

Running Head: FAMILY CAREGIVER EXPERIENCES

THE EFFECTIVENESS OF FAMILY CAREGIVER EXPERIENCES WITH VALIDATION
THEORY VERSUS REALITY ORIENTATION (RO)

by

CASSIDY FULLER

A Senior Honors Project Presented to the

Honors College

East Carolina University

In Partial Fulfillment of the

Requirements for

Graduation with Honors

by

CASSIDY FULLER

Greenville, NC

APRIL 1, 2021

Approved by:

DONNA W ROBERSON, PHD, FNP-BC, CDT, CADDCT

East Carolina University College of Nursing

Abstract

Introduction: Due to the increasing prevalence of dementia worldwide, it is imperative that all caregivers understand how to most effectively communicate and care for people living with dementia. Most of the care provided to people living with dementia is provided without pay by family or friends (Alzheimer's Association, 2019). There is little in the literature about the experiences of family caregivers using reality orientation versus Validation Theory, that is, responding to the person living with dementia as if their perceptions were reality. Validation Theory has also been described as meeting the person where they are, rather than arguing about reality. With a better understanding of caregiver experiences, education can be developed to support more effective communication. Training caregivers to communicate in a way that is therapeutic and beneficial to the person with dementia (PWD) is essential to delivering adequate care.

Purpose: The purpose of this study was to use qualitative inquiry to explore family caregiver experiences who use reality reorientation in an attempt to diffuse a situation versus using validation techniques.

Methodology: Following IRB approval, a qualitative inquiry was conducted. The sample was comprised of family caregivers of a person living with dementia in attendance at a virtual community caregiver training event. The participant must have spoken English, been currently caring for a person living with dementia and must have been able to provide informed consent.

Data Analysis: Both the researcher and the faculty mentor read the transcripts literally and in entirety, first to get an idea of the conversations and then re-read to mark comments thought to be related to pertinent family caregiver experiences. After individual review, the team met to arrive at consensus on the themes noted throughout each interview.

Results: The analysis of the transcripts found that frustration with reality orientation could escalate conflict between family caregiver and their person living with dementia. Participants who accepted the person in the time and place they thought they were in had much more peaceful interactions and decreased stress in communication.

Conclusion: The incidence of dementia is drastically increasing, and it is imperative that caregivers learn how to best communicate with their loved one as the disease progresses. This research project supplied a unique look into two different communication strategies and encouraged participants to discuss the effectiveness of each one side-by-side. It highlighted the communication dilemmas faced by many caregivers. Many would agree that good communication is at the heart of providing effective care. The issue arises when the person being cared for has a different view of his/her current reality. The present work offers some insight into effective communication techniques, as experienced by caregivers of people living with dementia.

The Effectiveness of Family Caregiver Experiences with Validation Theory versus Reality Orientation (RO)

One in ten people in the United States lives with dementia (Alzheimer's Association, 2019). Around 25% of hospital beds are occupied by people over the age of 65 years with a diagnosis of dementia (Handley et al., 2017). Due to the increasing prevalence of dementia worldwide, it is imperative that all caregivers understand how to most effectively communicate and care for people living with dementia. Most of the care provided to people living with dementia is provided without pay by family or friends (Alzheimer's Association, 2019). Training caregivers to communicate in a way that is therapeutic and beneficial to the person with dementia (PWD) is essential to delivering adequate care.

Background

Disorientation is a common symptom experienced by people living with dementia and can be a cause for unsafe behaviors leading to falls, wandering, or decreased quality of life for both the person and their caregiver. Validation Therapy is based on the overall principle of validation, the acceptance of the reality and personal truth of another's experience (Neal & Wright, 2003). Reality Orientation (RO) is a cognitive stimulation technique that operates through the presentation of orientation information such as time, place and person related. The goal is to provide the person with a greater understanding of their surroundings, possibly resulting in an improved sense of control and self-esteem (Spector et al., 2000).

Though previous studies have examined the effectiveness of using Reality Orientation (RO) to care for people living with dementia, there was little to no research that examined use of RO from a caregiver's point-of-view. Overall, there was a lack of literature concerning the topic of Validation Theory as it related to dementia care. The effectiveness of these two strategies had

only previously been examined separately. There was a need for current analysis of family caregiver experiences to better understand how caregivers can most effectively look after their loved ones while also preserving the dignity of those living with dementia.

A person living with dementia will gradually lose their ability to cognitively communicate. Learning to communicate with a person with dementia requires patience, good listening skills, and a basic understanding of the disease process. It is important to understand that people living with dementia often come to live in an altered reality that does not exactly fit actual reality (Bursack, 2018). In years past, the caregiver was taught to correct any remarks that did not coincide with reality (current date, time, situation, place). Unfortunately, dementia patients lose the ability to rationally think as the disease progresses and attempting to reorient them can cause agitation and anger (Bursack, 2018).

Instead of attempting to reorient a person incapable of rational thinking, the validation theory focuses on empathy and listening. It emphasizes a holistic view of people living with dementia as unique individuals (Bursack, 2018). The Validation Method (VM) was created by Naomi Feil, a social worker in geriatrics who became dissatisfied with the communication techniques being commonly used in practice (Empathy for Alzheimer's, 2019). Different forms of validation are widely used today by clinicians as a practical way to communicate with people living with dementia. The use of VM has been called deceptive or therapeutic lying when used in dementia care although it is employed in the best interest of the patient (James & Ciazza, 2018). Similar labels of VM include 'going along with a person's incorrect belief', 'redirecting a person's attention with a partial truth', and 'bending the truth' (James & Ciazza, 2018). It is thought that validating the belief or statement of the one living with dementia, instead of correcting them, increases their sense of dignity. Use of VM removes implications that the

person is “wrong” and reduces confusion by sharing truths that they are not able to understand (Bursack, 2018).

Past research on the use of lies within dementia care was highly criticized and rarely accepted (Schermer, 2007, as cited in James & Ciazza, 2018). Many found it unethical and dismissed the topic completely. However, more recent studies indicate an increasing acceptability regarding the use of lies from a person-centered perspective. Deception used in dementia care may be beneficial when used in the best interest of the patient (Elvish et al., 2010). Interestingly, the research indicates a higher rejection of ‘therapeutic lying’ in physicians (Cantone et al., 2019) and nurses are more likely to accept the validation approach, perhaps because they are the ones providing the most intensive face-to-face care. Current literature suggests that healthcare members are inclined to support a better understanding of communication techniques that can be used to engage with people with dementia and de-escalate problematic situations (James & Ciazza, 2018).

There is some literature that analyzes the effectiveness of reality orientation (RO) when combined with acetylcholinesterase inhibitors, a typical pharmacological treatment for dementia. A 2015 study conducted in Brazil suggested that if patients with mild to moderate dementia have weekly individual reality orientation sessions combined with pharmacological treatment, they experience an improvement in cognitive function (Camargo et al., 2015). However, there is limited research that supports the use of reality orientation alone to improve cognitive function in patients with dementia. A meta-analysis conducted in 2018 found that reality orientation therapy can be beneficial to patients living with dementia, but the positive effects were not significant (Chiu et al., 2018). Further research is required to provide a more accurate confirmation of the

benefits of reality orientation and other similar cognitive stimulation techniques (Camargo et al., 2015).

Previous research on the topics of reality orientation (RO) and Validation Theory date back to the late 1990s and early 2000s. More recent research highlighted the terms lies and deception rather than validation of a person with dementia's belief. Further review was conducted to investigate family caregiver experiences in recent years as it related to effective communication strategies. The argument was whether the caregiver should attempt to reorient their loved one with dementia as opposed to validating them in their incorrect belief, which may provide a sense of comfort and security. Specific aspects of reality orientation (RO) and Validation Theory were compared and contrasted in order to determine which approach resulted in the most positive outcome.

Purpose

The purpose of this study was to use qualitative inquiry to explore family caregiver experiences who used reality reorientation in an attempt to diffuse a situation versus using validation techniques. Analysis of the data included examination of which approach resulted in the most positive outcome for the sample.

Research Question

The following was the overall research question guiding the proposed study:

What is the experience of family caregivers when using reality orientation versus validation therapy techniques to effectively care for their person living with dementia?

The first aim of the proposed study was to ask family caregivers about their experience using reality orientation techniques and validation techniques to care for their loved one. The second

aim was to analyze the effectiveness of strategies used by caregivers to diffuse a situation and determine whether reorienting or validating yielded the most positive outcome.

Methodology

Following IRB approval, a qualitative inquiry was conducted. The sample was comprised of family caregivers of a person living with dementia in attendance at a virtual community caregiver training event. The participant must have spoken English, been currently caring for a person living with dementia and must have been able to provide informed consent. This study was approved by the University Medical Center Institutional Review Board.

Design

Five interviews were completed by the student researcher with consented family caregivers at the research mentor's virtual caregiving events in rural eastern North Carolina. Each interview lasted no more than 60 minutes. The research mentor was present at each interview to guide the student researcher interviewing techniques. Each one-one-one virtual interview was conducted and digitally recorded via Microsoft Teams. The interviews were transcribed verbatim by the student researcher. The results were then analyzed by the student researcher and the research mentor, Dr. Donna Roberson, PhD, FNP-BC.

The following interview questions were asked of each participant with refining questions as needed.

1. Have you tried re-orienting your person living with dementia when they forget the day, time, or circumstances?
2. (if yes) how did this strategy work for you?

3. Have you tried what is called Validation Theory – that is, meeting the person in their reality, agreeing with their perceptions of the day, time, and circumstances?
4. (if yes) how did this strategy work for you?
5. What seems to help you and your person the best when they are unsure of the date, time, season, and so on?

Data Analysis Procedure

Both team members individually read the transcripts literally, first to gain a flavor of the conversations and to begin identifying comments related to family caregiver experiences. Next, the transcripts were re-read with excerpts of participants' comments highlighted to support the communication experiences with reality orientation and Validation Theory. The excerpts were divided into positive and negative experience and four major themes were identified. During the analysis, the researchers wrote down perceptions of the transcripts to make sure personal bias did not influence the analysis process. The lead faculty (Roberson) conducted a parallel review of the transcripts and the student researcher met with faculty via WebEx to arrive at consensus on the themes. Finally, there was a team meeting to name, define and illustrate with quotes the themes that described family caregiver experiences using reality orientation versus Validation Theory.

Results

Analysis of the transcripts yielded rich data describing communication between the caregiver and person living with dementia both in early and late disease states. All five participants discussed changing communication style as the disease progressed, beginning with reality orientation in early stages and ending with Validation Theory in later stages. Reality orientation used in later stages of disease progression was only implemented when safety of the person was

at risk. Three major themes were identified from the results. The themes included conflict escalation with reality orientation, promoting ease and comfort with Validation Theory, and gap in professional guidance.

The first theme was conflict escalation with reality orientation. Conflict escalation included negative experiences with utilizing reality orientation as a communication technique. One participant said, "If you tried to redirect her into a true statement, it would just make her more upset." Similar sentiments were expressed by other participants. Another family caregiver stated that, "When people would try to correct my grandmother... it would get her more upset and more confused and make it worse."

The second theme was promoting ease and comfort with Validation Theory. This included positive experiences with taking a validation approach, although none of the participants had knowledge of Validation Theory. One participant explained that, "It was just easier to add onto what she thought was a true statement." Many acknowledged that as the disease progressed, it became increasingly important to ensure comfort and security. One family caregiver said, "As she progressed, we all just did whatever we thought would make her feel emotionally comfortable." Another said, "I just wanted to go along with her because I just wanted to keep her at ease... give her the comfort of thinking what she thought was true... seemed to make her feel at ease."

The last theme identified from the data was a gap in professional guidance. One family caregiver expressed that, "There really wasn't a lot of recommendations... I did not get any of what I would say is support." Another participant that worked in the healthcare field acknowledged the importance of taking time to educate family caregivers and provide guidance on what to expect as the disease progresses. She stated, "Probably what's most helpful is having

a little bit of background... a little bit of background and understanding. I would have done more to educate her caregivers, that would have been important.”

Discussion

Based on the results of this study, it was clear that for this sample, family caregivers affirmed that reality orientation could be useful in early stages. However, most participants quickly found that reality orientation caused distress as the dementia progressed. Switching to Validation Theory, although none used that term, improved the relationship with their person. The person living with dementia was more at ease and less likely to act out in fear or agitation. Validation Theory allowed the person living with dementia to keep their dignity and confirmed their place in the family.

The participants illustrated a gap in education provided by professionals that included communication strategies. Professionals tended to focus on physical changes in the person living with dementia and provided little guidance for the caregiver. Lack of education on communication with a person living with dementia was evident.

Limitations

The results of this study are limited by the characteristics of the sample, and further exploration with patients in other regions may be helpful. Although the researcher was a novice, the presence of established research mentors balanced the level of experience and improved the validity of the analysis. The use of secondary qualitative exploration is a good use of rich data that honors the participants words to inform nursing care.

Conclusion

The incidence of dementia is drastically increasing, and it is imperative that caregivers learn how to best communicate with their loved one as the disease progresses. This research

project provided a unique look into two different communication strategies and compared the effectiveness of each one side-by-side. It highlighted the communication dilemmas faced by many lay people providing direct care to people with dementia. Many would agree that good communication is at the heart of providing effective care. The issue arises when the person being cared for has a different view of his/her current reality. The present work offered some insight into effective communication techniques, as experienced by caregivers of people living with dementia.

This project helped give me a better understanding of what it's like to care for someone living with dementia, which will ultimately help to strengthen my role as a nurse. As I currently work with many dementia patients in my role as a nursing assistant, I am sure that will continue to be the case when I become a nurse. Having an improved understanding of how to communicate with dementia patients will allow me to provide better care and educate family caregivers regarding communication strategies that lend dignity and respect.

References

- 2019 Alzheimer's Disease Facts and Figures. (2019). *Alzheimer's Association*. Retrieved from <https://www.alz.org/media/documents/alzheimers-facts-and-figures-2019-r.pdf>
- Bursack, B. (2018, October 5). Is Using Validation for Dementia Calming or Condescending? Retrieved from <https://www.agingcare.com/articles/validation-method-for-dementia-calming-or-condescending-166707.htm>
- Camargo, C. H., Justus, F. F., & Retzlaff, G. (2015). The effectiveness of reality orientation in the treatment of Alzheimer's disease. *American journal of Alzheimer's disease and other dementias*, 30(5), 527–532. <https://doi.org/10.1177/1533317514568004>
- Cantone, D., Attenu, F., Cerrone, S., Fabozzi, A., Rossiello, R., Spagnoli, L., & Pelullo, C. P. (2019). Lying to patients with dementia: Attitudes versus behaviours in nurses. *Nursing ethics*, 26(4), 984–992. <https://doi.org/10.1177/0969733017739782>
- Chiu, H. Y., Chen, P. Y., Chen, Y. T., & Huang, H. C. (2018). Reality orientation therapy benefits cognition in older people with dementia: A meta-analysis. *International journal of nursing studies*, 86, 20–28. <https://doi.org/10.1016/j.ijnurstu.2018.06.008>
- Elvish, R., James, I., & Milne, D. (2010). Lying in dementia care: an example of a culture that deceives in people's best interests. *Aging & mental health*, 14(3), 255–262. <https://doi.org/10.1080/13607861003587610>
- Empathy for Alzheimer's: The Validation Method. (2019, July 23). Retrieved from <https://www.alzheimers.net/2013-11-07/validation-method-for-alzheimers/>
- Handley, M., Bunn, F., & Goodman, C. (2017). Dementia-friendly interventions to improve the care of people living with dementia admitted to hospitals: a realist review. *BMJ open*, 7(7), e015257. <https://doi.org/10.1136/bmjopen-2016-015257>

James, I. A., & Caiazza, R. (2018). Therapeutic lies in dementia care: Should psychologists teach others to be person-centered liars? *Behavioral and cognitive psychotherapy*, 46(4), 454–462.

<https://doi.org/10.1017/S1352465818000152>

Neal, M., & Barton Wright, P. (2003). Validation therapy for dementia. Retrieved from

<https://www.ncbi.nlm.nih.gov/pubmed/12917907>

Spector, A. E., Orrell, M., Davies, S. P., & Woods, B. (2000). Reality orientation for dementia. *Cochrane Database of Systematic Reviews*. doi: 10.1002/14651858.cd001119.pub2