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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. The need for caregiver respite 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. To the best of our knowledge, this is the first study to evaluate the demands and needs of caregivers providing respite care for persons with dementia.

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 conduct 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.

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

<table>
<thead>
<tr>
<th>Adult Day Center Site</th>
<th>Average percent of participants with dementia in VT adult day centers</th>
<th>56.50%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Gilt number of emergency respite cases last year (14 sites)</td>
<td>38</td>
</tr>
<tr>
<td></td>
<td>Average number of emergency respite cases last year in each adult day center</td>
<td>2.5 instances</td>
</tr>
<tr>
<td></td>
<td>Range of respite care duration (hours)</td>
<td>20-60 hours</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Agency</th>
<th>No. of nursing homes</th>
<th>No. of times asked to provide respite care</th>
<th>No. of times able to accommodate requests (%)</th>
<th>% of residents who need respite care for emergency?</th>
<th>% of residents who have used respite care in the past year?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Burlington</td>
<td>13</td>
<td>75</td>
<td>50</td>
<td>50</td>
<td>50</td>
</tr>
<tr>
<td>Green Mountain</td>
<td>3</td>
<td>10</td>
<td>50</td>
<td>50</td>
<td>50</td>
</tr>
<tr>
<td>Birchwood</td>
<td>20</td>
<td>75</td>
<td>50</td>
<td>50</td>
<td>50</td>
</tr>
<tr>
<td>Starr Farm</td>
<td>10</td>
<td>75</td>
<td>50</td>
<td>50</td>
<td>50</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Caregiver Focus Group at the Memory Center</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>If one issue of considerable physical and emotional fatigue</td>
<td>Acknowledged need for respite care, especially due to burnout.</td>
</tr>
<tr>
<td>Thought there is significant need for the proposed respite care program</td>
<td>Based concerns about trust issues and the need for familiarity of environment.</td>
</tr>
<tr>
<td>Asked about the idea of stage/appropriate services for the respite care program</td>
<td>Acknowledged need for respite care, especially due to burnout.</td>
</tr>
</tbody>
</table>

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 certified and trained volunteers.
- Promotes 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.
- Caregivers 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 for 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.”

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