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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 respite care is well-documented; however, it has shown to decrease emotional stress, burnout, anxiety and depression; and is considered vital to the overall well-being of the caregiver.2,3 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.1,2,7 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 coal 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.

Results

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

<table>
<thead>
<tr>
<th>Result</th>
<th>Definition</th>
<th>Adult Day Center Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average percent of participants with dementia in VT adult day centers</td>
<td>56.50%</td>
<td></td>
</tr>
<tr>
<td>Total number of emergency respite cases last year (all sites)</td>
<td>18</td>
<td></td>
</tr>
<tr>
<td>Average number of emergency respite cases last year in each adult day care site</td>
<td>2.5 instances</td>
<td></td>
</tr>
<tr>
<td>Range of respite care duration</td>
<td>2-16 hours</td>
<td></td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Result</th>
<th>Definition</th>
<th>Nursing Home Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agency</td>
<td>Burlington</td>
<td>Green Mountain</td>
</tr>
<tr>
<td># of times asked to provide respite care</td>
<td>13</td>
<td>3</td>
</tr>
<tr>
<td># of times able to accommodate requests (%)</td>
<td>75</td>
<td>3</td>
</tr>
<tr>
<td>Reserved beds for emergency?</td>
<td>no</td>
<td>no</td>
</tr>
<tr>
<td>Cost/day</td>
<td>$2890</td>
<td>$3123</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Result</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>types of respite care</td>
<td>Number of respondents to the caregiver questionnaire who would use the proposed respite care program and how often</td>
</tr>
<tr>
<td>Need for respite care, especially due to burnout</td>
<td>Amount of time in years</td>
</tr>
<tr>
<td>Thought there is significant need for the proposed respite care program</td>
<td>Time of usage per year</td>
</tr>
<tr>
<td>Based on the idea of stage/appropriate services for the respite care program</td>
<td>Type of Care Needed</td>
</tr>
</tbody>
</table>

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.”* 

Acknowledgements:
Raj Chalise, Dr. Tom Belaney, Dr. Jan Carney, and the members of the Memory Center Focus Group.

References:

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 coordinating trained volunteers.
- Provides flexible care on an emergency or scheduled basis with Host Families for up to 66 hours (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.
- 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.

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