

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

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Background:

As the population of elderly citizens in the U.S. continues to expand, paralleled by an increase in the prevalence of dementia, the role of respite care within the healthcare system will increase in importance. Respite care is defined as providing the primary caregiver with relief, or a reprieve, from care commitments on a short-term or emergency basis.¹ The need for caregiver respite is well-documented; has been shown to decrease emotional stress, burnout, anxiety and depression; and is considered vital to the overall well-being of the caregiver.²⁻⁵ While studies have shown that respite care is effective, there is an unmet need for more flexibility in existing programs to improve utilization rates and availability.^{1,6-7} We attempted to address this issue by adapting an existing model to increase respite care options available to caregivers in our region.

Methods:

We began with a literature review on the topics of dementia and respite care. We then collected data using a four-pronged approach. In order to assess the demand, existing resources, and cost for emergency and scheduled respite care, two telephone surveys and one written survey were administered. One telephone survey was utilized to consult the site director of fourteen adult day centers in Vermont; and the other was utilized to consult four nursing homes in the greater Burlington area. The written survey was distributed to all caregivers who visited the Memory Center at FAHC, and also all caregivers of clients at the three VNA adult day program sites, between October 15 and December 4, 2009. There were a total of 45 surveys collected from the Memory Center and the VNA adult day programs. Lastly, in order to better understand the needs of caregivers and obtain feedback regarding a proposed emergency and scheduled respite care program, a focus group was conducted with seven participants, all of whom are caregivers of clients of the Memory Center. The results are tabulated in the following tables and figures.

References:

1. Jeon YH, et al. Respite Care for Caregivers and People with Severe Mental Illness: Literature Review. Journal of Advanced Nursing. 2005;49(3):297-306.
2. Hayes J. Respite for caregivers: a community-based model in a rural setting. J Gerontol Nurs. 1999;25:22-26.
3. Nicholl M, et al. Satisfaction with respite care: a pilot study. Health Soc Care Community. 2002;10:479-484.
4. Hoskins S, et al. Stress in carers of individuals with dementia and Community Mental Health Teams: an uncontrolled evaluation study. J Adv Nurs. 2005;50:325-333.
5. Gaugler J, et al. Adult day service use and reductions in caregiver hours: effects on stress and psychological wellbeing for dementia caregivers. Int J Geriatr Psychiatry. 2003;8:55-62.
6. Department of Health and Family Services. The Respite Review Report. Canberra, Australia: Commonwealth Department of Health and Family Services; 1996.
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Results

Table 1. Results of the phone interview with 14 state certified adult day centers.

Adult Day Center Data	
Average percent of participants with dementia in VT adult day centers	56.50%
Total number of emergency respite cases last year (14 sites)	38
Average number of emergency respite cases last year in each adult day center	2.5 instances
Range of respite care duration	2hours - 168 hours
Most common concern for developing an additional respite care program	Funding

Table 2. Results of the phone interview with 4 Burlington area nursing homes.

Agency	Nursing Home Data			
	Burlington	Green Mountain	Birchwood	Starr Farm
# of times asked to provide respite care	13	3	20	40
# of times able to accommodate requests (%)	75	33	50	50
Reserved beds for emergency?	no	no	no	no
Cost/day	\$280	\$252	\$450	\$299

Table 3. Key points from the caregiver focus group at the Memory Center.

Caregiver Focus Group at the Memory Center
•Face issues of considerable physical and emotional fatigue.
•Acknowledged need for respite care, especially due to burnout.
•Thought there is significant need for the proposed respite care program.
•Raised concerns about trust issues and the need for familiarity of environment.
•Asked about the idea of stage/appropriate services for the respite care program.

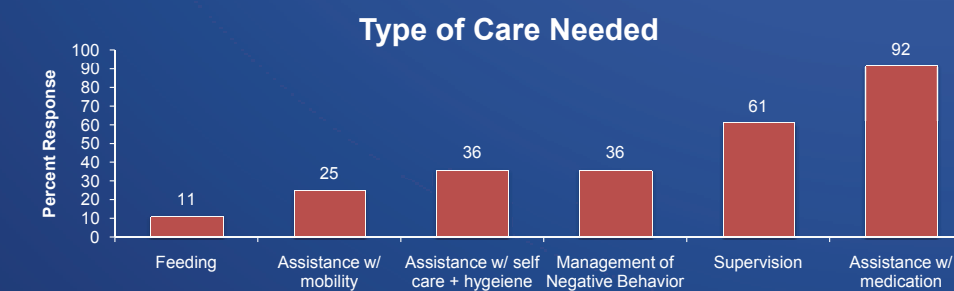


Figure 1. Percent of the respondents to the caregiver questionnaire indicating the type of care that their loved one needs.

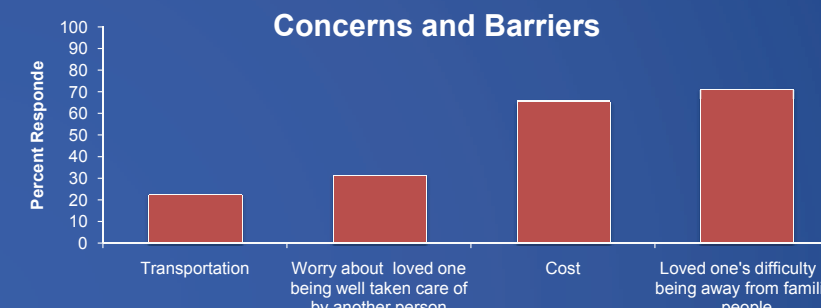


Figure 2. Percent of the respondents to the caregiver questionnaire indicating barriers to usage of the proposed respite care program.

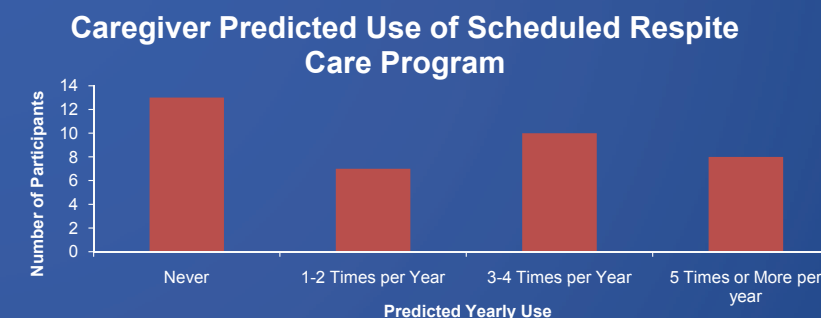


Figure 3. Number of respondents to the caregiver questionnaire who would use the proposed respite care program and how often.

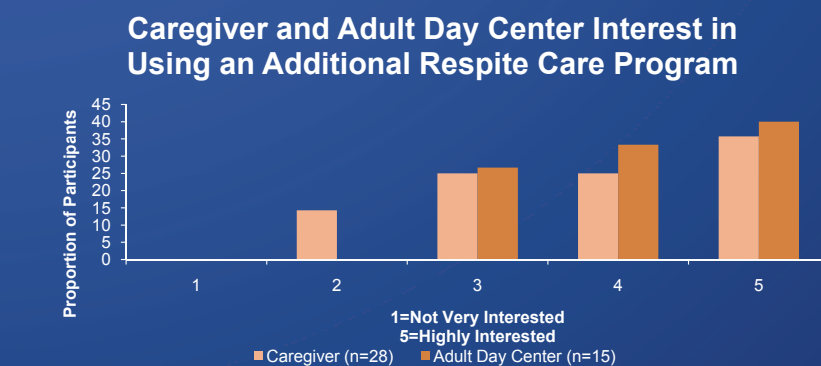


Figure 4. Comparison of the adult day center and caregiver interest in using an additional respite care program.

The Proposed Model:

The UVM Respite Care Model serves to fill a perceived gap in availability of care for persons with dementia by providing respite to caregivers in the following ways:

- Offers temporary care to persons with dementia by committed and trained volunteers.
- Provides flexible care on an emergency or scheduled basis with Host Families for up to 66hrs (e.g. weekends and nighttime) to allow caregiver respite.
- Promotes community involvement in the spirit of volunteerism to encourage the best care for persons with dementia, and the well-being of those caring for persons with dementia.
- Makes available affordable care with payment based on a sliding scale for expenses accrued.
- Host Family matched to client's physical, medical and cognitive needs; and with regard to socioeconomic status, occupation, location and Host Family setting.
- Respite care may take place either in the Host Family or client environment.
- Program coordination will be done through appropriate organizations such as the VNA and UVM's Center on Aging.
- Host Families will complete a Dementia Care Course and state required background checks.

Discussion:

Overall, our findings support the notion that there is a need for additional opportunities and flexibility for respite care. The survey of caregivers showed that 68% were interested in using a respite care program as described in the proposed model. The phone interviews of nursing homes and adult day centers demonstrated that there is an unmet need for affordable, emergency and scheduled respite care. The main concern regarding the development or use of such respite care is the cost. The focus group further highlighted the burn out experience by caregivers, and the need for emergency and scheduled respite care. Our proposed model aims to satisfy this gap in respite care while making it affordable. To conclude, further evidence that the program advocated by our poster is needed is emphasized by the following direct quotes from caregivers:

- "This program would be a lifesaver!"
 "For working individuals who are also caregivers, this overnight program would be ideal."
 "I do not know why a program [like this] is not in place."

Acknowledgements:

Raj Chawla, Dr. Tom Delaney, Dr. Jan Carney, and the members of the Memory Center Focus Group.