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Emergency and Scheduled Respite Care for Caregivers of Persons with Dementia: a Proposed Program

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INTRODUCTION

Respite care is defined as providing the primary caregiver with relief or a reprieve from care commitments on a short-term or emergency basis. (cite 1) Despite a demonstrated interest (cite 2) in and need for respite care programs, our research has shown that scarce resources exist via a statewide dementia respite program administered by Vermont's five Area Agencies on Aging (cite 3). Grants are small and many families do not fall within the eligibility requirements. In FY2010, only 290 families across the state met eligibility requirements (physicians' diagnosis of dementia, income less than 300% of poverty line, unpaid caregiver, primary residence in VT) and were awarded limited funding for the provision of outside care (up to \$750.00 each). For many of these families, this money is typically used to provide substitute care when the primary caregiver is not available. To date, there is no true emergency respite program in place for caregivers. This has placed a strain on families and day facilities, particularly when situations arise in which a caregiver is unable to pick up their family member due to an emergency situation. Our goal was to demonstrate the feasibility of a respite program to address this need.



METHODS

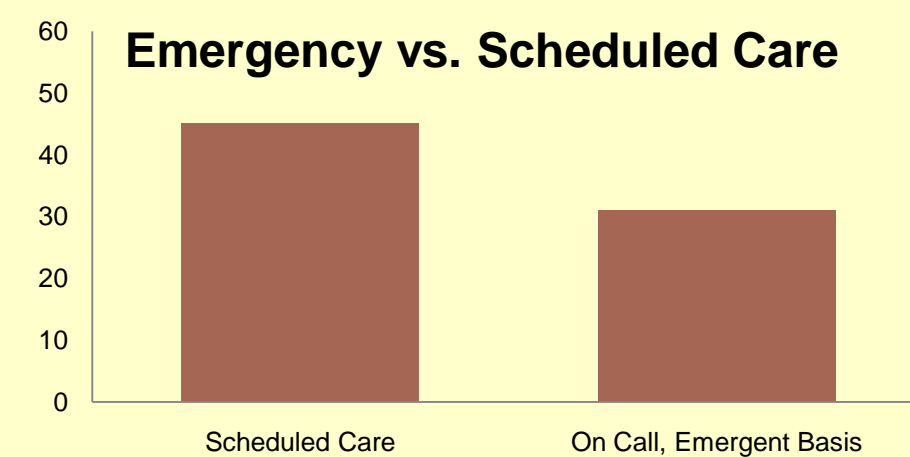
We began with a literature review and discussions with key agencies invested in the well-being of patients with dementia and their caregivers. These agencies included: The Visiting Nursing Association (VNA), Dept. of Disabilities, Aging and Independent living (DAIL), Vermont Chapter of Alzheimer's Association, and the Vermont Area Agencies on Aging. Based on the input of existing community agencies, we drafted a program proposal for emergency and scheduled respite. Recognizing the paucity of funding sources as a chief limitation to current models, we developed a survey to assess the feasibility of a volunteer-based program. An electronic survey was sent via Survey Monkey to the volunteer pool at Fletcher Allen; members of the UVM community; AARP; and the United Way of Chittenden County, which includes the RSVP Program with volunteers ≥55 years old. In an effort to reach as large a volunteer pool as possible, we cast a broad net with no expectation that the effort would yield a large number of responses, but rather to assess volunteer support and project feasibility. In addition, we investigated potential funding opportunities that the administrating agency (VNA) could pursue to provide administrative and volunteer expense reimbursement. The results of our survey, our proposed program, and suggested community and financial resources are detailed below.

RESULTS



	Expenses Pd	Expenses + Nominal Fee
UVM Community	27	19
United Way	15	8
Other	0	2

Table 1: Volunteer Interest by Group



Graph 1: Willing to provide emergency vs. scheduled care

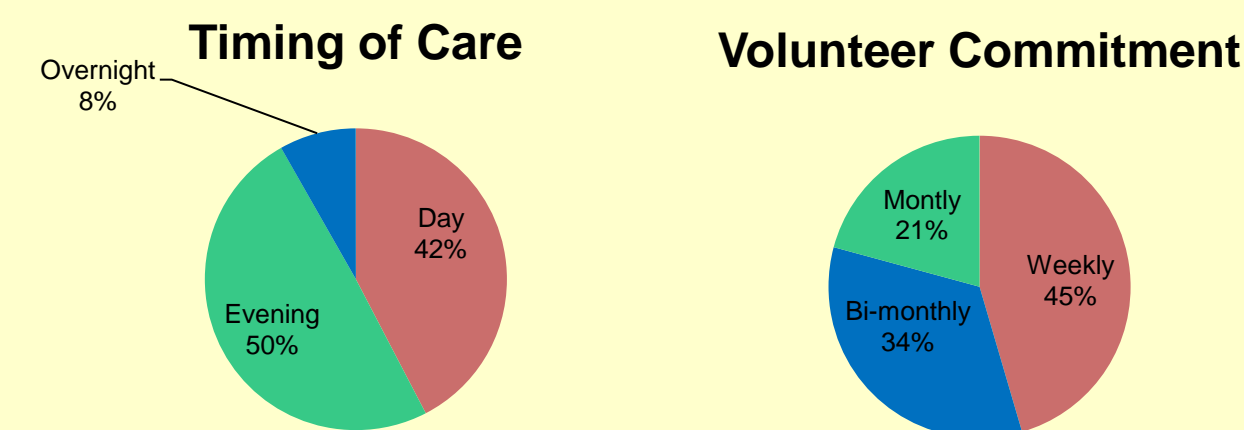
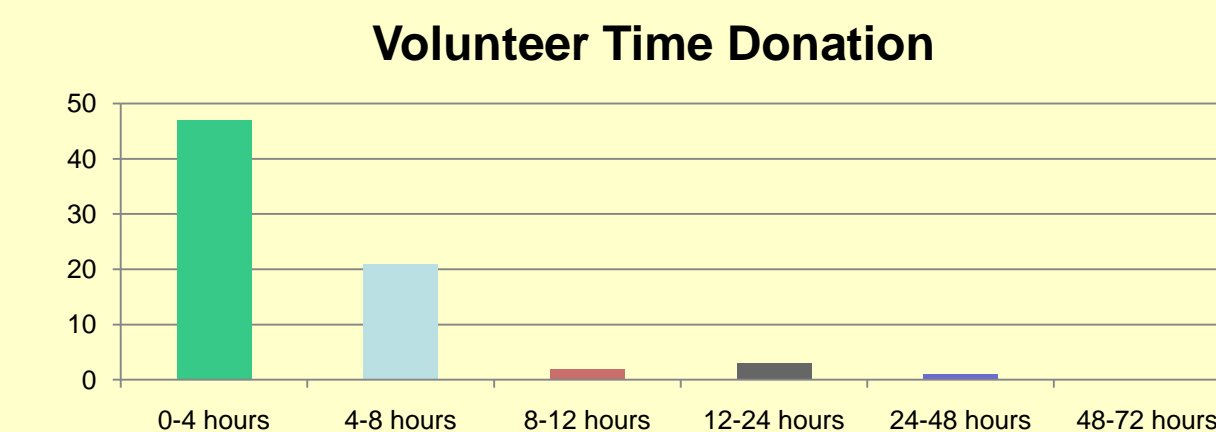


Chart 1: Timing of Care

Chart 2: Volunteer commitment



Graph 2: Volunteer Time Donation (# hours)

DISCUSSION

The results from our survey demonstrate feasibility for a volunteer-based program. Of 95 responses to our survey, 71 individuals responded that they would be willing to volunteer. Within that group, 42 individuals were willing to volunteer with expenses paid and an additional 29 were willing to participate if provided a nominal fee in addition to their expenses (Table 1).

Additionally, we surveyed willingness to participate in a training program and background check (100%), interest in coverage of emergency and/or scheduled respite care (graph 1), timing of care (chart 1), regular commitments (chart2), and donated hours (graph 2).

PROPOSED PROGRAM

Based on our results and investigations into local resources we would propose the following program and community partners:



Model

- *Provision of service: < 72 hours for on-call emergency care or scheduled respite
- *Program Administration by the Visiting Nurse Association of Chittenden and Grand Isle Counties
- *Utilization of community volunteers
 - Background Checks
 - Training Program
 - Reimbursement of out-of-pocket expenses
- *Specialized training in caring for patients with dementia

Budget

Our proposed budget includes the costs of annual administrative oversight (VNA), training (ElderWise), and estimated annual reimbursement costs for a pilot of 20 volunteers

VNA Admin. Coordinator (salary + overhead)	\$61,114
Training Costs	\$4,000
Gas Costs (est. 30 miles at 2.8 gallon at 4Xmth)	\$2,688
Food Costs (est. \$20/day at 4X mth)	\$960
TOTAL	\$68,762

COMMUNITY RESOURCES AND POTENTIAL FUNDING

Potential Community Partners:

- Administration: Visiting Nurse Association of Chittenden and Grand Isle Counties
- Training:
 - ElderWise system of Caregiving: adaptation of current 70 hour curriculum geared to non-medical caregivers. Development of standardized reporting and medication forms for consistent volunteer documentation and reporting to families. In addition, background checks could be provided through this service.
 - Alzheimer's Association: classroom and online training program

Volunteer Recruitment:

- RSVP Program (United Way of Chittenden County) has resources to recruit volunteers for the program pending established collaboration and supervision by an external agency.
- Legacy Corps is funded through the Corporation for National and Community Service (CNCS) as an AmeriCorps project. www.sph.umd.edu/hlsa/aging/legacy_corps/index.html

Funding Sources for Consideration:

- Administration on Aging: Lifespan Award: www.aoa.gov/AoARoot/AoA_Programs/HCLTC/LRCP/index.aspx#Grantees
- Medicaid Home and Community-Based Services Waiver Program: [www.cms.gov/MedicaidStWaivProgDemoPGI/05_HCBS_Waivers-Section1915\(c\).asp](http://www.cms.gov/MedicaidStWaivProgDemoPGI/05_HCBS_Waivers-Section1915(c).asp)
- Philanthropic support should be further explored with the potential for a named program.

Limitations: Although we demonstrated a viable volunteer interest base in our program, our selection of groups that we thought might have an interest in volunteering and our choice of an electronic survey were likely limitations in ascertaining broad interest in the program (including individuals in the RSVP program who lack computer access). In addition, although our data is based on 71 individuals who positively responded to our survey, 78 individuals (7 who said no to participation) went on to answer our survey questions. Finally, we worked to reach out to key agencies throughout this process but recognize that there may be additional community resources that were not identified in our efforts.

CONCLUSION

Previous research has demonstrated a need for additional services for caregivers of patients with dementia. Our group has demonstrated the feasibility of a volunteer-based program for the provision of emergency and scheduled respite care. In addition, our group has identified potential community partners and fiscal resources that should be further pursued to bring this much needed service to the community at large.

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