

# Formative Research on Needs and Supports for Family Members Caring for a Person with Cognitive Impairment

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## Introduction

There are an estimated 15 million family caregivers in the U.S. who are assisting seniors with functional and cognitive limitations. Family caregivers manage household tasks and finances, provide personal care and hygiene, and serve as care coordinators, thereby allowing the person living with dementia to remain in the community. In this formative research, we aimed to identify the training and resources caregivers need, the areas where they want to learn more, and obtain a better understanding of their unique challenges.

## Methods

- Public Opinion Strategies conducted 4 in-person focus groups (n = 36) in Chicago and an online survey (n = 500) with family caregivers. Family caregivers were recruited to meet certain criteria and gave informed consent.
- Family members were unpaid relatives, partners or friends who currently, or in the past year, cared for a family member or friend with dementia or Alzheimer's disease. In the focus groups, family caregivers who cared for person with a stroke or Parkinson's disease were also included.
- Family caregivers were asked about experiences, challenges and needs for guidance. In the focus groups, they ranked images that resonated with their experience.

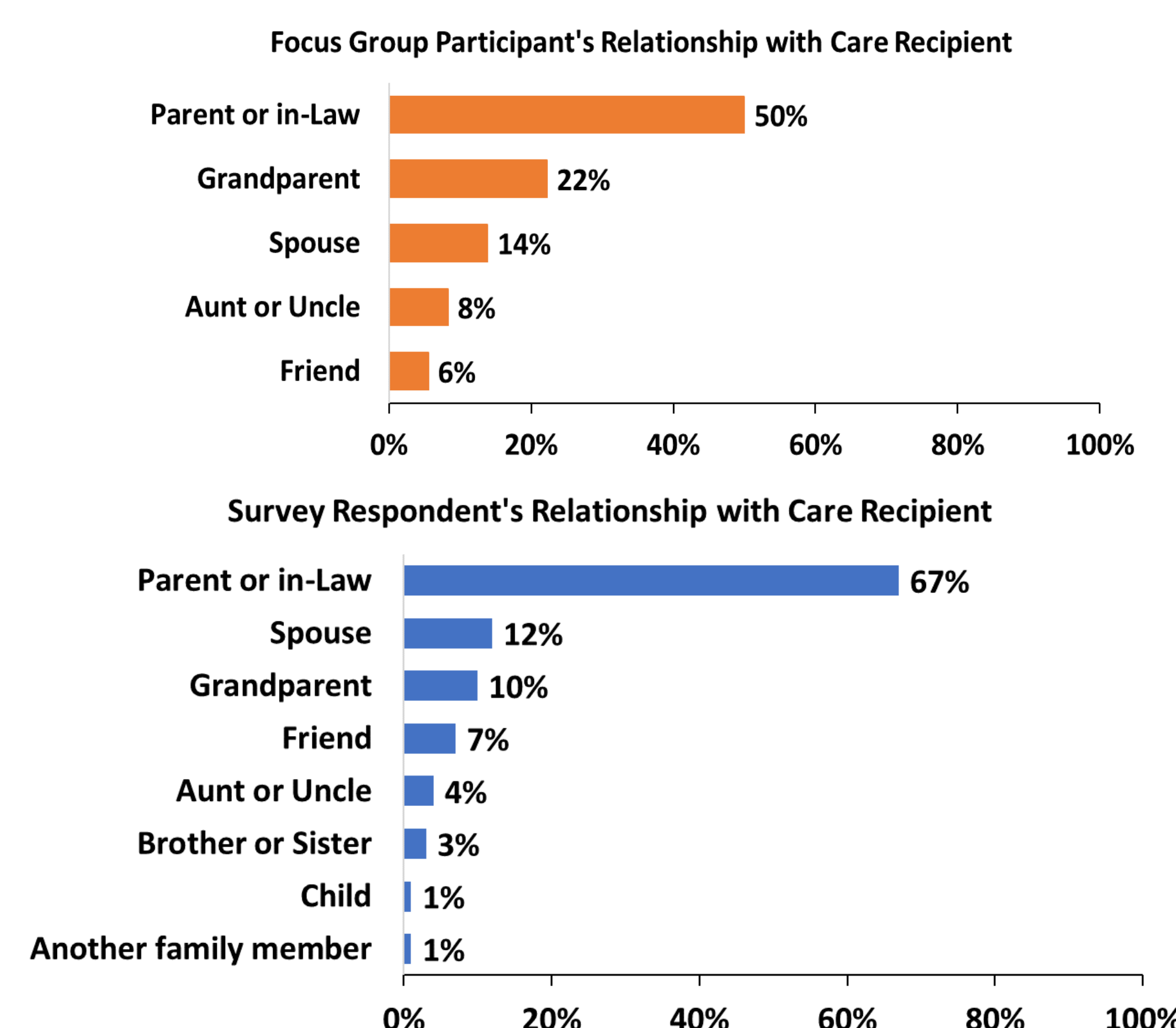


Figure 1: Relationship of focus groups and survey respondents to care recipients

## Results

### Focus Group Findings

#### Challenges in caring for a loved one with dementia: Sample of caregiver's voice from in-person focus groups

- "Having to always be available for them. Keeping them positive. Remembering who she was before her illness."
- "Keeping a positive attitude – patience. Making enough time in the day to assist with everyone's needs. Maintaining two households. Keeping track of finances- making financial decisions. Researching illnesses."
- "Reorganizing my life around his illness. Making him understand that things will not be the same. Convincing him he can have a good quality of life. Understanding his mental choices. Handling his outbursts toward life."
- "Bathroom duties. Watching their health decline. Trusting the doctors and medicine. Scheduling and time. Guilt."



Figure 2: Word Cloud of focus group participants' responses to challenges they face. The larger the word, the more prominent the response.

#### Caregivers' choice of images that resonate with experiences in focus groups



Family caregivers rated these images **highest** as they depicted happiness, love, support, hope and bonding in both care recipient and caregiver.

Family caregivers rated these images **lowest** as they seem sad or hopeless and did not include a caregiver (left image).

### Survey Findings

Most challenging behaviors (Percentage ranked as 1 <sup>st</sup> Choice)		Biggest caregiving challenges (Percentage ranked as 1 <sup>st</sup> Choice)	
Agitation or Aggression	25%	Dealing with memory loss and impact of the disease on your loved one	25%
Repetitive speech or actions	12%	Handling the stress and emotional toll on self	16%
Wandering or restlessness	10%	Having patience with your loved one	15%
Incontinence or constipation	10%	Handling loved one's mood swings or behavior changes	12%
Late-day confusion	8%	Daily activities (bathing, bathroom, dressing, meals)	11%
Sleeplessness	6%	Keeping loved one positive and motivated	8%
Refusal to eat	5%	Bills, finances, health insurance	4%
Paranoia	5%	Managing and administering medications	3%
Refusal to take medicine	4%	Speaking with loved one's health care providers	2%
Hallucinations	5%	Scheduling appointments and time management	1%
Refusal to bathe	4%		
Choking on food or liquids	4%		

#### Caregivers' preferred methods of receiving information

- Caregivers were 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, webmd.com, and Google were most highly utilized.

## Conclusions and Next Steps

Family caregivers face significant challenges in caring for persons with dementia or Alzheimer's disease. Comprehensive care for patients with dementia and their caregivers is lacking in the health system today, even though caregivers report clinicians as a trusted source for information. The Center to Advance Palliative Care and West Health Institute will work to fill this gap by developing training and operational toolkits for health systems and clinicians. This training will address topics such as assessing for and alleviating caregiver burden, connecting family caregivers to community resources, building assessments into workflows, and operationalizing best practices in dementia care.