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Factors Influencing Surrogate End-of-Life Healthcare Decision-Making for a Family Member with Alzheimer's Disease

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ABSTRACT

FACTORS INFLUENCING SURROGATE END-OF-LIFE HEALTHCARE DECISION–MAKING FOR A FAMILY MEMBER WITH ALZHEIMER'S DISEASE

by

SHARLENE DONALDSON TONEY

Alzheimer's disease (AD), a chronic terminal disease, progressively impairs cognitive function resulting in deterioration of intellect, memory, and personality. With disease progression, the surrogate decision-maker becomes more involved in intervention choices and end-of-life (EOL) care, which may or may not be based on patients' wishes or best practice guidelines. Yet surrogate decision outcomes involve important issues of medical futility, quality of life and death. The purpose of this study was to examine factors that influence surrogate health care decision-making for a family member during the terminal stage of AD.

A descriptive, predictive design was used to address the research questions: 1.What is the relationship between surrogate gender and decision motives?; 2. Do structure (surrogate age and gender, attachment, interpersonal conflict), interactional context (elder image, caregiving beliefs), situational context (dementia level), and perception (burden) variables predict the type of decision motive (reward seeking, altruistic, distress reduction, punishment avoidance) used by surrogates' when making healthcare decisions for their family member with AD?; 3. What healthcare decision choices do surrogate decision-makers make for a family member with AD?

A convenience sample of 58 women (67.2%) and men surrogates between the ages of 43 to 84 years of age (*M* = 62.22, *SD* = 9.67) living in one urban and several rural cities in a southeastern state were recruited. Participants were recruited during facility meetings for families at 15 long-term care facilities and 1 dementia care assisted living facility. The majority of participants were Caucasian (84.5%). Questionnaires were distributed to participants at a facility meeting. After the study was explained, written informed consent was obtained. Each participant was asked to complete the questionnaire booklet and return via mail in a stamped self-addressed envelope to the researcher.

Data were analyzed with descriptive and inferential statistics including frequencies, percentages, means, standard deviations, t-tests, and multiple linear regressions. Types of decision motives did not differ by gender. For the regression models, the independent variables included gender, feelings of attachment, interpersonal conflict with the elder, beliefs about caregiving, dementia level and caregiver burden. For the model predicting punishment avoidance decision motive, simultaneous multiple linear regression results indicated that the overall model significantly predicted the dependent variable. The regression model predicting reward seeking decision motive results indicated that the overall model significantly predicted the dependent variable. Two of the variables, dementia level and surrogate burden, significantly contributed to the variance in the reward seeking decision motive.

When asked about the decisions they have been asked to make in the past 12 months, surrogates were asked to make life supportive interventions (pain management and nutritional supplements) more frequently than life extending interventions. The most frequent life extending interventions chosen in descending order of frequency include surgery, central line placement, and feeding tube placement.

This study supports the importance of providing surrogate and family information on AD and end-of-life healthcare interventions in a therapeutic and supportive environment. Nursing implications address pain management of the cognitively impaired patient, advocacy for advance directive completion and non-futile care, and patient and family AD education. Health care implications include process for completion of an advance directive and the burden of medical futility.

FACTORS INFLUENCING SURROGATE END-OF-LIFE HEALTHCARE DECISION-MAKING FOR A FAMILY MEMBER WITH ALZHEIMER'S DISEASE

By

SHARLENE D. TONEY

A DISSERTATION

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“Only as high as I reach can I grow. Only as far as I seek can I go. Only as deep as I look can I see. Only as much as I dream can I be.”

Dorothy Jean Novello, RN

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I have been privileged to work with and be mentored by an exceptional doctoral committee, Dr. Cecelia Grindel, Dr. Carolyn Kee, Dr. Frank Whittington, and Dr. Laura Kimble. Your collective wisdom has provided me the foundation to become a novice scientist with a vision that integrates dimensions of nursing and sociology.

First, I would like to thank Dr. Cecelia Grindel. You have been with me throughout my Master’s and Doctoral education programs. Your leadership, continuous support, and encouragement have provided me guidance through the years. I am most grateful for your words of wisdom during the first semester of the doctoral program when I asked myself “What am I doing here?” I commented to you that I didn’t understand a thing you just discussed. You patted my arm and told me “It was all right. Someday you will, and then you will know where to find it.” You gave me permission to accept my novice intellect and the courage to continue through faith alone that one day I would understand and succeed. You have listened to my frustrations, life issues, and dreams. You are the salt of the earth. You helped to ground me. It is an honor to have you as my Dissertation Chair, and to call you Professor, nurse, and friend.

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"… follow the yellow brick road."

The Wizard of Oz

I have been fortunate to have worked with wonderful nurses who have supported me throughout my educational endeavors. Their collective impact on my professional life helped ground me and allowed me to grow and become. These special friends, who are role models for professional practice and patient and nurse advocacy, include Celia Hay and Deborah Burton. Working with each of you as peers, collaborators, leaders, educators, and students has been an honor. Through you and with you I found the yellow brick road.

"We are not human beings having a spiritual experience.
We are spiritual beings having a human experience."

Ken Blanchard

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"A Family United"

Kenny Donaldson

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Your commitment to research, education, and family support is essential to families who are also victims of Alzheimer's disease.

Most importantly, I would like to thank the men and women who participated in my study. They were willing to share a very sensitive piece of themselves with me and allowing their family member with Alzheimer's disease to participate as well. I deeply appreciate their contribution of time and self to help me and other healthcare providers understand how difficult healthcare end-of-life decisions are made for a family with Alzheimer's disease.

"I am hungry for the life that is being taken away from me. I am a human being. I have a family. I hunger for friendship, happiness, and the touch of a loved hand. What I ask for is that what is left of my life shall have some meaning. Give me something to die for. Help me to be strong and free until my self no longer exists...No theory of medicine can explain what is happening to me. Every few months I sense that another piece of me is missing. My life…my self…are falling apart. I only think half thoughts now. Some day I may wake up and not think at all…not know who I am. Most people expect to die someday, but who ever expected to lose their self first."

Song of Myself by James Thomas
Diagnosed with Alzheimer's disease at the age of 62

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ABBREVIATIONS

AD	Alzheimer’s disease
BACS	Beliefs About Caregiving Scale
BCRS	Brief Cognitive Rating Scale
CDC	Center for Disease Control
CNO	Chief Nursing Officer
CPR	Cardiopulmonary resuscitation
EIS	Elder Image Scale
EOL	End-of-Life
GDS	Global Deterioration Scale
LTC	Long-Term Care
PVS	Persistent Vegetative State
QOL	Quality-of-Life
SPSS	Statistical Package for the Social Sciences
TPN	Total Parenteral Nutrition

CHAPTER I

INTRODUCTION

Decision-making by a surrogate is a vital form of indirect caregiving during end-of-life (EOL) situations for patients with Alzheimer's disease (AD). AD is the most common form of dementia among people over 50 years of age (Killen, 2000; Maddox, Atchley, Evans, Hudson, Kane, Masora, Mezey, Poon, & Siegler., 2001; Miller, 1999). It is estimated that 4.5 million Americans have AD, and an estimated 19-million family members consider themselves direct and indirect caregivers for persons with AD (Gwyther, 2006; Keady, Clarke, & Adams, 2003; Maddox et al., 2001). AD occurs in 2% to 4% of adults 65-years of age and older and the prevalence doubles with every 5 year increase in age (Morgan & Kunkel, 1998). Miller (1999) estimates 50% of adults 85 years and older have AD. Approximately 100,000 AD patients die annually and 360,000 new cases are diagnosed. By 2050, it is estimated that 14 million Americans will have AD (Alzheimer's Society, 2004; McCance & Huether, 1998), many of which will have a surrogate decision-maker selecting EOL interventions.

Statement of Problem

Since the passage of the 1990 Patient Self-Determination Act, the primary identifiers for EOL care in health care environments have been advance directives. These autonomy based documents support patients' rights to choose the type of care they desire when they are no longer able to make health care decisions for themselves; however, it is widely recognized that many older adults do not complete an advance directive, nor do they take time to reflect on the values in their life that drive health care decision-making. Additionally, older adults fail to discuss their thoughts and preferences with the people who will ultimately make decisions for them (Harris, 2003; Nahm & Resnick, 2001; Resnick & Andrews, 2002; Roberto, 1999). Without supporting documents or testimony of patient choices, EOL decision-making becomes ethically and legally controversial (Cramer, Tuokko, & Evans, 2001; Erlen, 2005; Harris, 2003; Lacey, 2006). Often, a surrogate family member becomes the primary decision-maker for major health decisions for the AD family member. Multiple contextual factors may influence surrogate decision-making, including the surrogate's relationship with the patient, the environment, situation, time, and cultural beliefs (Noone, 2002; Phillips, Brewer, & Torres de Ardon, 2001; Searight & Gafford, 2005). However, little research exists about what factors are most influential in the decision process including what motivates decision-making processes.

Purpose of Study

The purpose of this study was to examine factors that influence health care surrogate decision-making for a family member during the terminal stage of AD. The study examined concepts associated with surrogate decision-making for an AD family member including the surrogate's gender, familial relationship, structure, interactional context, situational context, and perception of burden to the decision motives. Surrogate decision choices for the AD family member were also examined.

Significance of the Study

This research expanded understanding of the factors influencing difficult decisions made by a surrogate for their AD family member. This knowledge can assist nurses to provide and promote therapeutic support to surrogate decision-makers when choosing care interventions and while supporting the legal and ethical foundation of patient autonomy.

The study provides healthcare practitioners with broader understanding of the dyadic structure, defined as the surrogate (indirect caregiver) and the care receiver (family member with AD), and the dimensions of their relationship including attachment, conflict, elder image, beliefs about caregiving, perceived burden, and decision motives. Sensitivity to these concepts supports holistic care provided to the family unit through nursing interventions that increase the family's understanding of the AD disease process and reduce their stress when making decisions. Nursing interactions to support family members can provide a foundation for family members to transition into an Alzheimer's support group or other caregiving assistance programs. Nurses can also utilize knowledge gained from this study to help develop clinical pathways to guide and integrate patient and family care during stages of disease progression that support best practice standards and ethical principles of nursing practice.

Research Questions

The research questions guiding this study were:

1. What is the relationship between surrogate gender and decision motives?

2. Do structure, interactional context, situational context, and perception variables predict the type of decision motive used by surrogates' when making healthcare decisions for their AD family member?
3. What healthcare decision choices do surrogate decision-makers' make for their AD family member?

Theoretical Framework

Family Caregiving Dynamics theory and Motivation-to-Help theory were integrated to define the framework for this quantitative study. The Family Caregiving Dynamics theory developed by Phillips and Rempusheski (1986) is based on inductive research identifying concepts relevant to poor quality family caregiving provided to older adults within the home environment (Figure 1, page 7). Caregiving relationships evolve through time, vested emotions, and life events. Application within this study defines decision-making as an indirect form of caregiving within the long-term care (LTC) environment. Smith's (1990) Motivation-to-Help theory addresses helping behaviors as based on an individual's reaction to the person needing help (Figure 2, page 8). Personal identity of the older adult is central to both theories, serving as a uniting concept for this study. Concepts within the theories serve as antecedents in the conceptual definition of decision-making.

Phillips, Brewer, and Torres de Ardon (2001) define personal identity as the historical relationship between the older adult and the caregiver and serves as the foundation for the caregiver's ongoing interactions with the older adult, including decision-making for them, and determining realistic expectations of the older adult. Personal identity of the older adult is associated with four dimensions, including structure, situational context, interactional context, and caregiver perceptions. These conceptually create the mental image the caregiver has of the older adult as derived from past associations, present observations, and reconciliation of the past with present impressions.

Structure is the first theoretical concept and represents the background against which the interactions between the older adult and the caregiver are staged. Structure addresses historical factors that predate caregiving or that dyad members bring to the caregiving situation (Phillips et al., 2001). Demographic variables associated with structure include dyad members' age, gender, familial relationship, and living situations. Structure also includes the caregiver's feelings of attachment and previous interpersonal conflict with the older adult.

Context is the second theoretical concept related to personal identity and addresses variables with direct relevance to the current caregiving situation. Context includes interactional and situational variables. Interactional context addresses role expectations and images unique to the surrogate that provides the frame of reference for the caregiving situation, the surrogate's role and the surrogate's expected role of the care receiver. Variables associated with the interactional context include the caregiver's perceived identity of the older adult and the caregiver's beliefs about caregiving, representing role expectations for themselves.

Situational context addresses the type of care and the level of difficulty to provide care to the care receiver. This addresses the functional and cognitive status of the older adult. Caregiving encompasses direct and indirect forms of providing care as well as simplicity and complexity of the caregiving process. For this study, the dementia level defines the adversity of caregiving.

Perception is the third theoretical concept and addresses the subjective and objective meaning of the caregiving situation as defined by the dyad members. Subjective caregiver burden is the variable associated with this study due to the older adult's degree of cognitive impairment.

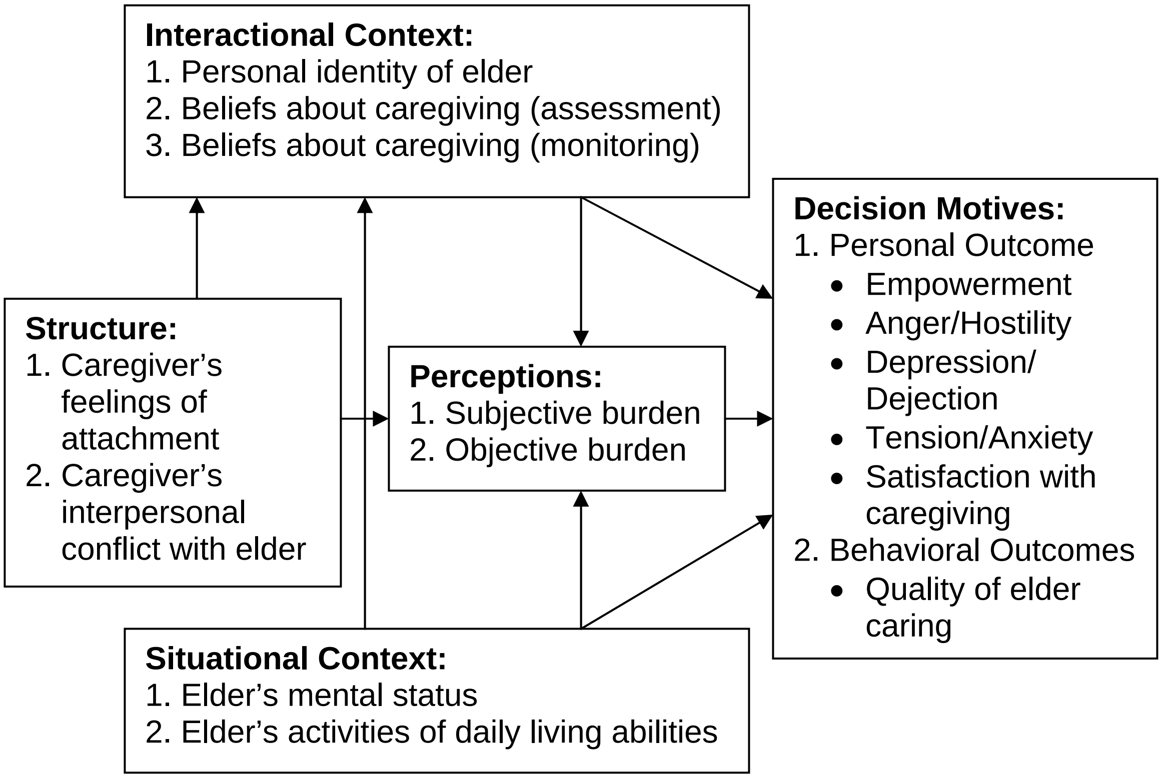

Figure 1. Family Caregiving Dynamics Model

The Motivation-to-Help theory is a nursing theory developed by Carol Smith (1990). This theory is derived from Batson's helping pathways research that described underlying reasons why one person helps another person.

Empirical studies support that an individual's reaction to the person needing help predicts the type of help given (Batson, 1983, 1991; Batson & Coke, 1981; Batson, O'Quinn, Fultz, Vanderplas, & Isen, 1987). Empirical studies "recorded and categorized the helping behavior into one of Batson's pathways and then inferred the underlying motivation" (Smith, Kleinbeck, Boyle, Kochinda, & Parker, 2001, p. 241). Smith's inductive and deductive research found that family caregiver's reasons for helping aligned with Batson et al. (1987) theoretical definitions and distinguishing characteristics. Smith's theory extends Batson's work by conceptually addressing motive stability across different helping situations.

Smith's theory identifies four pathways of helping motives and conceptual definitions. These definitions reflect the decision motives for this study and include reward seeking, altruism, distress reduction, and punishment avoidance decision motives. Reward-seeking motive is to help in a way that benefits the decision-maker through tangible or intangible means. Punishment avoidance motive is to help in a way that others view as socially acceptable while decreasing or eliminating the guilt associated with the decision made. Altruistic motive places the needs of the person needing help above the needs of others. Distress reduction motive is to help in a way that reduces the decision-maker's anxiety and emotional distress while wanting the patient condition to improve or maintain.

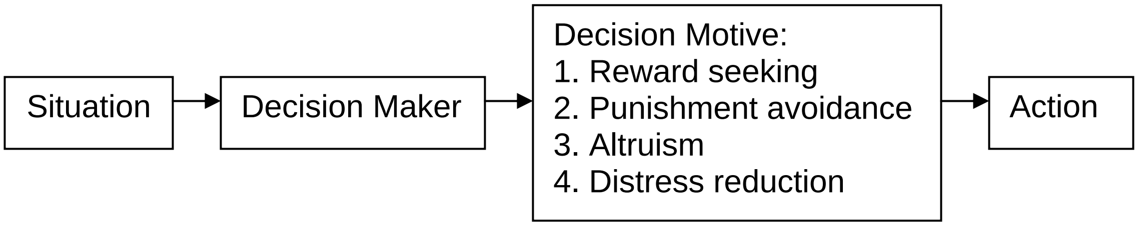

Figure 2. Family Caregiver Motives for Helping Model

In the integrated theoretical model (Figure 3, next page), the personal image of the AD family member is part of the interactional context and structure is an antecedent. Perception is the consequence of the surrogate’s personal image of the AD family member such as subjective burden. The decision motive is the consequence of the interactional context, the situational context, and the caregiver’s perceptions. The decision outcome is subsequently the direct result of the decision motive.

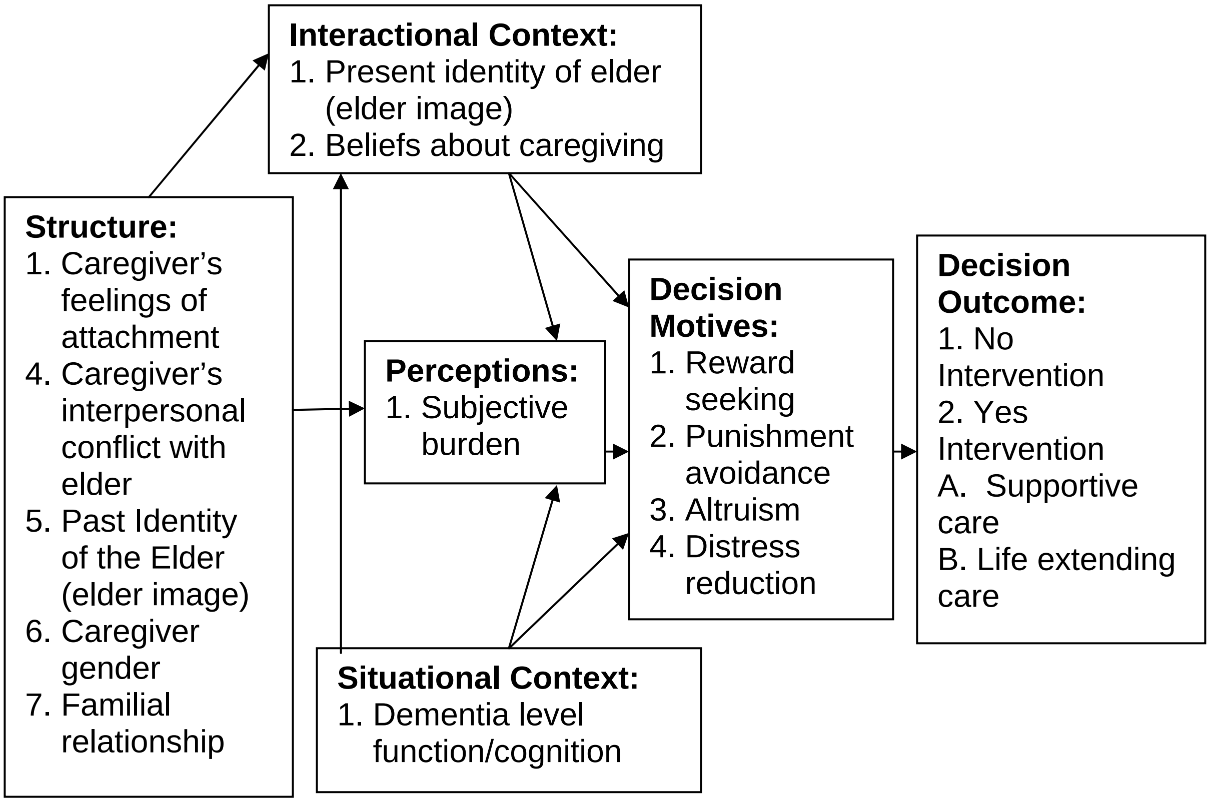

Figure 3. Integrated Conceptual Model of the Family Caregiving Dynamics Model and Family Caregiver Motives for Helping Model

Theoretical Assumptions

Assumptions for this study are derived from the Family Caregiving Dynamics theory that history and interpersonal factors shape the situation and affect the outcome of elder caregiving (Phillips et al., 2001). The authors posit one aspect of the caregiving phenomena:

1. Reconciliation of the past and present image of the care receiver by the caregiver may or may not occur.

An additional assumption derived from the Motivation-to-Help theory (Smith, 1990) is as follows:

2. Underpinning motives for helping are considered measurable and stable from situation to situation.

Researcher Assumptions

For the purpose of this study, the researcher acknowledged the following assumptions:

1. An individual who lives the decision-making experience is the most qualified person to describe his/her lived experience.
2. A surrogate will openly share their decision-making experiences for an AD family member.
3. Family decision-makers have important information to share with healthcare professionals which will enlighten approaches to improve holistic care.
4. Family is an extension of the patient, to be cared for and about.
5. Surrogate decision-making is a caregiver role.
6. Caregiving is expressed in indirect and direct caregiving work.
7. A surrogate decision-maker has a significant emotional relationship with the AD family member.
8. The relationship of the surrogate decision-maker and AD family member evolves over time.
9. End-of-life decision-making emotions vacillate along a spectrum of bipolar emotional descriptors ranging from denial to acceptance.
10. Life and death are a continuum deserving respect.

11. Grief work can begin prior to the death of a family member.
12. Dying can be quiet or not quiet.

Rationale for Using Theory

The family caregiving dynamics theory (Phillips & Rempusheski, 1986) define concepts integrated into family decision-making regarding the type and quality of patient care provided by family members. The motivation-to-help theory (Smith, 1990) supports and extends Phillips' and Rempusheski's defined concepts of past image, present image, and reconciliation of the past with the present image of the older adult by defining personal decision motives for making the decision to provide the type of care given. Linkage of the two theories is derived from the individual's personal identity of self and the older adult care receiver over time that subsequently serves as the catalyst for deciding the type of intervention decision made by the surrogate decision-maker.

The author chose the combined theories because of their utility. The theories reflect the complexity of decision-making yet are easily understood. The theories effectively integrate dimensions of the surrogate and the AD family member that collectively influence healthcare decision-making, thus providing an appropriate theoretical framework for this study.

Limitations of Theory

The Family Caregiving Dynamics theory and the Motivation-to-Help theory have not been integrated in a known previous study; therefore, this study extends both theoretical perspectives. This can be assessed as a strength or limitation, depending upon one's view of congruency of the integrated model.

Both theories originated using inductive research within the home care environment. The Motivation-to-Help theory evolved from a sample population of family caregivers who were providing care to an adult dependent on home total parenteral nutrition (TPN) infusion due to non-malignant bowel disease (Smith, 1993). Cognitive impairment of the older adult was not addressed in the study; however, mental competency of the caregiver was validated. Other research samples included caregivers for a family member requiring mechanical ventilation, and parents caring for children with cancer (Smith, Mayer, Parkhurst, Perkins & Pingleton, 1991; Smith, Garvis, & Martinson, 1983). This study used a deductive approach to apply the Motivation-to-Help theory within a sample population and a specific environment, long-term care, where it had not been tested before. This research focused only on a small part of the human experience of surrogate healthcare decision-making for a family member with AD and, therefore, provides a limited focus of the phenomena under study.

Conceptual Definitions

Conceptual definitions for this study include structure, situational context, interactional context, perception of burden, decision-motives, and decision outcome. These are conceptually defined as follows:

1. Structure is the background against which the interactions between the elder and caregiver are staged. Structure includes historical factors that predate the caregiving role and factors that each member of the dyad bring to the caregiving situation. Structure includes demographic elements of the AD family member and

caregiver, the caregiver’s feelings of attachment and previous interpersonal conflict with the AD family member (Phillips et al., 2001). For this study, structure was operationalized by the Surrogate Demographic Information Form, the Attachment Scale, and the Conflict with Elder Scale.

2. Situational context addresses issues related to the functional and cognitive status associated with terminal stage dementia. During this stage the AD person will lose all verbal abilities; however, early in this stage words and phrases are spoken but speech is very circumscribed. Later there is no serviceable speech at all, only unintelligible utterances with rare emergence of seemingly forgotten words or phrases. The person requires assistance with both toileting and feeding. Basic motor skills, such as the ability to walk, are lost with the progression of this stage. The brain appears to no longer be able to tell the body what to do. Generalized rigidity and developmental neurologic reflexes may be present (Reisberg, Ferris, de Leon, & Crook, 1982). For this study situational context was operationalized by the Global Deterioration Scale and the Brief Cognitive Rating Scale.
3. Interactional context is the role expectations and personal images that provide the mechanisms for caregivers to define the situation, making a caregiving role for self and defining role expectations of the AD family member. Concepts address personal identity of the AD family member and beliefs about caregiving which reflect the caregiver’s role

expectations (Phillips et al., 2001). For this study, interactional context was operationalized by the Elder Image Scale and the Beliefs About Helping Scale.

4. Perception is the expressions of meaning the surrogate decision-maker attaches to the caregiving situation. Perception is reflected in subjective caregiving burden (Phillips et al., 2001). For this study perception was operationalized by the Burden Interview Scale.
5. Decision motive: (Smith et al., 2001)
    a. Atruistic motive to help is to help in a way that is consistent with the needs of the patient.
    b. Reward-seeking motive to help is to help in a way that gains benefits such as praise, recognition, and/or financial reward.
    c. Punishment-avoidance motive to help is to help in a way that prevents guilt or social disapproval.
    d. Distress-reduction motive is to help in a way that lessens one's own anxiety or distress by seeing the patient improve or maintain status.

For this study decision motive was operationalized by the Motives for Helping Scale.

6. Decision outcome: The decision outcome is the result of integration of the structure variables, interactional context, situational context, perception, and decision motives. For this study the decision outcome is measured by the Surrogate Decision-Making Questionnaire.

Decision outcomes for this study are defined as follows:

a. No medical intervention is defined as a decision to not use supportive or life extending interventions.
b. Supportive interventions are defined as comfort measures that involve minimal invasive processes administered throughout disease progression till death. This includes pain management using oral, sublingual, dermal, intramuscular, or non-central line peripheral intravenous administration of an analgesic or drug with the intent to reduce pain and/or nutritional supplements administered orally including vitamins, minerals, appetite enhancer, Ensure, Boost or other disease-specific nutritional drinks.
c. Life extending interventions are defined as measures used to prolong the living/dying process during any stage of the disease progression that involves an invasive procedure and/or treatment that may result in patient trauma.
    i. Invasive procedures are defined as placement of a percutaneous feeding tube (PEG) to provide nutritional support and/or placement of a central line for medication administration using a peripherally inserted central catheter (PICC), implanted port or a tunneled catheter.
    ii. Treatments that may result in patient trauma are surgery, chemotherapy, and radiation therapy. Side effects of

chemotherapy are defined as nausea, vomiting, weakness, appetite suppression, and/or mucositis. Side-effects of radiation therapy are defined as skin damage, fatigue, mucositis, pulmonary fibrotic tissue, and/or gastrointestional system complications such as esophageal swelling and tissue inflammation.

Summary

The purpose of this study was to examine factors that influence health care surrogate decision-making for an AD family member, to examine gender differences in decision motives, and to explore decision outcomes for healthcare intervention decisions. This study was based on the theoretical framework of the Family Caregiving Dynamics theory (Phillips & Rempusheski, 1986) and the Motivation-to-Help theory (Smith, 1990).

CHAPTER II

REVIEW OF LITERATURE

This chapter provides a review of the empirical literature on the following concepts: structure, interactional context, situational context, perception of burden, decision-making, and decision outcomes. The literature focuses on what is known about each of these concepts in relation to the caregiver and decision-maker role and concludes with a summary of the findings.

Structure

Structure addresses the background elements of the dyadic relationship. This includes who the caregiver and the care-receiver are as well as the attachment between this dyad. The caregiver and care-receiver bring elements such as gender and familial relationship into the dyadic structure.

Dyadic structure. Seventy percent of all caregivers are women (Stone, Cafferata, & Sangl, 1987; Wolff & Kasper, 2006), and 73% of caregivers for a person with dementia are women (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). Research found that women caregivers were more likely to live with the older adult, whether they were a spouse or daughter (Covinsky et al., 2003; Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002; Jansson, Nordberg & Grafstrom, 2003; Rodriguez et al., 2003; Son, Wykle, & Zauszaniewski, 2003; Wolff, & Kasper, 2006). Women caregivers were found to be in poorer physical and psychological health than women noncaregivers (Zhang, Vitaliano, & Lin, 2006). Women caregivers tended not to be employed, had no in-household help, and self-reported their health status to be good (Gallicchio et al., 2002). In some studies, the caregivers' perception of being in good health was an indicator of caregiving satisfaction (Edwards, Zarit, Stephens, & Townsend, 2002; Son et al., 2003). Research identified working informal caregivers perceived their dual roles as having both positive and negative attributes (Edwards et al., 2002; Limpanichkul & Magilvy, 2004; Son et al., 2003).

Spouses providing care for their partner are confronted with unique emotional challenges that differ from adult-child caregivers, such as the loss of marital emotional support, loss of reciprocity during decision-making, loss of marital intimacy, decreased shared activities, and changes in the quality of shared communication (Baikie, 2002; Montogmergy & Williams, 2001). Caregiver spouses care for and care about their partners (Jansson, Nordberg, & Grafstrom, 2001). This role becomes more physically and emotionally challenging as the level of dementia progresses. The wife of a spouse with AD may perceive her identify as neither a wife or a widow (Almberg, Grafstrom, & Winbland, 2000, p. 86).

Attachment. Attachment is a behavior showing "affectionate regard" (Merriam-Webster's Collegiate Dictionary, 1999, p. 74). John Bowlby, an ethologist, pioneered attachment research by observing toddlers' behaviors associated with their mother's presence and absence. Although Bowlby's empirical research focused on infants and children, he believed that attachment could be observed throughout the life cycle (Hamilton, 2000; Kerns, Tomich, Aspelmeier, & Contreras, 2000; Pielage, Luteijn, & Arrindell, 2005). Bowlby empirically defined attachment as follows:

> Attachment behavior is any form of behavior that results in a person attaining or maintaining proximity to some other clearly identified individual who is conceived as better able to cope with the world. It is most obvious when the person is frightened, fatigued, or sick, and is assuaged by comforting and care-giving. At other times the behavior is less in evidence (1982, p. 668).

Based on Bowlby's definition of attachment, interactions with significant others who are available and supportive during stressful situations facilitate formation of a "cognitive-affective schema labeled the sense of secure base or attachment security" (Mikulincer et al., 2003, p. 299). These primary attachment relationships become internalized perceptions during childhood and become the foundation for future interactions with others throughout life (Sroufe, 1988).

Numerous research studies have used Bowlby's definition of attachment as a framework for explaining variations in mental health, emotion regulation, and interpersonal relations; however, few studies address the older adult population (Campbell, Simpson, Boldry, & Kashy, 2005; Radmilovic, 2005; Soares, Lemos, & Almeida, 2005; Turner, 2005). And the findings are sometimes counter-intuitive, such as one study of attachment involving older community-dwelling adults that found attachment security was associated with less guilt, contempt, and shame, but also greater joy. Avoiding attachment, meaning having a negative view of others and a tendency to avoid closeness and dependency, was associated with less joy, increased shame, and greater fear. Fearful attachment, meaning having a negative view of self and a tendency to worry about abandonment, was associated with a higher degree of joy, disgust, shame, and anxiety (Cassidy, 2001; Consedine & Magai, 2003; Lake, 2005; Mikulincer et al., 2003). Attachment studies of adults in a palliative care environment and another with adult daughters' bereavement process associated with their mother's death, indicated the strength of the emotional bond and the behavioral aspects of caregiving were indicators of secure, negative, or ambivalent attachment (Lake, 2005; Pratt, Walker, & Wood, 1992; Tan, Zimmerman, & Rodin, 2005).

Interactional Context

The interactional context addresses the personal image the caregiver has developed through time of the care-receiver and role expectations the caregiver has developed for self based on time, values, and culture. The combination of these elements defines the mechanisms for caregiving and establishing role expectations of the dyadic partners.

Elder image. Elder image evolves from interaction through time with the older adult. This is consistent with symbolic interactionism which contends the nature and quality of interpersonal relationships are defined by the relationship's history (McCall & Simmons, 1978). The relationship has a symbolic meaning defined by the individual based on the situation and personal expectations.

Through interactions over time, the caregiver and the care receiver develop an evolving mental picture of the other including relationship events, impressions and interpretations of the events, role expectations, and evaluations, that uniquely identifies one person with the other (Goffman, 1963). This image serves as the foundation for ongoing interaction between the dyad members.

Research conducted within the home-care environment exploring the dynamics of poor family caregiving identified conceptual views of the older adult as normalized or anormalized (Phillips & Rempusheski, 1986). Normalized views of the care-receiver were associated with the caregiver's positive perception of the dyadic relationship whereas an anormalized view was associated with a negative perception. The older adult care-receiver's image of the caregiver is affected by the older adult's affection for the caregiver, their perception of the caregiver's affection toward them, and the perceived quality of communication between the dyad members (Parsons, Cox, & Kimboko, 1989). A study of abused female caregivers by care-receivers found the difference between past and present image of the older adult is influenced by abusive events (Phillips, Torres de Ardon, & Briones, 2000). Wide differences in reconciliation of past and the present image of the care-receiver also indicated poor quality caregiving including abuse and neglect by the caregiver (Phillips et al., 1996). A study with mothers choosing a family member to be their probable caregiver found their decision choice was based on the degree of emotional closeness, similarity of gender, and attitudes over time (Pillemer & Suitor, 2006).

Beliefs about caregiving. Filial maturity is a significant concept denoting beliefs of caring for and caring about aging parents. It is not a dysfunctional role reversal but rather a relationship that retains viewing the older adult parent as an individual with their own needs, rights, and personal histories (Schaie & Willis, 2002). Studies have shown that strength of the relationship and felt obligation of the adult child are influenced by the degree of affection the child feels toward the parent, the absence of role conflict, and culture (Kim & Lee, 2003; Morgan & Kunkel, 1998; Piercy, 1998; Son et al., 2003). Caregiving behaviors illustrate retention of closeness to their primary attachment figures while accommodating life's situational and conditional changes through time (Sable, 2004). Some family caregivers experience a sense of fulfillment, increased closeness with the care-receiver, and pleasure through providing care (Harper & Lund, 1990; Kinney, Stephens, Franks, & Norris, 1995).

Caregiving beliefs are grounded in religious values, love and attachment between the dyad unit, and the sense of unavoidable duty to provide care (Limpanichkul & Magilvy, 2004). Religious traditions embedded within cultures and integrated within family dynamics uphold the values of service and self-sacrifice (Dilworth-Anderson, Williams, & Cooper, 1999; Doka, 2004; Hirschfield & Wikler, 2004; Son et al., 2003). Spirituality addresses the inner essence of who an individual is, including their perceived role as a caregiver (MacLean, Walker, & Matsuba, 2004; Miller, 1994).

Situational Context

The situational context addresses the intensity and adversity of the caregiving experience. AD leads to complete dependency for total care and 24 hour observation providing death does not occur sooner from another cause.

Functional and cognitive status. The chronicity of AD results in progressive impairment of cognitive function resulting in deterioration of intellect, memory, and personality. With progressive cognitive impairment, the person becomes unable to understand spoken or written language, unable to make purposeful movements, and unable to recognize objects by use of the senses (Chan & Brennan, 1999; Coen, O'Boyle, Swanwick, & Coakley, 1999; Heru & Ryan, 2006; Ignatavicus, 1999; Miller, 2003; Rapp, Schnaider-Beeri, Sano, Silverman, & Haroutunian, 2005; Scahie & Willis, 2002). Reisberg (1986) developed a seven-stage process for assessing the functional and cognitive status of the person with AD. The stages define objective measures within the parameters of normal to severe dementia. Typically in the early stage of AD, usually only those with close contact notice comments or decisions that indicate impaired judgment or short-term memory loss (Miller, 2003). Severe dementia parameters address the progressive loss of verbal and psychomotor abilities, as evidenced by the inability of the AD patient to hold his/her head up independently, verbal ability limited to six or less words, and inability to sit or walk without assistance (Reisberg, 1986). The person with advanced AD may express emotions nonverbally and behaviorally (Miller, 2003).

The physical and emotional demands for continuous care as the disease progresses can become too demanding for family home caregivers, thus requiring admission to a long-term care facility. A patient with severe dementia requires total care for all activities of daily living. Safety is a continuous concern for formal and informal caregivers (Miller, 2003). With disease progression, psychomotor skills decline resulting in immobility, incontinence, and nutritional compromise. Complications such as pneumonia, skin breakdown, urinary tract infections, and vascular complications can occur (Kukull et al., 1994; Sachs, Shega, & Cox-Hayley, 2004). With progressive decline in cognitive and functional status, the surrogate becomes more involved in addressing interventions and EOL care (Albinsson & Strang, 2002; Sugarman, Cain, Wallace, & Welsh-Bohmer, 2001).

Perception of Burden

Caregiver burden and quality of life (QOL) in the dyadic relationship are significant phenomena in the caregiver and care-receiver roles. Burden is the overwhelming sense of responsibility to care for another person that results in role strain, less satisfaction with life, depression, and personal health decline (Morgan & Kunkel, 1998). Role strain refers to role overload and psychological role conflict (Edwards et al., 2002). Caregiver burden is a dimension of the caregiver’s QOL (Benner, 1985).

The type and intensity of the care-receivers’ impairment and dimensions of the relationship between the caregiver and the care-receiver affect the degree of burden experienced (Baikie, 2002; Bertrand, Fredman, & Saczynski, 2006; Josephsson, Backman, Nygard, & Borell, 2000; Miura, Arai, & Yamasaki, 2005; Kim & Lee, 2003; Morgan & Kunkel, 1998; Piercy, 1998). AD presents physical, emotional, and financial burden on family caregivers (Bertrand et al., 2006; Edwards et al., 2002; Rodriquez et al., 2003; Son et al., 2003). Schaie and Willis (2002) reported poorer mental health in spousal caregivers of AD patients than with those caring for spouses with Parkinson’s disease. Spousal caregivers comprise 66% of informal caregivers for people with dementia (Stone et al., 1987). Some research has shown that adult-child caregivers experience a greater degree of stress than spousal caregivers. Research indicates this variance is due to violation of generational norms and role conflicts within the adult’s life related to marriage and parenting responsibilities (Chappell, 1990; Kim & Lee, 1998; Piercy, 1998). Cognitive impairment with associated behavioral problems such as wandering, agitation, and safety compromising behavior, increase caregiver burden (Chappell, 1990; Hagedoorn, Sanderman, Buunk, & Wobbes, 2002; Kim & Lee, 2003). The emotional stress of anticipatory grief due to the dying process also contributes to caregiver burden (Duke, 1998; Lieberman & Fisher, 2001).

Caregiver QOL studies show a correlation of decreased QOL with increased demands of physical and emotional burden (Hoskins, Walton-Moss, Clark, Schroeder, & Theil, 1999; Kavanaugh & Tate, 1996; Kim & Lee, 2003; Schaie & Willis, 2002). QOL is an abstract and multidimensional concept that has been studied in relation to disease progression and within the aging process showing direct correlation with decline in functional and cognitive status (Baikie, 2002; Barberger-Gateau, Febrigoule, Helmer, Rouch, & Dartigues, 1999; Bondevik & Skogstad, 1998; Ferrans & Powers, 1992; Guyatt, Walter, & Norman, 1987; Heru & Ryan, 2006; Miura et al., 2005; Rush & Ouellet, 1998; Upchurch, 1999). Emotional distress noted within adult-child caregivers is evidenced by modifications within family relationships, increased agitation and unease within the family unit, quarrelling among family members about sharing caregiving responsibilities, and a sense of guilt for neglecting their own families (Rodriguez et al., 2003). Women caregivers reported a higher incidence of depressive symptoms, anxiety, and general psychiatric symptoms than did male caregivers

(Gallicchio et al., 2002; Yee & Schultz, 2000). Women also experienced greater role strain, role burden, and role conflicts due to work and social responsibilities (Yee & Schultz, 2000). Edwards et al. (2002) found no difference in depression symptoms among family caregivers whether employed or non-employed; however, working caregivers experiencing work conflict due to increased work hours reported greater role strain. Long-term care placement of the AD family member had a positive impact on the home caregiver over time which was attributed to the ability of the caregiver to begin focusing on personal physical and emotional health (Grasel, 2002).

Decision-Making

Decision-making involves a situation needing resolution, a decision-maker, a motive or motives, and process steps to reach a decision. Integration of these elements results in a decision choice.

Surrogacy. A surrogate is defined as “one appointed to act in place of another; one that serves as a substitute” (Merriam-Webster’s Collegiate Dictionary, 1999, p. 1187). A surrogate is defined as a legally identified person or an identified person within a family to make decisions that affect the health and welfare of a patient (Mick, Medvene, & Strunk, 2003). The term surrogate decision-maker is a legally recognized and defined within natural death acts and living will statutes (Hayes, 2003; Parmley, 2002; Salmond & David, 2005). Since the passage of the 1990 Patient Self-Determination Act, the primary identifiers for EOL care in health care environments have been advance directives. These autonomy based documents support the patient’s right to choose the type of care they desire when they are no longer able to make health care decisions; however, it is widely recognized that many older adults do not complete an advance directive, nor do they take time to reflect on the values in their life that drive health care decision-making. Additionally, they fail to discuss their thoughts and preferences with the people who will ultimately make decisions for them (Davis, Burns, Rezac, Dillard, Kieffner, et al., 2005; Harris, 2003; Nahm & Resnick, 2001; Resnick & Andrews, 2002; Roberto, 1999).

Preferences for EOL care are influenced by a person's morals and values. Ethical decisions address what individuals purposefully choose to do or not do. The choices involve both good and bad features. Ethical decision-making involves opinions and judgments about values that identify differences between perceptions of what is good and bad, right and wrong (Devettere, 1995). Ethics are about moral beliefs and norms. Norms help to determine what beliefs are morally good or morally bad (Devettere, 1995). One choice can bring about damage and suffering but can also bring about some good.

Substituted judgment is a legal term for the processes used by a surrogate decision-maker. Substituted judgment requires a surrogate to make care decisions for a patient based on what the patient's wishes would be if he or she were competent and informed of available treatment and care options (Edwards, 2002). The surrogate decision-maker must possess a comprehensive understanding of the patient's values and vision for life in order to make the right decision. Substituted judgment does not apply if the surrogate's decision is based on the surrogate's personal choice for an intervention (Edwards, 2002;

Montminy, 1990). The substituted judgment principle is grounded in respect of patient autonomy.

Decision-making process. Decision-making, an essential process of daily living, is defined as “the act or process of deciding; a determination arrived at after consideration: conclusion; a report of a conclusion” (Merriam-Webster’s Collegiate Dictionary, 1999, p. 299). This process has been studied qualitatively and quantitatively to conceptually identify the processes people use in non-stress- and stress-related decision-making (Hsee, Zhang, Yu, & Yiheng, 2003; Noone, 2002; Zhang & Siminoff, 2003). Janis and Mann (1977) developed a conflict model of decision-making that serves as the foundation during stressful situational decision-making. This model integrates concepts of risk appraisal, success assessment, and time availability for decision-making. Decisional theory, used in statistics and utility theory, uses a mathematical framework to depict decision-making processes (Matsuura, Kamae, Nakamura, & Maruo, 2001; Noone, 2002). A noted criticism of these two classical decision-making models is that they may not always work in real life situations (Noone). Naturalistic decision-making theory integrates the contextual environment into the process with personal and situational influences (Noone). A decisional stress model developed by Balneaves and Long (1999) states conflict occurs when intervention options are provided. Conflict results from the mixture of personal and situational variables.

Beckingham and Bauman (1990) present a multidisciplinary model for use with elderly families in crisis and decision-making. Crisis is a sudden unanticipated or unplanned event that requires immediate resolution (Beckingham & Bauman). Essential elements of this process include understanding the definition of family, identification of the crisis being faced, and the health care system where interactions and decision-making takes place.

Decision motives. Emotional decision-making occurs daily in health care environments. Emotions are significant factors associated with intervention decisions and patient outcomes. Confronting a health care decision related to illness or a disease is a personal and emotional experience for a patient, surrogate decision-maker, or family member. Emotions are usually perceived as irrational occurrences that obscure judgment and distort reasoning ability; however, studies now indicate that rational and emotional processes function together rather than as adversaries (Barnes & Thagard, 1997). Emotions are associated with attachment and decisions to provide care (Consedine & Magai, 2003; Tan et al., 2005). Barnes and Thagard contend that emotions and cognition are both necessary to empathize with other people. Empathy involves an altruistic motive, whereas self-centeredness is a distress-reduction motive (Bierhoff & Rohmann, 2004). Empathy and social responsibility are core variables associated with altruism (Bierhoff, 2002).

Research has identified that an individual’s reaction to the person needing help predict the type of help given (Batson, 1983; Batson, 1991; Batson & Coke, 1981; Batson et al., 1987; Ciadini, Schaller, Houlihan, Arps, Fultz, et al., 1987). Empirical work by Batson identified four helping motives: reward-seeking, punishment avoidance, altruism, and distress reduction (Batson & Coke, 1981).

Smith et al. (2001) extended Batson’s work by conceptually defining these motives. Reward-seeking motive is to help in a way that benefits the decision-maker through tangible or intangible means. Punishment avoidance motive is to help in a way that others view as socially acceptable while decreasing or eliminating the guilt associated with the decision made. Altruistic motive places the needs of the person needing help above the needs of others. Distress reduction motive is to help in a way that reduces the decision-maker’s anxiety and emotional distress while wanting the patient’s condition to improve or maintain.

Bierhoff and Rohmann (2004) hypothesized that “as long as personal distress is stronger than empathetic concern, the observer will choose that action alternative that promises the least cost and the highest reward” (p. 352). The person experiencing the distress will leave the difficult situation where another individual is suffering. Leaving is a coping mechanism that alleviates the decision-maker’s personal distress. Their distress level is reduced even if the person suffering continues to suffer. In contrast, altruism results in a higher degree of personal stress since concern is centered on intervening for the individual suffering. The decision-maker’s stress level is reduced only when the person’s suffering is alleviated (Bierhoff & Rohmann).

Decision Outcomes

Decision outcomes address clinical interventions selected by the surrogate decision-maker and the resulting patient outcome. Medical futility is inclusive of surrogate and physician perspectives that reflect similar and contrasting ideas and beliefs that influence clinical intervention choices and thus the resulting outcome.

End-of-life decisions. Clinical interventions are care procedures rendered to a patient. Clinical interventions defined within five EOL studies include the following: 100% named cardiopulmonary resuscitation (CPR), 80% named antibiotics, 80% named surgery, 80% named mechanical ventilation, 80% named artificial nutrition and hydration, 60% named pain management, 60% named dialysis, 40% named diagnostic tests, 40% named transfusions, and 20% named chemotherapy (Brookwala, Coppola, Fagerlin, Ditto, Danks, & Smucker, 2001; Coppola, Bookwala, Ditto, & Lockhart, 1999; Nahm & Resnick, 2001; Resnick & Andrews, 2002; Roberto, 1999). EOL decisions primarily involve clinical Interventions, but an advance directive provides guidance for selecting the intervention choice.

Perceived barriers preventing completion of an advance directive by older adults include procrastination, present orientation, reluctance to think about death, trusting others to decide, feeling healthy, and needing help (Nahm & Resnick, 2001; Resnick & Andrews, 2002). Four themes identified as influential in health care decision-making include QOL, independence, personal burden, and religious beliefs. Older adults completing an advanced directive cited reasons for doing so as wanting to be in control of these decisions, wanting others to know the type of care desired, wanting to decrease burden on loved ones, having no relatives, and having witnessed the suffering or death of a loved one (Hamel et al., 2002; Nahm & Resnick, 2001; Resnick & Andrews, 2002; Roberto, 1999).

Bookwala et al. (2001) identified that desire for a dignified death significantly influenced patients’ medical treatment decisions and the worry of being dependent on others. Women preferred fewer overall life-sustaining interventions than men. A decline in cognitive function influenced EOL decisions. AD influenced the type of interventions desired by older adults when placed within decision-making scenarios (Coppola, Bookwala, Ditto, & Lockhart,1999; Hamel et al., 2002). Results indicated older adults value mental acuity more than physical integrity as evidenced by fewer life-sustaining treatments desired if cognitively impaired (Coppola). Cameron (2002) found older adults and their families wanted to face death with dignity, peace, and joy. Older adults and their families also wanted health professionals to help them resolve broken relationships from the past to allow emotional recovery to occur (Cameron).

Research identified significant disparities in EOL care decisions made by surrogates and other family members. Disparities were also identified among paired family members and within established care dyads as to consensus about EOL treatment preferences. Causes of decision disparities were attributed to lack of discussion, unfamiliarity of health care decisions, and inadequate decision-making processes within families regarding EOL care (Hamel et al., 2002; Leichtentritt & Rettig, 2002; Roberto, 1999).

Medical futility. Life sustaining interventions have increased rapidly during the past 40 years. During this time, bioethics has become integrated into everyday practice with patient autonomy serving as the guiding principle for health care decision-making (Lelie & Verweij, 2003; Russ & Kaufman, 2005). Futility was conceptually introduced into the medical arena due to patients' and society's pressures to provide medical treatments physicians considered useless (Brody, 1997). Quality of life (QOL) is considered a significant factor when determining the appropriateness of medical care and when determining the treatment endeavor to be futile (Finucane & Harper, 1999; Rosner, 2005; Schneiderman, Jecker, & Jonsen, 1990).

A life-sustaining intervention is futile if logical reasoning and experience indicate that patient survival is highly unlikely (Way, Back, & Curtis, 2002, 2002). The Council on Ethical and Judicial Affairs of the American Medical Association's (1994) futility position statement contends the physician is not ethically obligated to provide care if in their professional judgment the patient will not benefit from the treatment. Patients' and surrogates' demands for futile treatments can conflict with physicians' ethical obligation of nonmaleficience (Burt, 2002). The dual dilemma of duty to preserve life and "to ensure an acceptable quality of life, and in circumstances of medical futility, to ensure a comfortable and dignified death" creates professional stress (Henig, Faul, & Raffin, 2001, p. 80). Medically futile care serves no useful purpose, provides no immediate or long-term patient benefits, or does not benefit the patient as a person (Lee, 2002).

Dunphy (2000) defined futility as a significant ethical principle that supports a physician's unilateral decision to withhold or withdraw patient treatment. Unilateral withholding or withdrawal implies that the physician serves as the decision-maker for both competent and incompetent patients without surrogate input. No research was identified specifically addressing medical futility in terminal stage AD. Futility studies addressed care provided to young, brain-injured disabled patients, patients in a persistent vegetative state (PVS), newborns with anencephaly, and older adults with cancer (Burt, 2000; Darr, 2000; Dunphy, 2000; Mueller, Hook, & Fleming, 2004).

Dunphy (2000) reported that patients and surrogates dislike paternalistic treatment and want their values and goals to be recognized as greater than the physician’s. They believed patients may superficially seem to be very similar but as individuals may have very different outcomes as well as have very different views of QOL. Lack of communication and discussion between the physician and patient creates an environment of secrecy and distrust. Patients and surrogates felt that they have a right to refuse treatment as well as demand treatment (Dunphy, 2000; Jacobs & Taylor, 2005: Lelie & Verweij, 2003).

For family members, outcomes of medically futile interventions can result in financial stress, financial ruin, and emotional burden. The emotional burden of grieving the loss of a family member who is maintained on life support creates a quandary of emotions ranging from situational depression and chronic depression to unhealthy grief processes due to unresolved grief (Bailey, 2003; Eggenberger & Nelms, 2004; Etzioni & Rosenfeld, 2004)

Summary of Literature Review

The literature revealed that within the dyadic structure, women are the primary care providers for family members with dementia. Caregivers age range spanned middle-age to older adulthood. The caregiving role becomes more difficult to physically and emotionally manage with disease progression. There is minimal research addressing older adult attachment. Attachment can be positive or negative and influences relationships throughout the life span.

Within the interactional context, the caregiver's image of the older adult influences the type of care provided. A negative image of the older adult can result in poor quality care. Family values, religious beliefs, culture, situation, and environment influence caregiving beliefs. Within the situational context, disease progression is associated with a higher level of physical care and behavioral adversity experienced by the caregiver. A caregiver's subjective perception of burden is dependent upon the type and intensity of the care-receiver's limitations and their perceived relationship with the care-receiver.

Decision-making is influenced by personal, legal, moral, and ethical principles. Decision-motives are grounded in an individual's reaction to the person needing help. Decision outcomes involve both positive and negative results, depending upon the health care professionals' or the surrogates' definition of QOL, quality of death, and medical futility.

No studies examined the combined relationships between surrogacy, dyadic structure, attachment, caregiver's image of the care-receiver, caregiving beliefs, functional and cognitive status of the AD family member, and subjective perception of burden in relation to decision motives and decision outcomes. No studies were found that explained attachment of family members and cognitively impaired older adults; however, research addressing young adult dating and attachment, marital attachment, divorce, and family violence were identified (Adshead, 2002; Campbell et al., 2005; Cohen & Finzi-Dottan, 2005; Mikulincer, Gillath, Sapir-Lavid, Yaakobi, Arias, et al., 2003; Renn, 2002). A gap in knowledge exists related to the use of life-saving interventions and the stages of AD. Extensive research has been conducted about caregiver burden; however, research associated with surrogates' interpersonal conflict within the AD population was not found. Empirical testing of the concept of elder image is very limited, and no research was identified that integrated this concept with EOL decision-making. No research was identified addressing surrogate decision-motives and intervention modalities selected to provide EOL care, thus supporting the need for the proposed research study.

Conclusion

AD research has provided an extensive base to facilitate improvements in medical management of the disease process; however, limitations in holistic care continue to exist. The person with AD and the family unit are both victims of this progressive disease; therefore, research is needed to support provision of care sensitive to the dyadic units' physical, emotional, and spiritual dimensions. Filial attachment plays a significant role in the care of the AD family member and in the well-being of the caregiver. Research addressing interpersonal conflict associated with surrogate decision-making is needed. This knowledge could help facilitate more effective interaction among family members and professional providers. Research is also needed to explore and define surrogates' beliefs about caregiving associated with EOL for cognitively impaired older adults.

CHAPTER III

METHODOLOGY

This chapter describes the methodology used to conduct the study. The following sections are included: study design, sample, setting, methods used to protect human subjects, instruments to measure the study variables, data collection procedures, and data analysis plan.

Study Design

A descriptive predictive design was used to examine relationships among concepts associated with surrogate decision-making for a relative with AD, including age, gender, familial relationship, background structure, interactional context, situational context, perception of burden (independent variables), and decision motive (dependent variable). The study also examined surrogates' decision choice for their AD family member.

Sample and Setting

Sample. Thirty-five long-term care (LTC) facilities located within a southeastern state were identified as potential recruitment sites. The researcher visited 29 LTC facilities to discuss the study and identify internal approval processes to access participants at the site. Six LTC facilities refused to permit the researcher access during the initial telephone contact with the administrator or chief nursing officer (CNO). Fifteen LTC facilities (43%) agreed to permit access including one dementia care assisted living facility.

The researcher provided a letter of introduction including an invitation to participate in the study (Appendix L) and an educational flyer (Appendix M) to the administrator or CNO at each facility. The LTC facility distributed these documents via mail to families who had a relative residing within the facilities diagnosed with AD. A surrogate decision-maker was limited to a relative of the family member with AD through blood or marriage. Inclusion criteria required the surrogate decision-maker (a) to have known the relative with AD for a minimum of 5 years prior to the diagnosis of AD, (b) be able to read and write in English, and (c) reside within a 55-mile geographic area of the AD resident's facility. In addition, the AD patient had to reside in a LTC environment and have an accessible medical record.

An initial invitation to participate was extended to 82 individuals who met the inclusion criteria and agreed to participate in the study during the original meeting at the LTC facilities. Informed consent was obtained (*N* = 82). Seventy-one percent (*N* = 58) of those who completed the informed consent process completed and returned questionnaires to continue in the study. The convenience sample represented 58 men (32.8%) and women (67.2%) with a family member residing in a LTC facility located in one urban and seven rural cities.

Disclosure. The researcher for this study had previously worked in a health system that owns two of the LTC facilities. The researcher continues to serve as a community representative on the health system's Ethics Committee but has no direct responsibilities within the two participating LTC facilities. The researcher did not interact with the staff of these LTC facilities during recruitment. Recruitment was conducted in an auditorium environment with no LTC employee present.

Instruments

A surrogate demographic data form (Appendix N) and seven scales comprised the instruments completed by the surrogate decision-maker for this study. Demographic data included age, gender, familial relationship to the AD patient, ethnic background, education level, work status, and miles lived in proximity to the LTC facility where the family member with AD resides.

An AD resident's demographic and history form (Appendix V) was collected by the researcher through medical record review. Data elements collected included age, gender, primary and secondary diagnoses, length of time residing in the LTC, and presence of an advance directive. Length of stay was defined based on the original date of admission to the LTC facility. Data for the healthcare intervention history included life-supporting interventions, life-extending interventions, and no intervention choice. The researcher assessed the resident using the Global Deterioration Scale (GDS) (Appendix W) or the Brief Cognitive Rating Scale (BCRS) (Appendix X) to determine the dementia severity level of the AD family member.

Surrogate Decision-Maker Questionnaire. Decision outcome was operationalized by a researcher-developed 7-item questionnaire addressing knowledge of prior end-of-life planning by the AD patient and healthcare intervention options and choices made by the surrogate (Appendix O). Options were defined within the context of being asked to make an intervention decision by selecting either “yes,” “no,” or “I do not know.” Choices were defined within time periods of “the past 12 months” and “right now”. Decision outcome was defined as no intervention indicated by answering “none of the above”; supportive care as indicated by pain medicine and/or nutritional supplements (vitamins, minerals, appetite enhancers, Boost, Ensure, etc.); and life extending interventions as defined as chemotherapy, radiation therapy, feeding tube, central line placement, and surgery. Content validity was established by conducting content analysis. Four gerontological nurse experts examined the fit between the conceptual definition of decision outcome and decision choices with the proposed operational definition developed by the researcher. The questionnaire required four revisions to ensure the retained questions measured the theoretical construct. Questions retained met 100% agreement among the gerontological nurse experts.

The Attachment Scale. Conceptual assessment of structure was operationalized by the Attachment Scale (Appendix P). The 12-item instrument measures the caregiver’s feelings about the older adult, including love and closeness, perception of shared values, identification with the traits of the older adult, and feelings of comfort and ease. The instrument uses a four-point scale of strongly agree to strongly disagree. Higher scores indicate less attachment experienced by the caregiver to the older adult care recipient.

Cronbach’s alpha was .90 (Phillips et al., 2001). For this study Cronbach’s alpha was .81.

The Interpersonal Conflict Scale. The Interpersonal Conflict Scale also measured structure (Appendix Q). The 4-item instrument uses a visual analog scale to measure intensity and amount of conflict in the past and present. The visual analog range measures from “no conflict” to “as much conflict as possible.” Higher scores indicate a greater level of interpersonal conflict between the caregiver and the older adult care recipient. The alpha coefficient has been reported as .87 (Phillips et al., 2001). Cronbach’s alpha for the total scale in this study was .74. Subscales for this study include past and present interpersonal conflict. Cronbach’s alphas were .75 and .78, respectively.

Elder Image Scale (EIS). The interactional context was operationalized by the EIS (Appendix R). The instrument contains pairs of bipolar adjectives repeated on two subscales, the past image subscale and the present image subscale. Each subscale measures the caregiver’s feelings (semantic space) about the care receiver’s personal and affective attributes, affectional expressions, and adequacy of their role performance (Phillips et al., 2001). The instrument uses a 7 point response scale with a neutral point in the middle format. Sample items address “How I remember him/her” and “How I see him/her now.” The EIS is scored using Osgood, Succi, and Tannenbaum’s distance formula. This formula is based on the idea that feelings about concepts are reflected by three-dimensional space that is occupied by the way an individual’s ratings of the adjectives cluster. The relationship between concepts is measured using semantic differentials (past and present image). The distance formula involves subtracting the response of one adjective on the past scale from the response of the same adjective on the present scale, squaring the product, summing the responses and taking the square root of the result. Higher scores means more distance or discrepancy between past and present image (Phillips et al., 2001).

Four studies (Phillips et al., 2001) were used to assess psychometrics of the EIS which included 54 to 249 caregivers for elders with multiple chronic problems, including dementia. Support for construct validity was provided by factor analysis and the known-groups method (Phillips & Rempusheski,1986). Coefficient alpha reliabilities for the EIS were reported as 0.97 for the total score and subscale coefficients ranging from 0.95 to 0.97 over four studies (Phillips et al., 1986). Phillips and Rempusheski (1986) reported two week test-retest reliability coefficients of 0.94 for the total score and 0.93 for the subscales. For this study, Cronbach's alpha for the total score was .97 and .96 for past and present subscales.

Beliefs About Caregiving Scale (BACS). The interactional context was operationalized by the BACS (Appendix S). This 25-item instrument measures caregiver's beliefs about the standards and values that apply to their caregiving. The instrument uses a four-point scale of strongly agree to strongly disagree for each subscale. Higher total scores indicate less commitment to care for the older adult care recipient by the caregiver. Total score is obtained from the sum of all subscales. Two subscales include assessing/nurturing and monitoring. A lower subscale score indicates stronger beliefs in the caregiver role to assess/nurture or monitor the family member’s care. Cronbach’s alpha coefficients for the subscales have been reported as .87 for assessing/nurturing and .85 for monitoring (Phillips et al., 2001). For this study, alpha coefficients were assessed as .92 for the total score, .87 for the assessing/nurturing subscale, and .87 for the monitoring subscale.

The Burden Interview Scale. The Burden Interview Scale was used to measure the subjective perception of caregiving burden, the stresses experienced by family caregivers of older adults (Zarit, Reever, & Bach-Peterson, 1980) (Appendix T). The 22-item instrument measures the caregiver’s health, psychological well-being, finances, social life, and the relationship between the caregiver and the patient (Zarit, Todd, & Zarit, 1986). Subjective caregivers responses indicate the degree of felt impact the older adult’s limitations/ disabilities placed on their life. For each item, caregivers indicate how often they felt that way using a five-point Likert scale ranging from never (zero), through rarely, sometimes, and quite frequently, to nearly always (four). The Burden Interview is scored by summing the responses of the individual items. Higher scores indicate greater caregiver distress/burden. The alpha coefficient of.79 was previously reported. A second study reported an alpha of .90 (Phillips et al., 2001, p. 34). The correlation between the scale total and the criterion validity item was .72. For this study Cronbach’s alpha was .91.

Family Caregivers’ Motives for Helping Scale. The decision motive was operationalized by the Family Caregiver’s Motives for Helping Scale (Appendix

U). This scale is based on Batson’s helping pathway theory which asserts that an individual’s reaction to the person needing help predicts the type of help given (Smith et al., 2001). Qualitative methodology identified family members’ reasons for assisting with care over time. Findings were consistent with Batson’s Motivation-to-Help theory that evolved from helping pathways research.

Content and criterion validity for the study were established by a panel of five experts determining representation of the caregiver statements within one of the four motives-to-help concepts (reward-seeking; punishment-avoidance; altruistic helping; distress reduction). Fourteen items were retained on the scale, including 4 items for altruism, 5 items for reward-seeking, 3 items for punishment avoidance, and 2 items for distress reduction (Smith et al., 2001, p. 244). The instrument is scored using a 7 point Likert-type scale. Higher scores indicate greater amount of motive for helping. Sample items are “When I think about helping, I think how good it makes me feel” and “I would feel best when I helped.”

In previous research, internal consistency was assessed for each subscale. Cronbach alphas were .86 (reward-seeking), .78 (altruism), and .62 (punishment-avoidance). Subscale correlations ranged from .29 to .36 indicating each subscale measured a unique, but related, motive for helping (Zeller & Carmines, 1980).

For this study, Cronbach’s alpha was acceptable for reward seeking at .76. All items were retained for this subscale. The alpha coefficient for altruistic decision motive subscale was unacceptable at .44. Alpha-if-item-deleted statistics indicated Cronbach’s alpha would increase to .72 if item 6, “When I think about helping, I try to get someone to help," was deleted. Thus three of four original items were retained to measure altruistic decision motive. Cronbach's alpha for the punishment avoidance decision motive subscale was unacceptable at .14. Alpha-if-item-deleted statistics indicated increase in Cronbach's alpha to .45 if item 11, "Other people can help; I am not the only one who can help," was deleted. Given these statistics, two of the three items were retained to measure the punishment avoidance motive. The Cronbach's alpha for the distress reduction decision motive subscale was .22. While this alpha is low, the original subscale was retained due to only two items measuring the distress reduction motive.

Global Deterioration Scale (GDS) and the Brief Cognitive Rating Scale (BCRS). The situational context was operationalized by the dementia severity levels defined in the GDS. The BCRS was used within this study only to support the assessment staging for a person with a degenerative dementia (Foster, Sclan, Welkowitz, Boksay, & Seeland, 1988). If the researcher was unable to complete the BCRS due to a resident's inability to speak, the GDS was used to determine the level of dementia through medical record review and resident assessment.

The GDS is a widely used screening instrument in research to measure the severity of dementia and as a comparison tool when establishing reliability of other cognitive assessment instruments (Choi, et al., 2003; Hannesdottir & Snaedal, 2002; Heun, Papassotiropoulos, & Jennssen, 1998; Nambudiri, Teusink, Fensterheim, & Young, 1997; Reisberg, Finkel et al., 2001).The GDS screening criteria defines seven stages of deterioration of cognitive status associated with dementia. Each stage defines clinical characteristics, ranging from Level 1 (indicating no subjective complaints of memory deficit) to the most extreme Level 7. Stages 1 through 3 are pre-dementia and stages 4 through 7 are dementia stages. In Level 5 a person can no longer survive without assistance.

Original content and criterion validity of the GDS was completed through a 5 year retrospective analysis of the GDS scores and independent psychometric assessments of patients with very mild to moderately severe cognitive decline consistent with primary degenerative dementia (Reisberg et al., 1982). The GDS scores correlated with 13 of the 19 items in the Inventory of Psychic and Somatic Complaints in the Elderly scale. Correlation of GDS scores were also significantly correlated with 25 other psychometric measures. Significant correlations between GDS stages and anatomic brain changes were visualized on computerized axial tomography (CT) scanning ($r = .53$ *to* $.62$) and metabolic changes as determined by positron emission tomography (PET) scanning in patients with primary degenerative dementia ($r = .69$ *to* $.83$) (Reisberg).

Heun et al. (1998) assessed the validity of eight psychometric tools, including the GDS and the BCRS, for detection of dementia in a general elderly population. Results revealed the GDS had the second highest discriminatory power between dementia and normal cognition. The threshold for optimal distinction for sensitivity and specificity rated the GDS as 0.53 and 0.98 respectively.

The BCRS assesses five areas identified as axes. Four of the axes assess cognitive status through questioning to determine the level of impairment. The fifth axis assesses functional status primarily through observation. Scoring for the instrument determines the AD patient's level rating on the GDS. For this study, the alpha coefficient for the BCRS was .87.

Foster et al. (1988) assessed the inter-rater reliability of six rating scales used commonly within LTC environments. Both the BCRS and the GDS were used on two sample populations of 20 LTC residents. Inter-rater reliability coefficients for study one and two were 0.97 and 0.92, respectively. Inter-rater reliability coefficients for the five axes of the BCRS were 0.97 and 0.85 (concentration and calculation), 0.92 and 0.82 (recent memory), 0.95 and 0.90 (past memory), 0.97 and 0.93 (orientation), and 0.96 and 0.76 (functioning and self-care). For this study, assessment of the family member with AD was done only by the researcher. This provided consistency in assessment technique to reduce variability in process thus increasing reliability of assessment data.

Protection of Human Subjects

The study proposal was reviewed and approved by the Georgia State University Institutional Review Board (Appendix Y) and by the review processes defined by the participating LTC facilities from which the sample was recruited. Facility-specific approval was provided through administration (N =13), corporate level (N =1), and board member (N =1) level.

Potential participants were informed of the purpose and objectives of the study, approximate time required to complete questionnaires, and benefits and risks of the study. Participation was voluntary, and potential participants were informed of their right to refuse or withdraw from participating in the study at any time without affecting the quality of care or services provided by the LTC facility. The surrogate participant was informed that all information obtained by the researcher would be kept confidential, and no identifiers would be used to link any information to the surrogate participant, the AD family member, or the facility. Anonymity of the surrogate and family member with AD was maintained through use of a unique identifier. Participants had received an invitation from the LTC facility to attend an AD education session and a cover letter explaining the study prior to attending the recruitment session. Prior to distributing the surrogate questionnaire booklet, participants signed an informed consent document (Appendix Z) typed in 14-font type to increase visibility of content by the participant. Time was provided for needed clarification and questions.

Data Collection Procedures

Data collection occurred over a period of 6 months and involved the researcher visiting 15 LTC facilities. First, an educational session on AD was held at the LTC facilities during a family night event or at a facility-sponsored Alzheimer’s support group meeting. At the conclusion of the presentation, attendees were invited to participate in the study. After the participants had been informed of the purpose and objective of the study and agreed to participate, written informed consent was obtained. After the surrogate questionnaire booklets were distributed, the researcher explained the options for completing the questionnaires. Option one was to complete the questionnaires that night with the researcher available to answer questions or clarify instrument instructions, and option two allowed the participant to complete the questionnaires at home and return them in a pre-addressed, stamped envelope provided by the researcher. The researcher reviewed her contact information located on the inside cover of the booklet in the event that questions arose for participants completing questionnaires at home. Participants were asked to return the completed questionnaire by mail within one week. The researcher contacted participants completing consent forms who had not returned the questionnaire booklet within a two-week period. The researcher asked if the participant had any questions at that time and encouraged them to complete the questionnaires and return via mail.

Returned booklets were pre-coded with a number to ensure accuracy and appropriateness of information in the data entry and analysis process. A corresponding code was used to identify the family member with AD during the medical record review and level of dementia assessment. The list linking surrogate and AD family member names was kept in a locked file cabinet at the researcher’s home and was destroyed once the data collection period and data verification process is completed.

Data Analysis Plan

Data were analyzed with descriptive and inferential statistics using Statistical Package for the Social Sciences (SPSS) for Windows Release 12.0. Statistical methods included descriptive statistics, t-tests, and multiple linear regression.

Demographic data. Descriptive statistics including frequencies, percentages, means, and standard deviations were performed and reported on the following surrogate demographic variables: age, gender, familial relationship, marital status, educational level, employment status, and distance lived from LTC facility where the family member with AD resides. Descriptive statistics were also performed and reported on the following demographic variables for the family member with AD: age, gender, marital status, length of stay within the facility, and presence of an advanced directive.

Research questions. A *t*-test was conducted to analyze significant differences between male and female surrogates' decision motives. Regression analyses were conducted to determine if caregiving dynamics (attachment, interpersonal conflict, elder image, gender, familial relationship, caregiving beliefs, dementia level, burden) were predictors of decision motives (punishment avoidance, altruistic, reward seeking, and distress reduction).

Descriptive statistics including frequencies and percentages were performed and reported on decisions made by surrogate decision-makers for their family member with AD during the past 12 months. Frequencies were also calculated for decisions the surrogate would have made if they had been asked to do so in the past 12 months and for the immediate moment in time of this study.

Summary

This chapter described the methodology used to conduct the research study. Operational variables addressing surrogate and AD patient demographics, background structure, interactional context, situational context, perception of burden, (independent variables) and the decision motive (dependent variable) were defined through instrument descriptors and psychometrics. Additionally, the following sections were outlined: study design, sample, setting, methods used to protect human subjects, data collection procedures, and data analysis plan.

CHAPTER IV

RESULTS

The results of this descriptive study of structure, interactional context, situational context, perception of burden, and decision motives are presented in this chapter. Statistical analyses addressing the surrogate and AD family member demographics and research questions will be reported. The chapter concludes with a summary of the study.

Participant Demographics

Surrogate demographics. An initial invitation to participate in the study was extended to 82 individuals who met the inclusion criteria and agreed to participate in the study during the original meeting at the LTC facilities. The informed consent process was completed during this session. A total of 3 surrogates (4%) completed the questionnaires at the time of informed consent. Fifty-five individuals (67%) returned the questionnaire booklet via mail. Seventy-one percent (*N* = 58) of the 82 surrogates who signed the informed consent completed the questionnaires to continue in the study. Table 1 summarizes the frequency distributions for surrogate gender, age, marital status, familial relationship, ethnic background, educational level, employment status, and distance lived from LTC facility where AD resident resides.

Two-thirds of the surrogates were female (67.2%). Participants ranged in age from 43 to 84 years with a mean age of 62.22 years (*SD* = 9.67). The majority of participants were Caucasian (86.2%). African Americans represented 10.4% of the sample. The greatest number of surrogates were between the ages of 60 and 69 (36.2%) with 65 years of age (10.3%) as the most frequently reported age.

Table 1

Surrogate Decision-Maker Demographics (N = 58)

	N	*(%)*
Gender		
Male	19	(32.8)
Female	39	(67.2)
Age		
40 – 49	05	(08.6)
50 – 59	19	(32.8)
60 – 69	21	(36.2)
70 – 79	11	(19.0)
80 – 85	02	(03.4)
Marital Status		
Single	02	(03.4)
Married	47	(81.0)
Divorced	07	(12.2)
Widowed	02	(03.4)

(Table 1 continues)

(Table 1 Continued)

	N	%
Ethnic Background		
White/Caucasian	50	(86.2)
Black/African American	06	(10.4)
Latino/Spanish descent	01	(01.7)
Asian	01	(01,7)
Other	00	(00.0)
Familial Relationship		
Husband	01	(01.7)
Wife	07	(12.1)
Son	10	(17.3)
Daughter	32	(55.3)
Daughter-in-law	02	(03.4)
Son-in-law	01	(01.7)
Brother	02	(03.4)
Sister	01	(01.7)
Niece	01	(01.7)
Nephew	01	(01.7)
Educational Level		
Grade School	01	(01.7)
Junior High/Middle School	03	(05.2)
High School	18	(31.0)
Technical College	04	(06.9)
Some College	09	(15.5)
College graduate	12	(20.7)
Graduate School	11	(19.0)
Employment Status		
Employed outside of home	27	(46.6)
Work in home office	01	(01.7)
Homemaker	05	(08.6)
Retired	24	(41.4)
Unemployed at the present time	01	(01.7)

(Table 1 continues)

(Table 1 Continued)

	N	%
Distance Surrogate Lives from AD Family Member LTC Facility		
1 – 5 miles	31	(53.4)
6 – 10 miles	10	(17.2)
11 – 15 miles	08	(13.8)
16 – 25 miles	02	(03.4)
26 – 35 miles	02	(03.4)
36 – 50 miles	04	(06.9)
51 – 55 miles	01	(01.7)

	Observed Range	*M*	*(SD)*
Surrogate Age	43 - 84	62.22	9.67

Daughters represented the majority of surrogates. Four-fifths of surrogates were married, and 93% had at least a high school diploma. Almost 50% worked outside their home. Over half of the surrogates lived within 1 to 5 miles of the LTC facility where the AD family member resides.

AD family member demographics. Nearly three-fourths of the AD family members were female. Their age ranged from 63 to 98 years. The mode for AD age was 85 years (12.1%), and the mean age was 83.69 (SD = 7.8). Over half of the AD family members were widowed. The majority of AD family members' length of stay in the LTC facility was two years or less. Ninety percent of the AD family members had an advance directive active on the medical record.

Table 2

AD Family Member Demographics (N = 58)

	N	*(%)*
Gender		
Male	15	(25.9)
Female	43	(74.1)
Age		
60 – 69	02	(03.4)
70 – 79	12	(20.7)
80 – 89	35	(60.3)
90 – 99	09	(15.5)
Marital Status		
Single	02	(03.4)
Married	16	(27.6)
Divorced	04	(06.9)
Widowed	36	(62.1)
Length of Stay in LTC Facility		
2 years or less	35	(60.4)
3 to 4 years	19	(32.8)
5 to 6 years	02	(03.4)
7 to 8 years	02	(03.4)
Advance directive active on medical record		
Yes	52	(89.7)
No	06	(10.3)
Advance directive completed prior to LTC facility admission		
Yes	09	(15.5)
No	49	(84.5)

(Table 2 Continues)

(Table 2 Continued)

		N	*(%)*
Number of years advance directive completed prior to LTC facility admission			
2 years or less		03	(33.3)
3 to 4 years		02	(22.2)
5 to 6 years		04	(44.5)
	Observed Range	*M*	*(SD)*
AD Family Member Age	63 - 98	83.69	(7.8)

Descriptive Statistics for Study Variables

Structure. Table 3 shows the mean and standard deviation for the surrogates' feelings of attachment and interpersonal conflict. The observed range for attachment was 12 to 35 with a mean of 23.09 (*SD* = 4.97), indicating a moderate level of attachment. The observed range for interpersonal conflict was 11 to 347 with a mean of 138.72 (*SD* = 89.19), indicating surrogates reported a low level of interpersonal conflict between the surrogate and the AD family member.

Table 3

Possible and Observed Ranges, Means, and Standard Deviations for Attachment and Interpersonal Conflict (N = 58)

Variable	Possible Range	Observed Range	*M*	*(SD)*
The Attachment Scale	12 – 48	12 – 35	23.09	(04.97)
The Interpersonal Conflict Scale	0 – 400	11 – 347	138.72	(89.19)
Past conflict	0 – 200	5 – 185	74.74	(53.26)
Present conflict	0 – 200	3 – 192	63.98	(53.67)

Interactional context. Table 4 shows the means and standard deviations for surrogates' image of their AD family member and their beliefs about caregiving. The mean score for the Elder Image was 10.69 (*SD* = 4.83), indicating a moderate balance in reconciliation of the past with the present image of the AD family member.

Table 4

Possible and Observed Ranges, Means, and Standard Deviations for Elder Image and Beliefs About Caregiving (N = 58)

Variable	Possible Range	*Observed Range*	*M*	*(SD)*
Elder Image			10.69	(04.83)
Past Image	24 – 168	24 – 168	57.19	(26.69)
Present Image	24 – 168	31 – 165	88.95	(28.96)
Beliefs About Caregiving	25 – 100	45 – 97	64.78	(10.63)

Situational context. Table 5 shows the level of dementia of the AD family members according to the Global Deterioration Scale. The mean of 6.10 indicated that on average, the AD family members had moderately severe dementia.

Table 5

Possible and Observed Ranges, Means, and Standard Deviations for Global Deterioration Scale (N = 58)

Variable	Possible Range	Observed Range	*M*	*(SD)*
Global Deterioration Scale	1 – 7	3.30 – 7.00	6.10	(0.89)

Table 6 shows the means and standard deviations for the axes, total axes subscale score and the total score for the Brief Cognitive Rating Scale. The total score consists of the subscale scores divided by the number of axes. Similar to the Global Deterioration Scale, the mean score indicates the family members with AD had severe dementia and were severely impaired with little residual capacity in some assessment areas. Functional and self-care capacity indicated the AD family member required total assistance for all activities of daily living (ADL). The ability for the AD family member to recall recent or past memory events was almost nonexistent. The sample (*N* = 47) was limited to AD family members who met the descriptive criteria within the 5 axes.

Table 6

Possible and Observed Ranges, Means, and Standard Deviations for Brief Cognitive Rating Scale (N = 47)

Variable	Possible Range	Observed Range	*M*	*(SD)*
Brief Cognitive Rating Scale Score	1 – 7	3.20 – 7.00	06.10	(4.79)
Total axes subscale score	5 – 35	16 – 35	30.28	(4.79)
Axes subscales				
Axis I: Concentration	1 – 7	1 – 7	5.72	(1.78)
Axis II: Recent memory	1 – 7	3 – 7	6.30	(1.10)
Axis III: Past memory	1 – 7	3 – 7	6.04	(1.20)
Axis IV: Orientation	1 – 7	3 – 7	5.79	(0.88)
Axis V: Functioning and self care	1 – 7	5 – 7	6.43	(0.65)

Perception. Table 7 shows the mean and standard deviation for surrogates’ perception of caregiver burden. The mean of 28.01 indicated a low level of burden was perceived by the surrogate decision-makers.

Table 7

Possible and Observed Ranges, Means, and Standard Deviations for Perceived Burden (N = 58)

Variable	Possible Range	Observed Range	*M*	*(SD)*
Burden Interview	0 – 88	0 – 74	28.01	(14.63)

Decision motive. Table 8 shows the means and standard deviations for the Family Caregivers’ Motives for Helping subscales. Considering the different possible subscale ranges for the decision motives, the sample reported the highest scores in altruistic decision motive and the lowest scores in punishment avoidance decision motive.

Table 8

Possible and Observed Ranges, Means, and Standard Deviations for Decision Motives (N = 58)

Variable	Possible Range	Observed Range	*M*	*(SD)*
Family Caregivers' Motives for Helping				
Altruistic	3 – 21	9 – 21	18.78	(2.74)
Reward seeking	5 – 35	8 – 35	22.83	(6.48)
Punishment avoidance	2 – 14	2 – 14	8.10	(2.69)
Distress reduction	2 – 14	2 – 14	8.91	(3.11)

Initial Approach to Data Analysis

Prior to addressing the research questions, data were examined for normal distribution as well as the presence of outliers. The preliminary examination revealed that four variables had non-normal distributions. These included dementia level, elder image, altruistic decision motive and distress reduction decision motive. Three of the variables, dementia level, elder image, and altruistic decision motive, had mild outliers in the data; no extreme outliers were noted for any variable.

Univariate analysis of data indicated that for dementia level, four participants had values that were 1.5 times the interquartile range below the mean. Elder image was skewed with seven participants having values that were

1.5 times the interquartile range above the mean. Seven participants had values that were 1.5 times the interquartile range below the mean for altruistic decision motive. For the distress reduction decision motive variable, there were no outliers and it appeared that the non-normality was related to a restriction of range.

To address outliers in the data, the decision was made to implement the winsorization method (Wilcox, 1998). Winsorization involves retaining participants in the sample but adjusting their scores so they remain the highest or lowest scores within the sample, but not as extreme as was present in the original data. The scores of the four participants with dementia levels 1.5 times the interquartile range below the mean for dementia level were winsorized with the greatest outlier receiving a score of 4.1, bringing this score within two standard deviations below the mean. Subsequent values were adjusted and increased by 0.1 from this value. The seven participants with elder image values 1.5 times the interquartile range above the mean were winsorized with the lowest outlier above the mean having his/her score adjusted to a score of 17.8. Each subsequent value was changed and increased by 0.1 from this value. The seven participants with altruistic decision motive values 1.5 times the interquartile range below the mean for altruistic decision motive were winsorized with the greatest outlier receiving the score of 14.8. Each subsequent value was changed and increased by 0.1 from this value. Since violation of normality for distress reduction decision motive was not severe, it was decided to appeal to robustness and include the variable in subsequent analyses.

To continue with data analysis, univariate Pearson Product Moment correlations were run with the winsorized data. To increase power for the regression analyses and to make the model more parsimonious only independent variables with a univariate correlation with the outcome variables significant at a *p* value of .10 or less were entered into the regression models. All of the proposed theoretical independent variables met this criterion except the variable, elder image. Thus it was not included in the data analyses. Independent variables entered into multiple linear regressions with each decision motive as the outcome variable included surrogate gender, caregiver's feelings of attachment, interpersonal conflict with the elder, beliefs about caregiving, surrogate burden, and the AD family member's dementia level. For inferential statistics the *p* value was set at $p < .05$. The full correlation matrix is located in Appendix A.

Statistical Analysis for Research Question 1

Research question one concerned the relationship between surrogate gender and decision motives. Table 9 shows gender differences in surrogate decision motives. An independent-samples *t*-test comparing the mean scores of male and female surrogate decision-makers demonstrated no statistically significant difference between the two groups' mean for decision motives.

Table 9

t-Tests for Surrogate Gender Differences in Decision Motives (N = 58)

Decision Motive	Male Relative		Female Relative				
	M	*(SD)*	*M*	*(SD)*	*t*	*df*	*p*
Altruistic	18.89	(2.02)	18.72	(3.05)	0.23	56	.82
Reward seeking	22.79	(6.60)	22.85	(6.51)	-0.03	56	.98
Punishment avoidance	07.11	(2.96)	08.54	(2.45)	-1.95	56	.06
Distress reduction	04.95	(2.01)	04.97	(2.06)	-0.05	56	.96

Statistical Analysis for Research Question 2

Research question two asked if structure, interactional context, situational context, and perception variables predicted the type of decision motive used by the surrogates when making healthcare decisions for their AD family member. The question was addressed with multiple linear regressions using the trimmed model as previously described.

For all 4 regression models, the independent variables included gender, feelings of attachment, interpersonal conflict with the elder, beliefs about caregiving, dementia level and caregiver burden. For the model predicting punishment avoidance decision motive, simultaneous multiple linear regression results indicated that the overall model significantly predicted the dependent variable. Results of the regression analysis are presented in Table 10. The model accounted for 14% of the variance in punishment avoidance motive. Review of the *β* weights did not indicate that any of the independent variables uniquely contributed to the variance in the punishment avoidance decision motive.

Table 10

Summary of Regression Analysis for Variables Predicting Punishment Avoidance Decision Motive (N = 58)

Regression Variable	*B*	*SE B*	*β*	*p*
Structure				
Gender	1.447	.756	.255	.06
Feelings of attachment	0.002	.074	.040	.77
Interpersonal conflict with elder	-.005	.004	-.163	.26
Interactional Context				
Beliefs about caregiving	-.015	.033	-.059	.65
Situational Context				
Dementia level	-.740	.414	-.220	.08
Perception				
Burden	-.046	.026	-.249	.09
R^2		0.234		
Adjusted R^2		0.144		
F (p-value for model)		2.602 (*p* = .03)		

For the second regression model predicting altruistic decision motive, simultaneous multiple linear regression results indicated that the overall model was not significant. Table 11 shows the summary of the regression analysis.

Table 11

Summary of Regression Analysis for Variables Predicting Altruistic Decision Motive (N = 58)

Regression Variable	*B*	*SE B*	β	*p*
Structure				
Gender	.039	.622	.009	.95
Feelings of attachment	.005	.061	.013	.93
Interpersonal conflict with elder	-.007	.004	-.285	.07
Interactional Context				
Beliefs about caregiving	-.030	.027	-.152	.28
Situational Context				
Dementia level	-.679	.341	-.260	.05
Perception				
Burden	.016	.022	.115	.45
R^2		.138		
Adjusted R^2		.037		
F (p-value for model)		1.360 (p = .25)		

For the third regression model predicting distress reduction motive, simultaneous multiple linear regression results indicated that the overall model was not significant. Table 12 shows the summary of the regression analysis.

Table 12

Summary of Regression Analysis for Variables Predicting Distress Reduction Decision Motive (N = 58)

Regression Variable	*B*	*SE B*	*β*	*p*
Structure				
Gender	-.500	.605	-.117	.41
Feelings of attachment	-.104	.060	-.254	.09
Interpersonal conflict with elder	-.004	.003	-.157	.31
Interactional Context				
Beliefs about caregiving	-.022	.026	-.113	.42
Situational Context				
Dementia level	-.356	.332	-.140	.29
Perception				
Burden	.034	.021	.242	.12
R^2	.136			
Adjusted R^2	.034			
F (p-value for model)	1.335 (*p* = .26)			

For the last regression model predicting reward seeking decision motive, simultaneous multiple linear regression results indicated that the overall model significantly predicted the dependent variable. Table 13 summarizes the results of the regression analysis. The model accounted for 17% of the variance in reward seeking motive. Review of the *β* weights indicated that two of the variables, dementia level and surrogate burden, significantly contributed to the variance in the reward seeking decision motive. Dementia level and surrogate burden had inverse relationships with the reward seeking decision motive, such that greater severity of dementia and perception of burden were associated with lower reports of reward seeking as a decision motive.

Table 13

Summary of Regression Analysis for Variables Predicting Reward Seeking Decision Motive (N = 58)

Regression Variable	*B*	*SE B*	*β*	*p*
Structure				
Gender	-1.732	1.795	-.127	.34
Feelings of attachment	-.206	.177	-.158	.25
Interpersonal conflict with elder	.012	.010	.170	.24
Interactional Context				
Beliefs about caregiving	-.158	.078	-.260	.05
Situational Context				
Dementia level	-2.170	1.795	-.267	.03
Perception				
Burden	-.133	.062	-.300	.04
R^2	.257			
Adjusted R^2	.170			
F (p-value for model)	2.944 (*p* = .015)			

Statistical Analysis of Research Question 3

Research question three asked what healthcare decision choices were made by surrogate decision-makers for an AD family member. To answer this question, descriptive statistics were used to address surrogate decision-making and decision choices over time. Table 14 shows the frequencies for EOL information related to advance directive preparation, conversation between the surrogate and their family member, and discussion about healthcare intervention choices. Nearly all of the surrogates reported they knew what an advance directive was; however, half of the surrogates had never had a discussion with their family member regarding an advance directive prior to the diagnosis of AD. Over half of the surrogates had discussed healthcare treatments they would want when they were no longer able to make decisions for themselves. Over a third of the surrogates reported being asked about healthcare interventions for their AD family member over the past 12 months, but over half reported no such request.

Table 14

Surrogate Decision-Making Frequency Table (N = 58)

	N	*(%)*
Do you know what an advance directive is?		
Yes	51	(87.9)
No	07	(12.1)
Did your family member have an advance directive completed before they were diagnosed with AD?		
Yes	26	(44.8)
No	29	(50.0)
I do not know	03	(05.2)

(Table 14 Continues)

(Table 14 Continued)

Surrogate Decision-Making Frequency Table (N = 58)

	N	*(%)*
Did you and your family member ever talk about the kind of healthcare treatment they wanted when they could no longer make decisions for himself/herself?		
Yes	36	(62.1)
No	20	(34.5)
I do not know	02	(03.4)
Have you been asked by a healthcare provider to make a decision about any of the following types of care for your AD family member in the last 12-months? (Pain medicine; nutritional supplements; chemotherapy; radiation therapy; feeding tube; central line; surgery)		
Yes	23	(39.7)
No	30	(51.7)
I do not remember	05	(08.6)

Healthcare intervention choices over time and type. Table 15 shows the frequency over time in the intervention choices surrogates made or would make for their AD family member. Intervention choices were defined as (a) no intervention, (b) life supportive, and (c) life extending. No surrogate reported making a “no intervention choice” for their AD family member if asked during the past 12-months. Of the surrogates who were asked to make a decision choice, 50% were life supporting interventions for their AD family member, and 18.9% were life extending interventions.

Surrogates also reported that if they had been asked to select a life supporting intervention for their AD family member, over half would have selected pain medication and almost half would have selected nutritional supplements. Surrogates' were not provided 'no intervention choice' as an optional answer by researcher design for this question during this time frame to force surrogates response. In descending order of frequency, surrogates' reported they would have selected the following life extending interventions: central line, surgery, chemotherapy, radiation therapy, and placement of a feeding tube.

The surrogates reported based on their family member's current condition, the decision choices they would make 'right now'. Three would select 'no intervention' to support or extend life. Nearly half of the surrogates' reported they would select life supporting interventions including pain medicine and nutritional supplements. In descending order of frequency, surrogates' reported they would select the following life extending interventions: central line, surgery, chemotherapy, radiation therapy, and placement of a feeding tube.

Table 15

Surrogate Decision Choice Frequency Table Over Time and Intervention Type (N = 58)

	Decision Choice made in past 12-months		Decision Choice would have made if asked in past 12-months		Decision Choice would make right now considering AD family member current condition	
	N	*(%)*	*N*	*(%)*	*N*	*(%)*
No Intervention selected	00	(00.0)	--	--	03	(05.2)
Life Supportive Intervention						
Pain Medicine	15	(25.8)	31	(53.4)	47	(81.0)
Nutritional Supplements	14	(35.0)	27	(46.6)	43	(74.1)
Life Extending Intervention						
Central Line	3	(05.2)	9	(15.5)	12	(20.7)
Surgery	6	(10.3)	7	(12.1)	9	(15.5)
Feeding Tube	2	(03.4)	3	(05.2)	2	(03.4)
Chemotherapy	0	(0.00)	5	(08.6)	2	(03.4)
Radiation Therapy	0	(0.00)	5	(08.6)	2	(03.4)

Current healthcare interventions for AD family member. Medical record review was used to obtain data displayed in Table 16. Over a third of the AD family members’ were receiving pain medication and nearly three-fourths were receiving nutritional supplements. Three of the residents had documentation of a feeding tube.

Table 16

AD Family Member Current Healthcare Interventions Based on Medical Record (N = 58)

	N	*(%)*
Life Supportive Interventions		
Pain management	22	(37.9)
Nutritional supplements	42	(72.4)
Life Extending Interventions		
Feeding tube	3	(05.2)
Chemotherapy	0	(00.0)
Radiation therapy	0	(00.0)
Central line	0	(00.0)
Surgery	0	(00.0)

Summary

Data were analyzed with descriptive and inferential statistics including frequencies, percentages, means, standard deviations, *t*-tests, and multiple linear regression. Surrogates were between the ages of 43 to 84 years of age. The majority of surrogates were Caucasian, female, and daughters of the AD family member with moderately severe to very severe AD.

There were no significant differences between men and women in their report of decision motives. Multiple linear regression analysis revealed the the trimmed model significantly predicted punishment avoidance decision motive; however, none of the independent variables uniquely contributed to the variance. The model also significantly predicted reward seeking decision motive. It was found that dementia level and surrogate burden had inverse relationships with reward seeking decision motive that contributed to the variance in the reward seeking decision motive.

In the past 12-months, surrogates were asked to make life supportive interventions (pain management and nutritional supplements) more frequently than life extending interventions. The most frequent life extending interventions in descending order of frequency included surgery, central line placement, and feeding tube placement.

CHAPTER V

DISCUSSION

Chapter V presents a discussion of study results and subsequent conclusions. Study limitations are addressed initially as results must be viewed within the context of identified limitations. Answers to research questions, implications for nursing, healthcare, theory development, and recommendations for future research are presented. The chapter concludes with a summary of the study.

Limitations of Study

The study had several limitations which may have affected external validity, statistical conclusion validity, and internal validity of the study findings. First, the use of convenience sampling and homogeneity of the sample limited the external validity or generalizability of the results. The majority of participants in this study were Caucasian and female. It is unknown whether similar results would be found in Non-Caucasian, male surrogate decision-makers.

The small sample size reduced statistical power of the data analysis. With a larger sample size, more relationships between the theoretical predictor variables and decision motives may have been identified. Another substantive limitation of the study was poor psychometric characteristics of the Caregiver Helping Motives for Caregiving questionnaire, specifically the low internal consistency reliabilities for two of the subscales. The low internal consistency for the subscales potentially attenuated correlations within the regression models and thus may have also contributed to the lack of statistically significant findings. Given that the Caregiver Helping Motives for Caregiving Questionnaire is a new research instrument, additional item development for measurement of distress reduction and punishment avoidance decision motives along with subsequent psychometric testing is recommended prior to using this instrument in another study.

Finally, threats to the internal validity of the study included that an educational program was provided for surrogates prior to participant recruitment about how families can better cope with having an AD family member. It is feasible that the educational intervention may have influenced surrogates perceptions of the AD family member, the caregiving situation, and their decision-making processes; however, the effect of this educational intervention on the responses of the surrogates to the questionnaires is unknown. In addition because the data were collected cross-sectionally it cannot be concluded that the independent variables caused surrogates to exhibit specific decision motives.

Issues with Participant Recruitment

The final sample for the study was smaller than anticipated because of recruitment difficulties. Recruitment barriers included gaining approval to access potential participants in LTC facilities and overcoming surrogate reluctance to participate in the study. Facilities permitting access were eager to support the research purpose and quickly facilitated access. However, one facility stated they did not participate in research studies and others provided no explanation for declining access. Two system-owned LTC facilities presented a hierarchical structure with multiple levels of required legal processes and an extended approval time frame, thus preventing timely access to potential participants.

Attendance at facility education sessions ranged from 5 to 80 family members. Family members wanted information about AD, effective communication, and the AD EOL trajectory, but were hesitant to participate in the research study. On occasion, the researcher engaged in crisis intervention with surrogates requiring care coordination activities external to the research study. While surrogates rationale for not wanting to participate in the research study are largely unknown, it may be that decision-making motives are a sensitive and potentially revealing area of inquiry. Surrogates may have been reluctant to participate due to fear of revealing personal conflicts or guilt with making EOL decisions. They may have been concerned about what others might think of them, or that participation might require them to think about issues they would rather avoid.

Surrogate Demographics

In this study, the majority of surrogate decision-makers were women, which is consistent with current literature on family caregivers (Stone et al.,1987; Wolff & Kasper, 2006). However, an interesting finding was related to the extended family members who served as surrogates. An example was the daughter-in-law who serves as the AD family member's sponsor and surrogate because all other immediate family members are deceased.

Most surrogates were well educated and fell within the baby boomer age population. Collectively, baby boomers are more highly educated than their parents, desire healthcare information, and are more engaged in care decisions (Willis, 2006).

AD Family Member Demographics

Most AD family members were females, widows, and between 63 and 98 years of age. Most had been a resident of a LTC facility for two years or less which is consistent with published Center for Disease Control (CDC) nursing home data (CDC, 2000). The CDC also reported that residents living within LTC facilities were primary white, widowed, functionally dependent, and 85 years of age and older.

Research Question One

Research question one addressed gender differences related to decision motives. No difference in decision motives were found between male and female surrogates in the study. The sample size may have been too small to detect a statistically significant difference for this study.

Research Question Two

Multiple regression analysis revealed the model which included the variables of surrogate gender, feelings of attachment, interpersonal conflict with the elder, beliefs about caregiving, the dementia level of the AD family member, and surrogate burden accounted for 14% of the variance in the punishment avoidance decision motive. However, no individual variable was found to contribute more uniquely than another in the model to predict use of the punishment avoidance decision motive.

Multiple regression analysis revealed the model, also including surrogate gender, feelings of attachment, interpersonal conflict with the elder, beliefs about caregiving, the dementia level of the AD family member, and surrogate burden variables, accounted for 17% of the variance in the reward seeking decision motive. The AD family member's dementia level and surrogate burden were found to significantly contribute to the model to predict use of the reward seeking decision motive. Higher levels of dementia of the AD family member, and higher levels of surrogate burden uniquely contributed to the prediction of less use of the reward seeking decision motive. It may be that as the family member's dementia worsens and requires more care, the surrogate is less concerned with others' opinions of their decision choices.

Research Question Three

Advance directive planning was completed by only a few of the AD family members prior to admission to the LTC facility which left EOL healthcare intervention decisions to the surrogates. A few AD family members remained without an EOL directive at the time of the study and were full code status. Completion rates prior to admission to the LTC facility are consistent with current literature that indicates 15 to 25 percent complete an advance directive which is usually after a hospitalization or experiencing a serious illness (Jezewski & Meeker, 2005; Salmond & David, 2005; Stearight & Gafford, 2006).

A few of the surrogates reported they did not know what an advance directive was. Current research confirms that lack of understanding is prevalent as is lack of trust in the advance directive process (Jezewski & Meeker, 2005; Lacy, 2006). Because healthcare professionals place greater value on an advance directive than patients or their family members (Drought & Koenig, 2002; Mitchell, Kieley, & Hamel, 2004), AD family members and their surrogates may not appreciate how advance directives can assist decision-making in their future.

Surrogates reported decisions for life supportive interventions were requested by healthcare providers more frequently than life extending interventions. This may reflect a shift in the public and medical communities' perception of futile care, indicating that accepting the role of ensuring a comfortable and dignified death is more important than the science of extending life at all cost for a terminal stage disease process (Henig et al., 2001).

Less than half of the AD family members were receiving pharmacological pain management. This is consistent with the literature that has identified that patients with dementia receive less pain management than any other patient population (Cook, Nivens, & Downs, 1999; Cunningham, 2006; Dawson, 1998; Nygaard, 2005). Patients with dementia also have arthritis and other medical conditions that cause pain. Studies support the correlation with age and associated pain, revealing that up to 84% of older adults experience chronic pain (Gibson, 1998; Tsai & Chang, 2004). Review of the AD family member's medical record during this study found no pain assessment instruments for cognitively-impaired older adults were used in the LTC facilities. Multiple pain instruments for this population exist; however, demonstration of instrument reliability and validity is extremely limited (Stolee, Hillier, Esbaugh, Bol, McKellar, & Gauthier, 2005).

The majority of patients were receiving nutritional supplements while only three AD family members had a feeding tube in place. One of the three AD family members had their feeding tube removed subsequent to recovering from a surgical procedure. This low number may reflect a difference in clinical practice based on evidence from research studies indicating tube feedings and other life extending procedures may cause undue pain, decrease QOL, increase suffering, and fail to sustain life in advanced AD (Abronheim, Morrison, Baskin, Morris, & Meier, 1996; Casarett, Kapo, & Caplan, 2005; Rosner, 2005).

Implications for Nursing

Findings from this study have implications for nursing practice in the areas of pain management for AD patients, patient advocacy for EOL care, and AD patient and family education. Each has unique contributions to practice that can strengthen the quality of nursing care provided to AD patients and their family members.

Pain Management for AD Patients

Findings from this study support previous findings that AD patients are undertreated for pain. Nurses need to assess adequacy of pain management provided to AD patients within their clinical practice through the use of valid instruments for the cognitively impaired population. This clinical assessment data can provide information needed to manage the AD patient’s pain. Nurses need to evaluate the effectiveness of both pharmacological and non-pharmacological pain management interventions. Non-pharmacological pain management options, such as aroma and music therapy, are not expensive and easily available for use within a home environment and in-patient facilities. Music therapy has proven to effectively impact the quality of sleep, longer sleep duration, greater sleep efficiency, shorter sleep latency, less sleep disturbance, and less daytime dysfunction in cognitively intact and cognitively impaired patients (Lai & Good, 2004). Adequately managing pain in patients with cognitive impairment is essential to improved QOL, reducing risk for patient injury, and managing behavioral problems (Cunningham, 2006; McCraken & Iverson, 2001).

Patient Advocacy for EOL Care

The majority of patients today, including many of the family members of the surrogates in this study, face EOL without an advance directive in place. Family decision-making for EOL care for a family member can be driven by an array of emotions and the inability to accept the death of their loved one. Nurses, as moral agents, must respect the ethical principles that guide nursing practice. Patient autonomy is one such principle; therefore, nursing must proactively advocate for completion of advance directives to ensure patient autonomous EOL intervention choices are defined and respected. Completion of an advance directive decreases the burden experienced by family and healthcare professionals. It can also facilitate more effective communication between family members and healthcare providers when the burden to continue care outweighs any patient benefits (Pierce, 2006).

Nonmaleficence, to do no harm, is a professional ethical principle that is not consistent with medically futile interventions. Nurses, as moral agents, must continue to question the legitimacy of EOL healthcare interventions that will result in undue pain, suffering, decreased QOL, and difficult death for the AD patient.

AD Patient and Family Education

Educating patients and family members about disease processes and disease management is central to nursing practice. AD patient education needs to be initiated during the earliest stage of diagnosis when comprehension of disease information and management interventions, such as visual cueing to support function and performance, is possible. If deemed competent during the earliest stage of diagnosis, EOL decisions could be made through completion of an advance directive. Anecdotal data gained from the researcher's interactions with family members during the education sessions suggested family members' knowledge about AD and the disease trajectory within this study was minimal. Nurses must educate family members about AD, including laymen's basic pathophysiology, stages of functional and cognitive decline, effective communication techniques, EOL interventions, QOL for the AD patient and family members, caregiver burden, effective coping skills, and grief work. The scope of patient and family centered care supports integration of this education content within the nursing environments of office practice, home care, acute and long-term in-patient care, and palliative care.

Implications for Healthcare

Findings from this study have implications for healthcare in the areas of advance directives and medical futility. Each uniquely contributes to improving healthcare practices associated with EOL care for the AD patient and their family members.

Advance Directives

Within LTC facilities, the advance directive is discussed at the time of admission. Lacy (2006) found answering such questions during the admission process was problematic to families because they felt too overwhelmed to make decisions of this magnitude during this time. Addressing the need for an advance directive sometime after admission to a LTC facility when families have had time to adjust to this major event might better facilitate advance directive completion.

Low completion rates of advance directives by the general public may be an indication that the delivery process as designed by federal and state statutes is flawed and needs to be reevaluated. The current federal statute mandates patients are asked at the time of admission to an acute care facility if they have an advance directive or if they would like information about an advance directive. Perhaps a more effective process would be to place initial contact for completion of the advance directive with the patient's primary care provider, similar to their role in office practice as a care coordinator. This could at minimum begin the discussion of EOL care with the appropriate players, as opposed to a non-medical person with limited knowledge of the document's intent and the ability to answer medical questions.

Medical Futility

The financial impact of healthcare costs for aging adults is high. The average cost of LTC in the United States is $4,654 per month (Roper, 2001). Data from the Centers for Medicare and Medicaid Services (2001) show the annual cost of hospital care in the United States as $451.2 billion. Health care cost is also greatest during the last year of life for older adults, accounting for 26.9% to 30.6% of total Medicare expenditures during the past three decades (Forrest, Goetghebeur, & Hay, 2002). Integrated into these healthcare costs are interventions that are medically futile during terminal stage AD. As shown in the literature, outcomes of medically futile interventions can result in increased pain and suffering for the patient (Casarett et al., 2005; Hancock, Chang, Johnson, Harrison, Daly, et al., 2006; Kring, 2006) and financial stress, financial ruin, and emotional burden for family members (Bertrand, Fredman, & Saczynski, 2006; Edwards et al., 2002; Harris & Noble, 2006; Rodriquez et al., 2003; Son et al., 2003). Healthcare facilities, acute and LTC, need to assess the fiscal expense of clinical practice with patient and family outcomes, including expense by payer source, QOL for patient and family members, quality of death of the patient, family coping, and surrogate resilience. Results can provide a foundation to move forward with a model of care delivery that values and integrates patient, family, clinical practice and organizational needs.

Implications for Theory Development

Support for the integrated model of Family Caregiving Dynamics and Caregiver Motives for Helping was equivocal in this study. Because of the low statistical power and poor reliability of two of the major outcome variables, the theory could not be adequately tested in this study. Of all the theoretical variables identified, the level of dementia appeared to be the most important in relation to decision motives. More research is needed to examine what happens when surrogates acceptance of the terminality of AD is internalized. This may represent a pivotal point of acceptance and initiate the surrogate's grief process.

Implications for Future Research

Future work is needed with the Family Caregiver's Motives for Helping instrument. The psychometrics of the subscales for this study, with the exception of the reward seeking decision motive, was below acceptable levels (.70) for a new instrument (Burns & Grove, 2001). The instrument needs additional items developed and tested for validity for altruistic, punishment avoidance, and distress reduction decision motives. Testing of the full instrument for validity and subsequent psychometrics is needed.

Few quantitative and qualitative studies have been conducted examining decision motives within the context of healthcare. Qualitative research looking at surrogate decision motives and family dynamics influencing healthcare EOL decision-making for their AD family member could provide additional information healthcare professionals need to better understand the phenomena of decision-making. Additionally, triangulation studies could offer validation of qualitative and quantitative findings.

Research has found that age, gender, ethnicity, religious beliefs, education, and severity of illness influence the completion of an advance directive (Mezey, Leitman, Mitty, Botrell, & Ramsey, 2000; Perkins, Geppert, Gonzales, Cortez, & Hazuda, 2002; Waters, 2001). These influencing factors have been studied by many healthcare disciplines; however, little is known about how these factors interact with one another to influence completion rates. This knowledge may help provide useful information to support redesign of the advance directive document and a more effective approach to completion of these autonomy based documents.

Adequate research exists to validate the disparity and inadequacy of pain management for cognitively-impaired patients; however, the validity of pain management instruments within the cognitively impaired population is needed. Limited research evaluating the effectiveness of pharmacological and non-pharmacological pain management interventions in the cognitively-impaired population exist. Research addressing these interventions with patient outcomes such as patient falls, sleep duration and quality, and behavioral issues can provide information to improve patient safety and patient QOL.

Conclusion

This study affirms the importance of providing surrogate and family information on EOL healthcare interventions in a supportive environment. In order to sustain this environment, healthcare professionals must develop a greater understanding of factors that influence surrogate EOL healthcare.

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Appendix A

Correlations Between Structure, Interactional Context, Situation Context, Perception and Decision Motives

Appendix A

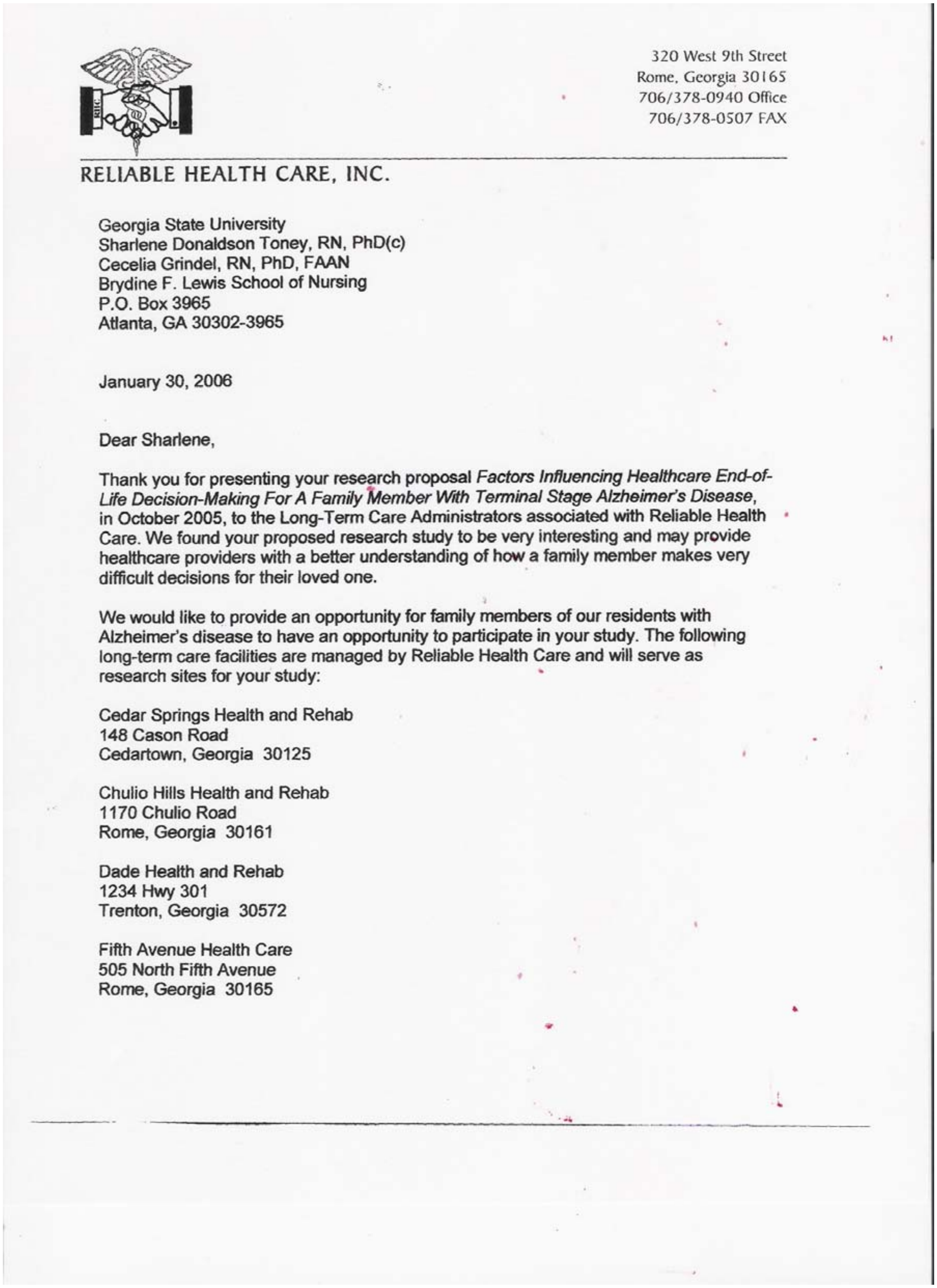
Correlations Between Structure, Interactional Context, Situational Context, Perception and Decision Motives. N = 56

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**
Structure											
1. Gender	-	-.376*	.046	.165	-.207	-.055	.016	.038	.004	.252**	.004
2. Attachment		-	-.104	.215	.297*	.077	.035	-.022	-.237**	-.082	-.230**
3. Interpersonal conflict with elder			-	.188	-.162	-.033	.504*	-.195	.079	-.264*	.009
Interactional Context											
4. Elder Image				-	-.006	.053	.009	.066	.040	.081	.037
5. Caregivers' beliefs about caregiving					-	.011	-.074	-.116	-.289*	-.057	-.158
Situational Context											
6. Dementia level						-	-.026	-.254**	-.273*	-.220**	-.156
Perception											
7. Caregiver burden							-	-.010	-.196	-.316*	.164
Decision Motives											
8. Altruistic								-	.267*	.282*	.245**
9. Reward seeking									-	.282*	.179
10. Punishment avoidance										-	-.006
11. Distress reduction											-

* p = < .05. ** p = .05 - .10.

Appendix B

Letter of Agreement from Recruitment Site



320 West 9th Street
Rome, Georgia 30165
706/378-0940 Office
706/378-0507 FAX

RELIABLE HEALTH CARE, INC.

Georgia State University
Sharlene Donaldson Toney, RN, PhD(c)
Cecelia Grindel, RN, PhD, FAAN
Brydine F. Lewis School of Nursing
P.O. Box 3965
Atlanta, GA 30302-3965

January 30, 2006

Dear Sharlene,

Thank you for presenting your research proposal *Factors Influencing Healthcare End-of-Life Decision-Making For A Family Member With Terminal Stage Alzheimer's Disease*, in October 2005, to the Long-Term Care Administrators associated with Reliable Health Care. We found your proposed research study to be very interesting and may provide healthcare providers with a better understanding of how a family member makes very difficult decisions for their loved one.

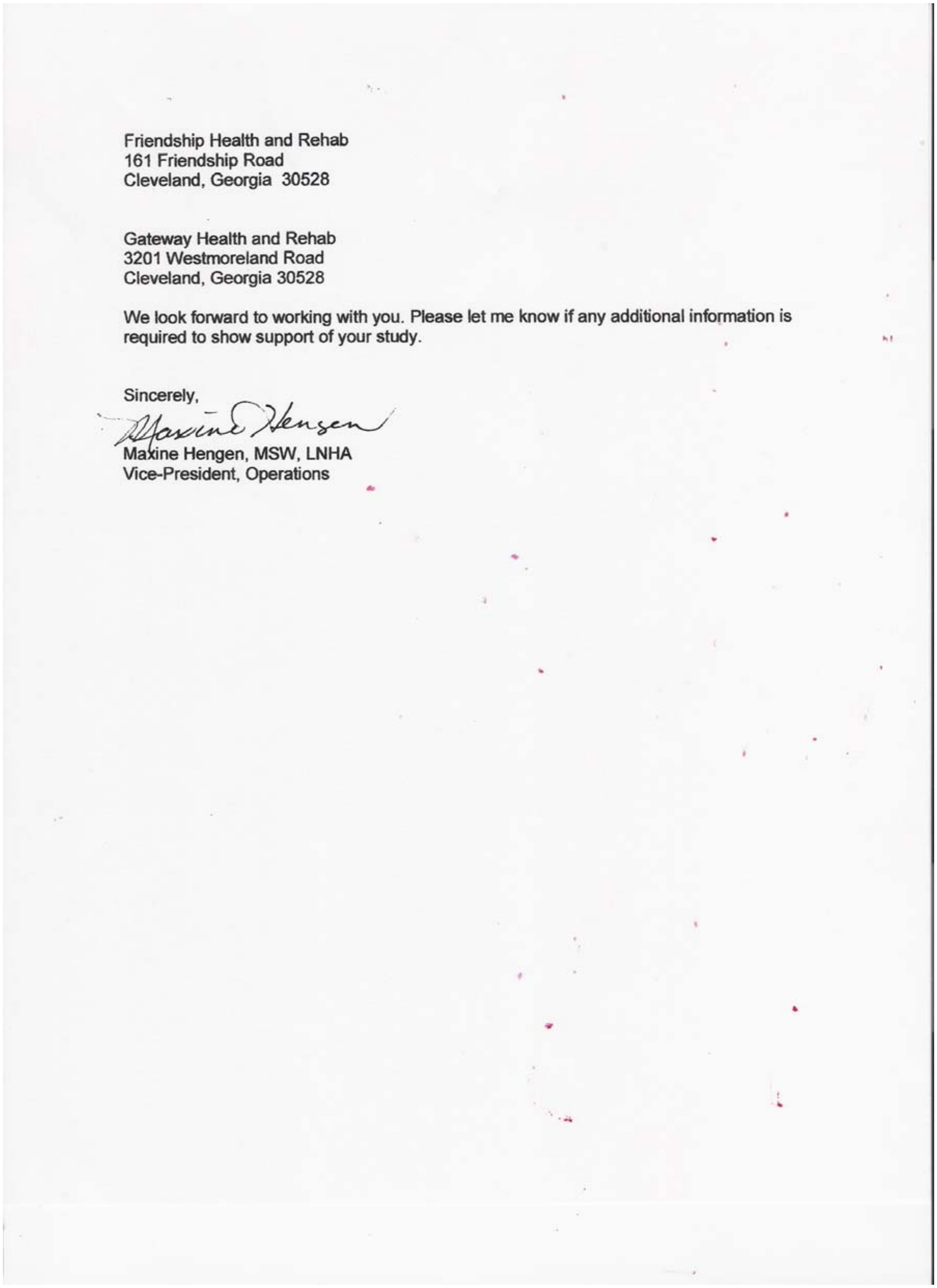
We would like to provide an opportunity for family members of our residents with Alzheimer's disease to have an opportunity to participate in your study. The following long-term care facilities are managed by Reliable Health Care and will serve as research sites for your study:

Cedar Springs Health and Rehab
148 Cason Road
Cedartown, Georgia 30125

Chulio Hills Health and Rehab
1170 Chulio Road
Rome, Georgia 30161

Dade Health and Rehab
1234 Hwy 301
Trenton, Georgia 30572

Fifth Avenue Health Care
505 North Fifth Avenue
Rome, Georgia 30165



Friendship Health and Rehab
161 Friendship Road
Cleveland, Georgia 30528

Gateway Health and Rehab
3201 Westmoreland Road
Cleveland, Georgia 30528

We look forward to working with you. Please let me know if any additional information is required to show support of your study.

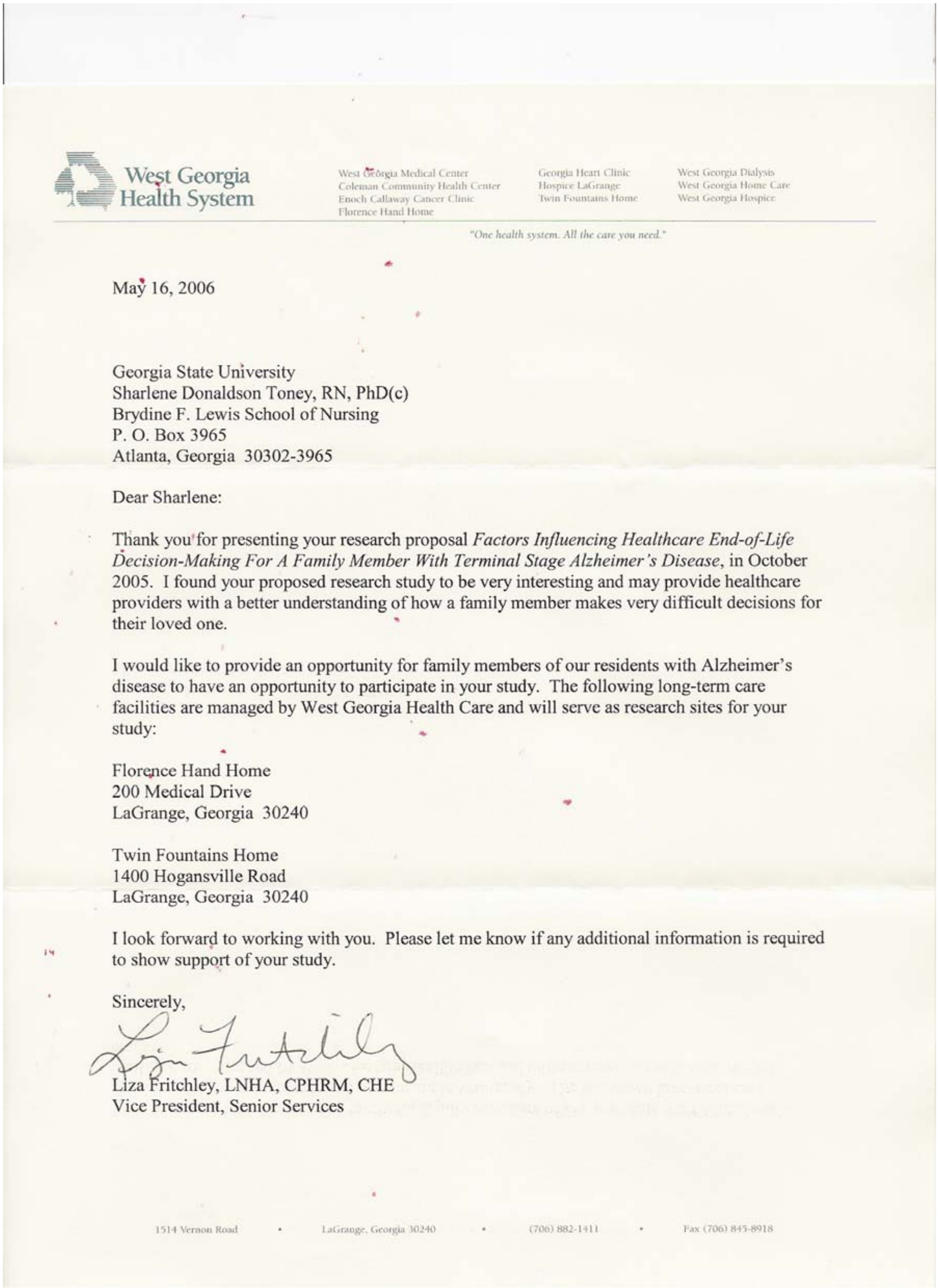
Sincerely,

Maxine Hengen

Maxine Hengen, MSW, LNHA
Vice-President, Operations

Appendix C

Letter of Support from Recruitment Site



West Georgia
Health System

West Georgia Medical Center
Coleman Community Health Center
Enoch Callaway Cancer Clinic
Florence Hand Home

Georgia Heart Clinic
Hospice LaGrange
Twin Fountains Home

West Georgia Dialysis
West Georgia Home Care
West Georgia Hospice

"One health system. All the care you need."

May 16, 2006

Georgia State University
Sharlene Donaldson Toney, RN, PhD(c)
Brydine F. Lewis School of Nursing
P. O. Box 3965
Atlanta, Georgia 30302-3965

Dear Sharlene:

Thank you for presenting your research proposal *Factors Influencing Healthcare End-of-Life Decision-Making For A Family Member With Terminal Stage Alzheimer's Disease*, in October 2005. I found your proposed research study to be very interesting and may provide healthcare providers with a better understanding of how a family member makes very difficult decisions for their loved one.

I would like to provide an opportunity for family members of our residents with Alzheimer's disease to have an opportunity to participate in your study. The following long-term care facilities are managed by West Georgia Health Care and will serve as research sites for your study:

Florence Hand Home
200 Medical Drive
LaGrange, Georgia 30240

Twin Fountains Home
1400 Hogansville Road
LaGrange, Georgia 30240

I look forward to working with you. Please let me know if any additional information is required to show support of your study.

Sincerely,

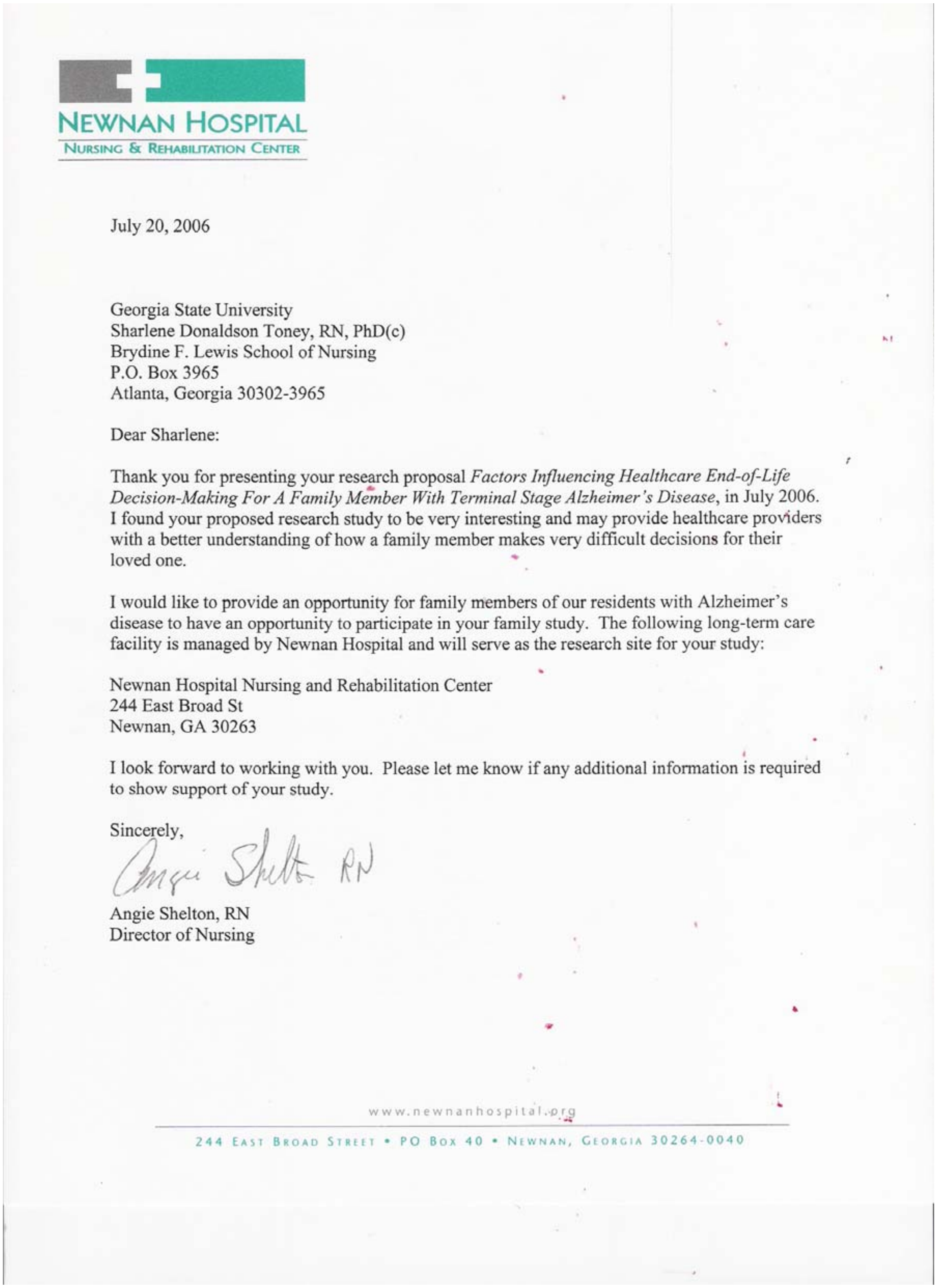
Liza Fritchley

Liza Fritchley, LNHA, CPHRM, CHE
Vice President, Senior Services

1514 Vernon Road • LaGrange, Georgia 30240 • (706) 882-1411 • Fax (706) 845-8918

Appendix D

Letter of Support from Recruitment Site



NEWNAN HOSPITAL
NURSING & REHABILITATION CENTER

July 20, 2006

Georgia State University
Sharlene Donaldson Toney, RN, PhD(c)
Brydine F. Lewis School of Nursing
P.O. Box 3965
Atlanta, Georgia 30302-3965

Dear Sharlene:

Thank you for presenting your research proposal *Factors Influencing Healthcare End-of-Life Decision-Making For A Family Member With Terminal Stage Alzheimer's Disease*, in July 2006. I found your proposed research study to be very interesting and may provide healthcare providers with a better understanding of how a family member makes very difficult decisions for their loved one.

I would like to provide an opportunity for family members of our residents with Alzheimer's disease to have an opportunity to participate in your family study. The following long-term care facility is managed by Newnan Hospital and will serve as the research site for your study:

Newnan Hospital Nursing and Rehabilitation Center
244 East Broad St
Newnan, GA 30263

I look forward to working with you. Please let me know if any additional information is required to show support of your study.

Sincerely,

Angie Shelton RN

Angie Shelton, RN
Director of Nursing

www.newnanhospital.org
244 EAST BROAD STREET • PO BOX 40 • NEWNAN, GEORGIA 30264-0040

Appendix E

Letter of Support from Recruitment Site

The Fountainview Center for Alzheimer's Disease
2631 North Druid Hills Rd. N.E.
Atlanta, Georgia 30329
(404) 325-7994
(404) 325-1213 – Fax

July 13, 2006

Georgia State University
Sharlene Donaldson Toney, RN PhD(c)
Brydine F. Lewis School of Nursing
P.O. Box 3965
Atlanta, Georgia 30302-3965

Dear Sharlene:

This is to acknowledge our approval and acceptance of your proposed research study to be performed here at our center: *Factors Influencing Surrogate Healthcare End-of-Life Decision-Making For A Family Member With Terminal -Stage Alzheimer's Disease.*

We are excited that you have chosen our center for participation in your project. We will be very interested in the outcome of your study and would appreciate the opportunity of learning so that we may better assist our families in these end-of-life decisions that can sometimes be very difficult and emotional for them.

We look forward to working with you as you move forward with this study. If there is anything else I can assist you with please feel free to contact me.

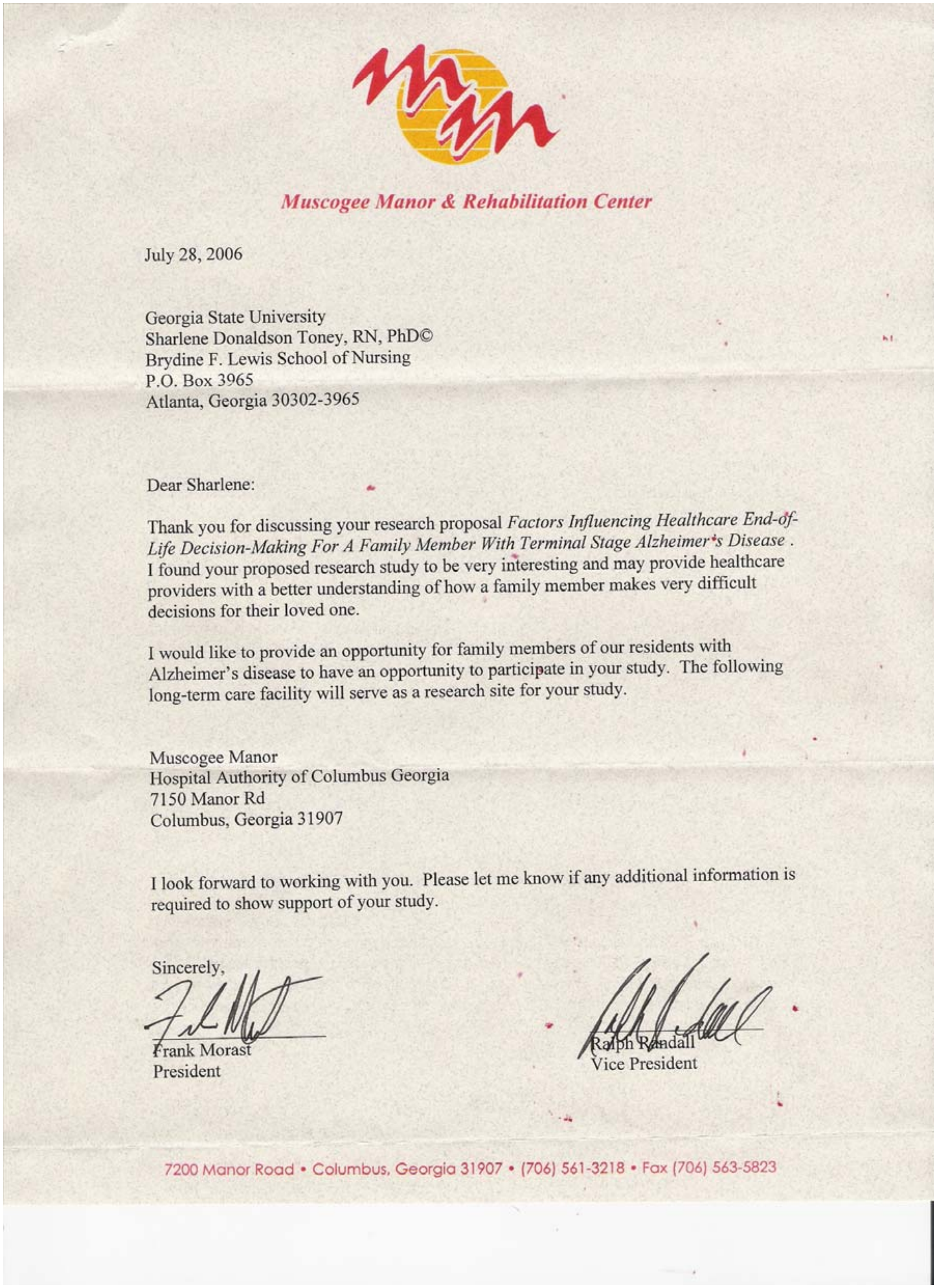
Sincerely,

Linda Kimball

Linda Kimball, LNHA
Executive Director

Appendix F

Letter of Support from Recruitment Site



Muscogee Manor & Rehabilitation Center

July 28, 2006

Georgia State University
Sharlene Donaldson Toney, RN, PhD©
Brydine F. Lewis School of Nursing
P.O. Box 3965
Atlanta, Georgia 30302-3965

Dear Sharlene:

Thank you for discussing your research proposal *Factors Influencing Healthcare End-of-Life Decision-Making For A Family Member With Terminal Stage Alzheimer's Disease* . I found your proposed research study to be very interesting and may provide healthcare providers with a better understanding of how a family member makes very difficult decisions for their loved one.

I would like to provide an opportunity for family members of our residents with Alzheimer's disease to have an opportunity to participate in your study. The following long-term care facility will serve as a research site for your study.

Muscogee Manor
Hospital Authority of Columbus Georgia
7150 Manor Rd
Columbus, Georgia 31907

I look forward to working with you. Please let me know if any additional information is required to show support of your study.

Sincerely,

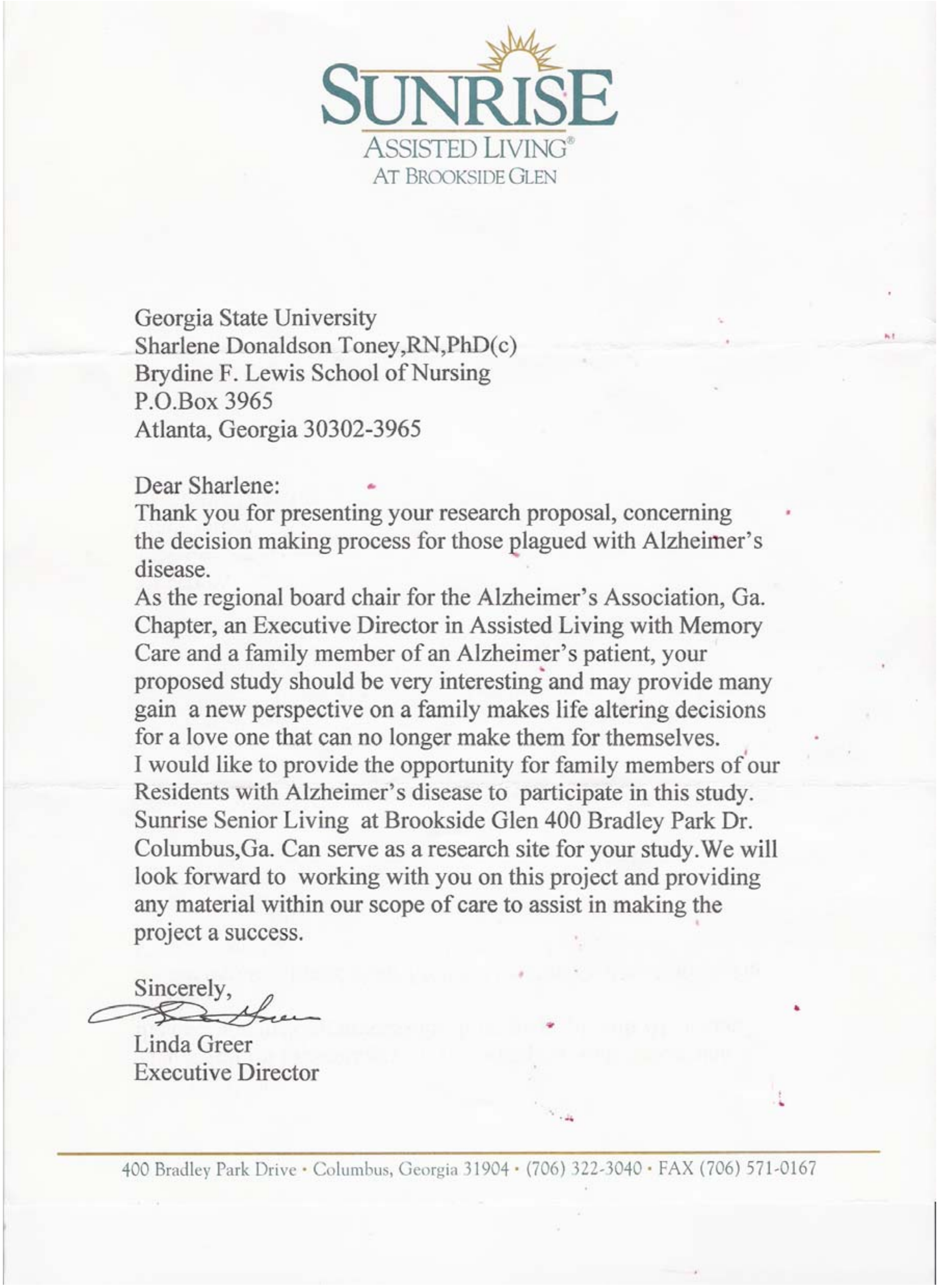
Frank Morast
President

Ralph Randall
Vice President

7200 Manor Road • Columbus, Georgia 31907 • (706) 561-3218 • Fax (706) 563-5823

Appendix G

Letter of Support from Recruitment Site



SUNRISE
ASSISTED LIVING®
AT BROOKSIDE GLEN

Georgia State University
Sharlene Donaldson Toney,RN,PhD(c)
Brydine F. Lewis School of Nursing
P.O.Box 3965
Atlanta, Georgia 30302-3965

Dear Sharlene:
Thank you for presenting your research proposal, concerning the decision making process for those plagued with Alzheimer's disease.
As the regional board chair for the Alzheimer's Association, Ga. Chapter, an Executive Director in Assisted Living with Memory Care and a family member of an Alzheimer's patient, your proposed study should be very interesting and may provide many gain a new perspective on a family makes life altering decisions for a love one that can no longer make them for themselves.
I would like to provide the opportunity for family members of our Residents with Alzheimer's disease to participate in this study. Sunrise Senior Living at Brookside Glen 400 Bradley Park Dr. Columbus,Ga. Can serve as a research site for your study.We will look forward to working with you on this project and providing any material within our scope of care to assist in making the project a success.

Sincerely,

Linda Greer
Executive Director

400 Bradley Park Drive • Columbus, Georgia 31904 • (706) 322-3040 • FAX (706) 571-0167

Appendix H

Letter of Support from Recruitment Site

COLUMBUS REGIONAL
Nursing Center

Azalea Trace Nursing Center

July 27, 2006

Georgia State University
Sharlene Donaldson Toney, RN, PhD(c)
Brydine F. Lewis School of Nursing
P.O. Box 3965
Atlanta, Georgia 30302-3965

Dear Sharlene,

I would like to thank you for presenting your proposal "Factors Influencing Healthcare End-of-Life Decision-Making for A Family Member With Terminal Stage Alzheimer's Disease", last week July 21, 2006. I found your proposed research study to be very interesting and may provide healthcare providers with a better understanding of how a family member makes very difficult decisions for their loved one.

I would like to provide an opportunity for family members of our residents with Alzheimer's disease to have an opportunity in your study. We would like to serve as a research site for your study:

I look forward to working with you. Please let me know if any additional information is required to show support of your study.

Sincerely,

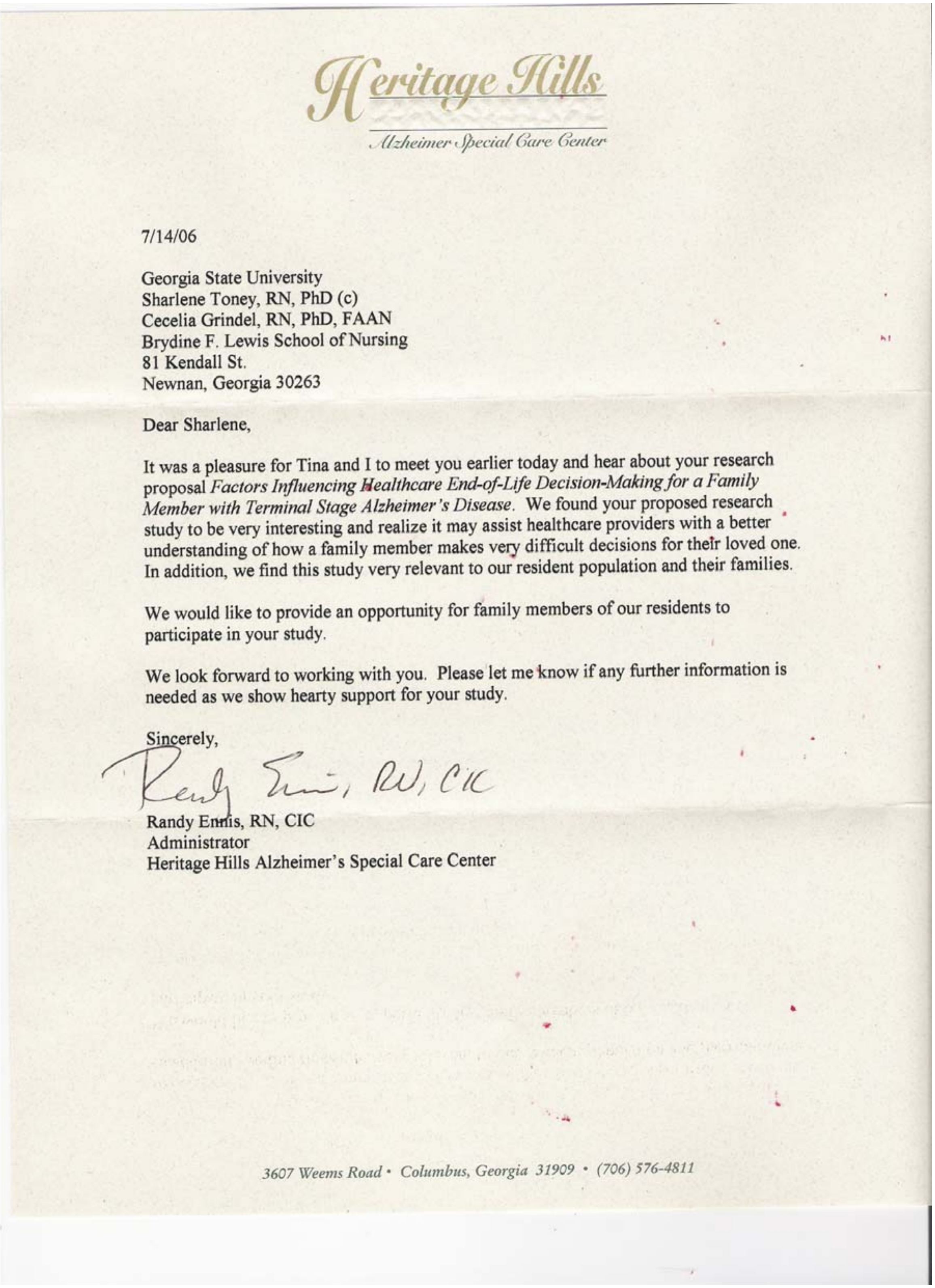
Todd West,
Administrator

VHA
United to Improve America's Health

910 TALBOTTON ROAD ☐ COLUMBUS, GEORGIA 31904 ☐ 706/323-9513

Appendix I

Letter of Support from Recruitment Site



Heritage Hills
Alzheimer Special Care Center

7/14/06

Georgia State University
Sharlene Toney, RN, PhD (c)
Cecelia Grindel, RN, PhD, FAAN
Brydine F. Lewis School of Nursing
81 Kendall St.
Newnan, Georgia 30263

Dear Sharlene,

It was a pleasure for Tina and I to meet you earlier today and hear about your research proposal *Factors Influencing Healthcare End-of-Life Decision-Making for a Family Member with Terminal Stage Alzheimer's Disease*. We found your proposed research study to be very interesting and realize it may assist healthcare providers with a better understanding of how a family member makes very difficult decisions for their loved one. In addition, we find this study very relevant to our resident population and their families.

We would like to provide an opportunity for family members of our residents to participate in your study.

We look forward to working with you. Please let me know if any further information is needed as we show hearty support for your study.

Sincerely,

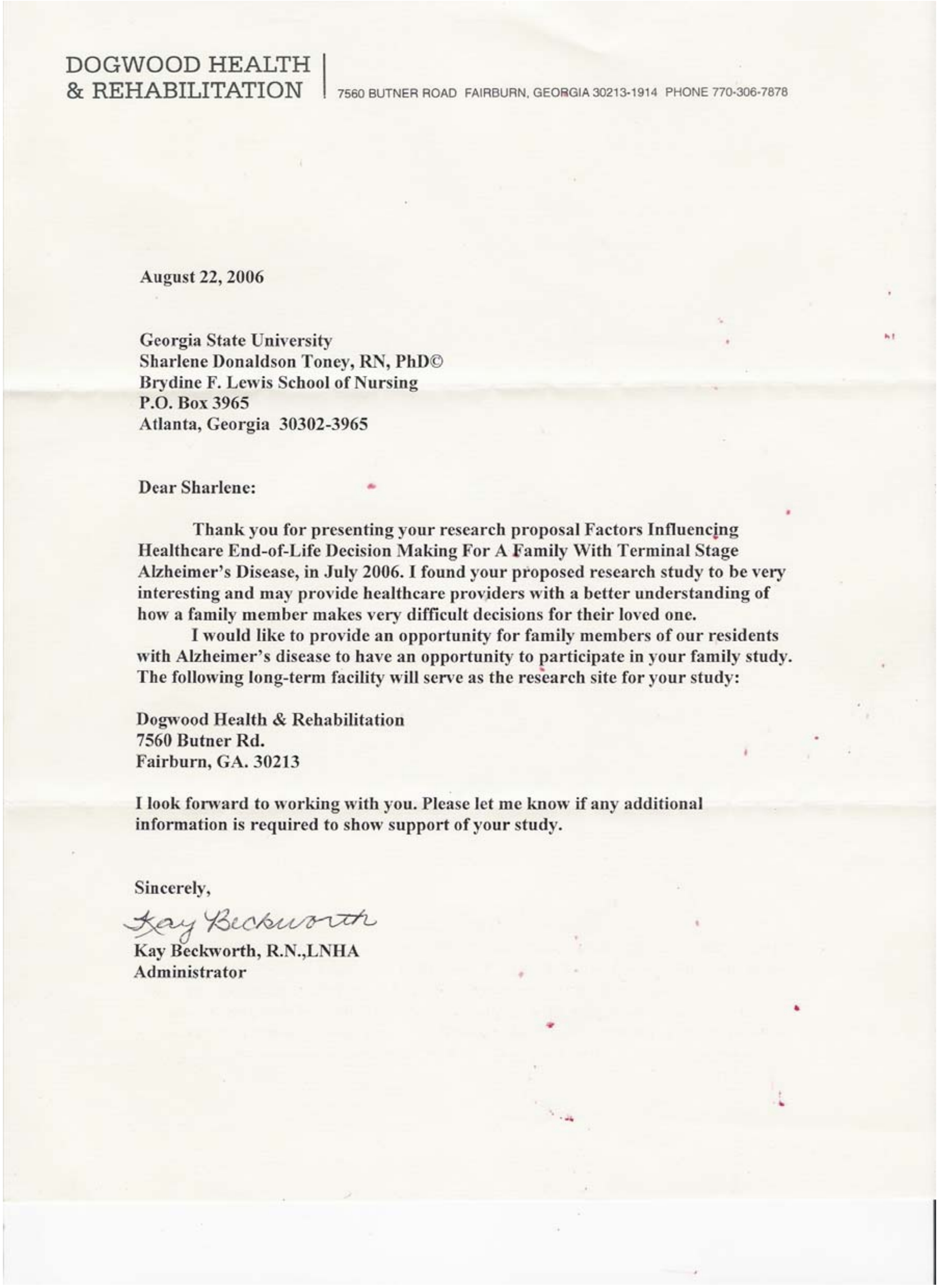
Randy Ennis, RN, CIC

Randy Ennis, RN, CIC
Administrator
Heritage Hills Alzheimer's Special Care Center

3607 Weems Road • Columbus, Georgia 31909 • (706) 576-4811

Appendix J

Letter of Support from Recruitment Site



DOGWOOD HEALTH
& REHABILITATION | 7560 BUTNER ROAD FAIRBURN, GEORGIA 30213-1914 PHONE 770-306-7878

August 22, 2006

Georgia State University
Sharlene Donaldson Toney, RN, PhD©
Brydine F. Lewis School of Nursing
P.O. Box 3965
Atlanta, Georgia 30302-3965

Dear Sharlene:

Thank you for presenting your research proposal Factors Influencing Healthcare End-of-Life Decision Making For A Family With Terminal Stage Alzheimer's Disease, in July 2006. I found your proposed research study to be very interesting and may provide healthcare providers with a better understanding of how a family member makes very difficult decisions for their loved one.

I would like to provide an opportunity for family members of our residents with Alzheimer's disease to have an opportunity to participate in your family study. The following long-term facility will serve as the research site for your study:

Dogwood Health & Rehabilitation
7560 Butner Rd.
Fairburn, GA. 30213

I look forward to working with you. Please let me know if any additional information is required to show support of your study.

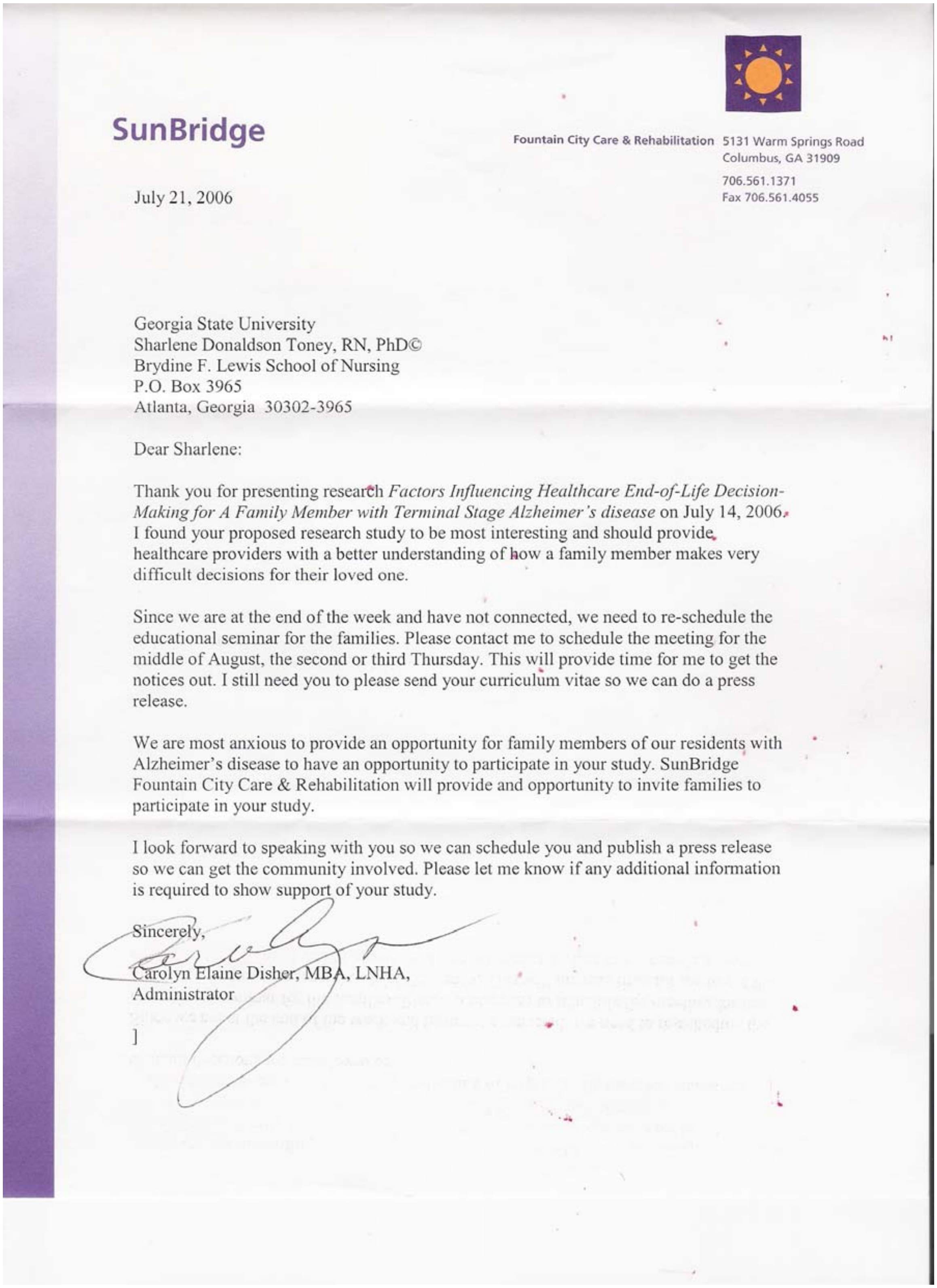
Sincerely,

Kay Beckworth

Kay Beckworth, R.N.,LNHA
Administrator

Appendix K

Letter of Support from Recruitment Site



SunBridge

Fountain City Care & Rehabilitation
5131 Warm Springs Road
Columbus, GA 31909
706.561.1371
Fax 706.561.4055

July 21, 2006

Georgia State University
Sharlene Donaldson Toney, RN, PhD©
Brydine F. Lewis School of Nursing
P.O. Box 3965
Atlanta, Georgia 30302-3965

Dear Sharlene:

Thank you for presenting research *Factors Influencing Healthcare End-of-Life Decision-Making for A Family Member with Terminal Stage Alzheimer's disease* on July 14, 2006. I found your proposed research study to be most interesting and should provide healthcare providers with a better understanding of how a family member makes very difficult decisions for their loved one.

Since we are at the end of the week and have not connected, we need to re-schedule the educational seminar for the families. Please contact me to schedule the meeting for the middle of August, the second or third Thursday. This will provide time for me to get the notices out. I still need you to please send your curriculum vitae so we can do a press release.

We are most anxious to provide an opportunity for family members of our residents with Alzheimer's disease to have an opportunity to participate in your study. SunBridge Fountain City Care & Rehabilitation will provide and opportunity to invite families to participate in your study.

I look forward to speaking with you so we can schedule you and publish a press release so we can get the community involved. Please let me know if any additional information is required to show support of your study.

Sincerely,

Carolyn Elaine Disher, MBA, LNHA,
Administrator

]

Appendix L

Letter of Introduction

Appendix L

Dear Family Members,

I am a graduate nursing student at Georgia State University. I am doing a study to understand how a person makes treatment decisions for a family member with Alzheimer's disease (AD).

I will talk about my study during a class for family members wanting to learn more about AD. At the end of the class, I will ask you to be a part of my study. I will ask you to sign a consent form. I will then give you surveys to complete about you and your family member. Your consent also allows me to assess your family member and read their chart.

Taking care of a family member with AD is very stressful. Your decision to admit your family member to a nursing home was probably very hard to make. I am interested in your treatment decisions and understanding how difficult caregiving has been for you.

I would like to invite you to attend one of the information classes. Dates and times are listed on the back of this letter. If you cannot attend a class but would like to be a part of my study, please call me at 770-252-9003. I will plan a time to meet with you personally. If you choose, I can mail the consent form and surveys to your home. I would then call you to answer any questions you may have.

Completing the surveys for the study will take about 45-minutes. The surveys include questions about you, your family member, caregiving, and stress.
Your survey answers will be kept private. Your name, the name of your relative, the nursing home's name, nor any other information that could identify you or your family will be released to anyone.

I know it is hard for you to make treatment decisions. Seeing your loved one change is difficult. I look forward to meeting you. I sincerely hope you will take time to be a part of my study.

Sincerely,
Sharlene Donaldson Toney, R.N.,
Brydine F. Lewis School of Nursing
Georgia State University, Atlanta, GA

Appendix M

Educational Flyer

Appendix M

Understanding the Stages of Alzheimer's Disease and How to Communicate

Family Members Are Invited To Attend This Special Education Session During Family Day

Date: ______________________________
Time: ______________________________
Location: ______________________________
____

Speaker: Sharlene Toney, PhD*c*, MS, RN
Georgia State University
Atlanta, GA

<u>Topics To Be Discussed:</u>

✶How common is Alzheimer’s disease?
✶What is it? What it is not!
✶How is it diagnosed?
✶How is it treated?
✶What are the stages of AD?
✶How do I talk with my family member?

Appendix N

Surrogate Demographic Information Form

Appendix N

Surrogate Demographic Information Form

Instructions: Place an **(X)** in the box or write the answer on the line to indicate the correct answer about yourself.

1. I am a: ☐ female ☐ male
2. I am ___________ years old.
3. I am ☐ married ☐ single ☐ divorced ☐ widowed
4. I am the ☐ husband ☐ wife ☐ son ☐ daughter
   ☐ ____
   of the resident with Alzheimer's disease.
5. My ethnic background is:
   - ☐ White/Caucasian
   - ☐ Latino/Spanish descent
   - ☐ African American
   - ☐ Asian
   - ☐ Oriental
   - ☐ European
6. The highest grade I completed in school was:
   - ☐ Grade school
   - ☐ Junior High/Middle School
   - ☐ High School
   - ☐ Technical School
   - ☐ Some college
   - ☐ College graduate
   - ☐ Graduate school
7. I am currently:
   - ☐ Employed outside of my home
   - ☐ Work in home office
   - ☐ Homemaker
   - ☐ Retired
   - ☐ Unemployed at the present time

8. I live within _____ miles of the nursing home where my family member with Alzheimer's disease lives.

   ☐ 1 – 5 miles
   ☐ 6 – 10 miles
   ☐ 11 – 15 miles
   ☐ 16 – 25 miles
   ☐ 26 – 35 miles
   ☐ 36 – 50 miles
   ☐ 51 or more miles

Appendix O

Surrogate Decision-Maker Questionnaire

Appendix O

Surrogate Decision-Maker Questionnaire

Instructions: Answer the following questions about your family member with Alzheimer's disease by placing an **(X)** on the box indicating your answer.

1. Do you know what an Advance Directive is? (Living Will or Durable Power of Healthcare Attorney)

☐ Yes ☐ No

If yes, what do you understand the purpose of an Advance Directive to be? (Write your explanation in the box below)

Questions continue on the next page.

2. Did your family member have an Advance Directive (Living Will or Healthcare Power of Attorney) completed before they were diagnosed with Alzheimer's disease?

   ☐ Yes ☐ No ☐ I do not know

3. Did you and your family member ever talk about the kind of healthcare treatment they wanted when they could no longer make decisions for himself/herself?

   ☐ Yes ☐ No ☐ I do not remember

Instructions: As you answer the following questions, think about the communication you have had with your family member's healthcare providers over time. This information may have been communicated during face-to-face discussions, telephone conversations, e-mail message, messages left on your telephone, etc. Answer the following questions about your family member with Alzheimer's disease by placing an **(X)** on the box indicating your answer.

4. HAVE YOU been asked by a healthcare provider to make a decision about any of the following types of care for your family member with Alzheimer's disease <u>in the last 12 months</u>?

Types of Care:

- Pain medicine
- Nutritional supplements *(vitamins, Ensure, Boost, etc.)*
- Chemotherapy, radiation therapy *(Cancer treatments)*
- Feeding tube (*a tube placed in the stomach through the abdomen to provide nutrition*)
- Central line (*a special intravenous line to give IV fluids, medicine, or nutrition)*
- Surgery.

   ☐ Yes ☐ No ☐ I do not remember

<u>If your answer is "no" or "I do not remember"</u>, skip question 5. Proceed to answer questions 6 and 7.

5. If you HAVE BEEN ASKED to make a decision about treatments in the last 12 months for your family member with Alzheimer's disease, what types of treatments did you choose? (Check all that apply)

☐ Pain medicine
☐ Nutritional supplements *(vitamins, Ensure, Boost, etc.)*
☐ Chemotherapy *(Cancer treatment)*
☐ Radiation therapy *(Cancer treatment)*
☐ Feeding tube *(a tube placed in the stomach through the abdomen to provide nutrition)*
☐ Central line *(a special intravenous line to give IV fluids, medicine, or nutrition)*
☐ Surgery
☐ Other: ______________________________
☐ None of the above

6. If you WOULD HAVE BEEN ASKED to make a decision about treatments in the last 12 months for your family member with Alzheimer's disease, what treatments would you have chosen? (Check all that apply)

☐ Pain medicine
☐ Nutritional supplements *(vitamins, Ensure, Boost, etc.)*
☐ Chemotherapy *(Cancer treatment)*
☐ Radiation therapy *(Cancer treatment)*
☐ PEG feeding tube (*a tube placed in the stomach through the abdomen to provide nutrition*)
☐ Central line (*a special intravenous line to give IV fluids, medicine, or nutrition to the resident)*
☐ Surgery
☐ Other:______________________________

7. RIGHT NOW, considering your family member's current condition which, if any of the following treatments, would you choose for your family member with Alzheimer's disease? (Check all that apply)

☐ Pain medicine
☐ Nutritional supplements *(vitamins, Ensure, Boost, etc.)*
☐ Chemotherapy *(Cancer treatment)*
☐ Radiation therapy *(Cancer treatment)*
☐ PEG feeding tube (*a tube placed in the stomach through the abdomen to provide nutrition*)
☐ Central line (*a special intravenous line to give IV fluids, medicine, or nutrition to the resident)*
☐ Surgery
☐ Other: ____
☐ I would not choose any of these treatments

Appendix P

Attachment Scale

Appendix P

ATTACHMENT SCALE

Directions: Please answer the following questions by **placing and (X) in the box** that indicates how you feel about the person for whom you provide care.

	Strongly Agree	**Agree**	**Disagree**	**Strongly disagree**
1. Being with him/her gives me warm feelings				
2. We understand each other without words.				
3. I love him/her very much.				
4. I am growing away from him/her.				
5. I feel sentimental about him/her most of the time				
6. We share important times.				
7. I am able to be myself with him/her.				
8. I am very fond of him/her.				
9. I like to spend time with him/her.				
10 I know what my elder needs without him/her having to ask..				
11. I know most everything about him/her.				
12. We are very close.				

Appendix Q

Conflict With Elder Scale

Appendix Q

Conflict With Elder
Directions: Please read each of the following statements carefully. Mark a straight line across the line to indicate your opinion. Let's do the example below.

EXAMPLE:
Generally, how much enjoyment do you get from being alone?

No enjoyment at all		As much enjoyment as possible

Participant Questions Begin Here:

a. Over the years, how much (the amount) internal conflict have you felt about your relationship with your elder?

I have felt no conflict		I have felt tremendous conflict

b. Over the years, how strong (the intensity) has been the internal conflict you have felt about your relationship with your elder?

Not strong at all		As strong as possible

c. Currently, how much (the amount) internal conflict do you feel about your relationship with your elder?

I feel no conflict		I feel tremendous conflict

d. Currently, how strong (the intensity) is the internal conflict you feel about your relationship with your elder?

Not strong at all		As strong as possible

Appendix R

Elder Image Scale

Appendix R

Elder Image Scale: Part A

DIRECTIONS:

First, think about how your family member used to be and respond to the phrase:

MY ________________ *family member's name)* **AS I REMEMBER HER/HIM.**

Second, consider each word set in order. You will notice that the words are strong opposites. All people have strengths and weaknesses. Look at the words in each set, and describe which word **best** describes how your family member used to be.

EXAMPLE:

WELL								SICK

Third, choose the extent to which the word you chose describes how your used to be; for example, EXTREMELY, QUITE, SLIGHTLY, and place an (X) in the box that represents your choice.

EXAMPLE:

	EXTREMELY	QUITE	SLIGHTLY	NEUTRAL	SLIGHTLY	QUITE	EXTREMELY	
WELL								SICK
	1st	2nd	3rd	4th	5th	6th	7th	

You will notice that the fourth (4th) or middle space is a neutral space. Try to avoid using this space. But if your choice falls in the middle between the two opposite words, go ahead and use the middle space.

How long have you known your family member? _______________**(years)**

MY ________________________ AS I REMEMBER HER/HIM

	EXTREMELY	QUITE	SLIGHTLY	NEUTRAL	SLIGHTLY	QUITE	EXTREMELY	
REASONABLE (Able to discuss things or cooperate)								UNREASONABLE
GENEROUS (Giving)								NOT GENEROUS
CALM (Relaxed)								AGITATED
LOVABLE								HATEFUL
KIND								CRUEL
PLEASANT								UNPLEASANT
FLEXIBLE (Adapt to a change in plans)								RIGID
MODEST ABOUT BODY								IMMODEST ABOUT BODY
AGREEABLE								DISAGREEABLE
UNSELFISH								SELFISH
PREDICTABLE (If she/he doesn't get something that she/he wants, do you know how she/he is going to act?)								UNPREDICTABLE
TRUSTING (Unquestioning)								SUSPICIOUS (Repeated or recurring questioning)

MY ________________*(family member's name)* AS I REMEMBER HER/HIM

	EXTREMELY	QUITE	SLIGHTLY	NEUTRAL	SLIGHTLY	QUITE	EXTREMELY	
EVEN TEMPERED								HOT TEMPERED
GRATEFUL								UNGRATEFUL
OPEN-MINDED (See things from many points of view)								NARROW-MINDED (Sees things only one way)
MATURE (Grown up)								CHILDISH
FAIR								SPITEFUL
SINCERE								DEVIOUS Sneaky or thing behind someone's back)
CONSIDERATE								ABUSIVE
EASY-TO-PLEASE								HARD-TO-PLEASE
REWARDING (Makes you feel good)								PUNISHING
HAPPY								SAD
WISE (Smart)								FOOLISH
UNDEMANDING (Makes few requests)								DEMANDING (Asking too many things)

Part B: Elder Image Scale

DIRECTIONS:

First, think about how your family member is now and respond to the phrase:

MY ________________ *(family member's name)* **AS I SEE HER/HIM NOW.**

Second, consider each word set in order. You will notice that the words are strong opposites. All people have strengths and weaknesses. Look at the words in each set, and describe which word **best** describes how your family member is now.

EXAMPLE:

WELL								SICK

Third, choose the extent to which the word you chose describes how your family member used to be; for example, EXTREMELY, QUITE, SLIGHTLY, and place an (X) in the box that represents your choice.

EXAMPLE:

	EXTREMELY	QUITE	SLIGHTLY	NEUTRAL	SLIGHTLY	QUITE	EXTREMELY	
WELL								SICK
	1st	2nd	3rd	4th	5th	6th	7th	

You will notice that the fourth (4th) or middle space is a neutral space. Try to avoid using this space. But if your choice falls in the middle between the two opposite words, go ahead and use the middle space.

MY ________________*(family member's name)* **AS I SEE HER/HIM NOW.**

	EXTREMELY	QUITE	SLIGHTLY	NEUTRAL	SLIGHTLY	QUITE	EXTREMELY	
REASONABLE (Able to discuss things or cooperate)								UNREASONABLE
GENEROUS (Giving)								NOT GENEROUS
CALM (Relaxed)								AGITATED
LOVABLE								HATEFUL
KIND								CRUEL
PLEASANT								UNPLEASANT
FLEXIBLE (Adapt to a change in plans)								RIGID
MODEST ABOUT BODY								IMMODEST ABOUT BODY
AGREEABLE								DISAGREEABLE
UNSELFISH								SELFISH
PREDICTABLE (If she/he doesn't get something that she/he wants, do you know how she/he is going to act?)								UNPREDICTABLE
TRUSTING (Unquestioning)								SUSPICIOUS (Repeated or recurring questioning)

MY _______________*(family member's name)* **AS I SEE HER/HIM NOW.**

	EXTREMELY	QUITE	SLIGHTLY	NEUTRAL	SLIGHTLY	QUITE	EXTREMELY	
EVEN TEMPERED								HOT TEMPERED
GRATEFUL								UNGRATEFUL
OPEN-MINDED (See things from many points of view)								NARROW-MINDED (Sees things only one way)
MATURE (Grown up)								CHILDISH
FAIR								SPITEFUL
SINCERE								DEVIOUS (Sneaky or thing behind someone's back)
CONSIDERATE								ABUSIVE
EASY-TO-PLEASE								HARD-TO-PLEASE
REWARDING (Makes you feel good)								PUNISHING
HAPPY								SAD
WISE (Smart)								FOOLISH
UNDEMANDING (Makes few requests)								DEMANDING (Asking too many things)

Appendix S

Beliefs About Caregiving Scale

Appendix S

Beliefs About Caregiving Scale

Directions: Please show how much you agree or disagree with each statement by **placing an (X) in the box of your choice.**

	Strongly agree	Agree	Disagree	Strongly disagree
1. As a caregiver, I must allow certainsituations to occur to teach my elder lessons.				
2. I have the responsibility of encouraging my elder to participate when interesting things are going on.				
3. Punishing my elder when s/he deliberately makes a mess is something I must do.				
4. As a caregiver, I have the responsibility of arranging my daily activities to accommodate my elder's social needs.				
5. I have the responsibility making sure that my elder takes a bath regularly.				
6. I have the responsibility of helping my elder not to embarrass her/himself.				
7. As a caregiver, letting my elder know I'm the boss is something I must do.				
8. I have the responsibility of arranging the living quarters to make it easier for my elder.				

	Strongly agree	Agree	Disagree	Strongly disagree
9. I have the responsibility of helping my elder to enjoy life.				
10. As a caregiver, I have the responsibility of providing the food my elder likes.				
11. I must help my elder to keep his surroundings clean.				
12. I must arrange my daily work to make it easier for my elder.				
13. As a caregiver, I must see my elder takes her/his medications as ordered.				
14. I have the responsibility of making my elder’s life more comfortable.				
15. I have the responsibility of confronting my elder with his/her mistakes.				
16. Making sure that my elder follows the rules of proper behavior is something I must do.				
17. I have the responsibility of correcting my elder’s mistakes.				
18. As a caregiver, “laying down the law” to my elder is something I must do.				
19. I have the responsibility of checking that my elder does things right.				

	Strongly agree	Agree	Disagree	Strongly disagree
20. As a caregiver, treating my elder like a child is something I must do for his/her own good.				
21. I must help my elder to do the things that he/she is supposed to do.				
22. As a caregiver, I have the responsibility of punishing my elder when he/she is deliberately aggravating.				
23. I have the responsibility of making sure that my elder doesn’t do anything to embarrass others.				
24. I must see that the way my elder uses the bathroom is not offensive to others				
25. As a caregiver, I must test my elder’s ability to make sound decisions.				

Appendix T

Burden Interview Scale

Appendix T

The Burden Interview Scale

INSTRUCTIONS: The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, **circle one answer** that best indicates how often you feel that way; never, rarely, sometimes, quite frequently, or nearly always. There are no “right” or “wrong” answers.

1. Do you feel that your relative asks for more help than he/she needs?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently

   4. Nearly Always

2. Do you feel that because of the time you spend with your relative that you don’t have enough time for yourself?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently

   4. Nearly Always

3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently

   4. Nearly Always

4. Do you feel embarrassed over your relative’s behavior?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently

   4. Nearly Always

5. Do you feel angry when you are around your relative?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently

   4. Nearly Always

6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently

4. Nearly Always

7. Are you afraid what the future holds for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently

4. Nearly Always

8. Do you feel your relative is dependent upon you?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently

4. Nearly Always

9. Do you feel strained when you are around your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently

4. Nearly Always

10. Do you feel your health has suffered because of your involvement with your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently

4. Nearly Always

11. Do you feel that you don’t have as much privacy as you would like, because of your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently

4. Nearly Always

12. Do you feel that your social life has suffered because you are caring for your relative?

    0. Never 1. Rarely 2. Sometimes 3. Quite Frequently

    4. Nearly Always

13. Do you feel uncomfortable about having friends over, because of your relative?

    0. Never 1. Rarely 2. Sometimes 3. Quite Frequently

    4. Nearly Always

14. Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?

    0. Never 1. Rarely 2. Sometimes 3. Quite Frequently

    4. Nearly Always

15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?

    0. Never 1. Rarely 2. Sometimes 3. Quite Frequently

    4. Nearly Always

16. Do you feel that you will be unable to take care of your relative much longer?

    0. Never 1. Rarely 2. Sometimes 3. Quite Frequently

    4. Nearly Always

17. Do you feel you have lost control of your life since your relative's illness?

    0. Never 1. Rarely 2. Sometimes 3. Quite Frequently

    4. Nearly Always

18. Do you wish you could just leave the care of your relative to someone else?

    0. Never 1. Rarely 2. Sometimes 3. Quite Frequently

    4. Nearly Always

19. Do you feel uncertain about what to do about your relative?

    0. Never 1. Rarely 2. Sometimes 3. Quite Frequently

    4. Nearly Always

20. Do you feel you should be doing more for your relative?

    0. Never 1. Rarely 2. Sometimes 3. Quite Frequently

    4. Nearly Always

21. Do you feel you could do a better job in caring for your relative?

    0. Never 1. Rarely 2. Sometimes 3. Quite Frequently

    4. Nearly Always

22. Overall, how burdened do you feel in caring for your relative?

    0. Never 1. Rarely 2. Sometimes 3. Quite Frequently

    4. Nearly Always

Appendix U

Caregivers Helping Motives for Caregiving

Appendix U

Caregiver Helping Motives for Caregiving

Instructions: Continue to think of that person and how you feel or felt about them when you were helping. C**ircle the number** that indicates if you agree or disagree with each of the following statements about helping others.

Circle one number:	Strongly Disagree						Strongly Agree
1. It makes me feel good when I help, even when help isn't needed……………………	1	2	3	4	5	6	7
2. I prefer helping the person myself instead of having someone else help…………..	1	2	3	4	5	6	7
3. When I think about helping, I think how good it makes me feel……………………	1	2	3	4	5	6	7
4. My major concern is that the person gets help he/she needs………………………..	1	2	3	4	5	6	7
5. I would rather help even if someone more qualified could………………………	1	2	3	4	5	6	7
6. When I think about helping, I try to get someone to help………………………..	1	2	3	4	5	6	7
7. When the person doesn't want help, I will stop helping…………………………….	1	2	3	4	5	6	7
8. I would rather help the person than have someone else help …………………….	1	2	3	4	5	6	7
9. I often find myself helping the person even when the help isn't really needed…	1	2	3	4	5	6	7
10. I would feel best when I help…………..	1	2	3	4	5	6	7
11. Other people can help the person; I am not the only one who can help…………..	1	2	3	4	5	6	7
12. One reason I help the person is that I would feel awful if I don't help……	1	2	3	4	5	6	7

Circle <u>one</u> number:		Strongly Disagree						Strongly Agree
13.	When I think about helping, I think about the person feeling better………	1	2	3	4	5	6	7
14.	When I think about helping, I think of what help would work or be effective…	1	2	3	4	5	6	7

Appendix V

AD Resident Demographic and History

Appendix V

Code:

AD Resident Demographic and History

Age:	**Gender:**	**Marital Status:**
	Male	Single:
	Female:	Married:
		Divorced:
	Admission to LTC:	Widow:
	Date:	
	Length of time in LTC:	**Primary diagnosis:**
	Years/Months ____________________	1.
		Secondary Diagnosis:
		2.
Intervention History:		3.
(Non- invasive interventions)		4.
Pain Management:		5.
		6.
Nutritional Supplements:	**Instrument Rating:**	7.
	GDS level:	8.
Chemotherapy:	BCRS:	9.
		10.
Radiation Therapy:	**Advanced Directive:**	
	Yes ___ No ___	
Other:		

(Invasive interventions)	**Notes**
PEG tube:	
Central Line:	
PICC Port Tunneled	
Surgery:	
Discontinuation of intervention:	

Appendix W

Global Deterioration Scale

Appendix W

The Global Deterioration Scale for Assessment of Primary Degenerative Dementia	
Level	Characteristics
1 No cognitive decline	No subjective complaints of memory deficit. No memory deficit evident on clinical interview.
2 Very mild cognitive decline (Age Associated Memory Impairment)	Subjective complaints of memory deficit, most frequently in following areas: (a) forgetting where one has placed familiar objects; (b) forgetting names one formerly knew well. No objective evidence of memory deficit on clinical interview. No objective deficits in employment or social situations. Appropriate concern with respect to symptomatology.
3 Mild cognitive decline (Mild Cognitive Impairment)	Earliest clear-cut deficits. Manifestations in more than one of the following areas: (a) patient may have gotten lost when traveling to an unfamiliar location; (b) co-workers become aware of patient's relatively poor performance; (c) word and name finding deficit becomes evident to intimates; (d) patient may read a passage or a book and retain relatively little material; (e) patient may demonstrate decreased facility in remembering names upon introduction to new people; (f) patient may have lost or misplaced an object of value; (g) concentration deficit may be evident on clinical testing. Objective evidence of memory deficit obtained only with an intensive interview. Decreased performance in demanding employment and social settings. Denial begins to become manifest in patient. Mild to moderate anxiety accompanies symptoms.

Level	Characteristics
4 Moderate cognitive decline (Mild Dementia)	Clear-cut deficit on careful clinical interview. Deficit manifest in following areas: (a) decreased knowledge of current and recent events; (b) may exhibit some deficit in memory of ones personal history; (c) concentration deficit elicited on serial subtractions; (d) decreased ability to travel, handle finances, etc. Frequently no deficit in following areas: (a) orientation to time and place; (b) recognition of familiar persons and faces; (c) ability to travel to familiar locations. Inability to perform complex tasks. Denial is dominant defense mechanism. Flattening of affect and withdrawal from challenging situations frequently occur.
5 Moderately severe cognitive decline (Moderate Dementia)	Patient can no longer survive without some assistance. Patient is unable during interview to recall a major relevant aspect of their current lives, e.g., an address or telephone number of many years, the names of close family members (such as grandchildren), the name of the high school or college from which they graduated. Frequently some disorientation to time (date, day of week, season, etc.) or to place. An educated person may have difficulty counting back from 40 by 4s or from 20 by 2s. Persons at this stage retain knowledge of many major facts regarding themselves and others. They invariably know their own names and generally know their spouse’s and children's names. They require no assistance with toileting and eating, but may have some difficulty choosing the proper clothing to wear.

Level	Characteristics
6 Severe cognitive decline (Moderately Severe Dementia)	May occasionally forget the name of the spouse upon whom they are entirely dependent for survival. Will be largely unaware of all recent events and experiences in their lives. Retain some knowledge of their past lives but this is very sketchy. Generally unaware of their surroundings, the year, the season, etc. May have difficulty counting from 10, both backward and, sometimes, forward. Will require some assistance with activities of daily living, e.g., may become incontinent, will require travel assistance but occasionally will be able to travel to familiar locations. Diurnal rhythm frequently disturbed. Almost always recall their own name. Frequently continue to be able to distinguish familiar from unfamiliar persons in their environment. Personality and emotional changes occur. These are quite variable and include: (a) delusional behavior, e.g., patients may accuse their spouse of being an impostor, may talk to imaginary figures in the environment, or to their own reflection in the mirror; (b) obsessive symptoms, e.g., person may continually repeat simple cleaning activities; (c) anxiety symptoms, agitation, and even previously nonexistent violent behavior may occur; (d) cognitive abulla, i.e., loss of willpower because an individual cannot carry a thought long enough to determine a purposeful course of action.
7 Very severe cognitive decline (Severe Dementia)	All verbal abilities are lost over the course of this stage. Frequently there is no speech at all -only unintelligible utterances and rare emergence of seemingly forgotten words and phrases. Incontinent of urine, requires assistance toileting and feeding. Basic psychomotor skills, e.g., ability to walk, are lost with the progression of this stage. The brain appears to no longer be able to tell the body what to do. Generalized rigidity and developmental neurologic reflexes are frequently present.

Appendix X

Brief Cognitive Rating Scale

Appendix X

Brief Cognitive Rating Scale (BCRS)		
Assessment Date:		Rating
Circle the Highest Rating Attained		Axis I: Concentration
1	1=	No objective or subjective evidence of deficit in concentration.
2	2=	Subjective decrement in concentration ability.
3	3=	Minor objective signs of poor concentration (e.g., subtraction of serial 7's from 100).
4	4=	Definite concentration deficit for persons of their backgrounds (e.g. marked deficit on serial 7's; frequent deficit in subtraction of serials 4's from 40).
5	5=	Marked concentration deficit (e.g., giving months backwards or serials 2's from 20).
6	6=	Forgets the concentration task. Frequently begins to count forward when asked to count backwards from 10 by 1's.
7	7=	Marked difficulty counting forward to 10 by 1's.
		Axis II: Recent Memory
1	1=	No objective or subjective evidence of deficit in recent memory.
2	2=	Subjective impairment only (e.g., forgetting names more than formerly).
3	3=	Deficit in recall of specific events evident upon detailed questioning. No deficit in recall of major recent events.
4	4=	Cannot recall major events of previous weekend or week. Scanty knowledge (not detailed) of current events, favorite TV shows, etc.
5	5=	Unsure of weather; may not know current President or current address.
6	6=	Occasional knowledge of some events. Little or no idea of current address, weather, etc.
7	7=	No knowledge of any recent events.

Circle the Highest Rating Attained		
		Axis III: Past Memory
1	1=	No subjective or objective impairment in past memory.
2	2=	Subjective impairment only. Can recall two or more primary school teachers.
3	3=	Some gaps in past memory upon detailed questioning. Able to recall at least one childhood teacher and/or one childhood friend.
4	4=	Clear-cut deficit. The spouse recalls more of the patient's past than the patient. Cannot recall childhood friends and/or teachers but knows the names of most schools attended. Confuses chronology in reciting personal history.
5	5=	Major past events sometimes not recalled (e.g., names of schools attended).
6	6=	Some residual memory of past (e.g., may recall country of birth or former occupation).
7	7=	No memory of past.
		Axis IV: Orientation
1	1=	No deficit in memory for time, place, identify of self or others.
2	2=	Subjective impairment only. Knows time to nearest hour, location.
3	3=	Any mistakes in time >2 hours: day of week > 1 day; date > 3 days.
4	4=	Mistakes in month > 10 days or year > 1 month.
5	5=	Unsure of month and/or year and/or season; unsure of locale.
6	6=	No idea of date. Identifies spouse but may not recall name. Knows own name.
7	7=	Cannot identify spouse. May be unsure of personal identity.

Circle the Highest Rating Attained		
		Axis V: Functioning and Self-Care
1	1=	No difficulty, either subjectively or objectively.
2	2=	Complains of forgetting location of objects. Subjective work difficulties.
3	3=	Decreased job functioning evident to coworkers. Difficulty traveling to new locations.
4	4=	Decreased ability to perform complex tasks (e.g., planning dinner for guests, handling finances, marketing, etc.)
5	5=	Requires assistance in choosing proper clothing.
6	6=	Requires assistance in feeding, and/or toileting, and/or bathing, and/or ambulating.
7	7=	Requires constant assistance in all activities of daily life.
	=	Total Score
/5=	/5=	Stage on Global Deterioration Scale (GDS)

Axis II: Impairment of Recent Memory –

> Ask "What did you do last weekend? What did you have for breakfast? What is the weather like today? Who is the president, the governor, etc."

Axis III: Impairment of Past Memory –

> Ask "What primary school did you attend? Where was it located? Who were your primary teachers? Where were you born? Who were your childhood friends? What kinds of things did you do with your childhood friends?"

Axis IV: Orientation –

> Ask hour, day of week, date, place, identity of self.

Axis V: Functioning and Self-Care

Appendix Y

Georgia State University IRB Approval

Appendix Y

Georgia State University

INSTITUTIONAL REVIEW BOARD

Mail: P.O. Box 3999
Atlanta, Georgia 30302-3999

In Person: Alumni Hall
30 Courtland St, Suite 217

Phone: 404/463-0674
Fax: 404/654-5838

April 11, 2006

Principal Investigator: Grindel, Cecelia Marie

Student PI: Sharlene Donaldson

Protocol Department: B.F. Lewis School of Nursing

Protocol Title: Factors Influencing Surrogate End-of-Life Healthcare Decision-Making for a Family Member with Terminal Stage Alzheimer's Disease

Submission Type: Protocol H06338

Review Type: Expedited Review

Approval Date: April 11, 2006

Expiration Date: April 10, 2007

The Georgia State University Institutional Review Board (IRB) reviewed and approved the above referenced study and enclosed Informed Consent Document(s) in accordance with the Department of Health and Human Services. The approval period is listed above.

Federal regulations require researchers to follow specific procedures in a timely manner. For the protection of all concerned, the IRB calls your attention to the following obligations that you have as Principal Investigator of this study.

1. When the study is completed, a Study Closure Report must be submitted to the IRB.
2. For any research that is conducted beyond the one-year approval period, you must submit a Renewal Application 30 days prior to the approval period expiration. As a courtesy, an email reminder is sent to the Principal Investigator approximately two months prior to the expiration of the study. However, failure to receive an email reminder does not negate your responsibility to submit a Renewal Application. In addition, failure to return the Renewal Application by its due date must result in an automatic termination of this study. Reinstatement can only be granted following resubmission of the study to the IRB.

3. Any adverse event or problem occurring as a result of participation in this study must be reported immediately to the IRB using the Adverse Event Form.

4. Principal investigators are responsible for ensuring that informed consent is obtained and that no human subject will be involved in the research prior to obtaining informed consent. Ensure that each person signing the written informed consent form (ICF) is given a copy of the ICF. The ICF used must be the one reviewed and approved by the IRB; the approval dates of the IRB review are stamped on each page of the ICF. Copy and use the stamped ICF for the coming year. Maintain a single copy of the approved ICF in your files for this study.

All of the above referenced forms are available online at https://irbwise.gsu.edu. Please do not hesitate to contact Susan Vogtner in the Office of Research Integrity (404-463-0674) if you have any questions or concerns.

Sincerely,

ACKruger

Ann C. Kruger, IRB Chair

Georgia State University

INSTITUTIONAL REVIEW BOARD

Mail: P.O. Box 3999 In Person: Alumni Hall
Atlanta, Georgia 30302-3999 30 Courtland St, Suite 217
Phone: **404/463-0674**
Fax: **404/654-5838**

June 5, 2006

Principal Investigator: Grindel, Cecelia Marie

Protocol Department: B.F. Lewis School of Nursing

Protocol Title: Factors Influencing Surrogate End-of-Life Healthcare Decision-Making for a Family Member with Terminal Stage Alzheimer's Disease

Submission Type: Amendment #1 for H06338

Review Type: Expedited Review

Approval Date: April 11, 2006

Expiration Date: April 10, 2007

The Georgia State University Institutional Review Board reviewed and **approved** your amendment to your above referenced Protocol. This amendment includes adding two sites.

This approval period is listed above and must be renewed at least 30 days before the expiration date if research is to continue beyond that time frame. Renewal proposals may be resubmitted in abbreviated form.

Any adverse reactions or problems resulting from this investigation must be reported immediately to the University Institutional Review Board. For more information, see the hand out on IRB procedures available from the Research Office.

For more information visit our website at www.gsu.edu/irb.

Sincerely,

ACKruger

Ann C. Kruger, IRB Chair

Federal Wide Assurance Number: 00000129

Georgia State University

INSTITUTIONAL REVIEW BOARD

Mail: P.O. Box 3999
Atlanta, Georgia 30302-3999

In Person: Alumni Hall
30 Courtland St, Suite 217

Phone: **404/463-0674**
Fax: **404/654-5838**

July 25, 2006

Principal Investigator: Grindel, Cecelia Marie

Protocol Department: B.F. Lewis School of Nursing

Protocol Title: Factors Influencing Surrogate End-of-Life Healthcare Decision-Making for a Family Member with Terminal Stage Alzheimer's Disease

Funding Agency:

Submission Type: Amendment #2 for H06338

Review Type: Expedited Review

Approval Date: April 11, 2006

Expiration Date: April 10, 2007

The Georgia State University Institutional Review Board reviewed and **approved** your amendment to add an additional site for recruitment (Fountainview Center for Alzheimer's Disease) to your above referenced Protocol.

This approval period is listed above and must be renewed at least 30 days before the expiration date if research is to continue beyond that time frame. Renewal proposals may be resubmitted in abbreviated form.

Any adverse reactions or problems resulting from this investigation must be reported immediately to the University Institutional Review Board. For more information, see the hand out on IRB procedures available from the Research Office.

For more information visit our website at www.gsu.edu/irb.

Sincerely,

ACKruger

Ann C. Kruger, IRB Chair

Federal Wide Assurance Number: 00000129

Georgia State University

INSTITUTIONAL REVIEW BOARD

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July 25, 2006

Principal Investigator: Grindel, Cecelia Marie

Department: B.F. Lewis School of Nursing

Protocol Title: Factors Influencing Surrogate End-of-Life Healthcare Decision-Making for a Family Member with Terminal Stage Alzheimer's Disease

Funding Agency:

Submission Type: Amendment #3 for H06338

Review Type: Expedited Review

Approval Date: April 11, 2006

Expiration Date: April 10, 2007

The Georgia State University Institutional Review Board reviewed and **approved** your amendment to add an additional site (Heritage Hills) to your above referenced Protocol.

This approval period is listed above and must be renewed at least 30 days before the expiration date if research is to continue beyond that time frame. Renewal proposals may be resubmitted in abbreviated form.

Any adverse reactions or problems resulting from this investigation must be reported immediately to the University Institutional Review Board. For more information, see the hand out on IRB procedures available from the Research Office.

For more information visit our website at www.gsu.edu/irb.

Sincerely,

ACKruger

Ann C. Kruger, IRB Chair

Federal Wide Assurance Number: 00000129

Georgia State University

INSTITUTIONAL REVIEW BOARD

Mail: P.O. Box 3999
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Phone: **404/463-0674**
Fax: **404/654-5838**

In Person: Alumni Hall
30 Courtland St, Suite 217

July 27, 2006

Principal Investigator: Grindel, Cecelia Marie

Protocol Department: B.F. Lewis School of Nursing

Protocol Title: Factors Influencing Surrogate End-of-Life Healthcare Decision-Making for a Family Member with Terminal Stage Alzheimer's Disease

Submission Type: Amendment #4 for H06338

Review Type: Expedited Review

Approval Date: April 11, 2006

Expiration Date: April 10, 2007

The Georgia State University Institutional Review Board reviewed and **approved** your amendment to your above referenced Protocol. This amendment includes adding a site.

This approval period is listed above and must be renewed at least 30 days before the expiration date if research is to continue beyond that time frame. Renewal proposals may be resubmitted in abbreviated form.

Any adverse reactions or problems resulting from this investigation must be reported immediately to the University Institutional Review Board. For more information, see the hand out on IRB procedures available from the Research Office.

For more information visit our website at www.gsu.edu/irb.

Sincerely,

ACKruger

Ann C. Kruger, IRB Chair

Federal Wide Assurance Number: 00000129

INSTITUTIONAL REVIEW BOARD

Mail: P.O. Box 3999 In Person: Alumni Hall
Atlanta, Georgia 30302-3999 30 Courtland St, Suite 217
Phone: 404/463-0674
Fax: 404/654-5838

August 1, 2006

Principal Investigator: Grindel, Cecelia Marie

Protocol Department: B.F. Lewis School of Nursing

Protocol Title: Factors Influencing Surrogate End-of-Life Healthcare Decision-Making for a Family Member with Terminal Stage Alzheimer's Disease

Submission Type: Amendment #5 for H06338

Review Type: Expedited Review

Approval Date: April 11, 2006

Expiration Date: April 10, 2007

The Georgia State University Institutional Review Board reviewed and **approved** your amendment to your above referenced Protocol. This amendment includes adding a site.

This approval period is listed above and must be renewed at least 30 days before the expiration date if research is to continue beyond that time frame. Renewal proposals may be resubmitted in abbreviated form.

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Sincerely,

Ann C. Kruger, IRB Chair

Federal Wide Assurance Number: 00000129

INSTITUTIONAL REVIEW BOARD

Mail: P.O. Box 3999 In Person: Alumni Hall
Atlanta, Georgia 30302-3999 30 Courtland St, Suite 217
Phone: **404/463-0674**
Fax: **404/654-5838**

August 3, 2006

Principal Investigator: Grindel, Cecelia Marie

Protocol Department: B.F. Lewis School of Nursing

Protocol Title: Factors Influencing Surrogate End-of-Life Healthcare Decision-Making for a Family Member with Terminal Stage Alzheimer's Disease

Submission Type: Amendment #6 for H06338

Review Type: Expedited Review

Approval Date: April 11, 2006

Expiration Date: April 10, 2007

The Georgia State University Institutional Review Board reviewed and **approved** your amendment to your above referenced Protocol. This amendment includes adding a site.

This approval period is listed above and must be renewed at least 30 days before the expiration date if research is to continue beyond that time frame. Renewal proposals may be resubmitted in abbreviated form.

Any adverse reactions or problems resulting from this investigation must be reported immediately to the University Institutional Review Board. For more information, see the hand out on IRB procedures available from the Research Office.

For more information visit our website at www.gsu.edu/irb.

Sincerely,

ACKruger

Ann C. Kruger, IRB Chair

Federal Wide Assurance Number: 00000129

Georgia State University

INSTITUTIONAL REVIEW BOARD

Mail: P.O. Box 3999
Atlanta, Georgia 30302-3999
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30 Courtland St, Suite 217
Phone: 404/463-0674
Fax: 404/654-5838

August 7, 2006

Principal Investigator: Grindel, Cecelia Marie

Protocol Department: B.F. Lewis School of Nursing

Protocol Title: Factors Influencing Surrogate End-of-Life Healthcare Decision-Making for a Family Member with Terminal Stage Alzheimer's Disease

Submission Type: Amendment #7 for H06338

Review Type: Expedited Review

Approval Date: April 11, 2006

Expiration Date: April 10, 2007

The Georgia State University Institutional Review Board reviewed and **approved** your amendment to your above referenced Protocol. This amendment includes adding a site.

This approval period is listed above and must be renewed at least 30 days before the expiration date if research is to continue beyond that time frame. Renewal proposals may be resubmitted in abbreviated form.

Any adverse reactions or problems resulting from this investigation must be reported immediately to the University Institutional Review Board. For more information, see the hand out on IRB procedures available from the Research Office.

For more information visit our website at www.gsu.edu/irb.

Sincerely,

ACKruger

Ann C. Kruger, IRB Chair

Federal Wide Assurance Number: 00000129

Georgia State University

INSTITUTIONAL REVIEW BOARD

Mail: P.O. Box 3999
Atlanta, Georgia 30302-3999
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30 Courtland St, Suite 217
Phone: 404/463-0674
Fax: 404/654-5838

August 29, 2006

Principal Investigator: Grindel, Cecelia Marie

Protocol Department: B.F. Lewis School of Nursing

Protocol Title: Factors Influencing Surrogate End-of-Life Healthcare Decision-Making for a Family Member with Terminal Stage Alzheimer's Disease

Submission Type: Amendment #8 for H06338

Review Type: Expedited Review

Approval Date: April 11, 2006

Expiration Date: April 10, 2007

The Georgia State University Institutional Review Board reviewed and **approved** your amendment to your above referenced Protocol. This amendment includes adding two sites.

This approval period is listed above and must be renewed at least 30 days before the expiration date if research is to continue beyond that time frame. Renewal proposals may be resubmitted in abbreviated form.

Any adverse reactions or problems resulting from this investigation must be reported immediately to the University Institutional Review Board. For more information, see the hand out on IRB procedures available from the Research Office.

For more information visit our website at www.gsu.edu/irb.

Sincerely,

ACKruger

Ann C. Kruger, IRB Chair

Federal Wide Assurance Number: 00000129

Appendix Z

Informed Consent

Appendix Z

BYRDINE F. LEWIS SCHOOL OF NURSING
College of Health and Human Sciences

PO Box 4019
Atlanta, GA 30802-4019
Phone: 404/651-3040
Fax: 404/651-3096

GeorgiaStateUniversity

Informed Consent Form

Title: Factors Influencing Surrogate Healthcare End-of-Life Decision-Making for a Family Member with Terminal Stage Alzheimer's Disease

Principal Investigator:	Cecelia Grindel, PhD, RN, FAAN
Student Investigator:	Sharlene Toney, MS, PhDc, RN

My name is Sharlene Toney. I am a nurse working on a graduate degree at Georgia State University. I am seeking people who make treatment decisions for a family member who has Alzheimer's disease (AD) to be a part of my research study. The purposes of this study are to:

1. See if a spouse and child make different types of treatment decisions
2. See if men and women make different types of treatment decisions
3. Understand how feelings of closeness, difficulty in care-giving and the family bond affects the decision-maker's choice of treatments

I need 150 people for this study. I am asking you to be a part of my study because you make treatment decisions for your family member with AD.

Procedures: If you decide to be a part of my study, you are giving me permission to assess your family member level of dementia. I will need to review their medical record. You will answer 7 surveys about yourself and your family member with AD. The surveys will take about 45 minutes to finish. The surveys include questions:

1. about your age, family relationship, employment
2. about treatment decisions you have made for your family member
3. about feelings of closeness to your family member

4. about conflict you have faced with your family member
5. about your feelings about your family member in the past and now
6. about care giving beliefs
7. about difficulties you have faced in caring for your family member, and
8. about why you provide care for your family member.

Risks: There is a chance your family member may become restless during my assessment. I will stop until your family member is calmer. This restlessness is the same that occurs when nurses assess and give daily care to your family member. It will take me about 2-hours to assess your family member and look at their chart.

There are no physical risks or discomforts to you for being a part of my study. You may remember some painful thoughts or memories while answering the questions.

Benefits: There are no benefits to you for being a part of my study. Health care workers may better understand how people make decisions for a family member.

Voluntary Participation and Withdrawal: Being a part of my study is voluntary. You can decide not to be a part of the study at any time. You can quit at any time without any harm coming to you or your family member. If you quit, then questions already answered will be used but no more information will be obtained.

Confidentiality: I will try to keep your personal information private. Your privacy will be kept to the extent allowed by law. I will remove all information that can identify you. If you decide you want to be in this study it means that you agree to let me use and share your information for reasons I have listed in this Consent Form.

I may use only the information that you have given me (your name, age, gender) during this study. I will be the only person looking at you and your family member's information. I may also share your information with the Georgia State University Institutional Review Board (IRB) and my advisor, Dr Cecelia Grindel. Your personal health information may be shared by the people or places I have listed. It will be shared in a way that does not fall under the protection of federal rules.

BYRDINE F. LEWIS SCHOOL OF NURSING
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Fax: 404/651-3096

GeorgiaStateUniversity

If you sign this form you are letting me use your personal information until the end of this study. You can tell me not to use your personal information after I have collected it. If you do not want me to use your information anymore, you must write a letter asking me not to use your information. I will be the only person who will be able to know which surveys are yours. Because the surveys do not have your name or address on them, I might not know which surveys are yours. If you don't want me to use your information anymore, I will stop using it, but any information already used in the study will not be removed.

You may not be able to look at or get a copy of the information that you gave me while I am doing the research but you will be able to look at or get a copy at the end of the study.

This research may be shown to other researchers in an aggregate format without identifying you. This study may be published, but steps will be taken to make sure that you cannot be identified.

If you have any question about this study, or believe you have suffered any injury because of being a part of this study, you may contact Sharlene Toney, MS, PhD(c), RN at 770-252-9003. Your personal doctor will make available or arrange for appropriate management and treatment for any physical or emotional injury resulting from this study. Georgia State University, however, will not pay for your care or compensate you if something should occur.

Contact Person: Call Cecelia Grindel, PhD, RN, FAAN at 404-6513212 or Sharlene Toney, RN at 770-252-9003 if you have questions about this study.

If you have questions or concerns about your rights as being a part of this study, you may call the Institutional Review Board (IRB) which oversees the protection of human research participants. Susan Vogtner, in the Office of Research Integrity, can be reached at 404-463-0674.

We will give you a copy of this consent form to keep.

BYRDINE F. LEWIS SCHOOL OF NURSING
College of Health and Human Sciences

PO Box 4019
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Phone: 404/651-3040
Fax: 404/651-3096

GeorgiaStateUniversity

If you are willing to volunteer for this research, please sign below.

__________________________________ _______________________
Participant’s Signature Date

__________________________________ _______________________
Participant’s Name (PRINT) Date

__________________________________ _______________________
Investigator’s or Designee’s Signature Date