FAMILY DEMENTIA CAREGIVERS’ PERCEPTIONS OF THE VIRTUAL DEMENTIA TOUR®: A CHANGED REALITY

by

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Family dementia caregiving involves many challenges that often lead to stress and frustration. A subjective understanding of the daily struggles associated with dementia is not possible unless one has the disease; therefore, the family dementia caregiver's perception of dementia might be incongruent with their family member’s lived experience.

The Virtual Dementia Tour®(VDT) provides a vicarious first-person perspective for six of the most common symptoms of dementia. Although extensive evidence supports the use of the Virtual Dementia Tour® in the healthcare profession and education, no research studies were found investigating the Virtual Dementia Tour® with family dementia caregivers.

This hermeneutic phenomenological study discovered family dementia caregivers’ perceptions of the VDT® and its impact on family dementia caregivers’ perceived reality of their family member living with dementia. Ten participants were recruited for in-depth open semi-structured interviews following participation in the Virtual Dementia Tour® at a community event. Data analysis was performed using a modification of Colaizzi’s (1978) method for phenomenological analysis. One over-arching theme, *It Changed Me*, described the culmination of the participants’ experiences leading to a changed reality of their family member living with dementia. Four supporting subthemes described the participants’ internal processes toward empathic understanding, interpretation, and responsiveness.

The findings suggest that family dementia caregivers interpreted their experience in the Virtual Dementia Tour® with empathic understanding and responsiveness. The VDT® had a powerful impact that led to an eye-opening epiphany about the lived experience of dementia and served as a “call to action” for several family dementia caregivers who subsequently changed their expectations and approach to care.

This study begins to fill a gap in the body of nursing knowledge and caregiving research about the value of the Virtual Dementia Tour® with family dementia caregivers in community settings. Moreover, it highlights the need to combine this experience with formal training to improve the quality of family dementia care.

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DEDICATION

This dissertation is dedicated to my husband Mark, whose patience, wisdom, love, and support made this journey possible.

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1: INTRODUCTION

By 2025, epidemiologists project a 40% increase in the prevalence of Alzheimer's disease and related disorders (ADRDs), estimated to affect seven million individuals in the United States by 2050 (Alzheimer's Association, 2017a; Hebert, Weuve, Scherr, & Evans, 2013). Alzheimer's disease and related disorders hereafter referred to as dementia, are a devastating cluster of neurocognitive syndromes affecting primarily older adults (Alzheimer's Association, 2017a). Dementia touches all aspects of life and relationships with significant socioeconomic, psychosocial, and physiological implications as the disease progresses.

Over 80% of those who live with moderate and late-stage dementia receive most of their day-to-day care from family caregivers, hereafter referred to as the "family dementia caregiver" (Alzheimer's Association, 2017a; Brodaty & Donkin, 2009; Friedman, Shih, Langa, & Hurd, 2015). In 2016, unpaid family dementia caregivers provided 18.2 billion hours of care valued at 230 billion dollars (Alzheimer's Association, 2017a). When extrapolated over a possible twenty-year trajectory, the monetary value of family dementia care could exceed four trillion dollars, which would economically devastate the current payment system for dementia care in a long-term care setting (Alzheimer's Association, 2017a; Zanetti, Solerte, & Cantoni, 2009).

Research Problem Statement

The primary goal of family dementia caregiving is to prolong or avoid a transition to long-term care. A subjective understanding of the daily struggles associated with dementia is not possible unless one has the disease. Dementia behaviors might be perceived as antagonistic from the family dementia caregiver's perspective with the potential for unintended physical, emotional, and psychological mistreatment of either the caregiver or care recipient

(Beville, 2002; Matthews et al., 2016; McFadden, 2012). Simulated vicarious dementia experiences like the Virtual Dementia Tour® provide a first-person perspective of dementia, thus allowing a family dementia caregiver to experience the neurocognitive deficits of advancing dementia (Beville, 2002; Hojat, 2016).

Purpose Statement

The purpose of this qualitative study was to discover family dementia caregivers' perceptions of the Virtual Dementia Tour®.

Significance of the Study

Family dementia caregiving is often counterintuitive and usually challenging due to the neurocognitive deficits associated with dementia, especially in later stages when two-way communication is no longer possible (Family Caregiving Alliance, 2017). Thirty-five percent of family dementia caregivers report personal consequences associated with family dementia caregiving including the loss of mental, emotional, or physical health as a result of their caregiving responsibilities (Alzheimer's Association, 2017a). The stress and communication difficulties of family dementia caregiving can cause frustration, which in its worst form might trigger unintentional mistreatment of the individual living with dementia (Family Caregiving Alliance, 2017). Approximately 50% of caregivers admit to some form of mistreatment of their family member living with dementia (Beach et al., 2005; Cooper et al., 2009; Cooney, Howard, & Lawlor, 2006; Dong, Chen, & Simon, 2014). The stress and coping associated with family dementia caregiving depend on the characteristics of the dyadic relationship before dementia, perceived stressful aspects of caregiving, and perceived consequences on the caregiver's sense of well-being (Dilworth-Anderson, Williams, & Cooper, 1999; Matthews et al., 2016; Papastavrou, Kalokerinou, Papacostas, & Sourtzi, 2007).

Significance to Nursing Science

Knowledge gained from this research might inform the value of the Virtual Dementia Tour® in providing caregivers with a different perspective and the possibility of a mutual relational benefit. The Virtual Dementia Tour® and other vicarious dementia simulations are tools widely used in retirement communities, nursing homes, healthcare professional education, and informal caregivers to sensitize and increase awareness of dementia. (Beville, 2002; Finn, 2017; Gibbons, 2016; McFadden, 2012; Rankin, 2015). Virtual dementia simulation has been used in the health science disciplines to challenge conventional attitudes towards dementia and enhance empathy, which is considered to be a precursor for appropriate care practices (Donahoe, Moon, & Van Cleave, 2014; Stevens, Bluteau, Clouder, Adelfila, & Graham, 2015; Werner, Powell, & Clark, 2014). Although extensive evidence supports the use of the Virtual Dementia Tour® in the healthcare profession and education, no research studies investigating the Virtual Dementia Tour® with family dementia caregivers were found.

Primary Guiding Research Questions

Two research questions guided this inquiry:

- What is the family dementia caregiver's perception of the Virtual Dementia Tour®?
- How might the Virtual Dementia Tour® impact the family dementia caregiver's reality of the person living with dementia?

Philosophical Approach to Qualitative Inquiry

Interpretative (hermeneutic) phenomenology is best suited to discover the family dementia caregivers' experience with the Virtual Tour®. Hermeneutic phenomenology guides researchers' inquiry into holistic questions of meaning believed to manifest from the milieu of life as it is experienced (Creswell & Poth, 2018; LeVasseur, 2003; Smith, 2016; van Manen, 2016). One’s perception and meaning of an experience are influenced by personal ontologies, life contexts, and inherent ambiguous realities. Through interpretative phenomenology, one aims to understand the meaning of some “thing,” a phenomenon, or one’s perception of an experience (Munhall, 2012; van Manen, 2016).

Historical Perspective of Phenomenology

Edward Husserl, considered to be the founding father of (transcendental) phenomenology, held an ideology about true knowledge that directly contradicted the traditional schools of empirical and positivism of his predecessors and contemporaries (Farina, 2014). One of the most foundational precepts of Husserl’s phenomenological framework was his rejection of the facticity of objects that were posited to apply to human phenomena (Husserl, 2014; Stiver, 1992). For Husserl, phenomenology pertained to the essence of consciousness and intentionality with a transcendental approach whereby the outside world is “bracketed” off from experience (Husserl, 2014; Smith, 2016). Husserl posited that one must remove all preconceived assumptions to uncover the true meaning of a phenomenon (Farina, 2014; Husserl, 2014; Stiver, 1992). Husserl believed one must use a technique known as epoché (“bracketing”) to exclude extraneous biases acquired from language, culture, science, history, or tradition to experience any given phenomenon as it exists (Farina, 2014; Husserl, 2014; Stiver, 1992).

In contrast to Husserl’s transcendental phenomenology, Martin Heidegger approached phenomenology from an interpretative viewpoint to understand how humans exist within the world around them (Farina, 2014; Heidegger, 1953/2010; Smith, 2016). Heidegger supported a hermeneutic phenomenology and posited that humans are one with the world, explicitly contradicting the partitioned nature of Husserl’s reduction theory (Wrathall, 2005). A contemporary, Maurice Merleau-Ponty, known for embodiment phenomenology, concurred with

Heidegger about one’s inability to “disembody” from what is already known in the existential lived experience (Merleau-Ponty, 1962/1962; van Manen, 2016). This study will be based on an ontology from which one makes explicit their understandings, beliefs, biases, assumptions, and presuppositions to encourage a genuine openness and self-critical awareness (Heidegger, 1953/2010; Merleau-Ponty, 1962/1962; van Manen, 1990).

Reflection, a crucial aspect of phenomenological inquiry, is neither inductive nor logical but is instead reductive (van Manen, 2016). In this context, the reduction is not referring to a rule or process, but an “attentive turning to the world when in an open state of mind, effectuated by the epoché” (p. 218). The *epoché* and eidetic reduction work in an opposing, yet complimentary fashion to allow the essence of lived experience to reveal itself as it exists (van Manen, 2016). The term *epoché* describes the process of opening of one’s mind to recognize, acknowledge, and hold any preconceived ideas or beliefs in abeyance thereby allowing the researcher to uncover the true nature of a phenomenon (Stiver, 1992; van Manen, 2016). The method of eidetic reduction allows one to glean insight into the meaning of a phenomenon or event by adopting an attitude of openness and “unknowing” (Mackey, 2012; van Manen, 2016). Eidetic reduction focuses on “what” and “how” a phenomenon shows itself. The symbiosis of *epoché* and eidetic reduction can reveal the phenomenon as it exists, in its complexity, and thus might allow the exposure of unknown patterns of “knowing” (Farina, 2014; Munhall, 2012; Stiver, 1992; van Manen, 2016).

Philosophical Assumptions

The ontological, epistemological, and axiological assumptions are unique to the interpretive phenomenological approach to qualitative inquiry.

Ontology. The critical ontological assumption of phenomenology is the belief there are multiple realities (Sandelowski, 1993; Smith, 2016; van Manen, 2011, 2016). This ontological foundation guides several aspects of phenomenological research (i.e., sampling, approach, and aspects of trustworthiness).

Epistemology. According to van Manen (2011), the epistemology of phenomenology is knowledge as the product of the research, knowledge as understanding, and knowledge as being (personal knowing):

> Phenomenology does not provide us with 'information' in the usual sense of the term. Instead, the practical significance of phenomenological knowledge is formative: It enhances our perceptiveness, it contributes to our sense of tact in human relations, and it provides us with pathic forms of understanding that are embodied, situational, relational and enactive [*sic*]. (§ 1.3)

Axiology. Interpretative phenomenological research is value-laden; therefore, recognition and explicit acknowledgment of biases and presuppositions are crucial (van Manen, 2011, 2016). Positionality about the context and setting of the research is vital, as the researcher is the measurement tool in qualitative research.

Theoretical and Conceptual Framework

The conceptual foundation for this study is an adapted synthesis of the theoretical and conceptual frameworks of Agosta's (2014) multidimensional process of empathy and Selder's "Life Transition Theory" (1989; See Figure 1). Agosta's (2014) multidimensional introspective process is grounded in psychology and fills a gap in Selder's (1989) theory by adding internal and subjective processes that might influence the possibility of a change in reality after experiencing a vicarious experience.

The family dementia caregiving synthesis model provides a framework illustrating a family dementia caregiver's transition perceived through an "as if" experience that prompts the internal dialogue necessary for a change in reality. The "as if" refers to an experience that simulates a situation or condition for the participant *as if* one has the condition, in this case, deficits associated with dementia. The Virtual Dementia Tour® is an "as if" experience posited to provide the impetus for internal cognitive and affective dialogue about one's preconceived reality and assumptions about living with dementia.

The Virtual Dementia Tour® provides a first-person vicarious experience of what it is like to have dementia (Beville, 2002). During the eight-minute Virtual Dementia Tour®, participants attempt to perform five ordinary daily activities (e.g., folding towels, setting the table, making a grocery list, and matching socks) while wearing poorly fitting gloves, reduced vision glasses, noise producing earphones, and distracting shoe inserts. The sensory deprivation and attire simulate the neurocognitive domain deficits commonly seen in advancing dementia (language, learning and memory, social cognition, complex attention, executive function, and perceptual motor function; Sachdev et al., 2014; Shaik & Varma, 2012).

Selder's Transition Theory

According to Selder (1989), a successful life transition requires one to recognize the unalterable event that disrupted reality, acceptance of the permanency of the disrupted reality, and the recognition of the possibilities associated with these changes with a resolution of uncertainty (Mitchell, 2010; Selder, 1989). Originally intended for life transitions during pregnancy, this nursing theory applies to other life transitions. For this study, Selder's transition theory is applied to family dementia caregiving.

Dementia causes the family dementia caregiver's disruption of reality. This disruption often propels the family dementia caregiver into uncertainty with the need to transition to a different and evolving reality (Selder, 1989). The family dementia caregiver may experience the loss of role identity, loss of place, or sense of being in life that adds to their sense of uncertainty. Given the insidiously slow trajectory of dementia in most cases, the future family dementia caregiver can often employ changes to avoid a disruption in their reality for several years (Alzheimer's Association, 2017a; Selder, 1989). However, a definitive point exists in the trajectory of any form of dementia when a disruption in reality is imminent. This event, referred to as a "crucial event," forces the family dementia caregiver to consider the permanency of the change in reality (Selder, 1989). A crucial event might occur when a dependent elder individual living with dementia has a "near miss" event placing themselves or others in danger (Selder, 1989). Examples of such events might include leaving on the stove burner with a subsequent accidental house fire, getting lost while driving in a familiar area, or walking away from home in inclement weather. A crucial event might be the stimulus for the family dementia caregiver's receptivity to a change in reality.

Agosta's Unified Multidimensional Process of Empathy

Researchers hypothesize that failed attempts to measure empathy as an outcome variable are due to the construct's conceptual and operational ambiguity (Agosta, 2014; Hemmerdinger, Stoddart, & Lilford, 2007; Yu & Kirk, 2009). This ambiguity lends credence to Agosta's (2014) recommendation to re-conceptualize empathy as a process within a hermeneutic circle. A hermeneutic circle describes the whole of some "thing" in relation to each component within the circle. Reference to any one component is incomplete without considering the circle's wholeness. Agosta's (2014) hermeneutic circle contains a minimum of four constructs necessary for an empathic process: “empathic receptivity,” “empathic understanding,” “empathic interpretation,” and “empathic responsiveness” (See Figure 1).

Empathic receptivity brings openness to a change and progresses in an individualized manner depending on one’s connectedness and relatedness to another (e.g., the family dementia caregiving dyad; See Figure 1). The family dementia caregiver’s cultural, situational, and personal contexts shape their receptivity (Dilworth-Anderson, Williams, & Gibson, 2002; Roberts, Connell, Cisewski, Hipps, Demissie, & Green, 2003). An attribute of empathic receptivity is the “as if” or vicarious experience. According to Agosta (2014):

> The “vicarious” in vicarious experience is experience once-removed from the events in life as it occurs unreflectively. Yet do not underestimate the ability of a vicarious experience to shake one to the core of one’s being….When the event in question turns out to be difficult, overwhelming, or traumatic, empathy is actually a healthy protective device—one might say “defense”—against compassion fatigue, burn out, or fragmentation (p. 17).

Moreover, empathy can be described as “vicarious [as if] introspection” in which “vicarious” refers to an evocative event (Agosta, 2014). Through vicarious introspection, one processes information through self-reflection without filtering it through a cognitive process. Thus, introspection brings the spontaneous vicarious feelings to the surface of consciousness to be processed through empathic understanding, interpretation, and subsequent empathic response. The internal emotional and cognitive process of vicarious introspection forms an interpretative (hermeneutic) circle (See Figure 1).

According to Agosta (2014), “empathic interpretations are often implicit and unacknowledged and draw from a variety of cognitive methods of interpreting, framing, conceptualizing, and formulating otherness such as a transient identification, projection, introjection, and related transformations" that sustain ongoing engagement and create the understanding of possibility (p. 6). The way the family dementia caregiver empathically responds, interprets, and understands their "as if" experience will determine their perspective, perception, and outcome of the possibility of a change in reality.

Family Dementia Caregiving Synthesis Model

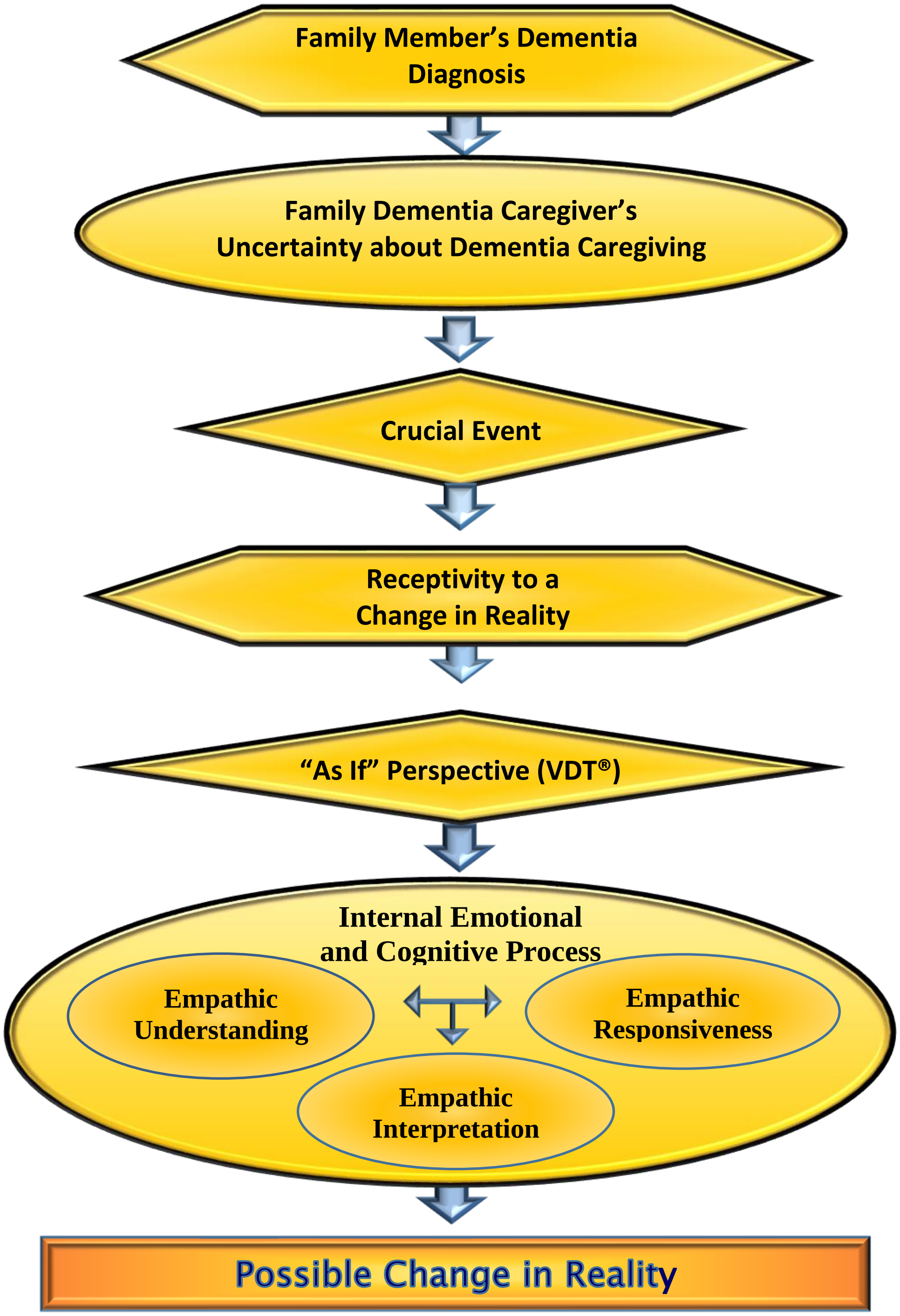
The family dementia caregiving synthesis model is a synthesis of Selder's transition theory (1989) and Agosta's (2014) unified multidimensional process of empathy. This synthesis describes a complete chain of events possibly associated with a family member's diagnosis of dementia, the family dementia caregiver's resulting uncertainty, and the possibility of a change in reality to ameliorate or resolve the sense of uncertainty associated with becoming a family dementia caregiver. The use of an "as if" virtual dementia experience (i.e., the Virtual Dementia Tour®), provides a vicarious experience described by Agosta as an opportunity for openness and possibility (2014).

The family dementia caregiving synthesis model begins with an older family member's diagnosis of dementia. The medical confirmation of dementia creates feelings of uncertainty about the future role as a family dementia caregiver (Selder, 1989). A determinate point exists in every dementia trajectory of any form of dementia when a disruption in reality is imminent for the safety and well-being of the family member living with dementia, referred to as a "crucial event." Following the crucial event, the family dementia caregiver must become receptive to a change in reality to reduce the uncertainty caused by the life-changing crucial event (Agosta, 2014). Openness to a change in reality progresses in an individualized manner depending on the family dementia caregiver's connectedness to their dependent elder living with dementia. He or she demonstrates receptivity to a change in reality and openness to a new perspective of dementia by participating in the Virtual Dementia Tour®.

The “as if” refers to the Virtual Dementia Tour® that simulates a situation or condition for the participant *as if* they have the condition, in this case, deficits associated with dementia. Following the “as if” Virtual Dementia Tour® experience, Agosta’s (2014) hermeneutic multidimensional constructs of empathic interpretation, responsiveness, and understanding are crucial to explaining the introspective processes of the family dementia caregiver's experience and the impact of the Virtual Dementia Tour®. This process is depicted as a hermeneutic circle (See Figure 1). Empathic interpretation refers to an individual’s ability to interpret an experience “as if” one was another. Empathic understanding is defined as an acknowledgment of the other and their lived experience. Empathic understanding is thought by some to have a therapeutic effect because it facilitates the sharing and cleansing of conflicting emotions necessary to gain insight (Agosta, 2014; Berger, 1984).

The way the family dementia caregiver empathically responds, interprets, and understands their "as if" experience will determine their perspective and outcome toward the possibility of a change in reality. One emerges from the family dementia caregiving synthesis model with the possibility to remain unchanged in his or her current reality with ongoing uncertainty, the possibility for a change in reality and resolution of uncertainty, or any number of outcomes representing multiple realities.

Figure 1 Family Dementia Caregiving Synthesis Model



Adapted from Agosta, 2014; Selder, 1989

Definition of Terms

For this study, the following definitions will guide the conceptualization and theoretical approach:

Family. Family is defined in two ways: 1) a group related by blood, marriage, or adoption with a common ancestral relationship based on commitment or obligation and 2) a voluntarily committed bond in a relationship, friendship, and companionship with one or several others.

Family dementia caregiver. The familial individual who forms a relational dyad with the individual living with dementia serves as an advocate, assumes the primary responsibility, and accepts accountability for the individual living with dementia at the point the dyad became necessary for their dependent elder’s safety and well-being.

Dementia. Dementia refers to pathologically distinct progressive neurocognitive syndromes that initially present as mild cognitive impairment (MCI) and culminates in progressive and terminal deterioration in all neurocognitive domains. Regardless of the neurological etiology, those living with dementia exhibit progressive neurocognitive impairment in one or more of six neurocognitive domains: Language, learning and memory, social cognition, complex attention, executive function, and perceptual motor function (Sachdev et al., 2014; Shaik & Varma, 2012).

Reality. According to Selder (1989), reality “is imbued with personal meaning and values which are essential in determining how the self and the world are defined” (p. 437). An individual’s reality has temporal stability and creates meaning based on the individual’s life assumptions and expectations (Selder, 1989).

Perception. A sub-concept of reality, perception is defined as an interpretation based on the internal and subjective frame of reference to understand another's experience, behavior, and feelings.

Perspective. A sub-concept of reality, perspective is a point of view that is influenced by one's attitude and based on the individual's reality and perspective as the family dementia caregiver.

Crucial event. A crucial event is a definitive point in the trajectory of any form of dementia when a disruption in reality is imminent.

"As If" perspective. Based on Agosta's (2014) theory, the Virtual Dementia Tour® was used to provide an "as if" experience. The "as if" refers to an experience that simulated a situation or condition for the participant *as if* they have the condition, in this case, deficits associated with dementia. The "as if" perspective provided the family dementia caregiver with a first-person perspective of the neurocognitive deficits commonly seen in advancing dementia (perceptual-motor function, complex attention, executive function, and memory impairment).

Empathic receptivity. Empathic receptivity refers to the family dementia caregiver's openness to receive the possibility of a changed reality about another's experience. The family dementia caregiver must be open to a new perspective and meaning to understand their dependent elder's experience with dementia through an "as if" scenario.

Empathic understanding. Empathic understanding is the family dementia caregiver's internal and subjective frame of reference to understand another's experience, behavior, perception, and feelings.

Empathic interpretation. Empathic interpretation refers to the family dementia caregiver's ability to interpret their experience "as if" he or she were a dependent elder living with dementia.

Assumptions

For this study, the following assumptions apply:

- The individual living with dementia has cognitive impairment severe enough to require supervision and provision of care by a family member for instrumental activities of daily living or activities of daily living.
- Family dementia caregivers:
    - Demonstrate receptivity to a change in reality by participating in the Virtual Dementia Tour$^{®}$.
    - Are cognitively able to fulfill their role and have no cognitive impairment that impedes their ability to be a family dementia caregiver.
    - Provide care for altruistic purposes and are advocates for the best interest of their family member living with dementia.

Summary

As more individuals develop dementia, family dementia caregivers continue to be a critical and valuable resource to prolong or prevent transitions to long-term care facilities. Interpretative phenomenology's approach is used to uncover meaning through perception. The conceptual foundation for this study will involve an adapted synthesis of Agosta's (2014) multidimensional process of empathy and Selder's "Life Transition Theory" (1989). The family dementia caregiving synthesis model provides a framework illustrating a family dementia caregiver's transition as perceived through their lived experience lens.

CHAPTER 2: LITERATURE REVIEW

Due to the paucity of literature to inform the proposed research questions, an overall discussion of the literature review focused on (1) an overview of dementia (Alzheimer's disease and related disorders), (2) perceptions of dementia, (3) family dementia caregiving (4) perceptions of family dementia caregiving, (5) technology for caregiver support, and (6) various types of vicarious dementia simulation. An extensive literature review was conducted to identify all published evidence for the concepts of interest and virtual dementia simulation technology. Date range limitations were dependent on the lack of evidence and were extended in five-year increments until salient literature was found. The research describing the perception of dementia, characteristics, similarities, ethnocultural differences in family dementia caregivers, and consequences of family dementia caregiving spanned 30 years from the 1980s to present. Seminal studies and classical systematic reviews were repeatedly cited in recent publications (Aranda & Knight, 1997; Connell & Gibson, 1997; Dilworth-Anderson, Williams, & Cooper, 1999; Picot, Debanne, Namazi, & Wykle, 1997; Pinquart & Sörensen, 2005; Roberts et al., 2003). Therefore, some of these primary sources were included in this review regardless of the date of publication. Due to the lack of published literature for virtual dementia simulation for family dementia caregivers, these concepts were searched without time limitations.

Dementia

"Dementia" is an umbrella term for several neurocognitive syndromes (American Psychiatric Association [APA], 2013). The literature describes these syndromes based on the neurochemical pathology and origin within the brain. This section will discuss pathology, clinical presentation, and disease trajectories of the four most common neurocognitive syndromes: Alzheimer’s disease, frontotemporal degeneration, vascular cognitive impairment (previously known as vascular dementia), and dementia with Lewy bodies (Shaik & Varma, 2012). All of these forms of dementia follow a “dwindling” trajectory whereby functional and cognitive debility are progressive and gradual with each severe illness causing an irreversible decline (Murray, Kendall, Boyd, & Sheikh, 2005). Except for vascular cognitive impairment, diagnoses are based on clinical findings with postmortem confirmation upon autopsy.

Dementia Typologies

Reisburg, Ferris, De Leon, and Crook’s (1982) Global Deterioration Scale provides a standardized method of staging the progressive degenerative characteristics of dementia. The Global Deterioration Scale consists of seven stages. Deficits are not socially evident until stage three when decreased performance becomes evident in demanding work or social situations. It is at this stage that one might get lost in familiar surroundings. Stage four represents a later confusion state in which those with dementia may have difficulty with serial subtraction, which might cause difficulty in managing personal finances. A moderately severe cognitive decline is notable in the fifth stage. Those in this stage are no longer able to survive without assistance. The ability to dress is retained, although perhaps in a seasonally inappropriate manner or method (e.g., wearing a winter coat in the summer or placing shoes on the wrong feet). Stage six marks the middle phase of dementia with severe cognitive deficits. Individuals in this stage may occasionally forget family members’ names and require substantial assistance with personal needs like dressing, bathing, and toileting, leading to incontinence if not reminded of the need to toilet on a schedule. Diurnal rhythm changes are common at this stage, creating challenges for family dementia caregivers who begin to suffer from sleep deprivation. Variable personality and neuropsychiatric symptoms like delusions, hallucinations, and repetitive questioning may become evident during the sixth stage. Those in the seventh stage are considered to have late-stage dementia with very severe cognitive impairment. Loss of psychomotor skills and the ability to verbally communicate become evident. The neural connections from the brain to distal neurons break down with loss of the ability to walk, talk, and eventually swallow. Alzheimer's disease, frontotemporal degeneration (FTD), vascular cognitive impairment, and dementia with Lewy bodies collectively represent approximately 95% of all dementia subtypes and are categorized by neurological etiology (Sachdev et al., 2014; Shaik & Varma, 2012). These types of dementia are explained below.

Alzheimer's disease. Alzheimer's disease is thought to cause 75% of dementias (Alzheimer's Association, 2017a). More than 90% occur in those over the age of 65, thus are referred to as late-onset dementia (Alzheimer's Association, 2017a). The exact pathological mechanism of Alzheimer's disease remains unknown (Shaik & Varma, 2012). The presentation is similar in all age groups with progressive and terminal impairment in memory, cognition, language, motor impairment, and loss of bowel and bladder function, ability to swallow, and ability to communicate. The disease trajectory ranges from four to twenty years (Alzheimer's Association, 2017a).

Frontotemporal degeneration (FTD). FTD is caused by neuronal degeneration of the temporal and frontal cortex of the brain (Alzheimer's Association, 2017b; Bang, Spina, & Miller, 2015). Underlying etiologies include abnormalities in tau protein, protein TDP43, and genetic factors (Alzheimer's Association, 2017b). The two most common phenotypes' clinical presentations differ. BvFTD causes drastic changes in personality, socially inappropriate behavior, disinhibition, loss of empathy, and loss of foresight (Alzheimer's Association, 2017b). Primary progressive aphasia (PPA) results in degeneration in language skills, writing, and comprehension. As frontotemporal degenerative dementia worsens, the symptoms of the clinical variants can converge with global cognitive, motor dysfunction, and parkinsonian features (Bang, Spina, & Miller, 2015). FTD's disease trajectory is shorter than Alzheimer's disease with death usually resulting from pneumonia or secondary infection (Bang, Spina, & Miller, 2015).

Vascular cognitive impairment (VCI). Vascular cognitive impairment is the recommended nomenclature to describe the subcortical vascular changes that result in all forms of vascular dementia (Alzheimer's Association, 2017c; Gorelick et al., 2011). Pathogenesis may result from cardioembolic, atherosclerotic, ischemic, hemorrhagic, or genetic factors (Gorelick et al., 2011; Shaik & Varma, 2012). VCI is the only cause of dementia with known modifiable risk factors. The clinical trajectory of VCI is approximately eight years from diagnosis to death (Alzheimer's Association, 2017c). The clinical manifestations of VCI mimic Alzheimer's disease (Alzheimer's Association, 2017c; Gorelick et al. 2011). Mortality is more often due to subsequent cerebrovascular events (Alzheimer's Association, 2017c; Gorelick et al. 2011).

Dementia with Lewy bodies (DLB). An abnormal accumulation of the protein deposits of alpha-synuclein known as Lewy bodies in the cortico-subcortical areas of the brain causes Lewy body dementia (Ballard et al., 2006). Misfolded alpha-synuclein occurs in stages whereby a few misfolded molecules clump to form small complexes called "oligomers." (Lewy Body Dementia Association, 2016). The oligomers then form fibrils, which then aggregate into larger clumps and eventually form Lewy bodies (Lewy Body Dementia Association, 2016).

The resulting and progressive debilitation presents with parkinsonian movement symptoms, neurocognitive impairment, changes in personality, vivid hallucinations, and rapid eye movement disorders in which the individual acts out his or her dreams. The brain's ability to regulate autonomic control of temperature, blood pressure, bowel function, and bladder control are also adversely affected (Koehler, 2013). Individuals living with DLB may present with more difficulties in visual processing and executive function, but experience less severe memory impairment in comparison with other subtypes of dementia (Koehler, 2013).

Regardless of the neurological etiology, those living with dementia exhibit progressive impairment in one or more of six neurocognitive domains: Language, learning and memory, social cognition, complex attention, executive function, and perceptual motor function (Sachdev et al., 2014; Shaik & Varma, 2012). As neurodegenerative changes progressively worsen, the individual living with dementia will experience some, if not all, of the effects resulting from progressive neurodegeneration. As the disease progresses, the care recipient becomes more dependent with a subsequent increase in the physical, mental, and emotional needs that necessitate around the clock caregiving. Some individuals who are living with dementia experience emotional behaviors (neuropsychiatric symptoms) that might create challenges for caregivers, especially as two-way communication progressively diminishes.

Neurocognitive Domains

At the point the impairment is significant enough to be tested, changes in one or more of the following domains become evident in the behavior of an individual living with dementia.

Language. Language impairments include loss of fluency, word finding, object naming, grammar, and syntax (changes in the order of words in a sentence), and receptive language (Sachdev et al., 2014). These deficits become evident when an individual is unable to follow directions for tasks (put on your shirt and tie), understand a story or figurative language (e.g., irony, a metaphor, or quip).

Learning and memory. This domain consists of the loss of the capacity to learn without awareness of the products of learning (implicit learning). An individual may have difficulty with free recall of information, cued recall of information, or recognition memory whereby the brain matches a current experience or presented information to stored memory images, thus creating a signal for recognition (Sachdev et al., 2014).

Social cognition. Those who develop impairment in social cognition lose insight and the ability to understand that others' principles, wishes, intentions, and viewpoints are different from their own (Sachdev et al., 2014). A loss in the ability to recognize others' emotions is also typical.

Complex attention. An individual with deterioration in this domain will lose the ability to divide their attention between two stimuli whereby simultaneous attention is required to process information (e.g., cooking a meal). A notable reduction in the speed with which information is processed becomes evident. The ability to ignore competing stimuli while concentrating is progressively lost, thus affecting the capability to perform complex sequenced tasks.

Executive function. Executive functions are the complex cognitive processes required to manage day-to-day living activities. Often early changes in executive function are ignored until the impairment disrupts one's ability to maintain a façade of normality. These activities include planning, decision-making, inhibiting impulses, flexibility, working memory, and responding to feedback (Sachdev et al., 2014). Those who lose executive function have difficulty maintaining a bank account, planning activities, and may lose the ability to self-regulate their behavior.

Perceptual-motor function. When one develops impairment in this domain, the individual has reduced visual perception and impaired visuospatial construction (i.e., the ability to recognize that an object or task as a set of parts and then use those parts to replicate the original). Examples of skills requiring visuospatial construction include the ability to make a bed or button a shirt. Perceptual-motor coordination, a component of perceptual-motor function, is necessary for gross and fine-motor skills like tracking objects and hand-eye coordination.

Perceptions of Dementia

Perceptions of dementia are interpretations based on the internal and subjective frame of reference to understand another's experience, behavior, and feelings. These concepts provide the necessary background information for this phenomenological inquiry.

In studies investigating beliefs, knowledge, and information sources based on ethnicity, consistent similarities and differences about concerns, knowledge, and beliefs about dementia were noted (Ayalon, 2013; Ayalon & Arean, 2004; Gray, Jimenez, Cucciare, Tong, & Gallagher-Thompson, 2009; Roberts et al., 2003). Researchers found that links between ethnicity and one's perception of dementia were too complicated for predictive disease models (Dilworth-Anderson, Williams, & Gibson,1999, 2002; Gray, Jimenez, Cucciare, Tong, & Gallagher-Thompson, 2009; Janevic & Connell, 2001). A seminal study by Roberts et al. (2003) explored the differences between African American and Whites' perceptions of dementia to design appropriate healthcare services and education programs. The researchers sent a questionnaire to adult citizens in the southeastern United States (n = 452; 61% White, 39% African American; 78% female, 33% with a family history of dementia). Survey items were organized in four domains: Illness beliefs (symptoms, risk factors, and possible treatments for dementia); knowledge about well-known dementia facts; sources of information; and the perceived threat of dementia. Group similarities were noted in areas of symptoms, risk factors, and behavioral interventions. However, African Americans more often reported the belief a cure would be found within the next five years ($p < .001$). White respondents reported more frequently the belief that nursing home placement would eventually be needed for any individual living with dementia ($p < .05$). Group differences were noted in the factual knowledge domain with White respondents answering 60% of the questions correctly compared with 42.5% African Americans [adjusted mean (White) = 7.6 vs. adjusted mean (African American) = 5.6, p < .001]. African Americans reported fewer information sources about dementia compared with Whites [adjusted mean (White) = 4.7 vs. adjusted mean (African American = 3.5, p < .001]. The most common sources of information included reading, media, healthcare professionals, and friends. African Americans were more likely to believe dementia was part of healthy aging (26%) in comparison with White counterparts (12%, p < .001). The authors reported these findings should be interpreted with caution due to the nonrepresentative sample.

Gray, Jimenez, Cucciare, Tong, & Gallagher-Thompson (2009) explored ethnic differences in knowledge attitudes and beliefs about dementia (*n* = 215). The sample included 85 non-Hispanic White, 83 Hispanic/Latina, and 48 Chinese-American female family dementia caregivers. Caregivers were asked about epidemiology, etiology, perceptions of dementia treatment effectiveness, the perceived threat of dementia, and information sources. In comparison with Hispanic/Latina and Chinese-American participants, the non-Hispanic White group demonstrated significantly more knowledge about the disease (*p* < .001). Hispanic/Latina (*p* < .001) and Chinese-American (*p* < .01) participants were more likely to report the perception that medical interventions reduced, prevented, and delayed dementia when compared with the non-Hispanic White group. Hispanic/Latina and Chinese-American were more likely to perceive Alzheimer’s disease as a threat, but White participants reported dementia was the worse disease they could imagine (*p* < .001). Three most commonly endorsed sources of information included 1) printed media sources (77.2%); 2) health care professionals (66.5%); and 3) TV and radio (61.9%). These findings were similar to the Roberts et al. (2003) study.

Ayalon (2013) evaluated data from a US national study of adults over 50 years of age and their spouses. The sample consisted of Whites (*n* = 939), African Americans (*n* = 171) and Latinos (*n* = 120) who answered a 13-item survey about dementia concerns, knowledge, and beliefs. Following adjustments for education, gender, age, having a family member with dementia, depressive symptoms, and medical comorbidity, logistic regression revealed four ethnic differences. In comparison with White respondents, Latinos were less likely to perceive mental activity as a protective factor against dementia. African Americans were less likely to report family history as a risk factor for developing dementia. Latino and African American respondents were more likely to perceive stress as a risk factor for developing dementia.

Several researchers cautioned readers to be wary of research findings reporting minority group comparisons (Connell, Roberts, McLaughlin, & Akinleye, 2009; Dilworth-Anderson, Williams, & Gibson, 2002; Dilworth-Anderson, Pierre, & Hilliard, 2012; Roberts et al., 2003). Minority groups are more likely to have disproportionate health disparities, socioeconomic inequalities, historical influences, macrosocial factors, and inequivalent group samples. Regardless of ethnic or cultural origin, the diagnosis of dementia causes a great deal of uncertainty for all those involved (Aspesoa-Varano, Tang-Feldman, Reinhard, Choula, & Young, 2015; Connell, Roberts, McLaughlin, & Akinleye, 2009; Dilworth-Anderson, Williams, & Gibson, 2002; Ivey, Laditka, Prices, Tseng, Beard, & Liu, 2012; Pinquart & Sörensen, 2005).

Family Dementia Caregiving

Over 80% of those living with moderate and late-stage dementia receive most of the day-to-day care from family caregivers, hereafter referred to as the “family dementia caregiver” (Alzheimer’s Association, 2017a; Friedman, Shih, Langa, & Hurd, 2015). Family dementia caregiving is influenced by deeply rooted cultural ideologies spanning several generations. These value and belief systems include filial piety, reciprocity, and duty.

Filial piety is a concept repeatedly cited in research studies and refers to one's familial devotion or respect for one's parents or elders (Aspesoa-Varano, Tang-Feldman, Reinhard, Choula, & Young, 2015; Connell & Gibson, 1997; Dilworth-Anderson, Williams, & Gibson, 2002). This devotion is deeply embedded in one's cultural value and belief system. Duty and reciprocity are also deeply ingrained in some cultural value and belief systems. Within a cultural context, duty refers to one's sense of obligation to family, while reciprocity refers to one's desire to reciprocate for care and love provided to them at an earlier time in his or her life. Duty and reciprocity affect the manner in which care is provided to dependent elders with notable differences in how minority and non-minority family dementia caregivers perceive and interpret the meaning of duty and reciprocity.

Powers and Whitlatch (2016) found that African Americans and White family dementia caregivers have divergent interpretations of duty (n = 202). Exploratory factor analysis examined the factor structure of subscales within the Cultural Justifications for Caregiving Scale (Dilworth-Anderson et al., 2005). A two-factor solution emerged from a Varimax rotation explaining 60% of the variance. Both African Americans and White caregivers expressed high levels of agreement with reciprocity than with duty. However, when subsamples were examined separately, different factor loadings were found for African Americans and White caregivers. White family dementia caregivers reported higher levels of duty (α .76, r^2 = .19 - .32, p < .01) and were correlated with male gender, younger age, and reported dyadic relationship strain. African American family dementia caregivers also reported higher levels of duty (α .80, r^2 = .28 - .41), but these levels correlated with relationship type, dependent elder experiencing depression, dyadic relationship strain ($p < .05$), and financial strain ($p < .01$). These researchers found reciprocity was only highly correlated in African American adult child family dementia caregivers (e.g., daughter, son, or grandchild) or other family members (e.g., cousin, sister).

Aspesoa-Varano, Reinhard, Choula, and Young (2015) conducted a synthesis of 248 studies on multi-cultural caregiving patterns in Latino, American Indian/Native American, Asian American, and African American family caregivers from 1980 to 2013. Of these, 86 compared two ethnic groups and 45 compared at least three ethnic groups. Most of the comparison studies included non-minority White participants. The researchers categorized studies by caregiving experience; social support; access to and use of caregiving resources; predictors and outcomes of caregiving; and interventions to augment psychosocial skills (e.g., burden, psychosocial support, and problem-focused coping). Traditional norms and filial piety were an expectation in Asian American families. As the second and third generations became acculturated to American norms, this expectation was a common source of family conflict. Values of familial reciprocity and family decision making were a hallmark of Latino and African American families. Within these studies, African American families viewed family caregiving as an expression of love, respect, and spirituality. Reciprocity and duty were a matter of family integrity and role modeling in African American families. The authors' review suggested that most ethnic minorities had a sense of distrust of healthcare institutions and outside aid driven by experiences of racism and discrimination (African Americans), language barriers (Asian Americans and Latinos), pride, and shame in asking for help (Asian Americans). Although little is known about American Indian experiences in caregiving, four studies included in this review suggested care was provided through a communal and complex exchange system with limited formal support (Hennessy & John, 1996; Jervis, Boland, & Fickenscher, 2010; Korn et al., 2009; Spencer, Goins, Henderson, Wen, Goldberg, 2013). American Indian family caregivers were found to have opposing experiences of high rewards as well as caregiving burdens, role and family conflicts, negative feelings, and low self-efficacy.

One randomized control trial was included in the review evaluating the benefit of polarity therapy to reduce caregiver stress and depression in American Indian family caregivers (Korn et al., 2009). Forty-two Pacific Northwest American Indian family caregivers were randomized to either a polarity therapy or enhanced respite care group. The researchers described polarity therapy as "gentle pressure on energy points and biofields to help achieve physiological relaxation" (Korn et al., 2009, p. 368). An improvement was noted in stress, bodily pain, vitality, and general health ($p \leq .05$; no effect size reported). The authors noted the large categories within their review did not account for many subpopulations with distinct histories, sociocultural values, and contextual experiences. However, the authors did not discuss the inequivalent group comparisons (minority with non-minority groups).

Perceptions of Family Dementia Caregiving

Cultural values and beliefs among different ethnic groups often affect how one assigns meaning to dementia. As far back as 1999, Dilworth-Anderson, Williams, and Cooper (1999) conducted a seminal study (n = 330) to understand different contexts in which African American caregivers provided care and the influence of these contexts on the primary caregivers' emotional well-being. These researchers theorized that emotional well-being was perceived differently depending on situational, sociocultural, temporal, interpersonal, and personal contexts. For instance, the situational context of caregiving included factors directly related to caregiving duties, such as the dependent elder's level of functional and cognitive impairment, the level of care needed for activities of daily living, and the perceived strain and burden of caregiving. Sociocultural context included family history, beliefs of reciprocity, filial obligation, and duty. These researchers conceptualized the temporal context as the timing of events that created secondary stressors for the family caregiver such as concurrent caregiving responsibilities for dependent children and a dependent elder living with dementia. Within the researchers' framework, the interpersonal context referred to the caregiver's relational history with the dependent elder living with dementia and others in their social support network. The family dementia caregiver's interpersonal context might be a mediator or moderator for a family member's receptivity to a change in reality that was integral to becoming a family dementia caregiver. The personal context referred to the family dementia caregivers' personality traits, age, and health status. These researchers found that situational, personal, and interpersonal contexts were predictive of emotional distress in caregiving. The researchers posited that African Americans' social norms, values, beliefs, and social support systems might balance some of the competing caregiving demands, thus explaining the lack of predictive value of the sociocultural and temporal contexts. Aspesoa-Varano, Reinhard, Choula, and Youngs' (2015) suggested that Latino, Native American, and Asian American family caregivers have similar characteristics including perceived family discord as a source of stress and caregiver burden.

In a seminal meta-analysis, Pinquart and Sörensen (2005) investigated "ethnic differences in caregiver background variables, objective stressors, filial obligations[,] beliefs, and psychological and physical health." (p. 90). The results of 116 empirical studies published between 1983 and 2004 were integrated into the meta-analysis. Sixty-three studies compared African American with White caregivers, 22 studies from convention presentations, nine from dissertation research, and two electronic files of raw data. Sources of caregiving stress in minority groups with small effect sizes included functional deficits (43 studies, *n* = 22,605), the severity of cognitive impairment (28 studies, *n* = 10,479), hours of care (21 studies, *n* = 9,655), and years of care (39 studies, *n* = 12,567). Filial obligation beliefs had a medium effect on caregiver stress (10 studies, *n* = 1,967, *p* < .05 with a reported publication bias). Moreover, the meta-analysis showed that ethnic minorities were less likely to be spouses, younger, provided more hours of care per week, and performed more caregiving tasks per week than non-minority caregivers. The analysis found that White family dementia caregivers experienced more perceived burden (55 studies, *n* = 19,568, *p* <.001), while African American family dementia caregivers expressed improved well-being (44 studies, *n* = 11,824, *p* < .05) and found caregiving to be uplifting (20 studies, *n* = 6,315, *p* < .001).

Ivey et al. (2012) conducted a qualitative study using focus groups to examine experiences and concerns among non-Hispanic White and Filipino caregivers of community-dwelling individuals (*n* = 75). The researchers neither specified the number of participants in each group nor explained the unequal representation in groups. Ivey et al.'s (2012) themes included caregivers' described challenges, emotional reactions to caregiving, and coping strategies. The participants expressed feelings of concern about the care recipients wandering, getting lost, and getting hurt. Participants' perceptions of challenges were associated with care recipients' symptoms. The non-Hispanic White group participants expressed feelings of frustration and guilt about their desire to have time away from caregiving. The Filipino participants perceived caregiving as a learning opportunity. All subthemes of coping strategies most commonly described by caregivers were congruent, which included help from friends and family, a respite from caregiving, and seeking information or support. Both non-Hispanic White and Filipino groups expressed limited social interactions due to caregiving responsibilities, while only Filipino participants believed they gained emotional strength from their caregiving experience. Filipino family caregivers were more likely to be an extended family member who was paid for their service. The researchers did not collect those specific data in the demographic survey and did not address the unequal representation of the sample.

Technology for Caregiver Support

An extensive body of evidence spanning thirty years described interventions to improve the health and well-being of family dementia caregivers. However, none of the studies included in this review used virtual reality. Topo (2009) performed a literature review of 46 studies to evaluate the technology used to meet the needs of family dementia caregiver dyads. Some of the technologies included interventions using computer software, internet applications, telephone interaction, and other adaptive support mechanisms intended to ease the burden of caregiving (Godwin, Mills, Anderson, & Kunik, 2013; Topo, 2009). For instance, Mihailidis, Boger, Craig, and Hoey (2008) examined the efficacy of a computerized device (COACH) intended to reduce caregiver burden by aiding care recipients ($n = 6$) with handwashing. COACH was an audio-visual aid that guided an older adult with moderate to severe dementia through handwashing activities. The researchers used a single subject research design with two alternating baselines (COACH not used) and intervention (COACH used) phases. The outcome variables were the number of prompts and necessary interactions with the family caregiver during the handwashing task. Participants performed 11% more handwashing steps independently with 60% fewer interactions with a human caregiver when COACH was used.

In a systematic review to examine the efficacy of technology-driven interventions for caregivers of individuals with dementia, Godwin, Mills, Anderson, and Kunik (2013) reviewed eight studies that met the inclusion and exclusion criteria from an original search of 295 studies. This review included random controlled trials from three more extensive studies

(Bass, McClendon, Breenan, & McCarthy, 1998; Beauchamp, Irvine, Seeley, & Johnson, 2005; Brennan, Moore, & Smyth, 1995; Casper, Calvitti, Brennan, & Overholt, 1995; Eisdorfer, Czaja, Loewenstein, Rubert, Arguelles, & Mitrani, 2003; Finkel, Czaja, Schulz, Martinovich, Harris, & Pezzuto, 2007; Gitlin, Belle, Burgio, Czaja, Mahoney, & Gallagher-Thompson, 2003; Mihailidis, Boger, Craig, & Hoey, 2008). Beauchamp et al. (2005) aimed to evaluate the efficacy of internet caregiver support groups (*n* = 299). They found significant improvement in positive aspects of caregiving, caregiver strain, depression, and anxiety. Brennan, Moore, and Smyth (1995) aimed to provide caregivers with a support network for decision-making confidence, skill, and social support to reduce psychological symptoms of caregiver strain. Conversely, Bass, McClendon, Breenan, and McCarthy (1998) found no reduction in caregiver strain with a similar intervention. Significant improvements were noted in decision-making confidence and skill that correlated with the number of times and amount of time the computer software was used (Brennan, Moore, & Smyth, 1995; Casper, Calvitti, Brennan, & Overholt, 1995). The REACH studies aimed to provide psychosocial support using computer automated interactive voice response (Eisdorfer, Czaja, Loewenstein, Rubert, Arguelles, & Mitrani, 2003; Finkel, Czaja, Schulz, Martinovich, Harris, & Pezzuto, 2007; Gitlin, Belle, Burgio, Czaja, Mahoney, & Gallagher-Thompson, 2003). According to Godwin, Mills, Anderson, and Kunik (2013), the studies in this systematic review had limited generalizability due to measurement inconsistencies and variability in outcomes. Although the systematic review was considered current, the studies reviewed were dated (1995-2007). None of the studies used simulation or virtual reality as interventions (Godwin, Mills, Anderson, & Kunik, 2013).

Vicarious Dementia Simulations

Vicarious experiences are any experience that provides a point of view "as if" it was from a first person's perspective. A vicarious dementia simulation using "virtual reality" can mimic the experience of dementia and offer the family dementia caregiver a first-person perspective of the neurocognitive domain deficits seen with the perceptual-motor function, complex attention, executive function, and short-term memory impairment. A limited number of studies were located due to the scarcity of published research related to dementia simulations. These are described below.

"Through the Dementia Lens"

Wijma, Veerbeek, Prins, Pot, and Willemse (2017) implemented a feasibility study in the Netherlands utilizing a virtual reality simulation designed from a repurposed truck-size intermodal shipping container. Informal caregiver participants (*n* = 35) were recruited through case managers. The intervention consisted of an electronic course and a 13-minute simulation movie played on a virtual reality device from a first-person perspective. The virtual simulation enabled viewers to have a 360 degree perspective of their environment depicting events seen in early dementia. During the activity, the participants experienced everyday bouts of forgetfulness, inability to complete complex tasks, and discomfort in social settings. The electronic-course content consisted of teaching points on common perceptions of dementia, appropriate communication skills, and common feelings in social settings when living with dementia. The primary outcome measures for patient-centeredness measured with the subscale of the Dutch translations of the Approach to Dementia Questionnaire were unchanged (ADQ; α = .83). The patient-centeredness subscale was intended to measure how staff recognizes the individual value of those with dementia as sentient beings.

Willemse et al. (2015) validated the translation of the ADQ instrument using a national cross-sectional survey with paid caregivers in a nursing home population. A statistically significant change with a small to moderate effect size (p = .0006) was found in perspective taking (PT) subscale of the Interpersonal Reactivity Index (IRI; α = .71). The Interpersonal Reactivity Index measured the tendency of those without neurocognitive deficits to adopt the psychological perspective of another individual (Davis, 1980; translated by De Corte et al., 2007; Wijma, Veerbeek, Prins, Pot, & Willemse, 2017). The Dutch version of the IRI showed validity, reliability, and a good model fit for use in the general community (De Corte et al., 2007).

MyShoes **Gaming Goggles**

In the *myShoes* project, researchers conducted a study using a prototype of gaming goggles to simulate an avatar like virtual experience with open-ended scenarios (Stevens, Bluteau, Clouder, Adelfila, & Graham, 2015). The computer-generated dementia immersion experience aimed to promote health care professionals' affective empathy through a vicarious experience of individuals living with dementia. These researchers conducted a nonexperimental study with a sample of 55 student participants from various health and social care degree programs, which included nursing, clinical psychology, and allied health. Forty-three percent of the participants reported components of empathic understanding following the simulation relating, “the theoretical knowledge they had did not enable them to consider how scary, depressing, frustrating or isolating dementia is likely to be.” (p. 20).

Adelfia, Graham, Clouder, Bluteau, and Ball (2016) used the same "*myShoes*" prototype to conduct an exploratory study reporting a mixed methods approach to investigate the use of “*myShoes”* virtual reality in dementia training with health science students and professionals (*n* = 55). It was unclear if this sample used the same participants from the previous study. The aims focused on four major aspects of dementia training: Increasing symptom awareness, supporting an increase in empathy, encouraging participants to reflect on their practice concerning their care, and improving dementia competence. The "*myShoes*" study immersed the participant in a virtual body, which simulated an avatar like virtual experience with open-ended scenarios to allow the participant options like real-world experience. The researchers reported the use of three validated unnamed scales to measure perspective-taking and empathic concern for others. Some of the participants' summative statements were included in the findings. Although the researchers reported the use of a validated scale to measure empathy with a 7.10% increase noted at the post-test, the researchers decided empathy was not a measurable construct during data analysis and made a post hoc change to a compassion self-report "number." An inverse correlation was reported between empathy and compassion.

"A Walk in My Shoes"

Eymard, Crawford, and Keller (2010) conducted a qualitative analysis of 42 senior baccalaureate nursing students' journals following a service-learning project within the context of their curriculum. The students took part in education sessions at area long-term care facilities and hospitals. The service-learning project covered four main topics including body systems, disease processes, stereotypes, and successful aging. The students led their in-service participants through four simulation stations, which included a chronic obstructive pulmonary disease torso simulator, a physical limitations bodysuit, a chronic vision disease simulation using sets of simulation glasses, and models of skin integrity disorders including pressure ulcers and unhealthy foot models. Twenty codes with four themes were revealed: *Nervous/anxious*, *Fun*, *The Role of Educator*, and *Empathy,* which the researchers stated were evident in journal entries but not explicitly reported. Although this qualitative analysis did not involve dementia simulation in the methodology, it did highlight simulation and its effect on nursing students.

The Virtual Dementia Tour®

The Virtual Dementia Tour ® is a tool widely used in community and nursing home training to improve health sciences professionals' and informal caregivers' awareness of dementia (Beville, 2002; Campbell, Warnock-Matheron, and Larche, 2013; Finn, 2017; Gibbons, 2016; McFadden, 2012; Rankin, 2015). No published research investigations were found documenting the results of its use in family dementia caregivers.

In a multicenter study using the Virtual Dementia Tour® (*n* = 146), nurses, aides, social workers, activity directors, administrators, and Directors of Nursing, completed 2.5 of the five assigned household tasks while wearing the tour components (Beville, 2002). Participants' behaviors mirrored those living with dementia. Based on the findings from the pre-post test study results, Beville posited that informal caregivers' expectations might be too high for those living with dementia, thus triggering expressions of frustration, inappropriate behavior, and withdrawal (2002).

The Virtual Dementia Tour® was used in academia to improve empathy in healthcare provider education, specifically in medical education (Donahoe, Moon, & VanCleave, 2014; Stevens, Bluteau, Clouder, Adelfila, & Graham, 2015). Donahoe, Moon, and VanCleave (2014) used the Virtual Dementia Tour® in an undergraduate social work program as a form of experiential learning for students (i.e., learning through reflection following psychomotor learning activities). These researchers reported they chose the Virtual Dementia Tour® as a novel learning activity to build empathy that was not readily accomplished through standard role play or other live actor simulations, as it was designed to replicate the most prevalent symptoms of dementia previously described.

Harrington, Neil, Roberson, and Hardin (2017) conducted a qualitative research study exploring adult-gerontology primary care (AGPCNP) and family nurse practitioner (FNP) students' (*N* = 21) perceptions and understanding of dementia following the Virtual Dementia Tour®. The nurse practitioner students reported they experienced dementia behaviors similar to those witnessed in nursing practice. Several themes were discovered from verbatim transcript analysis. The critical theme *Developing Empathic Perspective* included statements believed to increase the likelihood that health care providers will engage in altruistic helping behaviors, emerged from participants' language. Subthemes were *Mirroring Dementia Behaviors, Provoking Emotions, Wearing Down,* and *Detaching*. The findings supported the ongoing use of dementia simulation in experiential learning for nurse practitioner students. Nursing implications included increasing the nurse practitioner students' alacrity to embed health promotion and disease prevention activities for cognitive impairment and dementia into their routine care practices.

Campbell, Warnock-Matheron, and Larche (2013) conducted a qualitative study with nursing home staff (*N* = 26) five to nine months following their participation in the Virtual Dementia Tour® to determine its long-term impact. The researchers used an interpretative phenomenological method to analyze data. They noted the participants vividly recalled their experiences and the feelings the Virtual Dementia Tour® evoked. The themes that emerged from the data included: *Being more patient*, *adapting communication style to fit residents' needs*, and *approach behaviors from a problem-solving perspective to search for meaning and potential cause*.

Dementia LIVE®

Dementia LIVE® is a dementia simulation program developed in 2009 that provides participants with an immersion experience of cognitive impairment and sensory change similar to the Virtual Dementia Tour® (AGEducate Training Institute, 2018). Sensory deprivation within the simulation environment includes glasses that replicate low vision and tunnel vision, large gloves, and headphones with distracting noises. In addition to the immersion experience, a program of education referred to as empowerment training is included (AGEducate, 2018). The training has been designed for healthcare professionals only and has no supporting published evidence to date (P. Brandon, AGEducate founder, personal communication, July 27, 2018).

Innovative technology using virtual reality and simulation including person-in-context vicarious experiences were emergent in the literature. However, none of these studies explored virtual dementia simulation with family dementia caregivers. Consistent limitations of these studies included expense, portability, and culturally embedded content.

Summary

As the medical complexities of dementia develop, their effects influence one's ethnocultural perceptions of dementia. The literature shows that perceptions of family dementia caregiving are individualized across and within cultural and ethnic groups, which are shared through collective history, language, group-held values, and normative expectations of aging (Dilworth-Anderson, Williams, & Gibson, 1999, 2002; Janevic & Connell, 2001; Pinquart & Sörensen, 2005). Findings from the extant body of literature highlight a thirty-year conundrum on interventions to mutually benefit dementia caregiving dyads. The roles that ethnicity, culture, and minority status play in family dementia caregivers' coping processes are a result of various risks, perceived burden, stress-mediating factors, access to, and utilization of formal and informal services. The heterogeneity, inconsistent results across time, populations, and settings might be due to the propensity to generalize findings from inequivalent comparison groups. Research has not yet yielded effective interventions to improve family dementia caregivers' long-term health and well-being. The use of non-theoretical frameworks and methodological challenges (e.g. nonrandomized control trials, cross-sectional designs, the use of self-report surveys in impoverished populations, and sampling issues) might also explain the heterogeneity seen in research findings (Dilworth-Anderson, Williams, & Gibson, 2002; Godwin, Mills, Anderson, & Kunik, 2013; Pinquart & Sörensen, 2005; Roberts et al., 2003).

Multiple vicarious simulations were found in the literature. Given the limitations of other tools (e.g., expense, portability, culturally appropriate context, and complexity), the Virtual Dementia Tour® provides a culturally neutral, inexpensive, mobile, and low fidelity virtual simulation suitable for this proposed study. Moreover, The Virtual Dementia Tour® has been studied in health science, education, and professions over the past 15 years with nonexperimental research designs. This literature review supports the proposed interpretative phenomenological inquiry of family dementia caregivers' perception of the Virtual Dementia Tour®.

CHAPTER 3: METHODOLOGY

The study was approved by East Carolina University's (ECU) University and Medical Center Institutional Review Board (UMCIRB) on April 19, 2018 (See Appendix A.) Research findings for the use of the Virtual Dementia Tour® and its impact on perceptions of dementia in the lay population are scarce. This interpretative phenomenological study used open semi-structured interviews with ten participants who were recruited from a community event offering the Virtual Dementia Tour®. A modification of Colaizzi's (1978) method for phenomenological analysis guided this inquiry.

Research Questions

1) What is the family dementia caregiver's perception of the Virtual Dementia Tour®?

2) How might the Virtual Dementia Tour® impact the family dementia caregiver's reality of the person living with dementia?

Rationale for Hermeneutic (Interpretative) Phenomenology Study

This phenomenological inquiry intended to capture the true essence of how one experiences the Virtual Dementia Tour® using rich and rigorous language. Phenomenology was well-suited to holistic questions of meaning that manifested from and were central to poorly understood lived experience in a situated context (Creswell & Poth, 2018; LeVasseur, 2003; van Manen, 2016). This study aimed to understand the *meaning* of a phenomenon (e.g., an experience like the Virtual Dementia Tour®), which was consistent with this study's design and research questions (Munhall, 2012; van Manen, 2016). The Virtual Dementia Tour® provided an eight-minute person-in-context situation to understand what family dementia caregivers' consciousness perceived and understood about the person living with dementia (Larkin & Thompson, 2012; van Manen, 2016).

Method

Alzheimer's North Carolina (AlzNC$^{®}$); the Gentle Expert Memorycare (GEM); and the Mid-East Commission, Upper Coastal Plain Council of Governments, Eastern Carolina Council, and Albemarle Commission Area Agencies on Aging partner to provide half-day workshops and full day caregiver conferences. At these events, family dementia caregivers learn coping and communication skills, self-care, and concepts of healthy aging in an attempt to ameliorate the health burdens associated with family dementia caregiving. The researcher had an established relationship with these agencies through prior involvement in programs related to a service grant. These agencies provided letters of support (See Appendix B) where they agreed to provide advanced notice of the study with the event registration materials and place the study flyer (See Appendix C) in the handout packets at the workshops or conferences. Also, they granted permission for the researcher to attend the events and recruit volunteers. The researcher's presence was imperative, as it provided an opportunity to describe the research study using the approved script (See Appendix D), answer questions, screen participants (See Appendix E), and consent those interested in volunteering (See Appendix F.)

Setting and Recruitment Plan

Two caregiver workshop conference dates were chosen for data collection in collaboration with community partners in May and June 2018. The community partners offered the Virtual Dementia Tour$^{®}$ at both events. The participants for this study were recruited from the family dementia caregiver conference offered by the Upper Coastal Plain Council of Governments Area Agency on Aging and AlzNC$^{®}$ on May 23, 2018.

Sampling Plan

Sample sizes for interpretative phenomenological research tend to be small, as the purpose of an in-depth interview study is to understand the experience of those who are interviewed, not to predict outcomes or control the experience (Miller & Salkind, 2002; Sandelowski, 1995, 2001; Seidman, 2013; van Manen, 2016). Based on the nature of the interpretative phenomenological study, saturation and maximum variation were not appropriate measures. The researcher intended to get a homogenous sample of rich lived experiences to allow reflection and interpretation of those experiences (Smith, 2016; van Manen, 2016). Therefore, the convenience sample for this study consisted of ten participants.

Inclusion and Exclusion Criteria

All participants met the following inclusion criteria. The family dementia caregiver:

- Must be a family member who has the primary caregiving responsibility and accountability for an elder living with dementia who is no longer able to function independently.
- Must be over the age of 18.
- Must agree to be interviewed within two weeks following participation in the Virtual Dementia Tour®.

No participants declined or withdrew consent to participate, which was the only exclusion criteria.

Data Collection

After UMCIRB approval, study flyers were forwarded to AlzNC®, Upper Coastal Plain Council of Governments Area Agency on Aging for the May event and the Mid-East Commission Area Agency on Aging for the June event. All registrants for the May conference received the study flyer with their event registration materials. The researcher introduced the study at the beginning of the workshop and situated herself in a quiet but visible conversation area in the corner of the atrium. Conference attendees approached the researcher at their convenience during the day-long conference. Potential participants were screened using the UMCIRB approved electronic survey. The consent was read to those who met the inclusion criteria. Contact information was collected from consented participants and included the participants' phone numbers, email address, interview date, and time within the following two weeks. In-home interviews were offered to every participant. Ten in-depth open semi-structured interviews (See Table 1) ranged from 44-110 minutes in length and were held between May 29, 2018, to June 2, 2018 (See Appendix G). The researcher transcribed the recordings and kept an observation journal describing the textural description of participants that helped the researcher gain insight through writing. The richness of the data collected from these ten participants negated the need for further data. Therefore, the researcher notified the Mid-East Commission Area Agency on Aging event planners that data collection was complete and requested they withhold distribution of the study flyers for the June conference. The researcher attended the June conference as a courtesy.

Interpretative Phenomenological Analysis

A systematic approach is necessary to support rigor in interpretative phenomenological analysis. Diverse analytic approaches to phenomenological analysis range from descriptive (transcendental) to interpretative (hermeneutic) in nature. In the traditional descriptive analysis, one is not concerned with the interpretation of meaning (Farina, 2014; Smith, 2016). Conversely, the interpretative phenomenological analysis involves how an individual understands and interprets experiences through one’s contextual lens and results in multiple realities (Mackey, 2012; Smith, 2016; van Manen, 2016).

Table 1: Open Semi-Structured Interview Questions

Interview Questions
1. Was there a crucial event in your (fill in the blank with relative’s relationship) or time when you knew he or she could no longer live independently without constant supervision?
2. Share with me how you became a family caregiver for your____ (fill in the blank with an appropriate relative).
3. Let’s go back to the Virtual Dementia Tour®. Walk me through your thoughts and feelings as you tried to complete the tasks.
4. What did the Virtual Dementia Tour® mean to you as your (______fill in the blank with the appropriate relative’s) caregiver?
5. How did the Virtual Dementia Tour® impact how you thought about dementia?
6. Is there anything else you would like to share with me about your Virtual Dementia Tour® experience?
Guiding questions were provided to help recall.

Colaizzi (1969) developed a method of phenomenological analysis grounded in Husserl’s transcendental (descriptive) philosophy and philosophical assumptions. By 1978, Colaizzi’s work transitioned to a focus on description, the meaning of the experiences, and thematic analysis, which were congruent with interpretative phenomenological analysis. This approach was widely adopted in phenomenological analyses (Abushaikha & Massah, 2013; Hyun, Kim, Kang, & Nam, 2012; Rae & Rees, 2015). Based on this transition and the prevalent use of this modified approach in qualitative research, it was postulated that descriptive and interpretative phenomenological analytic approaches were not mutually exclusive (Colaizzi, 1978; Hyun, Kim, Kang, & Nam, 2012; Rae & Rees, 2015). A modification of Colaizzi’s (1978) phenomenological analysis incorporating an interpretive approach was appropriate for this study's research design (See Table 2). Colaizzi's (1978) last step to return the interpretation to the participants for validation was not considered appropriate because it might prevent discovery of the true essence of family dementia caregivers' lived experience with the Virtual Dementia Tour®. Instead, participants were offered an opportunity to review their personal transcripts and make comments earlier in the analysis process.

Table 2. Colaizzi's (1978) Modified Method of Phenomenological Analysis

Steps
1. Transcribe all the participants' interviews and descriptions.
2. Provide participants with an opportunity to review their transcripts and make comments or corrections.
3. Extract significant statements that directly relate to the phenomenon by manually reviewing and highlighting key phrases. Any statements in the participants' narratives about the Virtual Dementia Tour® are considered significant. Data statements will be uploaded to NVivo11® qualitative software for data management.
4. Create thematic clusters of meanings from the transcripts.
5. Aggregate formulated meanings into thematic clusters from field notes, reflection journals, and interview transcripts.
6. Organize thematic clusters into themes using a team approach.
7. Describe the essence of the experiential phenomenon as it is revealed through the interpretative analysis and supported by participant statements.

Protection of Human Subjects

UMCIRB approval was a crucial element to ensure the protection of human subjects. The interview process was not intrusive or invasive and carried no more than minimal risk. Trillium, a local government counseling service to those living with dementia and their caregivers and was present at the event. Since there was a week delay between the time participants signed their consents and participated in the interviews, the consents were reviewed with the participants at the time of the interview. Each participant received a copy of their signed consent. Refusal to participate did not affect caregivers' ability to participate in any caregiver programs. All participants were provided with multiple opportunities to ask questions before signing consent forms and before the interviews. All participants were instructed that they may opt out of the study and participation at any time without penalty. A $50 gift card to a familiar store and thank you note were provided at the end of the interviews for compensation of the participants' time, as these individuals needed to take time away from caregiving to allow participation in an uninterrupted interview. No adverse events occurred. Participants were offered an opportunity to review and comment on their personal transcripts; however, all declined.

Data Management

The interview recordings were transcribed into Word® documents and then uploaded into NVivo11®, a qualitative data management software application designed for interpretative qualitative data analysis. The researcher's computer was protected with face recognition software, manual passwords, and pin numbers. Pseudonyms were applied to the transcripts to protect the true identity of the participants. Until transcription was completed, the recordings remained in possession of the principal investigator and were kept in a locked drawer in a locked office at the student's faculty office when not in use. Recordings were deleted after the files were transcribed. All consent forms were handled securely and placed in a locked drawer in the student's faculty locked office that is accessible only to the principal investigator. All transcription records will be kept for three years after the publication of results.

Bias Management

"Self-as-instrument" was used for this study, which requires consideration of the personal ontological, epistemological, and axiological perspectives (Rew, Bechtel, & Sapp, 1993). One's awareness of biases, assumptions, and presuppositions maintains the integrity of the hermeneutic reduction (van Manen, 2016). The researcher has 28 years of experience in the field of gerontology and 13 years of experience as a board-certified adult-gerontology primary care nurse practitioner counseling a multitude of individuals living with dementia and their family caregivers from diagnosis to end of life. The presuppositions included the belief that the positive aspects of family dementia caregiving are not well documented. A second presupposition included the belief that those living with dementia wish to stay in their homes and receive care from family caregivers if possible. Furthermore, the ability to "walk in another's shoes" has the potential to change one's perspective for positive effectual long-term outcomes.

Appropriate boundaries between researcher and clinician roles were critical and maintained through the use of scripts for the introduction and closure. The provision of open-ended questions allowed the participants to share the meaning of their experience in a context-specific manner (i.e., the Virtual Dementia Tour®). Conversational interviewing was the key to building a rapport quickly, so participants felt comfortable enough to share their stories and perceptions. This interview style established authenticity. Intuitiveness in phenomenological research was demonstrated by the ability to synthesize the experience of the participants through reflection and discernment of meanings regarding the "whole." Openly hearing and listening to the information demonstrated sensitivity for the personal nature of participants' experiences. This attribute supported the chosen research design.

Criteria for Evaluation

Trustworthiness

Trustworthiness in interpretive phenomenological research was achieved using several strategies. According to van Manen (2016), “the validity of a phenomenological study has to be sought in the appraisal of the originality of insights and the soundness of the interpretative processes demonstrated in the study” (p. 348). Phenomenological underpinnings guided the inquiry and were reflected in the research design through implementation and analysis, thus providing rigor through epistemological integrity (Koch, 1996; Thorne, 2016; van Manen, 2016). The research and interview questions were epistemologically congruent with the interpretative phenomenological underpinnings. The interpretative strategies and analysis of multiple data sources followed logically from the research questions.

Credibility

Credibility was established by providing believable accounts and analytically logical findings (Koch, 1996; Sandelowski, 1993; Thorne, 2016). Analytic logic was reflected by an explicit decision trail in the research process. Believability was achieved by the provision of detailed and rich descriptions of the participants’ lived experiences, which was supported by multiple data sources. Participants were provided an opportunity to review and comment on their interview transcripts. Contextual awareness was vital to this process and was accomplished by maintaining the participants’ quotations and truth value, which included freedom from bias in the analysis and interpretation of the transcripts (Sandelowski, 1993; Thorne, 2016; van Manen, 2016). The research teams’ interpretations were grounded in rich verbatim accounts, as they revealed a vivid and eidetic picture of the Virtual Dementia Tour® as a lived experience (Ponterotto, 2006; van Manen, 2017).

Triangulation

Triangulation was provided through multiple reviewers' transcripts, field notes, memos, and reflection journals, as well as confirming the findings in multiple modes (manual transcript review, NVivo11®, and Word®).

Confirmability

Multiple reviews and within-subject notations established a confirmable auditable decision trail of the vertical (individual transcripts) and horizontal (across transcripts) analysis discussed under data analysis (Koch, 1996; Selamat, 2008; Thorne, 2016). Concurrent analysis and interpretive consensus by research team members also provided confirmability. The research team reached consensus after a prolonged discussion.

Transferability

This original phenomenological study's findings were not intended to be transferable or generalizable to other contexts, situations, and settings (van Manen, 2016). However, the findings could be used in future research to understand better how cultural and historical contexts shape family dementia caregivers' receptivity to a change in reality.

Summary

This chapter discussed this study's methodology and rationale for the chosen design. Philosophical assumptions and the methods necessary to manage biases were discussed.
An interpretative phenomenology sampling plan, recruitment plan, settings, and ethical considerations to ensure the safety and well-being of participants were provided. Methods of data collection, management, and a detailed explanation of the interpretative data analysis were described. The practice standards to ensure rigor in interpretative phenomenological research were discussed.

CHAPTER 4: ANALYSIS OF FINDINGS

Hermeneutic phenomenology and modification of Colaizzi’s (1978) method of phenomenological analysis guided this inquiry. The gaps in the literature related to family caregivers’ perceptions of the Virtual Dementia Tour® guided the research purpose and questions. The sample size of ten interviews was determined to be sufficient based on the richness of the data collected, as saturation and maximum variation were not appropriate measures. The researcher collected a homogenous sample of rich person-in-context experiences following the Virtual Dementia Tour®, which allowed reflection and interpretation of those experiences (Smith, 2016; van Manen, 2016). The findings included:

Participants’ Demographic Characteristics

All participants were female whose ages ranged from 49 to 81 years. Their care recipients’ ages ranged from 62 to 93 years (See Table3).

Table 3 Care Dyads’ Characteristics (N = 10)

Characteristic	*M*	*SD*
Caregiver Age	63.3	10.3
Care Recipient Age	82.5	8.76

Four of the ten participants were white and married. Six participants were African American, one of whom was single, one was divorced, and four were married (See Table 4). Two participants were responsible for the care for more than one family member. One of these care dyads consisted of the caregiver’s mother and father who lived in the same house, while the other consisted of the caregiver’s husband and mother who lived in different homes.

Table 4 Demographic Characteristics of Participants (N = 10)

Characteristics	*n*	%
Relationship		
Husband	1	10
Mother	4	40
Father	1	10
Sister	1	10
Mother in Law	1	10
Mother and Father	1	10
Husband and Mother	1	10
Ethnicity		
African American	6	60
White	4	40
Marital Status		
Single	1	10
Married	8	80
Divorced	1	10
Years of Care		
One to Three	1	10
Four to Six	4	40
Seven to Nine	2	20
Ten to Twelve	1	10
Thirteen to Fifteen	1	10
More than Fifteen	1	10
Days of Care Per Week		
Less Than One	1	10
Two to Three	2	20
Six to Seven	7	70
Hours of Care Per Day		
Less than Eight	5	50
Eight to Twelve	2	20
Twenty-one to Twenty-four	3	30
Number of Times in VDT®		
First Time	5	50
Second Time	5	50

The number of years of caregiving varied with the highest frequencies of four to six years (*n* = 4) and seven to nine years (*n* = 2), followed by one to three years (*n* = 1), 10-12 years (*n* = 1), 13-15 (*n* = 1), and more than 15 years (*n* = 1). Four African American caregivers reported caregiving responsibilities six to seven days a week, while three White caregivers reported the same. Of the seven who reported care responsibilities six to seven days a week, three caregivers reported caregiving responsibilities 21-24 hours a day, two stated they provided 8-12 hours, and two conveyed responsibilities requiring less than eight hours of caregiving responsibilities per day on the days caregiving duties were required. This Virtual Dementia Tour® was the second experience for five participants.

Interview Process

Seven participants chose to be interviewed at area assisted living facilities, while the remaining three participants requested the researcher interview them in their homes. The libraries at the assisted living facilities were quiet and private rooms that were available to the community members when facility activities were not scheduled. The participants signed their consents at the time of screening. The UMCIRB approved introductory and closure scripts were used for all interviews. The open semi-structured interviews were provided in a conversational style with variable lengths based on the participants' responses and willingness to share their stories. Baseline interview questions provided a uniform guide for the interviewer (See Appendix G). Guiding questions were provided to trigger recall of the Virtual Dementia Tour® experience and to allow participants the opportunity to expound on their discoveries. As a conversation opener, the participants described their family dementia caregiving journey, which transitioned smoothly into the interview content. The interviews were recorded with a digital recorder for transcription later. Brief notes were taken during the interview to document inflection, facial expressions, and gestures. More complete observational notes were made following the interview to ensure data accuracy for the interpretative analysis. Following the closing script, the participants were given a copy of their signed consent, a thank you note, and $50 gift card to a familiar store in compensation for their time.

Analytic Process

A modification of Colaizzi's (1978) method of phenomenological analysis guided this inquiry. The modified steps were as follows:

Step one: The researcher completed a verbatim transcription of all interview recordings within one week to ensure data integrity. The electronic transcripts were verified for accuracy by repetitive review of the recordings and transcripts. The use of self-transcription supported data integrity. Interview recordings were deleted after the transcript content was verified for accuracy. Original names were then replaced with pseudonyms in the transcript files and analysis documents.

Step two: Each participant was asked if they wished to review and comment on their transcripts; however, all declined.

Step three: Each transcript was repeatedly read with notations and memos added to each document. Salient and poignant quotations and phrases that directly related to the Virtual Dementia Tour ® were highlighted. Repetitious transcript reviews kept the researcher close to the data. Case summaries described the nuances of participants' relationships with their family member living with dementia. Colored flags were used to mark transcripts and other documents with similar quotations. The transcripts were uploaded to NVivo11® for data management. In this step, significant statements about the Virtual Dementia Tour® were extracted and organized.

Step four: The data analysis team consisted of two veteran phenomenological researchers and this researcher, all of whom independently analyzed the transcripts and formulated meanings. The process of identifying collective meanings was repeated and compared to the results in the first stage. To increase triangulation, the researcher combined all transcripts into one Word® document to replicate the process of text searches used for NVivo11®. The NVivo11® files were forwarded to the research team after preliminary thematic clusters were formulated in NVivo11®.

Step five: Formulated aggregate meanings from field notes, reflection journals, and interview transcripts were identified.

Step six: The data analysis team discussed their findings and identified thematic clusters of meanings from the transcripts and files. The research team organized the thematic clusters into themes and developed thematic definitions. The analysis resulted in one over-arching theme and four subthemes.

Step seven: The essence of the Virtual Dementia Tour® for these participants was uncovered through the interpretative analysis and supported by participants' statements.

Over-arching Theme

Based on participants' statements, the over-arching theme, *It Changed Me,* was uncovered. The participants shared in great detail how valuable the Virtual Dementia Tour® was to their roles and perceptions as a family dementia caregiver. *It Changed Me* emerged from the data as the culmination of the participants' vicarious experiences and empathic introspection, which led to a change in reality for most participants (See Figure 2). Participants' statements described a life-changing process that had a deeply felt and personal impact. The participants' statements supported the introspective process of understanding, interpreting, and responding to their vicarious dementia experience. Several subthemes emerged, which supported the over-arching theme.

Subthemes

The participants' statements described their experience from the time they entered the "as if" experience until the interviews. Four subthemes were uncovered by participants' statements: (1) *Befuddled and Bewildered;* (2) *I Just Didn't Know*; (3) *Eye Opener*; and (4) *Doing Differently*.

Subtheme one: Befuddled and bewildered. This theme described the participants' initial reactions to the Virtual Dementia Tour®. *Befuddled and Bewildered* was defined as the feeling of aggravation, frustration, confusion, and stress voiced by participants in the Virtual Dementia Tour®. Participants found their experiences challenged their preconceived thoughts about the behavior they witnessed with their family members living with dementia. Sally shared, "I could not believe it. I could not believe it. It just got me all befuddled and everything. It just befuddled me that this is actually what happens." Martha expressed the feeling of being bewildered:

> I just stood there. I saw other people doing different things. Nobody told me what to expect. I saw stuff on the table. I thought am I supposed to put on these clothes? There was no instruction as to what to expect. That is why I was bewildered."

Nancy also voiced feeling bewildered and provided a vivid and eidetic description of her Virtual Dementia Tour® experience:

> The most bewildering thing about the whole situation was when I got the glasses, the headset and gloves, and everything when she was explaining to me what I was supposed to do. I really couldn't hear what she was saying because of all the background noises.

> When I got in, the last thing I heard her say was put the batteries in the flashlight, and that was ALL I heard through the whole direction. Then I looked around and saw a table full of stuff and thought, 'what in the world am I supposed to do?' Then someone pointed me to a sign on the wall. I went over to the paper, and I couldn't read a thing on it. I was so bewildered; it was like when you don't know what to do, don't do anything. I just stood there. I thought if I stood here long enough I would pick up on something. But I never did get it.

Cathy shared that the chaos and noise she heard through the earphones created a sense of confusion she found bewildering. Amanda's Virtual Dementia Tour ® experience exemplified common dementia behavior of feeling befuddled by clutter. She recognized during her Virtual Dementia Tour ® experience that she was not able to cope with the intentional distractors:

> I knew I was supposed to do something with the clothes, but they were all bunched together, so I said I am not going to deal with that. I am going to move over here to this table it was not as much clutter. I remembered something about the clock, but I couldn't remember what--so I put that back down [pause]. The simplest projects [pause] pile of clothes on that table, I will come back to that. That was the first thing I thought about. It was too much; I will come back to that.

The theme *Befuddled and Bewildered* captured the participants' feelings and thoughts as they attempted to sort through the intentional distractors to complete five ordinary tasks during their Virtual Dementia Tour® experience.

Subtheme two: I just didn't know. *I Just Didn't Know* described the participants' ability to understand their family members' experience, behavior, perception, and feelings following the Virtual Dementia Tour ®. Several participants voiced they did not realize dementia affected multiple body systems. For example, Betty shared that she did not realize her husband's dementia affected him physically as well as mentally. She stated, "I didn't understand why the need of it was. Honestly, I am so arrogant; I thought it was a mental issue and not a perception issue. I am not; I don't know how to explain it." When asked if she was referring to dementia, she responded:

> Right. When I got home and watched him ever so closely, just more closely, his hand doesn't open up. I don't know when that happened. I really don't. I did not notice it until after the tour. When he goes to hold a glass, his hand opens up like that [partially open], and he uses his other hand to push the cup into his palm. I had never paid attention to it before [pause.] He squeezes it with both hands until he gets it in his hand until he grasps it [pause.] I never thought about it being a physical thing, always just thought it was a mental thing. I just did not realize, I thought dementia was just a mental issue. I didn't realize his diagnosis of Alzheimer's affects him physically."

Diane shared similar feelings:

> I had no clue. My gosh! The 'Doctor Magoo' glasses. I could not half see. I could not hear….I just wanted to see and feel what she is feeling and what she is seeing so I can get a better idea so I can work with her better, I can understand her better, I can be more patient cause I just didn't know.

Some participants shared they did not know what living with dementia felt like until they experienced feeling perturbed and flustered by perceptual deficits simulated in the Virtual Dementia Tour $^{®}$. Many who live with dementia might stand in the middle of a room or ask repetitive questions. Nancy said her inability to hear the instructions immobilized her. She shared that she felt flustered and decided to stand still. Pat explained how irritated she felt by not hearing the instructions due to the noise and the fear of not knowing what she was asked to do. Amanda shared that she did not previously understand how her mother experienced complicated situations, “The more complicated something was, the more frustrated I got because I didn’t know how to get myself back to feeling normal.” Betty mirrored Amanda’s feelings and understanding of her husband’s experience when she expressed how unnerved she was by her inability to concentrate and thoughts that she should mirror others’ actions. She related that she now understood why her husband followed members of a hunt club who leased their property because he may have felt the same way.

The theme *I Just Didn’t Know* described the participants’ new found understanding of their family members’ daily challenges. Upon reflection, some participants realized that their family members’ lived experience with dementia was different than they previously believed.

Subtheme three: Eye opener. *Eye Opener* described the revelation and reaction to the Virtual Dementia Tour® as a profound experience whereby the participants emotionally and cognitively processed and interpreted their vicarious experience. Participants’ interpretations of their Virtual Dementia Tour® experience were related to the discovery that the lived experience of dementia was not as they expected. For instance, Sally imparted, “It hits home. Can I do something to make it easier for him? Is there anything I can do to help it be easier for him?” Amanda realized dementia affects more than one’s mind. She shared, “It opened my eyes that dementia is not just a disease of the mind, it is a disease of the mind, the body, and the heart and soul of an individual.” Bonny also felt the Virtual Dementia Tour ® experience was eye-opening. She shared, “It [the Virtual Dementia Tour ®] is definitely an eye-opener!” After Amanda had the opportunity to process her Virtual Dementia Tour® experience, she realized through the interpretation of her experience that the magnitude of neurocognitive degeneration associated with dementia encompassed all aspects of one’s being. She related:

> It [the Virtual Dementia Tour®] opened up my eyes to the other things the mind body and soul things. I was not going to remember the instructions and I get in, and I heard part of it but did not know what to do. It was the process that was broken. You can hear, but if you can’t process it, you can’t get from here to here. For me, the Virtual Dementia Tour® taught me the processing of information and communication is not getting there. It is not even about remembering it; it is about absorbing it. It can’t come out the same way.

The Virtual Dementia Tour® provided an enlightening experience for other participants as well. JoAnn shared her epiphany following the Virtual Dementia Tour®, “A wake-up! It.is.a.wake.up.call that what you think that your mother is thinking and doing [pause] is really not too complicated. When you take the virtual tour it makes sense; it makes sense out of everything.” Martha said, “I think it [the Virtual Dementia Tour®] is an eye-opener, just to realize it is not that they can, it is just a sickness. It would help the family a lot.” Nancy discovered her mother’s behavior was not what it seemed. She related:

> I was thinking that a lot of the stuff we were taking as a personality *shift*, it really was the dementia setting in because we were thinking sometimes she was just being evil, you know, mean. She treats different siblings a different way, and that was not like Mama. It was like Mama is just being mean, but now I understand it is the disease.

Pat’s reality changed as a result of the Virtual Dementia Tour®. She saw this vicarious experience as a source of power through the acquisition of knowledge. She related wisdom that helping others involves helping oneself and provided an example of the potential power of the vicarious dementia experience:

> I [pause] the virtual tour really gave me the ability to understand. [Pause] What she is going through as closely as I can to what she is going through, which opens up understanding and knowledge [pause] putting yourself outside of who you are and getting inside somebody else's feet as much as you can of what they are going through, which opens up your sense of empathy, sympathy, the ability to understand so you can do things differently. When you take a step in their shoes, it sits you back, and you quiet yourself like I did before the tour, it was like Wow! It is deep and strong.

Conversely, one participant expressed that the Virtual Dementia Tour® provided no new insight but reinforced what she already knew. Instead of relating to her sister's lived experience, Martha referred to others when asked about her perceived value of the Virtual Dementia Tour® in understanding her sister's lived experience. She shared:

> Definitely. Definitely. I think people that I know that have loved ones that are going through, I would say 99% of them don't have a clue what their loved ones are experiencing; they think they are just mean, and they CAN do better. I think it is an eye-opener, just to realize it is not that they can, it is just a sickness. It would help the family a lot. One of the thing [*sic*] I am trying to tell my coworker is get involved with the caregiver program, so you experience and talk to other people that are going through.

Martha shared that she attended the conference and Virtual Dementia Tour® for the continuing education credits. When asked if she experienced anything that applied to her specific situation, she could not foresee her future based on the situations previously encountered through her employment, "Taking calls from social services that there is nothing they can do. By not walking away, you know, I don't see any answers to her situation for where she is right now." When asked if she felt like the Virtual Dementia Tour® helped her understand her sister better, she responded, “No, I think I was already there [chuckling]. Between my Mama and her and the people I work with and being involved so long now. It just reinforced it.” Before leaving, Martha stated, “You know, I didn’t buy into this [family dementia caregiving]. I have my own life.”

Eye Opener captured many of the participants’ epiphanies that their perception of their loved ones’ lived experiences with dementia were not as they expected. This subtheme served as a “call to action” for several family dementia caregivers.

Subtheme four: Doing differently. The theme *Doing Differently* was best defined by changes participants made in their caregiving practices because of the Virtual Dementia Tour®. *Doing Differently* described participants’ responsiveness to their Virtual Dementia Tour® experience. The concepts described in *Doing Differently* included *de-cluttering*, *calmness*, and *patience*.

De-cluttering referred to changes made in their family member’s living environment or approach to care in response to participants’ Virtual Dementia Tour® experiences. For instance, as a result of her experience with embedded distractors during the Virtual Dementia Tour®, Betty stated:

> …it [the Virtual Dementia Tour®] has made me look at my house. I am not nasty, but just the everyday clutter are in his way. They could be in his way. I tried to remove; I just started trying to get rid of extras that don’t need to be. Magazines, trinkets, just “things” that don’t need to be…. It showed me why I can’t tell him two things. Why I have to say go to the pharmacy and call me when you get there. Like I said it let me experience things the way he experiences them.

Amanda reiterated Betty's responsiveness to the Virtual Dementia Tour$^{®}$ distractors:

> We cleaned out a lot of clutter in her home. A lot of things she didn't need. There was one person in her apartment. She would take down every plate, every cup, every spoon, and every fork and have it piled up in the…use it and pile it up in the kitchen. When she got that clutter, Mom you need to wash your dishes and keep your kitchen clean because they have inspections in the apartments. So eliminating the clutter was vital to making sure she was taken care of. We got her using paper plates and paper cups so she could throw away and it won't be in the way.

Conversely, Martha's experience with *Doing Differently* was not well received. Martha said when she attempted to de-clutter her sister's kitchen:

> She was very happy at first. She likes to save all the containers and stuff. When I got ready to take them outside, she couldn't take it anymore. I mean I had to literally wrestle that bag of garbage out of her hands [chuckles]. She was going to go back through it and keep a lot of stuff. I had to force it from her. She got so upset.

Several participants decided *Doing Differently* meant changing their approach to care by practicing calmness. The concept *calmness* referred to participants' emotional responses when communicating with their family member living with dementia. From her experience, Diane found the stress of the day was lessened when she practiced doing dressing time in the state of calmness. She shared:

> When I do her clothes and lay them out just like she is going to put them on (in order). I will sit on the bed and let her do it. If I see she is getting a little confused, I can guide her…no no, start right here just like that, front, step in. Next thing the camisole. Less

> stress on her. That was the whole idea; the less stretched she is, the less stressed we are. It is calm and peaceful.

Pat related that, following her experience in the Virtual Dementia Tour®, she had a better understanding that she needed to relax so her voice tone would have a calming effect on her mother. Nancy shared that *Doing Differently* meant changing her expectations about how her husband placed linens in the closet, which had a calming effect on him. She explained, "he is a lot calmer, and he doesn't think I am picking on him." Diane shared that *Doing Differently* during bath time helped the stress of care. She stated:

> I have to do things a little differently….Now, I will stand at the door or sit on the commode while she washes. She is at the stage that with her bodily functions that she might not realize if she is wiping herself good. For me, I have calmed down and tell myself it is not that serious….It just helped me to [pause] calm down.

The concept *patience* referred to participants' *Doing Differently* in their communication with their family member living with dementia. Several participants reflected they made changes in their approach to care as a response to the Virtual Dementia Tour®. When asked if she made any changes in how she provided care to her mother as a result of her experience in the Virtual Dementia Tour®, JoAnn responded:

> Patience. Then you understand why they are doing what they are doing and you are doing what you are doing. What you are saying, you're coming across short-tempered. [pause] It is such simple things to transition. Like before I go into her house, I say OK, you are here. Now is when you turn on your patience. This is your Mom.

Cathy shared that she made similar changes, "To understand no matter what the situation is, you still have to have a kind heart, a loving heart, and patience most of all…."

One who lives with dementia requires more time to process and articulate thoughts. Cathy shared that she was *Doing Differently* by giving her mother time to articulate her thoughts, "…it made me be patient enough to wait. I used to try to finish her sentences for her because I kind of knew what she was saying." Sally echoed the others' responses by sharing that her responsiveness required an attitude of patience, "If you don't have patience, learn patience because it does not help them to see you get upset. It does not help."

One participant's statements provide a deeper aspect of *Doing Differently*. Betty shared a story about how she provided her husband one task for the day to keep him occupied while she was away from home. He was to take clothes from the washer, place them in the dryer, and place them on the bed when they were dry. Her husband followed all her instructions except he forgot to turn on the dryer. After some time had passed, he removed the wet clothes and placed them on the bed. The insight she gained through her experience in the Virtual Dementia Tour® profoundly changed her reaction to his behavior. When asked if this experience reduced her stress, she responded:

> It [the Virtual Dementia Tour®] has lessened my aggravation with him so if that means less stress then yes. The stress is still there knowing that when I get home, I am just as apt to have wet clothes on the bed than dry clothes. It has at least let me see what "his food tastes like" [pause] And it changed from sympathy because being sympathetic with him allowed me to be aggravated and frustrated that 'You should do better.' It changed it to empathy that I realized that you can't, so let's work around so that you can.

The concepts *decluttering*, *calmness*, and *patience* illustrated the subtheme *Doing Differently*. Many facets of the participants' lives changed in response to their vicarious experience in the Virtual Dementia Tour®. Based on the participants' language, *Doing*

Differently described how some participants changed the details of care provision by simplifying tasks, while others changed their communication style and response to their family member living with dementia to make their lives as comfortable as possible.

Summary

The Virtual Dementia Tour's® value as an experiential phenomenon for these family dementia caregivers was uncovered through phenomenological interpretative analysis of the participants' responses. This chapter included a description of the participants and the findings of the interpretative phenomenological analysis. Ten participants were interviewed in conversational style open semi-structured interviews. The research team used a modification of Colaizzi's (1978) method of phenomenological analysis to interpret the participants' language. One over-arching theme, *It Changed Me,* and four subthemes emerged from the participants' quotations. The subthemes included *Befuddled and Bewildered*; *I Just Didn't Know, Eye Opener*, and *Doing Differently*. Subthemes within *Doing Differently* demonstrated responsiveness through changes participants made in their approach to care and caring. Some participants decluttered, others changed the way they performed a daily event such as dressing, while others developed a state of calmness and an attitude of patience.

The first research question, "What is the family dementia caregiver's perception of the Virtual Dementia Tour®?" met the study's purpose, which was reflected in all subthemes. The community-based Virtual Dementia Tour® provided a person-in-context situation consistent with this study's design and research questions (Larkin & Thompson, 2012; Munhall, 2012; van Manen, 2016). The second research question explored the impact of the Virtual Dementia Tour® on the participants' reality of their family member living with dementia. Based on their responses, the Virtual Dementia Tour® had a powerful impact on some participants, which supported the over-arching theme *It Changed Me* and the subtheme *Doing Differently*.

Interviews were intentionally delayed one week following the event to allow participants time to reflect on and process their vicarious experience. The research team did not consider excluding those who previously experienced the Virtual Dementia Tour®. Prior involvement in the Virtual Dementia Tour® ranged from three months to three years. All participants who experienced the Virtual Dementia Tour® the second time shared that each experience was unique and valuable because their lived experience changed with the progression of their loved one's dementia. The research team was intrigued that several family dementia caregivers made changes in their care practices within one week after the Virtual Dementia Tour®.

CHAPTER 5: DISCUSSION

The purpose of this hermeneutic phenomenological study was to discover family dementia caregivers' perceptions of the Virtual Dementia Tour®. Based on the participants' language, the Virtual Dementia Tour® had a profound impact on their reality of living with dementia. Most participants expressed that their primary goal as family dementia caregiver was to understand their family member's lived experience and improve their quality of life (to make things easier for them.)

In this study, the Virtual Dementia Tour® replicated six of the seven most prevalent symptoms of dementia: Agnosia (failure of recognition through the senses), aphasia (loss of language ability), apraxia (loss of coordination), altered perception (loss of depth perception), amnesia (loss of short-term memory), apathy (difficulty initiating activities) and attentional deficits (Alzheimer's Society, 2017). This experience provided a person-in-context perspective of dementia, thus allowing a family dementia caregiver to experience the neurocognitive deficits of progressing dementia that would otherwise be impossible (Beville, 2002; Hojat, 2016). This study uncovered how family dementia caregivers perceived the debilitating physical and mental effects of dementia simulated in the Virtual Dementia Tour® experience. Some were not aware of their unrealistic expectations for their family members. Adjustment in expectations had the potential to reduce the relational tension as evidenced by several participants' language.

Comparison of Findings to Existing Research

No research studies were found in the literature search describing the use of the Virtual Dementia Tour® in the family dementia caregiver population. However, cultural and historical contexts were apparent and supported by the body of research on family dementia caregivers (Connell & Gibson, 1997; Dilworth-Anderson, Williams, & Cooper, 1999; Roberts et al., 2003).

For instance, filial piety was evident among the majority of participants whereby family dementia caregivers provided care based on respect and love for their elders (Aspesoa-Varano, Tang-Feldman, Reinhard, Choula, & Young, 2015; Connell & Gibson, 1997; Dilworth-Anderson, Williams, & Gibson, 2002). Conversely, some participants voiced caregiving responsibilities based on duty and familial expectations due to birth order and geographic distance from their family member living with dementia. Most often, these family dementia caregivers were the oldest sibling, the oldest female, or the closest geographically (Powers and Whitlatch, 2016).

Contradictory to the literature, there were no apparent ethnic differences about the method or manner in which these participants acquired family dementia caregiving responsibilities (Connell & Gibson, 1997; Dilworth-Anderson, Williams, & Gibson, 2002). Although the literature referenced cultural contexts including geographic locale, participants who provided care for a family member who had lived on their private farms for the majority of their lives saw no risk of their family member living with dementia getting lost or wandering because they believed one could not get lost in familiar territory.

Two questions guided this research. Each question and the results that correspond to the literature were as follows:

Research Question One

What is the family dementia caregiver's perception of the Virtual Dementia Tour®?

The Virtual Dementia Tour® has been used in education, healthcare professions, and communities in which outcome variables were measured by summative answers to questions. Findings from these studies included improved empathy, empathic understanding, awareness of, and sensitization to those living with dementia (Beville, 2002; Donahoe, Moon, & VanCleave, 2014; Stevens, Bluteau, Clouder, Adelfila, & Graham, 2015; Werner, Powell, & Clark, 2014). The themes uncovered using this question included:

Subtheme one: Befuddled and bewildered. Within the context of the current study, this theme's formulated meaning was defined as the feeling of aggravation, frustration, and confusion voiced by participants in the Virtual Dementia Tour®. Provocation of emotional responses was a common finding across all published results of the Virtual Dementia Tour® experience and were consistent with the findings of this study (Beville, 2002; Donahoe, Moon, & VanCleave, 2014; Finn, 2017; Gibbons, 2016; Harrington, Neil, Roberson, & Hardin, 2017; McFadden, 2012; Stevens, Bluteau, Clouder, Adelfila, & Graham, 2015; Werner, Powell, & Clark, 2014). The participants voiced many instances of aggravation, frustration, and confusion as they navigated the Virtual Dementia Tour®. Several participants mentioned they had observed their personal behaviors in similar situations with their family members who live with dementia, which changed how they viewed and cared for their loved one.

In their qualitative study, Harrington, Neil, Roberson, and Hardin (2017) found that participants ($N = 21$) verbalized some level of disorientation consistent with the exhibited behaviors of those living with dementia (e.g., wandering, mirroring others, or asking repetitive questions). Harrington, Neil, Roberson, and Hardin's (2017) themes *Mirroring Dementia Behaviors* and *Provoking Emotions* were consistent with wandering, apathy, and giving up on tasks due to frustration or perceived inability to complete the tasks due to lack of recall and were consistent with the participants' statements in the current study. For instance, a participant talked about how complicated things became while taking the tour and subsequently led to intensifying frustration until she finally moved on to a simpler task. Another participant mirrored these feelings of frustration because she knew she could do the tasks but could not concentrate to complete them.

In Harrington, Neil, Roberson and Hardin's (2017) study, one participant's response echoed typical behaviors seen in those living with dementia in her account of amnesia, apathy, and attention deficits. As she went through the Virtual Dementia Tour®, she became confused about which way to go and how to do the assigned tasks. The participant gave up and threw the items down. The participants in the current study expressed similar feelings through their inaction (standing still), tactile perception deficits, inability to perform multiple step tasks, and amnesia (forgetting the assigned tasks.) The subthemes (*Bewildered and Befuddled, I Just Didn't Know, Eye Opener, and Doing Differently*) supported Agosta's (2014) hermeneutic circle of empathic introspection that described the wholeness of some "thing" in relation to each component within the circle.

Components of a hermeneutic circle of empathic introspection include empathic understanding, empathic interpretation, and empathic responsiveness. The wholeness of empathic introspection is not possible without all these components. Reference to any one component is incomplete without considering the circle's wholeness, similar to the movement of a clock. Each component can work independently, but unless they are synchronized as a whole, the clock does not function. When the clocks' movements are synchronized, there is a seamless and simultaneous result. Similarly, when participants simultaneously and intuitively processed their vicarious dementia experience to empathically understand, interpret, and respond to their experience, they could experience a changed reality.

Subtheme two: I just didn't know. *I Just Didn't Know* described participants' ability to empathically understand their family members' experience, behavior, perception, and feelings following the Virtual Dementia Tour ®. Empathic understanding, the first component of empathic introspection, is thought by some to have a therapeutic effect by facilitating the sharing and cleansing of conflicting emotions necessary for one to gain insight (Agosta, 2014; Berger, 1984).

Most participants better understood the difference between their previously perceived impression of dementia and their family members' lived experience with dementia following the Virtual Dementia Tour®. A common realization involved recognition of the physical and mental changes seen with progressing dementia. For example, two participants shared that they did not realize their family members' dementia caused physical as well as mental deficits. Multiple participants' language in the theme *I Just Didn't Know* were consistent with Harrington, Neil, Roberson, and Hardin's (2017) theme *Developing Empathic Perspective* in which one nurse practitioner student shared that one could read about dementia and study it without empathically understanding the experience. She recognized that dementia affected every part of the body and became cognizant of the need for awareness of their experience.

Research Question Two

How might the Virtual Dementia Tour® impact the family dementia caregiver's reality of the person living with dementia?

This question addressed the impact the Virtual Dementia Tour® had on participants' perceived reality of their family member living with dementia. This question resulted in the culminating over-arching theme that led to a changed reality for most participants, The over-arching theme was supported by two subthemes that reflected the participants' empathic introspection, approach to care, and caring.

Over-arching theme: It changed me. *It Changed Me* described the profound impact the Virtual Dementia Tour® had on caregivers' reality of the person living with dementia and represented new knowledge in our understanding and family dementia caregivers' lived experience. This theme reflected the culmination of participants' internal emotional and cognitive processes after their Virtual Dementia Tour®. These processes involved empathic understanding, empathic responsiveness, and empathic interpretation with the possibility of a changed reality as the outcome. No previous research with healthcare professionals or students captured the Virtual Dementia Tour's® profound impact on family dementia caregivers' reality as articulated by these participants.

Several participants uncovered insights that supported empathic introspection. Upon reflection after the Virtual Dementia Tour®, one participant shared a particularly profound revelation that her feelings changed from sympathy for her husband whereby she was frustrated and aggravated by his behavior to empathy whereby she realized the reality of his lived experience and explored ways to improve his situation. Another participant discovered that, as a result of the Virtual Dementia Tour's® deep impact, her "as if" experience provided the ability to open her sense of empathy. The subthemes *Eye Opener* and *Doing Differently* supported this over-arching theme.

Subtheme three: Eye opener. *Eye Opener* was consistent with empathic interpretation, the second component of empathic introspection according to Agosta (2014). Empathic interpretation referred to the revelation and reaction to the Virtual Dementia Tour® as a profound experience "as if" one was another. Participants' reactions to the Virtual Dementia Tour® described their discovery that the lived experience of dementia was not as they expected. One person realized the profound effects when she realized it was not just a disease of the mind, but of the body, heart, and soul of the person. She believed it would be difficult to explain "how the disease robs them" without a vicarious dementia experience. Likewise, congruences between *Eye*

Opener and Harrington, Neil, Roberson, and Hardin's (2017 theme *Developing Empathic Perspective* were noted. One participant in Harrington, Neil, Roberson, and Hardin (2017) expressed an empathic understanding of those who live with dementia and stated she experienced a tiny glimpse of what it felt like to live in a constant state of confusion.

Subtheme four: Doing differently. This subtheme was best defined by changes participants made in their caregiving practices based on their experience in the Virtual Dementia Tour® and described the empathic introspections' third component, empathic responsiveness. Concepts within this subtheme included *de-cluttering*, *calmness*, and *patience*. When compared with Harrington, Neil, Roberson, and Hardin's (2017) study, the differences and similarities between study samples became more evident in this subtheme. Harrington, Neil, Roberson, and Hardin (2017) found nurse practitioner students felt that the patience required to provide nursing care for someone living with dementia was daunting. Their participants' statements in the theme *Wearing Down* were congruent with this study's subtheme *Doing Differently*. One nurse practitioner student who worked in intensive care expressed how the Virtual Dementia Tour® provided a different perspective that helped her maintain an attitude of patience with those who are cognitively impaired (Harrington, Neil, Roberson, and Hardin, 2017).

Campbell, Warnock-Matheron, and Larche (2013) conducted an interpretative phenomenological study to determine if nursing home staff retained their impressions from the Virtual Dementia Tour® five to nine months after the staffs' virtual experiences (N = 26). Campbell, Warnock-Matheron, and Larches' (2013) themes were congruent with this study's subtheme *Doing Differently*. The themes that emerged from their data included: *Being More Patient*; *Adapting Communication Style to Fit Residents' Needs*; and *Approach Behaviors from a Problem-Solving Perspective.*

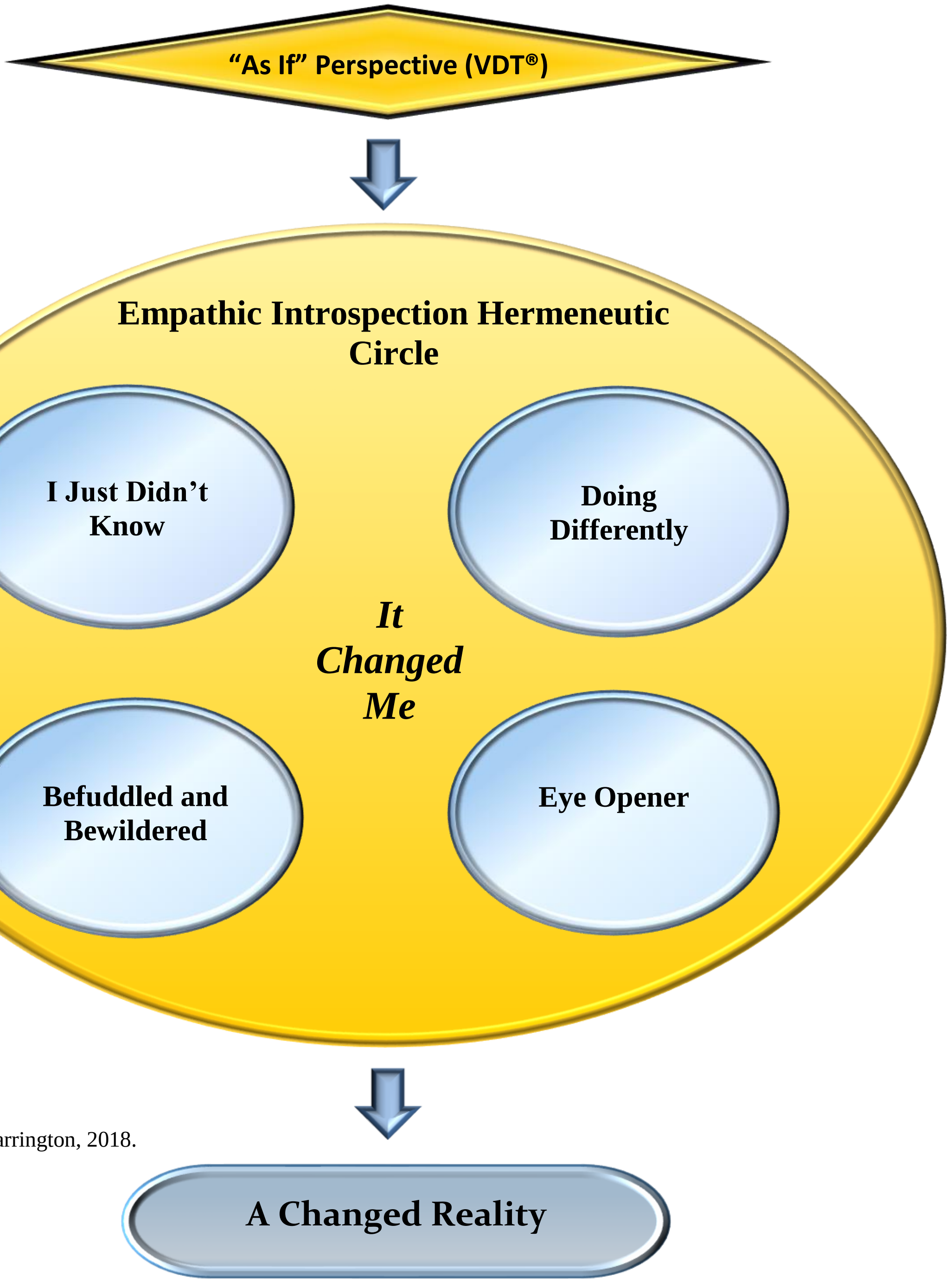
Theoretical Implications

The Virtual Dementia Tour$^{®}$ provides an “as if” vicarious dementia experience for family dementia caregivers not otherwise possible without having the disease (Agosta, 2014). The resulting family dementia caregiver empathic introspection model (See Figure 2) describes the processes beginning in the “as if” experience and the following emotional and cognitive process of empathic introspection conceptualized by a hermeneutic circle. The gold hermeneutic circle represents the over-arching theme *It Changed Me* and Agosta’s (2014) empathic constructs for empathic introspection (empathic understanding, empathic interpretations, and empathic responsiveness). The hermeneutic circle depicts the wholeness of the Virtual Dementia Tour$^{®}$ experience in relation to each component within the circle. Reference to any one subtheme within the circle is incomplete without considering the circle’s wholeness, the overarching theme *It Changed Me*, and the empathic introspection constructs. The blue shapes inside the hermeneutic circle represent the emergent subthemes and explain the participants’ concurrent emotional and cognitive processes toward empathic introspection. The way the family dementia caregiver empathically understood, interpreted, and responded to their "as if" experience determined their perspective, perception, and outcomes following the experience.

One participant in this sample provided insight into a counter experience that was incongruent with the other participants and provided theoretical support for the importance of empathic receptivity. This participant was her sister’s family dementia caregiver who attended the Virtual Dementia Tour$^{®}$ for continuing education and repeatedly referenced her relationships with colleagues and senior residents at her place of employment. When asked if her Virtual Dementia Tour$^{®}$ experience provided an understanding of her sister’s experience with dementia, she responded that she already understood. As the interview ended, she shared, “You know; I did not buy into this [family dementia caregiving], I have my own life.” This statement and her rationale for participating in the Virtual Dementia Tour® support a lack of empathic receptivity necessary to become open to possibilities. Ultimately, this participant did not express a change in reality or an empathic understanding of her sisters’ lived experience with dementia. Upon reflection, if one does not have empathic receptivity (an a priori assumption) before an “as if” experience, it is less likely that individual would be open to empathic introspection within and following the experience, which is consistent with the theoretical underpinnings of this study.

Based on the participants’ poignant language, the over-arching theme *It Changed Me* represented a pinnacle of the participants’ experiences, which led to the outcome, a changed reality. The participants’ statements described core shaking revelations and insight that provoked strong emotions and changes in their perception of dementia as well as their perception of their family members’ lived experience with dementia.

Figure 2 The Virtual Dementia Tour® Empathic Introspection Model



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Contributions to Nursing Science

Given the paucity of published research found using the Virtual Dementia Tour® in the family dementia caregiver population, this original study provides new knowledge about the value of the Virtual Dementia Tour® in caregiving research and nursing science.

Research Implications

This study supports Agosta's (2014) recommendation to reconceptualize empathy as a process instead of an outcome in empathy research. This recommendation might be an important discovery in family dementia caregiver research. An extensive body of evidence exists on the study of empathy, but conceptual and operational ambiguity have precluded advancement in understanding this phenomenon with resulting lack of consensus on valid, reliable, and predictive measurements (Hemmerdinger, Stoddart, & Lilford; Yu and Kirk, 2009).

Researchers' conundrum to accurately quantify and empirically measure empathy as an outcome variable might relate to a linguistic issue in the English language. "Empathy" is not an exact translation of the original German term *Einfühlung.* The resulting inconsistency in meaning might contribute to empathy's conceptual ambiguity and defiance of a standardized definition documented in published research over the past thirty years. Additionally, past research has shown that empirical measurement cannot capture or quantify the individuality of another's cultural, social, and historical contexts (Zahavi and Overgaard, 2012). These considerations are important in future research design.

Nursing Implications

Those living with dementia might be vulnerable to mistreatment and abuse because of the nature of the disease and their dependence on others. To protect this vulnerable population, family members and the healthcare team must remain vigilant to recognize signs of mistreatment and intervene for the care recipient's wellbeing (Beach et al., 2005; Family Caregiving Alliance, 2017).

In this study, the participants' language indicated feelings of frustration, aggravation, and stress associated with family dementia caregiving, which might predispose them to unintentional abusive reactions over time. In addition, this study provided evidence that the Virtual Dementia Tour® positively changed family dementia caregiver participants' perspective toward dementia and their loved one's lived experience with the disease. However, it is unknown how long this effect lasts in this population. Participants' expressed that yearly participation in the Virtual Dementia Tour® was necessary, as the progression of dementia changes one's experience.

The change in perspective alone does not provide family dementia caregivers with the communication tools needed to effectively approach the inherent frustrating and stressful situations in family dementia caregiving. Caregiver education about the behavioral changes caused by neurocognitive deterioration and anticipatory approaches to care are critical measures toward protecting the emotional, mental, and physical well-being of those living with dementia and their family caregivers. Nurses should advocate for caregivers to practice self-efficacy by encouraging them to utilize any available respite services without feelings of guilt. Based on the aging population and propensity of geriatric family caregiving, nurses should advocate for concurrent outpatient visits for the caregiver and the care recipient to improve family caregivers' access to health care services, which might prevent or ameliorate the emotional, mental, and physical demands of caregiving and improve self-efficacy.

Recommendations for Future Research

Future research should consider family dementia caregivers' cultural, social, and historical contexts in understanding those living with dementia and family dementia caregivers' lived experiences. Based on this study's findings, further research is needed to explore the cultural nuances of agricultural family dementia caregiving, as this appears to be a unique subculture within rural communities.

A longitudinal study may be helpful to examine whether family dementia caregivers' experiences in the Virtual Dementia Tour® has a long-lasting effect and, if so, how long these effects last. Reported reductions in frustration, aggravation, and stress voiced by the participants might improve caregiving longevity and mutually beneficial care for the family dementia dyads. Family dementia caregiver education and support are crucial for this desired outcome. Before any intervention can be successful in improving lives, one must become aware of personal biases and presumptions about their family member living with dementia and their lived experience. Additional study is needed to investigate the Virtual Dementia Tour® combined with a dementia care education program, which should include objective measures to longitudinally assess changes in family caregiver burden, stress, depression, and compassion fatigue following such combination programs. The long-term outcomes should be ongoing health, caregivers' perceived well-being, and time delay in nursing home placement due to family caregiver overburden.

Strengths of the Study

The pre-existing relationship with the researcher's community partners was a strength in reaching large numbers of potential participants. As agreed, the community partners notified conference attendees with the approved study flyers before the event. This notification resulted in an overwhelming response from family dementia caregivers. The researcher received eight phone calls from family dementia caregivers who wanted to participate but did not plan to attend the conference. When the researcher explained that recruitment could only take place at the event, two of the eight callers registered and attended. Based on the facial expressions of the attendees when the study was introduced at the beginning of the event, the $50 gift cards were considered a strong motivating factor that led to the recruitment of the complete study sample in one event.

The phenomenological conversation style interviews provided the opportunity for family dementia caregivers to share their experience in rich detail and a relaxed environment. Although a limitation initially, the researcher's interview skill improved with each interview. The individual participants' language and journeys were individually rich. All participants lived within thirty minutes of the event location, which was considered a strength because it added to the homogeneity of the sample. The research team did not consider the necessity to exclude those who participated in the Virtual Dementia Tour® in the past. This oversight was an unexpected strength that allowed the research team to uncover the strong impact of repetitive experiences with the Virtual Dementia Tour® and changes family dementia caregivers made in their approach to caring over the span of one week to three years. Additionally, the participants expressed that their experiences were unique each time because their family member's dementia was at a different stage with each experience. Several participants recommended that formal and informal family dementia caregivers do a "refresher" experience every year or so, which was supported by professional caregiver research (Campbell, Warnock-Matheron, and Larche, 2013).

Limitations of the Study

One disappointing limitation was the absence of interested male family dementia caregivers. The convenience sampling method was appropriate for this study's methodology. However, a more robust sampling method in replication studies might allow for homogenous data comparisons based on cultural and historical contexts. The research team planned to wait one week to begin interviews following each Virtual Dementia Tour® to allow for reflection and processing. The team also chose to set a two-week window for the interviews due to lack of supporting evidence about lay participants’ ability to recall their Virtual Dementia Tour® experience in detail. The two-week time limitation was considered a logistical limitation because the robust response and interview window resulted in the necessity to complete ten interviews in one week.

Conclusion

This original research provided a person-in-context situation to understand better what the consciousness perceived and understood about the lived experience of dementia. A modification of Colaizzi’s (1978) method was used for phenomenological analysis. The study findings suggested that family dementia caregivers interpreted their experience in the Virtual Dementia Tour® with empathic understanding and responsiveness. For most, this experience led to a powerful impact and changed reality toward their family member living with dementia.

This study begins to fill a gap in the body of nursing and caregiver research about the value of the Virtual Dementia Tour® with family dementia caregivers in community settings and highlights the need to combine the Virtual Dementia Tour® with formal training to improve family caregivers’ understanding of dementia, effective methods of care provision, and relational harmony. Moreover, knowledge gained from this research might enable nurse scientists to use the Virtual Dementia Tour® to develop more effective interventions that support family dementia caregivers’ longevity and the provision of safe and efficacious care. Advances in caregiving research are critical to family dementia caregivers’ success, as they are the most valuable geriatric workforce in the United States.

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APPENDIX A: IRB APPROVAL

EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review Board
4N-64 Brody Medical Sciences Building· Mail Stop 682
600 Moye Boulevard · Greenville, NC 27834
Office **252-744-2914** · Fax **252-744-2284** · **www.ecu.edu/ORIC/irb**

Notification of Initial Approval: Expedited

From: Social/Behavioral IRB
To: Candace Harrington
CC: Janice Neil
Date: 4/19/2018
Re: UMCIRB 18-000186

Family Dementia Caregivers' Perceptions of the Virtual Dementia Tour

I am pleased to inform you that your Expedited Application was approved. Approval of the study and any consent form(s) is for the period of 4/18/2018 to 4/17/2019. The research study is eligible for review under expedited category #6, 7. The Chairperson (or designee) deemed this study no more than minimal risk.

Changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. The investigator must submit a continuing review/closure application to the UMCIRB prior to the date of study expiration. The Investigator must adhere to all reporting requirements for this study.

Approved consent documents with the IRB approval date stamped on the document should be used to consent participants (consent documents with the IRB approval date stamp are found under the Documents tab in the study workspace).

The approval includes the following items:

Name	Description
Dissertation Proposal Final Approval	Study Protocol or Grant Application
Letter of Request AAA Albemarle	Additional Items
Letter of Request AAA Upper Plain	Additional Items
Letter of Request AlzNC.Levine	Additional Items
Letter of Request ECCAAA	Additional Items
Letter of Request GEM Sonesso	Additional Items
Letter of Request Mideastern Commission AAA	Additional Items

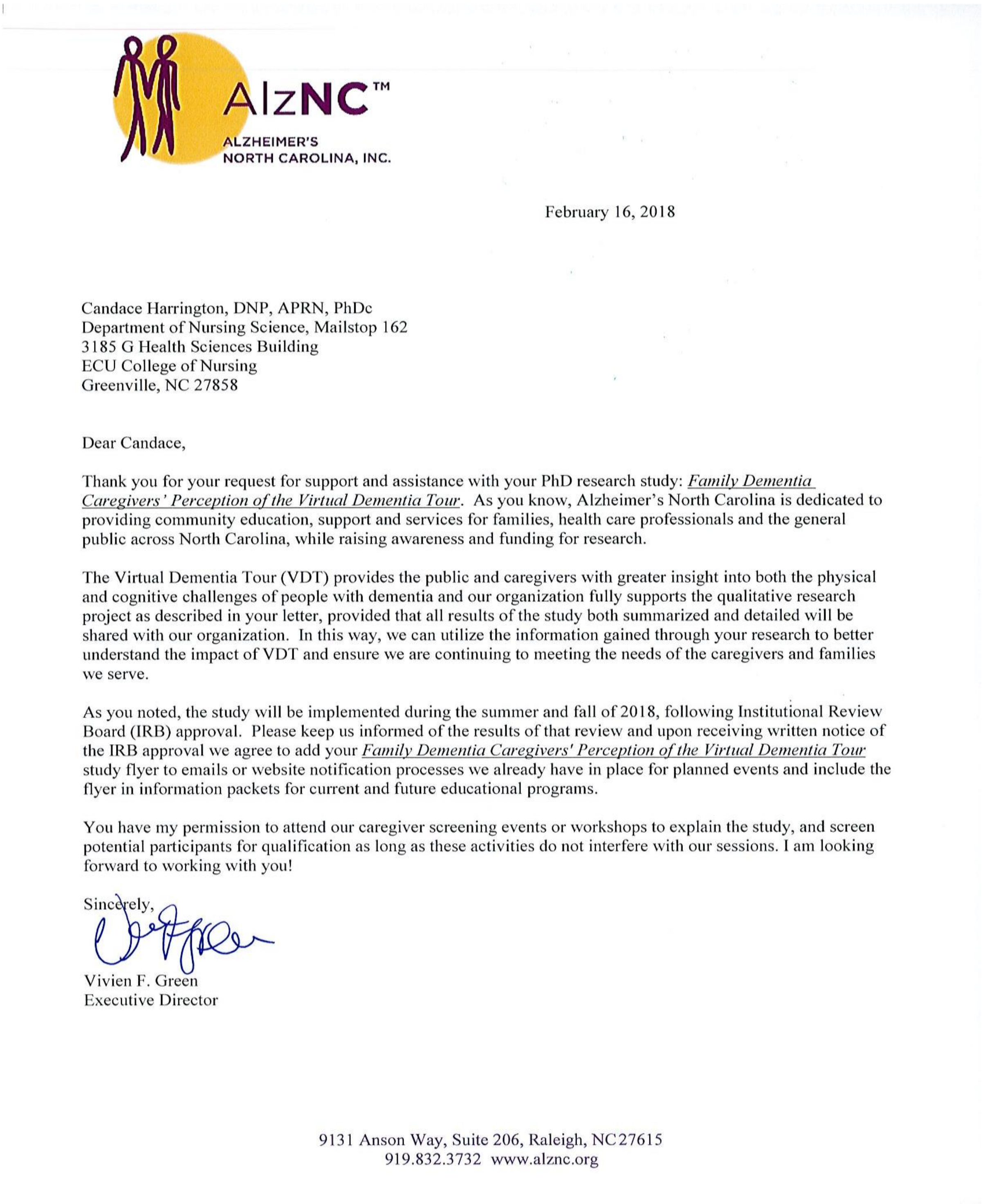
Recruitment Flyer	Recruitment Documents/Scripts
Revision.Informed Consent.FamilyCaregiverPerceptions.ch.04.05.2018	Consent Forms
Screening and Demographic Data. harrington. dissertation.docx	Data Collection Sheet
Screening and Demographic Data. harrington. dissertation.docx	Surveys and Questionnaires
Script and Guiding questions for open semistructured interviews	Interview/Focus Group Scripts/Questions
Script for Introduction of Study at the Events	Interview/Focus Group Scripts/Questions

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

IRB00000705 East Carolina U IRB #1 (Biomedical) IORG0000418

IRB00003781 East Carolina U IRB #2 (Behavioral/SS) IORG0000418

APPENDIX B: COMMUNITY PARTNER LETTERS OF SUPPORT



AlzNC™
ALZHEIMER'S
NORTH CAROLINA, INC.

February 16, 2018

Candace Harrington, DNP, APRN, PhDc
Department of Nursing Science, Mailstop 162
3185 G Health Sciences Building
ECU College of Nursing
Greenville, NC 27858

Dear Candace,

Thank you for your request for support and assistance with your PhD research study: *Family Dementia Caregivers' Perception of the Virtual Dementia Tour*. As you know, Alzheimer's North Carolina is dedicated to providing community education, support and services for families, health care professionals and the general public across North Carolina, while raising awareness and funding for research.

The Virtual Dementia Tour (VDT) provides the public and caregivers with greater insight into both the physical and cognitive challenges of people with dementia and our organization fully supports the qualitative research project as described in your letter, provided that all results of the study both summarized and detailed will be shared with our organization. In this way, we can utilize the information gained through your research to better understand the impact of VDT and ensure we are continuing to meeting the needs of the caregivers and families we serve.

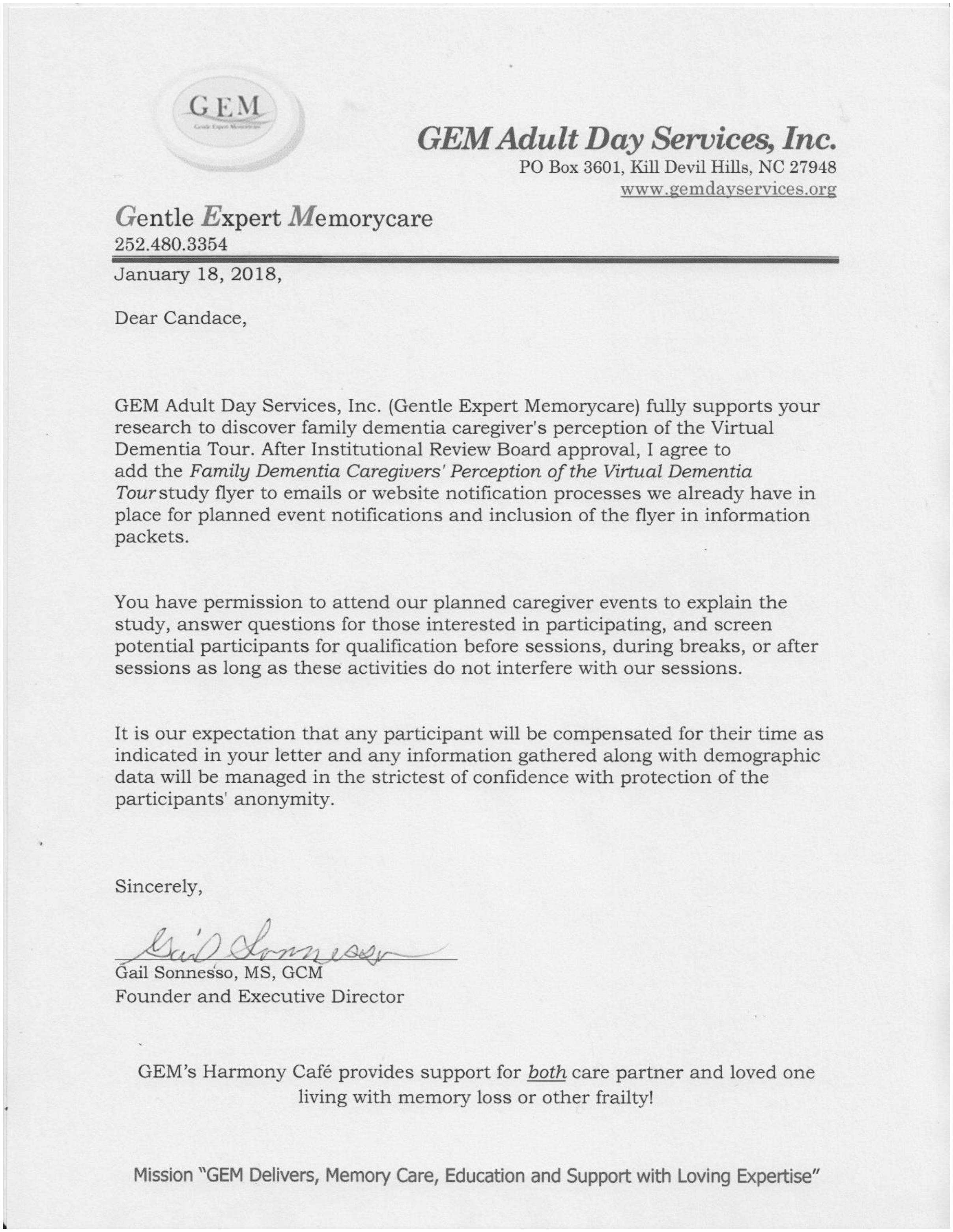
As you noted, the study will be implemented during the summer and fall of 2018, following Institutional Review Board (IRB) approval. Please keep us informed of the results of that review and upon receiving written notice of the IRB approval we agree to add your *Family Dementia Caregivers' Perception of the Virtual Dementia Tour* study flyer to emails or website notification processes we already have in place for planned events and include the flyer in information packets for current and future educational programs.

You have my permission to attend our caregiver screening events or workshops to explain the study, and screen potential participants for qualification as long as these activities do not interfere with our sessions. I am looking forward to working with you!

Sincerely,

Vivien F. Green
Executive Director

9131 Anson Way, Suite 206, Raleigh, NC27615
919.832.3732 www.alznc.org



GEM Adult Day Services, Inc.
PO Box 3601, Kill Devil Hills, NC 27948
www.gemdayservices.org

Gentle Expert Memorycare
252.480.3354

January 18, 2018,

Dear Candace,

GEM Adult Day Services, Inc. (Gentle Expert Memorycare) fully supports your research to discover family dementia caregiver's perception of the Virtual Dementia Tour. After Institutional Review Board approval, I agree to add the *Family Dementia Caregivers' Perception of the Virtual Dementia Tour* study flyer to emails or website notification processes we already have in place for planned event notifications and inclusion of the flyer in information packets.

You have permission to attend our planned caregiver events to explain the study, answer questions for those interested in participating, and screen potential participants for qualification before sessions, during breaks, or after sessions as long as these activities do not interfere with our sessions.

It is our expectation that any participant will be compensated for their time as indicated in your letter and any information gathered along with demographic data will be managed in the strictest of confidence with protection of the participants' anonymity.

Sincerely,

Gail Sonnesso

Gail Sonnesso, MS, GCM
Founder and Executive Director

GEM's Harmony Café provides support for *both* care partner and loved one living with memory loss or other frailty!

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Candace Harrington, DNP, APRN, AGPCNP-BC, PhDc
Adjunct Faculty Brody School of Medicine Dept. of Geriatrics
East Carolina University
3185-G Health Sciences Building Greenville, NC

February 5, 2018

Dear Candace,

As a Family Caregiver Resource Specialist of the Mid-Eastern Commission Area Agency on Aging, I fully support your research as requested. Following Institutional Review Board approval, we agree to add the *Family Dementia Caregivers' Perception of the Virtual Dementia Tour* study flyer to emails or website notification processes we already have in place for planned events notifications and inclusion of the flyer in information packets as requested.

You have permission to attend our caregiver screening events or workshops to explain the study, answer questions for those interested in participating, and screen potential participants for qualification before sessions, during breaks, or after sessions as long as these activities do not interfere with our sessions.

It is our expectation that any participant will be compensated for their time as indicated in your letter and any information gathered along with demographic data will be managed in the strictest of confidence with protection of the participants' anonymity.

Sincerely,

Tamyra Jovel

Tamyra Jovel, MSW
Family Caregiver Resource Specialist
Mid East Commission Area Agency on Aging

Serving: Beaufort County • Bertie County • Hertford County • Martin County • Pitt County

"Auxiliary aids and services are available upon request to individuals with disabilities."
Relay numbers for the Hearing Impaired:(TTY) 1-800-735-2962 (voice) 1-800-735-8262

ALBEMARLE COMMISSION
REGION R COUNCIL OF GOVERNMENTS
Area Agency on Aging

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CURRITUCK
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PERQUIMANS
TYRRELL
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CRESWELL
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EDENTON
ELIZABETH CITY
GATESVILLE
HERTFORD
KILL DEVIL HILLS
KITTY HAWK
MANTEO
NAGS HEAD
PLYMOUTH
ROPER
SOUTHERN SHORES
WINFALL

Dear Candace,

As director of the Albemarle Commission Area Agency on Aging, I fully support your research as requested. Following Institutional Review Board approval, we agree to add the *Family Dementia Caregivers' Perception of the Virtual Dementia Tour* study flyer to emails or website notification processes we already have in place for planned events notifications and inclusion of the flyer in information packets as requested.

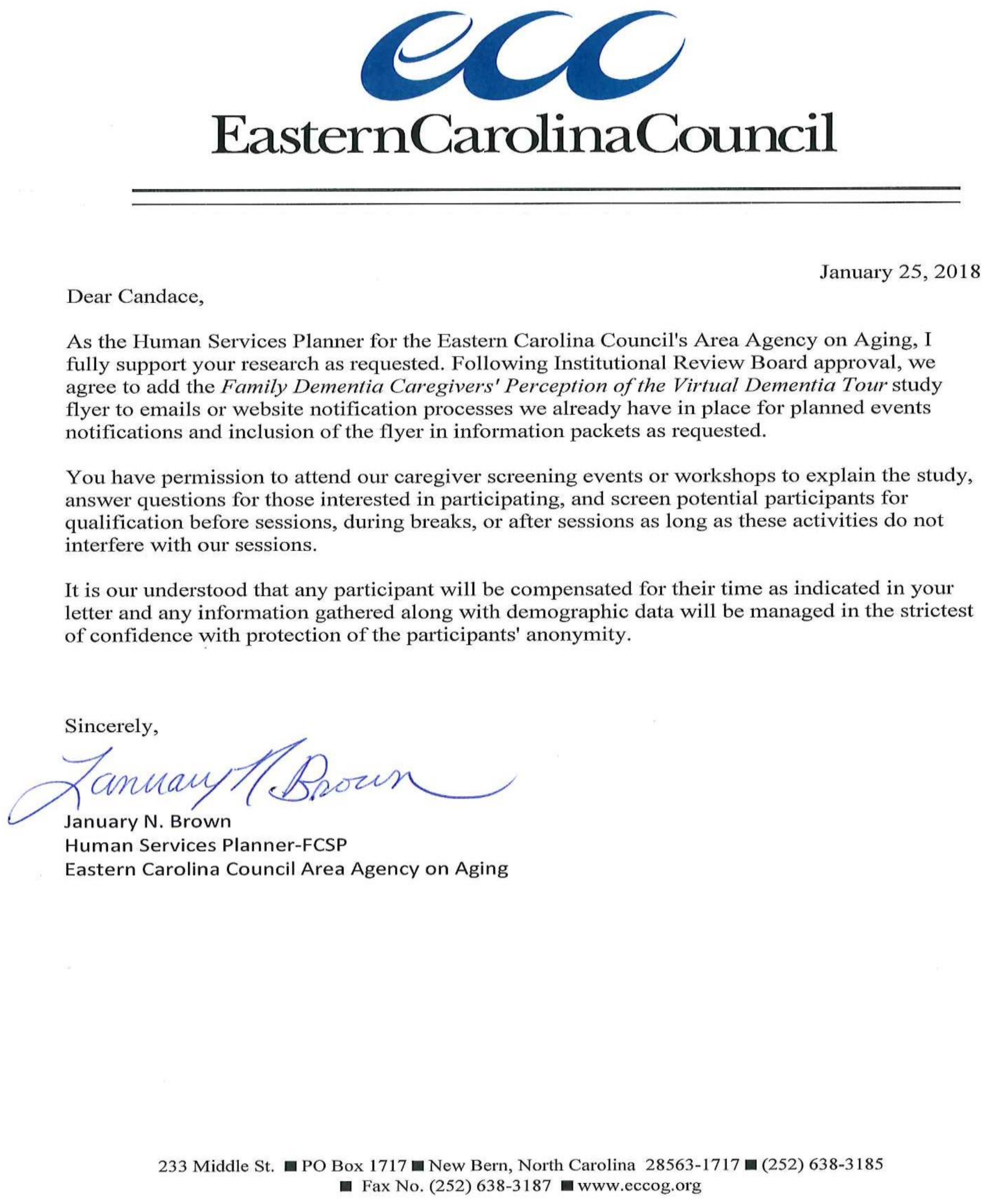
You have permission to attend our caregiver screening events or workshops to explain the study, answer questions for those interested in participating, and screen potential participants for qualification before sessions, during breaks, or after sessions as long as these activities do not interfere with our sessions.

It is our expectation that any participant will be compensated for their time as indicated in your letter and any information gathered along with demographic data will be managed in the strictest of confidence with protection of the participants' anonymity.

Sincerely,

Laura Alvarico, Director
Albemarle Commission Area Agency on Aging

512 South Church Street
Hertford, NC 27944
www.albemarlecommission.org
P: 252.426.5753
F: 252.426.8482



EasternCarolinaCouncil

January 25, 2018

Dear Candace,

As the Human Services Planner for the Eastern Carolina Council's Area Agency on Aging, I fully support your research as requested. Following Institutional Review Board approval, we agree to add the *Family Dementia Caregivers' Perception of the Virtual Dementia Tour* study flyer to emails or website notification processes we already have in place for planned events notifications and inclusion of the flyer in information packets as requested.

You have permission to attend our caregiver screening events or workshops to explain the study, answer questions for those interested in participating, and screen potential participants for qualification before sessions, during breaks, or after sessions as long as these activities do not interfere with our sessions.

It is our understood that any participant will be compensated for their time as indicated in your letter and any information gathered along with demographic data will be managed in the strictest of confidence with protection of the participants' anonymity.

Sincerely,

January N. Brown

January N. Brown
Human Services Planner-FCSP
Eastern Carolina Council Area Agency on Aging

233 Middle St. ■ PO Box 1717 ■ New Bern, North Carolina 28563-1717 ■ (252) 638-3185
■ Fax No. (252) 638-3187 ■ www.eccog.org

UPPER COASTAL PLAIN
COUNCIL OF GOVERNMENTS
AREA AGENCY ON AGING
121 W. NASH STREET (27893)
P. O. BOX 9
TELEPHONE: 252.234.5952 WILSON, NORTH CAROLINA 27894 FAX: 252.234.5971

January 19, 2018

Candace Harrington, DNP, APRN, AGPCNP-BC, PhDc
East Carolina University College of Nursing
Department of Nursing Science
Health Sciences Building
Greenville, NC 27858-4353

Dear Candace,

As the Family Caregiver Resource Specialist for the Upper Coastal Plain Area Agency on Aging, I fully support your research as requested. Following Institutional Review Board approval, we agree to add the *Family Dementia Caregivers' Perception of the Virtual Dementia Tour* study flyer to emails or website notification processes we already have in place for planned events notifications and inclusion of the flyer in information packets as requested.

You have permission to attend our caregiver screening events or workshops to explain the study, answer questions for those interested in participating, and screen potential participants for qualification before sessions, during breaks, or after sessions as long as these activities do not interfere with our sessions.

It is our expectation that any participant will be compensated for their time as indicated in your letter and any information gathered along with demographic data will be managed in the strictest of confidence with protection of the participants' anonymity.

Sincerely,

Kim Emory

Kim Emory
Family Caregiver Resource Specialist
Upper Coastal Plain Council of Governments
Area Agency on Aging

APPENDIX C: RECRUITMENT FLYER

Participants Needed

for a Research Study

"Family Dementia Caregivers' Perceptions of the Virtual Dementia Tour®"

The purpose of this study: To discover family dementia caregivers' perceptions of the Virtual Dementia Tour®

This study is open to family members who provide the majority of care for older adult relative who has Alzheimer's or another kind of dementia and is no longer able to live independently.

Time commitment: A one-time interview of approximately one hour within the following two weeks after participating in the Virtual Dementia Tour®

Place: A meeting place and time that is most convenient for the participant.

Time Compensation: $50 gift card upon completion of the one-time interview.

For additional information, contact

Candace Harrington at 704-978-7131
harringtonc13@students.ecu.edu

Principal Investigator: Candace Harrington, DNP, APRN, PhDc, Doctoral Student
Faculty Advisor: Janice Neil, PhD, RN, CNE
East Carolinia University College of Nursing
Greenville, NC 27858

ECU

APPENDIX D: EVENT SCRIPT

Script for Events:

My name is Candace Harrington. I am a student in East Carolina University's College of Nursing. I am conducting interviews to discover family dementia caregivers' perceptions of the Virtual Dementia Tour in partial fulfillment of my Doctor of Philosophy in Nursing degree. This research study is open to family members who provide the majority of care for a relative over the age of 65 years who lives with dementia and is no longer able to live independently.

The study will involve up to one hour of your time for one interview within the two weeks at a place and time that is most convenient for you. You will be compensated for your time at the end of the interview with a $50 gift card. If you are interested in sharing your experience with the Virtual Dementia Tour or wish to speak with me further, please come see me during the breaks or afterward. I will be…(site the location the sponsor sets up a place for me).

APPENDIX E: SCREENING AND DEMOGRAPHIC DATA COLLECTION TOOL

The following questions help us describe our study sample.

(Shaded areas do not appear in the survey and indicate skip logic design)

Q1 **I am _________years old.**

Q2 **I am the primary caregiver who provides the majority of care for a family member living with dementia.**

○ Yes (1)

○ No (2)

If Yes (1): Skip to the next question

If No (2): Skip to question 13 Thank you for your time

Q3 **My family member living with dementia is 65 years of age or older.**

○ True (1)

○ False (2)

If True (1): Skip to the next question

If False (2): Skip to Question 13 Thank you for your time…

Q4 **My family member cannot safely live alone and depends on me for household chores and personal care.**

○ Yes (1)

○ No (2)

If Yes (1): Skip to the next question

If No (2): Skip to Question 13 Thank you for your time…

Q5 **I related to my family member living with dementia by:**

- ○ We are related by blood, marriage, or adoption. (1)
- ○ We are committed to one another as friends, companions, or partners who are not related by blood, marriage, or adoption. (2)
- ○ None of the above descriptions apply to my relationship. (3)

If we are related by blood, marriage, or adoption (1): skip to the next question

If we are committed to one another as friend… (2): skip to the next question

If none of the above (3): skip to question 13 Thank you for your time….

Q6 **I provide care for which relative(s) living with dementia? (choose all that apply)**

- ○ Wife (1)
- ○ Husband (2)
- ○ Daughter (3)
- ○ Son (4)
- ○ Sister (5)
- ○ Brother (6)
- ○ Aunt (7)
- ○ Uncle (8)
- ○ In- law (please specify) (9) ____
- ○ Partner or Companion (10)
- ○ Cousin (11)
- ○ Step-relative (please specify) (12) ____
- ○ Grandmother (13)
- ○ Grandfather (14)

Q7 **I have been in charge of the care of my family member for how long? (please choose one answer)**

○ Less than 1 (one) year (1)
○ 1 (One) to 3 (three) years (2)
○ 4 (four) to 6 (six) years (3)
○ 7 (seven) to 9 (nine) years (4)
○ 10 (ten) to 12 (twelve) (5)
○ 13 (thirteen) to 15 (fifteen) years (6)
○ More than 15 (fifteen) years (7)

Q8 **I give care (personal or household chores) __________days a week?**

○ less than 1 (one) day a week (1)
○ 2-3 (two to three) days a week (2)
○ 4-5 (four to five) days a week (3)
○ 6-7 (six to seven) days a week (4)

Q9 **On these days, I provide care how many hours?**

○ less than 8 (eight) hours each day (1)
○ 8-12 (eight to twelve) hours each day (2)
○ 13-16 (thirteen to sixteen) hours each day (3)
○ 16-20 (sixteen to twenty) hours each day (4)
○ 21-24 (twenty-one to twenty-four) hours each day (5)

Q10 **My ethnicity is _______? (Choose all that apply)**

- ○ White non-Hispanic (1)
- ○ Black or African American (2)
- ○ American Indian or Alaska Native (3)
- ○ Asian (4)
- ○ Native Hawaiian or Pacific Islander (5)
- ○ Latino/Hispanic (6)
- ○ Other (7) ____

Q11 **I am_______.**

- ○ Male (1)
- ○ Female (2)

Q12 **My marital status is_________.**

- ○ Married (1)
- ○ Widowed (2)
- ○ Divorced (3)
- ○ Separated (4)
- ○ Never married (5)

Q13 **Thank you for your time. I would like to express my sincere gratitude for your willingness to participate.**

APPENDIX F: INFORMED CONSENT

Study ID:UMCIRB 18-000186   Date Approved: 4/18/2018   Expiration Date: 4/17/2019

Informed Consent to Participate in Research

Title of Research Study: **Family Dementia Caregivers' Perceptions of the Virtual Dementia Tour®**

Principal Investigator: Candace Harrington, DNP, PhDc, Doctoral Student
Chairperson/Faculty Supervisor Janice Neil, PhD, RN
ECU College of Nursing, Department of Nursing Science
Address: 3185 G Health Sciences Building, Mailstop 162 ECU Greenville, NC 27858 Telephone #: 744-252-0270 or 704-978-7131

Researchers at East Carolina University (ECU) study issues related to society, health problems, environmental problems, behavior problems and the human condition. To do this, we need the help of volunteers who are willing to take part in research. This research study is being done in partial fulfillment for a Doctor of Philosophy degree in Nursing at ECU College of Nursing.

Why am I being invited to take part in this research?

The purpose of this research is to is to understand what caregivers think of the Virtual Dementia Tour and what it means to them as a caregiver. You are being invited to take part in this research because you are a caregiver for an older adult family member who is living with dementia. The decision to take part in this research is yours to make. By doing this research, we hope to understand more about how the Virtual Dementia Tour helps caregivers have a better understanding of dementia.

If you volunteer to take part in this research, you will be one of 10 people to do so.

Are there reasons I should not take part in this research?

I understand I should not volunteer for this study if I am, under 18 years of age, I do not speak English, or I do not care for an older family member who is living with dementia.

What other choices do I have if I do not take part in this research?

You can choose not to participate. You may still participate in any activities offered through the community.

Where is the research going to take place and how long will it last?

The research will be conducted at a place of your choice on a date and time at your convenience within two weeks following your participation in the Virtual Dementia Tour one time during the study. The total amount of time you will be asked to volunteer for this study is approximately 1 hour within the next two weeks.

What will I be asked to do?

You will be asked questions about your experience in the virtual dementia tour completed at a community event. These interviews will be audio-recorded only for the purpose of transcription.

Study Title: Family Dementia Caregivers' Perceptions of the Virtual Dementia Tour®

What might I experience if I take part in the research?

We don't know of any risks (the chance of harm) associated with this research. Any risks that may occur with this research are no more than what you would experience in everyday life. We don't know if you will benefit from taking part in this study. There may not be any personal benefit to you but the information gained by doing this research may help others in the future.

Will I be paid for taking part in this research?

We will be able to pay you for the time you volunteer while being in this study. Compensation for your time will be provided in the form of a $50 Walmart gift card at the completion of the interview.

Will it cost me to take part in this research?

It will not cost you any money to be part of the research.

Who will know that I took part in this research and learn personal information about me?

ECU and the people and organizations listed below may know that you took part in this research and may see information about you that is normally kept private. With your permission, these people may use your private information to do this research

- Any agency of the federal, state, or local government that regulates human research. This includes the Department of Health and Human Services (DHHS), the North Carolina Department of Health, and the Office for Human Research Protections.
- The University & Medical Center Institutional Review Board (UMCIRB) and its staff have responsibility for overseeing your welfare during this research and may need to see research records that identify you.

How will you keep the information you collect about me secure? How long will you keep it?

The recorder and recordings, data, and consent forms will be stored in the student's faculty office and kept in a locked drawer, locked office and suite when not occupied and are only accessible to the PI (student) for a minimum of three years after completion of the study. Until transcription is complete, the recordings will remain in the possession of the principal investigator and kept in a locked drawer in a locked office at the student's office in the College of Nursing when not in use. The interview recordings will be transcribed and then destroyed immediately following transcription by deleting the files from the recorder. The transcription documents will contain only de-identified information using false names upon transcription. There will be no recordings stored after the files have been transcribed. All consent forms will be handled securely and placed in a locked drawer in a secured and controlled location accessible only to the PI in her faculty office locked desk drawer office 3185G Health Sciences Building in the College of Nursing. The keys to the office and drawer are in the PI's possession at all times. All transcription records will be kept for three years after publication of results. De-identfied data and transcription documents will be completed on a computer with facial recognition and password protection and stored on the CON faculty's ECU research pirate drive. Only the PI and dissertation committee will have access to the data.

What if I decide I don't want to continue in this research?

You can stop at any time after it has already started. There will be no consequences if you stop and you will not be criticized. You will not lose any benefits that you normally receive.

Study Title: **Family Dementia Caregivers' Perceptions of the Virtual Dementia Tour®**

Who should I contact if I have questions?

The people conducting this study will be able to answer any questions concerning this research, now or in the future. You may contact the Principal Investigator at ***919-200-0775 or 252-744-0270*** (days, between ***8 am-5 pm Monday through Friday***).

If you have questions about your rights as someone taking part in research, you may call the Office of Research Integrity & Compliance (ORIC) at phone number 252-744-2914 (days, 8:00 am-5:00 pm). If you would like to report a complaint or concern about this research study, you may call the Director of the ORIC, at 252-744-1971

Are there any Conflicts of Interest I should know about?

The Principal Investigator (or the sub-investigator, research staff member, or family member) have no potential conflicts of interest.

I have decided I want to take part in this research. What should I do now?

The person obtaining informed consent will ask you to read the following and if you agree, you should sign this form:

- I have read (or had read to me) all of the above information.
- I have had an opportunity to ask questions about things in this research I did not understand and have received satisfactory answers.
- I know that I can stop taking part in this study at any time.
- By signing this informed consent form, I am not giving up any of my rights.
- I have been given a copy of this consent document, and it is mine to keep.

Participant's Name (PRINT)	**Signature**	**Date**

Person Obtaining Informed Consent: I have conducted the initial informed consent process. I have orally reviewed the contents of the consent document with the person who has signed above, and answered all of the person's questions about the research.

Person Obtaining Consent (PRINT)	**Signature**	**Date**
Principal Investigator (PRINT)	***Signature***	***Date***

Consent Version Date: 04.05.2018
Template Version 02.05.18

APPENDIX G: SCRIPT FOR INTERVIEWS

No protected health information will be collected. After obtaining the consent, a script will be used for an introduction with these semi-structured questions:

Script:

Thank you for allowing me to speak with you about your experience with the Virtual Dementia Tour. My name is Candace Harrington, and I am a doctor of philosophy in nursing student at East Carolina University. This research is being done as a required portion of my program. I would like to first talk about how you became the primary caregiver for your (family member________fill in the relationship). Then I will ask you about your thoughts and feelings as you went through the Virtual Dementia Tour. I am recording our conversation only for the purpose of transcribing it into a written format. The recording will then be destroyed. Your name and identity will not be used in any way and will not be traceable back to you after the transcription is complete. You may stop the interview at any point. Do you have any questions? The interview is an open semi-structured interview.

1. Was there a crucial event in your (fill in the blank with relative's relationship) or time when you knew he or she could no longer live independently without constant supervision?
2. Share with me how you became a family caregiver for your____ (fill in the blank with an appropriate relative).
3. Let's go back to the Virtual Dementia Tour®. Walk me through your thoughts and feelings as you tried to complete the tasks.
4. What did the Virtual Dementia Tour® mean to you as your (______fill in the blank with the appropriate relative's) caregiver?

5. How did the Virtual Dementia Tour® impact how you thought about dementia?

6. Is there anything else you would like to share with me about your Virtual Dementia Tour® experience?

Guiding questions will be provided to help recall if needed.

Closing: Thank you for your time today. I appreciate your willingness to share your experience from the Virtual Dementia Tour. If you have any questions or concerns after I leave, you may contact me at the telephone number or email provided on my contact (business) card (given to every participant) or information flyer.