RESISTIVENESS TO CARE AS EXPERIENCED BY FAMILY CAREGIVERS
ASSISTING PEOPLE WITH DEMENTIA

A Dissertation in
Nursing
by
Pamela C. Spigelmyer

©2015 Pamela C. Spigelmyer

Submitted in Partial Fulfillment
of the Requirements
for the Degree of
Doctor of Philosophy

August 2015
The dissertation of Pamela C. Spigelmyer was reviewed and approved* by the following:

Judith E. Hupcey  
Professor of Nursing and Professor of Medicine, College of Medicine  
Associate Dean for Graduate Education, Nursing  
Dissertation Advisor  
Chair of Committee

Lisa Kitko  
Assistant Professor of Nursing

Susan J. Loeb  
Associate Professor of Nursing  
Associate Professor of Medicine, College of Medicine  
Faculty Affiliate, Gerontology Center

Carol A. Smith  
Associate Professor Emeritus of Nursing, Penn State University

Robert Schrauf  
Professor of Applied Linguistics

*Signatures are on file in the Graduate School
Abstract

Currently in the United States the vast majority of all people with dementia are cared for in their homes by a family caregiver. Many of these family caregivers have expressed distress with behaviors displayed by the person with dementia during caregiver-assisted activities. Nurse researchers interested in dementia behaviors have defined these episodes as resistiveness to care and have investigated the use of interventions with family caregivers to modify the resistive behaviors and to decrease family caregiver distress when the behaviors occur. Only modest success has been achieved with these current interventions. Therefore a scientific phenomenology study was conducted to investigate the lived family caregiver experience of resistiveness to care. This method incorporates a human science approach, a disciplinary perspective, and is ideal for studying behavioral phenomenon that may not be readily studied by the natural sciences. A nursing disciplinary perspective was used during the analysis of this study and permitted the nurse researcher to grasp objectively the subjective structural meaning assigned to this phenomenon by family caregivers. The outcome of the descriptive scientific phenomenology method is to identify and define perceptions of an experience. Upon Institutional Review Board approval eight dementia family caregivers were recruited from Alzheimer’s support group meetings, provided informed consent and were interviewed individually at a mutually agreed upon location. Each participant provided in depth descriptions of chosen resistive events that they experienced. Analysis using the scientific phenomenology method revealed a structure of resistiveness to care experience that nurses can use to gain incites into resistiveness to care as perceived by family caregivers. The structure contained five essential constituents. These constituents included, self-questioning of abilities; signal for increased future caregiver responsibilities; changed perception of personal self; unexpected
emotional responses; and sees changed person not the disease. The findings are representative of the family caregiver’s lived perception of resistiveness to care, which appears to be very different from the current research literature relating to nurses’ perceptions of resistiveness to care. The identified structure also provides focal points for future research and interventions to help family caregivers to mediate the stress of resistiveness to care.
# TABLE OF CONTENTS

List of Tables .................................................................................................................. xi
List of Figures .................................................................................................................... xii
Acknowledgements .......................................................................................................... xiii

Chapter 1 Introduction...................................................................................................... 1
  Background and Significance .......................................................................................... 4
  Prevalence of Dementia .................................................................................................. 4
  Family Caregiving ......................................................................................................... 6
  Dementia Family Caregiving ............................................................................................ 9
  Identifying Factors Contributing to Caregiver Stress ...................................................... 11
  Variations in Caregivers Appraisals ............................................................................. 12
  Cumulative Effects of Stressful Caregiving .................................................................... 14

Statement of the Problem ................................................................................................. 16

Purpose of the Study ........................................................................................................ 20

Professional Significance ................................................................................................ 21

Theoretical Frameworks Applicable to the Phenomenon of Resistiveness to Care ............ 22
  Needs Driven Dementia Compromised Behavior Theory (NDDB) .............................. 23
  Progressively Lowered Stress Theory (PLST) ............................................................. 23
  The Stress Process as a Model of Caregiving (SPM) ..................................................... 24
  Summary of Theoretical Frameworks ............................................................................ 25

Scientific Phenomenological Method of Inquiry ............................................................... 27

Research Questions ........................................................................................................ 29

Definitions ........................................................................................................................ 30
  Family Caregiver .......................................................................................................... 30
  Assisted Care .................................................................................................................. 30
  Resistiveness to Care ..................................................................................................... 31
  Stress .............................................................................................................................. 32
  Distress .......................................................................................................................... 33
  Lifeworld ........................................................................................................................ 33
  Phenomenological Attitude/Phenomenological Reduction .............................................. 34
  Meanings ......................................................................................................................... 36
  General Meaning Structure ........................................................................................... 36
  Essential Constituents .................................................................................................... 36
  Meaning Unit ................................................................................................................. 37

Assumptions ..................................................................................................................... 38

Chapter Summary ........................................................................................................... 38

Chapter 2 Literature Review ............................................................................................ 41
  Introduction ..................................................................................................................... 41
  Resistiveness to Care ..................................................................................................... 43
Conceptualization of Resistiveness to Care.................................................................44
  Scientific measure of resistiveness to care.........................................................47
  Use of measurement tools for resistiveness to care...........................................49
  Context of resistiveness to care........................................................................49
  Relationship with other concepts.......................................................................50
  Summary of resistiveness to care as defined in the literature review ..................51
Gaps in understanding resistiveness to care identified in the literature.......................51
Dementia................................................................................................................52
  Types of dementia..............................................................................................55
    Frontotemporal dementia................................................................................55
    Lewy Body dementia.......................................................................................56
    Vascular dementia.........................................................................................58
    Alzheimer’s disease.......................................................................................59
Family Caregiving..................................................................................................62
Family Caregivers of People with Alzheimer’s Disease...........................................64
  Challenges to Providing Care for People with Dementia.....................................67
Theoretical Frameworks Applicable for Resistiveness to Care Research...................70
  The Needs-Driven Dementia-Compromised Behavior Theory (NDB)....................71
    Complexity.....................................................................................................73
    Usefulness to nursing.....................................................................................73
    Use in resistiveness to care research.............................................................76
  The Progressively Lowered Stress Threshold Model (PLST)...............................78
    Complexity.....................................................................................................81
    Usefulness to nursing.....................................................................................82
    Use in resistiveness to care research.............................................................83
  Stress Process Model of caregiving....................................................................84
    Stress process applied to family caregivers of people with dementia.................84
    Usefulness to nursing.....................................................................................89
    Usefulness for resistiveness to care research..................................................90
Phenomenology......................................................................................................92
  Historical developments of the philosophy of phenomenology..........................93
  Phases of change in the philosophy of phenomenology........................................94
    Preparatory phase...........................................................................................94
    German phase..................................................................................................94
    French phase...................................................................................................96
Tradition in Phenomenology................................................................................97
  Transcendental phenomenology........................................................................97
  Existential phenomenology..............................................................................98
  Hermeneutic phenomenology............................................................................98
Historical changes in the phenomenology of practice........................................99
Phenomenology as a Method..................................................................................100
Descriptive phenomenology method.................................................................100
Interpretive phenomenology method...............................................................102
Utrecht school of phenomenology...................................................................104
Descriptive Phenomenology Influenced by Husserl and Interpreted by Giorgi......105
Chapter Summary..............................................................................................106

Chapter 3 Research Methodology......................................................................108
Introduction.........................................................................................................108
Scientific Phenomenology Method.....................................................................109
Design................................................................................................................112
Scientific Phenomenology Method.....................................................................112
Purpose...............................................................................................................115
Specific Aims.......................................................................................................115
Procedures...........................................................................................................116
Study Setting.......................................................................................................116
Sample/Participants............................................................................................119
Inclusion and exclusion criteria........................................................................121
Number of participants recruited.....................................................................122
Subject recruitment............................................................................................124
Participant incentives.........................................................................................124
Protection of Human Subjects...........................................................................125
Measures.............................................................................................................126
Data Collection....................................................................................................127
Instruments.........................................................................................................127
Interviews..........................................................................................................127
Demographic survey..........................................................................................128
Observational field notes..................................................................................129
Distribution of Data Collection.........................................................................129
Interview Techniques.........................................................................................130
Data Analysis.......................................................................................................131
Transcription of Phenomenology Interview Data.............................................131
Prescription to ensure transcripts reflect lived realities...................................132
Transcription conventions.................................................................................133
Acceptable transcription practices among phenomenology researchers.........133
Attitude of Phenomenological Reduction.........................................................134
Assuming a Nursing Disciplinary Attitude.......................................................135
Transforming the Data.......................................................................................135
Essential Structure Used to Clarify and Interpret the Raw Data.......................137
Validity of Scientific Phenomenology Findings……………………………………………….137
Credibility……………………………………………………………………………………137
Trustworthiness………………………………………………………………………………138
Credibility and Trustworthiness of Scientific Phenomenology Data Analysis………………139
    Credibility of Data Analysis………………………………………………………140
    Trustworthiness of Data Analysis…………………………………………………141
Items Incorporated in an Audit Trail…………………………………………………………141
    Contextual Documentation…………………………………………………………142
    Methodological Documentation…………………………………………………143
    Analytic Documentation…………………………………………………………144
    Documentation of Personal Awareness…………………………………………146
Chapter Summary………………………………………………………………………………148

Chapter 4 Study Findings……………………………………………………………………151
    Apparatus and Method………………………………………………………………151
    Apparatus………………………………………………………………………………151
    Participants…………………………………………………………………………….152
        Participant (Alice): Demographics…………………………………………..154
        Participant (Alice): Summary of Caregiving Experience…………………154
        Participant (Grace): Demographics………………………………………..156
        Participant (Grace): Summary of Caregiving Experience………………156
        Participant (Margie): Demographics………………………………………157
        Participant (Margie): Summary of Caregiving Experience………………158
        Participant (Jenny): Demographics………………………………………..160
        Participant (Jenny): Summary of Caregiving Experience…………………160
        Participant (Peggy): Demographics………………………………………..161
        Participant (Peggy): Summary of Caregiving Experience…………………162
        Participant (Deloris): Demographics…………………………………….162
        Participant (Deloris): Summary of Caregiving Experience………………163
        Participant (Eve): Demographics………………………………………..165
        Participant (Eve): Summary of Caregiving Experience…………………..165
        Participant (Sam): Demographics………………………………………166
        Participant (Sam): Summary of Caregiving Experience…………………..167

Results………………………………………………………………………………………..168
    The Structure of Resistiveness to Care as Experienced by Family Caregivers of People
    With Dementia………………………………………………………………………168
    Constituents and Empirical Variations for Dementia Family Caregivers………………171
        Key constituents for the structure: The experience of resistiveness to care during
        family caregiving………………………………………………………………171
        Key constituents for the structure: The experience of resistiveness to
Appendix A: Approval of Submission ................................................................. 229

Appendix B: The Lived Experience of Families Caring for People With Dementia-Demographic Tool ................................................................. 231

Appendix C: Summary of Explanation of Research ........................................... 232

Appendix D: Informed Consent Form for Social Science Research ............................ 233

Appendix E: Family Caregiver Interview Guide ................................................... 235

References ........................................................................................................ 236
LIST OF TABLES

Table 3.1: Data Transformation Table Example.........................................................145

Table 4.1: Summarized Family Caregiver Demographics..............................................153

Table 4.2: Individual Family Caregiving.................................................................153

Table 4.3: Essential Constituents of the Structure and Empirical Variations Lived by Each Family Caregiver.................................................................170

Table 4.4: Essential Constituents of the Structure and Empirical Variations Lived by Each Family Caregiver.................................................................170
LIST OF FIGURES

Figure 2.1: Caregiving and The Stress Process .......................................................... 87

Figure 4.1: General Meaning Structure of Resistiveness to Care ............................. 190
Acknowledgements

Partial funding for this dissertation is gratefully acknowledged from the Beta Sigma Chapter of Sigma Theta Tau International.

Special acknowledgement goes to Dr. Amedeo Giorgi for his gracious support and guidance throughout the dissertation journey. Without his methodological clarifications and guidance this dissertation would not have been of the academic rigor true to the scientific phenomenology method presented in this dissertation.

Special acknowledgment goes to my dissertation committee. Dr. Judith Hupcey for leading my committee and helping me to reach the finish line. Dr. Carol Smith for assisting with my analysis and for the initial inspiration to obtain my doctoral degree. Dr. Susan Loeb for providing a wealth of writing and research experience. Dr. Lisa Kitko for being the understanding sounding board when times became difficult. Dr. Robert Schrauf for providing alternative perspectives to the study of dementia family caregiving.

Special acknowledgement goes to the Alzheimer’s support group meeting leaders that permitted the introduction of this study and the recruitment of participants. Additional acknowledgement goes to the family caregivers who were willing to relate their life experiences caring for someone with dementia. Without them this study would not have contributed to the science in the manner that it did.

Special acknowledgement goes to my fellow colleagues and cohort members Dr. Peggy Shipley and Dr. Kim Fenstermacher. We started this journey together and were each other’s cheerleaders during difficult times and we made it. I treasure your friendship and support to this day. I don’t think we could have had a better support system than we made ourselves. It has held strong enabling us to pick up where we left off whenever we meet. I also want to
acknowledge another colleague who provided the inspiration at a time when I most needed it—Janet Fogg. Your support will forever be connected with my dissertation and I will continue in the same spirit of passing it forward.

Permission to use the figure “Caregiving and the Stress Process” for this dissertation as cited in The Gerontologist, was granted by the Oxford University Press on November 24, 2014.
Dedication

This dissertation is dedicated to my family, who have lovingly encouraged and supported me on this academic journey with their sacrifices of time and resources. To my parents, John and Betty Clouser who instilled in me the idea that anything in life is possible if you work hard and persevere. Although they did not entirely comprehend the time and effort that would be needed to complete this degree, they stood by and supported me on each leg of the journey. They provided celebrations when goals were met and provided reinforcement when insurmountable obstacles arose. I am thankful that they taught me how to think rather than what to think. This parenting skill afforded me the means to navigate the various ways of learning on my nursing journey.

To my brothers, Dennis and Brian I am indebted to you for your wisdom and advice at times when I most needed the encouragement and guidance. Although you never knew exactly what I was facing, you provided a sounding board for me to work through the many difficulties on this journey and gave me the reassurance that “I could do it.” I am very fortunate to have such supportive brothers and I thank you both.

I also dedicated this dissertation to my grandparents. I first want to mention my grandmother Genevieve Clouser. Genevieve always wanted to be a nurse but through circumstances not of her own, she became a secretary instead. She was strong and caring and an inspiration to me. She carried herself with grace and dignity throughout life, even into death. I will treasure these traits and constantly try to emulate them. I became the nurse she was not able to be. Next, I want to mention my grandparents Ray and Mildred Rodkey. Ray was the inspiration for this dissertation. He was the family caregiver to my grandmother Mildred who
had Alzheimer’s disease. He not only cared for his wife, he also cared for their mentally challenged adult son who was also physically challenged. His dedication to caregiving inspired me to want to help family caregivers especially those who care for people diagnosed with dementia.

Last by never least, I wholeheartedly dedicate this dissertation to my two children Lauren and Levi. They made the biggest sacrifice of anyone- giving up part of their time with their mother so that she could pursue her dream in nursing. They endured fast foods for supper, being picked up very late from football practice, and even having to problem solve a fender bender long distance because their mom was at school working on her dissertation. Despite inconveniences, set backs, and difficulties of having a mom in school, Lauren and Levi were a source of encouragement and inspiration for me to pursue my dream. They continue to be my cheering squad in life and I will always treasure them for it. They will never know the depths of my gratitude for their patience and support or my love for them. This dissertation is also my way of showing them what my father taught me. Anything in life is possible if you work hard and persevere. I hope that they will take on life’s challenges by looking to my example and say “if mom could do it, so can I.” I love them both and will forever be their cheerleader in life-on whatever journey they decide to take. I am very proud to say Lauren and Levi are my children.
Chapter 1

Introduction

“Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical function, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment.” (World Health Organization, 2010). In the early stages, dementia may be easily explained as “old age” or forgetfulness. However, as the disease progresses, these changes become more pronounced, prohibiting people with dementia from remembering new things, solving problems or performing familiar tasks (Alzheimer's Association, 2012; Rabins, 2013). As a result of these changes, the assistance of a caregiver becomes vital to ensure the overall well-being and safety of the person with dementia.

Dementia was initially called senility, imbecility, and stupidity prior to the adoption of the 17th century Latin root word “demens” meaning “being out of one’s mind (Berrios, 1987, p. 830). Dementia is a broad term for prolonged cognitive impairment with decreased memory and judgment and has been consistently used to describe the neurologic disease (Berrios, 1987). There are many types of dementia, of which Alzheimer’s disease is the most commonly known form. Other forms include vascular dementia, dementia with Lewy Bodies, frontotemporal dementia, Huntington’s disease and Creutzfeldt-Jakob disease (Alzheimer's Association, 2012). Currently, an estimated 5.3 million Americans have the common form of dementia known as Alzheimer’s disease; however, this overwhelming number is expected to double by the year 2030 as advancements in healthcare assist the aging “baby boomer” generation to live longer into older age (Alzheimer's Association, 2015). The proliferation of this disease will require even more caregivers to ensure the safety and well-being of people with dementia.
Adding to the growing prevalence of dementia is the fact that dementia is a slow and insidious disease process (Reisberg, 1981; Schaie & Willis, 2002). On average, a person diagnosed with dementia will live between four to eight years after being diagnosed; however, some have lived as long as 20 years with the disease (Alzheimer's Association, 2012). Therefore, as more people live longer into older age, the incidences of dementia will increase. The longevity of the disease, coupled with deteriorating cognitive and physical functioning, necessitates that people diagnosed with dementia will eventually need tremendous degrees of assistance from a caregiver.

Currently in the United States, 85 percent of all people with dementia are cared for in their homes by a family caregiver and less than 10 percent are cared for by a paid caregiver (Alzheimer's Association, 2015). These family caregivers are invaluable providers of care, saving the United States government billions of dollars (Alzheimer's Association, 2012). Family caregivers often manage the coordination of administering medications, preventing injury, providing functional support, and assessing the person with dementia for signs of when professional health services may be needed (Grant & Ferrell, 2012). Family caregivers today are co-providers of care, assuming care once provided by professional nurses. Although rewarding at times, providing care for people with dementia is challenging and stressful, placing the overall well-being of the family caregiver at risk.

Nearly two-thirds of family caregivers have admitted distress with behaviors displayed during assisted personal care activities for people with dementia (Sloane, Hoeffer, Mitchell, McKenzie, Barrick, & Rader, et. al., 2004). Caregivers frequently experience resistiveness to care when helping their care recipient with bathing, dressing, toileting, eating, or grooming (Fauth, Zarit, Femia, Hofer, & Stephens, 2006; Sloane et al., 2004). When the dementia
behaviors such as resistiveness to care become too much, caregivers will resort to placing their family member or friend with dementia into a long-term care facility (Mittleman, Haley, Clay, & Roth, 2006). Currently, research pertaining to resistiveness to care focuses on the behaviors and does not address family caregivers’ perceptions of their experiences with the behaviors. Researchers Kinney and Stephens (1989) and Pearlin, Mullan, Semple, and Skaff (1990) have suggested that uncovering family caregivers’ meanings of the encountered behaviors may provide insight into family caregivers’ reports of distress during caregiving and ultimately reveal ways to help family caregivers mediate their perceived stress, enabling them to persevere in caregiving for their dementia-afflicted family member or friend at home.

Therefore, investigating areas in which nurses can support family caregivers experiencing a potentially distressful phenomenon—resistiveness to care—is paramount to plan interventions for family caregivers (co-providers of care for people with dementia) that help them continue providing care for their family member or friend at home. As a result, a descriptive phenomenological study was undertaken to clarify family caregivers’ lived experience of resistiveness to care encountered when they provide care for someone with dementia. Findings from this study will provide information relating to the meaning structure of the resistiveness that family caregivers experience and provide nurses with a more accurate understanding of this phenomenon in order to better assist family caregivers dealing with the associated distress. Nurses are in a position to ultimately help family caregivers sustain their caregiving for people with dementia. This study was based upon family caregivers’ descriptions of their actual lived experience caring for someone who was perceived to be resistive. This chapter presents the background and significance of dementia and providing care for people with dementia, states the purpose and research questions, defines key terms, provides a brief overview of the method that
was used to answer the study questions and concludes with a summary.

**Background and Significance**

**Prevalence of Dementia**

Currently in the United States, there are an estimated 5.3 million people with a form of Alzheimer’s disease or other dementias (Alzheimer's Association, 2015). This translates to one in nine older Americans with dementia. However, the disease of dementia is often under-diagnosed and many may not know that they have it (Alzheimer's Association, 2015). Without a diagnosis of dementia, many Americans care for people who have dementia without the advantage of treatment and services currently available.

Dementia is a slow and subtle disease process affecting both cognitive function (memory and judgment) and physical abilities of the person afflicted. Its definitive diagnosis is based upon the Diagnostic and Statistical Manual of Mental Disorders (DSM-MD), which requires that there be a decline in memory that is severe enough to impede daily life functioning and at least one of the following symptoms (Alzheimer’s Association, 2015):

1. Difficulties generating coherent speech or understanding the spoken or written language.
2. Difficulties recognizing objects despite intact sensory function.
3. Difficulties executing motor activities despite intact motor function, sensory function, and comprehension of the required task.
4. Difficulties thinking abstractly, making sound judgments, planning and carrying out complex tasks.

A definitive diagnosis of dementia is made after exhausting all other treatable causes for the dementia-like symptoms (Alzheimer's Association, 2015). Treatable conditions resembling
Dementia include depression, delirium, altered thyroid function, vitamin deficiencies, excessive alcohol intake, and adverse effects of medications. All must be ruled out prior to arriving at a diagnosis of dementia (Alzheimer's Association, 2015). To date, the only assured diagnosis of Alzheimer’s disease is made post mortem by examining brain tissue looking for the telltale signs of plaque formations and tangles (Rabins, 2013; Shagam, 2009). Therefore, a definitive diagnosis in a living person is not often timely and difficult to obtain delaying appropriate management of the disease.

Dementia is characterized by memory loss and impaired judgment. More specifically, nerve cells, particularly in the hippocampus section of the brain, are not able to transmit signals along the neuro pathways and die, causing problems with cognition, memory, and behavior (Rabins, 2013). In the nerve cell degenerative process, plaques and tangles are present and are believed to further compromise neuro transmissions. However, an exact cause of dementia has not been found (Alzheimer's Association, 2015; Rabins, 2013). Risk factors for dementia have been identified and include genetic tendencies, being a female, and being older in age.

Scientists have determined that having a family member with Alzheimer’s disease increases other family members’ risk of the disease. In fact, family members (first degree relatives) of someone diagnosed with Alzheimer’s disease have a greater chance of inheriting the disease whether through an abnormal gene, shared environment, or possibly similar lifestyles (Alzheimer's Association, 2015; Rabins, 2013). Being female is another risk factor. Researchers are not clear why women tend to display symptoms of the disease more so than men, but are looking into estrogen levels as a possible reason for the gender differences (Rabins, 2013). Lastly, the strongest risk factor for dementia is being 65 years of age and older. The risk for dementia actually doubles every five years past the age of 65 and nearly half of those over the
age of 85 have the disease (Rabins, 2013). This is of concern as the “baby boomer” generation [an unusually large cohort of the population born between 1946-1964] (Schaie & Willis, 2002) have started turning 65, further increasing the United States’ proportion of elderly people.

Other factors thought to contribute towards the development of dementia include: presence of apolipoprotein gene called APOE 4, elevated lipoprotein levels, presence of cardiovascular disease, Down syndrome, history of head injury, and a history of depression (Rabins, 2013). Over twenty years ago it was believed that exposure to aluminum contributed the disease. However, further investigations into the exposure to aluminum through consuming products containing aluminum or food cooked or stored in aluminum containers have shown this not to be the case and have deemed that there is no increased risk of dementia with aluminum exposure (Rabins, 2013). Despite the identification of contributing factors no cure has been found and the incidence of dementia is expected to increase.

The prevalence of dementia is not expected to diminish anytime soon. The opposite is true; the occurrence of dementia is expected to increase as improvements in healthcare enable our older populations to live longer. The number of Americans aged 65 and older is expected to double by the year 2030 and by 2050 the number of people living with Alzheimer’s disease and other dementias is expected to reach nearly 13.8 million provided there is no medical cure or prevention by that time (Alzheimer’s Association, 2012; 2015). As the disease progresses, the growing number of people with dementia will eventually need assistance from a caregiver.

**Family Caregiving**

Families frequently offer to care for a family member or friend who becomes sick or disabled and they consider caregiving to be part of their familial obligation (Zarit & Zarit, 2007). In the United States, family caregivers provide vast amounts of unpaid care and the amount of
care provided is expected to rise as the number of people with disabilities or chronic illnesses (needing assistance) continues to increase (Grant & Ferrell, 2012; Zarit & Zarit, 2007). Typically caregivers are the spouses of the recipient of care, with both husbands and wives equally represented as family caregivers (Zarit & Zarit, 2007). When there is no spouse to provide the care, children will become caregivers [with daughters or daughter-in-laws providing care more than sons] (Zarit & Zarit, 2007). It is when there are no children to provide care that distant family members (siblings, grandchildren, or niece/nephew) or friends and neighbors will become the caregiver for the person with disabilities (Zarit & Zarit, 2007).

The number of family caregivers is on the rise. Currently in the United States, family members provide 85 percent of unpaid care for older adults (Alzheimer’s Association, 2015). This increase in family caregivers is often attributed to the increase in the number of people living with chronic illnesses; however, changes in the way healthcare is delivered—decreasing lengths of stay and changes in hospitalization reimbursement policies—are expected to contribute to this increase (Grant & Ferrell, 2012). As a result, when patients are discharged from healthcare facilities, family caregivers are charged with becoming co-providers of care and are expected to: manage complex symptoms of diseases; coordinate medication administrations and treatments; as well as determining when to call the physician [such as when the disease condition changes] (Grant & Ferrell, 2012). These duties were previously charged to healthcare professionals (nurses) and not family members.

Caregiving for family member or friend is increasingly stressful. A wide range of research into family caregiving has acknowledged that the caring for a family member or friend is demanding and caregivers frequently report feelings of depression and distress (Grant & Ferrell, 2012; Zarit & Zarit, 2007). Caregiver burden has been conceptualized as both subjective
factors [feeling of distress or strain in the role as caregiver] and objective factors [tasks required in caregiving, and financial burdens related to caregiving] (Bedard, Pedlar, Martin, Malott, & Stones, 2000; Pearlin et al., 1990). Both Bedard and colleagues (2000) and Gort and associates (2007) agree that caregiver burden is a real phenomenon and one that, if left unchecked, will usually result in the placement of the care recipient into a long-term care facility.

Contributing to the challenges of caregiving is the fact that caregiving has changed dramatically over the last several decades. Elderly people did not usually live into their 80’s or 90’s thus caregiving was not a common occurrence. People did not live as long or with the severity of illnesses that they do today. In addition, the resources that family caregivers once depended upon to care for their family member or friend are shrinking. For example, people do not have the large extended families to help with the caregiving role as they once did. Women typically did not work outside the home enabling more time for caregiving. Divorce rates were not as high as they are today, which may limit the options for family care providers (Zarit & Zarit, 2007).

The Stress Process Model of caregiving depicts caregiving stress as a multi-dimensional process in which coping and social supports appear to be potential buffers against stressful caregiving (Pearlin et al., 1990). Family caregivers who receive caregiving help from other family members or outside social support services appear to do better in their caregiving role than those family caregivers who have limited family help or do not take advantage of outside social support services (Zarit & Zarit, 2007). In addition, family caregivers who have the ability and skills to cope with situations that occur during caregiving fare much better than those who do not. Those who are not able to deal with the stress of caregiving may consider placing their family member or friend in a long-term care facility earlier in the caregiving trajectory.
However, placement does not necessarily decrease the stress on the family caregiver, as they may need to travel a distance to see their family member or friend, may become uncertain of their new role (working with other caregivers) while visiting at the facility, and they may endure financial stressors as a result of the placement (Zarit & Zarit, 2007). Dementia family caregivers share these same stresses and burdens. However, dementia caregivers provide care for longer durations than caregivers of people without dementia (usually over many years), are almost ten years older than other disease caregivers (Alzheimer's Association, 2015), and perceive more distress and burden (Pearlin et al., 1990) in their caregiving role.

**Dementia Family Caregiving**

Once diagnosed with dementia, it is inevitable that at some point people diagnosed with dementia will need someone to care for them. As noted earlier over 85 percent of people diagnosed with Alzheimer’s disease and other dementias are being cared for at home (Alzheimer's Association, 2015). In 2012 it was estimated that greater than 15 million family members, friends, or neighbors in the United States are providing over 17.9 billion hours of unpaid care for someone with dementia (Alzheimer's Association, 2012); thus, the cost of care is placed on the individual and not the United States healthcare system. Informal caregivers today are valuable co-providers of care as they save the healthcare system an estimated $217.7 billion in care costs annually (Alzheimer's Association, 2015). This figure is nearly eight times the amount of total revenue that McDonald’s reported in 2013 [$28.1 billion] (Alzheimer’s Association, 2015). The dollar value assigned to unpaid dementia family caregivers is said to almost equal the costs of direct medical care and long-term care of people with dementia (Alzheimer’s Association, 2015). Cumulatively, these figures show that providing care for someone with dementia is expensive, and when family caregivers provide care for people with
dementia, the government and taxpaying public save tremendous amounts of financial resources.

Providing care for people with dementia is personally demanding. Sixty-one percent of family caregivers reported high amounts of emotional stress in caring for their family member or friend with dementia (Alzheimer's Association, 2012). The following diary excerpt of a daughter caring for her father exemplifies family caregivers’ stress and frustration when dealing with resistiveness during assisted personal care. “We had our weekly battle to wash Dad’s hair and have a bath. I managed the hair but he refused point blank to get in the bath. Under duress he had a strip wash” (Clarke, 1999, p. 714). A second family caregiver illustrates her distress. “[My mother] asked me for water about 2-3 o’clock in the morning. She tried to do it by herself, not wanting to disturb my sleep. But she frequently makes mistakes, wetting her clothes. I had to clean up the mess that she made in the middle of the night” (Han, Choi, Kim, Lee, & Kim, 2008, p. 521). These passages vividly describe the stress, frustration, and involvement when caring for someone with dementia.

The amount of time and personal sacrifice needed to care for someone with dementia can be appreciated when examining the typical day of a dementia caregiver. Caregivers who live with a person diagnosed with dementia must provide 24 hours of supervision; 7 days a week in order to prevent persons’ with dementia from wandering off, getting lost, or hurting themselves (Alzheimer's Association, 2008). Stress is further added by the fact that caregivers have little respite, especially at night. As described by a family caregiver in the previous paragraph, many people with dementia awaken needing assistance with toileting or other care needs. Caregivers’ duties increase as the care recipient’s cognitive function declines, leaving family caregivers with less and less free time (Aguglia, Onor, Trevisiol, Negro, Saina, & Maso, 2004). Without support, family caregivers run the risk of burnout and health consequences relating to these
caregiving demands. Therefore, it is vital that healthcare providers recognize early signs and risk factors to prevent caregiver burnout and poor health outcomes (that result from providing care for those with dementia), which ultimately prevent caregivers from continuing to provide care.

**Identifying Factors Contributing to Caregiver Stress**

In order to support family members caring for their dementia afflicted family member or friend, social scientists (Pearlin et al., 1990) investigated factors that contribute to caregiver stress and feelings of distress. Although they were not able to isolate a specific factor that makes this task so difficult, they were able to reaffirm that providing care for people with dementia is a difficult task and identify multiple contributing factors. As a result, they developed a theory called the Stress Process Model of caregiving that identifies multiple contributing factors that lead to caregiver stress or feelings of distress (Pearlin et al., 1990). By using the Stress Process Model of caregiving, and a clear understanding of stressful caregiving situations, interventions can be formulated targeting identified factors that impact family caregivers’ distress. By decreasing family caregiver distress, healthcare providers are able to help family caregivers sustain their caregiving role and prevent placement of the person with dementia.

Within the Stress Process Model, contributing factors include primary stress indicators--behavioral symptoms of the disease: hallucinations, agitation, aggression, irritability, and delusions, which may be considered forms of resistiveness to care if they occur within the context of daily care activities (Volicer, Bass, & Luther, 2007). Dealing with the behaviors that result in resistiveness to care are distressing for caregivers (Matsumoto, Ikeda, Fukuhara, Shinagawa, Ishikawa, & Mori, et. al., 2007; Robinson, Adkisson, & Weinrich, 2001). Pot, Deek, van Dyck, and Jonker (1998) identified strong correlations between behaviors of people with dementia and caregivers’ distress. Gaugler, Davey, Pearlin, and Zarit (2000) noted from findings
in their study that behaviors such as resistive behaviors displayed by people with dementia are predictive of the amount of stress family caregivers perceive. In fact, 65 percent of family caregivers admit difficulties with providing personal care because the person with dementia becomes aggressive or agitated (Sloane et al., 2004). Thus, as the dementia disease progresses, providing assistance for people with dementia can become increasingly stressful particularly when resistiveness to care is added to the financial and time-consuming burdens of caregiving.

**Variations in Caregivers Appraisals**

Despite the Stress Process Model of caregiving postulating that caring for people with dementia is stressful researchers have found variations in caregivers’ perceptions of the dementia behavioral symptoms such as those that manifest as resistiveness to care. It appears that caregivers’ appraisals of the behaviors are positively correlated with caregiver distress but highly individualized. For example, Gaugler, Davey, Pearlin, and Zarit (2000) noted that the frequency of behavioral symptoms did not always predict increased family caregiver distress with the behaviors. Family caregivers who experienced frequent behaviors did not always report distress with the behaviors. Some family members who experienced a particular behavior infrequently also reported distress. Consequently, family caregiver appraisal of the behaviors was a better indicator of family caregiver distress than the objective frequency of behaviors.

In this same line of thought, Lawton, Kleban, Moss, Rovine and Glicksman (1989) agree that family caregivers’ subjective appraisals of stressors such as resistiveness to care are a better determinant of caregiver distress than the objective stressor—the behaviors or their frequency. They argue that not all caregivers will appraise the same situation as stressful or burdensome. The Mittleman, Roth, Haley, and Zarit (2004) study adds support that family caregivers’ appraisals of the behaviors are a better indicator of caregiver distress than the rates at which the
behaviors occur. Robinson and colleagues (2001) also noted that caregivers’ perceptions of the severity of the dementia behaviors were more influential in their reaction to the behaviors than the objective frequency with which the behaviors occurred.

Variation in caregivers’ perceptions of the dementia behavioral symptoms (such as those that manifest as resistiveness to care and perceived distress with the behaviors) may be relationally linked. The Gaugler, Davey, Pearlin and Zarit (2000) study findings indicate that spousal caregivers report more stress in caregiving than non-spousal caregivers. Pot, Deeg, van Dyck, and Jonker (1998) also found differences in caregivers’ perceived pressure and reported distress of the caregiving experience based upon the relationship between the family caregiver and the person with dementia. In fact, Pot and colleagues (1998) found that non-spousal caregivers’ perceptions of caregiving pressure tended to mediate their reported level of caregiver distress more so than spousal caregivers.

Although caregivers’ perceptions of stressful caregiving situations (such as providing assistance with daily care activities for people with dementia) have been empirically correlated with caregiver distress, and caregiver interventions have been trialed to reduce caregiver stress and decrease perceptions of distress, these interventions have met with limited success (Zarit & Femia, 2008). Several explanations for this exist. First, current interventions relating to dementia behaviors are usually tested using a clinical trial approach and view caregiving as a disorder similar to clinical depression, which may not be suited for individual variability in perceptions of caregiving. These studies use relatively small sample sizes. A second possible explanation is that caregiving is relationship-dependent and that some family caregivers are not willing to make suggested changes that may relieve their stress (Zarit & Femia, 2008). One such example is that caregivers find it difficult to relinquish some of the care in the use of community
offered services—adult day care and in-home caregiving assistance. Gaugler, Kane, Kane, and Newcomer (2005) noted in their study findings that family caregivers of people with dementia did not embrace community-based services despite their potential to provide intermittent respite for the caregivers. These researchers have recommended further investigation into contextual and life-course issues relating to dementia caregiving to further refine the stress process and to add clarification of the dementia caregiving experience.

Despite ample current research aimed at helping dementia family caregivers manage behaviors and improve caregivers’ perceptions of the caregiving experience, a paucity of research still exists. In particular, family caregivers’ descriptive perceptions, thoughts, and meanings of the phenomenon resistiveness to care as factors that could mediate caregiver distress have not been thoroughly studied. Qualitatively uncovering more details relating to resistiveness to care may help nurses gain insight into new ways to help family caregivers manage these stressful situations. Kinney and Stephens (1989) postulate that care recipients’ behaviors may be symbolic to family caregivers. They propose that the behaviors displayed by people with dementia may be reminders to family caregivers of the changing person with dementia and that this reminder may be more distressing than the behaviors themselves. Gaining this information from family caregivers may provide insights into their experience of resistiveness to care, so that nurses can more compassionately assist family caregivers and help them reduce their stress through understanding of what the behaviors mean to them, potentially improving the caregiving experience for them.

**Cumulative Effects of Stressful Caregiving**

The cumulative effect of stressful caregiving situations must also be acknowledged. Ongoing, stressful caregiving situations have the potential to seriously affect the health of the
caregiver. In fact, 33 percent of dementia family caregivers report symptoms of depression and 75 percent reported being concerned about maintaining their own health since they became caregivers (Alzheimer's Association, 2012). Social scientists (Anthony-Bergstone, Zarit, & Gatz, 1988; Gaugler et al., 2000) have identified that repeated exposure to caregiving stresses could impact family caregivers’ physiological health and overall well-being. Pearlin, Schieman, Fazio and Meersman (2005, p. 214) ascertain that although the consequences of stress may vary, “the persistence, bundling or layering of stressors across time, can add to what is called the allostatic load. The greater this load the more difficult it is for bodily systems and their biological products to function optimally”. Therefore, the overall health and wellbeing of family caregivers may be in jeopardy.

This is particularly serious for older persons who are caregivers. Elderly caregivers are less likely than younger caregivers to be able to handle the stressors of providing care in negative situations (Arking, 2006). Of the more than 15-million dementia family caregivers, 34 percent are age 65 or older (Alzheimer’s Association, 2015). Sixty-six percent of caregivers are women, non-Hispanic white, are married or in long-term relationships, and most caregivers either live either with the care recipient or live within 20 minutes of the person with dementia (Alzheimer's Association, 2015; Gaugler et al., 2000; Matsumoto et al., 2007; Mittleman et al., 2004). Compared with other caregivers, the mean age of dementia caregivers is 8 years older than caregivers for other disease conditions (Alzheimer's Association, 2012). Thus the potential exists for serious health consequences among this group of caregivers.

The current research surrounding dementia caregiving has established that negative caregiving situations such as repeated exposure to caregiver appraised stressful events (like resistiveness to care) could be detrimental to the elderly family caregivers caring for people with
Therefore, it is imperative that healthcare providers (especially nurses) understand perceived stressful aspects of family caregiving (such as experiences of resistiveness to care) in order to help family caregivers (co-providers of care) remain healthy themselves and sustain their caregiving role. Nurses who understand and value what caregivers experience are more sensitive to caregiver issues and have an increased ability to diagnose and intervene early to give the needed family caregiver support. To further understand the lived experience of resistiveness to care from a family caregiver’s perspective, a descriptive phenomenology study was done exploring the structural meaning of dementia family caregivers’ lived experiences of resistiveness to care. The nursing disciplinary perspective used during data analysis enabled the researcher to gather nursing relevant insights.

**Statement of the Problem**

One of the most challenging aspects of providing care for people with dementia is the behavioral and psychological symptoms of the disease (Matsumoto et al., 2007). This is particularly true when these behavioral symptoms occur within the context of caregiver actions such as assisting with activities of daily living (ADLs) and become known as resistiveness to care. The potential for resistiveness is high; 70-90 percent of people with dementia will exhibit these behaviors (depression, irritability, restlessness, agitation, and verbal or physical aggression) at some time during their illness (Davis & Tremont, 2007). Reportedly, the most distressing of all behavioral symptoms for informal family caregivers are verbal agitations [repeating questions and verbally resisting routine activities] (Rowe, Straneva, Colling, & Grabo, 2000). Therefore, persons caring for people with dementia will at some point experience behavioral symptoms of dementia and perceive these experiences to be stressful especially if the verbal resistance is in the form of a strong “NO” response.
Resistiveness to care (displayed by dementia patients) frequently occurs during caregiving interactions such as bathing and other activities of daily living (Hoeffer, Talerico, Rasin, Mitchell, Stewart, Mckenzie et al., 2006). Wells, Dawson, Sidani, Craig and Pringle (2000) noted “morning care is most difficult for residents [of long-term care facilities] and [nursing] caregivers because it is the time when touch and close intimate contact occur” (p. 422). Sloan and colleagues (2004) also acknowledge that morning care such as bathing, dressing and toileting are time of high touch that may contribute to the discomfort of both the dementia caregiver and care recipient, contributing to the prevalence of resistiveness and stress for caregivers.

Nurse scientists (Hammar, Emami, Gotell, & Engstrom, 2011; Mahoney, Trudeau, Penyack, & Macleod, 2006; Sloane et al., 2004; Wells et al., 2000) have agreed that resistiveness to care experienced during a caregiving encounter is difficult for caregivers to manage and have developed ways in which nurse caregivers and family caregivers can intervene to manage the resistiveness to care. Nursing interventions target issues surrounding incontinence, toileting, feeding, and walking, but the majority of interventions focus specifically on resistiveness to care displayed during bathing and dressing (Athlin & Norberg, 1987; Hoeffer et al., 2006; Mahoney et al., 2006; Rogers, Holm, Burgio, Granieri, Hsu, Hardin et al., 1999). Several nurse scientists (Kovach, Noonan, Schildt, Reynolds, & Wells, 2006; Mahoney et al., 2006; Simpson, Stevens, & Kovach, 2006) have proposed interventions to improve nurse caregivers’ recognition of and interventions to decrease the occurrence of resistive behaviors that occur during caregiver-assisted activities such as assisted ADLs. However, these interventions, which consisted of algorithms to detect resistiveness to care and suggested ways that nurses might intervene when resistive behaviors occurred have not met with the robust results that were hoped for. Although
the interventions did decrease resistive behaviors associated with assisted care, nurses reported
more time and effort was needed to implement the interventions, making the interventions less
likely to be used. Rogers and colleagues (1999) reflected upon the cost of implementing these
interventions and concluded that the additional time required to implement the interventions
might not be cost effective. In fact, decreased agitation and improved functional abilities for the
person with dementia was achieved at almost twice the usual amount of caregiving time needed
to complete the ADL tasks prior to using the interventions.

Further evaluation of these proposed interventions by Rodgers and associates revealed
that the interventions to decrease behaviors displayed by people with dementia during caregiver-
assisted ADLs were either difficult to implement or did not improve the overall caregiving
experience for the caregivers. Mahoney and colleagues (2006) found that despite the
intervention decreasing levels of agitation in the people with dementia, caregivers perceived that
the ease of providing care and their level of stress did not improve. Lastly, Wells and colleagues
(2000) concluded that providing care for people with dementia is a tremendously difficult task.
They recommended that future interventions go beyond just reducing the occurrence of care
resistive behaviors during caregiver assisted ADLs to include a more holistic approach to
caregiving that includes consideration of both caregiver and care recipient.

Mahoney and colleagues (2006) noted that situational factors occurred at the same time
when caregivers attempted to implement the interventions to prevent or stop resistive behaviors.
These situational factors also caused an escalation in resistance making it difficult for caregivers
to continue with the interventions. An example from their study demonstrates this as one family
caregiver attempted to assist her husband using the resistiveness intervention. She stated, “Oh
please, there is no satisfaction in this! ….I am just waiting until I have a chance for another life.”
She had experienced domestic violence by her husband and found it difficult to implement the intervention approach to accomplish the task of caregiving (Mahoney et al., 2006, p. S13). Many factors contribute toward caregiver’s overall perception of the caregiving experience. Some of these factors may include individual caregiver perspectives of whether caregiving is a difficult job and situational factors that occur while performing the task.

The frequency at which resistiveness to care occurs has been documented. In studies investigating family caregivers and the occurrence of resistiveness to care, “family caregivers report that as many as 65 percent of persons with dementia become aggressive during care” (Sloane et al., 2004, p. 1795), which can lead to resistiveness to care. Despite family caregivers’ frequent encounter with resistiveness to care, there is a lack of nursing research investigating family caregivers and the phenomenon of resistiveness to care. The majority of published research studies focused on nursing caregivers and their experience with dementia patients’ resistiveness to care.

The problem that is the focus of this study is the current lack of understanding of what the caregiver is actually experiencing during resistiveness to care and the impact of this experience on their caregiver role. Enhanced understanding can provide insights for the development of interventions aimed at improving measures used to help caregivers managing this distressing experience. This researcher contends that by understanding the caregiver’s lived experience of resistiveness to care, nurses will increase their thoughtful actions when they assist dementia family caregivers to cope with the phenomenon of resistiveness to care. Nurses will be able to respond more holistically to the entire phenomenon of resistiveness to care and not just focus on the presenting physical behaviors of resistiveness to care.
**Purpose of the Study**

The purpose of this study was to explore from a nursing perspective the phenomenon of resistiveness to care that family caregivers frequently encounter when interacting with or providing care for people with dementia. Through the use of a modified Husserlian approach to descriptive phenomenology called the *scientific phenomenological method*, family caregivers’ everyday lived experiences of resistiveness to care were described. These descriptions, when analyzed from a nursing disciplinary perspective, provided insight for future interventions that sociologists studying dementia behaviors may have missed.

Giorgi, the creator of the scientific phenomenology method contended that modifications to the Husserlian method were necessary in order to conduct research on human experiences from a scientific standpoint rather than a philosophical standpoint (Giorgi, 2009). He also thought it was important to include a disciplinary perspective during analysis to improve understanding of the phenomenon as the traditional philosophical phenomenology analysis would not capture the human experience of the phenomenon adequately (Giorgi, 2009). The following are adaptations to the Husserlian approach integrated into the method by Giorgi (2009):

1. Obtaining research data from the experiences of others rather than the researcher.
2. Using a form of phenomenological reduction that remains closer to the lived reality (human experience) than the radical transcendental reduction.
3. Ultimately seeking psychological essences represented as an invariant meaning structure (analogues to a measure of central tendency or common meaning given all variations of the experience) rather than seeking the most universal essence as with the philosophical approach.
The researcher believed that by using the scientific phenomenological method, an identified descriptive meaning structure of the dementia family caregivers resistiveness to care experience would be revealed. The researcher also believed that the meaning structure would provide clues into nursing sensitive areas that nurses could identify with and use to help support dementia family caregivers as they manage the often-stressful phenomenon of resistiveness to care.

**Professional Significance**

“Caring is a genuinely experiential phenomenon both on the side of the recipient and the giver. This means that the care given has to be responsive to the other’s entire situation in the world and not just to the medical and technical aspects of the person’s body” (Giorgi, 2005, p. 82). Therefore, this study is designed to increase nurses’ understanding of family caregivers’ lived experiences of resistiveness to care during caregiver-assisted daily activities to support development of a more holistic approach to caring for family caregivers. Family caregivers are considered co-providers of care. They are challenged with providing care for people with dementia that was once provided by professional healthcare providers [nurses] (Grant & Ferrell, 2012). The researcher believes that it is in the best interest of nurses to support family caregivers as co-providers of care in the dementia care dyad (person with the dementia and family caregiver) and to be concerned with family caregivers’ overall wellbeing (when dealing with stressful aspects of caregiving such as resistiveness to care).

Using the scientific phenomenological method (Giorgi, 2009) as a way to understand the phenomenon of resistiveness to care was unique in that the researcher was able to gain a sense or awareness of the caregiver’s world of resistiveness to care with sensitivity to nursing care. The understanding gained from this study was not from conceptualizations, but rather it came from looking at resistiveness to care from a more tangible perspective—the family caregiver’s lived
experience—and was analyzed incorporating a nursing disciplinary perspective to gain clarity of the life course issue of resistiveness to care as it was presented by family caregivers. In addition, the insights gained from this study can be used to advance nursing praxis in resistiveness to care behavior, as well as enable nurses to have empathy toward the family caregivers as they assist them to identifying their needs, and better manage the resistiveness to care behavior. The identified family caregiver structural meaning of resistiveness to care, can provide a base for future nursing research to identify theoretical formulations for the identified structure; to define the utility of the structure for use in nursing clinical practice; and to determine the feasibility of interventions to assist family caregivers in coping with the experience of resistiveness. The ultimate goal is to provide groundwork of data that supports development of strategies that enable dementia family caregivers to sustain satisfaction with their caregiving role. It is proposed that increased knowledge can help prevent premature placement of the care recipient in a care facility—a win for both families and the nation.

**Theoretical Frameworks Applicable to the Phenomenon of Resistiveness to Care**

Theory and research are intertwined as “theory directs research and research findings shape the development of theory” (Reed, Shearer, & Nicoll, 2004, p. 11). Specifically, theory (the systematic elucidation or prediction of the relationships between and among constructs or concepts) guides all phases and all forms of research (Morse & Field, 1995) either as theory building or theory testing (Reed et al., 2004). Popper (1965) acknowledges that even qualitative researchers use some theoretical observations as a framework in forming their research approach. Several theoretical frameworks have influenced this study as well.

At this time, three theoretical frameworks are considered to be instrumental in the formulation of research studies investigating the phenomenon of resistiveness to care.
experienced by family caregivers of people with dementia. The frequently used theoretical frameworks include the Needs Driven Dementia Compromised Behaviors theory [NDB] (Whall, 2002), the Progressively Lowered Stress Theory [PLST] (Hall & Buckwalter, 1987), and the Stress Process Model of caregiving [SPM] (Pearlin et al., 1990). A brief overview of each theory is given in this section. A more detailed description and application of each theory is presented in Chapter Two.

**Needs Driven Dementia Compromised Behavior Theory (NDB)**

The NDB theory posits that background and proximal factors contribute to behaviors displayed by people diagnosed with dementia and are in response to a need that cannot be verbalized due to the dementia disease progression. Background factors of NDB are characteristics such as personality, progression of the dementia disease, and cognitive impairments that result from the disease process. These background factors are said to be relatively fixed and unchangeable.

In addition, this theory posits that proximal factors such as the environment (temperature or lighting of a room), interaction between caregiver and care recipient, and spacial relationships within a confined area (furniture or human occupation) can be modified, changed, or altered to potentially reduce or diminish the resulting needs-driven behaviors (Algase, Beck, Kolanowski, Whall, Berent, Richards et al., 1996). Many of the current nursing interventions using this theory target proximal factors as potential ways for caregivers to diminish need-driven behaviors. However, it has been found that complete elimination of the behaviors is not possible as increasing neurologic destruction causes more behaviors.

**Progressively Lowered Stress Theory (PLST)**

The PLST proposes that people with dementia experience a lowered stress threshold than
those persons without the disease of dementia (Smith, Gerdner, Hall, & Buckwalter, 2004). The
theory also suggests that because of cognitive and functional declines, stress thresholds of people
with dementia can become taxed within a 24-hour day as stressors pile up. When the person
with dementia becomes stressed, behaviors occur making it difficult for care to be provided.

The premise of the PLST is to decrease the stress of people with dementia and is
accomplished by both educating family caregivers to the potential stressors and planning ways to
help family caregivers decrease the stress through environmental modifications (Smith et al.,
2004). Through the use of PLST, family caregivers are encouraged to manage the stress by
providing rest periods throughout the day for the person with dementia and assessing the person
with dementia frequently to identify early behaviors as potential warning signs that the stress is
becoming too much.

The Stress Process as a Model of Caregiving (SPM)

Similarly, the Stress Process as a model of stressful caregiving focuses on stress but from
the perspective of caregivers rather than people with dementia. The SPM explains factors
contributing to why people appraise an event to be a harm, a threat, or a challenge and ultimately
stressful. There are four components to this model: the background and context of stress; the
stressors; the mediators of stress; and the outcome manifestations of stress. The appraisal
process occurs at the time of the event and continues when the outcome of the event is
unfavorable. This is a cyclic process with continued reappraisals. When the continued
reappraisals are negative, it has the potential to produce a condition of chronic stress.

The appraisal of an event is very individualized. Two people can experience the same
event but each can appraise the event differently. One person may find the event non-threatening
and not stressful, while a second person may find the event very challenging and therefore
stressful. This stress appraisal process is applied to family caregivers of people with dementia and can be specifically applied to the stressor—resistiveness to care. Not all family caregivers will appraise resistiveness to care as a threat or harmful, but many find it challenging. Stress appraisals can be mediated by factors such as coping, social support, or social networks. Theoretically, dementia family caregivers have the potential to mediate their stress response to resistiveness to care through coping, social support, or social networking.

**Summary of Applicable Theoretical Frameworks**

While both the NDB and PLST are appropriate theoretical frameworks for research studies pertaining to resistiveness to care, several reasons exist why the NDB and PLST theories were not selected for this proposed research study. First, both the NDB and PLST focus exclusively on the behaviors of resistiveness to care displayed by the person with dementia and ways to reduce or prevent the behaviors. Focusing on the causation of behaviors, both the NDB and PLST provide plausible explanations of why behaviors occur in people with dementia and provide rationale for interventions to decrease the occurrence of these behaviors. However, the scope of such a study would be limited to needs-driven behaviors or resulting stress-related behaviors and not provide insights into family caregivers’ appraisals of the behaviors or the experiential meaning caregivers have for resistiveness to care. In contrast, the aim of this study was to gain more understanding of the phenomenon by going to the things themselves (Giorgi, 2009) and holistically examining the phenomenon of resistiveness to care from the lived experience of the family caregivers as they live with the resistiveness to care phenomenon. This study was not limited to specific types of resistiveness to care behaviors or the rationale for why the behaviors occurred.

A second reason for not using the NBD or PLST theories was the theoretical constraints
and limitations. As a unidirectional model, the NDB proposes that background and proximal factors both combine to influence the outcome of need-driven behaviors. This research study sought to understand an unidentified relationship between family caregivers, people with dementia, and the resistiveness to care that occurs. The potential existed that the interrelationship among these three variables was multidirectional and not represented by the unidirectional NDB theoretical model.

The PLST as a theoretical framework is based upon the concept that people with dementia experience decreasing stress thresholds as the disease progresses. This has never been empirically tested (Volicer & Hurley, 2003). Although the PLST theorists have demonstrated successful outcomes by caregivers using their theory to reduce the occurrence of behaviors theorized to be the result of decreased stress thresholds, and indirectly decrease stress for family caregivers (Gerdner, Buckwalter, & Reed, 2002; Gerdner, Hall, & Buckwalter, 1996), there is no empirical evidence to support that people with dementia actually experience lowered stress thresholds than persons without the disease (Volicer & Hurley, 2003). To base a study on the premise of lowered stress thresholds for people with dementia when empiric evidence to support lower stress thresholds does not exist, would have decreased the validity of this study’s findings.

Consequently, neither the NDB nor PLST theory was considered as a theoretical framework for this proposed study due to the narrow focus on resistive behaviors, the single directionality of the NDB theoretical model, and the incomplete evidence for progressively lowered stress thresholds of people with dementia. Instead, the Stress Process Model of caregiving aided the researcher in the formulation this study. Using the identified gaps in current research surrounding resistiveness to care and unexplored areas of the SPM the researcher focused the current study toward examining the lived experience of family caregiver’s encounter
with resistiveness to care during caregiver-assisted activities and the meaning they ascribe to this potentially stressful phenomenon.

One unexplored aspect of the SPM posited that the attention required by resistive behaviors could serve as a constant reminder to the family caregiver (that the person displaying these behaviors is no longer the person he or she used to be), poses a challenge, and as a result is a potential stressor for the family caregiver to endure (Pearlin, et. al., 1990). In addition, it is known that family dynamics and relationships change when a family member is diagnosed with dementia (Zarit & Zarit, 2007). This too, has the potential to be a major source of stress for family caregivers and may contribute to the stressfulness of resistiveness to care. Therefore, this descriptive scientific phenomenological method study used the Stress Process Model of caregiving as a means for identification of under developed areas in the exploration into the lived experience of resistance that family caregivers encounter when assisting their care recipient with dementia in daily care activities. The current study provided insights into the potentially stressful phenomenon of resistiveness to care, identified a meaning structure of family caregivers experience with resistiveness to care, provided clarification of this phenomenon and a foundation for future research, and provided nursing insights into areas of opportunities to help family caregivers deal with this potentially stressful phenomenon.

**Scientific Phenomenological Method of Inquiry**

A descriptive scientific phenomenological method [a modified Husserlian approach by Giorgi (2009)] was conducted to further investigate the human phenomenon of resistiveness to care experienced by family caregivers when assisting their family member or friend diagnosed with dementia in daily activities. Descriptive phenomenology was developed in the early nineteenth century by a philosopher named Husserl to investigate his interest in how “things”
present themselves to the human consciousness and the meaning associated with the way in which the “thing” is presented (Husserl, 1964; Mohanty, 2008). Research during this time period relied heavily upon the positivistic paradigms of the math and physics disciplines and Husserl believed that these ontological perspectives were not congruent with understanding human phenomena (Mohanty, 2008). Husserl believed that preconceived theories and notions of the naturalistic inquiry introduced biases during analysis of experiential descriptions of phenomena.

Husserl’s goal was to capture the pure subjective characteristics of the human lived experience, but he wanted to ensure that the new method was rigorous enough to have scientific merit (Husserl, 1964; Mohanty, 2008). Thus Husserl’s descriptive phenomenology method was created utilizing the tenets of transcendental philosophy with the expressed goal to develop universal descriptions of phenomenological experiences (Husserl, 1964). However, a fellow phenomenologist and psychologist, Giorgi (2009) felt universal descriptions were not close enough to the actual human experiential phenomena; therefore, he modified the Husserlian approach into the scientific phenomenological method. This method provides the outcome of a general description of a specific phenomenon rather than a universal description of an experiential phenomenon, which Giorgi contends does not adequately define the experience as it is lived.

The purpose of the modified Husserlian approach, otherwise known as the scientific phenomenological method, is to provide “an approach to human phenomena that respects the essential characteristics of humanness throughout the research process” (Giorgi, 2009, p. 70). When dealing with human beings, Giorgi realized that humans or relationships under study could not be reduced to things as in the philosophical approach designed by Husserl (Giorgi, 2009).
He also realized the importance of studying “things” that may not be real such as dreams, hallucinations, or thoughts and realized that the philosophical approach to phenomenology was not appropriate for dealing with these psychological phenomena (Giorgi, 1997). Therefore, the scientific phenomenological method was established.

The scientific phenomenological method is performed at the scientific level rather than the philosophical abstract level to maintain the rigor of the study, much like the philosophical phenomenology methodological approach. However, the scientific phenomenological method approach is generic enough to incorporate varied disciplinary perspectives for data collection and analysis (Giorgi, 2009). This makes the method ideal for studying a phenomenon such as resistiveness to care and use a nursing disciplinary perspective during analysis.

It was the belief of this researcher that by going into the family caregivers’ everyday world in which resistiveness to care took place, a deeper understanding of this phenomenon would be obtained. From the revealed descriptive meanings that family caregivers have of resistiveness to care, future interventions could be developed. Therefore, a descriptive scientific phenomenological method influenced by Husserl as modified by Giorgi was employed to elicit descriptions from family caregivers about their common experiences with resistiveness to care.

**Research Questions**

The following research questions guided this study.

1. What is the lived meaning of resistiveness to care as experienced by family caregivers when they assist people with dementia in daily activities?
2. What is the general meaning structure of the phenomenon resistiveness to care as experienced by family caregivers when they assist people with dementia during daily activities?
Definitions

Family Caregiver

A family caregiver is an unpaid caregiver who is primarily a family member (wife, husband, parent, child, or grandchild), but also can include friends and neighbors (Alzheimer's Association, 2012). Almost 66 percent of family caregivers tend to be female and nearly 34 percent of all caregivers are between the ages 65 or older (Alzheimer's Association, 2015). Over half (55 percent) of all caregivers provide care for their parents and about 50 percent of these caregivers also care for their children who are under the age of 18 (Alzheimer's Association, 2015). Of all dementia caregivers, approximately 27 percent live with the person with dementia, 46 percent live close by, and 75 percent report that they are also employed (Alzheimer’s Association, 2015). These family members provide indirect care (such as emotional support, financial support or transportation assistance) or direct support (providing meals, assisting with medications and ADLs). For this study, a family caregiver was a person who provided care to someone related to them or was considered a significant other. Caregivers did not need to live with the person who had dementia but had to provide indirect or direct care for the person with dementia. The family caregiver could not be paid for their caregiving.

Assisted Care

Assisted care refers to the assistance that a caregiver provides for the person with dementia. The assistance can be physically helping with tasks such as instrumental activities of daily living or completing the tasks such as shopping for groceries, preparing meals, or providing transportation for the care recipient (Alzheimer's Association, 2012, 2015). It can also be a non-physical support in the form of verbal assistance, such as giving encouragement or directions on how to accomplish the task so that care recipients can complete the task themselves. People with
dementia require at least ten percent more help from caregivers for specific activities such as getting out of bed, dressing, toileting, bathing, and eating than caregivers of older people with other diseases (Alzheimer's Association, 2012, 2015). For the purpose of this study, assisted care denoted either verbal or physical assistance that the caregivers provided for their family member or friend with dementia.

**Resistiveness to Care**

Resistiveness to care is considered to be acts invoked from the caregiving encounter that are either verbal or physical and thwart the care effort (Mahoney et al., 1999). It can be a meaningful response to the environment [a perceived threat, or disability]; a means of communicating needs [conflict, rejection]; or an unwilling acceptance of an interaction between a caregiver and a care recipient (Jablonski, Munro, Grap, & Elswick, 2005; Kolanowski, Litaker, & Baumann, 2002; Volicer & Hurley, 2003). Factors contributing to resistiveness to care may include: a distorted understanding such as cognitive impairments and immature cognitive development (Gibson, 1997); dependence on another for care (such as physical or psychological limitations); anxiety; apprehension; or an unmet physical or psychosocial need (Jablonski, Munro et al., 2005; Kolanowski et al., 2002). Ultimately, resistiveness to care can result in the interruption of care, use of force, use of physical restraints, or use of pharmacological restraints in order to provide the care (Herz, Volicer, Ross, & Rheume, 1992; Kirkevold, Sandvik, & Engedal, 2004; Volicer & Hurley, 2003). It can also result in increased distress and discomfort for both caregiver and care recipient.

For the purpose of this study, resistiveness to care was any occurrence that family caregivers perceived as a time they had difficulty while assisting with care for their care recipient and was acknowledged as it was described by family caregivers. Validation of whether or not
resistiveness to care actually occurred as the family caregiver described was not ascertained in this study as both real and unreal phenomena are acknowledged within the scientific phenomenological method (Giorgi, 2005). It was not the object of the experience—resistive behaviors that was of importance to the researcher, but rather the subjective experience of resistiveness to care as it was perceived by the care provider.

**Stress**

Lazarus, Delongis, Folkman and Gruen (1985) viewed stress as a process in which a person appraises the relationship between a stimulus and its relevance to the person’s well being. In this process the effect of the stimulus in relation to a person’s resources for managing the stimulus is also appraised. If the stimulus is appraised as being greater than the resources at hand to handle the situation, the stimulus is considered to be taxing and stressful. Adverse outcomes of the stress process are measured as depression, negative attitudes or thoughts, and sometimes level of distress. Pearlin, Mullan, Semple and Skaff (1990) measure stress as an outcome, namely depression, anxiety, poor physical health and relinquishing the caregiving role to someone else.

For the purpose of this study, stress was not objectively measured but was what the family caregivers perceived their resistiveness to care encounters to be. Family caregivers were asked to describe a recent encounter of resistiveness to care. It was the expectation of the researcher that family caregivers would provide detailed descriptions of resistiveness to care so that the researcher was able to identify the meaning resistiveness to care has for family caregivers of people with dementia and associated stress.
Distress

Providing care for people with dementia can be stressful and cause caregivers distress (Lawton et al., 1989; Pot et al., 1998). Although stress and distress may appear to overlap, Lazarus and colleagues (1985) do not consider them the same. Stress is considered a cognitive state of negatively appraising a situation and distress is the negative emotional state that results from that negative appraisal. In fact, Pearlin and associates (1990) believe that emotional distress is most likely to appear first in a stressful situation and, if left unchecked, may eventually affect the person’s physical well being. For the purpose of this study, family caregiver distress is an impetus for further exploration into this potentially stressful phenomenon. This study did not objectively measure distress since it was the family caregivers’ subjective perceptions of resistiveness to care that were of interest to the researcher and the meaning family caregivers had of the resistiveness to care experience.

Lifeworld

In phenomenology, the lifeworld is the common every day world that humans live in. It has been described as a world of ordinariness (Giorgi, 2009). Husserl believed that the lifeworld was the “ground world” from which investigations into other worlds (business, entertainment, academics, and science) emerge (Giorgi, 2009, p. 11). It is the starting point for inquiry into specialized worlds; understanding first the lifeworld. For this study the lifeworld is the everyday world of family caregivers as they assist people with dementia and experience resistiveness to care. The researcher believed that the lifeworld of family caregivers was the best starting point for understanding the phenomenon of resistiveness to care in light of the paucity of current nursing research on this phenomenon.
**Phenomenological Attitude/ Phenomenological Reduction**

The scientific phenomenology method requires the researcher to assume the attitude of phenomenology throughout the entire research process. To adopt this attitude the researcher must look at all objects from the perspective of consciousness or how they are reportedly experienced in the consciousness of the person regardless of whether there is evidence that the report is accurate or not (Giorgi, 2009). For example, a dream may be experienced as real even though it is not really actually lived. In the phenomenological attitude, the dream is a real experience and is accepted as real. This attitude is maintained throughout the study from the beginning of data collection through to analysis of the findings.

The scientific phenomenology method also requires the researcher to maintain a phenomenological reduction throughout the research study. In this reduction the researcher puts aside personal past experiences and past knowledge of the phenomenon so that the researcher is able to gain a view that is at a closer level to the lived reality of the experienced phenomenon. Some have called this bracketing (Smith, Flowers, & Larkin, 2009). While it is not possible to forget or unlearn past knowledge of the phenomenon, the researcher simply does not let past knowledge influence the research study. Giorgi uses the example of a courtroom judge asking the jury to disregard remarks made by the legal team. Although the jury heard the testimony statements they were asked not to let those statements influence their decision (Giorgi, 2009). The same is true with bracketing past knowledge and experience of a phenomenon.

For the purpose of this study, the researcher adopted the phenomenological attitude toward the research data accepting as real the descriptions of family caregivers’
experiences of resistiveness to care. The researcher did not attempt to verify if the experiences were real as the perceptions of family caregivers were that the descriptions were real and their perceptions constituted reality for them. The researcher also bracketed past experience and past knowledge of resistiveness to care during the research project only permitting her nursing disciplinary perspective to be present during the analysis to ensure nursing sensitive aspects of the phenomenon would be highlighted (A. Giorgi, personal communication, March 11, 2013).

This was achieved by the researcher creating an electronic journal audit of all current knowledge the researcher had about resistiveness to care and caregiving for someone with dementia before participants were enrolled in the study (including theories and theoretical perspectives on caregiving for people with dementia). The electronic journal was reviewed periodically as needed during the study to ensure bias did not interfere with the study. A specific time the researcher used the electronic journal audit trail to ensure preconceived ideas did not influence the study occurred during participant interviews.

The researcher became concerned that the phenomenon of interest was not captured in the first several interviews and was considering whether or not to change the interview plan. After reviewing the journal audit, confirming adherence to the method, and identifying that the current interview plan was not biased, the researcher continued with the planned interview questions and process. This was critical as the researcher later identified new insights regarding resistiveness to care that were very different from current understandings of resistiveness to care (from the nurses perspective). Had the researcher not checked potential biases listed in the journal audit, not bracketed identified
bias from the study and changed the interview process to what the researcher thought
would capture the phenomenon better, new insights probably would not have been found.

**Meanings**

The goal of scientific descriptive phenomenology is to uncover the meaning of an
experienced phenomenon. Meanings are acts of consciousness that involves a specific
relationship between an act of consciousness and the object toward which the act is directed.
“Meaning is the particular way in which the object is experienced” (Giorgi, 2009, p.80). For this
study meaning was an experiential meaning of the way family caregivers experienced
resistiveness to care. The experiential common meaning of resistiveness to care was expressed
as a general meaning structure.

**General Meaning Structure**

The general meaning structure consists of essential constituents for the experiential
phenomenon and is a way of communicating meaning of all the variations in the raw data [the
research participant descriptions] (Giorgi, 2009). It is comprised of essential constituents that
can be compared to statistical variations explained by measures of central tendency (Giorgi,
2009). For this study a single general meaning structure was obtained and it represented family
caregivers’ lived experience of resistiveness to care as they cared for someone with dementia.
The general meaning structure transcended all situations in which resistiveness to care was
described and represented a common meaning of resistiveness to care for the participants. The
study’s general meaning structure also revealed amplified nursing aspects of resistiveness to care
that may not have been uncovered by another phenomenology method.

**Essential Constituents**

Essential constituents are commonalities abstracted from the experiential data that are
interrelated and necessary to describe the experiential phenomenon. Unlike “elements, which are independent of the whole in which it resides”, one constituent cannot stand-alone (Giorgi, 2009, p. 102). Rather, all essential constituents are needed to define the whole meaning structure. For the structure of the family caregiver’s experiences of resistiveness to care, five essential constituents were identified. Each played a role in comprising the meaning structure. The essential constituents were developed from meaning units in the raw data by using a method call free and imaginative variation. Free and imaginative variation enabled the researcher to stretch the boundaries of a meaning unit to determine which units were key constituents in contribution to the phenomenon (Giorgi, 2009). Through free and imaginative variation meaning units were added and then taken away from the structure to see which ones are essential to the phenomenon and which ones are not. The resulting essential constituents formed the general meaning structure.

**Meaning Unit**

The raw interview data is divided into meaning units by the researcher. The researcher places a marking in the data to signal a change in the caregiver’s thoughts. There is no theoretical weight given to the meaning units (Giorgi, 2009). It is only meant to subdivide the otherwise lengthy raw data transcribed description into a manageable size for the researcher to analyze. Meaning units are then analyzed for their contribution to the phenomenon of interest. Meaning units that do not have any contribution to the phenomenon are not considered in the final analysis. For this study, all meaning units were analyzed and 115 meaning units were identified as relating to the nursing sensitive phenomenon of resistiveness to care. It was from these 115 meaning units that 5 essential constituents were identified as comprising the general meaning structure of resistiveness to care.
Assumptions

This study presupposed the following statements to be true:

1. Providing assistance for a person with dementia in the presence of resistiveness to care can be stressful for both the caregiver and the care recipient.
2. A caregiver’s perception of the stressful event has the potential to alter or modify the caregiver’s perceived and actual stress levels.
3. Not all care recipients will have a definitive diagnosis of dementia but may have manifestations of the disease process as reported by their family caregiver.
4. Human beings are conscious of the world around them and their conscious interaction with objects contains meaning.
5. Human beings cannot reflect upon lived experiences introspectively as they are living it, but rather reflectively as it has passed or been lived through.

Chapter Summary

An estimated 85 percent of people with dementia are living in the community setting and are cared for by family members or friends (Alzheimer's Association, 2015). Approximately 66 percent of family caregivers are female (wives or daughters of the care recipient) and 34 percent were 65 years of age or older (Alzheimer’s Association, 2015). Twenty-seven percent of all dementia caregivers reside in the same home as the person with dementia and 23 percent also care for children under the age of 18 (Alzheimer's Association, 2015). As the dementia progresses and neurologic functioning declines, the person with dementia will need the assistance of a caregiver and will likely display resistive behaviors toward assisted care. Family caregivers (co-providers of care) experience significantly more physical and emotional responsibilities as the disease progresses. This amount of responsibility is typically greater than
non-dementia caregivers experience during caregiving (Alzheimer’s Association, 2015). Therefore, providing assistance for someone with dementia is challenging, especially for family caregivers who may be elderly themselves.

Researchers have theorized that the frequency of behavior symptoms such as resistiveness to care displayed by a person with dementia to be a predictor of caregiver distress (Gaugler, Zarit, & Pearl, 2003; Hepburn, Tornatore, Center, & Ostwald, 2001; Matsumoto et al., 2007). However, when studied, not all caregivers reported behavior symptoms such as resistiveness to care to be distressful. In fact, new insights into dementia behaviors purport that the caregiver’s meaning of the behavioral symptom (in this case resistiveness to care) rather than the objective stressor (frequency of resistiveness to care behaviors) may influence the stress response and have the potential to alter the caregiver’s perceived level of distress (Kinney & Stephens, 1989; Robinson et al., 2001). In light of these research findings, it was important to understand caregivers’ perceptions of resistiveness to care that occur during caregiver-assisted activities.

Understanding the lived experience of resistiveness to care from the family caregivers’ perspective is important for researchers. Appreciating the descriptive phenomenology meanings obtained from the dementia family caregivers’ lived experience is essential for nurses to holistically understand and offer ways to help distressed caregivers (co-providers of care) cope with the potentially stressful task of providing care and to help them sustain family caregiving for their care recipient with dementia. One way to ascertain an understanding of resistiveness to care is to qualitatively inquire about the lived experience from family caregivers. Consequently, a descriptive scientific phenomenological method study was used to explore this phenomenon of resistiveness to care. The following chapter will give further details into the exploration of this
phenomenon through a review of the conceptual and theoretical literature that helped guide the research question and research method for this study.
Chapter 2

Literature Review

Introduction

Providing care for people diagnosed with dementia is stressful and challenging. As neurologic degeneration occurs, people with dementia will lose their cognitive and physical abilities; necessitating higher levels of caregiving. Decreasing physical and cognitive abilities often contribute to the increasing behavioral and psychological symptoms of dementia (Volicer & Hurley, 2003). These symptoms often manifest as problems with short-term memory recall, disorientation, restlessness, mood regulation, aggression, and sleep disturbances (Fauth, Zarit, Femia, Hofer, & Stephens, 2006). Other behavioral symptoms related to deteriorating neurologic functions include wandering, agitation, and moodiness (Lann-Wolcott, Medvene, & Williams, 2011). Nurse researchers have categorized these behaviors as problematic, disruptive, and resistive to care (Algase et al., 1996; Lann-Wolcott et al., 2011; Mahoney et al., 1999), all of which can be difficult and stressful for caregivers to deal with on a daily basis.

The phenomenon of resistiveness to care that family caregivers experience when they assist their care recipient diagnosed with dementia was the focus of this study. The purpose of this study was to uncover the meaning dementia family caregivers express when they describe their experience with this phenomenon. As family caregivers increase their assistance with daily personal activities for people with dementia, resistiveness to care is more likely to occur. The research reveals the presence of resistiveness to care during ADLs adds an additional challenge managing these behaviors (Keady & Jones, 2010; Mahoney et al., 2006). Adding to this challenge is the fact that spousal caregivers may not be able to manage their feelings about the behaviors because they are unable to separate themselves from the caregiving situation (Pot et
al., 1998). This is even more critical as behaviors associated with dementia have the potential to cause long-term effects on family caregivers’ wellbeing (Gaugler et al., 2000). Finally, Mittleman and colleagues (2004) identified a correlation between family caregivers’ perceptions of the behaviors as severe and their decision to place their family member or friend in a long-term care facility, which can produce even more stress for family caregivers. It becomes even more vital that nurses know how to assist and support family caregivers (co-providers of care) so that they are able to maintain and sustain their dementia family caregiving role.

Unfortunately, to date there has been a dearth of published research focused on the family caregiver’s experience of resistiveness to care when they assist their care recipient as recommended by Kinney and Stephens in 1989. The importance of uncovering family caregivers’ perceptions and meanings of caregiving experiences with behaviors such as resistiveness to care has been supported by research (Kinney & Stephens, 1989; Pearlin et al., 1990). Pot and colleagues (1998) found that spousal caregivers’ perceptions of caregiving mediated the association between caregiving and the distress that they perceived; however, these researchers also noted that spousal caregivers found it more difficult to step back from the caregiving situation and maintain a sense of control when behaviors occurred. It was the belief of this researcher that the meaning family caregivers have of the resistiveness to care may provide new information for nurses on how to help family caregivers during these stressful caregiving situations with their care recipient.

To gain more information about this phenomenon, a Husserlian descriptive phenomenology approach, modified by Giorgi (the descriptive scientific phenomenological method) was utilized to explore the lived experience of resistiveness to care within the context of family caregivers providing care for people with dementia. This chapter will begin with a review
of the literature pertaining to the phenomenon of resistiveness to care, followed by a review of related concepts. Related concepts include associated dementia behaviors, dementia diseases diagnoses, family caregiving, and family caregiving for people with dementia. In conclusion, the chapter will end with a summary of the literature review and a preview of the scientific phenomenological method that will be discussed in more detail in the third chapter.

Resistiveness to Care

In order to determine a global understanding of resistiveness to care as a concept, a preliminary literature search was undertaken. This search included an effort to identify all research that would contribute to the scientific understanding of resistiveness to care. Using the tenants of a conceptually driven literature search, the search term of “care resistive behaviors” was used within the following databases: CINAHL, ProQuest, Psych Info, and PubMed (Medline). This first search yielded less than 30 articles. Careful reexamination of the initial search terms revealed a narrow focus on physical behaviors and was believed by the researcher to not represent the phenomenon of resistiveness that family caregivers experience. Therefore, the researcher re-identified the concept as “resistive to care” and “resistiveness to care” to more accurately represent this phenomenon.

The newly identified terms of “resistive to care” and “resistiveness to care” were then searched within the same databases of CINAHL, ProQuest, Psych Info and PubMed (Medline). This search produced 362 citations. Duplicate references were noted and deleted from the citation list (generated from the multiple data bases), lowering the number of references to 292. Citations from unpublished sources and citations not in the English language were omitted as the focus was on empirical literature that contributed to the science. Other non-contributory citations included articles pertaining to respiratory airways resistance, vascular resistance,
sonographic conduction resistance, and exercise resistance training, which were not related to the concept of interest resistiveness to care in the context of caregiving activities. After these exclusions were made, 35 viable conceptually driven data citations remained for the analysis of resistiveness to care.

In addition to the conceptually driven literature search of resistiveness to care, a search was undertaken to find journal articles relating to dementia and family caregiving for people diagnosed with dementia to further the understanding of this phenomenon. The identified literature searches helped the researcher gain knowledge of the concepts within the phenomenon and identify gaps in understanding for the phenomenon of resistiveness to care. The identified gaps helped the researcher to formulate a research question: What is the experiential meaning that dementia family caregivers have of resistiveness to care, which they frequently experience as they help their care recipient with daily activities? This question then helped identify a specific phenomenology research method to answer the research question. A descriptive scientific phenomenological method was identified as the most appropriate method to describe the meaning of resistiveness to care as experienced by family caregivers of care recipients with dementia when little is known about this experiential phenomenon.

**Conceptualization of Resistiveness to Care**

As stated earlier, a conceptually driven literature review of the concept of resistiveness to care was undertaken. Findings gathered from the literature review revealed that the concept of resistiveness to care was used primarily by four disciplines: nursing, medicine, psychiatry and dentistry. Further analysis of the data revealed that all disciplines except psychiatry used the caregiving encounter as the context for resistiveness to care. In addition, the discipline of dentistry was the only discipline to include children as well as adults when referring to the
concept of resistiveness to care (Chalmers & Pearson, 2005; Nathan, 2006).

Within the above four mentioned disciplines, resistiveness to care was defined by six differing explicit definitions. The most cited explicit definition was that derived by Mahoney and colleagues (1999) and is quoted as “invoked by a care giving encounter and …defined as the repertoire of behaviors with which persons with dementia withstand or oppose the efforts of a caregiver” (p. 28). This explicit definition was primarily found in the nursing discipline. The medical and psychological disciplines minimally use this explicit definition while the discipline of dentistry did not use the explicit definition at all (Volicer & Hurley, 1999; Volicer & Hurley, 2003; Werner, Tabak, Alpert, & Bergman, 2002).

Other less cited examples of explicit definitions included: resistiveness to care as a form of communication or as “indicators that may reflect unmet needs or desires of persons suffering from dementia” (Cunningham & Williams, 2007, p. 47; Kovach, Noonan, Schildt, & Wells, 2005); or communication of emotions “such as fear and anger” (Jablonski, et al., 2005, p. 79). Still others defined resistiveness to care as overt aggression (Cunningham & Williams, 2007; Gibson, 1997); intentional aggression such as “angry objections and verbal abuse; deliberate stiffening to thwart care and various levels of physical rejection including assault” (Herz, et al., 1992, p. 720); or refusal of care (Jablonski, Munro et al., 2005; Jablonski, Munro, Grap, Schubert, Ligon, & Spigelmyer, 2009). In contrast, Talerico, Evans & Strumpf (2002) defined resistiveness to care from the perspective of the caregiver and thus state that resistance to care occurs when the care recipient “resists my attempts to help him/her” (p. 876).

Although explicit definitions of resistiveness to care existed, the majority of data sources (including nursing) cited implicit meanings, which were indistinct to defined resistiveness to care. Implicit meanings were often unclear and vague in their meanings of the concept. The
current scientific citations using implicit definitions state that resistiveness to care occurred as a result of apprehension, depression, anxiety, fears, and could include unclear perceptions and expectations of both caregivers and care recipients as rationale for the behaviors. “… The cause [of resistiveness to care] is the patient’s belief that the care does not have to be provided or [the patient] just not understanding the motivation and actions of the caregiver” (Volicer & Hurley, 2003, p. 838). In this view of the care recipient, the care is perceived as a threat and they [the care recipient] feel a sense of powerlessness (Anonymous, 2008; Fedele, Jones, Volicer, Herz, & Oppenheim, 1993; Gibson, 1997; Herz et al., 1992; Mahoney et al., 1999; Nathan, 2006; Newton, Patel, Shah, & Sturmey, 2004; Simpson et al., 2006; Stewart, Gonzalez-Perez, Zhu, & Robinson, 1999; Volicer et. al., 2007; Werner et al., 2002) when they are displaying resistiveness to care.

Implicit meanings of resistiveness to care also included noncompliance, defiance, being uncooperative, and a behavioral problem—all of which result in a negative connotation of the behavior. In particular, negative overtones to resistiveness to care were seen in the disciplines of psychiatry implicit meanings of the concept. Resistiveness to care was perceived to be highly disruptive (Nathan & West, 1987), uncooperative (Newton et al., 2004) and as non-compliant either verbally or physically (Kirkevold et al., 2004; Nathan, 2006; Ryan & Bowers, 2005).

Finally, some of the implied definitions suggested that the outcomes of resistance to care manifest as encumbered care, reduced quality of life (Mahoney et al., 1999; Volicer & Hurley, 1999) and missed appointments or treatments. An example of missed appointments was when parents did not believe the diagnosis of mental illness for their child and therefore did not keep their prescribed appointments or follow recommended treatments (Gorman, 1973). Implied definitions of resistiveness to care also suggested that care recipients experience discomfort and
anxiety especially when they were initiating resistiveness to care and that resistiveness to care could escalate their behaviors into agitation, aggression, repetitive behaviors and vocalizations (Kovach, Noonan et al., 2006; Mahoney et al., 1999; Volicer, Mckee, & Hewitt, 2001), possibly requiring physical or pharmacological restraints to manage the care recipient (Connick & Barsley, 1999; Kamenir, 1999; Nathan & West, 1987). For the formal caregiver (paid caregiver), the resistiveness to care produced stress, but for the informal caregivers (non-paid family caregiver) it led to role overload, and burnout and distress (Cunningham & Williams, 2007; Fedele et al., 1993; Mahoney et al., 2006; Williams, Herman, Gajewski, & Wilson, 2009).

**Scientific measures of resistiveness to care.** The scientific data revealed an historic trend in the use of and operationalization of the concept resistiveness to care especially for persons with dementia. Prior to Mahoney’s resistance to care scale published in 1999, few concretely measurable definitions existed. Resistiveness to care was considered at that time to be a problematic or disruptive behavior much like aggression, agitation, insomnia and repetitive motions (Fedele et al., 1993). Researchers at that time also viewed resistiveness as deliberate acts to thwart care. They empirically rated the resistance on levels of physical rejection (mild, moderate, and severe) with examples such as willfully ignoring requests and voluntary rigidity to being severe, as when the person with dementia starts hitting, kicking and biting (Herz et al., 1992).

Since Mahoney published the resistiveness to care scale in 1999, nurse and physician researchers have published their findings based upon data obtained using this tool as a means of empirically measuring resistiveness to care (Anonymous, 2008; Cunningham & Williams, 2007; Mahoney et al., 1999; Volicer & Hurley, 1999; Werner et al., 2002; Williams et al., 2009). However, other methods of measuring resistiveness to care currently exist. These include
nursing staff scoring of behaviors exhibited by care recipients using Likert scales (0 = no resistiveness, 1= ignoring verbal request…3= injuring or attempting to injure staff) as utilized by Stewart and associates (1999).

In addition, the United States federal government has mandated that long-term care facilities report resident resistance and have devised their own tool. This resistance to care is assessed by nursing staff using the Minimum Data Set (MDS) instrument, last updated in 2010. Chapter three, section E of the MDS relates to behaviors that may cause distress or be potentially harmful to the resident, other residents or staff and is specific for residents resisting care in long-term care facilities. This assessment tool defines and documents resistiveness to care behavior as resisting medication administration, injections, ADLs, or eating. The MDS also specifies that this behavior must have occurred within the last seven days of the assessment and the behavior must not easily be altered for it to be considered resistive to care (Bharucha, Vasilescu, Dew, Begley, Stevens, Degenholtz et al., 2008; Volicer et al., 2007).

The conceptually driven literature search and review further exposed multiple different measurement tools researchers used to measure resistiveness to care. The researcher determined the use of varied tools occurred when resistiveness to care researchers synonymously use other concepts such as aggression, agitation, discomfort, being protective, stubborn, and non-cooperative to describe resistiveness to care and thus measured resistiveness to care as such (Brodaty, Draper, & Low, 2003; Connick, Palat, & Pugliese, 2000; Kirkevold et. al., 2004; Nathan, 2006; Nathan & West, 1987; Newton et. al., 2004; Simpson et al., 2006; Werner et al., 2002). However, some researchers realized that describing resistiveness to care using other concepts causes confusion and they debate the differences. One such debate involved the differences between agitation and resistiveness (Gibson, 1997; Talerico et al., 2002; Volicer et
al., 2007). Hurley and colleagues (1999) state that resistiveness can be categorized as disruptive behaviors with agitation, but measured as resistiveness to care using the Scale of Observed Agitation of Persons with Dementia (SOAPD). While Volicer and colleagues (2007) state that agitation and resistiveness to care are different but can occur at the same time. This lack of consensus regarding measurements of resistiveness to care further adds to the blurring of concepts and lines of distinctions between agitation and resistiveness to care reported in the research.

**Use of measurement tools for resistiveness to care.** While Mahoney and colleagues (1999) intended the Resistiveness to Care Scale as an empiric measure to aid nurses in the identification of resistive behaviors and to identify when and what treatments to use with the overt behaviors, they stated that “clinical staff using the instrument tended to omit behaviors that did not interfere with care, even when behaviors could have been cues to escalating behaviors or consequential from the resident’s perspective” (Mahoney et al., 1999, p. 36). Simpson and associates (2006) also admit that resistive behaviors are not easily identified by nursing staff and acknowledges that other researchers have found that resistive behaviors are missed or under-reported by caregivers (Bharucha et al., 2008). In addition, formal caregivers (paid caregivers) have difficulties remediating resistiveness to care. Researchers described this difficulty as “staff concentrated more on the aggression accompanying the resistive behavior than on seeking the mediating factors explaining the resistance” (Werner et al., 2002, p. 466). In fact, researchers found that overt behaviors, such as behaviors that disrupt others were the ones that nurses act upon, whereas subtle behaviors tended to be considered part of a resident’s normal behavior (Simpson et al., 2006).

**Context of resistiveness to care.** Resistiveness to care as cited in the scientific literature
occurred primarily within the context of providing assistance with personal care such as bathing, dressing, eating and brushing of the teeth of persons with dementia (Jablonski, Munro et al., 2005; Jablonski et al., 2009; Mahoney et al., 1999; Volicer et al., 2007; Williams, Herman, Gajewski, & Wilson, 2009). However, resistiveness to care also occurred within the context of providing dental care for the elderly [with impaired cognition such as dementia] and providing dental care for young children (Connick et al., 2000; Nathan, 2006; Nathan & West, 1987). People with a psychiatric diagnosis and parents of children with a mental illness diagnoses were also identified as displaying resistiveness to care (Ryan & Bowers, 2005; Werner et al., 2002). However, this type of resistiveness to care did not occur in direct patient care but when parents fail to accept the diagnosis of mental illness for their child, do not participate with recommended treatments for their child, and are then perceived to be resistive to care by the healthcare provider (Gorman, 1973).

Nurse researchers debated whether the perspective in which resistiveness to care ought to be evaluated should focus on the caregiver or care recipient. Some claimed that resistiveness to care directly relates to the assistance provided by the caregiver (Mahoney et al., 2006). While other nurse researchers stated that resistiveness to care should not be limited to the caregiver’s perspective as “the resident resists my attempts to help him/her” is pejorative toward the care recipient (Talerico et al., 2002). In fact, Talerico and associates preferred the terms aggressive/protective as better terminology to describe the concept of resistiveness to care.

**Relationship with other concepts.** When resistiveness to care behaviors escalated, the concept was then found to resemble other concepts such as aggression and agitation, which further impeded its detection or mediation until the point of escalation (Simpson et al., 2006). Boundaries between concepts blurred even more as different empiric measurement scales are
used to measure the behaviors that resulted from resistiveness to care. The similarities to other concepts and varied measurements caused delays in early detection and preventions especially when resistiveness to care escalated and resembled aggression and agitation.

**Summary of resistiveness to care as defined in the literature review.** The concept of resistiveness to care had poorly defined boundaries as evidenced by the interchangeable use of explicit and multiple varied implicit definitions. The interchange of definitions to describe resistiveness to care was found not only within the nursing discipline, but also within the medical discipline. The lack of nursing disciplinary agreement on a definition of resistiveness to care added to the blurring of this concept. This was further aggravated with the intermixing use of related concepts such as disruptive and problematic behaviors. Often the concept of resistiveness to care was used interchangeably with aggression, combative and agitation (Kovach, Cashin, & Sauer, 2006; Simpson et al., 2006). As a result, researchers used various different empiric measurements for the concept, which gives further evidence of the concept’s lack of a clear definition (Hurley et al., 1999; Mahoney et al., 1999). Lastly, the blurring of this concept with related concepts also contributed to the difficulties experienced by nurse researchers when they attempt to identify resistiveness to care behaviors exhibited by people with dementia during care-ADLs. Ultimately this caused difficulties for nurses when they try to intervene to decrease the behavior and to lessen the care recipient and caregiver distress.

**Gaps in Understanding Resistiveness to Care Identified in the Literature.** By understanding what was known in the state of the science surrounding the concept of resistiveness to care, gaps and inconsistencies in the use of this concept were identified. These gaps included inconsistencies in defining, identifying, and measuring the concept of resistiveness to care. Therefore, it was evident that further research endeavors were needed to advance this
concept enabling consistent use of the definitions not only by nursing but other disciplines as well. It is through concise explicit definitions and measurement that this concept will be able to be used effectively to gauge the success of future interventions aimed to not only improve care for persons who display resistiveness to care, but also to reduce the burden of providing care to persons who exhibit resistiveness to care behaviors.

As the concept of resistiveness to care has been shown to need further refinement, the researcher anticipated that by using a descriptive scientific phenomenological method to explore the lived experience of resistiveness to care as experienced by dementia family caregivers, holistic insights for nurses would be obtained. It was hoped that a rich understanding of this phenomenon from the caregiver’s perspective would be gained by going to the family caregiver to learn more about their experience with this everyday phenomenon.

**Dementia**

Dementia comes from the Latin word “demens”, which means out of one’s mind or senses (Berrios, 1987). In the eighteenth century, “dementia” was used to describe people who lacked competence and therefore could not manage their affairs without assistance from others (Shagam, 2009). Early Victorian researchers noted that the cognitive decline of persons with dementia differed from the cognitive changes of persons with depression or schizophrenia. This was done through post mortem comparisons of brains belonging to people with dementia, compared to the brains of people without dementia. Differences were noted and included enlarged ventricles and cortical atrophy in the brains of the people with dementia (Shagam, 2009). In 1906, a scientist named Alois Alzheimer examined the brain of a deceased woman who was known to have language and cognitive decline for many years prior to her death. He explored deeper and noted the presence of senile plaques and neurofibrillary tangles in stained
Dementia is the slow decline of intellectual cognition that affects abstract thinking and language (Rabins, 2013). This decline is insidious, often happening over a period of months to years. It is the slow progression of cognitive decline that differentiates dementia from acute and rapid cognitive changes known as delirium. The slow and sometimes subtle cognitive decline is manifested as forgetting recently learned information, performing usual daily tasks with difficulty, forgetting or using inappropriate words in communication, being disoriented to time and place, displaying poor judgment, having difficulties with reasoning or logical thinking, misplacing items or placing items in illogical places, and displaying significant changes in behavior, mood, and personality (Rabins, 2013). Although the progression of the disease can be slowed with the use of medication, to date there is no cure for dementia.

One in nine people over the age of 65 in the United States has a form of dementia (Alzheimer's Association, 2015). “Almost two-thirds of Americans with Alzheimer’s are women” (Alzheimer's Association, 2012, p. 14, 2015). Alzheimer’s disease is the sixth leading cause of death in America (Alzheimer's Association, 2015). In fact, the prevalence of dementia in the United States increases with age and this increase can be seen within the last two years. In 2010, the percentage of people who were age 80 and had dementia was about 5 percent and those who were over the age of 95 equaled about 38 percent (Jellinger & Attems, 2010). In 2012, 44 percent of people 74-84 years of age had dementia and nearly half (46 percent) of those who were 85 years of age and older had dementia (Alzheimer's Association, 2012). These numbers are projected to increase. In fact, it is suspected that by the year 2050 there will be just over 13 million people with dementia (Alzheimer's Association, 2012, 2015). As the prevalence of this
disease is expected to increase, an accurate diagnosis for treatment will be imperative to help those afflicted with this disease.

Diagnosis of dementia is accomplished through a detailed review of a medical history and a comprehensive physical exam of the person who is displaying symptoms of dementia. Physicians must first rule out sensory deficits or depression as possible contributors to memory loss (Alzheimer's Association, 2012). These alternative causes of memory loss may be treated and may even reverse memory losses. Although imaging, screening, and diagnostic tools have been used in research for diagnosis purposes, standard confirmatory procedure for determining dementia is currently done by post mortem brain pathology findings [showing the presence of senile plaques that are composed of tangles of dying nerve cells in the presence of amyloid protein] (Rabins, 2013; Shagam, 2009). As a result of the difficulties diagnosing dementia in living humans, the National Institute on Aging assembled a work group to establish diagnosis criteria for dementia.

In 2011, the National Institute on Aging-Alzheimer’s Association workgroup put forth new guidelines for Alzheimer’s disease diagnosis (Alzheimer's Association, 2012). To meet the criteria for having Alzheimer’s disease, suspected persons needed to have a history of memory loss that was gradual in onset over months or years, as opposed to days or hours. The cognitive impairment should be in learning, recent memory recall, trouble finding words when speaking, or difficulties in judgment and problem solving. Home screenings (while available) are not recommended, due to the high probability of false positives (Alzheimer's Association, 2012; Rabins, 2013).

Currently there are three stages for dementia and they are described as mild/early, moderate/mid, and severe/late stages (Alzheimer's Association, 2012). Researchers believe that
dementia actually is present before the first stage is noted. Disease changes are believed to be present and identifiable early and are known as pre-clinical dementia or mild cognitive impairment. However, diagnosis of this early pre-stage of dementia through the use of biomarkers looking for levels of beta-amyloid accumulations and nerve cell degeneration in the brain are not well established yet (Alzheimer's Association, 2012). Therefore, reliance is upon physicians’ assessment and health history for a diagnosis.

**Types of dementia.** Several different types of dementia exist. These include frontotemporal dementia, dementia with Lewy Bodies (known as dementia with Parkinson’s disease), vascular dementia, and Alzheimer’s disease (Alzheimer's Association, 2012; Rabins, 2013). Huntington’s disease and Creutzfeldt-Jakob disease are two other types of dementia that are considered extremely rare and will not be discussed here in detail. Although distinguishing characteristics of each type of dementia abound, it is common for persons with one type of dementia to display characteristics that could be considered part of one or more other types of dementia, making diagnosis and treatment planning difficult.

**Frontotemporal dementia.** Frontotemporal dementia was first identified in 1892 when a German neurologist and psychiatrist cared for an elderly patient who displayed a progressive loss of speech and dementia (Shagam, 2009). It was later upon autopsy that researchers noted the brain atrophy of this patient was different than typical Alzheimer’s-disease brains. In frontotemporal dementia, the atrophy is contained in the frontal and temporal lobes, unlike that of the known Alzheimer’s disease in which the atrophy is diffuse.

Frontotemporal dementia accounts for less than five percent of all dementia and is the least common form of dementia (Rabins, 2013). As its name implies, frontotemporal dementia affects the frontal and temporal lobes of the brain causing language and executive function
difficulties (inability to focus on a task, and being easily distracted) as well as displaying personality changes (Johns et al., 2009; Rabins, 2013). These changes progress more rapidly than the commonly known Alzheimer’s disease type of dementia. Frontotemporal dementia is diagnosed by clinical symptoms rather than its underlying pathology such as atrophy of the frontal and temporal lobes, neuronal loss and microvacuolation (Johns et al., 2009). However, the use of functional imaging can detect areas of reduced metabolism and perfusion as a means of diagnosis (Shagam, 2009).

**Lewy Body dementia.** Lewy Body dementia (LBD), which includes dementia associated with Parkinson disease (PDD), is the next type of dementia. LBD accounts for only five to fifteen percent of all dementias (Bothe, Uttner, & Otto, 2010; Rabins, 2013). It is characterized by motor disturbances, hallucinations, problems with sleep and arousal, and changes in cognition (Bothe et al., 2010; Johns et al., 2009; Rabins, 2013). Parts of the brain affected by Lewy Body protein aggregation include the limbic and neuro-cortical regions (Bothe et al., 2010; Rabins, 2013). Between 20 to 40 percent of all Parkinson’s patients will develop dementia (Johns et al., 2009; Rabins, 2013). Differential diagnosis of cognitively impaired LBD from Parkinson’ disease is difficult due to the motor-symptoms involved, and slowed thoughts of people with Parkinson’s disease, which has lead to inconsistencies among diagnosticians (Bothe et al., 2010). Neuroimaging using CT scans, MRIs, and brain perfusion scans such, as SPECT are helpful to clinicians for detection of brain lesions, hematomas, tumors, atrophy, and cerebral vascular diseases. However, no confirmed set of characteristics or diagnostic values exists to determine the diagnosis of LBD using imaging scans alone (Tateno, Kobayashi, & Saito, 2009).

The presence of co-morbidities such as vascular dementia or Alzheimer’s disease in conjunction with Parkinson’s disease ultimately increases the difficulty of diagnosing this form
of dementia. For example, basing diagnosis on the symptom of altered executive functioning alone, LBD and Frontotemporal dementia both exhibit executive function abnormalities and a definitive diagnosis may be difficult. Johns et al. (2009) decided to see if they could find a measurement that would discriminate between the two different types of dementia (LBD and frontotemporal) since both had characteristics of altered executive function.

Johns et al. (2009) compared 17 frontotemporal patients with 15 LBD patients to determine differences between the groups on six measures of executive functioning. While the frontotemporal group and the LBD group displayed similar difficulties with executive functioning on all measures, these researchers found that the Stroop test (aimed at differentiating inhibitory control) was the only measurement tool to discriminate clearly the variations of executive function loss between LBD and Frontotemporal dementia. Tests for working memory, verbal fluency and planning were not significant for determining differences between the groups, further reinforcing that separations between different types of dementia is not always possible. This is especially so with overlapping signs and symptoms that occur when more than one type of dementia presents co-morbidly (Shagam, 2009).

Treatment challenges follow diagnosis difficulties. Each type of dementia is managed a little bit differently. Without a definitive diagnosis, appropriate treatment modalities may be overlooked or neglected dependent upon the type of dementia that is diagnosed. For example, a family caregiver presents to the emergency room stating that the person with dementia is hallucinating. The person with dementia has Lewy Body dementia but family members and the hospital staff is unaware since a differential type has not been diagnosed. If the emergency room clinician prescribed antipsychotic medications for the hallucinations, the person with dementia of the Lewy Body type may have an unwanted exaggerated response to the medication such as
immobility, facial tics, and loss of coordination or over-sedation (Shagam, 2009). This adverse medication effect is not desired and could be lethal.

However, sometimes the dementia patient’s response to medication can give clues to the type of dementia presenting. Some people who actually have Lewy Body dementia but are diagnosed, as Parkinson’s disease will not respond to Parkinson disease medication as most patients do (Johns et al., 2009). People with Lewy Body dementia will respond best to cholinesterase inhibitors such as those used for Alzheimer’s disease patients (Johns et al., 2009). The altered response to medications can be a clue to the clinician that another type of dementia is present than originally suspected.

**Vascular dementia.** Vascular dementia is the second most common type of dementia accounting for 10-20 percent of all dementias and is the result of small infarcts in the brain (Formichi, Parnetti, Radi, Cevenini, Dotti, & Federico, 2010; Kalaria & Ballard, 1999; Rabins, 2013). Individually these little strokes are not significant. However, over time the increased number of infarcts causes brain tissue to die resulting in impaired cognitive and physical functioning. Symptoms of vascular dementia can appear suddenly. Persons with vascular dementia may present with decreased physical functioning such as a loss of bladder control. Co-morbidities of other diseases such as heart disease, diabetes, high cholesterol and high blood pressure can increase the likelihood of vascular dementia occurring.

Imaging vascular infarcts is one way to diagnose vascular dementia. The presence of a new infarct (small or large vessel) on imaging scans, along with the reported onset of physical symptoms (stumbling, unbalanced gait or lack of coordination) and cognitive symptoms (memory recall), helps clinicians to diagnose vascular dementia (Gustaw-Rothenberg, Kowalczuk, & Stryjecka-Zimmer, 2010). However, diagnosing vascular dementia apart from
Alzheimer’s disease continues to be difficult due to the overlap in pathologies (Formichi et al., 2010; Kalaria & Ballard, 1999). Scientists have discovered that along with amyloid deposits, cerebral vascular lesions indicating possible infarcts or hemorrhages also occur in the brains of people with dementia of the Alzheimer’s type (Kalaria & Ballard, 1999). This co-morbidity makes definitive distinctions between the various types of dementia rather complex. It is difficult to determine whether vascular changes in the brain have lead to the development of Alzheimer’s disease or whether persons with Alzheimer’s disease are at an increased risk for vascular disease (Kalaria & Ballard, 1999).

**Alzheimer's disease.** The most common form of dementia is Alzheimer’s disease (AD), which accounts for 60-80 percent of all dementia and is a progressive and fatal neurodegenerative disorder (Rabins, 2013). The greatest risk factor for AD is living past the age of 65 years (Alzheimer's Association, 2012). Although people younger than 65 years have been diagnosed with AD, it is primarily a disease of older age and increases in prevalence up to age 85-90 (Breedlove, Ropsmzweig, & Watson, 2007). The number of people with AD could reach 13.2 million by 2050 (Alzheimer's Association, 2012; Cummings, 2004). As the most common form of dementia AD symptoms have become synonymous with dementia.

AD symptoms include slow onset memory losses (impairment of new memory initially), personality changes (increased apathy, dependency, and aggressiveness) and declines in physical abilities [can no longer perform activities such as bathing and grooming which typically occurs in the later stages] (Zarit & Zarit, 2007). Early in the disease process, persons with dementia may have some awareness that their memory is compromised but will deny problems if questioned directly (Zarit & Zarit, 2007). These cognitive and physical changes are the result of “nerve cells that stop functioning lose connections with each other and ultimately die” (Rabins,
AD symptoms are insidious and in the beginning often explained away by those having the disease. However, the nerve degeneration is real and progressive.

Hallmarks of dementia are the presence of neurofibrillary tangles and Amyloid plaques along with cognitive impairment (Rabins, 2013). A second characteristic of dementia is the lack of acetylcholine (neurotransmitter) production and is the cause of diminished neurological and physical functioning in people with dementia (Breedlove et al., 2007). Together these biomarkers are expected to help in definitively diagnosing people with dementia in the near future.

Dementia is categorized into three stages based upon patterns of decline. In the early stages, there are minor cognitive changes (mild forgetfulness). The person with dementia may forget recent events, have lapses in judgments, or miss important appointments (Rabins, 2013). The person with dementia may be clever enough to cover up any inconsistencies in their memory, so that many family members of people with dementia may be unaware that there is a problem at this stage.

In the middle stages or second stage of the disease, cognitive changes become worse and more apparent. The person affected may have more difficulty managing daily routines and as a result, personal care may decline (Rabins, 2013). Assistance may be required for bathing, dressing or overall grooming. At this stage, people with dementia may not be able to express themselves and may develop hallucinations or delusions (Rabins, 2013). It is during this stage that resistiveness to care becomes apparent.

In the third and last stage, the person with dementia will be completely dependent on another for daily care. These persons cannot walk, feed themselves, or communicate clearly. All reasoning abilities are lost at this stage (Rabins, 2013). Resistiveness to care becomes extinct
during this very dependent stage. The person with dementia is highly vulnerable as susceptible to illness and disease (Rabins, 2013). Most persons diagnosed with Alzheimer’s disease die of pneumonia (Rabins, 2013).

In 2011 the National Institute on Aging and the Alzheimer’s Association proposed the addition of a pre-clinical stage of dementia. This stage is thought to occur before the mild/early stage and is characterized by brain changes along with the presence of cerebral spinal fluid and blood biomarker but without memory loss at this point. However, these biomarkers are not currently available for diagnosing people with dementia, as more research is needed (Alzheimer's Association, 2012). Thus the pre-clinical stage is relatively new to dementia staging.

Currently, there is no cure for dementia. Treatment usually consists of medications to maintain neurologic functioning, improve symptoms of depression and reduce behavioral symptoms, anxiety and distress. The ultimate goal of medical therapies is to preserve cognitive functioning for as long as possible (Rabins, 2013). Current medications to promote memory include cholinesterase inhibitors and receptor antagonists. Researchers believe that a deficiency in the neurotransmitter acetylcholine may be responsible for memory loss (Rabins, 2013). In addition, anti-anxiety and anti-depression medications are sometimes used to alleviate behavioral symptoms that occur. Current experimental drugs include immunotherapy, statins, anti-inflammatory drugs, estrogen therapy, and dietary supplements (Rabins, 2013). An early diagnosis is key for prescribing medication to prolong the effects of neuron destruction and preserve memory.

A physician’s diagnosis of the disease is usually based upon clinical characteristics such as impairment in memory along with cognitive function impairment [inability to engage in social activities or work] (Zarit & Zarit, 2007). Co-morbidities such as heart disease, diabetes, and
vascular insufficiencies hinder the diagnosis of a definitive type of dementia. Often persons with Alzheimer’s disease have been found to have vascular dementia pathologies along with Alzheimer’s type pathological findings. A definitive diagnosis is only possible with a post-mortem autopsy (Zarit & Zarit, 2007). Therefore, it is difficult to accurately diagnose a person with dementia by relying on physical findings and family reports of symptoms.

Regardless of a definitive diagnosis, many people with dementia symptoms will eventually need the assistance of a caregiver for their safety and wellbeing. As the disease progresses (cognitive and physical deficits become more pronounced) people with dementia are unable to care for themselves and come to rely on a caregiver. Caregivers can be formally trained (nurses or nursing assistants) or informal untrained volunteers (family members and friends). The majority of caregivers for people with dementia are family members or close friends (informal caregivers).

**Family Caregiving**

Family caregivers often provide care for their family member or friend who may be ill, immobile, or elderly and do not usually think of it formally as “caregiving” but instead view it as merely “helping” their family member or friend (Family Caregiver Alliance, 2013). In the United States there are roughly 44 million caregivers who are overwhelmingly female (wife or daughter), providing unpaid care for adult friends or family members with chronic conditions (Brown, Friedemann, & Mauro, 2012; Family Caregiver Alliance, 2013; Papastavrou, Charalambous, Tsangari, & Karayiannis, 2012). The average age of family caregivers is 46; however, 12 percent of all family caregivers are age 65 or older (Family Caregiver Alliance, 2013). The vast majority of caregivers are a direct relative of the family member or friend for whom they provide assistance and contribute almost 20 hours of caregiving each week (Family
Caregiver Alliance, 2013). Although family caregivers generously provide unpaid care for their family member or friend, more than half of all family caregivers have either a part-time or full-time job in addition to their caregiving responsibilities, necessitating planned management of competing priorities—life, work, and caregiving (Family Caregiver Alliance, 2013). The average family caregiver manages these responsibilities over an estimated period of 4 years (Family Caregiver Alliance, 2013). The task of providing this much care has both rewards and difficulties for family caregivers.

While some caregivers report their caregiving experience as rewarding [by the development of close intimacy with their family member or friend, or the creating of cherished memories during the time spent together] (Brandon, 2013; Toljamo, Perala, & Laukkala, 2012), many family caregivers have described their caregiving situations as stressful, overwhelming, and similar to a job—requiring caregiving seven days a week (Family Caregiver Alliance, 2013; Mc Ghan, Loeb, Baney, & Penrod, 2013; Mittleman, Haley, Clay, & Roth, 2006; Zarit, Stephens, Townsend, & Greene, 1998). As a result of this reported stress, researchers (Mittleman et al., 2006; Zarit et al., 1998) have developed and tested measurements of caregiver burden (Caregiver Burden Inventory-CBI) in order to develop interventions to ease the distress of family caregivers. They have identified that younger family caregivers report more burden than older caregivers and that longer terms of caregiving leads to caregiver burden (Brandon, 2013; Papastavrou et al., 2012). In addition to the burdens of providing care, family caregivers often neglect their own healthcare needs while they are caregivers, which may contribute to the higher incidences of poor health among these caregivers (Family Caregiver Alliance, 2013; Mc Ghan et al., 2013).

Researchers (Blum & Sherman, 2010; Grant & Ferrell, 2012; Mc Ghan et al., 2013) have recognized the value of family caregivers (co-providers of care) in defraying local, state, and
federal costs of providing assisted care for ill or disabled individuals living in the United States and have recommended that healthcare providers identify and assist family caregivers experiencing distress during their caregiving in order to help family caregivers sustain their caregiving role. The Stress Process Model is a prominent model used by researchers to explain caregiver stress, to identify coping mechanisms that family caregivers use to deal with the stress, and to create ways for caregivers to reduce their stress (Blum & Sherman, 2010; Brandon, 2013; Mittleman et al., 2006; Pearlin et al., 1990). This model has been found to be useful for caregivers of people with various diseases and conditions, but was initially designed for family caregivers of people with dementia. Dementia family caregivers have similar responses to caregiving as general caregivers. However, their demographics and durations of caregiving are notably different.

**Family Caregivers of People with Alzheimer’s Disease**

Eighty percent of people with dementia live at home and are cared for by a family member [spouse or child] or a friend [neighbor or friend] who provide an estimated 17.9 billion hours of unpaid care (Alzheimer's Association, 2015). More than 15 million caregivers provide unpaid care for people with dementia, and they tend to be older than caregivers of other diseases, predominantly female, married, and Caucasian (Alzheimer's Association, 2015). The majority of female caregivers are either a spouse or child of the person with dementia.

Caring for someone with dementia is both financially and physically expensive. In 2007, the cost of global dementia care was estimated to be more than $315 billion a year, of which the United States costs alone exceeded $100 billion a year (Shagam, 2009). In 2011, the 17.4 billion hours of unpaid care (provided by family caregivers) is estimated to have saved the U.S. government over $210 billion in dementia care costs (Alzheimer's Association, 2012). Currently
it is estimated that unpaid caregivers save the nation approximately $217.7 billion in assistance (Alzheimer’s Association, 2015).

In addition to the estimated monetary costs, there are physical and social costs (such as a lack of personal time, loss of social contacts, and the increased physical needs of the person with dementia)—all having the potential to affect the family caregivers. Providing dementia caregiving is a 24/7 responsibility with little time for respite. Many family caregivers feel as if they are providing care for 36 hours in the 24-hour day (Mace & Rabins, 2006). In addition, some family caregivers (especially children of the care recipient) not only care for the person with dementia, but also have the added responsibility of caring for their immediate family members (such as their own children). This generation of caregivers has been termed the “sandwich generation” (Alzheimer’s Association, 2015; Schaie & Willis, 2002). Typically these caregivers must juggle caregiving with their own employment, and other family responsibilities.

As a result of these competing responsibilities and the demands of caring for someone with dementia, family caregivers are in danger of increased health risks. In particular, family caregivers for people with dementia are at greater risk of dying than persons their same age who are not caregivers (Alzheimer’s Association, 2015; Shagam, 2009). The hypothesized reason for this increased risk of death is attributed to the added stress and fatigue of caregiving for people with dementia.

Caregiving for a family member with dementia is rated as emotionally stressful and is associated with financial and relationship strains (Alzheimer's Association, 2012). One possible contributor to the stress is the fact that caregiving is embedded in ordinary relationships such as wife-husband, child-parent, and as such, is not viewed as a separate role by many caregivers (Pearlin et al., 1990). Therefore, when changes occur in the relationship such as when the person
with dementia is no longer able to reciprocate affections and assistance within the relationship, and the efforts of the relationship become unidirectional going from caregiver to care recipient only, the caregiver can experience emotional distress (Pearlin et al., 1990). One caregiver expresses her distress over the changes in her husband.

He has such clear moments when he seems so endearing and so like his old self and they’re flashes that just come, you know. But when you see those flashes, oh man, you know, it just changes the way that you want to do everything. But they are just flashes, and you know that. You’re not dealing with your best friend. You’re not dealing with that person that you relied on for so long. (Perry, 2002, p. 312).

Relational deprivation is considered one of two indicators of primary stressors that caregivers experience when they provide care for a family member or friend (Pearlin et al., 1990). Steadman, Tremont, and Davis (2007) examined the pre-morbid relationship among caregivers and persons with dementia to determine its correlation with caregiver burden. They reported that caregivers with low pre-morbid relationship satisfaction professed greater caregiver burden than caregivers who reported high relationship satisfaction prior to the care recipient’s dementia diagnosis. These findings allude to correlations between pre-dementia relationships of the caregiver and care recipient and the appraised level of burden acknowledged by the caregiver.

Caring for a person with dementia has been described as a “36 hour day” (Mace & Rabins, 1999). Caregivers who live with people with Alzheimer’s diseases or related dementias provide assistance around the clock, seven days a week and even get up during the night with the care recipient (Alzheimer's Association, 2008). “The daily challenges and frustrations of caring,
for an individual with dementia can leave family members feeling both physically and emotionally drained” (Rabins, 2013, p. 65). As the disease progresses people with dementia need constant supervision and cannot be left alone for fear they may wander away, get lost, or hurt themselves (Alzheimer's Association, 2008). The constant vigil without respite causes mounting stress for family caregivers.

Challenges to providing care for people with dementia. Zarit and colleagues (1998) have stated that caring for an older person who suffers from dementia can be challenging, overwhelming, and stressful especially as the disease progresses to moderate and severe stages, when the person with dementia is dependent upon the caregiver for their daily care. Providing care for a person with dementia can range from providing supervision only, to providing hands-on assistance with bathing, dressing and eating (Jansson, Nordberg, & Grafstrom, 2000). One caregiver described the experience, as “it’s hard working seven days a week, 24 hours round the clock for three to four months without time off.” (Butcher, Holkup, & Buckwalter, 2001).

Jansson and colleagues (2000, p. 811) conclude that a family caregivers’ “responsibilities are much more complex and extensive than is indicated by the visible tasks they perform.” The invisible tasks include giving reminders, guidance in activities, and just physically being there for the person with dementia (Jansson et al., 2000). Dementia caregiving responsibilities assumed by family caregivers included “trying to live as ‘normal’ a life as possible with their impaired spouse,” “engaging their partner in the productive work activities they had always performed,” and “highly active supervisory care” in which the caregiver closely watched their family member or friend with dementia for daily difficulties necessitating ready help whenever needed (Jansson et al., 2000, p. 810). Jansson and colleagues surmise that physically demanding aspects of dementia caregiving contribute to caregivers’ perceptions of burden.
Perry (2002) identified that “women [caregivers] often gave up activities they enjoyed, hid their feelings, and restricted visits from other family members and friends in order to stabilize the emotional environment and keep their husbands comfortable” (p. 313). Women caregivers were more likely to report higher levels of caregiver burden than male caregivers (Campbell, Wright, Oyebode, Job, Crome, Bentham et al., 2008; Irvin & Acton, 1997; Kinney & Stephens, 1989). Although family caregivers of people with dementia varied in the level of reported burden, it is very evident that family caregivers sacrifice a great deal to keep the person with dementia safe and contented. Unfortunately, when caregivers sacrifice their leisure activities and family support systems, they can set themselves up for further caregiver stress.

Not only do dementia family caregivers report physical and emotional exhaustion (Teel & Press, 1999), but they also have the potential to suffer from social isolation because of caregiving. Campbell and colleagues (2008) determined that the strongest predictor of dementia caregiver burden was the caregiver’s sense of role captivity. Role captivity occurs when the caregiver feels trapped in the caregiving role and no longer has a sense of self (Campbell et al., 2008). However, Gaugler, Zarit and Pearlin (2003) found that caregivers who transitioned gradually over longer periods of time in the caregiving role adapted to this role and had less distress than caregivers whose transition was quicker and of a shorter period of time. Although it appears that gradual transition into the caregiving role may be of benefit to the family caregiver, the long-term demands of the person with dementia (such as increases in physical assistance) may lead to feelings of being “trapped” in the role with little time for caregiver “self”.

As the dementia progresses into the middle stages, people with dementia will often increase their display of behaviors, which adds to the stress of caregiving. These behaviors are a result of increasing destruction of the neuro pathways and are considered problematic by some
caregivers. Slone and colleagues (2004) found that 65 percent of family caregivers admitted difficulties with providing personal care because their family member or friend became aggressive and agitated. Additionally, Robinson, Adkisson & Weinrich (2001) found gender differences between caregivers’ reaction to problematic behaviors; they found female caregivers to have a greater negative reaction to disruptive behaviors than male caregivers. The identified gender differences in the caregivers’ perceptions of behaviors such as resistiveness to care provides an area to target for future interventions aimed at helping family caregivers (particularly female caregivers) cope with the future of increasing behaviors that are expected as the disease progresses.

There is no doubt that the dementia caregiving experience is stressful, especially when aggressiveness or agitation escalates and impedes personal care, becoming known as resistiveness to care. This stress is further compounded with the knowledge that the neurological damage is irreversible and will only progress, causing more amplified behaviors. Along these lines, Kinney and Stephens (1989) found that family caregivers, who reported more behavior and cognitive “hassles” with their dementia family member or friend, also verified greater distress in social and psychological functioning. However, these distresses did not translate to the increased physical assistance required with activities of daily living for their family member or friend with dementia. One explanation the researchers hypothesize is that the difficulties of behavioral and cognitive decline may be symbolic to the family caregiver. These symbolic cognitive and behavioral changes may be a constant reminder to the family caregiver of the ever-changing person with dementia and in turn may be more challenging to deal with than the actual cognitive or behavioral actions such as resistiveness to care.

Along similar lines, researchers Perry and Olshansky (1996) realized that a diagnosis of
dementia means many changes not only for the person with dementia but also for other family members, especially family caregivers. They set out to study how family members of persons diagnosed with dementia make meaning of the changed family structure with the increasing physical and behavioral changes in the person with dementia. Their study results pointed to these changes as every member of the family constructed a new identity for their family member or friend with dementia, as well as redefined their relationship with their family member or friend with dementia.

Although a shared family meaning of the changed person was targeted in order to plan support for the family, differing individual family member meanings prevented the researchers from reaching this goal. Heeding the findings of this study, it may be advantageous to ascertain individual family caregivers’ perceptions of resistiveness to care in a future study in order to target areas where nurses can be of assistance to individual family caregivers. An interpretative phenomenology study may be best suited to uncover individual family caregiver meanings of the changed person in the experience. This is especially important as individual family caregivers each encounter their own stressful challenges of resistiveness to care while assisting people with dementia.

**Theoretical Frameworks Applicable for Resistiveness to Care Research**

Several theoretical frameworks have been used to guide the research of resistiveness to care that happens during the caregiving experience. Two frequently cited nursing theories relating specifically to Alzheimer’s disease but applicable to other dementias are the Needs-Driven Dementia-Compromised Behavior (NDB) theory and the Progressively Lowered Stress Threshold Theory (PLST). Nurse scientists (Buckwalter, Gerdner, Kohout, Hall, Kelly, Richards et al., 1999; Whall, 2002) have used these theories to frame interventions aimed to help both
informal (family caregivers) and formal (nursing) caregivers modify or reduce dementia behaviors displayed by care recipients.

In addition, social science researchers (Fauth et al., 2006; Gaugler, Zarit, & Pearlin, 2003b) have also framed research surrounding resistive behaviors during caregiving but have used the Stress Process Model of caregiving (SPM). This theory is specifically applied to family caregivers of people with dementia. A distinct difference among the three theories is that while the NDB and PLST focuses on reducing the behaviors displayed during caregiver assisted activities, the SPM targets reducing stress that the behaviors often cause for family caregivers. The Stress Process Model of caregiving proposes ways to reduce caregiver stress or burden by identifying contributing factors and mediators of family caregiver stress as potential areas for intervention. Each of these theoretical frameworks are described in relation to their contributions to the phenomenon of resistiveness to care as well as how these theoretical frameworks have informed the researcher’s understanding of resistiveness to care experienced by family caregivers of people with dementia.

The Needs-Driven Dementia-Compromised Behavior Theory (NDB). The Needs-Driven Dementia-Compromised Behavior theory (NDB) was developed in 1996 by nurse researchers to explain in more detail the occurrence of behaviors encountered when others care for people with dementia. Prior to this theory, dementia behaviors were described as disruptive or problematic. However, in 1996 nursing researchers felt these terms were too pejorative (Whall & Kolanowski, 2004). Therefore, Algase and colleagues (1996) investigated factors that influenced the occurrence of disruptive or problematic behaviors such as resistiveness to care. They identified that interactions between relatively stable background factors (e.g. cognitive function of a person with dementia) and modifiable proximal factors (e.g. room temperature,
noise, and lighting) occurred and contributed to what they then termed as need-driven behaviors (Algase et al., 1996). A premise of the NDB is that individuals with dementia display behaviors that are a result of an expressed need or goal that cannot be verbally communicated. Therefore, NDBs manifest in behaviors such as physically non-aggressive behaviors, aggressive behaviors, problematic vocalizations, or problematic passivity (Whall & Kolanowski, 2004). Theoretically, when caregivers identify these behaviors, they are then able to identify the non-verbalized need of the person with dementia and then assist them with that need. By correctly identifying the need, caregivers can theoretically prevent the behaviors by anticipating the needs of their family member or friend with dementia.

Components of the NDB theory include background factors, which include the degree of neurological function and cognitive ability, as well as their state of health and psychosocial history. These background factors are not readily altered and thus considered relatively stable. However another component, the proximal factors (physiological need states such as being tired, hungry, or cold; psychological need states such as being over-stimulated or bored; physical environment such as being too loud or too bright; and social environment such as being in isolation versus overcrowding) are considered to be modifiable by the caregiver. By considering background factors and modifying identified proximal factors, the occurrence of NDBs (wandering, problematic vocalizations, and physical aggression) can theoretically be prevented or minimized.

The scope of research with the NDB theory may be considered limited. The NDB theory is a middle range theory used primarily for the study of persons with dementia. However, it can be used with people having other forms of cognitive impairments as well. Researchers who use the NDB model feel it represents a holistic approach to disruptive behaviors. This holistic
approach is evident by the model’s consideration of both background and proximal factors encompassing the whole person with dementia.

**Complexity.** The involvedness of the NDB theory may appear to be quite simplistic with only two representative variables influencing need driven behaviors. However, despite only two variables representing the outcome of NDB, this theory is complex as it uses sub-factors such as personal and environmental factors as well as neurologic, cognitive, psychosocial, and general health factors to further explain potential contributors to the outcome of needs driven behaviors. The use of sub-factors allows “for the confounding effects of the other variables” to be explained (Algase et al., 1996, p. 16). The sophistication of this theory is echoed by the founding nurse researchers’ own words. They describe this theory as a “comprehensive framework” (Algase et al., 1996, p. 16). Despite its appearance of simplicity, it is obvious that researchers using this theoretical framework believe it is all-inclusive for explaining dementia behaviors as will be evidenced in the section that follows.

**Usefulness to nursing.** Clinical value of the prescriptive NDB theory has been evident in part or whole as nurse scientists have attempted to validate the assumptions of the model. They have used the model to test interventions aimed at modifying behaviors such as wandering, aggression, and vocalizations in long-term care facilities and in the community setting (Mitty & Flores, 2007; Whall & Kolanowski, 2004). Specifically, the NDB theory has been the framework for clinical research to modify specific NDBs such as passivity, agitation and resistive behaviors occurring in long-term care settings (Fitzsimmons & Buettner, 2002; Kolanowski et al., 2002; Kolanowski et al., 2005; Kovach, Cashin, & Sauer, 2006). Clearly the usefulness of the NDB theory has been shown1, especially in long-term caregiving settings where much of the research has taken place.
Algase and colleagues further expressed the usefulness of the NDB theory. They ascribed the versatility of the NDB theory by stating that researchers can target clinical subgroups of an individual’s characteristics or target specific needs-driven dementia-compromised behaviors when designing research proposals (Algase et al., 1996). The NDB theory’s usefulness is further enhanced by its cultural adaptability. Flexibility of the NDB theory in its application for different cultures is further proven by the fact that this theory was used in a non-western nursing culture. Whall, Shin and Colling (1999) compared the NDB theory with Korean nursing care of people with dementia and concluded that despite several differences in the views of holism and self-healing, the NDB theory is closely aligned with traditional Korean nursing and could be integrated for strategies of care.

While the previous-mentioned research targeted specific recreational interventions to engage people with dementia and decrease NDBs, the research of Kovach, Noonan, Schildt, Reynolds, and Wells (2006) focused their use of the NDB theory toward improving nurses’ recognition and assessments of NDBs as well as nurses following through with their assessments to treatment of behaviors. By using an individualized treatment protocol, researchers found that nurses were able to decrease identified NDBs in long-term care residents. Specifically, the ‘Serial Trial Intervention’ treatment protocol was created to help nurses address individual needs of the long term care residents with dementia based upon their assessment of NDBs (Kovach, Noonan et al., 2006). The treatment aim of this intervention was to improve the comfort of the person exhibiting NDBs and to return the person with dementia to a baseline level of the behavior as identified by the nurse.

The most frequent behaviors identified by the nurses who participated in the study were vocal, combative, resistive behaviors, and restless body movements. The proposed protocol was
a five-step intervention based on physical and affective behaviors along with a trial of both non-
pharmacologic and pharmacologic comfort treatments (Kovach, Noonan et al., 2006).
Analgesics were used if the nurse assessed that the behavior may have been related to pain. If
the nurse continued through all steps but was not able to identify the cause or appropriate
treatment course, a consult was placed with a nurse practitioner, physician, geropsychiatrist or
hospice designates (Kovach, Noonan et al., 2006). Utilizing the NDB theoretical framework,
researchers developed this useful protocol for identification and treatment of behaviors displayed
by people with dementia residing in long-term care facilities.

The utility of the NDB theory was reinforced when nurse researchers claimed success
with the protocol’s use for patients demonstrating vocalized behaviors. However, Kovach,
Cashin and Sauer (2006) admitted that the nursing staff did not treat all patients exhibiting
behaviors. Patients who were quietly wandering or who were non-intrusively displaying
restlessness were not treated. In fact, other researchers confirmed that if the behavior
demonstrated was disruptive to others or a threat to others it was most likely noted by the
assessment nurse; otherwise, it was not addressed as needing intervention (Simpson et al., 2006).
Other limitations of this experimental design included methodological errors. These errors
included identified non-compliance of the nursing staff to follow the experimental protocol
sequentially, with many steps missed or omitted (Kovach, Cashin et al., 2006). For example,
positive assessments of behaviors identified by nursing staff were not always followed with an
intervention. The researchers identified a lack of time that nurses had to complete the protocol
(limited number of staff to perform patient care) and a lack of nursing staff that were interested
in using the protocol (Simpson et al., 2006). These were several reasons for a lack of follow
through by nurses using the protocol. More research is needed with the NDB and its application
to intervention protocols requiring nurses to identify behaviors and follow specific protocols to decrease or eliminate dementia behaviors typically found in long-term care, especially when nurses assist dementia patients with daily care.

Another group of researchers who have used the NDB theory as a framework for their intervention with nurses working in resident care was Chrzescijanski and associates (2007). Chrzescijanski, Moyle, and Creedy (2007) used an interrupted time series design with nursing staff of a resident facility to test the effectiveness of an educational training intervention to decrease resident aggression and improve staff attitudes toward managing people with dementia. These researchers noted a sharp decrease in aggression behaviors within the first two weeks following the educational intervention; however, the mean difference of scores over time was not statistically significant (Chrzescijanski et al., 2007). They did not find a significant difference in nurses’ attitudes toward their work caring for people with dementia. Staff claimed positive attitudes regarding their work both before and after the intervention.

In contrast to the experimental and intervention uses of the NDB theory, researchers have also used the NDB to either develop concepts relating to the theory or further develop the NDB theory itself. Colling (1999) used the NDB framework as a comparison for her development of the concept of passivity—a needs-driven, dementia-compromised behavior. Specifically, five categories of passive behaviors were identified. A taxonomy of these five categories was compared to the NDB theory. The conceptual taxonomy was found to be well-matched with the NDB theory and the researcher proposed that the concept development would enhance the NDB theory’s testability.

*Use in resistiveness to care research.* The NDB theory has been shown to be congruent with the paradigmatic stance of nursing (valuing a holistic approach to care of people with
dementia) and useful for enhancing the clinical practice of nurses caring for people with dementia in many ways. As a middle range theory, its application as a prescriptive guide for interventions to modify NDBs has proven fruitful. The NDB theoretical model uses a deductive focus when aimed at the behavior manifestations of the dementia disease (such as behaviors associated with resistiveness to care). It is this focus that helps nurses modify or eliminate the behaviors by nursing caregivers. Although the NDB theory provides an explanation of why these behaviors occur and helps nurses intervene early preventing the behaviors, it does not address the physiologic progression of neurologic changes and increases in behavior frequency that result. The increase in behaviors makes it more difficult to identify specific needs of the person with dementia. It is the view of the researcher that as the neuro degeneration progresses and the cognitive functioning of the person with dementia declines, the behaviors or actions of the person with dementia increase in frequency, and become primal and reactive rather than intentional non-verbal communicated acts of a need. The increase in these behaviors becomes very stressful for family caregivers. Therefore, it was the belief of the researcher that further investigation into ways to decrease the stress that family caregivers will encounter (as the disease progresses and the behaviors increase) was of greater value to the dementia family caregiver than attempting to decrease behaviors that will only increase with the disease’s progression. In addition, it was the hope of the researcher that by obtaining descriptions of the family caregivers’ experiences with behaviors such as resistiveness to care (through interviews with the family caregiver themselves) and uncovering the meaning family caregivers have for resistiveness to care that nurses would be able to holistically support the caregivers in this difficult task of providing assisted care for people with dementia.

Further evaluation of the NDB theory has shown the NBD theory as a unidirectional
model. Background and proximal factors both combine to influence the outcome of need driven behaviors. However, the NDB researchers have hypothesized that there may be an inter relationship among these three variables (background, proximal factors, and outcome behaviors), leading towards a multidirectional model that is not explicitly representative of the current unidirectional NDB theoretical model (background and proximal factors lead to outcome of behaviors). Therefore, it was the hope of the researcher to begin investigating whether an unidentified relationship exists between family caregivers, people with dementia and the resistiveness to care that occurs during caregiver-assisted activities using the proposed study as a starting point.

Lastly, the NDB postulates that family caregivers may contribute to NDBs (in the form of proximal factors), such as in their verbal communications (the way they speak) with the person with dementia (Herman & Williams, 2009; Williams & Herman, 2011). The model does not allow for family caregivers’ perceptions of these occurrences or the effect the occurring behaviors have on the caregiver in terms of stress. Rather, it focuses on the person with dementia and recognition of the unmet needs of the person with dementia and does not address the needs of the family caregiver who is vital to the care of the person with dementia.

**The Progressively Lowered Stress Threshold model (PLST).** A second theory used to frame research with caregivers of people who have a diagnosis of dementia and display dementia-related behaviors is the PLST theory. In 1985, nurse scientists derived the PLST theory from several existing theories. The existing theories include the “acute confusion theory, client-centered therapy, anxiety, stress, coping, and Ecological Theory of Aging” (Smith et al., 2004, p. 1756). After clinically observing older adults with Alzheimer’s disease and related dementias (ADRD) in an Alzheimer’s unit of a nursing home, researchers noted the older adults
displaying three clusters of behavior symptoms: cognitive, affective, and executive (planning difficulties). Further observations revealed a fourth cluster of behaviors believed to be the result of a lowered stress threshold. The PLST theory was then created and added as a fourth cluster of behaviors. Adding this fourth cluster was based upon identified behaviors that appeared to be related to environmental and internal demands that exceeded the person with dementia’s ability to cope or adapt (Smith et al., 2004).

A tenet of the PLST theory is that all people have set or fixed stress thresholds as they approach adulthood. However, the PLST theory posits that people with dementia have stress thresholds that decrease as the disease progresses, and as people with dementia become taxed in their ability to manage the increased stress, the behaviors occur (Smith et al., 2004). According to the PLST theory, as people with dementia progress throughout the day, they are exposed to stressors. With lowered stress thresholds, repeated stress exposure causes dysfunctional behaviors in people with dementia (Smith et al., 2004). Examples of stressors for people with dementia include pain, illness, fatigue, the caregiving environment, or cognitive changes (Mitty & Flores, 2007). Three levels of behaviors are proposed within the PLST theory. These include baseline behavior, increasingly anxious behavior, and dysfunctional behavior. These stress behaviors are known to progress through the three levels as the stress threshold is exceeded (Smith et al., 2004). The theory proposes that interventions to reduce behaviors should occur before people with dementia reach the dysfunctional behavior level. Through utilization of this theory, it is hoped that people with dementia will experience less stress than if left to escalate from the baseline behavior into the dysfunctional behavior level.

The intent of the PLST theory is to provide an explanation of the biomechanics of coping by showing how changes in the biomechanics can lower stress thresholds. Interventions are
individualized and designed in collaboration between the researcher and caregivers. The researchers teach caregivers how to modify stress-inducing triggers as well as teach caregivers how to assess behaviors for stress modification. Evaluation of the success of an intervention is also incorporated into the plan of care for caregivers (Smith et al., 2004).

There are six principles for caregiving that when implemented, reduce excessive stress thresholds for people with dementia (Smith et al., 2004, p. 1757). The principles are identified below:

1. Maximize the safety of the person with dementia by supporting functional losses.
2. Provide a positive environment.
3. Use the emotional behaviors of the person with dementia as a guide to determine stimulation levels that may produce stress.
4. Teach caregivers to observe and listen to patients.
5. Modify the environment to support safety despite functional losses of the person with dementia.
6. Provide ongoing education and supportive care along with problem solving skills.

A generic plan of care for someone with a lowered stress threshold includes reducing internal and external stressors (such as reducing caffeine use, eliminating excessive noise levels, and decreasing the number of people occupying a given space). Within the PLST theory, caregivers are taught to intervene for the people with dementia and are encouraged to ensure personal interests and preferences of the people with dementia are considered when decreasing stress exposure (Mitty & Flores, 2007). In addition, caregivers are cautioned not to reduce the stress levels to the point of sensory deprivation, as this could lead to the people with dementia becoming agitated [an expression of boredom caused by a lack of simulation] (Smith et al.,
A fine balance is needed when reducing stress as too little stress is as detrimental as too much stress.

The scope of the PLST theory is broad, covering the concepts of dementia impairments (cognitive and functional), stress thresholds, adaptation, and caregiver burden. These concepts are combined under a framework, which suggests that environmental and internal demands relating to behaviors displayed by people with dementia are directly related to increased stressors, taxing decreased stress thresholds for people with dementia. The PLST theory does encompass both biological and behavioral observations of people with dementia, thereby making it important for nursing. As the PLST theory relates to the human phenomenon, it has increasing appeal for nursing because it focuses on improving patient outcomes.

**Complexity.** While the complexity of the PLST theory seems limited, increasing stressors on a decreased threshold results in dysfunctional behavior. However, the stress threshold may be more complex. Adding to the complexity of the stress threshold is the knowledge that a fine line exists between knowing how much of a reduction is needed to decrease the stress level and the risk of removal of too much stress causing agitation. Researchers Ragneskog, Gerdner, Josefsson, and Kihlgren (1998) realized this difficulty when they studied agitation in relation to stress using the PLST theory. Using videotapes, the researchers attempted to identify the reasons for the agitated behaviors; however, they experienced difficulty identifying the antecedents for the agitated behaviors that occurred. Adding to the complexity, this theory postulates that stress levels are lowest at the beginning of the day and as the person with dementia is exposed to different stressors the stress level increases. However, this theory does not account for the possibility that stress levels could remain elevated from the previous day and carry over into the next day compounding the stress
level to begin the new day.

**Usefulness to nursing.** PLST theory is practical for changing clinical practice. Management of the behaviors displayed by people with dementia frequently entails medication use. This theory was developed as a means for nurses and family caregivers to understand and ultimately intervene to manage displayed behaviors using non-pharmacological interventions (Smith et al., 2004). This theory provides an alternative approach to behaviors caused by stressors in the environment that when altered decrease the incidence or severity of displayed behaviors. In fact, Kim and Buschmann (2004) have proposed a theoretical model for nursing practice and research based upon the use of touch as an intervention to improve the emotional and behavioral symptoms of people with Alzheimer’s disease. The model is the Touch-Stress Model and incorporates the PLST theory with the Touch model.

In a review of the literature by Lindsey and Buckwalter (2009), they identified that although psychotic manifestations of dementia cannot be eliminated, altering the negative effects of such behaviors may indirectly decrease stress for caregivers. Stolley, Reed, and Buckwalter (2002) highlighted the importance of caregiver’s cognitive and affective appraisal of the caregiving situation as a determinant of caregiver stress. These researchers utilized the PLST theory as basis to test a caregiver-training program to develop a more positive appraisal of the caregiving situation by those in the intervention group as opposed to usual care group. The intervention included a personalized care plan for the caregiver to follow (based upon the needs of their family member or friend) and support. The usual care received information about dementia and other supportive care options of support groups and counseling. Findings showed caregivers’ positive appraisals of the caregiving situation increased in the intervention group. Additionally, perceived burden scores were higher prior the intervention but decreased by the
end of the intervention (Stolley, Reed, & Buckwalter, 2002). This suggested to the researchers that a potential learning curve existed within the intervention group but that burden decreased, as caregivers were more adept at using the PLST interventions (Stolley et al., 2002). Current research however, shows limited success with long-term behavior changes. Training programs for nursing staff have demonstrated short-lived effects as well as limited changes in behavior severity or occurrence (O’Connor, Ames, Gardner, & King, 2009; Oh, Hur, & Eom, 2005).

**Use in resistiveness to care research.** The PLST theory is primarily focused on the formulations of interventions aimed at reducing the care recipient’s stress threshold when stress levels are high. Although Stolley et al. (2002) looked at caregiver appraisals during care recipients’ stressful times, the appraisals were not of the behaviors such as resistiveness to care but were appraisals of caregiver burden, skill mastery of providing care (efficacy and confidence), and caregiving satisfaction. Another limitation is the theoretical incongruencies noted with this theory. The PLST is based upon the fact that people with dementia experience decreasing stress thresholds as the disease progresses (Volicer & Hurley, 2003). Yet, there has been no empirical evidence to support that people with dementia actually experience lowered stress thresholds than people without the disease (Volicer & Hurley, 2003). Once again, the premise of this theory is to have caregivers proficiently identify behaviors, modify environmental factors to anticipate and reduce the behaviors in the future, and ultimately decrease the stress for both the person with dementia and the caregiver. However, the neurologic degenerative progression of the disease dictates that the behaviors will increase as the disease progresses making it impossible to eliminate all the behaviors. It was the belief of the researcher that, as there is no cure for this disease, instructing caregivers in interventions to manage and eliminate the behaviors may be stressful, particularly when the behaviors will increase with the
disease progression. The researcher maintained that nurses should help the caregiver manage their perceptions of stress when dealing with these behaviors that are known to occur. As there is little research to date with this focus, it was the belief of the researcher that research aims should focus on the caregiver’s perception of the phenomenon in order to identify areas where nurses can help family caregivers who are co–providers of care for people with dementia.

**Stress Process Model of caregiving.** Lazarus, Folkman and colleagues first developed the theory of stress and the outcome of adaptation and coping in the early 1980’s. They proposed the theory after identifying that events, which are stressful to one person, may not be stressful to another and therefore concluded that it is the relationship of the person to the environment that determines how stressful a situation is to any one person (Lazarus et al., 1985). Their stress rubric identifies causal antecedents, which incorporate personal variables (personal values and beliefs) along with environmental variables (social support networks) that are mediated by primary and secondary appraisals (how high are the stakes and what coping options are there) to ultimately impact immediate and long term effects of the stressor (Lazarus et al., 1985). Appraisals influence the coping process by determining if the person-environment encounter (stress) is a “potential harm or benefit with respect to commitments, values or goal” and “what if anything can be done to overcome or prevent harm or to improve the prospects for benefit” (Folkman, Lazarus, Dunkel-Shetter, Delongis, & Gruen, 1986, p. 993). Therefore, the theory of stress as a process is very individualized. Two people experiencing the same stressor may not appraise the situation the same and as a result, their levels of stress will be appraised differently.

**Stress process applied to family caregivers of people with dementia.** Pearlin, Mullan, Semple and Skaff (1990) have applied the theory of stress process to caregiving for the
chronically ill, namely family caregiving of people with dementia. These researchers believe that caregiving is a potential context in which persistent stress can and does occur (Pearlin et al., 1990). Just as Lazarus and Folkman identified antecedents and causal variables for stress, Pearlin and colleagues (1990) applied primary stressors, secondary stressor as well as background and contextual factors as contributing toward caregiver stress. In keeping with the tenets of the Stress process model of caregiving, Pearlin and associates also included mediators, which also have the potential to influence the outcome of caregiving stress.

Primary stressors such as the needs of the care recipient comprised of cognitive status, presence and frequency of problematic behaviors, amount of activities of daily living (ADLs), and instrumental activities of daily living dependencies (IADL-finances, transportation, meal preparation), are considered objective primary stressors (Pearlin et al., 1990). Caregiver role overload and the experience of a changed relationship with the care recipient (relational deprivation) are regarded as subjective primary stressors. Primary stressors directly affect secondary stressors.

Examples of secondary stressors include role strain, self-esteem, loss of self, and competence (Pearlin et al., 1990). Role strain occurs when caregivers experience conflict regarding the degree of impairment of the care recipient, the amount of attention given to the care recipient and the acknowledgement given to the caregiver. Intrapsychic strain occurs when “internal conflict and guilt [are] felt by caregivers whose family members disagree about the amount of time one family member spends providing care compared with other family members” (Bolden & Wicks, 2008, p. 76). Secondary stressors can also include occupational and economic strains. A relationship exists between primary and secondary stressors. Objective and subjective primary stressors (needs of the care recipient comprised of cognitive status, presence and
frequency of problematic behaviors, amount of activities of daily living and instrumental activities of daily living dependencies) have a direct influence on secondary stressors (whether or not a caregiver feels overloaded and burned out). However, other influences exist.

The background and context of the caregiving situations has a direct impact on primary stressors as well as secondary strains. These background variables include the socioeconomic status of the caregiver and care recipient, the length of time spent in the caregiving relationship, the extent and composition of the family and network support, as well as the availability of resources and community programs lending support to the caregiver.

Applying the Stress Process Model for informal caregiving (for people with dementia) Pearlin, Mullan, Semple and Skaff (1990) found that stress could be mediated through coping and support strategies. “Mediators may serve both to lessen the intensity of stressors and to block their contagion at the junctures between primary and secondary stressors” (Pearlin et al., 1990, p. 590). The first mediator, coping, entails the “behaviors and practices of individuals as they act on their own behalf” (Pearlin et al., 1990, p. 590). Coping has three functions: to manage the situation, to give meaning to the situation, and to manage the symptoms of the stressful situation (Pearlin et al., 1990).

The second mediator is social support. Social support can be both a direct buffer of secondary stressors or it can prevent secondary stressors (Pearlin et al., 1990). Two types of social support exist. These include instrumental support (someone who assists with the caregiving or household chores) and expressive support (persons deemed as a confident, trustworthy and encouraging) that may be consulted for emotional support (Pearlin et al., 1990).

If used by family caregivers, these above-mentioned strategies can ultimately influence the outcome of the caregiving experience (Bolden & Wicks, 2008). Adverse stress outcomes
include depression, anxiety, cognitive disturbances, physical health and yielding of the caregiving role. Researchers who measure outcomes of the stress process not only measure objective stress as listed above, but also frequently use measures of subjective negative feelings or reactions called distress as an outcome measure (Lazarus et al., 1985). Figure 2.1 is a conceptual model of Alzheimer’s caregiver’s stress process.

*Figure 2.1. Caregiving and the Stress Process*


The scope of the stress process model is broad, highlighting its significance. The relationship among the conditions, stressors and mediators of stress develops and changes over time, leading to the outcome of caregiver stress. With its many concepts, the Stress Process Model provides a reference for conceptualization of the many varied constructs of primary and secondary stressors relative to the outcome of caregiver stress. The broad scope of this model is also important for use in nursing because it includes biological observations and behavioral observations as well.
Although Pearlin, Mullan, Semple and Skaff (1990) viewed the Stress Process Model as pertaining to caregivers of people with dementia, this theoretical perspective can be applied to caregivers of any chronic condition or situation. Researchers have used the Stress Process Model to assess family caregiver stress when caring for a family member or friend with liver failure and when caring for a family member or friend at the end of their life (Bainbridge, Krueger, Lohfeld, & Brazil, 2009; Bolden & Wicks, 2008). Stress Process Model has also been used to understand family adaptation when placing their family member or friend into a long-term care facility and to understand family functioning as a potential intervention points for placement stress and care issues. This model’s scope has also included research aimed toward improving social workers’ understanding and assessing for risk factors associated with increased stress and maladaptation in women who have experienced domestic violence (Lindhorst, Nurius, & Macy, 2005). The Stress Process Model has also been used in assessments predicting health outcomes of people with psychological disorders, particularly panic disorders (Katerndahl & Parchman, 2002).

Since the scope of the Stress Process Model relates to family caregivers as well as people with chronic conditions (as mentioned in the above research areas with mental health and domestic violence recipients), it can be said to encompass a holistic approach to conceptualizations of chronic conditions. This holistic approach is in alignment with the paradigmatic stance of nursing, which incorporated the concepts of man, environment, illness and health, further emphasizing this theory’s compatibility with the philosophy of nursing science (Fawcett, 1985). In addition, the Stress Process Model considers, not only the biological neuro degenerative changes that occur during the advancement of the dementia, but it also considers the behavioral observations of the caregiver stressors and distress indicators.
Pearlin and colleagues (1990) testify to the broad scope of the Stress Process Model, by their admission that caregiver stress is “not an event or unitary phenomenon. It is instead a mix of circumstances, experiences, responses, and resources that vary considerably among caregivers…this mix is not stable” (Pearlin et al., 1990, p. 591). Although the Stress Process Model is modeled as unidirectional, Pearlin and colleagues (1990) encourage future researchers to consider testing whether the relationship among the constructs of caregiver stressors, mediators and the outcome of stress and/or distress could be reciprocal. This consideration would further increase the scope of this theory.

**Usefulness to nursing.** Stress Process Model has the potential to be valuable in nursing to give direction to clinical practice and to improve patient outcomes, which in this case are optimal family caregiver outcomes while caring for someone with dementia. The Stress Process Model provides a theoretical relationship among the variables of problematic behaviors, daily dependencies of the care recipient, range of caregiving activities, role overload and burnout that impact a family caregiver’s wellbeing, physical health, mental health, and the family caregiver’s ability to sustain their social roles. The practice of nursing not only focuses on patients with dementia and their outcomes but also incorporates family caregivers in the care of the people with dementia. Nurses also are concerned for their overall well-being.

The relevance of the Stress Process Model for nursing is evident in current research. Both Mittleman and colleagues (2004) and Bluestein and Bach (2007) used the Stress Process Model to guide their research aimed at lowering stress levels of family caregivers dealing with nursing home placement of their family member or friend with dementia. Mittleman and others (2004) wanted to predict family caregivers’ outcome of stress and to determine when family caregivers would place their family member or friend in a long-term care facility. In addition,
Bluestein and Bach (2007) wanted to understand family caregivers’ adaptation when placing their family member or friend in a nursing home and exploring possible areas that health care providers can intercede to help family members transition to the placement with less stress.

Both Bainbridge and colleagues (2009) and Bolden and Wickes (2008) have used the Stress Process Model with family caregivers of persons facing the end of life to assess which variables in the Stress Process Model contribute to caregiver stress and which areas that nurses can target to be of support for the family caregiver. For Bainbridge and others (2009) the care recipients were mostly cancer patients and in the research of Bolden and Wickes (2008), the care recipients were awaiting or had received liver transplants. Both research studies’ findings were in support of future research aimed toward improving nursing assessment and providing interventions for improving the outcomes of family caregiver’s experience in end-of-life caregiving situations.

**Usefulness for resistiveness to care research.** The scope of the Stress Process Model relates to family caregivers as well as people with chronic conditions (as mentioned in the above research areas with mental health and domestic violence recipients). In addition, it encompasses a holistic approach to conceptualizations of chronic conditions. This holistic approach is in alignment with the nursing metaparadigm, which incorporated the concepts of person, environment, health, and nursing (Fawcett, 1985), further emphasizes the Stress Process Model’s compatibility with the philosophy of nursing science. The Stress Process Model when used with caregivers of people with dementia considers the biological variables of changes that occur during the advancement of the dementia such as decreased cognitive and executive functioning necessitating increased care needs (assistance with ADLs and IDALs). It also takes into consideration caregiver behavioral observations of their family member or friend with dementia.
in relation to their own stressors, and caregiver distress responses to the behaviors they experience.

Although the Stress Process Model has shown to be ideal for the exploration of interventions to help family caregivers dealing with behaviors such as resistiveness to care, Pearlin and colleagues (1990) admonish future researchers to consider testing whether the relationship among the constructs of caregiver stressors, mediators and the outcome of stress and/or distress could be reciprocal. An in-depth study of this theory, has lead the researcher to conclude that more research was recommended to examine family caregivers’ perceptions of the behaviors displayed by people with dementia. Specifically, does the actual occurrence of resistiveness to care behaviors themselves cause distress for family caregivers, or do the behaviors represent a changed person and does this manifestation of a changed person causes distress for family caregivers (Kinney & Stephens, 1989; Pearlin et al., 1990)?

Although the Stress Process Model’s theoretical framework is appropriate for interventions aimed at reducing the behaviors that occur during caregiver assisted ADLs and IDALs, the researcher acknowledged that further exploration of the caregiver’s lived experience of resistiveness to care is needed to provide more details as to what is stressful for the family caregiver. The caregivers’ descriptions of their lived experience and an identified meaning structure for the resistiveness to care that they experience may provide clues for nurses of what may be beneficial for family caregivers in resistiveness to care situations. Because there was very little published research relating to this phenomenon, it was the intent of the researcher to go back to the things themselves—family caregivers to gain detailed description of the phenomenon of resistiveness to care, which was considered a problematic behavior frequently occurring during dementia caregiving that is stressful for caregivers. The descriptive scientific
Phenomenological method was utilized for this study to gain a more detailed description of the resistiveness to care phenomenon that could support new nursing care insights regarding interventions strategies.

**Phenomenology**

Phenomenology has been referred to as the science of essences or an eidetic science (Husserl, 1912-1929/1982) and is both a philosophy and a research method that is used to delve into the real meaning of behaviors in order to advance human understanding of experiential phenomena (Morse & Field, 1995). In particular, the study of phenomenology pertains to the phenomena experienced within the common everyday world of humans (lifeworld) and by the phenomenological method of comparing, distinguishing, “dividing into parts,” and “forming connections” (Husserl, 1964, p. 46) the researcher is able to clarify and determine experiential meaning. Therefore, descriptive phenomenology was developed as a means to discover the “experiential underpinnings of knowledge” (Denzin & Lincoln, 2005, p. 484).

Phenomenology seeks to understand any “given,” whether it is a person, an object, or a situation that is experienced through human consciousness from the perspective of the person who experiences the phenomenon (Giorgi, 1975). Specifically, descriptive phenomenology is focused on how the phenomenon is experienced by the experience rather than analyzing the phenomenon itself. It is the premises of descriptive phenomenology that all “objects” presented to human consciousness have meaning, and by clarifying the actual lived experience, the possibility exists to make beneficial changes as the way “things” or “objects” are experienced are not always the way they are described (Giorgi, 2005). Therefore, it is only logical to go back to the “things themselves” to gain a rich description about the “everyday” phenomenon—resistiveness to care and the meaning family caregivers ascribed to it. This is especially so when
current investigations have not adequately captured resistiveness to care from the family caregiver’s perspective. It is from these rich family caregiver descriptions that one is able to build future research and understanding of resistiveness to care.

**Historical developments of the philosophy of phenomenology.** Phenomenology originated in the disciplines of philosophy and psychology and is considered to be a cause for the philosophical revolution (Edie, 1987). Immanuel Kant first used the term phenomenology in a scientific context in 1786 (Edie, 1987). By definition phenomenology is “the study of phenomena and the appearance of things” (Cohen, 1987, p. 31). The aim of the phenomenology philosophical revolutions was to improve the application of science for human concerns.

During the early nineteen century, research in psychology used phenomenology methods heavily influenced by the math and physics positivistic paradigm. This paradigm focused greatly on objective physical dimensions and their relationship with human concerns, and as a result, psychology was primarily focused on objective measures of the phenomenon (Giorgi, 2009). Nineteenth century scholars interested in phenomenology realized that the current application of scientific principles was very limited and was not adequate to answer questions concerning humans and their relationships with phenomena. Husserl believed that the positivists’ use of a single lens perspective to examine only objective data left a gap in human understanding (Giorgi, 2009; Smith, Flowers, & Larkin, 2009). This occurred especially when the examined phenomena of interest were human beings and their interactions with the world in which they live in. Husserl believed that a rigorous phenomenology accounting of experiences was a necessary precursor to further scientific exploration of a phenomenon (Smith, Flowers, & Larkin, 2009). Despite the strong positivistic influence, phenomenology was broadening to include a subjective lens in which to study human beings and their interaction with phenomenon more
holistically.

**Phases of change in the philosophy of phenomenology.** In phenomenology, the move away from positivistic inquiry was not an abrupt occurrence. Rather, the change from a positivistic inquiry was more of a transition to gain a richer understanding of phenomena and it occurred as phases in a movement. Three phases have been identified in the phenomenological movement, the preparatory phase, the German phase, and the French phase (Cohen, 1987). Although these phases occurred sequentially, changes in philosophies both across and within philosophers make it difficult to isolate each phase as separate and as non-overlapping.

**Preparatory phase.** During the preparatory phase, phenomenology scientists used empirical means to study the world with a positivistic lens (Cohen, 1987). Religion greatly influenced science at this time (Cohen, 1987). This included the philosophy of phenomenology. There are two influential people that played a part in preparing for a change of this positivist view of phenomenology. They were Franz Brentano and his student Carl Stumpf. Brentano aspired to make psychology a true science (Cohen, 1987). In turn, Stumpf used experimentation to study the effects of sound making connections between elements that were previously only perceived (Cohen, Kahn, & Steeves, 2000). Together, Brentano and Stumpf aimed to reform philosophy by providing answers based in science rather than religion.

**German phase.** The second phase was called the German phase. Key figures in this developmental period include Edmund Husserl, a German mathematician, and Martin Heidegger, his assistant. Both were noted for their contributions to the changing of the philosophies of phenomenology. These included a turning away from the epistemological assumptions of equal objective and subjective aspects of an experience to a greater emphasis on subjectivity as the source of all objectivity (Cohen, 1987; Cohen et al., 2000; Giorgi, 2009; Smith, Flowers, &
Although this dramatic epistemological shift in subjectivity occurred, Husserl continued to be influenced by the positivistic scientific notions of the day (Cohen, 1987). This was especially noted in his view of rigor. Husserl felt that it was important to make sure of the basic concepts used in phenomenology research. However, later in this phase Husserl had a change of thinking and criticized positivism, stating that to only look at what is positive missed what was vital: the essence (Cohen, 1987; Husserl, 1912-1929/1982). Husserl believed that phenomenologist needed to go back to the “roots” or “beginnings” to describe phenomenon and not just observable facts.

In order to go back to the roots, several notable concepts emerged during this phase of phenomenology. These included bracketing, intersubjectivity, and life-world. Bracketing or eidetic reduction means to reduce from the particular to the general essences (Cohen et al., 2000; Giorgi, 2009; Husserl, 1912-1929/1982). In order to do reduction, one must “bracket out one’s prejudices and personal commitments, to understand meanings as they are for those describing the experiences” (Cohen et al., 2000, p. 7). Researchers hold at bay (or bracket) previous knowledge, theories, or past experiences about a phenomenon under study in order to see the phenomenon as it occurs in its purest sense without contamination from bias of previous knowledge, in order to experience the phenomenon as the participant described. Intersubjectivity refers to the possibility of multiple subjectives, that when placed together share a common world (Husserl 1912-1929/1982; Spinelli, 2005). Husserl went further to label the world of the lived experience as the life-world and stated in unpublished works that humans can’t understand the world of the everyday experience with the “natural attitude” and that people often take it for granted because it is so commonplace. This “natural attitude” is the original thoughts or actions prior to critical or theoretical reflection (Cohen et al., 2000). Husserl thereby impressed the use
of descriptive phenomenology to examine this lived experience.

Husserl’s ideas regarding phenomenology influenced others. One such person was his assistant, Heidegger. Heidegger’s important contributions to phenomenology included the notions of being and the notion of time [because being is temporal] (Cohen, 1987). Although Husserl had great hopes for Heidegger, it may have been philosophical differences that ended the working relationship of these key contributors (Cohen et al., 2000). The war in Germany under the Nazi regime ended further phenomenological investigations during this phase. Despite the end of this phase, Heidegger’s ideas are thought to have influenced the French phenomenologists.

**French phase.** The last phase is the French phase of phenomenology. This phase occurred when phenomenology moved from Germany to France post-German war era (Cohen, 1987). Key phenomenologists of this phase included Griel Marcel, Jean-Paul Sartre, and Maurice Merleau-Ponty. Marcel, although not a phenomenologist, viewed phenomenology as a starting point for analysis of “Being.” This start was considered as a first step in metaphysical reflection (Cohen, 1987). Marcel realized that one needed to use phenomenology (as influenced by Husserl and Heidegger) as a starting point toward understanding phenomena relating to human experiences.

Another influential contributor to the French phenomenology movement was Sartre. He was a French philosopher who brought his literary approach to phenomenology. Sartre was a novelist, playwright, critic, and editor (Cohen, 1987). Sartre is known for reactivation of phenomenology by reconciling “the subjective and the objective.” He felt that “a person’s concrete consciousness and concrete behavior (existence) precede a person’s character (essence), character being the outcome of free acts” (Cohen, 1987, p. 33). Sartre was also interested in
investigating the presence and absence of relationships to other people (Smith, Flower, & Larkin, 2009). His major concern was what we will be rather than what we are.

Although the contributions of Sartre were considered scientific, Merleau-Ponty, a personal friend of Sartre, was even more concerned with showing how science could include human beings and their individual experiences. Merleau-Ponty was concerned with embodied relationships to the world and sought to describe these relationships (Smith, Flowers, & Larkin, 2009). This thought ran counter to the positivists of his time (Cohen, 1987). By investigating human beings and their embodied experiences, Merleau-Ponty demonstrated that by using phenomenological approaches to study human phenomena, one gained added insights from personal experiences and that these insights contributed greatly to the science.

**Traditions in phenomenology.** Three traditions developed as a result of the historic phases in phenomenology. They are the transcendental phenomenology, the existential phenomenology, and the hermeneutic phenomenology traditions. All three traditions have influence on phenomenology research today.

**Transcendental phenomenology.** Transcendental phenomenology focuses on uncovering the pre-predictive and preconscious structures of an experience to get at the essence of the lived experience (Edie, 1987). This is considered independent of human experience of the phenomenon but within the range of knowledge. “Transcendental thinking manifests as perception, imagination, and thinking” (Edie, 1987, p. 99). In transcendental phenomenology, researchers go beyond and beneath the ordinary, commonsense and “taken for granted” evidence of the everyday life to describe lived experiences. Transcendental phenomenologists are “interested in the qualities of consciousness and not necessarily human consciousness” (Giorgi, 2012, p.9) and tend to seek universal descriptions of a phenomenon. Husserl, the father of
phenomenology was a prominent transcendentalist along with Moustakas and Van Kaam.

**Existential phenomenology.** Existential phenomenology realizes that existential and experiential factors contribute toward human experiences and that these factors are important for understanding those human experiences (Giorgi, 2009). Fundamental existential themes that pervade the lifeworld of humans include life, death, being, otherness, meaning and mystery (Van Manen, 1990). In addition, there are four existentials to being in the world and they include: lived space; lived body; lived time; and lived human relation (Van Manen, 1990). Prominent existential phenomenologists include Heidegger, Sartre, and Merleau-Ponty. All of these phenomenologists agree that investigations into pure consciousness should include analysis of the human existence as a unitary whole (Edie, 1987). Tenants of existential phenomenology have been used in the practice of psychology and the psychological analysis of patients. Van Kaam, a Dutch immigrant began a psychology department in a graduate program based upon the existential phenomenology philosophy for better psychoanalysis and understanding of patients (Giorgi, 2009). Existential phenomenologists realize that is important to consider the role that existential and experiential factors contribute toward the holistic understanding of human experiences.

**Hermeneutic phenomenology.** Originally hermeneutics was used as a means to interpret Biblical text more rigorously and with more accuracy then expanded to other historical texts and documents. Hermeneutic phenomenology is a method that seeks to uncover intentions and original meanings of an author and their relevance to present day through interpretation. It assumes that individuals perceive and make sense of their lived experience according to the personal significance it has for them (Standing, 2009) and that this meaning can be uncovered through interpretative methods. Its central concept indicates a connection between mind and
body, the lived experience and social context (Standing, 2009). Hermeneutic phenomenology is attentive to how things appear, and believes all things can be interpreted— “interpretive in that it claims that there are not such things as uninterpreted phenomena” (Van Manen, 1990, p. 180). There are three noted hermeneutics theorists. These include Schleiermacher, Heidegger and Gadamer (Smith, Flowers, & Larkin, 2009). Schleiermacher believed that written text not only carried the grammatical aspects but also contained psychological aspects relating to the author that were waiting to be interpreted. He claimed that each writer was unique and that they could be understood both by the text and intuiting aspects about the writer using the text (Smith, Flowers, & Larkin, 2009). The second theorist was Heidegger. He believed that hermeneutic phenomenology provided a means to understand “being and time” through examination of those things that are concealed or latent through interpretation (Smith, Flowers, & Larkin, 2009). Lastly the theorist Gadamer was primarily interested in analysis of history or literary texts and their importance on traditions. He too used an interpretative process as well as aspects of both Heidegger and Schleiermacher (Smith, Flowers, & Larkin, 2009). All three have been influential in the development of hermeneutic phenomenology.

**Historical changes in the phenomenology of practice.** During the same historical time period mentioned above, changes were happening in the practice of psychiatrists and psychologists. These disciplines were attempting to understand various treatment techniques used by therapists and their curative effect on patients (Cohen, 1987). Specifically, they were interested in discovering the phenomena occurring within the patients’ treatment experience. It was soon discovered that phenomenological-based treatment approaches were most successful in clinical practice. Therapists were able to obtain descriptions from their patients during interviews using phenomenology methods. Through these interviews, successful therapists were
better able to understand what the patients were experiencing. This was in contrast to previous therapies in which therapists would view the patient from the therapist’s perspective using the therapist’s own theories about the patient and conclude what the patient was experiencing (Cohen, 1987). The use of phenomenology methods was the beginning change for psychiatry and psychology practices.

**Phenomenology as a Method**

There is not just one method of analysis in phenomenology; rather several different “schools” exist. These include the descriptive and the interpretive schools (Cohen et al., 2000; Morse & Field, 1995; Polit & Beck, 2005; Van Manen, 1990). The father of phenomenology Husserl developed the descriptive “school” and the primary question of this descriptive inquiry asks what is the lived experience of a given phenomenon? (Giorgi, 2009; Smith, Flowers, & Larkin, 2009). Through this method of research, rich descriptions and the core structures and features of human experience are sought. Heidegger a student of Husserl moved away from Husserl to focus on meaning as fundamentally part of living in the world and questioned the existence of knowledge outside the interpretive process. Heidegger’s work provides the base for phenomenological research that incorporates the intuitions of the researcher during the investigation and is known as the interpretive (as opposed to descriptive) phenomenological method.

**Descriptive phenomenology method.** Generally the descriptive phenomenology method seeks to remain close to the data providing a summary statement of the experiential meaning or core structure as the final outcome of the analysis. There are four main steps involved with descriptive phenomenology research methods. These include reduction (bracketing), intuiting, analyzing, and describing (Polit & Beck, 2005). Reduction or bracketing
is when the researcher identifies any preconceived ideas regarding the phenomenon of interest and then holds in abeyance these beliefs and opinions in order to see the phenomenon as presented to the human consciousness. Although phenomenology researchers realize that total abeyance is not possible, they make every attempt to bracket presuppositions in order to confront the data in pure form (Polit & Beck, 2005). Bracketing is not a once-and-done process. It is ongoing, with systematic evaluations and feedback of the effectiveness of bracketing. Some researchers elect to use a reflexive journal to make notes, clarify or identify possible conflicts as they conduct the research study to ensure that bracketing or reduction has been accomplished. A reflexive journal was used for this study to help ensure that bracketing had been accomplished. Reduction and the use of bracketing are essential in descriptive phenomenology methods in order to obtain a rich description of the phenomenon as it presented itself to consciousness without the introduction of bias.

Intuiting is the next step in descriptive phenomenology. In this step, it is imperative that the researcher remains open to what meaning the informant attributes to the phenomenon of the lived experience (Morse & Field, 1995; Polit & Beck, 2005). After all, it is the informant who has lived the experience of phenomenon and has interpreted the experience and ascribed meaning to it. It is by listening to the informant or by reading the informant’s descriptions of the experience that the researcher experiences the phenomenon of interest.

Next, the researcher analyzes the information given by the informant. This data is usually collected as a personal in-depth interview with open-ended questions aimed at eliciting as much detail of the experience as the informant will give. Descriptive phenomenology analysis will vary by the descriptive method. Typically, the researcher reviews all of the data to gain a sense of the whole before analyzing the parts. Some descriptive methods extract significant
statements, categorize words and phrases, and look at the structure of the phenomenon, in order to make sense of the essential meanings of the lived experience of interest (Morse & Field, 1995; Polit & Beck, 2005). Others descriptive methods seek to find essential meaning units that will formulate a meaning structure to represent the experience (Giorgi, 2009).

There are three frequently used methods of descriptive phenomenology and three different ways for verifying the analysis. These include Colaizzi, Giorgi, and Van Kaam. All three are from the Duquesne school of phenomenology and are similar in analysis techniques, with the exception of validating the findings (Polit & Beck, 2005). With the Colaizzi method, validation is achieved by returning to the study participants for verification of findings. Giorgi’s analysis relies on the researchers to ensure their own results (Giorgi, 2009) and Van Kaam requires agreement from expert judges to determine intersubjective agreement within the study findings (Polit & Beck, 2005). Despite these analytic differences, the final descriptive phase of descriptive phenomenology occurs when the researcher achieves an understanding of the lived experience and is able to define the phenomenon under study.

Lastly, the researcher describes the lived experience in rich detail so that the reader of the written descriptive text can understand the meaning of the informant’s lived experience as communicated through the written description (Morse & Field, 1995). The validity of the written text becomes apparent when the written text exemplifies the lived experience, in that it is considered to be believable to the reader. Therefore, the richer the detail the more believable the experience will be to the reader.

**Interpretive phenomenology method.** The second “school” of phenomenology inquiry is considered the interpretative phenomenological method called Heideggarian because Heidegger’s philosophical stance moved away from the descriptive viewpoint of Husserl and
serves as the base for the research method. Heidegger’s view emphasized the ontological questions of existence and what persons are involved in that makes the world meaningful, moving beyond description to include an interpretative stance (Denzin & Lincoln, 2005). The question asked for interpretive phenomenology is what is being? (Polit & Beck, 2005). By asking this question, Heidegger sought to address the importance of not only describing but also interpreting and understanding people’s lived experiences as they are actually lived, including the meaning they assign to these experiences.

Interpretive or Hermeneutic phenomenology entails similar steps as the descriptive phenomenology. It includes intuiting, analyzing, and describing but does not include bracketing. Heidegger believed that it was not possible for the researcher to bracket his or her own being-in-the-world (Polit & Beck, 2005). In fact, with the Heideggarian method it assumes that the researcher has prior understanding of the phenomenon (Polit & Beck, 2005). Van Manen also agrees that attempting to bracket out prior knowledge is not successful. He contends that the prior biases, assumptions, and theories will slowly creep back into the analysis because they cannot be forgotten or unlearned (Van Manen, 1990). Therefore, there is no need to bracket this information but to be aware that it does exist and to hold it at bay or integrate it openly into the data.

Interpretative phenomenology researchers Pollio, Henley and Thompson utilize a form of bracketing that is unlike Husserl’s bracketing. Pollio and colleagues begin their research study not by interviewing informants but rather by interviewing the researcher (Polit & Beck, 2005). The purpose of the first interview is to raise the researcher’s awareness to presuppositions that the researcher may have about the phenomenon under study before the researcher interviews the informants (Polit & Beck, 2005). After the researcher has become aware of his or her
presuppositions, the researcher is then able to begin interviewing the study informants.

Phenomenological interpretation consists of continually relating parts of the transcribed interview texts to the whole of the transcribed interview text. This interpretation process can occur in three different ways: by grouped meanings, by particular descriptions, or by general themes (Polit & Beck, 2005). In the end, verification of findings is dependent upon the data and whether or not the interpreted findings are supported by the data.

Utrecht school of phenomenology. Lastly, incorporation of both descriptive and interpretive schools of thought by the Dutch approach is otherwise known as the Utrecht School of phenomenology (Polit & Beck, 2005; Van Manen, 1990). Phenomenologists who use this approach have combined the use of both descriptive and interpretive analysis methods in their research. A frequently used method of analysis for the Utrecht approach is the method developed by Van Manen. Using this approach, researchers try to find the essential meaning of the experience being studied. This is achieved using one of three ways: through the holistic approach [when researchers uses the transcribed interviews as a whole to identify meanings]; through the selective approach [in which researchers identify statements or phrases that seem essential]; or through the detailed approach [when researchers analyze each sentence in the transcribed interview text] (Polit & Beck, 2005). The interpretive addition comes in when the researcher uses artistic sources from which to collect thematic descriptions of the phenomenon under study. It is through these artistic forms that Van Manen believes insights in the reflective process are enhanced, aiding the phenomenology researcher to interpret essential meaning of the phenomenal experience being studied (Polit & Beck, 2005; Van Manen, 1990). Therefore through the use of artistic mediums, phenomenologists enhance their interpretive responsiveness to the phenomenon under study.
Descriptive Phenomenology Influenced by Husserl and Interpreted by Giorgi

The purpose of this research was to study the phenomenon of resistiveness to care experienced by family caregivers of people with dementia when assisting them during their daily care. This was accomplished using a descriptive scientific phenomenological method influenced by Husserl and modified by Giorgi to transform individual family caregiver’s described experiences of resistiveness to care into general descriptions and essential meaning structures of the experience of resistiveness to care. Descriptive phenomenology was an ideal methodology to use for this research because the philosophy of phenomenology targets going back to the “things themselves” or actual experiences of others in the natural setting to obtain descriptions and ultimately gain meanings as all persons ascribe meaning to the experiences they encounter (Giorgi, 2009; Spinelli, 2005). Since there was a lack of research on family caregivers’ subjective perceptions of resistiveness to care, and inconsistencies with the concept of resistiveness to care (and its use relating to preventing resistiveness to care behaviors) more information was needed relating to this phenomenon. A descriptive phenomenology method by Giorgi was logical. In addition, using a method that involves the natural setting and descriptions from the family caregivers who experience the phenomenon of interest was the most appropriate choice in order to build an eidetic foundation for further knowledge relating to resistiveness to care. Therefore, a descriptive scientific phenomenological method approach was utilized for this study.

The phenomenological practice of going to the “thing” or individual as a source of more detailed information was congruent with research in nursing. Nursing theorists Leininger, Parse, Peplau, and Watson have stressed the importance of understanding the patient’s perspectives as being essential for appropriate nursing care—phenomenology does just that (Cohen, 1987). By
using phenomenology methods to gain insight into the meanings that patients ascribe to their experiences, nurses are able identify patient needs and thereby find ways to help patients meet those needs (Cohen et al., 2000). Consequently, descriptive phenomenological method was appropriate as a method to gain a richer and deeper understanding from a nursing disciplinary perspective of the lived experience of resistiveness to care experienced by family caregivers of people with dementia.

**Chapter Summary**

Resistiveness to care is currently defined as behaviors that impede the caregivers’ efforts to provide care (Mahoney et al., 1999). Resistiveness to care occurs in caregiving situations with people who are cognitively impaired such as those diagnosed with dementia; particularly those who are in the mild to moderate stages of dementia. Family caregivers of people with dementia, who experience resistiveness to care, report feelings of distress (Anthony-Bergstone et al., 1988; Pot et al., 1998). Although researchers have sought to find interventional ways to decrease the occurrence of resistiveness to care or quantitatively lessen the burden of resistive behaviors, these efforts have met with less than anticipated results.

The findings of previous research investigations surrounding resistiveness to care have led the researcher to explore more deeply into this phenomenon by turning to the family caregiver’s lived experience of this phenomenon. The theoretical frameworks most frequently used by previous researchers investigating resistiveness to care are the Needs Driven Dementia Compromised Behavior Theory, the Progressively Lowered Stress Threshold Theory and the Stress Process Model of caregiving. While all have contributed to the understanding of dementia behaviors and to the formation of interventions to reduce these behaviors and alleviate caregiver distress, the Stress Process Model of caregiving is the only theoretical model that posits that the
caregiver’s subjective individualized perception of resistiveness to care may contribute to caregiver distress rather than the objective behaviors themselves (Pearlin et al., 1990). Previous research findings revealed an identified gap in current nursing research—an in depth description of the family caregiver’s actual lived experience that could alter their perceptions of resistiveness to care.

Therefore, in order to elicit caregivers perceptions of their experience with resistiveness to care so that nurses may help family caregivers (co-providers of care) deal with this often stressful phenomenon, the next chapter details a descriptive scientific phenomenological method based upon the assumptions of Husserl and interpreted by Giorgi as the method used to obtain caregiver descriptions of resistiveness to care. The utilization of the scientific phenomenological method clarified the meaning of family caregivers’ lived experience of resistiveness to care and to created a general structure of the meaning of resistiveness to care that was analyzed from a nursing perspective in order to reveal insights for application to nursing praxis. The next chapter discusses descriptive phenomenology and the modifications made by Giorgi; the scientific phenomenology method and purpose; details of the method (setting, participant recruitment); data collection and management; analysis; as well as credibility and trustworthiness of the study.
Chapter 3

Research Methodology

Introduction

One of the most challenging aspects of providing care for people with dementia is the behavioral and psychological symptoms of the disease (2007). This is particularly true when these behavioral symptoms occur within the context of caregiver-assisted activities of daily living (ADLs) and become known as resistiveness to care. The potential for resistiveness is high; 70-90 percent of people with dementia will exhibit these behaviors (depression, irritability, restlessness, agitation, and verbal or physical aggression) at some time during their illness (Davis & Tremont, 2007). Of these behavioral symptoms, the most distressing symptom for family caregivers is verbal agitation [repeating questions and verbally resisting routine activities] (Rowe et al., 2000). Therefore, persons caring for people with dementia will at some point experience behavioral symptoms of dementia and perceive these experiences to be stressful especially if the verbal resistance is in the form of a “NO.”

Resistiveness to care frequently occurs when caregivers assist people who have dementia in their activities of daily living (ADLs), and is perceived as distressing for caregivers (Pot et al., 1998; Rowe et al., 2000; Sloane et al., 2004). The current state of the science reveals that while empiric interventions exist to decrease resistiveness to care, they are not easy for nurses and family caregivers to implement and when resistiveness to care decreases, it does not always correlate with decreased caregiver distress (Pot et al., 1998; Robinson et al., 2001; Wells et al., 2000). Therefore, the current focus on the behaviors of resistiveness to care appears to be debatable for improving caregivers’ distress when resistiveness to care occurs.

It was the perception of this researcher that the epistemological perspective of the natural
Science methods was too narrow for studying human behaviors such as resistiveness to care. By employing a human science method—descriptive scientific phenomenology—with a nursing disciplinary perspective toward the phenomenon of resistiveness to care—the researcher gained rich descriptions from family caregivers about their lived experiences of resistiveness to care and further advanced the current state of nursing science surrounding this phenomenon.

This chapter begins by presenting a brief philosophy and design of descriptive scientific phenomenology methods influenced by Husserl and interpreted by Giorgi. Next, application of the descriptive scientific phenomenology method is demonstrated for this study investigating the phenomenon of resistiveness to care, as experienced by family caregivers of people with dementia. Specifically, participant selection, data collection, data management, and analysis are presented in congruence with the tenets of descriptive scientific phenomenology. The chapter concludes with a summary of the descriptive scientific phenomenology method used in this study.

**Scientific Phenomenology Method**

Descriptive phenomenology originated with the research and teachings of Edmund Husserl in the early part of the twentieth century. The methods of descriptive phenomenology seek to understand how “givens” present themselves to human consciousness without adding to or taking away from what is described (Giorgi, 2009; Smith, Flowers, & Larkin, 2009). It is by using descriptive phenomenology analysis that a richer understanding and structural meaning of the phenomenon is gleaned. Ultimately, by clarifying these structural meanings, the potential exists to make constructive changes. What is lived is not always what one has perceived to be lived (Giorgi, 2009).

The primary focus of descriptive phenomenology is human subjectivity, intentionality,
the meaning of actions (givens presenting to consciousness), and the freedom and responsibilities that inherently belong to the meaning of actions. Human subjectivity refers to the human perceptions of how something was experienced or “given to consciousness” (Giorgi, 2009, p. 68). Intentionality “refers to the fact that a large group of acts of human subjectivity are directed toward objects or situations in the world” (Giorgi, 2009, p. 184). The object of the intentional act always exceeds the act in which it emerges and it is this relation that is the source of meaning in descriptive phenomenology (Giorgi, 2009). Ultimately when a phenomenon is experienced, the act of presenting to consciousness creates meaning for the experiencer that may not have been recognized pre-reflectively. It was this meaning that the researcher wanted to obtain from family caregivers who experienced resistiveness to care in order to better understand their reality.

Therefore, by obtaining descriptions of the experience from those who have experienced the phenomenon, phenomenological researchers are able to experience the phenomenon and ultimately present a clarified structural meaning that conscious acts hold. The outcome of descriptive phenomenology analysis is not universal but rather general knowledge of a phenomenon. Contextual boundaries of phenomenon prevent universal transference of the phenomenological findings when using the scientific phenomenology method.

Amedeo Giorgi presents a modified approach to Husserl’s descriptive phenomenology. This approach is called the descriptive scientific phenomenological method and is performed at the scientific level rather than the philosophical level. There are several steps to the analysis that need to be followed systematically. These include the researcher first assuming the attitude of phenomenological reduction throughout the entire study (accepting what is presented as it is presented without question); bracketing past knowledge; gaining a sense for the whole description; discriminating “meaning units” (identification of shifts in meaning throughout the
interview data) from within the description; transforming each identified “meaning unit” (rewrading original text) into a disciplinary sensitive expression relating to the phenomenon of interest; and subjecting all the meaning units to free and imaginative variation (to determine its essentialness to the general meaning structure). Lastly, the essential structure of the experience is identified by describing the relationship among invariant meaning units and written as a guide for further understanding of the raw data (Giorgi, 2009). The analysis is discipline-sensitive rather than philosophical and is focused on understanding anything that can be experienced through consciousness. The analysis is not a purely object analysis of what is experienced (verifying what is real and what is not), but stays close to what was described by those who experience the phenomenon and is very sensitive not to add to or take away from the given experience as perceived by the participant during the analysis process.

Scientific phenomenology method incorporates rigorous human science, a disciplinary perspective such as psychology or nursing for data collection and analysis, and is ideal for studying phenomenon that cannot readily be studied using the natural science approach. Application of this method in the exploration of resistiveness to care experience by family caregivers was further justified. First, resistiveness to care is an experiential phenomenon for both the person with dementia and the family caregiver and has not been well understood using the natural science methods of inquiry. Second, scientific phenomenology claims that if nurses wish to understand resistiveness to care, they must first grasp the subjective meaning structure consciously assigned to the situation by family caregivers in an objective way. Lastly, while naturalistic inquiries existed for the context of resistiveness to care and included the behaviors of resistiveness to care, the person with dementia, and the family caregivers, a humanistic inquiry into the invariant meaning structure of resistiveness to care from family caregivers’ perspective
had not been scientifically uncovered. For these reasons, this researcher believed that scientific phenomenology as influenced by Husserl and interpreted by Giorgi was ideal for adding to the science of nursing research. A contribution from this study includes the identification of a meaning structure as perceived by family caregivers when they encounter the phenomenon—resistiveness to care.

**Design**

**Scientific Phenomenological Method**

Amedeo Giorgi (2009) developed the scientific phenomenological method of analysis for descriptive phenomenology in psychology and its utility has been well established. Giorgi has published more than 125 scholarly papers on phenomenology and has advised more than 100 doctoral students on the use of Husserlian phenomenology methods (Kleiman, 2004). Giorgi has also supported the use of scientific phenomenological methods by other disciplines, including nursing. He believes that by using phenomenology (a human science perspective), nurses have the potential to gain insights into patient experiential processes. Therefore, for this research study, a Husserlian descriptive phenomenological method as interpreted by Giorgi was used to describe the lived experience of resistiveness to care experienced by family caregivers when they assist their family member or friend with dementia.

A descriptive scientific phenomenological method starts with going to the things themselves. Participants are recruited if they perceive they have experienced the phenomenon of interest. At least three participants are needed to ensure variation in the raw data—participant descriptions of the experiential phenomenon (Giorgi, 2009, p. 198). The greater the number of detailed descriptions of the phenomenon described by each participant the fewer number of participants needed. It is the number of instances of the phenomenon and not the number of
participants that dictates the sample size. Therefore, the data consists of interviews conducted by
the researcher with persons who have lived through the “sharable” phenomenon of interest—
resistiveness to care.

Although philosophical phenomenology requires the researcher to reflect upon the
researcher’s own lived experience of the phenomenon, scientific phenomenology asserts that the
researcher is able to “live” the experience through both hearing and reading the descriptions of
others (Giorgi, 2009). Typically one interview is conducted with each participant. The goal of
the interview is to have the participant describe experiences with the phenomenon pre-
reflectively. If more than one interview is conducted with each participant the possibility exists
that the participant will reflect upon the experience and add interpretations or rationale for the
experience. The participant is asked to describe a recent incident or incidences when they
experienced the phenomenon. If during the analysis the researcher has questions or identified
gaps in understanding of the described phenomenon a second interview may be requested with
the participant to gain more information and close the gap. Using phenomenological reduction
(being open to what is actually present without presuppositions), the researcher is able to glean
intellectual clues and factors that help the researcher understand the phenomenon as experienced
by others.

Analysis in the scientific phenomenological method requires the entire transcribed
interview data to be transformed verbatim and an attitude of phenomenological reduction
(accepting a given as it presents to consciousness and not validating the given) is applied during
all parts of the study. This is not the same as the philosophical phenomenology transcendental
reduction, which transcends the perspective of human consciousness. Giorgi believes the
transcendental reduction is not sensitive enough for psychological clarification. Rather, in the
scientific phenomenological reduction, the object of the experience is reduced for clarification of meaning but stays close to the level of the lived reality rather than becoming more abstract. Using the scientific phenomenological reduction, all data are assumed to be experienced as described by the interviewee regardless of whether it is true or not.

Before the data can be reduced, the researcher must also enter into the human science phenomenological reduction to perform the analysis. This is accomplished when the researcher accepts what is given as it is given, without attempting to justify or verify its existence; both real and unreal objects (such as dreams and hallucinations) present to consciousness. In addition, the researcher must bracket (epoché) all personal and professional past experiences, knowledge, and biases relating to the phenomenon in order to become more focused and aware of the present experience. This does not mean that the researcher must forget all past knowledge of the phenomenon, but rather the researcher attempts to stay in the present and not let this past knowledge interfere while performing the analysis. By doing this, the researcher ultimately seeks a tangible structure of an eidetic invariant meaning (meanings that do not vary and remain stable), which ultimately clarifies the meaning of the phenomenon.

During the scientific phenomenological method the research informants (interviewee) never enter into the phenomenology reduction. By not doing so, the researcher is able to maintain the natural attitude in which participants report events in everyday language without bias in order to gain a rich description of the experience. The participant and not the researcher select the descriptions of the situation in which the phenomenon occurred. Thus, further adding to the integrity of what was experienced. The concrete steps of the scientific phenomenological method are outlined below.
1. Reading the entire interview text for a sense of the whole.

2. Determining units of meaning throughout the entire text.

3. Transforming the participant’s natural expressions into phenomenological nursing sensitive expressions.

4. Each transformed meaning unit is subjected to free and imaginative variation in order to establish a level of invariance in the variable meanings (this expresses the raw data in a more secure way—a level of generality).

5. Essential transformed meaning units are used to write the general meaning structure of the experience.

**Purpose**

The purpose of this research was to describe the phenomenon of resistiveness to care as experienced by family caregivers when providing care for people with dementia. By transforming individual family caregivers’ described experiences of resistiveness to care, a description and general structure of resistiveness to care was obtained and further clarified the experience. A descriptive scientific phenomenological approach influenced by Husserl and interpreted by Giorgi was utilized for this study.

**Specific Aims**

The specific aim of this scientific phenomenological study was to clarify the experiential meaning of resistiveness to care encountered during caregiver activities by family caregivers of people with dementia and to describe the invariant structural meaning of resistiveness to care. Often there is a discrepancy between what is actually lived and what is perceived as lived experience. Therefore, the results of this analysis provided general knowledge of the lived experience of resistiveness to care experienced by family caregivers of people with
dementia. Although these findings may be applicable to other similar situations, they are not considered universal, as the context prevents universality.

**Procedures**

Upon receipt of Penn State’s Institutional Review Board (IRB) approval (see Appendix A), family caregivers of people with dementia were recruited from Alzheimer’s support groups located in central Pennsylvania. The researcher contacted leaders of each identified Alzheimer’s support group meeting to gain permission to attend a meeting at which time the study was introduced. Those in attendance were given a brief overview of the research study and provided an opportunity to ask questions. Interested family caregivers were encouraged to speak with the researcher after the meeting to ensure they met the inclusion criteria and understand study requirements. After giving verbal agreement to participate, participants signed a consent form. During this time this researcher arranged a time and place for a private meeting with the participant in which to conduct the interview. The interview was expected to take about an hour to complete. At the conclusion of the interview, the participant received a gift card incentive in the amount of ten dollars for their time during this research study.

**Study Setting**

Phenomenological research is conducted in the real world setting where the phenomenon of interest occurs and where the participants are most comfortable to describe their experience. Morse and Field (1995) state that the setting for selecting participants should be somewhere optimal in the intensity and frequency of the phenomenon that the researcher plans to study. For this research, five different Alzheimer’s support groups were chosen. Three of the support groups were located in one county and two were located in another county. One support group was conducted in a conference room of the local hospital. Three support groups were conducted
in local nursing care facilities and one support group was conducted in a local church reception hall. Participants were recruited during one of the nine-support group meetings attended by the researcher. All family caregivers who attended the support group meetings were non-Hispanic white and related to their care recipient as, son, husband, wife, or daughter except one caregiver who was the female significant other to her care recipient. Five out of the 39 caregivers who attended the support group meetings were male.

The decision to recruit from Alzheimer’s Support Group meetings was based on several facts. First, Alzheimer’s support groups guaranteed the researcher that the care recipient had a form of dementia. Although the Alzheimer’s Association’s name depicts only Alzheimer’s disease, the organization provided resources and services for caregivers of other dementias as well as Alzheimer’s disease [the largest proportion of dementia diseases] (Alzheimer's Association, 2013). Second, this researcher had prior experience recruiting dementia family caregivers from Alzheimer support group meetings.

A pilot study was conducted by the researcher to test the feasibility of recruiting dementia family caregiver participants from an Alzheimer’s support group meeting between the fall of 2009 and the spring of 2010. The pilot study sought to investigate the association between the frequency of resistive behaviors and the level of caregiver upset with the displayed behaviors. Not enough family caregivers participated to adequately test the proposed association. This researcher planned to recruit 30 participants from a total of 5 different support group sites. However, after 6 months of attending 10 support group meetings only 17 caregivers agreed to participate. Several factors were identified as contributing to this lack of enrollment. The data collection began in late fall and the winter was unusually heavy with snow cancelling five planned support group meetings. In addition, the winter holiday season limited the availability
of support group meetings in the months of November, December, and January (most support groups only have one support group meeting per month). This researcher identified these limitations and altered data collection plans. These changes included selecting non-holiday and warmer weather months for recruitment, and changing the counties of the support group sites visited. However, using five different support groups in the pilot study yielded 17 participants; therefore, this researcher anticipated that five different support groups would easily yield the planned 10 participants for this study and did not change the number of different support groups needed for recruitment of participants.

Although initial contact with family caregivers took place at Alzheimer’s support group meetings, the proposed research interviews were conducted at the home of the family caregiver informant or at another mutually agreed-upon place that facilitated private conversations in a relaxed environment for the participant. Denzin and Lincoln (2005) discuss the qualitative interview process. They state that an interview is a conversation between the interviewer and interviewee that requires “openness, emotional engagement, and the development of a… trusting relationship” between the two (Denzin & Lincoln, 2005, p. 643). Permitting the participant to choose the place for the interview gave the participant some control over the interview and helped to ensure that the interviewee was comfortable enough to provide a rich accounting of the experience. Some of the caregivers preferred to have the interview in a public place. The researcher took additional measures during these interviews to ensure participant privacy and confidentiality. These measures included selecting a seating area away from others, pausing the interview when people approached the area, reminding the participant that proper names were not required for the interview but if provided, it would be removed during the transcription verification process. The researcher also used non-verbal cues from the participant to gauge
when the participant became uncomfortable retelling a specific story. At this point the researcher reminded the participant he or she was not obligated to provide information that was uncomfortable for them to retell. The participant was also reminded that they could end the interview at any time. No participant ended the interview early.

**Sample/Participants**

Credibility is the authenticity or internal validity of a qualitative study and seeks to ascertain whether or not the research findings make sense and accurately reflect the statements of the participants chosen (Miles & Huberman, 1994, p. 363). The findings of a phenomenology study are said to be credible when enough rich descriptions of the phenomenon are presented to the reader so that the reader is able to experience the phenomenon just from reading about it (Miles & Huberman, 1994; Morse, 1995). To be assured that rich descriptions of the phenomenon are obtained, the researcher selected participants that were able to provide concrete and expressive descriptions. For this phenomenology study, the researcher recruited dementia family caregivers who perceived they had experienced the phenomenon of resistiveness to care while assisting their care recipient during caregiving situations and were willing and able to provide details about their encounter(s) with resistiveness to care.

Sampling technique for this phenomenology study consisted of a purposive convenience sample technique. Purposive sampling is not a random or unstructured sampling but rather a purposeful sampling is used to ensure that the sample of participants/informants is representative of the phenomenon of interest (Morse & Field, 1995). Family caregivers of people with dementia were used as informants in this study.

In order to confirm appropriate sampling of family caregivers for the phenomenology proposal aimed at exploring the family caregiver’s lived experience of resistiveness to care when
they assist their family member or friend, a brief review of the resistiveness to care literature was conducted to determine if a certain type of care recipient cognitive impairment (dementia or Alzheimer’s disease) was selected as criteria for caregiver participation in other studies. Of the 59 articles (relating to resistiveness to care) reviewed by the researcher, 75 percent included caregivers of care recipients with dementia and only 25 percent specifically stated caregivers of care recipients with Alzheimer’s disease in their sampling strategies.

The resistiveness to care literature also revealed the fact that confirmation of the presence of dementia was rarely done. The majority of studies used the family caregiver’s report of the disease rather than an empirical validation tool. One study by Kovach (2006) used the BEHAVE-AD instrument specifically designed to be sensitive for identifying resistive behaviors in people with the Alzheimer’s disease diagnosis for their care recipient’s diagnosis with dementia. From the resistiveness to care literature it appears that there is little difference between the diagnosis of Alzheimer’s disease and the broad umbrella term “dementia” in the presence of resistiveness to care behaviors.

The above conclusions are in direct alignment with the dementia literature that reports the difficulty of diagnosing a specific type of dementia. Although eight different types of dementias have been identified, it is common for people with the disease to display characteristics of one or more types making the differential diagnosis difficult (Alzheimer's Association, 2012; Rabins, 2013). Resistiveness to care behaviors occur as neurologic degeneration progresses (Rabins, 2013) and because dementia is an umbrella term for the varied types of dementia—all causing neurologic degeneration, it was deemed appropriate to use this general term dementia when describing the care recipient for the proposed study. The only advantage to identification of a specific type of dementia would have been to determine specific types of resistive behavior that
may have occur during resistiveness to care. However, the aim of the proposed research was not the objective behaviors of resistiveness to care but rather to investigate the subjective experience of the family caregiver (who experienced the phenomenon). Therefore, family caregivers who perceived they had experienced resistiveness to care regardless whether the care recipient had a professional diagnosis of dementia (Alzheimer’s disease or other dementia type) or the caregiver self reported a dementia diagnosis for the care recipient, either was sufficient. Specifically, family caregivers were defined as people who provided unpaid caregiving assistance for people with dementia and had perceived they had experienced resistiveness to care when they assisted with caregiving activities for their care recipient with dementia.

For this study, proof of resistiveness to care was not empirically substantiated. Family caregivers only needed to have perceived that they experienced resistiveness to care when providing assistance with their family member or friend with dementia. The validation of the actual experience of resistiveness to care was not of importance to the researcher as was the sense that resistiveness to care occurred and was revealed in the caregivers description of the phenomenon (Giorgi, 2009). It was how resistiveness to care presented to the caregiver and how the family caregiver experienced resistiveness to care that was of importance for descriptive phenomenology (Giorgi, 2009). The family caregiver as informant had to be able and willing to provide a detailed description of their experience of resistiveness to care in order that the researcher gain a rich description of the phenomenon.

**Inclusion and exclusion criteria.** Research informants were considered if they met the inclusion criteria. The inclusion criteria consisted of family caregivers of people with dementia who were unpaid family members, provided physical or verbal assistance such as physically helping the person with dementia or verbal cueing (praise during dressing, grooming, eating or
toileting care) for a person with dementia, and had experienced the phenomenon of interest—resistiveness to care while assisting someone with dementia. In addition, the potential participant had to be 18 years of age or older, and have the ability to both speak and understand the English language in order to provide a rich detailed description of their experience during the interview. Potential language barriers were discerned through conversations that occur during the initial meeting between the interested participants and the researcher. The researcher identified no language barriers while interacting with family caregivers during this study.

Participants were not excluded based upon gender, ethnicity, racial group, or sexual orientation. The participant did not have to dwell with the care recipient. Although no participants were excluded from this study, family caregivers would have been excluded from if they did not provide assisted care for someone with dementia, did not speak or understand the English language, or did not experienced the phenomenon of interest—resistiveness to care, while assisting their family member or friend during caregiving activities.

**Number of participants recruited.** The number of informants needed for a scientific phenomenology method project was dependent upon the variation of the phenomenon experienced. Typically with qualitative research, data collection ceases when data saturation occurs. The amount of data collected is deemed adequate when no new insights emerge from the data and saturation has occurred (Morse & Field, 1995). However, using the scientific phenomenology method the goal was a structure of the phenomenon experienced obtained from varied instances of the phenomenon experienced and was said to be complete when enough varied instances flourished to determine a general structure of the experienced phenomenon (Giorgi, 2009). Scientific phenomenologists recommend that at minimum three subjects be interviewed to ensure variations in the raw data ensuring an invariant meaning structure of the
phenomenon experienced (Englander, 2012; Giorgi, 2009, p. 198).

Within the scientific phenomenology method, the variances occur when the participant describes different instances of the phenomenon. Therefore, the unit of variance is the instance of the phenomenon and not the participant. No two instances described by a participant are identical within the scientific phenomenology method, thus providing a separate data point for each described instance of the experienced phenomenon (Giorgi, 2009). Within this method it is possible to have a large number of data points from just 10 participants. Giorgi provides a further example. When he conducts a research study using the scientific phenomenology method and obtains “50 pages of descriptions on a phenomenon there are usually 30-40 times that the phenomenon has been described often with varied circumstances” (A. Giorgi, personal communication, September 15, 2013). Therefore it was most important for the researcher to ask, “Do you have the experience I am looking for?” when selecting informants for the study and to suspend pre-understanding in order to be able to ascertain the essential structure of the phenomenon (Englander, 2012, p. 19). Using a large number of informants would tax the researcher during analysis and lead toward an enhanced understanding of the variability of the phenomenon (a different epistemological purpose) rather than a superior generality of this scientific phenomenological study’s results (Englander, 2012; Giorgi, 2009). Unlike typical qualitative methods that use data saturation as a determinant of adequate sampling size, the scientific phenomenological method uses the number of varied instances described by participants to form a general structure of the experienced phenomenon. It is possible that only a few participants could describe many different instances of the experience enabling the researcher to form a general structure of the phenomenon or it could take more participants if each participant describes only a few instances.
Based upon the admonition of Giorgi (2009), it was estimated for this proposed descriptive scientific phenomenology study between eight and ten participants would provide a rich detailed meaning of resistiveness to care experienced by family caregivers of people with dementia. Ten family caregivers stated verbal agreement to participate but only eight made arrangements for an interview and signed a consent form to participate. As the interviews were conducted and the data transcribed, data analysis began. After eight family caregiver participants had been interviewed, 115 instances of the phenomenon in the transcribed data were found. Further analysis revealed that 115 instances were more than enough instances of the phenomenon from which a general meaning structure was identified for the caregiver’s experience of resistiveness to care.

**Subject recruitment.** Upon IRB approval, potential participants were recruited from Alzheimer’s support group meetings. To recruit potential participants from Alzheimer’s support groups, this researcher contacted the designated support group leader in advance of the meeting asking to be present at the next support group meeting. During the support group meeting, the support group leader introduced this researcher and research study. A study summery was given to all interested participants (see Appendix C). Potential candidates meeting inclusion criteria were invited to participate in the study. All interested participants were given an opportunity at the end of the support group meeting to meet with the researcher to review the study requirements, ask questions regarding the study and if willing to participate, sign a study consent form (see Appendix D).

**Participant incentives.** To compensate consenting informants for their time during the study interviews and for completing demographic information, all participants were given a ten-dollar gift card incentive at the conclusion of the interview.
Protection of Human Subjects

Participant information and responses remained confidential, available only to the researcher and her advisor. In addition, all recorded data (participant’s transcribed interview) were coded to protect his or her identity. No identifiable information was collected on the demographic form (see Appendix B). The only identifiable sources of information were contact information and the written consent form. Participants were coded with a letter (A-E) that corresponded with the support group that they were recruited from and a number to further protect their identity. A codebook linking participant codes with their consent form and contact information was also kept but was accessible only by the researcher. This contact information was necessary in the event that the researcher needed to speak with a participant regarding an interview or to arrange another interview for further clarification of what was or was not said during the original interview.

Because this was not an experimental design, adverse effects resulting from treatment were not anticipated. Adverse effects of this research study were expected to be minimal and no greater than that experienced in everyday life. However, the researcher did consider retelling the experience of resistiveness to be potentially distressful to some participants. Therefore each participant was reminded of their right to disclose only information they are comfortable disclosing and that they may discontinue their participation in the research study at any time should they feel uncomfortable in their participation. If an adverse situation between the caregiver and the person with dementia would have become apparent to this researcher, even if not the result of the research project, the researcher had available local contact numbers for crisis intervention units and was prepared to give the contact information to the participant.

In addition, this researcher disclosed to consenting participants at the beginning of the
interview that she was a nurse licensed in the state of Pennsylvania and required by law to report any suspected endangerment of elders, or suspected elder abuse. If during the recruitment or interview process this researcher suspected such abuse or endangerment, she was prepared to report such incidents to the appropriate officials as required by law. However, no suspicions of abuse or endangerment arouse during the interviews.

**Measures**

This study employed a scientific phenomenology approach using researcher-initiated interviews with family caregivers of people with dementia to answer the question: What is the invariant meaning structure of the lived experience of resistiveness to care experienced by family caregivers when they provide care for people with dementia? The definition of resistiveness to care was not formally operationalized prior to conducting this study. Scientific phenomenology does not focus on validating the actual occurrence of the phenomenon of resistiveness to care, but rather seeks to clarify the meaning of resistiveness to care as experienced by family caregivers of people with dementia and to describe a general structure based upon invariant meanings of resistiveness to care. By not operationalizing resistiveness to care, family caregivers were able provide their own experience and meaning of resistiveness to care without restriction or preconceived notions of the phenomenon (Mc Cracken, 1988). It was expected that this richly detailed accounting would provide varied instances of the phenomenon from which a general structure of resistiveness to care would be identified. It was also expected that the identified invariant meaning structure would be beneficial to help nurses and others disciplines to understand this phenomenon as experienced by family caregivers of people with dementia and provide an empirical foundation for future intervention research aimed at helping the family caregivers who experience distress with resistiveness to care.
Data Collection

Instruments

Due to the nature this scientific phenomenology research and the data collection methods, the investigator was referred to as the instrument for not only data collection but also data analysis. Qualitative research depends upon the creative thoughts of the investigator for the formulation of the research study design as well as organization, categorization and searching the data for patterns and associations, thereby relying upon the expertise of the investigator to complete the objectives set forth at the start of the study. The creative techniques chosen by this researcher to clarify the meaning of resistiveness to care as experienced by family caregivers when providing assistance for people with dementia included personal interviews conducted with family caregivers of people with dementia. The interviews were expected to elicit instances of the phenomenon enhancing understanding of the lived experience of resistiveness to care through the identification of an invariant meaning structure of the phenomenon.

In addition to the interviews, a demographic survey extracting characteristic information of both the family caregiver and the person with dementia was completed. Lastly, observational field notes were written by the researcher immediately following each family caregiver interview relating to mannerism, environmental occurrences at the time of the interview, and other details that may influence the retelling of the experience for the family caregiver. This researcher also maintained a reflexive journal of the entire research process from recruitment, data collection, data analysis, and writing the findings to ensure that the phenomenological reduction and bracketing was preserved throughout the entire research process.

Interviews. An open-ended personal interview was conducted with each family caregiver participant to gain their rich description of the lived experience of resistiveness to care
that typically occurs during caregiving activities for people with dementia. The interview started by the researcher asking participants to describe what it was like to be a caregiver for someone with dementia (see Appendix E for interview guide). Caregivers were next asked to describe a recent time when they experienced difficulty while assisting the care recipient. Probing questions were asked to help redirect family caregivers’ descriptions if they deviated from the phenomenon or to help family caregivers describe the experiences in more detail. Each interview lasted approximately one hour but was dependent upon the amount of response the participant contributed to the interview. It was expected that some informants would have been able to describe more details than others. If few details were presented, the interview would have been shorter than the expected hour. To facilitate rich descriptions, a list of “probing questions” was created to elicit richer details of the experience from the informant. It was expected that each participant would be interviewed once. However, if during analysis of the transcribed interview text, questions regarding the interview were raised, a second interview would have been requested to further answer these questions. No second interviews were needed.

All interviews were digitally recorded with the permission of each family caregiver. Once digitally recorded, the interviews were transcribed verbatim into text and verified by the researcher comparing it with the original digital audio file to ensure accuracy of the transcription. After transcription, the text interviews were cleaned of all identifiable information prior to analysis. All audio files and transcription files were stored on the locked computer of the researcher.

**Demographic survey.** (see Appendix B). All participants were asked demographic questions at the end of the interview process to elicit demographic information. These questions
were used to describe the characteristics of the sample of caregivers and the care recipients. The demographic items were selected as they represent characteristics associated with family caregivers as found in the scientific literature. These characteristics include:

- Age and gender
- Relationship between the caregiver and care recipient
- Time spent in the caregiving role/ length of time since diagnosis of dementia
- Amount and types of assistance provided or needed

**Observational field notes.** The researcher recorded observational field notes as soon as possible after each interview to describe the events during the interview and any pertinent information regarding the family caregivers’ mannerisms that may add to the detail of description of the experience of resistiveness to care. All field notes were cleaned of any identifiable information and stored electronically in locked computer files.

**Distribution of Data Collection**

After the family caregiver gave written consent to be enrolled in the research study, the researcher attempted to establish a rapport with the family caregiver before beginning the interview. It was during this time that informal conversation occurred allowing the participant to become acquainted to the researcher and familiar with the research process. Once the researcher felt the participant was comfortable with her presence, the researcher asked the participant to describe a recent situation in which they had experienced resistiveness to care. This was the basis of the interview. At the conclusion of the interview, the participant was asked the demographic survey questions. Total time to complete the demographic survey questions and interview was estimated to be about one hour. No interview and demographic questions were longer than one hour and fifteen minutes.
Interviewing Techniques (See appendix E).

The interview was conducted in a place that has been mutually agreed-upon by both the researcher and the participant. It was somewhere that afforded a quiet and private place to talk. The interview started with the researcher asking a grand tour question to start the participant talking about the phenomenon of interest (McCracken, 1988). Such grand tour questions might be "Describe for me a situation when you encountered difficulties helping (the person with dementia) with their care" (Englander, 2012). Floating prompts were added to keep the family caregiver focused on the details of what was actively lived through. These included a raised eyebrow from the principal investigator or repeating the last key term used by the participant (McCracken, 1988; Morse, 1995). However, if the participant did not expand upon prior statements, planned prompt questions/statements were utilized (Englander, 2012). These included statements such as “please describe for me in more detail one of the last times you experienced difficulty assisting (the person with dementia)” or “please provide more concrete details of your encounter when (the person with dementia) resisted your care.” The interviews concluded when no further new information was given by the family caregiver and there were no further questions to be asked by the principal investigator.

All data collected was considered confidential and kept in a locked file cabinet in the home office of the researcher. The data was only accessible to the researcher and her advisors. However, a transcriptionist was used to transcribe the digital recordings of the interview into text. The transcriptionist had training to ensure the confidentiality of the family caregivers who participated in the study. All data shared between the transcriptionist and researcher were secured using password protected shared files. Data from the scientific phenomenology interviews and demographic survey questions were managed using the computer software files.
All digital audio files were maintained in a secure folder on a password-protected computer in the locked home office of this researcher. These files were transcribed verbatim into a Microsoft Word document. All interview documents had identifiable information removed and replaced with code identifiers. A codebook containing coded identifiers was maintained in a locked secure home office belonging to this researcher. The data collected from this study will be maintained securely for the recommended time of five years following final publication of the study as required by the Pennsylvania State University institutional review board (IRB).

**Data Analysis**

Data analysis for this study was according to the scientific phenomenological method as developed by Giorgi and applied to the phenomenon resistiveness to care experienced by family caregivers of people with dementia. In doing so, this researcher maintained the attitude of phenomenological reduction as well as a nursing disciplinary attitude and sensitivity toward the phenomenon resistiveness to care throughout the process. The data analyzed consisted of text transformed from family caregivers’ digitally recorded descriptive experiences of resistiveness to care obtained through face-to-face interviews with this researcher.

**Transcription of Phenomenology Interview Data**

Typically data collected in a qualitative study namely phenomenology, is interview data that has been audio recorded. Morse and Field (1995) labels data obtained from an interview as textual narratives that are transcribed from interviews. Giorgi (2009) refers to transcription as a way of preserving speech represented in the raw data that is necessary for the conducting of the analysis. He feels that transcription is merely a form of visual stabilization to facilitate the process of analysis. Sandelowski (1994) believes that while some researchers claim transcriptions to be the researcher’s ‘raw’ data from an interview, this data is never truly ‘raw’.
It is actually created from a combination of a social interaction and a reduction of personal expressions into words. Despite the label researchers apply to data that has been transcribed, special consideration is needed to ensure that textual data is prepared according to the rigor of the qualitative study from where it was produced (Mclellan, Macqueen, & Neidig, 2003). The validity of phenomenology research may be in jeopardy if the data collection and analysis are not to be trusted due to transcription errors (Easton, Mccomish, & Greenberg, 2000). These errors or misrepresentations of the original interview have the potential to impact the credibility and dependability of the research.

**Prescriptions to ensure transcripts reflect lived realities.** To prevent errors and ensure the accuracy of the data transcribed from qualitative interviews, recommendations have been published to standardize data transcription. Researchers (Mclellan et al., 2003; Morse & Field, 1995) recommend that all audio recorded data be transcribe verbatim—word for word including expressions. There should be no paraphrasing in the transcribed text rather inclusion of mispronunciations, slang, filler words (uh, huh) are expected for a more accurate representation of the spoken data (Mclellan et al., 2003). Researchers agree (Easton et al., 2000; Mclellan et al., 2003; Morse & Field, 1995) that if possible the researcher should be both the interviewer and the transcriber of the data. The researcher is closest to the data and most likely to be able to represent what was said most accurately.

If this is not possible (for the researcher to both conduct the interview and transcribe the data) and a transcriptionist separate from the research project transcribes the interview data, the researcher is expected to be the one to verify transcript for accuracy. By comparing transcribed text with the original audio recordings the data is considered verified (Easton et al., 2000; Mclellan et al., 2003; Morse, 1995). To ensure validity of transcribed text, it is imperative that
the resulting interview text is compared with the interview audio recording to ensure the accuracy of the transcription.

**Transcription conventions.** All of the interview audio data is to be transcribed. This includes so called “messy” parts of the interview conversation that may include filler words, slang terminology, and mispronunciations. McLellan and colleagues (2003) have published a prescriptive system for transcription of language issues that arise from interview data being transcribed into text. They have documented appropriate ways to signal difficult parts of conversations such as non-verbal emotions, enunciation documentation standards, filler words, word phrase repetitions, overlapping speech, pauses, and questionable text. This documentation represents a form of standardization from which qualitative researchers can safely transcribe questionable aspects of speech into text that will be understood by others.

**Acceptable transcription practices among phenomenology researchers.** As mentioned previously, verification of all transcription with the original audio to ensure the accuracy of the transcription is recommended. Husserl believed descriptions that are transcribed and printed still constituted descriptions (Giorgi, 2009). Giorgi (2009) notes that some researchers claim that anything written should be considered text and that the text should be analyzed using interpretive strategies. However, he believes that not everything written should be considered text. In fact, text is just a mode of reifying and communicating language non-verbally (Giorgi, 2009). Giorgi recommends that the focus should be on descriptions of the text. These descriptions should not go beyond what is given by the interviewee and that the meaning obtained from the descriptions should be based only upon what is present in the transcribed data without interpretations (Giorgi, 2009). Giorgi (2009) does add that if ambiguities exist, it is up to the researcher to obtain more data to fill in the missing gaps and not resort to speculation or
interpretations.

While consensus among qualitative researcher regarding whether or not transcriptions of interview data are representative of the spoken data obtained during a qualitative interview may be lacking, they do agree that the validity and credibility of the research findings depends upon the accurateness of the transcription to reflect the audio-recorded data from the interview. Several prescriptive procedures have been recommended to accomplish this goal. This includes the unanimous recommendation that researchers transcribe all data verbatim and in its entirety.

Attitude of Phenomenological Reduction

Assuming the attitude of phenomenological reduction means that the researcher withholds existential substantiation of what is being experienced or “resist from positing as existing whatever object or state of affairs is presented to her. The researcher [will consider] what is given to her but she [will treat] it as something that is present to her consciousness and she [will refrain] from saying that it actually is the way it [will present] itself to her” (Giorgi, 2012, p. 4). The objects are therefore considered experienced realities but not necessarily as existing the way that they are present (A. Giorgi, personal communication, March 11, 2013). This is not the same as a transcendental reduction, which focuses on consciousness and reducing the acts of consciousness, not human consciousness (Giorgi, 2009). In a phenomenological reduction, only the objects of human consciousness are reduced, not consciousness. For this study the researcher maintained the attitude of phenomenological reduction from the beginning (recruitment of participants) through the analysis of study findings. The researcher accepted what the family caregivers stated relating to their experience of resistiveness to care as being as stated and did not attempt to verify or add to those statements.
Assuming a Nursing Disciplinary Attitude

The scientific phenomenology method contains a disciplinary attitude for the analysis that is integrated with the phenomenological principles. For this study a nursing disciplinary attitude was employed, as this researcher is a nurse and was interested in the family caregivers’ experience from a nursing perspective. This researcher believes that using a nursing disciplinary focus enabled her to look at the everyday life experiences in the data and provided highly relevant insights that other disciplines may have missed. While this researcher needed to utilize “bracketing” or a holding in abeyance past knowledge of the phenomenon, she still used her experiences as a nurse (nursing sensitivity) when analyzing the data (A. Giorgi, personal communication, March 11, 2013). This researcher also used her nursing sensitivity to tell her what parts of the data were interesting to develop further; however, she remained open so that new things could be discovered rather than simply seeing things already known. After the above described phenomenological attitude had been ensured, the remaining steps in the analysis were employed. The phenomenological reduction attitude was maintained throughout the entire analysis process.

Transforming the Data

The next step in the analysis consisted of reading the entire transcribed text of the digitally recorded interview description in order to gain a sense for the whole description. It was imperative (in the scientific phenomenological method) that the researcher gets a sense of the whole description of resistiveness to care as experienced by family caregivers of people with dementia in order to be able to segment and further analyze the data into smaller and easier to manage meaning units or transitions in meaning.

Once the researcher had a grasp of the family caregiver’s experience, she went back to
the beginning of the description and reread it to determine where she experiences shifts or changes in meaning, called transitions. Transitions were noted with a mark placed in the text where the meaning shifts. The identified transitions were then considered “meaning units” as expressed by the family caregiver. This process of identifying transitions was called “constituting parts” and carried no theoretical weight but was correlated with the nursing attitude of the researcher (Giorgi, 2012). Constituting parts helped to reduce a very large description into manageable parts for analysis.

After identifying family caregiver expressed “meaning units,” this researcher transformed the meaning unit data. This was the heart of the analysis and was the most labor intensive. Transforming meaning units was accomplished by restating into third person what informants described. It also included rewording the meaning unit using a nursing attitude and sensitivity toward the phenomenon of interest, resistiveness to care. By transforming the data, this researcher experienced the phenomenon of resistiveness to care rather than restating what the caregiver has described. In addition, the nursing value of what the family caregivers stated about resistiveness to care was made clearer. Not every meaning unit carried the same amount of importance and not every meaning unit was transformed more than once. The transforming process may have be done multiple times until the meaning unit was fully transformed and not all meaning units had the same number of transformations, as not all descriptions carried the same richness or depth of details.

Finally, the transformed meaning units were subjected to “free imaginative variation.” This was a process in which “the actually given data were imagined to be different from what they were in order to ascertain higher-level categories that retain the same [nursing] meaning but were not embedded within the same contingent facts” (Giorgi, 2009, p. 132). The use of free
imaginative variation did not add to or take away from what was given and did not push the data to a level of universality, but rather generality was the goal. The researcher started with rich data and during the analysis teased out general nursing-sensitive meanings that were embedded in the concrete description as contextual limitations prevent universality. Universality would have been too abstract and would not have been appropriate for revealing nursing characteristics of resistiveness to care.

**Essential Structure Used to Clarify and Interpret the Raw Data**

As the researcher applied free imaginative variation to the transformed meaning units, she varied the meaning unit by imagining the opposite of what she would like to state, looking to see if the meaning unit remained the same or was changed with the variation. This process continued until an appropriate expression was achieved in which the meaning unit remained intact but was raised to a higher level and expressed generally. Identify the nursing-sensitive expressions were necessary in the formation of the essential structure of resistiveness to care and the structure of the experience was written (Giorgi, 2009). Finally, the newly constructed essential structure of the experience of resistiveness to care was written and then used to clarify and interpret the raw data provided by the informants. The end result was a general meaning structure for the phenomenon resistiveness to care.

**Validity of Scientific Phenomenology Findings**

Validity of a research project is paramount for believability in the research findings. Using phenomenological research methods, validity is ensured when the discussion of the phenomenon at the end of the study is so rich in detail that the essence of the experience makes sense to the reader and is believable. Generalizability is typically thought of as the ability of the researcher to ensure that the findings of the research study could be applied to others with similar
characteristics or in the same situation and context. However, with phenomenological methods, generalizability is based on similar meanings rather than reproducing the essence (Morse & Field, 1992).

Research studies are often deemed rigorous if the measures employed are reliable and the findings are found to be valid. This is the standard to which many researchers strive when designing their research studies and stems from the positivistic research traditions of seeking to find concrete and absolute truth in the research findings. Qualitative researchers are also expected to provide research studies that are just as rigorous. However, the terms reliability and validity are often replaced with the terms credibility and trustworthiness, as qualitative research assumes multiple realities that are constructed rather than single realities that are tangible. In the following paragraphs credibility and trustworthiness are defined, as they will be used in this study.

**Credibility**

Credibility is also known as authenticity or internal validity and seeks to ascertain whether or not the findings of the research study make sense and accurately reflect the statements of the participants (Miles & Huberman, 1994). In qualitative inquiry, credibility is achieved if the descriptions of the findings are rich with detail and are meaningful. Findings must also make sense and be accurate representations of what participants stated. In a phenomenology study, the findings are said to be credible when enough rich descriptions of the phenomenon are presented to the reader so that the reader is able experience the phenomenon just from reading about it (Miles & Huberman, 1994; Morse & Field, 1995; Van Manen, 1990). Therefore using qualitative standards, the findings are said to be credible if they make sense to the reader and if the reader can envision the phenomenon being described as if they lived it.


**Trustworthiness**

Trustworthiness is also known as authenticity of findings and is validated through review of the research procedures and methods employed. The research methods must adhere to the tenets of the method to be considered trustworthy. If deviations from the method are made, the use of an audit trail (recording rationale for any changes to the method) enhances the trustworthiness of qualitative findings (Giorgi, 2009; Miles & Huberman, 1994). Changes from the method may also include potential biases that the researcher may have encountered during the study, necessitating changes to improve trustworthiness of the findings. No matter what rationale is used for a change, a detailed documentation of the change and reason for the change is important to maintain trustworthiness of research studies.

Audit trails are primarily a means to show that the research process was consistent and stable and in accordance with the chosen method of study (Miles & Huberman, 1994). They show that sometimes research designs and analysis must take a different course than prescribed, but through documentation of the path taken, trustworthiness is maintained. This is particularly important with phenomenology methods of analysis. Phenomenology methods employing a descriptive approach to the analytic process and can easily be influenced by biases from the researcher or others. In the end, the use of appropriate documentation of methods and procedures used by the researcher in the form of an audit trail improves the overall trustworthiness of the research findings by detailing the decisions made throughout the study.

**Credibility and Trustworthiness of Scientific Phenomenology Data Analysis**

For this study the phenomenology data analysis followed the Giorgi method of analysis. This approach used descriptive methods to grasp the essential meaning of the phenomenon. Included in this process were bracketing, intuiting, imaginative variation analysis, and describing
the meaning structure identified (Giorgi, 2009). By following the tenets of scientific
phenomenology, credibility and trustworthiness of the data was maintained.

**Credibility of Data Analysis**

Credibility of the data analysis is attained when a rich and detailed description of
resistiveness to care is uncovered from the data obtained in the interviews with the selected
informants and revealed during the analysis process. For this study eight informants provided
115 instances of the phenomenon ensuring the formulation of a meaning structure and summary
statement of the experiential phenomenon (Giorgi, 2009). The researcher utilized the process of
data collection, analysis, and writing of essential meaning structures of the phenomenon of
resistiveness to care to bring forth a rich structural description of the phenomenon—the lived
experience of resistiveness to care, as experienced by family caregivers when providing care for
people with dementia. With these processes, credibility of this research study was established.

Another way to improve the credibility of this analysis is through the use of credible data.
This was achieved through the use of digitally recorded interviews and field notes. Digital
recordings were used to ensure that all of what was said during the interview was captured in the
data rather than relying upon the researcher to remember at a later time, or potentially disturbing
the thought process of the informant with the researcher taking notes during the interview. To
further enhance the credibility of the data, all recordings were transcribed verbatim and
transcription was verified for accuracy. In addition, data was managed using Microsoft Word—a
software program. Using computer software to store and manage the data provided a record of
the meaning unit analysis strategies used, along with the invariant meaning units employed in the
analysis to develop the structural meaning of family caregivers’ experience of resistiveness to
care.
In addition to transcribing the interview data, all participants were given a code number to maintain informant confidentiality; however, a code book was maintained by the researcher in order to identify which interview data belongs to which informant in the event that further information or clarification was needed on a particular interview. Being able to return to an informant to gain additional data increased the credibility of the findings. In addition to coding the interviews, all field notes and researcher notes were also coded so that they corresponded with their respective interview. This process also improved the credibility of the research analysis by adding another layer to the richness of the description of the phenomenon.

**Trustworthiness of Data Analysis**

To improve the trustworthiness of the data analysis process, the researcher utilized an audit trail to record all the steps and decisions made during this phenomenology research process. These included the formulation of the research question, recruitment of participants, data collection methods, as well as data analysis. Decisions made that changed the course of this research project from the projected plan were recorded along with rationale for the decision or deviation from the protocol that was made. By keeping accurate records in an audit trail it was possible for others to gain insight as to whether or not descriptive phenomenology analysis methods were adhered to or not by the researcher.

**Items Incorporated In an Audit Trail**

Although an audit trail is essential for trustworthiness and credibility of a qualitative research study, there are several key elements that should be documented for added trustworthiness of the study. These include: contextual documentation, methodological documentation, analytic documentation, and documentation of personal awareness (Rodgers & Cowles, 1993). Rationale for why each of these key elements should be included in the audit
trail is provided along with examples of how the researcher used each item to ensure trustworthiness and credibility of this research.

**Contextual Documentation**

Contextual documentation refers to the documentation of non-verbal cues, descriptions of the surroundings, interactions between the interviewer and the informant, and interruptions or disruptions that occur during the interview with the informant. This documentation also includes field notes of the researcher’s perceptions, feelings, and thoughts that occur before, during and after the interview with the informant. Together these notes help to build contextual richness into the lived experience more so than would be possible using the audio recorded interview data alone. With audio recordings by themselves, facial expressions or surround interactions may not be added to the analysis. However, a researcher using contextual data that is captured in a researcher field note of these observed occurrences has the potential to add to the data enriching outcome findings.

Contextual documentation was added to the researcher’s field notes to add richness to the data, and to reflect upon the interview gaining insights into how the interview progressed. The first interview conducted took place in a local restaurant of the participant’s choosing early in the morning. Despite choosing the location, the participant appeared nervous that someone should hear the conversation and stopped talking whenever the waitress arrived to the table. In the middle of the interview the participant requested the recorder be turned off while she ate. This interruption as well as the conversation and soft verbal speaking tone during this “off” time were recorded in researcher’s field notes to document the context of the interview in detail. A second interview also at a restaurant of the participant’s choosing became very noisy when a family with small children decided to sit nearby. Despite the increase in noise the participant continued with
her descriptions as if the family were not even present. This event was also recorded in the researcher’s field note to provide this context to the transcribed interview.

**Methodological Documentation**

Methodological documentations are notations of the methodological plan for the study and how that plan will be carried out. Any deviations away from that plan are also documented along with the reasons why the deviation occurred. The researcher used methodological documentation to record recruitment and purposive sampling techniques (including inclusion and exclusion criteria), the interview process, data collection, (audio recorded interviews and researcher field notes) data management, and data analysis. Providing written documentation of the plan of study and reasons for changes helped establish an audit trail enhancing the credibility and trustworthiness of the proposed study.

A record of each step of the study’s process was documented in an electronic word document table to ensure methodological rigor and adherence to the scientific phenomenology method. Each detailed step of the research process was described in detail and dated to establish a timeline of implementation. For example, recruitment of participants took place at Alzheimer’s support group meetings. The researcher recorded the date as well as details of each meeting in which family caregivers were asked to participate. The details included total number of family caregivers present at the meeting, gender and caregiving relationship of caregivers present, as well as the number of family caregivers who verbally agreed to participate.

The researcher also documented each participant’s scheduled interview and any changes to the schedule. One participant arranged for an interview on a specific day but later called to reschedule the day because she had been in an auto accident the day before. The researcher also recorded when audio files were sent to the transcriptionist; when the final transcriptions were
received from the transcriptionist; when the researcher verified the transcripts for accuracy; and when the analysis of that interview began. These records helped the researcher to remain focused and ensured forward progression of the study.

During the analysis phase of the study, the researcher documented methodological steps such as identification of meaning units, transformation of meaning units, and identification of essential meaning units that would be used in the core constituents of the general meaning structure for each interview analyzed. The audit trail enabled the researcher to go back over the data to retrace her steps ensuring adherence to the tenants of the scientific method for descriptive phenomenology. During the analysis of this study there were no instances in which the researcher needed to deviate from the method.

**Analytic Documentation**

Documentation of the analytic process was maintained using the computer software program as well as notes written in the researcher’s journal. Detailed documentation included meaning units that emerge from the data as well as how these meaning units were decided upon and how they relate to the structure of the phenomenon of resistiveness to care. Strategies used to identify invariant meanings were also documented to provide evidence of thoughtful decision making rather than impromptu decisions regarding the analysis of the data. In addition, the analytic documentation also contained information for future research exploration of resistiveness to care to help maintain the focus of the researcher and provide others with direction to extend this research surrounding the phenomenon of resistiveness to care.

A table (Table 3.1) was created using a software program in which a transcribed interview was uploaded into the first column on the left. Rows were created in the adjacent columns to the right. Identified meaning units were placed into the adjacent right hand column
in different rows. Transformations of the meaning units were recorded in the subsequent rows and columns to the right. The final transformations (identified essential meaning units to be used in the formation of essential constituents) were in the very last column on the right side of the table. This documentation using a structured process enabled the researcher to follow each transformation and retrace the steps of the analysis for each transcribed interview to ensure adherence to the method. This was very important as each transcribed interview ranged in size from 27 pages to 48 pages (mean table document page size was 42). Within each individual interview, data transformed with varying number of columns. The least number of data transformations was three columns and the most was five columns.

Table 3.1. Data Transformation Table Example

<table>
<thead>
<tr>
<th>Raw interview data segmented into meaning units</th>
<th>Meaning units separated for transformation</th>
<th>Meaning unit reworded with a nursing sensitive and phenomenon specific focus</th>
<th>Meaning unit transformed using free and imaginative variation</th>
<th>Final transformed meaning unit to be considered for creating the general meaning structure</th>
</tr>
</thead>
<tbody>
<tr>
<td>“It myself.” <em>We have solved the toothpaste problem, my daughter suggested that I just put the toothpaste on the brush and hand her the brush. So I did that sometimes, my wife got very shy, and she didn’t want me to be in the bathroom with her, so I was a little bit out of the picture as to what was going on. My daughter came and told me you know you have to make sure she cleans herself and all that stuff. /But it seemed to be okay, she misses.</em></td>
<td>We have solved the toothpaste problem, my daughter suggested that I just put the toothpaste on the brush and hand her the brush. So I did that sometimes, my wife got very shy, and she didn’t want me to be in the bathroom with her, so I was a little bit out of the picture as to what was going on. My daughter came and told me you know you have to make sure she cleans herself and all that stuff. /</td>
<td>Sam has solved the toothpaste problem. Sam’s daughter said to put the toothpaste on the brush and hand it to PWD. Sam does that now. His wife got very shy and she didn’t want Sam in the bathroom with her, so I was a little bit out of the picture as to what was going on. My daughter came and told me you know you have to make sure she cleans herself and all that stuff. /</td>
<td>Sam had difficulty knowing if his wife brushed her teeth so Sam and his daughter came up with the solution to put the toothpaste on the toothbrush and hand it to PWD to use. Sometimes PWD will not let Sam in the bathroom while she is performing her personal hygiene so Sam doesn’t know if she brushed her teeth. /</td>
<td>As caregiver Sam doesn’t really know if his wife is getting clean as he tries to respect her privacy in the bathroom while bathing but his daughter doesn’t like this and insists that Sam be in the bathroom with her mother. /</td>
</tr>
</tbody>
</table>
Documentation of Personal Awareness

Not only do researchers document the methodological steps used in a phenomenological study, but researchers must also be continuously aware of potential biases that can influence research findings. One way that researchers can become aware of personal biases is through the use of a reflective journal. Within a reflective journal, researchers write about what they currently know regarding the phenomenon under study so as to become aware of their thoughts and ideas, and then monitor them. In this way, they scrutinize their biases so they do not influence the research findings. This journal is called reflective in that the researcher writes in the journal not only at the beginning of the study but throughout the study. The researcher will also return to what is written during the study to continually remind himself/herself of the potential biases that exist.

The researcher used a reflective journal to help bracket any personal biases regarding resistiveness to care and family caregiving for people with dementia so that she could intervene if these biases threaten to influence the research project. If biases were identified, the researcher reviewed the data at that point to find out if the biases influenced the data collection or analysis. If bias influence was found, the researcher re-established the phenomenological transformation and reanalyzed the data. A notation of the reanalysis would have been logged in the audit trail for the study.

The reflective journal was created prior to the beginning of the study. In it the researcher identified and made a list of all that she knew regarding resistiveness to care and family caregiving for people with dementia. Throughout the study, the researcher periodically returned to the reflective journal to ascertain if biases were present or threaten the research study. In addition to using the reflective journal to identify potential biases, the researcher documented
strategies that helped her maintain a neutral position within the research process. This included frequent review of the reflective journal and comparisons with this study’s research findings; not returning to the scientific literature to read about the phenomenon until after the study analysis was complete; as well as selecting a fellow researcher to discuss thoughts and feelings regarding the phenomenon of interest while the study was progressing.

Lastly, the researcher incorporated documentation of any psychological or emotional strains that this research project may have place on the researcher in the reflective journal. Interviewing family caregivers of people with dementia who were experiencing distress was difficult. When the researcher experienced distress after an interview, she used mediation and reflection on the experience as well as running to clear her thoughts before resuming work on the study. By documenting these feelings or emotions, the researcher monitored their effect on the research project to prevent an adverse influence on the research, leading to biased results.

Credibility and trustworthiness were necessary to ensure rigor in phenomenology research and were achieved by using meticulous record keeping of the research process before, during, and after the interviews. The use of audit trails helped to ensure that the researcher documented all decisions and changes made during the research project and also provided evidence that the research method was followed consistently. The researcher also maintained a reflective journal to ensure a personal awareness of personal bias and distress that can occur during a study. The researcher maintained credibility and trustworthiness of the scientific phenomenology research data analysis using an audit trail that includes contextual, methodological, analytical, and personal (reflexive journal) documentation. Through the use of these processes, credibility and trustworthiness of the proposed lived experience of this resistiveness to care study was established.
Chapter Summary

In order to clarify the structural meaning of the lived experience of resistiveness to care as experienced by family caregivers of people with dementia, a Husserlian influenced descriptive scientific phenomenological approach as interpreted by Giorgi was performed for this research study. The study utilized transcribed in-depth interview descriptions from eight family caregivers to elicit their lived experience of resistiveness to care. Interviews took place either in the home of the family caregiver informant or at a mutually agreed-upon place by both the researcher and family caregiver informant. All interviews were conducted in a place that was chosen by the family caregiver (where they felt comfortable telling their stories). Descriptive scientific phenomenological analysis methods as interpreted by Giorgi were applied to the personal interviews. In addition, observational field notes were maintained for each interview.

Through this analysis, this researcher was able to analyze the rich detailed lived experience of family caregivers using the human science phenomenological reduction. By bracketing during analysis, invariant meaning units were used to create an invariant structure of the meaning (clarify the experience of resistiveness to care and the meaning it has for these caregivers). The identified meaning structure for the experience of resistiveness to care added to the nursing science surrounding family caregivers’ lived experience by providing an empirical foundational and direction for future research particularly in the area of support for family caregivers perceiving resistiveness to care as stressful.

In personal communication with A. Giorgi (March, 2013), he stated that using a nursing disciplinary perspective during the study would produce highly relevant insights for nursing that sociologists and psychologist might miss. Review of the social science literature suggests that caregivers perceptions of the caregiving experience has the potential to mediate their reported
levels of distress when experiencing caregiving phenomenon such as resistiveness to care (Pot et al., 1998). With that in mind the potential exists to focus future research on the meaning family caregivers describe in their experience with this phenomenon and work with those perceptions to help mediate their overall reported feelings of distress.

Researchers Kinney and Stephens (1989) have purposed that the resistiveness family caregivers experience may be a subjective representative of the changed person with dementia and is more stressful than the actual objective behaviors. This study provided more insights into this theory by providing a base which future interventions can be trialed to help family caregivers come to terms with the changes in people with dementia.

With these examples and the previously mentioned research studies, it is evident that phenomenological research findings are beneficial for not only advancing the science surrounding a phenomenon through discover of new concepts, factors, or their relationship but are useful for impacting policy and practice changes (evidence based practices), as well as for educational purposes. Likewise, this phenomenology study will impact nursing and the care nurse provide for their patients. These influences may be in the form of support and resources (for care of the person with dementia or the family caregiver), practice changes that are holistically focused incorporating the family caregiver when planning care for the person with dementia, or nursing curriculum changes to include the study findings surrounding family caregivers’ experiences with resistiveness to care for educating nurses.

The following chapters detail the descriptive scientific phenomenological analysis results of the family caregiver interview data. Clarification of the meaning family caregivers have when they experience resistiveness to care are presented as invariant structural meaning highlighting aspects of resistiveness to care from the nursing disciplinary perspective. In addition to the
current study findings, potential limitations of the current study, along with recommendations for future nursing research expanding upon the phenomenon of resistiveness to care as experienced by family caregivers of people with dementia, are presented.
Chapter 4

Study Findings

This chapter begins with a description of each participant and a summary of their caregiving related to the experience. The scientific phenomenology method and analysis process is discussed next in detail. The meaning family caregivers assign to the phenomenon—resistiveness to care are presented as the structure of resistiveness to care. Essential component of the structure are identified. Empirical and nursing variances of the structure are also considered. A summary of what constitutes the experience of resistiveness to care for family caregivers of people with dementia is provided. The chapter ends with a brief overview of the findings and proposed applications for both nurses and family caregivers of people with dementia. Directions for future research related to this phenomenon are also posited.

The purpose of this research was to empirically study the phenomenon of resistiveness to care as experienced by family caregivers when providing care for people and to identify a general meaning structure of the phenomenon. For the purpose of this scientific phenomenology study, resistiveness to care was defined as any experience that family caregivers perceived as resisting the care being provided. Family caregivers’ descriptions of experiences of resistiveness to care were transformed by applying the scientific phenomenology method and analyzed to obtain detailed meaning units that revealed a general structure of the resistiveness to care, as it was actually experienced.

Apparatus and Method

Apparatus. A voice recorder was used to digitally record all consenting participants as they were interviewed. The recorder was kept in the participant’s view and the participant was informed when the recorder was turned on and when it was turned off.
**Participants.** Family caregiver participants were recruited from Alzheimer’s support group meetings. Alzheimer’s support group leaders from five different support groups (three conducted in nursing care facilities; one conducted in a local hospital; one conducted in a local church) were given information about the study and agreed to introduce the researcher and research study at various support group meetings. Family caregivers were recruited over a six-month time period. Interested family caregivers who believed they had experienced the phenomenon of interest approached the researcher after the support group meeting. The researcher then determined if the potential participant met the inclusion criteria and if so made arrangements for an interview with the researcher. A total of 10 family caregivers verbally agreed to participate in the study. However, there were two family caregivers who gave verbal willingness to participate but did not follow up to schedule an interview with this researcher. One of these caregivers later informed the researcher at a follow up support group meeting that she thought about the study after agreeing to participate but did not feel she had experienced enough of the phenomenon to provide details for the research project. A total of eight family caregivers from five different support groups (each support group meeting was coded with a letter [A-E]; each participant was coded with their support group letter and a number) signed consent forms to participate in the study and made arrangements for an interview time and place. Participants were then asked to describe their experiences with resistiveness to care. Family caregivers chose what experiences they described for the researcher. Each family caregiver was given a ten-dollar gift card after their interview as compensation for their time during the interview. Demographic information about each participant and a summary of their resistiveness to care are presented next in tables (Table 4.1 and Table 4.2) as well as summarized narratively.
### Table 4.1. Summarized Family Caregiver Demographics

<table>
<thead>
<tr>
<th>Age: (in years)</th>
<th>Family Caregiver</th>
<th>Care Recipient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Range</td>
<td>71.1</td>
<td>62.1</td>
</tr>
<tr>
<td></td>
<td>60-82</td>
<td>72-95</td>
</tr>
<tr>
<td>Gender:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Duration as Caregiver/Care Recipient: (in years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median Range</td>
<td>4-5</td>
<td>4-5</td>
</tr>
<tr>
<td></td>
<td>2-20</td>
<td>0.5-20</td>
</tr>
<tr>
<td>Care Recipient Residence</td>
<td>Lives With Caregiver 4</td>
<td>Lives in Nursing Care Facility 4</td>
</tr>
<tr>
<td>Types of Resistiveness Described by Caregiver</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wanting to Leave</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Refusing Personal Hygiene</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Wanting to Drive</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Not Wanting Help with Finances</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Resisting Everyday Caregiving</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

### Table 4.2. Individual Family Caregiving

<table>
<thead>
<tr>
<th>Caregiver</th>
<th>Caregiver Gender</th>
<th>Amount Of Caregiving Provided/Needed</th>
<th>Care Recipient Gender</th>
<th>Care Recipient Residence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alice</td>
<td>F</td>
<td>Able to do ADLs with prompting from caregiver</td>
<td>Male</td>
<td>Lives with caregiver</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Caregiver must manage financial affairs and stimulation to prevent wandering</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Takes the care recipient to all doctor visits or “any place she [care recipient] wants to go”</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Considers herself the “major caregiver” for the care recipient “I am the main one they [care facility] would contact”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grace</td>
<td>F</td>
<td>Needs assistance and prompting with ADLs</td>
<td>Male</td>
<td>Lives with caregiver</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Needs reminded to shower</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Assistance needed after toileting</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Prompting needed during dressing</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Can be left alone for parts of the day but not long periods of time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Margie</td>
<td>F</td>
<td>Visits Care recipient 2-3 times per week for 30 minutes each visit</td>
<td>Female</td>
<td>Lives in assisted care facility past 3-4 yrs Prior lived alone</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Takes the care recipient to all doctor visits or “any place she [care recipient] wants to go”</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Considers herself the “major caregiver” for the care recipient “I am the main one they [care facility] would contact”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jenny</td>
<td>F</td>
<td>Needs minimal assist with ADLs</td>
<td>Male</td>
<td>Lives with Caregiver</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Regulate the water temperature for a shower</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Provide clothing choices for dressing</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Will make a sandwich if ingredients are in the refrigerator</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Can be left alone for parts of a day</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Able to mow the lawn but not start the mower</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Able to perform task with prompting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peggy</td>
<td>F</td>
<td>Needs prompting to perform ADLs on own</td>
<td>Male</td>
<td>Lives with Caregiver</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Needs redirecting to do tasks</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Can be left alone for short periods of time</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Needs supervision for wandering</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dario</td>
<td>F</td>
<td>Needs 2 assist with toileting, needs assistance with eating</td>
<td>Female</td>
<td>Lives in a Facility past 3 yrs Prior lived with caregiver</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unable to walk uses a wheelchair</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Caregiver manages finances and does the laundry for the care recipient</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Visits care recipient on days off work for several hours each visit</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eve</td>
<td>F</td>
<td>Manages the finances for the care recipient</td>
<td>Male</td>
<td>Lives in a care facility past 2 yrs Prior lived alone</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Requires assistance with ADLs and supervision to prevent wandering</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Visits when visiting daughter who lives nearby (not as often as liked)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sam</td>
<td>M</td>
<td>Promoting and assist needed with ADLs</td>
<td>Female</td>
<td>Lives in a care facility Prior lived with Caregiver</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Turning on the water for bathing</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Putting toothpaste on the toothbrush</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Preparing meals</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Supervision for wandering and management of behaviors</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Visits care recipient daily for several hours each visit</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Each participant was assigned a fictitious name for the detailed summaries to improve readability of the caregiving summaries.

**Participant (Alice): Demographics.** Alice is a white widowed woman in her late 70’s caring for her male significant other in his late 70’s. They started to “date” four years ago and have lived together for the past two years. Alice has been a caregiver since she moved in with her significant other and he was diagnosed with dementia shortly after. Although her significant other can perform many of his activities of daily living (ADLs) with minimal prompting and can be left alone for short periods of time, Alice must manage his financial affairs and provide stimulation to prevent him from wandering. Alice finds the caregiving role to be exhausting and something she had not expected or wanted in a relationship; however, she is able to see many benefits to the relationship.

**Participant (Alice): Summary of Caregiving Experience.** Alice became a caregiver shortly after she moved in with her significant other and started to notice that things were a little “off” but did not really think anything about it. The first time that Alice as caregiver became scared and did not know what to do was when she experienced her significant other not liking where they were. Despite her efforts to reassure him that they were home he became insistent to look for his home. His insistence surprised Alice and she became concerned he would not listen to her reasoning and leave the house and get lost. In need of answers, she called the Alzheimer’s support group number for advice. Alice was familiar with support group help from her previous marriage. Her deceased husband was an alcoholic and she attended AA for many years finding comfort in their support. The Alzheimer’s support group informed Alice that her significant other was not looking for his childhood home but rather a place where he felt safe. Alice interpreted this to mean that he did not feel safe with her in their home. This challenged Alice’s
perceptions of herself as an adequate caregiver. Other challenges included times when her significant other appeared to Alice to be “normal” and without the disease. It was during these “normal-like” times that Alice questioned the diagnosis wondering if the doctor made a mistake. However, out of nowhere her significant other would insist that their home was not where he lived and he would want to leave to find his home. This mostly occurs in the morning shortly after he awoke and came to the kitchen for breakfast. Sometimes it occurred in the afternoon but always unexpected and catching Alice off guard. Alice attempted to use reasoning in the beginning of the disease to answer his questions and keep her significant other from leaving. This only lead to arguing so Alice dropped the discussions to prevent further arguments. Alice has since discovered that if she keeps her significant other stimulated with things to do, he is less likely to ask about his home and leaving. Alice manages an agenda of activities for each day to ensure that her significant other is stimulated. She finds this to be exhausting but believes that it is very worthwhile. Rainy or bad weather days are the most challenging and difficult for Alice. On these days her significant other will become very insistent about leaving causing much distress and frustration for Alice. These are not the only times that are distressful for Alice. She also finds managing her significant other’s finances very stressful. Alice feels bad that her significant other can no longer do this for himself and believes if he knew that she has been managing his finances he would not like being dependent upon her. Alice has reflected on what her life has become since she moved in with him. She realizes that she is losing her freedom; not doing the things she did before she moved in with her significant other. Alice does not consider herself a caregiver and reasons that she is not married to the care recipient and doesn’t have the same obligations as a wife. Alice ponders whether she would have moved in with her significant other if she had known about his disease process in the beginning. Later she rationalizes that she
has many benefits with her significant other that off set the many challenges and that she would have still moved in with him. Alice reasons that even when a husband and wife marry they do not know what the future holds. Alice does receive help from their friends and Alice’s daughter who is a nurse but rarely from her significant other’s son and daughter-in-law who live in another state. She feels strongly that the Alzheimer’s support group meetings are beneficial and wishes that they were offered more frequently or with personal coaches, as is the case with AA support groups. Alice feels that caregivers would gain tremendous day-to-day support from a mentor/coach rather than relying on one monthly meeting.

**Participant (Grace): Demographics.** Grace is a white female caregiver who lives with her husband of over 60 years. Together they have 5 grown children—two daughters and three sons. Grace is in her early 80s and considers herself as caregiver for the past several years although her husband—the care recipient has only been diagnosed with dementia for the last few years. Her husband can be left alone for parts of the day but not all-day or overnight. Grace must supervise his interactions with women. He likes to “hug” women. The women he hugs interpret this interaction as inappropriate. At first Grace considered the hugs innocent but now feels uncomfortable with him hugging other women. Grace needs to prompt and sometimes assist her husband with ADLs such as reminding him to shower, assisting him with care after toileting, and prompting with dressing. Grace receives some caregiving assistance from her daughters but this is limited. Only one daughter lives in the same town as Grace. The other daughter and sons live out of state.

**Participant (Grace): Summary of Caregiving Experience.** Grace has experienced many distressful caregiving situations both before her husband was diagnosed with dementia and after. The first distressing situation that Grace had to deal with was inappropriate “hugging.” Grace
became aware of this inappropriate behavior when attempting to drive her husband to his volunteer job at a local healthcare facility but he did not want to go. It was at this time that Grace learned that her husband was not welcome to volunteer anymore because he was hugging the women. Grace was extremely embarrassed but rationalized that the facility just did not understand her husband’s innocent ‘hugs.’ It was after several other incidents both at their home and at a neighbor’s home that Grace also realized the hugs were inappropriate and not acceptable. Grace was so embarrassed that she could not bring herself to tell her five children about their father and tried handled the situations alone. It was during this time that her husband was diagnosed with dementia and other acts of resistiveness started to appear. Grace has trouble with her husband not wanting to engage in hygiene practices. When Grace attempts to assist her husband with his shower he passively agrees to take a shower but never does. He also insists on sitting on his bedspread to undress leaving soiled marks on the spread, signaling to Grace that he is not keeping up with his personal hygiene practices. Grace has tried to reason with her husband on these matters but it doesn’t seem to make a difference. He is still non compliant and she becomes more frustrated. Grace has since told her daughters about their father and gets support from them. Despite the children being aware of their father’s dementia, Grace did not think they truly understood all that she had to do during the day to care for their father. Grace had friends that knew about the dementia but did not know the full extent of her husband’s behaviors. She was not comfortable telling them all the details and so they said things like “poor [care recipient]” and this made Grace angry because she knew that he was not aware of a lot of things, was very happy in his own world, and was not suffering. On the other hand it was she who has the hard work and knowledge of all the behaviors and stated it should be “poor [Grace]!”

**Participant (Margie): Demographics.** Margie is a white female daughter to the care
recipient, her mother. Margie has been in the caregiving role since her mother was diagnosed with dementia. Margie’s mother who is now in her late 80’s lived alone in her own home during the initial diagnosis but had been living in an assisted care facility for the past several years. Margie and her siblings decided to move their mother to the care facility when they thought it was no longer safe for her to be alone in her home. Margie visits her mother several times per week for 30 minutes or so and they play cards. When not at the facility, Margie does her mother’s laundry, pays her mother’s bills, and takes her mother anywhere she wanted to go including doctor visits or appointments. This is taxing for Margie as she had been diagnosed with Multiple Sclerosis and struggled with her own limitations. Margie lives with her husband whom she considered to be very supportive despite not having prior caregiving experience himself. Margie’s siblings (a brother and a sister) also provide various level of caregiving support.

**Participant (Margie): Summary of Caregiving Experience.** Margie considers herself the major caretaker for her mother. She stated that her mother was very easy going. Margie plays cards with her mother when she visited. Her mother had played cards since she was a little girl and it is one thing she remembered how to play. Margie realized that conversations with her mother were useless, as her mother could not remember things and questions often put her mother on the spot. Margie does not want to make her mother uncomfortable with questions and playing cards was something they both could enjoy. She had experienced several instances of resistiveness when caring for her mother. The first instance was when she and her siblings decided to remove their mother’s car for her own safety. Her mother was away visiting her sister in another state when Margie and her brother removed the car from their mother’s garage. When Margie’s mother returned Margie called her asking if she had been in her garage. Her mother
replied that she had not. Margie then informed her that they had taken her car. At first there was silence and Margie knew it wasn’t good. Later when Margie went to visit her mother she realized the amount of anger that her mother still had when her mother slammed the door in Margie’s face. This was the first time Margie saw her mother so angry, very angry. Margie reasoned that her mother had been so independent and her children were taking away her independence by taking away her car. Despite this rational understanding of the situation and the need for safety, Margie stated she felt like the bad guy and wondered if they had done the right thing. Shortly after this incident with her mother, Margie was at the mall and noted an elderly lady in distress wandering in the parking lot. She realized the woman could not find her car and decided to help her. After the car was found and the woman drove off, Margie thought about how that could have been her mother if she had not taken the car. She admitted that she felt scared to realize that not everyone would be as helpful as she was with the elderly woman and that someone could take advantage of a confused elderly woman—namely Margie’s mother. Margie consulted the Alzheimer’s support group leader to gain reassurance that she did the right thing. She again experienced resistiveness from her mother when she and her siblings moved their mother into an assisted living facility for her own safety. They thought the neighborhood where their mother lived was too dangerous for an elderly woman living alone. After moving into her room, Margie helped her mother unpack her belongings. Margie’s brother called later to informed Margie that their mother was not happy where she was. When Margie returned the second day she found her mother had repacked all of her belongings. Margie had to unpack her mother’s belongings for a second time and this made Margie feel very sad that her mother didn’t like the facility. This was not Margie’s first experience with dementia. As a little girl she remembers her grandfather with dementia. He would have mean outbursts and Margie knew it
was the dementia and not her grandfather that caused those behaviors. Margie hopes that her mother will not get like that. Despite knowing the behaviors are part of the disease, she admits that it would hurt her if her mother were to treat her with meanness. Margie finds comfort in the Alzheimer’s support group meetings. She feels that her husband while supportive can become over burdened with her frustrations and concerns of caring for her mother but the support group is a safe and non-judgmental place to vent her emotions.

Participant (Jenny): Demographics. Jenny is a white woman in her late 60’s and is the caregiver for her husband who is in his early 80’s. They have two adult children (one son and one daughter) who assisted frequently with the caregiving responsibilities. Jenny has been the caregiver for over 20 years since her husband was diagnosed with dementia. Although her husband required minimal assist during ADLs, Jenny may have needed to regulate the water temperature for a shower, provide clothing choices when dressing for the day, or ensure there were appropriate sandwich ingredients for him to make a sandwich while she was at work. Jenny admitted that while her husband could be left alone for parts of a day she felt worried that he would wander away when she was at work. She often asked neighbors or relatives to look in on her husband during the day. Despite working for more than 30 years, being near retirement age, and family urgings Jenny was not ready to give up her full-time job working in a local nursing home stating, “what would I do at home? [pause] No, I like the contact with the world.”

Participant (Jenny): Summary of Caregiving Experience. The first time Jenny experienced resistiveness from her husband was many years ago when he urgently wanted to leave. They were vacationing thousands of miles from home when he woke Jenny in the middle of the night insistent to leave at that moment. The request seemed to come out of nowhere and took Jenny by surprise. Jenny had to reason with him that it wasn’t possible to leave in the
middle of the night and after awhile Jenny was successful. Her husband gave up his request to go home, which was a relief for concerned Jenny. This had been a recurrent theme that Jenny dealt with frequently. Sometimes Jenny was not so successful with the reasoning and had to give in to her husband’s requests to leave. Recently on one very cold winter morning Jenny was awaken at two in the morning by her husband insisting that he go home. Jenny tried to reorient her husband by showing him the neighbors’ house through the window in hopes he would know he was home. It worked for only a short period of time and he was again requesting to leave. In the end Jenny had to dress and drive her husband around the block to settle him from his desire to leave and look for home. Jenny admitted it broke her heart to see her husband acting like this and at the same time she would get angry. Jenny also experienced resistance when her husband wanted to drive despite the physician taking his license several years prior. When her husband was insistent to drive Jenny was comforted to know that her husband did not remember how to start the car if he should ever get the keys. Jenny stated she had a myriad of emotions as caregiver for her husband. These included sadness, dread, jealousy, and anger. At times Jenny wished she could just make him realize that he cannot do the things he wants to do but knows that it was useless. Jenny had the support of her two children and her sister. They would often take turns so that Jenny could have a night out singing in the church choir or shopping. She admitted that one night out a week was not enough sometimes she needs more. During these weeks her family would come to her rescue. Jenny had a mother-in-law and several sister-in-laws that were diagnosed with dementia. Both Jenny and her family were very aware of the disease process and know what to expect with her husband/their father.

**Participant (Peggy): Demographics.** Peggy is a white woman and wife of the care recipient—her husband. They knew of each other when they were younger but married later in
life. They have lived together for a few years of which the last several years Peggy has been the caregiver. Peggy’s husband was diagnosed with dementia four years ago shortly after their wedding. Both Peggy and her husband are both in their 70s, have grown children that no longer live with them and a granddaughter in her middle teens that did live with them. They have several houses, one they lived in and one in a nearby town that they were remodeling. Peggy has several health problems that limit her caregiver abilities at times and relies on their friends to assist her when she is not feeling well.

**Participant (Peggy): Summary of Caregiving Experience.** Peggy became caregiver shortly after she married her husband. Peggy stated she felt they are very compatible and enjoyed many of the same things. Peggy had not planned to be a caregiver, it just happened. Peggy started to notice that things that she said and did upset her husband when they had not before. It was not long before Peggy found out her husband had dementia. It began with him forgetting his keys and other items and now has progressed to him not being able to do simple tasks like ordering from a menu, starting the lawn mower, or placing a wet bathroom towel on the towel bar to dry. Peggy stated that her husband needed prompting with his ADLs; simple direction or redirection when performing tasks; and supervision for wandering and was unable to be alone for long periods of time. Peggy often called upon friends to assist her with caregiving activities such as sitting with her husband, taking him to lunch while Peggy was at a doctor appointment or shopping. Peggy admitted to overprotecting her husband when out in public as she was not sure how others will respond to him. She was afraid of what others will do if he should say the wrong thing. Peggy confided that this could be very stressful.

**Participant (Deloris): Demographics.** Deloris is a white female and daughter to the care recipient—her mother. She is close to retirement age and has been caring for her mother who
has been in a care facility for the past three years. Deloris stated she felt like she was the
primary caregiver of her mother for the past five years since her diagnosis of dementia.
Deloris’s mother is currently wheelchair bound (unable to walk), needs a two-person assist with
toileting and supervision assistance with eating. Deloris visits her mother on her days off work
and spends several hours with her at each visit. When she is not visiting her mother, Deloris
does her mother’s laundry and manages her mother’s finances. Prior to living in the care facility,
Deloris lived with her mother in her mother’s home along with Deloris’ son and his girlfriend
and at times with Deloris’ brothers. Deloris had hoped to inherit the family home when she
retired but was upset to find out the expenses for the care facility may necessitate her selling the
home.

*Participant (Deloris): Summary of Caregiving Experience.* Deloris has been the
primary caregiver for her mother for the past few years since her mother’s dementia diagnosis.
Deloris had hoped to gain help from her son and brothers. Her son and one brother had provided
some assistance but are not reliable. Deloris’ son moved to another state, her younger brother
died suddenly in his mid 40’s and her other brother did not want to see his mother with dementia.
He preferred to remember her before the disease. This left the majority of care for Deloris. She
does have a sister that lived in another town and was not able to help with the day-to-day care for
their mother but did provide emotional support. The fact that Deloris had to work and was
unable to stay with her mother during the day made it very difficult for Deloris to manage her
mother’s care by herself and necessitated her mother’s placement in a care facility. Deloris stated
this made her feel very guilty. She had promised her mother years before that she would never
put her in a nursing home. Deloris managed all of her mother’s finances as she has done before
she was diagnosed with dementia. She stated that she felt like she was the only one who could
“take the best care of her [her mother]” despite her mother being in a care facility. She visits her mother several times a week. When her mother was first placed in the care facility Deloris would visit daily. Doris stated this was exhausting. It was at the Alzheimer’s support group meetings that Deloris learned the importance of taking care of herself and not losing herself in caregiving. Deloris first encountered resistiveness from her mother early in the diagnosis when they were living together. Her mother would suddenly become angry about something and Deloris would not be able to reason with her and become frustrated and angry herself. This would lead to an argument after which Deloris would feel terrible about how she treated her mother. In fact, she wondered if their arguing contributed to her mother’s decline and need to be placed in the care facility. Deloris believed that if her sister lived closer they would be able to care for their mother at home and she would not need to be in the care facility. She wished she did not have to work so that she could care for her mother but stated that she was not financially able to retire yet. In addition to caring for her mother, Deloris had become the caretaker for her mother’s small dog. Deloris’ mother could not have the dog with her in the care facility. Although Deloris admitted that she was not a dog lover, she had come to like the dog and would take it to the care facility on visits to see her mother. These visits were just one example of how Deloris experienced resistance from her mother. At times her mother did not want Deloris to take the dog home and would not release her hold on the dog. Deloris had to call for assistance from the care facility staff to wrestle the dog from her mother while her mother screamed “NO” and Deloris worried the dog would bark loudly disturbing everyone. These instances were emotionally difficult for Deloris but she continued to take the dog because she knew her mother enjoyed the visits. She had also experienced resistance when her mother would hallucinate and Deloris would try to reorient her or when Deloris tried to protect her from harm when she would
wander outside during the night. At first Deloris thought her mother was having a nervous breakdown but later came to realize that these resistive episodes were part of the dementia disease. She limited her visits to her mother and managed to find time to go out with friends at least once a week so that she would not burn out caregiving for her mother.

**Participant (Eve): Demographics.** Eve is a retired white female daughter caring for her father who is in his mid 90’s. Eve is well educated with an advanced degree. Although she considered herself retired, she still accepts occasional job assignments working from home to keep her busy. Eve’s father is also well educated and worked until his retirement. He is widowed and used to live in his own home. Several years ago he decided to have a female significant other move in with him until his placement in a care facility two years ago. Eve has considered herself a caregiver for the past few years although her father has been diagnosed with dementia since his late 80’s. In the beginning of the disease, Eve only needed to manage her father’s finances but since his placement in the care facility, he now requires assistance with his ADLs, and supervision to prevent him from wandering. Eve lives several hours away from her father and found it difficult to ensure his safety from afar and placed him in the care facility. This decision was made with her siblings (two brothers) who live a distance away from Eve and their father.

**Participant (Eve): Summary of Caregiving Experience.** Eve found being a caregiver a huge job and tried not to think emotionally about all the work that she had done. She knew it had to be done to keep her father safe. When Eve first noted that there was a problem with her father, she was shocked to find out that he had not been managing his finances for a long time. He had always been meticulous about finance and even helped others with their finances. Eve was initially overwhelmed with the amount of work that she had to do to get her father up-to-
date financially. He had many investments and bank accounts that were neglected. She also learned that he had not filed taxes in more than five years and the years filed prior to that were not correct. Eve was also shocked at her father’s reaction to their helping him get his affairs in order. This was their first encounter of resistiveness. Her brother’s reaction was to become angry with his father and refuse to help his father. Although unpleasantly surprised, Eve optimistically knew she would be the one to take care of things. She reasoned she lived closer to her father and knew how she could manage the finances without her father knowing. Eve felt she could use deception to take over his finances preventing her father from becoming more angry and resistant. She also experienced her father’s resistance one winter late at night when he wanted to go to his parent’s home. His live-in significant other at the time called Eve’s brother to tell him their father was insistent to go outside and she was afraid he would go outside. Eve and her brother were fortunate that the significant other was able to eventually prevent him from going outside in the cold despite his insistence. They sought placement for him shortly after. Since that time, Eve had learned that her father became very agitated and resistive when he was suffering from a urinary tract or other type of infection. The care facility would call her to inform her that they had sent him for treatment of the infection. Eve was not upset with the calls but was thankful that they were taking good care of her father. In return, she provided them with knowledge of several things (a newspaper and chocolate) that her father liked to help them manage the resistive behaviors.

**Participant (Sam): Demographics.** Sam is a white male who is the husband of a woman diagnosed with dementia six months ago. Over the past two and a half years Sam has been a caregiver for his wife. Both are in their 80’s. Sam is well educated with an advanced degree. He likes to read and learn about things that interested him. Until recently, Sam and his wife
lived together (for more than 50 years). Sam and his daughter decided to place Sam’s wife in a care facility six months ago. Although Sam was the primary caregiver for his wife, his daughter was the most vocal about her mother’s care. Providing care for Sam’s wife consisted of prompting and physical assistance with ADLs such as turning on the water for a shower, putting toothpaste on the toothbrush, preparing her meals, and keeping her safe. Sam relied heavily on the Alzheimer’s support group meetings for advise and comfort. He would often attend multiple different meetings each month for support.

**Participant (Sam): Summary of Caregiving Experience.** As a caregiver before his wife entered into a care facility, Sam provided supervision to prevent his wife from wandering and attempted to manage many of her aggressive and agitated behaviors. Often Sam was the target of his wife’s aggression and agitation resisting his care. She would threaten with physical harm using a rake or stick. In the course of caregiving, Sam differed with his daughter on how to care for his wife/her mother. To prevent further disagreements between father and daughter, Sam let his daughter manage the situation when she was present. He often refers to his daughter as the “task master” while he preferred a more relaxed approach to caregiving. In the beginning Sam did not call his daughter when he encountered extreme aggressive physical resistance from his wife. He reasoned that she had her own family and he did not want to bother her. Sometimes during these episodes Sam had to sit outside in the family car for several hours in the very early morning hours waiting for his wife to calm down (after she resisted his care and forcefully threw him out of their house). Conflicting images of his wife caused Sam to second guess his caregiving decisions. In the moment of resistiveness he could not believe that his small wife (five-foot two inches) could physically throw him (a tall six-foot man) out of the house. When his wife is making sense he believes her but when she is resistive he feels like he is limited in his
options. Although conflicted, Sam stated he felt he did not have a choice but to place his wife in a care facility. Caring for her had become extremely difficult and more than he felt he could handle. Sam admitted that placing his wife in the care facility had been the hardest decision because he still loved his wife very much and wanted to be with her. He still questioned whether his decision to place her was the right one. Although he admitted he knew it was the disease that has caused this to happen, he stated he felt sad that he had to place her. Sam had hoped that the care facility would be able to manage his wife’s medications enough that she would be able to come back home with him. He stated that he feels disappointment that it has not happened. To cope with caregiving Sam had started eating biscotti and reading a good book in the evenings. He felt this was his treat for enduring the daily tumultuous visits with his wife.

**Results**

This section highlights the structure of resistiveness to care, which represents the constituents of meaning family caregivers cognitively assign to the resistiveness as they experience it while caregiving for someone with dementia. A table showing an overview of the constituents in the structure of resistiveness is presented. Empirical variations among the caregivers are discussed in terms of nursing meaning—caring and consequences. The section ends with a discussion of resistiveness to care as it relates to overall caregiving.

**The Structure of Resistiveness to Care as Experienced by Family Caregivers of People with Dementia**

Resistiveness takes place in the context of providing care for someone with dementia and usually occurs in a situation in which the family caregiver is engaged or interacting with the person with dementia. Sometimes resistiveness to care occurs when a caregiver has an agenda or goal and the care recipient is not compliant. In other situations, a sudden unexpected care
recipient action or behavior will drive the family caregiver into an experience of resistiveness to care. Once engaged in resistiveness essential components for the structure of resistiveness to care are assigned meaning in the consciousness of the family caregiver and were uncovered by the researcher. These essential components include self-questioning of abilities, signal for future caregiving responsibilities; changed perception of personal self; unexpected emotional responses; and sees changed person not the disease. In response to resistiveness to care family caregivers developed strategies to manage or avert the resistive behaviors they were experiencing. These strategy choices included a struggle between telling the care recipient ‘little white lies’ and being honest; using reasoning with the care recipient; and deciding to relinquish the goal or agenda they had for the encounter. The potential existed that unsuccessful strategies utilized by family caregivers would propel the dyad (family caregiver and person with dementia) back into resistiveness to care repeating the cycle of caregivers having to manage the new situation with strategic choices. The ultimate desire was to reach a stable state in which the resistiveness was averted. Since resistiveness to care occurs along with the progression of the disease process, this stable state was only a transient stable state as permanent stability was unlikely. The potential for more resistive experiences is ever present when caring for someone with dementia. The following tables (Table 4.3 and Table 4.4) graphically outlines the various essential constituents. Each constituent is described for each family caregiver as they experienced resistiveness to care.
Table 4.3. The Essential Constituents of the structure and empirical variations lived by each caregiver

<table>
<thead>
<tr>
<th>Essential Constituents</th>
<th>A1 (Alice)</th>
<th>A2 (Grace)</th>
<th>A3 (Margie)</th>
<th>B1 (Jenny)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Caregiver Self-Questioning of Abilities</strong></td>
<td>“I don’t know this role as a caregiver...the funny part is he isn’t even my husband”</td>
<td>“I feel like I’m not doing enough for him”</td>
<td>“When I took my mom’s car [the support group leader] was the one to reassure me”</td>
<td>“My kids want me to retire...what would I do at home? No I like the contact with the world”</td>
</tr>
<tr>
<td><strong>Signal for increased Future Responsibilities</strong></td>
<td>“It really takes a lot of what I was doing, you know. That I could come and go and do.”</td>
<td>“It makes a lot of work. I know it’s not going to get any better because each day...I notice he’s doing something different”</td>
<td>“It is very difficult to take her to the doctor...it’s draining for somebody like me...I have MS so it makes it worse”</td>
<td>“I’m very lucky in most ways. I’m very lucky. Very fortunate in a lot of ways, it could be a lot worse”</td>
</tr>
<tr>
<td><strong>Changed Perception of Personal Self</strong></td>
<td>“so it’s like holy good god look what my life is cut out for” “I’m getting more of a caregiver!”</td>
<td>“I have close friends...they know he has dementia...it’s poor [Grace’s husband]”</td>
<td>“...My mother took care of me when I was a baby and now it’s my turn to take care of her”</td>
<td>Husband gets all the attention - it is all about him but wants some recognition too</td>
</tr>
<tr>
<td><strong>Unexpected Emotional Responses</strong></td>
<td>“I don’t give a shit if he asked for it or not, I can’t...I can’t handle it”</td>
<td>Feeling bad for husband and pity for self-Anger with need to be firm as a parent with a child</td>
<td>“I guess I was thinking ‘well I’m the bad guy here”</td>
<td>“Oh NO! [Dread]I get very angry, I just feel like if I just shake him and make him realize, but I know I can’t”</td>
</tr>
<tr>
<td><strong>Sees Changed Person Not the Disease</strong></td>
<td>Only sees FWD asking to go home “I can’t see the disease”</td>
<td>He’s like a 7-year old boy “He’s 6’4” and its hard for me to treat him like a little boy”</td>
<td>“as close as my mother and Ed were...she doesn’t talk about him which I don’t understand”</td>
<td>“I see him the way he is now, and the way he used to be”</td>
</tr>
</tbody>
</table>

Table 4.4. The Essential Constituents of the structure and empirical variations lived by each caregiver

<table>
<thead>
<tr>
<th>Essential Constituents</th>
<th>B2 (Peggy)</th>
<th>C1 (Deloris)</th>
<th>D1 (Eve)</th>
<th>E1 (Sam)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Caregiver Self-Questioning of Abilities</strong></td>
<td>“I think that’s the main reason: it’s been difficult because I didn’t know what to expect”</td>
<td>Guilt-Wondering if mother would not have declined if they hadn’t argued</td>
<td>“I knew I’d be able to do it by sneaking things”</td>
<td>“Are we doing the right thing?” “You gradually begin to realize that it is a hopeless case”</td>
</tr>
<tr>
<td><strong>Signal for increased Future Responsibilities</strong></td>
<td>“...over protect him for not knowing if he’s going to say the wrong thing. That’s what I was getting into problems with...I want to fix it but I can’t”</td>
<td>“I know in my heart I can take the best care of her...probably if my sister lived closer...we would have her at home”</td>
<td>“It’s a huge, huge job and emotionally you just don’t...you know, you’re caught up in all this work and emotionally just don’t sit back and think about it”</td>
<td>“I couldn’t do the job those people do in the nursing homes. I wouldn’t be able to handle it. I think it’s a tough job”</td>
</tr>
<tr>
<td><strong>Changed Perception of Personal Self</strong></td>
<td>“I have to keep remembering he loves me. I don’t have to forget I love him...”</td>
<td>“I love my mom and I’m ashamed of myself for the way you know I talked to her back then...”</td>
<td>Feeling overwhelmed with the amount of work and time as caregiver</td>
<td>“I wasn’t allowed to visit her [wife] because I was the enemy with the love child and mistress”</td>
</tr>
<tr>
<td><strong>Unexpected Emotional Responses</strong></td>
<td>“You son of a bitch” its all I could think of, I wasn’t supposed to be bawling”</td>
<td>Sometimes I would get fed up and I would scream right back”</td>
<td>Surprise but determined to provide care “I knew that I would just do it”</td>
<td>“...guilt...not sure if you are doing the right thing” “so we were sort of stuck”</td>
</tr>
<tr>
<td><strong>Sees Changed Person Not the Disease</strong></td>
<td>“there are some days he is his old self and I love those days”</td>
<td>“In my mind I’m thinking ‘why can’t you understand this? And she’s...screaming at me’”</td>
<td>Eve sees a “very bright man with a long career and his mind is a jumble”</td>
<td>“...most of the time when I talk to her she makes perfect sense and I agree with her”</td>
</tr>
</tbody>
</table>
Constituents and Empirical Variations for Dementia Family Caregivers

Key constituents for the structure: The experience of resistiveness to care during family caregiving. This section elaborates upon the previous Table 2a and 2b, which was based upon the previously mentioned structure of resistiveness to care as experienced by family caregivers of people with dementia. The following includes an elaboration of each constituent and empiric variations as resistiveness to care was actually experienced by each caregiver.

Key constituents for the structure: The experience of resistiveness to care.
Resistiveness within in the context of providing care for someone with dementia is triggered by a goal or agenda established by the family caregiver that is rejected by the care recipient or triggered by a sudden unexpected care recipient action or behavior. Either will drive the family caregiver into an experience of resistiveness to care. The following includes a detailed description of each constituent and the concrete empirical variations of the resistive experience each family caregiver encountered when providing care for someone with dementia. Family caregiver constituents and empirical variants included:

• Self-questioning of abilities. When exposed to resistiveness from the care recipient, all family caregivers were triggered to evaluate their abilities as caregivers. The majority of caregivers appraised their abilities negatively; however, Eve appraisal was different. Caregivers questioned how they handled the situation, their ability to manage the resistiveness, whether they had done enough and whether they were doing the right thing. Although stating that she was unpleasantly surprised with the resistiveness, Eve seemed to know exactly what needed to be done and was confident that she would be the one to handle the situations. Despite whether caregivers questioned their ability to handle the situation and appraised their ability as a negative or positive, all intuited increased caregiver responsibilities as they experiencing resistiveness to care.
• **Signal for increased future caregiver responsibilities.** When resistiveness to care occurred, family caregivers sensed their caregiver responsibilities and duties would increase as the disease progressed. Grace stated that each time she saw her husband do something new and different that it signaled that her life would not get easier. For Sam the perceived increased caregiver responsibilities necessitated placing his wife in a care facility. Jenny a family caregiver for the longest duration was the most positive with the increased caregiving responsibilities. She acknowledged that things could have been worse and was thankful that her husband could do as much as he could with minimal assist. While enduring the resistiveness to care, caregivers were aware of an evolving relationship with the care recipient that was different from what they had before the dementia diagnosis. Caregivers also observed changes in themselves and the roles and relationships that they had.

• **Changed perception of personal self.** All other family caregivers described an awareness of changes such as becoming more of a caregiver and not the significant other; noticing friends expressing sympathy for the care recipient but not the caregiver; and role reversals with offspring family caregivers caring for the parent care recipient as a child. Margie described how her mother had cared for her when she was little and now she feels obligated to care for her child-like mother. Sam described feelings of turmoil when his wife rejected him and he was not able to care for her as the husband that he was. The changing perceptions of self were distressing for caregivers. In addition, to the distress of changing perceptions of themselves, many of the family caregivers were also distressed by how the resistiveness to care triggered their emotions.

• **Unexpected emotional responses.** The unexpected resistiveness to care triggered many
different emotions for the caregiver. These emotions were not singular as caregivers experienced more than one emotion during resistiveness. Emotions also varied among caregivers in the spectrum of anger toward the care recipient, situation, or disease; fear of the unknown and unexpected in the situation; to frustration and irritation with the care recipient for the resistance. All caregivers experienced unpleasant surprise and confusion toward the resistance, felt sadness for the person with dementia, and guilt for their reactive thoughts and responses to resistiveness to care. This guilt emerged despite justification of caregiver responses—need to protect the person with dementia or self.

Margie stated she felt guilty for having to be the bad guy and take away her mother’s car, while Grace said she felt guilty that she has to become forceful, as a parent must with a child to get her husband to shower. Eve was the only caregiver who despite feeling surprised and overwhelmed during the resistiveness to care episode stated she felt confident and was determined to provide the needed care. Amid the many emotions of the encounter all caregivers admitted that in the moment of resistance, they were unable to see the behaviors as part of the disease process but rather only the changed person before them.

- **Sees changed person not the disease.** During resistive encounters, all caregivers admitted that they see the care recipient but not the disease. This creates conflict in the minds of the caregivers as they experience resistiveness to care behaviors. Grace saw her husband as the 6’1” man but the behaviors and his responses were that of a 7-year old little boy causing Grace confusion and she was unsure how to respond. Deloris was completely at a loss for why her mother was acting resistive—so out of character causing Deloris to wonder if her mother was having a mental breakdown. Margie was also perplexed with
the conflicting images knowing that her mother was very close to a gentleman friend from many years but now does not talk about him at all. Sam also had difficulty with the differing images he has of his wife. At times she made perfect sense and then other times she was accusatory and violently angry. Peggy admitted that she tries to remember her husband cannot control the resistive behaviors but has difficulty in the moment and sees him as her husband before the disease. It was only after the episode was over and upon retrospection that family caregivers acknowledge that they are able to discern the behaviors as manifestations of the disease.

When resistiveness to care is experienced family caregivers use strategic choices to manage the situation. These choices included the use of reasoning, logic, telling “little white lies” or being honest. The use of reasoning and logic appeared to be intuitive for family caregivers to handling conflict. When family caregivers realized that reasoning and logic do not work, they resorted to telling a “little white lie”—something they were taught at the Alzheimer’s support group meetings. However, many family caregivers struggled with telling lies as opposed to being honest with their care recipient. If one or more of these strategic choices failed to divert or eliminate the resistiveness, family caregivers relinquished their original goals or agenda. Alice, Peggy, and Grace attempted to use reasoning with their care recipients during a resistive episode. These three caregivers admitted that it was not effective and lead to arguments and resentment. Jenny and Deloris used reasoning but when it was not effective they switched to using “little white lies.” Both admitted that using the lies helped to smooth things over and avert controversy but made them feel guilty for deceiving the care recipient. Margie, Eve, and Sam also felt guilty for using “little white lies” but did not use reasoning. Eve preferred to let her father remain in his own world without trying to reorient or reason with him and Sam felt that
logic did not work and did not even try to use it. Whether the caregivers used reasoning or “little white lies” to manage the resistiveness to care many times the family caregivers were not successful in adhering to their initial agenda.

When caregivers have tried to manage the resistiveness with whatever they know, they ultimately relinquished the goal or agenda in order to preserve the relationship. All caregivers except three admitted to giving up the goal or agenda of the encounter and some have assisted the care recipient in their opposing agenda to maintain the peace. Jenny gave up the goal of preventing her husband from leaving and assisted him to look for “Annie” safely and Grace gave up the idea of having her husband shower for several days when she met resistance. Caregivers Margie and Eve were able to maintain their agenda to reach their goal. Margie stuck to her plan of taking the car from her mother despite resistance. Eve used stealth to remain true to her goal to keep her father’s identity and financial wellbeing safe. Sam was conflicted with giving up his goal of not challenging his wife. He felt that if he gave in and admitted the indiscretions that his wife violently accused him of he was not being true to his values. When caregivers changed their goals or agendas they ran the risk that new care recipient behaviors would result. These new behaviors had the potential to force the caregiver into another round of resistiveness to care. The ultimate aim for family caregivers was to achieve a stable state in which resistiveness was no longer occurring. However, the stable state was only temporary as resistiveness was a product of neurologic degeneration and would occur again at some point during the caregiving experience as the degenerative process continues.

For Alice resistiveness to care was experienced when her significant other asked questions about where they live and wanted to go home. It appeared to come out of nowhere and surprised Alice. This first experience of resistiveness came when Alice least expected it. She
did not know how to handle his insistence and wanted help to keep her significant other safe from wandering. She called an Alzheimer’s support group to get answers. The support group told Alice that her significant other was not looking for his home but rather he did not feel safe and was looking for safety in “home”. This made Alice feel sad that her care recipient did not feel safe in their home with her and she questioned her abilities as a caregiver. Alice admitted to feeling scared when the care recipient started to ask questions about going home and used distraction as a means to get her significant other’s mind on something else and prevent him from leaving. This was a lot of work for Alice and she often wondered what the future would hold for her and her significant other. Alice admitted that at times when he was trying to find home she hated her significant other despite feeling deep love for him. She admitted she could not see the disease when he was asking so many questions and searching for home; she only saw the person he was before the disease. Alice attempted to use reasoning as a way to keep her significant other from looking for home but this usually lead to arguing and Alice usually dropped the subject. When things got really tough Alice felt like she could not handle being a caregiver despite her reasoning that she was not his wife and therefore not a true caregiver. She realized that caregiving had taken much of her time and she was not able to do many of the things she used to do for herself. Alice wondered if she would have agreed to move in with the care recipient if she had known about the dementia disease earlier but then realized that no one knows what the future will hold for anyone.

For Grace, resistiveness to care was experienced when she attempted to help her husband with his personal hygiene. She did not like when she could smell her husband’s body odors and her goal was to ensure that he kept himself clean. Grace became frustrated when her husband would agree to shower but did not carry through with the activity on his own. When Grace
wanted her husband to shower she was surprised that her husband acted like a little boy. Grace attempted to use reasoning by saying things like “the water is running, you can’t waste that water” but ended up forcefully saying things like “alright now get up and get in there!” Many times Grace was not successful and had to relinquish the goal of a shower knowing it would be days before her husband would shower again. In these instances Grace stated she felt sad for her husband and for herself as caregiver knowing she was losing the person she married and realized what it meant for her as caregiver. It was during resistive times that she felt inadequate—like she was not doing enough for her husband as his caregiver. She reasoned that she was trying to make life easier for him by providing him with conveniences but felt like it was not working. Every time her husband did something different and unexpected, Grace realized that things would not get easier for her as caregiver. Grace said she felt the inequality of the relationship. She said that she had close friends that knew her husband had dementia and supported her. But when the friends said things like “poor [Grace’s husband] poor Grace” Grace felt like it was not poor [Grace’s husband]. Grace stated that he was happy as a lark and oblivious to what was happening while she was the one to endure all the resistance and embarrassment of the situations. She felt she had the heavier load in being the caregiver and realized that in the future she may not have the time to do things with her friends as she did now.

For Margie, resistiveness to care was first experienced when she and her siblings took the car away from their mother to ensure her safety and again when they placed her in a care facility. The main focus of caregiving for Margie and her siblings was to keep their mother safe from harm or injury. Despite this noble goal, their mother resisted their efforts by slamming the door in Margie’s face after they took her car away. She was angry and this made Margie feel guilty. Margie received much needed reassurance from the support group leader. He told her that she
had done the right thing. Margie experienced another episode of resistance from her mother when she and her brother moved her into a care facility. Margie’s mother did not want to stay and repacked her belongings and waited for Margie to come and get her. Margie said she felt bad and expressed the day as “a pretty rough time;” especially when Margie heard that her mother had everything packed again after she and her brother unpacked her belongings the day before. Margie and her brother prepared to use logic and reasoning to convince their mother to stay at the care facility. As an example, they were going to take their mother to a skilled care facility to show her the alternative to where she was currently staying but their mother forgot that she did not want to stay where she was. Margie stated being surprised by the conflicting images she had of her mother. She did not understand how her mother cannot talk about someone she was very close to for many years. As a result of her mother’s resistance Margie had second-guessed her decisions as caregiver and wondered if she had done the right thing for her mother. Margie was very protective of her mother and used “little white lies” to keep her from getting upset. Although caring for her mother was difficult at times and an added responsibility, Margie said she was aware that the relationship with her mother changing. She stated that her mother took care of her when she was a baby and now it was her turn to take care of her mother.

For Jenny, resistiveness to care was experienced when her husband became anxious wanting to find “Annie.” Jenny described him as being insistent with an urgent need to look for “Annie.” In order to protect her husband from harm sometimes Jenny had to physically stand in front of the door to keep him from going outside; especially late at night. The first time that Jenny’s husband urgently wanted to leave was 20 years ago. They were vacationing thousands of miles from home when he woke Jenny in the middle of the night insistent to leave at that moment. The request seemed to come out of nowhere and Jenny said she was surprised. She
attempted to reason with him that it wasn’t possible to leave in the middle of the night. After
awhile Jenny was successful and her husband gave up his request to go home. Sometimes Jenny
was not so successful. She admitted that at times she felt anger, jealousy, and dread when her
husband insistently wanted to look for “Annie.” Recently on one very cold winter morning
Jenny was awaken at two o’clock in the morning by her husband insisting that he go home.
Jenny tried to reorient him by having him look out the window to see the neighbors’ house and
how cold it was in hopes he would give up the idea to go outside. In the end Jenny had to dress
and drive her husband around the block to settle him from leaving. It broke Jenny’s heart to see
her husband acting like this and at the same time she got angry. She said she felt as if she
wanted to just shake him and make him realize, but knew she could not. It would not do any
good. Jenny also stated that she felt dread when her husband awaken her in the middle of the
night knowing what was coming and what she would have to do to keep him safe. Over the
years as caregiver, Jenny admits that she cried a lot and that she had learned to swear and pray a
lot. She also admitted that she had had fights with God asking him ‘How can you do this to my
husband—such a good man?’ At times when Jenny’s husband was looking for “Annie” Jenny
would make up little white fibs like “she’s on vacation” and “she didn’t come tonight.” She
would keep trying until something worked. Despite the years as caregiver, Jenny was thankful
that her husband could do as much as he could for himself. She realized that things could have
been much worse and that she could have had to do much more for him. However, despite being
retirement age she did not want to stay at home all day with her husband. Although Jenny could
count her blessings as caregiver, there were moments of jealousy. Jenny admitted that the
relationship was not equal. She said it felt like her husband got all the attention but as caregiver
she would have liked some recognition too. She admitted that sometimes she felt like it was all
about him, but then paused and realized “yes” it was all about him.

For Peggy, resistiveness was experienced when she tried to keep her husband safe from wandering off. Peggy admitted the most difficult part of caregiving was that she did not know what to expect. The resistiveness was sudden and unexpected. Peggy and her granddaughter were watching TV with her husband when he suddenly got up from the couch saying “if you don’t want me to talk I’m not going to stay here!” and he stormed out of the house slamming the screen door preventing Peggy from following after him. Peggy said she became very angry and irritated. She did not know what to do. She knew she was not supposed to be bawling, it was just her first inclination. When resistiveness occurred, Peggy tried to use logic and reasoning but to no avail. During these instances Peggy questioned her ability as a caregiver. She could not figure out what she had been doing wrong that bothered her husband so badly. She also wondered if he was bothered by something that she did not even know about. Often times Peggy would give in to prevent further arguing. Peggy had to remember that her husband could not help the behaviors but this was hard when there were days he was his “old self” mixed with days of confusion. It was during the days when her husband was his “old self” that she would have loved to lock him away with her and talk about things that they could do that he was going to remember. Peggy had noted an increase in caregiver responsibilities, as she wanted to over protect him not knowing if he was going to say the wrong thing. She stated she wanted to fix things that could not be fixed. Peggy also acknowledged a changed relationship by stating that she had to keep remembering that her husband loved her. She admitted that she loved him but did not get the affectionate reinforcement from him that she had before the disease.

Resistiveness to care for Deloris was experienced when she tried to provide for her mother’s safety and security. The first instance of resistance Deloris said was a surprise. Her
mother accused her of not caring about her welfare when Deloris did not immediately find an injury in the area that her mother was pointing to on her body. Deloris’ mother then started to scream and cry stating that Deloris did not care about her. Her mother just started changing. Deloris stated she felt as if her mother was going crazy. Her mother would scream “NO!” Then she would get mean. During these times Deloris stated she often felt frustration and guilt for the heat of the moment arguing with her mother. Deloris said she questioned her ability as caregiver and wondered if her mother would not have declined as quickly as she did if they had not argued so much in the beginning of the disease. As caregiver she learned to manage the resistiveness by smoothing things over to prevent fights but wondered about the cost of doing so. She said she hated lying to her but from what Deloris has learned at the support group meetings it was really not a lie; she was just trying to smooth over the situation. Deloris also admitted that she wondered if when she goes to heaven was she going to have to answer for her lies. Often times Deloris would relinquish the desired goal set before the resistiveness occurred. On such situation was when Deloris wanted to take her mother to the store to buy a necklace. Her mother saw the necklace in a store flyer add and really liked it. Deloris admitted she thought it would be a nice thing to do for her mother. In the process of getting ready to leave for the store, Deloris’ mother announced she was taking the family dog along in the car. It was the middle of summer and very hot outside. Deloris tried to tell her mother that they could not take the dog because it was too hot. Her mother adamantly insisted they take the dog so they ended up staying home and her mother cried a lot. Deloris admits that when the resistiveness occurs she could not see the dementia. In her mind she is wondering why her mother could not understand what she was saying. Deloris said she would get fed up and scream right back at her mother but later she would think of what she had done and feel guilty for yelling. Deloris admitted that she just did
not understand that her mother did not understand a word she was saying. Eventually as the
dementia progressed, Deloris had to place her mother in the care facility due to increase
caregiver responsibilities that Deloris was not able to achieve. Deloris divulged that she felt
guilty for placing her mother in the facility. She said she knew they were taking good care of her
but she felt that she was the one to take the best care of her mother and it hurt. Deloris said she
believed that if her sister lived closer they would be able to care for their mother at home.

For Eve, resistiveness to care was experienced when she and her brother noticed that their
father was no longer keeping up with his finances and bills. Together they approached him and
Eve’s brother being the executor said he thought it was time to take over managing their father’s
funds. Neither Eve nor her brother expected the threats of violence and physical harm that their
father issued in response to the request. He threatened to get a gun and shoot anybody who
wanted to take away his belongings. Eve’s brother became so offended he declined to pursue the
issue further but Eve said she knew that someone had to protect the safety of her father and that
she would be the one to do it despite his resistance. Eve said she was very surprised with her
father’s behavior at that moment. She said she knew that he had outbursts as she had
experienced them when she was younger but had not experienced them in a long time. This was
new for him. Eve stated that she felt that it was a hard job trying to manage her father’s affairs
without him knowing what she was doing. Eve stated that she knew the only way she would be
able to have access to his accounts was to sneak and lie about what she was doing or else her
father would resist even more.

Eve also had to deal with her father’s insistence to wander out of the house late at night in
the middle of winter. This was scary and especially difficult for Eve as she lived two hours away
from her father. Eve’s brother received a call late one night informing him that his father was
attempting to go outside in the middle of a cold winter night. Eve said she was thankful that her father’s live-in significant other was able to thwart her father’s efforts to go outside but realized that she could not depend on this woman to prevent him from going out again as she too had dementia. It was at this point that she and her brother decided to place their father in a care facility.

Eve often talked with the staff at the care facility and gave them tips on managing the resistiveness of her father. She told them that he loves to read his newspaper and eat chocolate. She used these items when she wanted to gain access to his finances. Eve often resorted to telling her father “little white lies” when she had his mail redirected to her house. Her father questioned why he was not getting any mail and she said that maybe the mailman couldn’t find his house but later felt bad for telling the lie. Eve attributed her ability to handle her father situation with the previous experiences she has had caring for her husband’s mother and uncle who both had dementia. It helped her understand the progression of the disease and caregiving responsibilities needed. Despite knowing what to expect Eve said she realized that caring for her father’s financial and physical safety was a huge amount of work. At times she admitted that she has felt overwhelmed with the amount of time and work needed to be a caregiver of a person with resistiveness. Eve acknowledged a different relationship with her father. She often used the analogy of handling the resistive situations with her father to that of handling similar situations with toddlers. Many times Eve’s father did not recognize her as his daughter.

Resistiveness to care for Sam was experienced when he attempted to provide care for his wife and she tried to forcibly remove him from their home at three o’clock in the morning threatening physical harm to him with a rake. Sam’s main objective was to protect himself while keeping his wife safe. Often Sam was forced to sit outside in his car waiting for his wife to calm
down. As he waited to re-enter the house he did not know whether his wife was safe inside the house or whom she would call to her rescue. Sam had experienced visits from the police and fire departments on numerous occasions when his wife called to say he was trying to kill her. Sam stated he was surprised that his wife who did not remember any phone numbers somehow managed to dial 911 for help. Sam experienced many emotions during these resistiveness episodes. In addition to surprise he felt fear for his safety, denial that it was really happening, felt out of options and stuck when he could no longer manage his wife’s resistance and had to place her in a care facility. Sam also admitted he felt conflicted when his wife appears to be making sense one moment and then became resistant and out of character the next. Sam said he was conflicted between telling lies and being honest in order to prevent further resistiveness. The resistance stemmed from his wife’s allegations of his infidelity. When Sam was honest with his wife and said that it never happened, it appeared to challenge her and create more resistance but on the other hand when he used lies and said he did do it, he felt very guilty. He stated that he had been faithful to her. He also stated that he had found that logic did not work with people who are cognitively impaired. After placing his wife in a care facility because of her resistive behaviors, Sam admitted that he questioned his decisions as caregiver. He stated that he wondered if he did the right thing. Unable to be the main caregiver and husband to his wife while she was in the care facility and unable to visit his wife in the care facility due to her resistance, caused Sam to become aware of a changing self and his relationship with his wife. All these things made Sam admit that he felt bad as his wife still had his heartstrings despite the disease and resistance he endured. Although the meaning structure carried empirical variations and meaning in the analysis of caregiver descriptions, nursing variations and meanings were also uncovered.
Nursing Variations and Empirical Variations

This section elaborates on the scientific phenomenological method’s disciplinary perspective (nursing) used during the analysis of family caregiver descriptions of resistiveness to care. The nursing disciplinary perspective for analysis was important as the current nursing literature was void of the subjective experience of family caregivers as it related to resistiveness to care. Since family caregivers are considered co-providers of care (Grant & Ferrell, 2012; McGhan, Loeb, Baney, & Penrod, 2013) it is important for nurses to understand the subjective experience of family caregivers in order to improve nursing praxis. Intersubjectivity provides a rationale for humans to gain a general sense of what another individual experiences.

All family caregivers had experienced some form of resistiveness to care, which may have been different, however their experiences were not so unique that a general meaning structure could not be formed. The general structure was obtained from the data of constituents. As expected every constituent varied at the empirical level; each family caregiver had a different first hand experience of the resistiveness to care that they experienced. Alice experienced resistiveness when her significant other did not feel safe in their home and wanted to find his home. Jenny experienced resistiveness when her husband insistently wanted to search for “Annie” at all hours of the night or day. Grace experienced resistiveness when her husband passively agreed to bathe but would never follow through with a bath. Margie experienced resistiveness when she and her siblings wanted to keep their mother safe from driving her car. Deloris met with resistance with unexpected changes in her mother’s disposition. Eve encountered resistance when she and her brothers wanted to help with their father’s finances to protect his identity. Peggy met with resistance daily with small projects that she had for her husband to do. Sam faced resistance when his wife forcibly tried to throw him out of their home.
in the middle of the night. Each caregiver experienced the resistiveness in different contexts and with different types of resistiveness causing the structural constituents to vary from the empirical perspective.

While caregivers each experienced different resistive situations and responses from their care recipients during caregiving activities, the analysis revealed that nursing meaning of the structural components were the same for all five constituents (caregiver self-questioning of abilities; signal for increased future responsibilities; changed perception of personal self; unexpected responses; and sees changed person not the disease). However, two empiric constituents of resistiveness to care did vary. These were “self-questioning of abilities” and “signal for increased future caregiving responsibilities.” The significance of these nursing variances and similarities are discussed as follows.

**Self-questioning of abilities.** All family caregivers when experiencing resistiveness questioned their ability to be a caregiver. Caregivers Alice, Grace, Margie, Peggy, Deloris, and Sam all expressed thoughts of not handling the situation well; feeling inadequate as caregiver; second guessing caregiving decisions; feeling confused and not being able to figure out what to do in situations; and feeling guilt over the decisions made. However, caregiver Eve although she questioned her ability as caregiver, had a very positive appraisal of her caregiver abilities. Eve did not express uncertainty. In fact she stated she was extremely confident in her caregiving role and expressed that she was certain of what needed done and that she would be able to do it despite the tremendous amount of work needed. This was in stark contrast to the remaining caregivers who doubted themselves and felt unsure as they encountered the resistive situation with their care recipient. From a nursing perspective this constituent has great significance. It could be a determinant of whether or not a family caregiver will be able to remain in the
caregiving role. In fact, a positive caregiver attitude toward caregiver ability may be a significant factor for caregivers considering whether or not to place the care recipient in a care facility. However, caregiver Eve expressed a positive perspective toward her abilities as caregiver, she did eventually place her father in a care facility. Nurses need to be cognizant of this constituent in order to understand family caregivers perceptions of their ability to care for their care recipient with dementia.

**Signal for increased future caregiver responsibilities.** All family caregivers expressed that when resistiveness to care occurred they realize that it was getting more difficult to perform caregiving duties; sensed that it was a lot of work and it wasn’t going to get any easier; and felt overwhelmed to the point of considering placing the care recipient in a care facility. Caregiver Jenny was the only caregiver to acknowledge awareness of increasing caregiver responsibilities but expressed that she was thankful that her caregiving responsibilities and duties were not greater than they were. Jenny acknowledged that the responsibilities could grow in the future but she remained optimistic in the present. From a nursing perspective this was significant. Her positive attitude may have contributed to Jenny’s ability to stay in the caregiving role for as long as she had. She has been caregiving for her husband for the longest period of time (20 years). For nurses this constituent ties in with caregiver’s perceptions of ability as caregiver. If family caregivers are questioning their abilities, appraise their abilities negatively and perceive the future responsibilities will increase; they will be less likely to sustain their caregiving role. The opposite may also be true. If caregivers are positive in their abilities they may be able to accept the increased future responsibly enduring caregiving for longer periods of time.

**Changed perceptions of personal self.** When in a resistive episode, all caregivers expressed noticing a changed perception of personal self. Whether it was becoming a caregiver
instead of a significant other, finding all the attention focused on the person with dementia and no attention to the caregiver, suddenly caring for the parent care recipient as a child, or unable to be the spouse or main caregiver for the care recipient, all caregivers were cognizant of their changing view of themselves. The feelings of changed personal self had significant nursing meaning. The perception of a changed personal self was not natural or pleasant for family caregivers and caused distress. It confused family caregivers and triggered them to question the way that they responded to the care recipient during resistive episodes; they could only see the changed person not the disease. This distress had the potential to influence the family caregiver regarding their ability as caregiver and ultimately decision whether to place the care recipient in a care facility.

**Unexpected emotional responses.** All caregivers felt the resistiveness to their care was neither expected nor predictable and they responded to the resistance in ways that later distressed the family caregivers. Although the resistiveness to care caused individual caregiver’s to feel different emotions, all caregivers emotional were negative. These negative emotions were directed toward the person with dementia or the caregiving situation and may have contributed to relinquishing the caregiver goal or questioning their ability as caregiver. From a nursing perspective this was significant constituent, the perceptions caregivers have of their emotional responses to resistiveness to care may have also contributed to caregivers questioning their ability as a caregiver. This may ultimately impact the duration as a caregiver and may propel family caregivers to consider placement for their care recipient with dementia.

**Sees changed person not the disease.** When in the moment of resistiveness to care, all caregivers described various conflicting images of the person with dementia. They claimed to see a changed person before them but not the disease. Grace saw her husband as a seven-year
old little boy during resistance. Jenny recalled how her husband used to be before the disease when the resistiveness occurs. Sam found conflicts with the days when his wife seems to make perfect sense and he agrees with her that he should take her home but later realized that it is really the dementia talking. Despite seeing the changed person and not the disease, all caregivers had the same nursing meaning—seeing the care recipient before the disease and seeing the care recipient differently at the time of resistiveness causing caregiver confusion and uncertainty as to how to handle the situation. Nurses want to be aware of this constituent. The uncertainty and conflicting images of the care recipient may have impacted the strategic choices that family caregivers used to avert or diminish the resistance. Nurses need to be aware of why caregivers make the choices they make during resistive episodes in order to be able to assist caregivers in choosing the appropriate strategic choice for them. Failed strategic choices may create negative caregiver perceptions of their ability to provide care and ultimately cause family caregivers to consider placing their care recipient in a care facility. Nurses can be instrumental in helping caregivers succeed by helping them choosing appropriate strategic choices to manage resistiveness to care.

**Resistiveness to Care in the Context of Caregiving**

Resistiveness to care was a phenomenon that was not readily discernable to family caregivers in the moment that it was happening. It encompassed certain contextual factors that were contained within a caregiving episode. All family caregivers did not experience the same contextual factors during resistiveness to care but all family caregivers experienced resistiveness to care. For caregivers Alice, Margie, Peggy, Eve, and Jenny the context was to keep the care recipient safe from wandering away. For caregiver Sam the context was in protecting himself. Despite these contextual differences data analyzed from family caregiver interviews provided the
essential interrelated constituents from which the structure of resistiveness to care was produced.

Figure 4.1 is a schematic representation of the general meaning structure of the phenomenon—resistiveness to care and its relationship among contextual factors as described by family caregivers when they actually experience the phenomenon.

*Figure 4.1. General Meaning Structure of Resistiveness to Care*

An examination of Figure 4.1 revealed that resistiveness to care either resulted from a family caregiver’s set agenda or goal of the encounter or from unexpected behaviors or responses from the care recipient. Sometimes the unexpected care recipient behaviors triggered the family caregiver to create an agenda or goal for the encounter. In either case care recipient responses
were in the form of resistance. These responses were unexpected surprises to family caregivers and often out of character for care recipients. This caused conflict in the minds of family caregivers as they saw their care recipient before them yet the responses they exhibited were sometimes childlike or opposite to what caregivers were expecting. Intuitively family caregivers attempted to use reason and logic with their care recipients as a strategy to maintain their goal or agenda for the encounter. However, some family caregivers switched strategies and resorted to telling lies when reasoning became ineffective. The majority of family caregivers relinquished their goal or agenda when both of these strategic measures were unsuccessful. In this process, family caregivers became confused, angry, and acted or retaliated in ways that they regretted and felt guilty about later—upon retrospection. Family caregivers also realized the increased amount of caregiving required to manage the resistiveness and realized their perceptions of personal self had changed. These changes may have been a reflection of their changing relationships, changing caregiver responsibilities, or changing roles. Resistiveness to care led the family caregiver to question their ability as a family caregiver especially when they have difficulty managing the situation. For example, when family caregivers used strategic choice sometimes these choices triggered more unexpected behaviors from the care recipient propelling the caregiving encounter back into resistiveness to care further exasperating the family caregiver and perpetuating the cycle. When strategic choices did not produce the results that family caregivers desire, family caregivers tried to set new goals or agendas for the encounter. These new goals or agendas had the propensity to trigger more resistiveness to care causing more tension and distress. The ultimate goal for family caregivers was to achieve a transient stable state in which resistiveness did not occur. This state was temporary as resistiveness was the result of neurologic degeneration and would occur again at some point during caregiving experiences as
neurologic degeneration continued in the disease process.

**Chapter Summary**

A scientific phenomenology method was used to study the phenomenon of resistiveness to care from family caregivers’ perspective and to analyze the data from eight family caregivers of people with dementia who actually experienced the phenomenon of interest. A general structure of resistiveness to care was uncovered through transformations of family caregivers’ described experiences of resistiveness to care. This structure was then used to further clarify their actual experience of resistiveness to care.

Participants were recruited from Alzheimer’s five different support group meetings of which three support group meetings were conducted in nursing care facilities, one was conducted in a hospital, and one was conducted in a church. Participants were white and predominantly females (7). Only one family caregiver was a male. Ages range of family caregivers were from the early 60’s to early-mid 80’s. The mean length of caregiving was four-five years with the longest time in caregiving as twenty years and the shortest at two years. Five of the care recipients were male and three were female. Five family caregivers were caring for their spouse or significant other and three family caregivers were caring for a parent. The majority of family caregiver interviews took place primarily outside the home of the family caregiver. Five participants (Alice, Grace, Jenny, Peggy, and Deloris) opted to talk to this researcher at a restaurant rather than in their home with the care recipient. These family caregivers felt that is was a treat for them to eat out and talk with someone other than their care recipients. No one was inhibited by the fact that others were eating nearby rather each caregiver provided emotion-laden details of their experiences. One caregiver (Sam) requested to meet at the support group facility (care facility where his wife was placed) for his interview. The remaining two family
caregivers (Eve and Margie) elected to be interviewed in their home and did not have the care recipient living with them.

The analysis of data was conducted assuming the attitude of phenomenological reduction, a nursing disciplinary perspective, and sensitivity to resistiveness to care. Each interview was read through in its entirety to gain a sense of the whole interview. Next meaning units were segmented throughout the data. This was accomplished by noting changes or transitions in thought throughout the interview data and marking these changes in the data. This helped to make the data more manageable by breaking it into parts. There was no theoretical significance or weight attributed to these segments. Each meaning unit was then transformed from everyday language into phrases expressing nursing context more directly. Imaginative variation (expressing the meaning unit in different ways sometimes stretching the boundaries of the meaning unit) was applied to all transformed meaning units to detect essential meaning units that would be used in the general meaning structure. An essential structure was identified using the identified essential meaning units as constituents for the phenomenon of resistiveness to care. The resulting structure of resistiveness to care included the following constituents: caregiver self questioning of abilities; signal for increased future responsibilities; changed perception of personal self; unexpected emotional responses during the encounter; and conflicted images of the person-sees changed person not the disease.

Further analysis among constituents revealed that all caregivers experienced empiric variations among all constituents, which was expected with differing context for resistiveness to care. However nursing variations among caregivers occurred only within the constituents of “caregiver self-questioning abilities” and “signal for increased future responsibilities.” The following chapter will discuss the significance of these findings and their application for nurses
and family caregivers, the current research literature relating to resistiveness to care, insights relating to resistiveness to care experienced by family caregivers, limitations of this study and recommendations for future research of this phenomenon.
Chapter 5

Discussion, Implications, and Limitations of Findings

Introduction

A common daily event for many giving care to family members with dementia is resistiveness to care, making this experience an integral part of the families’ life-world (reality). Therefore, phenomenology was an ideal research method to use to gain a deeper understanding of the resistiveness to care phenomenon. Findings uncovered in phenomenological research have the power to make us more empathetic to the experiences of others and can provide new insights into these experiences. Enhanced understanding enriches our personal viewpoints, and helps us be more sensitive to specific needs of patients. Therefore the findings of this study provide nurses with insight into the reality of resistiveness to care as it was actually lived by family caregivers (Morse & Field, 1995). The discoveries from the descriptive phenomenological research process used for this study, as opposed to other phenomenological methods, allowed the researcher to establish the essential features of the phenomenon (resistiveness to care) in terms of a general meaning structure. The in depth analysis process of descriptive phenomenological method was ideal because it allowed integration of a nursing disciplinary perspective. The analysis process highlighted elements that pertain to caring and caregiving aspects of the phenomenon that are most applicable to nursing.

Current research on the concepts of family caregiving, people with dementia, and the phenomenon of resistiveness to care reports a great deal of empirical literature on objective aspects of resistiveness to care (Mahoney et al., 1999; Pearlin, Mullan, Semple, & Skaff, 1990; Pot et al., 1998; Volicer & Hurley, 2003). However, very little was found that pertained to the subjective experience of the family caregiver who lived within this stressful phenomenon.
Researchers often recommended that research was needed to adequately investigate the subjective family caregivers experience of providing care for someone with dementia to adequately understand this complex care event (Kinney & Stephens, 1989; Mahoney, Trudeau, Penyack, & Macleod, 2006; Pearlin et al., 1990). Based upon this gap in research literature, the current research study focused on a research question designed to gather more information about the subjective experience of family caregivers: What is the actual lived experience of resistiveness to care experienced by family caregivers as they provide care for persons with dementia?

As the research question drives the research method to answer the question (Morse, 1995), the researcher decided a descriptive phenomenology method would be the best choice for uncovering the experience of resistiveness to care from a family caregiver’s actual lived perspective. The researcher reviewed different epistemological ways of analyzing the phenomenology data (descriptive and interpretive) and decided that the descriptive method modified by Giorgi was the most appropriate. Several reasons impacted this decision. First, the current research surrounding the phenomenon of resistiveness to care is objectively evaluated or measured and predominantly uses theories and assumptions relating interventions for alleviating resistiveness to care but has not been successful in alleviating family caregiver distress associated with this phenomenon. The researcher wanted a subjective approach that would allow her to remain as close to the data as possible during the collection and analysis, limiting the risk of theoretical assumptions or ideas to ensure an accurate representation of family caregivers’ everyday lived experience (Giorgi, 2009). Second, by using the scientific phenomenology approach, the researcher was able to use her disciplinary perspective of nursing to further enhance the importance of the findings for nurses.
The significance of this study’s findings related to improvement of nursing praxis in the care of family caregivers for people with dementia; new information for family caregiver support and resources; and identification of future research opportunities are presented in this chapter. In addition, this chapter provides significant research findings relating to key elements of resistiveness to care for caregivers and application of key insights to nursing. The discussion progresses with the application of structural findings for family caregiver support and resources and recommendations for future research. This chapter concludes with the study limitations and a summary of key nursing care issues to consider in light of the study results.

**Discussion of Significant Findings**

A meaning structure of resistiveness to care as experienced by family caregivers of persons with dementia was identified using the descriptive phenomenology method and a nursing disciplinary perspective for analysis. The identified meaning structure was a significant contribution to the science because to date no research has used a subjective perspective to objectively identify what resistiveness to care is like for family caregivers (the largest pool of caregivers providing care for people with dementia). The identified general meaning structure of the experience provided awareness for nurses and others of the family caregiver’s experience and gave recognition and real validation of what family caregivers deal with on a daily basis. The resulting general meaning structure also provided a pictorial representation of what their “life world” was like.

The nursing disciplinary perspective used in the research enabled the researcher to focus on nursing sensitive areas of family caregivers’ experiences in order to gain a better nursing understanding of the experience from the co-provider of care—family caregiver’s perspective. The identified structure of resistiveness to care consists of five constituents that occur during
resistiveness to care for the family caregiver. They are as follows: (1) self-questioning abilities; (2) signal for increased future caregiver responsibilities; (3) changed perception of personal self; (4) unexpected emotional responses and (5) sees changed person not the disease. All constituents were found to vary empirically in the way that resistiveness to care was experienced by the family caregiver but only two constituents were found to vary in their nursing meaning. Variations in the constituents will be discussed in the next sections.

**Key Elements of Resistiveness to Care for Family Caregivers**

Resistiveness to care occurred during a caregiving encounter and was often triggered by a caregiver goal or agenda that was rejected by the care recipient. However, resistiveness also occurred spontaneously from a care recipient action or behavior that was unexpected. In either case, the family caregiver attempted to redirect or nullify the behavior. When the care recipient resisted care by the caregiver, the dyad was considered engaged in what the current nursing literature calls a resistive event. However, family caregivers’ descriptions of these events did not use the term resistant despite their descriptions of a resistive event. Instead a structural experience of resistiveness to care was identified using essential meaning units derived from the caregiver descriptions.

This study revealed five key elements that occur in a resistiveness to care episode (resistiveness event) to form the structural experience of the phenomenon as experienced by family caregivers. Although the essential elements were present in every caregiver’s experience of resistiveness to care, the elements were different in appearance as each caregiver experienced the resistiveness to care in a different way.

**Self-questioning of abilities.** When resistiveness to care occurred, all caregivers expressed they felt challenged and questioned their ability to be a caregiver. The majority of
caregivers expressed a lack of confidence in their abilities to manage the caregiving role. Many caregivers expressed not knowing the role, feeling like they weren’t doing enough, and questioned whether they did the right thing. Caregiver Grace stated, “I feel like I’m not doing enough for him” [her husband- the care recipient]. The incidence of negative caregiver feelings and appraisals are supported in the research literature. Croog, Burleson, Sudilovsky and Baume (2006) reported that family caregivers of persons with dementia often state they feel anxiety about their caregiving and feel as if they need to do more for the care recipient. Gaugler, Davey, Pearlin, and Zarit (2000) found that over long durations of caregiving, family caregivers begin to have more positive appraisals of their caregiving experiences. However, even caregiver Jenny who had been a caregiver the longest (20 years) stated she still questioned her abilities when her children asked her to retire and stay at home with her husband the care recipient. Her response was “…what would I do at home? [Pause] No, I like the contact with the world.” Although the literature states that longevity in the caregiving role may help to reinforce confidence in caregivers’ ability to provide care, the caregivers in this study all questioned their ability as caregiver when they experienced resistiveness to care.

**Signal for increased future caregiver responsibilities.** As family caregivers encountered resistiveness to care they developed a sudden sense that their caregiving duties and responsibilities would increase and anticipated that change. Grace was a prime example of this. She stated, “it [resistiveness to care] makes a lot of work. I know it’s not going to get any better because each day…I notice he’s doing something different.” The findings of this study were supported in the work of researchers Williams, Morrison and Robinson (2014) who found that caregivers of persons with dementia anticipate and actually come to expect more caregiving demands in the future. In fact Mittleman, Roth, Haley, and Zarit (2004) identified that family
caregiver reaction to behaviors such as resistiveness to care was a significant predictor of whether or not a family caregiver would place the care recipient in a care facility. Based on these reports, family caregivers who anticipated growing responsibilities in the future would begin to think about placement in a care facility for their care recipient. This was the case with caregiver Sam who expressed “I couldn’t do the job those people do in the nursing homes. I wouldn’t be able to handle it. I think it’s a tough job.” Sam had placed his wife in a care facility just a few months before our interview. He stated he found he was not able to handle the resistiveness to care behaviors and often needed professional assistance often. The frequent need for professional assistance precipitated the placement of his wife in a care facility.

**Changed perception of personal self.** While family caregivers were enduring episodes of resistiveness to care they became aware that their relationship with the care recipient was changing. They also became more cognizant of the fact that they themselves were changing. They notice their roles were different and the relationships that they had prior to becoming a caregiver began to disappear.

All of the family caregivers interviewed expressed awareness of becoming more of a caregiver and less of a significant other. Roles of children were reversed. Children caregivers were now in a parent-like role caring for their parent with dementia, as the parent became less functional. This was evident with caregiver Margie, who stated “…my mother took care of me when I was a baby and now it’s my turn to take care of her.” Alice expressed distress when she realized her personal identity was changing. “…So it’s like holy good god look what my life is cut out for. I’m getting [to be] more of a caregiver [than a significant other]!” Caregiver Sam voiced sadly, “I wasn’t allowed to visit her because I was the enemy with the love child and mistress.” He realized his role as husband was being transformed to “unwanted caregiver” and
This notion of a changed self was supported in the literature. Croog, Burleson, Sudilovsky and Baume (2006) identified that limitations of family caregivers’ social lives and personal time contribute to the perception of a changing personal self. Simpson and Acton (2013) reported that family caregivers who take on the parenting role during caregiving are doing it as part of what they call “emotion work” in order to keep their care recipient safe from harm. Emotion work entails struggling to do what is right and changing ones feelings to be more appropriate with what is accepted either by society or by the family caregiver personally. Sometimes caregivers took on the parenting-like role to protect the care recipient from harm and took on emotion work. Whether the changes were due to limited social or personal time or the need to become protective, the changing perceptions of themselves appeared to be distressing and difficult for family caregivers to understand and accept.

**Unexpected emotional responses.** Many of the family caregivers expressed they were astonished by their emotional responses to the behaviors exhibited during resistiveness to care. Resistiveness to care is usually unanticipated and sudden and prompts unexpected and varied responses from caregivers. The caregivers in this study expressed not singular but multiple emotional responses during resistiveness to care episodes. Emotional responses included anger toward the care recipient, anger toward the situation or disease, and fear of the unknown and unexpected aspects of the situation. Other emotions included frustration and irritation with the care recipient themselves. All of the caregivers interviewed for this study experienced unpleasant surprise and confusion toward the resistance that was associated with sadness for the care recipient and expressed guilt for their reactive thoughts and emotional responses to the behavior. Caregiver Margie was typical and expressed this guilt in her description of taking the
car away from her mother. “I guess I was thinking ‘well I’m the bad guy here.’” Grace also felt guilty with her forceful responses to her husband’s reluctance to bathe. Eve related she felt surprised by the resistance from her father and struggled to be optimistic in her ability to handle the situation. The surprise response was supported in the literature surrounding caregiving for persons with dementia. As previously mentioned Simpson and Acton (2013) identified that family caregivers who are struggling to “do the right thing” wrestle with their behavioral responses to resistiveness and what they think their responses should be. This was evident with Grace as she struggled with having to be forceful like a parent would be with a child. Yet her husband was not a little boy even though he displayed little boy-like behaviors. Grace did not want to treat her husband like a little boy who needed to be told to bathe but was not successful getting her husband to bathe using adult reasoning.

**Sees changed person not the disease.** Upon analyzing caregiver interviews it was apparent that during resistiveness all caregivers could see the care recipient as a changed person during the moments of resistiveness; they did not identify these changes with this disease process of dementia. Polk (2005) disclosed that family caregivers who attributed behaviors such as resistiveness to care to the person with dementia and not a result of the disease process tended to have less patience with the care recipient. Many of the caregivers in this study identified that when resistance occurred they did not see the disease process but rather the care recipient acting in ways that were not typical to what the family caregivers were accustomed. The family caregivers expressed anger or frustration with these “new” care recipient behaviors or actions and did not relate them to the disease process.

As a result, caregivers were conflicted in how they should respond and struggled with the responses they chose. When Deloris experienced resistance from her mother she could only see
her mother acting strangely. “In my mind I’m thinking ‘why can’t you understand this?’ And she’s …screaming at me.” In the beginning Deloris stated that she was so confused and she wondered if her mother’s resistant behaviors were manifestations of a mental breakdown. Alice also admitted that in the moment of resistance she was taken off guard and only saw her significant other resisting her care. “I can’t see the disease, I cannot see the disease.” Caregiver Sam also experienced conflicted images of his wife. He stated that at times she made perfect sense and he believed her and at other times she became accusatory and violent. He was confused with these behaviors in the moments of resistance but did not associate these behaviors with the disease process. This was very true with Grace. She only saw the resistance in the form of reluctance to bathe but did not attribute this to the dementia disease process. Interviewed family caregivers supported what Polk (2005) disclosed; many caregivers were not able to see the disease process when resistiveness to care occurred but rather a changed person.

It was only upon retrospection that family caregivers acknowledged that they were able to discern the behaviors as manifestations of the dementia. Each of these caregivers described their struggle and distress with resistance and seeing images of a changed care recipient that were not consistent with how the care recipient was prior to their life before the disease. These findings validated the speculations of Kinney and Stephens (1989) and what Pearlin, Mullan, Semple, and Skaff (1990) posited in the stress process model; primary stressors such as problematic behaviors (resistiveness to care) may not be the actual stressor for family caregivers but rather the behaviors’ trigger of a sudden reminder to the family caregiver of the changing person (care recipient). Family caregivers in this study described the changing person with dementia as distressful and difficult to comprehend.

Patton, Johnston, Katona, and Livingston (2004) also reported that caregivers are not able
to attribute the behavioral symptoms of dementia to the disease process; despite their awareness of the disease. Pot, Deeg, Van Dyck, and Jonker (1998) state that family caregivers are too close to the situation and unable to step back and see the behaviors as part of the disease process. They postulate that this may be why spousal caregivers perceive more distress with behavioral problems associated with dementia than non-spousal caregivers. In this study both spousal and children caregivers expressed that they were unable to see the behaviors as manifestations of the disease despite their awareness of the dementia diagnosis. Family caregivers' inabilities to recognize the manifestations of the disease were noted in their descriptions. This aspect of the phenomenon as very distressful and caused caregivers much guilt and may have played a part in how family caregivers managed the resistiveness to care that they experienced.

**Caregivers’ Management of Resistiveness to Care**

Family caregivers attempted to manage the resistiveness when it occurred by using similar tactics that appeared to be strategic and intuitive. These included the use of reasoning and logic. When the resistive behavior occurred, the family caregivers would reason or try to use logic with the care recipient to overcome the resistance. However when these choices were ineffective family caregivers would resort to “telling little white lies,” which they are taught at the Alzheimer’s support group meetings as a means to prevent resistiveness. Many family caregivers said in their interviews that they had moral struggles with using lies with their care recipient and weighed this strategic choice against being honest with the care recipient. Caregivers Margie, Sam, and Eve stated feeling guilty for deceiving their care recipient with lies. This struggle was identified in the research of Simpson and Acton (2013) as family caregivers often feel conflicted between what they should do and what they feel is right to do with the care recipient. Simpson and Acton (2013) noted family caregivers often change their feelings to be
more appropriate with what is considered expectable behavior on the part of the caregiver. Family caregivers were often noted in their descriptions of resistiveness to abandon their goal or agenda as a more acceptable way to manage the resistance.

When one or more of these strategic choices failed to eliminate or lessen the resistance, family caregivers abandoned their goal or agenda. Only three caregivers admitted they gave up their goal or agenda for the caregiving encounter when they encountered resistance that was not averted using reasoning, telling lies, or being honest. These caregivers (who were the exception) were confident in their ability to successfully reach their goals during resistive episodes. Despite giving up the original goal or agenda during resistiveness, ultimately the aim for family caregivers was to achieve a stable state where resistiveness to care did not occur. However, all family caregivers stated they realized the stable state was only temporary and there was the potential for more resistiveness to care increases as the disease process continues to destroy neurologic functioning.

**Application of Key Insights to Nursing**

Scientific phenomenology is a method that highlights the relationship among the subject, others and the situation in which the phenomenon occurs using a specific disciplinary perspective to investigate the relationship (Giorgi, 2009). The application of the descriptive phenomenology method (Giorgi, 2009) enabled the researcher to use her disciplinary perspective of nursing during the analysis and reveal new caring and caregiving (nursing) aspects of resistiveness to care that can be useful in treatment of persons with dementia. The objective analysis provided findings that were accurate descriptions of the phenomenon—resistiveness to care without preconceived notions, expectations, or theoretical frameworks directing outcomes (Morse & Field, 1995). The structure of resistiveness to care found in this study is a non-
theoretical, objective understanding from the family caregivers subjective experiences of the phenomenon—resistiveness to care. This is a new perspective.

The current understanding of resistiveness to care is largely understood using theories and assumptions from a professional caregivers’ perspective [not family caregivers] (Mahoney et al., 1999; Pearlin, Mullan, Semple & Skaff, 1990; Pot et al., 1998; Volicer & Hurley, 2003; Whall, 1999). This study investigated the subjective experiences of family caregivers, the largest population of caregivers providing around the clock care for people with dementia. Many of the nursing developed interventions relating to resistiveness to care have yielded very limited improvement in the resistiveness behaviors and very little change in the level of distress for the caregiver. The findings in this study provide a foundation for future intervention research on resistiveness to care for family caregivers of persons with dementia.

Findings from this study enhance nursing understanding of the phenomenon resistiveness to care. As a concept, resistiveness to care has been defined from a nursing disciplinary perspective and is usually occurs in professional nurse caregiving settings during activities of daily living (ADLs). The findings from this study show that resistiveness to care is not a concept family caregivers use to describe situations in which their care is impeded or refused. Instead family caregivers describe these situations as difficult and stressful not “resistive.” Family caregivers do not focus on the struggles of providing the tasks (ADLs) but rather what the experience of resistance means for them—the identified elements of resistiveness to care. These elements appear to be different than what professional nurse caregivers experience when caring for people with dementia and may be an indicator why some of the current nursing interventions aimed at reducing family caregiver distress do not work as well as expected.

All identified elements (constituents) of resistiveness to care identified in this study
provide information for nurses to consider to better understand the subjective experience of family caregivers as they encounter resistiveness to care. Since family caregivers are now providing care that was once done by formal nursing caregivers (managing medications, symptoms, and assessing when the care recipient is in need of formal medical care), family caregivers are considered co-providers of care (Grant & Ferrell, 2012; McGhan, Loeb, Baney & Penrod, 2013). Therefore nurses need to be aware of this study’s identified differences in caregiver experiences and understand the distressful aspects of resistiveness to care (specific constituents of the structure) to improve their praxis in empathetic support of family caregivers.

In their descriptions, all family caregivers expressed that the resistiveness was neither expected nor predictable and all experienced varied emotional responses to the episodes. Each family caregiver’s response toward the resistance was negative. Theses negative responses were either directed toward the person with dementia or caregiving situation and may have contributed toward caregivers’ questioning their ability as a caregiver. In addition, all caregivers described various conflicting images of the care recipient and noticed changes in their own perceptions of themselves. Lastly, the family caregivers questioned their abilities as a caregiver and noted the episodes of resistance signaled a potential increase in future responsibilities. It is within these last two constituents: questioning abilities as caregiver and signal for future responsibilities that family caregivers differed. While all family caregivers questioned their ability as caregiver and saw resistiveness as a signal for increased caregiver responsibilities, only two caregivers described a positive attitude despite the distressful situation at the time.

Gaugler, Davey, Pearlin, and Zarit (2000) have posited that as caregiving progresses over time caregivers adapt to the caregiving situations and as a result the adaptation limits the impact of care demands and or role overload on their caregiving experience-lessening caregiver burden
or distress. If nurses are aware of the structural experience that family caregivers encounter during resistiveness to care, they will be better prepared to assess and intervene when family caregivers experience problems within these episodes in order to help family caregivers sustain their caregiving efforts. These constituents and their variations are explained using caregiver exemplars to show their significance to nursing.

**Self-questioning of abilities.** All family caregivers provided evidence that they questioned their ability to be a caregiver when they experienced resistiveness to care. The majority of caregivers appraised their ability with uncertainty. Seven caregivers expressed concerns of not handling the situation well; felt inadequate as caregiver; second guessed their caregiving decisions; felt confused and not able to figure out what to do in a situation; and expressed guilt over the decisions made during the encounter. However, one caregiver when questioning her ability evaluated her abilities positively. Eve, although she questioned her abilities, was very confident in her caregiving role and described with a positive attitude how she was certain of what needed done and her capability to do it despite the tremendous about of work needed and her fathers extreme resistance. This was in stark contrast to the other caregivers who doubted themselves and felt unsure when they encountered a resistive situation with their care recipient.

The current literature supports family caregivers’ perceptions of their abilities as caregivers can directly impact their perceived level of distress when resistiveness to care occurs (Gaugler, Davey, Pearlin & Zarit, 2000). Croog, Burleson, Sudilovsky, and Baume (2006) also identified that caregivers often feel anxiety about their caregiving and wish that they could do more for the care recipient. Therefore, nurses who are familiar with the structural experience of resistiveness to care and encounter a family caregiver that are negatively appraising their abilities
can be understanding and supportive to the family caregiver.

Nurses who understand the family caregiver experiences will be able to reassure the family caregiver that these appraisals are common among caregivers. Nurse can also direct the family caregiver to the appropriate support and resources to help them feel more confident in their ability in order to help them sustain their caregiving role. Although the goal is a positive perception of caregiver abilities in order to help caregivers sustain their caregiving role, nurses need to be aware that perception of abilities may not be the only constituent during resistiveness to care that impacts a decision to place a care recipient in a care facility. One caregiver (Eve) appraised herself optimistically in her ability to provide care for her father however later decided to place her father in a care facility. Nurses should provide support of whatever decision the family caregiver makes regarding their caregiving abilities.

The impact of a caregiver’s perceived ability to be a caregiver has been documented in the caregiving literature. Intrieri and Rapp (1994) reported that the more resourceful a caregiver is the less perceived caregiving burden and the more positive the appraisal of caregiving by the caregiver. Eve was well educated and did seek out assistance as a caregiver. When she wondered about her father’s financial situation she sought out the advise of a lawyer that specialized in legal issues dealing with the elderly and cognitive impairment. Eve’s resourcefulness likely contributed to her ability to view the difficult caregiving situation positively. Resourcefulness may also impact a caregiver’s reaction to behaviors such as resistiveness to care and may prevent placement of the care recipient in a care facility (Mittleman, Roth, Haley & Zarit, 2004). Nurses knowledgeable in this fact will want to help family caregivers who may not be resourceful to obtain the resources they need to feel more confident in themselves and their abilities to handle resistiveness to care situations.
Nurses should also be aware that not all family caregivers are receptive to outside support and resources. Several family caregivers in this study expressed that in the beginning episodes of resistiveness to care they preferred to handle the resistance in isolation (not wanting to bother family or friends). They reasoned that their children had families of their own and did not want to add to their current obligations. Family caregivers not availing themselves of resources and help, is not something new. Gaugler, Kane, and Newcomer (2005) identified that family caregivers do not readily embrace community services. Nurses need to be aware of this constituent (questioning ability as caregiver) and its impact on caregiver distress. Nurses are in the best position to champion for the family as co-providers of care for persons with dementia.

**Signal for increased future caregiver responsibilities.** When family caregivers experienced episodes of resistiveness, it triggered a sense in family caregivers that responsibilities and amount of time caring for the care recipient would increase. The majority of caregivers interviewed described how much work is was to care for the care recipient; how difficult is was at times to provided the needed care; the struggle to do and say the right thing; and wishing they could do more than what they were able to do for the care recipient when they encountered resistance. One caregiver (Jenny) stated that she felt the future would increase in caregiving demands but chose to be optimistic in the present as caregiver. Despite dealing with resistance she stated, “I’m very lucky in most ways. I’m very lucky. Very fortunate in a lot of ways, it could be a lot worse.” Jenny had been caregiving for the longest period of time (twenty years) and was positive in her perceptions of the constituent signal for increased future responsibilities. She believed that she was lucky and fortunate in her current caregiving responsibilities and knowing the future she could be burdened with a lot more.

This optimistic or positive attitude is very important as Mittleman, Roth, Haley, and Zarit
(2004) have identified that family caregivers who appraised resistiveness to care negatively (negative appraisal of signal for increased future responsibilities) may be more likely to place the care recipient in a long-term care facility. Nurses want to be aware of the importance of family caregiver’s perceptions of future responsibilities on their ability to sustain their caregiving role. This constituent may play a part in the “tipping point” when family caregivers decide to place their care recipient in a care facility. The negative and optimistic (positive) variance of this constituent is of importance for nurses when supporting family caregivers in decisions of whether or not to place their care recipient in a care facility. Nurses who find caregivers with a negative outlook on the future could work with these caregivers to find ways to focus their efforts to remain positive in their caregiving role or to help them transition care of the care recipient to a care facility. Nurses should also assess family caregivers to determine if they are at or near their “tipping point” and help support them in their choice of care decisions.

**Changed perception of personal self.** Further insights into family caregivers descriptions of resistiveness to care uncovered that family caregivers portrayed themselves as changing. When resistiveness to care occurred, all family caregivers had awareness that their personal self was not what it used to be. For some family caregivers this was a shocking revelation. Alice stated, “So it’s like holy good god look what my life is cut out for! I’m getting more of a caregiver.” Others began to feel themselves as lesser in the relationship stating that the care recipient was getting all the attention and they were not receiving as much as the caregiver. Pearlin, Mullan, Semple, and Skaff (1990) posited that caregivers of persons with dementia experience a restructuring of the caregiver-care recipient relationship in which the former interchanges become unidirectional toward the care recipient and less returned to the caregiver causing distress for the caregiver. They also noted that caregivers notice a separation of
themselves from parts of their lives that had been supported by their relatives and call this relational deprivation (Pearlin, Mullan, Semple, & Skaff, 1990). Yet others noted a role change. They were the one to take care of their parents who were now childlike. For Sam, he felt as if he was no longer able to be the husband caring for his wife. “I wasn’t allowed to visit her because I was the enemy with the love child and mistress.” All family caregivers’ described this constituent as unexpected or unforeseen. It was as if they could not believe this was happening.

Croog, Burleson, Sudilovsky and Baume (2006) state that family caregivers often need to limit social and personal time in order to care for the care recipient and that decreased personal and social experiences and involvement with others outside the caregiving role contribute to the feelings of a changing person.

Nurses educated on this essential component of resistiveness (changed perception of personal self) are able to encourage family caregivers that these feelings are often felt by family caregivers who encounter resistiveness to care and offer ways in which family caregivers deal with these feelings. Nurses can be instrumental in helping family caregivers identify coping strategies for these feelings and direct family caregivers to the appropriate resources to help them manage their perceptions of a changing self.

**Unexpected emotional responses.** All of the family caregivers interviewed described feelings of surprise and astonishment toward their initial responses to the resistance that they experienced. Many caregivers felt anger toward the care recipient, anger toward the situation, and fear of the unknown in the situation. This negative appraisal of the caregiving situation in which resistiveness to care occurs was validated in the family caregiving research. Pot, Deeg, van Dyck, and Jonker (1998) identified in their research findings that it is difficult for family caregivers to step back from the caregiving situation and feel a sense of control. Family
caregivers described unexpected emotional responses such as “I don’t give a shit if he asked for it or not,” feeling angry with having to deal with care recipient as a child, to feelings of dread “Oh NO,” and feeling overwhelmed. Many of these emotional responses occurred when family caregivers were experiencing resistiveness to care and could not see the dementia disease causing the behaviors but rather a changed person from who they were used to seeing. These feelings of family caregivers have been validated in the research. Polk (2005) described how family caregivers have less patience with their care recipient when they attribute the behaviors to the person with dementia rather than to the disease process. Additionally, Simpson and Acton (2013) have identified that family caregivers often struggle to do the right thing and often struggle with their behavioral responses in situations such as resistiveness to care.

Nurses’ awareness of family caregivers’ inability to step back from the resistive situation and control their responses can help family caregivers understand that their response to behavioral situations such as resistiveness to care, and that it is similar to other caregivers. Nurses can be instrumental in helping family caregivers work through their distress. Nurses can be advocates for family caregivers by helping them to identify resources and coping strategies for their responses in order to help them remain optimistic and enable them to sustain their caregiving role.

Sees changed person not the disease. Family caregivers described seeing a changed care recipient during episodes of resistance. The image of a changed care recipient was difficult for family caregivers. They stated that they were expecting their family member or friend but when they saw the changed persons being resistant they were unsure how to respond in these situations. The findings from this study are similar to those of Paton, Johnston, Katona, and Livingston (2004) who also found in their study that family caregivers did not attribute the
symptoms or behaviors of dementia to the disease despite knowing the symptoms of the disease. In fact many family caregivers in Paton et al study believed that the behaviors were in the control of the care recipient. Similarly all family caregivers in the present study could see the changed person but not the disease.

As Pot and colleagues (1998) propose, family caregivers may be too close to the situation to recognize resistiveness to care as part of the disease process. Instead they only see the care recipient as a changed person from whom they once knew. The inability to see the disease despite the changed person with dementia is supported in the research by Pot, Deeg, Van Dyck and Jonker (1998). Caregivers are too close to the situation and unable to step back to see the behaviors as part of the disease process causing the caregiver great distress. In addition, researchers have posited that primary stressors such as resistiveness to care may not be as distressing for family caregivers as what the behaviors represent—a changed person with dementia (Kinney & Stephens, 1989; Pearlin, Mullan, Semple & Skaff, 1990). Upon reflection and later realizing the behaviors during the resistance were part of the disease process, caregivers expressed feeling guilty for their responses.

Nurses aware of this essential constituent of the family caregivers experience of resistiveness to care can help family caregivers to realize this is a common experience that many family caregivers experience. Nurses can strategize with family caregivers on ways to respond to the resistive episodes. The findings of this study identified common ways that family caregivers manage resistiveness to care (being honest, telling little white lies, and giving up the goal or agenda). Nurses aware of these management strategies can work with family caregivers to identify new ways of responding to the changed person during resistiveness to care that are less distressful and more therapeutic for family caregivers.
Family Caregiver Support and Resources

Insights from the identified general meaning structure can provide valuable insights for nurses to support and offer resources to family caregivers who experience resistiveness to care. “Caring is a genuinely experiential phenomenon—both on the side of the care recipient and caregiver” (Giorgi, 2005, p. 82). As a result, nursing care of family caregivers and persons with dementia should be holistic—not just focused on the technical aspects of disease.

“Phenomenology [study findings] makes us more empathetic and provides insights into other’s experiences while enriching our own” (Morse & Field, 1995, p. 192). The general meaning structure of resistiveness to care as identified by this study embodies a holistic approach to supporting family caregivers of people with dementia.

Rather than a disease focus this study centered on the experience of resistiveness from the family caregivers’ perspective. It identified essential components of the phenomenon (resistiveness to care): self-questioning of abilities; signal for future responsibilities; changed perception of personal self; unexpected emotional responses; and sees changed person not the disease. These essential components provide nurses with an all-inclusive structural picture of the phenomenon as it is actually experienced by family caregivers. This picture should enable nurses to improve their praxis by understanding the interrelatedness of all constituents in lived experience and realizing the individuality of each component. Nurses could then holistically assess and provide assistance to family caregivers (co-providers of care) where appropriate to help them succeed in their caregiving role.

Advanced practice nurses utilizing the nursing sensitive outcomes from this study will understand more clearly the lifeworld of the family caregiver, co-providers of care for people with dementia (Giorgi, 2012). In fact, “looking at the everyday life experiences from a nursing
perspective will give you highly relevant insights that a psychologist or sociologist might miss” (A. Giorgi, personal communication, March 9, 2013). Using the knowledge of essential constituents representing the resistiveness to care experience, the advanced practice nurse can develop nurse-family partnerships with the family caregivers and together they can make sense of the resistiveness to care experience. Knowledge of the constituents can be used by advanced practices nurses to help family caregivers understand the changed person with dementia and to help family caregivers achieve “new normal.” Advanced practice nurses can also help family caregivers understand the transient stable state and help them realize that it is always changing (never the same).

At a minimum, the findings of this study provide advanced practice nurses with insightful reflection on the family caregiving experience with resistiveness to care and help nurses recognize distress and be able to offer appropriate support for family caregivers [co-providers of care] (Ferrell & Baird, 2012). Advanced practice nurses will be able to target their help for family caregivers based upon the constituents of the phenomenon: see changed person not the disease, unexpected emotional responses, self-questioning of abilities, changed perception of personal self and signal for increased future caregiver responsibilities. The objective of this assistance and support is to sustain the family caregiver (co-provider of care) in their caregiving role.

The structure of resistiveness to care and its essential constituents can be used in the creation of educational and support resources for dementia family caregivers and student nurses. The constituents provide accurate depictions of the lived experience from dementia family caregivers perspectives rather than relying on theoretical assumptions. Previous phenomenology research findings have been used in educational instruction to improve practice. Sandelowski,
Trimble, Woodard, and Barroso (2006) testified to the feasibility of translating their study findings into practice by developing an educational DVD about HIV-related stigma to be shared with patients diagnosed with HIV while they waited for their clinic appointments. Similarly, the structural constituents of resistiveness to care can be incorporated into an educational resource for new dementia caregivers who may not have yet experienced the phenomenon of resistiveness to care but are expected to encounter it in the future.

Current educational resources for dementia family caregivers focus on the disease process and caregiver emotional response to behaviors but fail to address aspects of the constituents identified in the structure of resistiveness to care as described by family caregivers. Namely, current caregiver education recommends that caregivers separate themselves from the resistive situation to realize the behavior is part of the disease process. Given the current research and research by Pot, Deeg, Van Dyck, and Jonker (1998) caregivers are not able to step back when in the resistive moment. Family caregivers are too close to the situation in the moment and unable to see the behaviors as part of the disease process.

One family caregiver in the current study Sam voiced his concern with the current support group instruction for family caregivers regarding the resistive behaviors. He was attending a support group meeting in which a video was shown depicting care recipient’s behaviors and what appropriate caregiver responses should be. The family caregivers were instructed in the video to separate themselves from the behaviors and realize the behaviors are part of the disease process and not the care recipient. Sam a well-educated caregiver voiced his concern after viewing the video by saying that when his wife was being aggressive and agitated he could only see her as his wife despite knowing that it was the dementia acting out. Sam identified that while intellectually he could rationalize the behaviors, however in the moment—
emotionally he could not. Future educational resources with more accurate information based upon the current study findings will help both nurses and family caregivers understand the emotional responses to resistiveness and how these responses impact family caregivers’ perceptions of themselves and their ability to be a caregiver.

**Recommendations for Future Research**

**Recommended Future Research Based on Findings**

The use of descriptive phenomenology as a method to explore family caregivers’ lived experiences of the phenomenon—resistiveness to care provided an objective understanding of the “life world” of family caregivers that was previously explained using theoretical perspectives or empirically using objective measures of the subjective experience. Resistiveness to care is poorly defined as a concept. Despite family and friends providing care for 85 percent of the people with dementia living in the United States, resistiveness to care has not been explored from the subjective experience of the family caregiver (Alzheimer’s Association, 2015). According to Giorgi (2014)—the creator of the descriptive phenomenology method, life-world is the ground for all further elaborations or developments surrounding a phenomenon. The findings from this study provide the base for further research surrounding resistiveness to care.

**A base for theoretical development.** The identified structure of resistiveness to care can be used for more accurate future theoretical formulations surrounding this phenomenon. The structure should be used as a base to provide a clear understanding of resistiveness to care to build future intervention research. The identified structure of resistiveness to care helps researchers to form more accurate theoretical formulations about resistiveness to care and raises new questions for further research. One such question was also posited in the work of Kinney and Stephens (1989) is the subjective representation of a changed person with dementia more
stressful than the objective behaviors or resistiveness to care? The current structure identifies that family caregivers notice a changed person when resistiveness to care occurs and this was distressful, however it is not clear whether this changed person alone was distressful or whether the combination of all constituents of resistance added to family caregiver distress. Further investigation into this hypothesis is needed in order to develop appropriate interventions to help decrease family caregivers’ distress so they can sustain their caregiving role.

Another area for theoretical development is the relationship of the five essential constituents and whether or not they can be moderating factors in the perception of distress with resistiveness to care. Gaugler, Davey, Pearlin, and Zarit (2000) posit that positive outlooks or perceptions of family caregiver regarding primary stress factors have potential to lessen the perception of distress with the caregiving role. Several family caregivers described positive attitudes toward several constituents of the distressing experiences with resistiveness to care. These included self-questioning their abilities and signaling an increase in future caregiver responsibilities. Findings from this study could enhance theoretical formulations surrounding the concept of resistiveness to care and their potential to be moderating factors to decrease family caregivers perceptions of distress.

Lastly, the trajectory of dementia appears to be similar to that of heart failure. Family caregivers stated in their interviews that they noticed periods of normal (when the care recipient was not confused and appeared like themselves) and then there were periods of confusion. This finding is similar to findings from an end-of-life caregiving study with caregivers of heart failure care recipients (Penrod, Hupcey, Shipley, Loeb, & Baney, 2012). Further investigation should include the applicability of the end of life caregiving trajectory (Penrod, et. al, 2009) testing its utility for supporting dementia caregivers at the end of life.
Further investigations could include the use of a chronic illness caregiving trajectory framework (Corbin, & Strauss, 1991; Robinson, Bevil, Arcangelo, Reifsnyder, Rothman, & Smeltzer, 1993) to investigate its utility for identifying when families reach their tipping point [signal of increased future responsibilities] and either decide to place their care recipient in a care facility or decide to keep them at home and when would they benefit from the nursing support and palliative care. Research into the use of the trajectory framework may also identify areas of opportunities to intervene and how nurses can intervene with support and resources to help family caregivers—co-providers of care succeed in their caregiving role.

**Intervention research.** This study also supports the need for future intervention research with a focus on interventions directed toward the subjective family caregiver’s lived experience (captured in the general meaning structure’s five constituents) rather than objective behaviors (resistiveness). This research focus would enable advanced practice nurses to find best practice ways to be helpful toward their co-providers of care (family caregivers).

A possible exploration could be to investigate interventions to manage family caregiver responses in the resistive situations. This study identified five essential constituents of resistiveness to care that family caregivers identify as potentially distressful. These included caregivers’ unexpected emotional responses to the resistiveness and seeing the changed person not the disease. Although research supports that caregivers often feel guilty for their responses, interventions such as the use of mindfulness may be a therapy that could be used with family caregivers.

Mindfulness is a state of being openly aware of and in the present moment (Brantley, 2007). With mindfulness the participant obtains an awareness in which he or she develops a consciousness that is light sensitive and clear within the present moment when resistiveness to
care occurs (Brantley, 2007). Researchers have used mindfulness therapy as a method to enhance coping with life situations (Carmody, Baer, Lykins, & Olendzki, 2009; Lynch, Gander, Kohls, Kudielka, & Walach, 2011). Both of these studies reported a reduction in stress outcome of the participants and increased mindfulness. In light of these research findings, mindfulness may be an appropriate intervention therapy for family caregivers encountering resistiveness to care (in particular when they react to the resistance or see the changed person and not the disease) to help caregivers change their emotive responses.

**Translating research finding into clinical practice.** Another area for future research relating to resistiveness to care would be to further explore the utility of the identified structure as it applies in the clinical setting. Application in the clinical setting would have a two-fold objective. The first would be to study the findings effectiveness on changing nursing practice and the second would be the impact on family caregivers.

This study’s findings have the ability to change practice by improving the nursing care provided to family caregivers. Research prior to this study encouraged family caregivers to find ways to reduce or eliminate resistive behaviors by modifying the environment of their responses to the behaviors. The goal was to achieve a stable state in which behaviors such as resistiveness to care no longer occurred. Family caregivers were taught to use “telling white lies” as a strategic choice to manage or prevent resistive situations and to distance themselves emotionally from the resistive encounter. Insights from this study show that resistiveness to care will not diminish (until the neuro degeneration has progressed to its end stages) no matter what environmental changes and a focus on family caregivers responses to behavior only identifies one of the constituents (unexpected emotional response) of the event and does not recognize the other four (self-questions abilities; signal for increased future caregiver responsibilities; changed
perception of personal self; and sees changed person not the disease). Nursing practice that includes all five of the essential constituents would be more holistic and sympathetic to the needs of family caregivers.

Nurses having a greater awareness to resistiveness to care would be able to respond to family caregiver needs and situations with enhanced integrity. Advanced practice nurses caring for people with dementia and their family caregivers could use the current study findings to accurately understand the lived experience of family caregivers and be able to holistically assess and treat both the person with dementia and the family caregiver providing care for the person with dementia. Future research would include determining the effectiveness of these study findings for improving nursing praxis in the assessment and identification of distress in caregivers who experience resistiveness to care. Understanding the family caregiver’s experience (general meaning structure) will help expert nurses comprehend the experiences of family caregivers and then be able to know when and how to intervene with instructions, support, and resources for the family caregiver. Nurses who understand the experiences of family caregivers would have the opportunity to develop nurse-family partnerships in which they could work closely with families making sense of the resistiveness to care together in order to help family caregivers care for their care recipient with dementia.

The second area for applying this study’s results to clinical practice would include investigating the usefulness of educational and support resources. Current education for families caring for someone with dementia recommends families remove themselves emotionally from a resistive situation. Future educational information based upon this study’s findings of five essential elements of the structure of resistiveness to care could be created and shared with family caregiver or for student nurses providing them with accurate information about what is
happening in the moment from a family caregiver’s perspective. This education could be in the form of DVDs depicting scenarios in which family caregivers experience episodes of resistiveness from the care recipient similar to the experience from this study. Several different realistic approaches to handle the situation might be presented to engage family caregivers and nursing students in discussion of what might be realistic in each caregiving situation. Future research would investigate the usefulness and effectiveness of this type of educational resource for nurses and family caregivers.

Lastly, findings from this study will help nurses be more sensitive to the experiences of family caregivers as they experience resistiveness to care. Nurses can be instrumental in helping family caregivers understand their new normal and the changed person with dementia that they care for. By understanding of the identified five constituent of the resistive experience nurses can also help family caregivers know when and how to intervene by providing them with support, resources, and appropriate interventions congruent with this studies findings.

**Study Limitations**

**Findings Are General Claims Not Universal**

Descriptive phenomenology studies have the goal of defining the essence (essential structure) of the descriptions given and do not go beyond the “given.” They do not theorize or interpret (Giorgi, 2009). Therefore the resulting claims for this study are general descriptions and not universal claims. The findings of this descriptive study are not expected to be used for policy changes but can impact the care provided to family caregivers. Nurses aware of the study findings can be more empathetic to the family caregiver’s lived experience due to the insights gained.

**Descriptive Phenomenology Findings are Contextually Bound**
The current study only renders visible the quality of the relationship among the family caregiver, the person with dementia and the situation that constitutes the experience of resistiveness to care. It does not fill in the gaps uncovered but provides the impetus for further investigations. Future studies of resistiveness to care need to be conducted for broader application of this studies findings since this study is limited to the sociocultural context of family caregivers’ experience of resistiveness to care.

**Participant Gender Variation**

The current study had only one male caregiver who described his difficulties caring for his care recipient with dementia. While his descriptions contributed to the general meaning structure, the fact that his descriptions were the only male descriptions may be considered a limitation of this study. However, with the scientific phenomenology method, it is the number of different detailed instances of the phenomenon that is the variable of interest to a study and not the variance among those who provided the descriptions. Future studies with a more robust male sampling would be needed to determine whether the general meaning structure (measure of central tendencies of the phenomenon) would change with more male descriptions of resistiveness to care.

**Interviewer Profession**

Another potential limitation for this study was the fact that the interviewer for this study was a nurse. Participants may have been compelled to describe their experiences in a way that they thought the interviewer wanted to hear. The participants may have used filters to limit or present only the detail that they felt the interviewer wanted. This researcher was aware of this potential limitation but considered its potential impact on the study to be very minimal. Because nurses are generally considered caring and trusted as a profession the researcher did not believe
the interviewer’s profession as nurse limited the descriptions participants provided for this study.

Descriptive Phenomenology Provides a Base For Future Research

Lastly, descriptive phenomenology as a method is designed to uncover human science meanings of experiential phenomenon by using a descriptive approach to phenomenon rather than a philosophical meaning of the experience. The results of a descriptive phenomenology method are a synthesized summary statement that outlines the general structure of the phenomenon under investigation. The findings from this study do not delve further than the raw data given but provide a rich description of the actual lived experience of family caregivers (addressing a gap in the nursing research surrounding this phenomenon). The objective of the descriptive phenomenology method is to develop an invariant structure that makes sense of the variations contained in the raw data (Giorgi, 2009). This is similar to finding a central tendency or mean in statistics. While the current study provided the invariant meaning structure of resistiveness to care as experienced by family caregivers, it did not provide theoretical suppositions based on these findings. However this research can raise new questions and provide the stepping off point for future theoretical formulations and research.

Chapter Summary

Dementia is a disease that is increasing in prevalence globally as the baby boom generation advances to old age. The biggest risk factor for the disease is being 65 years of age or older (Alzheimer’s Association, 2015). People diagnosed with dementia will need personal assistance at some point in the disease process. This assistance will be in the form of providing guidance in tasks, assisting with activities of daily living, and ensuring the safety of the person with dementia. Providing care for someone with dementia has been called a 36-hour day (Mace & Rabins, 1999, 2006). Despite long hours caregivers must also deal with behavioral symptoms
of the disease, which includes resistiveness to care. The current research on resistiveness to care was found to be limited to a focus on formal caregivers (nurses) and the objective behaviors of resistance. Very little research was found that focused on the subjective experience of the largest group of caregivers. Family caregivers provide care to 85 percent of all people diagnosed with dementia (Alzheimer’s Association, 2015). They perform care duties that were once provided by nurses. Because of healthcare reform and restructuring of payment reimbursements, family members or friends are now caring for people with dementia at home.

In order to learn more about the subjective experience of resistiveness to care, this study used a descriptive phenomenology method developed by Giorgi (2009) to uncover a structure of family caregivers lived experiences of resistiveness to care. The structure provided a clearer understanding of the family caregivers’ perceived experience of resistiveness to care and added to the science of resistiveness by identifying five essential constituents of the meaning structure. These constituents included: self-questioning abilities; signal for increased future caregiver responsibilities; changed perception of personal self; unexpected emotional responses: and seeing changed person not the disease. Each caregiver expressed distress with resistiveness to care however two caregivers described positive outlooks with self-questioning of abilities and signal for increased future caregiver responsibilities. According to Gaugler, Davey, Pearlin, and Zarit (2000) these positive views may be moderating factors that can help caregivers to sustain their caregiving role longer. Future research will be needed to test this hypothesis.

This study added significant foundational support for future research. It provides the basis for accurate understanding of the lived experience of family caregivers who experience resistance. Previously researchers theorized what family caregivers were experiencing during resistiveness to care and used interventions based on those theories to reduce family caregiver
distress with minimal success. Researcher utilizing this study’s meaning structure will be able to focus on actual family caregivers’ experiences and their meaning structure as they described it. The findings from this study also provided evidence that descriptive phenomenology as a method was appropriate for understanding human phenomenon and producing validated groundings.

Although the identified general meaning structure of resistiveness to care defined in this study enhances our understanding of this phenomenon it also encourages future research to learn more about this experience. This study revealed that family caregivers do not focus on the difficulty performing the tasks at hand but rather see the changed person under their care as someone who has changed. As a result, family caregivers have difficulty focusing on the disease process being responsible for the changes. Further research is needed to explore the relationship between the family caregiver’s perception of a changed person and the distress associated with resistiveness to care, and how to help families better understand the reason for these changes. Research is also needed to investigate theory development related to the identified general meaning structure. Potential moderating factors such as caregiver’s perceived abilities as a caregiver and a positive view of increasing future caregiving responsibilities and their role in sustaining the caregiving role are several areas for investigation. Based upon the identified essential constituents, future explorations could involve use of the caregiving trajectory applied to dementia caregiving as a way to identify “missed opportunities” or “tipping points” as critical areas that nurses can intervene with support to help caregivers sustain their caregiving role. Findings from this study can also provide valuable information for future education relating to resistiveness to care for family caregivers and student nurses. Future research would evaluate this study’s utility for educating and supporting future family caregivers of people with dementia and nurses.
Limitations of this study included the fact that findings of descriptive phenomenology are general and not universally applicable. Descriptive phenomenology seeks to remain close to the raw data and does not delve deeper into theoretical suppositions. The results from this study are contextual and bound to the sociocultural context of the individuals who have experienced the phenomenon—resistiveness to care. Lastly, because descriptive phenomenology seeks to remain close to the raw data is provides a clearer understanding of the subjective experience objectively and provides the base for future theoretical formulations surrounding resistiveness to care rather than theoretical development of the phenomenon.

Despite these identified limitations, this study provided the researcher the ability to use her nursing disciplinary perspective in the analysis and this has been valuable to the researcher for uncovering nursing sensitive elements in the data that has the potential to help nurses improve their care of family caregivers—co-providers of care for persons with dementia.
Appendix A

**APPROVAL OF SUBMISSION**

**Date:** April 7, 2014  
**From:** Julie James  
**To:** Pamela Spigelmyer

<table>
<thead>
<tr>
<th>Type of Submission:</th>
<th>Continuing Review</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title of Study:</td>
<td>Resistive Behavior in the Context of Informal Caregiver-Assisted Activities of Daily Living for People with Dementia</td>
</tr>
<tr>
<td>Principal Investigator:</td>
<td>Pamela Spigelmyer</td>
</tr>
<tr>
<td>Study ID:</td>
<td>PRAMS00031489</td>
</tr>
<tr>
<td>Submission ID:</td>
<td>CR00000323</td>
</tr>
<tr>
<td>Funding:</td>
<td>Sigma Theta Tau International Nursing Honor Society</td>
</tr>
<tr>
<td>Grant ID:</td>
<td></td>
</tr>
<tr>
<td>IND, IDE, or HDE:</td>
<td>Not Applicable</td>
</tr>
</tbody>
</table>

**Documents Reviewed:**  
- FAMILIES CARING FOR PEOPLE WITH DEMENTIA-demographic tool 3.21.14.docx (0.01), Category: Data Collection Instrument  
- FAMILIES CARING FOR PEOPLE WITH DEMENTIA ELIGIBILITY REQUIREMENT 3.27.14.docx (0.01), Category: Data Collection Instrument  
- FAMILIES CARING FOR PEOPLE WITH DEMENTIA-Interview guide 3.6.14.docx (0.01), Category: Data Collection Instrument  
- SUMMARY EXPLANATION OF RESEARCH-script of invitation to participate 3.6.14.pdf (0.01), Category: Recruitment Materials  
- HRP-503f-Protocol for Human Subject Research 3.27.14.pdf (0.01), Category: IRB Protocol  
- 31489_Spigelmyer_ICF_1_(05-06-13)_Informed modified 4.3.14.pdf (0.01), Category: Consent Form

On 4/7/2014, the IRB approved the above-referenced Continuing Review. This approval is effective through 4/6/2015 inclusive. You must submit a continuing review form with all required explanations for this study at least 45 days before the study’s approval end date. You can submit a continuing review by navigating to the active study and clicking ‘Create Modification / CR’.

If continuing review approval is not granted before 4/6/2015, approval of this study expires on that date.
APPROVAL OF SUBMISSION

Date: April 7, 2014
From: Julie James
To: Pamela Spigelmyer

<table>
<thead>
<tr>
<th>Type of Submission:</th>
<th>Modification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title of Study:</td>
<td>Resistive Behavior in the Context of Informal Caregiver-Assisted Activities of Daily Living for People with Dementia</td>
</tr>
<tr>
<td>Principal Investigator:</td>
<td>Pamela Spigelmyer</td>
</tr>
<tr>
<td>Study ID:</td>
<td>PRAMS00031489</td>
</tr>
<tr>
<td>Submission ID:</td>
<td>MOD00000519</td>
</tr>
<tr>
<td>Funding:</td>
<td>Sigma Theta Tau International Nursing Honor Society</td>
</tr>
<tr>
<td>Grant ID:</td>
<td></td>
</tr>
<tr>
<td>IND,IDE, or HDE:</td>
<td>Not Applicable</td>
</tr>
<tr>
<td>Documents Reviewed:</td>
<td>Study Team Member Qualification Document</td>
</tr>
</tbody>
</table>

On 4/7/2014, the IRB approved the above-referenced Modification. This approval is effective through 5/5/2014 inclusive. You must submit a continuing review form with all required explanations for this study at least 45 days before the study’s approval end date. You can submit a continuing review by navigating to the active study and clicking ‘Create Modification / CR’.

If continuing review approval is not granted before 5/5/2014, approval of this study expires on that date.

To document consent, use the consent documents that were approved and stamped by the IRB. Go to the Documents tab to download them.

In conducting this study, you are required to follow the requirements listed in the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library within CATS IRB (http://irb.psu.edu). These requirements include, but are not limited to:

- Documenting consent
- Requesting modification(s)
- Requesting continuing review
- Closing a study
- Reporting new information about a study
- Registering an applicable clinical trial
- Maintaining research records

This correspondence should be maintained with your records.
Appendix B

THE LIVED EXPERIENCE OF FAMILIES CARING FOR PEOPLE WITH DEMENTIA

Demographics Tool

Participant ID: __________

Caregiver:

Gender___________ Age___________ Time in Caregiving Role _________yrs

Relationship to Care Recipient___________________________________________

Living with Care Recipient _____Yes ______No

If not living with care recipient:

Amount of time spent caring for care recipient __________ hrs/wk

Care Recipient:

Gender ______________ Age __________

Time since diagnosis of dementia ________yrs

ADL ability level (bathing, dressing and eating):

How much assistance is needed for bathing?

_________ Some assist __________ Total assist ________None

How much assistance is needed for dressing?

_________ Some assist __________ Total assist ________None

How much assistance is needed for eating?

_________ Some assist __________ Total assist ________None
Appendix C

**SUMMARY EXPLANATION OF RESEARCH**

**Title of the Project:** THE LIVED EXPERIENCE OF FAMILIES CARING FOR PEOPLE WITH DEMENTIA

**Principal Investigator:** Pamela C Spigelmyer MS, RN, CNS

You are being asked to voluntarily participate in a research study conducted by a doctoral candidate in the school of Nursing at Penn State University. Your participation is completely voluntary with the right to withdraw from participation at any time.

The purpose of this study is to gain descriptions of the caregiving experience from the perspective of family caregivers who assist people with dementia in their everyday activities. The findings of this exploratory study will inform and influence future investigations pertaining to family caregivers of people with dementia. If you agree to participate, the principle researcher Pamela Spigelmyer will contact you to arrange for a meeting to obtain information regarding your experience as a caregiver for a family member or friend with dementia.

There is no direct benefit to you for participating in this research. It is hoped that information from this research project will increase understanding of caregivers experience assisting people with dementia during activities such as bathing, dressing and eating when resistiveness to care is likely to occur. You will be compensated with a ten-dollar gift card for your time involved with the research project.

This research project involves a meeting with the researcher at a location of your choosing whether it be at your home, or another mutually acceptable location. At this meeting questions will be asked about your experience as the caregiver as well as caring for your family member or friend with dementia. In addition you will be asked to describe in detail a recent time when you encountered difficulty providing care for the person with dementia.

There is no risk to you the caregiver. It may be difficult to retell a situation in which you had difficulties assisting the person with dementia in everyday activities however; you can decide which occurrence how much detail to give the researcher. No names or other identifying information will be used for this research project. All questionnaires and interviews will be kept confidential.

You must be 18 years of age or older to participate in this study. If you have any questions, complains, or concerns you should contact Pamela Spigelmyer at 717-437-4975.
Appendix D

Informed Consent Form for Social Science Research
The Pennsylvania State University

Title of Project: Families Caring for People with Dementia

Principal Investigator: Pamela Spigelmyer, PhD(c), APRN, B.C.
203 HHDE, University Park, Pa 16802
Pcs146@psu.edu 717-437-4975

Advisor: Dr. Judith Hupcey, EdD, CRNP
210 HHDE, University Park, Pa 16802
Jsh37@psu.edu 814-863-2211

1. Purpose of the Study: The purpose of this research is to obtain family caregivers’ descriptions of their experience assisting people with dementia during everyday activities such as eating, dressing and bathing. Approximately 30 caregivers are expected to participate in the study.

2. Procedures to be followed: You will be asked to describe in detail a recent experience when you had difficulties providing assisted care for a person with dementia. In addition, the researcher will ask questions about your relationship with the person with dementia as well as how long you have been care-giving. All interviews will be audio recorded. If after review of the initial interview, the researcher still has additional questions or needs further clarification upon what was already discussed, the researcher may contact you to request another interview to gather more information. The maximum number of interviews is two although most likely only one will be conducted.

3. Discomforts and Risks: There are no risks in participating in this research beyond those experienced in everyday life. Some of the questions are personal and might cause discomfort. If participating in this research caused you to feel concerns beyond normal daily living, please contact Crisis Intervention at 570-784-2262 (Lycoming County) or CAN Help 800-643-5432 (Centre County) for assistance.

4. Benefits: Some family caregivers may find it therapeutic to retell their experiences however, there are no immediate benefits to you. The benefits to society include better understanding of difficulties caregivers experience during caregiving activities such as eating, dressing and bathing in the future.

5. Duration/Time: Participation in this study should take no more than one hour for the initial interview and completion of the demographic questions. Although unlikely, if an additional interview is needed for further clarification it is expected that these will only take less than an hour to complete.

Statement of Confidentiality: Your participation in this research is confidential. The all data including recorded interviews will be stored and secured in a locked office in a locked file cabinet and will be accessible only to the researcher and the researcher’s advisor. The recorded interview data will be destroyed 3 years after the study is closed. Please note the researchers may report suspected elder abuse. Penn State’s Office for Research Protections, the Institutional Review Board and the Office for Human Research Protections in the Department of Health and Human Services may review records related to this research study. In the event of a publication or presentation resulting from the research, no personally identifiable information will be shared.

6. Right to Ask Questions: Please contact Pamela Spigelmyer at (717) 437-4975 with questions, complaints or concerns about this research. You can also call this number if you feel this study has harmed you. If you have any questions, concerns, problems about your rights as a research participant or would like to offer input, please contact The Pennsylvania State University’s Office for Research Protections (ORP) at (814) 865-1775. The ORP cannot answer questions about research procedures. Questions about research procedures can be answered by the research team.

7. Payment for participation: Compensation for your participation in this research study will include a $10 gift card that will be presented at the conclusion of the interview.
8. **Voluntary Participation:** Your decision to be in this research is voluntary. You can stop at any time. You do not have to answer any questions you do not want to answer. Refusal to take part in or withdrawing from this study will involve no penalty or loss of benefits you would receive otherwise.

You must be 18 years of age or older to consent to take part in this research study. A copy of this form will be given to you for your records. By signing this consent form, you indicate that you voluntarily choose to be in this research and agree to allow your information to be used and shared as described above.

____________________________________________________________________________________________

Person Obtaining Consent

Date

____________________________________________________________________________________________

Person Obtaining Consent Signature

Date
Appendix E

THE LIVED EXPERIENCE OF FAMILIES CARING FOR PEOPLE WITH DEMENTIA

Family Caregiver Interview Guide

(1.) Can you describe for me what it is like caring for (name of care recipient with dementia)?

(2.) Can you describe for me as detailed as possible, a time when you experienced difficulties while assisting your family member or friend who has dementia?
   a. Maybe a time when you helped with everyday activities? (Such as bathing, dressing, eating, or toileting).

(3.) Can you tell me more about a problematic time when things didn’t go well?
   a. Exactly what happened- how did it go?

(4.) Let me ask you this, how has this experience affected your life?
   a. What kind of impact has it had on your life?

(5.) Is there anything else you would like to add?

References


alzheimer’s patient: Problem responses to caregiver burden. *Aging and Mental Health, 10*(2), 87-100.


psychological symptoms of dementia and caregivers' stress appraisals: Intra-individual
stability and change over short-term observations. Aging and Mental Health, 10(6), 563-
573. doi: M4257G82624K8273 [pii]
10.1080/13607860600638107
Nursing Education, 24(6), 226-229.
medication on parotid salivary flow rates in an individual with dementia of the
Alzheimer's type. Special Care Dentistry, 13(5), 215-218.
Ferrell, B.R., & Baird, P. (2012). Deriving meaning and faith in caregiving. Seminars in
Oncology Nursing, 28(4), 256-261. doi: 10.1016/j.soncn.2012.09.008
Fitzsimmons, S., & Buettner, L. (2002). Therapeutic recreation interventions for need-driven
dementia-compromised behaviors in community-dwelling elders. American Journal of
Alzheimer's Disease and Other Dementias, 17(6), 367-381.
stressful encounter: Cognitive appraisal, coping, and encounter outcomes. Journal of
biomarkers profile in Cadasil-a model of pure vascular dementia: Usefulness in
differential diagnosis in the dementia disorder. International Journal of Alzheimer's
time: The longitudinal impact of behavior problems. Psychology and Aging, 15(3), 437-


Husserlian approach. Pittsburgh: Duquesne University Press.


Philadelphia: Lippincott, Williams & Wilkins.


transforming qualitative research findings for use in practice. *Qualitative Health Research, 16*(10), 1350-1370. doi: 10.1177/1049732306294274


VITA

Pamela C Spigelmyer
511 N Arch Street, Montoursville, PA 17754, pcs6427@aol.com

EDUCATION

August 2015  Doctor of Philosophy in Nursing  Pennsylvania State University
Minor: Gerontology

2006  Masters of Science in Nursing  Pennsylvania State University

2003  School Nurse Certification  Millersville University

1987  Bachelor of Science in Nursing  Bloomsburg University

FUNDING

2013  Beta Sigma Chapter- Sigma Theta Tau International Research Award
Dissertation Project- Scientific Phenomenology Study of Resistiveness to Care as Experienced by Dementia Family Caregivers

2009  Beta Sigma Chapter-Sigma Theta Tau International Research Award
Pilot Research Project- Resistive Behaviors in the Context of Informal Caregiver-Assisted Activities of Daily Living for People with Dementia

TEACHING EXPERIENCE

2014-Present  Clinical Instructor of Medicine- The Commonwealth Medical College, West Campus Williamsport, PA

2013-2014  Adjunct Faculty- Duquesne University, School of Nursing Pittsburg, PA

2006-2008  Part-Time Faculty- Pennsylvania College of Technology, Nursing Department Williamsport, PA

2005-2007  Part-Time Clinical Instructor- Pennsylvania State University, Department of Nursing University Park, PA

RESEARCH EXPERIENCE

2009-2011  Research Assistant
Infusing End-of-Life Care into Complex Organizations: The Prison Study
PI Team: Susan Loeb, Janice Penrod, and Chris Hollenbeak
Funded by NINR: 1R01NR011874-01

2009-2010  Research Assistant
Exploring the Formal/Informal Caregiver Interface Across 3 Death Trajectories
PI: Janice Penrod- Funded by: NINR 1R01NR010127-01

2008  Research Assistant
A Prescription for Enhancing Resident Quality of Life
PI: Ann Kolanowski – Funded by: NINR

SELECTED PUBLICATIONS


