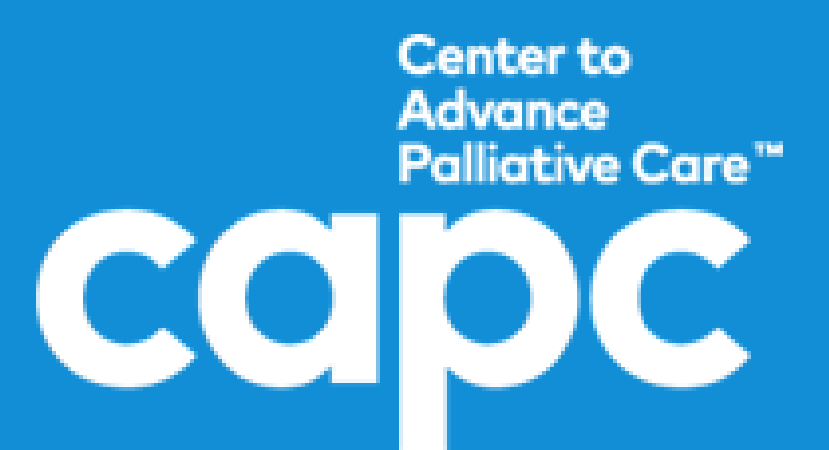


Identifying the Needs of Family Caregivers of Dementia and Alzheimer's Disease Patients: A National Survey



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 A collaboration between Center to Advance Palliative Care (CAPC) and West Health Institute (WHI)

Objectives

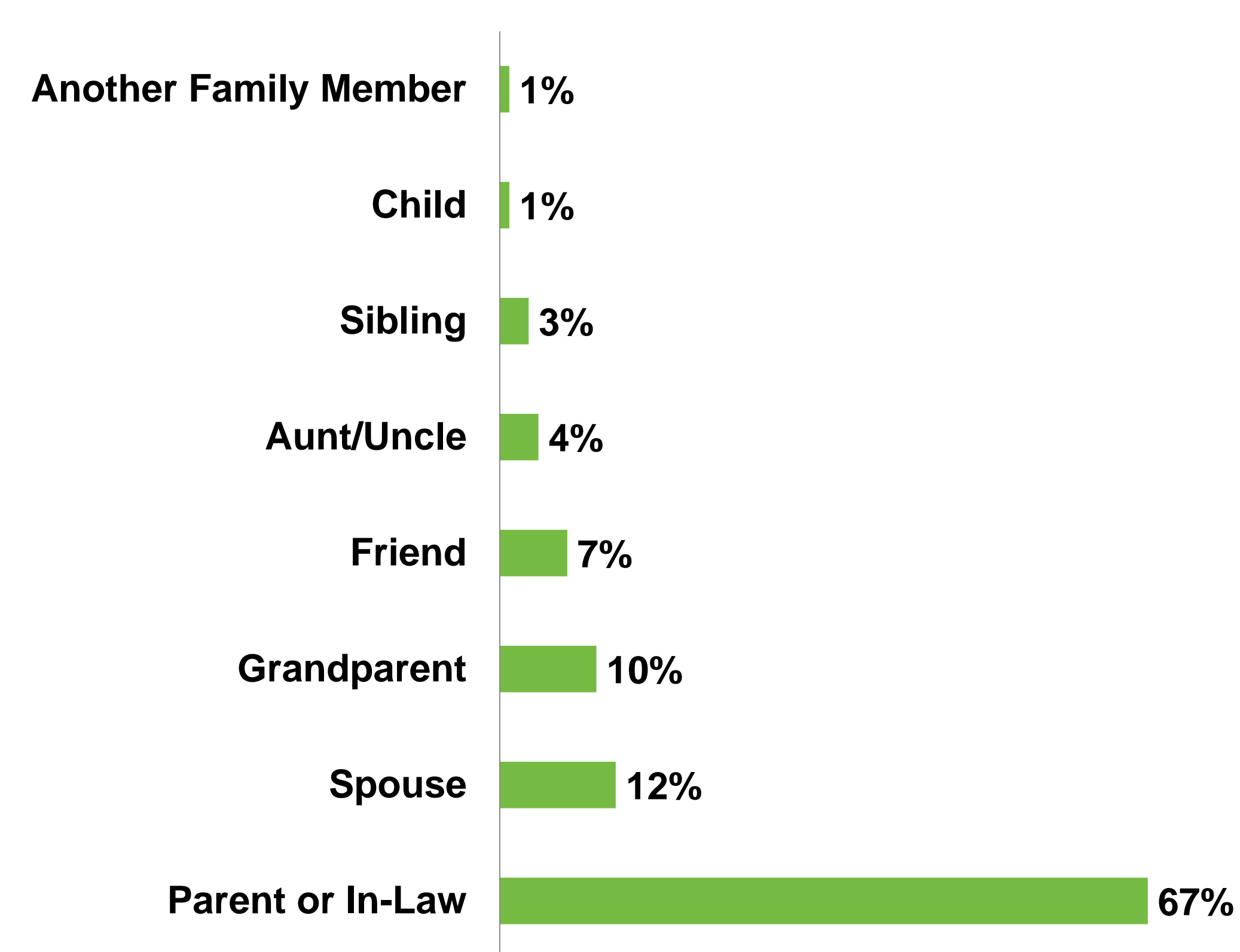
1. Characterize challenges and needs of family caregivers caring for a loved one with dementia
2. Understand whether family caregivers receive information about caregiving strategies from online content

Methods

Public Opinion Strategies (POS) developed a national survey in collaboration with CAPC and WHI based on feedback from focus groups. The survey was conducted in January 2017 using an opt-in online panel of people who have consented to participate in survey research. Survey participants (N=500 family caregivers) were matched to national family caregiver demographics and met a set of inclusion criteria around unpaid caregiving for a loved one with Alzheimer's disease or dementia. Participants answered a series of questions around challenges, gaps in learning, and preferred educational formats.

Respondents

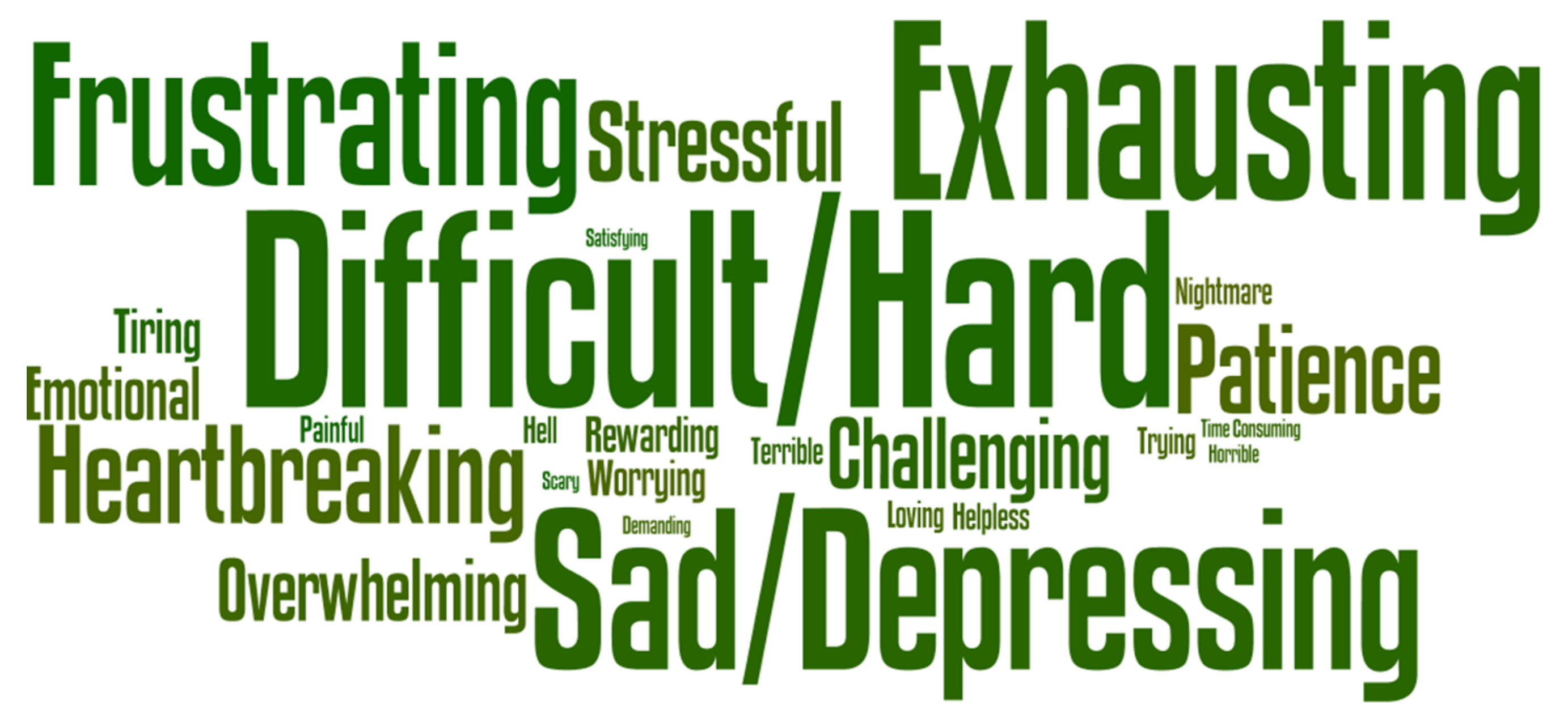
Profile of respondents by loved one they care for:



Note: The percentage of respondents totals greater than 100 because respondents were allowed to select more than one answer choice.

Results

Words caregivers use to describe their experience caring for their family member or friend with Alzheimer's or Dementia:



Most challenging behaviors (Percentage ranked as 1 st Choice)	
Agitation or Aggression	25%
Repetitive speech or actions	12%
Wandering or restlessness	10%
Incontinence or constipation	10%
Late-day confusion	8%
Sleeplessness	6%
Refusal to eat	5%
Paranoia	5%
Refusal to take medicine	4%
Hallucinations	5%
Refusal to bathe	4%
Choking on food or liquids	4%

Biggest caregiving challenges (Percentage ranked as 1 st Choice)	
Dealing with memory loss and impact of the disease on your loved one	25%
Handling the stress and emotional toll on self	16%
Having patience with your loved one	15%
Handling loved one's mood swings or behavior changes	12%
Daily activities (bathing, bathroom, dressing, meals)	11%
Keeping loved one positive and motivated	8%
Bills, finances, health insurance	4%
Managing and administering medications	3%
Speaking with loved one's health care providers	2%
Scheduling appointments and time management	1%

Discussion

Caregiver Training

- Caregivers are highly interested in learning more about what to expect at every stage of illness and how to manage behavior changes in their loved one.
- Dementia caregivers expressed interest in receiving information in a number of formats, and ranked fact sheets, checklists, and educational videos as the most likely to use.
- Over half (55%) of respondents do not use online tools to help them care for their loved one. Among those who have used online resources, Alz.org, Web MD, and Google were most highly utilized.

Conclusion

- In addition to handling the stress and emotional toll of caregiving, family caregivers struggle to manage treatment options for their loved one and to cope with their loved one's memory loss. Training and assistance for caregivers in disease and behavior change management, as well as training around mindfulness and other forms of stress relief, are important for preventing caregiver burnout and sustaining this informal, but critical, workforce.

Dementia-Friendly Health Systems Initiative

In response to these research findings, CAPC and WHI have developed a project focused on training providers in the clinical and operational aspects of caring for dementia patients and supporting their family caregivers. Over the course of the coming two years, CAPC and WHI will collaborate with national leaders in dementia care to develop a series of continuing education courses and a dementia care toolkit for all providers who encounter people with dementia and their caregivers. Training will include how to assess for and alleviate caregiver burden, best practices in dementia care, and connecting family caregivers to community resources.

