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# The Impact of Hospice and Dementia Special Care Units on End-of-Life Care for Individuals with Dementia

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The Impact of Hospice and Dementia Special Care Units on End-of-Life Care for  
Individuals with Dementia

by

Catherine E. McCarty

A dissertation submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy  
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## Dedication

This is dedicated to my parents, Paul and June McCarty who showed me the value of hard work, compassion and persistence. I am ever so grateful that their commitment allowed me the opportunity to pursue my education and to Laura Schmidt Pazaretti who taught me to dive.

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## Table of Contents

List of Tables	iv
List of Figures	v
Abstract	vi
Chapter One: Introduction	1
Unique Contribution	1
Organization of the Dissertation	2
Chapter Two: Background and Literature Review End-of-Life in Long-Term Care	4
Palliative Care in Long Term Care	4
Hospice Benefit in Long Term Care	7
Hospice Utilization in Long Term Care	8
Family Satisfaction with Hospice	9
Barriers to Hospice Utilization in Long Term Care	9
EOL for Individuals with Dementia in Nursing Homes	13
Estimating Prognosis	14
Palliative Care for Individuals with Alzheimer’s disease	15
Dementia Care in Long Term Care	16
Dementia Special Care Units (DSCU) in LTC	17
Environmental Theory	17
Person-Centered Focus	20
DSCUs and Inter-Disciplinary Team	21
Hospice & DSCU Shared Strengths	24
Reality of Access	25
Access to Hospice for Individuals with Dementia	26
Access to DSCUs	27
Chapter Three: Theoretical Overview & Research Questions	29
Theory	29
SPO Theoretical Components	31
Research Questions	32
Study Components	33
Resident Risk Characteristics	33

Structure Characteristics	34
Process Characteristics	35
Outcome	36
Chapter Four: Research Design and Methods	38
Study Design	38
Procedure	39
Measures	41
Resident Risk Characteristics	41
Structure Characteristics	41
Process Characteristics	42
Decedent Care Model-DSCU Enrollment	42
Gerdner & Beck's IDT Care Plan Criteria	43
Outcome Measures	43
Data Collection	45
Analysis	47
Chapter Five: Results	50
Resident Risk Characteristics	50
Descriptive Results	50
Facility Structure Characteristics from Administrator Survey	50
Facility Structure Characteristics by Decedent Group Enrollment	51
Facility Process Characteristics	52
Gerdner & Beck's DSCU Criterion Compliance	53
IDT Descriptives	53
Inter-Item Correlation Findings	53
Outcome	56
Research Question One Findings	56
Hospice's Association to Better EOLD	56
SWC Findings	56
Comfort At Death	59
Research Question Two Findings	59
DSCUs Association with Better EOLD	59
Comfort At Death Findings	60
Research Question Three Findings	62
IDT as Moderator	62
Chapter Six: Discussion	65
Policy Implications	68
Study Limitations	71
Future Directions	77
Summary	80
References	82

Appendices	99
Appendix A: Facility Protocol	100
Appendix B: Measures	104
Appendix C: DSCU Manager Criteria	110
Appendix D: Gerdner & Beck DSCU Criteria	118
Appendix E: Survey Respondent Information	123
Appendix F: Outcome Scatterplots Prior to Replacement	125
About the Author	END PAGE

## List of Tables

Table 4.1 Outcome Reliability	46
Table 4.2 Study Outcomes by Enrollment Distribution	46
Table 5.1 Structure (Facility) Characteristics by Decedent Enrollment	52
Table 5.2 Facility Process Characteristics by Number Enrolled in Group	52
Table 5.3 IDT (Process) Descriptive Information	53
Table 5.4 Inter-Item Correlation	55
Table 5.5 Satisfaction with Care	58
Table 5.6 Comfort At Death	61
Table 5.7 Interaction of IDT and DSCU Enrollment	63



## List of Figures

Figure 1: Resident Risk Characteristics, Structure, Process and Outcome Variables	34
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## ABSTRACT

Hospice and Dementia Special Care Units (DSCUs) have been shown to be gold standards of care for individuals who are dying and for those with dementia in nursing homes. Using a retrospective administrator and family survey, this study investigated whether the processes of care used in hospice and DSCUs are associated with increased quality of end of life (EOL) care for individuals with dementia. A convenience sample of 17 facilities in four states (FL, PA, MD and MA) was included in the study. Nursing home administrators were surveyed between September 2008 and October 2009. The administrators identified 116 family members of decedents with dementia who were surveyed with the End-of-Life Dementia (EOLD) scale as the outcome. The Donabedian Structure-Process-Outcome theory was used to test the hypothesis that the process characteristics of hospice and DSCU will be associated with higher EOLD scores. Hierarchical regression models were conducted for two of the three subscales of the EOLD. The resident risk characteristics (decedent length of stay and resident immobility), the structure characteristics (profit status, percent Medicaid and presence of other palliation), and the process characteristics (hospice, DSCU, dual, and traditional enrolled, and strength of inter-disciplinary team (IDT)] were entered into the model to determine their association with Satisfaction With Care and Comfort At Death. Strength of the IDT was included as a moderating factor of this association. Only DSCU

enrollment was associated with increased Satisfaction With Care (SWC; DSCU:  $b = .31$ ,  $p < .01$ ). The moderation analysis showed that strength of IDT did significantly moderate the association between DSCU enrollment and increased SWC (DSCU:  $b = -.09$ ,  $p < .05$ ). Study implications include the need for more research into DSCUs and Strength of IDT as best practices in EOL care. This study contributes to an expanding body of research on the extra value of enrollment in a DSCU and the role of IDT in quality of EOL care for individuals with dementia in nursing homes.

## **Chapter One: Introduction**

In the nursing home setting approximately 50-75% of residents have a diagnosis of dementia (Magaziner, German, Zimmerman, Hebel, Burton, Gruber-Baldini, et al., 2004). Nationally, 67% of individuals with dementia die in nursing homes (Volicer, 2005). Models of hospice and Dementia Special Care Units (DSCUs) have guided and promoted better care for those who are dying and for those with dementia. Research about the impact of hospice and DSCUs on quality of end of life (EOL) care for nursing home residents with dementia is lacking. It is important to make a case for the potential of improved EOL outcome for individuals with dementia from both models based on their unique shared features (e.g., inter-disciplinary team, family involvement, person-centered care philosophy). This study explored the association between hospice, DSCUs and the quality of EOL care for individuals with dementia in nursing homes. A retrospective family satisfaction survey was conducted for a sample of 116 decedents with dementia from 17 nursing homes.

### **Unique Contribution**

This study makes a contribution to the understanding of the quality of EOL care for persons with dementia living in nursing homes. The literature shows that EOL for individuals with dementia is unique in suffering and in limited access to comfort care (Aminoff & Adunsky, 2005; Luchins, Hanrahan, & Murphy, 1997; Miller, Mor, Wu, Gozalo, & Lapane, 2002; Peppersack, 2010; Teno, 2005). Because both hospice and

DSCUs have shown improved outcomes for dying residents and individuals with dementia respectively, it is important to determine their impact on EOL for terminally ill individuals with dementia (Demiris, Oliver, & Wittenberg-Lyles, 2008; Hanson, Eckert, Dobbs, Caprio, Sloane, & Zimmerman, 2008; Licentiate, Karin, Sandman, & Norberg, 2002; Parker Oliver, Porock, Demiris, & Courtney, 2005; Zeisel, Silverstein, Hyde, Levkoff, Lawton, & Holmes, 2003).

A review of the literature reveals few other studies that have examined the quality of EOL care for individuals with dementia in nursing homes in the context of hospice and Dementia Special Care. Because of the limited research on EOL care for individuals with dementia in nursing homes, the inadequate enrollment of individuals with dementia in both models, and the increasing rate of individuals with dementia dying in nursing homes, this study has critical policy implications.

### **Organization of the Dissertation**

Chapter one of the dissertation consists of the abstract, a brief introduction, and the organization of the dissertation. Chapter two is the background and literature review of EOL in Long Term Care (LTC). Sections on palliative care, hospice benefit in LTC, dementia hospice utilization in LTC, family satisfaction and barriers to utilization provide a backdrop for the major literature review. The first section of the major literature review discusses EOL for individuals with dementia, estimating prognosis, and palliative care both in and out of nursing homes. The second section of the major literature review reviews the history of dementia care and the development of DSCUs. A review of DSCU

theory and practice includes findings on person-centered care and Inter-Disciplinary Teams (IDTs). The final section of chapter two is a discussion of the shared features of both models and access for individuals with dementia.

Chapter three explains the theoretical overview and research questions for the study. Structure Process Outcome (SPO) theory is discussed in light of gaps in the literature. Study variables which represent SPO characteristics are discussed.

Chapter four presents the research design and methods. It delineates the sample, measures, and SPO study characteristics. Chapter five provides the results of the analyses with the findings for each research question provided. Finally, chapter six includes the discussion, policy implications, study limitations, design issues, future directions, and an overall summary.

## **Chapter Two: Background and Literature Review of End-of-Life in Long Term Care**

### **Palliative Care in Long Term Care (LTC)**

Palliative care is the overall care and comfort of the dying individual. It has been defined by the National Hospice and Palliative Care Organization as “aggressive symptom management, supported decision-making and optimal EOL care that is family and patient-centered” (Kirk & Mahon, 2010, p. 914). There are many forms of palliative care (Barazzetti, Borreani, Miccinesi, & Toscani, 2010). Palliative care in nursing home settings is an important research area because of the increasing percentage of people dying there (Munn, Zimmerman, Hanson, Williams, Sloane, Clipp, et al., 2007). Nursing home deaths accounted for 20% of all deaths in the U.S. (Mezey, Dubler, Mitty & Brody, 2002). A forecast of the locations where Americans will die projects half of all adults dying in nursing homes by 2030 (Meier et. al., 2009).

Although, initial EOL research focused on pain and symptom management (Thompson & Chochinov, 2006), deficient pain treatment in nursing home care continues to be a significant problem (Saliba & Buchanan, 2008; Teno, Kabumoto, Wetle, Roy, & Mor, 2004). Along with inadequate pain control documented for EOL in nursing homes, there is a heightened rate of tube-feeding and a decreased rate of hospice (Sachs, Shega, & Cox-Hayley, 2004; Volicer & Hurley, 1998). EOL palliation continues to be deficient in nursing homes (Munn, Hanson, Zimmerman, Sloane, & Mitchell, 2006). Problems

with resident cleanliness, shortness of breath, and symptoms affecting nutritional intake are documented to be more prevalent in nursing homes than in other residential care settings (Hanson, Eckert, Dobbs, Caprio, Sloane, & Zimmerman, 2008).

Subjective measures of palliation suggest unmet palliative care needs. Both family and professional caregivers reported unmet need when questioned about dying long-term care residents (Munn et al., 2006). Only 31.8% of families perceived that their deceased loved ones were treated with respect (Parks, Haines, Foreman, McKinstry, & Maxwell, 2004). The inadequacies of EOL care in LTC settings validate the need for continued research (Munn, Zimmerman, Hanson, Williams, Sloane, Clipp et al., 2007). However, there have been recent changes in traditional palliative care. Preliminary research into non-hospice palliation shows stronger results than previously reported; including increased symptom management, but the need for more psychosocial and spiritual care continues (Hallberg, 2006). LTC administrators and direct care providers rate their own palliative programs as satisfactory, but research shows that LTC palliative care lacks optimal staffing, psychosocial and existential support, and family inclusion in care (Dobbs, Hanson, Zimmerman, Williams, Munn, & Sloane, 2006; Hallberg, 2006; Keay & Schonwetter, 2000; Teno et al., 2004).

LTC staff is often resistant to a shift to palliative care after having worked with the resident's chronic condition for an extended time (Thompson, Menec, Chocinov & McClement, 2008). This is called the overprotection phenomenon. Families also experience overprotection, and may insist on maximal life-sustaining care because of their inability to accept the death of their loved one (Aminoff & Adunsky, 2005). The



combined reluctance of staff and family for palliation results in the high use of life-sustaining treatments despite the lack of evidence for any curative effect (Volicer & Hurley, 1998). A palliative care trial in hospital patients with advanced dementia found that despite the palliative care approach overall intervention showed consistently high daily phlebotomy rates of 41%, systemic antibiotic rates of 75%, and new feeding tube rates of 44% (Anronheim, Morrison, Morris, & Meier, 2000). Not only have studies shown no curative effect to these efforts, there is evidence of increased pain and suffering from such life-sustaining measures (Anronheim et al. 2000; Aminoff & Adunsky, 2005; Volicer & Hurley, 1998). Palliative care plans to prevent such ineffective life-sustaining treatments were much less likely to influence the care of advanced dementia residents in the hospital (Ahromheim et al., 2000). This is despite research showing that 95% of older people are opposed to life-sustaining treatments in the face of end-stage dementia (Gjerdingen, Neff, Wang, & Chaloner, 1999).

Hospitalization of an individual with end-stage dementia is also considered detrimental because of the disruption to healthcare continuity. Healthcare continuity is a term used to denote consistency of staff and facility and has been shown to improve both resident palliation and healthcare outcomes (Lorenz, Lynn, Dy, Shugarman, Wilkinson, Mularski et al., 2008). A systematic review of improved palliative care shows that little research has addressed improving continuity of care for dying dementia residents (Lorenz et al., 2008).

## **Hospice Benefit in LTC**

Hospice enrollment in LTC has been shown to improve the quality of EOL care. Hospice's principles of resident and family autonomy, self-determined life closure, safe and comfortable dying, and effective grieving are all benefits of hospice enrollment (NHPCO, 2008). "The dominant model of how we provide good EOL care in this country is hospice," according to G. Sachs, M.D. (Schmidt, 2000). The additional benefits of hospice care have been shown to include less hospitalization, more pain analgesic, more attention to advance directives, better personal hygiene, more comfort, and more spiritual care (Miller & Mor, 2002; Munn et al., 2006; Parker, Porock, Zweig, Rantz, & Petroski, 2003). Hospice's holistic care model yields improved family satisfaction with care and reduced spouse mortality rates (Christakis & Iwashyna, 2003; Teno, Clarridge, Casey, Welch, Wetle, Shield, et al. 2004). Residents enrolled in hospice were less likely to have physical restraints, receive intravenous feeding and medication, receive intramuscular injections, or have feeding tubes (Miller, Gozalo, & Mor, 2000). Miller and colleagues (2000) found a "spill-over effect" in both education and better care practices that resulted from hospice's presence in a nursing home. This effect was evident only in facilities where there was strong collaboration between hospice and nursing home (Miller et al., 2000; Miller & Mor, 2002). Included in their findings was less hospitalization and better pain management for all residents regardless of hospice enrollment (Miller & Mor, 2002). Other research indicated more frequent use of non-verbal pain scales for individuals with dementia in facilities with strong hospice

collaboration (McCarty & Volicer, 2009). The value of non-verbal pain scales is their ability to recognize pain in the individual no longer able to communicate due to cognitive and/or verbal deficits (Hurley, Volicer, Hanrahan, Houde, & Volicer, 1992). In 2008, new regulations strengthened collaborative care between hospice and nursing home staff by requiring the hospice agency's participation in facility care plans, charting in the facility health chart, and training nursing home employees who work with the resident (Stevenson & Bramson, 2009).

The overall attitude toward hospice in nursing homes has been studied through administrator surveys. This research has found that nursing home administrators with nursing degrees were more positive about the emotional and social support that hospice added to their residents' EOL care (Dobbs et al., 2006). Hospice benefits in nursing homes have been well documented and contribute to hospice's status as the gold standard for palliative care (Christakis et al., 2003, Miller & Mor, 2002; Miller et al., 2000; Munn, et al., 2006; Schmidt, 2000; Sloane, Zimmerman, Williams & Hanson, 2008; Teno et al., 2004).

### **Hospice Utilization in LTC**

Despite the benefits and its status as the main source of palliation in the U.S., nursing home hospice rate was only 29% for nursing homes in 2010 (NHPCO, 2010). Annually, over one million elderly utilize the hospice benefit (Connor, 2009). One study documented an increase in hospice care in nursing homes from 14% to 33% from 1999 to 2006 (Miller, Lima, Gozalo, & Mor, 2010). This utilization rate is still well below the

overall national hospice enrollment average of 50% in individual homes and hospitals (NHPCO, 2010). Payment and eligibility challenges are partially responsible for the lower utilization, but there is also need for stronger communication between hospice and nursing home care teams (Stevenson & Bramson, 2009).

### **Family Satisfaction with Hospice**

The inconsistency in hospice utilization in nursing homes is not due to family dissatisfaction. Hospice's added value yields positive family perceptions of improved symptom management and homelike environment (Baer & Hanson, 2000). Research shows that families identify communication of information about their loved one as key to their satisfaction (York, Jones, & Churchman, 2009). Unfortunately, one out of ten families felt that the referral to hospice was too late (Teno, Shu, Casarett, Spence, Rhodes, & Connor, 2007). Despite their role as the preferred decision-makers, family members are often not well-informed regarding palliative care options (Haley, Allen, Reynolds, Chen, Burton, & Gallagher-Thompson, 2002). Studies show that only 40% of residents and family are aware of hospice prior to an informational visit and only 27% know that hospice's focus is on comfort and symptom management (Casarett, Fishman, O'Dwyer, Barg, Naylor & Asch, 2008). This is unfortunate because of hospice's clear commitment to holistic EOL care (NHPCO, 2008).

### **Barriers to Hospice Utilization in LTC**

Lack of family knowledge of hospice benefit is one of several barriers to hospice utilization in nursing homes. Despite improved utilization rates, other key barriers to

hospice access in LTC include inaccurate estimations of prognosis in non-cancer diagnoses, lack of communication among decision makers, and lack of agreement or implementation of EOL care plans ( Dobbs et al., 2006; Travis, Bernard, Dixon, McAuley, Loving, & McClanahan, 2002).

Residing in a nursing home adds an extra barrier to palliative care and hospice utilization for individuals with dementia because of the regulatory goal in nursing homes to promote maximum functioning and rehabilitation for the resident (Hoffman & Tarzian, 2005). In the recent past, the Omnibus Budget Reform Act (OBRA) mandated nursing homes to “maintain or enhance” resident function (Keay et al., 2000) and linked the bulk of payment to curative care. Therefore a nursing home resident was supposed to have improving health rather than declining health. Curative and palliative care philosophies of care were competing in the nursing home assessments prior to the latest Minimum Data Set (MDS) 3.0. Until October of 2010 the nursing home summary assessment of each resident lacked any palliative care characteristics. This was evidenced by the lack of standardization in assessing a resident’s terminal status and inattention to quality of life issues (Miller, Teno, & Mor, 2004). Therefore terminal symptoms such as weight loss, reduced respiration, decrease in function, and dehydration were misinterpreted as poor quality of care on the part of the nursing home rather than as symptoms of approaching death (Kapp, 2003). The new Minimum Data Set (MDS 3.0) has added a component of palliative care assessment to address this problem. The MDS 3.0 was released October 2010 and has been difficult to implement according to anecdotal report. The impact of adding a palliative care component has not yet been evidenced in research. The

American Health Care Association (AHCA) cautions that MDS 3.0 will need to have at least a 5-months learning curve (AHCA, 2010). Certainly the move to include palliation in reimbursement assessment is a positive direction yet to be quantified.

Efforts to maintain or enhance health coupled with the difficulty in predicting death due to chronic disease quickly depletes the Medicare skilled nursing benefit (Hoffman & Tarzian, 2005). Once there is a determination of terminality, funding continues to be a problem. If a resident enrolled in hospice has exhausted both Medicare and private funds, they are referred to Medicaid, which becomes the sole payee (Gozalo, Miller, Intrator, Barber, & Mor, 2008). The Medicaid hospice benefit has been \$145 less per day than the Medicare hospice benefit (Hoffman & Tarzian, 2005) and Medicaid funds only a few hours of direct resident care (Keay et al., 2000). Therefore, the resident with less financial resources and a chronic disease receives less care. Medicaid payment rates are consistently associated with nursing home quality in research (Grabowski, 2004). Most recently research documented the variable impact of a \$10 increase in Medicaid funding resulting in a 41% increase in urban nursing home hospice utilization (Miller, Gozalo, Lima, & Mor, 2011).

In addition, the issues surrounding predicting terminality of residents with chronic illnesses decrease the likelihood of Medicare or Medicaid referral for hospice. When finally referred, the resident may have a shortened and less than optimal hospice length of stay (LOS), resulting in reduced benefit of care and comfort for the family and resident.

Another disincentive to hospice utilization in nursing homes is “pass-thru”, which occurs when an individual who is dually eligible elects hospice (Miller & Mor, 2002). Dual eligibility is care funding through both Medicaid and Medicare (Miller & Mor, 2002). Medicaid is federally mandated to allocate funds to pay for hospice services first. Hospice then “passes thru” 95%-100% of the allotment to the nursing home for room and board (Miller & Lima, 2004; Miller & Mor, 2002). Several states pass 100% of hospice funds through to the nursing home, while other states only pass 95% of the funds through. This creates an obvious disadvantage for nursing homes operating in states that only provide 95% of the funds for room and board. Compounding the disadvantage is the additional time it takes to receive the payment. Even in states where the nursing home gets all 100% of the funds, there is still a time lag before receiving the funds. States passing 100% through to the nursing home have higher collaboration rates between hospice and nursing homes because of the extra 5% funding (Miller & Lima, 2004).

Conversely, if the individual is eligible for the skilled nursing benefit, the Medicare reimbursement rate is higher than the hospice benefit. Logically the nursing home accesses skilled nursing before hospice for chronic disease residents because of the financial incentive as well as the inability to determine if EOL is imminent. There is not a Medicare provision to simultaneously access hospice as well as skilled nursing because of hospice’s focus on comfort rather than cure (Miller & Mor, 2002; NHPCO, 2010; Wiener & Tilly, 2003).

Another barrier to hospice utilization for individuals with dementia is a lack of coordination between nursing home and hospice staff (Miller & Mor, 2002).

Development of this partnership requires a “joint production of care” (Stevenson & Bramson, 2009), which can be confounded by differences in philosophy, expertise, and role competition (Miller, Teno, & Mor, 2004). This includes communication gaps between family, hospice and nursing home staff as well as lack of agreement and implementation in the EOL care plan (Dobbs et al., 2006). Qualitative evidence points to a higher prevalence of these gaps in small and rural areas, with small hospices in rural areas expressing a need for nurse training in dementia care and a discomfort with EOL symptoms for non-cancer diseases (McCarty & Volicer, 2009).

### **EOL for Individuals with Dementia in Nursing homes**

Nearly half of elders over the age of 85 with dementia will reside and die in a nursing home (Meier, Lim, & Carlson, 2010). In a retrospective study of six months of decedents in a nursing home, Alzheimer’s disease was the most common cause of death (Goldberg & Botero, 2008). Until recently, EOL care research for individuals with dementia in long term care settings has been sparse and focused primarily on symptom management and hospice utilization (Aminoff & Adunsky, 2005; Luchins et al., 1997; Miller & Mor, 2002; Teno et al., 2004). Pressure sores, restlessness, medical instability, and a significant level of suffering were documented in a study of dying dementia residents (Aminoff & Adunsky, 2005). Suffering was documented through lab reports showing decreased albumin (a protein made by the liver), heightened temperature, and increased hand restraint usage, IV fluids, antibiotics, and narcotics. In this study, suffering increased despite significant increase in narcotic analgesics. This deficiency in



pain management was more prevalent in dementia EOL care than in cancer EOL care (Miller & Mor, 2002).

### **Estimating Prognosis**

Prescribing and administering narcotic pain medication at EOL is dependent on the determination of EOL. The decline of individuals with dementia often is one of increasing frailty, which can make palliative efforts difficult and fraught with uncertainty (Glaser & Strauss, 1968; Mezey et al., 2002). The dying trajectory of an individual with dementia is a slow decline of Activities of Daily Living (ADL) coupled with steadily progressive disabilities of cognition and communication (Keay et al., 2000; Luchins et al., 1997; Schonwetter, Han, Small, Martin, Tope, & Haley, 2003; Thompson & Chochinov, 2006). The trajectory of dementia decline particularly that of Alzheimer's disease, is not definite (Snowden, McCormic, Russo, Srebnik, Comtois, Bowen et al., 1999). Traditionally, dementia has been staged with clinical measures that bottom out as the disease enters late stage (Appollonio, Gori, Riva, Spiga, Ferrari, Ferrarese et al., 2005; Schonwetter et al., 2003). Therefore late-stage and end-stage have little measurable distinction. Physicians and clinicians have difficulty identifying when the individual with late-stage dementia has entered end-stage. The end-stage can be quite protracted with late-stage dementia not perceived as terminal (DiGiulio, Toscani, Villani, Brunelli, Gentile, & Spadin, 2008; Thompson & Chochinov, 2006). This inability to determine terminality results in a high percentage of individuals being denied the additional benefits of palliation and hospice enrollment (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003).

## **Palliative Care for Individuals with Alzheimer's disease**

Palliative care for individuals with Alzheimer's disease is a new area for intervention research. One palliative care intervention that addresses healthcare continuity, symptom management and EOL quality of care has been successful (Shega, Levin, Hougham, Cox-Hayley, Luchins, Hanrahan et al., 2003). Palliative Excellence in Alzheimer Care Efforts (PEACE) is a disease management model for dementia that focuses on resident-centered care, family support, and palliative care. Generated by the collaboration of primary care geriatric practitioners, PEACE is one of the few dementia palliative care models in the nation. PEACE includes residents throughout the course of dementia. This approach is not financially feasible for the current hospice payment schedule, though larger community hospices offer palliative transition or bridge programs for pre-hospice palliation (Braveman, 2008; Cassarett & Abram, 2001; Cassarett, Fishman, O-Dwyer, Barg, Naylor, & Asch, 2008; McCarty & Volicer, 2009). Bridge programs are hospice collaborations with home health agencies or other healthcare providers offering pain and symptom management, and emotional support for residents not yet ready or able to elect the hospice benefit (Miller & Lima, 2004; McCarty & Volicer, 2009). Hospices hosting palliative transition or bridge programs had a much higher enrollment of individuals with dementia (McCarty & Volicer, 2009). The benefits of these programs should be included in future study models of dementia care.

## **Dementia Care in LTC**

In order to best understand the benefits offered by a DSCU, it is necessary to look at the history of dementia care in long term care. Prior to the first DSCU in 1974, dementia care in long term care reflected two approaches. Individuals without behavioral problems were mainstreamed or commingled with the general long term care population (Teresi, Holmes, & Monaco, 1993). Individuals with difficult behaviors were placed in specified locked dementia units modeled after psychiatric units where physical and psychotropic restraints were used for behavioral symptom management (Maslow, 1994). These early dementia units were generally offered only in the larger non-profit long term care settings. Commingling was justified with reduced stigma, heightened cognitive stimulation, and behavior maintenance. However there were conflicting viewpoints on human rights, individual dignity, staff and family discomfort (Teresi et al., 1993). Some studies found that commingling of individuals with dementia with cognitively intact residents had detrimental consequences for the person with dementia, while the cognitively intact residents experienced negative mental and emotional consequences (Ragneskog, Gerdner, & Hellstrom, 2001; Teresi et al., 1993; Wiltzius, Gambert, & Duthrie, 1981). Ragneskog and colleagues (2001) found that commingling of “lucid” residents and residents with dementia in hospitals and LTC units resulted in an increase in anxiety, fear, and irritation (Ragneskog et al., 2001). Commingled dining resulted in lost appetite among the lucid resident and increased agitation for the demented resident as

a response to the lucid resident's intolerance and disrespect. Further investigation into commingling is needed to better evaluate the importance of special care.

### **Dementia Special Care Units (DSCU) in LTC**

The challenges of dementia care and the rapid growth of both an aging population with dementia prompted the first DSCU in 1972 (Liebowitz, Lawton, & Waldman, 1979). A DSCU is an area within a facility that represents itself to the public as primarily focused on dementia-care. This area is separated from the larger facility by closed doors and contains the majority of residents with dementia. Termed first generation DSCUs, physical design, staffing intensity, activity planning, and family involvement were implemented within traditional facilities (Albert, 2004). There were no safe outdoor areas and little staffing changes. In the 1980's the DSCU focus shifted to increased activities and marketing with providers typically being for-profit nursing homes.

Second generation, purpose-built DSCUs included safe outdoor access, minimal restraints, enhanced activities, a home-like environment, better staffing with dementia-specific training, and the continuum of care known as aging in place (Albert, 2004; Kaplan & Hoffman, 1996; Maslow, 1994).

### **Environmental Theory**

The DSCU environment maximizes safety, function, and staff selectivity while reducing or controlling sensory stimulation (Maas, Meridean, Reed, Park, Specht, Schutte et al., 2004). Loss of cognitive ability makes coping and managing stress difficult, often leading to behavioral symptoms (Heschong, 2003; Kahana, Liang, & Felton, 1980).

Purpose-built DSCUs were based on the Environment-Behavior model that links environmental design features with behavior typical of individuals with dementia (Calkins, 1987; Cohen & Weisman, 1991; Lawton, 1990; Zeisel et al., 2003).

Progressively Lowered Stress Threshold is a dementia specific model of the interaction between person and environment that is accommodated in the lighting and design of a purpose-built DSCU (Calkins, 1987; Cohen & Weisman, 1991; Heschong, 2003; Kahana et al., 1980; Smith, Hall, Gerdner & Buckwalter, 2004). Camouflaged exits, privacy, unique non-institutional common spaces, multi-sensory walking paths, residential character, sensory comprehension and therapeutic gardens have each been validated to reduce agitated dementia behaviors while promoting positive dementia behaviors and quality of life (Zeisel, et al., 2003).

The Composite Above Average Quality Score (CAAQS) was designed to measure physical and social nursing home environments for people with mid to late stage dementia. The CAAQS showed a statistical difference between Special Care Facilities (SCF) and Traditional Institutional Facilities (TIF) with SCF rated above average by 71.4% of the responders (Slaughter, Calkins, Eliasziw, & Reimer, 2006). The Special Care Unit Environmental Quality Scale (SQUEQS) was created to assess quality of care and quality of life items resulting from the provision of safety, security, physical health, orientation, provision of privacy, control, autonomy, stimulation (positive and negative), enhancement of socialization, and personalization/familiarity (Sloane, Mitchell, Weisman, Zimmerman, Foley, Lynn, et al., 2002).

Gerdner & Beck (2001) developed a DSCU measurement tool based on the Alzheimer's Association guidelines for DSCUs: Promotion of rights, dignity, comfort, and independence in the least restrictive environment. The measure consists of seven criteria: Certified Nursing Assistant (CNA) staffing-to-resident ratio, RN staffing-to-resident ratio, LPN staffing-to-resident ratio, Departmental SCU training, Inter-disciplinary team regularity, participation and membership, activity provision, and selected environmental features (Gerdner & Beck, 2001).

An overview of DSCU research initiated in 1994 by the Office of Technology Assessment documented that only 10% of the 1,500 nursing homes identifying themselves as providing "special care" qualified as a DSCU (Maslow, 1994). Many nursing homes offering DSCUs made no adaptations beyond segregating those individuals with dementia behind a locked exit system (Maslow, 1994). Less than one half of the DSCU programs featured support groups for families or aging in place. Few featured increased activities, and one quarter lacked dementia training for the staff (Maslow, 1994). However all DSCUs had increased costs of care as well as increased cost to residents.

The Office of Technology Assessment overview identified contradictory conclusions about the value of DSCUs. Measurement inadequacies, unclear definition of outcomes, sample size, and lack of comparison group were cited as research inconsistencies in four of the six studies showing no significant difference between traditional dementia care and dementia special care (Maslow, 1994). More recent research has included comparison group design, better outcome measurement, and larger

sample size. With the advancement of design, research has shown significant differences between traditional dementia care and DSCU (Luo, Fang, Liao, Elliott, & Zhang, 2010; Reimer, Slaughter, Donaldson, Currie, & Eliasziw, 2004; Slaughter, et, 2006; Ziesel, et al., 2003; Weyerer, Schaufele, & Hendlmeier, 2010).

Improvements in research design have validated the added value of DSCU compared to traditional dementia care. Added value is a term given to the extra benefit of a health-care program (Jennings, Ryndes, D'Onofrio, & Bailey, (2003). Staff and family proxies observed reduced decline in Activities of Daily Living (ADL), increased sustained interest, and less negative affect when comparing DSCU residents to traditional care residents (Reimer et al., 2004).

### **Person-Centered Focus**

Part of the added value of DSCUs comes from a person-centered perspective (Drebing, McCarty & Lombardo, 2002, Lutz & Bowers, 2000; Schrijnemaekers, von Rossum, Candel, Frederiks, Derix, Sielhorst, & van den Brandt, 2002). Rather than a provider-centered, disease-focused framework, DSCU re-organizes the environment to include themes of confirmation, familiarity, communion, and relationship-centered care (Zeisel et al., 2003). This focus has resulted in decreased social withdrawal, negative behavior and cognitive decline for residents of DSCUs as well as increased personalization and expression of personhood (Donovan & Dupuis, 2000; Licentiate, Karin, Sandman, & Norberg, 2002; Zeisel et al., 2003).

A study looking at the impact of dementia-specific person-centered care showed increased staff satisfaction and confidence with a correlation between staff hope and better resident quality of life ratings (Spector & Orrell, 2006; Zimmerman, Sloane, Williams, Reed, Boustani, Preisser et al., 2005). This person-centered care focus is a distinction that the DSCU model shares with the hospice model. Both hospice and DSCUs have the person and the family as central. Family involvement has been pivotal in DSCU research not only as proxy raters but as evidence of a quality of care that conforms to the residents' preferences. Montgomery (1994) affirmed in a study of family measures in DSCUs that families' judgment of satisfaction reflects residents' satisfaction with quality of care. The importance of looking at multiple components including environment, programming, staffing, and emotional care are key to family satisfaction and ultimately resident satisfaction (Montgomery, 1994).

### **DSCUs and Inter-Disciplinary Team**

The thorough integration and support of the family is part of DSCU's added care benefit. Family involvement includes being a part of the care recipient's inter-disciplinary team (IDT). IDT is part of the shift from traditional care planning (Benedict, Robinson, & Holder, 2006). The IDT model is based on different disciplines assessing and planning care collaboratively with shared leadership, and role overlap (Fulmer, Flaherty, & Hyer, 2003). The IDT is defined as a "group of professionals, para-professionals, and non-professionals who possess the knowledge, skill and expertise to accurately identify the comprehensive array of the individual's needs, and design appropriate services and specialized programs responsive to those needs" (Gerdner &



Beck, 2001, p. 292). The Gerdner & Beck IDT criteria consists of an RN, activity director, social worker, registered dietician, physician, CNA, physical therapist, occupational therapist, music therapist and family member (Gerdner & Beck, 2001).

The 1999 revision of the Federal Regulations Code for States and Long-Term Care facilities requires professional program staff participation in an IDT. The IDT is mandated to participate in “relevant aspects of the active treatment plan” (Title 42: Public Health). The long-term care IDT includes an attending physician, a registered nurse who is responsible for the resident, and other appropriate staff in disciplines determined by the resident’s needs. The resident, resident’s family, or legal representative is to be included “to the extent practicable” (Title 42: Public Health). The IDT is to review and revise the resident’s plan of care at admission, quarterly, if there’s a significant change with the resident, annually, and prior to discharge.

The literature contains reference to both IDTs and multi-disciplinary teams. The 1999 mandate for IDT is more progressive than a multi-disciplinary team, which was the standard health care model in the past (Retrieved November 15, 2010, from [www.edocfind.com/en/ppt/team-5.html](http://www.edocfind.com/en/ppt/team-5.html)). A multi-disciplinary team is organized hierarchically based on professional level with the physician as the primary voice, nurse-secondary, and social worker-tertiary. Each team member had a defined role, with limited formal and informal interaction with the resident. The multi-disciplinary team physician is the sole decision-maker. Joint decision-making is a key differentiation between IDT and a multi-disciplinary team, with IDT focused on both resident and

family as the center of care (Retrieved November 14, 2010 from <http://www.seniorsmentalhealth.ca/interdisciplinary.pdf>).

Research on IDT shows its influence on efficient and coordinated continuity of care (Benedict et al., 2006). The Acute Care of the Elderly (ACE) model for interdisciplinary management includes a specifically designed environment, resident/family-centered care and IDT (Benedict et al., 2006; Counsell, Holder, Liebernauer, Palmer, Fortinsky, Kresevic et al., 2000). Results showed higher satisfaction among residents, caregivers, physicians and nurses among the intervention group (Counsell et al., 2000). The ACE model of IDT included promotion of a positive climate, care improvement, practice change, and increased decision-making at the point of care which resulted in more timely referrals (Benedict et al., 2006). Studies of the benefits of IDT in dementia-specific assisted living produced trends for decreasing hospitalizations and deaths (Bellantonio, Kenny, Fortinsky, Kleppinger, Robison, Gruman, Kulldorff et al., 2008).

The Omnibus Budget Resolution Act mandating IDT allowed great variability in application in traditional long-term care. The regulations were broad enough in language to allow a minimalization of discipline, stating that “appropriate staff be guided by resident needs” (Title 42: Public Health, Retrieved April 12, 2008). However the hospice model and the DSCU model delineate each discipline to be included. Although the resident’s plan of care is the focus of the Omnibus Budget Resolution Act IDT regulations, the inclusion of the resident, family, or legal representative is not mandated. In many facilities this results in little effort to include family, resident or legal representative. The mandated frequency of care plans makes the presence of the

physician very rare, with nursing staff relaying the critical information needed for physician approval post-IDT care plan.

### **Hospice & DSCU Shared Strengths**

A resident-centered care focus is a distinction that the DSCU model shares with the hospice and dementia palliation model. The commitment to the individual as central to the care model is prevalent in both hospice and DSCU. Holistic care that targets not only the physical component of care, but the social, psychological and emotional, requires family involvement and a strong IDT. Both hospice and DSCU have strong IDT with unique disciplinary input and commitment. Both models include the resident and family as the central focus. Although family is not a requirement for either team to meet, the centrality of the family is recognized and encouraged (Parker et al., 2005)

The hospice IDT is composed of a physician, a nurse, a social worker, a chaplain, a certified home health aide, a volunteer and ancillary therapist who are specially trained in working with dying residents and their families (Parker et al., 2005). The determination of which care level and plan is most appropriate for the needs of the resident is made by the members of the IDT with input from the resident and family. The hospice IDT role is to develop an individualized plan of care for each new resident and to review it on at least a quarterly basis. The strong hospice IDT with regular and accurate communication, provision of emotional support, and identification of a single nurse assigned to their loved one were strongly associated with family satisfaction (Rhodes,

Mitchell, Miller, Connor, & Teno, 2008). It is the IDT that coordinates holistic care with the strength of the united disciplines focusing on the individual. A strong IDT may be foundational to the added value of both care models.

### **Reality of Access**

With the established better outcomes of two care models comes the need for better access. The actual desire for care by a member of a population at risk often contrasts with the ability to access that care. Jennings & colleagues (2003) term this—“realized access” (pg. 16). As shown in the literature on both hospice and DSCU, realized access continues to be low (Connor, 2009; Davis et al., 2000; Gage, Miller, Coppola, Harvell, Laliberte, Mor, et al., 2000; Kovach, 1998; Maslow 1994; Mezey et al., 2002; NHPCO, 2010). Even in the state of Florida, where aging demographics have supported nursing home growth and broader state-specific hospice eligibility, access to both hospice and DSCU is still low for individuals with dementia. A preliminary survey of existing DSCUs in a 15 county region shows a 50% decrease in number of units over two years with the remaining located in high income regions (Gulf Coast Alzheimer’s Association DSCU Roster, 2005).

A pilot study of hospice utilization for individuals with dementia showed higher realized access in regions hosting community hospices (McCarty & Volicer, 2009). Community hospices are independent, non-profit entities governed by a board of directors committed to the needs of the dying (Beresford, 1993). In large community hospices this translates into services beyond those reimbursed by Medicaid and Medicare

(Miller & Lima, 2004). The provision of palliative pre-enrollment programs, called bridge or transition programs, through community hospices was correlated with higher hospice enrollment for individuals with dementia (McCarty & Volicer, 2009).

### **Access to Hospice for Individuals with Dementia**

Efforts on the part of hospice have increased utilization. Hospice utilization for individuals with dementia has been documented to be as low as 11% in an early study and 22% more recently (Luchins et al., 1997; Munn et al., 2006). Analysis of nursing home residents dying with advanced dementia found hospice life expectancy was much less than six months. Therefore, such terminal residents had met the Medicare intermediary eligibility guideline of a six months prognosis (Christakis & Escarce, 1996; Huskamp, Buntin, Wang, & Newhouse., 2001; Huskamp, Newhouse, Norcini, & Keating, 2008; Mitchell, Morris, Park, & Fries, 2004). A look at hospice LOS for individuals with dementia by state show many states have a high percentage of LOS of seven days or less (Miller, Lima, Gozalo, & Mor, 2010). Although the length of stay in 2010 had doubled and the non-cancer diagnosed had risen 14%, individuals with dementia are still underserved (Christakis & Escarce, 1996; Miller, Lima, Gozalo et al., 2010). Individuals with dementia in nursing homes are therefore appropriate candidates for hospice but not given full access.

Access is also affected by income. Traditional hospice care starts with the Medicare hospice benefit along with a spend-down on the individual's assets. This

Medicare per diem payment system has not been re-tooled since 1980, and the Medicaid benefit is not accessible for many individuals until they are practically bankrupt (Huskamp et al., 2008). The expense of traditional curative EOL care frequently causes bankruptcy (Keay et al., 2000). Medicaid recipients are 69% less likely to use hospice than those without Medicaid suggesting that low socio-economic status is associated with less hospice use (Huskamp, Stevenson, Chernew, & Newhouse, 2010; Iwashyna, Zhang, & Christakis, 2002). By the time the Medicaid hospice benefit is in place, LOS is much shorter and expenses are higher because the last days of a hospice resident's life are the most expensive (Miller & Lima, 2004).

### **Access to DSCUs**

Because of restrictive NH policies, DSCUs offer limited access to some individuals with dementia. First generation DSCUs that were segregated within the facilities were more likely to be in large non-profit facilities. Non-profit facilities have been shown to provide more direct care support staff hours per resident than for-profit facilities (Gerdner & Beck, 2001; Holmes, Ory, & Teresi, 1994; McGregor, Cohen, McGrail, Broemeling, Adler, Schulzer et al., 2005). Studies have shown a clear selection bias with DSCU accepting enrollment of only the least offensive behavioral and physical problems in order to keep the environment pleasant for private pay residents who often pay a premium to live on a DSCU (Grant, Kane, & Stark, 1995; Kovach, 1998). Kovach (1998) referred to a class or caste system with DSCU being the *Cadillac* not accessible to the most vulnerable financially, behaviorally, or physically. This is despite some states offering higher Medicaid reimbursement. Second generation DSCUs continue to find a

higher proportion of private pay residents (Davis, Sloane, Mitchell, Preisser, Grant, Hawes, et al., 2000). The declining number of DSCUs in Florida's less affluent counties is evidence of a shift in realized access. Preliminary discussion with admissions directors suggests that the LOS of an individual with dementia exhausts private funding with nursing homes losing money as the individual switches to public funds (McCarty, et al., 2009). The fact that the nursing home does not get Skilled Nursing Medicare funds for most individuals with dementia results in less per diem income (Zimmerman, Gruber-Baldini, Hebel, Burton, Boockvar, Taler et al., 2008). The better physical health of the resident with dementia is actually preventing access to a better model of care.

In light of the literature's validation of both hospice and DSCU access issues for individuals with dementia, it is important to further research the impact of both care models on EOL care. With research suggesting the added benefit gained from both hospice and DSCU for individuals with dementia and their families, shared components may be responsible. Therefore, there may be shared components of both models that are responsible. The components of strong IDT, holistic care, and family involvement may well be the variables that add value to care for individuals with dementia residing in nursing homes. The empirical evidence noting the deficiencies of nursing home EOL care for individuals with dementia calls for a study to evaluate how hospice and DSCU impact EOL care.

## **Chapter Three: Theoretical Overview and Research Questions**

### **Theory**

Donabedian's Structure-Process-Outcome (SPO) model (Donabedian, 1966; 1988) is used to address the research questions in this study about end of life quality of care in nursing homes. This well-known model has been widely used in health care utilization research and argues that good structure (e.g., physical environment, staffing levels, programming) leads to good process (admission and discharge criteria, staff training, activity involvement, administrator's attitudes) which results in better outcomes (Donabedian, 1988). The SPO theory has been used to conceptualize quality of care in long term care with the premise that good facility structure will increase the probability of good facility process, which in turn increases the probability of good care outcomes (Kruzich, Clinton, & Keller, 1992). The use of the SPO model has evolved to focus not only on the linear progression of quality from structure to process to outcome, but to a non-linear progression with process characteristics being the dominant indicator of quality of care (Brannon, 1992; Donabedian, Wheeler, & Wyszewianski, 1982).

SPO has been used to evaluate nursing care quality as the outcome in a variety of studies. Prevalence and incidence of resident outcomes ranging from quality of life to skin status have been assessed (Karon & Zimmerman, 1998; Weech-Maldonado, Meret-Hanke, Neff, & Mor, 2004; Zimmerman, Karon, Arling, Clark, Collins, Ross et al., 1995). However, literature review shows that SPO has been used most frequently to look



at structural indicators and traditional process indicators like care planning and appropriateness of medical care (Sainfort, Ramsay, & Monato, 1995). SPO has been used directly or indirectly in the study of nursing home quality in 57% of the research between 2005 and 2010 (Castle & Ferguson, 2010).

Because SPO was not developed specifically for nursing homes there have been adaptations and expansions to include a variety of characteristics (Scott, Poole, & Van De Ven, 2004). Unruh and Wan (2004) expanded the traditional SPO framework to look at the contextual background inter-linking the three components. Social, legal, and political contexts indirectly play a role in resident outcomes, yet they have not been addressed in the traditional SPO. Also added to Unruh & Wan's (2004) model are organizational components that play a direct role in affecting resident outcome but are not well-suited for analysis with SPO. This expanded SPO has been used to link the role of job and employment rate with staff turnover, the role of nursing home location with nursing continuity, and the role of chain membership with profit status (Unruh & Wan, 2004).

Similarly, researchers have called for the expansion of SPO to look more specifically at structure characteristics through the components of organizational structure, culture, incentives, design, and information technology. They posit that this expansion better assesses indicators of healthcare quality (Glickman, Baggett, Krubert, Peterson, & Schulman, 2007). The present study is unique in that it looks at two models of care as process indicators of quality using the traditional SPO theoretical model.

## **SPO Theoretical Components**

Resident risk characteristics are the categorical name for the components of the population studied. These have included race, age, gender, marital status, education, functional status, and cognitive performance (Chapin & Dobbs-Kepper, 2001; Helmes, Csapo, & Short, 1987; Munn et al., 2006). Structure is the set of organizational components that are the attributes of the facility setting. These include facility size, staffing patterns, and type of ownership (Dobbs & Montgomery, 2005; Munn et al., 2006). Process is the set of organizational components that are the manner of care delivery (Donabedian, 1988; Kruzich et al., 1992). Process components include care planning, support of function and autonomy, management of physical and/or emotional symptoms, discharge policies, and philosophies of care (Munn et al., 2006). SPO quality outcomes studied in the literature have included mortality and discharge rates, change in functional status, and resident and/or family satisfaction (Dobbs & Montgomery, 2005; Kruzich et al., 1992; Volicer, Hurley & Blasi, 2001). Castle (2010) posits that current nursing home quality indicators represent a medley of all three components which confounds improvement in nursing home quality improvement. In keeping with Donabedian (1988), this study focuses on the process characteristics of enrollment in hospice and Dementia Special Care Units (DSCU) and their impact on the outcome of EOL care for individuals with dementia.

## **Research Questions**

Using this SPO theoretical framework, the first research question was based on the strong association between hospice's added benefit to EOL quality of care as evidenced in the literature review (Miller & Mor, 2002; Munn et al., 2006; Parker et al., 2003). Applying this to hospice enrollment for individuals with dementia, the question is: Will hospice enrollment have a positive association with quality of EOL care for individuals with dementia in nursing homes compared to traditional care enrollment when controlling for other resident risk, process, and structure characteristics? The first hypothesis was that families with decedents in hospice would rate EOL care better than families with decedents in traditional care.

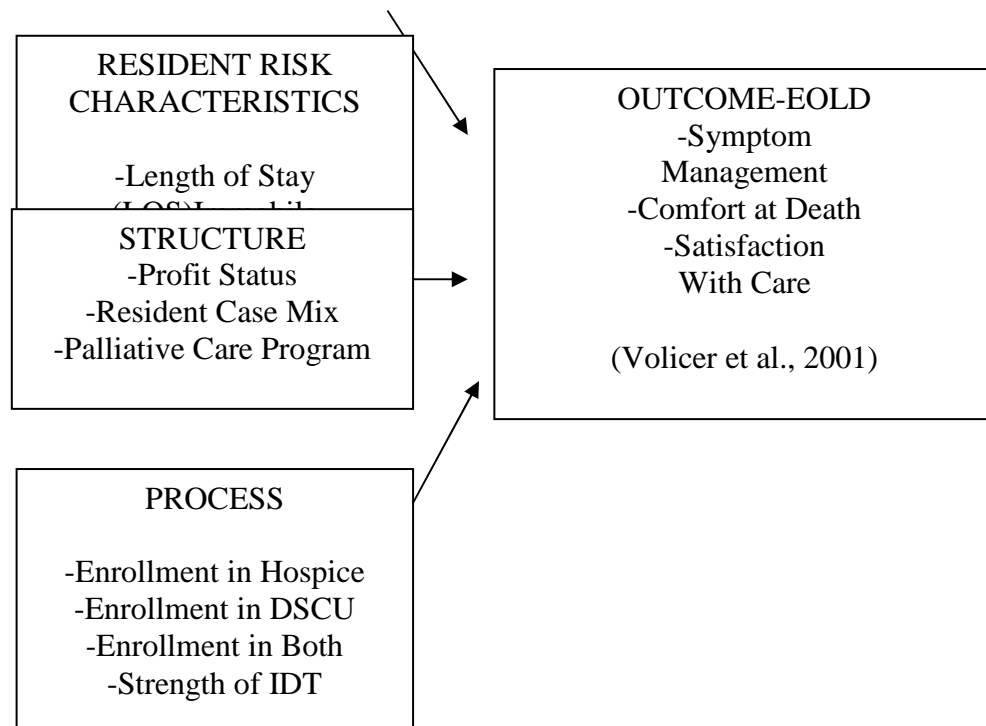
Based on the association between family satisfaction, resident quality of care, and DSCU as evidenced in the literature (Montgomery, 1994; Spector & Orrell, 2006; Zimmerman et al., 2005) the second research question was: Will DSCUs have a positive association with the quality of EOL care for individuals with dementia in nursing homes compared to traditional care when controlling for resident risk, process, and structure characteristics? The second hypothesis was that families with residents in DSCU would rate EOL care better than families in traditional care units. This hypothesis was based on the positive environmental correlates to morale and family satisfaction associated with person-centered care in DSCU research (Maas et al., 2004; Zeisel et al., 2003; Zimmerman et al., 2005).

The final research question was: Will the shared features of strong hospice and DSCU Inter-Disciplinary Teams (IDT) be associated with better quality of EOL care for individuals with dementia residing in nursing homes compared to individuals residing in traditional care? An answer to this question would determine if the strength of the EOLD scores associated with hospice and DSCUs is reliant on the IDT. The third hypothesis was that the strength of IDT would act as a moderator to better quality of EOL care for individuals with dementia residing in nursing homes.

## **Study Components**

### **Resident Risk Characteristics**

The following resident risk characteristics were determined to be the most pertinent for analysis based on the literature review of hospice and DSCU: length of stay (LOS) and care recipient immobility. LOS is a resident risk characteristic based on research suggesting an association between LOS and functional decline, increased hospice cost, and probability of increased mortality (Abicht-Swenson & Debner, 1999; Keay et al., 2003). LOS as a variable is important in the increased hospitalization of short-stay nursing home residents compared to long-stay residents (Hogan, Lunney, Gabel, & Lynn, 2001). Decedent LOS is therefore controlled for in the analysis. Care recipient immobility is a symptom identified in the Functional Assessment Staging Tool that is frequently used in determining a terminal diagnosis (Reisberg, 1988). Immobility refers to the individual's inability to move. The study model is shown in Figure One.



*Figure 1: Resident Risk Characteristics, Structure, Process and Outcome Variables.*

### **Structure Characteristics**

Profit status was included as a structure characteristic because of its association with quality of care. Profit status has been linked to staffing ratio, use of restraint, toileting schedules, and resident well-being. Certification deficiencies and odds of dying in a hospital are also affected by profit status (Dobbs & Montgomery, 2005; McGregor et al., 2005; Menec, Nowicki, Blandford, & Veselyuk, 2009). Resident case mix, the proportion of Medicaid residents, was included as a structure characteristics based on research confirming its significance with satisfaction as a quality of care outcome (Dobbs & Montgomery, 2005; Munn et al., 2006). Resident case mix has been included as a

structure characteristic in similar surveys (Dobbs & Montgomery, 2005; Munn et al., 2006). It could provide important data on the reality of access to hospice and DSCU based on Medicaid/Medicare dual eligibility (Donabedian, 1988; Donabedian, Wheeler, & Wyszewianski, 1982; Grant et al., 1995; Hays, Veitch & Evans, 2005). The presence of a palliative care program was controlled for as a structure characteristic because of its influence on EOL for traditional care residents.

### **Process Characteristics**

The process characteristics were chosen as the most pertinent for analysis based on the literature review of hospice and DSCU (Benedict et al., 2006; Grunier et al., 2007; Grunier et al., 2008; McKay & Cripp, 2008; Miller & Mor, 2002; Miller et al., 2003). The two process characteristics to be analyzed are enrollment at death and strength of IDT. Enrollment at death is the process characteristic that includes hospice/non-hospice enrollment as well as DSCU/non-DSCU enrollment. There were four different enrollment groups in the study: Hospice only, DSCU only, traditional care only, and dual enrolled hospice and DSCU only. Decedents were enrolled in just one of the groups with no overlap in order to distinguish hospice and DSCU as models of care.

Literature support for IDT as a study variable shows that hospice IDT has resulted in a 41% lower mortality rate, increased nurse satisfaction, reduced cost, and greater responsiveness to resident and family (McKay & Crippen, 2008). A dementia-specific IDT resulted in higher satisfaction among residents, caregivers, and nurses as

well as satisfaction for 79% of the physicians (Benedict et al., 2006; Counsell et al., 2000).

## **Outcome**

The outcome measure chosen for the study was the EOLD scale because it is the only scale that has been developed and validated as a reliable quality of EOL care measure for individuals with dementia (Thompson & Chochinov, 2006; Volicer, Hurley & Blasi, 2003). EOLD is a measure designed specifically for long term care settings and distinct to dementia. This dependent variable was chosen as the most pertinent for analysis based on the literature review of hospice and DSCU and the unique nature of EOL for individuals with dementia. With few exceptions (Munn et al., 2007) EOL research has focused predominately on indicators of EOL quality that were not appropriate for those with dementia (Thompson & Chochinov, 2006; van Soest-Poorvliet, van der Steen, Zimmerman, Cohen, Munn, Achterberg et al., 2011). The individual with dementia's rate of cognitive decline has been perceived as a hindrance to valid self-report in the late to terminal stage of the disease (Ready, Ott, & Grace, 2006; Thorgrimsen et al. 2003). The dying person with dementia may not have the cognition or the communication skills to provide prospective self-report measurement. Studies relying on proxy measures of the quality of EOL care in long term care found staff and family measures well correlated, with observational and resident measures much less correlated (Sloane, Zimmerman, Williams, Reed, Gill & Preisser, 2005). For example, resident suffering was rated lower by family than by staff, but family awareness of impending

death was higher than staff awareness (Aminoff & Adunsky, 2005; Sloane, Zimmerman, Hanson, Mitchell, & Reidel-Leo et al., 2003).

The EOLD consists of three subscales that measure satisfaction with care, symptom management, and comfort at death. Using families as proxy respondents for long term care decedents with dementia is a way of assessing the satisfaction of an important half of a partnered clientele (Cohen-Mansfield, 2002). Montgomery supports family measures in her DSCU study (1994). Family satisfaction indirectly reflects assessment of quality. Munn and colleagues affirm this stating that EOL care is by necessity both resident-centered and family-centered (2007). The primary decision-makers in hospice enrollment are predominantly family members (Haley et al., 2002). Family members' retrospective definition of "good death" included a high value placed on staff attitudes and empathy (Munn et al., 2006).



## Chapter Four: Research Design and Methods

### Study Design

Based on the literature review, the research was designed to assess how hospice care and dementia care models address the unique EOL care of individuals with dementia when compared to traditional care. Because primary data allows choice in the selection of measurement, sample, and method, the study included a retrospective survey of family members of decedents in nursing homes as well as a survey of nursing home administrators. The literature confirms that both proxy measure and retrospective design are valid approaches to the study of quality of EOL care for individuals with dementia (Thompson & Chochinov, 2006). Though retrospective measurement is the preferred method for studying quality EOL care for individuals with dementia, it has its challenges. The tendency for negative memory to be more easily recalled than positive can affect retrospective measurement. This could skew the caregiver proxy's response to questions about pain (Bradley, Mogg, & Millar, 1996). Because retrospective reports have shown validity up to 15 months from the death, the study included families of decedents who had died in the last 15 months or less (Munn et al., 2006).

The analytic technique chosen for the research questions was Ordinary Least Squares (OLS) hierarchical regression. Sample calculations for good effect size were based on the ratio of cases to independent variables (IV). The formula commonly used:  $N \leq 50 + 8M$  with  $M$  being IV's (Tabachnick & Fidell, 2001). The sample size of 130 was the target sample size based on 9 independent variables (IV) in the model. The

description of the resident, structure, process and outcome characteristics, are presented in Chapter Five.

## **Procedure**

This was a cross-sectional study about satisfaction with EOL care for a sample of 116 decedents with dementia (family proxy used) from 17 nursing homes in four states. The original sample targeted at least 10 Florida nursing homes expecting to yield 10 nursing home surveys and at least 150 family surveys. After a four month time period with only two nursing homes agreeing to participate, the sample was expanded to other states. Maryland, Pennsylvania, and Massachusetts nursing homes were added based on the doctoral candidate's prior clinical experience in these states that would pre-dispose participation by several nursing homes. Participating facility administrators identified decedents with a diagnosis of dementia who had died within a 15 month period (Munn et al., 2006). It was a sample goal to include at least 50% of facilities with DSCUs and Hospice. Facilities were chosen from the Alzheimer's Association's list of providers with DSCUs. Initial cold calls were made to determine administrator name and introduce the study with succeeding contacts consisting of emails, calls, and regular mail. Of the 102 facilities contacted, 17 agreed to participate resulting in a 16.7% facility response rate. The average number of contacts to refusal was 6.6 (SD = 4.1). The average number of contacts to acceptance was 18.6 (SD = 6.5). The reported reasons for refusal included change in administrators, budget and survey windows, level of work requested, and inability to delegate a person to be responsible. Of the 17 participating nursing homes,

seven were in Florida, nine from Maryland, one from Pennsylvania, and one from Massachusetts.

A retrospective survey of nursing home administrators and family members was conducted. The nursing home administrator survey included questions about the structure and process features of the facility as well as administrator demographics. Nursing home administrators also provided the decedent contact names. Informed consent was obtained from the facility prior to mailing the family surveys. The Administrator/Director of Nursing (DON) questionnaire was completed either prior to or during the facility visit. This questionnaire took approximately 15 minutes to complete and provided the structure characteristics (profit status, percent Medicaid as primary payer, & other palliative care program). In order to confirm the DSCU process characteristics, a facility walk-through was conducted and took approximately 10 minutes. This confirmed that the environmental features provided by the administrator were those expected from the Gerdner & Beck (2001) DSCU check-list. See Appendix A. The family questionnaire included items about the resident risk characteristics (i.e., LOS), and care recipient immobility), process characteristics (i.e., hospice enrollment, DSCU enrollment, & strength of IDT), and outcomes ((i.e., Satisfaction With Care (SWC), Comfort at Death (CAD), and Symptom Management (SM)). The completion and return of the survey served as implicit Informed Consent as suggested and approved by the University of South Florida Institutional Review Board. The family members were identified by the facility in compliance with facility-specific Health Information

Portability and Accountability Act regulations <http://www.hhs.gov/ocr/privacy> (HIPAA, 1996).

## **Measures**

### **Resident Risk Characteristics**

One item was used to measure the immobility of residents ( $I = Yes$  and  $0 = No$ ). The measure was obtained from the Functional Assessment Staging Tool (FAST), as an indicator used within the FAST to diagnose terminality (Reisburg, 1988). See Appendix B.

Decedent LOS was measured in months based on the number of months or portions of a month provided by the family respondent for nursing home, hospice, and Dementia Special Care Unit (DSCU).

### **Structure Characteristics**

The structure characteristics that were included on the administrator survey were the facility features of: Profit status, resident case mix, and the presence of other palliation. Profit status was a *Yes/No* response to the question: “*Is your facility a for-profit facility?*” A *Yes* response was coded as  $1$ , *No* as  $0$ . Resident case mix was based on the administrator’s answer to the percentage of residents on Medicaid as the primary payer. The percentage of residents receiving Medicaid funds was entered as a continuous measure. The range for this measure was 28-85 with a mean of 54.11 (SD = 14.5).

The final structure characteristics controlled for was the presence of a palliative program other than hospice (*Yes/No*) where  $1 = \text{yes}$  and  $0 = \text{no}$ .

### **Process Characteristics**

The process variables were hospice enrollment, DSCU enrollment, both enrollment, and strength of IDT. Each was provided by the family respondents on the family questionnaire. Care recipient enrollment in hospice/non-hospice, DSCU/non-DSCU, and enrolled in both hospice and DSCU/non-both enrolled was controlled for in the process variables. Each decedent was coded with  $1 = \text{enrollment}$ ,  $0 = \text{non-enrollment}$  for the enrollment variables. The strength of IDT measure included fourteen items on the family questionnaire pertaining to inclusion in decision-making, accurate communication and emotional support. See Appendix B. These were rated on a 5 point Likert scale with coding as 1- *Strongly Disagree*, 2- *Disagree*, 3 - *Neither Agree or Disagree*, 4 - *Agree*, 5 – *Strongly Agree*. The scale had a possible range of 5 – 70; an average of 53.20 (SD = 10.51) and a Cronbach's alpha score of .70.

### **Decedent Care Model-DSCU Enrollment**

To confirm both the administrator and the family definition of DSCU, the Gerdner and Beck (2002) DSCU criteria was applied to each facility. In this study, five of Gerdner & Beck's DSCU criteria were used for assessment. These were Certified Nursing Assistant (CNA) staffing-to-resident ratio, departmental DSCU training, Inter-Disciplinary Team (IDT), activity provision, and environmental features (Gerdner & Beck, 2001). The study used the mean CNA staffing-to-resident ratio observed in the

Gerdner & Beck study to be the cut-off criteria for confirming a DSCU. The day shift mean was one CNA for every 10 residents. The evening shift mean was one CNA for every 12 residents. The night shift mean was one CNA for every 17 residents. DSCU criteria was based on greater than or equal for each of these means. Greater than the mean was coded as *1*, less than the mean was coded as *0*.

Departmental DSCU training, the second Gerdner & Beck criteria, was assessed with a Yes/No response for the departments of nursing, activities, physician, dietary, social work, therapy, and family members where *1 = yes* and *0 = no*. The Gerdner & Beck criterion expected all departments (100%) to have DSCU training. Each department's DSCU training was coded as *dementia training = 1* and *no dementia training = 0*.

### **Gerdner & Beck's Care Plan Criteria**

Gerdner & Beck (2001) provided a format for the optimal care plan team with inter-disciplinary participation, which was applied to this study sample. The IDT for DSCU participation was assessed from the Administrator questionnaire with *Yes/No* responses for the following disciplines as participants: registered nurse, activity director, social worker, registered dietician, physician, CNA, physical therapist, occupational therapist, music therapist, and family member. These ten IDT for DSCU participation questions were combined as a composite score. For example, if the score = 10, the IDT for DSCU participation was met and coded as *1 = Yes if  $\geq 10$ , 0 = No if  $< 10$* .

The Gerdner & Beck (2001) assessment of activity was included in the administrator's questionnaire. See Appendix D. It quantified the number of activities per weekday, weekend day, and evening with activity categories of music, art, reminiscence, and physical games. Gerdner & Beck (2001) observed no differences in number of weekday activities in DSCU and non-DSCU. However, the observed percentage of DSCU activities for weekends was 100% compared to only 65% weekend activities on traditional units. The observed evening percentage of activities in DSCU's was 63% compared to 50% on traditional units (Gerdner & Beck, 2001). Therefore, the current analysis focused only on percentage of activities per weekend and evenings. This variable was coded as  $1 = \text{yes}$  for those providing *both evening and weekend* activities and  $0 = \text{no}$  for those not providing *both evening and weekend* activities. A DSCU had to offer both evening and weekend activities.

Environmental features were assessed with a *Yes/No* response to the following ten physical features: home-like environment; secured unit with electronic device; separate dining room within the unit; access to secured outdoors; high visual contrast between walls, floors, and doorways; non-reflective floors, walls, and ceilings; visual contrast between plates, eating utensils and table; emergency only use of public address system; dementia-specific mission statement; and quality assurance protocol for DSCU. Each was coded  $1 = \text{yes}$  and  $0 = \text{no}$ . They were totaled in a composite score. A score of 10 met the criteria for DSCU environment.

DSCU criteria were a composite of five Gerdner & Beck criteria (2001) with facilities having a score of 5 were coded as  $1$  and *less than 5* coded as  $0$ .

## Outcome Measures

In investigating the hypotheses that hospice and DSCU enrollment predict better quality EOL care, the EOLD scale was chosen as the outcome measure (Kiely, Volicer, Teno, Jones, Prigerson, et al., 2006). The EOLD consists of three subscales which were analyzed as separate dependent variables.

The three subscales are Satisfaction With Care (SWC), Comfort At Death (CAD), and Symptom Management (SM). See Appendix B. SWC assessed family satisfaction with decision-making, communication with healthcare professionals, family understanding of the resident's condition, and the resident's medical and nursing care. It included 10 items measured on a three-point Likert scale coded as *1 = Strongly Disagree*; *2 = Disagree*; *3 = Agree*. The scale had a possible range from 10 to 30. The higher the score, the more satisfied the family was with EOL care. The EOLD subscales (regardless of enrollment group) yielded a mean of 26.5 (SD = 3.5) for SWC, and 32.3 (SD = 3.7) for CAD as shown in Table 4.1. Because a documented hospice LOS for individuals with dementia is less than a month, it was decided to change the EOLD look-back period for families to a seven day perspective instead of the longer periods used in previous studies (Kiely et al., 2006; Miller & Mor, 2001; Volicer et al., 2001). Each subscale was analyzed for reliability after collecting the data (Kiely et al., 2006; Volicer et al., 2001). The reliability of the SWC was .83 and .70 for CAD.



*Table 4.1. Outcome Reliability*

EOLD Subscale Satisfaction With Care (SWC)	Mean (sd) 26.5 (3.5) Range 10-30	Cronbach's Alpha .83
Comfort at Death (CAD)	32.3 (3.7) Range 14-42	.70

CAD assessed decedent symptoms of comfort: physical and emotional distress, and well-being. The CAD included 14 items measured on a three-point Likert scale with coding as *1 = A Lot; 2 = Somewhat; 3 = Not at All*. The scale had a possible range of 14 to 52. The higher the score was, the less comfortable the decedent was in the last seven days of life.

The median scores of all care models were quite similar, with DSCU scores being highest and traditional scores being lowest. See Table 4.2. The means for totaled SWC for decedents in DSCU (27.3) and dual enrolled (27.0) were higher than those in hospice (26.3) or traditional care (23.7). CAD score means were less consistent with DSCU and hospice decedent scores being slightly higher than dual enrolled and traditional enrolled decedents.

*Table 4.2. Study Outcomes by Enrollment Distribution*

<b>Outcomes</b>	<b>Hospice</b>	<b>DSCU</b>	<b>Dual Enrolled</b>	<b>Traditional</b>
		<b>Mean (SD)</b>		
Totaled CAD Scores	32.0 (4.1) Median 32.7	33.2 (3.8) Median 32.3	31.9 (2.8) Median 32.0	31.6 (4.2) Median 32.3
Totaled SWC Scores	26.3 (2.8) Median 27.0	27.3 (2.8) Median 27.5	27.0 (2.7) Median 27.0	23.7 (5.2) Median 26.0

## **Analysis**

After data was collected, data files were created including all the variables using SPSS 19.0. Initial descriptive statistics were conducted to determine range values, and missing data. Missing data that were randomly missing and higher than 10% were imputed with the mean of that variable based on the review of the variable scatterplot and distribution curve for extreme values and outliers (Tabachnik & Fidel, 2000). See Appendix F & G. Bivariate correlation analysis was conducted to determine how closely the variables were related and for multi-collinearity. An Analysis of Variance (ANOVA) was used to describe the continuous independent variables.

In assessing the data for normality, extreme values were found in the LOS variable for each care model. These outliers were in cases with extremely low number of days of decedent enrollment and extremely high number of days. Initially, LOS of each enrollment group was analyzed but this was confounding two variables, that of group enrollment and of Length of Stay (LOS). Consequently decedent LOS is the variable used. The distribution was positively skewed because of the shorter LOS for hospice for individuals with dementia (Miller, 2010). It was determined that we would include the subjects with minimal LOS in order to have an adequate sample for hospice decedents. Therefore log transformation was conducted to address the non-normality of the data (Tabachnick & Fidell, 2000). Because of the positive skew of the data, the arbitrary number 3 was added to allow log transformation on the data that was 0 or less than 1

(Tabachnick & Fidell, 2000). The results of running the OLS regressions with or without the transformed variables were comparable with the change in  $F$  having the same significance with both log transformed and non-log transformed units of measurement. As a result, the non-transformed relationships are presented in further analyses as the estimates are in their original units of measurement.

Hierarchical multiple regression was the chosen method for final analysis because of its ability to describe the relationships between the study variables (Tabachnik & Fidell, 2000). Hierarchical regression has to be based on theory in order to create the model sequence (Tabachnik & Fidell, 2000). Structure, Process, Outcome (SPO) guided the model entry order. With SWC as the dependent variable, a separate regression analysis was conducted for each theoretical component (resident risk characteristics, structure characteristics, process characteristics, and outcome). First the resident risk characteristics were entered into the equation (i.e., Care Recipient Immobility, decedent LOS). The second group of independent variables entered into the equation was the structure characteristics (i.e. Profit Status, Percent Medicaid, and Presence of Other Palliation). Third, the process characteristics were entered into the regression equation (i.e., hospice enrollment, DSCU enrollment, enrollment in both hospice and DSCU, and Strength of IDT Scores). The same modeling was conducted for CAD as the dependent variable. Due to a high rate of Not Missing at Random data on the SM subscale of the EOLD (56%), the SM scale was excluded from further analysis. Respondents' written reasons for not answering the SM scale questions indicated a non-random classification. It was determined that the missing data in CAD was missing at random by looking at the

scale's scatter plot for outliers and extreme values. Imputation with the mean was used to handle the CAD scale's 26% rate of missing at random data.

## **Chapter Five: Results**

This chapter provides the descriptive for each SPO variable as well as the inter-item correlations, and hierarchical regression results to answer each of the three study research questions.

### **Descriptive Results**

#### **Resident Risk Characteristics**

Decedents in the sample included 44.8% who were immobile (unable to move independently). Fifty percent of family members reported that decedents enrolled in the hospice enrollment group and the traditional care groups were immobile. Thirty percent of family reported that decedents enrolled in DSCU were immobile and 70% of decedents enrolled in both hospice and DSCU were immobile.

The average decedent LOS was 23 months with a range of .07 months (2.1 days) through 144 months (SD = 31).

#### **Facility Structure Characteristics from Administrator Survey**

Of the facilities sampled (N=17) 31.9 % were for profit. Religious affiliated facilities represented 33.3% of the study sample. The average percentage of Medicaid beds was 54.1 (SD = 14.5). All of the facilities reported a hospice contract and 94.1% stated having a DSCU. Another palliative program other than hospice was present in 45.7% of the facilities.

The reported percentage of dementia among residents ranged from 20-100% with an average of 62.7%. The mean number of beds was 176 (SD = 32.8).

### **Facility Structure Characteristics by Decedent Group Enrollment**

Five facilities provided family respondents for hospice enrolled decedents, 15 facilities provided the family respondents for DSCU enrolled decedents, 11 the dual enrolled family respondents, and 12 facilities provided family respondents for the traditional enrolled decedents. The largest percentage of decedents from for-profit facilities (57.1%) was in hospice enrollment and traditional enrollment (47.4%). Thirty-two percent of decedents who were dual enrolled died in a for-profit facility. See Table 5.1.

There were a high percentage of facilities providing other palliation in all enrollment groups. Facilities with other palliation programs provided the bulk of hospice decedents (86%), 53% of the traditional decedents, 32.3% of the dual enrolled group and 40.4% of the DSCU enrolled. See Table 5.1.

The percentage of residents receiving Medicaid in the nursing home was collected as a continuous variable based on each administrator's answer to the question "What percentage of residents has Medicaid as their primary payer?" The highest mean Medicaid percentage was for the dual enrollment group (56.1) with a standard deviation of 55.7.

*Table 5.1. Structure (Facility) Characteristics by Decedent Enrollment<sup>a</sup>*  
*N = 116*

<b>Structure Factor</b>	Hospice Enrollment N (% of Decedents)	DSCU Enrollment N (% of Decedents)	Both Enrollment N (% of Decedents)	Traditional Enrollment N (% of Decedents)
Facility For Profit	8 (57.1%)	10 (19.2%)	10 (32.3%)	9 (47.4%)
Presence of Other Palliation	12 (85.7%)	21 (40.4%)	10 (32.3%)	10 (52.6%)
	<b>Mean (SD)</b>			
Facility % Medicaid	42.5 (8.9)	55.6 (14.8)	56.1(55.7)	55.4 (15.0)

<sup>a</sup>The enrollment group is a dichotomous variable, the facility characteristics are continuous. Therefore the totals will not sum 116.

### **Facility Process Characteristics**

Of the 17 facilities sampled, decedent enrollment in hospice was 12%, in DSCU was 46%, 27% enrolled in both, and 16.4% enrolled in traditional care as shown in Table 5.2. The sample exceeded study projections of hospice contracts in 50% of the facilities with all 17 administrators reported contracting with hospice.

*Table 5.2. Facility Process Characteristics by Number Enrolled in Group*  
*N=116*

<b>Process Characteristic</b>	<b>Hospice Enrollment</b>	<b>DSCU Enrollment</b>	<b>Both Enrollment</b>	<b>Traditional Enrollment</b>
Decedent Group Enrollment	N = 14 (12%)	N = 52 (46%)	N = 31 (26.7%)	N = 19 (16.4%)

## **Gerdner & Beck’s DSCU Criterion Compliance**

Of the 17 facilities surveyed, 10 (71.6%) met the five DSCU criteria: CNA staffing ratio, DSCU training, environment, activity provision, and IDT. When projecting sample size for the study, there was the realization that the Gerdner & Beck (2001) criteria may limit sample. It was determined that DSCU criteria may be adapted after analysis. Because of the need for increased sample, all facilities with four or more of the DSCU criteria were analyzed rather than the proposed five criteria. All 17 facilities met the four or more criteria.

## **IDT Descriptives**

The mean Strength of IDT scores were highest for the dual enrolled decedents (55.1) followed by DSCU (54.3) and hospice (54.0) respectively. Traditional enrolled decedents had the lowest mean (46.4). See Table 5.3.

*.Table 5.3. IDT (Process) Descriptive Information*

	<b>Hospice Enrolled</b>	<b>DSCU Enrolled</b>	<b>Dual Enrolled</b>	<b>Traditional Enrolled</b>
<b>Other Process Characteristics</b>		<b>Mean (SD)</b>		
Strength of IDT Scores	54.0 (10.7) Median 51.6	54.3 (10.6) Median 54.0	55.1 (9.0) Median 55.0	46.4 (10.7) Median 47.0

## **Inter- Item Correlation Findings**

The preliminary inter-correlation analysis used Spearman’s Rho to show the following associations. See Table 5.4. All resident risk characteristics were included to



assess their association and lead in determining which variables to include in the SPO framework for analysis. Hospice enrollment was associated with non-ambulation ( $r = .20, p < .01$ ). Decedent LOS was positively associated with percent Medicaid ( $r = .19, p < .05$ ). There was an association between incontinence and non-ambulation ( $r = .31, p < .01$ ).

DSCU enrollment was negatively associated with facility profit status and presence of other palliation ( $r = -.22, p < .05$ ;  $r = -.30, p < .01$ ). DSCU enrollment was positively associated with the Strength of IDT score and the total SWC score ( $r = .30, p < .01$ ;  $r = .20, p < .05$ ). Profit status was also associated with the presence of other palliation programs ( $r = .56, p < .01$ ) which is consistent with the facility's financial disincentive for hospice (Miller & Lima, 2004). The positive association of Strength of IDT with SWC supports hypothesis three ( $r = .70, p < .01$ ).

The resident risk characteristic of immobility was included in the hierarchical regressions based on the high percentage of care recipients with immobility as well as immobility's strong association with dual enrollment ( $r = .28, p < .05$ ; profit status ( $r = .29, p < .01$ ); and other palliation ( $r = .21, p$ ). The correlation results indicated no evidence of multi-collinearity.

*Table 5.4. Inter-Item Correlation*

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1 Hospice	--	.0	-.22*	-.21*	.15	.20**	.20	.15	.08	-.33**	.05	-.05	.00	-.14
2 DSCU		--	-.54**	.18	.20	.07	-.02	.05	-.22*	.11	-.30**	.30**	.20*	-.03
3 Both			--		.14	.23*	.28*	.23*	.00	.06	-.16	.12	.04	.12
4 Decedent LOS				--	-.07	.08	-.01	-.12	.09	.19*	-.03	-.06	.10	.13
5 Incontinent					--	.31**	.03	.15	-.09	-.14	-.06	.05	.02	.00
6 Non-Ambul.						--	.31**	.25**	.12	-.10	.08	-.08	.06	-.02
7 Immobile							--	.18*	.29**	-.13	.21*	-.04	-.09	-.07
8 Lose Weight								--	.31**	.06	.21*	-.03	-.06	-.14
9 Profit Status									--	.05	.56**	-.17	-.15	.01
10 Percent Medicaid										--	.04	.07	.14	-.07
11 Other Palliation											--	.17	-.16	.01
12 Strength of IDT												--	.70**	.08
13 Ttl SWC													--	.19*
14 Ttl CAD														--

\*p<.05, \*\*p<.01, \*\*\*p<.001

## **Outcome**

### **Research Question One Findings: Hospice's Association with Better EOLD**

Of the three subscales of EOLD, only SWC and CAD were analyzed. Therefore the findings of question one and two are presented in Tables 5.5 & 5.6.

The first research question was: Will hospice enrollment have a positive association with quality of EOL care for individuals with dementia in nursing homes compared to traditional care enrollment when controlling for other resident risk, process, and structure characteristics? Therefore hypothesis one was: Enrollment in hospice will be associated with better EOLD scores. This was analyzed with ordinary least squares (OLS) hierarchical regression analyses, looking at the two outcomes of EOLD (SWC, CAD) with the dichotomized predictor variable hospice/non-hospice care. See Table 5.7.

### **SWC Findings**

For Satisfaction With Care, in model one, the resident risk model accounted for 1% of variance in the outcome of SWC but was not significant ( $R^2 = .01, p < .66$ ). The effect size was insignificant ( $\Delta F = .66$ ). In model two facility structure characteristics accounted for an additional 1% in variance in the outcome of SWC ( $R^2 = .01, p < .80$ ). The effect size was insignificant ( $\Delta F = .67$ ).

Within model three's facility process characteristics only the hosting of another palliation program was a significant contributor to variance ( $p < .05$ ). The standardized regression coefficient ( $\beta$ ) for hospice enrollment was not significant ( $p = .60$ ). Strength

of IDT was the most significant contributor to the model variance at ( $p < .001$ ). Model three's entire contribution to variance in the outcome of SWC was an additional 58% ( $R^2 = .60, p < .001$ ). The effect size was significant ( $\Delta F = 15.17^{***}$ ).

5.5 Satisfaction With Care

Variable	Model 1			Model 2			Model 3		
	b	SE	B	b	SE	B	b	SE	B
<b>Resident Risk</b>									
Care Recipient Immobile	-.60	.66	-.10	-.60	.70	-.10	-.60	.50	-.08
Decedent Length Of Stay Structure	-5.40	.01	.00	.00	.02	.01	-.57	.50	.12
Facility for Profit				-.47	.86	-.06	-.02	.60	.00
Facility % Medicaid				-.03	.02	-.1	-.01	.02	-.10
Facility Hosts Another Palliative Program Process				.21	.80	.03	1.22	.58	.18*
Strength of Inter-Disciplinary Team							.22	.02	.67***
DSCU Enrollment							2.10	.69	.30**
Both Hospice & DSCU Enrollment							2.23	.82	.30**
Hospice Enrollment							.83	.97	.08
<b>p</b>		.66			.80			.000***	
<b>R<sup>2</sup></b>		.01			.02			.60	
<b>F for change in R<sup>2</sup></b>		.66			.67			15.17***	

\*p<.05, \*\*p<.01, \*\*\*p<.001

## **Comfort At Death**

For Comfort At Death, the model one analysis showed that there were no significant Resident Risk contributors to variance in CAD scores. Resident risk characteristics accounted for only 6.0% variance in the outcome of CAD ( $R^2 = .06$ ,  $p < .03$ ). The effect size was insignificant ( $\Delta F = .66$ ).

In model two, controlling for facility structure characteristics, the only significant contributor to variance in CAD scores was contributed by decedent length of stay ( $p < .05$ ). The structure characteristics added a minimal 1% of variance in the outcome CAD ( $R^2 = .07$ ,  $p < .14$ ). The effect size was insignificant ( $\Delta F = .77$ ).

Model Three's control of facility process characteristics showed decedent LOS ( $p < .05$ ) was still a significant contributor to the increase in variance. Model three's contribution to variance in the CAD scores was an additional 3% ( $R^2 = .10$ ,  $p < .30$ ). The effect size was insignificant ( $\Delta F = .50$ ). For the EOLD subscale, CAD, neither hypotheses one or two were supported by the analysis, with group enrollment having no significant association on the outcome measure, CAD. See Table 5.6.

## **Research Question Two Findings**

### **DSCUs Association with Better EOLD**

The second research question was: Will DSCUs have a positive association with the quality of EOL care for individuals with dementia in nursing homes compared to traditional care when controlling for resident risk, process, and structure characteristics?

The second hypothesis was that families with residents in DSCUs will rate EOL care better than families in traditional care. This was analyzed with OLS hierarchical regression analyses looking at the two outcomes of EOLD (SWC, CAD) with the dichotomized predictor variable DSCU/ non-DSCU. The standardized regression coefficient ( $\beta$ ) for DSCU enrollment's prediction of SWC was significant ( $\beta = .30, p < .01$ ). Therefore DSCU enrollment played a role in improvement in the dependent variable SWC. However, the regression analyses of CAD did not produce a significant standardized regression coefficient ( $\beta$ ) for DSCU enrollment ( $\beta = .22$ ). Therefore as an independent variable DSCU was not associated with improved CAD scores. See Tables 5.5 and 5.6.

### **Comfort At Death Findings**

As described previously, the CAD analysis showed no significant association for any of the SPO models in the regression. For the EOLD subscale, CAD, neither hypotheses one or two were supported by the analysis, with group enrollment having no significant association on the outcome measure, CAD.

Table 5.6 *Comfort At Death*

Variable	Model 1			Model 2			Model 3		
	b	SE	B	b	SE	B	b	SE	B
<b>Resident Risk</b>									
Care Recipient Immobile	-1.30	.70	-.17	-1.33	.72	-.18	-1.18	.76	-.16
Decedent Length Of Stay	.02	.01	.18	.02	.01	.19*	.03	.01	.20*
<b>Structure</b>									
Facility for Profit				-.50	.90	-.06	-.19	.93	-.02
Facility % Medicaid				-.02	.02	-.06	-.02	.03	-.06
Facility Hosts Another Palliative Program Process				.75	.83	.10	.80	.90	.11
Strength of Inter-Disciplinary Team DSCU Enrollment							.02	.04	.06
Both Hospice & DSCU Enrollment							1.62	1.1	.22
Hospice Enrollment							1.04	1.30	.12
Hospice Enrollment							.74	1.50	.07
P		.03			.14			.30	
R <sup>2</sup>		.06			.07			.10	
F for change in R <sup>2</sup>		.03			.77			.50	

\*p<.05, \*\*p<.01, \*\*\*p<.001



## Research Question Three Findings

### IDT as Moderator

The final question was: Will the shared features of strong hospice and/or DSCU Inter-Disciplinary Team (IDT) be associated with better quality of EOL care for individuals with dementia compared to IDT in traditional care nursing homes? The third hypothesis is that if indeed better EOLD scores are associated with hospice and DSCU enrollment is this relationship moderated by the strength of IDT? In order to examine the moderating role of IDT in association with SWC, a separate hierarchical regression analysis was conducted based on the significant effect found in decedents of DSCUs. The DSCU interaction was entered into the SWC regression equation as a fourth step (Table 5.7). The change in  $F$  statistic was significant indicating that the effect of DSCU enrollment on SWC is modified by the Strength of IDT ( $p < .001$ ). In order to show how IDT modifies the link between DSCU enrollment and SWC the DSCU sample was divided into two groups, DSCU enrolled and non-DSCU enrolled. A bivariate correlation was conducted between the Strength of IDT scores and the SWC (DSCU:  $r = .50$ ,  $n = 64$ ; non-DSCU:  $r = .70$ ,  $n = 52$ ). In order to analyze the significant difference between the two correlation coefficients, a *Fisher's  $r$  to  $z$*  transformation was conducted ( $z = -1.66$ ). The correlation between IDT and SWC in DSCU enrolled was not significant when compared to non-DSCU enrolled ( $p = .10$ ). There is evidence of a trend but the comparisons have low statistical power.

Table 5.7. Interaction of IDT and DSCU Enrollment

Satisfact. with Care	Model One			Model Two			Model Three			Model Four			
	Variable	b	SE	B	b	SE	B	b	SE	B	b	SE	B
<b>Resident Risk</b>													
Care Recipient Immobile													
Decedent Length Of Stay													
<b>Structure</b>													
Facility for Profit													
Facility % Medicaid													
Facility Hosts Another Palliative Program													
<b>Process</b>													
Strength of Inter-Disciplinary Team													
DSCU Enrollment													
Both Hospice & DSCU													
Hospice Enrollment													

Strength of Inter-Disciplinary Team x DSCU				-.11	.05	-.22*
<i>p</i>	.66	.80	.000		.000	
<i>R</i> <sup>2</sup>	.01	.02	.54		.56	
<i>F</i> for change in <i>R</i> <sup>2</sup>	.42	.48	15.17***		14.33***	

\**p*<.05, \*\**p*<.01, \*\*\**p*<.001

In summary, the analyses supported hypothesis two with DSCU enrollment being significantly associated with SWC. Hypothesis three was also supported, with a significant interaction found between DSCU enrollment and IDT. Further analysis did not show how strength of IDT modified the link between DSCU enrollment and SWC.

## Chapter Six: Discussion

The first section of the discussion will summarize the study findings and contributions. Policy implications and study limitations follow in the second section with a summary in conclusion.

This study showed support for two of the three hypotheses based on the OLS hierarchical regression. Hospice enrollment was not associated with improved EOLD scores, however DSCU enrollment was associated with one subscale of EOLD. This positive association between DSCU enrollment and SWC was moderated by the strength of Inter-Disciplinary Team (IDT) as hypothesis three predicted.

The lack of significant association between hospice enrollment and EOLD may be the result of hospice enrollment's smaller sample size ( $n = 14$ ). A more robust hospice sample may have resulted in a positive association with SWC. The positive association with SWC in the dual enrolled group ( $\beta = .24, p < .05$ ) is notable; however which enrollment group is responsible for the significance (hospice or DSCU) is not able to be analyzed separately in the current study because of the inability to individually isolate the impact of the models. This study supports the added value of DSCUs compared to traditional care in family EOLD assessment of SWC. As a process characteristic, enrollment in DSCU contributed significantly to variance in SWC ( $p < .05$ ). That DSCUs show significant positive results is re-iterated in research showing less hospitalization, pressure ulcers, and weight loss for individuals with dementia residing in

a DSCU compared to those in a traditional nursing home unit (Gruneir, Miller, Intrator, & Mor, 2007; Luo et al., 2010).

The value of family satisfaction as an outcome is supported in a study looking at healthcare proxies' decision-making satisfaction (Givens, Kiely, Carey, & Mitchell, 2009). Healthcare proxies for decedents on DSCUs had higher levels of overall decision satisfaction as well as satisfaction with decedent comfort. Family satisfaction ratings are included in nursing home report cards in several states (Ejaz, Straker, Fox, & Swami, 2003). With the large amount of varied quality assessments being used nationally, consumer voice is uncommon because of the cost of collecting the data (Sangle, Bernard, Buchanan, Keller, Mitchell, Castle et al., 2007). This study's outcome measure of SWC is valuable because of its focus on consumer-voice which is validated by its continued use in EOL research (Sampson, Jones, Thune-Boyle, Kukkastenvehmas, King, Leurent et al., 2011).

The study's determination that DSCU as a care model increases satisfaction with EOL care further supports the need to improve access to DSCUs for individuals with dementia. For example, persons receiving Medicaid have less access to dementia care. The disparity in Medicaid hospice payments and Medicare payments for DSCUs is prohibiting individuals with less income from accessing quality dementia care (Grant et al., 1995; Huskamp et al., 2010; Iwashyna et al., 2002); Miller & Lima 2004; McCarty & Volicer, 2009).

The process characteristic of Strength of IDT was a significant moderator of SWC ratings and a strong contributing characteristic to the variance in SWC outcome. This finding is consistent with prior research that indicated satisfaction with decision-making was higher on DSCUs, with provider reassurance and support, amount of information received about treatments, and time spent with care providers being central to family satisfaction (Givens et al., 2009). As research on IDT increases, so does support of its dynamic role in satisfaction with care. Family participation in the IDT has been shown to improve outcome ratings by five times (Wittenberg-Lyles, Parker-Oliver, Demiris, Burt, & Regehr, 2008). The need for the inclusion of many disciplines in EOL care is supported by recent research on interventions to improve hospice IDT (Demiris et al., 2009; Torke, Holtz, Hui, Castelluccio, Connor, Eaton et al., 2010; Zwijsen, Smalbrugge, Zuidema, Koopmans, Bosmans et al., 2011). A geriatric team intervention resulted in decreased hospitalizations and mortality (Bellatonio et al., 2008). The value of IDT is re-iterated in research that affirms its value in communication, information sharing, shared decision-making, and acknowledgement of caregiver preferences for care (Steinhauser, Christakis, Clipp, McNeilly, McIntyre, & Tulsky, 2000; Thompson & Chochinov, 2008; Torke et al., 2010). Improved information sharing and decision-making results in less aggressive interventions for loved ones in nursing homes and less suffering (Aminoff & Adunsky, 2005; Mitchell, Teno, Kiely, Shaffer, Jones, Prigerson et al.; 2009; Teno et al., 2004; Torke et al., 2010). The current study highlights IDT as a key feature of model EOL programs which is supported by the literature (Torke et al., 2010; Wiener & Tilly, 2003; Zwijsen et al., 2011).

The descriptive findings of the care enrollment groups represent trends in facility characteristics related to EOL care for individuals with dementia in nursing homes. The largest percentage of decedents from for-profit facilities (57.1%) was in hospice enrollment and traditional enrollment (47.4%). Only 19% percent of DSCU decedents and 32% of dual enrolled decedents died in a for-profit facility. Although this study sample is a convenience sample, it is consistent with DSCU literature suggesting a connection to non-profit status (Gruneir et al., 2007).

Profit status was correlated to another structure variable, other palliation ( $r = .56$ ,  $p < .01$ ). The profit loss to facilities with hospice enrollment appears to be associated with palliative alternatives (Resnick, Foster, & Hickman, 2009). The relatively high percentage of other palliation programs in all decedent enrollment groups calls for further research into how other palliation programs improve the quality of EOL care for individuals with dementia without increasing the costs of care compared to hospice.

### **Policy Implications**

With evidence of improved outcome in EOL care from the process characteristic of DSCUs, policy initiatives to improve access for individuals with dementia are needed. Stevenson & Bramson (2009) suggest that a separate Medicare benefit be considered for nursing home residents who are not receiving rehabilitation. The individual with dementia whose health decline is predominantly cognitive would benefit from Medicare coverage. Nursing homes could receive a bundled payment of post-acute, long-term, and EOL care in a single payment from Medicare (Huskamp et al., 2010). This

expansion beyond a curative focus has been conceptualized in several ways. Calling for payment modification, more staff training and regulatory change, Meier et al. (2010) conceive of simultaneous access. Policy change would no longer require the necessity for determination of terminal status but would offer both palliative and restorative care. Relieving suffering and improving quality of life are not exclusive to improving physical and emotional wellness (Meier et al., 2010). Because of the high percentage of nursing home residents with dementia, this expansion of Medicare benefits would increase access to both hospice and DSCUs. The researchers found evidence of cost-savings for the dual enrolled in an insurance study that showed reduced hospitalization and interventions costs (Meier et al., 2010; Spettell, Rawlings, Krakauer, Fernandes, Breton, Gowdy et al., 2009). The toll of hospitalization on the individual with dementia is well-documented (Cowdell, 2010; Sampson, Blanchard, Jones, Tookman & King, 2009; Volicer et al., 1998). The increased cost of care on a DSCU often results in an inability to stay in the unit through the EOL (Grant et al., 1995; Kovach, 1998). Yet decedents who remained in DSCUs until the EOL had lower Medicare expenditures (Goldfield, Stevenson, Hamel & Mitchell, 2011). Policy change that would alleviate the increased hospitalization rate and the cost of pre-hospice care would be beneficial to individuals with dementia.

The barrier to diagnosing end-stage dementia could also be addressed through policy change. Capitated funding for hospice care would facilitate earlier availability of hospice services and more flexibility in the type of services that are provided. The individual with dementia is denied rehabilitation while receiving palliative care because of the focus on comfort not cure (Miller & Mor, 2002; NHPCO, 2010; Wiener & Tilly,



2003).. The continued use of inadequate staging tools to diagnose end-of-life has to be addressed (McCarty & Volicer, 2009). There are studies showing more reliable assessments that have not been translated into clinical practice (Schonwetter et al., 2003). Policy could require assessment tools that are appropriate.

The present study's added evidence of DSCU as a better model of care calls for more research. More comparison research needs to be conducted looking at the health and well-being effects of commingling individuals with and without dementia. With the up-to-date proof of care disparity, policy changes would be more likely to be considered. In addition, the financial disincentive anecdotally noted in recent research (Gruneir, 2009; McCarty & Volicer, 2009) needs to be quantified.

Finally, there is clear evidence in the present study and other studies that IDT is a moderator of family satisfaction with care outcomes. There is little enforcement of the OBRA mandate for IDT care plans. Policy change could better delineate the federal expectation of participation in the IDT care plan. States could prompt surveyors to focus on the thoroughness of IDT care planning, the inclusion of disciplines and family members and cite facilities based on the translation of IDT research. The IDT tool developed in this study was highly correlated which explains the high percentage of variance with the outcome. SWC and Strength of IDT are potentially measuring family satisfaction though with different care elements. Development of a more objective measure of IDT would better quantify the role of IDT.

## **Study Limitations**

There are important limitations that should be acknowledged. Foremost is the lack of sample generalizability. The convenience sample limited representation and may have introduced biases in the results. Although the predominant sample came from states with mandatory training for dementia, the differences in state regulations may have biased the overall results by having stronger IDT and care models than states without mandatory training.

Generating the sample was much more difficult than projected in the proposal. HIPAA and IRB constraints on access to resident medical records put the burden of labor for generating the family sample on the nursing home administrator. For example, mailing the study introduction and informed consent to nursing home administrators was ineffective. The follow-up calls confirmed that administrators did not have the time to read the information. Telephone calls were more successful but as the results show, administrators were more likely to decline participation, with the average contacts to refusal being 6.6 and the average contacts to acceptance being 18.6. For most, acceptance was based on having the study approved by corporate management. This sometimes took several months. Emails were more readily answered, but there were several facilities that changed administrators during the collection process necessitating re-introduction. Those administrators who were not openly refusing had time constraints that they expressed regarding state survey or budget preparation that pre-empted study participation. A primary concern of administrators was how best to protect resident information and honor HIPAA regulations, which was consistent with the parameters of the USF IRB. The

overall data generation was time-consuming for the administrator, and thereby may have led to a smaller sample in all three care models. The reluctance of the administrators to participate made the goal of having a large representative sample of care models unrealistic. The inequality in number of traditional care compared to DSCU and hospice is a limitation. A more representative sample of individuals in each care model would have reduced the chance of Type II error.

On the family participant level, generalizability is equally limited. The high percentage of white, non-Hispanic respondents is a biased representation of family caregivers. The demographics are consistent with other samples in EOL study, but future research should try to expand sample representation.

The sample size of family respondents is shy of the statistical formula projected. With nine SPO characteristics, a sample of 130 would have been ideal. The smaller sample of 116 reduced the statistical power of the analysis and possibly produced Type II errors that hid detection of smaller or more moderate statistically significant differences. Future studies would benefit from an increase in number of family participants.

This study was cross-sectional rather than longitudinal. Data collection was only a single report of family satisfaction at EOL rather than a time span of several reports. A longitudinal study could have resulted in less missing data.

The high rate of missing data may have resulted from the shortened look-back period of seven days for the EOLD subscales. Unless the family members were vigilant the last seven days, they may well have felt uncomfortable answering the subjective

questions. Earlier use of the EOLD employed a 30-90 day look back period (Kiely et al., 2006; Volicer et al., 2001).

Likewise, the method of family selection of decedents with dementia by the administrators was not systematic. Only one of the 17 administrators used actual medical records in the form of the Minimum Data Set, to generate a mailing list for family respondents. All others accessed accounting files and discharge records. This resulted in a less than rigorous approach to determining dementia diagnosis. The sole use of data from the nursing homes' Minimum Data Set would have been more systematic but required more time and resources. However the family survey did confirm dementia diagnosis. Only one respondent declined participation because her loved one did not have a dementia diagnosis.

The study would have benefitted from a questionnaire that used lay language to better explain some of the measures. In examining resident risk factors, the FAST (Reisburg, 1980) questions about the decedent should have explained the meaning of non-ambulation and immobility. The high rate of immobility and low rate of non-ambulation in dual enrolled decedents were most likely a result of not understanding the question.

Another limitation was that hypotheses two and three were supported by only one subscale of EOLD. SWC had only 6.9% missing data while CAD and SM had 26% and 56% respectively. The differences in amount of missing data may have accounted for the lack of significant findings for the latter two scales.

Though disappointing, the presence of missing data in end-of-life research is not a unique phenomenon. Retrospective self-administered surveys are “plagued by low response rates” (Fowler et al., 1999). The dynamics behind this are diverse. In the present study, the SWC subscale is objective, from the family member perspective, with “*T*” statements rather than the subjective “*Your loved one*” statements of the CAD and SM subscales. The CAD and SM subscales are subjectively measuring symptom management of the decedent’s physical decline, emotional distress, well-being, and dying symptoms. Subjectivity is a possible explanation for missing at random data for CAD & SM subscales. It is easier for the family members to answer from their own perspective than to answer from the perspective of their dying loved one (Rich, Williams, & Zimmerman, 2009). The poor response rate for the Symptom Management (SM) scale was qualitatively explained by many of the respondents through hand-written explanation. The predominant rationales given for not answering the scale questions referred to the decedent’s lost verbal ability and the subjectivity of the questions. Of the SM questions, the questions with the lowest percentage of response were: Depression, Calm, Fear, and Anxiety ranging from 10 to 14%. CAD questions that had the highest percentage of non-response were: “*Fear*” and “*Anxiety*” both at 13.8%. Subjectivity is evidently one explanation for the disparity in family response.

One explanation of higher rates of missing data in EOL study overall is the heightened family sense of guilt over institutionalization, reluctance to be more involved, and an admiration of the staff’s ability to deal with difficult behaviors (Lubart, Leibovitz, Shapira, Peled, Baumoehl, & Hamad, 2004; Turriss, 2005; van der Steen, Gijsberts,

Muller, Deliens, & Volicer 2009). Another explanation that applies to the present study is response timing. Responding closer to the decedent's time of death has been shown to produce more missing data (Cartwright, Hockey, & Anderson, 1973). The method of survey delivery may account for some of the missing data as well. A validity and reliability study for the EOLD was done by telephone interview of both healthcare proxies and primary care nurses (Kiely et al., 2006). The fewer missing responses from health care workers are easy to understand. With Subscales SM and CAD, subjective answers would be more likely to be answered by healthcare workers because of their higher levels of involvement in care (Rich, Williams, et al., 2009). A healthcare worker would have an easier time attesting to the decedent's experience of *shortness of breath* or *resistiveness to care* than a family member. They are more likely to be aware of the symptoms and are used to responding objectively to such questions about their residents.

The choice of telephone interview rather than mailed survey may have accounted for less missing responses from healthcare proxies to subjective questions in CAD and SM. EOL studies using telephone survey have had less missing data as well as more socially desirable answers (Addington-Hall, Walker, Jones, Karleson, & McCarthy, 1998). Depending on the scripting of the telephone survey, the surveyor may give extra guidance and cues in response to the respondents' hesitancy or questions (Tourangeau & Smith, 1998).

Another limitation affecting the study's generalizability is the possibility that the participating administrators were innovative leaders. Innovative choice in nursing homes begins with leadership, and nursing home leaders who tend toward more innovative ideas

have better care outcomes (Castle, 2001). One study looking at the impact of the introduction of a DSCU found no impact on outcome (Gruneir, Lapane, Miller, & Mor, 2008). Instead the outcomes were already stronger than average before introducing a DSCU. The improved care outcomes that are associated with facilities with DSCUs compared to facilities without DSCUs may be associated with organizational difference in innovative choice (Grant et al., 1995; Grant, Potthoff, & Ryden, 1998; Leon, Cheng, & Neumann, 1998; Teresi, Holmes, & Ory, 2000; Volicer, Collard, Hurley, Bishop, Kern & Karon, 1994). A limitation of the study is the lack of information on the facilities that declined participation. It is conceivable that the act of participating in a study looking at model EOL care is indicative of an administrative team that is more committed to care than those who decline participation. Participating administrators are stating openness to change and innovation by being participants. This study reinforces that possibility. The multiple logistic regressions found a 2.4 times greater likelihood of dual enrolled decedents (hospice & DSCU) to have died in a facility hosting another palliation program. The high likelihood may be evidence of both the innovation of DSCUs and other palliative care programs which are consistent with research supporting other palliative care programs as products of innovative choices (Resnick et al., 2009). The final limitation was the lack of decedent demographics on the family survey. When this omission was realized, modification request from the IRB was obtained and the age, gender, and race of decedent information were added. Unfortunately the data obtained was insufficient to analyze. Family demographics were analyzed however.

## **Future Directions**

Despite limitations, this study's spotlight on the dynamic role of DSCU enrollment in quality of EOLD calls for research that looks at innovation in nursing homes (Castle, 2001). By expanding to include the innovative style of the facilities' leadership as a contextual link, the question of the impact of DSCUs on better EOL care could be more thoroughly explored (Unruh & Wan, 2004).

This same theoretical approach could be used to analyze the structure characteristics of profit status for its association with EOLD. Investigating any association that may exist between profit status and innovation could be enlightening. Non-profit status has been associated with less EOL hospitalization and less hospital mortality for long-term care residents confirms its value in quality of EOL dementia care studies (Menec et al., 2009). If more innovative administrators participated, what association was there to the profit status? The sample's predominance of non-profit facilities calls for further exploration of both profit's and innovation's role in DSCU outcomes.

Another structure characteristic that calls for more research is the hosting of another palliation program. One study has shown that a nursing home's focus on EOL intervention resulted in decreased terminal hospitalization, increased advance care planning, and pain treatment (Levy, Morris, & Kramer, 2008). Equally encouraging is a study that showed nursing homes with an EOL program were more likely to have other specialty programs, dementia services, and palliative care training for the staff (Resnick



et al., 2009). Support of improved outcome from the presence of other palliative care programs includes better survival rates amongst nursing home residents (Mitchell, Teno, Kiely, Shaffer, Jones, Prigerson et al., 2009; Kurella, Covinsky, Chertow, Yaffe, Landefeld, & McCulloch, 2009). Is innovative leadership a predictive link to specialty programs specifically and better care outcomes overall? Hosting another palliative program is a structure characteristic that calls for further investigation.

All of the process characteristics of the current study call for more research. Hospice continues to be a popular care model for study even though the current study may confirm a diminishment in added value in LTC (Munn et al., 2006). Palliative care is recognized as an important component of LTC. Hospice's added value in symptom management, personal care, spiritual support, and family satisfaction is no longer as consistent when compared to non-hospice EOL care (Munn et al., 2006). This change needs to be researched from both the hospice perspective and the non-hospice palliative care perspective. Comparison analysis of the impact of other palliative programs and hospice would be valuable in assessing both from an overall perspective and a dementia perspective. Thorough investigation as to the rationales for offering another palliative program as well as comparison of the outcomes would go far in improving EOL care for individuals with dementia. This research could be foundational to future policy initiatives mandating EOL training for LTC workers. Study results of other palliative programs on EOL outcome could shape Medicare/Medicaid EOL funding and promote better palliative care.

The process characteristic of DSCU enrollment also needs more specific research. DSCU research has been classically hindered by design flaws (Albert, 2004). More recent studies with improved design support its added value (Slaughter et al., 2006; Smith et al., 2004; Wood, Harris, Snider, & Patchel, 2005; Ziesel et al., 2003). In light of anecdotal reports of a decline in DSCUs in some areas of the country and an increase in others, continued traditional care and DSCU comparison research is needed (Gruneir, personal communication, 2009; McCarty & Volicer, 2009).

Particular to DSCUs, the significance of a home-like environment within the DSCU needs to be investigated. The present study did not analyze environmental features as a separate structure or process characteristic. Nonetheless, the value of environment continues to be upheld in research with therapeutic environment being associated with lower Medicare costs (Zimmerman, Gruber-Baldini, Hebel, Burton, Boockvar, Taler et al., 2008). The environment's impact on EOL care is one process characteristic being analyzed in studies of Scandinavian nursing homes with anthroposophic care (Arman, Ranheim, Rehnsfeldt, & Wode, 2008; Gijbets, van der Steen, Muller, & Deliens, 2008). The term anthroposophic reflects a holistic approach to care that includes therapeutic environment along with other therapies. This care model found better EOLD scores on the subjective subscales of CAD and SM (Gijbets, van der Steen, Muller & Deliens, 2008). The Unruh and Wan expansion of SPO (2004) would be an excellent theoretical base to look at how DSCU environment has acted as a contextual link between structure characteristics like staffing and number of beds and

process characteristics like staff training and administrator attitudes to produce better outcomes in terms of family satisfaction or survey results.

IDT as a process characteristic in care outcome calls for further research also. The strong correlation noted between SWC and Strength of IDT needs to be addressed in future research. The Strength of IDT measure needs to be analyzed for internal consistency and test-re-test validity. This would allow a more thorough analysis with SWC that may result in less correlation between the two measures. IDT research is increasing, but the importance and role of each individual discipline has not been analyzed in enough detail (Wittenberg-Lyles et al., 2008). The current study found a low satisfaction rate for the role of physician on the IDT. This is re-iterated in other EOL research that refers to physicians as “missing in action” (Shield, Wetle, Teno, Miller, & Welch, 2005). Equally low in this study was the satisfaction with the role of social worker and chaplain on the IDT. Hospice team dynamics research shows role conflict between chaplains and social workers (Wittenberg-Lyles et al., 2008). Other studies that focused on the role of the IDT as well as the value and interaction of its disciplines would further validate its significance in care models.

### **Summary**

Overall, this study was successful in validating better SWC at EOL when an individual is enrolled in DSCU prior to death. This study adds to the growing evidence of DSCUs as a gold standard model of care. The significance of IDT for improved care outcomes was further supported. It is hoped that the study will serve as groundwork for

continued investigation into EOL care for individuals with dementia and lead to policy changes to increase access to EOL care for them and their families.

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## Appendices

## Appendix A: Facility Protocol

- Phone contact with administrator/DON to explain the study objectives, questionnaires, facility walk through and decedent family contacts list. (*Take Informed Consent with Stamp, to be signed if necessary*)
- Mailed introduction letter explaining study objectives, questionnaires, facility walk through and decedent family contacts list. Asking for Informed Consent to be mailed back; faxed; emailed.
- Schedule visit with DON/Admin. Interview once Informed Consent is mailed back.

At visit:

- DON or administrator interview with survey
- Brief walk through with environmental factor check list. Printed copy with ID.
- Provide questionnaire/recruitment packets for family mailings.

## DSCU Walk-Through

Special Features	Yes	No
Homelike Environment		
Secured unit with electronic device (acceptable features for emergency exit)		
Separate dining room within DSCU		
Access to secured outdoor area		
High visual contrast between walls, floors, and doorways in resident areas		
Non-reflective floors, walls, and ceilings to minimize glare		
Visual Contrast between plates, eating utensils, and the table		
Emergency only use of public address system		
Philosophy and mission statement (specific to dementia)		
Quality-assurance protocol for effectiveness of SCU		



## Facility Walk-Through

Special Features	Yes	No
Homelike Environment		
Secured unit with electronic device (acceptable features for emergency exit)		
Separate dining room within DSCU		
Access to secured outdoor area		
High visual contrast between walls, floors, and doorways in resident areas		
Non-reflective floors, walls, and ceilings to minimize glare		
Visual Contrast between plates, eating utensils, and the table		
Emergency only use of public address system		
Philosophy and mission statement (specific to dementia)		
Quality-assurance protocol for effectiveness of SCU		

- Thank administrator and ask if follow-up call will be acceptable for any missing information.

- Follow up with phone call in two weeks to confirm mailings, number of mailed and ask for access to excess packets. Record number mailed.
  
- Send out Thank you letters to facilities and families once data is collected.

## Appendix B: Measures

Please answer the following questions based on the last 30 days of your Care Recipient's life. Your completion of the entire questionnaire will offer the best input for this study.

### Satisfaction with Care

Based on the last 30 days of your Care Recipient's life:	Strongly disagree	Disagree	Agree
1. I felt fully involved in all decision making.			
2. I would probably have made different decisions if I had had more information.			
3. All measures were taken to keep my care recipient comfortable.			
4. The health care team was sensitive to my needs and feelings.			
5. I did not really understand my care recipient's condition.			
6. I always knew which doctor or nurse was in charge of my care recipient's care.			
7. I feel that my care recipient got all necessary nursing assistance.			
8. I felt that all medication issues were clearly explained to me.			
9. My care recipient received all treatments or interventions that he or she could have benefited from.			
10. I feel that my care recipient needed better medical care at the end of his or her life.			

## Symptom Management

Please answer the following questions based on the last 30 days of your Care Recipient's life. Did your loved one experience:

Symptom	Never	Once a month	2 or 3 days a month	Once a week	Several days A week	Every day
1. Pain						
2. Shortness of Breath						
3. Skin Breakdown						
4. Calm						
5. Depression						
6. Fear						
7. Anxiety						
8. Agitation						
9. Resistiveness to Care						
10.						

## Comfort At Death

Please answer the following questions based on the last 30 days of your Care Recipient's life. Did your loved one experience:

Item	A Lot	Somewhat	Not at All
1. Discomfort			
2. Pain			
3. Restlessness			
4. Shortness of Breath			
5. Choking			
6. Gurgling			
7. Difficulty Swallowing			
8. Fear			
9. Anxiety			
10. Crying			
11. Moaning			
12. Serenity			

13. Peace			
14. Calm			

**Strength of Inter-Disciplinary Team**

<b>Based on the last 30 days of your Care Recipient's life</b>	Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
1. You were regularly informed about your loved one's condition.					
2. You felt the team provided the right amount of emotional support.					
3. You felt the team provided you with accurate information about your loved one.					
4. There was a primary contact that you could access with concerns.					

<b>Based on the last 30 days of your Care Recipient's life</b>	Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
<b>5. The team gave you a consistent message.</b>					
6. You were included in Care Plan decisions for your loved one.					
7. The Physician played a vital role in my loved one's last days.					
8. The Nurse played a vital role in my loved one's last days					
9. The Nurses' Aide played a vital role in my loved one's last days.					
10. The Social Worker played a vital role in my loved one's last days.					
11. The Chaplain played a vital role in my loved one's last days.					

12. The Volunteer(s) played a vital role in my loved one's last days.					
13. The Respiratory/Physical Therapist played a vital role in my loved one's last days.					
14. You were asked for input into your loved one's care.					

**Functional Assessment Staging Tool**

Incontinent \_\_\_\_

Semi-verbal \_\_\_\_

Non-ambulatory \_\_

Immobile \_\_\_\_

Losing weight \_\_\_\_

Failure to thrive \_\_



**Appendix C: DSCU Manager Criteria**

**Facility Identification # \_\_\_\_\_**

1. Does your facility segregate or provide a special program or special unit for residents with a diagnosis of probable Alzheimer’s disease or related dementia; and that advertises, markets or otherwise promotes the facility as providing specialized Alzheimer’s/dementia care services.”

YES NO

**DSCU Criteria**

2. Which departments below are required to attend formal Dementia Special Care Unit training?

Department	No	Yes
Nursing		
Dietary		
Housekeeping		
Volunteers		
Maintenance		

3. Check the environmental features present in your Dementia Special Care Unit.

Special Features	Yes	No
Homelike Environment		
Secured unit with electronic device (acceptable features for emergency exit)		
Separate dining room within DSCU		
Access to secured outdoor area		
High visual contrast between walls, floors, and doorways in resident areas		
Non-reflective floors, walls, and ceilings to minimize glare		
Visual Contrast between plates, eating utensils, and the table		
Emergency only use of public address system		
Philosophy and mission statement (specific to dementia)		
Quality-assurance protocol for effectiveness of SCU		

4. Please mark below the number of activities provided on the Dementia Special Care Unit on weekdays, weekends and evenings.

Activity	Number of Activities per Week Day	Number of Activities per Weekend Day	Number of Evening Activities
Music			
Art			
Reminiscence			
Pet			
Physical Games			

**Staff-Resident Ratio**

5. Using the tables below record the staff-to-resident ratio you provide for each shift.

**CNA**

Shift      CNA Staff Ratio    DSCU

Day        1: \_

Evening   1: \_

Night     1: \_

**LPN**

Shift      LPN Staff Ratio    DSCU

Day        1: \_

Evening   1: \_

Night      1: \_

**RN—Including DON**

Shift      RN Staff Ratio    DSCU

Day        1: \_

Evening   1: \_

Night      1: \_

6. Which departments below are participants of the Interdisciplinary Care Plan team?

Discipline	No	Yes
Registered Nurse		

Activity Director		
Social Worker		
Registered Dietitian		
Physician		
can		
Physical Therapist		
Occupational Therapist		
Music Therapist		
Family Member		

**DSCU Inter-Disciplinary Care Plan Team:**

	Always	Sometimes	Rarely	Never
7. Meets weekly at regularly scheduled time				
8. Actively reviews status of the individual and family				
9. Members feel equally invested in team and quality of care outcome				

10. Has a climate that promotes & supports improvement and change of care plan				
11. Provides continuity of care				
12. Every member is considered equal				
13. Every member has an important expertise				

**Which departments below are responsible for the given tasks? N/A if not applicable.**

Dept.	Get Social History At Admission	Use Community Resources	Conduct ¼ family Support group meeting	Identify & Use Alzheimer' Assoc. Networks	Implement Life Review	Family Invited to Care Plan Meetings
14. Social Worker						
15. Activity Director						
16. Other _____						

17. What are your discharge policies for DSCU?

\_\_\_\_\_

**Demographics of the Facility**

Facility Characteristics	Yes	No
18. Is your facility a for-profit facility?		
19. Is your facility associated with a religious organization?		

20. How many years old is your facility? \_\_\_\_\_

21. How many beds are in your facility? \_\_\_\_\_

22. What percent of your residents have a diagnosis of dementia? \_\_\_\_\_%

23. What percent of your residents have Medicaid as the primary payer? \_\_\_\_\_%

24. What percent of your residents are non-white? \_\_\_\_\_%

**Administrator Characteristics**

25. Are you male or female? \_\_\_\_\_

26. Are you non-white or white? \_\_\_\_\_

27. How many years have you been in school? \_\_\_\_\_

28. How many years have you been administrator of this facility? \_\_\_\_\_

29. How many years have you had an administrative license? \_\_\_\_\_

30. How old are you? \_\_\_\_\_

31. Do you have a business, nursing, or other degree? \_\_\_\_\_



## Appendix D

### Gerdner & Beck DSCU Criteria

As discussed in chapter four, confirmation of the administrator and family definition of DSCU was determined using the Gerdner and Beck (2002) DSCU criteria. The following are the descriptives of the Gerdner and Beck criteria as found in the sample facilities.

#### DSCU Environmental Features

Out of the 10-item environmental DSCU checklist (Table 5.2.), none of the facilities met all 10 of the DSCU criteria (Gerdner & Beck, 2001). Features that were not represented in at least 70% of the facilities were access to the outdoors; contrasting eating utensils and plates; philosophy and mission statement; and a quality-assurance protocol.

#### *Percentage of Dementia Special Care Features*

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<b>Special Features</b>	<b>Yes</b>
Homelike Environment	75%
Secured unit with electronic device (acceptable features for emergency exit)	87.5%
Separate dining room within DSCU	94%
Access to secured outdoor area	69%
High visual contrast between walls, floors, and doorways in	75%

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resident areas	
Non-reflective floors, walls, and ceilings to minimize glare	81%
Visual Contrast between plates, eating utensils, and the table	62.5%
Emergency only use of public address system	75%
Philosophy and mission statement (specific to dementia)	44%
Quality-assurance protocol for effectiveness of SCU	62%

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### **Gerdner & Beck's DSCU Staffing Ratios**

The Gerdner & Beck DSCU criteria prescribed DSCU Certified Nursing Assistant (CNA) staffing ratios for both day and evening shift were met in 85.7% of the facilities, however the DSCU night shift criteria was only met in 64%. See table 5.3.

#### *DSCU Staffing Ratio*

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CNA Daytime Staffing Ratio	Facilities (n = 17) Meeting the Criteria
1:10	85.7%
CNA Evening Staffing Ratio	85.7%
1:12	
CNA Night Staffing Ratio	64.3%
1:17	

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## **Gerdner & Beck's DSCU Dementia Training**

The percentage of training participation observed in the current study varied per discipline with: nursing at 100%; dietary at 67%; housekeeping at 67%; volunteers at 63%; and maintenance at 50%. Disciplines with above 50% were chosen, therefore the DSCU training disciplines included nursing, dietary, housekeeping, and volunteers. Specific DSCU training per discipline in sampled facilities was diverse, with nursing with the highest percent of trained staff; support staff also had more than 50%. *DSCU Training Criteria*

<b>Training Criteria</b>	<b>Facility Percentage Meeting the Criteria (n = 17)</b>
Nursing DSCU Trained	100%
Dietary DSCU Trained	67%
Housekeeping DSCU Trained	67%
Volunteers DSCU Trained	63%
Maintenance DSCU Trained	50%

### **Gerdner & Beck's DSCU Inter-Disciplinary Team Participants**

Ninety-three percent of the 17 facilities have nursing and activity directors on their IDT; 100% of them had social workers on their IDT, but only 40% of the facilities reported doctors on their IDT (see Table 5.5). Both CNA's and physical therapists accounted for 86.7% of facilities' IDT with occupational therapists participating in only 73.3% of the sample facilities IDT. Music therapists were represented in only 13.3% of the facilities' IDT. Family members were represented in 80% of the facilities' IDT.

#### *Gerdner & Beck's IDT Criteria*

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<b>Discipline Represented</b>	<b>% of Facilities in Compliance</b>
Nursing	93.3%
Activity Directors	93.3%
Social Workers	100%
Doctors	40%
CNA's	86.7%
Physical Therapist	86.7%
Occupational Therapist	73.3%
Music Therapist	13.3%
Family Members	80%

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### **Gerdner & Beck's DSCU Activity Provision**

Only 35.7% of the facilities with a DSCU provided the amount of activities prescribed in the criterion.

## Appendix E Survey Respondents Information

### Family Respondent Characteristics

The family respondent characteristics are displayed in Table 5.1. Of the family respondents, most were white, non-Hispanic with over half being female. The average age was 64.3 years (SD = 11.5). The average years of education was 15.5 (SD = 3.3). Their relationship to the decedents included 30.7% daughters, 22.8% spouses, 21.9% sons, and 24.6% as other relatives. Of the 109 who rated their past involvement, 78% of them rated their involvement as *very high* or *high*. Close to 23% responded that they did not expect their loved one to die.

Table 5.1. Family Sample Characteristics (N=116)<sup>a</sup>

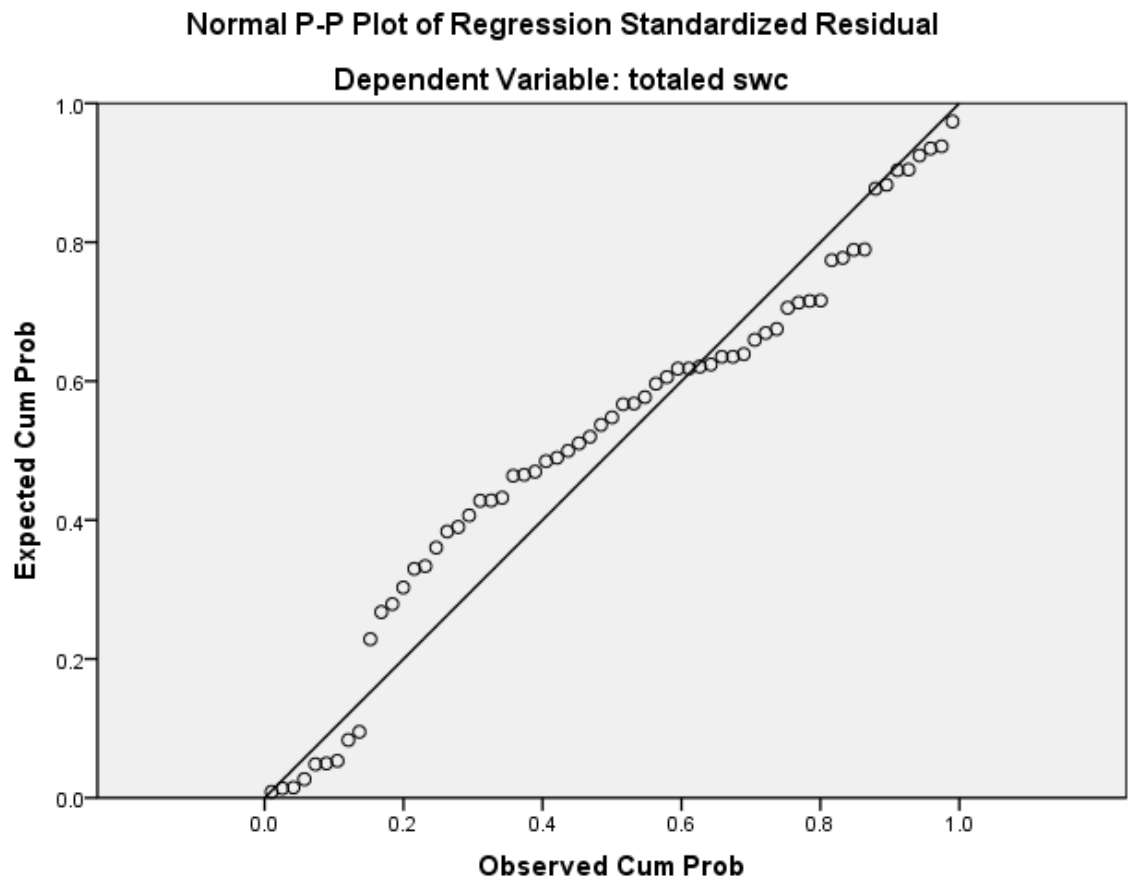
Variable	Mean (SD)	Percent
Age	64.3 (11.5)	
Gender		66.4% Female
Years of Education	15.5 (3.3)	
Race		95.5% White
Ethnicity		99.1% Non-Hispanic
Relationship to Decedent		30.7% Daughter 22.8% Spouse 21.9% Son 24.6% Other Relative
Past Involvement		78% Very High-High Level
Expected Decedent to Die		77.1% Yes

<sup>a</sup>Due to missing data, sample sizes for individual items range from 105-116

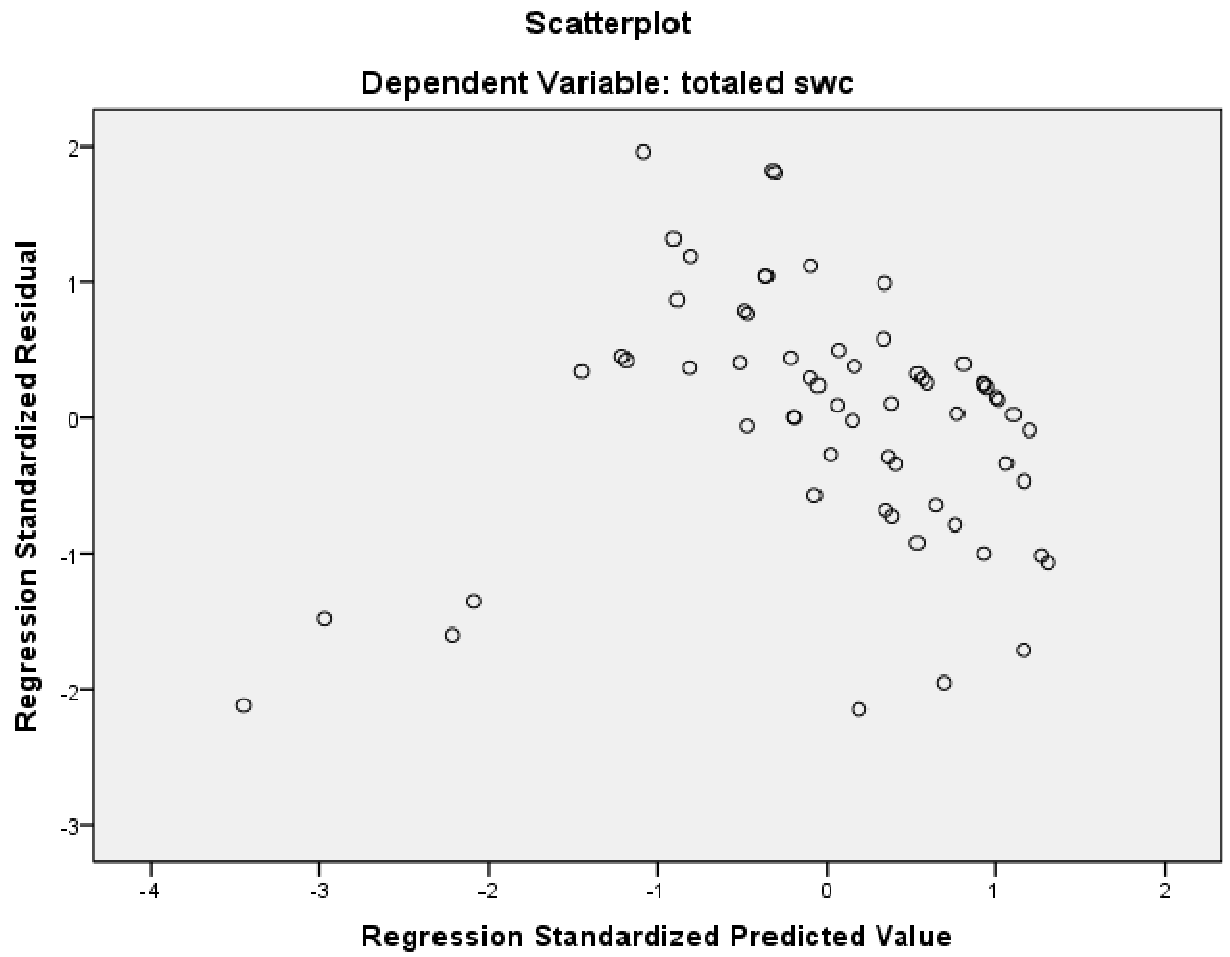
### **Administrator Demographics**

Of the administrator respondents (N=17), 53.3% were female, and 86.7% were white. Degrees in education and nursing were predominant in the sample totaling 78.6%, with 86% having 16 years of education or more. The average age range of administrators was 49.6 years (SD = 7.25). The range of age was from 36-63 years.

**Appendix F. Outcome Scatterplots Prior to Replacement with the Mean**

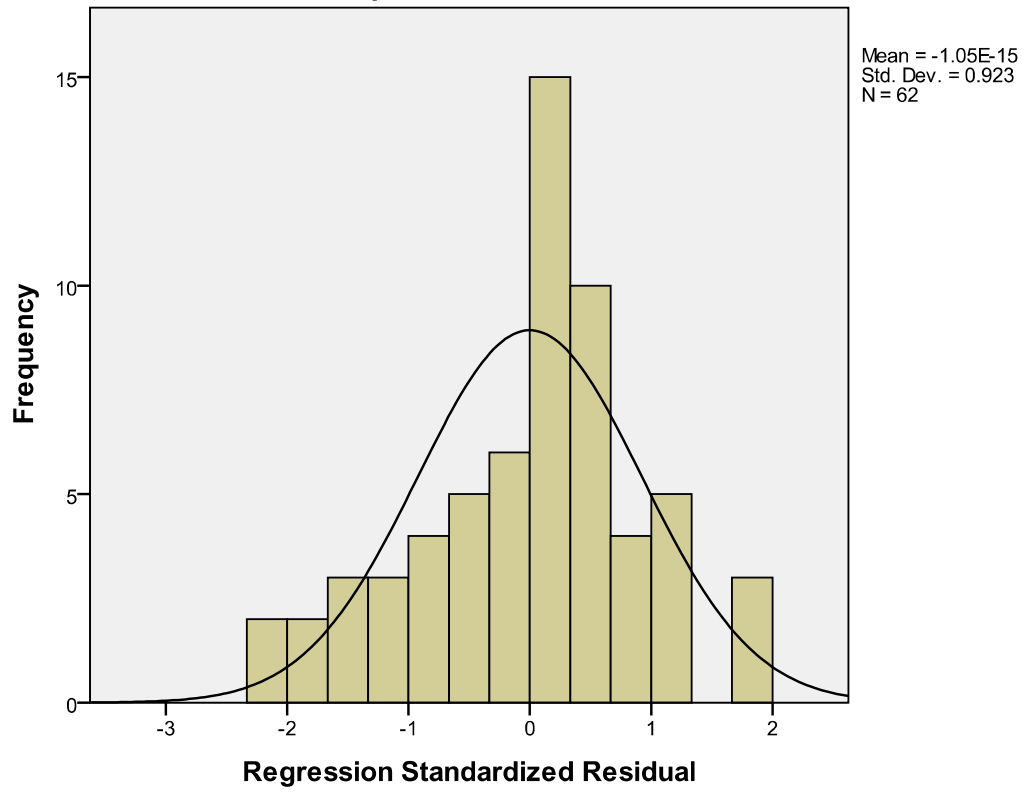






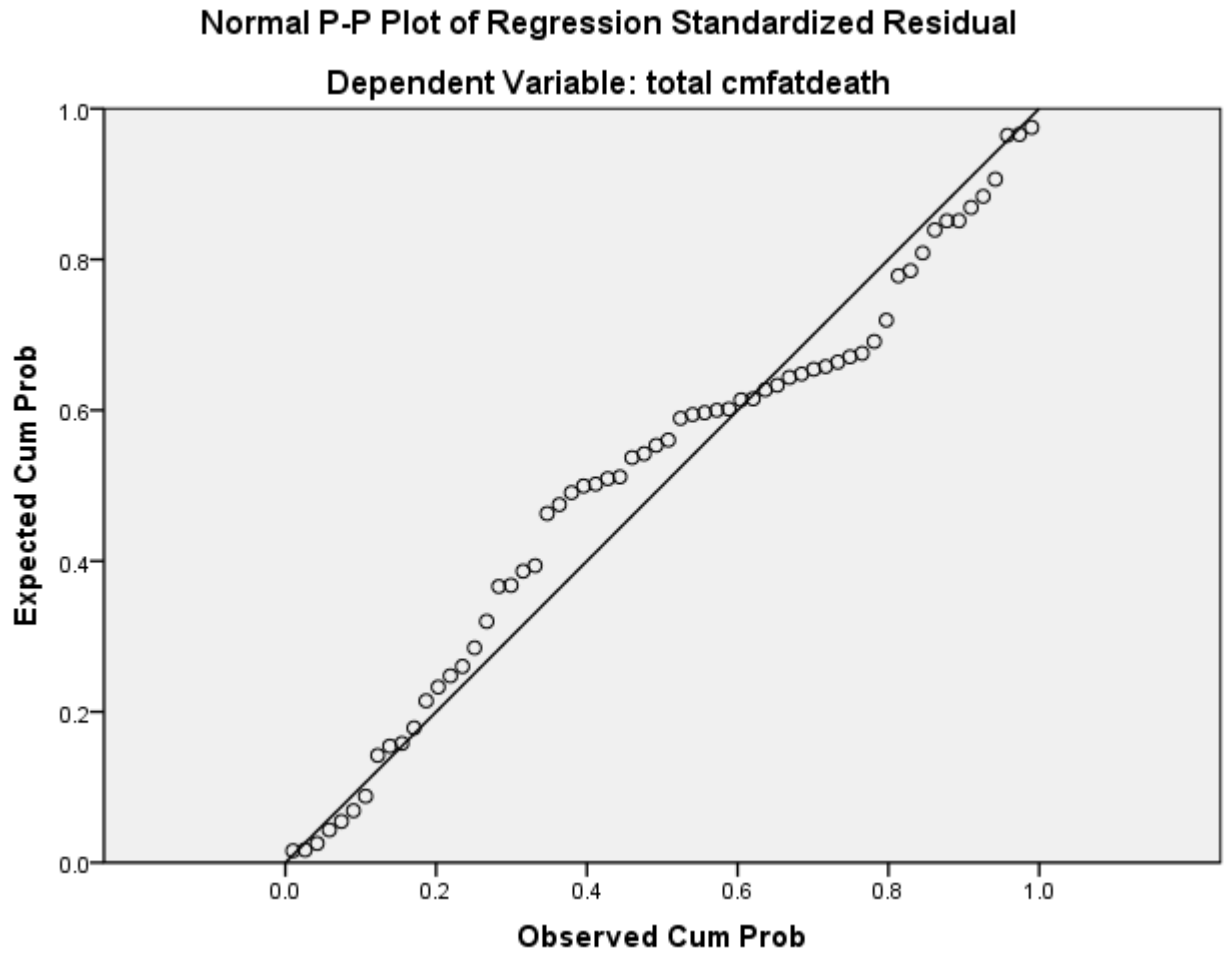
### Histogram

Dependent Variable: totaled swc



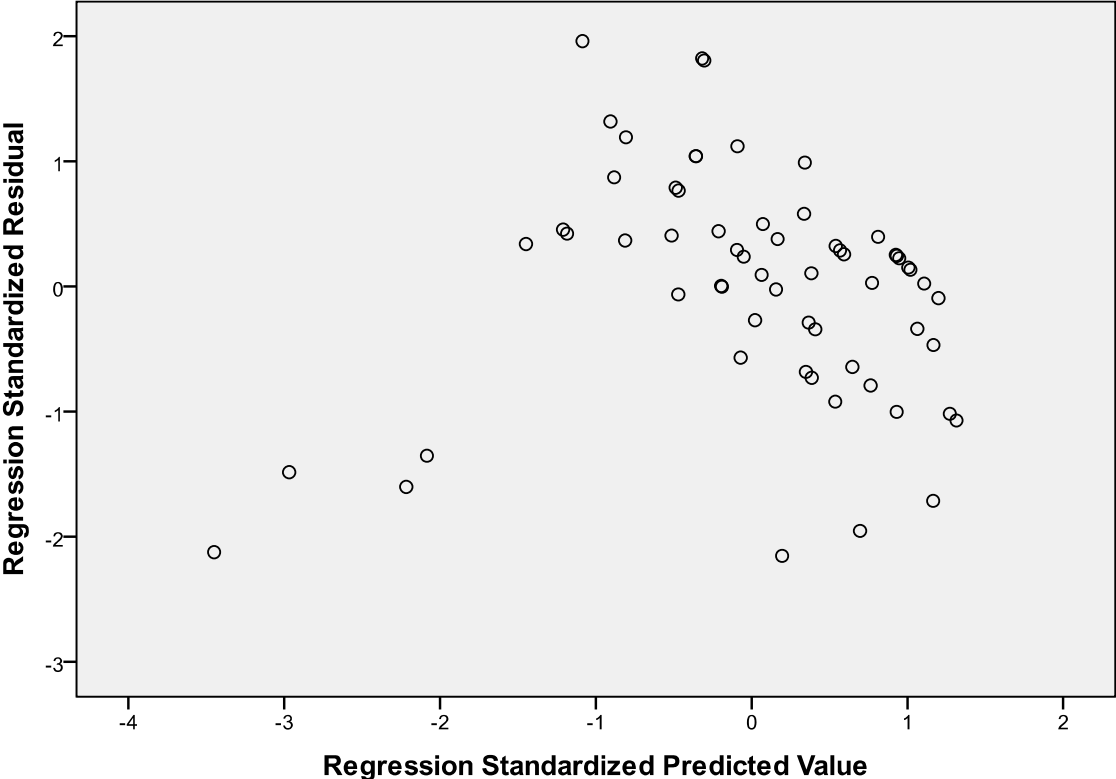
CAD Prior to Replacement with

Mean



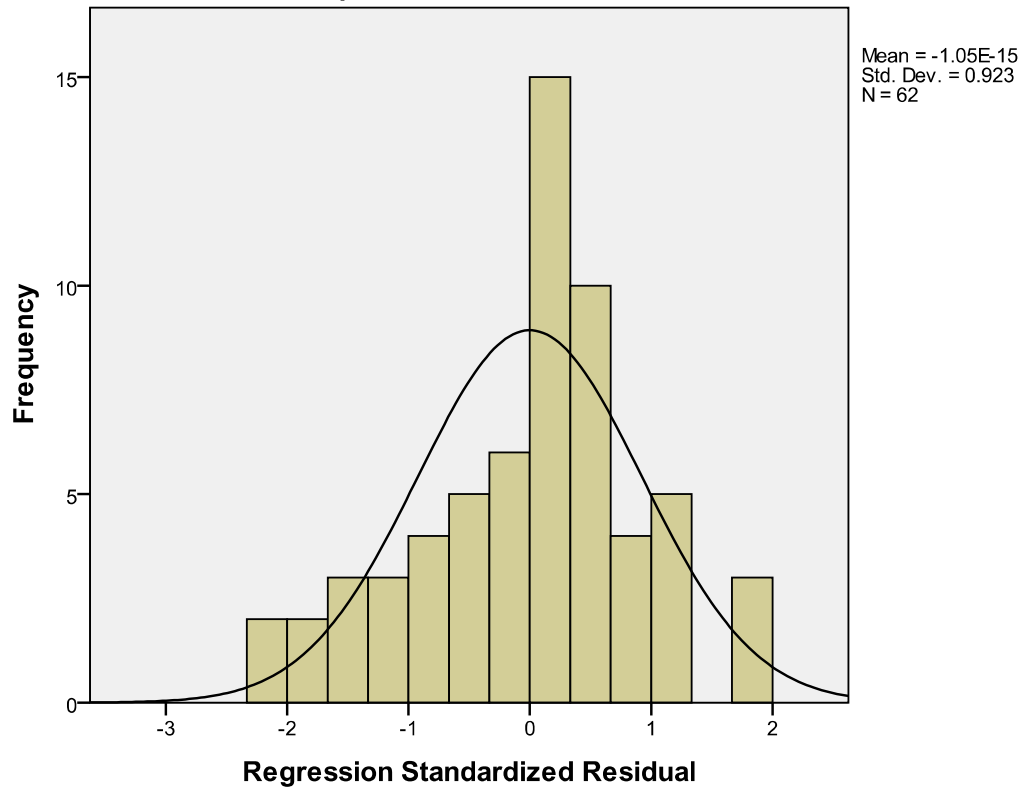
**Scatterplot**

**Dependent Variable: total cmfatdeath**



### Histogram

Dependent Variable: total cmfatdeath



### **About The Author**

Catherine McCarty has over 35 years of dementia care experience from nursing assistant to activities professional. She came to University of South Florida with a Master's degree in Thanatology from Hood College. This study combined years of dementia experience with a passion for quality of end-of-life care for individuals with dementia.