Trends in Family Caregiving
Drawing from Caregiving Research Studies

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NATIONAL ALLIANCE
FOR CAREGIVING
Overview

• Study of the e-connected family caregiver: from caregivers who are already on-line, what do they think about 12 technologies to help caregivers? What are barriers to technologies? What sources of information do they trust?

• First-ever study of caregivers of Veterans: their demographics and the challenges that they face

• Study of Alzheimer's caregivers and what made them think that their family member had the disease
Study on Caregiving Technology

2010 study on family caregivers' receptivity to technology.

Evaluated 12 technologies -- helpfulness and barriers to use.

Screened online panelists to identify 1,000 technology-using family caregivers:

- Age 18 or older
- Provided at least five hours per week of unpaid care
- Had already used some sort of technology to help them with caregiving
  (such as searching for caregiving information or support on the Internet, participating in an online forum or blog, using an electronic calendar or organizer, or using some other device or system)
## Helpfulness of Technology

<table>
<thead>
<tr>
<th>Feature</th>
<th>Very Helpful</th>
<th>Somewhat Helpful</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Personal health record tracking</strong></td>
<td>45%</td>
<td>32%</td>
<td>77%</td>
</tr>
<tr>
<td>A website or computer software to keep track of patient history, symptoms, medications, tests, etc.</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td><strong>Medication support system</strong></td>
<td>42%</td>
<td>28%</td>
<td>70%</td>
</tr>
<tr>
<td>Reminder/dispenser, alerts caregiver if dosage not removed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Symptom monitor and transmitter</strong></td>
<td>40%</td>
<td>31%</td>
<td>70%</td>
</tr>
<tr>
<td>Sends symptom readings to dr. or care manager, and allows tracking over time</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Caregiving coordination system</strong></td>
<td>35%</td>
<td>35%</td>
<td>70%</td>
</tr>
<tr>
<td>Shared electronic log for appts, volunteers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Interactive system for physical, mental, and leisure activities</strong></td>
<td>35%</td>
<td>31%</td>
<td>66%</td>
</tr>
<tr>
<td>With menu of physical/mental activities</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Technology</td>
<td>Very Helpful</td>
<td>Somewhat Helpful</td>
<td>Total</td>
</tr>
<tr>
<td>------------------------------------------------</td>
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<td>--------</td>
</tr>
<tr>
<td>Video phone system</td>
<td>33%</td>
<td>29%</td>
<td>61%</td>
</tr>
<tr>
<td>Passive movement monitoring system</td>
<td>31%</td>
<td>27%</td>
<td>58%</td>
</tr>
<tr>
<td>Caregiver training simulations</td>
<td>22%</td>
<td>30%</td>
<td>52%</td>
</tr>
<tr>
<td>Caregiving decision support tool</td>
<td>21%</td>
<td>31%</td>
<td>52%</td>
</tr>
<tr>
<td>Caregiving coaching software</td>
<td>21%</td>
<td>26%</td>
<td>48%</td>
</tr>
<tr>
<td>Transportation display</td>
<td>21%</td>
<td>22%</td>
<td>43%</td>
</tr>
<tr>
<td>Caregiver mentor matching service</td>
<td>11%</td>
<td>24%</td>
<td>36%</td>
</tr>
</tbody>
</table>
Study of Caregivers of Veterans

2010 study of caregivers who provide care to a veteran with an injury or illness due to service

To learn about their challenges and needs

Information gathered through:

- 45 qualitative interviews
- 6 focus groups
- 462 caregivers in online study – snowball sample
## Basics of the Caregiving Situation

<table>
<thead>
<tr>
<th></th>
<th>Caregivers of Veterans (n=462)</th>
<th>Caregivers of Adults Nationally (n=1,307)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female caregiver</td>
<td>96%</td>
<td>65%</td>
</tr>
<tr>
<td>Spousal caregiver</td>
<td>70%</td>
<td>6%</td>
</tr>
<tr>
<td>Caregiver lives with care recipient</td>
<td>80%</td>
<td>23%</td>
</tr>
<tr>
<td>Primary caregiver</td>
<td>82%</td>
<td>53%</td>
</tr>
<tr>
<td>Caregiving for 10 years or more</td>
<td>30%</td>
<td>15%</td>
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# Impact of Caregiving

<table>
<thead>
<tr>
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<th>Caregivers of Veterans (n=462)</th>
<th>Caregivers of Adults Nationally (n=1,307)</th>
</tr>
</thead>
<tbody>
<tr>
<td>High emotional stress (4+ on 5-point scale)</td>
<td>68%</td>
<td>31%</td>
</tr>
<tr>
<td>High physical strain (4+ on 5-point scale)</td>
<td>40%</td>
<td>14%</td>
</tr>
<tr>
<td>Stopped working or took early retirement (among those who worked while caregiving)</td>
<td>47%</td>
<td>9%</td>
</tr>
<tr>
<td>High financial hardship (4+ on 5-point scale)</td>
<td>50%</td>
<td>13%</td>
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</tbody>
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Top Challenges

• Not knowing what to expect medically with the veteran’s illness or condition

• Not being aware of services the VA has that can help veteran or caregiver

• Not knowing how to address certain behaviors or problems related to his/her PTSD or mental illness [IF RELEVANT]

• Difficulty getting through bureaucracy in order to obtain services for veteran

• Not knowing where to turn to obtain financial assistance

• Not knowing where to turn in order to arrange a break from caregiving
Key Recommendations

1) Provide Training and Information for Common Veteran Conditions
   • Create condition-specific caregiver information packets and training.
   • Offer a toll-free 24-hour phone line with support, information, and referrals.

2) Harness the Word of Mouth by Helping Caregivers Help One Another
   • Develop a central website for caregiver support groups, forums, and blogs.
   • Establish a caregiver peer mentoring program.

3) Teach Caregivers About Resources That Are Available
   • Ensure that all caregivers receive a directory of VA programs and services as well as other governmental and community caregiver resources.
   • Teach caregivers about advocacy resources and methods.
   • Create a list of financial assistance resources available to veterans and their caregivers.
   • Direct caregivers to legal assistance.
   • Facilitate caregiver searches for specialized care facilities.
Key Recommendations

4) Help Caregivers Find Respite and Relief
   • Develop programs that connect caregivers of veterans with volunteers.
   • Help caregivers find respite care.
   • Improve veteran transportation services.

5) Improve Dissemination of Existing Resources
   • Package existing information in a way clearly meant for family caregivers.
   • Review existing materials to ensure that they meet caregivers’ needs.
   • Improve methods for connecting caregivers to existing information.

6) Sensitize Health Care Providers to Caregivers’ Role
   • Periodically sensitize health providers about the important role that caregivers play in providing care to veterans.
   • Ensure that caregivers are shown how to properly administer medical treatments, care, or medications.
   • Empower care managers to provide services for the caregivers themselves.
2011 study of 1,000 family caregivers of people with Alzheimer's, using an on-line panel.

Purpose two-fold:
1) what were initial signs of diagnosis
2) what were positive as well as negative aspects of caregiving
Positive as Well as Negative Aspects

• Half say experience was equally positive/negative

• Positives: chance to give back; closer personal relationship

• Related to stage of illness; whether there was a choice
Signs of Disease

• Nine of ten caregivers were first to see signs: trouble remembering conversations or words

• For nearly half, it was 2yrs+ between first symptoms and caregiver being certain

• 91% have had doctor confirm diagnosis, about half by primary care doc
What do Caregivers do after Diagnosis

- Go for info to docs first (70%), then Internet (48%), family and friends (32%), and Alzheimer's Association (27%)

- Actions taken:
  
  Arranged for care recipient to see doc (94%)
  
  Spent more time with them (91%)
  
  Researched Alzheimer's (90%)
  
  Got involved with finances (86%)
  
  Restricted his/her driving (84%)
Trends to Watch for in Caregiving Policy

- Alzheimer's--NAPA
- Caregiver assessment
- Paid caregiving
- Respite care--lifespan respite and respite senior employment programs
For More Information:

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  • gailhunt@caregiving.org

• National data on family caregiving:
  • www.caregiving.org