

CAREGIVER PERCEPTIONS REGARDING THE EXPERIENCE
OF AND USE OF MIRRORS FOR A PERSON
WITH DEMENTIA

A DISSERTATION

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF DOCTOR OF PHILOSOPHY
IN THE GRADUATE SCHOOL OF THE
TEXAS WOMAN'S UNIVERSITY

COLLEGE OF NURSING

BY

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DENTON, TEXAS

MAY 2019

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DEDICATION

To my siblings:

who cheered me on and put up with me missing family events
and pushed me through the finish line when I wanted to quit.

To my nieces, nephews and friends:
Thank you for unending love and support

To the Organization who supported the recruitment process.

To my late mother and father,
Who always believe that I could achieve anything if I put my mind to it?

ACKNOWLEDGMENTS

There were many who supported and cheered me on through this journey; the journey of academic excellence and for this, I must pause to say thank you. First, I would like to extend my sincere gratitude and thanks to my husband for putting up with an absentee wife through these years. Further acknowledgement goes to my family members, who put up with me for missing important family events because there were deadlines to be met. I cannot forget my friends who understood when I could not attend social events, yet they surrounded me with love.

Most importantly, I want to extend my sincere gratitude to my dissertation chair Dr. Wyona Freysteinson. Her tireless guidance, support and cheerleading has helped me tremendously along the path, especially during at times when I felt like giving up due to life circumstances. I also want to thank her for her guidance and perspective on my publication processes. I've learned much from these experiences. Joining in this tireless effort was my dissertation committee Dr. Anne Young and Dr. Rachelle Nurse. I could not have succeeded without your support and ongoing guidance throughout this process. I'm equally thankful for the program director Dr. Sandra Cesario for her welcoming support and direction throughout the program.

However, this acknowledgment would be incomplete without mention of my late parents who taught us that the sky is the limit and we can achieve anything if we are willing to work hard for it. Their past thoughts and prayers have certainly carried me

through these years. Finally, but not least, I would like to acknowledge the receipt of the Carter Dissertation Grant in 2014 toward completion of my research.

ABSTRACT

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CAREGIVER PERCEPTIONS REGARDING THE EXPERIENCE OF AND USE OF MIRRORS FOR A PERSON

WITH DEMENTIA

MAY 2019

The purpose of this hermeneutic phenomenological study was to explore caregivers' perceptions and understandings of the experience of observing a person with dementia viewing self in the mirror. The study was conducted in a large metropolitan city in the Southern region of the United States. Participants were recruited from a registered professional national organization headquartered in the US that offers services to caregivers of persons with dementia. To gain insight into the understanding of the experience, caregivers of persons with dementia were recruited as this could not be accomplished by directly interviewing persons with dementia. Purposive sampling was used to secure a sample of approximately 18 caregivers who met the following criteria: have provided needed care and assistance for an individual with dementia, are 18 years and older, are English-speaking and witnessed the person with dementia whom they cared for viewing self in the mirror. Sampling continued until saturation was reached. Data was collected using two instruments developed by the researcher, a demographic data form, and a semi-structured interviews guide. Audio-recorded, face-to-face

interviews lasted approximately 30 minutes. Data analysis was conducted using Ricoeur's hermeneutic phenomenological theory of interpretation. Structural analysis revealed two themes in the home and long-term care setting consisting of the number of mirrors available and the caregiver's actions. Mirrors of all types were more readily available in homes versus long-term care settings. Home caregivers more consistently incorporated mirrors in to care, particularly early in the disease trajectory. While some long-term care staff used mirrors to enhance care, it was less consistent, particularly in facilities without mirrors or when dealing with staff who felt mirror viewing was inappropriate for Dementia patients.

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CHAPTER I

INTRODUCTION

Focus of Inquiry

The population of adults 65 years of age and older is projected to reach 72 million over the next 25 years, accounting for at least 20% of the US population (Center for Disease Control and Prevention [CDC], 2016). A report produced from a joint effort by CDC (2016) and United States (U.S.) Department of Health and Human Services (DHHS) attributes the extraordinary growth in the population of older adults both to the aging of the baby boomers and to increased longevity. One concern is the risk for development of dementia in this aging population is significant. Globally, 47.5 million people are affected with dementia, with 7.7 million new cases diagnosed each year (World Health Organization [WHO], 2016). By 2030, the number of those affected with various forms of dementia is estimated to be 75.6 million and is further projected to triple to 135.5 million cases by 2050 (WHO, 2016). The increase in the elderly population, combined with the increased risk of dementia in those 65 and older, is a major public health concern worldwide (Alzheimer's Association, 2018; WHO, 2016).

Dementia is an irreversible, progressive syndrome characterized by loss of cognitive function that severely impacts activities of daily living (ADL) (WHO, 2016). Dementia may be characterized as early, middle, or late stage and is further differentiated into seven descriptive stages that detail the specificity of each stage as is seen in

Alzheimer's disease. A person in the early stages of the disease may function independently, performing his or her normal day-to-day activities. She or he may drive, participate in social activities, and hold a job. As the disease progresses, the individual loses cognitive ability and eventually becomes reliant on a caregiver (WHO, 2016).

In stage five (moderate stage), gaps in memory are noticeable. Day-to-day activities become challenging and usually require assistance. Despite memory gaps, details about self and family members remain intact.

In stage six to seven, the final stages of the disease, cognitive decline is quite apparent, and interaction with the environment ceases. Individuals at these stages require assistance with ADL (WHO, 2016). Words or short phrases may be spoken, but the ability to carry out a coherent conversation has been lost. Memory, thinking and reasoning, visual perception, speech and language, bathing, dressing, brushing one's teeth, and walking become challenging for the person with last-stage dementia. Lastly, the person with dementia may no longer recognize when he or she is thirsty or hungry and will eventually need assistance with all activities of daily living (Alzheimer's Association, 2016).

The greatest risk factors for developing dementia are found in those 65 years of age and older with an even higher rate of dementia found in those 85 and older (WHO, 2016). The estimated risk for developing Alzheimer's disease (AD), the most common form of dementia, doubles every five years and accounts for 60 to 70% of the cases (WHO, 2016). Currently, there is no cure, nor is there a means by which to slow its

progressive course (WHO, 2016). Alzheimer's disease is the sixth leading cause of death in the United States. Approximately 5.3 million Americans are currently afflicted with the disease; that number is expected to more than double by 2050. Estimates indicate that 3.2 million women and 2.1 million men in the United States are currently afflicted with the disease. American women in their 60s are more likely to develop Alzheimer's disease during their lifespan than they are likely to develop breast cancer (Alzheimer's Association, 2016).

Vascular dementia, which often occurs after a stroke, is the second most common type of dementia. Other dementias include Lewy body, frontal lobe, and mixed dementia (diagnosed with more than one type of dementia), Parkinson's disease, Creutzfeldt-Jakob disease, normal pressure hydrocephalus, and Huntington's disease contribute to dementia symptoms, ultimately impacting activities such as self-care and self-recognition (Alzheimer's Association, 2016).

Dementia is not a normal part of aging. This syndrome affects not only memory but thinking, orientation, judgment, comprehension, language and learning capacity. Deterioration and loss of cognitive function—the ability to process thought is of primary concern for this population group. Due to the progressive decline in cognitive ability, self-recognition in a mirror may be challenging. Mirror use is a daily event for most individuals. Yet, for individuals with dementia, this may prove to be challenging. Currently, little is known quantitatively or qualitatively about the perceptions and

understanding of dementia individuals when they view themselves in a mirror (Alzheimer's Association, 2016, WHO, 2016).

A comprehensive literature review revealed limited research studies or published guidelines regarding the use of mirrors for persons in this population group. The inspiration for this study was drawn from the author's personal experience in caring for someone with dementia (Kelsick & Freysteinson, 2013) presented in Chapter II. Viewing herself in the mirror was an everyday phenomenon for Rose who had several full-length and half-sized (from the torso up) mirrors in her home. Rose took pride in her appearance. However, as her mental state deteriorated, she became forgetful, followed by frustration, agitation, hallucination, and delusions, all common experiences for those with dementia. In the late stages of her disease, Rose no longer recognized herself in the mirror; the person whose image she saw in the mirror was a stranger to her (Kelsick & Frevsteinson, 2013). No family members had any formal training or guidelines to follow as they struggled to care for Rose. Understanding Rose's mirror encounter experience was challenging and seemed important to explore and understand.

Problem of Study

Caregivers experience may influence their decisions on the care they provide to individuals with dementia. Although mirror viewing is an everyday event for most individuals, this can be difficult for individuals with advanced stages of dementia. The purpose of this hermeneutic phenomenological study was to explore caregivers' perceptions and understandings of the experience of observing a person with dementia

viewing self in the mirror. This description provides a foundation for future studies aimed at developing and testing patient-centered mirror-care interventions for those with dementia.

Rationale for the Study

Use of a mirror is an everyday event for most people who use a mirror for self-care activities such as hair-combing, teeth-brushing, shaving, applying make-up, and just to see what one looks like and to see what others may see (Freysteinson, 2010). With the projected increase over the next several decades in the number of dementia patients, an understanding of the impact of the disease on the various activities of daily of living is of great importance. This study examined one component of activities of daily living in the context of the progression of the disease: the trajectory of the experience of viewing self in the mirror for the person with dementia. Almost 40 million Americans provide unpaid care to a family member or friend. In the 18 to 34-year-old age range, men are as likely as women to be caregivers (National Alliance of Caregiving, [NAC], 2015). The NAC (2015) reports the age range of caregivers as 75 years and older, and they provide at least 21 hours of care per week. The mean reported age of caregivers is 47 which congruent with this study with a mean age of 48. This care commitment doubles to 44.6 hours per week if the person is providing care to a spouse or partner. Twenty-five to 29% of caregivers assist persons 50 years and older with cognitive impairments. Approximately 50% of all caregivers are responsible for managing the difficult and most common tasks associated with providing personal care: dressing, personal grooming, and getting in and

out of bed (NAC, 2015). This caregiving population represents the best access for understanding the mirror experience of persons with dementia. Knowledge of such experiences may provide healthcare providers with guidelines for the care of patients with dementia when they view themselves in the mirror and serve as an impetus to open dialogue for future research that will improve outcomes for patients with dementia.

Philosophical Underpinnings

The philosophical foundation and methodology for this study were underpinned by the precepts of Paul Ricoeur's philosophy of hermeneutical phenomenology (Ricoeur, 1966, 1975, 1976, 1981). Ricoeur is widely recognized as one of the most influential philosophers of the 20th century, with more than 500 publications including the philosophy of the will. Ricoeur's philosophy was influenced by the existentialism of German philosophers Edmund Husserl, the founder of phenomenology, Karl Jasper, and French philosophers Gabriel Marcel and Jean Paul Sartre. The philosophy of the will, which embodies the theory of lived experiences, draws from Husserl's concept of intentionality, which refers to the act of consciously connecting to one's world. The experience of viewing self in a mirror can, therefore, be considered an intentional act (Ricoeur, 1966).

Ricoeur's phenomenological philosophy posits that the essential underlying structures and meanings of experiences can be extracted from everyday experiences. Phenomenology extracts "from lived experiences the essential meanings and structures of purpose, project, motive, wanting, trying, and so on" (Ricoeur, 1981, p. 316). Ricoeur

viewed motives and purpose as common everyday experiences that could be better understood. However, when Ricoeur confronted the challenge of incorporating symbolic language into lived experience, he was obliged to solve this linguistic conundrum by introducing hermeneutics. Hermeneutics is the theory of interpretation of linguistic and non-linguistic expressions. Ricoeur's focus is on textual interpretation, the primary aim of hermeneutics. He viewed interpretation as the hinge that links language to the lived experience. Interpretation of the text is finding the hidden meaning within the texts by peeling back the various meanings that may exist within the literal meaning (Ricoeur, 1974).

Phenomenology is a philosophical approach to the study of lived experience and is concerned with the experience that encompasses individualities, commonalities, and shared meanings. Hermeneutics is the theory of interpretation rooted in Heidegger's philosophy (Lindseth & Norberg, 2004).

Ricoeur believed that text is discourse fixed in writing (Ricoeur, 1981). Hermeneutic phenomenology allows for the interpretation of multiple perspectives of the lived experience. Ricoeur postulates that text is understood at three levels: 1) explanation – the interpreter explores something about what the text says by examining the nature of the text; 2) interpretation – the interpreter explores the “*thing*” that the text speaks about to reach a deeper understanding of the text; and 3) appropriation – the interpreter appropriates the text world to gain knowledge and perception. Fundamental to Ricoeur's theory is the

understanding of text through his concepts of distanciation and appropriation, and explanation and understanding.

Distanciation and Appropriation

Ricoeur focused on textual interpretation. The dialectical movement between distanciation and appropriation and explanation and understanding are key foundations of his work. Borrowing from the philosophical roots of Antoine Gadamer, Ricoeur saw distanciation as embedded in the narration and influenced by the past, occurring through union of the text from the interpreter's perspective (Ghasemi, Taghinejad, Kabiri, & Imani, 2011). Gadamer's world is one of shared history (Gadamer, 1990). During the initial reading, the reader is distanced from the text but is later able to orient self to the text. The reader then interprets the text and appropriates it, making it his own (Ricoeur, 1974).

Explanation and Interpretation

Ricoeur's philosophy of textual interpretation evolved over time. The initial analysis of the text entails explanation of the text, and Ricoeur used linguistic theory to support his stance. Text through foundation in language as discourse is both expressed and unexpressed. Achieving understanding of both expressed and unexpressed text is an important element for the reader (Ghasemi et al., 2011).

Interpretation of the text is a dialectical movement that stems from both the structural analysis and the phenomenological interpretations of the text. The dialectic movement between the parts and the whole allows a comprehensive understanding of the

author's interpretation of what the text says about being in the world. This ongoing cyclical movement is described as the *hermeneutic arc* a trademark of Ricoeur's theory of interpretation (Ricoeur, 1966, 1975, 1976, 1981).

This study provided a conceptual framework of the experience of viewing self in the mirror for patients with dementia. This conceptual framework assisted in developing interventions and guidelines that may influence the practices of caregivers for individuals with dementia. According to Parse, Coyne, and Smith (1985), the study of lived experiences may guide the practice of nursing by recognizing and honoring the uniqueness of each individual experience of being in the world. Concepts from this study may assist in opening the dialogue for future research related to patients with dementia and observed experiences of viewing self in the mirror.

Research Questions

The two research questions guiding this study are:

1. What are caregivers' perceptions of what they see and believe when they observe dementia patients whom they care view themselves in a mirror?
2. How do caregivers' perception of that experience change over time as the dementia worsens (e.g. over one, two, or greater than two years)?

Summary

The aging population in the United States continues to grow at an unprecedented rate leading to an increased risk of developing dementia. While mirrors are used daily for performing activities of daily living, controversy exists about how mirrors should be used

for individuals experiencing memory loss (such as in dementia). There is little or no literature to guide caregivers in their daily interactions with patients who has dementia on when to use or not use mirrors. This phenomenon has unlocked and provided new knowledge about this experience. The use of hermeneutic phenomenology will provide an appropriate methodology to explore this otherwise untapped experience for this population group. The researcher hopes that this study will begin a dialogue about using mirrors that has otherwise been silent and unexplored.

CHAPTER II

WHO IS THAT STRANGER IN THE MIRROR?

A MIRROR EXPERIENCE FOR ELDERLY PATIENTS WITH DEMENTIA

A paper published in *Holistic Nursing Practice* 2013, 27(5), 268–272

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When viewing self in a mirror, healthy individuals recognize themselves; looking at oneself in a mirror may, however, be challenging or upsetting for an individual in advanced stages of dementia. Modifications to home surroundings may be required, including adequate lighting and attention to type, size, and placement of mirrors. The decision when to use or not use mirrors for persons with dementia may need to be considered. Investigating mirror viewing in dementia patients may offer both better understanding of behaviors related to self-recognition or lack of it, and the possibility for future interventional studies for individuals with dementia.

Abstract

Use of the mirror is an everyday phenomenon for most individuals. There seems to be limited evidence-based studies that address the use of mirrors in patients with dementia. Using a case study, the purpose of this study is to begin a dialogue with the nursing community on practical nursing interventions and the need for research in this area.

KEY WORDS: Alzheimer's, dementia, mirrors, nursing practice.

Case Study

Rose was a delightful woman who enjoyed every aspect of her life. She was a matriarch, wife, grandmother, great grandmother, stepmother, sister, and aunt. She was a meticulous homemaker and took great pride in gardening. Rose was also a great cook and enjoyed working in her flower garden. Children, neighbors, and friends would seize any opportunity to enjoy her delicious meals and would flock to get a taste of Rose's food.

At the age of 76 years, Rose was diagnosed with Parkinson's disease and at the age of 80 years, she was diagnosed with dementia, more specifically, Alzheimer's disease (AD). Before her diagnosis, Rose was an active person who was full of life and loved her independence. She was able to meet her everyday needs and responsibilities in caring for herself and took extreme pride in her personal appearance. In the pre-diagnosis phase, Rose ensured that not only did she look her best but also that her family looked their best. Her motto was—never leave the house without taking a good look in the mirror. It seems as if there were mirrors everywhere in the house. There were mirrors in the bathroom, living room, and at the entrance of the door. There were 3 full-length mirrors, and small face mirrors were available for personal use. Although her children were grown and were away from home, she remained active in raising and assisting with her grandchildren, great grandchildren, family members, and friends who were unable to care for themselves. She was an active member of her church and enjoyed performing community services.

The deterioration of Rose's mental state seemed to have slowly eroded over 6 years and was like the slow erosion of seashore. The insidious forgetfulness would often lead to frustration, agitation, and depression, which is often seen in patients with Parkinson's disease and dementia. In addition, periods of delusions, hallucination, and paranoia crept seamlessly into the most rationale and sound being that everyone knew as the most amazing woman who lived on the face of the earth.

During a typical morning routine, as she walked past a full-length mirror, she stopped for a moment and stared at the reflection in the mirror. Rose rattled out a series of questions: "Why is this man staring at me? Why do you have your man staring at me? Can you ask him to stop looking at me? Did you ask him to come here and live with us?" Several attempts to interject and orient her to the present environment were unsuccessful. She was gently moved away from the mirror, toward the direction of the bathroom. Her morning routine of bathing and oral care started. Rose viewed herself in the half-length bathroom mirror while brushing her teeth. However, Rose showed no signs of agitation when she looked in the half-length bathroom mirror as she brushed her teeth.

The woman known as grandma, Rose to her husband, and to her children as mama was my dear beloved mother. She passed away on May 13, 2001, at the age of 86. Rose's mirror story is the impetus for this article. The purpose of this article is to review the literature regarding mirrors for the persons with dementia and make recommendations for nursing practice and research.

Dementia

The Centers for Disease Control and Prevention¹ describes dementia as “an umbrella term” for groups of cognitive disorders characterized by memory impairment, motor activity object recognition, and behavioral disturbance. According to a survey conducted by Alzheimer’s Disease International and published by the Alzheimer’s World Report,² it was found that 75% of both men and women and 64% of caregivers in their countries have negative perceptions about those diagnosed with dementia. Fear exists in dementia patients themselves, who are fearful of the reaction of others and in caregiver and societal perception. In developed and underdeveloped societies, having a diagnosis of dementia may pose a sense of exclusion from emergency resuscitation, nursing home care, and inpatient units. Many people diagnosed with dementia admitted to wanting to hide their disease because of a sense of shame, low self-esteem, and inadequacy, while others felt a sense of relief in sharing their lived experiences. Patients who have received an early diagnosis of dementia are more likely to receive timely treatment and therapeutic intervention for managing the behavioral aspect of the disease.¹⁻³

Alzheimer Disease

Alzheimer is a progressive disease, and the most common form of dementia among adults 65 years and older.¹ This disease may also occur at an early onset at 40 to 50 years of age. It is estimated that 5% of those diagnosed with AD experienced early onset of the disease.³ According to the Alzheimer’s Foundation of America,⁴ AD is among the top 10

leading causes of death among older adults in the United States and accounts for 50% to 80% of dementia cases. Alzheimer disease affects the part of the brain (i.e., amygdala, frontal lobe, temporal lobe) that controls the ability to make decisions, think, and recall recent events. Cognitive impairment is an outcome in AD and is typically one of the first signs of the disease.⁵ Because of memory lapses, the ability to care for self becomes progressively impaired in the later stages of the disease.¹ The Alzheimer's Association⁶ lists 7 progress stages of AD. In stage 1, there is no impairment. In stages 2 and 3, there is mild decline. By stages 4 and 5, there is moderate to severe decline. In stage 6, there is severe decline, and by stage 7, there is severe decline of all physical and cognitive functions. Of greatest concern in this article is stage 6, where severe cognitive decline is evident. In this stage, an individual can distinguish familiar faces but may forget individual's names. Individuals may need extensive help with their activities of daily living such as dressing and caring for their appearance. Episodes of suspiciousness and delusions may also occur. In stage 7 or late-stage AD, the muscles are rigid, and reflexes are abnormal. In addition, they lose the ability to care for self and others.⁷

Mirrors

A mirror is typically a flat or curved surface made of glass that has a reflective coating applied to its surface. Reflective surfaces such as highly polished stainless steel, glass covering pictures, glass windows, and the pupil of another person's eye may also act as mirrors. Actual mirrors are found in many places within our society: homes, grocery and department stores, cars, private and public restrooms, and in health care

facilities. At an international level, nurses report mirrors are often more common in elevators and hospital lobbies than inpatient hospital rooms.⁸

The many myths associated with mirrors may be a reason why mirrors are associated with vanity and superstition. For example, the concept of souls is often connected to mirrors. Mirrors are sometimes covered when someone dies because it is believed that the mirror can trap the soul of a person. Some individuals believe that a broken mirror shatters the soul causing 7 years of bad luck. Many churches banned the use of mirrors, as mirrors were believed to be associated with a vanity akin to the devil.^{9,10} Individuals do not ask for mirrors as it is considered vain to be seen looking into a mirror.¹¹ And yet, many use a mirror for many aspects of self-care (i.e., application of make-up, hair combing, shaving) and to see what one looks like and to see what others may see.¹² The literature concerning the mirror viewing experience and use of mirrors for the person with dementia appears to be limited.

Research on Mirrors

Tabak, Bergman, and Alpert conducted an exploratory study of mirrors with 100 patients diagnosed with dementia. Several mirrors of various sizes were placed on the unit. The findings suggested that 71% had a positive outcome of calmness demonstrated by a subjective measure of a favorable change in their mood. Overall, most responses of viewing self in the mirror were positive and included laughter, enjoyment, and an increased level of self-care awareness. One man displayed feelings of despair and anger

when he viewed self in the mirror. This initial outburst was reported to be followed by emotions of calmness. The report concluded that therapeutic use of mirrors for dementia patients adds to the sense of well-being for both patients and staff.¹³

In 1994, a woman living in a nursing home and confined to a chin-driven wheelchair confided to Freysteinson that she had not seen the lower half of her body in 7 years. She was concerned that she was not able to look to see if her catheter was showing.¹⁴ Freysteinson's concern for a lack of mirrors in health care facilities for the elderly patients was confirmed in a survey of mirrors in 10 skilled nursing homes.¹² There was exactly 1 full-length mirror in all 10 agencies. That mirror was in the lobby of 1 nursing home. Several residents (some in wheelchairs) were seen viewing self in that mirror. Mirrors for the bedbound resident were only found in 1 agency. Wheelchair-bound residents did not have a mirror in 3 of the agencies. Similarly, in a study of the environment of 1988 resident nursing home rooms, Cutler et al¹⁵ found only 10% of the rooms had a mirror that was appropriate for the resident in a wheelchair. Questions nurses may ask concerning the lack of mirrors for the nursing home resident are as follows: Why is there a lack of mirrors in skilled nursing homes? Did nurses choose to limit the mirrors in consideration of those residents with dementia? Although nurses may be the best health care individuals to determine the mirror type and placement in health care facilities, this is doubtful as nurses from around the world report that they have not been taught the use of mirrors in their schools of nursing.⁸

Theories of Self-Awareness and Body Image

Grogan indicated that body image is comprised of the thoughts, feelings, and perceptions we have about ourselves. These insights apparently play an important psychological role in our overall well-being.¹⁶ The Theory of Objective Self-Awareness by Duval and Wicklund postulated that the reflection of self in the mirror produces a heightened state of self-awareness. In this theory, the key construct of self-awareness allows an individual to view self in a mirror and to look closely at what others may see.¹⁷ Freysteinson used Lawton's theory of environmental gerontology to suggest that mirrors maintain, support, and stimulate. Mirrors may help elderly residents maintain their own appearance and, as such, preserve independence. Mirrors may help support self-orientation and self-recognition. Finally, Freysteinson suggested mirrors may help to enhance and stimulate social interaction. Viewing self in the mirror was suggested as one way in which individuals may check their appearance to ensure they are respectable enough to be seen in public.¹²

Web-Based Education about Mirrors

There appear to be many misconceptions about the use of mirrors for patients with dementia. For example, without any evidence-based data, many believe that mirrors should be covered up because of the inability of dementia patients to recognize self. A Web page for eldercare urges readers to cover up all mirrors, including mirrors on medicine cabinets, shaving mirrors, and/or anything else such as windows that may

reflect an image.¹⁸ Similarly, another Web site lists removal of mirrors as part of the safety checklist for patients with dementia.¹⁹ On a Web site, DeMarco gives the following advice:

I read recently that some Alzheimer's patients get confused or upset when they look in the mirror and see themselves. Well, obviously they don't see themselves, they see a stranger. If that happens, it would be a good idea to cover the mirrors.²⁰

This advice although well meaning, may be daunting, as there is little or no evidence-based research to support these interventions. As written, it would not be surprising to find a caregiver or loved one who may perceive this advice is applicable for any person in any stage of dementia or AD. Perhaps nurses may be the best health care providers to assess whether mirrors should be covered.

Implications for Nursing Practice

The goals of nursing are to protect, support, and optimize health; alleviate suffering; and advocate on behalf of patients. The primary objective of nursing is to diagnose, plan, intervene, and implement a plan of care that will help patients regardless of their diagnosis.²¹ The knowledge regarding mirror viewing and the use of mirrors for individuals with dementia is based on tradition, self-knowledge, and “best guess” practices. Currently, much of that knowledge is geared toward covering mirrors. There is no known research to support this intervention. Freysteinson found that although there is a lack of evidenced-based studies, patient testimonies suggest that utilizing a mirror to view

self is an everyday reality.^{8,11,14} Nursing personnel play an important role in the care of patients with dementia. Helping preserve self-acceptance and self-recognition in a mirror and independence in activities of daily living, which require a mirror, is important. Rose had cared for her own appearance while looking in mirrors for decades. Fortunately, Rose's half-size bathroom mirrors did not cause her to see others when she cared for her own appearance. Rose looked in a mirror every day to wash her face, comb her hair, brush her teeth, and apply her face powder. Had all the mirrors been covered or removed on the day Rose perceived a stranger in 1 mirror, it is quite likely that she would have lost some, if not all, ability to do her daily personal self-care. Rose would have had to relearn how to perform those same tasks without the use of a mirror. This would have been very difficult for an 86-year-old woman with dementia. In addition, without mirrors Rose would never have seen her own face again. How this may have affected her self-recognition and self-orientation is unknown. Equally significant is protecting patients from elements in the environment, which may add to negative delusional states.

In the advanced stages of dementia, the nurse may find the caregiver to be the most reliable source of information. The nurse should ask the caregiver if the patient has shown any untoward emotions when viewing self in a mirror. If a caregiver is not available, the nurse should try to ascertain if a patient is upset when viewing self in a mirror. This assessment should occur when a patient appears calm and alert, and ideally during an activity that would typically involve viewing self in a mirror (i.e., shaving, combing hair).

If a patient consistently appears distraught when using any mirror, the mirrors should be covered. The nurse must instruct the caregiver to seat the patient with dementia in the car to avoid potential mirror viewing in a car mirror. In addition, caregivers should avoid all department stores, grocery stores, and public restrooms where mirrors are typically found. Caregivers may want to preview all health care facilities prior to taking a patient to, for example, a physician's office to ensure there are no mirrors in the elevators or lobbies of these buildings. The authors have rarely seen mirror phobias this severe.

Many patients may be like Rose who had periods when she saw a man in a full-length mirror, and yet most of the time when viewing self in that same full-length mirror, she did not see a stranger: she saw Rose. Smaller mirrors did not appear to cause Rose to have hallucinations or see another person in the mirror. Nurses should begin an assessment of mirrors with small pocket-sized mirrors. If there appears to be no untoward effect, the nurse can progress to assessing mirror self-recognition in moderate and then larger-sized mirrors. There may be periods of the day when a patient with dementia may be independent in using a mirror for self-care, and other periods where the patient may perceive another person reflected in the mirror. Research as to when to cover mirrors and when not to allow access to mirrors should be undertaken. Future studies on the use of mirrors with patients who have dementia are vital to overall care and management of this population. Some questions that may be explored are as follows: (1) Is there a correlation between the ability to care for one's own hygiene and the use of mirrors? (2) Do mirrors

preserve self-recognition and self-awareness? (3) Do full-length mirrors lead to an increase in agitation or delusions when compared with smaller mirrors? In addition, tools to assess mirror viewing for those with dementia need to be designed and tested. Finally, nurses need to understand the mirror viewing experience for patients with advanced dementia who do not recognize self in the mirror. Is this experience always an episode of terror, or are there individuals with dementia who see and talk with a friend in the mirror?

Conclusion

On the basis of the literature search, there are few evidence-based studies that address the use of mirrors in patients with dementia. A few studies and articles by Freysteinson^{8,11,12,14} and Freysteinson and Cesario²² exploring the concept of mirrors has begun to surface, bringing this phenomenon to the attention of health care providers and caregivers. There is a need for evidence-based research studies for this patient population. Because of a lack of research in this area, nurses are limited in their knowledge as to how to effectively assess and manage the mirror-viewing experience for people with dementia. When to use or not use mirrors in the management of patients diagnosed with dementia will remain a question that needs to be answered through clinical research. With research, we will uncover a mirror spectrum from removal of mirrors to increasing the number of available mirrors in health care facilities. The management of Rose may have benefited from such knowledge as her daughter would have had evidence-based practice mirror guidelines.

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CHAPTER III

REVIEW OF LITERATURE

The purpose of this hermeneutic phenomenological study was to explore caregivers' perceptions and understandings of the experience of observing a person with dementia viewing self in the mirror. The following literature review presents a comprehensive discussion of the published literature that relates to persons with dementia and their experiences with mirror viewing.

A literature search was conducted using online searches of electronic databases, including the Academic Search Complete, Administration of Aging, Agency for Healthcare Research and Quality (AHRQ), Cumulative Index of Nursing and Allied Health Literature (CINAHL), Medline, Education Resources Information Centre (ERIC), Hartford Institute for Geriatric Nursing (HIGN), Nursing Improving Care for Healthsystems Elders, (NICHE), PubMed, PsycINFO, Cochrane Review, Sociology and Social Work and Psychology. Governmental agencies such as the CDC and Prevention, National Institute of Health (NIH), and the National Association of Caregiving (NAC) were also explored. Attempts to confine articles to the ten-year period between 2006 and 2016 resulted in considerable limitations; therefore, the literature search was expanded to earlier periods greater than ten years to present a broader perspective. Key words included dementia, Alzheimer's, mirrors, self-recognition, grooming, environment, quality of life and nursing practice. Initially, each term was searched separately, and then

various combinations of these terms were formed to enhance the search process. Inclusion criteria were studies that addressed individuals with dementia, grooming, mirror viewing of self, quality of life and environment of care. Studies that addressed caregivers of animals; mirror reflections of animals, objects, and the body image of ballet dancers; and children's caregivers were excluded.

Ancestry searches (Whittemore & Knafl, 2005) of the reference lists for the selected articles that met the criteria for review were also conducted in the hope of capturing additional related articles that might have been missed during the original search. The initial search results yielded over 2,350 articles that included mirror viewing of non- dementia individuals including the elderly, ballet dancers, exercise techniques using a mirror and children. Also included in the original search were mirror viewing and reflection of animals and mirror reflections of objects. The search terms were further narrowed to include only mirror viewing of individuals with dementia and Alzheimer's disease within their environment, self-recognition, grooming, quality of life and environment. The final search results yielded 10 articles that met the above criteria and usefulness in addressing the overall scope of the phenomenology under study. There were five intervention studies that addressed response to mirror encounters, two reported studies on environment of care and availability of mirrors, and three case studies addressed dementia patients, mirror and self-recognition. This chapter presents information on mirrors, quality of life and grooming, mirrors in the environment and mirrors and self-recognition.

Mirrors

Mirrors are reflective surfaces designed to provide immediate reflection of an image, an object or self and routinely used by most individuals for self-care activities. There are many uses for mirrors. Mirrors have also been viewed as an index of self-recognition and provide one an opportunity to become familiar with oneself. Grooming activities such as, combing one's hair, brushing one's teeth and applying make-up are typically performed in front of a mirror.

A mirror facilitates self-awareness. An integrated awareness of self and a normal part of early human development is considered an everyday and ordinary event for most individuals when language and visuospatial memory remain intact. These two factors are often affected in those with dementia, impacting the ability to recognize self in a mirror (Grewal, 1994).

Self-recognition and grooming may be impacted by impedance in accessing a mirror. Freysteinson (2010) found access to mirrors in a long-term care (LTC) facility was related to a lack of mirrors, obstruction, or inappropriate placement of mirrors. Lack of access to mirrors may also be related to advice found on websites such as, Caring.com Scott, 2017) urging readers to cover up or remove mirrors for individuals with dementia. Quality of life may be impacted when access to self-care activities such as grooming was impeded due to unavailability of mirrors (Zimmerman, 2005). Caregivers' actions may also impact care provided to

individuals with dementia based on caregivers' personal own values and beliefs about mirror use for individuals with dementia.

Quality of Life

The quality of life for individuals with dementia was important and may vary for this population group. Quality of life was defined as a broad multi-dimensional concept that encompasses subjective reports of both negative and positive aspects of one's overall well-being (World Health Organization, 2015). Quality of life may include such personal attributes as mental and physical health, religion, ethnicity, culture, and geographic location (Heggie, 2012). Sousa et al. (2013) posited that quality of life for people with dementia should be a priority. In a systematic review of more than 126 studies, Bowling et al. (2015) addressed quality of life in more than 40 studies and found that it appeared to be the best researched measure for patients with dementia and their caregivers. Overall, the studies suggested that measures of quality of life for patients with dementia and that of the caregivers might be different. Likewise, Sousa et al. (2012) reported that quality of life for individuals with dementia was challenging and difficult to measure due to the validity of self-reporting. Patients with mild to moderate dementia rated their quality of life differently using independent functionality as a strong indicator, while caregivers who served as proxies rated quality of life for individuals with dementia based on aspects related to their own value system and immediate need. This discrepancy may present a bias (Arons, Krabbe, Scholzel-Dorenbos, Wilt, & Rikkert, 2013). As the disease progresses and individuals can no longer express their health-related quality of life

alternative measures such as proxies and behavioral observations becomes necessary, but results should be interpreted with caution (Arons et al., 2013). This study will serve as a model by using caregivers as proxies for understanding the experience of individuals with dementia when they view themselves in the mirror by relaying that experience through their individual stories.

Grooming

Further investigation of quality of life was initially pursued by Zimmerman et al. (2005), who explored overall dementia care in residential care (RC)/assisted living (AL) and nursing homes using grooming as a key indicator. The purpose of this study was to explore elements in dementia care in RC/AL and nursing homes facilities associated with quality of life. A purposive selection of 35 RC/AL facilities and 10 nursing homes (a total of 45 facilities) were selected. The total sample size of 421 participants 65 years and older with diagnosis of dementia was randomly selected from each facility. Cross-sectional data were collected spanning over two-years, followed by a post six-month telephone follow-up call. Eleven standardized quality of life measures were used to evaluate quality of life as reported by participants and providers (nurses, aides, and supervisors). The response rate was 95% of residents (n = 400), 84% of the most involved family members (n = 354), 98% of direct care providers (n = 412), and 100% of the administrators of the facilities (Zimmerman et al., 2005).

Dementia care was measured across all facilities. Residents' appearance was related to at least one quality of life parameter. Grooming was perceived to be an inherent

indicator of dignity and thus may be an implicit marker for poor quality of life. Residents who were un-groomed reported poor quality of life which was comparable to reported quality of life by their care providers. The study findings showed that degree of cognitive impairment influenced quality of life. Poor quality of life may be related to a lower level of cognitive impairment (23% - 42%) in RC/AL facilities compared to a higher level of cognitive impairment (more than half) in nursing homes. Residents ($n = 402$) with higher impairment had a significantly lower quality of life as compared to less impaired residents (-2.6 versus -2.1 , $p < .01$). Staff training (more training) seemed to positively influence reported quality of life

In conclusion, grooming, level of impairment, and staff training may impact quality of life for individuals with dementia. However, this was difficult to definitively assess since this was a descriptive study with no applied controls in place. Grooming as an inherent indicator for quality of life was of particular interest to this study. In most situations, a mirror was used by most individuals for daily grooming activities. Patients with dementia may still be concerned with their overall appearance when viewing self in a mirror. For example, in the studies that will be later presented (Tabak, Bergman, & Alpert, 1996; Biringer, Anderson, & Strubel, 1988) the participants used the mirror to appropriately comb and arrange their hair, clothing and showed interest in their overall appearance.

Generalizability of this study (Zimmerman et al., 2005) was limited; as the population of participants included both dementia and non-dementia specific care areas

across the participating facilities. Further research on how grooming relates to quality of life should be a focus for future investigation.

Mirrors in the Environment

Individuals with dementia are sometimes housed in hospitals and long-term care facilities to meet their needs. In care facilities, mirror use was constrained by environmental considerations. Freysteinson and Cesario (2008) surveyed the availability of mirrors in 10 hospital post-surgical rooms in a large city in the southern US. Mirrors were not available for bedbound patients in seven (70%) of the hospitals. In two (20%) of the hospitals, the mirrors were very small and placed high on the wall allowing one to view only one's face if one could stand. In nine hospitals (90%) of the mirrors were impeded by a sink or a counter limiting view of self from the chest up. In 60% of the hospitals surveyed, there was no privacy offered for viewing of self in a mirror.

In 2010, Freysteinson conducted a preliminary survey on availability and access of mirrors in ten LTC facilities in a large city in the southern U.S. Accepting the underlying assumption of this study that "it was a basic human right to view one's own body" (p. 35), Freysteinson posited that mirrors are essential items that may assist in eliciting awareness and promote and maintain independence in caring for oneself. Lawton's theory of environmental gerontology was used to guide the study. This theory suggested the environment should maintain, support, and stimulate to promote self-awareness and independence.

The location, type of mirrors, and total number of available mirrors to residents daily were inventoried and measured. The overall environment of mirror accessibility and availability was negligible. In nine (90%) facilities, there were no mirrors available for residents who were bedbound. Three (30%) facilities had no accessible mirrors for residents in wheelchairs. In eight of 10 (80%) facilities, only one mirror located in the bathroom, was available to residents which were a mirror in the bathroom. Two facilities (20%) had mirrors in the dining room and one facility (10%) had a full-length mirror in the foyer: many residents were observed walking or wheeling their wheelchairs to this mirror to view themselves. There were no other full-length mirrors available in the other nine (90%) facilities. In one (10%) facility, residents only had access to one small bathroom mirror above the sink measuring 0.2 m². In most facilities, small and handheld mirrors were not allowed for cited safety reasons. The key limitation in both studies was the small convenience sample size that limits generalizability.

Mirrors and Self-Recognition

Human beings are unique in using mirrors to reflect an image of themselves, thus facilitating self-awareness. The ability to recognize self using a mirror incorporates that awareness as could be viewed from another's perspective. Self-recognition was viewed as an important aspect of one's self-awareness (Grewal 1994). Kelsick and Freysteinson (2013) presented a case study of an elderly woman, Rose (see Chapter 2), whose mirror experience varied depending on size and location of mirrors. At times, Rose saw a stranger in the mirror, and at other times her mirror actions appeared

appropriate appeared appropriate. Kelsick and Freysteinson concluded that self-recognition for someone with dementia may vary from day to day, with the reflection at times perceived as self and perceived at other times as the reflection of someone else. As was seen in mirrored self-misidentification (which was the failure to recognize one's reflection in a mirror) loss of self-recognition was a common event seen in individuals with advanced dementia (Biringer, et al., 1988).

An experimental study was conducted by Biringer et al. (1988) with female participants ($n = 18$) with senile dementia of the Alzheimer's type at the geriatric center location in France. The purpose of the study was to observe the reactions of participants when they viewed themselves in the mirror in two situations: 1) when a "visible mark" was placed on the forehead, and 2) when a visible mark was placed on the back of the hand at another time.

Participants were diagnosed using the Global Deterioration Scale (GDS) for assessing cognitive functions in persons with dementia. The GDS ranges from level one through seven (from no cognitive impairment to very severe cognitive impairment). Participants in this study were placed in three groups according to their GDS scores of five, six, or seven. A level five score indicates moderate dementia ($n = 6$), level six indicates moderately severe dementia ($n = 6$), and level seven indicates very severe dementia ($n = 6$). The severity of dementia in patients in this study ranged from moderate to very severe.

Participants were placed in front of a mirror, and each subject's mirror reactions were noted. Participants were rated on a behavioral classification rating scale: "1-no observable reaction, indifferent, 2-speaks to the reflection, 3-active interest in the reflection, 4-active interest and touches the mirror and 5-appropriate use of the mirror" (Biringer et al., 1988, p. 178-179). The fifth item on the rating scale, appropriate use of the mirror, consisted of activities such as adjusting clothing or hair while viewing self in the mirror.

A visible mark was placed on each participant's forehead and on the back of each participant's hand to test for self-recognition and motivation to investigate the "visible mark." Reactions to the visible mark on the forehead and the visible mark on the hand were observed and documented. The findings of the study revealed all six participants at stage five (moderately severe cognitive decline) demonstrated clear evidence of appropriate identification of the 'mark' on their forehead while viewing their reflection in the mirror. Although only three participants at stage six responded appropriately to their reflection, all participants at this stage appropriately reacted to the 'visible mark' on their hands. None of the participants at stage seven on the GDS scale reacted to the unfamiliar 'mark' on their foreheads, yet one attended to the visible 'mark' on the hand. Conversations with their reflections in the mirror were noted by three participants at stage six and one participant at stage seven, but only one of these participants from both stage six and seven recognized the visible mark on the forehead. The participants were further observed for five minutes for appropriate use of the mirror such as, adjusting their

clothing or hair of which four of the stage five participants and two of the stage six participants responded appropriately by confirming self-recognition. However, at GDS seven no subjects showed any evidence of self-recognition of their reflection in the mirror (Biringer et al., 1988).

Based on the results of this study, responses to the visible mark on the forehead and hand varied among the individuals at stages six and seven. This may indicate that self-recognition may still be possible at the advanced stages of the disease (stages six) for some individuals with dementia. In general, cognitive decline in advanced dementia contributes to systematic mirrored self-misidentification – failure to recognize self in the mirror (Biringer et al., 1988).

In a subsequent study, Biringer and Anderson (1992) assessed participants with senile dementia of the Alzheimer's type ($n = 29$) for self-recognition when presented with a mirror and a noncontingent video image. The sample was drawn from a long-term facility located in France. The primary aim of this study was to assess self-recognition when presented with a mirror and a video image. The reported age of the sample was 63-96 years of age ($M = 84.9$). Participants were recruited from a long-term care facility with a length of stay from one to six years ($M = 2.8$). Twenty-five participants were tested using the Extended Scale for Dementia which consists of 23 items such as pattern recognition, number memorization, object naming and verbal recognition with a maximum score of 250. Progressively lower scores indicated progressive severity of

dementia. All 29 subjects were tested on the GDS. Thirteen participants were classified at stage five and 16 participants at stage six.

The participants were first tested for self-recognition using a mirror by placing a 1.0m x 0.75m mirror at a distance of one meter in front of each participant. The participants were observed for five minutes and any adjustments to clothing or hair while looking in the mirror was noted. After five minutes the participants were turned away from the mirror and a 'mark' was covertly placed on their foreheads and they were repositioned in front of the mirror for an additional five minutes. The participants were observed and any attempts to investigate the visible mark on their foreheads were noted. Lastly, while pointing at the reflection in the mirror, the participants were asked, "who was that?" (p. 386). This verbal probe was repeated up to three times if necessary and responses noted. Additionally, a visibility mark was placed on the back of the hand which was directly visible without the use of a mirror. All noted reactions were documented.

On the GDS at stage five all participants met at least one criterion for self-recognition when compared to 25% ($n = 4$) participants at stage six who demonstrated fewer measurements of self-recognition. Twenty-five of the 29 patients (86%) demonstrated self-recognition per the established criteria when presented with a mirror meeting at least one of three of the criteria. All 13 participants (44.8%) at stage five recognized self and seven (54%) met all three performance criteria. Although four participants at stage six did not recognize themselves, two of the four responded by investigating to the visible mark on their hands. The researchers concluded that the

curiosity of investigating the visible mark' showed attentiveness about their appearances. The reported mean age for this group (stage five) was 84.9 years which was considered not significantly different from those who did not recognize self (stage six) with a reported mean age of 86.0 ($t = 0.25, P = 0.81$). Five participants at stage five failed the 'mark test.' Four of the five participants at stage five showed no reaction or investigated the visible mark on their hands and were viewed as showing inattentiveness to appearance. Limitations in both studies (Biringer et al., 1988; Biringer & Anderson, 1992) were related to the small sample size affecting the generalizability of the studies.

Bologna and Camp (1995) presented a single case study ($n = 1$) of a 77-year-old woman with probable AD from the New Orleans area had a Mini-Mental State Examination (MMSE) score of one out of a maximum score of 30 and a GDS of seven (very severe cognitive decline) using previous established criteria by Biringer and Anderson (1992). The aim of this study was to determine whether an individual with AD who lacked the ability to recognize self, could display self-recognition through contextual manipulation and whether there was evidence of explicit versus implicit dissociation. Explicit dissociation was referred to as conscious self-recognition while implicit dissociation was unconscious self-recognition such as, recognition of reflective image/objects but lacks the ability to recognize self.

The participant was observed for five minutes while seated in front of a mirror. Next a 'visible mark' was placed on her forehead followed by questions regarding the identification of the reflection in the mirror and was observed for another five minutes.

The participant failed to identify self-using all three criteria (Bologna & Camp, 1995). The participant displayed a variety of behavioral responses such as, engaging in friendly conversation with the image in the mirror, at times displaying anger and aggression towards the reflective image; identifying the person in the mirror as someone else (cousin, sister in-law, her daddy or a little boy). She once asked the reflection in the mirror her name. When asked by the researcher who was the reflection in the mirror she responded, "I don't know" (p. 52), or would name one of the previous people as mentioned above. An effort to produce conscious (explicit) self-recognition by placing a label with the word "MIRROR" was correctly identified. Participant also correctly identified the mirror, yet she failed to appropriately recognize self in the mirror. A name tag was placed on the participant. The participant identified the reflection in the mirror as having the same name as her. Lastly, to produce unconscious (implicit) self-recognition the participant was given a comb and a verbal prompt that they (researcher and participant) were about to leave. The participant appropriately used the mirror to comb her hair yet, was unable to identify the reflection in the mirror as that of herself (Bologna & Camp, 1995).

In conclusion, the participant was unable to recognize self despite using several cues to illicit self-recognition. However, the participant correctly used the mirror to guide her behavior to comb her hair. This was an intentional and independent action. The researcher concluded that dissociation existed in her ability to recognize self, while her procedural/implicit memory remained functional. Based on the results of this study, there

was some evidence that there may be some functionality of self-care (combing one's hair) that may remain despite the level of impairment. This action was an important aspect for this study as it relates to self-awareness and self-recognition in understanding the overall experience of someone with dementia viewing self in the mirror. This case study presented significant limitation due to the sample size of one participant. Therefore, results may not be transferrable to similar population

Bologna and Camp (1997) attempted to replicate their previous study (Bologna & Camp, 1995) to determine whether dissociation between overt and covert self-recognition for people with AD was possible among various persons and experimental situations. Overt self-recognition was the ability to appropriately recognize self in a mirror. Covert or unconscious self-recognition was simply the inability to recognize self. Three screening procedures for self-recognition were used to evaluate self-recognition of the participant: 1) a mirror, 2) identification of a 'marked test' and 3) a verbal response indicating that the reflection in the mirror was that of the participant. Fifteen older adults were recruited from adult day care centers in the New Orleans area. Inclusion criteria were a diagnosis of probable Alzheimer's disease using the National Institute of Neurologic Disorders and Stroke – Alzheimer's disease and Related Disorders (NINDS-ADRDA) criteria; had normal or corrected vision; and were not involved in an ongoing experimental study. Three participants ($n = 3$) met the screening criteria and were available for the study, of which two were women. Participant one was 77-years old, with nine years of education; GDS Level of six, and a MMSE score of 3. Participant two was

85-years old, eight years of education; GDS Level of three, and MMSE score of three. Participant three was 78 years old, education level of 12 years; GDS Level of seven and a MMSE score of two. Mean age of the sample was 78. Participants were asked to read their names and the word 'mirror' printed in very large fonts.

A baseline intervention was conducted to establish that the participants were unable to recognize self. This involved using three five minutes screening procedures. First participants were placed in front of a mirror, followed by the mark test and lastly a verbal probe – “who is that?” (p. 196). All observations were video recorded. Participants achieved overt self-recognition when they appropriately (1) responded to the mirror-only challenge, by verbally indicating self-recognition, (2) recognizing the mark in the mirror, examining and attempting to remove or commenting on the mark and (3) verbally indicating that the reflection in the mirror was that of the participant. Overt self-recognition was assumed when all three criteria were met. When the conditions were applied, all three participants failed to overtly recognize themselves. The Cohen’s Kappa for interrater reliability was 0.978.

The findings of this study replicated the previous study (Bologna et al., 1995) suggested that although mirror use was necessary, this condition was not sufficient for overt self-recognition in advanced stages of AD. The results suggested that covert self-recognition could occur in the absence of overt self-recognition. These findings indicate the dissociation between implicit-declarative and the explicit non-declarative memory sphere of self-recognition. Although the use of environmental cues was sufficient to

reinstate self-recognition, this was only temporary. Manipulation of the environment was required to illicit self-recognition for a person with advanced stages of dementia.

Researchers continue to seek answers on how best to interact with person with dementia when self-recognition was challenged. Earlier studies such as Grewal (1994) sought to gain insight into individuals with moderate to severe dementia. A prospective study with participants ($n = 20$ moderate, $n = 19$ severe) was conducted on participants with moderate to severe dementia. The mean age for each group was 83 and 81, respectively. The purpose of the study was to explore the ability of self-recognition in participants with moderate and severe dementia. A MMSE score of 7 to 15 was classified as moderate dementia and a score of less than 6 was classified as severe dementia. Self-recognition and the ability to name two body parts were used to score each participant. Participants with visual deficits were excluded. The ability to name one's body parts is considered a normal part of early human development. Body parts were assessed by administering two tests. The first test instructed the participant to identify their nose and elbow. If the participant was unable to point to the body part, the researcher gently touched the body part and asked the participant to identify it. In the second test, the participant was instructed to identify the person in the mirror. The mean scores for Test one and Test two were 0.5 and 0.2, respectively. The mean MMSE score in the severely demented group was 1.9. Correlation scores with the MMSE for Test one was 0.85 ($p < .001$) and Test two was 0.88 ($p < .001$). The reported mean score for the moderately

demented group was 10.7. The mean scores for Test one and Test two for this group was 2.0 and 1.0, respectively.

In general, the study suggests individuals with AD with moderate dementia are still capable of recognizing self but as the disease advances that ability was eventually lost. Individuals with severe dementia significantly impact their ability to recognize themselves. Generalizability to other groups was limited because the ethnic composition of the sample was not disclosed.

Dementia of various types may also present challenges with self-recognition. Gil-Ruiz et al. (2013) presented a case study of an 85-year-old woman, TS. She was diagnosed with dementia probable of the Lewy body type. As her cognitive decline continued, she was placed in a nursing home. Six months after her diagnosis TS confined herself to her room and complained that someone was staring at her in the mirror. TS appeared to see a familiar face, someone she believed lived next door whom she called Maria, a perceived neighbor, in the mirror. TS appeared to believe that their room was connected through the bathroom mirror. TS suggested that Maria went everywhere she would go such as, to the hairdresser. Placing a stool behind her door became a routine for TS to prevent anyone from breaking into her room. Despite her delusional ideology, TS had no difficulty in performing her daily activities such as combing her hair, in front of the mirror. She would stand in front of the mirror and converse with the caregiver standing behind her without turning around (Gil-Ruiz et al., 2013).

Over time, TS's delusions got worse. The 'mirror sign' condition was later added to her diagnosis. The term 'mirror sign' describes the inability of some dementia individuals to recognize self in a mirror but the ability to recognize familiar faces remains intact (Connors et al. 2012). On her neurological exam, TS scored 19 on the MMSE and 4 on the GDS. The MMSE is a 30-point questionnaire widely used to measure cognitive impairment in the clinical and research settings. A score of 27-30 indicates intact memory. A score of 10-26 suggests mild to moderate dementia while a score of less than 10 indicates severe dementia. The GDS is used for assessing cognitive functions in persons with dementia. The GDS ranges from level one through seven (from no cognitive impairment to very severe cognitive impairment). A level five score indicates moderate dementia, level six indicates moderately severe dementia and level seven indicates very severe dementia.

She performed poorly on the auditory verbal attention test. Ultimately, TS delusional state influenced her moods and behavior and she expressed the desire to end the helplessness and harassment subjected to by the woman (Maria) in the mirror (Gil-Ruiz et al., 2013).

This study provided a possible solution for managing TS 'mirror sign' behavior that led to irritation, suspicion and distrust. The size of the mirror was reduced from being a mirror where one sees one's entire body from the waist up to a smaller mirror by placing a paper frame around the mirror, which only allowed TS to view her neck and face. Modification to the mirror size helped reduced her irritation, suspicion and distrust.

TS no longer placed the stool behind her bedroom door when she left the room and her mirror and social interactions were more appropriate. Allowing TS to actively participate in the intervention appeared to facilitate a sense of well-being.

Individuals with dementia frequently experience delusions as was evident in Rose and TS's mirror encounters. This finding supports similar findings from Bologna and Camp (1997)'s study (above), which suggested manipulation of the environment as a non-pharmacologic intervention for managing the mirror experience for individuals with advanced stages of dementia. Manipulation of the environment as a non-pharmacologic intervention may be beneficial when providing care to this population versus removal or covering up of mirrors.

In TS's example, reducing the size of the mirror was an intervention that led to changes in her overall positive response to her mirror experience. Study findings are also in alignment with facial recognition for dementia patients. For the dementia population this could simply mean that individuals with mild to moderate dementia may respond to mirror activities for activities of daily living (ADL) such as, combing one's hair, brushing one's teeth and applying one's make-up without a perceivable threat as was evident with TS when the size of the mirror was reduced. Therefore, mirror use for patients with dementia should not be discounted as unimportant during their daily routines since visibility of one's image may stimulate a sense of well-being (Grewal, 1994).

Tabak, Bergman, and Alpert (1996) conducted a pilot exploratory study to explore the experience of individuals with dementia ($n = 100$) when they view

themselves in the mirror. The study participants consisted of 67 women and 33 men between the ages of 76 and 85 years old. The aim of this study was to examine changes in behavior of individuals with dementia when they look at themselves in a mirror. The findings were reported in two groups; the effect of the study on the participants and the effect of the study on the staff.

Mirrors of various sizes were used (handheld mirrors, and wall mirrors). The hand-held mirrors were placed on a table in front of each participant. There were 21 wall mirrors. The behavioral responses to the mirror interactions were noted and documented. The length of time spent looking in the mirror varied. Of the 100 participants, 39 (39%) spent more than five minutes looking in the mirror, five (5%) participants spent five minutes, 36 (36%) participants spent two minutes, while 20 (20%) participants spent only one minute of looking in the mirror. The majority (55%) of the participants appeared to recognize themselves in the mirror. Those who recognized themselves commented on their appearance (“I look pretty; I have too much make up on; touched their faces and arranged their hair,” etc.). Thirty-eight percent did not appear to recognize themselves, while eight percent were unsure of whom the image in the mirror was (Tabak et al., 1996, p. 157). Participants who recognized themselves in the mirror demonstrated positive reactions such as; laughter and joyfulness and pleasure, thus raising the awareness of self.

In relation to the staff, this intervention was rewarding and increased their awareness of things that they previously ignored such as attention to details such as, the selection of clothing, combing hair, and introducing the use of a mirror during bath

routines. Tabak et al. (1996) also postulated that the use of mirrors facilitated more effective communication between the nurses and individuals with dementia by entering their world as it is experienced.

Three limitations to the study are worth mentioning. First, the study was conducted at a single facility. Therefore, this may have limited the overall demographics make-up and overall characteristics of the study participants. Secondly, caregivers consisted of trained professionals (formal) versus untrained caregivers (informal) and may of itself influence the caregivers' perspectives. Thirty men (caregivers) were excluded from the study since women have historically provided caregiving. This limitation may contribute to bias against gender differences, which may have been gained from a male perspective.

Overall, the findings suggested that the therapeutic use of mirrors contributes to a sense of well-being for both individuals with dementia and staff. This measure requires minimal resources and can be incorporated in the daily routine at a time convenient to all.

Discussion

This review of literature on the various studies of dementia supports the need for further investigation of individuals with dementia viewing self in the mirror. Overall, 10 articles pertaining to the study were reviewed. The sample size ranged from one to 421 participants. The level of evidence included: one experimental study, five descriptive/observational studies, one exploratory study and three case studies. Overall, there were limitations of the retained studies noted throughout the chapter. One common

theme was that as the dementia progresses, some individuals do not recognize themselves in the mirror. Two case studies let us enter the experience of another through the eyes of the daughter and the nurse. Because literature on caregiver perception regarding the experience of and use of mirrors for a person with dementia was limited, studies focusing on self-recognition, grooming, environment of care, and quality of life were considered as part of the literature review. The measurement of quality of life remains complex and multifaceted and may vary depending on level of cognition and the ability to recognize self. In general, findings from one study presented suggest residents' appearance influence at least one quality of life measures as rated by the providers, residents, and their caregivers (Zimmerman, 2005). While several findings of the studies were discussed in this chapter, there was no direct evidence addressing the phenomenon under study.

Studies by Freysteinson and Cesarion (2008) and Freysteinson and Cesario (2010) showed the availability of mirrors in the hospital and LTC facilities were limited. However, when mirrors were available, access to the mirrors was lacking or was difficult for bedbound and wheelchair bound patients. While mirrors in LTC were limited and inaccessible at times, this was not the case for Rose and TS in the case studies provided by Kelsick and Freysteinson (2013) and Gil-Ruiz (2013). The size of the mirror in both cases seemed to have made a difference in the ability to recognize self. Using a bathroom mirror that reflected her image from the shoulder up was adequate to prevent Rose from seeing a stranger. Similarly, TS's mirror delusions ceased when slight modification to decrease the size of her mirror was made.

The studies by Biringer et al. 1988; Biringer & Anderson, 1992; Bologna (1995, 1997); and Grewal, 1994 suggested that self-recognition in persons with dementia may vary depending on the level of the global MMSE and GDS. Variations in self-recognition were noted at stages five, six, and seven. Biringer et al. (1988; 1992) and Bologna (1995; 1997) found that even when unable to recognize self, participants appropriately used the mirror to comb their hair, arrange their clothing and check their appearances. Self-recognition in the later stages of dementia may require additional prompting and/or testing. In general, self-recognition was evident in most of the studies presented despite the inability to investigate an unusual 'mark' on the hand or forehead in some cases. When self-recognition was evident, the participants in most cases took interest in their appearances by straightening their clothes and arranging their hair.

Despite the severity of dementia, Tabak et al. (1996) found most participants had a positive response when viewing self in a mirror and concluded that the overall experience of viewing self in the mirror contributed to a sense of well-being for both participants and staff. Findings also suggested that use of a mirror improved communication between staff and patients.

Overall, studies highlighting mirror interactions for individuals with dementia use mirror image as indices of measurement for the presence of self-recognition. However, although this phenomenon was highly accepted and fairly described, the inability to recognize self for individuals with dementia is still not well studied.

In conclusion, evidence regarding mirror location, grooming and self-recognition for individuals with dementia appears in the literature as empirical data. There were no phenomenological studies of the experience of viewing self in the mirror found in the literature that directly focus on and delved into the experience to try to capture the world as seen by those with dementia. Understanding the inner experiences of viewing self in the mirror needs to be further explored.

This review of literature confirmed a fundamental gap regarding this phenomenon. This fundamental gap leaves the questions to be answered of what we can know about this experience, which can only be explored through the lens of the caregiver. Qualitative studies are needed to understand the experiences of individuals with dementia when they view themselves in the mirror. Analysis of this research gap can be used as a basis for prioritizing future qualitative research that adds value to understanding the inner experiences of individuals with dementia viewing self in the mirror. In addition, analysis of this gap provides a foundation for future mirror intervention studies for this population. This study will seek to investigate caregiver's perceptions and understandings of the experience of observing a person with dementia viewing self in the mirror and enhance the literature giving us a better understanding of that experience.

CHAPTER IV

PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

The purpose of this hermeneutic phenomenological study was to explore caregivers' perceptions and understandings of the experience of observing a person with dementia viewing self in the mirror. According to Creswell (2013) and Ricoeur (1974, 1975, 1976, 1981), hermeneutic phenomenological studies are conducted with the goal of exploring and understanding the experiences of individuals as they experience them. This approach allows the researcher to consider what it means to be a person freely interacting with the world before attempting to answer questions regarding knowledge and theory (Benner, 1985; Lopez & Willis, 2004). The findings of this study represent an effort to understand the experiences of dementia patients when they encountered a mirror as revealed by their actions through the perceptions of their caregivers. This chapter informs the reader of information regarding research methodology, setting, sample selection criteria, protection of human subjects, analysis of findings, and scientific rigor.

Setting

This hermeneutic phenomenological study was conducted in a large metropolitan city in the United States. Participants was recruited from a registered professional national nonprofit organization recognized for providing care to individuals with dementia, conducting research and offering support to caregivers.

The mission of this organization is to support scientific advances in research for Alzheimer's disease and to improve public awareness and dissemination of knowledge

through clinical and scientific communities. The organization is a strong global advocate for research and support for this devastating disease, with the vision of “a world without Alzheimer’s disease” (Alzheimer’s Association 2016). The researcher conducted all interviews by telephone, or in the home setting of the participants.

Participants

Purposive sampling method (Creswell, 2013) was used to recruit approximately 18 participants who were individuals caring for a person with dementia. A snowball strategy was employed to enhance recruitment (Polit & Beck, 2017). The final sample size was determined when data saturation was reached. Saturation was further confirmed by interviewing an additional two to three participants.

Inclusion Criteria

- Participants are 18 years and older
- English-speaking
- Have been told by a physician that the person they care for has dementia
- Provide care for individuals with dementia for at least 3 months or more in a private home setting. This time frame allows the caregiver an opportunity to develop a relationship with the individual.
- Informal or formal caregivers
- Witness the person with dementia whom they care for interacting and viewing self in the mirror.

Protection of Human Subjects

Approval from the Institutional Review Board approval (IRB) of Texas Woman's University, Houston, Texas, was obtained to conduct this research study (Appendix B). Each prospective participant was screened for eligibility before participating in the study. The informed consent document was reviewed with the participant. All questions were answered, and clarification given when requested; the informed consent process took approximately 30 minutes. The participant's signature was obtained when the criteria mentioned were met. Each caregiver participant was provided an overview of the study's purpose, incentives, and time commitment before any research data was collected. Potential risks and benefits of the study were discussed. All participants were told at the time of consent they could stop the interview and leave the study at any time. The researcher addressed any interviewee's emotional distress by stopping the interview session and provided support to the participant as needed.

Steps were taken to ensure the confidentiality of any identifiable data. A code name was provided for each participant, and immediately following the recorded interview, the participant's audio file was uploaded and sent to the transcriptionist through a secured "Box" storage (<https://app.box.com/files>) on a password-protected computer. All recordings were transcribed verbatim. The researcher retained the digital recordings and data analysis files in a locked file cabinet to which only the researcher had access. The demographic data, consent forms, and other study-related notes will be shredded, and all

digital recordings mechanically destroyed no later than five years after completion of the study.

Instruments

Two data collection instruments designed by the researcher were used in this study: a demographic questionnaire (Appendix C) was used in describing the sample, included, age, gender, ethnicity, marital status, employment status and number of years as a caregiver. A semi-structured interview guide was used to guide the researcher (Appendix D). The guide consisted of nine stem questions that explore mirrors in the home, mirror use, and responses of person with dementia to mirror use. These questions allowed the researcher to further prompt the participants for additional clarification on the experience and observation as they told their stories.

Data Collection

Recruitment of participants began with an approved flyer inviting participants to participate in the study. Interested participants called the researcher on the phone number provided on the flyer. The participants were screened for eligibility using the eligibility criteria. Prior to the interview, participants were consented using the approved consent form. After the participants were consented, they were asked to complete the demographic form. Participants who met the criteria spent 40 minutes in a one-on-one audio-taped face-to-face, or telephone interviews. The researcher acting as an instrument facilitated the discussion. All interviews were conducted in the home setting to ensure privacy, comfort, and confidentiality. All interviews were recorded for accuracy, with

notes taken to capture the essence of nonverbal cues to support the recorded data such as vocal intonations and physical expressions and gestures. A gift card of \$25 was given to each participant on completion of the study.

Data Analysis

Initial data analysis began prior to the first interview. The researcher began the first step of the audit trail by explicating any of her own beliefs, biases, and pre-understanding of the phenomenon under study, thus allowing the reader to understand the researcher's prior knowledge of the phenomenon through the documentation of the phenomenon description. Ricoeur (1976; 1981) states documentation of this pre-understanding is not a form of bracketing as postulated by Husserl (1962) but is rather a means of informing the reader of the researcher's current beliefs, theories, understandings, and explanations of being in the world. An approved professional transcriptionist transcribed the audio-recorded interviews. The researcher listened to each audio-recording while simultaneously reading the transcription to verify the accuracy and make any necessary revisions to the transcriptions. Each participant's transcript was manually analyzed using Ricoeur's hermeneutic phenomenology interpretation theory. The researcher delved deeply into the written text while formulating new meanings as understood (Ricoeur, 1966; 1976; 1981).

A word document was used to organized thoughts, categories and themes. This approach uses three methodological steps: 1) naïve reading (grasping the meaning of the whole by familiarizing herself with the text with the initial reading), 2) structural analysis

(identifying and explaining the parts of the whole, looking for concepts and themes, formulating categories), and 3) Phenomenological interpretation (performing in-depth hermeneutic interpretation of the text by carefully examining the transcripts). This methodology assisted in chronicling the inner experiences of caregivers as they described their perceptions of the mirror experiences of individuals with dementia

Researcher's Pre-understanding of the Phenomenon

Viewing self in the mirror is regarded as an everyday event; the experience of viewing an unidentifiable self in the mirror is, so far, not part of my own mirror-viewing experience. Despite my lack of immediate experience of the inability to recognize self, I have some proximity to and familiarity with this phenomenon. As a prior caregiver of someone with dementia who at times did not recognize herself in the mirror, I believe that this experience would, at a minimum, guide my thoughts, actions, decisions, and understandings.

Naïve reading. Naïve reading was the first step in data analysis and entailed a superficial reading of the text several times, an activity that allowed the researcher to familiarize herself with the text and achieve a grasp of the textual meanings. This initial understanding was confirmed, rejected, or expanded as the author delved deeper into the text. The author's initial thoughts and understandings were noted on each transcript.

Structural analysis. Structural analysis was the second step in the data analysis process. The researcher sought to find the plot while looking for any opposing actions (Ricoeur, 1981).

Using a word document to keep track of the various concepts and categories, the researcher explored text statements within the texts and assigned conceptual headings. All similar and commonly related actants and actions within each story been told were then cut and pasted under the assigned conceptual heading most related to the concept. This process was ongoing throughout the course of the study as the researcher sought to narrow down, or merge categories that were initially identified. The researcher continued to compare data across transcripts looking for similarities that may result in further collapse of categories of the conceptual grouping, thus resulting in fewer categories

Phenomenological interpretation. The researcher performed an in-depth hermeneutic interpretation by carefully reviewing the transcripts. Interpretation of the text involved a dialectic movement (hermeneutic arc) between the various types of readings. The researcher looked for any reference relating to the experience of the phenomenon under study: viewing self in the mirror. A word document was maintained to keep track of the various testimonials from the transcripts that spoke about the phenomenon. Text not related to the phenomenon or that may possibly relate to the phenomenon were placed in separate categories. These unrelated or possibly related categories were revisited repeatedly to ensure any key elements relating to the phenomenon were not missed.

On completion of this critical reading and rereading, as the interpreting subject, the researcher moves back and forth between parts of the text and the understanding of the world of discourse (Ricoeur, 1981). Ricoeur (1976; 1981) posits analysis is a process

of distancing and appropriation. The text is distanced from the reader who, through the process of interpretation, begins to appropriate the text. Complete interpretation of the text is appropriation of the text as the reader makes it his or her own (Ricoeur, 1966, 1976, 1981). The goal in utilization of this analytical process is to acquire an in-depth description of each participant's understanding of his or her own individual experience.

Scientific Rigor

Scientific rigor was achieved by using the following established criteria of Lincoln and Guba (1985). Trustworthiness was established using Lincoln and Guba's (1985) framework that includes credibility, transferability, dependability, and confirmability, as cited by Streubert and Carpenter (2011). According to Munhall (2010), the goal of trustworthiness in qualitative research is to ensure methodological soundness and adequacy in accurately representing the data. Dependability is the ability to evaluate the adequacy of the analysis and follow the decision-making process. Each participant was interviewed using the same process with a semi-structured interview guide, digital recording, and note-taking. The data were analyzed using phenomenological hermeneutics. Specific examples were used to support the structural analysis and the phenomenological interpretation.

Credibility in a qualitative study is the match between the participant's perception of the phenomenon and what the researcher has interpreted to ensure the true picture is being presented (Lincoln & Guba, 1985). To further establish the validity of the study,

the researcher used a validation process to confirm the findings with two to four participants to ensure saturation has been reached.

According to Lincoln and Guba (1985) transferability is the ability to transfer the knowledge learned in one setting to a similar population, sites and, or situation. Utilizing a systematic approach in data collection and providing rich and dense data are means of enhancing transferability (Lincoln et al., 1985; Schofield, 1993, Strauss & Corbin, 1990). Lincoln et al. (1985) define confirmability as the degree to which the results can be validated by others. Thus, using two to four participants to confirm findings once saturation was reached further strengthened the credibility and validity of the study. Additionally, documentation of all analysis was sent to the dissertation chair and committee members for further discussion, assessment and input on data interpretation. The data collection and analysis procedures were examined several times to ensure accuracy of interpretation.

Validation of Findings

Findings were confirmed as the researcher reviews the data, together with the audit trail, and through discussions with the chair. Additionally, a selection of three participants was contacted to verify whether the description of the experience of the person viewing self in the mirror was correctly captured.

CHAPTER V

EXPERIENCES OF VIEWING SELF IN THE MIRROR FOR MEN AND WOMEN WITH DEMENTIA AS PERCEIVED BY THEIR CAREGIVERS:

A PHENOMENOLOGICAL STUDY

A Paper Submitted to

Applied Nursing Research, March, 2019

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Abstract

Aim: To explore and discuss the perceptions and experiences of caregivers who rendered care to persons with dementia who viewed themselves in the mirror.

Background: Considerations must be given to caring for those with dementia due to the steady rise of adults 65 and older living with dementia. A literature reviewed revealed limited experiential knowledge concerning aspects of mirror-viewing for persons with dementia.

Methods: This phenomenological hermeneutic study was analyzed using Ricoeur's theory of interpretation. Eighteen participants who cared for individuals with dementia in the home, and long-term care facilities took part in the study. A semi-structured interview guide with open-ended questions facilitated an open dialogue about their experiences while caring for persons with dementia when they view themselves in the mirror. Two questions guiding the study were: 1) What are caregivers' perceptions of what they see

and believe when they observe dementia patients whom they care view themselves in a mirror? 2) How do the caregivers' perceptions of that experience change over time as the dementia worsens?

Results: The structural analysis uncovered a considerable difference between the numbers of mirrors available in the homes as compared to the long-term care facilities. Two phenomenological findings were uncovered: 1) decision to look in the mirror, and 2) viewing self in the mirror. Six subsequent subthemes; mirror as a tool, wanting to look presentable, self-recognition, self-confirmation seeing another and the latent stage were revealed.

Conclusion: A mirror assessment is needed for individuals who have dementia

Keywords: Dementia, Mirror, Self-recognition

Introduction

The aging population in the 21st century is a major public health concern and priority in the United States (Center for Disease Control and Preventions (CDC), and [CDC], 2018; World Health Organization, 2018) and the world (Manthrope et al. (2013). The population growth for those 65 years and older increased from 36.2 million in 2005 to 47.8 in 2015 and is expected to double to 98 million by 2060 (Mayer, 2016). Defined by the National Institute of Neurological Disorders and Stroke (NINDS), dementia is a progressively irreversible syndrome characterized by a group of symptoms caused by disorders that affect brain function leading to loss of cognitive ability severely affecting activities of daily living (NINDS, 2018; CDC, 2018; CDC, 2013). By 2050, it is estimated

that the number of Americans living with dementia will increase from five million to 14 million with a projected estimated cost from 236 billion to one trillion (Alzheimer's Association, 2016). The estimated rate of the aging population life expectancy continues at approximately two years per decade, posing a significant risk for developing dementia (Administration of Aging, 2013). Dementia is the fifth leading cause of death in the United for those 65 years and older (Alzheimer's Association, 2016).

The National Association of Caregiving (NAC, 2013) reported that 25-29% of caregivers provide assistance to persons 50 years and older with cognitive impairment. About 50% of all caregivers are responsible for managing the difficult and most common tasks associated with providing personal care such as: getting dressed and personal grooming (Freysteinson, 2010). Using a mirror to perform these tasks is an everyday phenomenon for most individuals.

1.1 Mirrors in the Environment

Mirrors are reflective surfaces that have been around since the beginning of time and serve multiple purposes such as: viewing one's image, decorative purposes, used as scientific instruments such as telescopes, and even entertainment (Enoch, 2006). Duval and Wicklund's (1972) Theory of Objective Self-Awareness suggests that reflection of one's self in the mirror contributes to an increased sense of self-awareness. In general, this awareness contributes to our overall well-being.

Individuals with dementia are sometimes cared for in hospitals and long-term care facilities in order to meet their needs. However, mirror availability and use may be

constrained by environmental considerations. A survey was conducted by Freysteinson and Cesario (2008) on the availability of mirrors in post-surgical rooms of ten hospitals. Most hospitals (70%) did not accommodate mirror viewing for wheelchair or bed-bound patients. Two of the 10 hospitals had available mirrors. Due to the high placements of the mirrors above the sink and placement of the counter, access to these mirrors was difficult for patients whose mobility was aided by using wheelchairs. Similarly, in 2010, Freysteinson conducted a preliminary survey on the availability and access of mirrors in 10 long-term care facilities and found access and availability of mirrors in long-term care facilities were challenging. Mirrors were either lacking, or the placement of mirrors were not accessible for patients in wheelchair or those who were bed-bound. In 90% of the facilities there were no available mirrors for patients who were bedbound, and only 30% of the facilities had accessible mirrors for patients using wheelchairs. Two facilities had mirrors in the dining room and only one facility had a full-length mirror.

Lawton paved the way for theory of environmental concerns for the elderly (Lawton, 1989). Lawton's theory of environmental gerontology suggests that mirrors support, maintain and stimulate the user in the environment. Providing support to the user requires a barrier free environment where mirrors are easily available and accessible for patients, whether ambulatory, or using wheelchairs or bed-bound. An environment that mimics the home setting presents an environment that is home-like for the person with dementia who at times may want to apply their lipstick, make-up, shave, brush their teeth and comb their hair; typical tasks done using a mirror by most individuals. Reducing

inconsistency in the environment will enhance familiarity and promote independence and a sense of well-being. Mirrors encourage social stimulation within a functional environment. Viewing self in the mirror and looking to see what others may see may be a source of self-entertainment that can produce joyful emotions by seeing one's own reflection, or that of others. The availability of mirrors in one's environment also promotes a sense of well-being (Freysteinson, 2010). However, for the person with dementia, these activities may prove to be challenging and frustrating as the disease progresses.

The purpose of this study, a phenomenological design was to explore the lived experience of the individual with dementia viewing self in the mirror and to explore the ability to develop guidelines that may influence caregivers' actions. The experience of the individual living with dementia is different for each person, therefore a uniform non-evidence-based advice is not recommended. Providing patient-centered care should be the focus of meeting the needs of individuals with dementia. The inspiration for this study was based on the researcher's personal experience in caring for her mom who had dementia.

2. Methods

2.1. Participants and Setting

An institutional review board approval was obtained prior to conducting the present study. A snowball sampling technique was used to select participants from a well-known national organization. Inclusion criteria were 18 years and older, English-

speaking, formally or informally cared for persons with dementia for at least three months or more in a private home setting or facility setting. All potential participants were contacted by the researcher by telephone. The final sample size was determined when saturation was reached, and no additional information was elicited in the final three validation interviews.

2.2 Data Collection

The researcher developed two instruments: a demographic form (Appendix C) and a semi-structured interview guide (Appendix D) that was used to elicit responses pertaining to the participants' experience in caring for someone with dementia when they viewed themselves in the mirror. Face-to-face interviews were conducted with each participant and lasted approximately 40 minutes. Participants received a \$25 gift card on completion of the interview.

2.3 Data Analysis

Ricoeur's (1976, 1981) method of textual analysis was applied to this study. The initial data analysis began prior to the first interview. The first step of the audit trail began with the researcher explicating her feelings, biases and pre-understanding of her prior knowledge of the phenomenon under study. The researcher's knowledge was informed by her experiences and beliefs in caring for a person with dementia. The researcher dealt with her own presuppositions to ensure openness was maintained throughout the process of inquiry. This allows the reader to formulate their understanding of the researcher's prior knowledge of the phenomenon through concise documentation

and description of the phenomenon. According to Ricoeur, this pre-understanding is not a form of bracketing postulated by Husserl (1962) but is rather a means by which the reader is informed of the researcher's beliefs, theories, explanation, and understanding of being in the world.

All interviews were audio-taped and professionally transcribed by an approved transcriptionist for accuracy. The researcher listened to each audio-recording simultaneously while reading the transcript to check for accuracy in the data transcription. Appropriate revisions were made to the transcripts if necessary. Each transcript was manually analyzed.

Using a Word document, thoughts, categories and themes were organized to begin the three methodological steps used in Ricoeur's (1976, 1981) data analysis: 1) naïve reading. This first step allowed the researcher to grasp the meaning of the whole by becoming familiar with the written text, 2) structural analysis. In this step concepts and themes within the text were identified that made up the structure of the text, that and 3) phenomenological interpretation. An in-depth interpretation of the experience of viewing self in the mirror was uncovered by carefully examining each transcript. The researcher probed deeply into the written text formulating new meanings as these became known and understood. Following this process helped the researcher to collate and make sense of the voluminous amount of data. This methodology facilitated chronicling the inner experiences of caregivers as they described their perceptions of the mirror experiences of individuals with dementia.

2.4 Study Rigor

Qualitative rigor or trustworthiness is based on the framework of Lincoln and Guba (1985) criteria of credibility, dependability, transferability, and confirmability for qualitative research. Credibility was achieved through prolonged exposure, engagement, and review of the phenomenon throughout the data collection and analysis. Three participants confirmed/validated data saturation. Dependability was established through an audit trail that detailed how decisions were made during the data analysis. Confirmability was achieved by accuracy in capturing the data objectively as reported without subjective input from the researcher. Transferability is the ability to transfer the study method and findings to similar settings or groups and is determined by the reader. Demographic data were collected and descriptive data and rich texts provided support themes that depicted the caregiver's experiences and demographic data. Providing this information will help the reader determine if the study results are transferrable.

3. Findings

All participants were females ($N = 18$). Twelve were married and six were single. Participants' ages ranged from 28 to 67 years with a mean age of 47.5. This corresponds to the average age for caregivers of 48 years (Alzheimer's Association, 2018). There were nine formal caregivers (trained professionals) and nine informal caregivers (family and friends). Fifty percent (9) of care was delivered in the home and 44% (8) was

delivered in a facility. One participant shared experiences about care delivered in both a facility and home setting.

4. Structural Analysis

The structural analysis uncovered two themes within the home and long-term care environments: number of mirrors and caregivers' actions.

4.1 Home Environment

There was a marked difference in the number of accessible mirrors in the homes and facilities. In the homes, there were several mirrors available. In the LTC facilities, mirrors were primarily found bathrooms above the sink where there was limited and restricted access for residents in wheelchairs.

All nine homes (100%) were equipped with six or more mirrors. Mary stated: *"it's almost impossible to avoid a mirror... everyone pretty much encounters a mirror whenever they enter the house."* The locations of mirrors were primarily in the home entrance ways, hallways, bathrooms, bedrooms, dining areas, and closets. The highest frequency use of the mirrors was in the bathrooms. There were various sizes of mirrors: full-length, half-length- mirrors that reflect the image from the waist up, and shoulder height mirrors which reflect the image from the shoulder up. Also, many participants described hand-held, lipstick, and compact mirrors. Access to mirrors in the home was unimpeded for individuals who were ambulatory or used wheelchairs. Portable hand-held or purse-size mirrors were readily available for individuals who were confined to bed. Some mirrors served two purposes: 1) decorative, and 2) functional.

Some caregivers said it was rewarding when they took their loved ones to the mirror. Mara said, *“it is important for them to look in the mirror”* Another (Geran) commented, *“she pays attention to the mirrors in the bathroom.* During the late stage, three of caregivers in the home covered, or removed some, or all the accessible mirrors. Denise’s father used the bathroom mirror to brush his teeth, comb his hair, and shave. He even commented to his daughter that he needed a haircut. However, she covered the mirror on the dresser in the bedroom because her father *“would stand there for several minutes and stare and did not seem to have any real purpose.”* Mary chose to cover the mirror based on the advice of friends and her internet research. Mary was advised by her friends based on their experience in caring for individuals with dementia, to cover the mirrors because it would reduce frustration and agitation. She felt assured that this was right thing to do because when she searched the internet the advice offered was almost identical. Martha chose to cover the mirrors in the bedroom and foyer with newspaper as she had also searched the internet and had found that mirrors should be covered for those with dementia.

4.2 Long-Term Care Environment

Mirror accessibility was a challenge in five of the nine long-term facilities. There was only one mirror in the residents’ bathroom in eight of the facilities. This mirror was above the sink where there was limited and restricted access for residents in wheelchairs. The mirror provided an image of the head and shoulders. Only one of nine facilities had an extra-long rectangular shatter proof mirror covering the entire surface of the wall in

the dining area where all residents (ambulatory and wheelchair dependent) could view themselves. According to Martha, one woman had a hand-held mirror which became *“something personal to her. She took it everywhere she went”* and would carry it in the pocket of her walker, in the pockets of her clothes, and in her handbag.

One long-term care facility had no mirrors. There were no mirrors in the bedrooms, elevators, or commonly used areas such as the lounges where both family and residents would spend time visiting. One family member commented that it seemed strange to her that there were no available mirrors for residents, or even for the visitors. Marsha recalled *“there were no mirrors in the hallways... or other places. ...I don’t know if it’s because residents didn’t ask for them, or the facility didn’t supply them.”*

Family members who wanted to enhance the mirror experience for their loved one were met with resistance. They were cautioned that access to and availability of mirrors would contribute to increased frustration. This resistance may also have been due to a perception or belief that elderly people do not like to look in mirrors. Emily stated, *“older people usually don’t like looking at the mirror because they see themselves aged and everything.”* Another belief or concern was related to the residents’ safety. According to one participant, the fear of causing bodily injury was the reason for the lack of, or availability of mirrors in the long-term care facilities.

Some caregivers in the facilities sought out ways to incorporate mirrors into the daily routines of the residents they cared for. Two caregivers stated that they would offer mirrors to the residents during their activities of daily living and would comment on how

pretty they looked. This gesture frequently elicited a positive response such as a smile, and sometimes a verbal response such as “*I do*” and other residents would respond by asking “*do you think so?*” This response was often followed by a smile. Caregivers expressed feelings of joy and fulfillment as they watched the residents come to life as they smiled when placed in front of the mirror. One caregiver indicated that placing the resident in front of the mirror would elicit a response from the resident when all other actions failed. One caregiver stated that caring for and interacting with someone with dementia made her “*feel good.*” Tasha said, “*I used to enjoy just actually just taking them to the mirrors, standing there with them and, um, you know, just having a chat while looking in the mirror.*” Brie would say to the residents: “*Look at yourself, look at how you look pretty, as a source of encouragement before we took them out to meet everybody else.*” None of the participating participants in the facilities covered the mirrors. However, one caregiver reported that the mirrors in one facility were covered with paper prior to her arrival.

5. Phenomenological Analysis of Decisions to Look in a Mirror

5.1 Mirror as a Tool

There were several reasons, or decisions to look in a mirror. For some individuals, viewing self in the mirror played an important role in their daily routine for the person with dementia. When used as a tool, the mirror facilitated and promoted independence for performing activities of daily living such as, brushing one’s teeth, combing one’s hair,

getting dressed and shaving. Mostly strikingly, these individuals enjoyed looking at themselves because they seem to care about what they wore.

5.2 Wanting to Look Presentable

Overall appearance appeared to be important for the individuals with dementia. Ongoing assessment of general appearance conveyed a subtle message that they cared about how they looked. Wanting to look presentable and checking self before venturing out in public was important and a key motive for looking in a mirror. Mary said, it was important for her to “*check herself to see how he/she looks.*” Tasha indicated that the residents were: “*very particular for some reason about what they wear, and so they’re constantly looking in the mirror to see how they look ...she would look in the mirror, you know, to see how beautiful she looked.*” Geran added that: “*when she’s dressing, like when she is getting ready to go to church....She wears hats a lot ...she’ll make sure her hat is on properly.*” Gayle said, “*So then she would stand in front of the dressing table and she would fix herself and watch herself in the, in the glass door before she goes out and fix herself and see if she’s looking good, you know?*”

6. Phenomenological Analysis of Viewing Self in the Mirror

Trajectories of cognitive decline are often evident in dementia and this leads to a decline in the mirror viewing experience. The overall experience of viewing self in the mirror changed over time as cognitive decline worsened. Viewing self in the mirror over time occurred in the following stages: self-recognition, self-confirmation, seeing another in the mirror, and latent stage: no mirror viewing.

6.1 Self-Recognition

In the early stages of dementia, mirror use was minimally affected. Daily use of a mirror to perform activities of daily living allows individuals with dementia to maintain their independence. Use of the mirror provided some measure of self-reassurance. Tasha said: *“It’s a good way of just keeping in touch with themselves.”* An uplifting mood that elicited emotions such as; laughter, smiles and excitement was evident in the early stages of dementia. Mary said: *“in her early stages it (mood) was uplifting.”* Marsha thoughts it is *“important for them to have mirrors in their room where they can see themselves on a daily basis.”*

6.2 Self-Confirmation

During the progression of the disease, the individual with dementia tends to take a second look to confirm *“it’s me,”* touching self to be sure it’s me in the mirror. Martha indicated *“In the later stages if her dementia, it’s usually, Oh, it’s you!”* Gertrude said, *“And they’d just touch their face; like just to make sure it really was them.”* Interactions during a mirror encounter were sometimes engaging and positive. Tasha said, *“So most of the time they looked in the mirror, they were really happy.”*

The person with dementia may assess their face closely and perceive that the version of self in the mirror is old. Gertrude stated *“They would say, well, who is that person?Oh, that is me, but boy do I look old.”* Marsha said, *“she would say that’s not me, I’m only 17...because they see themselves as a 17-year-old, or a 23-year-old.”* The

image in the mirror may be discomfoting Sonya said, *“she goes; I’m not that old... you’re wrong!”*

6.3 Seeing Another in the Mirror

As the dementia worsens, individuals with dementia may not always recognize themselves. Sometimes they may see a stranger in the mirror. These experiences did not occur in all mirrors but were more evident in full length mirrors as compared to smaller mirrors that capture the body from shoulder and above.

Martha noted that, *“every time she walked by the mirror, on numerous times throughout the day that she would engage with that person or that image in the mirror. And quite often it was not a positive engagement”* Mary found that: *“in the latent stage, it angered here...arguing, crying constantly.....when she encountered a mirror, she thinks she is encountering, or meeting someone other than herself. ...I’m speaking to this person and they’re not answering me.”* Gayle noted that *“sometimes they were a little shocked and confused at the image in the mirror....I’d say there was sadness with it, um, and confusion.”*

6.3 Latent Stage

In the late stages of the disease, the need for or the use of a mirror for individuals with dementia was severely diminished. Mirror viewing appeared to elicit minimal or no response. Tasha said, *“It could be a quick look or maybe, sometimes standing and just staring at the mirror not reacting as they used to.”* Denise also noticed a change in that *“sometimes I noticed he would just stand there and stare at it (the mirror).”* Having a

blank stare was common. Sara said, “*she doesn’t elicit any type of response when she sees herself, or when she sees a reflection of herself ... she just stares.*”

7. Discussion

In reviewing the literature for mirror studies, some dated studies were found. Tabak, Bergman, and Alpert (1996) conducted a pilot exploratory study to explore the experience of individuals with dementia ($N = 100$). Several mirrors were placed on the unit. The aim of this study was to observe the reactions of individuals with dementia when they viewed themselves in a mirror. The majority of the participants appeared to recognize themselves in a mirror, commented on their appearance, and displayed positive emotions. These findings are congruent with this study in that caregivers reported positive emotions such as, smiles, joy and laughter and a concern for appearance.

Grewal (1994) conducted a prospective study ($N = 39$) to explore the ability of self-recognition for individuals with moderate and severe dementia. The researcher concluded that individuals with moderate dementia could recognize self when looking in a mirror. This finding is congruent with this study. Caregivers indicated self-recognition appeared to be apparent in most mirrors. In larger mirrors, however, a stranger was seen in the later stages of the disease.

Biringer and Anderson (1992) assessed self-recognition for persons with dementia ($N = 29$) using a mirror and video image, noting their behavioral responses. Twenty-five of 29 subjects with mild to moderate dementia confirmed self-recognition. However, as

the disease progressed, self-recognition appeared to be less likely in the advanced stages of the disease.

In 1988, Biringer et al. observed the ability of individuals with dementia to recognize self when a visible mark was placed on the forehead of subjects looking in a mirror. Subjects in the latent stage of the disease did not react to the mark on their forehead and hand. This finding is congruent with this study in that in the latent stages of the disease the caregivers indicated that the individuals stared into the mirrors with no visible signs of self-recognition, or interaction with the image in the mirror.

Researchers Vanhaudenhuyse, Schake's, Bredart, and Laureys (2008) posited that without the use of a mirror as a tracking device, several subjects in a study ($N = 51$) would have been misdiagnosed as being in a vegetative state. In a similar study, Haibo et al. (2014) found mirror visual fixation (staring) in 29 of 81 patients in a minimally conscious state. The authors theorized that visual self-recognition in a mirror is a higher-level self-referential stimulus, like responding to one's own name. In our study, caregivers said the persons with dementia in the latent stage stared into the mirrors, providing us with a reason to pause and wonder if there may be a degree of mirror self-recognition in the last stages of dementia.

In 1988, Biringer et al. observed the ability of individuals with dementia to recognize self when a visible mark was placed on the forehead of patients looking in the mirror. Participants in the latent stage of the disease did not react to the mark on their forehead and hand. This finding is congruent with this study in that in the latent stages of

the disease the caregivers indicated that there was not reaction, or interest in looking in the mirror.

Bologna and Camp (1995) presented a case study of an individual with dementia, in the latent stage whose environment was manipulated. The purpose of this study was to determine if self-recognition was evident after contextual manipulation of the environment. Participants were placed in front of a mirror and were asked a series of questions to test their ability to identify self. The participants failed to recognize self using the established criteria of the study. The findings of these this study congruent with this study in that in the latent stages of the disease as indicated by the caregivers.

Kelsick and Freysteinson (2013) presented a case study of an elderly woman, Rose, whose mirror experience varied depending on the location and size of the mirrors. Most of the time Rose appeared to recognize herself in the mirror as she groomed herself. However, full-length mirrors posed a challenge for her as she did not recognize herself but instead, she saw a stranger in the mirror. This case study is the most relevant and is congruent with the findings in this study. Manipulation of the environment allowed Rose to continue using the mirror as a tool during her activities of daily living. Similarly, the use of smaller and hand-held compact mirrors was less challenging for those with early stage dementia

Kelsick and Freysteinson (2013) presented a case study of an elderly woman, Rose, whose mirror experience varied depending on mirror location and size. Most of the time Rose appeared to recognize herself in the mirror as she groomed herself. However,

full-length mirrors posed a challenge for her as she appeared to see a stranger in the mirror. In Rose's case, the full-length mirrors needed to be covered in the later stages of the disease, allowing her access to smaller size mirrors that fulfilled her need to performing her activities of daily living. Rose would sometimes offer a brief smile when she viewed herself in the mirror. A similar finding was found in the case study done by Gil-Ruiz et al. (2013), who discovered that reducing the size of the mirror helped a woman with dementia recognize herself in the mirror as opposed to thinking the person in the mirror was looking at her through a window. This mirror reduction was accomplished by placing paper over most of the full-length mirror so that the resulting mirror was a small mirror that allowed viewing from the shoulders and face.

Due to a lack of existing guidelines, caregivers in this study sought advice through various means (i.e, family members, friends and online sources). For example, advice from online sources ranged from: remove all mirrors in the house; turn full-length free standing mirrors to face the wall; drape a cloth over the mirrors; hide the mirror by placing a poster over it; hang curtains over the mirror; and, cover large mirrors with self-adhesive contact paper (Daily Caring, 2019). As a result of this advice, some caregivers chose to cover up the mirrors. These actions may have had an impact on the overall well-being for the individual with dementia who may want to see how they look and/or continue caring for their own appearance.

7.1. Implications for Practice

Based on the findings of this study, mirrors appear to be important for self-recognition. Mirrors are used: as a tool for activities of daily living, and to enhance independence and self-confirmation. As a tool, the mirror supports and confirmed how presentable one is before venturing out into public

How and when mirrors are made available and used for persons with dementia will vary. There should be a focused assessment of mirrors in the environment and of the individual's reaction to various sized mirrors. Assessment will need to be done over time and at different times of the day. It should include:

1. Assessment of the environment to determine the availability of mirrors
2. Observe the person's reaction to mirrors of various sizes. Start with a small hand-held mirror advancing to a full-length mirror.
3. Assess if the mirror can be used for activities of daily living.
4. Observe for indications of: self-assessment (i.e., how do I look?), self-awareness, self-recognition and overall engagement while viewing self in the mirror

Providing some 'how to' manage the mirror experience education for individuals with dementia viewing themselves in the mirror may have a positive impact on the experience What type of mirror intervention is needed for each individual with dementia is a discussion that nurses and other health care professionals should have with caregivers. Caregivers should be taught to assess the mirrors in the environment to ensure

safety and use unbreakable mirrors if needed. Caregivers should observe for the receptive use of mirror for daily self-care for the person with dementia and determine the size of the mirror that is most appropriate for the individual, with the understanding that in the moderate stages of dementia full-length and larger mirrors may cause distress whereas a smaller mirror may not. Work with caregivers to discern if mirrors should be covered up, removed or reduced in size in order to appropriately meet the individual needs.

The concerns of individuals with dementia harming themselves if mirrors were made available to them were not supported in this study. However, consider using non-breakable mirrors to provide a safe environment. Mirrors that are unbreakable can be found on the internet.

7.2. Recommendations for Facilities

Based on the findings of this study, the following is recommended:

1. Design geriatric environments that are supportive of the dementia population to help maintain self-care abilities and, support self-orientation, and stimulate social interaction.
2. Adapt the mirrors in LTC facilities to mimic the home environment where appropriate.
3. Equip facilities with unbreakable mirrors in common areas and for personal use within the environment to address the concern of potential harm.

4. Develop internet and other training education modules on the mirror environment that is more appropriate to the mirror trajectory of those with dementia.

7.3. Study Limitations

Findings from this study are limited to the small sample size, population and geographic location. The geographic location was confined to a single large metropolitan state in the southern United States. Participant's statements were based on memories that may be inaccurate. Although men do care for persons with dementia, all participants who volunteered were female of which 50% was African American. Therefore, findings may not be transferrable to some populations.

8. Conclusion

The participants in this study were eager to share their stories about caring for individuals with dementia. Most encountered challenges while providing care to this population group and felt that additional mirror training would be helpful in preparing them to take on the task. They felt a sense of relief and were thankful that they were able to share their frustrations with someone who was willing to listen.

In conclusion, this study provided the caregiver's perspective of the person with dementia viewing self in the mirror. The experience as understood through the lens of the caregiver helps to bring a better understanding of the world for the person with dementia when they view themselves in the mirror. The applicability and usefulness of this

descriptive research is determined by the reader in guiding actions in managing the mirror experience for individuals with dementia.

CHAPTER VI

SUMMARY OF THE STUDY

The overall aim of this study was to gain insight into understanding the experience of those with dementia viewing self in the mirror. As this could not be accomplished by directly interviewing those with dementia, 18 caregivers were recruited to share their perceptions of this experience. The impetus for this study began when I took care of my mom (Rose) who was diagnosed with dementia and lived for eight years after her diagnosis (Kelsick & Freysteinson, 2013). Data from the sample of 18 participants revealed two overarching structural themes: home environment and long-term care environment. There were two overarching phenomenological themes: decisions to look in the mirror and viewing self in the mirror with six subthemes. The phenomenology decision subthemes revealed were: the mirror as a tool and wanting to look presentable. The trajectory of the mirror viewing experience themes were: self-recognition, self-confirmation, seeing another in the mirror and the latent and non-response stage.

Interpretation of the narratives provided some insights into the experience of individuals with dementia viewing self in the mirror. Through the narratives from the participants it was perceptible that the experience for individuals with dementia viewing self in the mirror varied depending on the stage of dementia. Some participants expressed positive emotions such as: smiles, joyfulness and laughter when interacting with the mirror. They showed interest, took pride in how they looked, and would talk about how

well their clothes fitted, the need to shave and or needing a haircut. Some individuals saw themselves as younger in the mirror. These sentiments were apparent that in the early stages of the disease as the individuals with dementia interacted appropriately when viewing self in a mirror. However, as the disease progressed the ability to recognize self was diminished to needing to confirm seeing self in the mirror, to seeing a stranger in some mirrors, and ultimately no response or reaction when viewing self in the mirror. Caregivers' actions depended on information and advice received from family members, friends, and the internet. Most participants used information from the internet that was based on personal experience and expert opinion and not sound evidence. These actions are congruent with my own experience as I struggled with decisions regarding mirror viewing for my mom in the mid to latent stages of the disease.

As a nurse, I thought I well-equipped to care for her. I would tell myself in my own silent voice: "I can do this... "I'm a nurse so; I know that I can do this... I must do this." Based on our culture, the expectation was that you care for your elderly parents until death. It was considered shameful and uncaring to remove them from their home environment, or to have a stranger care for them. Sadly, however, a decision had to be made to seek outside assistance. She was placed in a private facility where she remained for six months and was moved back home prior to her death. The journey was challenging but at the end, we felt rewarded and there were no regrets at the time of her death.

Over time, I reflected on the care I provided to my mom with assistance from my siblings, family members, friends and my dad who bore the burden for many years. Looking back, I often wondered if she was cared for in the best manner. Sadly, I can respond to my own self-uncertainty, the care provided was probably not optimal. The management of mirror viewing for Rose was at times challenging (Kelsick et al., 2013). Mom began to see another person in one of the full-length mirrors in our home. My dad was frustrated and perplexed as to why she could not identify herself in the mirror when this was a routine act all her life. The decisions and actions taken to manage the activities of daily living were based on unsolicited advice from family and friends. Advice ranged from avoiding the mirrors, covering up the mirrors to removal of the mirrors. I (we) chose to cover the full-length mirrors because at best, it would decrease the frustration and sometimes agitation when she saw who she perceived was a stranger. My thought was that mirror viewing for individuals with dementia may be challenging, yet, they deserved care that is based on sound evidence and not by trial and error. This study begins to form a foundation for that future evidence.

A survey of literature on the use of mirrors for individuals with dementia uncovered no direct studies related to the phenomenon under study. There were a few dated studies such as a study by Biringer et al., (1988) which investigated the ability of individuals with dementia to respond to a visible mark place on their forehead while looking in a mirror. Participants in the latent stage of the disease were unresponsive to the mark on their forehead when presented with a mirror. Biringer and Anderson, 1992 tested

twenty-nine participants with dementia for self-recognition using a mirror. Participants with moderate cognitive decline recognized themselves, whereas those with severe cognitive decline failed to recognize self. A prospective study by Grewal (1994) explored self-recognition for individuals with moderate to severe dementia. The study revealed that there was some preservation of mirror self-recognition for individuals with moderate dementia. Additionally, Bologna and Camp (1995) conducted a study to determine whether self-recognition was evident after contextual manipulation of the environment. The participants were placed in front of a mirror and were asked a series of questions related to self-recognition. The study concluded that participants failed to identify self while looking in the mirror.

Researchers Vanhauzenhuysse, Schnakers, Bredart and Laureys, 2008 investigated the use of mirrors to determine responsiveness of patients who were diagnosed as being vegetative when presented with a mirror used as a tool for tracking their reaction. The study concluded that use of a mirror as a tool to check participants' response was successful in determining a positive reaction for tracking, compared to using an object such as, a ball. The vegetative diagnosis was deemed inaccurate for 11 of the 51 subjects. With a lack of available evidence, it is important to explain and understand caregivers' perceptions of the mirror-viewing experience. The underpinning of this study was guided by Ricoeur's phenomenological hermeneutic (Ricoeur, 1976, 1981). A semi-structured interview guide guided the dialogue. All interviews were recorded and transcribed verbatim. The textual data was analyzed using Ricoeur phenomenological hermeneutics.

The process of analyzing the text was achieved through three methodological steps: naïve reading structural analysis and phenomenological interpretation (Ricoeur, 1975, 1976, 1981). Ricoeur (1981) posited that “text is discourse fixed in writing” (p.145). Yet, over time, the interpreter appropriates the text by finding new meaning.

According to Ricoeur, the relationship between explanation and understanding allows for the back and forth movement between the parts of the text and the whole as it relates to the interpretation. This dialectic movement is referred to as the hermeneutic arc (Ricoeur, 1981). Said differently, it is the back and forth movement between the world of the text and forming of new understandings of the world of discourse. Through analysis of the text, I sought to answer these two questions: 1) What are caregivers’ perceptions of what they see and believe when they observe dementia patients whom they care view themselves in a mirror? 2) Does the caregiver perception of that experience change over time as the dementia worsens?

The triad of explaining, understanding, and interpreting the text is accomplished through the structural analysis and phenomenological interpretation. The structural analysis facilitates the explanation of the text whereas, the phenomenological interpretation is a search for the meanings, and understanding of what the text speaks about. Eighteen participants (all females) who cared for individuals with dementia participated in the study. The structural analysis revealed a vast difference in the number of mirrors available in private home as compared to LTC facilities. Several mirrors were available in the home setting whereas there were very few mirrors in the LTC facility.

Caregivers of individuals with dementia used ad hoc practices to manage the mirror experience for individuals with dementia who view themselves in a mirror. To the best of their knowledge they used advice from friends, family members, and the internet to make the most informed decisions. However, the advice received was not based on sound evidence but rather hearsay and invalidated information.

The phenomenological interpretation revealed the decisions to view self in a mirror as simply using the mirror as a tool as one wants to look presentable. A trajectory of the mirror experience over time revealed the mirror was initially a tool for self-recognition, and as the disease progressed, the mirror provided self-confirmation. Sadly, at some point in the disease, some mirrors reveal another person in the mirror – a person who may be preserved as a friend or foe. In the latent stages of the disease, there appeared to be little to no reaction to viewing self in the mirror.

The nursing implications were derived based on the findings of this study and are considered practical and achievable. Providing some ‘how to’ manage the mirror experience education for individuals with dementia viewing themselves in the mirror may have a positive impact on the experience. What type of mirror intervention is needed for each individual with dementia is a discussion that nurses and other health care professionals should have with caregivers. Caregivers should be taught to assess the mirrors in the environment to ensure safety and use unbreakable mirrors if needed. Caregivers should observe for the receptive use of mirror for daily self-care for the person with dementia and determine the size of the mirror that is most appropriate for the

individual, with the understanding that in the moderate stages of dementia full-length and larger mirrors may cause distress whereas a smaller mirror may not. Work with caregivers to discern if mirrors be covered up, removed or reduced in size in order to appropriately meet the individual needs of the person with dementia. This research has revealed valuable information about individuals with dementia viewing self in the mirror. However, further research is needed on how best to manage the mirror viewing experience for those with dementia in the moderate to severe stage of the disease. Understanding and describing the experience is important as it opens a dialogue that brings to life experiences that have remained dormant without this study. The sharing and capturing of these experiences may open a world of possibilities that have not been captured or explored before.

Funding Source

Carter dissertation small research grant.

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APPENDIX A

Permission Letter Adapted from Holistic Nursing Practice for use of Chapter II
Article in Dissertation.

Permission to Use Article



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Title: Who Is That Stranger in the Mirror? The Mirror Experience for Elderly Patients With Dementia

Author: June Kelsick and Wyona Freysteinson

Publication: Holistic Nursing Practice

Publisher: Wolters Kluwer Health, Inc.

Date: Aug 13, 0902

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APPENDIX B

Institutional Review Board Approval



Institutional Review Board

Office of Research
6700 Fannin, Houston, TX 77030
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<https://www.twu.edu/institutional-review-board-irb/>

DATE: September 7, 2018
TO: Ms. June Kelsick
Nursing - Houston
FROM: Institutional Review Board (IRB) - Houston

Re: *Extension for Caregiver perceptions regarding the experience of and use of mirrors for a person with dementia (Protocol #: 17794)*

The request for an extension of your IRB approval for the above referenced study has been reviewed by the TWU IRB (operating under FWA00000178) and appears to meet our requirements for the protection of individuals' rights.

If applicable, agency approval letters must be submitted to the IRB upon receipt prior to any data collection at that agency. If subject recruitment is on-going, a copy of the approved consent form with the IRB approval stamp is enclosed. Please use the consent form with the most recent approval date stamp when obtaining consent from your participants. A copy of the signed consent forms must be submitted with the request to close the study file at the completion of the study.

This extension is valid one year from September 2, 2018. Any modifications to this study must be submitted for review to the IRB using the Modification Request Form. Additionally, the IRB must be notified immediately of any unanticipated incidents. All forms are located on the IRB website. If you have any questions, please contact the TWU IRB.

cc. Dr. Ainslie Nibert, Nursing - Houston
Dr. Wyona M. Freysteinson, Nursing - Houston
Graduate School

APPENDIX C
Demographic Form

DEMOGRAPHIC FORM

OFFICE USE ONLY: STUDY ID: _____

Caregiver Demographic Information

Age: _____

Gender:

Male

Female

Check Appropriate Box:

Marital Status:

Married (1)

Single (2)

Widowed (3)

Separated (4)

Divorced (5)

Ethnicity:

Hispanic or Latino (1)

Not Hispanic or Latino (2)

Race (please check all that apply)

American Indian/Alaskan Native (1)

Asian (2)

Black or African American (3)

Native Hawaiian or Other Pacific Islander (4)

Caucasian (5)

Other (6): _____ (Please specify)

Highest Education Level Obtained:

< 10 years of school (1)

10-11 years of school (2)

High School Diploma or GED (3)

2 years college (4)

Bachelor's Degree (5)

Master's Degree (6)

PhD/MD/JDS (7)

Household Income Level:

- Less than \$20,000 (1)
- \$20,000– 34,999 (2)
- \$35,000 – 49,999 (3)
- \$50,000 – 74,999 (4)
- \$75,000 – 99,999 (5)
- More than 100,000 (6)

Care Recipient Demographic Information

Age: _____

Gender:

Male

Female

Check Appropriate Box:

Marital Status:

Married (1)

Single (2)

Widowed (3)

Separated (4)

Divorced (5)

Ethnicity:

- Hispanic or Latino (1)
- Not Hispanic or Latino (2)

Race (please check all that apply)

- American Indian/Alaskan Native (1)
- Asian (2)
- Black or African American (3)
- Native Hawaiian or Other Pacific Islander (4)
- Caucasian (5)
- Other (6): _____(Please specify)

Highest Education Level Obtained:

- < 10 years of school (1)
- 10-11 years of school (2)
- High School Diploma or GED (3)
- 2 years college (4)
- Bachelor's Degree (5)
- Master's Degree (6)
- PhD/MD/JDS (7)

Household Income Level:

- Less than \$20,000 (1)
- \$20,000– 34,999 (2)
- \$35,000 – 49,999 (3)
- \$50,000 – 74,999 (4)
- \$75,000 – 99,999 (5)
- More than 100,000 (6)

How long ago was the person with dementia diagnosed?

- Less than 1 year
- 1-3 years
- 3-5 year
- 5-6 years
- 6-8 years

How would you rate the dementia?

- Very mild
- Mild
- Moderate
- Severe

Mobility

- Bed-bound
- Wheelchair-bound
- Use walker
- Walk without any device

Mirror Assessment

Assessment of mirrors in the home used by the person you care for. Describe the location, size of mirror, lighting, access, and frequency of use.

APPENDIX D

Semi-Structured Interview Guide

Semi-Structured Interview Guide

1. Tell me about how long you have been caring for___ (your wife/husband, etc.) with dementia?
2. How did you become prepared for caring for your___ (wife/husband, etc.) with dementia? (e.g. healthcare training, dementia support group etc.).
3. Tell me about the mirrors in your home.
 - What are the sizes of the mirrors in your home?
 - Where are the mirrors located in your home?
 - Do you have any compact mirrors, handheld mirrors or full-length mirrors?
 - Which of these mirrors does the person you care for use on a daily basis?
4. Tell me when the person you care for uses mirrors?
 - What appear to be the reasons he/she chooses to look into a mirror?
 - Does she (he) use the mirror for brushing his/her hair, brushing his/her teeth, shaving, or applying make-up?
 - Does (he) look in the mirror for no apparent reason

5. What emotions does she (he) display (i.e., happiness, joyfulness, elation, serenity, sadness, anger, fright, confusion)?
 - Has anything unusual happened when she (he) looks in the mirror?
 - Does he/she appear to stare at herself (himself) in the mirror

6. Do you take her (him) out in the community where there are mirrors or highly reflective surfaces (i.e.: church, rest rooms, shopping malls)?
 - How does he/she appear to be with mirrors that are in public places (i.e. public restrooms, etc.)?
 - What emotions does she (he) appear to have when she looks in that (those) mirrors? (i.e., happiness joyfulness, elation, serenity, sadness, anger, fright, confusion)?

7. How has the experience in caring for someone with dementia changed over time?

8. What else should caregivers know about mirrors for people with dementia?
 - What do you think is important for me to know about mirrors for people with dementia?

For caregivers who have chosen to remove or cover up all mirrors in the home, ask the following questions

9. Tell me what it was like before you covered the mirrors.
 - What appeared to be the reasons she (he) choose to look into a mirror?
 - Did she (he) use the mirror for brushing his/her hair, brushing his/her teeth, shaving, or applying make-up?
 - Does she (he) look in the mirror for no apparent reason?

10. What led you to cover the mirrors?
 - How did you learn about covering the mirrors (i.e. Google, books, friends)? What was it like after covering up the mirrors?
 - Did you need to cover all mirrors or just some of mirrors?
 - How did you feel when you covered the mirrors (happy sad, angry)?

11. Does she (he) still perform activity of daily living without the use of a mirror (i.e. combing his/her own hair, brushing her (his) own teeth)?
 - Does she (he) successfully perform her (his) activities without the use of mirrors?

12. Do you take him/her out in the community where there are mirrors? If so, how does she (he) appear to be with mirrors in public places (i.e. public restrooms, etc.)?

13. What emotions does she (he) appear to have when she looks in that (those) mirrors? (i.e., happiness, joy fulness, elation, serenity, sadness, anger, fright, confusion)?