Community Gatekeepers Training: An Initiative for Dementia Care Kasandra Kister with Dr. Robin Barry University of Wyoming Department of Psychology

Introduction

"Find a penny," one of the patients at the nursing home began saying to me. She had a massive grin on her face and was pointing at the ground. "Go on," she said. "Find a penny, pick it up. All day long, you'll have good luck." I looked where she was pointing and saw a white spot on the tile. I reached down and found not a penny, but a used piece of *chewing gum*. I pretended to grab the gum and then thanked the patient for the good luck. "Now you're going to have a great day," she told me with her ear-to-ear smile. I walked away to help another patient. I looked back a few minutes later and saw her talking to another nurse aid. She was pointing at the ground and saying, "Find a penny..." This was my first experience with someone who has dementia.

As a college student, I often feel like I live in a bubble where I am continually surrounded by young, healthy people. In this environment, it can be so easy to take being young and vibrant for granted. I had a change of perspective when I worked as a certified nursing assistant, or CNA, this past summer. Suddenly, I was spending time with people who had had more life experiences than I could possibly imagine. I saw that one of the most beautiful things about aging is the ability to share a lifetime of memories with loved ones. However, a devastating illness can prevent these moments from being possible.

A recent poll in the United Kingdom found that older people have more fear of developing dementia than cancer (The Telegraph, 2014). Dementia is defined as the loss of cognitive functioning and behavioral abilities severe enough to interfere with everyday life. Dementia ranges from mild to acute stages. Symptoms result when healthy brain cells stop working, lose connection with other neurons, and die. Dementia can be caused by many different diseases. Alzheimer's disease is the most common form of dementia, but other forms can result from Lewy body dementia and frontotemporal disorders (National Institute on Aging, 2017). The percentage of people with Alzheimer's dementia increases dramatically with age: 3% of people age 65-74 have Alzheimer's dementia, and this number increases to 32% percent of people age 85 or older (Alzheimer's Association, 2019). However, it is important to know that while dementia commonly occurs in older adults, it is *not* an inherent part of the aging process.

Community Gatekeepers Training Program

After my time as a CNA in my hometown, I came to the university with a desire to use my background to help those in the Laramie community. I got a position as a research assistant in Dr. Robin Barry's Care and Connect Lab. Dr. Barry is working to develop a Dementia Support Center at the University of Wyoming. The purpose of the Dementia Support Center is to enhance the dementia-capability of our community through education and services.

My role in the lab was to help develop a program to educate community members to recognize signs of dementia. Why is community involvement needed? Approximately one-third of people with dementia live alone (Mirando-Costillo, 2010). These individuals may not realize they need assistance or may have difficulty getting help. Oftentimes they are at a greater risk for social isolation and loneliness, in addition to safety hazards such as wandering ("Alzheimer's Society," 2014). The Community Gatekeepers Training program teaches community members to be mindful of individuals with cognitive deficits and provide resources to those affected by dementia.

The training program consists of multiple components. First, it describes dementia. Then it talks about identifying some of the behavioral and physical signs of dementia. These signs include repetition when talking and long, rambling sentences. Next, it offers suggestions for how to communicate with those who may have cognitive deficits. As recommended by the American Alzheimer's Association, this includes the TALK tactics. TALK stands for:

- Take it slow. Approach the person slowly and from the front. Speak in a calm, low voice
- Ask simple questions. Avoid multipart questions. Be patient waiting for answers.
- Limit reality checks. If the person believes that it is 1965 and his wife is still alive, then you should not try to convince him otherwise. If she believes that a piece of chewing gum is a lucky penny, then it's best to let her think that.
- **K**eep eye contact. This helps with hearing, perception or attention problems.

These simple strategies can be a tremendous benefit in communicating with someone with dementia.

Finally, the training program educates community members about all the resources that are available to support those affected by dementia. These include our local law enforcement if there is ever an emergency situation, Adult Protective Services, and the Dementia Support Center. Dementia is a disease that no one should have to face alone.

Experiment and Results

A pilot of the training was performed with other members of the Care n Connect Lab. Before the training, the participants took 5 different surveys to assess attitudes and knowledge about dementia. These surveys were the Dementia Knowledge, Dementia Attitudes Scale of Comfort, Dementia Attitudes Scale of Knowledge, Sense of Competency Building Relationships, and Sense of Competency Sustaining Personhood. The surveys included asked questions such as, "How well do you feel you can understand the needs of a person with dementia?" Each person ranked their answer on a scale from not at all to very much. We assessed their dementia knowledge by asking yes and no statements such as "Blood vessel disease can cause dementia." After training, the participants the same survey to see how their results changed. The results were very similar before the training versus after the training. This could be attributed to the fact that the lab members we already educated in many of these areas. There was also a very limited sample size of only five participants. This sample size was not statistically significant. We hope to expand this training to a much larger audience, many of whom may not already be familiar with many of the aspects of dementia.

Before Training								
	Dementia_Know	Dementia_Att_Com	Dementia_Att_Know	Sense_o_C_BR	Sense_o_C_SP			
JB	12	58	62	12	15			
MK	18	47	56	9	13			
RB	18	43	61	10	15			
KB	12	44	54	11	10			
AB	10	30	59	7	12			
Mean	14	44.4	58.4	9.8	13			
SD	3.346	8.957	3.006	1.720	1.897			

After Training								
	Dementia_Know	Dementia_Att_Com	Dementia_Att_Know	Sense_o_C_BR	Sense_o_C_SP			
JB	12	58	60	14	16			
MK	19	48	56	9	14			
RB	18	43	43	11	16			
KB	12	45	53	10	11			
AB	13	39	63	11	14			
Mean	14.8	46.6	55	11	14.2			
SD	3.059	6.406	6.899	1.673	1.833			



Conclusion

The Community Gatekeepers Training is a way to educate the public about signs of dementia. Alzheimer's disease alone affects approximately 5.8 million Americans, and far too many that we know and love (Alzheimer's Association, 2019). The UW Care n Connect Lab wants to help those in the community who may be affected by this disease and support their caretakers. The goals are to help people understand the signs of dementia and help people receive the help they need. The training will be expanded to reach members of the Laramie community. With people who are not familiar with dementia, we believe that this will be a valuable tool to teach the public about the disease. Remember, if you see a penny, pick it up. If you see a wad of chewing gum, maybe don't pick that up. But if you treat some who suffers from dementia with the respect and dignity he or she deserves, then all day long, you will have good luck.

Works Cited

- Alzheimer's Association. (2019). Alzheimer's Disease Facts and Figures. Retrieved from https://www.alz.org/alzheimers-dementia/facts-figures.
- Mirando-Costillo et al (2010) People with dementia living alone: what are their needs and what kind of support are they receiving. International Psychogeriatics, 22(4) 607-617
- National Institute on Aging. (2014, August 17). Older people are more scared of dementia than cancer, poll finds. Retrieved from https://www.telegraph.co.uk/news/health/elder/11008905/Older-people-are-more-scared-of-dementia-than-cancer-poll-finds.html.
- O'Connor, M. L., & McFadden, S. H. (2010). Development and Psychometric Validation of the Dementia Attitudes Scale. International Journal of Alzheimers Disease, 2010, 1-10. doi:10.4061/2010/454218
- Schepers, A., Orrell, M., Shanahan, N., & Spector, A. (2012). Sense of Competence in Dementia Care Staff (SCIDS) scale: Development, reliability, and validity. International Psychogeriatrics, 24(7), 1153-1162. doi:10.1017/S104161021100247X
- The Telegraph. (2014, August 04). Older people are more scared of dementia than cancer, poll finds. Retrieved from https://www.telegraph.co.uk/news/health/elder/11008905/Older-people-are-more-scared-of-dementia-than-cancer-poll-finds.html.
- Toye, Christine and Lester, Leanne and Popescu, Aurora and McInerney, Fran and Andrews, Sharon and Robinson, Andrew L. (2013.) Dementia Knowledge Assessment Tool Version Two: Development of a tool to inform preparation for care planning and delivery in families and care staff. Dementia: The International Journal of Social Research and Practice. 13 (2): pp. 248-256.