University of Rhode Island

DigitalCommons@URI

Open Access Dissertations

2014

THE RELATIONSHIP BETWEEN FAMILIES' PERCEPTIONS AND NURSES' PERCEPTIONS OF FAMILY NURSING PRACTICE

Kara Misto University of Rhode Island, kmisto@mail.uri.edu

Follow this and additional works at: https://digitalcommons.uri.edu/oa_diss Terms of Use

All rights reserved under copyright.

Recommended Citation

Misto, Kara, "THE RELATIONSHIP BETWEEN FAMILIES' PERCEPTIONS AND NURSES' PERCEPTIONS OF FAMILY NURSING PRACTICE" (2014). *Open Access Dissertations*. Paper 208. https://digitalcommons.uri.edu/oa_diss/208

This Dissertation is brought to you by the University of Rhode Island. It has been accepted for inclusion in Open Access Dissertations by an authorized administrator of DigitalCommons@URI. For more information, please contact digitalcommons-group@uri.edu. For permission to reuse copyrighted content, contact the author directly.

THE RELATIONSHIP BETWEEN FAMILIES' PERCEPTIONS AND NURSES' PERCEPTIONS OF FAMILY NURSING PRACTICE

BY

KARA MISTO

A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

ΙN

NURSING

UNIVERSITY OF RHODE ISLAND

2014

DOCTOR OF PHILOSOPHY DISSERTATION

OF

KARA MISTO

APPROVED:

Dissertation Committee:

Major Professor Laurie Lauzon Clabo

Dayle Joseph

Jacqueline Sparks

Nasser H. Zawia

DEAN OF THE GRADUATE SCHOOL

UNIVERSITY OF RHODE ISLAND

ABSTRACT

The prevalence of diabetes, a chronic illness, is expected to substantially rise over the next fifteen years (Whiting, Guariguata, Weil, & Shaw, 2011). One approach to ease the burden on the US health care system is the involvement and participation of family in care of the hospitalized adult. There is increasing evidence that involvement of family during exacerbations and hospitalizations increases client and family satisfaction during admissions and may also decrease length of stay and therefore cost (Powers & Rubenstein, 1999). The purposes of this study were to examine family members' perceptions of family functioning, family health and the social support received from nurses when an older adult family member with diabetes is hospitalized. Also examined were nurses' critical appraisals of their family nursing practice, as well as their experiences of the reciprocity and interaction in the nurse-family relationship. This study further explored the relationships between nurses' critical appraisals of their family nursing practice and nurses' experiences of the interaction and reciprocity in the nurse-family relationship with families' perceptions of family function, family health and perceived social support from nurses. Finally, this study examined if nurses' critical appraisal of their family nursing practice, and nurses' experience of the interaction and reciprocity in the nurse-family relationship, differed across nursing units, and what the impact was on families' perceptions of family function, family health and social support received. Wright and Leahey's Calgary Family Intervention Model (CFIM) (1994) undergirded this descriptive study, which was conducted on four medical-surgical units in a community hospital. Sixty registered nurses and sixty family members of older adult patients participated. Two instruments were used to

address the variables of interest in this study. Family member participants completed the Family Function, Family Health and Social Support Instrument (Astedt-Kurki, Tarkka, Paavilainen, & Lehti, 2002; Astedt-Kurki, Tarkka, Rikala, Lehti, & Paavilainen, 2009) as well as a demographic questionnaire. Registered Nurse participants completed demographics and the Family Nursing Practice Scale (Simpson & Tarrant, 2006). Significant variation was found across the four study units in how nurse participants reflected on their experiences with interaction and reciprocity in the nurse-family relationship. However, family member participants had no significant variation in their perceptions of family functioning, family health and social support received from nurses. This research informs practice by providing insight into nurses' perceptions regarding the advantages and the disadvantages of working with families. Additionally, this study contributes evidence of what nurses are currently doing to include families in their nursing practice. More research is needed which focuses on collaboration and inclusion of families in care of their loved one.

ACKNOWLEDGMENTS

This has been an incredible journey from beginning to end. I would first like to thank the wonderful and generous families and nurses who shared their time and thoughts with me for this research study. To the administrators and staff at The Miriam Hospital, I am deeply indebted to you and could not have done this without your support. I must acknowledge Maria Ducharme, VP and CNO of Nursing at The Miriam Hospital. Your support and enthusiasm has been so genuine, and I greatly appreciate it.

This study was made possible in part with generous scholarship support from Delta Upsilon, Chapter-at-large, Simga Theta Tau and The Robert Wood Johnson Foundation, Partners Investing in Nursing. Thank you so much for investing in this work.

I want to acknowledge my major professor Dr. Laurie Lauzon Clabo who began this journey with me at its onset. You have patiently guided me, championing me when needed and challenging me to move to the balcony! I am eternally thankful for your unending support. Dr. Dayle Joseph thank you for your guidance in this endeavor, as well as the professional growth you instilled in me as I began my academic career. To Dr. Jacqueline Sparks, thank you for offering me rich additional insights into working and collaborating with families. Dr. Mary Sullivan, I am appreciative of your time, patience, and unwavering composure. Your suggestions and recommendations have been a significant source of encouragement to me. Dr. Stephen Kogut thank you for your consideration and support of this work.

To the incredible faculty and staff I have had the joy of working with and who have listened to me discuss my work and have offered continuous encouragement, I am beyond grateful. I have had the blessing of wonderful friends along this journey both at the workplace and outside it. Your love and humor have been there when I needed either one. I have to thank my many students as well, you have compelled me to maintain my focus, and I have certainly needed that at times.

Most importantly, to my incredible family, I could not have done this without your constant support. Family is what brought me to this journey, family is what has guided me through it and I am forever grateful to you and the sacrifices you made. Words cannot express my love and appreciation of all you have done. To my husband, Jay you have truly been my partner in this, and to my sons, Everett and James....this has been a team effort for sure. To my Mom, my Dad and my sister Erin, thank you so very much for your constant support and encouragement, I could not have done this without you.

Dedication

I dedicate this work to my beloved Poppa and Grandma who inspired me to investigate family nursing. I may have lost you along the path to completing this endeavor, but your love and support has shaped who I am and will continue to influence me in all aspects of life.

TABLE OF CONTENTS

ABSTRACT ii
ACKNOWLEDGMENTS iv
TABLE OF CONTENTS vii
LIST OF TABLES viii
LIST OF FIGURESix
CHAPTER 1 1
INTRODUCTION
CHAPTER 2
LITERATURE REVIEW
CHAPTER 3
THEORETICAL FRAMEWORK
CHAPTER 4
METHODS
CHAPTER 5
RESULTS
CHAPTER 6
DISCUSSION
APPENDICES114
RIRLIOGRAPHY 130

LIST OF TABLES

TABLE	ìΕ
Table 1. Effect size estimates for the study	1
Table 2. Sample size required for chosen power	5
Table 3. Method of Analysis for research questions	6
Table 4. Nurse demographic data	7
Table 5. Family Demographic data)8
Table 6. Correlations between family demographic variables and family	
functioning, family health, and family perceived social support 11	0
Table 7. Correlations between nursing demographic variables and family nursing	
practice, practice appraisal, and nurse-family relationship 11	1
Table 8. ANOVA of study units and nurse perceptions	12
Table 9. ANOVA of study units and family member perceptions	13

LIST OF FIGURES

FIGURE	PAGE
Figure 1.	Problems or drawbacks to individual nursing practice reported by
	nurses when involving family in assessment and care planning 111
Figure 2.	Advantages to individual nursing practice when involving the family in
	assessment and care planning
Figure 3.	What nurses reported having done in the past week to involve families
	in their current nursing practice

CHAPTER 1

INTRODUCTION

The incidence of chronic illness is rising at a rapid rate due primarily to the increasing population of aging adults in the United States (US) (Centers for Disease Control and Prevention [CDC], 2011; National Center for Health Statistics [NCHS], 1999; National Center for Health Statistics [NCHS], 2011). This is likely to continue to increase as members of the "baby boomer" generation move into older adulthood and reach an age where they require greater numbers of health care services. This increased demand for health services related to the ongoing management of complex chronic illness is projected to further strain the already overburdened and inefficient US health system, creating challenges in the ability of the system to provide adequate or cost-effective health care to the growing numbers of chronically ill older adults (Wagner, Austin, Davis, Hindmarsh, & Schaefer, 2001). Chronic illnesses account for nearly three-quarters of the Unites States' health care costs, with diabetes at the forefront, accounting for an estimated \$174 billion in medical care costs annually (Gabbay, Bailit, Mauger, Wagner, & Siminerio, 2011). Further, exacerbation of chronic illness or deterioration secondary to chronic illnesses accounts for 90% of inpatient hospital expenses (Merrill & Elixhauser, 2005).

Those chronic illnesses presenting in middle-aged to older adults most commonly are hypertension, coronary artery disease, and diabetes mellitus. Chronic illnesses, most notably diabetes, are often marked by long periods of home management, interspersed with multiple hospitalizations either related to exacerbation of the disease or hospitalizations for other reasons that are complicated by the illness.

According to the Centers for Disease Control (CDC, 2011) and the Agency for Healthcare Research and Quality (AHRQ, 2000) diabetes is one of the leading causes of chronic illness in the general population, and medical expenditures are about 2.3 times higher for those with diabetes than those without. Currently, 7.8% of the US population has diabetes, and in 2007 alone, 1.6 million new cases were reported. The mortality rate for people with diabetes is twice as high (in any given age group) than for those without diabetes, and if current trends continue, 1 in 3 Americans will develop diabetes (CDC, 2011). Much of the expenditure associated with diabetes can be linked to inconsistencies in care, including ineffective management of glycosylated hemoglobin levels, blood pressure control and maintenance of cholesterol levels (Gabbay et al., 2011; Saydah, Fradkin, & Cowie, 2004). Patients diagnosed with chronic illnesses, especially those who are older or who have co-morbid conditions, are usually managed at home with assistance. These persons are the most likely to depend substantially on their family for assistance, especially at home (Institute for Family Centered Care, 2008).

Management of patients with chronic illnesses, such as diabetes, is rarely limited to only the individual with the disease, especially in aging adults who often have co-morbid conditions. In fact, it is estimated that family caregivers provide 75-80 percent of long-term care in the community (Levine, Halper, Peist, & Gould, 2010). Family caregivers of the older adult with chronic illness have a significant impact on the day-to-day life of their loved ones. Assistance may include supervision of activities of daily living, meal preparation, financial management, medication management, as well as skills specific to each disease, such as blood sugar

management for patients with diabetes. Over time, family caregivers develop competence in their care of chronic illness and in particular in understanding the specific constellation of symptoms and management strategies unique to the individual.

Individuals who most frequently require hospitalization include the very young, the very old and those discussed here, patients with chronic illness. Thus, throughout the trajectory of most chronic illnesses patients suffer exacerbations and must be hospitalized, an event that requires intricate care-planning and should include the family (Bauer, Fitzgerald, Haesler, & Manfrin, 2009). Upon admission to the hospital, however, the usual course of events is that the health care team takes over management of the patient's care with very little input from family, a process that neglects the family's expertise and knowledge of the patient and may inadvertently imply that the that the family is not competent in their care. Then, when the patient is discharged, family is expected to resume care with little or no ongoing preparation.

When hospitalizations occur, families whose needs are not met can suffer impairments in their ability to successfully manage the multiple crises that occur over the course of chronic illnesses (Rosenbloom-Brunton, Henneman, & Inouye, 2010; Rutledge, Donaldson, & Pravikoff, 2000a; Rutledge, Donaldson, & Pravikoff, 2000b). Several authors, however, have found that families who are involved during hospitalizations display increased satisfaction within the entire family system, while patients have demonstrated discernible improvement in their condition (Chesla, 1996; Rutledge et al., 2000a; Rutledge et al., 2000b). Furthermore, family members who are encouraged to participate in care-giving during hospitalizations report feeling less

anxious and more importantly less out of control (Wright & Leahey, 2005). There is increasing evidence that families are able to improve both patient outcomes and patient satisfaction when given appropriate opportunities to be directly involved during inpatient stays (Bauer et al., 2009; Grimmer, Moss, & Falco, 2004). Family participation during exacerbations and subsequent hospitalizations may not only increase client and family satisfaction during admissions but may also decrease length of stay and therefore cost to the health care system (Pearson Hodges, 2009; Rosenbloom-Brunton et al., 2010)

There is a critical need to provide effective health care for the chronically ill, while at the same time offering valuable partnerships with the family. Currently, however, there is a dearth of literature that examines the ways in which nurses might enhance family participation in the care of the hospitalized older adult. Further, while the importance of the nurse-family relationship has been explored in a variety of populations, there are no descriptions in the literature specific to the older adult hospitalized with diabetes. Therefore, the purpose of this study was to examine the relationships between the family and the nurse when an older adult with diabetes is hospitalized.

Theoretical Framework

There is some evidence available that suggests that family care and partnerships between nurses and family members during hospitalization may improve clinical outcomes for both the patient and the family, in part due to family member influence over client adherence with therapeutic regimens (Rutledge, et al., 2000a; Rutledge, et al., 2000b). This change in patient outcomes may in turn positively

impact nurses' perspectives on the importance of improving family nursing in practice. There is, however, limited theoretical or empirical attention given to the complexity of the relationships between nurse, family and patient.

One theoretical approach that attempts to provide a lens through which to examine these relationships is Family Systems Nursing (FSN). The FSN approach provides for exploration of family strengths and evaluation of interactive family behaviors (Robinson, 1994; Wright & Leahey, 1990). FSN focuses on the whole family as the unit of care, allowing the nurse to simultaneously focus on the patient, the family and their illness. FSN was developed as a way of creating partnerships between families and nurses, and this fundamental approach is intended to have implications which can change the nature of relationships within family systems and between patients, families and nurses (Wright & Leahey, 1990).

This study was undergirded by the Calgary Family Intervention Model (CFIM) (Wright & Leahey, 1994), which is a model developed using the FSN approach. One of the main assumptions of the CFIM is that the family-nurse relationship is characterized by reciprocity, which is the nature of the mutual relationship that develops during interactions between the nurse, the individual and the family. CFIM conceptualizes an intersection between one of three domains of family functioning (cognitive, affective and behavioral) and a specific intervention offered by the nurse (Wright & Leahey, 2005). The cognitive domain of family functioning encompasses beliefs that a family may have about illness, and, if a change is needed within this domain, nurses may work with the family to change perceptions about health problems. Affective domain family functioning concerns intense family emotions that

may be hindering a family's ability to problem-solve. In this case interventions that validate responses, encourage discussion, and promote listening are best suited. Behavioral domain family functioning includes the ways in which family members interact with or behave towards one another, specifically when health problems arise. When modifications in this domain of family function are indicated, interventions that offer family participation, respite or even rituals are suggested. The CFIM model suggests that interventions developed in collaboration between nurses and families may produce a change in any, or potentially all three, family functioning domains. Some families, however, may have specific needs in one domain versus another and the nurse may be able to offer solutions that target specific family functioning domains.

Purpose of Research

This study was designed to provide descriptive data regarding the relationships between the family and nurses when an older adult with diabetes is hospitalized. There were four aims of this study. The first was to examine family members' descriptions of family functioning, family health and social support that the family reports receiving from nurses when an older-adult family member with diabetes is hospitalized. The second aim was to explore how nurses on four nursing units caring for hospitalized older adults with diabetes value their family nursing practice and the reciprocal nurse-family relationship. The third aim was to explore if there is an association between the perceptions of nurses working with family members of older adults with diabetes who have been admitted to an acute care facility and how the family describes family function, family health and perceived social support. Finally,

this study examined if differences occur in nurses' appraisal of their family nursing practice across units and if so, were they related to families' perceptions of family functioning, family health, and perceived social support.

This study was designed to answer the following research questions:

- 1. How do families of older-adult, patients with diabetes describe their family functioning, family health and perceived social support from nurses during hospitalization?
- 2. How do nurses caring for older-adult, patients with diabetes, and their families, appraise their family nursing practice and how do they reflect on the nurse-family relationship?
- 3. What is the relationship between nurses' perceptions of their family nursing practice and families' perceptions of family function, family health and perceived social support from nurses?
- 4. Do nurses' appraisal of their family nursing practice differ across units and if so, are these related to families' perceptions of family functioning, family health and perceived social support?

As the incidence of chronic illness increases, it becomes more important to examine the relationship between nurses' family practice and how families evaluate their family functioning, family health and perceived social support when caring for a family member with diabetes. It was proposed that the results of this study would provide a description of the complex relationships between nurses' orientations to family practice and family members' perceptions of family health and functioning, as well as their descriptions of social support provided by nurses. These results will serve

as a foundation for the design of targeted family level interventions when older adults are hospitalized with diabetes. While there has been an increase in the nursing literature that addresses family participation, there is little empirical base that describes the effects the nurse-family relationships have on both nurses and family members when an older adult is hospitalized with diabetes. Existing studies that examine both the family and nurse are scarce, especially for the chronically ill adult populations (Fegran & Helseth, 2009). Thus, this study investigated if a relationship existed between how nurses perceived their family nursing practice and how families reported their family functioning, family health and the support they receive from nurses.

CHAPTER 2

LITERATURE REVIEW

Family caregivers of the older adult with chronic illness have a significant influence on the day-to-day life of their loved ones and there is reason to believe that the nature of the relationship between nurses and family members may impact family functioning and older adult outcomes. This study draws on broad bodies of literature that examine chronic illness, the effect of a family member's chronic illness on the family, the nature of family caregiving, and the trajectory of chronic illness through hospitalization and home. This study also builds on previous work that has examined family nursing and its potential impact in the acute care setting.

Chronic Illness in Older Adults

Chronic illness accounts for over 90% of hospitalizations in the United States (Merrill & Elixhauser, 2005). In 2009, the Centers for Disease Control (CDC) reported that while only 12% of the United States population was age 65 and over, this group required 43% of total days of hospital care and comprised 38% of all in-patient discharges (Buie, Owings, DeFrances, & Golosinksiy, 2010). According to Coleman (2003), older adults who require hospitalization are very likely to require multiple post-hospital transfers due to the complex nature of their numerous chronic conditions. These older adults with chronic co-morbidities are also presumably under the care of multiple health care providers for various conditions (Wenger & Young, 2007), which places them at increased risk for potential complications including medication errors, inconsistencies in disease management, and lack of preparation for caregivers (Coleman, Smith, et al., 2004). Coleman, Min, Chomiak and Kramer (2004) further

suggest that mismanaged post-hospital care can lead to costly consequences, including re-hospitalizations and even death.

Diabetes Mellitus

In 2010 over 26.9% of US citizens over the age of 65 were diagnosed with diabetes. Furthermore, the prevalence of diabetes has increased from estimates of approximately 245 million people worldwide in 2007 to over 366 million people in 2011, and is expected to rise to nearly 552 million by 2030 (Whiting et al., 2011). Diabetes is associated with a number of other serious health complications, including cardiovascular disease, stroke, hypertension, blindness, kidney disease, nervous system disorders, amputations, dental disease, and even mental health disorders. In 2004, cardiac disease was listed as the cause of death on 68% diabetes-related death certificates for patients 65 years of age or older (CDC, 2011).

As described, older adults with diabetes are very likely to develop multiple comorbidities that will often impair function and necessitate assistance at home with activities of daily living (ADLs), including bathing, dressing, eating, ambulating, moving out of bed, as well as instrumental activities of daily living (IADLs) including shopping, meal preparation, money management, transportation, housework, medication management and communication via phone calls (Martinez-Huedo et al., 2011). Martinez-Huedo et al. (2011) reviewed data from three National Health Surveys between 2000-2007 and found the incidence of impairment in ADLs, IADLs and mobility disability (MD, which is a measure of ambulatory ability) was higher in older adults with diabetes than those without diabetes (p < 0.05) and this impairment was greater at each survey.

For older adults who have diabetes in conjunction with other chronic illness conditions, the situation becomes even more complex. For instance, in a 2010 study of heart failure patients with and without diabetes, Bogner, Miller, De Vries, Chhatre and Jayadevappa (2010), investigated the cost and health resource utilization of 1,587 patients aged 65 years of age and older with a diagnosis of heart failure and compared it to 6,409 patients aged 65 years of age or older without heart failure. The groups were then broken down to four groups: heart failure and diabetes (n=498), heart failure only (n=1089), diabetes only (n=971), and no heart failure or diabetes (n=5,438). The results from this study indicated that costs, as well as lengths of stay, were significantly different between the groups, with the largest difference demonstrated between those that had heart failure and diabetes as compared to those with only heart failure or diabetes (Bogner, Miller, de Vries, Chhatre, & Jayadevappa, 2010).

Family Caregiving

While family care for adults with chronic illness is proposed to be very important, much of the published work related to family involvement in health care has revolved around the parents of pediatric clients (Rutledge et al., 2000a; Rutledge et al., 2000b). Family care in pediatrics came into focus largely due to the work of Shelton, Jeppson and Johnson (1987), who developed an approach to family-centered care (FCC) for children with chronic illness. This foundational work in FCC suggested that because families are ultimately the primary caregivers of the child, it is crucial that they are supported and allowed to participate in their child's health care (Shelton, Jeppson, & Johnson, 1987). Shelton, Jeppson and Johnson's approach to FCC includes several important elements, such as good collaborative skills for both health care

professionals and parents, increased opportunities for interaction, and attitudes that are open to collaboration. According to Shelton, Jeppson and Johnson (1987), once these elements become valued by the health care team, central FCC strategies can then be implemented, which includes sharing of all information and establishing institutional policies to better support family participation in patient care. The authors also suggest that gaining understanding of each family's strengths and resources as well as their coping strategies is essential to creating an environment of respect. In light of this work, there has been widespread adoption of many of the recommended practices in family-centered care in acute care facilities including implementation of extended visiting hours and parent rooming-in.

The data regarding family nursing in a pediatric population suggests how important family involvement is during a child's hospitalization. For instance, the early work of Cleary et al. (1986), demonstrated that children who have parents involved in their care during hospitalization cry less, are alone less when awake, had nearly 90% of their adult contact with family members and had greater social interactions than children whose parents were not present. Taylor and O'Connor (1989) reviewed 586 admissions to the National Children's Hospital in Washington D.C. over an eight month period and discovered that children who were admitted and accompanied by a "resident" adult had 31% shorter inpatient stays than those without a parent who resided with them. Benefits of family involvement include reduced anxiety and stress to children and parents, as well as decreased lengths of stay and less re-hospitalizations (Powers & Rubenstein, 1999).

Investigators of pediatric clients with chronic illness have recently begun to examine the experiences and possible effects that families have when their child requires hospitalization (Board & Ryan-Wenger, 2002; Mitchell et al., 2007; Sloper, 2000). In a study of distress in parents of children with cancer, Sloper (2000) collected data from parents of children with cancer at six months (time one) and eighteen months (time two) post-diagnosis. The researcher found that higher levels of distress were associated with lower levels of family cohesion, or perceptions of strong family relationships. Sloper also found that measures of family cohesion at time one were predictive of parental distress at time two. Similarly, Board and Ryan-Wenger (2002) examined long-term effect of pediatric intensive care hospitalization on families with young children. These authors found that parents of either ill or hospitalized children reported high stress symptoms and that they perceived their family as dysfunctional even after discharge from the hospital (Board & Ryan-Wenger, 2002). In a study of parents' perspectives and health care utilization in children with sickle cell disease, Mitchell et al. (2007) discovered that positive patient coping was related to positive family functioning and lower health care utilization.

Family Care Giving and Older Adults

Care giving for chronically ill older adults, with family members as the primary providers, has become increasingly common. According to Bass and Noelker (1987) eight out of ten functionally disabled older adults choose to live in a community setting and for many of these individuals, family members provide care. A family member, or members, may move into the role of caregiver due to a number of scenarios, including hospital discharge after an acute illness, transitioning back home

after an elective surgical procedure, or assistance needed because of the impacts of chronic illness (Bass & Noelker, 1987). A survey of 1,480 family caregivers, conducted for the National Alliance for Caregiving (NAC) and AARP (Greenwald, Naiditch, & Weber-Raley, 2009), reported that 44% of caregivers provide care for a person who is over 75 years of age, and that the average age of adult care recipients in the community has risen from 66.5 years of age in 2004 to 69.3 in 2009, with over 51% of all care recipients being over age 75. These statistics will be compounded by the predicted 17% increase in the 60 and over age group in the US by 2030 (Kreidler, Campbell, Lanik, Gray, & Conrad, 1994).

Interestingly, while the data suggest that family caregiving for older adults is becoming more common, there is a limited amount of published research that has focused on families of older adults managing chronic illness. In fact, Naylor and Keating (2008) proposed that many of the studies that purport to have examined family care only collect data from the adult patient who is the receiver of care.

Consequently, families have not been extensively studied and there is limited evidence available regarding what may improve caregiver outcomes like burden, stress or depression (Mattila, Leino, Paavilainen, & Åstedt-Kurki, 2009; Robinson, 1994).

Fisher (2006) described the "notable absence of studies that address adults with chronic disease and their families" (p. 375). Gavaghan and Carroll (2002) suggest that even though there is literature available that has addressed family member needs, nursing studies that might offer solutions are only beginning to emerge. There are deficits in our knowledge base regarding family systems impact on diseases such as diabetes, asthma/chronic obstructive pulmonary disease, obesity, and cardiovascular

risk as they relate to adults (L. Fisher, 2006; Mattila et al., 2009). Again in this population, there are few studies that have examined the relationship between caregiving and outcomes for patients or families. (L. Fisher, 2006; L. Fisher & Weihs, 2000; Mattila et al., 2009; Wright & Leahey, 2005).

There is also limited knowledge of the processes through which family members choose to become caregivers to an older adult or are able to sustain a caregiver relationship. In a 2007 study, Piercy interviewed intergenerational family caregivers in order to identify the characteristics that are associated with a strong commitment to caring for older adults at home. Interview data were analyzed from two qualitative studies asking similar questions directed at adult children, children-inlaw, grandchildren or nieces who were providing care for an adult family member age 65 years or older over a period of at least three months. Those providers with a strong commitment to caregiving (defined as providing hands-on care for at least 6 months) were found to share some commonalities, the foremost being that all primary caregivers with strong commitments were women. According to Piercy, those caregivers with strong commitments also "offered compassionate care and went to considerable lengths to preserve the home care arrangement, or intended to do so if it was threatened" (2007, p. S383). Piercy identified four common themes expressed by those exhibiting a strong commitment to care, including a moral or religious basis for providing care, embracing/internalizing the caregiver identity, affection for the care recipient and the ability to provide compassionate care. Strongly committed caregivers also used common strategies to sustain their commitment, including accepting the situation and making adjustments, seeking support from other family members,

making use of formal care services to supplement care or provide respite and conceptualizing caregiving as a growth experience. In contrast, those members of the sample with weaker commitments to care described ambivalent feelings and were unable to see caregiving as a growth experience that provided purpose or enhanced self-esteem. Those with weaker commitments also expressed concerns regarding the lifestyle restrictions imposed by caregiving and described strained relations within the family. The impact of caregiving on family functioning and family relationships described in this study are similar to that described in the literature regarding parent caregiving for chronically ill children. However, this study does not contain a specific assessment of family health or functioning that can be used in adult patients.

Gallant, Spitze and Prohaska (2007) used focus group methodology to explore the positive and negative influences that family and friends had on the management of chronic illness. Participants who were enrolled were placed into 13 focus groups with a professional moderator who used a discussion guide. Groups were audio taped and analyzed independently by the study's co-investigators (Gallant, Spitze, & Prohaska, 2007). Results demonstrated that family and friends had positive influences related to dietary activities, physical activity and health care appointments. Family members, more than friends, were more likely to offer support for activities specifically related to disease-management, such as dietary activities, medication management and relationships with primary care providers (Gallant et al., 2007). In the case of older adults with diabetes, family members are often intimately involved in the day to day management activities described above, as well as recognition of symptoms and strategies for treatment of hyperglycemia or hypoglycemia, yet there are no reported

studies that describe how the nature of the family's participation changes when an older adult is hospitalized.

Another study by Prohaska and Glasser (1996) examined patients' views of family involvement in health care decisions. The researchers sought to explain if the roles differed when family members accompanied older patients to office visits and how patients perceived the family member's role. This study also examined if older patients who were accompanied to an office visit differed in health outcomes, care received or family involvement in general (Prohaska & Glasser, 1996). The researchers conducted three interviews with older adults attending physician office visits. Initial interviews occurred with older patients in the waiting room prior to an office visit, then a second face-to-face interview one week after the office visit, and a third interview via phone discussion 10-12 weeks after the office visit. Most participants reported that having a family member, or friend, present during the appointment was an advantage. In fact, a majority reported that the companion assisted with physical help, aided in communication between physician and patient, assisted in patient understanding of treatments, and provided emotional support (Prohaska & Glasser, 1996). This study provides empirical evidence for the importance of having support from family and friends during interactions with the health care system. However, it does not examine the efforts of patients and families who cope with specific disease processes, such as diabetes, which require substantial care management, nor does it examine the nature of family participation during hospitalization, presumably when the older adult is more vulnerable due to acute illness

Diabetes is one of the leading chronic illnesses among older adults. However, limited research evaluating how to best target caregivers of adult patients with diabetes has been done. In an overview of the state of knowledge of family interventions in health, Chesla (2010) reviewed meta-analyses and literature reviews published between 2004 and 2009. The author reported that when searching for studies investigating family involvement in adult chronic illnesses, there were 70 studies that focused on people with specific disease processes, including dementia (44.3%), heart disease (21.4%), frail older adults (15.7%), and cancer (7.1%), while other very prevalent diseases such as diabetes had none (Chesla, 2010).

Armour, Norris, Jack, Zhang and Fisher (2005) also conducted a systematic review of published literature relating to the effectiveness of intervention strategies that specifically included people with diabetes and their families. Only studies that evaluated effectiveness of family-based diabetes interventions in persons with diabetes and residing family members were included. Of the 19 studies discovered, 13 of them focused exclusively on children with diabetes, and only six on adults. Two studies demonstrated that when spouses or partners participated in interventions, the family member with diabetes exhibited better metabolic control. In one study there were actually improvements in glycated hemoglobin (HbA1c) levels, as well as, better diabetes knowledge related to self-management (Armour, Norris, Jack, Zhang, & Fisher, 2005). Armour, et. al (2005) point out that there continues to be a need for more well designed studies that are longitudinal and include education and involvement of family members and patients with diabetes. Interestingly these studies did not explore the impact of family caregivers other than spouses or partners for those

with diabetes, even though the data suggest that adult children are frequently involved in the care of older adults with diabetes.

Transitions in Caregiving

The most challenging periods of caregiving in chronic illness care occur as patients move across care settings, either from the home into the acute care setting or from an inpatient setting back home. The literature regarding family needs during hospitalizations of adults has focused mainly on family member's psychological coping ability during critical care admissions to specialty care units. One example is a study by Auerbach et al. (2005) who investigated the needs of family members during an intensive care admission. The main focus of this investigation was to determine if family members believed that their needs were being met and how this related to emotional stress and psychopathological dysfunction in the family (Auerbach et al., 2005). The data demonstrated that family members had increased levels of stress during patient admission to an ICU setting and that family members expressed concern with unmet needs, including a lack of clear information regarding the patient's treatment plan and medical equipment being used.

Similarly, Kosco and Warren (2000) examined differences between nurses and family members perceptions of family needs during intensive care hospitalizations. There were significant differences found between nurses and family member's perceptions in several areas. Families found it more important than nurses to have a specific staff member who could be called for updates. They also reported wanting to have reassurance that there was someone caring for the well-being of their relative if they could not visit, while nurses did not find this as important. Additionally, families

described that their need to visit at any time was not being met, yet nurses believed they were meeting this need (Kosco & Warren, 2000).

Eggenberger and Nelms (2007) also explored the family experience during a critical illness of a relative using a hermeneutic phenomenological design, which included interviews with family members. The findings indicated that family members suffered along with their critically ill relative and many reported a sense of vulnerability and distress due to troubled nurse-family relationships (Eggenberger & Nelms, 2007). There is a sizeable amount of literature regarding family stress in critical care units; however, knowledge of the impact of general hospital admissions on family functioning is limited. What further complicates this situation in the older adult population is that the role of family changes dramatically from care for the older adult with diabetes at home to the loss of control over care when the older adult is hospitalized.

The impact of caregiving may be experienced at both the level of the individual family member and the family unit as a whole. Some studies have examined how family functioning, family health and perceived social support are impacted when chronically ill older adult family members become hospitalized (Astedt-Kurki, Lehti, Tarkka, & Paavilainen, 2004; Astedt-Kurki et al., 2002; Astedt-Kurki et al., 2009; Harju, Rantanen, Tarkka, & Astedt-Kurki, 2011; Paavilainen, Lehti, Astedt-Kurki, & Tarkka, 2006; Tarkka, Paavilainen, Lehti, & Astedt-Kurki, 2003).

In a study designed to describe the perceptions that one has about their family's health, the family of patients with heart disease were asked to explore five components, including knowledge, ill-being, activity, well-being and values. For the

purposes of this study, *knowledge* was defined as knowing when one is healthy in comparison to others, while *ill-being* referred to feelings of discomfort or pain. The component of *activity* was described as interests that promote health, such as exercise. *Well-being* referred to effortless coping, freedom from pain and a carefree existence and *values* included items such as a sense of freedom, security, aesthetics and relationship to the natural environment. The researchers reported that overall, study participants reported good family health, and the best predictors of family health were family stability, effects of symptoms on daily life and family relationships (Astedt-Kurki et al., 2004). Paavilainen, et. al. (2006) further investigated how family members of cardiac patients described their perceptions of family functioning including family relationships, family stability, family resources and friendships. This study demonstrated that families of heart patients described high levels of family function, which was positively correlated with greater instrumental support from nurses.

In a phenomenological study, Tanner, Benner, Chesla and Gordon (1993) explored the unique expertise that family can offer during hospitalization. This study aimed to describe how nurses acquire the practice of "knowing the patient." Tanner and colleagues discussed their findings within two broad categories of how 130 intensive care unit nurses describe knowing their patient(s). The first type of "knowing the patient" is to appreciate the patient's *patterns of responses*, or to be able to recognize their patient(s) routine(s), coping mechanisms, physical ability and characteristics, and how they may respond to therapeutic treatments. The other way that nurses know their patient is to *know the patient as a person*, or on a personal

level, which allows for advocacy and an immediate understanding of what is happening with the patient. Families can offer health care professionals the insightful ability to "know the patient" much earlier and may even be able to assist nurses to 'know' someone who is nonverbal or comatose (Tanner, Benner, Chesla, & Gordon, 1993). If allowed to, families can aide nurses in developing an understanding of the patient's everyday life, typical behaviors, and familiar patterns. This knowledge permits nurses to become aware of what may seem like insignificant warning signals of mounting distress (Tanner et al., 1993). This is especially important in patients who have diabetes because family members learn to become experts in this individual's experience of the disease. Family caregivers become skilled at recognizing symptoms of complications as wells as patient's responses to medications. However, often times during hospitalizations families feel that this expertise is overlooked or ignored.

During transitions in care, such as from the acute care environment back home, families may once again develop heightened levels of stress. Lough (1996) explored this hospital-to-home transition process in older adults diagnosed with congestive heart failure using a grounded theory approach. Semi-structured interviews were conducted with participants two weeks following discharge from an acute care facility. The core variable identified in this study was conceptualized as 'a tentative situation' and three central processes illustrated it. Older adults in this study reported that central to their tentative situation were the *ups and downs with managing a chronic illness*. The negative aspects of managing the disease, or downs, were related to uncertainty about new medication regimes as well as the daily impact of the disease on diet and prescribed activity levels. The positives, or ups of disease management, were focused

on how the social support they received from family and friends allowed older adults to maintain their independence. When patients discussed the concept of *caregiver issues*, they reported their frustrations with having to be dependent on another for ADL and/or IADL assistance. Participants also expressed the stress they experienced if they, themselves, were also caregivers as this increased their anxiety over who would care for their loved one, as well as the participant at home. Many study participants reported *quality of life challenges* such as feelings of hopelessness, depression, or self-blame if the illness had worsened (Lough, 1996). Although this study examined transitional inconsistencies at the individual patient level, it is also relevant when working with families caring for older adults with diabetes, as they are equally prone to the negative impacts of chronic illness management.

At times family caregivers in the home work in conjunction with more formal caregivers. While intended to be supportive, this can also lead to frustration. Thus, Sims-Gould and Martin-Matthews (2010) investigated the experiences that caregivers of older family members had with in-home formal support services using in-depth semi-structured interviews with family caregivers. The authors utilized a conceptual model that they developed in a previous study to guide analysis and theme organization after interviews were read, re-read and coded independently by three members of the research team (Sims-Gould & Martin-Matthews, 2010). Two main categories of care were used to organize emerging themes identified by family members: direct care (or care provided directly to the older person by a formal caregiver) and assistive care (care provided to one caregiver from another). Sims-Gould and Martin-Matthews (2010) found that under the category of 'direct care'

caregivers reported that they were often frustrated with the instrumental assistance/tasks that they are provided with from support services. Caregivers also pointed out the importance of affective assistance, or the relationship between the formal worker and the older patient. Under the category of 'assistive care,' caregivers described the importance of caring together, managing care, as well as the ability to assure/monitor quality care from formal workers (Sims-Gould & Martin-Matthews, 2010). This study highlights that collaboration of health care workers and family members, whether in hospital or at home, is especially important in the delivery of care to older adult patients with illnesses such as diabetes. The literature, however, is insufficient regarding nurse and family collaboration during inpatient admissions for older adults with complex chronic illnesses, which suggests the need for further study.

While family members describe the benefits and satisfaction of providing care for a loved one, there is also an associated cost. One consequence that has received a great deal of attention in the literature is caregiver burden. The strain of caregiving has been associated with physical and emotional exhaustion, as well as stress and suffering (Andren & Elmstahl, 2008; Faison, Faria, & Frank, 1999; Glasdam, Timm, & Vittrup, 2010; Greenberger & Litwin, 2003; Kim & Schulz, 2008; Walsh, Estrada, & Hogan, 2004). Caregiver burden research has focused mainly on the individual caregiver. However, because caring for older adults with chronic illness may involve the whole family unit, burden also has the potential to impact the entire family unit. Therefore it is essential to examine the effects that caregiving has on the family system and how nurses may offer better support.

Family caregivers in the home provide many types of assistance for patients, which range from relatively straightforward to highly complex skills. In a national survey of 1,002 informal caregivers, Donelan et al. (2002) found that 23% of respondents provided some type of health care assistance, such as ADLs, IADLs or more complex medical tasks. Fifty-four percent of caregivers who assisted with ADLs, such as feeding, bathing, toileting or lifting reported that they had received no formal training on how to safely perform these tasks. Fifty-four percent of caregivers also reported that their family member had been hospitalized during the year leading up to this survey and 74% stated that their family member had a chronic illness. This survey also described that 43% of caregivers who were surveyed were responsible for medical tasks, such as wound care, intravenous infusion pumps, home dialysis machinery, and medication administration. Most disquieting was the discovery that 37% of caregivers were responsible for administering more than five medications per day and 12% administered ten different medications per day. As the number of medications being administered by caregivers went up, so too did the number or caregivers reporting errors in administration. Many caregivers reported they received no instruction on how to properly administer medications (18%) or how to change dressings or use medical equipment (one-third) (Donelan et al., 2002). This study provides clear details of the complexities involved in family caregiving of chronically ill patients. The literature, however, provides relatively few descriptions of the specific nature of family caregiving for older adults with diabetes and even less about how this changes when older adult is hospitalized.

As one of the leading chronic illnesses with great potential for complications as well as ADL or IADL impairments, diabetes has a great potential for leading to high levels of caregiver burden. This was corroborated by a national US study that computed the amount of hours of weekly caregiving that caregivers undertake when caring for older adults with diabetes (Langa et al., 2002). This study examined the amount of time and cost associated in the informal care of 7,438 older adults and found that caregivers of family members who have diabetes spend greater amounts of time providing care than caregivers of family members without diabetes. The amount of weekly hours in caregiving was mainly associated with medication administration, with patients who require insulin administration averaging the highest weekly hours at 14.4 hours (p < 0.01) (Langa et al., 2002).

The amount of weekly hours in relation to the number and type of activities, especially medication administration, needed by care recipients imposes a significant burden on caregivers. One study highlights what types of caregiving, as well as characteristics of the caregiver, are associated with higher levels of burden (Faison et al., 1999). In a descriptive survey study of 88 family caregivers of chronically ill patients, Faison et al. (1999) report a significant correlation between increased ADL assistance needed by care recipients and caregiver burden. Those direct care activities with the highest correlations to caregiver burden were bathing (r = .215, p < .05), transfer (r = .255, p < .05) and continence care (r = .269, p < .05); and indirect care activities relating to high caregiver burden were meal preparation (r = .325, p < .01), medication assistance (r = .237, p < .05) and housework (r = .294, p < .05) (Faison et al., 1999).

Andren and Elmstahl (2008) studied the relationships between caregiver burden, perceived health and sense of coherence in 130 family caregivers of people with dementia. In this study, 57% of respondents reported moderate levels of burnout, and the highest levels were associated with being a close relative of the person receiving care. Family caregivers were asked yes or no questions in relation to symptoms using the Nottingham Health Profile Scale, which measures energy, emotional reactions, social isolation, sleep, pain and physical mobility. The authors described strong correlations between high levels of burden, such as strain, isolation, disappointment and emotional involvement with perceived health and sense of coherence. Caregivers who reported higher levels of burden also reported a lower sense of overall health as well as a lower sense of coherence. Andren and Elmstahl (2008) found that a close relationship to the patient was correlated with higher burden for the caregiver. This study also highlighted the relationship between healthier caregiver coping strategies, such as considering problems as a challenge rather than a misfortune, with better-perceived health. This has great implications for how nurses can assist caregivers in positively reframing experiences through more effective coping strategies.

There are resources that nurses can use to better support families in attaining improved family functioning and overall family health. For instance, if families receive proper instruction, they may be better prepared to prevent future exacerbations that are so often associated with chronic illness. Levine, Halper, Peist and Gold (2010) point out that gaps in continuity of care, including lack of instruction, can occur because of poorly planned out transitions in care with family members. A breakdown

in communication between acute care providers and home caregivers has been linked to high re-hospitalizations, as well as low satisfaction rates, and most concerning, adverse effects (Naylor & Keating, 2008). Similarly, Jencks, Williams, and Coleman (2009) report that poor transitions in care can lead to multiple, costly and stressful rehospitalizations, with progressive deterioration and even death. Some research has begun to demonstrate, however, that improving communication between health care providers and families during hospitalizations of loved ones can decrease length of stay, resource utilization and psychological disturbances (Ahrens, Yancey, & Kollef, 2003; Bauer et al., 2009; Black, Boore, & Parahoo, 2011). For example Ahrens, Yancey and Kollef (2003) established a medical ICU communication team that aimed to evaluate the effectiveness of improved communication between health care professionals and families. The results of this study demonstrated that family participants who were enrolled in the intervention group and received increased communication from the team, had reduced lengths of stay (9.5 days for the standard care group compared to 6.1 days for the intervention group). Similarly, Black, Boore and Parahoo (2010) discovered that when nurses facilitated family participation in psychological care during critical care admissions patients have shorter lengths of stay and recovered better psychologically.

Tarkka, Paavilinen, Lehti and Astedt-Kurki (2003) examined the social support that families of heart patients described receiving from nurses during hospitalization of a loved one. For this study, social support was defined using Kahn's (1979) definition of social support:

...intentional human interaction that involves one or more of the following elements: *affect*, which refers to appreciation, admiration respect or love, as well as creating a sense of security; *affirmation* which includes reinforcement, feedback, and influencing the individual's way of making decisions and finally *concrete aid*, such as objects or money, and spending time in helping someone (Tarkka et al., 2003, p.737).

The concept of social support has been widely explored in the literature, and the definition used by Tarkka, et. al is consistent with House's (1944) foundational definition. House described four broad domains of support, including emotional support, instrumental support, informational support and appraisal support. The first category of social support is emotional support, which is providing empathy, love, caring, etc. Instrumental support constitutes those behaviors that directly help the person in need, such as paying bills or grocery shopping. Informational support includes those activities that provide a person with information that the person can use to better cope. The last domain is appraisal support, which is providing support that is significant to self-evaluation (House, 1944). Tarkka et al. (2003) found that families frequently describe receiving emotional support from nurses, however generally they were not satisfied with the amount of support they received. There were several predictors of increased satisfaction with social support including family structure, patient's age, gender of family member and previous hospitalizations for cardiac symptoms. Although there is a great need to do so, the perceptions of social support that family members caring for older adults with diabetes feel they have received have not yet been explored.

During very unpredictable times for families of chronically ill patients, nurses have the opportunity to being able to offer support. Levesque et al. (2010) explored the experience of caregivers taking care of aging family members at home. This study aimed to investigate the strategies that practitioners use to engage caregivers as partners and what the perceived benefits were for both caregivers and practitioners when working in partnerships. The researchers conducted qualitative focus groups with practitioners and interviews with family caregivers. The study revealed that practitioners used strategies such as sensitive listening or enabling questions (exploratory, non-confrontational questions) to determine caregiver needs and to encourage caregivers to problem-solve. The caregivers reported that an establishment of trust was important in allowing for expressions of concerns and reflection of their situation. Caregivers also described the importance of feeling as though they were participating in decision-making and that that their contribution mattered (Levesque et al., 2010). Contrary to this, Grimmer, Moss and Falco (2004) reported that many caregivers described being unprepared and imposed upon for their role as caregiver of an elderly person in their qualitative study utilizing semi-structured interviews with family caregivers. The researchers in this study analyzed data from repeated interviews, over the course of six months, with twenty-four family caregivers of an elderly person who had been discharged home after an acute hospital admission (Grimmer et al., 2004). The researchers noted that many participants believed they had no choice in becoming caregivers and were given little information to help them in caring for the patient after discharge. Overall caregivers described that receiving more education prior to discharge regarding what to expect, how to manage medications,

how to performs ADL's and where to seek assistance would have been beneficial (Grimmer et al., 2004). Often patients with diabetes are discharged home with changes to medication regimes, alterations in dietary needs and greater ADL assistance. However, family caregivers often receive very limited discharge instructions.

Some studies have attempted to evaluate the causes of the disparity between what families feel they need to know and what information or training nurses feel families should receive. In a descriptive qualitative study by Yen et al. (2010), patients' and health care professionals' were asked to describe their perspectives related to problems and solutions that are associated with chronic illness. The researchers conducted ten focus groups and seven interviews (n=88) to explore how health care professionals viewed the three main themes that were revealed in a previous qualitative study of 54 patients and 14 caregivers related to chronic illness concerns. The main concerns discovered were related to economic hardship, managing co-morbid conditions and managing multiple competing demands (Yen et al., 2010). Two main themes were identified, patient compliance and service fragmentation. Patient compliance was described as the perspective that patients frequently act in ways that are not in accordance with what their health care providers see as normal or optimal. The theme of service fragmentation relates to the gaps in communication and philosophy that so often exists between, and within, health care agencies. Health care professionals most often used the term 'compliance' as being the actual issue for patients who described problems in managing co-morbid conditions, daily lives and/or economic burdens related to chronic illness. Patients stressed their feelings regarding fragmentation of services, health care system inefficiencies and the inability of

individual agencies to collaborate and work together. In contrast, health care professionals faulted colleagues from other disciplines rather than addressing what their discipline could do differently (Yen et al., 2010). This study illustrates the inconsistencies in how families and nurses interact, and further demonstrates the importance of exploring the best ways to enhance nurse-family relationships.

Nurses have many different views about the best way they can work with families. Robinson (1994) has identified three main orientations impacting the way nurses collaborate with families, which she labeled as traditional, translational and non-traditional. Robinson proposed that these three orientations or approaches shape the way nurses practice family nursing. The traditional family orientation views the family as context rather than a unit of care (Robinson, 1994). The primary focus for health care providers who hold a traditional orientation in family intervention is the patient with the chronic condition. A nurse who holds a traditional orientation believes that family influences their loved one's experiences, therefore family treatments may only focus on the family as it assists them in caring for the client. Professional caregivers who hold traditional views of chronic illness care will often only seek out the family member most likely to give the desired response. If a family member resists a recommended intervention, then there must be something "wrong" with the family, and more offering of family education is often the recommended intervention (Robinson, 1994).

Robinson (1994) posited that nurses with a *transitional* orientation concentrate on the family as a group, made up of multiple individuals, not as a system with interacting parts. There is a belief that there is a "right" way for families to experience

and interact during chronic illness and that there is a "correct" approach. Transitional methods tend to be those that are more standardized and do not take into account the reciprocity which occurs in families (Robinson, 1994). Nurses who have a transitional orientation to family care may choose to intervene in ways that help family members individually cope with a chronic illness of a loved one but may not evaluate how the family unit impacts the progression and treatment of the illness. The practice of FCC is consistent with the transitional approach to family nursing, in which standard practices such as pre-scheduled family meetings are the main focus for all patients admitted to an institution.

Non-traditional orientations to family nursing have been identified as supporting a family's ability to change (Robinson, 1994). This orientation focuses on the family system as the client, as opposed to the more linear views of family, seen in the traditional and the transitional orientations. Nurses who intervene using a non-traditional approach to family care realize that there may not be one "correct" or "right" intervention. The main concentration in a non-traditional approach is on family interactions and relationships and the reciprocity between family functioning and chronic illness. Robinson (1994) proposes that families who are approached through a non-traditional family nursing orientation are able to reframe situations in a positive way, which enables better coping and problem-solving skills. As chronic illnesses of older adults become more and more of a family matter, nurses must become more adept at both holistic family assessments and the most beneficial family interventions for a particular family. Wright and Leahey (2005) point out that it is especially

important for family-level care to be individualized and based on a thorough assessment of each unique family.

Some researchers have explored the usefulness of non-traditional methods through such models as the Family Systems Nursing (FSN) approach. Duhamel, Watson and Wright (1994) explored how nurses can employ FSN as an approach with families caring for someone with hypertension. The researchers used a case-study design to investigate the usefulness of individualized family systems nursing sessions in family coping, perceived stress, anxiety levels and blood pressure readings. The results indicated that the FSN sessions were useful as the patient's blood pressure did decrease and stayed that way for over six months. The patient's perceived stress and anxiety scores also remained decreased from baseline, while the family's coping resources increased.

LeGrow and Rossen (2005) had similar findings in their qualitative study that evaluated the effectiveness of using a Family Systems Nursing approach in a pediatric rehabilitation center. Seventeen nurses and thirteen parents participated in focus groups, semi-structured interviews, and surveys that assessed the impact of using family systems nursing. The findings of this study revealed a positive impact of using the Calgary Family Assessment Model (CFAM) and the Calgary Family Interventional Model (CFIM) in a pediatric rehabilitation setting. Nurses in this study reported a greater awareness of how illness affects the family, the importance of focusing on the whole family as the unit of care and the need to establish good communications and interactions with families. Likewise families noted increased

communication and better rapport with nurses, which seemed to improve overall family health and function (Legrow & Rossen, 2005).

Summary

With chronic illness in the older adult population, notably diabetes mellitus, accounting for such large percentages of heath care expenditures, the development of nursing knowledge related to family care needs is necessary for improvement of future health care delivery. The literature presented describes the increasing evidence that involvement of family during transitions in care for chronically ill family members may not only increase client and family satisfaction during admissions, it may also decrease length of stay and therefore cost to the health care system. Family caregivers, however, are faced with a multitude of tasks related to care for their chronically ill family member and may feel inadequately prepared for their role.

Although there has been an increase in family nursing research over the past several decades, there are few studies that explore family involvement in adult patients with a chronic illness. There are large gaps in the literature that examine how caring for a chronically ill older adult with diabetes impacts families, especially when the older adult is hospitalized or discharged back home. There are also few studies that have explored how nurses may better support families, and none that specifically investigate families of older adults with diabetes. Therefore there is a need to further investigate if a relationship exists between how nurses perceive their family nursing practice and how families caring for older adults with diabetes view their family functioning, family health and the social support they receive from nurses.

CHAPTER 3

THEORETICAL FRAMEWORK

This study was framed by the Calgary Family Intervention Model, which is a model rooted in Family Systems Nursing. The Family Systems Nursing approach focuses on the whole family as the unit of care, allowing the nurse to simultaneously focus on the patient, the family and the patient's illness. Wright and Leahey (1990, 1994) point out that this is in contrast to the concept of *family nursing*, which focuses either just on the family or just on the individual patient. One example of family nursing is family centered care (FCC), which focuses predominantly on techniques such as nurses providing patient information for family and instituting better family visitation policies (White et al., 2002). FCC has been used primarily in pediatrics as a means of improving parent satisfaction, and although the ideal of FCC is promoted by many nurses, some authors are now reporting that it may not be as effective as was first thought (Berman, 1991; Shields, 2010).

Distinct from FCC is Family Systems Nursing, which establishes a partnership of mutual trust, regular communication and relationship building among nurses, patients and families, which equates to improved healthcare outcomes for patients (Leahey, Harper-Jaques, Stout, & Levac, 1995). By permitting such a multi-faceted interface, there is an opportunity for authentic and meaningful relationships to occur between the nurse and the family. This approach to family nursing is useful in a variety of client populations, including families who are managing the care of patients who have diabetes.

Family Systems Nursing (FSN) is first mentioned in the literature in 1990, although it was developed and used clinical slightly earlier (Wright & Leahey, 1990). The creation of FSN resulted out of what Wright and Leahey believed was a need to focus on the whole family as the unit of care. The foundational work by Wright and Leahey (Wright & Leahey, 1984) was truly the basis for the Calgary Family Assessment Model, while the Calgary Family Intervention Model was not added until 1994 (Wright & Leahey, 1994). Wright and Leahey developed FSN, CFAM and CFIM as a result of their experiences working as family nurse clinicians, teachers, researchers and authors.

The fundamental concept in Family Systems Nursing is the interaction between the family members, and the belief that the questions which best assess this interaction will focus on the relationships amongst all individuals that the patient considers significant. Family systems nursing was developed as a way of creating more structured partnerships between families and nurses, and the outcomes were intended to have implications for nursing practice, research and education (Wright & Leahey, 1990). They propose that the relationship between the health care professional and the family greatly affects the outcome of family nursing practices (Wright & Leahey, 1994). This is why examining the potential relationship between how families describe nursing support and how nurses describe their family nursing practice is so important.

The work of Family Systems Nursing is accomplished using two practice models, the Calgary Family Assessment Model CFAM and the Calgary Family Intervention Model (CFIM). A nurse who practices family systems nursing may

incorporate one, or both, the CFAM and the CFIM. Many family systems nurses incorporate a family assessment, which may utilize CFAM, in which the bio-psychosocial structure of the family is evaluated, allowing for application of individualized family nursing practice as suggested by the CFIM (Svavardottir, 2008). The CFAM can be used as an organizing framework or as a template to guide nurses when working with families. Both of these practice models are especially useful in family research where the objective is to investigate both family dynamics and specific nursing practices that enhance family functioning. Calgary Family Intervention Model (CFIM) gives nurses, as well as other health care providers, the tools to generate change for a family that is managing the tribulations and exacerbations that can occur during the course of a chronic illness such as diabetes.

Wright and Leahey (2005) assert that in order to accurately apply the underlying principles and meanings of the CFAM and CFIM models, it is important to understand their influences. Family systems nursing, as well as the CFAM and CFIM frameworks, have been developed from multiple philosophies and standpoints, such as: postmodernism, systems theory, cybernetics, communication theory, change theory, and biology of cognition. According to Wright and Leahey, CFAM and CFIM have been greatly influenced by a worldview know as the biology of cognition (Maturana & Varela, 1992). The biology of cognition suggests that there are two ways of viewing the world, objectivity and objectivity-in-parentheses (Wright & Leahey, 2005). In other words, we never really leave our own domain of activity, there is no independent object of study, thus there is nothing subjective either (Efran & Lukens, 1985). Maturana (1988) furthers this by stating that reality is not constructed, nor is it

independent of individuals, it is instead drawn forth. Therefore, there are multiple views of reality, or a multiverse, which we bring forth through our interactions with the world and others through language.

The Calgary family intervention model has also been influenced by frameworks such as postmodernism, which inspired Wright and Leahey to infuse their practice models with multiple ways of understanding and experiencing the world. These values are especially significant when working with families of patients with diabetes, as in this study, who experience and understand chronic illness in various manners (Wright & Leahey, 2005).

Wright and Leahey (2005) believe that if a connection can be made between a particular area of family functioning and activities offered by the nurse, there will be improvements in the family's health as well as enhancements in the nurse-family relationship. There are three domains of family functioning (a) the cognitive; (b) the affective; (c) the behavioral. The CFIM attempts to promote, improve and/or sustain change in any one of the domains, or all three simultaneously (Wright & Leahey, 1994, 2005). After a family assessment has been conducted, the nurse (or other health care professional) can then come to a decision regarding the best approach for that family. Nurses may work with families to invoke change in any of the three domains. However, modifications in the cognitive domain are believed to be the most compelling, as they impact family beliefs. Wright and Leahey (2005) additionally state that the family must be open to the ideas that are being offered. One potential lens for initially evaluating family systems nursing and the fit of CFIM is to describe if a relationship exists between how families perceive their family function and the

support received from nurses with the perceptions of nurses regarding their family nursing practice.

A significant factor that determines whether or not change will occur is allowing the family to feel as though they have contributed to the type of support that is most needed. Wright and Leahey (1994) state that while health professionals can suggest what methods may best help the family, family members must be willing participants, which may vary according to their genetic make-up and history of family interactions. The ability for the nurse to incite change is also profoundly influenced by the relationship between the nurse and the family and the nurse's ability to invite the family to contemplate the family unit's health problems (Wright & Leahey, 1994). This is why a study which aimed to examine associations between families' perceptions of social support received by nurses and nurses' perceptions of their practice and the nurse-family relationship is so important.

In their description of the CFIM, Wright and Leahey recommend the use of various techniques for nurses to carry out with families, many of which target a particular domain of family functioning. For example, if a family is having trouble coping with a health problem due to their perceptions, then the cognitive domain may be where the nurse will want to work at improving family function. The first technique suggested is to *commend family and individual strengths*, by observing patterns of behavior. There are a few considerations when offering commendations (a) compliments should not just be simple one-time occurrences; (b) they should be warranted; (c) they should occur within the first ten minutes of meeting with a family; (d) they should become part of a practice with each family. Also the *offering of*

information and opinions is important and places strong emphasis on giving patient information. Wright and Leahey (2005) recommend the use of easily readable literature, community support and encouragement of the family's continued pursuit of information. The avoidance of judgment if a family does not make use of the information is also relevant in family nursing practice.

The aim of increasing or reducing intense emotions, which may be interfering with family functioning, is part of the affective domain. In order for a family to resolve issues within this domain, it is crucial to decrease feelings of isolation, therefore *validating or normalizing emotional responses* is advised. Encouraging the use of "storying" (Wright & Leahey, 1994) or *the telling of illness narratives* (Wright & Leahey, 2005) is also suggested, with an emphasis on narrating the experience of the illness, not just the "medical story." Additionally, nurses can be a catalyst for enhancing therapeutic communication among family members by *drawing forth family support* and allowing all family members to feel heard. This is quite the opposite of what often takes place when an older adult family member with chronic illness is hospitalized and the family's input, feelings and knowledge are discarded.

The behavioral domain requires that the nurse facilitate alternative interactions among family members by encouraging the use of specific behavioral tasks. The first behavior suggested is to *encourage family members to be caregivers and offering caregiver support*. What this task really encourages is a family member's participation in care giving, while at the same time offering needed information, advocacy and support. Associated with this is the act of *encouraging respite*, so as to avoid burden and burnout. Devising rituals, especially when daily routines have become disrupted

due to illness can have a beneficial outcome on a family's behavioral interactions (Wright & Leahey, 2005)

Wright and Leahey (2005) also describe a simple, yet highly influential skill of questioning as a key technique offered by the CFIM. There are two basic types of questioning for nurses to use with families: linear and circular. Linear questions are directed at eliciting information from families, which may be significant to health care providers. However they may not provide information about the family's comprehension of a problem. Circular questions alternatively explore explanations of problems in an effort to change a family's behavior regarding either illness or a family difficulty (Simpson, Yeung, Kwan, & Wah, 2006; Wright & Leahey, 1994, 2005). Circular questions also assist nurses in learning a family's perceptions of an illness and the meanings of relationships. For example a linear question that explores a family member's perceptions about breast cancer may ask the patient's husband "when did your wife first begin complaining of pain?" In contrast, a circular question regarding the same illness may instead ask the patient's husband "who in your family is most concerned about Mrs. G's illness?" The circular question is not just concerned with information, but rather on meanings, values and beliefs about the illness and its impact on the family unit. By asking questions that gather information about the family's feelings or values, nurses may gain insight into what this family needs.

Wright and Leahey (2005) further expand the use of circular questions with the suggestion of four different question types (a) Difference questions; (b) Behavioral Effect; (c) Hypothetical/ Future-oriented; (d) Triadic questions. All four types can effect change in any or all three domains of family functioning, but are contingent on

the fit of the question within the domain that requires modification. Difference questions investigate the variations or discrepancies that can occur in families regarding ideas or beliefs. Questions that explore the effects that one family member's behavior may have on another member are of the behavioral effect type. It is also essential for nurses to have the tools to probe the 'what if...' situations that a family may encounter, and to potentially suggest alternative actions or meanings, which hypothetical questions may assist with. The last type are triadic, which ask an individual to consider the relationship of two other family members in terms of family functioning (Wright & Leahey, 2005).

Theoretical Description

Wright and Leahey (2005) have outlined several assumptions that are central to understanding and practicing the Calgary family models. These assumptions have implications for the nurse-family relationship, as well as clinical applications of the family nursing practice. The main assumption of Wright and Leahey's work is that *the nurse-family relationship is characterized by reciprocity*. The concentration in Family Systems Nursing is in creating "partnerships" built on mutual trust, on-going communication, and participation in meeting the health care needs of the client and their family. Wright and Leahey state that the pattern of the family and the nurse using Family Systems Nursing is "quite distinct from the positivist-based idea of two separate components, either family or nurse" (Wright & Leahey, 2005).

Family systems nurses view *the family-nurse relationship as non-hierarchical* (Wright & Leahey, 2005). Therefore, contributions to assessment and intervention are co-created by both family and nurses, where each person's involvement is needed and

valued. Wright and Leahey (2005) also believe that *nurses and families each have* specialized expertise in maintaining health and managing health problems. Because families are the ones living with, near and alongside chronic illnesses on a daily basis, nurses must recognize and appreciate the knowledge which families provide. Similarly, nurses also have expert knowledge based on their education and experience. Nurses must realize that their expectations of illness management are not necessarily the only way, nor even the best approach for individual families.

A family systems nurse believes that *nurses and families each bring strengths* and resources to the family-nurse relationship (Wright & Leahey, 2005). Nurses who identify individual resources within each family including those unique to a family's culture, ethnicity, and spiritual or other beliefs are able to assist families in acknowledging their strengths or their weaknesses. Another critical element in providing family systems nursing is to recognize that *feedback processes can occur simultaneously at several different relationship levels*. Wright and Leahey (2005) state that nurses should invite the family to reflect on their evaluation of the encounter they had with the nurse, while also self-reflecting on how they believed they impacted the family's health and/or coping.

Wright and Leahey (2005) additionally discuss guiding principles that a Family System's nurse should follow. Family System's nurses will conceptualize the interaction between an illness and the individual patient as well as having an understanding of the reciprocal influence that the patient (and family) has in maintaining, aggravating or ameliorating the illness. Therefore nurses must concentrate on the interconnections between illness, individual and family. Wright and

Leahey (2005) also suggest that nurses should reflect on research that illustrates these interconnections and should assess interaction at all systems levels and across system levels with a focus on intervening at the family system level with the greatest leverage for change (Wright & Leahey, 1990).

There are several essential concepts that are critical in understanding the FSN, CFAM and CFIM. The first is the family system, which is distinct for each family unit and can be defined as 'the family is who they say they are' (Wright & Leahey, 2005). In family systems nursing, the focus of care is seen as circular, so instead of 'either/or' it is 'both/and' (Wright & Leahey, 1990). Interaction is a second important concept to FSN, as it indicates the interrelatedness of the illness, the individual, the family and the nurse. The third central concept in FSN is reciprocity, which is best described as a family member's response to the patient and the illness and simultaneously the patient's response to the family and the illness. A fourth critical concept in FSN, especially the CFIM, is the domains of family functioning, which are the cognitive, affective, and behavioral domains. The cognitive domain focuses on the family's beliefs, while the affective domain relates to emotions that may be influencing a family's functioning and the behavioral domain concentrates on the ways in which family members behave towards one another.

The fifth concept, fit, is also of importance to FSN, CFAM and CFIM. Wright and Leahey (1994) use this concept to emphasize the suitability of a chosen nursing approach for the presenting problem. If a nursing approach fits, then it should cause change. Fit involves recognition of reciprocity between the health professional's ideas/opinions and the family's illness experience. The final concept, which in

comparison to other family nursing frameworks is exclusive to family systems nursing, is intervention. An intervention or approach to family nursing can be used to promote, improve or sustain function in one or all three domains of family functioning. Interventions suggested by CFIM include actions such as storying the illness experience, encouraging respite, and asking interventive questions are presented.

Summary

Older adults are particularly susceptible to errors occurring during the numerous transitions in care that they so often experience. A Family Systems Nursing approach, particularly using the CFIM, allows for the inclusion of family in care during transitional periods for older adults. By encouraging such thorough interactions, it has been suggested that there will be improvements in the family-nurse relationships as well as family well-being. Wright's and Leahey's (1984, 1990, 1994, 2005) approach recognizes the family as the individual unit of care, but some of the work in the literature around older adults suggests that while many members of the family are involved in care, they each have individual perceptions. This study used a family systems nursing approach, guided by the CFIM model to examine how the family describes family functioning, family health and perceived social support received from nurses and how this relates to nurses appraisal of their family nursing practice.

CHAPTER 4

METHODOLOGY

While the literature related to family nursing supports the belief that families who have an older adult hospitalized with diabetes may experience an interruption in their family's normal health and function (Chesla, 1996, 2010; Mattila et al., 2009; Rutledge et al., 2000a; Rutledge et al., 2000b), there are no comprehensive descriptions of these relationships in the literature. Similarly, while there is theoretical support for the belief that a nursing approach which values family participation may impact family function, family health and perceived social support (Wright & Leahey, 1994), the literature has not yet begun to explore these relationships as they relate specifically to the families of older adults hospitalized with diabetes.

This study explored family members' descriptions of their family functioning, family health and perceived social support during the hospitalization of an older adult family member with diabetes. Similarly, the study was designed to examine nurses' critical appraisal of their family nursing practice and nurses' experience of interaction and reciprocity in the nurse-family relationship. The relationship between nurses' critical appraisal of their family nursing practice, and nurses' experience of the interaction and reciprocity in the nurse-family relationship, with families' perceptions of their family function, family health and social support was also assessed. Finally, the study explored differences in nurses' critical appraisal of their family nursing practice, and nurses' experience of the interaction and reciprocity in the nurse-family relationship, across the nursing units as well as the impact these differences may have on family perceptions of family function, family health and social support received.

Research Questions

This descriptive study was designed to answer the following research questions:

- 1. How do families of older adult patients with diabetes describe their family functioning, family health and perceived social support from nurses during hospitalization?
- 2. How do nurses caring for older adult patients with diabetes, and their families, critically appraise their family nursing practice and what are nurses' experiences of interaction and reciprocity in the nurse-family relationship?
- 3. What is the relationship between nurses' critical appraisals of their family nursing practice and nurses' experiences of the interaction and reciprocity in the nurse-family relationship with families' perceptions of family function, family health and perceived social support from nurses?
- 4. Do nurses' critical appraisal of their family nursing practice, and their experience of the interaction and reciprocity in the nurse-family relationship, differ across the nursing units, and if so does this impact families' perceptions of family function, family health and social support received?

Design

This study was a descriptive correlational design conducted on four medicalsurgical units in a community hospital. Wright and Leahey's Calgary Family Intervention Model (CFIM) (1994) undergirded this study, which focused on nurses' critical appraisal of their family nursing practice and their experiences of the interaction and reciprocity in the nurse-family relationship as it relates to family members' reports of family functioning, family health and perceived social support.

Setting

A metropolitan community hospital was the setting for this study. This hospital has achieved ANCC Magnet designation on three occasions. Magnet designation is a recognition awarded by the American Nurses Credentialing Center (ANCC) to health care organizations based on quality patient care, nursing excellence and innovations in professional nursing practice. Approximately 6.61% of all US hospitals have achieved ANCC Magnet recognition status and eight of the top ten medical centers are ANCC Magnet organizations (ANCC, 2012). Health care organizations that have achieved Magnet status three times consecutively, unquestionably meet the main goals of the Magnet program: to promote quality in a setting that supports professional practice, identify excellence in the delivery of nursing services to patients/residents and disseminate best practices in nursing services (ANCC, 2012).

This study was conducted on four medical-surgical units within this community hospital. The units all have a similar average daily census of 32 patients and admit similar general medical-surgical patients, many of whom are older than age 65. Per quarter, all four units admit comparable numbers of patients with complications related to diabetes. There is an average of seven registered nurses providing patient care during the 7am-7pm shift and six nurses assigned during the 7pm-7am hours on each of the units.

Sample

Nursing is unique and differs from other health care professions where patients are cared for in a one-to-one patient-provider relationship. Nurses work as members of a team where patients may have multiple registered nurses caring for them within any given day. Previous work suggests that the particular nursing unit on which a nurse works profoundly shapes individual nursing practice (Lauzon Clabo, 2008). Additionally, nurses practicing on the same unit have remarkably similar orientations to practice that may vary widely across units in the same organization (Lauzon Clabo, 2008). Since patients and families received care from multiple nurses on a specific unit, the data in this study were analyzed by unit, rather than by individual.

Although Wright and Leahey's approach recognizes the whole family, and not just one member, as the unit of care, for the purposes of this study, family data were collected from one family member. Previous research (Astedt-Kurki et al., 2002; Astedt-Kurki et al., 2009) has suggested that in viewing the family as a whole unit, with individual members remaining in the background, one member can provide aggregate data on behalf of the family. Therefore, this study utilized a slightly different approach to that of Wright and Leahey. The older adult patient with diabetes was asked to identify one family member most responsible for their care.

The families included as participants in this study were a convenience sample of families of all older adults (age >65) admitted to the four medical-surgical units who had a diagnosis of diabetes. Family members or clients who were unable to consent to health care treatments, or who were unable to communicate in English,

were excluded. Family study participants had to be at least 18 years of age and patients had to living at home.

Sample Size

This study assessed two distinct populations on four medical-surgical units in one community hospital. The sample size of 60 was estimated using detectable difference for fixed samples. As Table 1 shows, to achieve 80% power a moderate to slightly larger than moderate effect size for two normally distributed variables (α =.05, two sided test) is determined. In order to detect a nonzero association when using a fixed sample, stronger associations (larger effect sizes or r) are needed to increase power. Table 2 illustrates correlation coefficients and effect sizes which remain in the moderate to slightly greater than moderate range for a sample size of 60 (n=60, r = 0.345, power=80%) (Cohen, 1988, 1992).

Measures

Two instruments were used to assess the variables of interest in this study. The Family Function, Family Health and Social Support Scale (FAFHES) (Appendix E) is designed to assess family perceptions regarding family health, family functioning and social support received from nurses, when a family member is admitted to a hospital (Astedt-Kurki et al., 2002). The FAFHES has demonstrated reliability in two studies (Astedt-Kurki et al., 2002; Astedt-Kurki et al., 2009), with all three subscales: family functioning subscale, ($\alpha = 0.92$ and 0.92), family health subscale ($\alpha = 0.76$ and 0.80) and social support subscale ($\alpha = 0.97$ and 0.98) demonstrating acceptable to excellent internal consistency reliability. The FAFHES instrument was also evaluated for construct validity, using factor analysis, as well as content validity, using expert

reviewers. The FAFHES was administered to family members of patients with diabetes admitted to four medical-surgical units of a community hospital during the data collection period. Family member participants additionally completed a demographic questionnaire.

The Family Nursing Practice Scale (FNPS) (Appendix I) (Simpson & Tarrant, 2006; Simpson et al., 2006) was administered to all Registered Nurses working on the same medical-surgical units as the family/patient participants at the same community hospital. The FNPS was used to assess two variables: 1) nurses' critical appraisal of their individual family nursing practice and 2) nurses' experiences of interaction and reciprocity in the nurse-family relationship (Simpson & Tarrant, 2006).

This FNPS instrument was developed using the frameworks of Family Systems Nursing, including the Calgary Family Assessment Model and the Calgary Family Interventional Model and has demonstrated reliability and validity in a preliminary psychometric analysis (Simpson & Tarrant, 2006). Simpson and Tarrant (2006) conducted a pilot study of the FNPS evaluating stability using test-retest reliability, as well as internal consistency which revealed acceptable internal consistency for each of the subscales (practice appraisal subscale: α =0.85 and nurse-family relationship subscale: α = 0.73). The instrument was also evaluated for face and content validity utilizing expert content review, and factor analysis was conducted to establish construct validity. The FNPS also includes three open-ended questions providing additional levels of rich detail in three domains, including: the advantages of involving families in nursing practice, the disadvantages of involving families in nursing practice and how nurses are currently including families in their nursing practice

(Simpson & Tarrant, 2006). In addition, all Registered Nurse participants completed a demographic questionnaire.

Ethical Considerations

Institutional Review Board approval from both the hospital and the University of Rhode Island was obtained prior to conducting this study. The timeline for the study included dissertation proposal approval from the author's dissertation committee in May 2012. The IRB application then began after the May 2012 meeting with data collection starting in November 2012 and ending in April 2013.

Procedure

Adult patients over the age of 65 admitted to any of the four medical-surgical units who had a diagnosis of diabetes (either as a primary diagnosis or as part of the patient's past medical history) were approached and if they permitted, the purpose of the study was fully explained. They were then asked for their verbal consent, via a patient script (see Appendix A) to consider accepting and giving a post-card (see Appendix B) to their family member, who they feel is their primary caregiver at home. This post-card explained the nature and purpose of this research study and what to expect if the family member chose to participate. It included the name and number of the doctoral student responsible for the research study. When a family member contacted the researcher, the researcher asked for verbal consent, via the provided family member script (see Appendix C). If the family member was willing to respond to survey questions from the Family Functioning, Family Health and Perceived Social Support (FAFHES) instrument, as well as the demographic questionnaire, they were asked if they would prefer to do so via a phone interview, or if they would rather have

the surveys mailed to them. If they preferred to respond to a mailed survey, the FAFHES instrument and demographic forms (see Appendices D and E) were mailed, as well as an informational letter (see Appendix F). They were asked to return completed surveys in the included stamped envelope to the researcher's address. Return of the completed FAFHES instrument, as well as the family member demographic form (see Appendices D and E) implied consent. Study participants took approximately 20 minutes to complete the questionnaire.

Additionally, the researcher asked all Registered Nurses employed on the four study units to complete the Family Nursing Practice Scale. The study's purpose and request to participate was explained through an informational letter (see Appendix G). Face-to-face discussion was also available if the nurses had any questions or concerns. Return of the completed FNPS instrument, as well as the nursing demographic form (see Appendices H and I) implied consent. Completion of the surveys took approximately 10-15 minutes to complete the questionnaire.

Data Analysis

Descriptive statistics (means, standard deviations, frequencies, and percentages) were used to summarize demographic characteristics for both the nurse and family samples. Continuous variable distributions were further examined for violations of normality. Additionally, demographics and study variables were examined at the unit level, using Chi-Square analysis to determine if these variables differed by medical-surgical unit. The method of analysis chosen for each research question is shown in Table 3.

Analysis of variance was used to examine differences in the continuous variables (family nursing practice, practice appraisal, nurse-family relationship, family functioning, family health and perceived social support) by medical-surgical unit. Chi Squared tests were used to assess the associations of categorical variables (age, gender, education, nursing years, current unit years, marital status, relation to patient, living arrangements (i.e. with or apart from the identified patient), years with diabetes, and number of times hospitalized) by medical-surgical unit (Polit & Beck, 2008). Accounting for the impact of the medical-surgical unit is very important since significant unit variations can adversely affect the ability to find statistically significant results in the variables of interest (Chen, 2012).

The relationships between nurses' critical appraisal of their family nursing practice and nurses' experiences of the interaction and reciprocity in the nurse-family relationship, with families' perceptions of family function, family health and perceived social support, were analyzed using linear regression analysis (Munro, 2005). To determine if nurses' critical appraisal of their family nursing practice and nurses' experiences of the interaction and reciprocity in the nurse-family relationship differed across units and if so, how this related to families' perceptions of family functioning, family health, and perceived social support, ANOVA with Bonferroni correction technique was conducted on the nursing data and the family data respectively (Munro, 2005). All analyses were conducted using SPSS Version 21.0 (SPSS IBM, New York, U.S.A). The significance level was set at .05 for all analyses.

Qualitative Data Analysis

The FNPS includes three open-ended questions posed to nurses. The first two questions: What problems or drawbacks are there in your nursing practice by involving the family in assessment and care planning? and What advantages, if any, are there for your nursing practice by involving the family in assessment and care planning? are designed to elicit greater detail regarding nurses' attitudes toward family nursing practice. The final question: What have you done in the past week to involve families in your current nursing practice? is designed to elicit specific examples of family nursing practice. The data collected from these open ended questions were analyzed using content analysis.

Content analysis may be used to examine the manifest content, the latent content, or both. An analysis that deals with the visible content, or the exact text is known as manifest content analysis. Latent content analysis involves an interpretation of the underlying meaning within the text. A manifest content analysis approach was chosen for this descriptive study because this method allows for visible, surface level content to be identified and categorized (Downe-Wamboldt, 1992; Kondracki, Wellman, & Amundson, 2002). In this method, the researcher creates category schemes that aim to generate knowledge about the phenomenon under study.

The data were analyzed using the approach to manifest content analysis described by Granehiem and Lundman (2004) where all open-ended textual data could be condensed and abstracted into meaningful codes and categories. All textual data were entered into a spreadsheet format. Each participant's responses were reduced into meaning units, or groups of statements that relate to the same central context

(Graneheim & Lundman, 2004). These were then further abbreviated into condensed meaning units and then abstracted and labeled with codes. The codes were then compared for similarities and differences and were finally sorted into sub-categories and categories.

Trustworthiness. While there are widely recognized methods for assessing reliability and validity in quantitative analysis, there are also a number of approaches posed in qualitative research to ensure trustworthiness. One such method for achieving trustworthiness in qualitative research is *credibility*, which according to Lincoln and Guba (1985), make it more likely that the findings will address the intended focus and, therefore be considered believable. The analysis conducted on the qualitative data for this study attempted to achieve credibility by using a peer debriefing method as described by Lincoln and Guba (1985). This aids the researcher in reporting the participants' perspectives as accurately as possible. The author and a member of the dissertation committee discussed and examined the categories and sub-categories until overall agreement was reached on the coding system. Granaheim and Lundman (2004) suggest that this is done not just to make certain that data are labeled and organized exactly the same, but to ensure that multiple researchers and experts could reach agreement in the way that data is sorted and labeled.

The coded data were additionally assessed for *dependability*, or the reliability and stability of the data (Lincoln & Guba, 1985). Determining interrater reliability, or the amount of agreement between two independent raters coding the same data, assesses for dependability. The interrater reliability for this analysis was calculated

with Cohen's Kappa and indicated high agreement (κ = 0.92 - 0.96) (Downe-Wamboldt, 1992).

Limitations

There were limitations to the study. First, the use of a convenience sample poses challenges that create a great risk for sampling bias (Polit & Beck, 2008).

Nurses who chose to participate in this study may not have been an accurate representation of all nurses working on these four units, or of nurses in general.

Additionally, nurses may have floated to multiple nursing units, which may then affect families' and nurses' perceptions of family nursing practice on individual units. The use of a convenience sample was a reasonable approach, however, in this initial descriptive study.

The quantitative results generated from this study have limited generalizability, as the study was conducted on four medical-surgical nursing units in one community hospital. The results therefore may not be generalizable to nurses and families involved in family care at other acute care facilities, in particular those institutions that do not have Magnet status. This study also used a small sample size, therefore the results may not be generalizable to larger populations of nurses and families.

Finally, although the approach of surveying one family member rather than the entire family unit is applicable to this study, it is important to note that other family members may have different perspectives regarding family function, family health and perceived social support.

CHAPTER 5

RESULTS

This study was designed to describe the relationships between the family and nurses when an older adult with diabetes was hospitalized. The study was guided by four research questions. The first question examined family members descriptions of their family function, family health and perceived social support during the hospitalization of an older adult family member with diabetes. The second question examined nurses' critical appraisal of their family nursing practice, and their experiences of interaction and reciprocity in the nurse-family relationship. The third question examined the relationship between nurses' critical appraisal of their family nursing practice, and nurses' experience of the interaction and reciprocity in the nursefamily relationship, with families' perceptions of their family function, family health and social support. The final question in this study explored differences in nurses' critical appraisal of their family nursing practice, and their experience of the interaction and reciprocity in the nurse-family relationship, across the nursing units. Additionally this study examined the impact these differences had on family perceptions of family function, family health and social support received.

A sample of 60 registered nurses and 60 family members of older adult patients admitted with diabetes to four medical-surgical units in a community hospital consented to participate in this study.

Characteristics of the Participants

Nurse participants. Sixty registered nurses working on four medical-surgical nursing units at one metropolitan community hospital completed the Family Nursing Practice Scale (FNPS). On each unit, 15 nurses consented to participate and return the survey. Nurse demographic data are displayed in Table 4.

Of the sample of sixty, nine nurses were between the ages of 18-25 (15%), twenty-two in the 26-35 age range (36.7%), twenty-two in the 36-45 age range (36.7%), five in the 46-55 age range (8.3%) and two in the 56 or older age range (3.3%). The majority of participants were female, (93.2%, n=55). Most nursing participants had either less than five years experience in practice (36.7%, n=22) or 5-10 years (36.7%, n=22) in practice. There were six nurses (10%) with 10-15 years of in practice, five nurses (8.3%) with 15-20 years of in practice, and five nurses (8.3%) with more than 20 years of in practice. Forty percent (n=24) of the current sample reported having less than five years in their current job assignment, 41.7% (n=25) reported having 5-10 years in their current job assignment, 10% (n=6) had 10-15 years in their current job assignment, 6.7% (n=4) had 15-20 years in their current job assignment and 1.7% (n=1) had greater than 20 years in their current job assignment. Of the sixty nurses who participated in this study, 3.3% (n=2) reported their highest level of education was a nursing diploma, 18.3% (n=11) had an Associate's degree, 75% (n=45) had a Bachelor's degree and 3.3% (n=2) had a Master's degree.

Family participants. There were sixty family members who completed the Family Functioning, Family Health and Perceived Social Support Scale (FAFHES). The participants were family members of patients admitted to the same four units

where nursing data was gathered. Fifteen surveys were completed by family members from each unit. As described in Table 5, most family members who completed the survey instrument were over the age of 56 (58.3%, n=35), 25% (n=15) were between age 46 to 55, 6.7% (n=4) were between the ages of 36 to 45, 3.3% (n=2) were in the 26-35 age range and 6.7% (n=4) were in the 18-25 age range. There were thirty-eight female participants and twenty-two male participants. The majority of family member participants had a high school degree (35%, n=21), some college (28.3%, n=17) or a bachelor's degree (18.3%, n=11). The majority of participants were married (71.7%, n=43). Thirty-three percent (n=20) were the patient's spouse. Fifty percent (n=30) were either a son or daughter to the patient currently hospitalized. Many of the patients lived with the family member who was completing the survey (61.7%, n=37) and a little more than half (54.2%, n=32) had been hospitalized 1-5 times in the past year. Participants in this study varied widely in the number of years they have lived with a diagnosis of diabetes. Twenty-five percent (n=15) had lived with diabetes less than one year, 16.7% (n=10) for 1-5 years, 16.7% (n=10) for 6-10 years, 16.7% (n=10) for 11-15 years, 6.7% (n=4) for 16-20 years, 16.7% (n=10) for 20+ years and 6.7% (n=1) were unsure.

Family Perspectives

Family members perceptions' of their family functioning, family health and perceived social support were positive for participants who had an older adult family member hospitalized.

Family functioning. Family functioning, defined as the family's sense of their family relationships, family stability, family resources and friendships outside the

family (Paavilainen et al., 2006) was reported as relatively high (M = 4.72, SD = .75) in this sample. There were no significant correlations found between family functioning and family member demographics, including age, gender, education level, marital status, relationship to the patient, living arrangements (i.e. with or apart from the identified patient), number of years with diabetes, or number of hospitalizations this year. Family correlation analysis results are illustrated in Table 6.

Family health. Family health is defined as the family's sense of knowledge, ill-being, well-being, activity, and values as it relates to the family unit (Harju et al., 2011). In this sample, family health was reported as high (M = 4.92, SD = .55). There were no significant correlations between family health and the family member participant's age, gender, education level, marital status, relationship to the patient, living arrangements (i.e. with or apart from the identified patient), or number of years with diabetes.

Table 6 illustrates the significant, small to moderate, negative relationship between the number of times that the patient had been hospitalized in the past year and the reported family health (r^2 [59] = -.268, p = .040). This suggests that as the patient is hospitalized more frequently, family members report an overall decline in family health.

Perceived social support. Social support is an intentional human interaction that involves affect, affirmation and/or concrete aid offered by someone (Tarkka et al., 2003). Nurses display affect as they show appreciation, respect, and the ability to create a sense of security. Affirmation consists of reinforcement, feedback or having some influence on decision-making, while concrete aid may entail spending time

helping patients and families or taking care of an issue (Tarkka et al., 2003). Family member participants in this study reported high levels of social support from nurses (M = 4.77, SD = .83). There were no significant correlations found between perceived social support and family member demographics, including age, gender, education level, marital status, relationship to the patient, living arrangements (i.e. with or apart from the identified patient), number of years with diabetes, or number of hospitalizations this year. Family correlation analysis results are illustrated in Table 6.

Nurses' Perceptions

The Family Nursing Practice Scale (FNPS) assessed nurses' critical appraisal of their family nursing practice, as well as nurses' experiences of the interaction and reciprocity in the nurse-family relationship, when working with older adults and their families. The FNPS tool is reverse coded; hence lower scores indicate higher critical appraisal of family nursing practice and higher perceptions of interaction and reciprocity in the nurse-family relationship, while higher scores indicate lower critical appraisal of family nursing practice and lower perceptions of interaction and reciprocity in the nurse-family relationship.

Practice Appraisal. Nurses' critical practice appraisal of their family nursing practice reflects nurses' assessment of their confidence, satisfaction, knowledge, skill and comfort when working with families (Simpson & Tarrant, 2006). For this sample, nurses' critical practice appraisal was reported as high (M = 1.86, SD = .58).

Spearman's correlation analysis was used to explore relationships between nursing demographic variables and nurses' critical practice appraisal. FNPS variable and demographic variable correlations are shown in Table 7. There were no significant

relationships between nurses' critical practice appraisal and gender or education level. There were, however, significant relationships between several other demographic variables and nurses' critical practice appraisal. There was a moderate and significant, negative relationship found between age and nurses' critical practice appraisal (r^2 [60] = -.450, p =.000). In this sample, the older the Registered Nurse, the more confident he/she was in family nursing practice.

There was also a moderate and significant, negative correlation between total years in nursing and nurses' critical appraisal of family nursing practice (r^2 [60] = -0.538, p =.000). For nurses in this study, the more years a nurse spent as a practicing nurse, the higher they critically appraised their family nursing practice. The total years that nurses have worked on their current unit also had moderate and significant negative correlation with nurses' critical appraisal of their family nursing practice (r^2 [60] = -.406, p =.001). This suggests that nurses with the most number of years on their current work unit critically appraised their family nursing practice higher than nurses' with fewer years working on their current unit. Registered Nurse correlation analysis results are illustrated in Table 7.

Reciprocity. The nurse-family relationship is a mutual relationship that develops during interactions between the nurse, the patient and the family (Simpson & Tarrant, 2006; Simpson et al., 2006). It is characterized by nurses' reflections on planning care, promoting family participation and reciprocity when working with families (Simpson & Tarrant, 2006). Appreciating reciprocity in the nurse-family relationship includes having the ability to assess family needs and issues, engaging and listening to the entire family unit, focusing on strengths and facilitating necessary

change (Simpson et al., 2006). Nurses in this study reported their experiences of the interaction and reciprocity in the nurse-family relationship as high (M = 1.78, SD = .47).

There were no significant relationships found between nurses' experiences of the interaction and reciprocity in the nurse-family relationship with either gender or education level. Age, however, was moderately, and significantly negatively correlated with nurses' experiences of the interaction and reciprocity in the nurse-family relationship (r^2 [60] = -.277, p = .032). These findings demonstrate that older nurses reported their experiences of the interaction and reciprocity in the nurse-family relationship higher than younger nurses in this study.

There was a significant, moderate and negative correlation between total years in nursing with nurses' experiences of the interaction and reciprocity in the nurse-family relationship (r^2 [60] = -0.342, p = .008). This indicates that nurses with more years in practice reported their experiences of the interaction and reciprocity in the nurse-family relationship higher than nurses with fewer numbers of years practicing. Registered Nurse correlation analysis results are illustrated in Table 7.

Nurses' Perceptions of Family Nursing Practice

The qualitative data from the three open-ended questions on the FNPS survey were analyzed using manifest content analysis. These questions examine problems or drawbacks nurses experience by involving family in assessment and care planning, the advantages of involving family and what strategies nurses recently implemented to include families.

Challenges when involving family in assessment and care planning. The first question, what problems or drawbacks are there in your nursing practice by involving the family in assessment and care planning? received responses from 50 of the 60 nurses (83%) who completed the FNPS. Using manifest content analysis, the nurses' responses to this question revealed five major categories that nurses reported as problematic when involving family in care. This included intra-family functioning, family conflict, nurse-family relationship issues, difficulties understanding the plan of care, and challenges in care coordination (Figure 1).

Intra-family functioning. Within this category, there were three subcategories, labeled as (a) family member issues; (b) no family presence; and (c) situational anxiety. Nurses indicated that it is difficult to involve families in care when families previously have their own difficulties or were unavailable during their loved ones' hospitalizations. Some nurses described this as a lack of physical family members presence. Still other nurses addressed problems that they see in families related to heightened anxiety brought on by hospitalization of their loved one. In some cases, families may not be able to completely support their loved one because of a diminished ability to cope.

Family member issues. Some nurses described family member issues, which may include challenges within the family unit prior to admission or family member health problems. One nurse stated, "sometimes the family members have health issues of their own [and] have no coping mechanisms." Another nurse explained that difficulties in working with families might stem from "old family habits."

No family presence. Nurses expressed concerns they have with some families being unavailable during their loved ones' hospitalizations. Some nurses described this as a lack of family member presence. Several nurses described that sometimes there is no family presence, or when patients are in the hospital, family are not available.

Nurses expressed this may be because family members are working or "they are nowhere to be found." While others were markedly different, expressing that family may not want to be included in care planning, "some families aren't willing to be involved or helpful."

Situational anxiety. Still other nurses addressed problems that they saw in families related to heightened anxiety brought on by hospitalization of their loved one. Nurses described situational anxiety as a problem that occurs when family members become apprehensive during their loved one's hospitalization. For example, one nurse stated, "families are very anxious about their ill family members. It can hinder their care at times." Another nurse reported there is sometimes a sense of family being overly concerned, "it can be difficult to involve family because they can be overwhelmed with their family member's illness."

Nurse-family relationship issues. Nurses reported issues related to families that are difficult to work with at times. On occasion, some family members are unable to maintain appropriate limits, are demanding or even become confrontational. There was three sub-categories found within the nurse-family relationship issues category (a) lack of boundaries; (b) intimidating; and (c) family-nurse disagreements.

Lack of boundaries. Some nurses described families as having a lack of boundaries, which may interfere with the patient's care. As one nurse explained,

"family needs appropriate boundaries with questions and calls repeatedly." Another nurse stated, "sometimes patients' families can make caring for their loved one more difficult" for example, "micro-managing their care, being very needy."

Intimidating. Families may also be perceived as intimidating to nurses, asking challenging questions, which may affect timely care. One nurse communicated this as "sometimes there are very overwhelming patient families who make it more difficult to care for patient and get all we need [to] done." Another nurse stated "sometimes family becomes intimidating with their questions."

Family-Nurse disagreement. Sometimes there are disagreements between the family and the nurse over care planning, which may cause discord. One nurse described this as "not letting you do your job - refusing medications, treatments, etc." Nurses also reported that some family members might be "...resistant to any changes in patient care..." and disagree with the nurse over best treatments for the patient.

Family conflict. Nurses described issues related to conflict that mainly related to differences in opinion which arise among family members. Within this category, there were two distinct sub-categories: family-family disagreements and family-patient disagreements.

Family-family disagreements. Nurses reported that there are sometimes disputes between family members over the care that their loved one should receive. This family-family disagreement may relate to the daily care patients receive, expressed by one nurse, as "family members may not be able to agree on [a] plan of care." Additionally, there are issues with communication, as another nurse stated, "…multiple family members involved who don't communicate with one another."

Family-patient disagreements. Some nurses described family-patient disagreements, which involve differences in opinion between family members and the patient over care. Nurses expressed concern that families sometimes don't listen to the patient. For example, one nurse described disagreements occurring with "family trying to decide what is best for their loved one instead of listening to the loved ones' needs/wants." Other nurses described how some families choose care for the patient "families swaying patient's wishes for their own."

Difficulties in understanding plan of care. Nurses also described difficulties that families have in understanding the plan of care while their family member is hospitalized. Within this category there were three sub-categories (a) limited knowledge; (b) unrealistic expectations; and (c) cultural / language barriers.

Limited knowledge. A general lack of understanding, or lack of education, was described as limited knowledge. One nurse explained "sometimes family members have a misunderstanding or lack of understanding / level of education, and they inhibit proper communication between the nurse and patient." Nurses also expressed that family sometimes do not realize what health care has to offer, or are not receptive to it. As one nurse stated, "the family can have their own predetermined way of thinking about health care."

Unrealistic expectations. Nurses described how some family members have unrealistic expectations about their loved one's illness and treatments. They expressed concern that families sometimes do not realize that nurses do not have control over the entire plan of care. For example, one participant wrote, "...some things, [like] the expectations of services and things are out of our control, and they don't like our

answers." Still other nurses explained at times, family members may not have realistic goals for the patient, as one nurse stated, "some families can't see the big picture in regards to their loved one and do not realize / truly understand the plans they participate in making."

Cultural / language barriers. Two nurses reported the challenges of caring for patients and families who are from different cultures or who speak other languages. It can be difficult for families who do not speak the same language as health care providers to comprehend the plan of care and treatment interventions that nurses discuss with them. One nurse stated this problem simply, as "cultural and language barriers."

Challenges in care coordination. Nurses described care coordination issues as problems that arise when families affected the nurse's ability to carry out their daily care activities. This category included 3 sub-categories (a) time consuming; (b) interruption of routine; and (c) limited value to the nurse.

Time consuming. Nurses described the considerable time they spend explaining and re-explaining patients' plans of care to multiple family members, or attempting to meet family needs, as time consuming. One nurse explained the challenges involved in "discussing patient plan of care multiple times with many different family members rather than having a set discussion / meeting time." This nurse suggested that families "use a family member as an appointed advocate to funnel the rest of the family's questions." Another nurse stated that one problem in working with families is "having enough un-interrupted time to listen to and fulfill family needs."

Interruption of routine. Some nurses related having frequent disruptions either directly from multiple family members or from the environment in which they work. One nurse wrote, "it can often be very difficult to include family when getting interrupted with overhead calls." On the other hand, another nurse pointed out "many times family members want to know test results and / or plan of care but they are not listed as contacts in the patient's record."

Limited value to the nurse. One nurse expressed a disadvantage of working with families in terms of having limited value to the nurse. This nurse disclosed "education for [the] patient is priority over family."

Advantages of involving the family in assessment and care planning. In this sample of 60 nurses who completed the FNPS, 58 (96%) nurses provided feedback to the second question, which asks "what advantages, if any, are there for your nursing practice by involving family in assessment and care planning?" Manifest content analysis was used to examine nurse's responses to this question, which revealed two primary categories: enhances patient care and strengthening the nursefamily relationship (Figure 2).

Enhancing patient care. Nurses described how including families in their practice enhances patient care, because families know patients in ways that nurses do not. This tacit knowledge provides nurses with insight into patients' daily lives, allowing better planning, which eases the transition process across healthcare settings. As nurses, patients and families collaborate towards shared goals, families are able to be more involved in direct, physical care, and can then assist patients to better understand their plan of care and treatments. There were seven sub-categories that

developed from the main category (a) help me know the patient; (b) better outcomes; (c) assists the nurse; (d) common goals; (e) help with planning; (f) building family capacity to care; (g) communicate / translate to patient.

Help me know the patient. Many nurses reported that including families in assessment and care planning enhances patient care because families help nurses to better know the patient. Nurses described how families provide valuable information about patients' home lives, likes and dislikes, and their history. One nurse stated, "Family are the ones who (usually) know the patient best." While another nurse reported, "The family know the patient best, they know what works and what doesn't work, [and are] able to give accurate history."

Better outcomes. Nurses believed that including families provides better outcomes, by improving discharge planning and increasing medication and treatment compliance. One nurse stated,

I think it is very important to involve families in care planning. A lot of the time families are worried and want and need to know what is going on. I think it's important they feel they can communicate their needs and ideas to the nurse to have a better outcome for their family member.

Assists the nurse. Several nurses expressed that including family assists the nurse because many families like to provide care to their loved one. Families may offer direct care, or they may offer psychosocial support in a way that nurses cannot. One nurse reported that including family "helps staff and the patient, [as well as] helps with confused patients" and another stated that family "help with care."

Common goals. Being able to share common goals with family was described by nurses as collaboration or shared agreement between family and the nurse regarding the patient's plan of care. One nurse expressed "it's great for the patient, [and] for the family to be on the same page," and another pointed out "some family members are realistic and very helpful and understand the goals we set for their loved ones."

Help with planning. Several nurses expressed that families help with planning, specifically with discharge planning or with care planning during acute care admissions. For example one nurse stated, "[family] can help with discharge planning with patients" and another described that working with families allows for a "more realistic plan of care."

Build family capacity to care. Some nurses believed involving families in care is a way to build family capacity to care for their loved one. This was described as continuity in care that keeps families and nurses informed about patients' conditions. One nurse explained, "they learn more about how to care for the patient in terms of skin care and treatments the patient may need." Another nurse described that the work in partnership with families may increase family members desire to care for the patient, she stated, "by educating the family well - some people are more inclined to monitor their loved ones."

Communicate / translate to patient. Some nurses described how families explain the plan of care and illness management in a very individual way, which the patient may understand better. They are able to communicate / translate to patient,

which is illustrated by one nurse who stated, "often, family can explain the plan of care and discharge plan in a way the patient can understand better..."

Strengthening nurse-family relationship. Many nurses communicated that the advantage of including family in care is that it can strengthen the relationship they develop with families. As families feel more involved, this creates a sense of trust and comfort level between the nurse, patient and family. Within this category there were two sub-categories labeled as: patient, family and nurse satisfaction and reducing family anxiety.

Patient, family and nurse satisfaction. Several nurses reported that when they involved families in care, it increased patient, family and nurse satisfaction. One nurse stated, "By involving the family you avoid family members feeling upset, angry... The more they feel involved, the more confidence and satisfaction they feel with the hospital." Another described it in terms of nurse satisfaction, "I get great satisfaction in keeping the family informed."

Reduces family anxiety. Many nurses also described that including families reduces family anxiety. Involving families in the plan of care allows families to be more at ease, as well as, increases their trust in the nurse. For example, one nurse stated "I think it is very important to involve families in care planning. A lot of the time families are worried, and want, and need to know what is going on." Another nurse explained how involving families "can make the family feel more at ease because they are aware of how the treatment [and] patient is [doing]."

How nurses currently involve families in their current nursing practice.

The last question asked, "What have you done in the past week to involve families in

an 88% response rate, with 53 out of 60 nurses providing feedback. Nurses replied mainly in terms of how including families in care helps the family or the patient; however, several discussed that partnering with the family enhanced their nursing practice, as well. Three main categories developed from the data collected from this question (a) reassurance; (b) provided education for family; (c) partnered with family (Figure 3).

Reassurance. Nurses described providing reassurance to families in ways that resulted in the labeling of two sub-categories (a) provided support; and (b) supporting family decision-making. Nurses reported offering reassurance when families struggled with difficult decisions regarding discharge living arrangements, end-of-life care, or when patients' conditions worsen.

Provided support. Several nurses described having provided support, or making family members feel comfortable. As one nurse stated, "[I] eased family members mind", and another states that "[I] consulted with patient and daughter regarding discharge home with oxygen and [visiting nurse agency] VNA; [I] allayed fears and nervousness; [I] educated family regarding end of life care (why mom is not eating...) and provided emotional support."

Supporting family decision-making. One nurse described being able to offer encouragement to a family by supporting family decision-making. This nurse explained that doing this "reassured family [when they are] making difficult end of life decisions for their family member."

Provided education for family. When participants were asked how they had involved families in their nursing practice, many nurses described having provided education for the family. There were two sub-categories regarding the education nurses provide: teaching and providing information. Family member teaching was explained as more formal, sometimes mandated education, while providing information was described in more intimate terms and was on an ongoing, daily basis.

Teaching. Some nurses described the education they gave to families as teaching, or formal explanation of discharge instructions, illness management or instructions about medications. As one nurse explained "teaching families safe transfer; teaching families safe feeding techniques; teaching families about medications and how to perform dressing changes." Another nurse stated "I have involved a patient's daughter by teaching her how to care for her mother's wounds at home."

Provided information. Many of the nurse participants reported having provided information to families. For some nurses, this involved keeping family members informed about patients' conditions, explaining diagnostic tests or describing what the nurse was doing for the patient. For example, one nurse communicated how she provided information in this way:

I recently had a family whose mother was very sick; they had a lot of questions about what was going on; what the plan was, and what was going to be done.

They found it helpful that I answered all the questions they had.... They felt relief knowing they were in good hands, and now they knew / understand

everything that was going on, [for] example, what certain lab values meant and what the [patient's] progress was.

Partnered with family. Nurses described some of the experiences they had with families, which fostered relationships between the family, the patient and the nurse. Within this category there are four sub-categories: actively encouraged family to help me know the patient, drawing into care team, advocating for families' wishes and comfort from home.

Actively encouraged family to help me know the patient. Nurses illustrate the ways they actively sought information from family members, rather than family simply offering it to them, within the subcategory actively encouraged family to help me know the patient. Nurses believed that by doing this, it made caring for the patient easier because they gained a sense of the patients' habits, baseline and wishes. As one nurse describes:

[I] got a sense of what works for the patient at home and what foods the patient is most likely to eat, how the patient prefers to take her pills and any small habits.... that the patient may have to better understand when the patient is at her baseline.

Drawing into care team. The sub-category drawing into care team illustrates how nurses can invite families to become active caregivers for their loved one. One nurse explained that the "patient was agitated, [and this] registered nurse was able to call daughter and she came in [to the hospital]. This helped to settle the patient for the rest of the night". Another described how he/she "set up family meeting with palliative care and medical doctors' for [a] patient that needs hospice but, the [patient's] father

was unable to accept. This same nurse also related an example of a "confused patient [who] was able to call [her] sons at any time and [they had a] rotating schedule, so someone was [always] with patient."

Advocating for families' wishes. Several nurses referred to advocating for families' wishes in the past week by assisting families in staying with their admitted family member rather than just visiting. Some nurses saw that by contacting other health care providers and asking them to discuss the plan of care with the family, they were serving as a liaison for the family. One nurse explained how he/she was "making sure their wishes were passed onto the next nurse coming on." Another nurse described advocating for family by following through on a diagnostic suggestion from a family member, "[1] took daughter's suggestion of obtaining a UA [urinalysis]."

Comfort from home. Some nurses discussed how they had created partnerships with families by encouraging families to bring in some comfort from home. This mainly involved dietary items, which the nurses believed would help improve the patient's nutrition, as well as allow the family to feel involved. One nurse stated "I had family bring in a patient's favorite food to a patient that had a very poor po [oral] intake." Another nurse described how family could be "encouraging [the] patient to increase participation in [activities of daily living] ADL's and increase intake at mealtimes. I encourage patient's families to bring in foods/ drinks the patient enjoys."

The Relationship Between Nurses' and Family Members Perceptions

Linear regression analysis evaluated the relationship between nurses' critical appraisal of their family nursing practice, and nurses' experience of the interaction and reciprocity in the nurse-family relationship, with families perceptions of their family

function, family health and social support received existed. Linear regression analysis allowed each family's scores on all three subscales to be analyzed by including the corresponding nursing unit's aggregated scores as a covariate. There was no significant relationship (R^2 =.009, F(2, 57) =.263, p = .770) found between nurses' critical appraisal of their family nursing practice, and nurses' experience of the interaction and reciprocity in the nurse-family relationship with family functioning. There was also no significant relationship found between nurses' critical appraisal of their family nursing practice, and nurses' experience of the interaction and reciprocity in the nurse-family relationship with family health (R^2 =.020, F(2, 57) = .593, p = .556). The last regression analysis, which assessed for a relationship between nurses' critical appraisal of their family nursing practice, and nurses' experience of the interaction and reciprocity in the nurse-family relationship with perceived social support (R^2 =.001, F(2,57) = .035, p = .966) was not significant.

Nurses' Perceptions Across Acute Care Units and Impact on Family Perceptions

As shown in Table 8, Analysis of variance (ANOVA) did not reveal significant differences in nurses' critical appraisal of their family nursing practice. There were significant (p < 0.05) differences discovered across the study units regarding nurses' experiences of the interaction and reciprocity in the nurse-family relationship (F(3,56) = 3.931, p = 0.013). Further analysis compared individual group means using the Bonferroni technique, which protects against making a Type I error when making multiple comparisons. The Bonferroni analysis revealed that units 1 and 3 demonstrated differences in nurses' experience of the interaction and reciprocity in the nurse-family relationship (p = .011).

There were no significant differences found across the units in family member perceptions, which is illustrated in Table 9. Therefore, there were no differences found between the nurses' critical appraisal of their family nursing practice, and nurses' experience of the interaction and reciprocity in the nurse-family relationship with families' perceptions of family functioning, family health and perceived social support across study units.

CHAPTER 6

DISCUSSION

The cost of caring for patients with chronic illness accounts for approximately 75% of the United States current health care spending (Anderson, 2005; Hoffman, Rice, & Sung, 1996). This cost is estimated to increase as the number of persons over the age of 65 doubles in the next 30 years (Wolff, Starfield, & Anderson, 2002). Considering that nearly 88% of Americans older than 65 have at least one chronic condition, it can be expected that health care spending will continue to rise, as will the need for specialized clinical care (CDC, 2009; Wolff et al., 2002). Nearly 25% of those diagnosed with one chronic condition have activities of daily living (ADL) limitations, which often necessitates that families assume caregiving needs in the home (Anderson, 2005). There is, however, a notable absence of research studies that specifically address the impact of caring for chronically ill older adults on family structure and function.

Diabetes is a leading cause of chronic illness, which costs approximately \$116 billion U.S. healthcare dollars annually (CDC, 2011). Many older patients managing chronic illnesses, such as diabetes, are taken care of at home by a family member. Often, however, those with illnesses such as diabetes require hospital admissions due to exacerbations of the disease or for other co-morbid conditions which often accompany diabetes. Hospitalized older adult patients with chronic conditions are more likely to experience poor coordination in their care leading to contraindicated medical treatment (Wolff et al., 2002). Health care professionals working in pediatrics have long recognized the importance that families have in ensuring the best possible

health outcomes for patients (Eichner & Johnson, 2012). There are, however, few studies that assess patient care coordination among older adult patients and their families. Therefore, this study aimed to examine the relationships between family and nurses when an older adult with diabetes is hospitalized.

The Calgary Family Intervention Model (CFIM) was used as the theoretical framework to guide this study. The CFIM is a model developed using a family systems nursing (FSN) approach. FSN provides a lens for examination of family strengths and evaluation of interactive family behaviors (Robinson, 1994; Wright & Leahey, 1990). FSN focuses on the whole family as a unit of care, allowing the nurse to simultaneously focus on the patient, the family and their illness. A Family Systems Nursing approach, particularly using the CFIM allows for the inclusion of family in care during transitional periods for older adults. The CFIM further advocates the importance of nurse-family reciprocity, which forms the foundation for mutual relationships that develop during interactions between the nurse, the patient and the family. By encouraging such purposeful interactions, this model proposes that there will be improvements in the family-nurse relationship as well as overall family well-being (Wright & Leahey, 1990).

The purpose of this study was to examine family perceptions of family functioning and family health during hospitalization, as well as family perceptions of social support received from nurses. This study also explored nurses' appraisal of their family nursing practice (FNP), as well as perceptions, or feelings, of the reciprocity involved in a nurse-family relationship. Also investigated was the relationship between the value that nurses place on a nurse-family relationship, and how families

describe their family function, family health and social support. Finally, this study explored differences in nurses' appraisal of their FNP across the nursing units, as well as, any correlations between nurse appraisal of FNP and family function, family health and perceptions of social support.

Family Perspectives Related to Family Functioning, Family Health and Perceived Social Support

Family functioning. Wright and Leahey (1994, 2005) define family functioning as the ways that family members behave towards one another. Family members were asked to assess the ability of all members to plan events, contribute to household tasks, voice positive feelings, feel supported, and to convey perspectives about relationships within and outside of the family unit. It was not anticipated that family members caring for older adults with diabetes would describe their family functioning favorably.

The Calgary Family Intervention Model, which uses a family systems approach views the entire family as a unit of care (Wright & Leahey, 1994, 2005). According to the tenets of the theory, then, it would be expected that chronic illness would negatively impact family functioning. The family as a whole unit, lives with, and alongside, the chronically ill family member thus making the illness a family experience, affecting the entire unit.

Family members in this study, however, reported their functioning as high. These results were somewhat higher than family functioning findings in a similar study using the same instrument (Paavilainen et al., 2006), which assessed the family functioning of Finnish families of adults with heart disease. In Paavilainen, et al.'s

(2006) study, family members of Finnish patients with heart disease were asked to describe their family functioning. These authors surveyed 161 participants, all of whom had a loved one diagnosed with heart disease.

The natures of these two diseases are very different. Home management of diabetes is likely to be considerably different from that of heart disease. Family members caring for an elderly person with diabetes describe being involved in meal planning, blood sugar monitoring and the administration of medications including injectable insulin. This is likely to have a substantial impact on family functioning. However, in illnesses such as diabetes there are periods of quiescence that allow families to adjust the ways in which they function. Cardiac illnesses can be considerably different and often require families to continually adjust and re-adjust to acute exacerbations (Newby, 1996).

In a study of pediatric patients with sickle cell disease, Mitchell et al. (2007) found that there was a relationship between patients coping abilities with family functioning. Additionally, these researchers uncovered a relationship between negative patients coping abilities with higher rates of health care utilization (Mitchell et al., 2007). This reinforces the tenets of the CFIM, which proposes that it is important to note the differences in how families are functioning given various chronic illnesses. According to Wright and Leahey (2005), this allows nurses to evaluate for the most appropriate nursing interventions, thus effecting the greatest change in families. Nurses or families may identify a concern in either their cognitive, affective or behavioral domain of family functioning. Once this determination has been made,

nurses can then decide on a nursing intervention that most fits the change needed in that domain of family functioning (Wright & Leahey, 2005).

Similar to the current study, many of the respondents in the Finnish study lived with the patient (83% in the Finnish study versus 61.7% in the current study) and most were married (92% in the Finnish study versus 71.7% in the current study). It is interesting to note that the ages of family member respondents were slightly different. The Finnish study's participants had a mean age of 56.5 years. In the current study, family member respondents were slightly younger, primarily between the ages of 46-55. There were also distinctions in gender noted between the studies. The Finnish study's respondents were primarily female; while the current study gender was more evenly distributed between male and female respondents. The difference in ages and gender of family member respondents may account for higher reports of family functioning in the current study. Earlier studies have demonstrated that younger, female caregivers tend to report more distress than older, female caregivers (Ebbesen, Guyatt, McCartney, & Oldridge, 1990; Okkonen & Vanhanen, 2006). Conversely, Sloper (2000) found that male parents were more likely to feel more distressed than female parents, especially with repeated hospitalizations of pediatric cancer patients.

Another important distinction in the study conducted by Paavilainen et al. (2006) is that patients' ages ranged from 19-89 years, while in the current study all patients were required to be older than 65. There was also considerable variation in the length of time with diabetes in this study (15 had diabetes less than one year, 10 for 1-5 years, 10 for 6-10 years, 10 for 11-15 years, 4 for 16-20 years, 10 for 20 or more years and one patient was unsure of onset). Conversely, the Finnish study mainly

included patients who have had heart disease for many years (Paavilainen et al., 2006). Other authors have suggested that family adaptation can be more stressful in chronic illnesses such as cardiac disease, which are more acute in onset, are progressive and are more likely to be viewed as life threatening. These types of illnesses often challenge family members to constantly adapt and adjust to the illness (Newby, 1996), which may explain why respondents in this study reported better family functioning than in the Finnish study.

Exactly half of the family respondents in this study were children of the patient hospitalized, and another 33% were spouses. The Finnish study was different with only 21% of the participants being offspring of the patient and 77% spouses. The findings in the current study of families of older adults reinforces Wright and Leahey's (1994, 2005) views that the adult children often consider family functioning to be higher than do spouses of chronically ill patients.

Family health. Astedt-Kurki, Lehti, Tarkka and Paavilainen (2004) define family health as a combination of people's values and everyday experiences, which incorporates family members' knowledge about health, health promotion, life progression, and how they feel physically and emotionally. In aligning with Wright and Leahey's (1984, 1990, 1994, 2005) approach of Family Systems Nursing, it was anticipated that families who are managing care of a family member with a chronic illness would perceive a negative impact on their family unit's health. Respondents from the current study, however, surprisingly reported family health scores as very high.

Asted-Kurki et al. (2004) note that high family health scores on the Family Functioning, Family Health and Social Support Scale (FAFHES) may occur because the FAFHES is designed to measure overall family health, and not just the *patient's* health or function status. Families were asked about their family's health including dimensions of safety, worry regarding the illness, and quality of life in spite of their family member's illness. The findings of this study suggest that, despite having a family member with a chronic illness who is currently hospitalized, family units recognize that their family is in good health and functions well. These findings endorse Wright and Leahey's (1987) description of family health as a dynamic state of well-being which can be attributed to a family's ability to organize and rally in the face of challenge. Sloper (2000) similarly, found that how parents of children with cancer perceive family cohesion was a significant predictor of how families perceived distress.

While the health of the overall family unit, and not solely the patient or solely the family members, has not been well described in the literature, there is some support in previous research that is comparable to the current findings. Asted-Kurki et al. (2004) examined perceived family health in 161 Finnish families who had a loved one suffering from cardiac disease. Although the sample size in the current study was smaller than that of the Finnish study, respondents from both studies reported good overall family health. As mentioned earlier, there are differences between the two samples from both studies, including age, gender and diagnosis of the patients.

Family health was inversely correlated with the frequency of hospitalization.

These findings are supported by an earlier study by Asted-Kurki et al. (2004) of the

family health of Finnish families of adults with cardiac disease. Research findings are comparable in the pediatric literature, with studies supporting the belief that children's chronic illnesses, especially repeated hospitalizations, have long-term consequences on family functioning and distress (Sloper, 2000; Board & Ryan-Wenger, 2002).

Conversely, in a study of prostate cancer patients and their families (Harju et al., 2011), the researchers found that previous hospitalizations of the patient were associated with a better sense of well-being. According to Harju et al. (2011) these differences may be explained by the fact that prostate cancer patients were interviewed in addition to their family members, and the prostate cancer patients may perceive themselves as having a good prognosis, as opposed to other illnesses such as cardiac disease or diabetes. The findings in this study suggest that it is important to note how often a patient has been hospitalized within a given year and how families think this affects their family health. Findings such as these have important implications for nurses' practice of family nursing. Determining how families perceive their health and functioning when managing chronic illnesses, enables nurses to become better equipped at how best to utilize the interventions recommended by the CFIM. Interventions can be aimed to improve a family's cognitive domain by affecting changes in the way a family perceives its health problems. Treatment goals can also be aimed to reduce or increase emotion as needed to create change in the affective domain, which may better enable families to employ problem-solving techniques. Finally, the behavioral domain of the family may have interventions directed at helping family members behave differently towards one another.

Perceived social support. Tarkka, Paavilainen, Lehti and Astedt-Kurki (2003) define social support as an intentional human interaction that involves affect, affirmation and/or concrete aid offered by someone. Families who participated in this study reported surprisingly high levels of social support from nurses, which differs considerably from the low social support scores described in a similar study of the families of Finnish cardiac patients using the FAFHES instrument (Tarkka et al., 2003). The identified patients in the Finnish study were adults, ranging in age from 19 to 89 years, while in the current study all patients were older adults, over the age of 65. This distinction in the age of patients is one possible explanation for the differences discovered in perceived social support found between these two studies. Tarkka et al. (2003) found that family members of older patients reported higher levels of social support received than family members of younger patients. It is probable that because the patients in the current study were older, as were the family member respondents in this study (58.3% were 56 or older), they had prior experience in caregiving for a loved one or had adjusted to the illness.

Although the length of illness was not significantly correlated with perceived social support in this study, as previously mentioned, family participants reported a wide range in length of time with diabetes. This may account for the higher levels of social support reported in this study when compared to a similar study by Tarkka et al. (2003) who found that family members of patients with advanced cardiac disease reported lower levels of social support.

According to Wright and Leahey (2005) nurses who practice family systems nursing will assist family members in discovering solutions to help alleviate suffering.

The high levels of perceived social support reported by respondents in this study suggests that nurses at this institution are currently employing many of the types of solutions suggested by the CFIM. This was to a certain degree unanticipated.

However, the rich descriptions offered by nurse participants in the qualitative data that was collected offers possible rationales into how families were integrated into care.

Nursing Perspectives Related to Family Nursing Practice Appraisal and Reciprocity in the Nurse-Family Relationship

Practice appraisal. Nurses caring for older-adult patients with diabetes and their families critically appraised their family nursing practice at high levels. This indicates that respondents in this study were confident in their knowledge, skill and comfort in working with families. Although the nurses in the current study appraised their family nursing practice at high levels, it is important to note that often times perceptions and practice are inconsistent. Bruce and Ritchie (1997) found incongruences between nurse and family perceptions in an earlier study of 124 pediatric nurses caring for children and their families in an acute care setting. The nurses in this study reported that there was a lack of support and a greater need for skill development in their family nursing practice (Bruce & Ritchie, 1997). The current study demonstrates that older nurses, and those who had a greater number of years in practice as a nurse, rated their family nursing practice more highly than those who were younger and had fewer years in practice. Bruce and Ritchie similarly found that the age of the respondent influenced nurses' perceptions of their family practice. However, years in nursing were not correlated with family nursing practice perceptions.

While there are limited studies reported in the literature regarding nurses' assessment of their family nursing practice with adults, some authors have explored nurses' perceptions of the emotional support they provide to families (Coco, Tossavainen, Jaaskelainen, & Turunen, 2013). In a study of 115 staff nurses caring for families and patients who had suffered traumatic brain injury (TBI), respondents reported that they regularly assisted family members' who were experiencing difficult emotions (Coco et al., 2013). Although Coco et al. did not specifically assess nurses' confidence, satisfaction, knowledge, skill and comfort in working with families, they did examine the level of competence nurses believed was needed to provide support to families.

The nurse respondents in the TBI study related that respecting and treating family members as individuals were basic competences that neurosurgical nurses should possess. In addition, there are more advanced skills, such as supporting family members ability to cope, which may need more training (Coco et al., 2013). A family systems nursing approach, such as that offered by Wright and Leahey in the CFIM (1994, 2005), which takes into account family needs and effective nursing interventions, may improve the skills needed for complex family nursing practice.

Reciprocity. It was anticipated that in a Magnet credentialed hospital, nurses would perceive family participation and inclusion as important. In the present study, nurses indeed reported high levels of the interaction and reciprocity in the nursefamily relationship. This is consistent with similar studies which have suggested that nurses feel positively about family presence (Astedt-Kurki, Paavilainen, Tammentie,

& Paunonen-Ilmonen, 2001), and value nurse-family interactions (C. Fisher et al., 2008).

C. Fisher et al. (2008) also examined nursing staff attitudes and behaviors towards family presence while a loved one is hospitalized. Their sample consisted of 89 nursing staff (including 22 certified nursing assistants) with a mean of 14.4 years of nursing practice. Gender differences in the sample were not reported. Similar to the current study, C. Fisher et al. (2008) found that nursing staff value family nursing, and support family presence through communication with family members, teaching, involvement of family in care and psychosocial support. Neither Fisher et al.'s study or Astedt-Kurki et al.'s (2001) study explain how nursing demographics may have been associated with findings. A comparable study would be interesting, because in the current study older nurses, with more years in practice, reported their experiences with interaction and reciprocity in the nurse-family relationship higher than younger nurses. Takemoto et al. (2007) found that longer length of clinical experience influences a nurse's ability to practice enhanced family nursing. Wright and Leahey (1994) state that beginning clinicians are often overwhelmed with the intricacies of providing family nursing. The findings in the current study suggest that there is a role for veteran nurses to coach younger nurses using a model such as the CFIM to target family-specific interventions.

Nursing challenges when involving family in assessment and care planning. Nurses inevitably influence the families they work with via their views, opinions, theories and thoughts (Wright & Leahey, 2005). Wright and Leahey suggest that reflecting on attitudes and perceptions regarding family nursing practice allows

nurses to better understand and contribute to the nurse-family relationship. The results of this study contribute to nursing knowledge development regarding nurses' perceptions of the advantages and the disadvantages of working with families. In addition, this research contributes data to describe what nurses are currently doing to include families in their nursing practice. Although nurses in this study embraced the importance of family nursing practice, some nurses pointed out a number of disadvantages, including intra-family functioning issues, nurse-family relationship issues, family conflict, difficulties in understanding plan of care and the challenges in care coordination. Likewise, C. Fisher et, al. (2008) found that even when nurses viewed family presence in the hospital favorably, they did not always engage in behaviors that supported this. This included lack of support for family presence during daily care as well as having family members visit whenever they wished (C. Fisher et al., 2008).

Bruce and Ritchie (1997) found that barriers to family nursing mainly related to a lack of education and skill development for nurses in areas of counseling, communication, interviewing, interpersonal relationships, family dynamics and clarifying health professional roles. Understanding such barriers for nurses, when working with families, is critical to developing interventions that can help overcome challenges found in family nursing practice. Wright and Leahey (2005) corroborate this with their recommendation that nurses should be given clear frameworks for family assessment and appropriate interventions so they can begin to think of family nursing in different ways.

Some nurses in this study related a disadvantage to involving families in care is that the family unit may have internal problems of their own stemming from diminished intra-family functioning. This may relate to other family member's issues, such as health care problems, a lack of family member presence in the hospital or to situational anxiety that family members may experience when a loved one is acutely ill. Simpson, Yeung, Kwan and Wah (2006) also found that family members are sometimes passive and do not initiate contact with the nurses.

Nurses in the present study also cited nurse-family relationship issues, including families sometimes having a lack of boundaries, families appearing intimidating or challenging to nurses, or family-nurse disagreements over best treatments for the patient as other disadvantages related to issues with intra-family functioning. Reflecting on the value of reciprocity and parity in the nurse-family relationship encourages nurses to utilize best practices and counterbalance issues in the relationship (Wright & Leahey, 2005).

Another difficulty described by nurses was family conflict, either between family members or the patient and their family members. Some nurses also reported families having difficulties in understanding the plan of care. This was associated with family members having limited knowledge, unrealistic expectations, or cultural or language barriers. Simpson et al. (2006) similarly found that nurses cited a lack of family education and cultural beliefs as posing disadvantages in family nursing care.

Lastly, nurses reported challenges in care coordination when involving families. According to the nurses in this sample, providing family nursing care can interfere with care coordination, as it is time consuming, may interrupt nurses'

routines or it may even be perceived as having limited value by the nurse. Simpson et al. (2006) also found that nurses reported family nursing to be difficult to manage in addition to their regular patient workloads. Likewise, Astedt-Kurki et al. (2001) found that a majority of nurses in their study believed that the family members are irrelevant to care or are an extra burden to nursing staff. Wright and Leahey (2005) recognize that time is of the essence in nursing care, especially in light of the numerous changes occurring in the health care environment. It is not inevitable, however, for families to become marginalized. According to Wright and Leahey when nursing practice is supported by sound knowledge of family care, interventions can be applied in very concise family encounters.

Advantages of involving the family in assessment and care planning.

Nurses in the current study articulated that the main advantages of involving families in care planning are that it enhances patient care and strengthens the nurse-family relationship. A key reason that nurses in this study believed involving families would enhance patient care is that it facilitates their ability to know the patient. This is in accord with Wright and Leahey's belief (2005) that family members and nurses both bring strengths and resources to the nurse-family relationship that may go unnoticed by health care providers.

Tanner, Benner, Chesla and Gordon (1993) also discovered that nurses described how family presence enabled them to know the patient in a unique, individual way, allowing for more informed and skilled clinical judgments. Nurses in this study also described better outcomes for patients when families are involved.

Similarly, Simpson et al. (2006) found that nurses in their study believed patients are more cooperative and are more accepting of advice when their families participate.

Several nurses in the current study described how including families assists the nurse in the provision of care because family members help provide physical or psychosocial care to their loved one. Simpson and colleagues (Simpson et al., 2006) likewise found that nurses described involving family as a time saver. According to nurses in the present study, as nurses and families work together they can share common goals. This can help with planning care or with discharge planning, which was also an advantage of family nursing described by nurses in this study.

Nurses in the current study described that including families builds family members' capacity to care for the patient. This allows for family members to better understand the patient and develop needed confidence and skills for care required after discharge (Simpson et al., 2006). Nurses also described that families enhance patient care because they can communicate or translate the plan of care to the patient in a way the patient may better understand. Many families have their own way of communicating with each other, both verbally and non-verbally. Wright and Leahey (2005) suggest that the best way for nurses to ascertain how families communicate with one another is to assess for verbal and nonverbal forms of communication.

Consideration of all communication amongst family members as meaningful and purposeful enables for a better determination of possible interventions needed by families (Wright & Leahey, 2005).

Nurses in an earlier study by Simpson and colleagues (Simpson et al., 2006) reported that family nursing promotes rapport between the patient, the family and the

nurse. Many nurses in this study also indicated that an advantage to family nursing is that it strengthens the nurse-family relationship. Nurses in the current study reported that involving families increases patient, family and nurse satisfaction. Other nurses believed that including the family reduces their worry and anxiety. This is consistent with Simpson et al.'s (2006) study, which showed that when nurses involve families, they believed they better understood the reciprocity between the family, the illness and the nurse (Simpson et al., 2006).

How nurses currently involve families in their nursing practice. Nurse respondents additionally described the ways in which they include families in their nursing practice. They discussed various methods used to include families in care, which ranged along a broad continuum from merely responding to a particular family need to more sophisticated strategies that actively encouraged family members to be part of the health care team.

Some nurses reported providing reassurance or education, while others actively engaged with families by creating partnerships. Much of the education that nurses reported providing was in the form of information sharing regarding the patient's plan of care or diagnostic tests. This is consistent with the earlier research of Astedt-Kurki et al. (2001), who found that nurses often associate family interactions primarily with information distribution. There were, however, some participants in this study who described more in-depth teaching practices they carry out with family members.

Nurses in this study also described more complex, indepth and bidirectional relationships that sometimes occur when they partner with families. Some nurses describe how they promote nurse-family relationships by actively encouraging family

members to help them know the patient. This may be shaped around interviewing family members to find out patients' tendencies and preferences, or drawing family members into the care team. These complex techniques that nurses employ are supported and encouraged by models such as CFIM (Wright & Leahey, 1994, 2005). The findings from this study reinforce the importance of how better descriptions of what nurses do to include families in care may help to inform best practices.

Relationship Between Family and Nurse Perceptions

This study explored the relationship between nurses' critical appraisal of their family nursing practice and their experiences of interaction and reciprocity in the nurse-family relationship with families' perceptions of family function, family health and perceived social support from nurses. This study found no relationship between nurses' critical practice appraisal and nurses' experiences of interaction and reciprocity in the nurse-family relationship with family functioning. There was also no relationship found between nurses' critical practice appraisal and nurses' experiences of interaction and reciprocity in the nurse-family relationship with family health.

Lastly, there was no relationship found between nurses' critical practice appraisal and nurses' experiences of interaction and reciprocity in the nurse-family relationship with perceived social support.

These findings suggest that, in this sample of nurses and families, there was no evidence that nurses' critical practice appraisal and nurses' experiences of interaction and reciprocity in the nurse-family relationship influences how families view their family functioning, family health or the social support received during hospitalization. This is in contrast to the findings of Maxwell, Stuenkel and Saylor (2007) who

assessed nurses' and family members' perceptions of needs being met in a critical care unit from one community hospital. These authors found significant differences in how families perceived their needs being met when compared to how nurses perceived meeting these needs. For example, nurses believed it was less important to talk to the family daily, inform the family how and why the patient was being treated and provide updates regarding the patient's condition. These inconsistencies may effect family perceptions, as well as family coping during hospitalizations (Maxwell, Stuenkel, & Saylor, 2007).

Finally, the current study tested to see if nurses' appraisal of their family nursing practice differed across units and if so, did these differences relate to families' perceptions of family functioning, family health, and perceived social support.

Findings suggest that there were significant differences in the way nurses perceived their family nursing practice between study units 1 and 3 in how nurses' experience interaction and reciprocity in the nurse-family relationship. Previous research has proposed that different nursing units within one organization may display considerable differences in the way a given unit's nurses practice, which supports the results found in this current study (Lauzon Clabo, 2008).

While there were differences in nurses' perceptions across the study units, there were no significant differences across the units in family member perceptions of nursing care and thus no relationship was found between nursing perceptions by unit and family perceptions by unit. This was not an expected finding, and may be associated with a threshold effect of investigating in one Magnet hospital. Hospitals that have been granted Magnet status are recognized for their quality patient care,

nursing excellence and innovations in professional nursing practice. Thus, patients and families may feel that they receive high-quality nursing care at a Magnet institution regardless of which nursing unit they are admitted to.

Study Limitations

Several limitations need acknowledgment when interpreting the findings of this pilot study. The first concerns generalizability of the quantitative data, which is limited firstly because this study was conducted at one acute care institution, which may limit its comparability to other institutions. The sample was a non-probability convenience sample, which was small, further limiting the ability to generalize findings to all medical-surgical nurses or to other families caring for older adults with diabetes. Although nursing perceptions differed across units, family member perceptions across units were not found to be significantly different. This may relate to the small sample size, or it may also be explained by the phenomenon of having a loved one admitted to one Magnet institution, which is known for encouraging family practice and nursing education. Therefore, a possible explanation for these unexpected findings is that although nursing perceptions may differ across units in one institution, their actual family nursing practice is fairly consistent and well received by families.

Also important to note, is that the nursing participants were primarily female. Previous work has suggested that male nurses tend to view families as less important and as less of a resource (Benzein, Johansson, Arestedt, & Saveman, 2008). It is, therefore, possible that if data had been collected from a larger more diverse sample, which included more male nurses, the responses may have differed. More research

with larger, more representative samples is needed to further examine if gender differences do exist in nursing perceptions towards family nursing practice.

This study utilized two instruments, the FNPS and the FAFHES. Both of these instruments have reported validity and reliability, however, they have had relatively limited use. Further testing of this instrument with larger sample sizes is recommended. The FAFHES provides important quantitative data regarding family perspectives about their family health, family functioning and social support received from nurses, with no qualitative component. This researcher discovered that, on several occasions, family members had a desire to share much more data than a quantitative survey collection method allows. Future studies are planned that would allow family member participants to share their thoughts and feelings in a more indepth way.

Further Implications

The findings of this study have several implications, including theory testing, research, clinical practice and educational initiatives.

Theoretical. A Family Systems Nursing approach, using the CFIM was used to guide this research study. The CFIM allows for an examination of family perceptions and nursing perceptions during care of the older adult with diabetes in the hospital. Family systems nursing and the CFIM were created so that whole families could be considered as the unit of care. One of CFIM's central tenets is the interaction between families and nurses. CFIM has been used to guide other research, but data has only been collected from either nurses or family members. Examining the possible relationship between how families describe nursing support, and how nurses describe

their family nursing practice, is critical in understanding the interactions between nurses and families.

In the current study, the nurses' critical appraisal of their family nursing practice and how they perceived their experiences with interaction and reciprocity in the nurse-family relationship did not significantly impact how families perceived their family functioning, family health and social support received. It is important to note, however, that this study was conducted in one community hospital with Magnet status, which has high standards and expectations in nursing care delivery. This suggests that further application and testing of this model in family nursing research, are pertinent at diverse acute care settings.

Future Research. The current study findings taken in conjunction with the available literature suggest the need for future research studies. There is a need to develop well-planned research studies, which focus on collaboration, and participation of families in care of their chronically ill loved ones. Nurses are an integral part of this process and must be able to support and promote reciprocity in the nurse-family relationship. Effective nurse-family relationships encourage family involvement and have the potential to influence length of stay (Powers & Rubenstein, 1999). Further research may include a pre-test/post-test design, with implementation of a family-level intervention that is designed to improve family outcomes, as well as family nursing practice. A post-test may then evaluate if Family Systems Nursing was employed, and if so, did patients, families and/or nurses recognize more effective family nursing support. There are also potential implications for using and evaluating Family Systems Nursing in additional patient areas within various acute care settings. Multiple settings

with larger sample sizes, which may have greater variability would permit for the use of stronger research designs, such as randomized control trials utilizing control and experimental groups.

Education and practice. This study offers implications for both nursing education and nursing practice. The first suggestion would be that schools of nursing and institutional administration provide greater learning opportunities, which promote the emphasis of family as a whole unit of care. Patients who suffer with chronic illness do not manage their conditions in isolation. Families of chronically ill patients, especially those with diabetes, provide tremendous amounts of care and should be encouraged to participate during hospitalizations as well as at home. Education about the value of including family in everyday nursing practice should be emphasized in nursing curriculums and continue into the practice setting. With utilization of a framework such as family systems nursing and a better understanding of family nursing practice, nurses will be much better prepared to assess and intervene when patients or families have an unmet need.

Table 1. Effect size estimate for the study

Power (α=0.05)	Effect Size / Estimated Correlation
75%	.327
80%	.345
85%	.366
90%	.392
95%	.428

Table 2. Sample size required for chosen power

Estimated Correlation	Sample Size for 80% Power	Standard Effect Size Class
.10	779	Small
.20	191	
.25	120	
.30	82	Moderate
.35	59	
.40	44	
.45	33	
.50	26	Large
.60	17	

Note. ($\alpha = .05$, 2-tailed test)

Table 3: Method of analysis for research questions

Research Question	Variables	Instrument	Method of analysis
How do families of older-adult, patients with diabetes describe their family	• Family functioning, family health, social support	FA, FH, ES	• ANOVA
functioning, family health and perceived social support from nurses during hospitalization?	• Age, gender, education, marital status, relation to patient, who patient lives with, years with diabetes, and number of times hospitalized	Demographic form	Chi Square
How do nurses caring for older-adult, patients with diabetes, and their families, appraise their family nursing	 Family nursing practice; practice appraisal; nurse – family relationship Age, gender, education, nursing 	FNPS Demographic form	ANOVAChi Square
practice and how do chey reflect on the nurse-family relationship?	years, current unit years, marital status	0 1	em square
What is the relationship between nurses' perceptions of their family	 Family nursing practice; practice appraisal; nurse – family relationship 	FNPS	Linear regression
nursing practice and families' perceptions of family function, family health and perceived social support from nurses?	• Family functioning, family health, social support	FA, FH, ES	analysis
Do nurses' appraisal of their family nursing practice differ across units	 Family nursing practice; practice appraisal; nurse – family relationship 	FNPS	ANOVA with Bonferroni correction
and if so, how are these related to families' perceptions of family functioning, family health, and perceived social support?	 Family functioning, family health, social support 	FA, FH, ES	

Note. FA, FH, ES = Family functioning, family health and social support scale; FNPS = Family nursing practice scale; ANOVA = analysis of variance.

Table 4. Nurse demographic data

(N = 60)

Nurse A	Age	
Age grouping	Frequency	<u>Percent</u>
18-25	9	15.0
26-35	22	36.7
36-45	22	36.7
46-55	5	8.3
56 or older	2	3.3
Total	60	100.0
Nurse Ge	ender	
<u>Gender</u>	<u>Frequency</u>	Percent
Male	4	6.7
Female	55 50 (1 missing)	93.2
Total	59 (1 missing)	100.0
Nurse Edu	cation	
Education level	<u>Frequency</u>	<u>Percent</u>
Nursing Diploma	2	3.3
Associate's Degree	11	18.3
Bachelor's Degree	45	75.0
Master's Degree	2	3.3
Total	60	100.0
Total years ir	n Nursing	
Number of years in Nursing	Frequency	Percent
Less than 5 years	22	36.7
5-10 years	22	36.7
10-15 years	6	10.0
15-20 years	5	8.3
More than 20 years	5	8.3
Total	60	100.0
Number of years in co	urrent assignment	
Number of years in current assignment	Frequency	Percent
Less than 5 years	24	40.0
5-10 years	25	41.7
10-15 years	6	10.0
15-20 years	4	6.7
More than 20 years	1	1.7
Total	60	100.0

Table 5. Family demographic data

(N = 60)

Fam	ily Members' Age	
Age grouping	<u>Frequency</u>	<u>Percent</u>
18-25	4	6.7
26-35	2	3.3
36-45	4	6.7
46-55	15	25.0
56 or older	35	58.3
Total	60	100.0
Family	y Members' Gender	
Gender	<u>Frequency</u>	Percent
Male	22	36.7
Female	38	63.3
Total	60	100.0
Family Me	embers' Education Level	
Level of education	<u>Frequency</u>	<u>Percent</u>
Grammar School	1	1.7
HS or equivalent	21	35.0
Some College	17	28.3
Bachelor's Degree	11	18.3
Master's Degree	4	6.7
Professional	2	3.3
Other	4	6.7
Total	60	100.0
Family M	lembers' Marital Status	
Marital Status	<u>Frequency</u>	Percent
Married	43	71.7
Divorced	3	5.0
Living with significant other	5	8.3
Widowed	1	1.7
Single	8	13.3
Total	60	100.0
Rela	tionship to patient	
Relationship to patient	Frequency	Percentage
Spouse	20	33.3
Son/Daughter	30	50.0
Son/Daughter Son-in-law/Daughter-in-law	30 2	50.0 3.3

Other	6	10.0
Total	60	100.0
Patient	lives with family member	
Same home	<u>Frequency</u>	Percent
Yes	37	61.7
No	23	38.3
Total	60	100.0
Years pat	ients had diabetes diagnosis	
Marital Status	<u>Frequency</u>	Percent
Less than one year	15	25.0
1-5 years	10	16.7
6-10 years	10	16.7
11-15 years	10	16.7
16-20 years	4	6.7
20+ years	10	16.7
Not sure	1	1.7
Total	60	100.0
Frequency of	f hospitalization in the last year	r
# times hospitalized	<u>Frequency</u>	Percentage
First time	23	38.9
1-5 times	32	54.2
More than five times	4	6.7
Total	59 (1 missing)	99.8

Table 6. Correlations between family demographic variables and family functioning, family health, and perceived social support

Spearman Correlations

		Family	Family	Perceived
		Functioning	Health	Social
				Support
Age	Correlation	.030	.062	.233
	Coefficient			
	<i>p</i> -value	.819	.639	.074
	N	60	60	60
Gender	Correlation	.132	.201	.075
	Coefficient			
	<i>p</i> -value	.315	.124	.569
	N	60	60	60
Education level	Correlation	.068	084	.211
	Coefficient			
	<i>p</i> -value	.606	.525	.106
	N	60	60	60
Marital status	Correlation	.146	.034	148
	Coefficient			
	<i>p</i> -value	.265	.795	.260
	N	60	60	60
Relationship	Correlation	029	134	141
•	Coefficient			
	<i>p</i> -value	.827	.308	.284
	N	60	60	60
Same Home	Correlation	190	206	160
	Coefficient			
	<i>p</i> -value	.146	.114	.221
	N	60	60	60
Diabetic Years	Correlation	190	001	.006
	Coefficient			
	<i>p</i> -value	.145	.995	.964
	N	60	60	60
Hospitalizations	Correlation	015	268*	052
this year	Coefficient			
,	<i>p</i> -value	.907	.040	.697
	N	59	59	59

Note. *Correlation is significant at the .05 level (2-tailed).

Table 7. Correlations between nurse demographic variables and family nursing practice appraisal and nurse-family relationship

Spearman Correlations

		Practice Appraisal	Nurse-Family Relationship
Age	Correlation Coefficient	450**	277*
	<i>p</i> -value	.000	.032
	N	60	60
Gender	Correlation Coefficient	.205	.025
	<i>p</i> -value	.117	.848
	N	60	60
Education level	Correlation Coefficient	069	008
	<i>p</i> -value	.598	.954
	N	60	60
Total Years practicing	Correlation Coefficient	538**	342**
nursing	<i>p</i> -value	.000	.008
	N	60	60
Total Years on current	Correlation Coefficient	406**	234
unit	<i>p</i> -value	.001	.072
	N	60	60

Note. **Correlation is significant at the .01 level (2-tailed); *Correlation is significant at the .05 level (2-tailed).

Table 8. ANOVA of study units and nurse perceptions

Nurse	Unit 1	Unit 2	Unit 3	Unit 4	F	<i>p</i> -value
Perceptions						
	Mean	Mean	Mean	Mean		
	(SD)	(SD)	(SD)	(SD)		
Practice Appraisal	1.59 (0.48)	1.77 (0.49)	2.07 (0.69)	2.00 (0.56)	2.350	.082
Reciprocity	1.48 (0.34)	1.75 (0.44)	2.00 (0.52)	1.88 (0.43)	3.931	.013*

Note. ANOVA = analysis of variance; SD = standard deviations; *Bonferroni Technique = significant differences between Unit 1 and Unit 3 p = .001.

Table 9. ANOVA of study units and family member perceptions

Family	Unit 1	Unit 2	Unit 3	Unit 4	F	<i>p</i> -value
Member Perceptions	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)		
Family Functioning	4.63 (0.85)	4.90 (0.49)	4.61 (0.93)	4.74 (0.70)	.459	0.712
Family Health	4.80 (0.54)	4.98 (0.43)	4.89 (0.41)	4.87 (0.31)	.458	0.713
Social Support	4.76 (0.66)	4.66 (0.59)	4.90 (0.69)	4.57 (1.04)	.513	0.675

Note. ANOVA = analysis of variance; SD = standard deviation.

Figure 1. Problems or drawbacks to individual nursing practice reported by nurses when involving family in assessment and care planning.

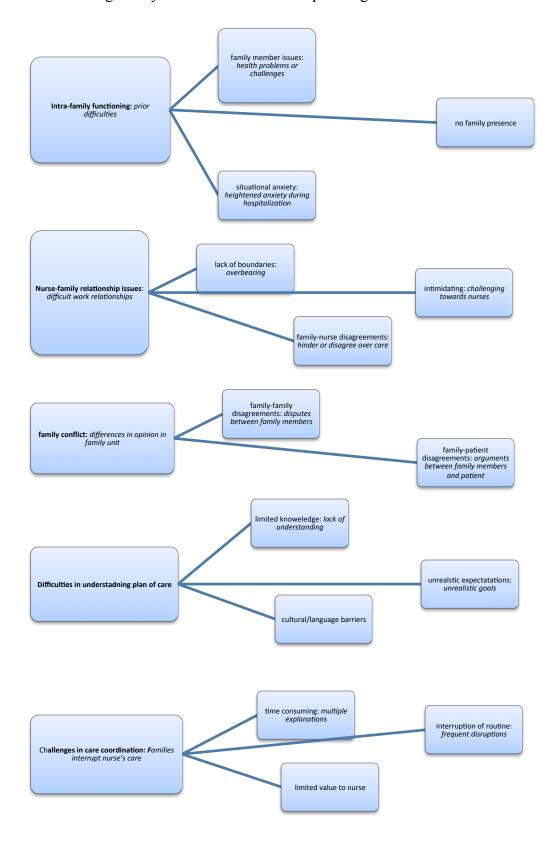


Figure 2. Advantages to individual nursing practice when involving the family in assessment and care planning.

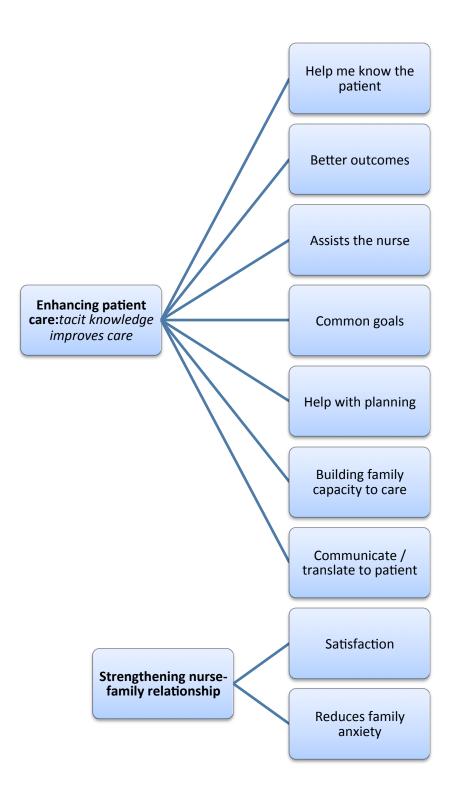
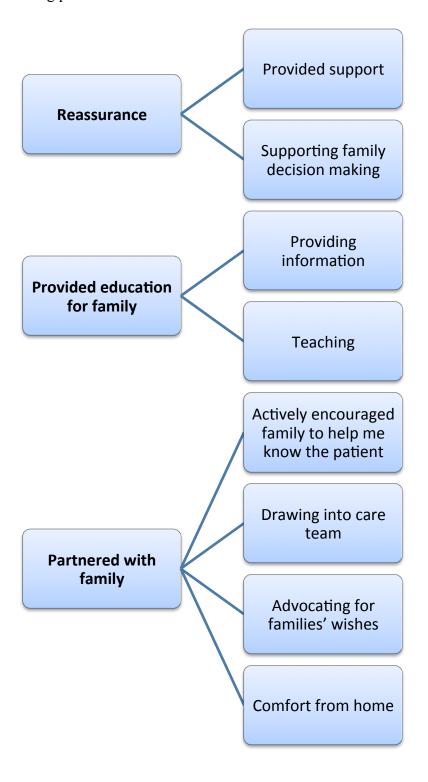


Figure 3. What nurses reported having done in the past week to involve families in their current nursing practice.



Appendix A

Patient Script

TMH IRB Approval: 8/8/2012 IRB Expiration: 8/7/2013

Thank you for agreeing to meet with me regarding my research study. My name is Kara Misto and I am a Doctoral student in the College of Nursing at the University of Rhode Island. I am conducting a research study in collaboration with Lifespan in which I hope to gain an understanding of how family members who care for older adults with diabetes describe their family's functioning and health, and the support they receive from nurses. I will also be exploring how nurses feel about working with families. You are being asked to take part in a research study entitled "The relationship between family members' perceptions of family functioning, family health and in-hospital social support with nurses' perceptions of their family nursing practice".

I would like to ask for your verbal consent to consider handing an informational card to one of your family member who you feel is your primary caregiver when you are at home. Participation for you and your family member is completely voluntary. If you choose to give the card to your family member, it will ask your family member if they would be willing to call me to discuss their consent to complete two questionnaires. The first is about some basic demographic information. The second is about family function, family health and support from nurses. If they choose to participate, your family member and I can either complete the survey questions together over the phone or I can mail it to them and they can return it in the envelope provided. Participation is completely voluntary and the survey data will be completely anonymous.

There are no anticipated *risks* for anyone who chooses to participate in the study, and although there will be no direct *benefit* to you for taking part in this study, the researcher may learn more about how nurses can work more effectively to support families. You can choose to *withdraw* at any time because participation is voluntary. The decision to withdraw will in way affect the health care services you normally receive.

The principal investigator for this study is: Maria Ducharme. If you have any questions about this study you can contact her at 401-793-2005. You may also contact the Doctoral Student responsible for this study, Kara Misto at 401-874-5305 (or kmisto@mail.uri.edu).

If you have any complaints or would like more information about research in general you can contact Patricia Houser, RN, MSJ in the Office of Research Administration, 401-444-6246

Thank you very much for your time.

Appendix B

Family Member post-card

Front



President of Patient Care Services and Chief Nursing Officer at The Miriam Hospital. I am working with Kara Misto, who is completing a PhD in the College of Nursing at University of Rhode Island. We are conducting a research study at The Miriam Hospital in which we hope to gain an understanding of how family members who care for older adults with diabetes perceive their family's functioning, family's health and the support that they receive from nurses. We would be most grateful for your input and participation! As the prinicipal investigator for this study you are welcome to contact me, Maria Ducharme, at 401-793-2005 with any questions.

If you are interested in taking the survey, please contact Kara Misto at 401-639-9124

Participation would include completing a 20-minute survey either by telephone or by filling out a copy that would be mailed to you.

Thank you for your consideration,
Maria Ducharme, RN, MS NE-BC & Kara Misto, PhD(c), RN

TMH IRB Approval: 8/8/2012 IRB Expiration: 8/7/2013

Back



Lifespan

A Research Study Considering:

The relationship between family members' perceptions of family functioning, family health and in-hospital social support and nurses' perceptions of their family nursing practice.

Maria Ducharme, RN, MS NE-BC VP of Patient Care Services and Chief Nursing Officer

The Miriam Hospital

Kara Misto, PhD(c), RN
Instructor, Medical Surgical Nursing
URI, College of Nursing

Appendix C

Family Member Script

TMH IRB Approval: 8/8/2012 IRB Expiration: 8/7/2013

Thank you for agreeing to meet with me regarding my research study. My name is Kara Misto and I am a Doctoral student in the College of Nursing at the University of Rhode Island. I am conducting a research study in collaboration with Lifespan in which I hope to gain an understanding of how family members who care for older adults with diabetes describe their family's functioning and health, and the support they receive from nurses. I will also be exploring how nurses feel about working with families. You are being asked to take part in this research study, entitled "The relationship between family members perceptions of family functioning, family health and in-hospital social support with nurses' perceptions of their family nursing practice."

I would like to ask you for your verbal consent to consider completing two questionnaires. The first is about some basic demographic information. The second is about family function, family health and support from nurses. If you choose to participate, we can either complete the survey questions together over the phone or I can mail it to you and you can return it in the envelope provided. Participation is completely voluntary and your survey data will be completely anonymous.

There are no anticipated *risks* for anyone who chooses to participate in the study, and although there will be no direct *benefit* to you for taking part in this study, the researcher may learn more about how nurses can work more effectively to support families. You can choose to *withdraw* at any time because participation is voluntary. The decision to withdraw will in way affect the health care services you normally receive.

The principal investigator for this study is: Maria Ducharme. If you have any questions about this study you can contact her at 401-793-2005. You may also contact the Doctoral Student responsible for this study, Kara Misto at 401-874-5305 (or kmisto@mail.uri.edu).

If you have any complaints or would like more information about research in general you can contact Patricia Houser, RN, MSJ in the Office of Research Administration, 401-444-6246.

Appendix D Family Member Demographic Sheet

		Number				
	Family member D	emographic Information				
	complete the following questions by p applies to you and your family.	placing a check next to the response which most				
1.	1. What is your age?					
	□18-25 □36-45 □56 or older	□26-35 □46-55				
2.	What is your gender?					
	Male	Female				
3.	What is the highest level of educat	ion you have completed?				
	Grammar school	Bachelor's degree				
	High school or equivalent	Master's degree				
	Some college	Doctoral degree				
	other	Professional degree (MD, JD, etc.)				
4.	What is your current marital statu	15?				
	Married	Single				
	Divorced	Separated				
	Living with another	Would rather not say				
	Widowed					
5.	What is your relation to your fami	ly member currently admitted to the hospital?				
	Spouse/significant other	Son/Daughter				
	Son-in-law/Daughter-in-law	Grandchild				
	Other relative/friend:(please indic relationship)	cate how you would describe your				
б.	Does your family member who is o you?	urrently admitted to the hospital reside with				
	□Yes					
	□No.					

Appendix E

Family Functioning, Family Health and Perceived Social Support Instrument

			NUMBE	:R
FAMILY FUNCTIONING,	FAMILY HEALTH	AND SOCIAL	SUPPORT	SCALE

The following list describes the ways that families evaluate their families perceive their family functioning, family health and the social support they receive from nurses when an older adult family member with diabetes is hospitalized. Please rate how your family perceives each item from a range of 1 (definitely disagree) to 5 (definitely agree). Please CIRCLE the most appropriate number.

		Definitely disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Definitely agree
FAMI	LY FUNCTIONING						
1.	As a family, we find it easy to plan things in advance.	1	2	3	4	5	6
2.	As a family, we do not drift along aimlessly, we proceed according to plan	1	2	3	4	5	6
3.	We share household duties evenly.	1	2	3	4	5	6
4.	In our family, each family member participates in domestic tasks.	1	2	3	4	5	6
5.	Our family spends a lot of time discussing family issues.	1	2	3	4	5	6
6.	In our family, there are no unsolved questions.	1	2	3	4	5	6
7.	In our family, there are no disagreements.	1	2	3	4	5	6
8.	Our family expresses positive feelings.	1	2	3	4	5	6
9.	We care for one another.	1	2	3	4	5	6
10.	Relationships within our family are well- balanced.	1	2	3	4	5	6
11.	Members of our family support each other.	1	2	3	4	5	6
12.	We often get together with our relatives	1	2	3	4	5	6
13.	Our family has good friends.	1	2	3	4	5	6
14.	We want to discuss our concerns with	1	2	3	4	5	6

Astedt-Kurki, P., Tarkka, M.T., Rikala, M.R., Lehti, K. & Paavilainen, E., 2009

	Definitely disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Definitely agree
people close to us.						
 Our family has good relationships with neighbors. 	1	2	3	4	5	6
 If necessary, it is easy for us to find mental support outside the family. 	1	2	3	4	5	6
 We do many things together as a family. 	1	2	3	4	5	6
 Hobbies are important to our family. 	1	2	3	4	5	6
 Our family shares hobbies and interests. 	1	2	3	4	5	6
FAMILY HEALTH	Definitely disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Definitely agree
 Each family member is allowed to express oneself freely. 	1	2	3	4	5	6
 We feel safe as a family. 	1	2	3	4	5	6
Members of our family have a similar sense of humor.	1	2	3	4	5	6
 We laugh at the same things. 	1	2	3	4	5	6
 A playful attitude often helps us overcome difficult situations. 	1	2	3	4	5	6
 Close relationships are important in our family. 	1	2	3	4	5	6
 Our ill family member does not experience pain frequently. 	1	2	3	4	5	6
 Our ill family member does not experience symptoms very often. 	1	2	3	4	5	6
 Our ill family member does not worry about his/her condition. 	1	2	3	4	5	6
29. Although one member of our family has an illness, our life is not too complicated.	1	2	3	4	5	6
 Occasional pain is part of our ill family member's illness. 	1	2	3	4	5	6

Astedt-Kurki, P., Tarkka, M.T., Rikala, M.R., Lehti, K. & Paavilainen, E., 2009

	Definitely disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Definitely agree
 His/her pain makes other family members worry. 	1	2	3	4	5	6
 Concern for the ill family member's condition causes distress in other family members. 	1	2	3	4	5	6
 The ill family member occasionally gets symptoms, he/she gets symptoms if he/she worries about the circumstances of other family members. 	1	2	3	4	5	6
 Occasional symptoms in one family member are part of our family situation. 	1	2	3	4	5	6
35. We know what kind of illness our family member has.	1	2	3	4	5	6
 We know that we can do many things together despite the illness. 	1	2	3	4	5	6
 We know where to get help if the symptoms fail to abate. 	1	2	3	4	5	6
38. We are certain that the healthcare system is capable of helping our ill family member.	1	2	3	4	5	6
 If other members of our family develop health problems, we know where we can seek help. 	1	2	3	4	5	6
 Our family maintains a healthy lifestyle in appropriate ways. 	1	2	3	4	5	6
41. As a family, we take care of our health.	1	2	3	4	5	6
42. As a family, we are used to making independent decisions about health issues	1	2	3	4	5	6

Astedt-Kurki, P., Tarkka, M.T., Rikala, M.R., Lehti, K. & Paavilainen, E., 2009

	Definitely disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Definitely agree
SOCIAL SUPPORT DURING HOSPITAL STAY						
 We are satisfied with how nurses involved the patient and family in care planning. 	1	2	3	4	5	6
44. Our family received sufficient explanation of what will happen in the care of our family member.	1	2	3	4	5	6
45. We received sufficient counseling in matters related to our family member's care.	1	2	3	4	5	6
46. We have been sufficiently engaged in discussions about the ill family members' course of illness.	1	2	3	4	5	6
47. We are satisfied with the amount of discussion about the patient's condition during hospitalization.	1	2	3	4	5	6
48. We are satisfied with the amount of discussion about the progress of care.	1	2	3	4	5	6
49. We have received sufficient explanation of treatment options for our family member.	1	2	3	4	5	6
50. Our family received adequate information about a diabetic patient's diet	1	2	3	4	5	6
51. Our family received sufficient explanation of what kind of exercise the ill family member can take.	1	2	3	4	5	6

Astedt-Kurki, P., Tarkka, M.T., Rikala, M.R., Lehti, K. & Paavilainen, E., 2009

	Definitely disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Definitely agree
52. Our family received adequate information about what to consider regarding the patient's mental exertion.	1	2	3	4	5	6
 Our family has received adequate information about risks to the patient. 	1	2	3	4	5	6
 Our family has received adequate information about how the illness affects sexual life. 	1	2	3	4	5	6
55. We have been sufficiently encouraged by nurses to become involved in the patient's hospital care.	1	2	3	4	5	6
 Nurses provide enough space for our family to express feelings. 	1	2	3	4	5	6
57. Nurses show sufficient compassion for our family.	1	2	3	4	5	6
 Nurses provide sufficient positive feedback for our involvement in care. 	1	2	3	4	5	6
59. Nurses show sufficient interest in our family affairs.	1	2	3	4	5	6
60. Nurses show sufficient appreciation for family involvement in the patient's care.	1	2	3	4	5	6
61. Nurses show sufficient consideration for the well-being of our family.	1	2	3	4	5	6
62. Nurses show sufficient interest in how our family copes with	1	2	3	4	5	6

Astedt-Kurki, P., Tarkka, M.T., Rikala, M.R., Lehti, K. & Paavilainen, E., 2009

		Definitely disagree	Disagree	Somewhat disagree	Somewhat agree	Agree	Definitely agree
Г	aftercare.						

Appendix F

Informational Letter for Family Members

TMH IRB Approval: 8/8/2012 IRB Expiration: 8/7/2013



The Miriam Hospital, A Lifespan Affiliate Informational Letter: Invitation to Participate in a Research Study

The relationship between family members' perceptions of family functioning, family health and in-hospital social support and nurses' perceptions of their family nursing practice.

Dear Sir or Madam:

My name is Maria Ducharme, I am the Senior Vice President of Patient Care Services and Chief Nursing Officer at The Miriam Hospital. I am working with Kara Misto who is a doctoral student in the College of Nursing at the University of Rhode Island. We are conducting a research study at The Miriam Hospital, which is designed to gain an understanding of how family members who care for older adults with diabetes describe their family's functioning and health and the support they receive from nurses. We will also be exploring how nurses feel about working with families. You are being asked to take part in this research study entitled "The relationship between family members perceptions of family functioning, family health and in-hospital social support with nurses' perceptions of their family nursing practice."

If you decide to take part in this study here is what will happen: You will be asked to fill out two brief questionnaires. Completing the questionnaires should take about 20 minutes. Filling out the attached questionnaires implies you have read the above explanation of the study, that all your questions have been answered and that you consent to participate in the study. Participation in the study is strictly voluntary. If you do no wish to participate, simply do not complete the questionnaires. If you would like to withdraw from participating, you may do so with no penalty by simply stopping completion of the survey and not returning it.

If you do choose to participate, your responses will be anonymous and confidential. None of the information will identify you by name. Questionnaires will only be coded by number, so neither I nor anyone else will be able to identify you. Records will be used for research purposes only, including Ms. Misto's dissertation and in various presentations of grouped data. All data will be treated as confidential medical records, and will be safeguarded according to the policy of the Lifespan institution. This policy is based on Rhode Island law, which promotes protection of confidential health care information.

If you have any questions about this study you are welcome to contact the doctoral student working with me on this study, Kara Misto at 401-874-5305(kmisto@mail.uri.edu). As the principal investigator for this study you can also contact me, at 401-793-2005. If you have any complaints or would like more information about research in general you can contact Patricia Houser, RN, MSJ in the Office of Research Administration, 401-444-6246.

Thank you for considering participation. Sincerely,

Maria Ducharme, RN, MS NE-BC

cc: Kara Misto, PhD(c), RN

Appendix G

Informational Letter for Registered Nurses

TMH IRB Approval: 8/8/2012 IRB Expiration: 8/7/2013



Lifespan

The Miriam Hospital, A Lifespan Affiliate
Informational Letter: Invitation to Participate in a Research Study
The relationship between family members' perceptions of family functioning, family health and inhospital social support and nurses' perceptions of their family nursing practice.

Dear Registered Nurse:

As the Senior Vice President of Patient Care Services and Chief Nursing Officer here at The Miriam Hospital, I would like to inform you of a research project that I am working on with Kara Misto, a doctoral student in the College of Nursing at the University of Rhode Island. We are conducting a research study at The Miriam Hospital which is designed to gain understanding of how nurses feel about working with families. You are being asked to take part in a research study entitled "The relationship between family members perceptions of family functioning, family health and in-hospital social support with nurses' perceptions of their family nursing practice." Studies have shown that family care for patients with chronic illness is very important, however, much of the published work related to family involvement in health care has focused on the parents of pediatric clients. Therefore this study aims to evaluate the relationships between the family and nurses when an older adult with diabetes is hospitalized. This study will specifically explore the perceptions of nurses working with family members of older adults with diabetes who have been admitted to an acute care facility. Additionally, this research project will explore families' perceptions of their family functioning, family health and the social support received from nurses, during hospitalization of an older adult family member who has diabetes.

If you decide to take part in this study here is what will happen: You are being asked to consider filling out a questionnaire regarding family nursing practice and the nurse-family relationship. If you choose to participate, please return the questionnaires in the enclosed envelope to the box provided on the nursing unit within two weeks. Completing the questionnaire should take about 10-15 minutes. Your filling out the attached demographic sheet and survey implies you have read the above explanation of the study, that all your questions have been answered and that you consent to participate in the study. Participation in the study is strictly *voluntary*. If you do no wish to participate, simply do not complete the questionnaires. If you would like to *withdraw* from participating, you may do so with no penalty.

If you do choose to participate, your responses will be anonymous and confidential. None of the information will identify you by name. Questionnaires will only be coded by number, so neither I nor anyone else will be able to identify you, or to identify nurses who choose not to participate. Records will be used for research purposes only, including Ms. Misto's dissertation and in various presentations of grouped data. As the responses are anonymous, the results of individual questionnaires will not be reported to your manager or used in any way to evaluate individual performance. All data will be treated as confidential medical records, and will be safeguarded according to the policy of the Lifespan institution. This policy is based on Rhode Island law, which promotes protection of confidential health care information.

If you have any questions about this study you are welcome to contact the doctoral student working with me on this study, Kara Misto at 401-874-5305 (kmisto@mail.uri.edu). As the principal investigator for this study you can additionally call me, Maria Ducharme at 401-793-2005. If you have any complaints or would like more information about research in general you can contact Patricia Houser, RN, MSJ in the Office of Research Administration, 401-444-6246.

Thank you for considering this request. Sincerely,

Maria Ducharme, RN, MS NE-BC

cc: Kara Misto, PhD(c), RN

Appendix H

Registered Nurse Demographic Sheet

		Number			
	Registered Nurse Demogra	phic Information			
	complete the following questions by placing a ch applies to you and your family.	neck next to the response which most			
1.	What is your age?				
	□ 18- 25 □ 26-35 □ 36-45 □ 46-55 □ 56 or older				
2.	What is your gender?				
	Male				
	Female				
3.	3. What is the highest level of nursing education you have completed?				
	Nursing Diploma Program	Doctoral degree in Nursing			
	Associate's degree in Nursing	Professional degree (MD, JD, etc.)			
	Bachelor's degree in Nursing	other			
	Master's degree in Nursing				
4.	How many years have you been practicing as	a registered nurse?			
	less than 5 years				
	5-10 years				
	☐10-15 years				
	☐15-20 years				
	more than 20 years				
5.	How many years have you practiced nursing	on your current nursing unit?			
	less than 5 years				
	5-10 years				
	☐10-15 years				
	☐15-20 years				
	more than 20 years				

Appendix I

Family Nursing Practice Scale

FAMILY NURSING PRACTICE SCALE	Number
(high importance/ strongly agree/ always) to 5 (ow importance/

Please indicate on a scale of 1 (high importance/ strongly agree/ always) to 5 (low importance/ strongly disagree/ never), which best reflects your feelings toward your work with families. Please CIRCLE the most appropriate number.

1	My confidence level in working with families is	high 1	2	3	4	low 5
2	My level of satisfaction with family nursing is	high 1	2	3	4	low 5
3	My knowledge level of family nursing is	high 1	2	3	4	low 5
4	My skill in working with the family system is	high 1	2	3	4	low 5
5	I feel comfortable in initiating family involvement in nursing care planning.	high 1	2	3	4	low 5
6	I plan nursing interventions in consultation with the patient and family.	always 1	2	3	4	never 5
7	Families always approach me about their ill relative.	Strongly agree 1	2	3	4	Strongly disagree 5
8	I promote patient/family participation, choice and control in meeting health care needs.	always 1	2	3	4	never 5
9	My involvement with families is mostly rewarding.	Strongly agree 1	2	3	4	Strongly disagree 5
10	I avoid interference of my own biases when collecting, interpreting and communicating data bout patients and families.	high 1	2	3	4	low 5

Please	comment on the following questions:
11.	What problems or drawbacks are there in your nursing practice by involving the family in assessment and care planning?
12.	What advantages, if any, are there for your nursing practice by involving the family in assessment and care planning?
13.	What have you done in the past week to involve families in your current nursing practice? Please comment.

Simpson, P. & Tarrant, M, 2006

REFERENCES

- Agency for Healthcare Research and Quality. (2000). *AHRQ Research on Diabetes**Care: Translating Research into Practice. from

 http://www.ahrq.gov/research/findings/factsheets/diabetes/tripdiab/index.html
- Ahrens, T., Yancey, V., & Kollef, M. (2003). Improving family communications at the end of life: implications for length of stay in the intensive care unit and resource use. *American Journal of Critical Care*, *12*(4), 317-323; discussion 324.
- ANCC. (2012). Magnet: Overview. 2012, from http://www.nursecredentialing.org/Magnet/ProgramOverview.aspx
- Anderson, G. F. (2005). Medicare and chronic conditions. *New England Journal of Medicine*, 353(3), 305-309.
- Andren, S., & Elmstahl, S. (2008). The relationship between caregiver burden, caregivers' perceived health and their sense of coherence in caring for elders with dementia. *Journal of Clinical Nursing*, 17(6), 790-799.
- Armour, T. A., Norris, S. L., Jack, L., Jr., Zhang, X., & Fisher, L. (2005). The effectiveness of family interventions in people with diabetes mellitus: a systematic review. *Diabetic Medicine*, 22(10), 1295-1305.
- Astedt-Kurki, P., Lehti, K., Tarkka, M. T., & Paavilainen, E. (2004). Determinants of perceived health in families of patients with heart disease. *Journal of Advanced Nursing*, 48(2), 115-123.

- Astedt-Kurki, P., Paavilainen, E., Tammentie, T., & Paunonen-Ilmonen, M. (2001).

 Interaction between adult patients' family members and nursing staff on a hospital ward. *Scandinavian Journal of Caring Sciences*, 15(2), 142-150.
- Astedt-Kurki, P., Tarkka, M. T., Paavilainen, E., & Lehti, K. (2002). Development and testing of a family nursing scale. *Western Journal of Nursing Research*, 24(5), 567-579.
- Astedt-Kurki, P., Tarkka, M. T., Rikala, M. R., Lehti, K., & Paavilainen, E. (2009). Further testing of a family nursing instrument (FAFHES). *International Journal of Nursing Study, 46*(3), 350-359.
- Auerbach, S. M., Kiesler, D. J., Wartella, J., Rausch, S., Ward, K. R., & Ivatury, R.
 (2005). Optimism, satisfaction with needs met, interpersonal perceptions of the healthcare team, and emotional distress in patients' family members during critical care hospitalization. *American Journal of Critical Care*, 14(3), 202-210.
- Bass, D. M., & Noelker, L. S. (1987). The influence of family caregivers on elder's use of in-home services: an expanded conceptual framework. *Journal of Health and Social Behavior*, 28(2), 184-196.
- Bauer, M., Fitzgerald, L., Haesler, E., & Manfrin, M. (2009). Hospital discharge planning for frail older people and their family. Are we delivering best practice? A review of the evidence. *Journal of Clinical Nursing*, 18(18), 2539-2546.

- Benzein, E., Johansson, P., Arestedt, K. F., & Saveman, B. I. (2008). Nurses' attitudes about the importance of families in nursing care: a survey of Swedish nurses.

 Journal of Family Nursing, 14(2), 162-180.
- Berman, H. (1991). Nurses' beliefs about family involvement in a children's hospital.

 *Issues in Comprehensive Pediatric Nursing, 14(3), 141-153.
- Black, P., Boore, J. R., & Parahoo, K. (2011). The effect of nurse-facilitated family participation in the psychological care of the critically ill patient. *Journal of Advanced Nursing*, 67(5), 1091-1101.
- Board, R., & Ryan-Wenger, N. (2002). Long-term effects of pediatric intensive care unit hospitalization on families with young children. *Heart and Lung*, *31*(1), 53-66.
- Bogner, H. R., Miller, S. D., de Vries, H. F., Chhatre, S., & Jayadevappa, R. (2010).

 Assessment of cost and health resource utilization for elderly patients with heart failure and diabetes mellitus. *Journal of Cardiac Failure*, *16*(6), 454-460.
- Bruce, B., & Ritchie, J. (1997). Nurses' practices and perceptions of family-centered care. *Journal of Pediatric Nursing*, 12(4), 214-222.
- Buie, V. C., Owings, M. F., DeFrances, C. J., & Golosinksiy, A. (2010). National Hospital Discharge Survey: 2006 summary *Vital Health Statistics*, *13*(168), 1-79.
- Center for Disease Control and Prevention. (2009). *The power of prevention*. from http://www.cdc.gov/chronicdisease/overview/index.htm

- Centers for Disease Control and Prevention (2011). *National Diabetes Fact Sheet:*national estimates and general information on diabetes and prediabetes in the

 United States. from http://www.cdc.gov/diabetes/pubs/pdf/ndfs_2011.pdf
- Chen, Q. (2012). The Impact of Ignoring a Level of Nesting Structure in Multilevel Mixture Method: A Monte Carlo Study. *Sage Open, 2*, 1-10.
- Chesla, C. A. (1996). Reconciling technologic and family care in critical-care nursing. *Image: Journal of Nursing Scholarship, 28*(3), 199-203.
- Chesla, C. A. (2010). Do family interventions improve health? *Journal of Family Nursing*, 16(4), 355-377.
- Cleary, J., Gray, O. P., Hall, D. J., Rowlandson, P. H., Sainsbury, C. P., & Davies, M.
 M. (1986). Parental involvement in the lives of children in hospital. *Archives of Diseases in Childhood*, 61(8), 779-787.
- Coco, K., Tossavainen, K., Jaaskelainen, J. E., & Turunen, H. (2013). The provision of emotional support to the families of traumatic brain injury patients: perspectives of Finnish nurses. *Journal of Clinical Nursing*, *22*(9-10), 1467-1476.
- Cohen, J. (1988). *Statistical Power Analysis for the Behavioral Sciences* (2nd ed.).

 New Jersey: Lawrence Erlbaum Associates.
- Cohen, J. (1992). Statistical power analysis. *Current Directions in Psychological Science*, *1*(3), 98-101.
- Coleman, E. A. (2003). Falling through the cracks: challenges and opportunities for improving transitional care for persons with continuous complex care needs. *Journal of the American Geriatrics Society*, 51(4), 549-555.

- Coleman, E. A., & Boult, C. (2003). Improving the quality of transitional care for persons with complex care needs. *Journal of the American Geriatrs Society*, 51(4), 556-557.
- Coleman, E. A., Min, S. J., Chomiak, A., & Kramer, A. M. (2004). Posthospital care transitions: patterns, complications, and risk identification. *Health Services Research*, *39*(5), 1449-1465.
- Coleman, E. A., Smith, J. D., Frank, J. C., Min, S. J., Parry, C., & Kramer, A. M.
 (2004). Preparing patients and caregivers to participate in care delivered across settings: the Care Transitions Intervention. *Journal of the American Geriatrics Society*, 52(11), 1817-1825.
- Donelan, K., Hill, C. A., Hoffman, C., Scoles, K., Feldman, P. H., Levine, C., & Gould, D. (2002). Challenged to care: informal caregivers in a changing health system. *Health Affairs*, *21*(4), 222-231.
- Downe-Wamboldt, B. (1992). Content analysis: method, applications, and issues. *Health Care Women International*, *13*(3), 313-321.
- Duhamel, F. E., Watson, W. L., & Wright, L. (1994). A family systems nursing approach to hypertension. *Canadian Journal of Cardiovascular Nursing*, *5*(4), 14-24.
- Ebbesen, L. S., Guyatt, G. H., McCartney, N., & Oldridge, N. B. (1990). Measuring quality of life in cardiac spouses. *Journal of Clinical Epidemiology*, *43*(5), 481-487.
- Efran, J., & Lukens, M. D. (1985). The world according to Humberto Maturana. Family Therapy Networker, 9(3), 23-28, 72-75.

- Eggenberger, S. K., & Nelms, T. P. (2007). Being family: the family experience when an adult member is hospitalized with a critical illness. *Journal of Clinical Nursing*, *16*, 1618-1628.
- Eichner, L. J., & Johnson, B. H. (2012). Patient- and Family-Centered care and the pediatrician's role. *Pediatrics*, *129*(2), 394-404.
- Faison, K. J., Faria, S. H., & Frank, D. (1999). Caregivers of chronically ill elderly: perceived burden. *Journal of Community Health Nursing*, *16*(4), 243-253.
- Fegran, L., & Helseth, S. (2009). The parent-nurse relationship in the neonatal intensive care unit context closeness and emotional involvement.

 Scandinavian Journal of Caring Sciences, 23(4).
- Fisher, C., Lindhorst, H., Matthews, T., Munroe, D. J., Paulin, D., & Scott, D. (2008).

 Nursing staff attitudes and behaviours regarding family presence in the hospital setting. *Journal of Advanced Nursing*, 64(6), 615-624.
- Fisher, L. (2006). Research on the family and chronic disease among adults: Major trends and directions. *Families, Systems, & Health, 24*(4), 373-380.
- Fisher, L., & Weihs, K. L. (2000). Can addressing family relationships improve outcomes in chronic disease? Report of the National Working Group on Family-Based Interventions in Chronic Disease. *Journal of Family Practice*, 49(6), 561-566.
- Gabbay, R. A., Bailit, M. H., Mauger, D. T., Wagner, E. H., & Siminerio, L. (2011).

 Multipayer patient-centered medical home implementation guided by the chronic care model. *Joint Commission Journal on Quality and Patient Safety*, 37(6), 265-273.

- Gallant, M. P., Spitze, G., & Prohaska, T. R. (2007). Help or hindrance? How family and friends influence chronic illness self-management among older adults.

 *Resarch on Aging, 29(5), 375-409.
- Gavaghan, S. R., & Carroll, D. L. (2002). Families of critically ill patients and the effect of nursing interventions. *Dimensions of Critical Care Nursing*, 21(2), 64-71.
- Glasdam, S., Timm, H., & Vittrup, R. (2010). Support efforts for caregivers of chronically ill persons. *Clinical Nursing Research*, 19(3), 233-265.
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105-112.
- Greenberger, H., & Litwin, H. (2003). Can burdened caregivers be effective facilitators of elder care-recipient health care? *Journal of Advanced Nursing*, 41(4), 332-341.
- Greenwald, M. a. a., Naiditch, L., & Weber-Raley, L. (2009). Caregiving in the U.S.:

 National Alliance for Caregiving and AARP.
- Grimmer, K., Moss, J., & Falco, J. (2004). Experiences of elderly patients regarding independent community living after discharge from hospital: a longitudinal study. *International Journal of Quality in Health Care*, *16*(6), 465-472.
- Harju, E., Rantanen, A., Tarkka, M. T., & Astedt-Kurki, P. (2011). Perceived family health in persons with prostate cancer and their family members. *Journal of Clinical Nursing*, 21(3-4), 544-554.

- Hoffman, C., Rice, D., & Sung, H. Y. (1996). Persons with chronic conditions. Their prevalence and costs. *Journal of the American Medical Association*, *276*(18), 1473-1479.
- House, J. (1944). *Work stress and social support*. Reading, MA: Addison-Wesly Pub. Co.
- IBM. (Released 2012). IBM Corp. Released 2012. SPSS Stastics for Windows, Version 21.0. Armonk, NY.
- Institute for Family Centered Care. (2008). What is patient- and family-centered care health care. from http://familycenteredcare.org/faq.html
- Jencks, S. F., Williams, M. V., & Coleman, E. A. (2009). Rehospitalizations among patients in the Medicare fee-for-service program. *New England Journal of Medicine*, *360*(14), 1418-1428.
- Kahn, R. L. (1979). Aging and social support. In M. W. Riley (Ed.), *Aging from Birth to Death: Interdisciplinary Perspectives* (pp. 77-79). Boulder, CO: Westview Press.
- Kim, Y., & Schulz, R. (2008). Family caregivers' strains: Comparitive analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *Journal of Aging and Health*, 20(5), 483-503.
- Kondracki, N. L., Wellman, N. S., & Amundson, D. R. (2002). Content analysis: review of methods and their applications in nutrition education. *Journal of Nutrition Education Behavior*, *34*(4), 224-230.
- Kosco, M., & Warren, N. A. (2000). Critical Care Nurses' Percpetions of Family Needs as Met. *Critical Care Nurse Quarterly*, 23(2), 60-72.

- Kreidler, M. C., Campbell, J., Lanik, G., Gray, V. R., & Conrad, M. A. (1994).Community elderly. A nursing center's use of change theory as a model.Journal of Gerontological Nursing, 20(1), 25-30.
- Langa, K. M., Vijan, S., Hayward, R. A., Chernew, M. E., Blaum, C. S., Kabeto, M.
 U., . . . Fendrick, A. M. (2002). Informal caregiving for diabetes and diabetic complications among elderly americans. *Journal of Gerontology: Social Sciences*, 57(3), S177-186.
- Lauzon Clabo, L. M. (2008). An ethnography of pain assessment and the role of social context on two postoperative units. *Journal of Advanced Nursing*, 61(5), 531-539.
- Leahey, M., Harper-Jaques, S., Stout, L., & Levac, A. M. (1995). The impact of a family systems nursing approach: nurses' perceptions. *Journal of Continuing Education in Nursing*, 26(5), 219-225.
- Legrow, K., & Rossen, B. E. (2005). Development of professional practice based on a family systems nursing framework: nurses' and families' experiences. *Journal of Family Nursing*, 11(1), 38-58.
- Levesque, L., Ducharme, F., Caron, C., Hanson, E., Magnusson, L., Nolan, J., & Nolan, M. (2010). A partnership approach to service needs assessment with family caregivers of an aging relative living at home: a qualitative analysis of the experiences of caregivers and practitioners. *International Journal of Nursing Studies*, 47(7), 876-887.

- Levine, C., Halper, D., Peist, A., & Gould, D. A. (2010). Bridging troubled waters: family caregivers, transitions, and long-term care. *Health Affairs*, 29(1), 116-124.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.
- Lough, M. A. (1996). Ongoing work of older adults at home after hospitalization. *Journal of Advanced Nursing*, 23, 804-809.
- Martinez-Huedo, M. A., Lopez de Andres, A., Hernandez-Barrera, V., Palacios-Cena,
 D., Carrasco-Garrido, P., Hernandez, D. M., & Jimenez-Garcia, R. (2011).
 Trends in the prevalence of physical and functional disability among Spanish elderly suffering from diabetes (2000-2007). *Diabetes Research and Clinical Practice*, 94(2), e30-33.
- Mattila, E., Leino, K., Paavilainen, E., & Åstedt-Kurki, P. (2009). Nursing intervention studies on patients and family members: a systematic literature review. *Scandinavian Journal of Caring Sciences*, *23*(3), 611 622.
- Maturana, H. (1988). Reality: The Search for Objectivity or the Quest for a Compelling Argument *The Irish Journal of Psychology*, *6*(1), 25-83.
- Maturana, H., & Varela, F. (1992). *The tree of knowledge: The biological roots of human understanding* (rev. ed.). Boston, MA: Shambhala.
- Maxwell, K. E., Stuenkel, D., & Saylor, C. (2007). Needs of family members of critically ill patients: a comparison of nurse and family perceptions. *Heart and Lung*, *36*(5), 367-376.

- Merrill, C. T., & Elixhauser, A. (2005). *Hospitalization in the United States, 2002*.

 Rockville, MD: Agency for Healthcare Research and Quality, Center for Financing, Access, and Cost Trends.
- Mitchell, M. J., Lemanek, K., Palermo, T. M., Crosby, L. E., Nichols, A., & Powers, S. W. (2007). Parent perspectives on pain management, coping and family functioning in pediatric sickle cell disease. *Clinical Pediatrics*, *46*(4), 311-319.
- Munro, B. H. (2005). *Statistical methods for health care research* (fifth ed.). Philadelphia: Lippincott Williams and Wilkins.
- National Center for Health Statistics (1999). *Health, United States, 1999, with Health and Aging Chartbook.* from http://www.cdc.gov/nchs/data/hus/hus99ncb.pdf
- National Center for Health Statistics (2011). *Health, United States, 2010: With Special Feature on Death and Dying.* from http://www.cdc.gov/nchs/data/hus/hus10.pdf
- Naylor, M., & Keating, S. A. (2008). Transitional care. *American Journal of Nursing*, 108(9 Suppl), 58-63.
- Newby, N. M. (1996). Chronic illness and the family life-cycle. *Journal of Advanced Nursing*, 23(4), 786-791.
- Okkonen, E., & Vanhanen, H. (2006). Family support, living alone, and subjective health of a patient in connection with a coronary artery bypass surgery. *Heart and Lung*, 35(4), 234-244.
- Paavilainen, E., Lehti, K., Astedt-Kurki, P., & Tarkka, M. T. (2006). Family functioning assessed by family members in Finnish families of heart patients. *European Journal of Cardiovascular Nursing*, 5(1), 54-59.

- Pearson Hodges, L. (2009). Patient-, family-centered care helps decrease LOS. Hospital Case Managament, 17(8), 121-122.
- Piercy, K. W. (2007). Characteristics of strong commitments to intergenerational family care of older adults. *Journal of Gerontology: Social Sciences*, 62(6), S381-387.
- Polit, D. F., & Beck, C. T. (2008). Nursing Research: Generating and Assessing

 Evidence for Nursing Practice (8th ed.). Philadelphia: Lippincott, Williams & Wilkins.
- Powers, K. S., & Rubenstein, J. S. (1999). Family presence during invasive procedures in the pediatric intensive care unit. *Archives of Pediatric and Adolescent Medicine*, 153(9), 955-958.
- Prohaska, T., & Glasser, M. (1996). Patient's views of family involvement in medical care decisions. *Research on Aging*, 18(1), 52-69.
- Robinson, C. A. (1994). Nursing interventions with families: a demand or an invitation to change? *Journal of Advanced Nursing*, *19*(5), 897-904.
- Rosenbloom-Brunton, D. A., Henneman, E. A., & Inouye, S. K. (2010). Feasibility of family participation in a delirium prevention program for hospitalized older adults. *Journal of Gerontological Nursing*, 36(9), 22-33.
- Rutledge, D. N., Donaldson, N. E., & Pravikoff, D. S. (2000a). Caring for families of patients in acute or chronic health care settings: Part I Principles. *The Online Journal of Clinical Innovations*, *3*(2), 1-26.

- Rutledge, D. N., Donaldson, N. E., & Pravikoff, D. S. (2000b). Caring for families of patients in acute or chronic care settings: Part II Interventions. *The Online Journal of Clinical Innovations*, *3*(3), 1-52.
- Saydah, S. H., Fradkin, J., & Cowie, C. C. (2004). Poor control of risk factors for vascular disease among adults with previously diagnosed diabetes. *Journal of the American Medical Association*, 291(3), 335-342.
- Shelton, T. L., Jeppson, E. S., & Johnson, B. H. (1987). *Family-Centered Care for Children with Special Health Care Needs*. Washington, D.C.: Association for the Care of Children's Health.
- Shields, L. (2010). Questioning family-centred care. *Journal of Clinical Nursing*, 19(17-18), 2629-2638.
- Simpson, P., & Tarrant, M. (2006). Development of the Family Nursing Practice Scale. *Journal of Family Nursing*, *12*(4), 413-425.
- Simpson, P., Yeung, F. K., Kwan, A. T., & Wah, W. K. (2006). Family systems nursing: a guide to mental health care in Hong Kong. *Journal of Family Nursing*, 12(3), 276-291.
- Sims-Gould, J., & Martin-Matthews, A. (2010). We share the care: family caregivers' experiences of their older relative receiving home support services. *Health and Social Care in the Community*, 18(4), 415-423.
- Sloper, P. (2000). Predictors of distress in parents of children with cancer: a prospective study. *Journal of Pediatric Psychology*, *25*(2), 79-91.

- Svavardottir, E. K. (2008). Excellence in nursing: a model for implementing Family

 Systems Nursing in nursing practice at an institutional level in Iceland. *Journal*of Family Nursing, 14(4), 456-468.
- Takemoto, H., Hagihara, A., Kinoshita, M., Matsuoka, M., Baba, M., & Nobutomo, K. (2007). Predictors of recognition and practice of family nursing among healthcare professionals in Japan. *Journal of Clinical Nursing*, 16(8), 1506-1515.
- Tanner, C. A., Benner, P., Chesla, C., & Gordon, D. R. (1993). The phenomenology of knowing the patient. *Image: Journal of Nursing Scholarship*, 25(4), 273-280.
- Tarkka, M. T., Paavilainen, E., Lehti, K., & Astedt-Kurki, P. (2003). In-hospital social support for families of heart patients. *Journal of Clinical Nursing*, *12*(5), 736-743.
- Taylor, M. R., & O'Connor, P. (1989). Resident parents and shorter hospital stay.

 *Archives of Diseases in Childhood, 64(2), 274-276.
- Wagner, E. H., Austin, B. T., Davis, C., Hindmarsh, M., & Schaefer. (2001).

 Improving Chronic Illness Care: Translating Evidence into Action. *Health Affairs*, 20(6), 64-78.
- Walsh, S. M., Estrada, G. B., & Hogan, N. (2004). Individual telephone support for family caregivers of seriously ill cancer patients. *MEDSURG Nursing*, *13*(3), 181-189.
- Wenger, N. S., & Young, R. T. (2007). Quality indicators for continuity and coordination of care in vulnerable elders. *Journal of the American Geriatrics*Society, 55 Suppl 2, S285-292.

- White, M. T., Smith, T. D., Bowar-Ferres, S., Salinas, T. K., O'Connor, L. J., Lucas, J. A., & Fitzpatrick, J. J. (2002). The nursing care quality initiative and its influence on nurses' clinical care and professionalism: One solution to nurse retention? *Policy, Politics, & Nursing Practice*, 3(2), 182-187.
- Whiting, D. R., Guariguata, L., Weil, C., & Shaw, J. (2011). IDF diabetes atlas: global estimates of the prevalence of diabetes for 2011 and 2030. *Diabetes Research and Clinical Practice*, 94(3), 311-321.
- Wolff, J. L., Starfield, B., & Anderson, G. (2002). Prevalence, expenditures, and complications of multiple chronic conditions in the elderly. *Archives of Internal Medicine*, *162*(20), 2269-2276.
- Wright, L., & Leahey, M. (1984). *Nurses and families: A guide to family assessment and intervention*. Philadelphia: F.A. Davis Company.
- Wright, L., & Leahey, M. (1987). *Families and Chronic Illness*. Springhouse, PA: Springhouse Corporation.
- Wright, L., & Leahey, M. (1990). Trends in nursing of families. *Journal of Advanced Nursing*, 15(2), 148-154.
- Wright, L., & Leahey, M. (1994). Calgary family intervention model: One way to think about change. *Journal of Marital and Family Therapy*, 20(4), 381-395.
- Wright, L., & Leahey, M. (2005). *Nurses and families: A guide to family assessment and intervention* (4th ed.). Philadelphia: F. A. Davis Company.
- Yen, L., Gillespie, J., Jeon, Y. H., Kljakovic, M., Brien, J., Econ, S. J., . . . Usherwood, T. (2010). Health professionals, patients and chronic illness policy: a qualitative study. *Health Expectations*, *14*(1), 10-20.