highlighted by statements such as:

- “The grief associated with ‘losing’ him little by little.”
- “Losing the love of your life yet having them right in front of you.”
- “Watching your spouse decline to where they are no longer your partner, but more like a child.”
- “Watching my brilliant husband slowly slip away in front of me.”



REWARDS OF CAREGIVING

When asked to identify the most rewarding aspect of being a caregiver, responses fell into three major categories related to 1) family responsibility and love/connection, 2) the ability to keep loved ones at home, and 3) ensuring safety for loved ones.

Family responsibility and connection was represented by quotes such as:

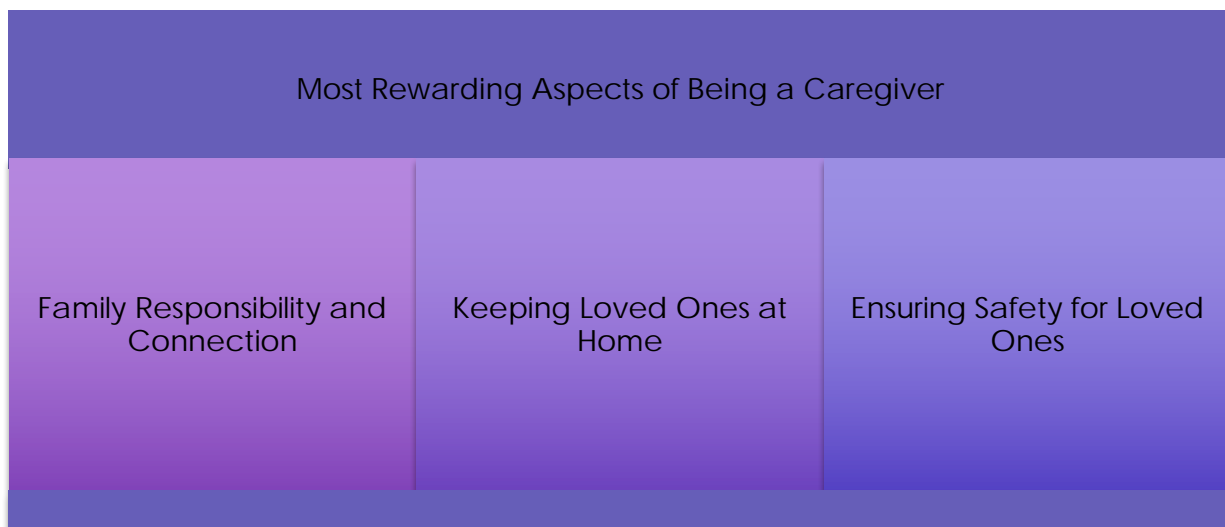
- “Fulfilling my marriage vow ‘for better or for worse, in sickness and in health.”
- “Mom and I have always had a very good relationship; this level of working as a team gives us both a sense of accomplishment and an even closer bond. It’s indescribable.”
- “Providing care for my mum is my way of honoring her and loving her.”
- “It has brought my family closer together.”

The ability to keep loved ones at home was articulated in comments such as:

- “Ability to keep spouse home with me.”
- “Avoiding nursing home care for my spouse.”
- “I am happy that my dad can stay in his own home which is important to him.”
- “I love my father and want him to be at home for as long as possible and it is safe for him to do so.”

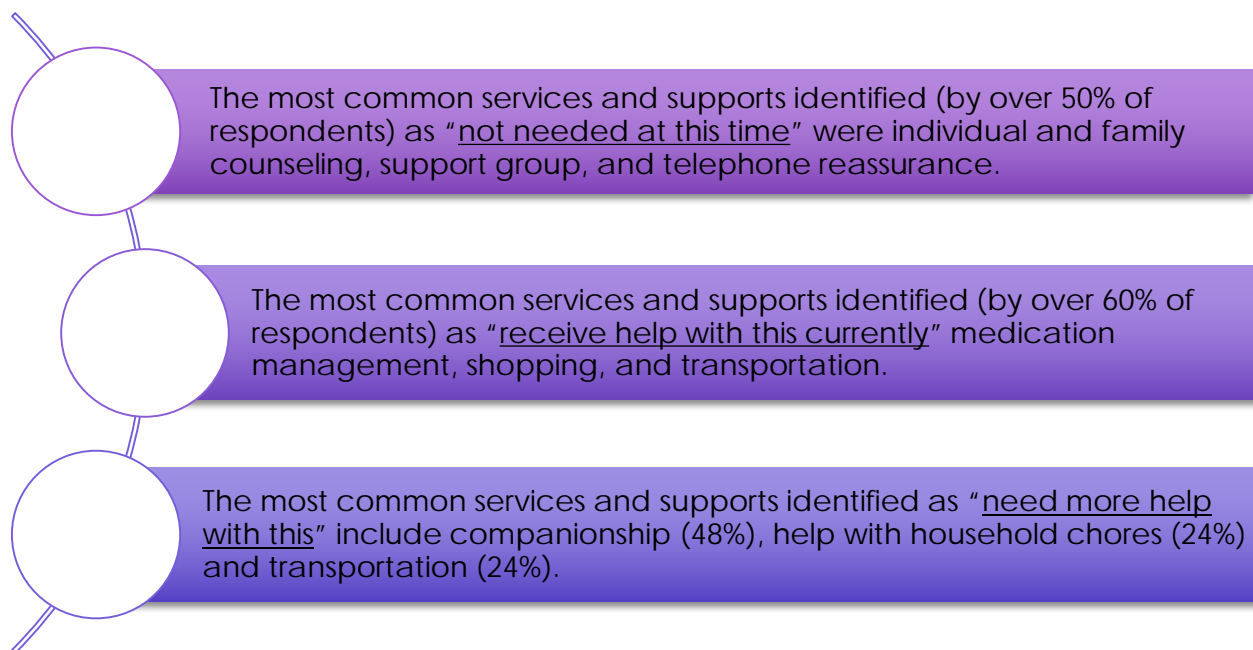
Ensuring safety was represented by comments such as:

- “Knowing she is safe and doing well.”
- “Knowing that my husband feels secure when I am there.”
- “Knowing that he is safe with me and isn’t being cared for by a bunch of strangers.”
- “Knowing that my mother is safe and well loved, respected, and living in a familiar place.”



CAREGIVER SUPPORT

Caregivers are providing a range of support for their loved ones. Participants were asked about the services and supports required by the person they care for, in terms of whether certain support was not needed, currently received, or if more help was needed.



Despite the amount of care they provide, the majority of respondents (91%) are not getting paid. About 1/3 of respondents (33%) report getting unpaid caregiving help from family or friends, and only 12% of respondents report that they currently pay for additional help to assist with caregiving. Further, the majority of respondents (66%) report they are not receiving caregiving help from social service programs (such as Medicaid or other government or state-funded programs). Among those who indicated that they are getting help from social services, the most common sources of support include a Respite Grant (19%), Home Health Care (14%) and Medicaid/Medicare (11%). A small number of respondents (8%) are on a waiting list to receive help.

About 1/3 of respondents (33%) report getting unpaid caregiving help from family or friends; 12% report that they currently pay for additional help to assist with caregiving.

When feeling stressed or overwhelmed with caregiving responsibilities, respondents turn to a variety of supports, including friends (49%), their spouse (37%), children (32%), siblings (28%), health care professionals (24%), and support group members or other AD/DRD caregivers (22%). A small number report seeking support from religious or spiritual leaders (14%) or co-workers (11%). 14% identified that they ‘do not turn to anyone.’ While the majority of respondents (61%) report they are familiar with the community resources available to help them, a notable 20% neither agreed nor disagreed with that statement.

When asked to identify where they have received information or services to help with caregiving, the most common sources (used by 50% or more) include:

| 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% |

When asked what, if anything, prevents them from receiving the services or resources they need but don't have, the most common response (32%) was "I can't afford them." Other reasons included "the person I care for is resistant to caregivers/supports" (25%) and "I don't know what is available" (25%).

25% of respondents indicate they have not received services or resources they need because "I don't know what is available."

While the vast majority of respondents (71%) report they will be able to continue to provide care in the near future, 20% are unsure. When asked if they think they will need to place the person receiving care in an assisted living facility, nursing home, or special care facility within the coming year, 22% said yes, 33% said no, and 37% were unsure; the remaining 8% indicated it was not their decision.

When asked to identify services and supports they would need in order to continue providing care, the most commonly identified services included respite (48%), access to a key contact person for questions and help (42%), and educational information about disease changes, coping strategies and resources (38%). It is interesting to note that the vast majority of respondents indicated they do NOT need more support/flexibility from their employer (71%) (which may be related to their employment/retirement status), training to provide medical care (68%), or medical care for themselves (57%) (which may be related to their Medicare/health insurance status).

In order to continue providing care, respondents need services such as respite (48%), access to a key contact person for questions and help (42%), and educational information about disease changes, coping strategies and resources (38%).

SERVICES AND SUPPORTS FOR INDIVIDUALS WITH ADRD AND THEIR CAREGIVERS

Participants were asked to make recommendations in terms of what could be done in Vermont to improve programs and services for individuals with ADRD and for caregivers.

Recommendations for improvements to programs and services for individuals with ADRD were largely related to 1) affordability and financial support, 2) availability and accessibility of support, and 3) training for both formal and informal care providers.

Affordability of care and financial support for services were represented by statements such as:

- “Expand funding for Dementia Respite; \$1500 is a discouraging amount for most families.... Lower the cost of Adult Day care through the VNA. Provide a grant so that the VNA can provide a sliding fee scale to low-income folks.”
- “More affordable adult day care services for those who do not qualify for Medicaid.”
- “Affordable respite care. Affordable transportation to respite care center, appointments, etc.”
- “Affordable assisted living services for non-Medicaid persons.”
- “Almost every program is income eligible and we do not qualify.... In some cases I would be willing to pay for a service, but I can’t do that!”

Availability and accessibility of support, including the process of was illustrated in quotes such as:

- “Assistance when a caregiver is in crisis mode.”
- “Provide more at home care services, adult day services, and respite for care provider.”
- “Providing better services to people in rural areas.”
- “Better job letting people know about the services that are available.”
- “A more streamlined approach to getting services approved.”
- “Provide a team to help navigate through all the systems available.”

Recommendations related to training were reflected in statements such as:

- “Helping primary care physicians be better trained and more proactive in helping patients with these conditions.”
- “Home caregivers with more skills working with people with dementia. Caregivers are often very nice but not sufficiently skilled.”
- “There needs to be more staff available that have the right temperament, knowledge and the stamina to work in this field.
- “Educate our doctors and healthcare workers!..... There are many forms of dementia.”
- “Provide more facilities and incentives for people to go into the caregiving fields (similar to what the state did to get people into special ed in the 1970s). Care for this population varies widely and needs improvement.”

Recommendations for improvements to programs and services for caregivers of individuals with ADRD were largely related to 1) affordability of care and financial support, 2) respite and support, and 3) information and communication.

Affordability of care and financial support were represented by statements such as:

- “Affordable services to keep person in home.”
- “Pay home care providers even if family.”
- “Better pay for caregivers at facilities. These are amazing, dedicated people who do incredible work for very little pay, so there seems to be constant turnover, which then requires more money to train new people. Not a very effective system.”
- “Provide care not based on income.”

Respite and support were frequently identified, as indicated by comments such as:

- “Respite for caregivers.”
- “The respite grant was a great idea but I was rarely able to use it because the aspects of care I provide are things that aides have not been able to provide.”
- “Develop a network of qualified respite volunteers who could fill in for or give caregivers a break so we could better maintain our own physical and mental health for the long haul. “
- “It would be fantastic if the state could provide a case manager to help caregivers.”
- “Support groups during different days and times of day.”
- “Provide a mentor-mentee group of individuals whose loved one has passed on to those currently experiencing it.”

A range of information and communication was recommended, such as:

- “Publicizing what is available.”
- “A better way to access information all in one place.”
- “Single point of entry for information and services.”
- “Have one umbrella organization for everything...PR and communication are needed.”
- “A database for Vermont Caregivers, also one for people who would like to assist on either a paid or volunteer basis.”

“There isn’t any one thing – what’s needed is a whole community of support.”

CONCLUSION

This study contributes to Vermont's objectives to "increase participation in dementia-related research that can benefit Vermont's population" (DAIL, 2009, p. 13). Survey results provide information on the experience of ADRD caregiving in Vermont, as well as service gaps and barriers, and caregiver perspectives on how limited resources should be targeted. Caring for caregivers is fundamental to the success of our long-term care system. As caregivers face increasing demands due to the aging of the population and prevalence of ADRD, a proactive, innovative approach will be imperative.

RECOMMENDATIONS

As is clearly indicated in the respondent recommendations for changes that could be made in Vermont to assist individuals with ADRD and their caregivers, there is a significant need for **affordable care options and financial assistance**, as well as increased **availability of respite care and support services**. ADRD caregivers highlight the high cost of in-home services, adult day care, and assisted living. Many noted that financial assistance is available for very low-income families, but not for those not yet Medicaid-eligible. In light of the aging of the population and the increasing need for home and community-based care, it will be essential that the lower cost services (such as home care and respite) are accessible and affordable if we are to delay or prevent more expensive long-term care.

While options such as expanded program eligibility, sliding scales, and individual grants are certainly worth exploring, other **creative solutions** may be necessary. One respondent suggested a Vermont Caregiver Database, which could provide **centralized access for those seeking a caregiver/caregiver support** as well as for those offering caregiver support, respite, or companionship on either a paid or volunteer basis. This could be similar to services provided by 'Vermont Nanny Connection' or a more locally monitored version of a service such as Care.com. In addition to coordination, such an effort would require some level of oversight to ensure the safety of all involved. Related, a common concern was related to the lack of training for both formal and informal caregivers. It would be beneficial to establish a **streamlined information and training program for caregivers**; perhaps an online version for family caregivers who are seeking basic information and are unable to easily attend in-person trainings and an ongoing series of online and/or in-person trainings for formal caregivers, respite providers, etc. As one respondent noted, there may be a need for incentives for encouragement; this could be in the form of training certificates/certifications or educational grants/loans in an effort to enhance one's career trajectory and/or earning potential. Related, and not insignificant, is the lack of geriatric medical and mental health providers in Vermont. It may be beneficial to partner with Vermont's educational institutions and Area Health Education Centers (AHECs) in terms of both an immediate and long-term strategy to address this crisis of care. This recommendation parallels the Vermont State Plan on Dementia recommendations related to involving communities, families and consumers, the dementia care infrastructure, and the dementia care workforce.

In addition to direct care support with caregiving, many caregivers are also in need of **emotional support**. While over 50% of respondents indicated they did not need a support group at this time, 'support' was also frequently listed as a recommendation for improvement. Support groups, offered at various days/times and in multiple modes (in person, online, phone), provide beneficial support for ADRD caregivers. It seems there is also a potential need for additional strategies to help caregivers combat the stress, isolation and grief they may be experiencing. Respite services are certainly one way to give caregivers time for social interaction, however more targeted outreach and services may be useful in light of the level of overwhelmedness many caregivers expressed. For example, geriatric mental health counselors could provide valuable support as caregivers experience high levels of stress and a slow unfolding of grief and loss.

For both existing and emerging services, there appears to be a need for more **streamlined information and access**. Many respondents are not aware of available services and/or find the process of accessing information too cumbersome. A statewide public information and information dissemination campaign may be necessary to help establish clarity about the point-of-entry for information and services for older adults and caregivers. Related, such an effort should be sensitive to the increasing diversity of Vermont's population and ensure language accessibility of both print/online information and call services. This recommendation parallels the Vermont State Plan on Dementia recommendation related to public information.

As previously stated, intervention strategies to support ADRD caregivers have been developed and evaluated, however rarely translated for delivery in different service contexts and they remain generally inaccessible to ADRD caregivers. Findings from this study can be used to evaluate existing programming and shape future efforts to translate evidence-based dementia caregiving interventions into practice throughout Vermont. The evidence-based NYU Caregiver Intervention (NYUCI), created by Mittelman and colleagues, was translated and studied in Vermont between 2007-2009. While outcomes mirrored those of the original NYUCI, this randomized control trial had a very small sample, with only 10 qualified caregivers (n=6 for the intervention group; n=4 for the control group). A next study could investigate statewide implementation of this program. Another potential direction is to study the translation of person-centered care in the dementia journey. Vermont has a well-established model of person-centered and participant-directed long-term services and supports. Future research could examine the implementation of person-centered dementia care transitions.

Findings from this study can be used to evaluate existing programming and shape future efforts to translate evidence-based dementia caregiving interventions into practice throughout Vermont.

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