

Primary Family Caregivers' Definition and Management of Nursing Home Placement

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THESIS

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This thesis is dedicated to my parents, Eleanor and the late Harold Koplow, who have always provided me guidance, love, and support to accomplish all of my goals and dreams.

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LIST OF ABBREVIATIONS

AARP	ASSOCIATION FOR THE ADVANCEMENT OF RETIRED PERSONS
ADL	ACTIVITIES OF DAILY LIVING
ALF	ASSISTING LIVING FACILITY
CCRC	CONTINUING CARE RETIREMENT COMMUNITY
CDC	CENTERS FOR DISEASE CONTROL AND PREVENTION
CMS	CENTERS FOR MEDICARE AND MEDICAID SERVICES
FMSF	FAMILY MANAGEMENT STYLE FRAMEWORK
HCBS	HOME AND COMMUNITY BASED SERVICES
IADL	INSTRUMENTAL ACTIVITIES OF DAILY LIVING
ILF	INDEPENDENT LIVING FACILITY
NIH	NATIONAL INSTITUTES OF HEALTH
NH	NURSING HOME
OFM	OLDER FAMILY MEMBER
POA	POWER OF ATTORNEY
PFG	PRIMARY FAMILY CAREGIVER
SLF	SUPPORTIVE LIVING FACILITY
SNF	SKILLED NURSING FACILITY
USDHHS	UNITED STATES DEPARTMENT OF HEALTH AND HUMAN SERVICES

SUMMARY

Primary family caregivers face one of the most major and difficult decisions in the trajectory of caregiving when they are unable to maintain care at home and have to consider nursing home placement. Many researchers have described the catalyst for this decision and transition as a “crisis event,” occurring after an unplanned medical event by the older adult that requires immediate attention or a breakdown in the primary caregiver’s ability to manage the relentless demands of care. While previous researchers have demonstrated the importance of caregivers in nursing home placement, few researchers have sought to understand the impact of the decision on the family and address the family context surrounding nursing home placement over time. The purpose of this qualitative descriptive study, guided by the Family Management Style Framework (FMSF), was to understand how caregivers define the situation surrounding care and placement, manage the care and placement, and perceive the consequences of care and placement on the family at initial placement (within the first 30 to 45 days) and 3 months post-placement.

Ten primary family caregivers, whose older family member recently entered a nursing home, were recruited from four nursing homes in the Midwest. The caregivers were interviewed within 30 to 45 days of initial placement of the older family member and then again 3 months post-placement. There were a variety of caregiving dyads in the sample. Digitally recorded interviews were transcribed verbatim, processed, and coded using the FMSF dimensions and components. Results of this study were used to understand the viewpoints and needs of the caregiver during the nursing home transition. Overall, there were similarities across caregivers, especially among spousal and non-spousal dyads. All caregivers identified themselves as responsible for care management and placement and acknowledged the importance of remaining involved post-placement. They also noted the significance of ensuring the nursing home staff and older family member recognize that the caregiver continues to be involved in management and available to provide ongoing support. Ultimately, this research will contribute to the

development of recommendations about nursing home placement decisions and tailored family-centered programs and interventions to assist in the adjustment for caregivers, older adults, and their families.

I. INTRODUCTION

A. Background

Long-term home and institutional care encompasses a wide variety of health, health-related services and supports that are provided over an extended period of time with the goal of maximizing independence and functioning (Gaugler et al., 2000; United States Department of Health and Human Services, 2011). Nursing homes are one of the largest providers of formal, institutionalized long-term care and provide an array of services including activities of daily living (ADLs) care, recreational activities, and medical support. Nursing homes often provide care for the most dependent individuals who are unable to receive care at home or a less supportive environment, which includes a large population of older adults (those age 65 and over) (Jones, Dwyer, Bercovitz, & Strahan, 2009; United States Department of Health and Human Services and Centers for Medicare & Medicaid Services, 2010). However, primary family caregivers continue to provide most of the long-term home care in the community to their older family members who may need assistance in a more supportive environment, such as a nursing home, because of the guilt, anguish, and sense of failure they feel about considering placement (Butcher, Holkup, Park, & Maas, 2001; Dellasega & Mastrian, 1995; Evashwick, 2005; Kaye, Harrington, & LaPlante, 2010; Kellett, 1999; Matthiesen, 1989).

Primary family caregivers are informal caregivers who provide many time- and labor-intensive tasks, such as completion of activities of daily living (ADLs) (e.g., bathing, grooming, feeding, etc.) and instrumental activities of daily living (IADLs) (e.g., laundry and clothing maintenance, money management, planning medical appointments, and overall health management) (Garity, 2006). Researchers of previous meta-analyses have shown that caregivers are at increased risk for psychological and physical health problems compared to non-caregivers (Pinquart & Sorensen, 2003; Vitaliano, Zhang, & Scanlan, 2003). Lack of support from other family members can make the decision to place an older family member even more difficult for caregivers (Butcher et al., 2001; Chang &

Schneider, 2010; Gaugler, Yu, Krichbaum, & Wyman, 2009). Few researchers have looked at the nursing home placement from a family context and the impact on the family over time (Gaugler, Zarit, & Pearlin, 2003; Mass et al., 2001; Paun & Farran, 2006). The researchers that have identified the importance of the impact of nursing home placement on the family have recognized that the challenges of providing care, needs, emotions, and the role of the caregiver can change over time.

B. Overview of the Problem and Purpose of the Study

Primary family caregivers face one of the most major and difficult decisions in the trajectory of caregiving when they are unable to maintain care at home and have to consider nursing home placement (Kellett, 1999; Ryan & Scullion, 2000). This likely decision is being faced by millions of caregivers as the number of older adults requiring long-term care is expected to nearly double from 13 million in 2000 to 27 million in 2050, as a result of the baby boomers reaching older ages (United States Department of Health and Human Services and United States Department of Labor, 2003). Many researchers have described the catalyst for the decision and transition into a nursing home as a “crisis event,” occurring after an unplanned medical event by the older adult that requires immediate attention or a breakdown in the caregiver’s ability to manage the relentless demands of care (“caregiver burden”) (Butcher et al., 2001; Chang & Schneider, 2010; Dellasega & Mastrian, 1995; Gaugler, Yu, et al., 2009; Hagen, 2001; Ryan, 2002; Ryan & Scullion, 2000). Due to the nature of the situation surrounding placement, caregivers often have the major responsibility for nursing home placement decisions (Buhr, Kuchibhatla, & Clipp, 2006; Dellasega & Mastrian, 1995). Despite this likely responsibility, caregivers perceived a lack of control over the situation, felt inadequately supported by healthcare professionals, and complained that they are unprepared and rushed (Butcher et al., 2001; Dellasega & Mastrian, 1995; Kellett, 1999; Paun & Farran, 2006; Rodgers, 1997).

Researchers of quantitative and qualitative studies have examined nursing home placement as a process. For example, researchers of quantitative surveys have examined characteristics of the older

adult that increase the risk for placement, such as dementia diagnosis, incontinence, ADL/IADL impairment, and behavioral symptoms (Andel, Hyer, & Slack, 2007; Buhr et al., 2006; Gaugler, Yu, et al., 2009). Several researchers of qualitative studies have described the process and experiences of nursing home placement decisions by the caregiver (Chang & Schneider, 2010; Garity, 2006; Kellett, 1999; Rodgers, 1997; Ryan & Scullion, 2000). While most of the researchers of these previous studies demonstrated the procedure involved in nursing home placement and the important role of caregivers, few researchers seek to understand the impact of management and placement on the family, especially for the caregiver. Because family members' level of support to the caregiver is a risk factor for institutionalization and can impact the transition, it is critical to understand the impact of the placement within a family context (Butcher et al., 2001; Chang & Schneider, 2010; Fisher & Lieberman, 1999; Gaugler et al., 2000). Few studies were found that addressed the family context surrounding nursing home placement over time, which is crucial because definitions, management, and perceived consequences could potentially change as the family adjusts to the placement (Maas et al., 2001; Paun & Farran, 2006).

Numerous researchers have suggested that management of care by families continues beyond placement and thus the needs and expectations of caregivers beyond initial placement should be explored (Kellett, 1999; Fink & Picot, 1995; Maas et al., 2001; Nolan & Dellasega, 1999; Paun & Farran, 2006, 2011). Caregivers have noted ongoing challenges post-placement, including adjusting to their new role within the nursing home environment and developing open communication and partnerships with staff members (Nolan & Dellasega, 1999). Paun and Farran (2006) investigated the challenges and emotions that change over time for caregivers of institutionalized family members with dementia. Caregivers reported that having practical guidelines for addressing their specific needs surrounding nursing home placement would be beneficial. Family-centered programs and interventions, such as the Chronic Grief Management Intervention and the Family Involvement in Care partnership

intervention, have examined the implementation of programs within long-term care settings to improve caregivers' knowledge, skills, and negotiation of care with staff (Maas et al., 2001; Maas et al., 2004; Paun & Farran, 2011). The aim of such programs is to minimize stress, provide emotional support, and provide resources that will give caregivers ongoing support. As the interaction of the caregiver with the long-term care system changes and their role continues to be delineated, there is a need for more studies on the perspective of caregivers about their expectations and challenges over time and how these needs can further tailor family-centered programs and interventions within the nursing home environment.

The purpose of my study was to understand the experiences of caregivers during nursing home placement and how they adjust to placement over time using the Family Management Style Framework (FMSF). A clearer appreciation of how caregivers define the situation surrounding care and placement, manage the care and placement of the older family member, and perceive the consequences of care and placement on the family at initial placement and 3 months post-placement has been elicited through this study.

C. Specific Aims

An older family member entering a nursing home can be a stressful and challenging time for the primary family caregiver (Hagen, 2001). Caregivers have reported a mixture of feelings about the decision, including guilt and regret, but also a sense of relief (Kellett, 1999; Nolan & Dellasega, 1999; Paun & Farran, 2006; Ryan, 2002). The stress over the placement decision can lead caregivers to experience problems with their own physical and mental health; problems that can continue to persist or worsen months after the placement (Gaugler, Yu, et al., 2009; Rodgers, 1997). Caregivers have reported that family support and validation (or lack thereof) contribute to the ability to deal with this stress and accept the placement decision (Butcher et al., 2001; Chang & Schneider, 2010). Family assistance to the caregiver and characteristics of family management of care has been associated with the likelihood to institutionalize the older adult family member (Fisher & Lieberman, 1999; Gaugler et al., 2000). Few

researchers have looked at the nursing home placement within a family context and the impact of the placement on the family over time (Butcher et al., 2001; Chang & Schneider, 2010; Maas et al., 2001; Paun & Farran, 2006).

Understanding the experiences of caregivers within a family context as they undergo the transition is important, as nursing home placement is a difficult decision that affects the entire family. Additionally, care management by the family continues beyond initial placement. Expectations for continued involvement in care over time have not been well-explored (Garity, 2006; Maas et al., 2004). An examination of caregivers' experiences and needs during this crucial transition will provide a foundation for future study in developing recommendations for successful nursing home transitions from a family context and eventual guidelines for overall long-term care planning. This study will also enhance the continued development of family centered interventions and programs that provide emotional support and partnerships within the nursing home environment (Maas et al., 2001; Maas et al., 2004; Paun & Farran, 2011). Successful long-term care planning and tailored family centered care can decrease some of the negative emotions and stress associated with nursing home placement and lead to collaborations between staff and family that will ultimately improve the quality of life for the caregiver and older family member.

I conducted a descriptive, two-time point study of 10 primary family caregivers, 21 years of age or older, who have recently placed a family member in a nursing home in the Midwest. I interviewed each primary family caregiver 30 to 45 days after initial placement of an older family member and again at 3 months post-placement. The Family Management Style Framework (FMSF) was adapted to facilitate an understanding of the nursing home transition experienced by caregivers in terms of how they define the situation surrounding placement, manage the care and placement of the older family member, and perceive the consequences of care and placement (Knafl & Deatrick, 2003; Knafl, Deatrick, & Gallo, 2008; Knafl, Deatrick, & Havill, 2012). Comparisons were made between initial

definition, management, and perception of consequences and the experiences at 3 months post-placement.

Specific Aims:

1. Describe the experiences of primary caregivers at initial nursing home placement (within 30 to 45 days) and at 3 months post-placement within the context of how they define the situation surrounding placement, manage the placement and care, and perceive the consequences of the care and placement.
2. Compare primary caregivers' experiences of defining, managing, and perceiving the consequences both within and across cases from initial nursing home placement to 3 months post-placement and used these comparisons to make recommendations for nursing home transitions for primary family caregivers.

II. CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW

A. Conceptual Framework

Understanding primary family caregivers' response to the challenges of nursing home placement within a family context is important for the development of recommendations for smoother nursing home placement transitions. This study was grounded in the Family Management Style Framework (FMSF). The FMSF was used throughout the study to develop the specific aims and methodology, including the interview guides, coding, analysis, and results. The FMSF was originally developed over 20 years ago to conceptualize family members' response to managing a child with a chronic condition (Knafl & Deatrick, 2003; Knafl et al., 2008; Knafl et al., 2012). The three components of the FMSF, definition of the situation, management behaviors, and perceived consequences, and their related dimensions provide a more complete understanding of how family members' view the condition, manage it, and view its consequences (Knafl & Deatrick, 2003; Knafl et al., 2008; Knafl et al., 2012). The FMSF can be used to identify family management styles that provide an understanding of overall family response to the phenomenon, although styles were not identified within this small sample descriptive study.

Although the FMSF has been developed and primarily used in a pediatric population, several recent studies have applied it to an adult population. The FMSF has been used to investigate the influence on spirituality to assist the daily management of people with Parkinson's disease and their families, to understand family response over time after withdrawal of life-sustaining therapy and eventual death of a family member, and to explore family caregiver management of an older adult with dementia in the community (Beeber & Zimmerman, 2012; Bingham & Habermann, 2006; Wiegand, 2012; Wiegand, Knafl, & Deatrick, 2008). The researchers of these studies noted the need to adapt the FMSF for specific use with an adult population. For example, there was a discussion of a broader definition of the term "family." In the original FMSF that was developed for use with pediatric

populations, family was noted to include the child, mother, father, and sibling. With adult populations, family may consist of other types of family members, including spouses and adult children, who may or may not reside with the care-recipient and/or be blood-related. Beeber and Zimmerman (2012) recognized that in the care of an older adult with a chronic illness, there might be multiple family caregivers involved. As such, the dimensions and components of the framework needed to account for the involvement and perspectives of all family members involved in different aspects of care. Additionally, there was recognition that the goals of family members involved in the care of an older adult may have an entirely different focus than those in a pediatric population. Within a pediatric population, the goals of management may be that the child will become independent and be able to eventually take on the responsibilities of their illness. With an older adult population, whose caregivers may be managing debilitating and deteriorating physical and cognitive conditions, the focus may be on maintenance and preparing for how to handle the decline.

In these previous studies guided by the FMSF for use in an adult population, the framework was adapted to reflect the perceptions of the family member undertaking care decisions (the caregiver) and the older adult (the care-recipient). While some parts of the framework remained salient in developing an understanding of family situations with adults, certain parts of the framework were less influential or had to be expanded. Similar to the previously mentioned FMSF studies, changes were made to the dimensions and related components FMSF to reflect the perspectives of caregivers and nursing home placement.

The most recent study about the conceptualization of the FMSF discussed the continued broader use of the framework to other types of contexts and caregiving as families encounter a variety of health care demands and challenges (Knafl et al., 2012). To better visualize the framework, components, and dimensions the latest revised figure of the FMSF is provided as Figure 1, granted with permission from the publisher and the first author.

My study was the first to use the FMSF for understanding the nursing home placement within a family context. While the FMSF can use multiple family members to understand the components and related dimensions, the focus of this study used only the view of one primary family caregiver because they are often responsible for nursing home placement decisions (Butcher et al., 2006; Dellasega & Mastrian, 1995). The primary caregivers interviewed in this study were asked questions about their view of other family members involved in the transition and of the older family member. Using the view of one family member to understand the experiences of other family members is a component of Feetham's criteria for family-related research (Feetham, 1991). According to Feetham (1991), family-related research is used to add to the knowledge of family functioning and family structure. This knowledge can lead to the development of focused interventions for the complex and multi-factorial problems that families face when interacting with the health-care system.

1. Related Terms

The framework for my study addresses how primary family caregivers define the situation surrounding placement, manage the care and placement of the older family member, and perceive the consequences of the care and placement on the family and family members at initial placement and at 3 months post-placement. The following are an explanation of the components and related dimensions of the FMSF and how they have been adapted to understand the experiences of primary family caregivers during the nursing home transition. A visualization of the adaptation of the framework is provided as Figure 2.

The primary family caregiver's view of the:

Definition of the Situation Surrounding Care and Placement

- **Older Family Member's Identity** - Identity of the older family member, including traits such as personality, capabilities, vulnerabilities, independence, and dependence and how this view impacted management of care, nursing home placement, and adjustment

- **Older Family Member's Health** - Seriousness and predictability (or lack of predictability) of the older family member's cognitive, mental, and physical health conditions and how these conditions influence the management of care, nursing home placement, and adjustment
- **Management Mindset** - Ease or difficulty of caregiving and their ability to manage care and placement and manage the care *after* placement, including the management of nursing home staff; how this impacted nursing home placement and adjustment
- **Family Mutuality** - Shared or discrepant views of the approach to the management of care and placement among family members

Management of Care and Placement

- **Primary Family Caregiver Philosophy** - Goals, priorities, and values that guide the caregiver's approach to management of care, placement, and adjustment
- **Approach to Management and Placement** - Incorporation (or not) of care management into daily routine and how being a caregiver impacts daily life; how routines, daily life, and other circumstances influenced approach to management and placement; how the management approach impacts ongoing involvement in care post-placement

Perceived Consequences of Care and Placement

- **Primary Family Caregiver Focus** - Balance between being a primary family caregiver and other aspects of family life, including the relationship with the older family member; how this balance (or imbalance) impacted the placement and adjustment and how the balance (and relationship) may have changed post-placement
- **Future expectations** - Assessment of expectations for the role as a primary family caregiver and the trajectory of functioning and adjustment for the older family member post-placement

With the FMSF as my guiding framework, my study provided a better understanding of primary family caregivers placing an older family member in a nursing home and their ongoing adjustment to the

placement. This understanding can lead to the development of family-centered recommendations for smoother nursing home placement transitions.

B. Literature Review

1. Background and Significance of Family Caregiving and Long-Term Care in the United States (US)

Caregiving for older adults in the United States is a complex system that involves the use of informal caregiving by family members and the use of formal services, such as those offered by nursing homes. In the community, family members make up the majority of care providers (Kaye, Harrington, & LaPlante, 2010). According to a 2003 United States Department of Health and Human Services and United States Department of Labor report, in 2000, there were approximately 22 million Americans providing informal care to older adults each week, a number that is expected to nearly double to 40 million by 2050. Many of the caregiving responsibilities include time- and labor-intensive tasks, such as completion of ADLs, laundry and clothing maintenance, money management, planning medical appointments, and overall health management (Garity, 2006). The economic value of this care was estimated at \$450 billion, which far exceeds the cost of all formal long-term social supports from any payer source of \$203 billion (Feinberg, Reinhard, Houser, & Choula, 2011).

Families are an important source of care and support to older adults. Historically and today, the role of the caregiver usually falls on a female family member. Approximately 65% of family caregivers are females, who are providing unpaid care to a relative (usually to a mother). These caregivers maintain the responsibility of caregiving while balancing other life routines, including working outside the home and familial relationships (Feinberg et al., 2011). Nearly 65% of the caregivers are married or living with a partner (International longevity center - Schmieding center for senior health and education taskforce: The caregiving project for older Americans, 2006). As the average lifespan continues to increase, caregivers are expected to provide ongoing support over longer periods of time. Caregivers reported that they felt obligated to deliver care because of a sense of familial responsibility to the older

adult (Feinberg et al., 2011). However, caregivers need to face these obligations with modern challenges, including competing demands, work balance, and financial strain (Feinberg et al., 2011). The complex nature of such challenges, the role of the caregiver, and the type of emotional strain may differ depending upon the type of familial relationship (e.g., spousal, adult child, or other) between the caregiver and care-recipient dyad (Meuser & Marwit, 2001). Identification of these caregivers and the types of encounters they face is important to helping them successfully provide care to their older family member and promoting optimum quality of life.

Through advocacy work for people with disabilities and the elderly as well as judicial and legislative decisions at the state and federal level, there has been an increased focus on the development of long-term care Home and Community Based Services (HCBS) (Kaye, LaPlante, & Harrington, 2009; United States Department of Health and Human Services Administration on Aging, 2012). The goal of community programs is to provide alternatives to institutionalized care to allow for increased independence and participation in family, community, and economic activities. Additionally, HCBS may lead to a reduction in total long-term care spending by state Medicaid programs (Kaye et al., 2009; Kaye et al., 2010). As such, there has been an increase in expenditures on HCBS in recent years, with approximately 11.7% of total Medicaid expenditure in 2005 being spent on HCBS, up from only 6.3% a decade earlier (Kaye et al., 2009). However, even with the increase in spending, nearly nine-tenths of the community-dwelling long-term care population continues to rely on a family member, friend, or volunteer as their primary source of assistance (Kaye et al., 2010). Researchers of numerous studies have examined predictors of nursing home entry to identify strategies to reduce caregiver stress, physical strain, and financial hardship to defer placement (Andel et al., 2007; Gaugler, Yu, et al., 2009; Spillman & Long, 2009). The implications of such studies are to determine interventions and resources that will effectively use HCBS expenditures to maintain older adults in the community.

The maintenance of such care in the community is not without potential burden and stress to family caregivers; these responsibilities have been associated with increased financial costs to caregivers, emotional stress, decreased time for social activities, and physical and mental health decline (International longevity center - Schmieding center for senior health and education taskforce: The caregiving project for older Americans, 2006). At a certain point during the trajectory of caring for an older adult, caregivers may have to make a difficult decision to place their relative into an institutionalized long-term care setting because they are no longer able to provide care at home (Kellett, 1999). Gaugler, Yu, et al. (2009) noted in their systematic review of the literature that the situation surrounding nursing home placement is very complex and characteristics of the caregiver are an important consideration to understanding placement. Ongoing stressors while providing care to an older family member, competing demands, and limited access to HCBS resources may necessitate the need for institutionalized long-term care services. Therefore, determining predictors in themselves may not be as important as understanding the unique family situation surrounding placement and their interactions with community and formal, institutional services. An exploration of individual family experiences may be better suited for the development of tailored and practical approaches to navigating the complex long-term care system.

Placing an older adult into a nursing home is a difficult and emotional process (Hagen, 2001). With the baby boomer generation reaching older ages, nursing home placement is becoming a more common decision for caregivers (Dellasega & Mastrian, 1995; Hagen, 2001; United States Department of Health and Human Services and United States Department of Labor, 2003). Even with the significant trend towards HCBS, caregivers may need to consider formal, institutionalized care options should they be unable to maintain care at home. Caregivers have reported that they need information regarding the large picture of nursing home placement as well as step-by-step information (Paun & Farran, 2006). There are many options for formal, institutionalized care, including nursing homes. Caregivers and older

adults need to be informed of the long-term care choices available to them, especially considering the best-fit option for their situation and financial cost.

When families are unable to maintain care in the community, there are a variety of formal long-term care institutionalized settings. The many formal long-term care institutionalized settings available to older adults vary by level of care provided and cost. Older adults and caregivers have to choose settings considering both of these factors. Two of the most costly options are continuing care retirement communities (CCRC) and independent living facilities (ILF). These communities offer individual homes or apartments to highly functioning older adults, but at an expensive price (United States Department of Health and Human Services and Centers for Medicare & Medicaid Services, 2010). Entrance fees can range from \$38,000 to \$400,000 with monthly payments of \$650 to \$3,500 per month; all costs are paid privately by the older adult. CCRCs and ILFs offer the benefits of communal living and some offer the ability to transition to other levels of care if needed, including nursing home care.

Another option is assisted living facilities (ALF). ALFs provide single or shared apartments with some level of ADL support. Meals and recreational activities are also provided. Specialized ALFs may also include memory and dementia care support. The price of ALFs is also expensive, with average costs varying from state to state and ranging from \$2700 to \$5,800 per month (The American elder care research organization, 2013; United States Department of Health and Human Services and Centers for Medicare & Medicaid Services, 2010). For most older adults, the costs of ALF care are paid privately. However, 42 states are now offering Medicaid Home and Community-Based Service Waivers for ALF care. ALFs covered by the waiver programs may have another name other than assisted living, such as residential care or supported living and the benefits may vary. In Illinois, supportive living facilities (SLFs) are affordable ALF models operated by the Department of Healthcare and Family Services (Illinois Department of Healthcare and Family Services, 2012). SLFs costs are either paid privately or by Medicaid and offer an array of services, including social programming, medication management, and

assistance with personal care. SLFs offer support and autonomy to persons with disabilities and older adults who may otherwise need a more structured care environment, such as a nursing home.

The largest providers of formal, institutionalized long-term care are nursing homes. According to the 2004 National Nursing Home Survey, there were 1.5 million nursing home beds in the US, with an occupancy rate of 86% (Jones et al., 2009). Of all nursing home residents, 88.3% were age 65 years and over and 45.2% were age 85 and over. Nursing homes provide an array of services, including ADL care, recreational activities, and medical support (United States Department of Health and Human Services and Centers for Medicare & Medicaid Services, 2010). Nursing homes often provide care for the most dependent individuals who are unable to receive care at home or a less supportive environment. The 2004 National Nursing Home Survey reported that more than one-half of all nursing home residents were either dependent or required extensive assistance in bathing, dressing, toileting, and transferring (Jones et al., 2009). This level of care can be very costly. Nursing home care costs can average \$50,000 per year, with some variability based upon location of the facility and level of dependence of the individual (Association for the Advancement of Retired Persons (AARP), 2010; United States Department of Health and Human Services and Centers for Medicare & Medicaid Services, 2010). Most residents use a variety of payment sources. According to the 2004 National Nursing Home Survey, at admission, most residents report using private sources (42%), followed by Medicare (36.4%), and Medicaid (34.8%). As their time in the facility progresses, residents report utilizing more private sources (66%) and Medicaid (59.7%) (Jones et al., 2009).

2. Overview of the Transition into a Nursing Home

A critical point in the beginning of the transition is the catalyst for the movement of the older adult from the home environment to the nursing home. This point in the movement has been termed throughout the literature as a “crisis event” (Buhr, et al., 2006; Dellasega & Mastrian, 1995; Hagen, 2001; Ryan & Scullion, 2000). The crisis may be an unplanned medical event by the older adult that

required immediate hospitalization, but could also be a breakdown of the caregiver's ability to manage the relentless demands of care (Butcher et al., 2001; Ryan, 2002). The situation surrounding nursing home placement may vary depending upon the type of familial relationship between the caregiver and older adult (e.g., spouse, adult-child, other relative) (Matthiesen, 1989; Meuser & Marwit, 2001; Paun & Farran, 2006).

In the case of the caregiver being unable to maintain care in the current home environment, it often involves a worsening in the physical or cognitive health of the older family member (Butcher et al., 2001; Rodgers, 1997). Caregivers become especially concerned about safety (Paun & Farran, 2006). As the intensity of the caregiving increase, caregivers reach a "breaking-point" when they are no longer able to provide all of the care their family members needs (Butcher et al., 2001). At this time, they often consider nursing home placement.

If the crisis event includes an acute hospitalization stay, the nature of the crisis event may place the older adult on a trajectory of rehabilitation and skilled nursing care with the expectation of transitioning to a more dependent level of care than the home environment (Rodgers, 1997; Ryan & Scullion, 2000). After hospitalization, the older adult may enter a skilled nursing facility (SNF) for sub-acute rehabilitation and continuing medical and nursing treatment. SNFs are temporary nursing and sub-acute rehabilitation facilities that provide an array of care services (United States Department of Health and Human Services, 2007). SNFs are often located in nursing homes. There are certain criteria the older adult must meet in order to qualify for Medicare SNF benefits, including a qualifying three-day acute care hospital stay and physician certification of need for care in a skilled facility (United States Department of Health and Human Services, 2007). Families are expected to participate in the discharge process from hospital to SNF and have their relative moved to the SNF in a timely manner.

The goal of the SNF is to provide sub-acute rehabilitation and care to allow the resident to function at their highest level. Payment for SNFs varies. If the older adult qualifies for Medicare Part A,

then the first 20 days of skilled care are covered entirely; the next 21 to 100 days, Medicare covers all but a co-payment (United States Department of Health and Human Services, 2007; US Department of Health and Human Services and Centers for Medicare & Medicaid Services, 2010). While an older adult is entitled to a maximum of 100 days of Medicare Part A payment of care, there is not a guarantee that Medicare will actually cover all 100 days. A resident may be discharged from Medicare Part A benefits if they no longer require skilled nursing and sub-acute rehabilitation services. Upon discharge from Medicare Part A benefits, the resident may choose to remain in the SNF and use another source of payment.

During the stay in the SNF, the interdisciplinary skilled care team (including nurses, physicians and nurse practitioners, rehabilitation staff, dietary services, recreational therapy, and social services) meets with the family and resident between days 14 to 21 of stay for a care plan meeting (United States Department of Health and Human Services, 2007). During the care plan meeting, the team advises the family about the resident's progress with the sub-acute rehabilitation and determines the appropriateness to returning back to the home environment or transitioning into a more structured institutionalized environment, such as a nursing home. The idea of the care plan meeting is to assist the family in understanding the next phase of the transition and the possibility that the older adult may require more care than could be provided in the home environment. The care planning process should be collaboration between the interdisciplinary team, the family, and the older adult.

3. Primary Family Caregivers Interactions and Perceptions of the Transition to Nursing Home

Regardless of the nature of the critical event, primary family caregivers are often the ones making this difficult decision and navigating the transition, so they have the most important roles in the process (Buhr, et al., 2006; Dellasega & Mastrian, 1995). While older adults are an important component of the decision and transition, the focus of much of the research has been on caregivers.

Despite the importance of the decision and the complexity of the steps involved, many researchers reported that caregivers often have felt unprepared, perceive a lack of control over the situation, have felt inadequately supported by healthcare professionals, and complained that they are rushed (Butcher et al., 2001; Dellasega & Mastrian, 1995; Kellett, 1999; Paun & Farran, 2006; Rodgers, 1997).

A critical element in the decision to place an older adult in a nursing home is for the caregiver to accept the need for placement (Rodgers, 1997). In a qualitative study of family caregivers, Rodgers (1997) discussed that many caregivers had considered the possibility of placing their relative in a nursing home, but dismissed these thoughts and decided that nursing home placement would never happen. When the time actually came to choose a nursing home (which usually occurred while the older adult was in the hospital), caregivers reported feeling both unprepared and rushed. Ryan and Scullion (2000) also noted that the experience of choosing a nursing home during the crisis event in the hospital can be quite traumatic for family caregivers as they recognize that their relative may never return home.

As caregivers struggled with this decision, they recognized the need to let go of the idealized caregiver role (Dellasega & Mastrian, 1995). To accept the need for nursing home placement could be seen as a failure or as “giving up” on their relatives. Caregivers needed help to recognize that moving their relative to a nursing home was not a failure, but an unavoidable and often final desperate step (Kellett, 1999).

While caregivers often rely on the advice of healthcare providers during the transition process, researchers reported that caregivers felt inadequately supported or disempowered (Butcher et al., 2001; Kellett, 1999; Paun & Farran, 2006; Rodgers, 1997; Ryan & Scullion, 2000). Kellett (1999) reported that caregivers’ felt a lack of control and powerlessness over the situation and the actual nursing home placement decision. Ryan and Scullion (2000) noted that many caregivers described that the decision was actually made for them by the healthcare provider or hospital. On the other hand, caregivers also felt unsupported by health care providers, as if the decision and choice of facility was entirely left on

them (Dellasega & Mastrian, 1995; Rodgers, 1997). Rodgers (1997) discussed how caregivers were told to select a facility, but given little criteria on how to make an appropriate choice. Caregivers did seek the guidance of health care professionals in the placement decision and felt reassurance when the provider was involved in the decision (Butcher et al., 2001; Paun & Farran, 2006).

Caregivers reported a mixture of feelings about the decision and transition into a nursing home. In Nolan and Dellasega's (1999) mixed-methods study of UK and US family caregivers, study participants reported conflicted feelings about placing a relative in a nursing home. Many caregivers stated that they felt guilty about being unable to continue caring for the older adult at home, but also a sense of relief. Ryan and Scullion (2000) also noted that caregivers described an assortment of feelings, including guilt, helplessness, loss, loneliness, and regret. Many caregivers indicated that these feelings were enduring, even as time went on. Rodgers work (1997) echoed these feelings and described that caregivers also expressed feelings of anger and sadness. Rodgers discussed how the stress could lead caregivers to experience problems with their own physical and mental health, such as high blood pressure and trouble sleeping. Caregivers' feelings of regret and stress often persisted or even worsened after the placement.

Many researchers have indicated that caregivers experience worsening emotional distress and burden after the nursing home placement (Garity, 2006; Gaugler, Mittelman, Hepburn, & Newcomer, 2009; Zarit & Whitlatch, 1992). In a secondary data analysis of data from the Medicare Alzheimer's Disease Demonstration Evaluation project (MAADE) (a case management home care program) Gaugler, Mittleman, et al. (2009) examined factors that influence caregiver burden and depression post nursing home placement. Overall, caregivers reported significantly less burden and depression post-placement. However, certain characteristics predicted worsening depression and burden post-placement, including hospital use by care-recipients (e.g., the older adult) during the nursing home transition, care-recipients with greater functional dependency, caregiver health impairment, being an older caregiver, being a

spousal caregiver, and being a female caregiver. These characteristics suggested that there are multiple factors in the caregiver and care-recipient dyad that may influence caregiver stress and burden.

Additionally, Zarit and Whitlach (1992) proposed that the nursing home placement shifts the responsibilities of caregivers and the nature of the burden. Instead of the distress from providing continuous hands-on care, caregivers experienced burden from having to become facilitators of care, interacting with nursing home staff to ensure needs of their relative are met, and handling the financial considerations of paying for care (Garity, 2006; Zarit & Whitlatch, 1992).

Researchers discussed how some of this anguish and distress can be alleviated through validation and support by healthcare providers, other family members and peers, and nursing home staff (Butcher et al., 2001; Dellasega & Mastrian, 1995; Garity, 2006; Paun & Farran, 2006; Paun & Farran, 2011). Caregivers wanted to feel legitimized with their choice both before the decision has been made and afterwards (Dellasega & Mastrian, 1995). Nursing home staff can especially be helpful in validating feelings by being receptive to the needs of families and communicating frequently (Garity, 2006; Paun & Farran, 2011). Information increased caregivers' beliefs that the decision to place in a nursing home was the right one and that their relative was receiving high quality care.

4. Primary Family Caregivers Remaining Involved in Nursing Home Care

Remaining involved in care is important for caregivers, as care does not end at the nursing home door (Kellett, 1999; Fink & Picot, 1995; Maas et al., 2001; Nolan & Dellasega, 1999; Paun & Farran, 2006; Paun & Farran, 2011). Addressing the needs of the caregiver both during and after placement can help improve family satisfaction with the nursing home care and lead to successful partnerships between family and staff. Paun and Farran's (2006) study of family caregivers involved with the nursing home placement of a relative with Alzheimer's disease noted the specific knowledge, practical skills, and emotional support needs that should be addressed to assist the caregiver prior to and after placement.

These identified needs led to a more successful adjustment for the caregiver and their older family member.

Caregivers reported that knowledge regarding financial requirements, rules, and regulations would be especially helpful in assisting with a successful transition (Paun & Farran, 2006). Nursing home staff need to provide caregivers with the overall larger picture of placement as well as the small steps involved. Caregivers benefited from understanding the appropriate staff to report problems, ask financial issues, and request information (Garity, 2006; Matthiesen, 1989; Paun & Farran, 2011). Nursing home staff can also provide a clearer understanding of the older family member's health and functional status in the long-term, which will help them prepare for future challenges (Paun & Farran, 2006). Furthermore, providing resources, including access to support groups and networks can help with the emotional strain of placement and focus on caregiver self-care and quality of life (Garity, 2006; Matthiesen, 1989; Paun & Farran, 2006; Paun & Farran, 2011).

Additionally, caregivers need information regarding the practicality of having an older family member in a nursing home. Multiple researchers have noted a change from in the caregiver role, from providing direct care to becoming facilitators and managers of care (Garity, 2006; Zarit & Whitlatch, 1992). As such, caregivers need to learn how to have successful interactions with nursing home staff and remain actively involved in decision-making. Staff can help caregivers learn how to transition into a new type of caregiving role and stay engaged (Butcher et al., 2001; Dellasega & Mastrian, 1995; Garity, 2006; Paun & Farran, 2006). Caregiver continual involvement in management is important for ensuring the delivery of quality care and the overall well-being of the older adult (Rodgers, 1997). While being a manager and facilitator of care is important, it can be difficult for the caregiver to relinquish control of the direct caregiving tasks (Nolan & Dellasega, 1999). Caregivers need to be able to observe positive interactions between the staff and the older adult and establish trusting relationships with staff to feel comfortable with the care that is being provided (Butcher et al., 2001; Kellett, 1999; Nolan & Dellasega,

1999). Developing these professional and caring relationships between nursing home staff and caregivers can take time. Creating family-centered programs to help promote partnerships and provide emotional support to caregivers has been the subject of interventional studies within nursing homes, such as the Chronic Grief Management Intervention and the Family Involvement in Care partnership intervention (Maas et al., 2001; Maas et al., 2004; Paun & Farran, 2011).

III. Methods

A. Design

A qualitative descriptive design was used to achieve the specific aims of this study. Qualitative description was an appropriate methodology for this study because it used the primary family caregivers' own language to obtain rich descriptions of how they define, manage, and perceive the consequences of nursing home placement and adjustment over time (Neergaard, Olesen, Andersen, & Sondergaard, 2009; Sandelowski, 2000; Sandelowski, 2010). Qualitative research is needed to obtain a better understanding of health and health-related issues, such as nursing home placement decisions, from the perspective of those experiencing those problems (Evans & Pearson, 2001; Pearson, Wiechula, Court, & Lockwood, 2007; Ulin, Robinson, & Tolley, 2005). The knowledge gained from this understanding can provide more tailored and practical information for addressing these problems (Ulin, Robinson, & Tolley, 2005).

B. Setting

The study recruitment took place at four nursing homes in the Midwest. A fifth nursing home was approved, but no caregiver participants were recruited from that site. Nursing Home A provided a continuum of services, including long-term care, sub-acute rehabilitation, and specialized dementia care on a memory care unit for approximately 140 residents; they accepted both Medicare and Medicaid. Nursing Home B also provided an array of services, including long-term care, sub-acute rehabilitation, and a memory care unit and has the capacity for 172 residents; they accepted both Medicare and Medicaid. Nursing Home C provided independent living, assisted living, and short and long-term nursing care options, for a capacity of 600 residents across their campus. This study recruited from their memory care unit, which provided long-term nursing home care for approximately 95 residents across three levels of cognitive impairment. Nursing Home C accepted Medicare and Medicaid; however all residents who resided in the memory care unit paid privately. Nursing Home D provided independent

living, assisted living, sub-acute rehabilitation, and long-term care on a campus of approximately 385 beds. Recruitment primarily focused on caregivers of residents from their sub-acute rehabilitation unit with residents whom had transitioned to long-term care. The sub-acute rehabilitation unit accepted Medicare for sub-acute rehabilitation and private pay for long-term care stays. They had the capacity for approximately 85 beds.

C. Sample/Subjects

1. Sample Criteria

This study recruited 10 primary family caregivers from four nursing homes in the Midwest. Building on purposive sampling to obtain a full range, scope, and uncover multiple perspectives of the phenomenon, criterion sampling was used to ensure all participants have actually experienced a nursing home placement (Creswell, 1998; Lincoln & Guba, 1985; Patton, 1990). According to Patton (1990), the purpose of criterion sampling is to understand cases that have some predetermined criteria of importance. From this information, there may be opportunities for in-depth analysis and eventual changes to the entire system. Miles and Huberman (1984) noted that sampling in qualitative research needs to consider the setting, actors, events, and processes that occur in order to answer research questions. Samples in qualitative studies are small, nested in-context, and studied in-depth (Miles & Huberman, 1994).

Feetham's criteria for family-related research guided the sample selection for the caregivers. In family-related research, the view of one family member can be used to understand the experiences of other family members and on the family unit. Only one caregiver was interviewed to understand the experience of nursing home placement within a family context (Feetham, 1991). "Family" was defined as a system or unit of which its members may or may not be related; where there is a commitment and attachment among the members, there is a future obligation, and the caregiving functions include protection, nourishment, and socialization of its members (Sabatelli & Bartle, 1995; Stuart, 1991).

The inclusion criteria for the primary family caregivers were: a) reported that they provide or manage the care, or are involved with nursing home placement for the older family member; b) placement of older family member occurred during initial 30 to 45 days after placement; c) 21 years of age or older; and d) reads and speaks English. The exclusion criterion for primary family caregivers was: a) unable to complete the interview. No restrictions were placed on the primary family caregiver in regard to sex, ethnicity, race, socioeconomic status, and education.

Although the older family members were care-recipients of the caregiving dyad and were not interviewed, they had inclusion criteria: a) 65 years of age or over; and b) anticipated by the professional nursing home staff to remain in the facility for at least 3 months or long-term care. No restrictions were placed on the older family member in regard to sex, ethnicity, race, disease status, socioeconomic status, and education.

2. Recruitment Methods

There were three methods for recruitment: 1) professional nursing home staff (e.g., directors, nurses, administrators, and social workers) received a packet of information to pass out to potential family caregiver participants. The staff was informed about the study and the criteria of potential participants. Nursing home staff then inquired with a potential participant as to whether they were willing to fill out a form with their contact information; this information was then either emailed or mailed to me; 2) a mail-in form with a postage paid envelope was provided in the information packet so that potential participants could mail their contact information to me; 3) the participant directly contacted the investigator from information provided in the packet or flyers posted in each nursing home. A copy of the study flyer is in Appendix I. Additionally, nursing home staff were contacted by the investigator on a semi-weekly basis and visited regularly. Methods of recruitment were tracked. Two of the participants contacted the investigator directly about the study from information via the study flyer. A member of the professional nursing home staff initially approached the other eight participants.

D. Data Collection Procedures

Initial interviews took place within 30 to 45 days of placement of the older family member into the nursing home. I conducted the initial placement face-to-face interviews at a location of convenience for the participant (e.g., their home, a quiet table within the nursing home, a private office in their workplace, a quiet corner of a coffee shop). At the beginning of the initial interview, the purpose of the study and study procedures were explained to the participants and consent forms were signed. A copy of the informed consent is in Appendix F. A demographic questionnaire was also completed during the initial interview. Primary family caregivers received a thank-you card in the mail approximately one week after the initial interview, which also served as a reminder of the 3 month post-placement interview. The investigator also called participants 6 to 8 weeks after the initial interview to document continued eligibility and to schedule the 3 month post-placement interview.

Three month post-placement interviews took place face-to-face or over the phone. Three of the participants choose to conduct the interview over the phone, one at a quiet corner of a coffee shop near his work, and the other six at their homes. Three month post-placement interviews occurred three to four months from the day of admission into the facility. This time frame was chosen because Medicare skilled benefits end after 100 days and then out-of-pocket expenses for nursing home care increase; these individuals who are remaining in the facility for 3 months or longer are more likely to stay at the nursing home for long-term care needs (Kaye et al., 2010; United States Department of Health and Human Services, 2007). Both initial and 3 month interviews lasted approximately 45-75 minutes and were digitally recorded. Participants were given a \$25 Target gift card at the completion of both the initial interview and 3 month post-placement interview.

E. Instrumentation

1. Screening for Initial and Continued Eligibility Forms

Initial eligibility was documented through completion of the Initial Eligibility Documentation form. A copy of this form is in Appendix G. One potential participant who was screened did not meet the eligibility criteria because the older family member had resided in the nursing home for over a year. The ten participants who met the initial eligibility proceeded onto the interview. Continued eligibility was documented through the completion of the Documentation of Continued Eligibility Form. Continued eligibility information was collected over the phone when participants were called at 6-8 weeks after the initial interview to follow-up, to determine their continued eligibility, and schedule the second interview. A copy of this form is in Appendix H.

It was determined that four older family members were no longer residing at the nursing home during completion of the continued eligibility form: one had been discharged to an assisted living, one had been discharged home, and two were deceased. Through consultation with members of the dissertation committee, it was determined to ask the primary family caregivers if they wanted to continue to the 3 month post-placement interview. All four caregivers agreed to participate in the 3 month post-placement interview. The older family member who was discharged to the assisted living stayed in the nursing home for approximately one month, the older family member discharged home stayed in the facility for approximately 3 months, and of the two older family members who died, one remained in the facility for approximately two months and the other for approximately 3 month. All 10 participants took part in the initial and 3 month post-placement interviews and their interviews were all included in the analyses.

2. Demographic Questionnaire

A demographic questionnaire about the primary family caregiver was completed at the beginning of each interview. The demographic questionnaire included questions about the relationship of the

primary family caregiver to the older family member, age, work status, education status, race, and ethnicity of the primary family caregiver. A copy of the demographic questionnaire is in Appendix J. The caregiver provided all sociodemographic information about the older family member during the interview. No information about the older family member was obtained through clinical records.

3. Initial and Three month Post-Placement Interview Guides

I conducted two separate semi-structured interviews with primary family caregivers, one at initial placement and one at 3 months post-placement. The initial interview guide is based on the FMSF components and dimensions as well as a review of pertinent literature. The 3 month post-placement interview guide was developed as the first interviews were conducted and was based on data analysis of the first interviews as well as the FMSF. For the four caregivers whose older family member had been discharged or died, the 3 month post-placement interview guide was not changed. Rather, the interview was unstructured and the caregivers commented on issues they thought important during the stay in the nursing home. No 3 month post-placement interviews were conducted until IRB approval for the interview guide was obtained. A copy of the initial interview guide and 3 month post-placement interview guide are in Appendices K and L.

F. Protection Against Risks

Procedures had been implemented to ensure confidentiality, privacy, and consent of the participants. IRB approval was obtained prior to any data collection and a copy of the IRB approval is in appendix E. Informed consent was reviewed and signed prior to the initial interview. Participants were informed at both the initial and 3 month post-placement interview that they have the right to refuse any or all study procedures at any time without consequence. Confidentiality was maintained through the use of participant codes on the interview transcripts and demographic data forms. For the data analysis procedure of the transcripts, all participants' names and the names of the nursing homes were removed and only ID code numbers were used to identify subject data. Consent forms and the original contact

information forms with participant's names and contact information were kept in a secure, locked file cabinet in a locked research office at the College of Nursing. The investigator was the only person with a key and access to this locked file cabinet. Destruction of the contact information forms was discussed with the participants during the informed consent process. Participants were asked to consent as to whether they agreed to be contacted for future studies. If they agreed, the original master list of names and contact information will be destroyed 5 years after completion of the study. If the participant did not agree to be contacted for future study, their name and contact information from the master list were destroyed immediately after the study was completed.

The data, including transcripts, were kept on a password protected computer in a secure folder at the college of nursing. Only the investigator and her advisor had access to this folder. The transcriptionist was sent the digital files over a secure SFTP server and transmitted the transcribed files back over this server.

Nursing home professional staff assisted with recruitment through the identification of potential caregivers that have met the inclusion and exclusion criteria. While nursing home professional staff assisted with recruitment, no information was shared with them as to the decision of the primary family caregiver whether to participate in the study. Only the investigator had knowledge as to whether the recruited caregiver decided to participate in the study. These decisions were kept on the Documentation of Initial Eligibility Form, which was stored in a locked file cabinet in a research office at the College of Nursing.

G. Ethical Considerations

Because the caregivers' experiences could be sensitive and draw from mixed emotions, the investigator assessed for cues that may signal indicators of distress during the interview and offered strategies for minimizing discomfort or fatigue (Kavanaugh & Ayres, 1998). As caregivers may have

continuing questions and issues after the interview, a list of caregiving resources in the area after the initial interview was provided to all participants. A copy of this list is in Appendix M.

H. Ensuring Quality and Rigor

To ensure quality and rigor, number of techniques proposed by Creswell (1998) and Lincoln and Guba (1985). First, peer debriefing, which is interacting and consulting with another researcher, provided feedback about methods, meanings, and interpretations. The investigator's advisor and other committee members served as peer debriefers. Second, rich, thick descriptions were collected to provide detail about the setting and context of the study to allow for transferability of the findings. Third, an audit trail and reflexive notebook were maintained to keep track of methodological and analytical thought processes throughout the study. Maintaining an audit trail enhances the transparency and dependability of the research.

I. Data Analysis

Analysis was based on guidelines and techniques from Creswell (1998) and Miles and Huberman (1984). Data management and analysis followed Creswell's steps that include a) Data managing; b) Reading, memoing, and initial coding; c) Describing the context; d) Analyzing and classifying data; e) Interpreting and making sense of the findings; f) Presenting a narrative of the data. Creswell describes this approach as a data analysis spiral, which indicates that it is non-linear and iterative.

More specifically, a professional transcriptionist transcribed interview data for each primary caregiver verbatim. ATLAS.ti Visual QDA (Qualitative Data Analysis), Version 5.7.1 was used to organize the data, manage coding, keep a reflective research diary using memos, and run queries. I uploaded each interview into the ATLAS.ti software. I read each interview in its entirety several times. Code lists were developed using the FMSF components and dimensions, pertinent issues derived from the literature, and emergent codes that arose from initial interviews. A list of 27 codes was developed and is in Appendix N.

Analysis occurred concurrently with data collection. Miles and Huberman (1984) note that analysis during data collection allows for the investigator to cycle between looking at the existing data and have new strategies for collecting new and better quality data. It can allow for self-correction and ensure that the analysis is linked to the data collection. This process of reading transcripts multiple times and cycling between data collection and analysis allowed me to immerse myself in the data. Reviewing initial interview transcripts prior to the three-month post-placement interview allowed me to familiarize myself with the individual caregiver's details and follow-up on significant statements. During the analysis, I examined the initial and 3 month post-placement transcripts of a single caregiver together to recognize similarities and changes over time. Reflexive data memoing allowed me to keep track of my thought process during the coding sessions and identify important similarities and differences across caregivers. Writing memos is important in the process of exploring the data (Creswell, 1998).

During the data analysis process, matrices were developed to organize the data according to the dimensions components of the FMSF. Miles and Huberman (1984) note that a summarizing table (such as a matrix) will allow the researcher to review the data more easily, carry out a more detailed analysis, and compare data across sites. The matrices allow descriptive data segments to be formatted around certain events. In this study, a matrix was created for each family and segmented based on the components of the FMSF. Two columns were created, which allowed for side-by-side comparison of each component at initial and 3 month-post-placement interviews. With the guidance of my advisor, codes were reviewed to determine how they corresponded to the components of the FMSF. ATLAS.ti allows the user to review documents quickly for certain codes by running queries. To find instances and quotations that matched the multiple codes that fit under the components and dimensions of the FMSF, a "Super Family Code" was created. This Super Family Code is a Boolean operator that allows multiple codes to be combined and when queried, to be searched for under a single name (Friese, 2012). For example, for the dimension of Approach to Management and Placement, a Super Family Code was

created with that name. The four codes, Making the permanent placement decision, Critical Incident, Development of a routine, pre-placement, and Development of a routine, post-placement were combined using the Boolean operator of “OR.” When a query using the Super Family Code was done, any segment of text that was coded with one of these four codes was identified. The queries were then used to organize a matrix based on respective parts of the framework. During the query runs and matrix building, important segments of the data were bolded. After all matrices were built and reviewed, a final matrix for each component of the framework and a summary was completed to be able to review each component, comparing similarities and differences across caregivers over-time. In total, there were three levels of matrix building from coding to the summaries.

The results summarized findings within each individual case and across cases to understand the individual case and recognize differences and similarities in experiences across cases and over time (Ayres, Kavanaugh, & Knafl, 2003). Describing the situation around each individual family (“within-case” analysis) allowed for the retention of context. Miles and Huberman (1984) note that understanding context is critical to illustrating the meaning of events. Reviewing across families and over time (“across-case” analysis) captured the variation of experiences involved in nursing home placement. Ayres, Kavanaugh, and Knafl (2003) described different strategies for conducting within and across case analysis, noting that it depends on interpretive choices and research aims. While strategies differ, the researchers argued using within- and across- case analysis techniques allowed for the preservation of rich context and capturing the variation in experiences.

IV. RESULTS

A. Sociodemographic Data

All 10 primary family caregivers identified themselves as being the primary family caregiver and ultimately responsible for management of care and placement. The caregivers ranged in age from 52 to 86, with a mean of 70 years of age. Eight of the caregivers were women, with the most prevalent relationship being wife (primary family caregiver) and husband (older family member). I interviewed two son-father dyads, one daughter-mother dyad, and two other types of familial relationships, which led to variability in the type of caregiver dyads and provided a rich backdrop for the study. Most caregivers were retired, but two maintained full-time work. Education ranged from high school to graduate degrees, with most being educated at the high school level or above. All caregivers identified themselves non-Hispanic, Caucasian. The older family members ranged in age from 72 – 90 years, with a mean of 83 years. Eight of the older family members were women.

B. Older Family Member Disposition Prior to and After Placement

Knowledge of the location of transition of the older family member from their previous living environment to the nursing home and their disposition at 3 months is an important consideration about understanding the situation surrounding placement as it can impact perspectives about the facility and interaction with staff. Four of the older family members entered the nursing home through the sub-acute rehabilitation unit. One older family member had a recent stay in a sub-acute rehabilitation unit in another nursing home, but was discharged home and remained there for two weeks. He then entered the long-term care unit of the nursing home. One older family member was admitted to the long-term care unit of the nursing home from the home he shared with his wife. Another entered the memory care unit of the nursing home from an independent living facility (ILF) apartment he shared with his wife. One family member was admitted to the memory care unit from the home he shared with his wife. Lastly,

two family members were admitted to the memory care unit of the nursing home from an assisted living facility (ALF) within the same community.

At the 3 month post-placement interviews, six of the older family members remained within the same nursing home. One that initially entered via sub-acute rehabilitation transitioned to long-term care within the nursing home. Another who entered via sub-acute rehabilitation was then placed into the memory care unit. The two that initially entered into the long-term care unit of the nursing home remained there. The two that transitioned from the ALF to the dementia care unit also remained there. Of the four who were no longer residing at the facility at 3 months, one was discharged to an ALF, one was discharged home, and two had died. A summary of the older family members' disposition prior to placement and at the 3 month post-placement interview is located in Table 1.

C. Caregiving Dyads: Within-Case Analysis

The within-case analysis allowed for an understanding of the rich context of each individual family. To conduct this within-case analysis, each family dyad was reviewed systematically. A description of their relationship, circumstances surrounding placement, other family members' involvement in the care and placement, and continued involvement in care management post-placement was described for each dyad.

Names and places had been removed so that each participant's identity was not compromised. Pseudonyms have been created for the primary family caregiver and older family member. All information provided in these descriptions came solely from the interviews with the primary family caregivers. No information from the nursing home staff or medical record was included in the data collection.

1. Dyad 1: Niece/Uncle

Bonnie was a 68-year-old women. Bonnie, together with her sister and cousin, managed the care and placement of her uncle, Gary. Her cousin and the cousin's husband held Power of Attorney (POA)

for health and finance for Gary. She described her family, as a typical close Italian family, growing up in the same apartment. Her uncle was a patriarchal figure in her family, caring for her grandmother, aunt, and mother through the years. Because of this close family relationship, Bonnie felt obligated to care for her uncle. Gary was a 90-year-old male, who prior to nursing home placement, was living alone.

Bonnie, her sister, and cousin had known that they would be unable to maintain Gary in his current home environment. However, Gary was extremely resistant to receiving any kind of home health assistance or considering long-term care placement, such as assisted living. Bonnie described Gary as strong-willed and stubborn. When assisted living was brought up, Gary said he had all of the support he needed through Bonnie and his family. Bonnie, her sister, and cousin took weekly turns visiting and calling Gary at his home, making sure it was kept clean, setting up his medications, and ensuring his needs were met. However, they were concerned about several safety issues that had occurred, such as the cleanliness of the apartment, his lack of consistency on taking medications and eating nutritious meals, taking rides from strangers to attend community events, getting lost, and spending money on sweepstakes through the mail.

Bonnie knew a “critical event” would lead to Gary’s nursing home placement. Gary had a fall outside of church that led to a hip fracture and replacement. During his hospitalization, Bonnie’s cousin selected a nursing home because of its proximity to their home. While hospitalized and during his transition to a sub-acute rehabilitation unit within a nursing home, Bonnie learned that Gary had dementia and renal failure. Gary eventually transferred to the dementia unit within the nursing home because of his persistent behavior issues, including verbal and physical abuse toward the nursing home staff. Gary received medication management. At the 3 month post-placement interview, Bonnie thought that Gary seemed to be better adjusted to the nursing home, but was progressively becoming more forgetful. Bonnie felt that the nursing home placement was a huge relief, especially in terms of concerns

about his safety. Bonnie and her family had established a routine for weekly visits and continue to remain involved in the management of his care.

2. Dyad 2: Wife/Husband

Amy was an assertive, 72-year-old woman. She identified herself as the primary family caregiver for her husband, Marshall. She has been married almost 50 years. She described their relationship as independent from one another, but they had a partnership and could depend on one another. Amy portrayed Marshall as a hard worker, but not someone who made the best decisions in life. She depicted him as a grumpy old curmudgeon, Archie Bunker-type who enjoyed being at home. Amy had three adult sons, each of whom were married and had children. She stated her children help with finances, but otherwise, decisions regarding Marshall's care were hers. Amy was happy with this arrangement because she understood that her children have their own concerns and their own lives. She noted that the circumstances may have been different if she had had daughters because of the way she could have communicated with them. She felt she had to be independent with her decisions regarding care for Marshall.

Amy's caregiving journey started when Marshall began having seizure activity. He was diagnosed by a neurologist with front-temporal lobe dementia. He had rapid decline in his cognitive status and ability to care for himself. For safety issues, Amy knew she would be unable to allow Marshall to remain at home alone. Amy hired a 24-hour live-in male caregiver, who provided the direct personal care to Marshall. Amy said she learned to be a peripheral person in her home, because she had to rearrange her home and life around her husband's needs. Marshall continued to have significant behavior issues, such as falling, urinating in inappropriate places, and even physically attacking Amy. She felt that providing care to Marshall was continuing to upset her that despite her best efforts to meet her husband's needs, nothing she provided was helpful. She consulted with a social worker and a psychologist regarding her situation, but ultimately, she did her own online research, and made the

decision for nursing home placement. One of her son's was supportive, but the other sons felt that she was "getting rid of dad."

Amy ultimately placed Marshall into a nursing home because she was unable to manage the demands of his care at home. She selected a nursing home close to a hospital, so she could easily manage his ongoing health issues. Initially, Amy had the support of a nurse liaison at the nursing home, who helped her with the transition. But, Amy described feeling like in a "cloud" and having "an empty-nest" at home within the days after placement. At the 3 month post-placement interview, Amy noted how she was still learning to adjust to living at home alone and making decisions without her husband. Amy illustrated how she was unsatisfied with the care provided by the nursing home staff. She felt he was not being cared for adequately, being left unclean, and had persistent safety issues, such as falling. At the 3 months post-placement interview, she felt she continued to be responsible for managing his care and spent the majority of her time troubleshooting the poor and inconsistent care of the nursing home. She was looking for a new nursing home that would be nicer, have a better staff ratio, and might alleviate her worries.

3. Dyad 3: Wife/Husband

June was a 78-year-old, frail woman. June and Peter had been married over 60 years, having met in high school. They have three adult children, with a daughter who was very involved in Peter's care. June provided a detailed history of their life together, which illustrated a very close relationship. Peter was a broker who had recently retired and was diagnosed with prostate cancer. June described Peter as a nice, non-demanding person. She noted that he had a rapid decline in his cognitive and physical abilities over the course of a year. June was his primary family caregiver, attending to all of his needs.

June and her children determined that it would be best for herself and Peter to move into an independent living facility (ILF) within a continuing care retirement community (CCRC). June had experiences with the specific ILF because her mother had previously resided there and she was on the

Auxiliary Women's Board. June and her children did not include Peter in the decision to move to the ILF. June tried to involve Peter in social activities at the ILF, but it became progressively more difficult because of his worsening cognition. June and her daughter eventually consulted hospice. Ultimately, the staff at the CCRC, June, and her family determined that Peter needed more care than could be provided in the ILF moved him into the nursing home, specifically the memory care unit. Looking back, June recognized that Peter probably remained with her at home longer than he should have. June visited Peter daily and felt that he adjusted well to living at the nursing home. At the 3 month post-placement interview, Peter had died. June did not discuss much about her grief over his death, but she did express that the nursing home provided excellent care (even with a fall and hospitalization) and had developed a good relationship with the staff. She felt positive about her decision to place Peter in the nursing home.

4. Dyad 4: Son/Father

Harold was a 55-year-old male who was married, with 3 children, and worked full-time. He was the primary family caregiver for his father, Andrew. He described his relationship with his father as very close and that they were best friends. He even pursued a career in advertising, like his father. Harold has a sister, who lived out-of-state, and who was semi-involved in Andrew's care. Harold's sister previously cared for their mother who had Alzheimer's dementia and had died over 5 years ago.

Andrew made the decision to move to an Assisted Living Facility (ALF) in a continuing care retirement community (CCRC) close to his son after his diagnosis of early stage Alzheimer's Dementia. Harold noted that this decision was not well communicated with his sister and she became quite upset because she assumed she would provide Andrew's care. Harold noted that growing up, his parents were typical 1950's style and did not always speak openly about family decisions. He thought Andrew's choice was primarily because he wanted to be closer to his grandchildren and his father may have been comfortable with a man providing his care. Harold felt that he had full responsibility for managing his father's care, ensuring that his healthcare, financial, and daily needs were all met. Harold described his

management as a compartmentalized routine and job, but that he felt rewarded and appreciated for providing this care.

Harold, his sister, and the staff at the ALF determined that Andrew's safety was an ongoing concern and that he needed to be moved a higher level of care. Andrew was having progressive difficulty performing his personal daily care and knocked over a lamp. It was decided he needed to be moved into the nursing home of the CCRC, specifically the memory care unit. Looking back, Harold noted that he probably could have initially moved his father to the nursing home and progressively transitioned to a greater level of supportive care within the memory care unit. Harold felt that moving Andrew to the nursing home was the right move, but in the beginning he had a hard time with it. He questioned whether his father needed such an intense level of care, but eventually recognized that it was necessary. Andrew originally struggled with the placement, wanting to return back to the ALF, but he ultimately adjusted and had even found a new girlfriend. Throughout this transition, Harold noted that Andrew was becoming warmer and more appreciative. At the 3 month post-placement interview, Harold felt that he was developing a better understanding and relationship with his sister, especially because they could share what each went through caring for a parent. He reflected on the philosophical undertaking of being a caregiver and his own considerations of aging. He acknowledges that, ultimately, it was up to him to continue visits and making sure his father's needs are met. Harold noted that his main concerns were visiting Andrew regularly. He was worried about safety because of his father's declining cognition, but was not concerned about the facility being able to provide safe care. He reported he had a good relationship with the director of nursing of the facility and spoke with her monthly about Andrew's care.

5. Dyad 5: Daughter/Mother

Jessica was a 52-year-old married woman who worked part-time. She was the 7th of 11 children. She had several siblings whom were actively involved in their mother, Gloria's care, but Jessica

identified herself as the primary family caregiver. She and her brother shared medical power of attorney (POA). Jessica coordinated the care, informed her siblings of any issues about their mother, and was the only sibling who visited their mother regularly. Gloria was a widow who lived out-of-state, but was moved to an assisted living facility (ALF) close to Jessica when it was determined she was no longer safe living independently. Jessica, her husband, and several of her sisters toured many ALFs, but ultimately it was Jessica who made the final decision. One of her sisters was upset about the decision to place her at that particular ALF (that did not have the card game bridge, which Gloria loved to play). Jessica and this sister recently had a discussion about visiting more often, but the issue remained unresolved because of the initial ALF decision.

Jessica described the sequence of events that led to Gloria's placement into the sub-acute rehabilitation unit of the nursing home. Gloria had osteoporosis and had recent falls. During a family trip, Gloria had intense back pain that required hospitalization. It was determined she had two bulging disc causing urinary retention. The physician at the hospital recommended intense rehabilitation, but Jessica decided to place Gloria in a sub-acute rehabilitation unit within a nursing home to receive skilled nursing care. Gloria had been at this nursing home previously when she broke her pelvis and received rehabilitation that allowed her to regain full functioning. For this recent hospitalization, Jessica coordinated the transition and ensured that her four involved siblings maintained a schedule in which one of them was present during the most of the day. Jessica felt it was important that Gloria had a family member present because of Gloria's occasional confusion and need for reminders to ask for the assistance and pain medication. Jessica described her relationship with Gloria as close, but explained that now she felt she was "grieving a portion of her mom" because she is not the same mother she had growing up due to her cognitive impairment.

At the 3 month post-placement interview, Gloria had returned back to her ALF. Initially, she needed extra assistance, but was able to get back to her normal routine. Looking back, Jessica did not

feel that the nursing home provided her mother with all of her necessary care. Jessica felt that if she did not ensure a family member was visiting, her mother would not have had all of her needs met. At 3 months, Jessica noted that her mother's cognition was only 95% of where she was previously and that she needed some reminders and cues. Jessica hoped that this incident would have encouraged more of her siblings to be involved, but this is not the case. Jessica was not upset that her siblings were not involved and that the care management was placed on her, but rather, she felt that her siblings should visit because of the familial obligation for their mother and because she looked forward to visits.

6. Dyad 6: Wife/Husband

Evelyn was an 86-year-old woman. She and Leo were married for 62 years and had six children and numerous grandchildren. Five children live close and assisted Evelyn as needed. She described their relationship as very close. Evelyn noted that she had been Leo's primary family caregiver for the past 5 years since he underwent an unsuccessful surgery for a pinched neck nerve. She provided assistance with his personal care, cooking, and driving. Leo required the use of a walker at home and needed some home modifications (steps with a grab bar). She said that being a caregiver had impacted her life, but when you love someone, you do it without thinking and it was easy. Evelyn said that she also had some limitations in her mobility due to her spinal arthritis.

Leo's journey from home to the nursing home began with a recent massive stroke. One morning, Evelyn noticed that Leo did not wake up in the morning when she let out the dog, which was their usual routine. Evelyn called their granddaughter and an emergency rescue squad. Initially, during his hospitalization, it was determined he did not have a stroke, but then it was confirmed several days later that he had a massive stroke. Leo then had a radical behavior change, becoming physically and verbally abusive. He was sent to a "mental health place", where he had a medication overdose of Coumadin. Evelyn was very scared at this time because she thought she might lose him, and she realized that with Leo's advanced age, it was a possibility. Eventually, it was determined that Leo needed to be placed in a

sub-acute rehabilitation unit in a nursing home to receive skilled nursing care. Evelyn determined to send him to a specific nursing home because of their previous positive personal experiences with the facility.

Evelyn visited Leo in the nursing home nearly daily. She said she really had a hard time living without Leo and described her experience as “just lonesome.” She wanted to be able to talk with him, but he was no longer at home. Her main desire was that he should return home. Evelyn recognized that she may need assistance with Leo’s care to start with. Evelyn and Leo knew that he needed rehabilitation because of his inability to walk and safety issues concerning falling. Evelyn felt at the time, that his current nursing home was the best place for his current needs.

At the 3 month post-placement interview, Leo had returned home with a 24-hour live-in male caregiver. He remained in a wheelchair and was dependent upon the caregiver for all of his personal needs. Evelyn was satisfied with the care provided by this caregiver. Evelyn noted a change in Leo since the stroke. She felt that he was content with having somebody wait on him. She loved him, but saw a different person. Evelyn was much happier that Leo was at home, especially because the travel to the nursing home was difficult. She did not feel there would be much change in Leo’s condition at this point, but said that she will just have to wait and see what would happen.

7. Dyad 7: Wife/Husband

Rose was an 83-year-old woman. She and David were married for 65 years. She described their relationship as having ups and downs, but they loved each other very much. Rose had four adult sons and a daughter-in-law who were very involved in helping manage David’s care. David had a progressive dementia and Rose had been providing and managing all of his care at home. Rose depicted her care for David as time consuming. She felt that she could not leave him alone for safety reasons, so she took him everywhere, including shopping and physician appointments. At home, David followed Rose around

constantly. She said that she felt she had no alone time, which really became overwhelming. Rose was worried about becoming resentful towards David and felt at times, she may have been.

Rose stated that she took care of David at home as long as she could, but her children were worried about her and her physician suggested she make other arrangements. Rose initially had David enrolled in adult day care two days a week for respite (which went up to 3 days a week). David did not like it at the onset, but he became acclimated to it and eventually looked forward to it. While this situation worked for a while, Rose realized that she could no longer manage David's care at home. She decided the best action would be to place David in an assisted living facility (ALF) across the street from her house. At first, David did not understand the need for his placement into the ALF and asked Rose to give him another chance. Rose tried to explain that it was not him, but his disease that made his care at home unmanageable.

Rose's journey began with a series of "critical incidents." On the very day she was discussing ALF placement with David, she went down to the basement, lost her balance, and fell. She was hospitalized for 8 days and sent to a nursing home for sub-acute rehabilitation. In the meantime, her sons transferred David to the ALF, as planned. Initially, David did not like the ALF, but he acclimated and adjusted. However, while at the ALF, David had a fall and broke his hip. While hospitalized, David quickly deteriorated. He was unable to swallow and had a feeding tube placed. He also has had recurrent urinary tract infections. David was sent to a sub-acute rehabilitation unit within a nursing home for skilled nursing care.

During the initial interview, Rose discussed the difficulties she had been having with the entire situation. She thought with the fall and hip fracture, David had been progressively deteriorating. He was received therapy, but had a hard time following directions. Her family had been at a crossroads, considering if David should stay in the nursing home for long-term care. He continued to have recurrent health related issues. Rose said that it felt as though as soon as one issue was resolved, another thing

came up. When she tried to take a day for herself, she was called back to the nursing home because David was being uncooperative with the staff. The stress of caregiving had caused Rose to lose 20 pounds and created issues with her blood pressure. She worried about something happening to her and felt like her children would have to take responsibility for managing David's care. Yet, she felt that her relationship with David was much easier since his nursing home placement and very loving because she could go home and not have the continued responsibility.

At the 3 month post-placement interview, David was residing at the nursing home for long-term care. He continued to need management for his tube feedings and recurrent urinary tract infections. Overall, Rose was very pleased with the care at the nursing home. She was happy that she could go and see David as often as she wanted and that he was very appreciative. She described his cognition as declining, sometimes he was "there" and often he was not. She did not feel resentful as before because she did not have the ongoing direct care responsibilities. Looking forward, she considered her life with him day-by-day. Rose noted in the beginning, she entertained the idea of removing the feeding tube, but now she could not because "he's there" and as long as he was still her David, she could not remove it.

8. Dyad 8: Son/Father

Jared was a 58-year-old married man with children. Jared was the primary family caregiver for his father, Robert. He described his relationship with Robert as close. Jared had a brother and sister who were not actively involved in Robert's care. After their mother died, it was noted that Robert was suffering from cognitive decline and having a hard time living on his own. While the three children all decided Robert needed more help, Jared's brother and sister made it clear that they would not take responsibility for his care. While disappointed, Jared was happy his siblings were honest as did not want his father to have to move twice, should he continue to decline. Robert moved to an independent living facility (ILF) within a continuing care retirement community (CCRC) near Jared. Jared and his wife agreed on this decision, but went to marriage counseling because they had a different sense of family

and wanted to make sure they could balance their own relationship with caregiving responsibilities. Jared's mother-in-law had dementia.

Over the next several years, Robert's cognitive status continued to decline and he had to be moved to an assisted living facility (ALF) within the CCRC. Jared noticed that Robert's confusion made his day-to-day care challenging. Robert would have long periods of delusions that were becoming increasingly more frequent. While taxing, Jared's philosophy towards his father's care was to go with the delusions and not challenge them. Jared decided to hire 16-hour per day private duty caregivers for additional support, but it was becoming progressively more difficult to manage Robert's behavior. Robert was having difficulty being redirected and becoming agitated. The staff at the facility recommended Robert be moved to the nursing home memory care unit within the CCRC. Jared's brother and sister were involved in the decision, but his brother would have preferred Robert stay in the ALF. Jared noted that his siblings rarely saw their father, so they did not have a real sense of where he was and the direction he was moving in. Jared understood that it was hard to acknowledge where a parent or loved one was. But, the social worker agreed with Jared in that it was time for Robert to move to the nursing home. Additionally, none of his siblings chose to attend the care plan meetings. Despite his siblings' lack of involvement, he was not angry or disappointed because it had been a long time since they have been involved. When they are available, Jared felt like it was a kind of bonus.

Jared said that he was there to be as supportive as he could be with his father, but he saw a change in their relationship due to Robert's dementia. There was less and less of him to share and the relationship became increasingly one sided. Although Jared said he could not be disappointed in his father because it was not Robert's fault, he had on occasion caught himself expecting Robert to be what he was. At the end of the initial interview, Jared said he was now considering whether to initiate a Do Not Resuscitate (DNR) order for his father. He thought his father would not have wanted a DNR because of his stubbornness and willingness to fight, but as his health care power of attorney (POA), the

decision was ultimately up to him. At the 3 month post-placement interview, Jared had a recent fall and broke his collarbone. He was wheel chair bound. Robert noted that he was still considering the DNR order. His siblings called often, but do not visit. Jared felt that while the staff and nursing home provide attentive care, Robert's overall quality of life was not good due to his cognitive impairment. He said the socialization opportunities and activities at the nursing home made a bad situation somewhat better.

9. Dyad 9: Wife/Husband

Lily was a 77-year-old woman. Lily and William had been married 50 years and had four adult children, with one son who lived with them and a daughter who was very involved in William's care. Lily said William was beloved by his children and grandchildren and they were extremely supportive of him. She described William as a social, charming man. Eight years ago, William had bilateral knee replacements that severely affected his mobility and caused him to be wheel-chair bound. Over the past 10 months, his mental status quickly deteriorated due to a series of transient ischemic attacks (TIAs). Lily was a retired registered nurse and identified herself as William's primary family caregiver.

Lily said her main goal was to keep William at home for as long as possible because she loved him. Lily described the situation as difficult to manage. She likened William's dementia to a cloudy day in which sometimes when the sun was out William would have moments of clarity, but eventually that became less and less. She noted William was incontinent, confused, and often has difficulty finding the right words to articulate himself, which was very frustrating. Eventually, his safety concerns came to a point in which Lily was unable to leave William at home alone. Lily had to give up her active social life in the community to care for William. Lily tried respite for 2 weeks, but insisted in caring for William at home. William continued to have TIAs and was sent to the Emergency Room at one point, but Lily recognized that hospitalizations would not reverse the situation and did not feel every change in his behavior warranted a trip to the hospital.

Eventually, with the assistance of her children and her family physician, Lily recognized that it was unsafe to keep William at home. She saw a psychologist at this point to help her make the decision. Ultimately, Lily said that it was her diminishing capacity to deal with the situation that led to the nursing home placement. She became irritable and frustrated and did not feel it was fair to William. Lily and her daughter visited several facilities, looking for one that seemed to have positive staff interaction with the residents. During the initial interview, Lily said she visited William daily because that was what she needed. She said she felt that the nursing home placement provided an opportunity for her to relate to William as a wife again, rather than a caregiver.

At the 3 month post-placement interview, Lily said that William had recently died. William had a massive stroke and with the support of her family physician and family, Lily decided to keep William in the nursing home and not transfer him to the hospital. William was placed on hospice. Although Lily had signed a DNR, her decision not to have William transferred to the hospital was uncomfortable. From the time of the stroke to William's death, he was bed-bound for fifteen days. Overall, Lily felt well supported by the staff and hospice. But, at times during the fifteen days, there were long stretches of ultimately knowing what was going to happen, but not expecting how long it would be. In one instance, a hospice nurse told Lily that William was not "actively dying", which concerned her because she was not sure if she had made a decision that was letting William die. But, a social worker assisted her during this time and brought her an end-of-life informational book, which helped affirm her decision.

Looking back, Lily has gained some perspective about William's time in the nursing home. She felt she had 3 months of quality time with William when she visited and related to him as his wife, rather than his caregiver. William initially had a difficult time adjusting to the nursing home placement, but Lily felt that staff were very patient with him and attentive to the entire family's needs. Lily noted that the staff were able to assist in bringing out his personality, his sociability, and his sense of humor. She continued to visit nearly daily, remarking that her primary responsibility was always to William.

Overall, Lily and her family felt it was the right decision to place William in the nursing home. She was very pleased with the staff, their care to William, and their responsiveness to her and her family's needs.

10. Dyad 10: Sister-in-Law/Brother-in-Law

Emily was a 73-year-old retired registered nurse. She was married with five children. Emily was the primary family caregiver for her husband, who has dementia. She was also the primary family caregiver for Max, her brother-in-law. Emily said that she had a good relationship with Max, but they were not extraordinarily close. Max never married. Emily noted that Max never investigated his health issues and let everything in his life continue on, without concern, including management of his home and finances. Over the past two years, Max had given up driving and Emily did his grocery shopping and took him out to lunch. Emily became Max's power of attorney (POA) for medical care and her son became his power of attorney for finances. Other than the occasional assistance, Emily did not feel she had to significantly provide assistance to Max.

Emily's journey with Max began with a critical incident in his health involving a hospitalization. Max was diagnosed as having uncontrolled diabetic with extremely elevated blood glucose readings. He also had significant urinary retention and a urinary tract infection due to prostate issues. Max was discharged to a sub-acute rehabilitation facility. At the facility, Emily felt she had to be actively involved and present as a family member to ensure Max would receive good quality care. She noted that she needed to manage Max's care because he seemed not to be interested and there was no one else who could step in. At the sub-acute rehabilitation facility, Emily had a difficult time interacting with the staff. The social worker was not clear on Max's progress and his care needs when he was to be discharged from the sub-acute rehabilitation facility back home. As Emily started looking over Max's home and finances, she recognized that Max was in "deep trouble." He did not maintain his house properly and had a reckless financial planner. Additionally, she realized that Max was unable to manage his daily

healthcare needs on his own. The sub-acute rehabilitation facility discharged Max home and it was Emily's responsibility to arrange nursing care options for his ongoing needs.

Emily described the time Max was at home after sub-acute rehabilitation as extremely difficult. She would spend her days trying to set up a routine for Max and the caregivers at his home, manage his finances, and took care of any lingering medical issues. Interacting with insurance and physician's offices on Max's behalf was frustrating and time consuming. She felt many barriers were placed, especially because she was not a spouse or adult-child caregiver. This time was very stressful for Emily and it took her away from her husband. After three weeks at home, Emily decided that she could no longer manage Max's needs and worked with the home health agency social worker to find an appropriate nursing home for Max. While Emily's children agreed with her decision, she did not feel that they recognized or appreciated her hard work. She did not tell Max all of the issues she was facing, because she did not want to make him feel guilty. Emily explained that her family relationship and her recognition that Max needed an advocate made her feel obligated to assist with managing Max's care.

At the 3 month post-placement interview, Emily felt that much of the stress had been alleviated due to Max's nursing home placement. She said Max was still not taking initiative, which forced Emily to step in, but that management was much easier. She visited twice a month, mainly to work out his care and finances. After his financial issues were resolved, Emily said she will continue to stay involved because she says it was important for the nursing home staff to know that residents have supportive family members.

D. Family Management Style Framework (FMSF) Components and Related Dimensions:

Across-Case Analysis

An illustration of each of the components and dimensions of the FMSF as defined by the family caregivers are provided. The components and related dimensions of the framework include:

Definition of the Situation Surrounding Care and Placement

- Older Family Member's Identity
- Older Family Member's Health
- Management Mindset
- Family Mutuality

Management of Care and Placement

- Primary Family Caregiver Philosophy
- Approach to Management and Placement

Perceived Consequences of Care and Placement

- Primary Family Caregiver Focus
- Future Expectations

These components and their related dimensions provide a clearer understanding of how families define, manage, and perceive the consequences of care and nursing home placement. Differences and similarities were noted as well as how the components and dimensions change across time. This across-case analysis allows for an appreciation of the variation across families.

1. Definition of the Situation Surrounding Care and Placement

a. View of Older Family Member's Identity

View of the older family member's identity referred to how the primary family caregiver viewed the older family member's identity, including traits such as personality, capabilities, vulnerabilities, and independence or dependence. A determination of how this view may have impacted management of care, placement, and adjustment was also explored.

Four caregivers noted during the initial interview that certain personality traits interacted with disease processes (such as dementia) thus placing the older family members at risk for inappropriate behavior and safety concerns. This process affected the caregivers' ability to manage all or certain parts of the daily care independently. In all four caregivers' situations, it was a dementia related issue

combined with strong-willed personalities that lead to the inappropriate behavior. The older family member would make poor decisions, become combative with staff, or even refuse care. Lily described how her husband William continued to have a strong personality, but his dementia would hinder his ability to make good decisions. This made managing William's care challenging for Lily. As Lily illustrated:

Well, yeah, William is - there's a line I've used that sort of tells you in a nutshell who he is and that is, "You can always," - he grew up in a household where they spoke German. "You can always tell a German but you can't tell them much." And I recognize the fact that I'm a control freak but so is William so that we would often be at loggerheads. He'd want to do it one way and I'd want to do it the other way, the problem being that I had a better sense of what was safe than he did and so that was part of the problem.

At the 3 month post-placement, three of the caregivers described how their older family members had ongoing issues at first with placement (e.g., combativeness with staff, agitation, difficulty adjusting) but this seemed to calm over time. In one case, it was related to medication management or adjustment, while in the other two cases, the decline in health and cognition increased the older members' cooperation and calmness. One caregiver noted that disease-personality interaction issues continue to persist over time. Amy indicated that her husband Marshall's disease-personality issues progressed to the point where they were affecting his care, such as refusing haircuts and to be shaved, or to receive incontinence care. Amy explained how she was having difficulty with the staff because of their inability to manage his personality-disease interactions:

They says, "Well, he has to have dignity." I says, "You know what? He has no dignity if he stinks and he's not shaven and he looks like a bum." I says, "His whole marriage he always said no. He's practiced that a lot." I says, "Just say, We're going to get you a shower." I mean, do I have to tell them that? You know, and even if it was like, should I ask him or shouldn't I ask

him, they should've asked me right away. Why should I come to that conclusion and tell them that he has more dignity being clean than looking like a bum? You know, what is this? You know what I mean? I'm paying a lot of money for this and I'm getting aggravated.

Three caregivers discussed at the initial interview, how certain disease states, specifically dementia, had taken away their family members' identities. The recognition of this loss of identity greatly affected their relationships and expectations for the management of care. Jared described recognizing how parts of his father Robert's identity was gone and how that impacted his approach to care management and to their relationship,

... I mean it's - I mean I'm there to be as supportive as I can be. There's less and less of him to share. He's more - he really can't focus on much more than himself and his world and his view gets smaller which I think is typical of either someone aging or someone with this type of dementia. So the relationship becomes more one-sided, but I mean you just have to accept it for what it is. You can't be disappointed that it's not what it was.

Jessica illustrated during the initial interview how she needed to grieve the loss of her mother Gloria's identity:

...but I do feel like I've had to grieve a portion of my mom now that I can - I'm trying to articulate it. She's just - I mean she's not the same mom that we had before just because of the memory issues and she might not even remember what I was talking about, you know, so a little bit. A small portion, you know, some of us feel like we've had to grieve that portion...

At the 3 month post-placement interview, two caregivers also noted that as the disease progressed, there was a loss of the personality and capabilities of their family member.

Six caregivers described how recreational activities and interaction with other residents and nursing home staff were an important part of maintaining identities, social practices, and bringing out personality. For some of the caregivers, it did not matter if their family member actually participated in the recreational activity, but just having the opportunity for socialization was important. Lily explained at the 3 month post-placement interview how her husband William's social personality and charm were useful for adjusting to the placement and in interacting with staff, even at times when his disruptive behavior was difficult to manage:

...Because what helped William tremendously, and I know it made it easier for the staff was he is a very, was always a very social person and he really enjoyed people and he – I said at one point he was really a flirt and he could really, when he wanted to he could really use that charm, which he did. He was well-liked on the unit. There was no question about that. So that was a good thing, and that worked in his favor so that they, I'm sure that made people a little more tolerant...

However, one caregiver, Harold, felt at both the initial and 3 month post placement interview that even with the social opportunities offered by nursing home placement, his father Andrew was alone. Harold described during the initial interview how it was hard to visualize his father, who he described as in "good shape", as the same as the other residents at the facility. At the 3 month post-placement interview, he highlighted his father's aloneness and how this contrasted to his father's previously active life:

He's there alone. He's with all these other people but the bottom line to it is he's there alone and even though he can't get out on his own and he'd be in harm's way, he was an outdoorsman, he was a sailor. He still thinks about escaping all the time. He needs that. Otherwise I come in there and he's sitting at a table with a bunch of people and they're all vegetables to a degree...

Interestingly, the two caregivers from other types of familial dyads (e.g., non-spouse, not adult-children) discussed how it was vulnerabilities and dependence issues that led to the need for them to take over management of care and placement. In both of these families, the family member was unmarried and had a history of being unconcerned with daily management of care. Both caregivers felt this lack of concern was a large vulnerability and that they needed to take over caregiving responsibilities. These concerns persisted at the 3 month post-placement interview as well. Emily discussed at the initial interview how her brother-in-law Max's lack of initiative required her to manage his care needs:

Max is not trying to - he's not worrying about one problem at all. As soon as somebody else is taking care of everything, he's not worrying about anything. He wasn't worrying about how he's going to manage at home, you know. He just took it for granted. So I was the only one that could worry about anything or consider what problems there were that had to be taken care of.

Overall, the view of the identity of the older family member had an impact on management of care and placement. There were similar views of personality, vulnerabilities, and dependency that permeate across caregivers and persistence of these views over time that influence definition of the situation surrounding care and nursing home placement and the approach to management.

b. View of Older Family Member's Health

The view of the older family member's health referred to how the primary family caregiver viewed the seriousness and predictability (or lack of predictability) of cognitive, mental, and physical health conditions; how health impacted and influenced the management of care, nursing home placement, and adjustment. Seven caregivers noted that serious impairment in cognition had the strongest influence on their ability to manage care and often necessitated nursing home placement. Cognitive impairment had an impact on physical health and inability to independently carry out daily care, often contributing directly to falls and injury. For these caregivers, worsening cognitive status

continued to be an issue at the 3 month post-placement interview. It made care unpredictable and difficult to manage. Jared described at the 3 month post-placement interview how his father Robert's worsening dementia had a significant impact on his father's physical health and care:

Well, he had a fall about three and a half weeks ago, fell and bruised a rib and broke his collarbone. That has impacted his ability to be somewhat more independent because he's now wheelchair-bound. He can't hold on to the walker with both hands, so that's been a change... He's, you know, he's feeling okay, you know, but that has made life a little more difficult for him. I mean his issue is primarily not physical. His issue is mental. He's confused most of the time and the dementia continues to advance but physically he's not significantly impacted by that.

At the 3 month post-placement interview, several caregivers noted that the worsening of conditions over time significantly impacted safety, further illuminating the need for care in a nursing home. Harold explained that his father Andrew's worsening dementia necessitated the need for ongoing management in the nursing home:

I would be concerned about safety anywhere, but they said yesterday that they didn't know where he was, they lost him, and he - but he's on the floor and the floor is secure. They lost him on the floor and then they found him in someone else's room on the floor kind of there. He had fallen and scraped himself. So my answer is, I'm concerned for his safety because it's life. I'm not concerned for his safety because of the facility and, you know, the only thing you can do at that point is lock him in a room every day and we're not going to do that. So the answer is, I'd be a heck of a lot more concerned if somehow we had him in independent living right now or, you know, assisted living care. He's on a supervised floor. I think it's, you know, obviously the right place to be.

Three caregivers conveyed how watching changes in cognition affecting their older family member's ability to independently carry out some aspects of care from the initial to the 3 month post-placement interview was particularly upsetting. Lily described observing her husband William's decline:

I mean, I could see the deterioration continuing in terms of, for example, when he got there he was able to shave independently. Within four weeks he wasn't able to do that anymore and in terms of communication – it's really, really hard for me to know – I think he always knew who I was...and this is, I grant you that this is definitely hindsight but the changes and the decline in abilities to do things independently kept declining.

Four caregivers discussed how the seriousness and/or unpredictability of health conditions influenced their perspectives on making future decisions beyond nursing home placement, such as end-of-life care options. Jared discussed the challenges and options regarding a Do Not Resuscitate Order (DNR), considering his father Robert's current health status and the unpredictability of the condition:

...because when he's here he's just really painfully lonely, when he's aware of where he is and when he's elsewhere sometimes he's happy where he is but often he's agitated that he's not where he wants to be or should be and so he seems to always be betwixt and between. So I don't know. And so when I'm been forming this question and talking to my sibs about the DNR, for whom would we not sign it? Would it be because we don't want him to pass or would it be because we think that he really isn't as confused as he is? So that's a harder conversation and we haven't worked our way through it yet but it's on the books right now.

Overall, the view of the older family member's health provided a perspective about how caregivers manage challenges (including seriousness and predictability) in health conditions. Multiple caregivers recognized the ongoing influence of cognition on physical health and the need for management of the condition in a nursing home. Three caregivers recognized that it was difficult to

watch their older family member deteriorate over time. The seriousness of such health conditions led four caregivers to think about future decisions regarding care management.

c. Management Mindset

Management Mindset reflected the ease or difficulty of caregiving and how this impacted their ability to manage care and placement. Post-placement, management mindset also incorporated the primary family caregivers' perceptions of the ease or difficulty of managing the care provided by the nursing home staff.

Six caregivers described during the initial interview how the unpredictability of the older family member's condition made management of care more difficult. Although the caregiver would try to set-up the situation to make caregiving easier, there were ongoing challenges that would make the situation unmanageable. Two caregivers even hired private duty personal aides, but the continuing deterioration of their family member's condition proved that the additional support was not always helpful. Amy tried to organize and troubleshoot solutions for her husband Marshall's care, but his declining cognition made care management too overwhelming:

Everything every day was a challenge. Every day I tried to do something that would make it easier. I mean I took all my dishes out of my breakfront and I bought little baskets and I put all his medicines in all the different things to try to organize it – the house so that it would be better. I got a gate there, you know, I bought the toilet seat, a non-spillable urinal thing, you know, with those things, and what does he do? He opens it and spills it all over the place. Like everything I did he just, like – there was nothing I could do to make it better... I made every attempt to make it better and it wasn't better.

Three spousal caregivers who lived with their older family member prior to placement indicated that the condition of their older family member deteriorated to point where they were unable to leave their family member home alone for safety reasons. Management of care became increasingly difficult, as

they were unable to maintain their own needs, such as grocery shopping or personal hobbies. Rose described how the unrelenting responsibilities of her husband David's care were very difficult and affecting their relationship:

He followed me everywhere. I had no alone time and that started to really bug me and I did not want to be resentful but there were times when I did become resentful. You know, for heaven sakes if I was upstairs, if I was in the bathroom too long, that he thought was too long, he'd be there knocking on the door and, you know, if I was okay and he always had to know where I was if he wasn't in the room with me and he always wanted to help but if he did help it would end up in a disaster and he tried. He wanted to be helpful but he couldn't.

At the 3 month post-placement interview, seven caregivers discussed how management of care had become significantly easier because the staff were effectively managing their older family member's condition. Many caregivers described how management was easier because they felt relieved knowing that their older family member was in a safe and structured environment, where they could get the appropriate care that they needed. Interestingly, four caregivers described incidents in which their older family member had fallen (two with some major injuries), but they still felt confident in the nursing home's ability to manage care. The caregivers noted that having direct contact with staff in the nursing home and being able to communicate concerns was an important consideration in making care management easier. Even if their family member's condition deteriorated, having openness with the staff was crucial in being able to manage care effectively and know that their family member's were well cared for. As Harold described about his father Andrew, even after a major fall, he felt that his care was well managed and effective because of his good relationship with the staff:

There's a woman who runs the whole facility. I have a direct line to her. I would send her emails, I've called her, and then once a month there's a status check-in on Dad. A 20-minute check-in. I received that call a week ago I think and talked to them and I talked to the spiritual

director, the activities director, the nurse, the head of the floor, and the head of the whole group and they're very good and I can ask anything and communicate to them about all of it. Yeah. My dad, when he had come through the injury from the fall, gotten all messed up, his skin looked horrendous on his face and they gave me some ointment that made it look like he, you know, his skin was going to fall off and it just looked terrible and I kind of, you know, didn't go the equivalent of wild but I certainly communicated like what is going on here? I've never seen him look worse in his entire life and then he healed and so the point being is I've got a group to call that I can raise things with.

However, at the 3 month post-placement interview, two caregivers communicated that the staff were not meeting their expectations for care, which made management increasingly more difficult for them. They felt that they had to continue to mount a large physical presence within the nursing home and that the staff was not providing care effectively. Amy discussed how she feels managing care of her husband Marshall was still difficult at the nursing home because of the inattentiveness of the staff. She illustrated how she thought her involvement and management of care seem to have not gotten any easier:

I almost feel like, you know, it's – I'm still caring for him. You know, I'm still caring for him and I'm getting aggravated. You know, I'm paying – as I said, I'm paying all this money and I have to be concerned about that he didn't shave. He wasn't bathing. He was falling and they didn't have his thing on him. My son found him on the floor one day and God knows how long he was there because they didn't have the thing on him, you know. I had the same thing here, you know, like concerns about certain things and taking care of it and here, I mean, I'm going and having concerns.

Management mindset included the caregivers' view of the ease or difficulty of caregiving and their ability to effectively manage care. The unpredictable nature of their family members' condition greatly impacted the caregivers' management mindset. Post-placement, management mindset also

incorporates the primary family caregivers' perceptions of how the staff provided care and whether it met their expectations. The nursing home staff's ability to carry out care to the standards of the caregiver had a large influence how they viewed the ease or difficulty of care.

d. Family Mutuality

Family mutuality referred to the extent to which family members had a shared or discrepant view about the approach to the management of care and placement. Family mutuality or lack of mutuality impacted the feelings of support felt by the primary family caregiver and whether they felt validated in their approach to care management.

Five caregivers discussed how the shared family views and support of the family caregiver made the decision to place and transition easier. Several caregivers described that being able to communicate their feelings with family members helped them accept the need for placement. As Harold shared about his sister helping him decide to place their father Andrew:

Yeah. You know, we all got to the point – my sister was – actually to my sister's credit from afar she was encouraging it because she thought it was the right thing to do and she could kind of hear the pieces and, you know, let me flip the other side is she talks to my dad almost every day...Okay. So she calls him all the time. She has trouble seeing him but she calls him and talks to him all the time and from afar she thought he should be moved and it was time. So I mean she encouraged it...

Multiple caregivers illustrated during the initial interview that family support was not just helpful on the emotional stress of dealing with nursing home placement, but in also managing the physical tasks of care and the move into the nursing home. Bonnie noted that her sister and cousin managed care of their uncle Gary together and that they supported each other in finding the most appropriate facility for him after his fall. They chose the nursing home that was most convenient to allow them to continue to share care management responsibilities and visits:

...there, okay, because he had to have the surgery, and like I said my cousin and I had looked and because they have power of attorney, she and her husband, they decided Nursing Home-X would be the best because they are in City-A, so by car they're five minutes. I can walk to Nursing Home-X in 15 minutes or less, so that's what they wanted, not Nursing Home-Y although we felt both were equal. So we looked at the fall as our saving grace, okay, that now we got the upper hand you might say... Yes. Right. We agreed on that. There was... Really there's never any confrontation between us. It's just not who we are.

At the 3 month post-placement interview, the continued family support was extremely helpful for the caregiver to be able to adjust to the placement and make other crucial decisions. Lily noted that her son provided her helpful guidance when deciding whether or not to hospitalize her husband William after a major stroke:

...so I called my oldest son who - they all have good heads on their shoulders but (son) has a - he's a really logical thinker and so I - and he is the oldest so at any rate I called (son) and we talked - I mean, I don't think we talked five minutes but it was enough and he was able to remind me of, you know, why I had made the decision in the first place, etcetera, etcetera, and so I was - I called them back and said we decided not to send William to the hospital and the doctor came on Saturday and spent a lot of time with us and was - I was a little uncomfortable but I know where he was coming from...

Harold noted at the 3 month post-placement interview that his relationship with his sister grew even closer after their father Andrew was transferred to the nursing home. He felt they were able to discuss shared caregiving experiences for their mother and father and had a more open relationship:

Totally. Totally. And I actually think, you know, we've gone through many phases in our life, not all easy between me and my sister. I think now, you know, I think this is bringing us closer together again. I think as we go through this whole process this will tighten us up all over again

and bring us closer together which it should. But yeah, I can totally relate to what she went through and she can totally relate to what I'm going through... Absolutely. Mm-hm. We have a very open relationship. We talk about all of it. Absolutely. Yeah.

Four caregivers discussed how other family members were not involved in care management and placement. The caregivers noted that lack of family assistance did not impact their own responsibility and obligations to provide care. All of these caregivers described how care management and all decisions ultimately fell on them. Jared reviewed how his brother had difficulty in accepting their father Robert's need to transition from assisted living to a nursing home. However, Jared noted that he was the only one who was actively involved and really had an appreciation for the level of care their father needed, so it was his responsibility to make the decision:

...I think so. I'm not sure. But, you know, it's hard – they didn't see him and I mean that however you want to define the verb, see. I don't mean just personally see but to have a real sense of where he was at and in which direction he was moving. If you weren't really involved, if you only called a few times a month, it's very hard to acknowledge that that's where a parent or a loved one is, so... At that point I think I basically said I think this needs to happen. He did call his social worker to confirm that she actually agreed with what I was saying, but then no one chose to come out to any of the meetings at which the decision was finally made, so -...

Two caregivers described that other family members did not understand the difficulties associated with managing the care and placement. The caregiver, at the least, wanted other family members to acknowledge the responsibilities of providing ongoing care. Emily discussed how her children did not appreciate all of the care management she provided to her brother-in-law Max:

So, anyway, and then I'm thinking, well, I don't think anyone really under -- the only people that had any clue about all this stuff I'm going through were some of my friends because I don't know if my children really knew how stressful this was. That was another thing. I really wanted

somebody to say, 'You're doing a good job', you know, and stuff and I wasn't getting the feedback that I wanted, you know.

At the 3 month post-placement interview, several of the caregivers discussed how they had adjusted to the lack of other family member involvement. Regardless if other family members were involved, they had continued obligations to care for their older family member. Jessica illustrated how she thought that her siblings would visit more after their mother Gloria's recent admission to the nursing home, but that she has grown accustomed to their lack of involvement and would not let her affect her responsibility in care management:

...I mean I thought it would be that way but because it hasn't been I just have to - you know, I just accept it and do it. You know, I'm okay with it. I mean, sure I wish they would but if they're not, I'm not going to drop the ball, so -...

Some of the caregivers even noted at the 3 month post-placement that they did not want their family members to get more involved. Amy described how she did not need her sons to become more involved in her husband Marshall's care, especially because she would have to then consider their perspectives on management:

...I don't think - well, because they were never that involved. What do they know? They're not dealing with any issues. They go visit, an hour. Boom, they're home. Maybe they'll feel bad but they're not, you know, taking any ownership. You know what I mean? ... Because what could they do? Then I'll have to deal with another person, you know? You know what I mean? Then they may have an opinion.

Family mutuality encompassed the shared or discrepant views that family members had towards their approach to care and management. These shared or discrepant views provided (or not) emotional and physical support toward the primary caregiver. While some families were very supportive towards the caregiver and continue to do so at 3 month post-placement, others choose to remain less involved.

Regardless of the involvement and support (or lack of), the caregivers reported that they are ultimately responsible for the care management and placement. Family support assisted in feeling validated by their decision, but the responsibility belonged to the caregiver.

2. Management of Care and Placement

a. Primary Family Caregiver Philosophy

Primary family caregiver philosophy encompassed the goals, priorities, and values that guided the caregivers' approach to management of care, placement, and adjustment. Their priorities influenced their approach to being a caregiver and decisions related to placement and care management. These priorities also impacted their ongoing involvement in care post-placement.

At the initial interview, the caregivers in the two son-father caregiving dyads and the two other familial dyads (e.g. non-spousal, not adult-children) discussed how they viewed their responsibility for care management as a family obligation. The priority for how they approach care was guided by their sense of respect and familial responsibility for their family member. Two caregivers described how their older family member had been an important part of the family and had previously provided for them, so it was now their job to ensure they received good care. In her description of her relationship and obligation to care for her uncle Gary, Bonnie noted the closeness of their family and Gary's role as a patriarch. Bonnie said that she, her sister, and cousin, had to provide his care because of familial obligation, "So we just did it because it needed to be done and he has been very good to our mothers, you know, and he's always been a good uncle."

This sense of family obligation also guided the caregivers' continued involvement in care management after the nursing home placement. Several of the caregivers noted the importance to visit and remain involved because they had the family obligation, but also because it provided meaningful time and interactions with the older family member. At the 3 month post-placement interview, Harold

illustrated why he felt an obligation to visit his father Andrew, but also why the experiences were so important:

I think it's an obligation for sure. My dad was always there for me through thick and thin my entire life. I mean completely. So I owe it to him. The other part of it is that, you know, it brightens up his whole day... it is an obligation but not in the – if there's multiple definitions to obligation, it's a loving obligation, not a painful obligation. And as I've said to my wife many times, I'll go there, have all kinds of shit going on at work or whatever else and then I get there, it's totally gone. That totally puts it all in perspective right there on the spot. It's a good thing. I never leave there not feeling better than before I went in the door.

The caregivers in the five wife-husband dyads did not discuss family responsibility as the priority for their philosophy towards care management. Rather, caregiving was just a natural progression in the course of their partnership and not considered to be an obligation. Two specifically mentioned that they loved their husbands very much, and this mutual love guided their approach to care and placement. Each of the wife caregivers kept their husbands at home with them for as long as possible. The main priority for the wife caregivers was to maintain and manage their husbands' care at home. As Lily illustrated about why she brought William home after two weeks of respite care:

Well, I really wanted – because I love him very much I really wanted to keep him home as long as I possibly could. It's just that we reached a point where it was no longer safe either for him or for me.

Several of the wife caregivers noted that their husbands' comfort in the home setting was their priority and they re-arranged their own lives to do so. Their husbands' needs were of the most importance, even if they were overwhelmed. Amy described how she prioritized Marshall's, even over having to manage her own needs:

Yeah, because – you had doctors, you had appointments, you had the medicines. I mean, you know, I did food shopping. You know, I had to take care of the money, pay the bills. You know, that was the peripheral part of what I was doing. You know what I mean? And then my husband had special – I mean all he wanted is bacon and eggs and whatever. I mean I got – so I had to get kinds of foods that he would eat just to make – you want to eat that, fine. You know what I mean? Just, whatever his life is – that makes you happy, fine. You know.

At the 3 month post-placement interview, the five wife caregivers continued to prioritize their husbands' needs. All of them noted that they visited nearly daily and checked with staff frequently to ensure their husbands had everything they needed. The daily visits were an important part of care management and adjustment. Lily described about her needing to visit her husband William daily was a part of her caregiving responsibilities:

Yeah, yeah, so at any rate, so I no longer had the - my responsibility as I saw it was to be there for William as much as I could and I really made a bargain with myself that as long as he was there I was going to go every day even though some advised me against it. So I was there every day.

Overall, all of the caregivers discussed that their main priority for care management and placement was ensuring that their older family member was well cared for. The focus of care management was to prioritize their older family members' needs. For wife caregivers, this meant placing their older family members' needs above their own. Whether through a sense of familial obligation or through a loving spousal partnership, the caregivers understood that it was their duty to manage the care and placement and they met the challenges of such responsibility with careful attention and respect.

b. Approach to Management and Placement

Approach to management and placement encompassed the primary family caregivers' view of how they were able to incorporate care management into a daily routine and how being a caregiver

impacts daily live. Approach to management and placement also included how routine, daily life, and other circumstances influenced the nursing home placement. Lastly, approach to management and placement involved the caregiver's approach to ongoing involvement in care post-placement.

For the non-spousal caregivers, the decision for nursing home placement was not necessarily due to an inability to manage care effectively and establish a daily routine for care. In three families, the older family member had a critical incident involving a hospitalization that led to nursing home placement. In two other families, the older family member's worsening cognitive decline facilitated a move to the safer care environment of the nursing home. In all five of the families, the situation that led to the nursing home placement did not drastically change the daily routine of the caregiver. At the 3 month post-placement interview, they continued to remain involved in their older family members' care and develop a routine for visiting and ensuring basic needs are met. The routine of caregiving post-placement was similar to the routine of caregiving prior to placement. As Bonnie noted about the visitation schedule for her uncle Gary at the nursing home that she had in place with her sister and cousin:

She and I sort of pick Thursday or Friday depending on what we have to do, okay, and if she has something to do I'll go on Thursday. My sister usually goes on Sunday because she works ... She really can't get over here during the week. It's just sort of falling into place. You know, if one of us has something to do we ask the other one ...

During the initial interviews, the five wife caregivers discussed that their daily routine revolved around their husbands' care needs. Several mentioned that the majority of every day was spent managing the care tasks for their husband. All aspects of life, including non-direct caregiving activities, had to include their husband (e.g., laundry, grocery shopping, etc.). Three wife caregivers said that they were unable to leave their husbands at home alone because of their need for ongoing supervision and concerns for safety. Many of the wife caregivers described that this daily routine of care was

overwhelming and often times unmanageable and unsafe for both the caregiver and older family member. Lily illustrated how her husband William's relentless daily needs had become an increasingly difficult routine:

From a standpoint of being able to handle him. He's a lot bigger than I am and the fact that I wasn't getting uninterrupted sleep at night. I guess those would be - the sleep interference and it was - it's an exhausting routine. There's no question about that.

Lily's situation of struggling to maintain the difficult daily routine was similar across the wife caregivers. Four of the five spousal caregivers noted that the inability to keep up with the routines and demands of care was a large factor in the decision to place their husbands into a nursing home. Rose explained that her decision to place her husband David was influenced by her inability to maintain his routine at home. This situation was seen across the wife caregivers. As Rose described:

Well, I took care of him at home as long as I could and the children kept saying that they were worried about me and my doctors kept saying I should make, you know, other arrangements because it was just too difficult and finally I realized I could no longer take care of him and I started making tentative arrangements...

At the 3 month post-placement interview, several of the spousal caregivers recognized how their daily routine still revolved around being able to visit their husbands, but some of the stress of caregiving was alleviated because their husbands were now in the nursing home. The daily routine involved visiting and reconnecting, instead of focusing on the direct tasks of care management. Rose discussed how her daily routine has changed since the placement of her husband David and she had more balance in her routine of caregiving and other tasks:

Otherwise, how do I feel? I'm happy that I can go see him as often as I can and that he is very, very appreciative and very happy when I'm there and I dread saying, "Well I have to go now." One time he said, "Well, you come but then you have to go." And I said, "Yes." And he said,

“What are you going to do?” And I will tell him I have laundry, I have to go to the store, etc. and he seems to accept that all right.

However, one spousal caregiver described that she felt more stressed since the placement because she was unable to establish a routine with the nursing home staff. Amy felt that the nursing home was not providing adequate care to her husband Marshall, so her daily routine continued to revolve around ensuring her husband’s needs were met:

Well, I wasn’t doing that much because I had a caregiver and now I have to travel to go to see him and then get aggravated and make phone calls. I don’t know. I still don’t feel like I’m out of it in any way. I really don’t. Up to this point, no. Until things maybe change and they get their act together, yeah. I don’t know. Right now, no.

For the five non-spousal caregivers, providing care management was an important aspect of life, but not all encompassing. None of the non-spousal caregivers had lived with their older family members prior to nursing home placement. Each caregiver described the routine for which they would visit and manage care, sometimes sharing the responsibility with other family members. The routine was manageable and did not necessarily impact other aspects of their life. They discussed how care involved making sure their older family members’ basic needs are met and spending time together. Bonnie illustrated how she rotated weekly visits to her uncle Gary with her sister and cousin and the routine she had set-up when it was her week:

When my husband and I would go over there, I would set up the meds, then change the bed, gather the towels, the sheets, and check any clothes hanging around that needed to be washed, cleaned the bathroom and the kitchen. Okay? Basically those were the two main areas and that was it and then we would go to lunch at Baker's Square, which... He hated eating alone, you know, and he was shopping for himself and he would make himself dinner.

Overall, the caregiver's ability to incorporate care into a daily routine was an important aspect of being able to effectively manage caregiving and the situation surrounding placement. There were differences in the development of a routine in spousal and non-spousal caregivers. For the spousal caregivers, care management was incorporated in *all* aspects of daily life, while the non-spousal caregivers did not consider care management to encompassing all parts of their life. Establishment of a new routine post-placement was an important part of remaining involved in the older family member's life, for both spousal and non-spousal caregivers.

3. Perceived Consequences of Care Placement

a. Primary Family Caregiver Focus

Primary family caregiver focus described how the caregiver was able to establish a balance between caregiving and other aspects of family life, including their relationship with the older family member. Being able to establish a balance between being a caregiver and other aspects of family life influenced the management of care, placement, and adjustment.

During the initial interview, four caregivers noted that there was a shift in their familial relationship as their older family member had a worsening decline in their cognitive or physical health. They recognized that the nature of the relationship changed into a caregiver-care recipient relationship. One caregiver noted that their relationship had become significantly one sided as their older family member's health continued to decline. For Lily, one of her goals with nursing home placement was to be able to move from identifying herself as her husband William's caregiver back to being his wife. She recognized during this move the magnitude of the transitions they had undergone during the course of their relationship:

Well, really I mean relating to him as a wife as I said earlier rather than as a caregiver. In a lot of ways having William at [Nursing Home] is – the separation is – I think what I'm trying to say is I recognize the fact that I'm probably going through a grieving process at this point because our

life has changed so dramatically and certainly it's not as final as death but it represents a different kind of finality in terms of our relationship, so...

For four wife caregivers, there was a discussion of the difficulty in adjusting to a change in their spousal partnership and aspects of home life without their husbands. Their husbands were such an integral part of family decision-making and daily life that it was difficult to adjust and find a balance without them. June discussed how some aspects of life were easier, but it was difficult to adjust to the change in her partnership and living apart from her husband Peter:

Well, you're used to living under the same roof with someone for, oh, 55 years or so. It's strange at home but it was easier in some ways... I mean it's - it was easier on me in some ways but also very different from - you just change your whole routine and so you, you know, are kind of you're there but you're not there every minute...

During the 3 month post-placement interview, Amy noted the challenges of having to make family and life decisions without her husband, Marshall. Even though she and her husband were independent people, she noted the struggle of living alone. Finding a balance between handling home issues and managing Marshall's care in the nursing home was difficult to accomplish:

So, you know, there's just a lot of different adjustments and issues that I'm capable of doing but I wasn't prepared to do. You know what I mean? All at once. It was just a lot of issues all at once and maybe I shouldn't have gotten the expensive, the air conditioner but I needed it. You know, Marshall and I had talked about it but he would never do anything. If I didn't do it he didn't do it. So I figured I'm doing it, you know, kind of thing. But then everything else falls in, you know, all the other responsibilities and then I was saying to myself, Oh, my husband would never do this for me and here I am – because I'm that kind of person. He's a human being and he has to be taken care of properly. You know what I mean?

The balance between caregiving and other aspects of daily life, such as transitioning from a caregiving relationship to relating to each other as family members was noted to be especially

challenging. The nursing home placement did ease some of the burden of the direct hands on tasks so that the focus can return to the familial relationship. However, with some types of relationships, such as spousal, it was difficult to find a balance and manage aspects of daily life independently without their spouse.

b. Future Expectations

Future expectations was defined as an assessment of expectations of the primary family caregiver for their continued role as a caregiver for their older family member and their view of the trajectory of functioning and adjustment for their older family member post-placement. At the end of both the initial and 3 month post-placement interviews, the caregivers were asked about their expectations for their older family member and their expectations for their own continued role in caregiving.

The majority of the caregivers discussed at both the initial and 3 month post-placement interview the importance of continuing to visit their older family member on a regular basis. Many of the caregivers described the purpose of visits and phone calls about being able to communicate with staff about ongoing care needs and planning activities they knew their older family member would enjoy. It was important for both the staff and older family member to understand that the caregiver continue to remain involved and was there to provide support. As Emily illustrated during the initial interview about the importance of visiting her brother-in-law Max:

...but I'll plan on visiting him to the extent that, you know, that the staff knows that he has family that's interested in him and so that things go well for him. I'm probably, you know - even if he didn't have a need for me to visit him to sign papers or whatever I probably still would plug it into my calendar to come and visit and probably bring my husband twice a month.

Two caregivers noted that regular visits were crucial for maintaining the health and well-being of their older family member. The caregivers commented that they felt their older family member would

mentally and physically deteriorate without frequent visits. Rose discussed during the 3 month post-placement interview about the significance of her visits with her husband David:

...there are stages and things that I've read and now he's talkative and he's aware of what's going on even when he has company in the room. His eyes may be closed but he hears every word. He's aware and there will probably come a time when he's not or won't respond in a way that I know that he understands and I know... I told one of the boys, I don't know but I think if I never went I think he would deteriorate completely. I think he lives for my visits.

During discussions about the trajectory of the functioning of their older family member, five caregivers described that they felt the next step would be deterioration in functioning and death. They expressed their understanding about the inevitability of their older family members' eventual death, but wanting to focus on ensuring that they were as comfortable as possible now. As Harold illustrated about the trajectory of his father Andrew's functioning and his own continued role in his father's life:

Well, what I've seen with the disease so far is it's not linear, so it isn't likely to just go along slowly like this. Something will happen. Maybe not a catastrophic event but it will be a trigger and all of a sudden we'll see a falloff in some way. I think it's for us to just be there. I think right now it's to set him up in the right place, which we're at where he can be taken care of in full. Make the effort to bring him out, be with him, connect with him, have other people see him which we did recently and had him over and a bunch of friends came and I think it's just to make this as comfortable for him as humanly possible through this journey. That will be it.

Across all caregivers, there was an understanding about the future expectations for their continued role with their older family member and an assessment of the trajectory of their health and functioning. Most caregivers continued to remain involved through regular visits and phone calls. These visits and phone calls were important to ensure that both the nursing home staff and older family member understand that the caregiver is available to provide support. There was also recognition by

caregivers during discussions about the nursing home placement about the next possible steps in the trajectory of functioning of their older family member, including death. Through this discussion, the caregivers noted the importance of maintaining comfort as their older family member progresses toward this eventuality.

E. Additional Analysis: Advice to Future Caregivers and Health Care Providers

During both the initial and 3 month post-placement interviews, primary family caregivers were asked if they had advice for caregivers or health care providers about nursing home placement. Caregivers shared their insights, recommendations, and suggestions for how caregivers could navigate the transition and adjustment into a nursing home and how health care providers could provide crucial assistance.

Four caregivers discussed how the nursing home placement journey was highly individual and personal. Several suggested that there are things in the transition that no one else can know beforehand and that the situation may be unpredictable. Caregivers noted that discussing the journey with others was helpful. Health care providers can provide support to the caregiver and validate their decision to place.

Three caregivers observed that having discussions with their older family member about their health and long-term care planning was important, especially while their older family member was still able to participate in these conversations. Although difficult, the caregivers noted that it was crucial to acknowledge the overall direction where the older family member was headed, such as their deteriorating functional status. The goal of these dialogues should be to do what was best for the older family member. While past relationship issues may make these conversations challenging, the caregivers noted that these issues needed to be put aside and the focus should be on the needs of the older family member.

Caregivers described characteristics they looked for when selecting a nursing home and feeling comfortable with the care. Some of the suggestions included looking at the staff ratio and the

interactions between staff and residents. Being able to establish a rapport with staff and having a staff member (such as nursing staff or social work) whom they could bring up issues was critical to ensuring satisfaction of the older family member. Cleanliness of the nursing home was an issue acknowledged by many caregivers. When selecting a nursing home, caregivers often brought along another family member to help them make the decision. Having an ally to ask questions and support the caregiver was useful. Lastly, multiple caregivers noted the importance of being available as an advocate for the older family member. Caregivers said they wanted staff to know that the older family member had a supportive family and felt this would ensure the older family member would receive quality care.

Caregivers had recommendations for how health care providers can ease the transition into the nursing home. Many caregivers commented about how open communication with staff was crucial. Staff needed to maintain details about the older family member's condition and keep caregivers informed, especially so that they are prepared during those initial months of the transition. Additionally, providing the caregiver with information on the overall big picture about the journey and triggers to look for that could signal a decline or a need to transition to a higher level of care would be very helpful.

F. Summary of Family Management Style Framework (FMSF) Comparisons Across Dyads and Over Time

Overall, primary family caregivers had more similarities than differences across definitions, management, and perceived consequences of care, especially those caregivers who had similar types of familial relationships (e.g. spousal caregivers, adult-children caregivers). All caregivers identified themselves as the primary family caregiver and noted that decisions regarding care were ultimately up to them. Remaining involved and ensuring that nursing home staff and the older family member recognize that caregivers continue to be available to provide ongoing support was crucial for the caregivers to feel confident that care needs will be met. As time progressed, caregivers acknowledged the importance of establishing a balance between a caregiver relationship to a more familial relationship.

There was a noted difference between spousal and non-spousal caregivers, including the living situation prior to placement, the events that precipitated the nursing home placement, and the adjustment post-placement. For all of the non-spousal caregivers in this study, the older family member lived in another location (such as their own private residence or an assisted living) and the caregiver took on the role as the primary family caregiver out of a sense of familial responsibility. In contrast, spousal caregivers (in this study, these were all wife caregivers), all lived with the older family member and took on caregiving responsibilities as part of their daily routine as their family member deteriorated in status. While caregiving was an important part of their routine for the non-spousal caregivers, caregiving was all encompassing of the routine for spousal caregivers. All five spousal caregivers noted that their inability to manage the constant demands contributed to the need for placement. While both non-spousal and spousal caregivers acknowledged the importance of visiting post-placement, several of the spousal caregivers recognized that their daily routine still revolved around visits and ensuring their husband's needs were met.

V. DISCUSSION

A. Comparison to Specific Aims and Previous Literature

My most important finding in this study was that the situation surrounding nursing home placement is complex and discursive. Families' trajectory towards nursing home placement was not linear, but involved multiple interactions with the larger long-term care system. For a majority of the caregivers (especially spousal caregivers), it was not a single critical incident that led to nursing home placement, but a variety of caregiver characteristics and situational factors, such as worsening physical and cognitive decline, ongoing safety concerns, and maintaining a balance between caregiving and other aspects of life. Remaining involved in the management of care post-placement was important so caregivers felt that their older family member was supported. Additionally, over time, caregivers recognized that some of the benefits of nursing home placement was establishment of a balance between caregiving and other aspects of daily life and transitioning to relating to each other as family members. Through follow-up with the caregivers over time, it allowed for a larger picture of understanding the nursing home placement and appreciation of insights that are gained with perspective.

The two aims of the study discussed describing and comparing the experiences of primary family caregivers at initial and nursing home placement over time. Each family's unique background and perspective influences how they viewed the placement and adjusted to it over time. Although each family's situation was different, caregivers had more similarities than differences, especially those caregivers who had similar types of familial relationships (e.g., spousal and adult-children). Through the use of within- and across-case analysis, the rich context of each individual family was maintained while comparing similarities and differences across families over time. This led to a deeper understanding of the nursing home placement, the identification of ongoing needs, and recommendations for smoother transitions.

In previous literature, it was noted that there is usually a “crisis event,” precipitating nursing home placement (Buhr et al., 2006; Dellasega & Mastrian, 1995; Hagen, 2001; Ryan & Scullion, 2000). This crisis event often occurred after an unplanned medical event by the older adult with acute hospitalization or in a breakdown in the caregiver’s ability to manage the demands of care (Butcher et al., 2001; Ryan, 2002). In this study, four caregivers specifically described a health-related emergency of the older family member that required immediate hospitalization that then led to the need for rehabilitation and nursing home placement. However, for a majority of the caregivers, there was a multitude of issues that led to nursing home placement, including worsening physical and cognitive decline of the older family member, concerns about safety issues in the current home environment, or even persisting health issues of the caregiver resulting in their inability to maintain care. There sometimes was no single catalyst that directly led to the nursing home placement. Usually, the caregiver recognized that they would be unable to maintain care in the home environment and needed to find an appropriate nursing home facility that could provide care in a more structured environment. A majority of the caregivers in this study had previous interactions with the long-term care system, either personally with their older family member, or with other family members who had resided in long-term care. The current nursing home placement was often not their first experience with the complex long-term care system.

In Gaugler, Yu, et al.’s (2009) systematic review of factors that predict nursing home placement, it was noted that caregiver and care recipient characteristics were associated with likelihood to institutionalize (i.e., severity of cognitive impairment, worsening stressors, and feelings of being “trapped” in caregiving responsibilities). This suggested that the model for nursing home placement was much more multi-factorial. While much of the focus of nursing home placement has been on a linear model of a crisis event that places the older adult on structured care pathways involving acute hospitalization and skilled nursing facility (SNF) stays, this was not always reflective of the situation for

most families. In this study, most families had previous experience with long-term care and the current nursing home placement did not involve a single crisis event with hospitalization and sub-acute rehabilitation. Avenues for future research and policy should look at the complex nature of nursing home placement and examine how these factors interact. Such strategies could alter the reimbursement system for structured care pathways and nursing home placement and the resource allocation for a variety of long-term care options.

In this study, as similarly reported by Meuser and Marwit (2001) in their model of caregiver grief, there are distinct differences between types of caregiving dyads, such as spousal and adult-child caregivers. Meuser and Marwit note that for spousal caregivers, as time progresses, there was recognition of the reality of the caregiving situation and burden, but a sense of accepted responsibility. There was a determination to provide the best care possible and not feel overwhelmed by the burden. Spouses acknowledged the loss of their companionship with their spouse and the development of a new type of relationship. After nursing home placement, spouses admitted that living without their partner was frightening and difficult. These results highlight some of the important concerns for spousal caregivers in this study. For the spousal caregivers, the daily routine revolved around their husbands' care needs, which persisted 3 months post-placement. This daily routine made it difficult to maintain a distinct spousal relationship aside from a caregiving relationship. Many of the spouses hoped that the nursing home placement would allow for a return to their companionship, but recognized that adjustment to life without their spouse was both physically and emotionally difficult.

For the adult-children caregivers, Meuser and Marwit (2001) findings echo much of the narrative found in this study. Early in the caregiving process, adult-children caregivers failed to recognize the declining health of their parent. Care was very task-oriented and intellectualized. Grief was not initially felt outright, but there was a sense of losing who their parent was. As time progressed, it was difficult to accept the future and significant decisions to be made, including nursing home placement. Once nursing

home placement did occur, there was a new philosophical perspective on the relationship and caregiving. The three adult-children caregivers in this study expressed many of these same sentiments. They discussed the need to grieve the loss of the identity of their parent due to the continual cognitive decline. All three discussed how siblings who were not actively involved in care often had a difficult time recognizing the severity of their parent's decline, which placed much of the responsibility on the primary caregiver. For the two son caregivers, care was easiest managed through being task-oriented and compartmentalizing the situation. Yet, as time progressed after nursing home placement, there was a more philosophical perspective on life, being an adult-child caregiver to a parent undergoing decline, and maintaining a relationship with their parent. The similarities between this study and Meuser and Marwit's study suggest that certain caregiving dyads have unique perspectives and needs. There needs to be recognition of the type of caregiving dyad within the nursing home in order for staff to adequately tailor family-centered programs and interventions.

Comparably illustrated by Fink and Picot (1995), multiple caregivers in this study stated that one of the benefits of nursing home placement was that there is a return back to relating to each other as family members. Visits were about the planning activities the older family member would enjoy and spending time together. The benefits from nursing home placement could be facilitated by staff in order to ease the negative emotions associated with placement and promote a smoother adjustment for the caregiver and older family member.

For all caregivers, as they accepted the need for placement and learned to adjust to the nursing home staff providing the hands on care, there was a realization of the need to let go of their role as a caregiver. As Dellasega and Mastrian (1995) described, caregivers struggled to let go of the idealized caregiver role and allow the nursing home to take on the caregiving responsibilities. Caregivers needed to feel confident in the nursing home staff's ability to carry out care and the ability to convey concerns with the staff (Garity, 2006; Paun & Farran, 2006). Multiple caregivers noted that they struggled to

watch the staff perform the care duties that they had once performed, especially if it was different than how they might have done the tasks. Relinquishing control of care to the nursing home can be very difficult. However, several family members commented that observing positive aspects of care provided by the nursing home staff made it easier to adjust. Caregivers who felt that the nursing home staff was meeting their expectations felt greater ease in the management of care, even if incidents such as falls or hospitalization had occurred. Observing good quality care has been identified as the basis for caregivers to feel validated for their decision to place, be able to remain involved through the development of a new type of role, and build relationships with the staff (Butcher et al., 2001; Kellett, 1999; Nolan & Dellasega, 1999).

Staff addressing the needs of caregivers through family-centered programs and interventions, has been the focus of recent research (Mass et al., 2001, Mass et al., 2004, Paun & Farran, 2006, Paun & Farran, 2011). Only one caregiver in this study noted initially that they had a formal support system by the nursing home in which a nurse was assigned to help them with the transition. However, there was no mention again of this nurse during the 3 month post-placement interview. No families discussed staff assisting with their knowledge, skills, or emotional needs, which has been identified as crucial to providing a successful transition for both the older family member and the caregiver (Paun & Farran, 2006). As the variety of long-term care options continues to expand, it would be beneficial for nursing homes to implement evidenced-based family centered care models and interventions to improve perceptions of their organization and elicit positive reviews from families.

B. Critique of Family Management Style Framework (FMSF)

While the FMSF has been previously adapted for use in adult populations, there are some limitations of the utilization of a framework originally developed for understanding family responses to caring for a child with a chronic condition (Beeber & Zimmerman, 2012; Bingham & Habermann, 2006; Wiegand, 2012; Wiegand, Knafl, & Deatrick, 2008). The familial obligations and societal expectations

of parents caring for children were significantly different than of a family member managing the care of an older adult (Beeber & Zimmerman, 2012). For example, multiple components and dimensions of the FMSF focus on the establishment of normalcy, with the expectation of children being able to contribute to management of the chronic condition and to overall family life (Knafl et al., 2012). As noted by Beeber and Zimmerman (2012), there was an understanding with children and parents that often the goal was for children to become independent in order to be able to successfully manage their condition. Additionally, the FMSF emphasizes the parent's need to be able to differentiate between the child's illness and their unique personality and identity.

In this study, the primary family caregivers did focus on maintaining normalcy, finding ways to preserve the older family member's identity, and incorporation of care into a daily routine. However, health conditions that precipitated the need for care management and nursing home placement of an older adult were progressively debilitating, and as such, the focus of maintaining normalcy became unmanageable. The goal of caregivers managing care for an older family member with a chronic and deteriorating condition may not be on independence, but on safety and planning care strategies to manage increasing dependence. Additionally, for caregivers of older adults, another objective is to preserve the identity of the older family member for as long as possible. As the illness progresses, caregivers grieve the loss of the identity of their older family member. The identification of differences between caregivers of older adults and parents of children with a chronic condition highlights the need for further development of the framework for use in a variety of populations and settings.

However, even with these challenges, there are benefits to using a family framework to understand care management and nursing home placement. While previous researchers focused on risk factors for nursing home placement and the process involved, the use of the FMSF in this study provided an appreciation of the context of family and the impact of placement on the family (Andel et al., 2007; Buhr et al., 2006; Gaugler, Yu, et al., 2009; Garity, 2006; Kellett, 1999; Rodgers, 1997; Ryan &

Scullion, 2000). The family context promotes a more comprehensive view of care management and the complexity involved in navigating the overall long-term care system.

When reviewing each of the conceptual components and related dimensions of the FMSF, it was noted that some parts were more readily adaptable and had a greater overall significance in understanding the primary family caregiver's definition, management, and perceived consequences of care and nursing home placement. The component of Definition of the Situation Surrounding Care and Placement had four related dimensions: Older Family Member's Identity, Older Family Member's Health, Management Mindset, and Family Mutuality. Older family member identity and health were important to understanding how the caregiver defines the situation surrounding care and assesses the needs, capabilities, and vulnerabilities of their older family member. However, it was difficult to establish a differentiation between identity and health, especially because debilitating illnesses (such as cognitive impairment) have such an impact on the caregivers' view of identity. Yet, the concept of how the caregiver maintained the older family member's identity, even as illness progresses, was a very interesting finding. An appreciation for the activities that the caregiver and nursing home staff perform to maintain and draw out identity could be the subject of further inquiry. Management Mindset was useful in determining the perceptions of the ability to carry out care, but this was difficult to clearly delineate from the dimension of Approach to Management and Care, reflecting the action of carrying out care and establishing a routine. The ease or difficulty of care management was highly related to the ability to maintain a routine. Lastly, while the dimension of Family Mutuality was useful in exploring the involvement and support of other family members in care management and placement; it was not a significant contributing factor to the nursing home placement. All the caregivers in this study noted that care management decisions and the nursing home placement was ultimately their responsibility.

The component of Management of Care and Placement includes the two related dimensions of Primary Family Caregiver Philosophy and Approach to Management and Placement. The dimension of

Primary Family Caregiver Philosophy was especially salient in understanding the priorities and values that determine the decision or obligation to become caregivers. Appreciating the rationale behind the decision reflects the attitudes towards being a caregiver and their motivation for continuing to manage care. These decisions were especially interesting in terms of understanding the reasoning for non-traditional types of family members to step into a caregiving role (e.g. son caregivers, other family relationships).

The component of Perceived Consequences of Placement includes the two related dimensions Primary Family Caregiver Focus and Future Expectations. In this study, the component of Primary Family Caregiver Focus was broadened to include an understanding of the balance between caregiving and maintaining a familial relationship with the older family member. While this component did not promote a better appreciation of the nursing home placement in itself, it was useful in highlighting the impact of caregiving and placement on family dynamics. It also illustrated an important differentiation between spousal and non-spousal caregivers. The wife caregivers in this study had a difficult time relating to their husbands in a familial relationship and adjusting to the daily aspects of home life without their husbands. Other types of caregiving dyads did not express these same challenges. The component of future expectations was valuable in being able to compare changes in perceptions of the placement over time to the placement and its impact on the caregiver.

C. Strengths of the Research

Although the sample size was small, there was variability in the types of caregiving dyads, which allowed for a rich backdrop and ability to make comparisons. Additionally, caregivers were followed over time, which allowed for recognition of how the challenges were dealt with as they continued to adjust. While some of the results were consistent with previous research, there were new insights that offered a better understanding about caregivers and nursing home placement and suggestions for future research and practice implications.

A major strength of this study was its strong theoretical underpinnings. According to Sandelowski (1993), whether explicit or implicit, the theory in qualitative research is always present and central to the way the research is conducted. Theory in qualitative research may function as a framework for organizing, interpreting, and re-presenting the data when conducting higher-level stages of analysis. The theory should “fit” the data and should not misrepresent the meaning of the data. This study was grounded in the FMSF and used to guide all phases, from the specific aims to the conclusions. The FMSF was readily adaptable for use in this family caregiving population. The use of the FMSF allowed me to meaningfully organize the data and conduct analysis at multiple levels to provide a high level presentation of the data.

The use of the FMSF in this study both strengthens the methodology of the framework and the study. The FMSF application to a diversity of contexts and caregiving populations aids in its continual development and recognition of the challenges faced by families managing chronic conditions (Knafl et al., 2012). Additionally, the use of theoretical underpinnings in all phases of qualitative research is crucial to the development and understanding of nursing-specific knowledge (Mitchell & Cody, 1993). According to Mitchell and Cody (1993), research questions, methodology, and interpretation are all viewed through a theoretical perspective. The best way to build the scientific knowledge base of the nursing discipline is through theory-laden research. This study adds to the current knowledge base about caregivers and nursing home placement through the theoretical lens of the FMSF. It also contributed to the further development of the FMSF in varied caregiving populations. Future larger research studies with multiple caregivers could continue to build the FMSF through depiction of family management styles related to nursing home placement.

D. Limitations of the Research

This was a small descriptive study to understand the experience of caregivers and nursing home placement over time. While there were a variety of caregiving dyads, the participants were not racially

and ethnically diverse. Attempts were made to contact administrators and nursing home staff of nursing homes with diverse resident populations, but the messages were not returned. Recruitment of participants in nursing homes was difficult. It was seen that facilitation through another researcher who previously worked with the nursing home staff was the best way to reach out and obtain a contact person within the facility who could assist with recruitment.

Recruitment was a slow and challenging process and the sample remained small, despite attempts to follow-up with staff. Nursing home staff was contacted on a semi-weekly basis, either over the phone or via email, to remind them about the study and provide guidance about recruitment strategies. Due to time delays in reaching out to potential participants, two initial interviews were conducted 45 to 60 days after initial placement. The other eight interviews were all conducted within 30 days of placement. While it was attempted to recruit only participants whom the nursing home staff anticipated had older family members who would remain at the facility 3 months post-placement, it was not always guaranteed that this would be the case. It was difficult to ensure that all participants remained in the nursing home until the 3 month post-placement interviews. Regardless of the location of the older family member at the 3 month post-placement interview, all 10 participants agreed to participate in both interviews and all data from the interviews were included in the analysis.

It was determined that four older family members were no longer residing at the nursing home during completion of the continued eligibility form: one had been discharged home, one had been discharged to assisted living facilities, and two were deceased. The time within the facility before discharge or death varied, from one month to 3 month. This limited amount of time within the facility could have impacted their perceptions of the nursing home. As such, during the 3 month post-placement interview, the interview was less structured and the caregiver was asked to comment as they could or felt necessary. These differences of caregivers' time with the facility may have altered the analysis as not all caregivers had the same experience with an older family member remaining in the nursing home.

However, each family's situation is unique and has an important contribution to an overall view of long-term care.

While elements had been built into the study to promote retention of the participants from the initial to 3 month post-placement interview, there was potential for loss of study participants. While no participants were lost to follow-up, it did require initial and 3 month post-placement interviews to be conducted later than planned. I sent out thank you cards in the mail approximately one week after the initial interview, which helped serve as a reminder for the 3 month post-placement interview. I called the participants 6 to 8 weeks after the initial interview to document continued eligibility and to schedule the 3 month post-placement interview. However, sometimes it was difficult to stay in contact the participants and I had to call multiple times and reschedule interviews. Some 3 month post-placement interviews were collected closer to four months.

A final limitation of the study was the challenges associated with memory recall of the participants of past events. Memory is not always reliable and consistent. During the interviews, I let the participants discuss the events they thought were relevant to the questions and to the nursing home placement. I had to trust the veracity of their statements. I felt that due to the strong emotional nature of the topic and my conducting multiple interviews, I was able to capture the true essence of the caregivers' perceptions about nursing home placement. While it may have been helpful to conduct an interview prior to the nursing home placement so that the events prior to placement were fresher, it would have been too difficult to identify potential participants who were contemplating nursing home placement and then ensure that they would have then actually placed their older family member.

E. Suggestions for Future Research and Policy Changes

Future research needs to be undertaken to understand nursing home placement from the perspective of specific types of caregiving dyads. As noted previously, there are distinct differences between different types of caregiving dyads (e.g., spouse, adult-child caregiver). While all the spousal

caregiving dyads in this study were wife-husband, it would be beneficial to expand to other types of partnership dyads, such as husband caregivers or same sex partners. Additionally, this study only had Caucasian, non-Hispanic caregivers. Although it can be difficult to recruit from diverse nursing homes, future research needs to specifically look at racially and ethnically diverse caregiving populations and their interactions with the long-term care system.

Another step in this research would be to utilize the recommendations offered by the caregivers in this study to tailor practice guidelines and family centered care within the nursing home. While there are some recent developments of family-centered programs and interventions to improve partnerships between families and staff in nursing homes, such as the Chronic Grief Management Intervention and the Family Involvement in Care partnership intervention, there continues to be the need for further tailoring of such interventions based on the needs specified by caregivers who have had multiple interactions with the complex long-term care system (Maas et al., 2001; Maas et al., 2004; Paun & Farran, 2011). Additionally, a major challenge of the implementation of family-centered programs and interventions are the lack of staff commitment to the program. In this study, there was no discussion by participants of structured family-centered programs and interventions. Yet, most caregivers recognized the need to strengthen the communication and relationship between families and nursing home staff. There is clearly a need to implement evidenced-based practice interventions within the nursing home to improve partnerships and family-centered care. Such programs could advance the perceptions of the nursing home industry as a whole and elevate the importance of family and resident outcomes, such as quality of life. The implementation of these programs may require changes to reimbursement policy that includes a way of measuring family and resident outcomes, including satisfaction, as well as incentives for nursing homes to improve staff and family relationships.

The long-term goal of my research is to provide healthcare providers, families, and older adults with information to make well-equipped decisions about long-term care and the development of tailored

interventions to ease their adjustment. As the nature of long-term care becomes increasingly complex with the variety of options for formal, institutionalized settings and the trend towards home and community based services, families have even more challenging decisions to make. Most families no longer solely operate in the structured care pathways involving skilled nursing facility stays and eventual nursing home placement. By the time families may decide on nursing home placement, they have likely had multiple interactions within the long-term care system. Long-term care policy needs to be updated to reflect these complex situations. Families need practical guidelines to review their options for long-term care and access to resources that can minimize time and costs. Nursing homes should not be viewed as a failure of families to care for their older family member in a less structured environment, but a part of the spectrum of options for long-term care.

F. Value of the Research to Nursing

During the final part of both interviews, participants were asked what it was like to participate in the interviews. Caregivers noted that they appreciated the opportunity to share their insights and reflect on their journey. Some said it was their first time thinking about this time all at once and putting all of that time together in one sitting. Oftentimes, it was their only time to think about their perspectives and story. Caregivers said that they hoped that sharing their experiences could potentially assist future caregivers.

Conducting this study with family caregivers undergoing a crucial point in the trajectory of caregiving (during the nursing home transition) is an important first step in addressing gaps within the long-term care system, including home and institutionalized care. Nurses are involved at multiple points within the nursing home placement and have a crucial role with assisting caregivers and older adults through the transition into a nursing home. Nurses also have a major role as advocates and can support the needs of the caregiver and older adults. Nurses can also educate other members of the interdisciplinary team about the unique situations faced by caregivers and older adults as they undergo

this transition. The influential role of nurses is crucial to the further development and implementation of family-centered programs and interventions that foster partnerships between nursing home staff and families.

There is an increased need for research about family caregivers of older adults because of the economic and social contributions of caregivers to the healthcare system and society. My study sets the foundation for my long-term research agenda focused on caregiving, development of programs for smooth transitions within the long-term care system, and overall guidelines for long-term care planning. Conducting this study with primary family caregivers is an important step in providing healthcare providers, primary family caregivers, and older adults with information to make clearer decisions regarding long-term care options and nursing home placement.

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APPENDICES

Appendix A

Table I

Disposition of older family member prior to nursing home placement and at 3 month post-placement interview

Family Dyad Number	Situation Prior to Nursing Home Placement	Entrance Method to Nursing Home	Situation at 3 month Post-Placement Interview
1	Living home alone	Acute hospitalization to sub-acute rehabilitation	Memory care unit in nursing home
2	Living with spouse with 24-hour live-in caregiver	Placed by caregiver	Long-term care unit in nursing home
3	Living with spouse in Independent living facility	Placed by caregiver	Deceased
4	Assisted living facility	Placed by caregiver	Memory care unit in nursing home
5	Assisted Living facility	Acute hospitalization to sub-acute rehabilitation	Assisted living facility
6	Living with spouse	Acute hospitalization to sub-acute rehabilitation	Living with spouse with 24-hour live-in caregiver
7	Living with spouse	Acute hospitalization to sub-acute rehabilitation	Long-term care unit in nursing home
8	Assisted living facility with 16-hour private duty caregivers	Placed by caregiver	Memory care unit in nursing home
9	Living with spouse	Placed by caregiver	Deceased
10	Living home alone with 16-hour daily caregivers	Placed by caregiver	Long-term care unit in nursing

Appendix B

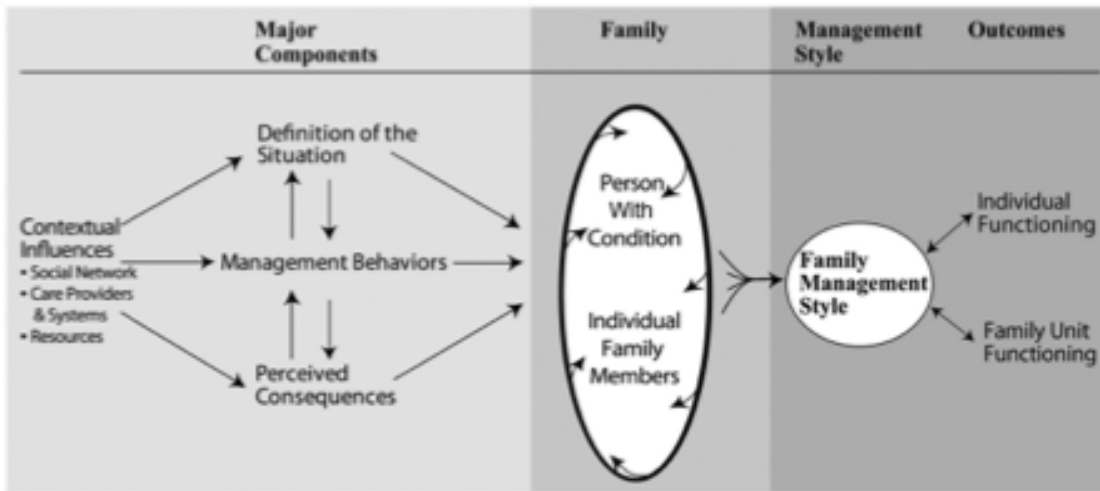


Figure I. Revised Family Management Style Framework. Reprinted from “Continued development of the family management style framework,” by K. A. Knafl, J. A. Deatrick, & N. L. Havill, 2012, *Journal of Family Nursing*, 18, p. 15. Copyright 2012 by SAGE Publications. Reprinted with permission.

Appendix C

Primary Family Caregivers' view of:

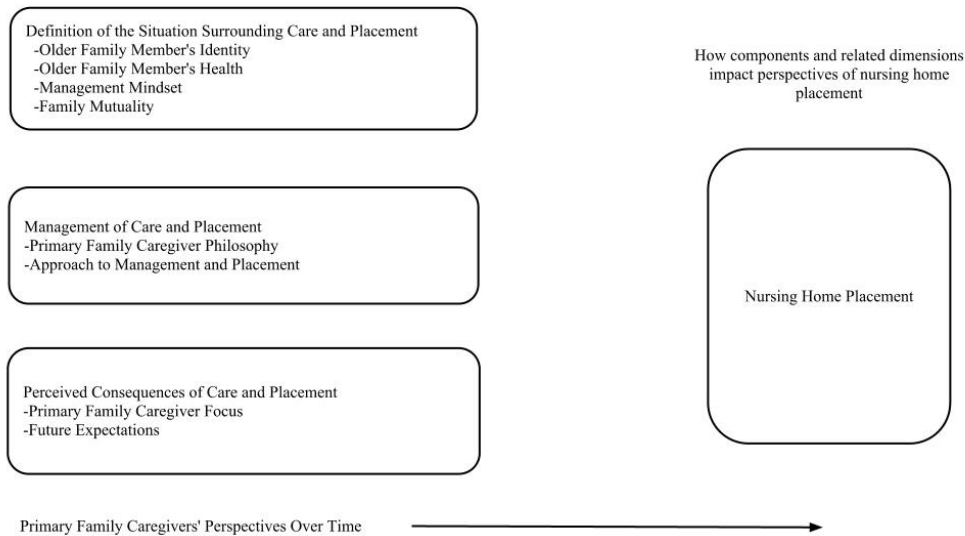


Figure II. Adaptation of FMSF for primary family caregivers and nursing home placement. Adapted from “Continued development of the family management style framework,” by K. A. Knafl, J. A. Deatrick, & N. L. Havill, 2012, *Journal of Family Nursing*, 18, p. 15. Copyright 2012 by SAGE Publications. Adapted with permission.

Appendix D

Permission to Reprint Revised Family Management Style Framework (FMSF) Figure



Appendix E

IRB Approval Letter

UNIVERSITY OF ILLINOIS AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice Initial Review (Response To Modifications)

December 13, 2011

Sarah Greco
Women, Child, & Family Health Science
845 S Damen Ave
M/C 802
Chicago, IL 60612
Phone: (312) 420-7816 / Fax: (312) 996-8871

RE: **Protocol # 2011-0904**
"Primary Family Caregivers Definition and Management of Nursing Home Placement"

Dear Ms. Greco:

Your Initial Review application (Response To Modifications) was reviewed and approved by the Expedited review process on December 12, 2011. You may now begin your research.

Please note the following information about your approved research protocol:

Please remember to submit the follow-up interview protocol prior to administering it to subjects. A copy of the follow-up interview protocol must be accompanied by an Amendment form when submitted to the UIC IRB.

<u>Protocol Approval Period:</u>	December 12, 2011 - December 10, 2012
<u>Approved Subject Enrollment #:</u>	50
<u>Additional Determinations for Research Involving Minors:</u>	These determinations have not been made for this study since it has not been approved for enrollment of minors.
<u>Performance Sites:</u>	UIC, Saint Matthew Center for Health - Park Ridge, IL, Bethany Terrace Health and Rehabilitation Center
<u>Sponsor:</u>	Chancellor's Education Award Funding 2011, Illinois Area for Health Education Centers Network Program Health Professions
<u>PAF#:</u>	Not applicable
<u>Grant/Contract No:</u>	Not applicable
<u>Grant/Contract Title:</u>	Not applicable
<u>Research Protocol:</u>	

- a) Primary Family Caregivers Definition and Management of Nursing Home Placement;
Version 2; 12/09/2011

Phone: 312-996-1711

<http://www.uic.edu/depts/ovcr/oprs/>

FAX: 312-413-2929

Appendix E (continued)

Page 2 of 3

Recruitment Materials:

- a) Letter from Nursing Home Study Site; Version 2; 12/09/2011
- b) Mail in Form; Version 2; 12/09/2011
- c) Permission to Share Contact Information; Version 2; 12/09/2011
- d) Continued Eligibility; Version 2; 12/09/2011
- e) Project Information Sheet; Version 1; 12/09/2011
- f) Nursing Home Staff Instructions; Version 1; 12/09/2011
- g) Initial Eligibility; Version 2; 12/09/2011
- h) Flyer (no footer)

Informed Consent:

- a) Informed Consent; Version 2; 12/09/2011
- b) A waiver of documentation of informed consent has been granted under 45 CFR 46.117 and an alteration of consent has been granted under 45 CFR 46.116(d) for recruitment/eligibility screening (minimal risk; subjects will be asked to provide verbal consent for screening; written consent will be obtained from subjects at enrollment)

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories:

- (6) Collection of data from voice, video, digital, or image recordings made for research purposes.,
- (7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
10/21/2011	Initial Review	Expedited	10/31/2011	Modifications Required
12/09/2011	Response To Modifications	Expedited	12/12/2011	Approved

Please remember to:

→ Use your **research protocol number** (2011-0904) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the enclosure,
"UIC Investigator Responsibilities, Protection of Human Research Subjects"

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

Appendix E (continued)

Page 3 of 3

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 996-2014. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Sandra K Costello

Sandra Costello

Assistant Director, IRB # 2

Office for the Protection of Research Subjects

Enclosures:

- 1. UIC Investigator Responsibilities, Protection of Human Research Subjects**
- 2. Data Security Enclosure**
- 3. Informed Consent Document:**
 - a) Informed Consent; Version 2; 12/09/2011
- 4. Recruiting Materials:**
 - a) Letter from Nursing Home Study Site; Version 2; 12/09/2011
 - b) Mail in Form; Version 2; 12/09/2011
 - c) Permission to Share Contact Information; Version 2; 12/09/2011
 - d) Continued Eligibility; Version 2; 12/09/2011
 - e) Project Information Sheet; Version 1; 12/09/2011
 - f) Nursing Home Staff Instructions; Version 1; 12/09/2011
 - g) Initial Eligibility; Version 2; 12/09/2011
 - h) Flyer (no footer)

cc: Rosemary C. White-Traut, Women, Child, & Family Health Science, M/C 802
Agatha M. Gallo (faculty advisor), Women, Child & Family Health Science, M/C 802

Appendix E (continued)

UNIVERSITY OF ILLINOIS AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice Amendment to Research Protocol and/or Consent Document – Expedited Review UIC Amendment # 1

April 23, 2012

Sarah Greco
Women, Child, & Family Health Science
845 S Damen Ave
M/C 802
Chicago, IL 60612
Phone: (312) 420-7816 / Fax: (312) 996-8871

RE: Protocol # 2011-0904
“Primary Family Caregivers Definition and Management of Nursing Home Placement”

Dear Ms. Greco:

Members of Institutional Review Board (IRB) #2 have reviewed this amendment to your research and/or consent form under expedited procedures for minor changes to previously approved research allowed by Federal regulations [45 CFR 46.110(b)(2)]. The amendment to your research was determined to be acceptable and may now be implemented.

Please note the following information about your approved amendment:

Amendment Approval Date: April 19, 2012

Amendment:

Summary: UIC Amendment #1 dated April 16, 2012 (Received by OPRS on April 16, 2012) is an investigator-initiated amendment to 1) submit the research protocol reflecting the two additional study sites and that the three month post placement interview guide has been developed (Protocol, version 3, 4/16/2012); 2) add Westminster Place of Presbyterian Home and Cantata Adult Life Services as study sites (Appendix K and letters of support submitted); 3) add funding that includes Midwest Nursing Research Society Dissertation Research Grant 2012, Sigma Theta Tau, Alpha Lambda Chapter Research Award 2012, and UIC College of Nursing Seth and Denise Rosen Research Award 2012 (Appendix Z and award letters submitted); 4) revise the consent to include the change of additional funding sources (Informed Consent, version 3, 4/16/2012); and 5) provide the Three Month Post Placement Interview Guide based upon information gleaned from the first set of interviews (Interview Guide, version 1, 4/16/2012 submitted).

Phone: 312-996-1711

<http://www.uic.edu/depts/ovcr/oprs/>

FAX: 312-413-2929

Appendix E (continued)

Page 2 of 3

Approved Subject Enrollment #: 50

Performance Sites: UIC, Saint Matthew Center for Health - Park Ridge, IL, Bethany Terrace Health and Rehabilitation Center, Westminster Place of Presbyterian Home, Cantata Adult Life Services

Sponsor: Chancellor's Education Award Funding 2011, Illinois Area for Health Education Centers Network Program Health Professions, Midwest Nursing Research Society Dissertation Research Grant, Alpha Lambda Chapter Research Award, UIC College of Nursing Seth and Denise Rosen Research Award, Sigma Theta Tau

PAF#: Not available, Not available, Not available, Not available, Not available, Not available

Grant/Contract No: Not available, Not available, Not available, Not available, Not available, Not available

Grant/Contract Title: Not available, Not available, Not available, Not available, Not available, Not available

Research Protocol(s):

a) Primary Family Caregivers Definition and Management of Nursing Home Placement; Version 3, 04/16/2012

Informed Consent(s):

a) Informed Consent, Version 3, 04/16/2012

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
04/16/2012	Amendment	Expedited	04/19/2012	Approved

Please be sure to:

→ Use only the IRB-approved and stamped consent document(s) and/or HIPAA Authorization form(s) enclosed with this letter when enrolling subjects.

→ Use your research protocol number (2011-0904) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the enclosure, "UIC Investigator Responsibilities, Protection of Human Research Subjects"

Please note that the UIC IRB #2 has the right to ask further questions, seek additional information, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

Appendix E (continued)

Page 3 of 3

We wish you the best as you conduct your research. If you have any questions or need further help, please contact the OPRS at (312) 996-1711 or me at (312) 413-1835. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,



Kathleen Loviscek, M.S.
IRB Coordinator, IRB # 2
Office for the Protection of Research Subjects

Enclosure(s):

1. **UIC Investigator Responsibilities, Protection of Human Research Subjects**
2. **Informed Consent Document(s):**
 - a) Informed Consent, Version 3, 04/16/2012

cc: Agatha M. Gallo (faculty sponsor), Women, Child, & Family Health Science, M/C 802
Rosemary C. White-Traut, Women, Child, & Family Health Science, M/C 802

Appendix E (continued)

UNIVERSITY OF ILLINOIS AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice Amendment to Research Protocol and/or Consent Document – Expedited Review UIC Amendment # 2

April 30, 2012

Sarah Greco
Women, Child, & Family Health Science
845 S Damen Ave
M/C 802
Chicago, IL 60612
Phone: (312) 420-7816 / Fax: (312) 996-8871

RE: **Protocol # 2011-0904**
“Primary Family Caregivers Definition and Management of Nursing Home Placement”

Dear Ms. Greco:

Members of Institutional Review Board (IRB) #2 have reviewed this amendment to your research and/or consent form under expedited procedures for minor changes to previously approved research allowed by Federal regulations [45 CFR 46.110(b)(2)]. The amendment to your research was determined to be acceptable and may now be implemented.

Please note the following information about your approved amendment:

Amendment Approval Date: April 27, 2012

Amendment:

Summary: UIC Amendment #2 dated April 25, 2012 (received by OPRS April 25, 2012) is an investigator-initiated amendment to add The Fountains of Crystal Lake as a research site (Appendix K, letter of support dated 04/24/2012, and revised Protocol, v4, 04/25/2012 included).

Approved Subject Enrollment #: 50

Performance Sites: UIC, Saint Matthew Center for Health - Park Ridge, IL, Bethany Terrace Health and Rehabilitation Center, Westminster Place of Presbyterian Home, Cantata Adult Life Services, The Fountains of Crystal Lake

Sponsor: Chancellor's Education Award Funding 2011, Illinois Area for Health Education Centers Network Program Health Professions, Midwest Nursing Research Society Dissertation Research Grant, Alpha Lambda Chapter Research Award, UIC College of Nursing Seth and Denise Rosen Research Award, Sigma Theta Tau

Phone: 312-996-1711

<http://www.uic.edu/depts/over/oprs/>

FAX: 312-413-2929

Appendix E (continued)

Page 2 of 2

PAF#: Not available, Not available, Not available, Not available
Grant/Contract No: Not available, Not available, Not available, Not available
Grant/Contract Title: Not available, Not available, Not available, Not available
Research Protocol(s):
 a) Primary Family Caregivers Definition and Management of Nursing Home Placement; Version 4; 04/25/2012

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
04/25/2012	Amendment	Expedited	04/27/2012	Approved

Please be sure to:

→ Use your research protocol number (2011-0904) on any documents or correspondence with the IRB concerning your research protocol.

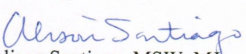
→ Review and comply with all requirements on the enclosure,
"UIC Investigator Responsibilities, Protection of Human Research Subjects"

Please note that the UIC IRB #2 has the right to ask further questions, seek additional information, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact the OPRS at (312) 996-1711 or me at (312) 355-0816. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,


 Alison Santiago, MSW, MJ
 IRB Coordinator, IRB # 2
 Office for the Protection of Research Subjects

Enclosure(s):

1. **UIC Investigator Responsibilities, Protection of Human Research Subjects**
2. **Data Security Enclosure**

cc: Agatha M. Gallo (Faculty Sponsor), Women, Child, & Family Health Science, M/C 802
 Rosemary C. White-Traut, Women, Child, & Family Health Science, M/C 802

Appendix E (continued)

UNIVERSITY OF ILLINOIS AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice Amendment to Research Protocol and/or Consent Document – Expedited Review UIC Amendment # 3

May 15, 2012

Sarah Greco
Women, Child, & Family Health Science
845 S Damen Ave
M/C 802
Chicago, IL 60612
Phone: (312) 420-7816 / Fax: (312) 996-8871

RE: Protocol # 2011-0904
“Primary Family Caregivers Definition and Management of Nursing Home Placement”

Dear Ms. Greco:

Members of Institutional Review Board (IRB) #2 have reviewed this amendment to your research and/or consent form under expedited procedures for minor changes to previously approved research allowed by Federal regulations [45 CFR 46.110(b)(2)]. The amendment to your research was determined to be acceptable and may now be implemented.

Please note the following information about your approved amendment:

Amendment Approval Date: May 14, 2012

Amendment:

Summary: UIC Amendment #3 dated May 8, 2012 (received 5/8/12) is an investigator-initiated amendment to submit the revised consent (Informed consent v4 5/8/12) reflecting the change of the number of sites from 2 to 5.

Approved Subject Enrollment #: 50

Performance Sites: UIC, Saint Matthew Center for Health - Park Ridge, IL, Bethany Terrace Health and Rehabilitation Center, Westminster Place of Presbyterian Home, Cantata Adult Life Services, The Fountains of Crystal Lake

Sponsor: Chancellor's Education Award Funding 2011, Illinois Area for Health Education Centers Network Program Health Professions, Midwest Nursing Research Society Dissertation Research Grant, Alpha Lambda Chapter Research Award, UIC College of Nursing Seth and Denise Rosen Research Award, Sigma Theta Tau

PAF#: Not available, Not available, Not available, Not available

Phone: 312-996-1711

<http://www.uic.edu/depts/ovcr/oprs/>

FAX: 312-413-2929

Appendix E (continued)

Page 2 of 2

available, Not available, Not available

Grant/Contract No:

Not available, Not available, Not available, Not

available, Not available, Not available

Grant/Contract Title: Not available, Not available, Not available, Not available, Not available, Not available

Informed Consent(s):

a) Informed Consent; Version 4, 05/08/2012

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
05/08/2012	Amendment	Expedited	05/14/2012	Approved

Please be sure to:

→ Use only the IRB-approved and stamped consent document(s) and/or HIPAA Authorization form(s) enclosed with this letter when enrolling subjects.

→ Use your research protocol number (2011-0904) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the enclosure, "UIC Investigator Responsibilities, Protection of Human Research Subjects"

Please note that the UIC IRB #2 has the right to ask further questions, seek additional information, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact the OPRS at (312) 996-1711 or me at (312) 413-1835. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,



Kathleen Loviscek, M.S.
IRB Coordinator, IRB # 2

Office for the Protection of Research Subjects

Enclosure(s):

1. UIC Investigator Responsibilities, Protection of Human Research Subjects
2. Informed Consent Document(s):
 - a) Informed Consent; Version 4, 05/08/2012

cc: Agatha M. Gallo (faculty sponsor), Women, Child, & Family Health Science, M/C 802
Rosemary C. White-Traut, Women, Child, & Family Health Science, M/C 802

Appendix E (continued)

UNIVERSITY OF ILLINOIS AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice Continuing Review

November 8, 2012

Sarah Greco
Women, Child, & Family Health Science
845 S Damen Ave
M/C 802
Chicago, IL 60612
Phone: (312) 420-7816 / Fax: (312) 996-8871

RE: **Protocol # 2011-0904**
"Primary Family Caregivers Definition and Management of Nursing Home Placement"

Dear Ms. Greco:

Your Continuing Review was reviewed and approved by the Expedited review process on November 5, 2012. You may now continue your research.

Please note the following information about your approved research protocol:

<u>Protocol Approval Period:</u>	November 5, 2012 - November 5, 2013
<u>Approved Subject Enrollment #:</u>	50 (Limited to data analysis from 10 subjects)
<u>Additional Determinations for Research Involving Minors:</u>	These determinations have not been made for this study since it has not been approved for enrollment of minors.
<u>Performance Sites:</u>	UIC, Saint Matthew Center for Health - Park Ridge, IL, Bethany Terrace Health and Rehabilitation Center, Westminster Place of Presbyterian Home, Cantata Adult Life Services, The Fountains of Crystal Lake
<u>Sponsor:</u>	Chancellor's Education Award Funding 2011, Illinois Area for Health Education Centers Network Program Health Professions, Midwest Nursing Research Society Dissertation Research Grant, Alpha Lambda Chapter Research Award, UIC College of Nursing Seth and Denise Rosen Research Award, Sigma Theta Tau
<u>PAF#:</u>	Not applicable, Not applicable, Not applicable
<u>Grant/Contract No:</u>	Not applicable, Not applicable, Not applicable, Not applicable, Not applicable
<u>Grant/Contract Title:</u>	Not applicable, Not applicable, Not applicable, Not applicable, Not applicable
<u>Research Protocol:</u>	
a) Primary Family Caregivers Definition and Management of Nursing Home Placement; Version 4; 04/25/2012	

Phone: 312-996-1711

<http://www.uic.edu/depts/over/oprs/>

FAX: 312-413-2929

Appendix E (continued)

2011-0904

Page 2 of 2

November 8, 2012

Recruitment Material:

a) N/A- closed to enrollment

Informed Consent:

a) N/A- closed to enrollment

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories:

- (6) Collection of data from voice, video, digital, or image recordings made for research purposes.,
 (7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
11/01/2012	Continuing Review	Expedited	11/05/2012	Approved

Please remember to:

→ Use your **research protocol number** (2011-0904) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the enclosure,
"UIC Investigator Responsibilities, Protection of Human Research Subjects"

Please note that the UIC IRB has the right to seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 355-2764. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Betty Mayberry, B.S.
 IRB Coordinator, IRB # 2
 Office for the Protection of Research Subjects

Enclosures:

1. **UIC Investigator Responsibilities, Protection of Human Research Subjects**
2. **Data Security Enclosure**

cc: Barbara McFarlin, Women, Child, & Family Health Science, M/C 802
 Agatha M. Gallo, Faculty Sponsor, M/C 802

Appendix F

Consent to Participate Form

Version 4, 5/8/12

University of Illinois at Chicago

Research Information and Consent to Participate in Social Behavioral Research “Primary Family Caregivers Definition and Management of Nursing Home Placement”

Why am I being asked?

You are being asked to be a subject in a research study to learn more about the experiences of family caregivers involved in placing an older family member into a nursing home. The study is conducted by Sarah Koplow Greco, PhD student at the College of Nursing at the University of Illinois at Chicago. You have been asked to participate in the research because you self-reported that you are a family caregiver over the age of 21 years who was involved in the care and/or placement of an older family member (over the age of 65) into a nursing home. I ask that you read this form and ask any questions you may have before agreeing to be in the research.

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of Illinois at Chicago nor the nursing home where your older family member receives care. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

Approximately 15 subjects will be enrolled from 5 Chicago area nursing homes.

Why is this research being done?

This research study on the experiences of family caregivers and nursing home placement is being done because not much information exists about family caregivers' experiences with nursing home placement over time. Family caregivers who participate in this study will have an interview with the researcher shortly after placement and three-months post-placement. The participant will receive a Target gift card worth \$25 after completion of the initial interview and again after completion of the 3 month post-placement interview. The gift card is my way of saying thanks for being in the study. The risks are minimal and what is learned from the family caregivers will be helpful in understanding the needs of caregivers and nursing home placement.

What is the purpose of this research?

The purpose of this research is to understand the experiences of family caregivers involved in nursing home placement over time. A number of federal agencies and national organizations believe that the role of family caregivers is important, but there is not much research that describes the perspectives of family caregivers and the impact of nursing home placement on the family over time.

What procedures are involved?

If you agree to be in this research, we would ask you to participate in two 45-60 minute interviews:

- First, you will be asked if you have any questions about the study.

Appendix F (continued)

- Then, you will be asked to fill out a form that asks for your relationship to the older family member, age, sex, education, employment, race, and ethnicity and other background information.
- Finally, you will be asked to describe the experiences of you and other family members and the care you provided for your older family member prior to nursing home placement, at placement, and after placement.

After each interview, you will receive a Target gift card of \$25. This gift card is my way of thanking you for your participation.

What are the potential risks and discomforts?

The research has minimal risks. Some participants may have feelings of stress related to responding to the interview questions about nursing home placement. Talking about issues related to nursing home placement may make some participants think more about their situation and may result in raising questions about their situation. You are allowed to stop the interview at any time and take a break. None of your individual answers will be shared with others. You can choose not to answer any of the questions asked. I will also be providing a list of Chicago area caregiving resources at the end of our initial interview.

To reduce any inconvenience, I will conduct the meetings at times and places that are convenient for you, including evening and weekend sessions.

Are there benefits to taking part in the research?

You will not directly benefit from the study. Interviews may provide the participant with previously unrecognized insights about the nursing home placement and their feelings associated with the placement. Ultimately, I hope the information learned from these interviews will lead to resources that will help other family caregivers undergoing the same experiences.

What other options are there?

At this time, we know of no research studies similar to this one available to you. However, you have the right to not participate in this study.

What about privacy and confidentiality?

The people who will know that you are a research subject are members of the research team. Otherwise information about you will only be disclosed to others with your written permission, or if necessary to protect your rights or welfare or if required by law.

Study information which identifies you and the consent form signed by you will be looked at and/or copied for checking up on the research by UIC OPRS. State of Illinois auditors may also monitor the research. The list of participants and all study forms will be kept in a locked file cabinet in a locked research office at the UIC College of Nursing. Only Sarah Koplow Greco will have access to the key to the locked cabinet. The information that you provide cannot be connected to you because the recorded answers obtained in the interviews will be typed out to paper copies and names will be removed. Your identifiers will not be kept with the subject data.

When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity.

Appendix F (continued)

I am also asking that you also consent to having your identification information kept for a period of 5 years after completion of the study for possible contact and participation for future research studies. Future research questions about the roles of caregivers and nursing home placement and care may arise from this study. As such, follow-up studies may be conducted with the participants from this current study about their continued adjustment to being a family member of an older family member living in a nursing home. If you consent to retaining your information for future research studies, your information will be kept in a locked cabinet in a locked research office at the college of nursing. If you do not consent to retaining your information for future research studies, your contact information will be destroyed immediately after completion of this current study.

☐ Yes, I agree to have my information retained so that I may be contacted regarding future research.
Initials _____.

☐ No, I do not agree to have my information retained and do not agree to be contact about future research.
Initials _____.

What are the costs for participating in this research?

There is no cost to you for participation in this research study.

Will I be reimbursed for any of my expenses or paid for my participation in this research?

There are two interviews for which you will receive a \$25 Target gift card. At the end of both the initial and three-month follow-up interview, you will receive a \$25 Target gift card for participating in the study.

Can I withdraw or be removed from the study?

You can choose whether to be in this study or not. If you decide to participate, you are free to withdraw your consent and discontinue participation at any time. You may also refuse to answer any questions you don't want to answer and still remain in the study. The researcher may withdraw you from this research if circumstances arise which warrant doing so.

Who should I contact if I have questions?

The principal researcher conducting this study is Sarah Koplow Greco. You may ask any questions you have now. If you have questions later, you may contact Sarah Koplow Greco at 312-420-7816 or at sgreco3@uic.edu

You may also contact Sarah Koplow Greco's research advisor, Dr. Agatha Gallo at 312-996-1868 or at agallo@uic.edu.

What are my rights as a research subject?

If you feel you have not been treated according to the descriptions in this form, or if you have any questions about your rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 312-996-1711 or 1-866-789-6215 (toll-free) or e-mail OPRS at uicirb@uic.edu.

Appendix F (continued)

Remember: Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University or the nursing home where your older family member receives care. If you decide to participate, you are free to withdraw at any time without affecting that relationship. You will be given a copy of this form for your information and to keep for your records.

Signature of Subject or Legally Authorized Representative

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I have been given a copy of this form.

Signature

Date

Printed Name

Signature of Researcher

Date (must be same as subject's)

Appendix G

Primary Family Caregivers' Definition and Management of Nursing Home Placement Documentation of Initial Eligibility Form

***Bold wording indicates actual wording said by interviewer.**

1. INTRODUCTION

Hello, (Ms., Mr.) _____. My name is Sarah Koplow Greco and I am PhD student at the University of Illinois at Chicago, College of Nursing. I am conducting a research study called "Primary Family Caregivers' Definition and Management of Nursing Home Placement." You filled out a form to be contacted about this study

This study is being done to learn about primary family caregivers experiences when an older family member enters a nursing home. I will be doing two digitally recorded interviews, one at initial nursing home placement and one 3 month post-placement. I will make an appointment to meet you at a convenient location to complete a basic background questionnaire and the interview. You and I will select a day and time that is most convenient for you. The first thing we will ask is for your permission or consent since this is a research study. Then, we will complete a basic background questionnaire. We will digitally record the interview because that is the best way for us to remember everything said. The interview will last approximately 45-60 minutes. You will be given a \$25 Target gift card after the completion of the initial interview and after completion of the 3 month post-placement interview.

2. ELIGIBILITY CHECK

Before we continue I need to ask you a few questions to be sure that you are eligible to participate

1. **How old are you?** (must be at least 21 years of age).
2. **How old is your older family member?** (must be at least 65 years of age).
3. **Did you provide care** (i.e., direct care, supervise care) **or were you involved in the nursing home placement?**
4. **What nursing facility did your older family member enter?**
5. **How long ago was this?** (must be within the last 30 days).
6. **Will you be willing/able to participate in another interview 3 months from now?** (must say yes).

Appendix G (continued)

- € If yes - **You meet criteria for participation, so we can proceed.**
- € If does not meet eligibility criteria - **I'm sorry, but I am only enrolling primary family caregivers who (meet the eligibility criteria - Give reason from above)**
Thank you for your time and for considering helping out with this study.

3. *SETTING APPOINTMENT FOR INTERVIEW*

Are you willing to participate in the interview?

- € If no –**May I ask why you think are not interested?**
If it is a matter of “timing” suggest calling at a later date as an alternative. Note date to call back or reason(s) for refusal on phone sheet, and terminate the call) **Thank you for your time and for considering helping out with the research study.**
- € **If yes:**
- € **I want to verify your contact information.** (on contact information sheet)
- € **I want to also ask where you heard about our study** (from the flyer, from professional nursing home staff).
- € **I would like to set up a convenient time and location for us to meet and conduct the interview.**
- € **Do you have any questions about the study? Thank you again and I look forward to meeting you with.**

Appendix H

Primary Family Caregivers' Definition and Management of Nursing Home Placement Documentation of Continued Eligibility Form

***Bold wording indicates actual wording said by interviewer.**

1. INTRODUCTION

Hello, (Ms., Mr.) _____. This is Sarah Koplow Greco, the PhD student at the University of Illinois at Chicago, College of Nursing. I interviewed you about 6-8 weeks ago about your experiences with your family member entering a nursing home. I am calling you to follow-up and to schedule our second interview.

I want to ask you some questions. Are you willing to participate in the second interview?

- € If no –May I ask why you think are not interested?
If it is a matter of “timing” suggest calling at a later date as an alternative. Note date to call back or reason(s) for refusal on phone sheet, and terminate the call) **Thank you for your time and for considering helping out with the research study.**
- € If yes – continue on to *Eligibility Check*

2. ELIGIBILITY CHECK

Before we continue I need to ask you a few questions to be sure that you are still eligible to participate

1. How is (Name of older family member)?

2. Where is (Name) living? (must be in that same facility as initial interview)

- € If yes - **You meet criteria for participation, so we can proceed. I want to verify your contact information.** (verify contact information)
- € **I would like to set up a convenient time and location for us to conduction our second interview.** (Can be over the telephone if desired) **to meet and conduct the interview.**
- € **Do you have any questions about the study? Thank you again and I look forward to meeting you with.**
- € If (OFM) does not meet eligibility criteria - **I’m sorry, but I am only enrolling primary family caregivers for the second interview whose family member still resides in the nursing facility. Thank you for your time and for considering helping out with this study.**

Appendix I

Study Flyer

UIC

COLLEGE OF
NURSING

UNIVERSITY OF ILLINOIS
AT CHICAGO

RESEARCH STUDY

?

**Has a family member recently
entered a nursing home**

If so, consider joining our research study.

?

RESEARCH TITLE

Primary Family Caregivers Definition and Management of Nursing Home Placement

RESEARCHER

Sarah Koplow Greco, PhD candidate

WHAT THE STUDY IS ABOUT

Nurse Sarah Koplow Greco will be interviewing family caregivers about views of an older family member who recently entered a nursing home.

WHAT WILL HAPPEN

Sarah will meet at a place convenient for you to conduct a 45-60 minute interview about your experiences with the nursing home placement. Then, she will interview you again 3 months later about how your life has changed since the first interview.

TO QUALIFY

Be a family caregiver who has been involved in the care of an older family member. Be 21 years of age or older.

COMPENSATION

You will receive a gift card after completing each interview.

CONTACT

If you are interested in participating or would like more information, please contact Sarah Koplow Greco. When you email me, please provide your name, telephone number, email address, and the best times to contact you.

TAKE CONTACT INFO

FAMILY
CAREGIVERS
STUDY

University of Illinois at Chicago
312-420-7816
sgreco3@uic.edu

FAMILY
CAREGIVERS
STUDY

University of Illinois at Chicago
312-420-7816
sgreco3@uic.edu

FAMILY
CAREGIVERS
STUDY

University of Illinois at Chicago
312-420-7816
sgreco3@uic.edu

FAMILY
CAREGIVERS
STUDY

University of Illinois at Chicago
312-420-7816
sgreco3@uic.edu

FAMILY
CAREGIVERS
STUDY

University of Illinois at Chicago
312-420-7816
sgreco3@uic.edu

APPROVAL EXPIRES
DEC 12 2011 TO DEC 10 2012
UNIVERSITY OF ILLINOIS AT CHICAGO
INSTITUTIONAL REVIEW BOARD

Appendix J

Primary Family Caregivers' Definition and Management of Nursing Home Placement Demographic Questionnaire

What is your relationship to the older family member?

☐ Spouse/Significant Other

☐ Daughter/Son

☐ Sibling

☐ Niece/Nephew

☐ Cousin

☐ Neighbor

☐ Friend

☐ Other _____

What is your sex/gender?

☐ Male

☐ Female

What is your date of birth?

☐ _____

Appendix J (continued)

What is the highest grade in school that you completed? (select the number/degree completed)

- 1 ☐ Grade school 1 2 3 4 5 6 7 8
- 2 ☐ High school 9 10 11 12
- 3 ☐ Vocational School
- 4 ☐ Some College
- 5 ☐ 2-year College degree
- 6 ☐ 4-year College degree
- 7 ☐ Graduate degree master' degree doctoral degree
- 8 ☐ Other (specify) _____

Are you currently employed?

- 1 ☐ Yes, part-time
- 2 ☐ Yes, full-time
- 3 ☐ No, retired
- 4 ☐ Not employed

What ethnicity do you consider yourself to be?

- ☐ Latino/Latina
- ☐ Hispanic
- ☐ Not Hispanic

Appendix J (continued)**What race do you consider yourself to be?**

- ☐ Native-American Indian/Alaska
- ☐ Asian
- ☐ Black
- ☐ African American
- ☐ Native Hawaiian/Other Pacific Islander
- ☐ White
- ☐ Multi-racial (specify) _____
- ☐ Other (specify) _____

Appendix K

Initial Interview Guide Primary Family Caregivers' Definition and Management of Nursing Home Placement

Introduction

I am talking to caregivers who have recently had an older family member enter a nursing home. I am especially interested in the situation surrounding the care and placement and the impact on your family. There are no right or wrong answers to any of the questions I will be asking and you don't have to answer any of the questions that you don't want to. I am going to start by asking some general questions about you and your family's situation surrounding the care and placement. Then I will be asking questions about how you and your family managed the care and placement of [Name]. Last, I will ask you questions about how you and other family members were affected or are affected by [Name's] placement into the nursing home. Please take your time to think about each question as we go through the interview. Before we start, do you have any questions for me?

I. Defining the Situation Surrounding Care and Placement

1. I have a couple of questions about your relationship with [Name].

a. Please tell me about your relationship or connection with [Name] (e.g., child, spouse/significant other, family, friend)

Probe – How often did you spend time together or talk together?

Probe – What kinds of activities did you do together?

b. Are there any other family members who were involved in the care and placement of [Name]?

Probe - Who are they?

Probe - What is their relationship/connection?

2. I have some questions about what it was like for you and [Name] prior to [his/her] placement.

a. Before placement, tell me about [Name] living situation and [his/her] overall health.

b. What usual activities and tasks was [Name] able to do for him or herself? (i.e., paying bills, managing the home, personal care (bathing, dressing, etc.).

c. What sorts of things did you (and/or your family/others) help with or provide for [Name]?

Probe - Did your family work together to provide [Name] this help? Tell me more about this?

Appendix K (continued)

Probe - Did you hire anyone to provide the care for [Name] or use any type of outside assistance (respite care, adult day care, private caregiver)? How often? How did this (outside assistance) help contribute to the overall care?

d. How easy or difficult was it for you and your family to manage (i.e., providing the direct care, supervision of the care) the care of [Name]?

Probe - What do you think made it easier for you to manage?

Probe - What do you think made it more difficult for you to manage?

3. I have some questions about life for you prior to the placement. Prior to the placement of (Name) how did being a caregiver impact your life?

Probe - For example, how much of your day/week was spent caring for [Name]?

Probe - Did you have a routine? Did other family members assist with this routine? Who? How did they help?

Probe - How did giving care to [Name] affect other parts of your life (i.e., family, job, finances, relationships with family members and theirs?) Were these experiences similar for other family members?

Probe - Has giving care to [Name] affected your health (i.e. your physical and mental health (e.g., worry, anxious, etc.)? How?

a. Has giving care to [Name] affected other parts of other family members' life (i.e., family, job, relationships)

b. Has giving care to [Name] affected the physical and mental health of other family members? How?

4. Before placement, what were your and your family expectations or goals for [Name's] care? (i.e., maintaining them at home, preventing further decline, keeping them healthy)

Probe - Did you and/or your family have any plans should [Name] be unable to remain in their current living situation?

Probe - Had you and your family ever considered placement, such as assisted living or a nursing home? What was your thinking about this?

Probe - What did you think about nursing homes? What did other family members think about nursing homes?

Appendix K (continued)

Probe - Did anyone (healthcare provider, another family member) ask you to consider planning for placement?

II. Managing the Care and Placement of the Older Family Member

Now, I'd like to ask you more specifically about [Name's] placement and care received.

1. Please walk me through the sequence of events that lead to the placement of [Name].

Probe: Tell me more about that, go on....

Probe: Did you and your family agree that [Name] needed to be cared for in a nursing home?

- a. Was [Name] involved in the decision? How? If not, why not?
- b. How did you and your family select a nursing home? Did you and family members select the home together? Visit different homes?

Probe: Tell me more about that.

- c. How did the decision to place [Name] affect you and your family?
- d. Looking back, what do you think about the way you and your family went about choosing a nursing home? What do you know now that you wish you knew then?

2. I am going to ask you some questions about the care [Name] is receiving now in the nursing home.

- a. What parts of the care is [Name] doing for his/herself (i.e., bathing, toileting, walking, etc.)

- b. Does [Name]'s health status affect their ability to participate in care?

Probe: Does [Name] do better in the morning or in the evening?

- c. What parts care is the nursing staff giving [Name]?

Probe: Is [Name] receiving rehabilitation (PT/OT/ST)? Are these services new?

- d. What parts are you and your family helping with or providing for [Name]?

III. Perceived Consequences of the Care and Placement on the Family

Now I'd like to ask about how you, your family and [Name] have been affected by the placement. .

1. What is your relationship like with [NAME] now?

Appendix K (continued)

Probe –Are you able to visit [Name]? If so, how often do you visit?
(other family members)

2. How easy or difficult is it for you and your family to manage (care, supervision of care) the care of [Name] now?

Probe - What do you think might make it easier for you to manage?

Probe - What do you think has made it more difficult for you to manage (i.e., provide direct care, supervise, etc.)?

3. What are your and your family's expectations or goals for [Name's] care now? (i.e., going back home, preventing further decline, keeping them healthy)?

Probe - What do you think [Name] ongoing needs will be?

Probe - Will [Name] stay here?

4. How do you think [Name] has adjusted to being in the nursing home? (e.g., developing a routine)
5. What are your expectations for your continued role and your family's continued role as a caregiver?

IV. Advice for family caregivers and healthcare providers

Wrapping up, I would like to ask you, **Is there anything else that you think would be important for health providers or caregivers to know about how to provide care or placing family member into a nursing home?**

V. Closure

1. What was it like for you to participate in this interview?
2. Were there any questions that you were unsure about or were difficult to understand?
3. Thank you for participating in this study.
4. Sometimes participating in a study like this may raise questions you have not considered before. Here is some information with resources in the area should you need any further assistance.

Appendix L

3 month Post-Placement Interview Guide Primary Family Caregivers' Definition and Management of Nursing Home Placement

Introduction

I want to give you an introduction to this second interview. I am talking to caregivers to follow-up on your experiences since our initial interview about the placement of your older family into the nursing home. I am especially interested in getting a better understanding of how things may have changed since the placement. There are no right or wrong answers to any of the questions I will be asking and you don't have to answer any of the questions. I'd like to start by talking about changes, which may have taken place over the last few months. Please take your time to think about each question as we go through the interview. Before we start, do you have any questions for me?

I. Defining the Situation Surrounding Care Post-Placement

1. I have a couple of questions about your relationship with [Name] now that placement has occurred.

a. Please tell me about your relationship with [Name] now.

Probe – How often do you spend time together or talk together?

Probe – What kinds of activities do you do together? How do you decide what activities to do?

Probe - What activities are important for you to do together? Why?

b. Are there any other family members who are involved in [Name's] care?

Probe - Who are they?

Probe - What is their relationship with [Name] like now?

2. I have some questions about what life is like for [Name] now.

a. Tell me about [Name]'s overall health. Is this a change since prior to placement?

b. What usual activities and tasks are [Name] able to do for him or herself? (i.e., personal care (bathing, dressing, etc.)?)

Probe - Does their health status affect their ability to participate in their care?

Probe - Does [Name] do better in the morning or the evening?

c. How does the nursing home staff help with these activities?

Appendix L (continued)

- d. Tell me about [Name's] daily life and activities. What does he/she enjoy doing? Are these activities similar to what they did prior to placement?
- e. What do you think about [Name's] feelings about their living situation? Adjustment to the nursing home? Adjustment and relationship with staff?
 Probe - Have you noticed any changes in [Name's] thoughts about [his/her] care and life?
- 3. I have some questions about life for you now. How does providing care to [Name] now impact your life?
 Probe - Is this a change since prior to placement?
 Probe - Do you and your family have a routine for providing care/visits?
 Probe - How does giving care to [Name] affect other parts of your life now (i.e., family, job, finances, relationships with family members and others?) Are these experiences similar for other family members? Is this a change since prior to placement?
 Probe - Has giving care to [Name] affected your health now (i.e., your physical and mental health (e.g., worry, anxious, etc.)? Are these experiences similar for other family members? Is this a change since prior to placement?

II. Managing the Care of the Older Family Member Post-Placement

Now, I'd like to ask you more specifically about the care that you and the nursing home staff are providing for [NAME] now.

- 1. What sorts of things do you (and/or your family/others) provide for [Name]? (i.e., personal care, money management, laundry, physician visits, family outings)
 Probe - Do your family work together to provide [Name] this help? Tell me more about this?
- a. How easy or difficult is it for you and your family to manage (i.e., providing the direct care, supervision of the care) the care of [Name]?
 Probe - What do you think made it easier for you to manage?
 Probe - What do you think made it more difficult for you to manage?

Appendix L (continued)

b. How do you think this care you provide have changed since placement?

2. What sorts of care activities does the nursing home staff do for [Name]?

Probe – What is your relationship with the nursing home staff? (e.g., nursing assistant, registered nurses, social worker) (positive, negative, neutral, other)?

Probe - What do you think makes it easier to work with the staff to manage [Name's] care?

Probe - What do you think made it more difficult to work with the staff to manage [Name's] care?

III. Perceived Consequences of the Placement on the Family

Now I'd like to ask about how you and your family have been affected since the placement.

1. How has the placement affected [Name]? You? Other family members?

Probe- quality of life

Probe - How might these things be different if they did not live in the nursing home?

2. What are your and your family's expectations or goals for [Name's] care now?

Probe - Will [Name] stay here?

3. What are your expectations for your continued role and your family's continued role as a caregiver?

IV. Advice for family caregivers and healthcare providers

Wrapping up, I would like to ask you, is there anything else that you think would be important for health providers or caregivers to know about providing care to an older family member who lives in a nursing home?

V. Closure

1. What was it like for you to participate in this interview for a second time?

2. Were there any questions that you were unsure about or were difficult to understand?

3. Thank you for participating in this study.

Appendix M

Caregiver Resources

AgeOptions

Non-profit Area Agency on Aging for older adults and families in Suburban Cook County
1048 Lake Street, Suite 300 Oak Park, IL 60301-1102
(800)699-9043 or (708)383-0258
information@ageoptions.org
<http://www.ageoptions.org>

Illinois Department on Aging

Michael A. Bilandic Building (also known as the State of Illinois Building)
160 North LaSalle Street
Suite N-700
Chicago, IL 60601-3031
(312) 814-2630
aging.ilsenior@illinois.gov

Senior HelpLine: (8:30 a.m. - 5:00 p.m., Monday through Friday)
(800) 252-8966

Suburban Cook County Long-Term Care Ombudsman

Robyn O'Neill, Regional Ombudsman
(888) 401-8200
roneill@lafchicago.org

City of Chicago Caregiving Assistance Services

Jaime Hersh-White, Chicago Department of Family & Support Services-Caregiver Initiative
(312) 746-6867
jaime.hershwhite@cityofchicago.org

North Shore Senior Center in Morton Grove

American Legion Memorial Civic Center
6140 Dempster Street
Morton Grove, IL 60053
(847) 470-5223
<http://www.nssc.org>

Appendix N

Coding List and Super Family Codes

Code List

View of OFM Identity:

- View of OFM pre-placement, identity - PFG and other family members comments related to the identity of the OFM, such as their capabilities, vulnerabilities, personality traits, independence/dependence and how this may have influence care in nursing home and PFG's relationship with OFM
- View of OFM post-placement, identity - PFG and other family members comments related to the identity of the OFM, such as their capabilities, vulnerabilities, personality traits, independence/dependence and how this may have influence care in the nursing home and PFG's relationship with OFM

View of OFM Health:

- View of OFM pre-placement, health - comments about the seriousness of any health conditions, predictability of health conditions, how health may have influenced management of care and placement; health can include physical health, mental health, and ability to perform ADLS/care
- View of OFM post-placement, health - comments about the seriousness of any health conditions, predictability of the health conditions, how health may influence care in the nursing home; health can include physical health, mental health, and ability to perform ADLS/care

Management Mindset:

- OFM feelings toward permanent placement - comments made about how the OFM feels about placement into a nursing home
- PFG feelings toward permanent placement - comments made about how the PFG and other family members feel/felt about nursing home placement for their OFM
- What's the next step/waiting/uncertainty about the situation - comments made about the PFG waiting; uncertainty about the management of care and nursing home placement
- PFG management of care pre-placement, easier - comments about things that made the PFG and other family members management of care prior to placement easier
- PFG management of care pre-placement, more difficult - comments about things that made the PFG and other family members management of care prior to placement more difficult
- PFG management of care post-placement, easier - comments about things that made the PFG and other family members management of care after the placement easier
- PFG management of care post-placement, more difficult - comments about things that made the PFG and other family members management of care after the placement more difficult
- Interactions with nursing home staff - interactions with nursing home staff by PFG and other family members - positive, negative
- Feelings of PFG post nursing home placement – concerns, relief, worries that continue, especially 3 months post-placement

Family Mutuality:

- Family mutuality, shared views - shared views of the PFG and other family members approach to care and placement

Appendix N (continued)

- Family mutuality, discrepant views - discrepant views of the PFG and other family members approach to care and placement

Primary Family Caregiver Philosophy:

- PFG philosophy towards care - PFG and other family members' goals, beliefs, values, priorities that guide their approach to care and management of OFM

Approach to Management and Placement:

- Making the permanent placement decision - comments made about events, decisions, influences, factors about how the PFG and other family members made the decision for permanent nursing home placement
- Critical Incident - acute hospitalization, fall, stroke, or some other medical/financial/situational event that contributed to the OFM entering a nursing home; this could be an event that happened to the OFM **or** the PFG (and thus the PFG was no longer able to manage care at home)
- Development of a routine, pre-placement - PFG and other family member's routine prior to placement (or lack of a routine), such as medication management, visits, phone calls
- Development of a routine, post-placement - PFG and other family member's routine after placement (or lack of a routine), such as visits, phone calls

Primary Family Caregiver Focus:

- Relationship prior to nursing home placement - comments made about the relationship between OFM (and other family member's) pre-placement and how this relationship was impacted by placement and adjustment; also includes how relationship impacted PFG's balance between caregiving and other aspects of life
- Relationship post nursing home placement - comments made about the relationship between OFM (and other family member's) post-placement - i.e., better, worse, same, closer, more distant; How this relationship was impacted by placement and adjustment; also includes how relationship impacted PFG's balance between caregiving and other aspects of life
- PFG adjustment to home life without OFM - comments made about how the PFG is adjusting to life with OFM in the nursing home and not in the family home

Future Expectations:

- Expectations for care, post-placement - PFG and other family member's expectations for their continued role as a caregiver and for their OFM's functioning

Advice to others/health care providers – PFG's advice to other caregivers and/or healthcare providers about the transition into nursing home placement (such as expectations, preparations, etc.)

VITA

Name

Sarah Koplow

Education

University of Illinois at Chicago, College of Nursing

Ph.D, Nursing Science

May 2013

Post-Masters Adult-Geriatric Nurse Practitioner Program

December 2013

George Mason University, M.S.N.

2009

University of Florida, B.S.N.

2005

Licensure

State of Illinois Registered Nursing License 041.37626, expires 5/2014

BLS CPR Certification

Work Experience

Graduate Teaching Assistant

2009 – Present

University of Illinois at Chicago College of Nursing

Chicago, IL

Office of Academic Programs

- Responsibilities include undergraduate and graduate tutoring, academic advising, admissions preparation, filing, recruitment events, and alumni functions
- Assisted with clinical coursework for pre-licensure students, including patient care, charting, and paperwork
- Assist with upkeep of immunization and clinical compliance records for all students, including the implementation and maintenance of an on-line clinical compliance system
- Created and implemented a 5 week summer pathophysiology review course for pre-licensure students
- Developed a prep workshop for incoming pre-licensure students, including review of pathophysiology concepts, APA guidelines, and nursing school tips

MDS RN Coordinator/RN Supervisor

2008 – 2009

The Residences of Thomas Circle Sub-acute Rehabilitation

Washington, DC

- Lead staff training and development through implementation of education, quality indicators, and infection control programs
- Coordinate the interdisciplinary team in completion of timely Minimum Data Set (MDS) assessments for Medicare and Medicaid and appropriate discharge planning
- Develop resident specific care plans to drive team nursing care

MDS RN Coordinator

2007 – 2008

Cherrydale Healthcare Center

Arlington, VA

- Responsible for timely scheduling and completion of MDS assessments for Medicare and Medicaid nursing home/skilled rehabilitation residents
- Facilitated implementation of care plans and lead interdisciplinary care plan meetings

MDS RN Coordinator

2006 – 2007

Woodbine Rehabilitation and Healthcare

Alexandria, VA

- Developed process flow program for the coordination and facilitation of MDS nursing assessments for Medicare and Medicaid nursing home/skilled rehabilitation residents
- Responsible for completion of MDS reporting to meet state and federal requirements by tracking and trending areas for continuous quality improvement
- Educational Resource coordinator for physicians and staff members, conducting in-services and clinical presentations to promote positive resident health assessments and outcomes

Registered Nurse

2005 – 2006

Malcolm Randall Veterans Affairs Medical Center

Gainesville, FL

- Geriatric extended care/skilled rehabilitation nursing, palliative care, and nursing home specialties
- Active member of palliative care and wound care committees
- Assisted senior management with chart review for documentation deficiencies

Teaching Experience

Summer in Excellence Program Pathophysiology Review Course

Summer 2012

University of Illinois at Chicago

Chicago, IL

- 5- week summer review course for incoming pre-licensure students, which included in-person and Blackboard components
- Developed comprehensive syllabi, course content, and course outline
- Created and implemented Powerpoint Presentations with multimedia components, in-class quizzes, and case study

Practicum and Seminar in Nursing Education II

Spring 2009

George Mason University

Fairfax, VA

- Preceptorship at a long-term care facility by a Master's prepared clinical nurse educator
- Developed checklists, teaching plans, and evaluation tool for nursing competencies
- Assisted in teaching critical thinking skills, skills check offs for CNAs, orientation for nurses
- Capstone project included the development of a Blackboard site for the conversion of the practicum into an online format

Practicum and Seminar in Nursing Education I

Fall 2008

George Mason University

Fairfax, VA

- Preceptorship in a undergraduate nursing research course by a PhD prepared faculty member
- Teaching two of the classes, attended lectures, assisted in the evaluation of student papers and projects, wrote test questions, and scantron test review
- Capstone project included redesigning the course syllabus and presentation of selected issues in nursing education

Publications & Presentations

Koplow Greco, S., Gallo, A., Gruss, V., & Knafl, K. (2013) Family caregivers define and manage nursing home placement: Implications for families and nursing, Refereed abstract for student poster competition, 37th Annual Midwest Nursing Research Society Conference, Chicago, IL, March 2013.

Koplow Greco, S. (2013). Family caregivers' definition and management of nursing home placement. Refereed abstract for poster presentation for American Society on Aging 2013 Aging in America Conference, Chicago, IL, March 2013.

Koplow Greco, S., & Gallo, A. (2012). Primary family caregivers' definition and management of nursing home placement, Refereed abstract for poster presentation, 36th Annual Midwest Nursing Research Society Conference, Dearborn, MI, April 2012.

Koplow Greco, S., & Hughes, S. (2012). Nursing home quality within the Affordable Care Act. Refereed abstract for oral presentation, American Society on Aging 2012 Aging in America Conference, Washington D.C., March 2012.

Greco, S.M. & Vincent, C. (2011). Disability and aging: An evolutionary concept analysis. *The Journal of Gerontological Nursing*, 37(8), 18-27. doi: 10.3928/00989134-20110329-04

Eldeirawi, K., Lee, C.K., & Greco, S. (2011). Association of Serum 25-hydroxyvitamin D and serum C-peptide in a nationally representative sample of adults in the United States. Refereed abstract for oral presentation, 3rd North American Congress of Epidemiology, Montreal, Quebec, Canada, June 2011.

Greco, S.M. & Vincent, C. (2011). Disability and aging: An evolutionary concept analysis. Refereed abstract for poster presentation, 35th Annual Midwest Nursing Research Society Conference, Columbus, OH, March 2011.

Professional Memberships

Graduate Student Nursing Organization,	
University of Illinois at Chicago, College of Nursing	2009 - Present
Vice President	2010 - 2011
President	2011 - 2012
Sigma Theta Tau International, National Nursing Honor Society	2009 - Present
Midwest Nursing Research Society (MNRS)	2010 - Present
MNRS Gerontological Research Section, Student Chair	2012 - 2013
Council for the Advancement of Nursing Science (CANS)	2011 - Present
American Society of Aging	2011 - Present
Nurse Educators of Illinois	2012 - Present

Academic and Professional Honors

Florida Bright Futures Scholarship, University of Florida	2001 - 2005
Graduate Award for Excellence in Nursing Education,	2009
George Mason University	
Aftercollege/American Association of Colleges of Nursing,	2011
Scholarship Fund Recipient	
UIC Chancellor's Student Service Leadership Award	2012
Nurse Educator of Illinois Scholarship	2012
UIC College of Nursing Gertrude Hess Nursing Scholarship	2012 - 2013
UIC College of Nursing Mayer Scholarship	2012 - 2013

Research Support

UIC Chancellor's Education Award Fund	2011
Illinois Area Health Education Centers Network,	2011

Health Professions Student/Fellowship Grant	
MNRS Dissertation Research Grant	2012
Sigma Theta Tau International, Alpha Lambda Chapter, Research Award	2012
UIC College of Nursing, Seth and Denise Rosen Research Award	2012