

# Focus Group Findings on Needs and Supports for Family Members Caring for a Loved One with Cognitive Impairment

Jill Slaboda, PhD<sup>1</sup>, Robin Fail, MPP<sup>2</sup>, Brynn Bowman, MPA<sup>2</sup>, Amy Wade, MPH<sup>1</sup>, Lisa Morgan<sup>3</sup>, and Gregory J. Norman, PhD<sup>1</sup>

(1) Gary and Mary West Health Institute; (2) Center to Advance Palliative Care; (3) LDM Strategies



## Introduction

There are a reported 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 senior to remain in the community and avoid institutionalization. In this formative research, we aimed to identify the training or resources caregivers need, the areas where they want to learn more and obtain a better understanding their unique challenges.

## Methods

- Public Opinion Strategies conducted 4 in-person focus groups (n=36) in Chicago and 1 online bulletin board focus group (n=20) with family caregivers in Sept. and Nov. 2016. 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, Alzheimer's disease, stroke or Parkinson's disease.
- In-person focus groups were separated by age, race and ethnicity.
- Family caregivers were asked about experiences, challenges and needs for help and guidance. They ranked images that resonated with their experience.

Who is the person you care for?				
Parent/In Law	Grandparent	Spouse	Aunt/Uncle	Friend/Sibling
26	11	8	4	7
What disease does the person you care for have?*				
Dementia	Alzheimer's	Parkinson's	Stroke	
34	18	7	6	
Currently vs. past year providing care for a family member or friend with these type of illnesses?				
Currently		Past Year		
48		8		

\* Nine respondents listed multiple illnesses.

Figure 1: Characteristics of focus groups and online bulletin board focus group combined

## Results

### 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."

### Top 5 areas caregivers want to learn more about (chosen from a list of options)

In-person Focus Groups	Online Bulletin Board Focus Group
1. Dealing with other medical conditions and possible complications.	1. How to manage behavioral changes such as screaming, aggression, agitation, paranoia, hallucinations, restlessness, wandering, late-day confusion.
2. Knowing what to expect at every stage of the illness.	2. Dealing with other medical conditions and possible complications.
3. How to manage behavior changes such as screaming, aggression, agitation, paranoia, hallucinations, restlessness, wandering, late-day confusion.	3. How to talk with doctors/the essential questions you should ask your loved one's doctor.
4. How to manage medication.	4. How to know when you need to seek medical help and when it may be necessary.
5. How to talk with doctors/the essential questions you should ask your loved one's doctor.	5. Assistance in decision-making and coordinating care with family members and others.

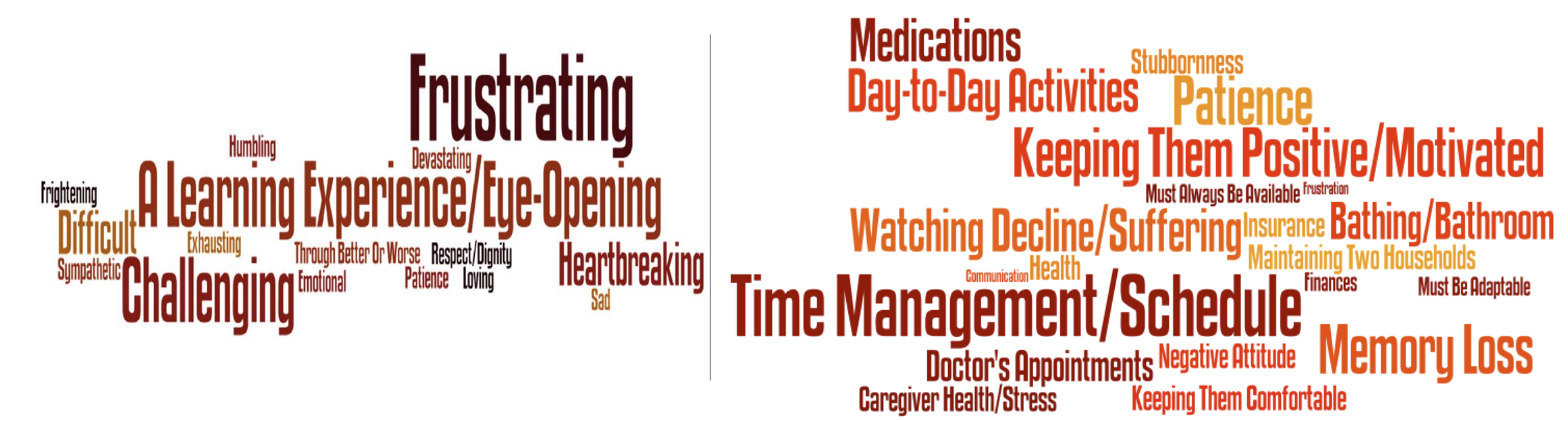


Figure 2: Word cloud of caregiver challenges during online bulletin board focus group (left) and in-person focus groups (right)

### Tools, resources and materials caregivers felt would be helpful

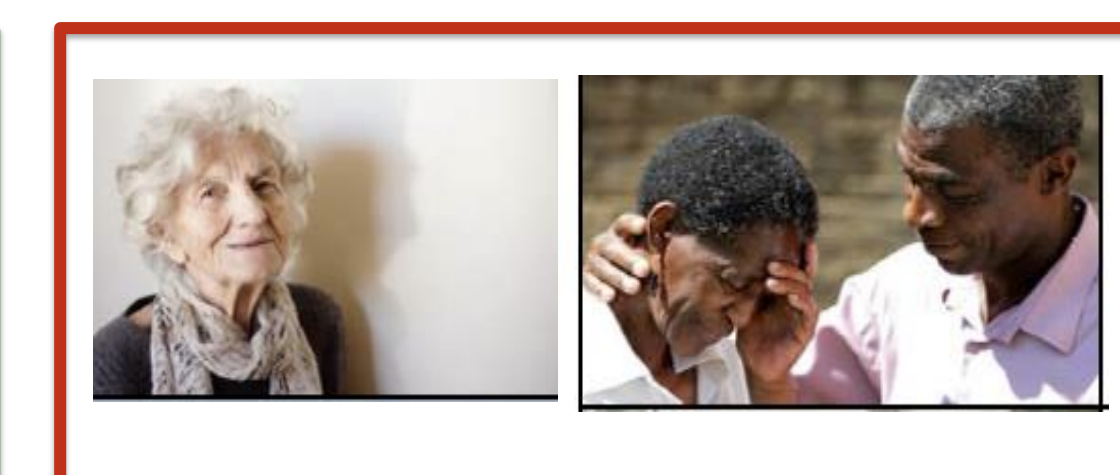
Most participants were not aware of resources for help and have little to no training on how to deal with their challenges.

- ✓ Caregivers wanted a way to interact and connect to other family caregivers to share advice and experiences. They need more emotional support and help learning how to become a better caregiver.
- ✓ Specific suggestions were an online forum for caregivers, desire for a network that can help within their community, factsheets of different example scenarios that caregivers face and how to respond/handle, and 24/7 communication with healthcare professionals.

### Caregivers' choice of images that resonate with experiences in focus group and online bulletin board 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).

## Conclusions and Next Steps

Family caregivers are facing significant challenges in caring for a person with dementia. Comprehensive care for patients with dementia and their caregivers is still lacking in the health system even though caregivers report clinicians as a trusted source for information. CAPC and WHI will 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 and building assessments into workflows, best practices in dementia care and how to operationalize these practices, and connecting family caregivers to community resources.

