

Rachel Harris

## **Introduction**

As the population ages, there is an increase in numbers of adults living with symptoms of cognitive impairment. The most common medical diagnosis in cognitive impairment is Alzheimer's Disease; however, there are many related disorders seen such as Vascular, Lewy Body and Frontotemporal lobe dementias (Johansson, Marcusson, & Wressle, 2015). For the purposes of this project, the term "dementia" will encompass any medical diagnosis related to cognitive impairment disease. The vast burden of care for those living with any type of dementia often falls to family caregivers (Alzheimer's Association, 2019). The family caregivers may have little to no preparation or training for this care and experience great stress as they must adapt to their new role. Family caregivers require education and training to improve their care for those living with dementia and such education may reduce caregiver burden. It is not well understood yet what types of education and training best helps the family caregiver understand dementia and improve their caregiving skills.

## **Background**

Dementia impacts between 17 and 25 million people world-wide and can affect many parts of the brain's functioning including: memory, impulse control, and personality. Dementia varies very differently from normal aging. With dementia, information that is recently obtained cannot be stored correctly (Dementia Alliance of North Carolina (DANC), 2019). The number of aging people is increasing as well. For the first time in the history of the United States, the number of older adults is greater than the number of children (US Census, 2018). According to the U.S.

Census Bureau's 2017 National Population Projections, in the year 2030 one out of every five residents will be retirement age. Because dementia can impact an individual's ability to take care of themselves, they often rely on the caregiving of a family member. In fact, more than 16 million Americans provide unpaid care for people with Alzheimer's or other dementias (Alzheimer's Association, 2019).

Caregivers give up a lot of their own independence, as well as bear the burden of the financial costs of caring for a person with dementia. It is estimated that these family caregivers devote 18.5 billion hours of care annual in the US. According to the Alzheimer's Association (2019), \$290 billion dollars will have been spent by the end of this year for medical and other expenses associated with Alzheimer's and other dementias. The estimated cost will rise to \$1.1 trillion by the year 2050 (Alzheimer's Association, 2019).

Social support has been thought to improve the well-being of family caregivers of dementia patients and perhaps reduce risk of elder abuse (Dam et al., 2016; Serra, et al., 2018). Improving caregiver self-efficacy was also shown to improve quality of life among dementia caregivers (Zhang, Edwards, Yates, Li & Guo, 2014). Other studies have examined depression and quality of life (Lee, Lee, Choi, Lim & Moon, 2019) but have not explored family caregiver preferences for educational experiences and support.

### **Purpose**

The purpose of this project was to explore the methods that have best helped family caregivers of a person living with dementia gain knowledge and support. By using a qualitative descriptive design, the family caregiver could explain directly to the researcher their preference for education and support. Use of qualitative inquiry in a phenomenon that has not previously

been examined thoroughly is appropriate (Kegler, etc., 2019). The research question for this study was: What support has best helped you to understand and best manage your care of someone living with dementia?

### **Methods**

This study was a small qualitative descriptive inquiry. The study was approved by the University and Medical Center Institutional Review Board. The participants were five women who were caring for a person living with dementia in rural eastern North Carolina and agreed to participate and signed informed consent. The participants were approached at a Geriatric Workforce Enhancement Program grant-provided community-based event that taught caregiving strategies using two commercial products, the Virtual Dementia Tour™ and the Positive Approach to Care®. Both products together contribute to the understanding of living with the disease by simulating the sensory deficits and challenges and provision of strategies to manage behaviors associated with dementia. Each participant was interviewed, and a digital recording was collected during the interview. The leading question was: “What through your experience has best helped you the most to understand people living with dementia?” Refining questions included “what changes will you make in your caregiving based on education from caregiving events,” “are you able to utilize skills that you’ve learned to teach others,” and “if a family caregiver came to you and asked for advice on how to better understand dementia, what advice would you give them?” These questions were used to solicit information about best educational offerings and support.

The participants were from four eastern NC counties and ranged in caregiving experience from 2.5 years to over 30 years. All the participants had experiences as paid and unpaid (family)

caregivers. There were no male participants, however, this was an expected finding since most caregivers tend to be female in the setting used.

The first researcher was a novice undergraduate senior nursing student and the second researcher a seasoned qualitative nurse scientist with experience in qualitative methods, and an educator in geriatric and family caregiving. The interviews were transcribed verbatim by the first researcher and reviewed for accuracy by the second. Each researcher reviewed the transcripts and determined individual themes. Then the researchers met as a team and determined the final themes and thematic definitions.

## **Results**

### **Theme 1: Hands on learning**

The first theme was the idea of hands-on learning. The participants enjoyed actively participating in learning about dementia by using their hands and practicing in a real-life scenario rather than listening or reading about the same material. Participant one highlighted hands-on learning by stating “I prefer to be hands-on... the more I do it, the more I get it and the more I know what for do..”. Participant five agreed and said, “experiential learning is always beneficial because you ingrain it differently.”

### **Theme 2: Frustration and patience**

The second theme illustrated the emotional toil experienced by the caregiver. In all the interviews, frustration and patience was discussed. Most conveyed that frustration was inevitable and that it was the caregiver's responsibility to have patience. It was important to understand that the person with dementia was not trying to be frustrating on purpose. Participant three emphasized that a caregiver should “just listen and don't react to their behaviors.” Participant

one said that “you control the atmosphere; you control it because they no longer have that control so it’s up to you as the caregiver...”. She said that her favorite saying was “you can go through the same situation with a new set of eyes.” By seeking out educational events that help develop a deeper understanding of dementia, participants said that it made caregiving easier. In order to develop patience, a better understanding of why the person with dementia is acting in the way that are reduces that frustration. Therefore, education is important.

### **Theme 3: Education leads to sharing knowledge**

In all of the interviews, the participants mentioned seeking information about dementia from other peers and in turn, teaching their peers what they have learned about dementia. After participating in a caregiver event, many of the participants remarked that they attempted to teach their family and friends what they had learned. In one case, the participant said that she did not teach her family because the family members felt it was too emotional or tough to deal with the decline of their family member and that they did not want to know more. This participant stated, “dementia is hard. It’s hard for family and friends to accept so everyone is not going to get it or rather shy away from it, you know?”

For four participants, the information that they learned at community caregiving events would be passed on as possible. Participant five wished that “there was some way to mimic that learning. Describing that could have a little bit of an impact, but by experiencing it - that is way different.” Participant four wanted to be able to share an impactful video that Teepa Snow, nationally recognized expert in managing dementia related behaviors, created about Alzheimer's Disease with her own family because she thinks it would be helpful for their understanding.

Not only does participant one use her formal nursing assistant education at work with residents living with dementia, she also teaches her family so that they can be better caregivers as well. She said that she “takes the education that I have, and I instill in in my son...What I get, I give back.” Later, she stated, “I feel like you shouldn’t do care taking just for the money. And you have a lot of people who are here just for the money and it’s just a job.”

#### **Theme 4: Understanding the person before dementia**

The last theme derived from these interviews was related to understanding how the person was before dementia. Participants noted that it was important to find out as much about the person before dementia as possible. For example, learning what their hobbies were, where they lived, what language was their first language, what they did for a living, and tips about what was their personality like prior to dementia all helped when working with the person. The understanding of the person before dementia was easier if you were a family caregiver or knew them personally before the illness. Participant four noted that her mother was a stay at home mother and that even with dementia, her mother still tried to take care of her husband and children even when she was mentally declining. She claimed that her mother “is always in that routine of cooking and doing that, and she wears herself out.” Participant two would encourage a caregiver to “get to know as much about that person as possible. If you want information about the person before this happened, you have a better shot at bonding with them.”

#### **Discussion**

The four themes in this study demonstrated the participants’ views on helpful education strategies and knowledge that supports caregiving. The participants strongest favorite experience

was the hands-on learning of skills. Caregivers liked trying out techniques, seeing videos of actual patients and talking about what works with their person. It was very clear that frustration was inevitable in caregiving; however, the participants recommended that by learning hands on, having a chance to learn through peer education, and learning who the person was before dementia were a big help in being able to manage their frustration. While there is not an absolute solution for frustrations, the participants would say other caregivers should prepare to expect that frustration will occur and that you must set the tone of the interaction and have patience. The fourth theme whereby participants recommended learning more about the person before dementia was a bit surprising because it was not a topic in the educational event they were attending that day. This theme derived from personal experiences and was elicited by the question of what advice would you give another caregiver.

All the themes combined to explain that each person with a cognitive impairment is an individual and there is not one clear and define solution for each problem that arises. By being able to practice hands-on, caregivers can utilize skills that may or may not work with their family member. Before working with a person living with dementia, the participants noted that a caregiver can perfect their approach using programs like the Positive Approach to Care® by Teepa Snow. Also, they can make changes in their caregiving based on these new experiences.

The one of the participants shared that one of their biggest helps to understanding dementia is to talk with a peer who is also a caregiver of those living with dementia. By being able to communicate with a caregiver who is taking care of a person in a more advanced stage of dementia, you can get better insight as to what to expect soon. In return, the participant felt like it their was responsibility to teach others about dementia. These comments illustrate the need for

caregiver events that provide education, strategies and by virtue of the caregivers present, offer support to each other. From this, more and more people would seek education about dementia and caregiving may improve. Three participants mentioned in their interview that they were going to go home and show their family members a video explaining more about dementia or try to find a Virtual Dementia Tour™ because they felt that hands-on learning was very beneficial.

### **Conclusion**

It is important to consider alternative education methods to deliver dementia caregiving content beyond the lecture. Helping family caregivers identify frustration and strategies to support patience is crucial. From this study, it was discovered that participants tend to like learning hands-on opposed to a lecture-style class. They also like hands-on learning because it gives them a chance to make mistakes and all five of the participants mentioned figuring out what works and what does not.

Another important thing to note is that participants believe that a good source of knowledge about dementia is from peers who are caregivers as well. This creates a chain of knowledge because each person feels compelled to share their findings. This also means that if one person attends a educational class about dementia, it is likely that they will encourage their caregiving peers to attend the event as well or if it's not possible to attend the event, they will educate them on what they learned themselves.

Dementia is a very individualized disease process. While formal education may be important, it was crucial that the caregiver took time to learn about the person before they got dementia. For example, what they did for a living, what were their hobbies, etc. If a caregiver

understands what the person was like, they have a better idea at how to handle the patient and that might decrease their frustration. The concept is intriguing and bears further exploration.

## References

- Alzheimer's Association. (2019a). Alzheimer's disease 2019 facts and figures. Retrieved from <https://alz.org/facts/overview.asp>
- Dam, A., de Vugt, M., Klinkenberg, I., Verhey, F., van Boxtel, M. (2016). A systematic review of social support interventions for caregivers of people with dementia: Are they doing what they promise? *Maturitas*, 85, 117-130. <http://dx.doi.org/10.1016/j.maturitas.2015.12.008>
- Dementia Alliance of North Carolina (2019). Understanding dementia symptoms. Retrieved from <https://dementianc.org/education-empowerment/understanding-dementia/#mixed>
- Johansson, M. M., Marcusson, J., & Wressle, E. (2015). Cognitive impairment and its consequences in everyday life: Experiences of people with mild cognitive impairment or mild dementia and their relatives. *International Psychogeriatrics*, 27(6), 949-958. doi:<http://dx.doi.org/10.1017/S1041610215000058>ohansson
- Kegler, M. C., Raskind, I. G., Comeau, D. L., Griffith, D. M., Cooper Hannah, L. F., & Shelton, R. C. (2019). Study design and use of inquiry frameworks in qualitative research. *Health Education and Behavior*, 46(1), 24-31. doi:<http://dx.doi.org/10.1177/1090198118795018>
- Lee, S., Lee, Y., Choi, S., Lim, T., & Moon, S. (2019). Clinical and demographic predictors of adverse outcomes in caregivers of patients with dementia. *Dementia and Neurocognitive Disorder*, 18(1), 10-18. <https://doi.org/10.12779/dnd.2019.18.1.10>
- Serra, L., Contador, I., Fernandez-Calvo, B., Ruisoto, P., Jenaro, C., Flores, N. ...Rivera-Navarro, J. (2018). Resilience and social support as protective factors against abuse of patients with dementia: A study on family caregivers. *International Journal of Geriatric Psychiatry*, 33, 1132-1138. doi:10.1002/gps.4905

US Census Bureau. (2018, December). Older people projected to outnumber children. Retrieved from <https://www.census.gov/newsroom/press-releases/2018/cb18-41-population-projections.html>

Zhang, S., Edwards, H., Yates, P., Li, C. & Guo, Q. (2014). Self-efficacy partially mediates between social support and health-related quality of life in family caregivers for dementia patients in Shanghai. *Dementia and Cognitive Disorders*, 37, 34-44.  
doi:10.1159/000351865