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ADULT CHILDREN'S PERCEPTIONS OF CRITICAL CAREGIVING
CONVERSATIONS WITH THEIR AGING PARENTS:
A PILOT STUDY

A thesis submitted In
Partial Fulfillment of the Requirements
for the Degree of
Master of Science
In
Nursing
at Minnesota State University, Mankato

by
WENDY CREGG

MAY 2012

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Wendy Cregg

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Wendy Cregg

This thesis has been examined and approved by the following members of the thesis committee.

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ADULT CHILDREN'S PERCEPTIONS OF CRITICAL CAREGIVING
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ABSTRACT

The purpose of this qualitative pilot study was to describe adult children's perceptions of critical caregiving conversations between themselves and their aging parents; barriers to these conversations; factors that facilitate these conversations; and the support from health care providers that adult children believe would help facilitate critical caregiving conversations between themselves and their aging parents. The overall purpose was to increase understanding of family communication processes that promote health as families age. Focus group interviews using a semi-structured interview guide were conducted with 16 adult children with caregiving experience of their aging parents. Data analysis was conducted utilizing Leininger's phases of Ethnonursing analysis and facilitated by use of QSR NVivo software for qualitative data analysis. Three themes emerged from the data: (1) navigation of caregiving in aging families, (2) negotiation of caregiving in aging families, and (3) coordination of caregiving in aging families. Study findings indicate the need to engage families and communities together as they navigate, negotiate, and coordinate caregiving conversations with aging adults. The findings of this study can be used for further nursing research on factors that influence family caregiving communication, and help nurses more effectively target communication interventions within the wider community.

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CHAPTER I

INTRODUCTION

Introduction to the Problem

For the first time in history, it can be said that we are getting older, not just as individuals, but also as a society (Minnesota Department of Human Services [MDHS], 2006; U.S. Census Bureau, 2010). Increased life expectancies, the aging of the baby boomers, and historical changes in family structure have created demographic changes resulting in an increasingly aging population, along with a corresponding need for caregiving to an aging population. Historically, family members, particularly daughters, have been a cornerstone in providing care to the elderly population; however, population changes such as smaller families, higher divorce rates, blended families, and increased participation of women in the workplace have challenged the ability of families to provide such care (MDHS, 2011; Levine, 2008). The support that older people receive from their adult children has been described as a crucial social issue of our times (Fowler, 2005). Although there has been significant study of the topic of caregiving in terms of the need for care, caregiver burden, stresses, and effects on health, there has been little study of how families plan for future care needs through communication. This chapter provides the background surrounding the need for such communication, identified as “critical conversations,” between adult children and their parents in planning future care needs, articulates the purpose of the study, provides a framework for examining critical conversations, and describes the research questions for this study.

Background

The first wave of ‘baby boomers’ began to turn 65 years of age in 2011, which will increase dramatically the number and proportion of the population over 65 over the next 20 years (National Center for Statistics, 2010). The number of those individuals over 65 years of age is projected to double, growing from 35 to 72 million, and from 13% to nearly 20% of the total population by the year 2030. As a result of increased life expectancy and the continued ‘boomer effect’ when the first boomers begin to turn age 85 in 2030, the numbers of the “oldest-old” (U.S. Census Bureau, 2011) are expected to triple over the next 30 years, increasing from 5.7 million to 19 million (Aging Statistics, 2011). Closer to the setting of this study, projections are similar in Minnesota with an expected doubling of Minnesotans over age 65 to 20% of the population by 2030, and the number of those over age 85 more than tripling, from 95,000 to 324,000, by 2050 (MDHS, 2006). The result is a significant increase in the proportion of the adult population who may need care and assistance as they age.

Numerous researchers have found that the vast majority of older adults receive assistance from their children as they age (MDHS, 2006; 2010; Levine, 2008; Fowler & Fisher, 2007, 2009; Kam, 2008; Dellmann-Jenkins, Blankemeyer, & Pinkard, 2001). Fowler (2005) found that the proportion of elderly adults reported as receiving assistance from their children ranged between 13% to 87%, depending primarily on how care or assistance were defined. The likelihood of providing care to an aging parent is especially high for women, with more than half of adult women assuming a caregiving role to a parent at some point in their lives (Fowler, 2005). The Minnesota Department of Human Services (MDHS) has estimated that 92% of the care needed by older people in

Minnesota is provided by family caregivers (MDHS, 2006). Evercare and the National Alliance for Caregiving estimated that approximately one in five households provide informal care to an adult, and among these informal caregivers, 57% are caring for a parent or parent-in-law (Kam, 2008). The probability of an adult child providing care to a parent is so great that some have described it as a “fourth developmental task of young adulthood” (Dellmann-Jenkins et al., 2001).

In spite of the likelihood that adult children will provide care to an older parent, there is typically limited communication that occurs between parents and children before the need arises (Bromley & Blieszner, 1997; Pecchioni & Nussbaum, 2000; Fowler & Fisher, 2007, 2009). Bromley and Blieszner (1997) found that only 40% of children had had discussions with their parents pertaining to caregiving. Pecchioni and Nussbaum (2000) found that adult children and their parents rarely have conversations about caregiving preferences, especially before the onset of dependency. Although adult children may consider the future needs of aging parents, they rarely prepare collaboratively with their parents for future care needs (Fowler & Fischer, 2007, 2009). As a result, adult children and their parents may be forced to react to the situation at hand, often under pressure and with less input, fewer options, and, therefore, less satisfactory outcomes, than if these conversations had occurred before the specific care need or crisis arose (Fowler & Fisher, 2009).

“Critical” is defined by the Oxford Dictionaries (n.d.) as “(a situation or problem) having the potential to become disastrous; at a point of crisis... having a decisive or crucial importance in the success or failure of something.” On a similar line of thought, a recent New York Times best seller uses the term “Crucial Conversations” to describe

conversations in which stakes are high, emotions are strong, and people have different opinions (Patterson, Grenny, McMillan, & Switzler, 2012). Although some caregiving conversations between adult children and their aging parents may have high stakes, strong emotions, and different opinions, perhaps all caregiving conversations may be considered critical in that they address a situation or problem having the potential to become a crisis, with crucial importance in the success or failure of caregiving. The term “critical” has thus been used to describe caregiving conversations between adult children and their aging parents (Kilpatrick, n.d.).

The centrality of communication to family health has been examined in nursing literature (Denham, 2003; Wright & Leahey, 2009; Wright & Bell, 2009). Denham (2003) identifies communication as one of seven core functional family processes related to health. According to Denham, family communication refers to “the way emotions are expressed and ideas, knowledge, skills and concerns related to health are transmitted” (p. 134), and is the primary way in which parents socialize children about health beliefs, values, attitudes, and behaviors (p. 125). Wright and Leahey (2009) emphasize that family communication occurs within a larger system in which each interaction influences others. Family communication serves to clarify family rules regarding behavior, help family members learn about their environment, explicate how conflict is resolved, nurture self-esteem of all members, and model expressions of emotional states constructively within the family (pp. 29-30). Wright and Leahey (2009) assert that both “instrumental functioning” (task-related), and “expressive functioning” (communication-related) are important to family health. Expressive functioning includes verbal and non-verbal communication, as well as emotions, problem solving, roles, influence and power,

beliefs, and alliances and coalitions (p. 117). Wright and Bell (2009) likewise highlight the influence of health beliefs and communication as central to family health. They assert that beliefs may constrain or facilitate health, and are often revealed in conversation. Conversation that invites reflection may be used to draw out facilitating beliefs, and thus provide a medium for change to promote health within families (Wright & Bell, 2009).

Problem Statement

There is little empirical research in the health care literature related to what specific communication regarding caregiving is lacking between adult children and their aging parents and how to facilitate that communication, especially from the perspective of the adult children themselves. Research aimed to fill this knowledge gap can contribute to health care provider knowledge and support the health of family and individuals by describing adult children's perceptions of critical caregiving conversations between themselves and their aging parents, barriers to those conversations, factors that facilitate those conversations, and the support from health care providers that adult children believe would help facilitate critical conversations between themselves and their aging parents.

Purpose of the Study

The purpose of this qualitative study is to describe adult children's perceptions of critical caregiving conversations between themselves and their aging parents; barriers adult children perceive to these critical conversations; the factors that adult children perceive would facilitate these critical conversations; and the support from health care providers that adult children believe would help facilitate critical caregiving

conversations between themselves and their aging parents. The overall purpose is to increase understanding of family communication processes that promote health as families age.

Research Questions

1. What are the critical conversations that adult children find difficult when planning care needs with their aging parents?
2. What do adult children perceive as barriers to critical caregiving conversations with their aging parents?
3. What do adult children perceive as factors that facilitate critical caregiving conversations with their aging parents?
4. What support from healthcare providers do adult children believe would help facilitate critical caregiving conversations between themselves and their aging parents?

Definition of Terms

Critical conversations. Conversations considered important to effectively meet the current or future care needs of older adults.

Care needs. Any need for assistance by an aging parent, whether it be social, instrumental (tangible assistance of resources or services), informational, or emotional support (Kam, 2008).

Adult children. Adults at least 40 years of age who currently provide, or expect to provide in the future, for one or more care needs of an aging parent.

Aging parents. Family members of adult children who are at least 60 years of age.

Older adults. Adults at least 60 years of age.

Family. A group of individuals with a commitment to the well-being of one another, who define themselves as family (Denham, 2003)

Barriers. Factors that hinder or discourage critical conversations from occurring

Facilitators. Factors that facilitate or encourage critical conversations to take place.

Support from health care providers. Actions of health care providers that help remove barriers or help facilitate the occurrence of critical conversations between adult children and their aging parents.

Health care provider. A professional that provides health care to an individual, group, or community; specifically those who provide primary health care and services to older adults and their families.

Assumptions

- The majority of adults will have increasing care needs as they age.
- Adult children are a major source of assistance to aging parents who have care needs.
- Most adult children expect to provide assistance in meeting the care needs of their aging parents.
- Adult children find some critical conversations difficult to initiate and engage in effectively with their aging parents.
- Critical conversations between adult children and aging parents will enhance the likelihood that care needs of aging adults will be met effectively.
- Focus group dynamics can generate authentic information

- Health care providers are in a position to assist families to identify and facilitate conversations that help families meet the current and future care needs of aging parents.
- Families' systems possess self-regulatory abilities as they seek to maintain stability and cohesion in a changing environment.

CHAPTER II

REVIEW OF LITERATURE

Introduction

This chapter will provide a review of the literature on what is currently known about critical caregiving conversations between adult children and their aging parents. This review of the literature will identify topics perceived as critical caregiving conversations between adult children and their aging parents, barriers and facilitators to those conversations, and support from health care providers that may remove barriers or help facilitate the occurrence of these critical conversations. The conceptual models providing the theoretical framework for this study will also be described.

Critical Conversations

This review of the literature found little empirical research identifying critical conversation topics between aging parents and their adult children regarding care needs, and none specifically from the viewpoint of the adult children. Even the terminology used to label these conversations is inconsistent. This review of the literature includes a summary from both empirical research and popular media that attempt to identify conversations considered important to effectively meet the current or future care needs of aging parents.

A common topic identified in the empirical health care literature regarding care planning for older adults focuses on communication surrounding end-of-life (EOL) care. Much of the research regarding EOL care has been conducted in critical care and

palliative care settings where care needs and potential death appear more imminent (Curtis & White, 2008; Nelms & Eggenberger, 2010; Wiegand, 2008), however, other researchers have identified the need to have these EOL care planning conversations earlier (Glass & Nahapetyan, 2008; Schirm & Sheehan, 2005; McDonald et al., 2003).

Glass and Nahapetyan (2008) interviewed 15 older adults, and 15 adult children about their parents' EOL preparations and preferences, finding that although most adults preferred to die at home, most do not discuss their preferences with their children until a crisis occurs. Glass and Nahapetyan identify the need to discuss more specifically the extent of care, the location of care, spiritual needs, and family interactions as components of EOL care.

Schirm and Sheehan (2005) also expanded the concept of EOL care to include not only advanced care directives, but also supportive care. Schirm and Sheehan provided an example of a workshop on EOL care choices within the long-term care setting. They emphasized the importance of discussions between parents and their adult children to include letting wishes be known regarding care preferences and spiritual caregiving.

In conducting interviews of 119 community-dwelling adults who had communicated their EOL preferences, McDonald et al. (2003) found the majority of conversations took place with family members, most often spouses (47.1%) or their children (40.3%). While one quarter of the respondents had communicated their preferences through a living will as a means to make their preferences clear, McDonald et al. suggested that a living will is still subject to interpretations as time and circumstances change, emphasizing the importance of on-going dialogue to ensure preferences are interpreted accurately.

Although the health care literature identifies EOL care as a critical conversation topic for adult children and their aging parents, other topics along the continuum of care also represent potential critical conversations. Fowler (2005) conducted a survey of 44 aging parents and 43 adult children to evaluate the quality of discussions between parents and adult children regarding future care needs. These topics extended beyond typical EOL care decisions addressed in advanced directives and living wills. Survey topics included the mode of care (professional, live-in, informal, etc.), the amount of care to be provided, the timing of care (when caregiving will begin), the location of care (home or facility), financing care, the impact on other family members, household and yard maintenance, parent's financial decisions, parent's health decisions, domestic assistance (housekeeping, meal preparation), personal assistance (bathing, dressing) and transportation. Fowler described the researcher's process of choosing these caregiving topics based on what gerontologists might consider critical conversations regarding caregiving.

Pecchioni and Nussbaum (2000) interviewed 36 mother-daughter dyads about communications regarding future care planning, addressing long-term care needs, medical interventions, and financial planning. Later topics of inquiry were end-of-life care preferences, housing, and advanced directives (Pecchioni, 2001). When developing an intervention to promote intergenerational care planning, Carpenter and Mulligan (2009) chose topics informed by the experiences of aging families in their clinical practice. Conversation topics identified as important to care planning included medical needs, legal decisions, housing needs, financial decisions, end-of-life decisions, and

family interactions. In discussing optimal parent care from a nursing perspective, Hujer and Neff (2009) recommend the following critical conversations topics between adult children and their aging parents based on their nursing clinical experience: safety, medications, driving, nutrition, exercise, helping parents stay involved/engaged with others, making sure parents have a primary care provider, scheduling a geriatric assessment, and finances.

Walz and Mitchell (2007) measured adult children's and their parent's expectations of future care needs in terms of six areas. These areas fit broadly into the categories described by Fowler (2005) as personal assistance (eating and dressing) and domestic assistance (shopping, meal preparation, walking, taking medications).

The concepts of personal assistance or domestic assistance described by Fowler (2005) correlate with health care concepts commonly described in the health care literature by the acronyms ADLs (Activities of Daily Living) and IADLs (Instrumental Activities of Daily Living). As summarized by Levine, Reinhard, Feinberg, Albert, and Hart (2003), ADLs include six basic daily activities of bathing, dressing, toileting, transferring, continence, and feeding. In contrast, IADLs represent activities that are instrumental to the ability to function independently in the community, such as shopping, cooking, housework, money management, and other domestic assistance. Levine et al. warn against limiting the definition of caregiving to assistance with ADLs and IADLs, noting that they do not describe the full spectrum or complexity of care provided by families. In particular, Levine et al. assert that a focus on ADLS and IADLS fails to recognize the central importance of emotional support that families provide, as well as activities such as behavioral supervision, management of home care, pain management,

and management of home-health care workers. Levine et al. suggest that caregiving be conceptualized as encompassing two primary domains: direct care and care management. Direct care includes not only assistance with ADLs and IADLs, but also skilled nursing care, and cognitive and emotional support. Care management includes both in-home and out-of home care management activities as varied as home modification, hiring and management of home care aides, and purchase and maintenance of assistive devices, to financial management, care coordination and transportation. They assert that family caregiving has additional complexities that make a caregiving definition based on ADL and IADL assistance inadequate.

The volume of publications in the popular media suggests a high desire for guidance from adult children who expect to care for an aging parent. Although some address “conversations before the crisis” (www.caregivers.org) in terms of EOL issues and the documentation of advanced directives, other sources within the popular media address critical conversations along a continuum of possible future care needs. Delehanty and Ginzler (2008) describe contemplating the need for care as “the new touchy subject” (p. 12). Delehanty and Ginzler provide six categories of important conversations: living arrangements, management of daily tasks, driving, physical and mental health, and finances. Taylor (2006) similarly categorizes critical conversations into six categories: discussing parent’s fears and hopes for the future, finances, property, housing needs, professional care needs, and legacy. Home Instead Senior Care sponsors a website titled “The 40-70 Rule” (www.caregiverstress.com), specifically geared to help adult children discuss sensitive caregiving topics with their parents. Topics suggested for these conversations are: health changes, driving, self-care and personal hygiene, living

arrangements (which they suggest is the most difficult conversation to have), “senior moments” and memory, medications, sibling relationships, health/safety at home, finances, dating, and legacies, including legal matters such as EOL planning and advanced directives. The “PBS Caregivers Handbook” (www.pbs.org) is another of many additional websites that identify similar critical conversation topics.

In summary, both the empirical health care literature and popular media demonstrate that the conversations adult children consider important to effectively meet the current or future care needs of their aging parents go beyond the discussions of EOL topics typically addressed in advanced directives and living wills, and cover a broader array of needs than suggested by ADLs and IADLs. Literature addresses topics along a continuum of care as aging parents move from independence to dependence. These may be described at one end as contemplating the need for care (Delehanty & Ginzler, 2008), and progress along a continuum of changing care needs ending with decision-making faced at the end of life. The mode of care, the amount of care to be provided, timing of care, location of care, financing of care, and the impact on other family members add additional layers of complexity for communication (Fowler, 2005). This review of the literature suggests that qualitative research describing and identifying critical caregiving conversations from the perspective of adult children planning for care needs with their aging parents is yet needed.

Barriers to Critical Conversations

Research identifying barriers to critical conversations between adult children and their aging parents regarding care needs is just beginning. While research identifies the need for communication between adult children and their aging parents regarding care

needs, there is less research describing what the barriers are to having those critical conversations.

Adult children's wish to respect their parent's autonomy, as well as denial on the part of adult parents, have been noted as barriers to critical conversations between adult children and their aging parents (Hujer & Neff, 2009). In interviews of 36 mother-daughter dyads, Pecchioni and Nussbaum (2000) found that although daughters tend to become more paternalistic as their mothers dependency grew, their behavior was affected by beliefs about paternalism and autonomy prior to dependency, indicating that life-long communication patterns affect decision-making.

Fowler (2005) noted the absence of research on role transitions and adjustment as the dependent role is reversed between parents and adult children, made more difficult by the lack of communication on the topic. Fowler studied predictors and evaluations of parent and adult child caregiving discussions in surveys of 87 aging parents and adult children (44 parents and 43 children). Variables evaluated were the frequency of parent-adult child interactions, gender, assessments of parental health, perceived understanding of care preferences prior to discussion, adult-parent child attachment, norms of filial obligation, intergenerational exchange, and approaches to conflict. Fowler found support for the influence of implicit decision-making and perceptions of autonomy and paternalism on caregiving conversations. A surprise finding in his research was that although daughters tend to spend more time with their mothers, sons reported having more thorough discussions of caregiving details. Fowler suggested a number of possibilities for this finding. It is possible that daughters, having spent more time with mothers, were more likely to have enhanced knowledge of their mother's preferences,

thus relying more on implicit decision-making without conversation. Another explanation is that sons have a more paternalistic tendency, and thus are more explicit in discussions. Fowler also considered the possibility that sons and daughters may have different contributions to caregiving discussions between adult children and their aging parents, suggesting another avenue for research. Subsequent research by Fowler and Fisher (2009) found that adult children who favored parental autonomy were less likely to have considered parental needs and, therefore, less likely to have engaged in discussions. While the effects of attitudes and perceptions of paternalism and autonomy on caregiving conversations may be complex, research clearly indicates the struggle of adult children as they navigate the need for parental autonomy with paternalistic care toward their parent in the face of changing care needs.

In interviews of 36 mother-daughter dyads, Pecchioni (2001) found that mothers did not feel a need for explicit discussion of planning for future care needs because they and their daughters knew each other well or observed a family history/pattern of caregiving. Pecchioni described this as implicit decision-making, which avoids conflict, and results from incremental decisions without planned verbal discussions. Pecchioni also found that neither mothers nor daughters wanted to acknowledge declining physical or mental health status of the mother. As a result they relied more on implicit decision-making. Pecchioni and Nussbaum (2001) further found that there was a strong preference for conflict avoidance, with preference for solutions-oriented strategies.

Pecchioni's (2001) finding that neither mothers nor daughters wanted to acknowledge declining physical or mental health status of the mother has support in recent research with families facing cancer. Zhang and Siminoff (2003) interviewed 26

families with cancer and found that two-thirds of them experienced communication difficulties in terms of avoidance of conversation about cancer and aspects of the disease. Zhang and Siminoff found that avoidance of family communication in families with cancer was associated with a desire to avoid psychological distress, a desire for “mutual protection,” and belief in positive thinking.

Fowler (2005) discusses the difficulty of balancing ‘instrumental’ goals of decision-making with ‘relational’ goals of maintaining positive relationships and self-concept of all members. This balance between instrumental goals and relational goals is similarly described by Wright and Leahey (2009) as instrumental and expressive functions of a family. The need to balance instrumental or task goals with relational goals lends credence to the idea that conflict avoidance and the need for conflict management may pose significant hurdles to critical conversations. Added to the complexity of conflict management in critical conversations is the difficulty of coordinating care planning with multiple siblings, adding additional negotiating factors to be considered (Connidis & Kemp, 2008; Roff, Martin, Jennings, Parker, & Harmon, 2007).

Fowler and Fisher (2007) found that critical conversations were less likely to occur if parents or children thought they had an extended time available before decisions would be acted upon. Unfortunately, Walz, and Mitchell (2007) reported that aging parents and their adult children have unrealistic optimism regarding their expectations of future needs, thus emphasizing how denial may pose a barrier to critical caregiving conversations.

In their work with families in the long-term care setting, Carpenter and Mulligan (2009) identified implicit decision-making, uncertainty about how to begin or what to discuss, beliefs about autonomy, conflict avoidance, discomfort in acknowledging frailty and mortality, difficulty coordinating with multiple family members, and lack of decision-making skills as barriers to critical conversations between adult children and their aging parents. Regarding implicit decision-making, they reported that adult children tend to assume they know what parents want. However, Carpenter and Mulligan question this assumption. In their intervention to increase family conversations regarding caregiving, they found that participants were repeatedly surprised at what they did not know about each other's values and preferences.

Glass and Nahapetyan (2008) conducted in-depth interviews of 15 older adults and 15 adult children focusing on family communication about EOL preparations and preferences. They identified four primary barriers to conversation: fear of death, older adults trusting other family members to make decisions, family dynamics, and uncertainty about preferences. Fear of death is consistent with other research findings regarding discomfort and denial in acknowledging frailty and immortality (Pecchioni, 2001; Zhang & Siminoff, 2008). Trusting others to make decisions implies both implicit decision-making and potential conflict avoidance strategies. The family dynamics identified by Glass and Nahapetyan as a critical conversation barriers included distance and lack of frequent contact, and a desire on the part of parents to protect their children from burden. Glass and Nahapetyan's findings are consistent with Fowler's (2005) findings that frequency of parent-adult child interactions and perceptions of autonomy and paternalism influenced the likelihood of critical conversations taking place.

Barriers to critical conversations identified in the health care research literature are reflected in the popular media. Popular media explores concerns of preserving parental privacy and self-reliance, helping parents preserve dignity, desire on the part of aging parents not to be a burden to their children, desire on the part of adult children to protect their parents' safety, and challenges in communication between generations (Delehanty & Ginzler, 2008; Home Instead Senior Care, 2010; PBS Caregivers Handbook [caringinfo.org]). In summary, barriers to critical conversations identified in the empirical literature and the popular media are similar. These barriers include the difficulty of balancing autonomy and paternalism, conflicts of task and relational goals, role transitions and role reversal, fear of conflict, denial, desire for mutual protection, and being unsure how to initiate or approach difficult conversations.

Facilitators of Critical Conversations

Given that research on barriers to critical conversations is just beginning, it is perhaps not surprising that there is limited research in the health care literature on the factors that facilitate critical caregiving conversations. The literature available consists primarily of qualitative studies. Frequent interaction between parents and adult children, indirect conversations that reduce the threat of impending frailty, increased awareness of the likelihood of future care needs, normalizing the need for critical conversations regarding care, a focus on recognizing values rather than agreement, and use of a facilitator are among factors suggested by the literature which may facilitate critical conversations between adult children and their aging parents.

Fowler (2005) examined several variables associated with the likelihood and thoroughness of critical conversations between adult children and their aging parents.

The frequency of interaction between adult children and their aging parents was the largest contributor. In this context, Fowler suggests that computer-mediated communication, such as e-mail, may help facilitate communication frequency between older parents and their children, thus increasing the likelihood of caregiving discussions. He found that the belief that an adult child understood their parent's preferences for caregiving before the discussion occurred was positively associated with the likelihood that conversation occurred. He interpreted this as indicating that frequent indirect conversations, such as hints, joking, and talking about similar situations in the news, may play a role in facilitating explicit conversations on caregiving. Fowler further suggested that because of the threat inherent in conversations that acknowledge impending or increasing frailty, strategies for conversation that help a parent keep a positive face, which some might refer to as a sense of dignity, may facilitate successful conversations.

Subsequent research by Fowler and Fisher (2007; 2009) found that adult children were more likely to discuss parental care needs when they thought it was likely that their parent would need care, indicating that increasing awareness of cues of parental care needs may facilitate critical conversations. It also suggests that health events such as illness or hospitalization may serve as triggers to critical conversations. Fowler and Fisher (2007; 2009) also found that views of shared autonomy, in which the parent made some decisions, but delegated others, were associated with a small, although statistically insignificant, increase in likelihood of discussion.

McDonald et al. (2003) interviewed 119 community dwelling adults who had communicated their EOL care giving preferences to significant others or a health care provider. Factors that facilitated the initiation of such conversations were having had

personal experience with illness or death, having a straightforward communication style, and having someone else facilitate the conversations. McDonald et al. suggest that "changing the context for end-of-life discussions from an illness focus to a normal life task focus" would help normalize EOL care discussions and make them less threatening. Their recommendations are similar to Fowler (2005) in referring to EOL care planning as a developmental task, and the need to acknowledge the threat of impending frailty such conversation may represent. They suggest that broaching topics of care be done when older adults are relatively healthy, making those conversations less threatening. Viewing EOL care as a normal part of aging changes the focus from that of avoiding conversation about death, to that of maintaining comfort and choices. This is consistent with Wright and Bell's (2009) assertion that core beliefs may be constraining or facilitating to health, and thus changing the perspective of a situation may increase solution possibilities and decrease suffering. McDonald et al. found that interview participants who had engaged in EOL care discussions were unable to identify suggestions to help others do so, thus they recommended that phenomenological study be conducted with those who have had successful EOL care discussions, to identify successful strategies that people use, but might not be aware of.

Glass and Nahapetyan (2008) interviewed 15 older adults and 15 adult children focusing on family communication about EOL preparations and preferences. Similar to McDonald et al. (2003), they found that acceptance of the reality of death, prior experience with death and life-prolonging measures, and a casual approach with frequent ongoing conversations were associated with increased likelihood of EOL care preparations. In addition, they found that religious or spiritual beliefs, as well as the

perceptions that conversations and preparations helped the family, were associated with EOL preparations.

Carpenter and Mulligan (2009) developed a workbook-based intervention to facilitate conversation between generations in planning care. They recommended a focus on recognition of values, rather than agreement, as an approach that facilitates conversations. This suggestion addresses the potential barrier of conflict avoidance, avoids issues of paternalism and autonomy, and is consistent with the role that saving face, reducing threat, normalizing conversations, and indirect conversations have in facilitating explicit critical conversations.

A number of websites and books in the popular media expand on concepts in the empirical health care literature by providing specific examples and suggestions as to how adult children might facilitate critical conversations with their aging parents. Examples are websites such as PBS Caregivers Handbook (www.pbs.org), “The 40/70 Rule” (www.caregiverstress.org), and “Conversations before the Crisis” (www.caringinfo.org), and books such as those by Delehanty and Ginzler (2008) and Henry (2006). Consistent with the empirical literature, common themes include having frequent small conversations over time, scheduling meetings, focusing on listening rather than agreement, using conversation triggers from media or recent events, considering both direct and indirect approaches, optimizing parental independence and control by asking parents for their input and solutions, considering sibling communications, and considering the services of a health care professional to facilitate conversation. An additional suggestion mentioned in the popular press, but not the empirical literature, is the need to plan conversations, including selecting the right setting, whom to include,

where, when, and possibly providing a pre-set written agenda. Other authors provide specific education on communication skills and problem solving, with emphasis on creating a partnership with parents (Ilardo & Rothman, 2001; Solie, 2004).

While both popular media and the empirical health care literature suggest factors that may facilitate critical conversations between adult children and their aging parents, additional qualitative research is needed to look at the factors that adult children believe would facilitate critical conversations between themselves and their aging parents.

Understanding the factors that help facilitate critical conversations between adult children and their aging parents will be important to guiding health care providers in actions that support the occurrence of these conversations.

Support from Health Care Providers

There is a paucity of empirical research identifying actions on the part of health care providers that adult children believe would be helpful to facilitate critical conversations between themselves and their aging parents. Research that is available is primarily from qualitative studies or interpreted from study of other research variables. Suggested support from health care providers include having routine dialogue with adult children and aging parents about care planning, offering written materials to serve as a focal point to guide conversations, serving as facilitator to family meetings, leading workshops, and serving as a consultant.

McDonald et al. (2003) interviewed 119 community dwelling adults to investigate the ways in which they communicate their EOL preferences. They found that of those who had communicated their EOL preferences, discussions were often initiated in response to death or illness; however, their health care provider (HCP) initiated these

discussions less than 5% of the time. McDonald et al. (2003) suggest that HCPs have routine dialogue with patients and their families to normalize discussions of EOL care before crisis occurs. They further suggest that HCPs target transition points in health care as opportunities to initiate dialogue. Admission to a nursing home was provided as an example of a transition point, however, other transition points requiring changes in health care might also serve as opportunities. Although not studied as a variable in their research, McDonald et al. suggested that instruments such as the Preferences for Care at the End of Life Scale (Gauthier & Froman, 2001) might be used by HCPs as a means to initiate conversation. They further suggest that initiating conversation when people are healthy and not facing a life-threatening situation may make these conversations less threatening.

Griffith, Brosnan, Lacey, Keeling, and Wilkinson (2004) conducted interviews and surveys of participants in family meetings at a geriatric rehabilitation hospital; participants included patients, staff, and family members. They concluded that both families and patients found family meetings helpful. Recommendations they made for successful family meetings were having a HCP who was skilled as a facilitator, assuring that patients participated with informed consent, and defining the purpose of the meeting ahead of time. The benefit of family meetings has also been demonstrated in research with families in critical care settings and EOL care (Curtis & White, 2008; Nelms & Eggenberger, 2010; Wiegand, 2008).

Carpenter and Mulligan (2009) tested a workbook-based intervention with 21 older parents and their adult children. The workbook was used in combination with a one-hour education session led by a trained facilitator in the patient's home. The goals

were to engage family members in discussions of care planning as parents aged, teach families decision-making and communication tools to assist them in care planning, and guide them through a set of topics that would help them prepare for future conversations. Carpenter and Mulligan reported advantages of a workbook as providing structure, comprehensive topic coverage, and enabling multiple people to participate. They concluded that the workbook-based intervention is acceptable to families, brings them together for conversation about parent care, and may provide the foundation for subsequent collaboration. Families reported that the intervention was simple, useful, and improved their decision-making and communication skills. Some families reported that the simple act of going through the workbook had improved communication and increased caregiving conversations. Carpenter and Mulligan posited that the workbook might be equally effective for families to use on their own, without the direct facilitation of a HCP.

Glass and Nahapetyan (2008) likewise suggest education sessions centering on a guided topic as an avenue to encourage discussions. They suggest specifically the ‘5 Wishes,’ as advocated by www.agingwithdignity.org, as a center point of discussion. They also found that the simple act of engaging in interviews stimulated caregiving conversations between elders and their adult children.

Schirm and Sheehan (2005) conducted weekly workshops with participants at a retirement community over a period of 4 weeks, which included health care providers, patients, and family members. The workshops were presented by health care providers and featured conversation about care needs in the end of life. Following the workshop, participants completed an evaluation questionnaire. Schirm and Sheehan reported that

the workshops increased open discussion about decision-making and preference for care. The identified advantages of the workshop were that the interactive format promoted dialogue and allowed family members opportunity to learn from other participants. The evaluation questionnaire found that 90% of participants would like to have a HCP available for consultations when making care decisions, but thought final decisions should be made by the family, with 94% saying that the family should be involved in health care decisions. In post-evaluation questionnaires, participants indicated that the workshops contributed to more open discussions about decision-making and preferences for care.

Research into the interventions and behaviors by healthcare providers that would be helpful to facilitate critical conversations between families and their aging parents is just beginning, with most research consisting of qualitative studies of small samples. There is an absence of research from the perspective of adult children themselves. Available research suggests that engaging in routine dialogue with adult children and aging parents about care planning, offering written materials such as workbooks to encourage family discussion, serving as facilitator to family meetings, conducting workshops on care planning, and serving as a consultant to families are health care provider behaviors that adult children may find helpful to facilitate critical conversations between themselves and their aging parents.

Conceptual Model

The theoretical framework for this study is based on an integration of two conceptual models, the Denham Family Health Model (Denham, 2003) and the Community-Based Collaborative Action Research Model (Pavlish & Pharris, 2012).

These conceptual models use an ecological approach that views individuals and families as part of a larger ecosystem and emphasize the multi-party interaction involved in communications.

The Denham Family Health Model (FHM) (2003) is an integrated approach to families based on an ecological approach from qualitative studies with families living in the Appalachian region of the United States. The Denham FHM views family health in terms of context, structure, and functional processes. Viewing the family in context recognizes that family health is affected by the internal family environment (members, household, resources, relationships), and the external environment (neighborhood, community, larger society). Family structure refers to the routines of a family as they relate to self-care and health behaviors. Family functioning refers to the processes used by individuals as they interact with each other over time to promote health. Denham describes seven core family processes of caregiving, cathexis, celebration, change, communication, connectedness, and coordination. The core family processes, particularly that of communication, are applicable to this study as they pertain to how adult children and aging parents plan and collaborate for current and future care needs. As noted by Denham, a lack of communication may prevent families from being able to work effectively as a unit and support each other. Communication is a core family process that can be targeted by nurses as they collaborate with families and others to optimize family health (p. 123). The Denham FHM provides the basis for family-focused care, in which the nurse uses skilled communication to provide narrative data to help the family understand individual and family health, which can then be used to collaboratively achieve family health outcomes (p. 250).

The Community-Based Collaborative Action Research Model (CBCAR) is defined as “community-driven systematic inquiry, conducted collaboratively between those affected by the issue being studied and those skilled in research methodologies, for purposes of education and taking action on effecting change” (Pavlish & Pharris, 2012, p. 17). CBCAR draws from theoretical foundations in social justice, unitary-transformative and participatory paradigms, and action science (p. 57). Social justice theory emphasizes responsibility to the common good, particularly to the vulnerable and suffering. In contrast to paternalistic advocacy, a social justice perspective seeks to partner with individuals and communities to understand health. Unitary-transformative and participatory paradigms assume that all living things are part of a unitary whole, and that change is transformational and unpredictable; action science is a process in which nurses are engaged in the environment, evolving with it in a democratic and participatory process (Pavlish & Pharris, 2012). Utilizing these three theoretical foundations, CBCAR is based on the premise that solutions to community problems are found within the community (Yang, Xiong, Vang, & Pharris, 2009).

This study draws on the Denham Family Health Model to collect and interpret narrative data of family context, structure, and functional processes to help the family understand individual and family health, which can then be used to collaboratively achieve family health outcomes (Denham, 2003, p. 250). This narrative data and understanding of family health will be combined with the CBCAR process of engaging community members in conversations to identify patterns of meaningful experiences, and engaging the wider community in dialogue into needed actions (Pharris, 2005; Yang et al., 2009).

Summary

Review of the literature found little empirical research regarding critical conversations that adult children consider important to have with their aging parents, barriers and facilitators to those conversations, or support from health care providers that may facilitate the occurrence of these critical conversations. The wealth of publications in the popular press providing practical advice to adult children on how to assist their aging parents suggests the perceived need among adult children for guidance; however, the research literature has not kept up in providing this guidance. The empirical literature does not yet have a consistent vocabulary for describing critical conversations. Review of the literature found varied terms, inconsistent definitions, and overlapping categories when describing communication between adult children and their aging parents regarding conversations considered important to effectively meet the current or future care needs of aging parents. There is even less research that examines these conversations, and the factors that influence them, from the perspective of adult children themselves. In studying parent-adult child discussions of caregiving needs, Fowler (2005) noted a significant lack of research, concluding that in addition to evaluating the discussions that aging parents and adult children have regarding caregiving, it would be equally valuable to examine factors that promote or inhibit initiation of these conversations. Fowler suggested that qualitative research to explore these variables would enable health care providers to better assist families with strategies for holding these conversations. This study addresses this gap by using the Denham Family Health and Community-Based Collaborative Action Research Models to engage adult children of aging parents in

dialogue to address this knowledge gap, with the end goal of bringing families together to communicate and collaborate to effectively meet the caregiving needs of older adults.

CHAPTER III

METHODS AND DESIGN

Introduction

The purpose of this qualitative pilot study was to describe adult children's perceptions of critical caregiving conversations between themselves and their aging parents; the barriers adult children perceive to having these critical conversations; the factors that adult children perceive would facilitate these critical conversations; and the support from health care providers that adult children believe would help facilitate critical conversations between themselves and their aging parents. This chapter includes information about the study design and methodology. Details of the setting, sample, ethical considerations, instruments, data collection, data analysis, and limitations of the method will be discussed.

Design

This study used a qualitative method study design using the Community Based Collaborative Action Research Model described by Pavlish and Pharris (2012). CBCAR research design may use either quantitative or qualitative methodologies. Data collection describing people's experiences generally involve qualitative data collection through interview and focus groups. Qualitative methodology is based on the premise that reality is based on perceptions that vary with each person and change over time; what is known has meaning only within the given context (Burns & Grove, 2009, p. 51). In developing

this CBCAR study, a traditional qualitative design for data collection was chosen (Pavlish & Pharris, 2012).

Advantages of the CBCAR qualitative method is that it focuses on experiences of the participants and, therefore, can examine more dimensions of a phenomenon than quantitative data. The disadvantage of CBCAR research is that it is difficult to extrapolate the findings to a wider population. This study seeks to explain the perspectives of adult children regarding critical conversations with their aging parents and to identify patterns of meaningful experiences. The following research questions guided the study:

1. What are the critical conversations that adult children find difficult when planning care needs with their aging parents?
2. What do adult children perceive as barriers to critical caregiving conversations with their aging parents?
3. What do adult children perceive as factors that facilitate critical caregiving conversations with their aging parents?
4. What support from healthcare providers do adult children believe would help facilitate critical caregiving conversations between themselves and their aging parents?

The results of this study will be used to collaboratively engage the wider community in dialogue toward needed actions.

Setting

This study was conducted in a South Central Minnesota community of approximately 40,000 (U.S. Census Bureau, 2010). The U.S. Census Bureau reports that

approximately 11% of the population is age 65 years and over, as compared to 13% statewide. Median household income is \$37,000, compared to a statewide average of \$57,000, with 27% of the population living in poverty, compared to a statewide average of 10%. Gender is evenly split between males and females. Ethnicity is predominately Caucasian; nearly 90% of the population is Caucasian, compared to a statewide average of 85%. Ninety-one percent of the population has a high school education or higher, with 33% having a bachelor's degree or higher, similar to the statewide average. It should be noted that there are four colleges in the community with a total student population of approximately 15,000 (Greater Mankato Growth, 2010). These students may have permanent residences outside the community and are likely to have different demographics than the community as a whole. In particular, it is likely that students are younger, with lower incomes, and perhaps higher education levels than the community population as a whole. These students may be counted in local census numbers while temporarily residing in the community during their college education, thus skewing community demographic statistics.

The community serves as a medical hub to surrounding communities with a comprehensive regional medical center that includes a hospital, and clinics that are comprised of over 100 physician health care providers. These healthcare systems provide a full range of ambulatory services including primary care and specialty services (Greater Mankato Growth, 2010). Interviews were conducted at public venues in Blue Earth and Nicollet counties.

Participants

Focus group participants were adult children of older adults who live in the greater Mankato community who responded to advertisements inviting them to participate in conversations to discuss caregiving and aging families. The desired size of focus groups was 6-10 individuals. The sample for this pilot study was comprised of two focus groups with adult children and one comprised of older adults who were providing care for their aging parents or had done so in the past. No limitations were placed on participation based on gender, culture, ethnicity, or socioeconomic status of adult children or their aging parents. In addition, no limits to participation were placed based on diagnoses or perceived care needs of aging parents. Although age was included within study variable definitions, adult children who wanted to participate were not excluded based on age of themselves or that of their aging parents.

Ethical Considerations

Institutional Review Board approval was obtained from the Minnesota State University, Mankato Institutional Review Board prior to the start of data collection (see Appendix A). There were no identified physical risks of participation in this study. Potential risks were emotional stress as the participants were asked about family dynamics, family communication, and factors that impact their ability to have conversations about aspects of aging. These risks were managed and minimized through the wording of questions and facilitating dialogue in a sensitive and appropriate manner. Investigators attended to nonverbal communication of the participants to identify emotional distress. Every attempt was made to minimize any emotional stress or distress in the participants in relation to the study. A minimum of one interviewer at each focus

group had experience with family interviews, family communication skills, and family experiences during aging processes. A semi-structured interview guide with possible probing questions was used to facilitate discussion groups.

Participants were verbally informed of the intent of the study, the names and contact information of the investigators, source of support, their rights, the intent of the study, potential risks to them, their right to withdraw from participation at any time, and confidentiality prior to the beginning of the individual interview or focus groups. Participants were given the opportunity to ask questions with responses given prior to data collection.

Written consent to participate in the interview or focus group was obtained prior to beginning data collection. Participants were given a copy of the informed consent. Informed consent (see Appendix B) was obtained prior to the start of each focus group, and participants were informed that they were free to withdraw their consent at any time.

Confidentiality and data security were maintained throughout the data collection procedure. No names or addresses that could be identified with the data were recorded during the study. A signed confidentiality agreement was secured from the professional transcriptionist prior to sharing the electronic audio recordings with them (see Appendix C). The interviews and focus groups were digitally audio recorded. Following the interview/focus group the digital recordings were uploaded to one of the primary researcher's password protected computer and then deleted from the recording device. The focus group audio recordings and field notes were transcribed into word documents by a professional transcriptionist with experience with confidential transcriptions in health care systems.

Once the primary researcher confirmed that the transcription was in a digital format that could be opened and used for analysis, the transcriptionist was instructed to delete the digital audio and transcription document from their computer. All investigators had electronic copies of the digital audio and transcripts on their password protected personal computer for data analysis purposes. These audio digital files were shared with the investigators via a direct data transfer from the recording device, and the digital transcriptions were shared via MSU email and marked as confidential. Once the investigators had downloaded the digital files from their email account to their computer they were deleted from their email.

Completed consent forms, demographic forms, confidentiality agreements, sound recordings, and transcriptions were placed for maintenance in the office of the primary researcher for 3 years after completion of the study, at which time they will be destroyed.

The researchers did not receive compensation for time spent on the research project. The study was supported by the Glen Taylor Nursing Institute for Family and Society, of Minnesota State University, Mankato. The study had no impact on health care that participants received from their health care provider(s).

Instruments

Research instruments included a demographic form, a semi-structured interview guide, and the researcher(s), who observed and facilitated the focus group discussions.

Prior to the focus group discussions, and after informed consent was obtained, participants were asked to complete a demographic questionnaire (see Appendix D). Data was compiled to obtain a demographic picture of the participants. This questionnaire did not include names or identifying information of the participants. In

addition, data was further de-identified by using an alphanumeric code for each participant prior to transcribing the data.

A semi-structured interview guide was developed in collaboration with other senior research associates who also served as focus group facilitators. Pertinent questions were created and sequenced to guide the interview(s), while allowing flexibility for conversation to develop among focus group participants. These questions are found in Appendix E.

Focus groups are a qualitative research method that use a “combination of interview, group interaction and participant observation” (Plumer-D'Amato, 2008, p. 69), thus providing a rich source of information. Focus groups are particularly useful in qualitative research for gathering information on sociocultural phenomenon and revealing community concerns and priorities, which may be used as a preliminary step in a larger CBCAR project (Pavlish & Pharris, 2012). Krueger (1994) defines a focus group as “a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment ... Group members influence each other by responding to ideas and comments in the discussion” (p. 6). Morgan (1996) describes focus group research as a method for data collection, with interaction as a source of data, and the researcher promoting discussion. Freeman (2006) presents definitions of focus groups by several leading focus group researchers, summarizing that “Focus groups are thus best characterized as a form of group interview that places particular importance on interaction between participants. They comprise group discussion among carefully selected individuals, guided by a moderator using a carefully designed topic guide” (p. 492).

A semi-structured interview process was used to provide flexibility and spontaneity in discussions. A structured interview uses a prescribed interview guide that is closely followed. In unstructured interviews, the interviewer poses the research topic without a prescriptive interview guide and engages the participants to allow conversation to develop within the interview; this allows participants to have more control over topic flow and content (Pavlish & Pharris, 2012). The semi-structured interview had planned phases, which allowed conversations to develop during each focus group discussion. These phases are described by Pavlish and Pharris as follows: (1) informational exchange: consisting of informed consent with research purpose explained and orientation to the interview, (2) conversational, descriptive, and straightforward questions, which serve as a warm-up for both the interviewer and participant, (3) experiential and explanatory questions, focused primarily on descriptions, (4) perspective and meaning-seeking questions, focused on beliefs and meaning, (5) closure, which includes toning down, asking participants to identify the most important topic, and asking if participants have anything more to say or any questions (Pavlish & Pharris, p. 191).

In focus group research, the researcher is also an instrument of data collection, as the researcher observes and facilitates discussion using the interview guide to frame and focus the discussion topic (Freeman, 2006). This researcher is a registered nurse with nursing knowledge and experience gained by working with individuals and families in a variety of settings over a period of decades, as well as personal experience with difficult caregiving conversations with her own aging family members, enabling the researcher to serve as an empathetic listener. The researcher holds personal values, assumptions, and experiences that influence how data is perceived and collected. This researcher holds

beliefs that families contribute to the health of the individuals as well as the family as a whole, and that families seek to maintain stability and regain cohesion when faced with change.

Data Collection Procedure

A combination of advertisements placed in the local newspaper and a snowball method were utilized to recruit participants for this study (see Appendix F). Potential participants were invited to attend focus groups to discuss conversations and caregiving in aging families, and directed to contact the School of Nursing office. An assistant scheduled the families in a scheduled focus group and informed them of the date, time, and location of the meeting. This method allowed the researchers to limit each focus group to 6-10 participants and respond to initial questions about the purpose and format of the study. This method did not prove successful in recruiting adequate numbers of participants for the study. IRB approval was sought and obtained to use an additional recruitment method in which principal investigators and community gatekeepers invited people they know personally and/or professionally that met inclusion criteria to participate in the study (see Appendix G). Additional participants were solicited through a snowball method whereby participants were asked to identify additional potential participants.

Data collection using focus group methodology and a semi-structured interview process was used. A semi-structured interview guide was developed to provide structure while allowing conversation to develop between participants. A copy of the semi-structured interview guide is provided in Appendix E.

Focus groups were conducted during a 2-month period and conducted on-site at community venues. The interviews with focus groups were digitally audio recorded. In addition to digital audio recordings, the researcher documented field notes of observations made during focus group discussions. Field notes included written notes of nonverbal communication as well as patterns of communication between participants. Observations of body language, facial expression, tone, intensity, emotions, and eye contact, as well as observations of frequency of participation and patterns of conversation flow between participants were documented.

Digital audio recordings and field notes were transcribed into digital word text by a transcriptionist with experience with confidential transcriptions in health care systems. Confidentiality and data security were maintained throughout the data collection procedure as outlined under ethical considerations.

Data Analysis

Four methods are available for shared qualitative data analysis within a CBCAR framework. These are phenomenological, narrative, grounded theory, and ethnographic study methods (Pavlish & Pharris, 2012, pp. 247-248). Ethnonursing data analysis methodology was utilized for this study. Ethnonursing data analysis methodology is appropriate for this study as the research questions seek to describe the perceptions and experiences of adult children regarding critical caregiving conversations between themselves and their aging parents.

Leininger (2001) describes four sequenced phases of ethnonursing data analysis. This methodology uses four phases of analysis in which data components are assigned descriptors, descriptors are coded into categories, categories are clustered into patterns,

and themes are identified from the categories and patterns. Focus group data was initially coded into what are called nodes within NVivo software. The researcher analyzed the transcripts line by line, assigning descriptors to the data. Analysis identified 55 concepts or descriptors which were coded into nodes. Transcription data was at times assigned to more than one descriptor. For example, a statement referencing disagreement among siblings regarding parental safety while driving may be assigned to separate descriptors of sibling conflict, safety, and driving. The researcher reflected on commonalities among the descriptors or nodes, while organizing them into categories. These categories were further clustered into patterns, which reflect the researcher's thoughts and reflections on relationships among the categories identified. Categories and patterns were identified to clarify key relationships among data with the recognition that there may be some overlap between descriptors, categories, and patterns. From the patterns identified, the researcher explicated themes that emerged the data.

NVivo qualitative analysis software was used to facilitate analysis of the data. Transcripts and field notes were saved as rich text formatted documents within the software program. The documents section of NVivo allows each document to be interpreted and coded (phase two). NVivo allows the researcher to view all text from all documents regarding a specific code, pattern cluster, or theme.

Rigor

Rigor in qualitative research is associated with openness and critical appraisal of the research to ensure dependability, transferability, and confirmability of the study findings. Direct quotes from focus group participants were used to ensure that the categories, patterns, and themes identified were supported by research data. Feedback

was sought from peers and faculty regarding the clarity of the research purpose and transferability of abstract concepts. Critical appraisal of this research study was done throughout the study by discussion and feedback with university faculty with expertise and experience in family and community research and practice.

Limitations

This study is a qualitative study using CBCAR Methodology identifying perceptions of adult children of caregiving conversations between themselves and their aging parents and conducted via a focus group format. Limitations of the qualitative method include:

- Multiple perceptions of varied participants require greater interpretation on the part of the researcher and a concomitant potential for introduction of researcher bias.
- Findings are limited by the degree to which focus group participants feel free to express their thoughts and perceptions candidly, which is influenced both by unique group dynamics of each focus group and the ability of the focus group moderator to facilitate this candid expression.
- Results are influenced by the unique variations in participant demographics and experiences.
- The participants in a focus group may not accurately reflect the perspectives of a larger population.
- Those who choose to participate in focus groups may vary in significant ways from those who choose not to participate, which also may limit the degree to which the results reflect the perspectives of the broader population.

Summary

In summary, this chapter includes information about the study design and methodology. A Community Based Collaborative Action Research design utilizing qualitative methodology was used to identify the perspectives of adult children regarding critical conversations with aging parents. Ethical considerations were made to protect informant's rights and privacy. Data was collected via focus group interviews of voluntary participants. Ethnonursing data analysis methodology was used to assign descriptors to the data, organize descriptors into categories, cluster categories into patterns, and identify themes emerging from patterns in the data. Details of the setting, sample, ethical considerations, instruments, data collection, data analysis, and limitations of the method were described.

CHAPTER IV

STUDY FINDINGS

Introduction

The findings of this study, utilizing ethnonursing data analysis of focus group interview data, will be presented in this chapter. This methodology supports a Community Based Collaborative Action Research design to identify the perspectives of adult children regarding critical caregiving conversation with their aging parents to increase understanding of family communication process that promote health as families age, and collaboratively engage the community in findings solutions.

Demographics

The findings summarize data from three focus group interviews consisting of 4-7 participants each, representing a total of 16 participants. All participants were Caucasian. This was not unexpected as the community is 90% Caucasian. Two focus groups consisted of participants responding to an invitation for adult children to discuss caregiving conversations between themselves and their aging parents. The third focus group consisted of older adult participants recruited to discuss caregiving conversations between themselves and their adult children. These older adult participants shared experiences of caregiving conversations with their own aging parents in addition to caregiving conversations with their adult children, adding additional dimension to the data.

There were nine adult children participants, eight female and one male, ranging in age from 49 to 71. All were married, with two of the participants married to each other. All had household incomes of over \$50,000 per year, which is higher than the median household income of \$37,000 for the community. Of the eight adult children participants who listed their education levels, all had education beyond that of a high school diploma, with five of the nine participants having attained a baccalaureate degree or higher. This reflects a higher education level than that of the community as a whole. Participants were currently caregiving for 1-4 older family members, ranging from 80-101 years of age.

Table 1

Demographics of Adult Children

Code #	Gender	Age	Marital Status	Parent .>60 #	Ages of Parents	Children	Ages of Children
AC-1	F	71	M	1	97	N	NA
AC-2	F	58	M	4	82, 83, 90, 92	Y	27
AC-3	F	47	M	3	70, 70, 73	Y	21, 18, 16, 13
AC-4	F	61	M	2	89, 90	Y	42, 34, 31
AC-5	F	49	M	2	82, 83	Y	18, 22
AC-6	F	60	M	1	94	Y	27, 30, 34
AC-7	F	64	M	1	101	Y	38, 33, 31
AC-8	F	55	M	1	80	Y	31, 27
AC-9	M		M	1	80	Y	31, 27

The older adult focus group consisted of seven participants, composed of three married couples and one widowed female, ranging in age from 66 to 83 years of age. All older adult participants reported an education level of a baccalaureate degree or higher, with just over half (four) reporting having obtained a graduate degree. This is a higher level of education than that of community as a whole. All participants listed incomes of less than \$50,000 annually, although it was unclear whether this represented individual income or household income. The older adult demographic questionnaire did not obtain data about number of parents cared for or parental age.

Table 2

Demographics of Older Adults

Code #	Gender	Age	Marital Status	Children	Ages of Children
OA-1	F	69	M	Y	48, 45, 41
OA-2	M	69	M	Y	48, 45, 41
OA-3	F	82	W	Y	60, 56, 55, 50
OA-4	F	80	M	Y	60, 58, 54
OA-5	M	83	M	Y	60, 58, 54
OA-6	F	70	M	Y	46, 44, 41
OA-7	M	66	M	Y	46, 44, 41

Presentation of Themes, Patterns, and Categories

Three themes emerged from the patterns and categories which permeated throughout the discussion of caregiving conversations between adult children and their aging parents. Themes, patterns and categories identified in analysis of the data are presented in the following table:

Table 3

Themes, Patterns and Categories

Themes	
Navigation, Negotiation, and Coordination of Caregiving in Aging Families	
Patterns	Categories
Caregiving Assistance	Instrumental Activities of Daily Living Activities of Daily Living Medical Management Financial and Legal Management Supervision of Executive Function
Role Expectations of Family Members	Siblings In-laws Gender Caregiving Professionals Historical Patterns of Communication
Geographical Distance	Distance from Parents Distance between Siblings
Independence versus Protection	Struggle for Independence Maintaining Dignity Respecting Choices Shared Decision Making Maintaining Safety

Table 3 (continued)

Themes	
Navigation, Negotiation, and Coordination of Caregiving in Aging Families	
Patterns	Categories
Lack of Preparation for Caregiving	Crisis Sudden Not Knowing Where to Turn Lack of Planning
Dialogue with Health Care Provider	Information Exchange Guidance to Resources Preventive Care: Potential Needs Technology/Assistance
Community Engagement	Community Where People Connect Convenient Preventive: Prior to Need Support Groups

Themes

Three recurring themes emerged from the data, permeating throughout the often overlapping categories and patterns. These themes are navigation of caregiving in aging families, negotiation of caregiving in aging families, and coordination of caregiving in aging families.

Navigation of Caregiving in Aging Families

Navigation is defined by the Oxford Dictionaries as “the process or activity of accurately ascertaining one’s position and planning and following a route.” In the context of caregiving conversations, navigation requires figuring out what the situation is,

what should be discussed, who the participants are, what the boundaries are, what the resources are, and what direction to take.

A participant described trying to navigate boundaries when attempting to communicate with her mother's healthcare provider regarding care needs: "That's getting more difficult for me, that's piece of communication that you're talking about. What's my boundaries, or what is not my boundaries..."

Another participant described the navigation surrounding communication of her mother's wishes for EOL care as follows:

Ya, the attorney gave her a form to fill out and she filled it out. The paperwork that goes around aging, I think, it's like some of the other things...you're just kind of out there fending for yourself and you know, for me all of this is really uncharted waters... because I don't know if I'm doing the right thing or not, and it's all a matter of trying to figure it out for the first time...Each step is uncharted, I mean each one.

Negotiation of Caregiving in Aging Families

Even when adult children were able to navigate the caregiving needs of their aging parent and the general direction required, caregiving conversations required the negotiation of multiple perspectives, and competing needs and resources. Caregiving conversations occur between multiple family members, spouses, health care providers, neighbors and friends, and community members, each requiring some level of negotiation. In describing the challenges of negotiating caregiving discussions as the primary caregiver of her mother-in-law, a participant noted that this negotiation is an ongoing process: "Just so the family, everyone is on the same page and you negotiate

some of the things that this is what we're going to do...and it will be different for every family, and it will change over time.”

Coordination of Caregiving in Aging Families

Participants frequently referred to the coordination required to meet the caregiving needs of their aging parents, requiring additional layers of caregiving conversations between themselves, their aging parents, and others who provided an aspect of caregiving assistance. Coordination was required between parents, siblings, health care providers, those performing household services, community service programs, neighbors, and other community members.

One participant described monitoring her mother's health and arranging for care needs while living in another state. In one example, she describes the coordination of resources required when she discovered her mother had no pills left, and had thus likely taken her medication incorrectly:

...I call her up at 5 o'clock and I said now remember you don't take any pills, and she says "I don't have any left." I said sure you do ... So I call a doctor at the clinic and he says take her to emergency room... So I call my cousin, she and her husband took her to the emergency room...and I get a call saying that Medicare will not pay this but Medicare Part B will... So my cousin spent that night ...But I happened to mention this to a neighbor of my mother's, ...who spent Saturday night with her...We had a home health nurse coming out once a month to take her blood ...We had an occupational therapist out to evaluate to look at the bathroom and make suggestions as to how it could be modified so the home health aide could start coming and help her take a bath....the OT had thought that she was

managing...And my cousin, and the neighbors...so I was pretty shocked when the doctor told me this but I really think, in retrospect it was 3 days worth of medicine...Basically we decided she is going home. We had the care conference today...

Patterns and Categories

Data revealed the following patterns, or category clusters, in focus group discussions of caregiving conversations between adult children and their aging parents: caregiving assistance provided, role expectation amongst family members, challenges of geographical distance, balancing parental desire for independence with concerns for parental protection, lack of preparation, dialogue with health care providers, and the significance of community engagement. These patterns and their relationship to the emerging themes are discussed below.

Caregiving Assistance

The types of caregiving assistance provided to aging parents fell into the categories of Instrumental Activities of Daily Living (IADLs), Activities of Daily Living (ADLs), medical management, financial and legal issues, and supervision to evaluate and assist with executive function. These tasks were generally more encompassing and time-consuming than caregivers expected which was often further complicated by geographic distance from the parent.

Participants mentioned assistance provided to aging parents in the category of IADLs most frequently. Assistance with IADLs included broad-ranging tasks that participants frequently expressed as considerably time-consuming, as well difficult to

predict or plan for. A participant described retiring from her full-time job only to find her time taken providing for miscellaneous unplanned care needs of her mother:

I just retired in June and I was finding myself with a new job, and it was taking care of mom, and spending a lot of time with such a variety of things, and I might go over to help her with one thing and then find out I need to help her with this too, and oh my goodness this needs attention and pretty soon almost the whole day is taken up...Like filling the humidifier, cleaning the cat box, taking her on errands, take her to her hair appointment, and miscellaneous.

Caregiving assistance with ADLS such as bathing and feeding ranged from arranging for ADL assistance provided in the parent's home, to caring for the aging parent in the home of the adult child. Identifying the need for care, negotiating care needs with the parent and siblings, and then implementing the actual care were repeating themes.

A participant described the process of trying to identify whether her mother-in-law needed assistance with bathing, considering sibling and family perceptions of need for care, attempts to maintain her mother-in-laws dignity, and how she went about providing assistance with bathing:

...it's always a little bit of a guessing game for me. And again, my husband is not in-tune with those things, and her daughter is not there to see it, so it's been both good and bad. I was the one that actually just...usually what I have to do is for giving her a bath, one day I just said this is it, we're going to do it. Laid out all the stuff and did it.

Another participant described how she and her husband took care of her mother – in-law in their own home, but arranged for a home health aide to come each morning to help with dressing, bathing, and eating, demonstrating how caregiving is often coordinated within a larger caregiving system.

Medical management included caregiving responsibilities such as attending health care provider appointments and medication management. Again, this medical management required navigation of the need for assistance, negotiating a plan, and considerable coordination. A participant described enlisting health care providers to enable her to manage her mother's medications, advocating for medication administration times to be more streamlined and simplified:

We now have all the medicine at the same time. It used to be that she had medicine 3 times a day... But in any event I would tell her to take her medicine in the morning, I would call her in the afternoon and I remind her that we had set an alarm clock, tell her to turn that on in the morning. So now when that goes off you put your eye medicine in.

This same participant described the further navigation, negotiation, and coordination that was required when medication management was not successful, as multiple people within the caregiving system were enlisted to determine what happened, how to respond, and how to prevent such outcomes in the future.

“We had the care conference today, people there agree... we're going to do more for home care, she is not going to take 3 days worth of medicine again.”

Attendance at medical appointments was another area for navigation, negotiation, and coordination. A participant responded to the question of whether she had asked to be

informed of her parent' medical appointments, describing how attending medical appointments depended on the given situation, whether she was needed, or whether the parent wanted her present, again describing the navigation and negotiation of the need for her to be there, as well as behind-the-scenes coordination:

I haven't even asked for that. But when my dad was, he was actually on a trial study with Mayo with his cancer which proved to be very beneficial of that, so I would go with him every month to that appointment, but as far as any decision making appointments where I knew they would be coming up, I would just prep them in, "make sure you ask this, make sure you...I'd be happy to be there...no we don't". But make sure you ask.

Another participant described this same navigation of the need for her to be at medical appointments, negotiating her presence with her mother-in-law:

We've been on both sides. If things are really bad then I'll be in there because I've had to do wound care for leg ulcers and things, and then she'll have me there. But then also when she feels better she wants her independence more, and when she was driving she would take herself to medical appointments.

Managing financial and legal issues such as wills and power of attorney created additional complexities for navigating, negotiating, and coordinating. Participants varied in the degree of communication they had with their parents regarding financial, legal, and EOL care issues. This ranged from no communication at all, to parents who had not only planned arrangements, but also communicated their plans via conversation and in writing. Most participants described communication as being somewhere between no communication at all and communication of detailed plans both via conversation and in

writing. Participants described having difficulty figuring out what resources were available, finding out what needed to be done, negotiating with their parents and siblings to make decisions, and coordinating to get things done. The multiple navigational and negotiation pieces meant that financial and legal plans were often made over an extended period of time, even when there was an awareness of the need. A participant described how she had obtained information and authority for her mother's financial and legal issues over time, yet this process is still not complete, demonstrating the navigation for the need for assistance, negotiation, and coordination:

You brought up the, in terms of power-of-attorney...I did not get... let's see, when she first broke her hip I got my name put on the checking account because I thought she was going to have...well I didn't know if she was going to get out of the nursing home that time... I am the executor of her will so I know what's in that, and it wasn't until this past summer that I got the power-of-attorney for her financial things. I thought, she had this stroke what if she gets disabled, what if we have to sell the house, we can't do that. So I have that. There is no...we do not have the medical power-of-attorney.

Supervising parental executive function and decision-making presented as a less tangible, but equally important, concern of adult children providing caregiving assistance to their parents. Navigation, or ascertaining the situation, again came to the fore. A participant with previous professional experience working with special needs children was able to articulate this navigation in ascertaining her mother's need for care:

...it dawned on me probably 6 months ago that my mom is having trouble with executive functioning... And executive functioning is the ability to recognize

what needs to be done, and to be able to initiate and to follow through on what needs to be done. And you know it just didn't dawn on me..... and it dawned on me that's where the difficulty is...she didn't recognize that there was a need. It wasn't all that she didn't want to ask for help, sometimes she doesn't recognize the need.

Addressing executive functioning and memory required navigation not just by adult children, but also other members of the family, along with additional negotiation and coordination to manage care needs. A participant described his conversations with parents regarding his mother's care needs: "My mother was starting to have some memory loss, and my dad did not want to acknowledge it. He would try to always, you know, think that everything was okay."

Another participant described her frustration negotiating care of her mother-in-law's care in the presence of memory problems, which the mother did not recognize or acknowledge:

She wouldn't admit that she had memory problems which further added to the stress, where its "I know I told you that...no you didn't tell me that, you're keeping secrets and trying to control me." So I had to write everything down.

Role Expectations of Family Members

Role expectations were an additional piece that participants described navigating and negotiating in order to successfully coordinate care. Role expectations included those of sibling, in-law, gender, spouses, parents, and special expectations of those who were professionals in a health care field. Added to these categories of role expectations

were historical patterns of communication within the family. Navigating these role expectations often created conflict, requiring additional negotiation when caregiving.

A participant referred to her challenges in navigating and negotiating role expectations within the family, as a daughter-in-law serving as the primary caregiver to an aging parent:

That was an interesting poll, like talking about how the family meets it, the family dynamics really came into play here and I didn't understand, being an in-law, how things worked until we went through this, and who the allies were, and it really came into play. ... for the kids, and I feel like in some ways since she was living with us, and my husband was working and I was home, and ... so none of them are here...

This same participant goes on to describe the role expectations within the family, "but I'm the daughter-in-law, to me, the husband makes it pretty clear that's his family when you're really trying to make decisions there... then he thinks maybe the older brother should say something, well the older brother..., it's passed around."

Several participants shared family role expectations that women provide nursing and domestic care, while men take care of financial and business matters, expectations that often required adjustment and role reversal as parents aged. One daughter-in-law described her perception of historical communication patterns within her husband's family, and how role expectations could help or hinder negotiation and coordination of caregiving needs:

And the way they were raised is that Mom ruled. And so what Mom wants is what Mom gets, so Mom can have. Sometimes it made it difficult, other times it

made it good because I'm not one of those siblings so I could suggest things and get things accomplished because I never had that relationship with her.

Geographical Distance

Geographical distance between adult children, aging parents, and siblings was frequently mentioned as a challenge to adult children providing care to aging parents. Most of the adult children described families where siblings were spread out at considerable distance across the county. This distance posed navigational challenges in ascertaining the needs of their parents and determining the resources that might be available. Geographical distance also created barriers in communication between siblings, health care providers, and other members of the community making negotiation of care needs more difficult.

A participant described the varying perceptions of he and his sister in assessing their parent's need for care and their expectations of how that care was to be provided, resulting in challenges in sibling communication that can require negotiation:

...I have one sister ... she lived very close to my folks mileage wise, just like 9 miles down the road in rural community. So she had more access to see them more often and yet I feel that she a lot of times took the easy route and would just call dad on the phone in the morning....And my sister not really stepping up sometimes, maybe she thought I didn't either because I was further away distance wise, I couldn't always be there. But I tried to, when I wasn't there, tried to call, and my sister thought it was good enough to call dad in the morning and just see how things were going.

Distance further added considerable logistical challenges to coordination of care. While participants saw technology as something that could ease the challenges of care coordination, it also created additional navigational challenges in finding out what technology was available and advocating for its use when coordinating caregiving with others.

Independence versus Protection

Balancing parental desire for independence with protection was a repeated pattern of discussion among focus group participants. Participants described balancing parental struggles to maintain independence and maintain dignity, against their own concerns for parental safety, while at the same time seeking to respect choices and share decision-making. Housing transitions, nutrition, and driving were examples of high concern to adult children.

Discussions about housing transitions and accepting assistance in the home were perceived as particularly difficult conversations between adult children and their aging parents, with even the suggestion sometimes creating conflict. An older adult participant expressed her irritation with her son broaching the topic of moving to a rest home or apartment:

I still have grandiose plans that I don't want anyone telling me I can't do this and that. I think that it's hard for me to accept, well I won't accept it. ...My son said to me the other day he said "you know Mom, one of these days you maybe have to kind of slow down". I said "never". It isn't exactly the conversation but it was along those lines, and then he said...and this I just almost couldn't tolerate... he said "the rest homes are nice apartments."

Challenges to these conversations included parents being unwilling to ask for help, and hiding their need for care, as a participant described her aging parent's attempts to hide the need for care, and her own attempts to assess caregiving needs:

She's got some major things that go on with her, and she won't let anybody know, and the only time I get information is sneak peek. She doesn't want me to know because she knows I'm the one who's going to move on it ...

Participants described evaluating their parent's diet and safety during cooking, while navigating resources available such food programs and in-home assistance. They also described attempts to determine driving safety, navigating the rules of what they could do to prevent unsafe driving, seeking out alternative transportation arrangements, and even threatening to call the local police if the parent continued to drive. These conversations represented additional topics of negotiation and coordination and points of conflict between parents and adult children, as each had different perspectives of the situation.

A participant described the conflict that resulted when suggesting that her mother-in-law should not be driving, while also being concerned for protecting not only her mother-in-law, but also others in the family who may be in the vehicle: "...she would get angry if I said I didn't think she should be driving, or I don't want you driving my kids places, and it was... was very difficult."

The challenge in negotiating a balance in respecting aging parent's desire for independence with a sense of protection of the parent was articulated by a participant:

“It’s hard walking a fine line because you don’t want to take over...you want it to be their decision but you also know you have a really strong sense of what would be good for them.”

Yet another participant described his belief that accepting services may actually serve to preserve greater parental independence, a belief not shared by his parents:

“Maybe that’s something you guys can figure out, how do you convince, or how do you convince people to realize that they can remain at home...that the services are out there if they will just utilize them.”

Lack of Preparation for Caregiving

Participants frequently mentioned being caught off guard by changes in their parent’s change in health status. Participants described how changes occurred suddenly, often triggered by a crisis, with a lack of planning and preparation for the caregiving needs that followed; yet, decisions still had to be made. An older adult participant described his experience of being forced into decision-making when unprepared to do so: “One of the things that happens there is that you’re forced to a decision. And that is sometimes a very unpleasant spot to get yourself pushed into. But you still have to do it.”

Some family members had attempted to broach medical care topics with their parent previously, but were unsuccessful in doing so, as one daughter described in attempting to discuss her parent’s wishes for medical care:

So I said to my dad I said now is there anything that I should know being the one here, and I will get the phone call. He said oh no, it’s nothing for you to worry about. (She and the group laugh heartily) So I still have no clue.

Sometimes these conversations were forced by a crisis or incident, as one daughter described:

We have either waited for professionals or health problem that forced the issue....it kind of depends, my father-in-law I think with the driving he actually has had like two or three little accidents, the garage door, and finally the police said uh-huh, no more license, which broke his heart.

Some older adult participants described how providing care for their aging parents influenced them to prepare for their own caregiving needs, and helped them understand how to navigate the process of planning for future care needs:

I think we learned about some things that are better to prepare ahead of time...and it's good to know about all of the services that are available...Sometimes we just do not learn of these things because we don't know what to do, don't know where to find them.

Dialogue with Health Care Provider

Communication with health care providers was valued by participants throughout the spectrum of care. Participants spoke of the value of the HCP in prompting them to think about planning for future care needs, sharing information with them that would help them care for their parent, providing guidance to resources available, and helping family members coordinate.

Participants spoke of the importance of communication being two-way and multi-directional, with information received from family members as well as provided to them. They expressed a desire for the HCP to not only explain information to them about their parent's health, but also understand that they could provide valuable information to the

HCP regarding their parent. As one participant stated: “I think especially since the doctor knew that she was living with us that she should know that our observations are equally as valid as hers.”

Participants valued the ability to contact the HCP, but at the same time expressed confusion about what the boundaries were. A participant described her lack of certainty on whether or how much she should contact her mother’s health care provider:

I have a tendency to call the doctor’s office to ask because it’s too difficult to take her in, and they do let me talk to the nurse, the nurse talks to the doctor, doctor gets back. I have a hard time wondering if I’m being too much of a bother, or how much can I ask, or how much should I be involved.

There was also some frustration expressed with coordination and communication between HCPs, resulting in differing advice and confusion among family members. Participants expressed difficulty in knowing how to contact their primary HCP during care transitions, such as a hospitalization. Along these lines, the value of a personal relationship with the provider over time was expressed.

Participants expressed interest in having some way to coordinate care to include all members of the family. A few participants had utilized HCPs, including psychiatrists, to help them negotiate and communicate difficult conversations with their aging parent, such as driving, memory problems, or recommending the parent receive services. One participant expressed a desire to have access to a HCP who could help the family negotiate caregiving and role expectations among family members right from the beginning. A suggestion of having a central contact for family members seeking assistance with navigating resources and coordinating care was well received.

Participants also suggested technology as an avenue in which HCPs could enhance communication with family members. Teleconferencing was a suggested option. It was noted that health care facilities such as hospitals and nursing homes often have family care conferences, but these services were typically not offered in the primary care setting. Teleconferencing and e-mail were suggested as methods to enhance information exchange among families.

Community Engagement

Data from all focus groups found a pattern of vocalizing the value of engaging the community in caregiving conversations. Throughout discussions of caregiving experiences, participants noted the value of multiple people in the community providing support to aging parents. Churches, friends, neighbors, distant relatives, landlords, law enforcement, elder-care organizations, and health care providers were all mentioned. An older adult participant summarized as follows:

...the idea of community and the more communities we have, or the more relationships in communities we have I think the better we are. Whether they are communities of interest, or similarity, or difference, or all of those pieces.

Participants suggested that services to older adults be based on the community they are engaged in, and that these be convenient to access. Along these lines, participants emphasized the importance of reaching out to aging families before the need arises, targeting not only older adults, but also their adult children who may be potential caregivers or care recipients as they age. Participants of all focus groups expressed the value to themselves of having others to talk to, to share ideas and provide support with others who faced similar challenges caring for aging parents,

Relation of Findings to the Research Questions

The findings will now be used to address and respond to the research questions that guided this study:

1. What are the critical conversations that adult children find difficult when planning care needs with their aging parents?
2. What do adult children perceive as barriers to critical caregiving conversations with their aging parents?
3. What do adult children perceive as factors that facilitate critical caregiving conversations with their aging parents?
4. What support from healthcare providers do adult children believe would help facilitate critical caregiving conversations between themselves and their aging parents?

Critical Conversations

Data from focus groups indicate that the critical conversations that adult children find difficult when planning care needs with their aging parents fall under the broad themes of navigation, negotiation, and coordination of caregiving in aging families. These conversations occur not only between themselves and their aging parents, but also with other family members, health care providers, and within the wider community.

Conversations that adult children find difficult to have with their aging parents include acknowledging and recognizing care needs, negotiating limits to maintain safety, negotiating how much care will be provided, who is to provide care, and where this care should be provided. Care topics of concern identified by adult children included IADLs, ADLs, medical management, financial and legal issues, and monitoring of parental

executive functioning and decision-making. Focus group data suggests that accepting care in the home, driving, meal planning, and potential housing transitions to assisted living or a nursing home are especially sensitive topics that often met resistance from parents. Legal matters such as finances, wills, and medical and financial power of attorney were also identified as difficult conversations that adult children would like to have, but were not always able to complete successfully with their parents.

In addition to conversations with their aging parents, focus group data indicates that adult children also find caregiving conversations difficult to have with their siblings and other family members. The discussion and negotiation of role expectations within the family was identified as difficult, which was sometimes managed successfully, and other times created conflict.

Barriers to Critical Conversations

Barriers that adult children perceived to critical caregiving conversations with their aging parent included lack of awareness, denial of care needs of the part of the parent, desire to maintain parental autonomy and dignity, role expectations, conflict avoidance, and lack of information about resources available. Data from focus group analysis indicate that adult children and their parents were sometimes unaware of parental care needs. Adult children's lack of awareness may be the result of geographical distance or infrequent contact, with a resulting lack of opportunity to observe parental care needs. Parents often did not share pertinent health information with their children and sometimes attempted to hide care needs from their children. Mental decline on the part of the parents may contribute to this lack of acknowledgement of care needs on the part of parents.

A consistent barrier to caregiving conversations was the parental struggle for independence and adult children's desire to maintain parental sense of dignity. This resulted in parents avoiding conversations or refusing to discuss care needs. Potential or actual conflict thus contributed to avoidance of what adult children perceived to be important caregiving conversations.

Focus group data indicate that role expectations within families contribute to conversation barriers. Participants voiced unspoken and spoken expectations influencing whether caregiving conversations took place. These included gender expectations of males versus female roles, the place of in-laws when making family decisions, and historical communication patterns within the family. Differences in sibling perceptions and sibling conflict regarding caregiving created further barriers to effective caregiving conversations.

Finally, lack of knowledge to guide families through the aging transition made it difficult for adult children to initiate and engage in caregiving conversations. Some participants indicated that they didn't know where to turn, and they didn't know who to ask for guidance.

Facilitators to Critical Conversations

Factors that adult children perceived as facilitating critical caregiving conversations with their aging parent included previous experience providing care for aging family members, geographic proximity, frequent interaction, indirect conversations, sibling support, getting parents alone, and use of a facilitator. Participants indicated that previous experience providing care to aging family members made them aware of the need for planning ahead of time, which served as a trigger for them to

initiate conversations. Focus group participants also indicated that geographical proximity and regular contact helped them to regularly observe and be attuned to parental care needs, and provided opportunities to initiate caregiving conversations. Indirect conversations such as hints, joking, suggesting, discussing examples of neighbors and friends receiving care were identified as helping to broach sensitive topics by “planting seeds over time.” As one participant described her attempts at initiating caregiving conversations with her parents, “it takes a lot of conversations...it doesn’t happen the first time you know, it takes a lot of...it’s a slow process getting them to move.”

Several participants reported that getting parents alone, one-on-one was helpful, as parental dynamics were often different when parents were together, noting that parents seemed to be more receptive to sensitive topics when approached alone. Sibling support was identified as facilitating caregiving conversations with aging parents, as siblings agreed and approached their parent together to discuss caregiving.

Finally, several participants voiced the benefit of having a HCP facilitate conversations, especially for sensitive topics such as memory decline, driving, or other limitations. HCPs were also identified as helping to facilitate communication between siblings, and negotiate role conflict in the family, promoting navigation and negotiation of care.

Support from Health Care Providers

Focus group data pointed to several health care provider behaviors that adult children believe would help facilitate critical caregiving conversations between themselves and their aging parents. Consistent with the themes of navigation, negotiation and coordination of caregiving, factors identified include providing a centralized place

for information exchange, initiating caregiving discussions on a preventive basis, including the family in decision-making, providing access to professionals to facilitate family role negotiations, and linkage to community based support services.

Participants spoke of the importance of communication being two-way and multi-directional, with information received from family members as well as provided to them. They expressed a desire for the HCP to not only explain information to them about their parent's health, but also understand that they could provide valuable information to the HCP regarding their parent.

Adult children indicated a desire for a centralized place to exchange information as they navigated the aging process and associated care transitions. Adult children indicated that they did not know who to turn to, or even what questions should be asked as they approached changes in parental care needs. A centralized place for information exchange would include the ability to ask questions of the HCP, provide information and feedback to the HCP, facilitate communication among multiple family members, and provide guidance to additional resources available. It was also hoped that this could serve to facilitate communication between HCPs. The suggestion of a care coordinator to centralize this information exchange and facilitate communication was well-received. Facilitating the ability to teleconference among families and conducting family care planning meetings was among the perceived advantages of having centralized access to information and care coordination.

The HCP was identified as an important source in initiating care discussions. Adult children suggested that these conversations be initiated on a preventive basis. Providing information about potential health changes and discussing expectations of

future care needs were seen as important discussions in a preventive care visit. Offering a family care conference to promote care planning on a preventive basis was suggested as a routine offering of health maintenance.

Adult children voiced the desire that family be included in decision-making regarding aging parents. This idea has more challenges in implementation due to privacy and autonomy concerns, but adult children emphasized that many health care decisions of aging parents have direct impact on their own lives. Adult children indicated a desire for HCPs to make efforts to engage family in care decisions of aging parents, and facilitate negotiation of shared decision-making with aging parents.

Access to a HCP professional trained to facilitate family role negotiations and conflict was recommended. Participants who had experience with family conflict in caregiving voiced the value of having a professional HCP to facilitate family negotiations and expectations. Participants who had accessed such services voiced concern that this option was underutilized, as families had to identify the need and seek these services on their own with little guidance. Providing information about, and access to, a trained facilitator was seen as a valuable support.

Adult children consistently indicated the value of the wider community in facilitating caregiving conversations with aging parents. Adult children recommended that HCPs use outreach through communities where aging parents and their adult children are currently engaged, whether this be churches, services, or other organizations, to help link those in need to available resources. Use of technology such as Internet and e-mail were also viewed as important avenues in providing information. The need for services to be convenient was viewed as paramount.

In summary, this chapter presented findings from data analysis of focus group interviews with adult children regarding caregiving conversations between themselves and their aging parents. Data analysis identified categories and patterns of caregiving conversations, from which three themes were identified. Themes identified were those of navigation of caregiving in aging families, negotiation of caregiving in aging families, and coordination of caregiving in aging families. The findings were then discussed in relation to the research questions.

CHAPTER V

DISCUSSION AND CONCLUSIONS

Introduction

The purpose of this qualitative study was to describe adult children's perceptions of critical caregiving conversations between themselves and their aging parents; barriers adult children perceive to these critical conversations; the factors that adult children perceive would facilitate these critical conversations; and the support from health care providers that adult children believe would help facilitate critical caregiving conversations between themselves and their aging parents. The overall purpose was to increase understanding of family communication processes that promote health as families age.

In this chapter, study findings are discussed in terms of consistency with review of the literature, and how this study adds to the body of knowledge regarding adult children's perceptions of critical caregiving conversations with their aging parents. The themes identified in data analysis of interviews with adult children regarding caregiving conversations with their aging parents are reviewed. These themes are: navigation of caregiving in aging families, negotiation of caregiving in aging families, and coordination of caregiving in aging families. These themes are discussed in relationship to the theoretical framework and conceptual models on which this study are based. Implications for nursing practice, nursing research, and nursing education are discussed.

Discussion

The study findings have demonstrated similarities to the literature in describing adult children's perceptions of critical caregiving conversations with their aging parents. Focus group data with adult children confirm that the conversations that adult children find difficult when planning care needs with their aging parents go beyond end-of-life (EOL) care, which has historically the emphasis of health care providers. Critical conversations cover the continuum from recognizing and acknowledging the need for care through the end of life. Findings in this study are consistent with previous research in identifying the types of assistance that adult children provide to their aging parents, and the need for caregiving conversations to occur before crisis occurs. Barriers to critical caregiving conversation that are consistent with the literature include lack of awareness, denial of care needs on the part of the parent, geographical distance, challenges balancing autonomy and paternalism, role expectations, conflict avoidance, and lack of information about resources available. Factors that facilitate critical conversations, which are consistent with the literature, are prior experience providing care to aging family members, frequent interaction, indirect conversations, and use of a facilitator.

This study adds to the body of knowledge regarding adult children's perceptions of critical caregiving conversations with their aging parents, in identifying the degree to which sibling communication and community engagement influence caregiving conversations. While initial review of the literature noted the role of sibling communication in caregiving conversations, there was limited study specifically of sibling communication in relation to adult children's perceptions of critical conversations

with their aging parents, including role expectations, geographical distance, and sibling conflict. Although the participants of focus groups in this study represent a small sample of adult children, sibling communication, role expectations, and conflict were a significant and recurring topic in each focus group. Geographic distance was also seen as compounding sibling communication difficulties.

Subsequent additional review of recent literature found scant research on sibling communication in caregiving of adult parents. The research that is available is consistent with the findings of this study. Ingersoll-Dayton, Neal, Ha, and Hammer reported on factors associated with sibling collaboration (2003b) and perceived inequities (2003a). A key factor promoting sibling collaboration identified by Ingersoll-Dayton et al. (2003b) was that of redefining the caregiving system. This requires “a shift from thinking of themselves as primary caregivers for their parents...to view themselves as being part of a caregiving system” (Ingersoll-Dayton, Neal, Ha, & Hammer, 2003b, p. 58). In a qualitative study of 10 multigenerational families examining the negotiation of parental support, Connidis and Kemp (2008) found that communication and consensus related to caregiving are generally limited within families. Geographic distance, role expectations, relationship history, and paid employment were among factors noted to affect caregiving conversations, with change in care arrangements required over time. Roff et al. (2007), who examined long distance parental caregiving with siblings, found that the experiences and expectations of caregiving differed between hometown and long-distance siblings, which affected caregiving decisions. Hequembourg and Brallier (2005) also noted role expectations among siblings based on gender and specialized knowledge as influences in sibling collaboration in caregiving. Focus group data is consistent with these studies

identifying the importance sibling communication and coordination, and noting the challenges of geographic distance, role expectations, perceived inequities, and potential for conflict. This study confirms the need for additional study of sibling communication in providing for care needs of aging adults.

This study also adds to the body of knowledge by identifying the emphasis that adult children place on the significance of community engagement in conversations regarding care needs of older adults. Discussions of the significance of the influence of community engagement went beyond discussion of programs that are available to serve the elder populations. Focus group participants spoke of community in terms of neighbors, friends, the cleaning lady, church, informal social groups, landlords, and even law enforcement. Both adult children and older adult focus groups spoke frequently of the importance of wider community networks in facilitating care as parents aged, and providing support systems for caregivers of older adults.

Themes

Three recurring themes emerged from the data, permeating throughout caregiving conversations. These themes are navigation, negotiation, and coordination of caregiving in aging families.

In the context of caregiving, navigation requires figuring out what the situation is, what should be discussed, who the participants are, what the boundaries are, what the resources are, and what direction to take. Focus group data indicated that navigation was a process that took place throughout the aging transition as care needs changed. Participants indicated that they often did not have the information they needed, and did not know where to turn. The sense of being in “uncharted waters” was expressed.

Even when adult children had a sense of the care needs of their aging parent and the general direction required, caregiving conversations required the negotiation of multiple perspectives, and competing needs and resources. Caregiving conversations occur not just with aging parents, but also between multiple family members, spouses, health care providers, neighbors and friends, and community members, each requiring some level of negotiation. Negotiation was required to agree on the need for assistance and limitations, negotiating how much care was to be provided, who should provide the care, and where it would be provided. Varying perspectives and expectations presented potential for conflict which required careful negotiation. Finally, with multiple people contributing to the care of aging parents, there was a need to negotiate and balance the requirements of each, whether they are siblings, spouses of the aging parent, neighbors, or paid assistance.

Participants frequently referred to the coordination required to meet the care needs of their aging parents, requiring additional layers of caregiving conversations between themselves, their aging parents, and others who provided an aspect of caregiving assistance. Coordination was required between parents, siblings, health care providers, those performing household services, community service programs, neighbors, and other community members. Geographic distance and transportation required additional logistical challenges. This theme of coordination was embedded throughout the caregiving process.

Conceptual Model Revisited

This study was based on an integration of two conceptual models, the Denham Family Health Model (Denham, 2003) and the Community-Based Collaborative Action

Research Model (Pavlish & Pharris, 2012). These conceptual models use an ecological approach that views individuals and families as part of a larger ecosystem, and emphasize the multi-party interaction involved in communications. The themes and findings of this study are consistent with Denham Family Health Model (FHM) and the Community-Based Collaborative Action Research Model (CBCAR).

The Denham FHM views family health in terms of context, structure, and functional processes (Denham, 2003, p. 11). Viewing the family in context recognizes that the internal family environment and the larger community affect family health. Family structure refers to family routines as they relate to self-care and health behaviors. Family functioning refers to the processes used by individuals as they interact with each other over time to promote health. Core family processes described by Denham (2003) include caregiving, cathexis, celebration, change, communication, connectedness, and coordination (p. 125).

The themes of navigation, negotiation, and coordination that emerged in this study are consistent with, and fit within, the seven core family processes described by Denham (2003). These study findings support the importance of communication as a core family process that can be targeted by nurses as they collaborate with families and others to optimize family health (Denham, 2003, p. 123). These themes of navigation, negotiation, and coordination are also consistent with the CBCAR Model in recognizing that solutions to community problems are found within the community.

The findings of this study indicate that caregiving conversations regarding aging parents involve interaction and communication beyond those between adult children and their aging parents. Caregiving conversations involve an interaction between adult

children, siblings, spouses, in-laws, health care providers, friends, neighbors, and the greater community. The conceptual models used in this study support study findings in the need to engage families and communities together as they navigate, negotiate and coordinate the caregiving system in caregiving conversations with aging adults.

Recommendations

Implications for Nursing Practice

The themes of navigation, negotiation, and coordination of caregiving in aging families demonstrate that caregiving conversations between adult children and their aging parents do not occur in isolation. Caregiving conversations are influenced by knowledge of and ability to navigate needs and resources, involve negotiation of multiple perspectives and competing needs, and require coordination of multiple parties and resources within the broader community.

Consistent with the themes of navigation, negotiation, and coordination of caregiving in aging families, health care providers can support adult children and their aging parents by providing a centralized place for information exchange, initiating caregiving discussions on a preventive basis, including the family in decision-making, providing access to professionals to facilitate family role negotiations, and linkage to community-based support services.

Communication is a core family process that can be targeted by nurses as they collaborate with families and others to optimize family health (Denham, 2003, p. 123). Communication with families should be considered as two-way and multi-directional, with information received from family members as well as provided to them and others involved their parent's care. Providing a centralized place to exchange information may

facilitate this communication. Establishing a care coordinator, facilitating the ability to teleconference, and conducting family care planning meetings are specific examples of how nurses may provide services aimed at enhancing family communication. Nursing practice must target communication processes as a family intervention to promote health in aging families.

Understanding the influence of the community in which aging parents and their adult children are currently engaged can be used to help families engage collaboratively with a wider network of support as they navigate caregiving transitions, negotiate, and coordinate care. Community resources may also be leveraged to enhance the effectiveness of community outreach programs for families providing care to aging adults.

Implications for Research

This research study provides a basis for part of a larger study with interest in development of community programs to better support family caregiving. Parallel studies of older adults, spouses, and health care provider's perceptions of caregiving conversations with older adults are also being conducted. These will be used in a larger Community Based Collaborative Action Research study to engage community members in conversations to identify actions to facilitate caregiving conversations. Measuring outcomes of resulting initiatives in terms of quality of care and family health will be important to build the knowledge base for further enhancement of programs to assist aging families.

The findings of this study can be used for further nursing research on factors that influence family caregiving communication, and help nurses more effectively target

communication interventions. Significant areas for additional research identified in this study are how families coordinate and collaborate when providing parental care from a long distance, as well as factors influencing sibling communication and collaboration in parental caregiving. Interviewing family members together, rather than individually, may provide additional insight into family communication processes. Research studying how individuals and families define and perceive the caregiving system may help expand the current focus of intervention and further enhance communication of caregiving conversations within families and communities.

Implications for Nursing Education

Education focusing on family, systems, and nursing theories can assist nurses as they form partnerships with individuals and the community to enhance family and individual health. This knowledge will enhance nurses' ability to influence organizational practices and complex family and community systems to improve health care for individuals, families, and communities. Education regarding aging transitions, preventive care, and information for families prior to crisis will help equip nurses for conversations that target family communication and caregiving, and enhance skills to foster communication, care coordination and shared decision making involving families.

Conclusion

This study sought to describe adult children's perceptions of critical caregiving conversations between themselves and their aging parents; barriers adult children perceive to these critical conversations; the factors that adult children perceive would facilitate these critical conversations; and the support from health care providers that adult children believe would help facilitate critical caregiving conversations between

themselves and their aging parents. The overall purpose was to increase understanding of family communication processes that promote health as families age.

The findings of this study indicate that caregiving conversations with aging parents involve interaction and communication beyond those between adult children and their aging parents. Caregiving conversations involve an interaction between adult children, siblings, spouses, in-laws, health care providers, friends, neighbors, and the greater community. The conceptual models used in this study support study findings in the need to engage families and communities together as they navigate, negotiate, and coordinate caregiving in aging families. Like the African proverb in which "it takes a village" to raise a child, so also, it "takes a village" to ease aging adults through their sunset years (Cowen-Fletcher, 1994). As families, communities, nurses, and other health care providers seek to engage each other in critical caregiving conversations, the more effectively they can assist aging adults through their sunset years.

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APPENDICES

APPENDIX A

Institutional Review Board Approval Letters



December 5, 2011

Dear Diane Witt, PhD:

Re: IRB Proposal entitled "[290057-2] Critical Conversations and Caregiving in Aging Families"
Review Level: Level I

Your IRB Proposal has been approved as of December 5, 2011. On behalf of the Minnesota State University, I wish you success with your study. Remember that you must seek approval for any changes in your study, its design, funding source, consent process, or any part of the study that may affect participants in the study. Should any of the participants in your study suffer a research-related injury or other harmful outcome, you are required to report them to the IRB as soon as possible.

The approval of your study is for one calendar year from the approval date. When you complete your data collection or should you discontinue your study, you must notify the IRB. Please include your log number with any correspondence with the IRB.

This approval is considered final when the full IRB approves the monthly decisions and active log. The IRB reserves the right to review each study as part of its continuing review process. Continuing reviews are usually scheduled. However, under some conditions the IRB may choose not to announce a continuing review. If you have any questions, feel free to contact me at patricia.hargrove@mnsu.edu or 507-389-1415.

The Principal Investigator (PI) is responsible for maintaining consents in a secure location at MSU for 3 years. If the PI leaves MSU before the end of the 3-year timeline, he/she is responsible for following "Consent Form Maintenance" procedures posted online.

Sincerely,

A handwritten signature in black ink that reads "Patricia Hargrove".

Patricia Hargrove, Ph.D.
IRB Coordinator

A handwritten signature in black ink that reads "Mary Hadley".

Mary Hadley, Ph.D.
IRB Co-Chair

A handwritten signature in black ink that reads "Richard Auger". The signature is written in a cursive style with a large, looping initial "R" and a long, sweeping tail on the "g".

Richard Auger, Ph.D.
IRB Co-Chair

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within Minnesota State University's records.



January 11, 2012

Dear Diane Witt, PhD:

Your proposed changes to your Minnesota State University approved research ([290057-3] Critical Conversations and Caregiving in Aging Families) have been accepted as of January 11, 2012. Thank you for remembering to seek approval for changes in your study.

If you make additional changes in the research design, funding source, consent process, or any part of the study that may affect participants in the study, you will have to reapply for approval. Should any of the participants in your study suffer a research-related injury or other harmful outcome, you are required to report them to the IRB as soon as possible.

The approval of your changes is attached to your original proposal; therefore, the original approval date has not changed. When you complete your data collection or should you discontinue your study, you must notify the IRB. Please include your log number with any correspondence with the IRB.

This approval is considered final when the full IRB approves the monthly decisions and active log. The IRB reserves the right to review each study as part of its continuing review process. Continuing reviews are usually scheduled. However, under some conditions the IRB may choose not to announce a continuing review or a modification.

I wish you success in your research. If you have any questions, feel free to contact me at patricia.hargrove@mnsu.edu or 507-389-1415.

Cordially,

A handwritten signature in cursive script that reads "Patricia Hargrove".

Patricia Hargrove, Ph.D.
IRB Coordinator

A handwritten signature in cursive script that reads "Mary Hadley".

Mary Hadley, Ph.D.
IRB Co-Chair

A handwritten signature in black ink that reads "Richard Auger". The signature is written in a cursive style with a large, looping 'A' at the end.

Richard Auger, Ph.D.
IRB Co-Chair

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within Minnesota State University's records.

APPENDIX B
Informed Consent

PRINCIPAL INVESTIGATORS: Diane Witt, PhD, RN, CNP
Sandra Eggenberger, PhD, RN, Don Ebel, PhD, Ernest Lampe, MD

SECONDARY INVESTIGATORS: Wendy Cregg, RN; Tamara O'Brien, RN; Heather Obermeyer, RN; and Sarah Pankonin, RN; graduate students of the Minnesota State University Mankato School of Nursing

You are invited to take part in a community based research project that is focused on communication in families with aging members. The goal of this project is to better understand family communication during the aging process and develop programs for families in the greater Mankato area. You are a potential participant because you are an older adult (greater than 60 years of age), the spouse or partner of an older adult, an adult child of an older adult, a health care provider serving families with an older adult member, or are a professional who serves the older adult population in the greater Mankato area.

Purpose

The purpose of the research is to describe what families perceive as the most important conversations to have when one or more of their members are aging, what makes it easier and harder to have those conversations, and what programs may help families have those discussions.

Procedures

If you agree to be in this research, and sign this consent form, we ask that you fill out a demographic survey and participate in an individual or group interview. This will take about 60-90 minutes of your time.

Risks and Benefits

There are no direct benefits to the participants of this study. It is possible that participation may help participants identify communication needs within their family and/or with health care providers to ease distress in families. Participation will benefit others by enhancing programs for families with aging members in the greater Mankato area. You will be asked to answer questions on your age, gender, race, marital status, educational attainment and annual household income. Some of the questions may be personal, but the information will not be shared with anyone else. You may refuse to answer any questions on the demographic form and the interview. We will not share with anyone details you tell us. In spite of these protections, loss of privacy is a potential risk because we cannot guarantee that group participants will not reveal each other's contributions to the group discussion once it has ended. Focus groups include discussions of personal opinions and extra measures will be taken to protect each participant's privacy. The risk level of this research is considered to be less than minimal.

Confidentiality

The researchers will begin and end the focus group by asking the participants to agree to the importance of keeping information and identities of group participants confidential. The records of this study will be kept private. Anything you discuss will remain confidential. In any sort of report of the study, we will not include any information that will make it possible to identify you. All written materials, audio recordings and consent forms will be stored in the Minnesota State University office of the principal investigator which is locked when it is unoccupied.

Voluntary nature of study

Your decision whether or not to participate in this research project will not affect your current or future relations with Minnesota State University, Mankato, your health care facilities, or the people helping with this study. You are under no obligation to participate in this study. You are free to withdraw your consent to participate at any time.

Contact

The principal researchers conducting this study are Dr. Diane Witt, Dr. Sandra Eggenberger, Dr. Don Ebel, and Dr. Ernest Lampe. You may contact the researchers at the University by calling (507) 389-6022. If you have any questions or concerns regarding the treatment of human subjects, contact: MSU IRB Administrator Minnesota State University, Mankato, Institutional Review Board, 115 Alumni Foundation, (507) 389-2321.

I have read the above information and understand that this survey is voluntary and I may stop at any time. I consent to participate in the study.

 Signature of participant

 Date

 Signature of researchers

 Date

- I agree to the audiotaping of the session.
- Participant received a copy.

MSU IRB LOG #**Date of MSU IRB approval**

APPENDIX C

Transcriptionist Confidentiality Agreement

Transcriptionist Confidentiality Agreement

I, _____ am providing transcription services for the Critical Conversations and Caregiving in Aging Families research project. I understand that what I hear when transcribing the interviews is confidential information and will not share it with anyone other than the investigators involved with the project. I fully understand the confidential nature of this research project data. I will keep the digital audio files and transcriptions on a password protected computer and will delete these files from my email account and computer when directed to do so by the project investigator/s.

Printed Name

Signature

Date

APPENDIX D

Demographic Questionnaires

Health Care Professionals and Adult Children Participants

Gender: Male ___ Female ___ Age: _____

Race:

- ___ White
 ___ Hispanic or Latino
 ___ African American
 ___ American Indian or Alaska Native
 ___ Asian
 ___ Native Hawaiian or Other Pacific Islander
 ___ Multiracial
 ___ Other

Marital status: Married ___ Divorced ___ Single ___ Never Married ___ Widowed ___

Do you have parents age 60 or above? Yes/No Their ages: _____

What city/state do your parents live in? _____

Do you have any children? Yes/No Their ages: _____

What city/state do your children live in? _____

Religion: _____

Highest level of education:

- ___ Less than High School Diploma
 ___ High School Diploma/GED
 ___ Trade School Certificate
 ___ Associate Degree
 ___ Bachelor's Degree
 ___ Graduate Degree

Where were you born? City/State _____

How long have you lived in the Mankato area? _____

Occupation: _____

Annual income

- ___ Under \$10,000/year
 ___ \$10,000-20,000/year
 ___ \$20,000-30,000/year
 ___ \$30,000-40,000/year
 ___ \$40,000-50,000/year
 ___ 50,000 or more/year

Demographic Questionnaire Older Adults and their Spouse/Partner Participants

Gender: Male ___ Female ___ Age: _____

Race:

- ___ White
 ___ Hispanic or Latino
 ___ African American
 ___ American Indian or Alaska Native
 ___ Asian
 ___ Native Hawaiian or Other Pacific Islander
 ___ Multiracial
 ___ Other

Marital status: Married ___ Divorced ___ Single ___ Never Married ___ Widowed ___

Do you have any children? Yes/No Their ages: _____

What city/state do your children live in? _____

Religion: _____

Highest level of education:

- ___ Less than High School Diploma
 ___ High School Diploma/GED
 ___ Trade School Certificate
 ___ Associate Degree
 ___ Bachelor's Degree
 ___ Graduate Degree

Where were you born? City/State _____

How long have you lived in the Mankato area? _____

Occupation: _____

Annual income

- ___ Under \$10,000/year
 ___ \$10,000-20,000/year
 ___ \$20,000-30,000/year
 ___ \$30,000-40,000/year
 ___ \$40,000-50,000/year
 ___ 50,000 or more/year

Do you have a Medicare insurance supplement? Yes ___ No ___ Not Applicable ___

APPENDIX E

Semi-Structured Interview Guide

Focus Group Semi-Structured Interview Guide

Please tell us about you and your family. For example who do you live with, how many people are in your family, where do you fit in in the family, what communities do your family members live in?

As (you, your spouse/partner, your parents) have aged how has life change? For example, how have your family roles and responsibilities changed? Please describe the impact that aging of a family members has had on your family communication?

Please describe the way you talk.... communicate or discuss challenges in your family? Difficult family situations? Or aging process in your family?....

What are the guidelines? Are there spoken or unspoken beliefs or perspectives about what you can talk about (in your family/with your patients/ with your healthcare provider)?

What topics do you believe are important to talk to (your patients, your spouse/partner, your parents, your adult children) about as (you/they) have aged?

Of those which topics have you talked to them about?

Can you tell us a about what prompted those discussions? Can you give examples of the discussions that went well and did not? When you had those discussions what went well?

What didn't?

What topics do your family view as difficult to discuss or off limits (in your family/with your patients/ with your healthcare provider)?

What happens if you bring up a topic that is "off limits"?

What topics would you like to talk about, but haven't, with (your patients, your spouse/partner, your parents, your adult children) about as (you/they) have aged?

What seems to have stopped you from having those discussions?

How can health care providers help (you/families) talk about these topics?

What have been your experiences with contacting a professional for help for (yourself, parent, spouse/partner)?

What do you feel most confident/insecure about in taking on the role of a caregiver?

Tell us what the communication between you, your spouse/parent and their primary care provider has been like. What did you find helpful in those conversations? What was not helpful?

Tell us about the contributions you/family members were able to make to the plan of care...

What are things that you think are important for families to be able to contribute or have opportunity to question in the plan of care

What programs or resources would you like to see to help your family? Parents? Adult children? Work with family caregivers?

Of all the things we have talked about today what you think was the most important?

What else you would like to share with us today?

Community Leaders/Gatekeepers Semi-Structured Interview Guide

Please tell us about your organization.

What services do you provide for older adults and their families?

How do people access your services?

How do people pay for your services?

What other programs for aging families are you aware of in the greater Mankato area?

What programs or services do you think are needed in the greater Mankato area for aging families?

What have you noticed regarding family communication in aging families?

Please tell us about your organizations involvement and experiences with family caregiving.

What do you think is the most important thing for us to take away from our conversation today?

What else you would like to share with us today?

APPENDIX F

Focus Group Advertisement

Support for Aging Families

You are invited to participate in a Community Based Research Project focused on family conversations and caregiving in aging families. We are interested in multiple perspectives within the family, including those of older adults, spouses/partners, adult children, and others who support them. The purpose of this project is to develop resources for families. If you are interested in participating in a group interview to share your perspective and experiences please call the MSU, School of Nursing office between x and y (times) on (dates) at 507-389-6022.

Sponsored by the Glen Taylor Institute
for Family and Society
(logo here)

APPENDIX G
Amendment to Recruitment

**COLLEGE OF GRADUATE STUDIES AND RESEARCH
INSTITUTIONAL REVIEW BOARD FOR THE PROTECTION OF HUMAN
SUBJECTS--MINOR MODIFICATION FORM**

IRB Log #: 290057-2

Date: 1/9/12

Title of Proposal: Critical Conversations and Caregiving in Aging Families

Principal Investigator: Diane Witt

Original Approval Date: 12/5/11

Expiration Date: 12/5/12

1. Please explain modifications to a research proposal: The ad we placed in the Mankato Free Press is not proving to be a successful way to recruit participants for this study. We would like to amend our participant recruitment procedure to include the following:

In addition to the approved recruitment methods the principle investigators and community gatekeepers will individually invite people who they know personally and/or professionally that meet inclusion criteria to participate in the study.

2. Is the consent/assent form as approved by the IRB still being used?

Yes No

If **no**, please download a new consent form.

3. Have problems arisen regarding the involvement and safety of subjects in this research project?

Yes No

If **yes**, were they reported to the IRB?

Yes No

If they were not previously reported to the IRB, provide a description of any problems which have arisen.

4. Has there been any psychological or physical injury to any subject?

Yes No

If **yes**, provide explanation:

5. Where are the signed consent forms presently being held?

Building: Wissink Hall Room #: 324 (Diane Witt's Office)

Person maintaining the forms: Diane Witt

By electronically signing the IRBNet proposal, I agree to the following:

I certify that the research has been and will continue to be conducted in accordance with The Policies and Procedures Governing the Participation of Human Subjects in Research at Minnesota State University, Mankato.

A member of the Minnesota State Colleges & Universities System. MSU is an Affirmative Action/Equal Opportunity university. This document is available in alternative format to individuals with disabilities by calling the College of Graduate Studies and Research at 507-389-2321 (V), 800- 627-3529 or 711 (MRS/TTY).