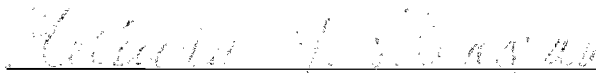FAMILY COMMUNICATION PATTERNS, RESILIENCE AND SOCIAL SUPPORT
AMONG HOSPICE FAMILY CAREGIVERS

by

Paula K. Baldwin
A Dissertation
Submitted to the
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of
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in Partial Fulfillment of
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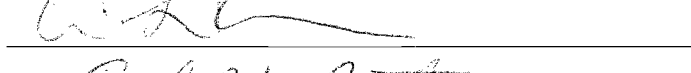of
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_____   Director

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_____   Department Chairperson

_____   Program Director

_____   Dean, College of Humanities
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                                       George Mason University
                                       Fairfax, VA

Family Communication Patterns, Resilience and Social Support
among Hospice Family Caregivers

A Dissertation submitted in partial fulfillment of the requirements for the degree of
Doctor of Philosophy at George Mason University

By

Paula K. Baldwin
Master of Arts
Texas State University-San Marcos, 2009
Bachelor of Arts
University of Texas at San Antonio, 2007

Director: Melinda M. Villagran, Professor
Department of Communication

Spring Semester 2012
George Mason University
Fairfax, VA

DEDICATION

Dedicated to my father, William H. Baldwin, who unfailingly supported me through this process despite only having earned a GED; my son, Christopher M. Tanis, who never questioned my desire to keep learning; my advisor, Dr. Melinda M. Villagran, who saw a thirst in me for knowledge and first set my feet upon this path all the while teaching me what it meant to be a rigorous scholar. And to the many friends and mentors, Dr. Elaine Wittenberg-Lyles, Dr. Debra Parker Oliver, Dr. Maureen Keeley, Dr. Joy Goldsmith, Dr. Sandra Ragan, and Dr. William J. McAuley, to name a few, who throughout the years saw something in me when I saw nothing in myself, I gratefully acknowledge your generous contributions.

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ABSTRACT

FAMILY COMMUNICATION PATTERNS, RESILIENCE AND SOCIAL SUPPORT AMONG HOSPICE FAMILY CAREGIVERS

Paula K. Baldwin, Ph.D.

George Mason University, 2012

Dissertation Director: Dr. Melinda M. Villagran

Improvements in modern medicine have changed the trajectory of terminal illnesses. That, along with an already burdened health care system, has resulted in an exponential growth in the number of family caregivers now providing care for their dying loved ones. Family communication is a significant factor in all hospice interactions. Research has shown that families have specific communication patterns that remain consistent through the trajectory of a terminal disease (Syren, Saveman, & Benzein, 2006). Family communication patterns may affect the types of social support available to the family members and the potential for resilience among family caregivers following the death of their loved one.

This study used in-depth, qualitative interviews with 15 hospice family caregivers to describe their family communication pattern styles, informal social support, perceptions of their personal resilience and usage of formal social support as provided

through hospice services. Data analysis based on a typology of family communication patterns (Wittenberg-Lyles, Goldsmith, Demiris, Parker Oliver, & Stone, 2012, in press) revealed evidence of three distinct patterns of family communication among caregivers in this study. The *Partner* type, when family communication was open and frequent, was the most prevalent communication pattern described by caregivers. The *Manager* type, where the family communication was open, but dominated by a single person, was the second most common communication pattern. Only one family caregiver self-identified as the *Loner* family communication type, where the caregiver has little to no communication with the family and was unsupported in the caregiver burden by other family members. None of the family caregivers identified as *Carrier* family communication type, which was a low support, low communication family communication pattern.

Only two caregivers used the hospice's bereavement counseling, although several caregivers utilized other hospice support services such as volunteer visitation. When asked about their resilience, caregivers rated themselves anywhere from a moderate resilience to a medium high resilience. Caregivers' resilience perceptions proved to be consistent with their narratives about their caregiving experience.

CHAPTER 1: INTRODUCTION

Improvements in medical science and health care have gradually changed the

nature of dying. Death is no longer likely to be the sudden result of infection or injury,

but is now more likely to occur slowly, in old age, and at the end of a period of chronic

illness. An estimated 65.7 million people in the U.S. have served as unpaid family

caregivers to an adult or a child (National Alliance for Caregiving, 2010). In 2009, 31.2%

of U.S. households reported that within the last twelve months, at least one person had

served as an unpaid family caregiver (National Alliance for Caregiver, in collaboration

with AARP, 2009). Research found that widespread reliance on informal caregivers in

the U.S. is so great that the cumulative amount of patient services delivered by family

members is more than the federal government provided in all possible settings combined

(National Alliance for Caregiving and Evercare, 2009).

Informal caregivers deliver support for patients suffering from a variety of

conditions, such as advanced age, dementia, cancer or any number of chronic or terminal

diseases. Informal caregivers play a particularly critical role in hospice care because

among millions of patients who accessed hospice services each year, almost 70% of

patients received care in their home from an informal caregiver (National Hospice and

Palliative Care Organization, 2010). The existing relationship between two people is

transformed as an adult child, spouse, or other relative becomes an integral part of a

patients' healthcare team. Existing patterns of communication among family members may lead to incongruence between existing patterns and new responsibilities for caregivers as their roles transform.

Hospice care is provided to patients facing a life-limiting illness. Hospice emphasizes quality of life rather than any curative practices, and utilizes a collaborative care approach. An interdisciplinary team (IDT) of health care professionals oversees medical care, pain and symptom management, and emotional and spiritual support for the patient, while family or friends act as informal caregivers for the patient. The majority of hospice care is provided in the patient's home (Emanuel, Fairclough, Slutman, & Emanuel, 2000).

Since the beginning of the modern hospice movement, support services to assist family caregivers were limited. In fact, most family caregivers receive little or no training to take on the responsibilities of caring for a dying patient (Kazanowski, 2005). The roles and duties of caregivers vary greatly, so there was a lack of evidence-based strategies to assess and respond to various family caregivers' needs (Hudson, Remedios, & Thomas, 2010). Even though the hospice team develops a formal patient treatment plan, on a day-to-day basis, healthcare professionals function more as consultants to caregivers who deliver in-home patient care (Whitten, Doolittle, & Hellmich, 2001). Hospice personnel are always on call, but it is the caregiver who provides around-the-clock custodial and nursing support for the patient (Whitten, Doolittle, & Hellmich, 2001). In a national survey, caregivers were asked what kind of help or information they needed to improve the quality of their lives (National Alliance for Caregiving and AARP, 2009). More than

one in three caregivers said they needed help to find more personal time in their

schedules. Three in ten caregivers reported trouble with balancing work and family

responsibilities as a caregiver, and managing emotional and physical stress was another

area that help was needed. Talking to doctors (22%) and getting help in making end of

life decisions (20%) were also requested (National Alliance for Caregiving and AARP,

2009). Half of those surveyed (51%) said caregiving responsibilities resulted in less time

for family and friends. A substantial number (44%) also reported giving up vacations,

hobbies and social activities (National Alliance for Caregiving with AARP and MetLife,

2004). In a study examining the impact of uncertainty on caregivers, perceived

uncertainty regarding the course of the illness was found to be significant in predicting

the caretaker's future distress (Sanders-Dewey, Mullins, & Chaney, 2001).

Caregivers of hospice patients reported a high degree of uncertainty, particularly

as it related to the responsibilities of handling pain management at home (Keefe et al.,

2003; Wittenberg-Lyles, Parker Oliver, Demiris, Petty, & Day, 2008). Caregiver pain

management responsibilities ranged from assessing patient pain and administering

medications, to monitoring symptoms and medication side effects, and to being the

primary communicator between the patient and the healthcare professionals (Keefe et al.,

2003). Any of these responsibilities can be overwhelming, particularly the ones related

to pain management, and it was not unusual for caregivers to be confused about

medications, from administering the various types of medication, indications and time for

administration to the desired outcome for the patient (Kazanowski, 2005). Caregivers

experienced acute distress at being unable to handle pain management especially near

their loved one's end of life when the patient's pain had intensified. The resulting stress of decision-making adversely impacted the caregiver's quality of life (Hull, 1992; Wittenberg-Lyles et al., 2008).

Perhaps one of the most demanding aspects of the caregiver role is the lack of support by their health professionals (Aoun & Kristjanson, 2005; Lowey, 2008). Caregivers are often unaware of the prognosis of the patient, how hospice functions and what types of challenges they may face daily while acting as a caregiver (Mangan, Taylor, Yabroff, Fleming, & Ingham, 2003). Hospice staff members often coached the family caregiver on the patient's care, provided respite care for the caregiver, and offered bereavement counseling (National Hospice and Palliative Care Organization, 2010) while hospice volunteers were more likely to provide emotional support (Egbert & Parrott, 2003). Although a variety of services are available, family caregivers still need more information, better communication, and increased services and support from community services (Aoun & Kristjanson, 2005; Evans, Cutson, Steinhauser, & Tulsky, 2006; Hwang et al., 2003; Wittenberg-Lyles et al., 2008).

Prior to a patient's admission into hospice care, most often healthcare professionals initiated and directed family discussions about hospice, but family communication remains an important factor in the hospice approach to care (Kenen, Arden-Jones, & Eeles, 2004). Hospice encourages communication about death between terminally ill patients and families (Bachner, O'Rourke, Davidov, & Carmel, 2009) to address medical, spiritual, psychosocial (Baker, 2005), and unresolved family issues (Keeley, 2004, 2007). Research reported families have particular communication styles,

and these family patterns of interaction are maintained through the trajectory of the terminal disease (Syren, Saveman, & Benzein, 2006). If the family practices open communication prior to their loved one being diagnosed with a terminal disease, that pattern will be maintained through the trajectory of the patient's illness and vice versa (Syren, Saveman, & Benzein, 2006) even though prior research indicates family members can view the communication norms within their family differently (Austin, 1993; Fitzpatrick & Ritchie, 1994). Therefore, due to the differences in family communication patterns, the ability of families to have open conversations about dying and death varies widely. In fact, although most families of hospice patients find it difficult to talk about death and dying, some families go to the extreme and do not tell the patient that he or she is terminally ill, hide hospice care, and request that the patient's healthcare providers do not mention hospice or discuss dying and death in front of the patient (Planalp & Trost, 2008). Research has shown that communication within families about the impending death and the dying process of a family member is difficult and therefore, is influenced by existing family communication practices (Wittenberg-Lyles et al., 2012, in press).

Family Communicative Influence

Family members' communication patterns have been studied in the context of two general dimensions of communication: socio-orientation and concept-orientation. Each of these approaches to family interaction could create a differing framework for caregiver communication with a loved one. In the socio-oriented family structure, the importance of pleasant family social relationships is emphasized, and conflict is minimized by the expected acceptance of the family values. In the concept-oriented family structure,

conceptual matters are emphasized, and individual family member's ideas are welcomed (Chaffee, McLeod, & Atkin, 1971; Ritchie, 1991; Ritchie & Fitzgerald, 1990). The intersections of these two dimensions produce four types of family communication patterns: *laissez-faire*, *protective*, *pluralistic*, and *consensual.*

Laissez-faire family communication patterns occur with low levels of socio- and concept-orientation and consequently encourage little hierarchal communication, such as between an adult and a child. This family communication style typically demonstrates low levels of interaction between the family members and a sense of emotional detachment from the communication. *Protective* family communication patterns stress obedience and are seen when socio-orientation is high and concept-orientation is low. *Pluralistic* family communication patterns encourage open discussion and are seen when there is high concept-orientation and low socio-orientation whereas *consensual* family communication patterns encourage discussion that does not threaten or disturb the internal harmony of the family.

These relational family communication patterns exist within the dyad prior to the diagnosis of a terminal illness of one-half of the dyad. These established communication patterns may affect whether or not the caregiver will seek social support and/or counseling, have a satisfactory relationship with the patient's provider, and be able to come to terms with the loss of their loved one, or feel able to cope with the demands of the patient's illness.

To date, the literature includes a limited number of empirical studies examining the relationship among family communication patterns, social support, and resilience for

hospice family caregivers. The goal of this study was to more fully describe the four family communication pattern types of hospice family caregivers communicative experience through a reflexive examination their social support networks, use of hospice social support services and resilience.

Chapter 1 provides a general overview of the study. This chapter discusses the background for the study and the purpose of the study. Chapter 2 contains the literature review and the resulting research questions. Chapter 3 describes the research population and sample along with the design of the study, instrumentation used, the data collection procedures and treatment of the data. Chapter 4 contains the findings of the study. In Chapter 5, the findings of the study are discussed. Chapter 6 discusses the limitations of the study, and Chapter 7 contains the conclusions of the study with recommendations for future research on this topic.

CHAPTER 2: LITERATURE REVIEW

This literature review begins with an examination of family caregivers, their

population characteristics, roles and responsibilities, caregiving burden, economic

impact, and physical impact. The review continues with a brief examination of family

communication patterns theory with a discussion of the conversation orientations of

consensual and pluralistic communication styles, and conformity orientations of

protective and laissez-fair communication styles. A discussion of the development of

family communication pattern typology follows. Next, there is a brief discussion of the

importance of social support for family caregivers, and finally, resilience is discussed in

terms of family vulnerability.

Family Caregivers

Although all family caregivers are not hospice caregivers, the majority of hospice

caregivers are family caregivers. The pursuant discussion of family caregivers

recognizes that although family caregivers provide many different types of support for

their loved one, when the curative treatments cease and the patient enters hospice care,

the family caregiver then becomes the hospice family caregiver. This discussion does not

separate the different names on family caregivers' trajectories, and therefore the terms,

family caregivers, caregivers, and hospice family caregivers, are used interchangeably.

Caring for a loved one with a debilitating disease can be stressful (Nijboer et al., 1998; Northfield & Nebauer, 2010; Schachter, 1992). According to the American Academy of Family Physicians, depression was the most common health problem among family caregivers. One study revealed that anxiety was present in 17.5% of caregivers, compared to 10% of control subjects (Cochrane, Goering, & Rogers, 1997). Among those caring for a person with dementia, rates of depression are significantly higher (Fitting, Rabins, Lucas, & Eastham, 1986). In discussing family caregivers, it is important to examine family caregiver population characteristics, the roles and responsibilities of caregivers, and the family burden of caregivers, both economically and physically.

Family caregiver population profiles. Family caregivers tend to be female (66%) and the average age of a family caregiver is 48. One-third of these caregivers are caring for two or more people (34%) and caregiving is prevalent across all economic levels and ethnic groups. Fifty-nine percent of non-Hispanic Whites in the U.S. are or have been caregivers, as compared with 53% of African-Americans, and 51% of Hispanic adults (Opinion Research Corporation, 2005). Caregivers remain in their role for an average of 4.6 years, with three in ten having given care to their loved one for five years or more (31%). The typical recipient of care is approximately 61 years old and female (62%). Seven in ten caregivers care for someone 50 years of age or older, 14% provide care for an adult age 18 to 49, while 14% take care of a child under the age of 18 (Caregiving in the U.S., 2009). Generally, one person tends to provide the majority of informal care in family situations (National Alliance for Caregiving and AARP, 2009), and on average, caregivers spend 21 hours per week on caregiving, with almost one-fifth

of caregivers providing constant care of 40 or more hours a week (National Alliance for Caregiving with AARP and MetLife, 2004).

Roles and responsibilities. A patient's terminal diagnosis impacts the entire family system as well as the patient (Hubbard, Illingworth, Rowa-Dewar, Forbat, & Kearney, 2010) as hospices are increasingly reliant upon the assistance of family caregivers for patient care (Wilder, Parker Oliver, Demiris, & Washington, 2008). Family caregivers take active communication roles in many aspects of patient care: decisions on patient treatment, interaction with the patient's provider and interdisciplinary team, as well as managing finances, day-to-day medicine administration and patient hygienic needs (Wilder et al., 2008). The family caregiver plays a pivotal role in helping the patient navigate his or her care and often acts as the primary advocate for the patient (Fleming et al., 2006; Hubbard et al., 2010; Wilder et al., 2008) and as the patient's condition deteriorates, the scope of this role increases. The communication patterns practiced within the family system influence the caregiver's choices and determine to some extent the level of cooperation and collaboration with the patient's healthcare team (Kenen, Arden-Jones, & Eeles, 2004).

Family burden of hospice caregivers. Hospice caregivers are challenged not only in terms of the enormous shift in roles and responsibilities, but also they are greatly impacted by impaired economics and physical challenges to their own health. Often caregivers work outside the home and provide care for their loved one simultaneously. The conflict between the caregiver's work and his or her familial obligations creates an additional stressor for the caregiver. Caregivers, faced with the additional stress of the

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time and physical energy needed to provide the care for their loved one oftentimes find their own health compromised, and frequently results in premature aging for the caregiver (Center on Aging Society, 2005). First, I will take a closer look at the economic impact of caregiving and then I will examine the physical impact of caregiving.

Economic impact of caregiving. Family caregivers are the dominant providers (80%) of all long-term care services in the U.S. (National Family Caregivers Association, 2011). Many caregivers (59%) provide care for their loved one while being employed, either full- or part-time (National Alliance for Caregiving with AARP and MetLife, 2004). More than half of working caregivers (57%) have work disrupted due to their caregiving obligations causing them to arrive late to work, leave early or take additional time off during the day (National Alliance for Caregiving with AARP and MetLife, 2004).

For some adult caregivers, their ability to work has been impacted significantly. According to a major study by AARP and the National Alliance for Caregiving (2009), caregivers have been affected in all areas of their employment including taking a leave of absence (17%), shifting to part-time work (10%), quitting work entirely (6%), losing job benefits (5%), turning down a promotion (4%), or choosing early retirement (3%) (2004), thus contributing to caregiver stress.

Work disruptions can cost family caregivers a loss of as much as $659,000 in wages, pensions, and Social Security (National Family Caregivers Association, 2011). The average family caregiver for someone 50 years or older spent $5,531 on out of pocket caregiving expenses in 2007, more than 10% of the median income for a family

caregiver that year (AARP Public Policy Institute, 2011). Not only is the caregiver's income and financial security affected, but also through reduced productivity costs, American businesses lose between $11 billion and $29 billion a year. These costs are directly related to their employee's caregiving responsibilities which result in workplace disruptions, scheduled and unscheduled absences, leaves of absence, reduction from full- to part-time work, early retirements, and leaving the workforce entirely to care for a loved one (MetLife Mature Market Institute, 2011). Although the economic impact of caregiving is significant, there is also a significant health risk involved for the caregiver as well.

Physical impact of caregiving. Compared to people who are not caregivers, caregivers perceive their own health status to be at risk (Pinquart & Sörensen, 2003; Vitaliano, Zhang, & Scanlan, 2003). In fact, more than one in ten family caregivers reported that caregiving has caused deterioration in their physical health (Center on Aging Society, 2005**).** Twenty-three percent of family caregivers caring for loved ones for five years or more reported their health was fair or poor **(**National Alliance for Caregiving and AARP, 2009**)**. Family caregivers experiencing extreme stress have been shown to age prematurely. High stress levels can take as much as ten years off a family caregiver's life **(**Epel et al., 2004**)**. Among those providing care 40 or more hours a week, 46% of caregivers rated their physical strain very high (i.e. a 4 or 5 on a 5-point Likert scale) (National Alliance for Caregiving with AARP and MetLife, 2004). As many as 40% to 70% of family caregivers demonstrated clinically significant symptoms of depression, with approximately a quarter to half of these caregivers meeting the

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diagnostic criteria for major depression (Zarit, 2006). In fact, 20% of employed female

caregivers over 50 years old reported symptoms of depression compared to 8% of their

non-caregiving peers (National Alliance for Caregiving, 2010). When asked to rate their

emotional stress on a 5-point scale, 63% of caregivers put their stress at a 4 or 5 (National

Alliance for Caregiving with AARP and MetLife, 2004). Family caregivers providing

care 36 hours or more a week were more likely than non-caregivers to experience

symptoms of depression or anxiety. For spouses, the rate was six times higher; for those

caring for a parent, the rate was twice as high (National Family Caregivers Association,

2009). The Caregiver Health Effects Survey reported that older spouses experiencing

caregiver strain had a mortality risk that was 63% higher than the control subjects (Schulz

& Beach, 1999).

Nearly three quarters (72%) of family caregivers report a decrease in monitoring

their own healthcare by not going to the doctor as frequently as needed or by skipping

their own doctor appointments (55%). Sixty-three percent of caregivers had poorer eating

habits than non-caregivers and 58% indicated a decline in their exercise habits due to

caregiving responsibilities (National Alliance for Caregiving and Evercare, 2009).

Caregivers were affected in almost every major area of their life, and these effects can be

observed in the family communication patterns. In a recent study, the influence of family

communication patterns on caregivers' concerns related to family roles and

responsibilities during hospice care were examined using family communication patterns

theory (FCP) as a framework (Wittenberg-Lyles et al., 2012, in press). These family

communication patterns provided not only an important insight in the communication

styles of family caregivers, but also provided the groundwork for the family communication pattern typology developed by Wittenberg-Lyles et al. (2012, in press).

<center>**Theoretical Construct**</center>

Family Communication Patterns Theory

Family communication refers to the communication patterns created and maintained within the family system. Through these patterns, family members learn how to communicate with others, both within and without the family system. The examination of family communication as patterns has its roots in McLeod and Chaffee's (1972) theory of family communication that posited three propositions regarding family dynamics. First, the structures and functions of families create and sustain a shared reality among the members through two primary orientations, concept orientation and socio-orientation (McLeod & Chaffee, 1972). Second, concept orientation occurs as family members create shared meaning through ideas and experiences related to a concept or construct (McLeod & Chaffee, 1972). Finally, the socio-orientation is the outcome of parental guidance, feedback or influence about a shared concept (McLeod & Chaffee, 1972).

In 1990, Ritchie and Fitzpatrick proposed a refinement of the theory of family communication that sought to more accurately reflect and measure family interpersonal underlying dimensions of conversation and conformity interactions. McLeod and Chaffee's (1972) original notion of concept orientation was redefined by Ritchie and Fitzpatrick as conversation orientation, and the original socio-orientation was renamed conformity orientation (1990, 1994). The Revised Family Communication Patterns measure (RFCP) was developed by Ritchie and Fitzpatrick (1990) to provide a more

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reliable and valid measure of family communication theory based on the proposed changes.

The revised theory of family communication led to a growing body of research which supports the argument that an individual family member's communication style is predicated upon family communication environment (Barbato, Graham, & Perse, 2003; Koerner & Fitzpatrick, 2002a, 2004; Orrego & Rodriguez, 2001); therefore, these types of family communication patterns, determined by the dimensions of *conversation orientation* and *conformity orientation*, define the family communication interactions (Koerner & Fitzpatrick, 2002a, 2002b, 2004). Even though the two orientations are distinctly different, some researchers have demonstrated small or moderate negative correlations between the two. The resulting communication styles affect the amount and type of information that is shared outside the family (Koerner & Fitzpatrick, 1997, 2002b). Furthermore, the two orientations can interact with each other to affect various outcomes. For example, the conversation orientation in the family of origin exacerbates the effect conformity orientation has on conflict behaviors (Koerner & Fitzpatrick, 2002c). With the intersections of the two orientations, four family types of communication interaction emerge: *consensual*, *pluralistic*, *protective*, and *laissez-faire*.

Conversation orientation. The conversation orientation is defined as the extent to which family members' communication interactions are frequent and spontaneous, and during which the topics discussed or the length of time in discussion is unrestrained. The two styles of family interaction created from this orientation are *consensual* family communicators and *pluralistic* family communicators. Consensual and pluralistic family

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styles result from a higher conversation orientation and protective and laissez-faire family styles result from a higher conformity orientation.

Consensual families. Consensual families are high in both conformity and conversation orientation. This style of family interaction includes a dialectical tension between open communication exchanges and pressure to agree in order to support the family's existing hierarchal structure and values (Koerner & Fitzpartrick, 1997, 2002b).

Pluralistic families. Pluralistic families' styles of communication result from low conformity orientation and high conversation orientation. The family is characterized by open and unrestrained communication with the goals being the production of new, independent ideas and fostering communication competence within the family members (Koerner & Fitzpatrick 1997, 2002b).

Conformity orientation. The conformity orientation is the polar opposite of the conversation orientation because it reflects a strong adherence to a centrally defined family belief structure. These types of interactions focus on strict obedience to the parents and existing hierarchy in order to maintain harmonious relationships within the family (Koerner & Fitzpatrick 1997, 2002a, 2002b). This type of orientation is exemplified by *protective* family communicators and *laissez-faire* family communicators.

Protective families. Protective families are high in conformity orientation and low in conversation orientation. There is little value placed on original ideas or enhanced communication competence. In fact, the communication within this communication style serves to maintain obedience and preserve family norms (Koerner & Fitzpatrick, 1997, 2002b).

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Laissez-faire families. Laissez-faire families are low in conversation orientation as well as conformity orientation. There is little communication interaction between family members and neither communication nor the integrity of the family unity is valued (Koerner & Fitzpatrick, 1997, 2002b).

According to family communication patterns theory (FCP), family members have both implicit and explicit rules for communicating with each other, both in conformity and conversationality, as established by their unique relationship history (Fitzpatrick & Ritchie, 1994; Harris et al., 2009; Koerner & Fitzpatrick, 2006; McLeod & Chaffee, 1973; Ritchie & Fitzpatrick, 1990). These family communication rules determine appropriate discussion topics of family conversation as well as establish a family member hierarchy that dictates family conformity (Fitzpatrick & Ritchie, 1994; Harris et al., 2009; Koerner & Fitzpatrick, 2006; McLeod & Chaffee, 1973; Ritchie & Fitzpatrick, 1990). Family conversation orientation ranges from open, spontaneous interaction between family members (high) to restrictions on family topics and time dedicated to communicating with other family members (low) (Fitzpatrick, 2004). Likewise, family conformity orientation varies from families with matching beliefs and family values that prioritize family harmony (high) to families with less emphasis on obedience to parents/elders (low) (Koerner & Fitzpatrick, 2002c).

A family communication pattern is formed by the interaction of the family conversation and conformity rules. Families with a consensual family communication pattern have high adherence to family conformity and high family conversation. Families negotiate the tension between agreeing and preserving hierarchy within the family, yet

still are able to explore new ideas freely (Koerner & Fitzpatrick, 2002c). Families with a protective family communication pattern are low on family conversation and high on family conformity. In protective families, one parent dominates as a hierarchical figure that then determines and directs the flow of family communication (Koerner & Fitzpatrick, 2002c). Families with a pluralistic family communication pattern demonstrate high family conversation and low family conformity. With pluralistic families, the parents are not necessarily the hierarchical figures and the families' open discussions involve most or all of the family members. Participatory decision-making, including multi-generational input, is valued in pluralistic families (Koerner & Fitzpatrick, 2002c). Finally, families with a laissez-faire family communication pattern are low in both family conversation and family conformity, resulting in little interaction between family members and high emotional detachment. Using FCP as a framework, this study explores caregivers' family communication patterns through a family communication pattern typology, social support and resilience.

Family Communication Pattern Typology

Family communication patterns theory posits family members have unique implicit and explicit communication rules based upon relational history (Fitzpatrick & Ritchie, 1994; Harris et al., 2009; Koerner & Fitzpatrick, 2006; McLeod & Chaffee, 1973; Ritchie & Fitzpatrick, 1990). Not only do these conversational rules dictate safe, appropriate topics for family discussion (family conversation), but also they serve as the sense-making structure for the family member hierarchy affecting the degree of conformity within the family (Fitzpatrick & Ritchie, 1994; Harris et al., 2009; Koerner &

Fitzpatrick, 2006; McLeod & Chaffee, 1973; Ritchie & Fitzpatrick, 1990).

Family communication patterns can be identified by examining family communication practices such as supportive messages, blocked communication where family members refuse to communicate with one another or set certain topics as off-limits, self-censored speech and the use of third parties as family relationship mediators (Kenen, Arden-Jones, & Eeles, 2004).

A recent study provided support for the idea that family rule adherence dictates family conformity (Wittenberg-Lyles et al., 2012, in press). The higher status family member in a hierarchical family dictates rule adherence among its members, and in the context of a terminal illness, the patient and caregiver conform to the predetermined rules of interaction. Although family members adhere to the family rules, conformity of communication does not indicate there is family agreement regarding the rules of interaction (Wittenberg-Lyles et al., 2012, in press). Further examination of family caregiver communication patterns led to a typology of the caregivers' experience with four caregiver types: *Manager*, *Carrier*, *Partner*, and *Loner* (Wittenberg-Lyles et al., 2012, in press).

The Manager caregiver type is most often found within families who place a premium on high conformity in attitudes, values, and behavior, accompanied by a high degree of conversationality. Manager caregiver types operate in a hierarchal structure that is typically dominated by one person. The role of Manager can be undertaken by either the caregiver or the patient, and sometimes by the caregiver acting in accordance with the patient's exact wishes.

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The Carrier type originates in a high conformity family, but one that demonstrates a low degree of conversationality. In addition, the Carrier caregiver type is defined based on a lack of frequency in conversation, and a limited number of acceptable conversation topics (Wittenberg-Lyles et al., 2012, in press). The Partner caregiver is a member of a family that demonstrates low conformity and high conversationality, both in topics and frequency. The Loner caregiver is seen in families with low conformity and low conversationality. Loners have few social relationships from which to gain social support for their duties as caregivers, and therefore, are relatively unconstrained by existing communication rules and patterns. Figure 1, as adapted from Wittenberg-Lyles et al. (2012, in press), illustrates how the intersections of the two orientations vary from high to low and therefore, result in four different family communication types and their corresponding family caregiver types. Each of these caregiver types hinges on existing family conversation styles of interaction and conformity to existing norms based on familial norms, rules and hierarchy (Wittenberg-Lyles et al., 2012, in press).

High

Consensual
(high conversation/high
conformity)/Manager

Pluralistic
(high conversation/low
conformity)/Partner

Conversation

High ←————————————————————————→ Low

Conformity

Protective
(low conversation/high
conformity)/Carrier

Laissez-Faire
(low conversation/low
conformity)/Loner

Low
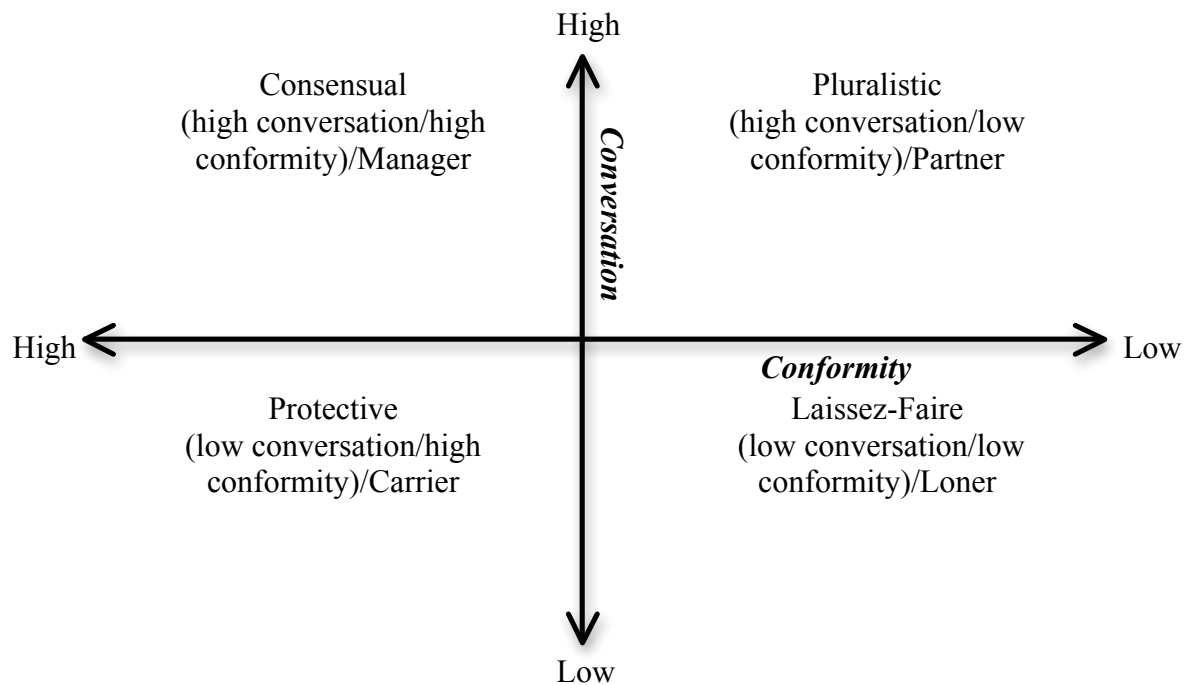
Figure 1. Overview of Family Communication Patterns/Family Caregiver
Types as adapted from Wittenberg-Lyles et al., (2012, in press).

Family communication patterns have a wider effect on the family than just

delineating topics neither discussed nor open for discussion. These communicative

practices may hinder or promote the family members' resiliency in negotiating the need

for patient's stay in hospice care based on the patient's impending death. The family

communication pattern typology could impact the formal and informal social support and

the caregiver's own personal resilience during his or her caregiving experience.

Social Support

Research conducted by the National Cancer Institute (2011) showed support for ameliorating the psychological and social impact on family caregivers by increasing social support, financial security, and work stability. Given the increasingly chronic nature of some terminal illnesses, caregivers found inconsistent levels of support in these areas over time (National Cancer Institute, 2011). Although caregivers may have a network of informal social support, over time this network can be challenged. Linking caregivers to formal hospice agency resources can help augment informal sources of social support (Ducharme, Lebel, Lachance, & Trudeau, 2006; Strang, Koop, & Peden, 2002). Acknowledging family dynamics and addressing family caregiver communication needs through increased social support opportunities and usage creates a healthier caregiver and a healthier caregiver is a necessary prerequisite for optimum care of the patient (Lai & Thomson, 2011; Rabow, Hauser, & Adams, 2004). Research also suggests that caregivers' resiliency could be enhanced by use of hospice agency social support services (National Institute on Aging, 2003). However, there is no literature examining the potential effect of family communications patterns on caregiver resilience.

Resilience

Resilience has had numerous meanings in prior research (Garmezy, 1994; Goldstein, 1997; Vaillant, 1993), but resilience generally refers to a pattern of functioning indicative of positive adaptation in the context of significant risk or adversity (Egeland, Carlson, & Sroufe, 1993; Kaplan, Turner, Norman, & Stillson, 1996; Ong, Bergeman, & Boker, 2009). In synthesizing five decades of resilience research, Luthar

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(2006) concluded that ''resilience rests, fundamentally, on relationships'' (p. 780). The

question of how social connectedness, defined as having quality social ties to others (Ryff

& Singer, 2000), was linked to biological and emotional resilience was particularly

pertinent for older adults, given the stability and centrality of interpersonal relationships

in late life (Carstensen, 1992; Lang & Carstensen, 1994).

Although much of the existing literature defines resilience as a psychological trait

based on individual cognition, a few studies advanced the argument that family

researchers create the schemas that provide the propensity for the resilience of the

individual (Caplan, 1982). Hawley and DeHaan (1996) described families in two

contexts. In the first context, the family is a risk factor detracting from resilience of its

members. In the second context, the family is a protective factor boosting the resilience

of its members. These two contexts affect the degree to which the family is vulnerable to

outside stressors. In this case, family vulnerability refers to "the interpersonal and

organizational condition of the family system" (McCubbin & McCubbin, 1996, p. 17)

and is determined by: (1) "The accumulation, or pileup, of demands on or within the

family unit, such as financial debts, poor health status of relatives, and changes in a

parent's work role or work environment, and (2) the normative trials and tribulations

associated with the family's particular life-cycle stage with all of its demands and

changes" (McCubbin & McCubbin, 1993, p. 28). Vulnerability, therefore, indicates how

vulnerable the family is to a particular stressor (Van Breda, 2001) as in the case of a

family caregiver dealing with the diagnosis, treatment, and death of one of the family

members.

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Research supports a wide variety of contextual and situational factors that could contribute to resilience (Bonanno & Mancini, 2008), including the type of loss and the person's environment. In bereavement, several variables have been identified that have a strong association with resiliency over the chronic or terminal illness trajectory (Mancini & Bonanno, 2009), including self-enhancing biases, attachment style, repressive coping, a priori beliefs, identity continuity and complexity, and positive emotions (Bonanno, Field, Kovacevic, & Kaltman, 2002; Fraley & Bonanno, 2004; Keltner & Bonanno, 1997). In context, these factors may interact with one another and with environmental factors in complex ways that we are only beginning to understand. Existing research findings suggest that the caregiver's perception of his or her own resilience or the ability to recover may have direct effect on health outcomes (Windle, Bennett, & Noyes, 2011). There is a dearth of studies examining hospice caregiver communication and resilience, and the growing prevalence and importance of this topic necessitates further scholarly attention.

Rationale

Communication scholarship in the end of life area became active beginning in the late 90s. A review of end of life studies from a wide range of disciplines, dating from 1990 to 2008 examined the theoretical qualitative perspectives by using the major healthcare and social science electronic databases (ERIC, CINAHL, MEDLINE, PsycARTICLES, PsycEXTRA, PsycINFO and the Psychology and Behavioral Science Collection). Four hundred articles were found using the search terms from three different categories: "(1) hospice, palliative care, end-of-life, death, dying, terminally ill or life

threatening; (2) qualitative research and (3) theory, theoretical framework or conceptual

framework (Wu & Volker, 2009, p. 2722). However, after the authors'

operationalization of theory and research was applied: being a qualitative study with a

theoretical application, a qualitative study designed to generate a new theory, and must

focus on some facet of end of life care), only 22 articles matched the authors' criteria

(Wu & Volker, 2009). Although it may appear there is substantial research occurring in

this area, the majority of it does not appear to theoretically-driven, and may be considered

less rigorous.

Most research has been conducted in areas of an organizational nature as in team

communication (Wittenberg-Lyles, Oliver, Demiris, & Baldwin, 2010; Wittenberg-Lyles,

Parker Oliver, Demiris, & Baldwin, 2009; Wittenberg-Lyles, Parker Oliver, Demiris,

Baldwin, & Regehr, 2008), or structural as in e-hospice (Kuziemsky, Jahnke, & Lau,

2006), or telehospice delivery (Demiris, Oliver, & Courtney, 2006; Whitten, Doolittle, &

Hellmich, 2001). Patient-centered inquiry has received a good amount of research

(Hickman, 2002; Keeley, 2004, 2007; Ragan, Wittenberg, & Hall, 2003) as well patient-

provider interaction research (Eggly et al., 2009; Sorensen & Iedema, 2007). End of life

research has been conducted in these areas, but a clear research gap remains in the area of

communication challenges for informal family caregivers.

Research has demonstrated that family caregivers experience extreme amounts of

stress; however, caregivers do not have consistent methods of coping with this stress and

stress has been shown to affect resilience (Bonanno & Mancini, 2008). When a

relationship is interrupted by a terminal illness, family caregivers struggle to meet the

needs of their relationships, their own personal needs, and their loved one's increasingly complex medical needs. The toll of caregiving after the death of a loved one makes resilience difficult to achieve, especially when there is lack of social support during the process of bereavement. The larger impact of family communication patterns of interactions between caregivers and hospice patients has not been examined as a possible contributor to the bereaved caregivers post-death experience. Research on hospice family caregivers is rooted in a larger body of end of life research.

This study used qualitative methods to explore the caregiver communication styles, their social support seeking behaviors, and resiliency. First, the caregivers were asked to identify their family communication style through four descriptions based on Wittenberg-Lyles et al.,'s (2012, in press) family communication pattern typology. This self-identification was further supported in narrative interviews with participants, undertaken to further understand how differences in caregiver communication styles shaped decisions regarding participation and use of formal hospice social support, informal social support networks, and perceived resilience. This exploratory examination of the family relational communication patterns, social support and resilience may help healthcare professionals identify caregivers burden and services related to existing communication patterns and needs. Questions guiding this investigation include:

RQ 1: How does caregivers' communication with other family members differ based on family communication pattern types?

RQ 2: How does caregivers' use of formal social support differ based on family communication pattern types?

RQ3: How does resilience differ across the family communication pattern types?

CHAPTER 3: METHOD

This study explored informal caregivers' resiliency and use of formal and informal social support based on their family communication pattern type. Although quantitative methodology is often used in some areas of the health communication discipline, such as health campaigns, in an area such as end of life where there is, of necessity, a reduced distance from the participant and a high amount of emotional labor, qualitative methodology is more prevalent and appropriate to the nature of this investigation.

Research Design

Qualitative methodology is a strongly preferred method among end of life researchers for conducting research in a sensitive population such as hospice family caregivers (Wohleber, McKitrick, & Davis, 2011). Qualitative methodology, whether interviews, as with this study, or participant observation, questionnaires, focus groups or case studies, allow the participants to guide the discussion about topics important to them (Kendall et al., 2007).

Using a qualitative approach in this study is an attempt to take the rich, thick data from participants' experiences, as caregivers for their dying loved one to describe each family communication pattern type's experiences of social support and resilience through

this trying time. Determining the differences and common characteristics for hospice

caregivers could help in targeting at-risk caregivers. Ultimately, further exploration of

the characteristics of these family communication caregiver types could lead to the

creation of communication interventions to assist end of life healthcare providers in

identifying at-risk family caregivers.

Qualitative research is based in the lived experiences of the participants and

requires the researcher to set personal experiences and biases aside in order to understand

the phenomenon on a deeper level (Merleau-Ponty, 1956). This bias/experience

reduction on the part of the researcher, called bracketing, serves two purposes: first, to

reduce any personal bias on the part of the researcher and second, to create a more open,

fertile and receptive environment on the part of the researcher (Colaizzi, 1978; Creswell,

1998; Streubert & Carpenter, 1999). As the researcher in the study, personally, I have

experienced little loss in my life. For the most part, I have only experienced grief

vicariously through my research fieldwork during my Master's program by interviewing

children ages 6 to 18 that were dealing with their grief following the loss of a loved one.

Participants

All participants were self-identified informal caregivers for patient using hospice

services and over the age of 18. The majority of the participant population was Caucasian

(93%), with only one African-American participant. The majority of the caregivers were

female and the average age of the caregivers was 60. Over 50% of the participants had at

least a university degree. Almost half of the participants were adult children taking care

of a dying parent and were employed full-time. See Table 1 for a further breakdown of

the participants' population characteristics.

Table 1

Characteristics of Hospice Family Caregiver Participants   n=15

Racial/Ethnicity	
Caucasian	14 (93%)
African-American	1 (7%)
Sex	
Female	13 (87%)
Male	2 (13%)
Education	
Less than High School/High School	4 (26%)
Some College	3 (20%)
Undergraduate/Graduate Degree	8 (53%)*
Employment Status	
Unemployed	2 (13%)
Part-Time Employment	1 (7%)
Full Time Employment	7 (47%)
Retired	5 (33%)*
Relationship to Patient	
Spouse/Partner	4 (26%)
Adult Child	7 (47%)
Sibling	1 (7%)
Other	3 (20%)*
Age (Mean = 60)	
40-50	3 (20%)
51-60	6 (40%)
61-70	2 (13%)
71-80	3 (20%)
81+	1 (7%)
Residence	
Resides with Patient	7 (47%)
Does not reside with Patient	8 (53%)

* Note: Total > than or < than 100% due to rounding.

Settings

Although four hospices agreed to participate in this study and received all the paperwork and guides for recruitment, only one of the hospices recruited any participants. Although the other three hospices were eager to participate, the fourth hospice is the only hospice with a staff member dedicated to recruitment on the premises of the hospice. Therefore, the hospice located in the Midwest, was the source of all the participants in this study. The hospice has served the Midwestern urban area since 1994. Part of a larger national network of hospices, this hospice offers a full range of standard hospice services for the patient, friends and families with complete interdisciplinary team care.

Composition of the Interview Guide

The interview questions were sourced from the family communication pattern typology (Wittenberg-Lyles, 2012, in press). Three questions were adapted from Lubbens Social Network scale on family social support and three questions were adapted from the Brief Resilience scale (Smith et al., 2008), which sought to help determine the caregiver's perception of their personal resilience.

The typology questions allowed the caregivers to self-identify into a unique family communication pattern category. The use of the social support and the resilience questions allowed the researcher to further understand how the family communication types informed their resilience and social support networks. In addition, the caregivers were asked open-ended questions about their experiences as caregivers, serving two purposes. First, the qualitative questions encouraged the participants to share the narratives of their experiences as caregivers. Second, questions were asked about the

usage of the hospice agency formal support services. Standard population characteristics had already been collected during the participant's enrollment in the larger study and therefore, no demographic profile questions were asked. Demographic information was captured through the larger study's database for the following areas: age, sex, race, education, work status (unemployed, part-time, full-time, retired), marital status, resided with the patient or not, relationship to the patient, and length of time caregiving.

Family communication patterns typology. The revised family communication patterns scale (Ritchie & Fitzpatrick, 1990) was used to establish a family communication pattern typology (Wittenberg-Lyles et al., 2012, in press). This typology was established through a separate study where four different types of family caregivers were identified (Wittenberg-Lyles et al., 2012, in press). Ten case studies were used to establish the typology, and the LSNS scores were examined to verify each caregiver's primary family social support network. A higher LSNS score represented larger family networks and a lower score (6 or less) represented less than two family members available for social support, making them socially isolated (Wittenberg-Lyles et al., 2012, in press). The second step involved determining the caregiver's quality of social life through the use of the Caregiver Quality of Life Index Revised (CQLI-R) where the lower scores reflected a lower quality of social life. These two scores (LSNS and CLQI-R) were juxtaposed and enabled the researchers to gauge the strength of the family networks in terms of number and frequency of contact and quality of interaction (Wittenberg-Lyles et al., 2012, in press).

The typology descriptions of each family communication style were used as a guideline in developing the single sentence description of each family communication pattern type. Two of the original typology authors (EWL and JG) reviewed the single sentence descriptions for accuracy. The participants self-selected their own family communication pattern based on the brief description of each of the family communication pattern types.

Lubben social network scale family subscale. Because this study was based on the family as a central communication source, the Lubben Social Network Scale's (LSNS) family subscale (three questions) was adapted (Lubben & Gironda, 2000). The caregivers were asked how many members of their family support networks were available to them with the following questions:

How many relatives do you see or hear from at least once a month?

How many relatives do you feel at ease with that you can talk about private matters?

How many relatives do you feel close to such that you could call on them for help? (Adapted from LSNS, 2000)

The participants' answers were noted. If the participant scored himself or herself high in informal social support, then the caregiver's narrative would reflect high levels of informal social support as well.

Brief resilience scale. The Brief Resilience Scale (BRS) (Smith et al., 2008) was used to expand the understanding of family caregiver resilience through an adaptation of the six questions designed to measure resiliency (Smith et al., 2008). Three of the

adapted BRS questions were omitted due to the confusion with the negatively worded questions on the part of the participants. Dropping these questions was done only after a literature review search was conducted and subsequently, support was found substantiating removal of those questions from the interview (Colosi, 2005; DiStefano & Moti, 2006; Kalton & Schuman, 1982; Patten, 1998). The participants were asked to comment on the following statements:

I tend to bounce back quickly after hard times.

It does not take me long to recover from a stressful event.

I usually come through difficult times with little trouble. (Adapted from BRS, 2008)

The participants' answers varied from very from low resilience to very high resilience.

Formal Social Support by Location

The hospice offered psychosocial, spiritual and bereavement counseling through private appointments or group therapy support groups with a staff of social workers, chaplains, and bereavement counselors. These services were consistent with the standard hospice practice of offering formal social support through counseling services, pastoral calls and visits, volunteer services, and interactions with social workers to all their patients and families.

The formal social support questions focused on the social support options available through the hospice: individual bereavement counseling, support group meetings, social work services, pastoral services, and volunteer visitation. These services were available to the caregivers before and after the death of their loved one. Using the

formal support services available to the caregiver through the hospice as a guide, caregivers were asked about their use of those services. For instance, the questions were "We are going to review a list of support services provided by your hospice for a moment. Let's begin with respite care. Have you taken advantage of this service? If yes, then ask what was that experience like for you? How was it helpful? If the answer is no, then ask why not? What kinds of barriers were there to you using this service?" (See Appendix A and Appendix A, Revised)

Data Collection

Data were collected from consenting hospice caregivers in an urban hospice program in the Midwestern U.S. Caregivers were receiving outpatient services from the participating hospice agencies. Caregivers enrolled in the study had to be 18 years or older and identified as a caregiver by the patient or family member who elected for hospice enrollment. This study was a part of a larger on-going research project assessing the benefits of family participation in hospice team meetings. The interview protocol for this study was added via an amendment to the current hospice study giving the researcher approval to interview participants and was approved by the supporting university's Institutional Review Board.

Caregivers were presented with the research opportunity upon admission to hospice by the hospice staff. Contact information for eligible caregivers interested in learning more about the study was sent to the research coordinator. Between days 5 and 18 of the hospice admission, the research coordinator visited the caregiver and obtained informed consent. Although through the protocol of the larger study, the caregivers

received two more visits by the staff researcher, only the final interview with the amended interview guide was analyzed.

Fourteen to 21 days after the patient had expired, the researcher called the family caregiver for his or her final interview in the study. The timing of the interviews was established by the protocol already in place for the larger research project. Research in the area of hospice caregivers has demonstrated that contacting family caregivers later than 21 days resulted in a substantially lower interview rate due to family caregivers becoming difficult to contact or locate. For example, twenty-seven family caregivers from the larger study were eligible to participate in this study, and attempts were made to contact all of them by telephone. Two of the eligible family caregivers declined to participate. Three family caregivers' telephone numbers had been disconnected, and seven family caregivers did not return the researcher's telephone call. The protocol previously established by the larger study allowed three phone calls to the caregiver; therefore, if the researcher was unable to make contact with the caregiver after three tries, no further attempts were made.

All interviews were conducted over the telephone at the caregiver's convenience and recorded for later transcription, and as the participants were part of the larger study, informed consent and participant characteristics had already been obtained at enrollment. The interviews pertaining to this study were conducted using a semi-structured focused format (Kvale, 1996; McCracken, 1988; Stewart & Cash, 2000) with several open-ended questions. After being asked questions about the verbal communication they had with their loved one who was dying, the participants were asked to select their family

communication pattern type, asked questions about their use of the hospice's formal support services, the three questions about their family social support, and finally, three questions about their perception of their own resilience.

The data were analyzed to describe the meaning of the participants' experiences through an examination of recurring patterns (Creswell, 1998; Strauss & Corbin, 1990). Using an inductive approach, grounded theory was utilized to identify primary themes in the interviews (Glaser & Strauss, 1967). Traditional grounded theory procedures were adapted to allow the researcher to consider emerging concepts within the framework of the family communication pattern typology proposed for hospice family caregivers by Wittenberg-Lyles et al., (2012, in press). Strauss and Corbin endorsed this approach, provided it is used to advance existing theory (Strauss and Corbin, 1998), as was the case with this study.

QSR NVivo 9 qualitative coding software (QSR International, Doncaster, Victoria, Australia) was used to organize and manage data analysis tasks. The researcher engaged in descriptive coding during which detailed labels were applied to segments of data based upon their content and/or meaning. Using the family communication types as a starting point, themes were identified utilizing open and axial coding wherein the open coding gives the broadest approach to identify saturation in the data for shared concepts and axial coding identifies thematic intersections in the data (Spradley, 1979; Strauss & Corbin, 1990). Then utilizing the constant comparative method, the meanings of the participants' statements were read numerous times to identify the important messages for each of the categories (Strauss & Corbin, 1990). Coding was compared both within and

among all interviews, leading to the generation of themes that provided a more in-depth view of the perceived benefits, challenges and recommendations for family caregivers associated with the different family communication types. Finally, the application of the family communication patterns typology as a conceptual framework served to organize these interviews and highlight the sense making that occurred around these messages.

Rigor and Trustworthiness of the Data

Rigor in qualitative research is enhanced by six strategies: prolonged engagement, triangulation, peer debriefing and support, member checking, negative case analysis, and/or auditing (Padgett, 1998). Trustworthiness of the data in qualitative research suggests that four factors be considered: credibility, transferability, dependability, and confirmability (Denzin & Lincoln, 1994). Although prolonged engagement, peer debriefing and support, and member checking are frequently used in qualitative interviews to test the accuracy of the data, due to the recent bereavement status of the participant population, none of those were viable options in this study. The caregiver's self-selection of the family communication pattern types and the information provided in his or her narratives were examined reflexively to establish triangulation. Negative case analysis was used to enhance the rigor in this study as well as the support provided by the audit trail of the codebook, coding scheme and transcript data.

Credibility. For this study, credibility was established through triangulation and negative case analysis. The caregiver's self-identification as one of the family communication types was compared to the caregiver narratives and each case was re-examined and verified that the emergent themes' characteristics applied to all like cases

(Padgett, 1998; Strauss & Corbin, 1990). The audit trail of the codebook, coding scheme, and the transcripts provided an acceptable level of trustworthiness for the data used in the study. For a review of the coding manual and rules used for this study, please refer to Appendix B.

      Transferability, dependability and confirmability. Because of the small participant size, transferability was not applicable. However, dependability and confirmability can be established at the same time (Lincoln & Guba, 1985; Padgett, 1998). In this case, both dependability and confirmability were established due to the appearance of three of the four family communication types, both in the self-selection process by the caregivers and the corresponding authentication of the family communication types in the narratives.

CHAPTER 4: FINDINGS

National family caregiver statistics reported that the majority of caregivers are female (Caregiving in the U. S., 2009) and that statistic was comparable in this participant sample where the majority of the caregivers were also female (87%). The mean age of this caregiver sample was 60 and somewhat older than the national average age of 48 (Caregiving in the U.S., 2009). Family caregivers were typically employed either part time or full time (54%), therefore this sample was consistent with the national average of employment (59%) for caregivers (Caregiving in the U.S., 2009). Even though this participant sample does not mirror exactly the national population characteristics for family caregivers, there are strong similarities.

Fifteen telephone interviews were transcribed and resulted in 165 pages of data. The length of the interviews ranged from 11:37 to 45:05 minutes (M = 32:06). The length of the interviews included the original questions from the larger study; however, the family social support questions were already part of the original interview protocol and the 14 questions on the original interview guide were either nominal or scale questions requiring very little time. Prior to the addition of the researcher's questions, the interviews averaged approximately 5.6 minutes.

Hospice Family Caregiver Communication Types

The hospice family caregiver participants were read a single descriptive sentence for each of the four family communication pattern types. They were then asked to reflect on how their family communicated and then select the type that they felt fit their family's style of communication.

Partner types. Ten caregivers self-selected themselves as the family communication type known as the Partner. The Partner family caregiver originated in a family where both the communication and the conformity style were high.

Manager types. The Manager, a family communication pattern type that was high in conversation, but low in conformity, had four caregivers self-select themselves into that category.

Loner types. One caregiver identified as a Loner, a family communication pattern type that was low in conformity and low in conversation.

Carrier types. When asked, none of the caregivers self-selected the Carrier family communication type. The Carrier family communication pattern type was high in conformity, but low in conversation.

See Table 2 for the family communication pattern type distribution in the participant population sample.

Table 2

Family Communication Pattern Type Distribution   n=15

Manager: One family member, the patient or the caregiver, is in charge of making decisions, and controls the decision-making process.	4
Carrier: Family members do not really talk about the patient's illness, rarely discuss options and care with each other, and find support from others outside of the family.	0
Partner: Family members talk openly about the patient's treatment, advance directives, death and dying, and family support each other.	10
Loner: Family members do not talk regularly and do not talk much about the patient's illness, leaving the primary caregiver with little support or help.	1

First, I will describe the caregivers' social support through a discussion of their use of formal and informal social support, and then I will describe the family caregivers' perceptions of their resilience and two emergent themes possibly related to caregiver resilience. Finally, I will describe the caregiver's perspectives on their hospice experience.

Social Support

Caregivers were asked about their use of the hospice's formal social support services. The caregivers were also asked about the family social support to see if there might be any consistency between the family communication types: how many relatives did they hear from or see during a month; how many relatives could they share private information with and how many relatives did they feel that could call on for help.

Formal social support. Most of the caregivers did not use the hospice bereavement counseling services, and when asked why, the caregivers indicated that their families provided adequate support. BW (Partner) said, "I didn't think I needed that [hospice grief counseling] and when I was feeling low, I had family support, so I didn't really need their services." Another Partner family caregiver, MAS, felt the same way,

> I have a really good support system here in town with lots of friends, and I felt like I had a really good support system with my family. And I felt like if I needed to grieve or talk or whatever, I would go to my family and not to hospice.

> Very few caregivers mentioned any kind of significant relationship with the hospice chaplain. Perhaps there does not appear to be a relationship with the hospice chaplain was because most of the caregivers described a strong relationship with their church. In fact, the caregiver often referred to that relationship as their "church family" implying a more familial-type relationship.

> Just over half of the family caregivers mentioned a volunteer coming in at least one time a week. Even though those caregivers seemed appreciative of the volunteers, the caregivers' references to the volunteers seemed to indicate the volunteers had more rapport with the patient rather than the caregivers.

Informal social support. Throughout the sample of family caregivers, there were considerable amounts of informal social support. The caregivers' narratives were sprinkled with descriptions of immediate and extended family members assisting in multiple tasks such as providing meals, doing laundry, and filling prescriptions. Six of the caregivers reported nine or more family members with whom they could rely on for

social support by either hearing from them each month, being able to count on them, or being able to communicate intimately with them. Three of the caregivers reported the same level of support from at least five to eight family members as in JS' case. JS had a high level of informal social support with anywhere from eight or more relatives offering support. She reported she could depend on, call on, or talk to at least eight relatives at any given time of the day or night:

> They [family members] visited. My son lives in CITY, STATE. He called all the time and talked with me all the time and everything, and he was one of the furthest away. So all the rest of them came and went all the time you know (JS, Partner).

Two of the caregivers reported the same level of support from three to four family members. Four caregivers reported they could count on two or less family members for any of the same support areas. When examining the narratives of the family caregivers, their informal social support was comprised of networks of immediate and extended family members. The caregivers who had less in numbers in terms of informal social support seemed to make up for the lack of quantity with fewer close, quality relationships.

The informal social support described by the caregivers was either task-oriented or psychosocial-oriented. Help with tasks became even more critical when the caregiver's own health became an issue as it did during TB's six months of caregiving:

> Well, his sister came over and helped because ya know I got real sick one time there for a bit. She'd come in and help and give me a break there and then other

people helped a lot too ya know. And my son, he was the biggest help, ya

know…they would clean the house, sit there [with the patient], cooking, and

things like that, ya know, talking, watching over (PATIENT) (Partner).

Often the informal assistance with tasks served to fill the gaps the caregiver was unable

to fill, either because of the inability to leave the patient or the lack of physical strength,

as in MC's situation: "[the biggest challenge] It wasn't with hospice; it was…well, as he

got weaker, it was hard to maneuver him by myself" (Partner). MC continued describing

her support this way,

Well, one lady brought out sheets when we got a single bed, several brought food.

Of course, my daughter and grandson came the day before he passed away and

my grandson was able to help lift him places where I couldn't (Partner).

As mentioned earlier, family members assisted in the daily caregiver tasks, both

inside and outside the home as well as provided emotional support through interpersonal

communication with the caregiver. The caregivers mentioned the comfort they received

from having family members to talk with about what was going on with their dying loved

one. JS described this regular visit with her aunt, made possible by the volunteer, as the

time she would have lunch with her aunt and what it meant to her: "Listening and talking,

she's [the aunt] only a couple years older than me, so we've always been close" (Partner).

In fact, this strong family support was the reason many caregivers gave for not needing

the hospice's formal support services. However, the caregivers' narratives demonstrated a

lack of knowledge of the hospice support services available for caregivers. This

information gap was particularly notable in narratives where caregivers expressed great fatigue and a desire for some additional relief from their caregiver responsibilities.

Resilience

The only two caregivers that utilized the hospice bereavement counseling services perceived themselves to be less resilient, but otherwise, there did not appear to be an appreciable difference in the reported resilience levels of the family communication pattern types.

Partner resilience. Two of the Partners saw themselves as very highly resilient and five of the Partners perceived themselves to be highly resilient. One of the Partners described herself as moderately resilient, even as she noted that "it's usually higher. I think it's just harder with family" (MM, Partner). Two of the Partners felt their resilience fell somewhere between low and moderate; one of these partners was currently utilizing the hospice bereavement counseling services.

Manager resilience. Two of the Managers described themselves at the highest level of resilience and the third Manager herself as highly resilient. The fourth Manager perceived himself to be somewhat low in resilience and was one of the two caregivers that used the hospice bereavement counseling services.

Loner resilience. The single Loner caregiver described herself as a moderately resilient person and felt strongly that she would seek counseling if she felt like she needed it. She mentioned that the death of her grandfather impacted her greatly due to their close relationship and her long-term caregiving of both her grandfather and grandmother and felt that might have reduced her resilience.

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Concerns about overuse of pain medication

One-third of the caregivers' narratives discussed concerns regarding the usage of pain medication. The caregivers' narratives seem to indicate differing levels of guilt, anxiety, and regret about not only the amount of pain medication used, but also in being the administrator of the pain medication. The lack of education about pain medication presented additional communication challenges for the caregivers.

Evaluation of the Hospice Experience

Although few of the family caregivers had suggestions to offer about improving the hospice experience for future caregivers, the majority of the caregivers reported being satisfied with the care their loved ones had received while under hospice care. Most of the suggestions revolved around communication challenges between the caregiver and the hospice nurses, lack of education about the death process and appropriate use of pain medication.

CHAPTER 5: DISCUSSION

Data from the family caregivers were examined and then organized according to

the four family communication types as self-selected by the hospice family caregivers:

Partners, Managers, Loners and *Carriers*. Additionally, the data were examined for

communication with other family members as detailed by the family caregiver, the

formal social support used, and the family caregivers' perception of their own resilience

and the resilience that appeared in their narratives. The implications of these findings

associated with each family communication type are addressed below. First, I will

discuss the hospice family caregiver types. Then, I will discuss the caregiver types use of

hospice formal social support services. Next, I will discuss resilience in the caregiver

types, followed by a discussion of caregivers' concerns about overuse of pain medication.

Finally, I will discuss the caregivers' evaluation of their hospice experience.

Hospice Family Caregiver Communication Types

Two family communication pattern types were prominent in the 15 interviews, the

Partner and the Manager family communication types. One of the family caregivers

identified as a Loner family communication type, and none of the family caregivers

selected the Carrier family communication type.

The first research question sought to determine how the communication with other family members differed among hospice family caregivers' types. Partner types demonstrated open communication consistent with the typology and Manager types demonstrated preservation of the hierarchal role by the caregiver that is also consistent with the typology. The Loner's narrative strongly reflected the types characteristics in Wittenberg-Lyles et al.'s (2012, in press) typology.

Partner types. Partner caregiver types are distinguished by open communication among family members and high levels of family engagement with the communication about the illness and death. Consistent with the Wittenberg-Lyles et al.'s (2012, in press) family communication patterns typology, the Partner caregivers reported that their families communicated freely with each other about their loved ones' situation, particularly in relation to the wishes of the patient. Also consistent with the typology, the Partner types frequently used inclusive language (we, us) when discussing their caregiving experiences in their narratives.

For example, in JS' situation, the patient was her mother. JS and her mother had lived together for over 10 years. Both of their spouses had passed away around the same time. JS described her mother as active and before she became ill, "we had a lot of fun together…but then all of a sudden one morning…she couldn't stand up (JS, Partner). When asked about her family's communication style, JS answered, "mother got to a place where she didn't want to have to do that she didn't want to make any decisions (Partner). Before her mother got ill, JS described those years as fun and as her mother's physical capabilities became increasingly challenged, JS began to take over the management of

her mother's care (Partner). Another Partner caregiver, AN, reported that her family was

extremely frank about their communication as described here:

> We all discussed my mom's condition with her present. And we all decided what
>
> would be the next step for her with her, and when she said no then that's the way
>
> it was going to be. We were all well informed.

Consistent with typology description of the Partner caregiver type, AN referred to family

conversations about the progress of her mother's illness and the death and dying process

in family meetings. AN, like other Partner caregivers, described her communication with

her mom and her family members as open, positive and supportive. TB discussed her

family's up-front communication about her brother's illness, "We all was open to each

other. We talked about it, and we knew it was coming, but when it came, we weren't

really prepared for it as soon as it did" (Partner). As seen in the examples of JS, AN, and

TB, descriptions of a candid, unreserved family communication style were typical. The

narratives of these Partner family communication types in this participant sample and

seemed to support the caregiver's self-selection of their own family communication type.

Partner types, because a characteristic of their family communication is group

participation, might most easily see themselves as an extension of the healthcare team. In

fact, the team concept, from the care of the patient through the use of an interdisciplinary

team to the inclusion of the family and friends in hospice care may be what makes

hospice services attractive to this type. Wittenberg-Lyles et al. (2012, in press) suggest

that hospice staff encourage team participation with this type by providing additional

information and resources to further higher feelings of inclusion.

Manager types. Manager caregiver types are distinguished by one family

member's dominance of the family communication surrounding the patient's illness. If

the patient is the dominant family member in the hierarchy, then the caregiver will focus

on fulfilling all of the patient's needs while preserving the hierarchy; if the caregiver is

the higher family member in the hierarchy, then he or she will employ limited

communication strategies with other family members and make all the decisions

concerning the patient (Wittenberg-Lyles et al., 2012, in press). In the narratives where

the hospice family caregiver self-identified the family communication style as Manager,

that family caregiver functioned as the primary communication conduit for the patient.

All of the Manager caregivers emphasized that they were acting in accordance with their

loved one's wishes.

For example, in RG's case, his wife had made all decisions regarding her

treatment, and eventually, her lack of treatment. Two weeks before his wife died, she

discussed her wish to be cremated and buried on the family plot (RG, Manager). His

wife not only discussed the details of her burial, but also discussed financial issues as

well as reassuring him that she would be all right and so would he, thereby not only

managing the practical and financial details of her impending demise, but also managing

his emotional burden (RG, Manager). Although RG functioned as the hierarchal figure in

this Manager caregiver family, all his actions were directed to fulfill her wishes:

> (WIFE) made the decisions about her treatments based on information from the
>
> oncologist. She made the final edit on all newsletters that I wrote. She ran the
>
> circus that we lived in. I fully supported this, since this was her body and her life.

If she had suddenly decided not to continue a treatment that *bought* [participant emphasis] her more time, but severely diminished quality of life, then I felt as though pushing my wants would have been selfish and unsupportive (RG, Manager).

Another Manager described a close, loving relationship with her dying uncle. JN painted a vivid picture of her uncle through her narrative, and she freely discussed personal and public details about his life. She said, "I just about died laughing because I knew how he was [about getting his personal hygiene taken care of by the female aides]. He wasn't a fan" (JN, Manager). JN talked extensively about her relationship with her uncle, referring to pictures on his funeral home web page of the two of them from the time she was a little girl. Even though JN had the power of attorney, she still discussed her uncle's affairs with family members. Of one such conversation, she reported, "Well, my cousin pretty much knew what I was doing…So she said I have more responsibility than she had even though she has the farm" (JN, Manager). The communication here was unrestricted within the family, but dominated by one person. This type of family communication interaction is consistent with the family communication pattern typology. There were high degrees of conversational orientation as JN discussed conversations she had with her cousins and family members about where her uncle was in his illness trajectory, and yet, there were specific references indicating she felt that the rest of the family recognized she knew her uncle best. Therefore, they seemed to be in agreement that she was best equipped to make decisions regarding his care according to his wishes.

Consistent with the typology for Managers, JM emphasized that although she directed the communication surrounding her mother's care, she was acting to carry out her mother's wishes. In this case, JM's mother had lived independently, and when her illness was no longer treatable, JM, her adult daughter, moved her mother into her home. The family made the decision jointly to care for JM's mother in their home. When the hospice physician told JM and her family that her mother was beginning to decline rapidly, the family asked, "Mom, who do you want to see?" JM's mother gave her a list that included a niece in Colorado, a missionary friend in China, grandchildren and friends. JM chuckled when she described her mother as "holding court." Her family members would come, sit, and talk with her for hours until she would go to sleep. Other family members would make food; JM remembers the whole process as "a group effort" and that "we talked about everything – with my Mom. It was so clear to me what she wanted and what everything was. I knew how she wanted to look before somebody came in to see her. I made the decisions" (Manager).

Another Manager caregiver, JS, referred to several other family or extended members (children, sister, brother-in-laws, nephews, grandchildren, long-term next door neighbors) during her narrative. She referenced multiple communications and interactions with them, but there was no question that JS was in charge of coordinating all aspects of her mother's end of life care.

One characteristic common in this group of Managers seemed to be that although they maintained a dominant role in the familial hierarchy for decision-making regarding the care of their dying loved ones, all the Managers were clear that they were doing so to

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honor their loved ones' wishes. Managers talked of the family communication using the person-centric pronouns, *I* and *me*, when describing their caregiver experiences. Although it was evident that other family members participated in the caregiving tasks and communication, the narratives evidenced support that the Manager's focus was on fulfilling the needs and wants of the patient, even though in all cases, the patient was the dominant family member with a higher place in the family hierarchy than the family caregiver. Because one family member might be intent on taking the dominant role, at least temporarily, in the family hierarchal structure, other family members' voices may not have an opportunity to be heard. Hospice staff members can create a positive environment for the less dominant family members to share their concerns and questions, by opening up the discussion to all family members.

Loner types. As previously discussed, the Loner family caregiver type originated in a family that is extremely low in conformity and low in conversationality. For example, upon hearing the descriptions of the four different family communication types, CH chose the Loner type without hesitation. In discussing her social support, CH had only three or four people that she felt she could count on for support for the two months her grandfather was under hospice care. CH (Loner) prided herself on her independence, "I am very self-sufficient," but she was adamant that the other members of her family, including her mother and her uncles were not supportive at all. CH expressed her feelings about their lack of support in this statement:

> Very angry. VERY angry. But I wasn't going to let my grandpa down. They
> were angry with him because they thought he should be in a nursing home and he

wanted to be home. So they just totally divorced themselves from the situation.

They NEVER came. Nothing (Loner).

When asked how that made her feel, she replied, "Angry! Very angry. As a matter of fact, now I don't want anything to do with them" (CH, Loner). CH was asked if she had talked to the other family members about where her grandfather wanted to spend his final days. CH was clear about her position, "There was no talking to them" (Loner). The closed communication with her family is consistent with the communication style identified in the family communication pattern typology developed by Wittenberg-Lyles et al. (2012, in press). Not only did CH perceive herself to be alone in her caregiving duties, but also she consistently identified other family members separately from herself as others (i.e., *they*, *them*). She made a point of saying that she was angry about the lack of communication, but was equally emphatic that she was not desirous of initiating any communication with them. One of the burdens discussed in Wittenberg-Lyles et al.'s (2012, in press) study for this caregiver type was the perception of isolation. This feeling of isolation was evident in CH's discussion of her grandfather's abandonment by his children. As far as her family providing support, she reported "my immediate family, yes. My husband. The other members of the – my uncles, my mother—no. They weren't" (CH, Loner). The minimal interaction and familial detachment described by CH were typical characteristics of this family communication style. However, CH remarked that her experience with hospice was highly positive:

I have absolutely nothing but positive things to say about hospice. This is my

second time dealing with them. My husband's dad – we had them for him for a

year before my grandfather passed away. They were wonderful with him and

they were wonderful with my grandfather. I think it's a program that cannot be

beat (CH, Loner).

Because this interview was conducted within 14 to 21 days of the loss of CH's

grandfather, CH's grief was probably at its highest and this could possibly affect her

assertion that she did not need or desire any communication. Theoretically, CH seemed

to fit the characteristics of the Loner type as defined by Wittenberg-Lyles et al.'s (2012,

in press) typology. However, because this study's interviews were conducted so soon

after the death of their loved ones, the typology may not account for the potential

disruption in the respondents' communication style due to the emotional state of the

caregivers.

As for the hospice staff, interacting with a Loner such as CH might lead them to

assume that he or she does not have any need for communication strategies. The hospice

staff should encourage the Loner to consider opening up the lines of communication with

the other members of the family. In this way, the hospice experience could possibly be

more complete for the entire family.

Carrier types. None of the hospice family caregivers chose to identify as a

Carrier family communication type. Carrier types have a superior-subordinate

relationship with the head of the family, defer to all others for decisions, employ limited

patient-caregiver communication, and keep any illness-related topics private (Wittenberg-

Lyles et al., 2012, in press). That no caregiver selected this type may be a product of the

methodology itself if descriptive sentence for Carriers (Family members do not really talk

about the patient's illness, rarely discuss options and care with each other, and find support from others outside of the family) did not adequately capture the fuller description of the Carrier type from the typology. However, another possible explanation is that the Carrier type, due to the family's emphasis on privacy and limited patient-caregiver communication, might be less likely to utilize hospice in the first place. Involvement in hospice emphasizes open family communication about death and dying and is dependent upon extensive patient-caregiver communication.

Formal Social Support Usage Among Caregiver Types

Formal social support originates with the hospice whereas informal social support services refers to the network of friends and family providing both psychological and task assistance. Use of hospice agency social support services could enhance caregiver resiliency (National Institute on Aging, 2003); therefore, research question two sought to describe the differences in formal social support use such as bereavement counseling, chaplain and volunteer services among varying caregiver types. I will discuss the use of hospice social support among the caregiver types. I will also discuss the lack of awareness of hospice support services available to caregivers.

Hospice bereavement counseling services. Each caregiver type has different communication styles and strategies and the theoretical explanations for each of the types should indicate how open the family is to using any type of social support services. For instance, the Loner and Carriers by definition are closed systems, which will vary in degrees of conformity or how much they conform to the set family beliefs and in degrees of conversationality or how frequently the family members talk and the diversity of

topics (Wittenberg-Lyles et al., 2012, in press). These types would be less likely to perceive a need for any kind of social support from the hospice.

In this sample of family caregivers, only two participants were using the hospice bereavement counseling services: RG, a Manager and AN, a Partner. CH, the Loner type did not utilize any of the hospice's bereavement services. Both RG and AN indicated that they began counseling very soon following the death of their loved one, derived comfort from the counseling, and had no plans to cease their counseling sessions any time soon.

Partner types. AN, a Partner, began seeing the hospice counselor immediately after her mother died. Because AN was concerned about the administration of the morphine to her mother for her pain, AN reported that she had discussed this extensively with her bereavement counselor:

> Now I'm not saying that last dose killed her, but I often wonder…did she really need something? We knew she was dying anyway. So those kinds of things I've been grappling with just philosophically. And I told my husband and I told my bereavement counselor with the hospice center that I've really started to look at how we administer pain medication here in the United States and what we have accepted as helping the patient then at the same time are we willing to look at things like Dr. Kevorkian?

The equation of hospice palliative care at her mother's end of life and Dr. Kevorkian was problematic for the caregiver. Instead of being comforted that her mother passed away peacefully, AN was left with a considerable amount of unresolved anxiety about her

mother's death. The negative implications for equating hospice with medical euthanasia are discussed later under resilience.

In contrast JS did not take advantage of the hospice bereavement counseling services. She explained:

It's simply because I don't grieve for my mom. She knew Jesus. She was a born-again Christian. There's no doubt in our minds, my sister and I, any of our family, where Mother is. We don't have to. I just can't grieve for her. I miss her. Boy, do I miss her. This place seems awfully empty without her, but I don't have any problems with grief (Partner).

The nature of this quote by JS not only speaks to the reasoning behind the lack of the need to use the hospice services, but also reinforces the consensual nature of this family's communication type. There was a high level of conversation and conformity in JS's narrative regarding her mother's dying and death. The conversations surrounding her mother's illness and death were occurring within this large family network, and there was a definite consensus about the process (JS, Partner). Another Partner, SP, who took care of her brother said, "I've got my own support group if you will. In my kids, and in people that I know I can talk to, ya know."

Partner types in the narratives seemed to derive a great deal of social support from their informal networks and therefore, although they might be comfortable using hospice bereavement counseling, they do not perceive a need for services outside their family network (Wallace Williams & Dilworth-Anderson, 2002).

Manager types. RG felt the bereavement counseling following the death of his

wife was very helpful (Manager). He expressed deep sorrow at the loss of his wife and

seemed appreciative of the hospice bereavement counselors. In RG's case, his wife was

the dominant member in the family hierarchy and although RG assumed that role during

his wife's care during hospice, the assumption of that role should be considered

situational in nature. If the assumption of the role of Manager is situational, then after the

patient dies, as in RG's case, this role change might have increased his need for

bereavement counseling. RG and his wife had no children and all of his social support

came from friends and extended family. The lack of immediate family may also have

influenced his use of social support. Although his parents came down and stayed with

RG following his wife's funeral, he recounts being very distraught and walking through

the rooms of their house howling in grief.

If, as with RG, the Manager role is assumed by the non-dominant family member,

it is possible that when that role is no longer needed, due to the death of the dominant

family member, the caregiver will experience higher levels of grief. In cases like this, the

recognition of stress of this role switch may create the need for additional support for the

grieving caregiver. If they are truly the non-dominant member, they may be more likely

to require use of the hospice's bereavement counseling. The typology used in this study

may not account for the disruption that occurs with the role change (Wittenberg-Lyles et

al., 2012, in press).

Loner types. CH, the one Loner family caregiver, did not utilize any of the

hospice bereavement services or any private counseling services. CH seemed confident

and self-assured and explained her position on seeking counseling like this:

> I'm okay. I'm at peace. If I was struggling with it more than was considered
>
> normal, my husband would be the first to tell me, "You need some help!" I knew
>
> it was coming so I was prepared to a degree, and then when it did happen, what I
>
> went through was just very normal. And everything got a little better and a little
>
> easier. If I had felt the need for it, I would have been there. I would have availed
>
> myself of it (CH, Loner).

Even though the Loner caregiver expressed great sadness at the passing of her

grandfather, she did not feel she needed the hospice services. Because this Loner may

take a particular stand apart from the family structure, the chances of isolation increase.

Perhaps because the Loner is at odds with the family, connecting with an outside source

for support, such a bereavement counseling would prove to be less threatening. Because

the source for the counseling exists outside the conflicted family structures, the Loner

would most likely feel comfortable using the services. In order to minimize the feelings

of isolation and the 'me against the world' mentality, Loners should be actively

encouraged to use the hospice counseling services.

Although two of the caregivers began using the hospice bereavement counseling

services immediately following the death of their loved one, this study's data were

captured during the 14 to 21 days following their loved one's passing. The original

typology does not account for any temporal element, so it is possible that after the

sharpness of the emotional grief begins to dull somewhat, other caregivers may choose to utilize bereavement counseling. Outside of formal counseling, there are other types of social support services provided by hospice. Social workers, chaplains and volunteers are also available to help caregivers during their loved ones' time with hospice. I will discuss the use of chaplain and volunteers by the family caregivers.

Chaplain and volunteer usage for all family caregiver types. Among hospice family caregivers types, there was very little variance in the use of other hospice support services. There were brief references to social workers, but more frequently mentioned in the narratives were chaplains and to a lesser extent, volunteers.

Chaplain usage. Caregivers reported using a range of coping mechanisms to deal with the demands of caregiving. Praying is the most commonly reported method of coping followed by talking with friends or relatives (National Alliance for Caregiving and AARP, 2009). Reading about caregiving in books or materials, exercising, and going on the Internet provide other outlets for dealing with stress (National Alliance for Caregiving, 2009). Seeking help from a professional or spiritual counselor and taking medication were less commonly used techniques. Only 27% of caregivers try coping with their caregiving stress by talking to a professional or spiritual counselor (National Alliance for Caregiving and AARP, 2009). This percentage is similar in the caregivers in this study, as fewer than 30% of the caregivers mentioned getting emotional support from the hospice chaplain or from their own personal pastor and church family.

When asked about the use of any of the hospice formal support services, MC who was caring for her dying husband of 62 years, said, "Hospice did send out a chaplain at

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one time, yes. We have our own minister who came out and also an associate minister so we had several people" (Partner). MC also described herself as highly resilient and she reported multiple instances of informal social support including physical assistance, food, and breaks from caring for her husband. MC also reported having more than nine people available to provide help and support if she needed it. MC expressed her feelings very simply:

> It was time for him to go and it was a relief. He wanted to go. He had lived a
> good life. He was tired out and he was ready and I wanted what he wanted.
> That's what he wanted so I'm glad he's in a better place (Partner).

Discussions of a church family or a connection with the hospice chaplain were evenly divided between the Manager family caregiver types and the Partner family caregiver types. There was no reference to a church family or a connection with a hospice chaplain by the Loner family caregiver.

Volunteer usage. Both the Manager and the Partner family caregiver types alluded to regular visits by volunteers. There was no reference of any volunteer visits by the Loner family caregiver. JS commented on her mother's volunteers:

> I had volunteers that came in and sat with mother twice a week for two hours each
> and so that I could go do what I needed to do. They were just super nice people.
> One of them has become a very dear friend. But they were both great. I couldn't
> ask for better (Partner).

When asked what having a volunteer meant for her, JS said, "It gave me a little bit of freedom. I just looked forward to it every week" (Partner). JS' case is particularly

interesting because her narrative was filled with examples of extensive informal family social support and yet, the scheduled, two hours a week visit from the hospice volunteer was important to her. Perhaps one of the values of regularly using a hospice volunteer, as opposed to a family member, might be the lack of any feeling of familial obligation on the part of the family caregiver or perhaps, given the circumstance, the inability to depend on regular help from family members.

Unfamiliarity with hospice support services. The caregivers were given information regarding support services during the hospice intake interviews. Enrolling a loved one in hospice care resulted in a high level of stress and required the absorption of a large amount of information at one time; therefore, caregivers may have been focused on their primary concerns of medical attention and medication administration rather than any of the hospice formal support options for the caregiver.

Oftentimes, the patient's family exhibits reluctance to use hospice services. This reluctance depends on three things: the emotional difficulty of accepting a terminal diagnosis, the desire, either on the part of the patient or family to continue life-prolonging treatment, and/or the inability of the physician to recognize the need for hospice care (Casarett & Quill; Weggei, 1999). Physicians are usually the first healthcare professionals to suggest hospice to patients, but research shows that the discussion of the benefits of hospice is limited and insufficient (Casarett, Crowley, & Hirschman, 2004; Chen, Haley, Robinson, & Schonwetter, 2003). Furthermore, bereaved caregivers reported learning more about hospice services after enrolling in hospice, (Casarett et al., 2004; Chen et al., 2003), suggesting that they might have missed that information during

the intake session. In spite of the fact that the physician is transitioning the patient to hospice care, the caregivers still look to the physician as the primary source of information about hospice (Csikai & Martin, 2010).

A number of caregivers reported experiencing confusion about hospice. This phenomenon reflects an unresolved area of communication between the referring physician and the caregiver. Several caregivers were unaware that even the most basic support services such as requesting a volunteer to sit with the patient in order to give the family caregiver time to run errands, grocery shop, attend to their own social and/or health needs, were available to them, at no cost. This lack of awareness of these services was apparent in SP's remark: "I don't think (OTHER CAREGIVER) or either one of us was aware any of them would've actually sat with him for a period of time for us to do whatever needed to be done yanno" (Partner) and in LF's case:

> [Would you have used volunteer services?] You know, I may have because on the days when we worked when she could still get around a little bit, I might have had somebody come in and just visit. Because when she moved in with us, she was like, "Oh my gosh, I love it here. I guess I was feeling kind of lonely. I loved being around people." So, I may have utilized it, yeah (Partner).

Bereavement counseling was also available to the caregivers, but some of the caregivers were either not aware the service was available as with BW (Partner), "Because they haven't really sent any of that information out" or as in BS' situation, she did not seem interested: "I just got the letter [about bereavement counseling] yesterday" and when asked if she might go, BS replied, "I might try to go to one of them, but I don't

know just when they are" (Partner). If caregivers were focused on the challenge of taking on a new role as a substitute healthcare professional, they were more likely to retain information about items related to the role as it related to the care of the patient, and much less likely to retain information related to helping ease their caregiver burden.

As an expansion on that theme, one family caregiver articulated that she and the other caregiver felt it was made clear that the attention and care was just for the patient. SP said:

> I don't think (OTHER CAREGIVER) or I felt like *they* (patient emphasis) were there for *us* (patient emphasis), in any way, shape or form. It's wonderful that y'all come in and help the patient or you talk to the patient and stuff like that. And yes, nine times out of ten, we're [caregivers] sitting there listening, but you're talking to the patient. We may interject a remark somewhere in the conversation, don't get me wrong, but we're well aware of the fact that you're talking TO THE PATIENT (participant emphasis). Sometimes maybe you need to talk to the caregivers (SP, Partner).

For a caregiver to feel that way directly contradicts the philosophy of the hospice mission which seeks to provide support not only for the patient, but also the family and friends during the end of life.

Recognition of the inability to absorb large amounts of information, particularly at such a stressful time, might require that the hospice follow up on the first intake meeting with reminders of the hospice services available to the caregivers. One example might be a mailer containing the range of hospice services and contact numbers that the caregivers

could read at their leisure. Regardless of the communication channel the hospice might use to communicate with the caregiver regarding support services, it was clear that not all the caregivers knew or remembered that this avenue of support was available to them.

Resilience

Research question three sought to examine how resilience might be reflected differently across the family caregiver types. Resilience is often discussed as a state where the assertion is made that a person must be born with resilience. However, research has shown support for the impact of family relationship pattern on the individual family members (Caplan, 1982). Scholars have long asserted that the family can function in one of two ways: as a risk factor that decreases the resilience of its members or as a protective factor that increases the resilience of its members (Hawley & DeHaan, 1996). This assertion can be applied to the hospice family caregiver types. The four different caregiver types have various communication strategies and each of those strategies have strengths and weaknesses that could affect the resilience of the types' family members. I will discuss the four caregiver types and resilience.

Partner types. Based on the typology, the Partner types practice open communication resulting in a collective decision-making process that most likely would enhance the resilience of their family members (Wittenberg-Lyles et al., 2012, in press). Oftentimes as a family, the Partner types talk frankly about advance directives, death, and dying. The permeability of the boundaries of the Partner allow for a free exchange of information between the family members, the patient, and the hospice care team. The defining characteristics of the Partner type indicate a very positive communication style,

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which serves to enhance the resilience of its family members (Wittenberg-Lyles et al., 2012, in press).

The Partner types in the study, with the exception of AN, described themselves as average or above in resilience. These elevated levels of resilience could be due in part to the high degree of family support. However, one partner, SP, perceived herself to be highly resilient, but reported only one person to which to turn. However, she reported a very close relationship with that one person (Partner). In examining resiliency in relationship to informal social support networks, it may necessary to account for not only the size of the network, but also the strength of the interpersonal relationships.

Manager types. The Manager types practice open communication but one family member, either the patient or the caregiver, dominates the communication (Wittenberg-Lyles et al., 2012, in press). In this caregiver type, the leadership of the dominant family member would determine whether or not the family functions as a risk or protective factor. If the Manager type practices open communication where consideration is focused on fulfilling the needs of the patient, then the argument might be made that this Manager's communication would enhance the resilience of the family members. The typology does not specify whether or not the Manager practices fluid open communication, so if the Manager's communication style is more controlling, then it might be possible the family members would experience less resilience. In narratives where the caregivers identified as Managers, the communication practices were open and focused on creating a positive experience for the patient.

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For example, RG had a large network of informal social support from family. At any given time, there were five to eight relatives offering assistance with care tasks, and over nine relatives provided personal support for RG. At his wife's request, RG wrote and sent out an informative newsletter, keeping their family and friends up to date with the progression of her illness. Even with this high level of family support, RG perceived himself to be low on resilience. In RG's case, there was a very high level of informal support, but he did not feel personally resilient. Due to the extended trajectory of his wife's illness, RG was a caregiver for five years before she went into hospice care. The length of RG's caregiver experience could account for his feeling of low resilience. During the interview, RG shared that his wife had handled the decision-making and planning aspects of their married life, and taking over her role might have also lowered his resilience.

JN's perception of her resilience was exceptionally high although she only had two family members to call upon for her informal social support (in person). JN did mention, and she was the only family caregiver to mention this, however, that she kept up with her husband's relatives via social media:

> On *Facebook*, I do have my husband's relatives. Now his family is growing and so I hear from his niece and great-niece on *Facebook*. They put pictures on there and all that so I do kind of hear from them every once in a while, they'll chime in to me. But, anyway, I can kind of keep up with his family on *Facebook* (JN, Manager).

Therefore, although JN had a limited amount of local, informal social support, she did derive some amount of needed support through her social media usage. Other communication channels than face-to-face interaction may support resilience. This finding has great potential for caregivers who have physical or other limitations and are otherwise able to connect to an informal social support network.

Loner types. Because Loner types feel unsupported in their family caregiving efforts by other family members, isolated, and angry, depressed and/or helpless, it seems like the lack of positive family communication could lead to increased risk factors of lowering resilience. Even though only one caregiver identified as a Loner caregiver type, her narrative strongly represented the characteristics of the Loner type as defined by Wittenberg-Lyles et al. (2012, in press). CH perceived her resilience to be average, but she did say that she felt her resilience was compromised by her grief (Loner).

For example, although CH described her resilience as average, she shared that the death of her grandfather was harder for her to overcome due their extreme closeness. For at least two years before the interview, CH had been an unofficial part-time caretaker of her grandparents. Even though CH had spent a minimum of three to four hours during the week and six to eight hours on the weekends with her grandfather, all the while working a full-time job, her single regret was that she had not taken a leave of absence from work to spend even more time with him. In the Loner type, resilience may become comprised by the isolation experienced. However, if they seek information and support from sources outside the family, this action on their part might enhance their resilience.

Carrier types. Although none of the caregivers identified as a Carrier type, the characteristics of the type as defined by Wittenberg-Lyles et al. (2012, in press) can be examined in terms of potential risk or enhancement factors for resilience. Carriers are defined by limited patient-caregiver communication and may have limited information-seeking skills in a family that keeps any illness topics within the family and private (Wittenberg-Lyles et al., 2012, in press). With those characteristics, a safe assumption might be that this type of family communication pattern type would not enhance resilience, and perhaps may seriously impair the resilience of the family members. These caregiver types are dealing with the diagnosis, treatment, and death of one of their family member and therefore, these family members are already vulnerable (Van Breda, 2001). None of the types are invulnerable to these stressors, but the different caregiver types can serve to enhance or detract from the resilience of its family members.

Concerns about Overuse of Pain Medication

Although specific questions about pain medication were not part of the interview guide, the caregivers were asked to recount their caregiving experiences. The theme that appeared in the caregivers' narratives reflected deep concerns about overuse of pain medication. The caregivers reported feeling conflicted about giving their loved ones pain medicine, oftentimes a form of morphine, as well as the amount of medicine their loved ones were receiving. I will examine the caregivers' concern regarding over-medicating their patients.

The fear of over-medicating their dying loved ones continues to be found in caregivers' narratives. Unfortunately, the debate about palliative care in hospice patients

has been and continues to be evident in the palliative literature (Claessens, P., Menten, J., Schotsmans, P. & Broeckaert, B., 2007; Lau, Berman, Halpern, Pickard, Schrauf, & Witt, 2010; Rietjens et al., 2008). One-third of the narratives contained expressions of concern, and only in the Partner family caregiver types. Their concerns were two-fold: one, were they actually hastening the death of their loved one, and two, was the hospice staff actually hastening the death of their loved one?

TM, a Partner family caregiver, felt ill-prepared for his role in administering his mother's pain medication, "I'm not a doctor and I don't know if I helped her go faster or slower or what. Hell, I don't know." That TM did not fully understand his role was evident when he said that he thought, "the hospice people would be here and they would be the ones administering her pain medication, but I guess I was TOTALLY misunderstood (participant emphasis) on that thing" (Partner). His mother had contributed to his confusion by telling him that at the end, the hospice people would be administering her medication. TM expressed feelings of conflict and confusion about his role as his mother's caregiver, guilty that he had potentially assisted in her death, and consequently, he was unhappy with his hospice experience. With better communication from the hospice staff about the process of pain medication, TM's experience with hospice might have been more positive.

SP, also a Partner family caregiver, on the other hand, was happy with the hospice experience for her brother, but also expressed concern about the amount of pain medication he received. When asked how comfortable she was with her brother's pain medication during his time with hospice, SP replied, "I'm conflicted…at the end, I feel

like he got way too much medicine…within an hour and a half he had received three doses of three different pain medicines which were doubled" (Partner). Asked how that appeared to affect him, SP replied, "He thought it was sweet, but he never woke up either…I mean I feel like that was gonna happen anyway…You know I just felt like that was kinda much. He didn't even know if he had any pain at that point. I mean, seriously, he didn't know where he was. He didn't know who he was. I'm not saying it was wrong, I don't know. I'm not a nurse, I'm not a doctor" (Partner).

In AN's case, she reported being told by the hospice nurse that sedating the patient is a way of prepping the body for death and her perception was, "But for the people who are living, it's very disconcerting because it's almost like assisted suicide" (Partner). Her mother was dying. AN was with her mother during her last hours and reported her death this way:

> And then about one or two in the morning, she started coughing. I knew that was sort of a sign of her body shutting down. She wasn't responding and so I called the nurse and said "She seems to be in some discomfort, she's like coughing." And so the nurse said she'd come and give her something and she did. Three hours later, she was dead. Now I'm not saying that last dose killed her, but I often wonder did she really need something? We knew she was dying anyway (Partner).

The concern about hastening the patient's death is possibly, as Fleming et al. (2006) noted, a by-product of the caregiver's depression due to the imminent and then recent loss of their loved one. When a person becomes a caregiver for his or her loved one and

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as the patient becomes less able to represent him or herself during the latter stages of illness, frequently the caregiver becomes the decision-making authority (Fleming et al., 2006). Research has demonstrated that trust between a patient and a physician is critical to that relationship (Safran et al., 1998) and caregivers already struggle with the first level of caregiving role expectations and the added responsibility of being the decision-maker adds an additional level of stress (Fleming et al., 2006). With these additional responsibilities and stress, trust in their loved ones' healthcare team members is paramount. Fleming et al.'s (2006) study also reported that the caregiver's level of depression was directly related to the patient's level of depression and that level of depression affected their satisfaction with the patient's healthcare and relationship with their physician. Caregivers with low levels of depression tended to view their relationship with the patient's positively or in the case of high levels of depression, negatively (Fleming et al., 2006). Mistrust about palliative care practices, combined with caregiver depression and trust issues with his or her hospice healthcare professionals create a fertile ground for misunderstandings and increased anxiety.

Over the past decade, illegal practices of euthanasia have been confused and associated with legal and ethically acceptable end of life care (Goldstein et al., 2012). Research studies suggest that patients, their families, the public and clinicians are unclear about end of life legal and illegal health care practices (Cohen et al., 2005; Ganzini, Beer, & Brouns, 2006; Goldstein et al., 2012; Meier et al., 1998; Racine, Amaram, Seidler, Karczewska, & Illes, 2008; Silveira, DiPiero, Gerrity, & Feudtner, 2000). For palliative

care physicians, their palliative care treatments may be misunderstood as hastening the death of their patients (Goldstein et al., 2012).

A recently published study surveyed 663 physicians (response rate 53%) from a national hospice and palliative medicine society. Over half of the respondents had at least one experience with confusion about their patients' palliative care treatments (Goldstein et al., 2012). Misconstruing palliative care practices not only occurred with the patient's family members, but also with other physicians or healthcare professionals (Goldstein et al., 2012). Palliative sedation is one of the two treatments most likely to be incorrectly viewed as euthanasia, as in the case of this study's family caregivers (Goldstein et al., 2012). Physicians and other healthcare professionals also struggle with the distinction between traditional medical applications and palliative care applications where the goals differ dramatically.

Evaluation of the Hospice Experience

There are many aspects of being a hospice family caregiver that are important to examine, but giving others the benefit of his or her caregiver experience can provide great insight for future caregivers as well as hospice agencies and healthcare professionals. The caregivers were asked about their challenges and for suggestions on improving the experience for other caregivers. MAS (Partner) had this to say,

> I think probably I would try to get some more information on the program before we got into it and maybe have a better understanding of what my role…what the caregiver's role is through that whole process.

MAS was not alone in thinking this as several participants in this study became caregivers out of love for the patient, but were unaware of the full extent of caregiving responsibilities as eloquently expressed by this caregiver, "I'm glad I did it, but I had no idea...it took a toll on ya. Took a toll on ya" (BW, Partner). Most of the caregivers were aware of their impending loss, and expressed their feelings much as CH (Loner) did, "The only thing I think I might have done differently is to have taken a leave of absence from work so I could have been with him more."

Sometimes it was the communication between the caregiver and the healthcare professional that proved challenging. MC described her first meeting with the hospice nurse this way:

I would say that the first meeting with the nurse was at the end of the day and I'm sure she was tired. The doctor had told us that hospice didn't mean the end of life and the first thing she said was, 'Well, if you're on hospice, you're not supposed to live more than six months.' And I didn't think that was very appropriate when the doctor had told us this was not necessarily the end of the line (Partner).

Not only were there conflicting messages from the healthcare providers as with MC's case, but also poor quality of communication can result in higher anxiety in already anxious caregivers. The caregivers made repeated references to their high anxiety levels, as MAS (Partner) reflected in this statement:

Oh, I think there was [a cost]. I mean I wouldn't have given it up for anything. That was something I could do for my mom. It's physical and emotional

exhaustion. You're trying to go in fifty directions at one time and when you've

got responsibilities at work that just adds to the stress.

The attitude of compromise and cooperation was very typical of the Partner families, as

demonstrated in MAS' (Partner) description of how her family pulled together:

My whole family has strong personalities, so in these last days, we

were…everybody just put aside their difference and just did it. We came together

for Mom. And everybody had times when they could help and times when they

couldn't. And if you couldn't help that particular week, it was OK – you'd do it

the following week or the week after that.

When asked, who was 'in charge' or who was the organizer, MAS replied, "Well, we all

were" (Partner).

In spite of some challenges, all but one of the caregivers were glad they had

utilized hospice services for their loved ones and said they would use hospice services

again as reflected in MAS' statement, "But, in retrospect, if I had to do it again, I'd do the

same thing. No doubt about it" (Partner). Even though some caregivers reported no

issues at all with their hospice experience, some caregivers experienced a few problems

with communication with the hospice staff or with the administration of pain medication.

The one caregiver who was unsatisfied with his mother's hospice care, expressed a great

deal of distress about having to give his mother pain medication, and because of that,

would not want to use hospice again (TM, Partner).

CHAPTER 6: LIMITATIONS

Participant recruitment in hospice can be difficult, not only in the actual recruitment process, but also in gaining access to this population (Kendall et al., 2007). Assimilating this study into the protocol for the larger study gave the researcher access, but the access was limited, not only by the constraints of the original study, but also by the fact that all of the participants were only 14 to 21 days past the death of their loved one, making them emotionally vulnerable. One of the other constraints of the study, in that causing any additional emotional distress was avoided, also meant that use of the family communication typology was limited in scope. In the original typology, each family communication pattern type had at least six defining characteristics. In explaining that to a participant over the phone meant that instead of hearing a one sentence description of each type, it would be 24 descriptions at the end of which the caregiver would have to decide into which category his or her family fit. To avoid interview fatigue, the one sentence derivative was used. Finally, the lack of appearance of all four of the family communication pattern types must also be acknowledged as a potential limitation for this study.

Recruitment

Recruitment in hospice can be challenging because health professionals often act "as overzealous gatekeepers, blocking recruitment or introducing a selection bias" (Kendall et al., 2007, p. 3). This study was accepted by four hospices and each hospice was supplied with a PowerPoint presentation outlining the project, and all forms and procedures to be used in recruitment. In addition to the PowerPoint and forms needed for the project, there were numerous interactions via emails, meetings, and telephone conversations outlining and explaining the project. Despite the other three hospices' willingness to participate, ultimately recruitment was successful only in the midwestern hospice. The recruitment success in the Midwestern can be attributed to the fact that the larger research project already in place used a strategy of enrolling participants in the study by having a research assistant stationed at hospice for the sole purpose of enrollment. This strategy enabled the collection of the data used in this dissertation, but the participants in the Midwest hospice study proved to be a predominantly Caucasian population, and therefore, limited the study's population diversity. Since minorities have been shown to under-utilize hospice services, the lack of diversity is not a surprising limitation (Wohleber, McKitrick, & Davis, 2011).

Respect for Caregiver's Experience

A second limitation on this project speaks to the nature of the hospice experience trajectory itself. Inasmuch as it would have been provident to conduct more extensive interviews with each of the participants, mindfulness of the freshness of the caregivers' loss and potential emotional distress, meant that the interviews be kept focused and allow

the caregivers themselves to dictate the length of the interview, as opposed to the flow being dictated by the use of additional structured questions or scales. Although the emotional state of the caregivers might seem to limit the length of the interviews, the caregivers interviewed shared freely and deeply about their caregiving experiences.

Derivative Use of Typology

Because the length of the interview and the emotional vulnerability of the participants was a high priority, it was not possible to ask all of the questions used in Wittenberg-Lyles et al.'s (2012, in press) presentation of their family communication pattern typology. Each of the four type descriptors was examined and with the assistance of two of the original authors of the typology (EWL and JG), was distilled into one descriptive sentence. However, being dependent on the caregiver's self-identification of his or her family communication style with one definition could be considered problematic. The derivative descriptor of the family caregiver type was not tested on any groups prior to being utilized in this study; however, because the authors were involved in the distillation process and the participants' interviews were used to verify the accuracy of the descriptor, this limitation was somewhat mitigated.

Lack of All Family Communication Types

A final limitation that must be considered is the lack of family caregiver identification as a Carrier family communication type and only one Loner family communication type. It is unknown to what extent all four types emerged in the original studies, but if data collection were to continue, most likely there would be stronger identification by family caregivers in all four types.

The fact that none of the family caregivers identified as Carriers, and only one as a Loner, may be considered not only a limitation, but also a potential finding. As a finding, it could indicate problems with either the methodology or the theory if the caregivers' identification may be limited by some aspect of the collection or by the theoretical construct itself. Another possible consideration that could be explored in a future study is that either of these types, the Loner or the Carrier, may be less likely to utilize hospice services in the first place.

These limitations, lack of diversity, lack of additional structured questions, use of an untested, derivative descriptor of each caregiver type, and lack of caregivers identifying as the Carrier family communication types, are shared not to diminish the value and findings of this study, but rather to serve as a reminder that this study demonstrates the need for further research and exploration in this area.

CHAPTER 7: CONCLUSION

The art of living well and dying well are one. Epicurus

By 2030, 20% of the United States population will be over age 65 (National

Palliative Care Research Center, 2012). The years after age 65 can be good ones, full of

health and independence. However, although some senior adults can enjoy good health

to the end of their lives, most will develop one or more chronic diseases that must be

monitored until death. Whether enjoying robust health or managing a chronic illness, the

senior adult years are marked by an increasing physical and psychological decline, a

progressive frailty and functional dependence and an increased need for informal support.

Whether a senior adult is facing the end of his or her life through the slowing down and

eventual cessation of their bodily functions or dealing with the effects of a chronic or

terminal illness, either situation means that hospitals, family members or friends will

assume the caregiver role and responsibilities.

Terry, Olson, Ravenscroft, Wilss, & Boulton-Lewis (2006) argue that research in

the end of life area is restricted because of societal taboos that inhibits speaking about

death and dying, and not necessarily any real ethical issues. However, talking about

death and dying and researching about death and dying present unique opportunities, on

both sides of the conversation and yet, there are only a limited number of Communication

scholars conducting research in the context of end of life. End of life is a context where quality communication interactions are most salient, critical, and appropriate.

 If, as Terry et al. (2006) claim, we are a nation with a taboo on discussing dying, death, and the communication issues surrounding death, then this is a rich area for future research by Communication scholars. For instance, in considering the many areas to study in the end of life, there are areas of policy, organization, small groups, teams, interpersonal and patient-provider interaction.

End of life research offers challenges: the population must be handled with care and sensitivity and the interviews themselves can be emotionally demanding for the researcher (Kendall et al., 2007). On the other hand, the generosity and honesty of the sample's narratives leaves an indelible impression on the researcher, thereby causing them to "re-evaluate their own lives in more positive ways, and in some cases, face their own mortality" (Kendall et al., 2007, p. 4). Researchers interviewed in Kendall et al.,'s study spoke of having their faith renewed in the "human capacity to receive and give love and support" (2007, p. 4).

Contributions to Theory

Several of the theoretical contributions center around the new family communication pattern typology identified by Wittenberg-Lyles et al. (2012, in press). The descriptive sentence used in the interview to identify the family communication pattern types proved successful at capturing the types as evidenced by the supporting confirming data found within the caregivers' narratives. As this typology is relatively untested, this confirmation provides additional support for its credibility for both the

typology and the derivative, descriptive sentence. The characteristics of each family communication type might influence each type's inclination to use hospice. For instance, Partner types are comfortable functioning as a part of a team and therefore, the structure of the interdisciplinary hospice team would fit into the Partner's communication style. Managers might experience some challenges integrating into the hospice team construct due to their family role as a leader and other family members' voice might be marginalized. Loner and Carriers, due to their communication orientations might need a hospice interaction that is more independent and self-guided in order to preserve their needs for control and privacy.

There was not a consistent use of hospice social support services across the types that might indicate a need for further investigation of the appropriate channel for these services. For this study, the average length of the telephone interviews was 32.06 minutes; the interviews conducted prior to the addition of this study the average length of interviews was just under six minutes. Even allowing for the additional questions from the interview guide, this is a fairly important increase in the lengths of the interviews and in light of the interview time frame (14 to 21 days following the death of their patient). This increase in interview length might indicate telephone counseling might be a viable option for bereavement counseling. Although hospice focuses on face-to-face counseling services, some research provides evidence that hospice caregivers have derived great satisfaction using the telephone for bereavement counseling (Kilbourn et al., 2011). Although all the caregivers evidenced differing levels of emotional distress periodically through the interviews, the length of the interview was determined by the caregiver thus

offering additional support for a telephone-based counseling service for hospice family caregivers. Additional support for alternative delivery channels for bereavement counseling, in the form of cognitive-behavioral therapy for hospice caregivers, have been investigated as well through the use of videophones (Demiris, Parker Oliver, Wittenberg-Lyles, & Washington, 2011). Both lines of research, telephone and videophone counseling, have demonstrated small, but positive results and offer future avenues of valuable research for caregivers.

Caregivers' concerns about over-medicating the patient were found in the narratives and provide additional support that the existing practices does not address this issue appropriately. As palliative care is an essential part of hospice care, creating a better understanding of pain medication use and administration is critical to reducing caregivers' anxiety surrounding this issue.

Practical Implications

From the caregivers' descriptions of their hospice experiences, three implications might be drawn. One, hospices are not doing a thorough job of educating the caregivers about the end of life physical process and the role of palliative care and pain medicine. This education must not be confined to the patient and caregivers, but also to the ancillary healthcare professionals that may be responsible for treating a patient before he or she officially enters the hospice program. Two, family caregivers are not healthcare professionals and do not have access to the same level of education and experience, and therefore, they are dependent upon the education provided to them at the time their loved one enters hospice care. Pain management during hospice care is one of their primary

goals and misunderstanding the appropriate usage of pain medications is highly

problematic. Finally, as previously mentioned, due to the high level of stress the

caregiver is experiencing at intake, this time might result in information overload for the

caregiver.

Future Directions

Currently all U. S. medical schools must provide training in palliative medicine

and in the last decade, hospital-based palliative care programs have increased by 60%

(National Palliative Care Research Center, 2012). However, the National Palliative Care

Research Center (2012) points out the current challenges:

> Unlike other areas of medicine, however, the knowledge base to support the basic
>
> elements of palliative care clinical practice (i.e., pain and symptom management,
>
> communication skills, care coordination) is small and inadequate and systems of
>
> care that truly support the needs of patients and families have yet to be developed.

The healthcare profession as a whole needs more thorough education about the principles

and practices of palliative care medicine. Because the discipline of palliative care is a

relatively new area of medical specialization, engaging ancillary healthcare professionals

in open dialogue about palliative care's principles and practices seems necessary and

critical to the future success of palliative care, particularly in the context of hospice.

People are not aware about the physicality of the dying process unless they have

been present when someone is actively dying. Without this knowledge, it is highly likely

that the image they have of someone dying will most likely come from the media where

more often than not, the person dying is shown to be cognizant to the end. A more

accurate approach is to say that although each death is unique to the person, a death such as portrayed through the movies is the exception, not the rule.

Further research into the rules and boundaries of family communication patterns can help us understand how hospices can better serve the needs of their patients and families. Creating new lines of research using communication theoretical perspectives can assist us in expanding what is known about the end of life communication. Continuing to describe the different social support networks and examining what effect these networks have on family communication in the end of life has the potential to develop and enhance our communications strategies.

Hospice and palliative care healthcare professionals seek to provide each person under their care with a *good death*. There are many opinions about what constitutes a good death, but in truth, our deaths are as unique as our lives. The manner of our deaths are shaped by the illness and medical treatments we undergo, our physical condition, our attitudes towards death and dying, and finally, the support of our family and friends. If we, whether as a patient, caregiver or healthcare professional, do not fully understand palliative care's critical role in the dying process, the good death may harder to achieve.

Families communicate differently; they have implicit and explicit rules about how their communication is shaped and shared. Social support, both formal and informal, can play a role in helping families during stressful times. Family communication patterns are reflected in their social support networks, and those variables may act together to affect their resilience. Family communication is consistent over the trajectory of a person's terminal illness and these family communication pattern types can help provide insight

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into family communicative practices. In this study, the caregivers grieved their loss and

depended heavily on their informal social support, and to a lesser extent, on their formal

social support. Continuing to examine family communication patterns, social support and

resilience through caregivers' narrative can possibly provide answers to our questions.

For scholars, research in the experiences of hospice and family caregivers is called

sharply into focus by the increasing demand and use of these services and future research

can provide rich insights, and further understanding into end of life communication.

APPENDIX A

1. Please listen to the descriptions for each category and choose the one that most closely describes your family's style of communication.

Family A (Manager)	Family B (Carrier)
One family member, the patient or the caregiver, is in charge of making decisions, and controls the decision-making process.	Family members don't really talk about the patient's illness, rarely discuss options and care with each other, and find support from others outside of the family.
Family C (Partner)	Family D (Loner)
Family members talk openly about the patient's treatment, advance directives, death and dying, and family support each other.	Family members do not talk regularly and do not talk much about the patient's illness, leaving the primary caregiver with little support or help.

2. For these next three questions*, think about your family: the people to whom are you are related by birth, marriage, adoption, etc.

*Note: Adapted from the LUBBEN SOCIAL NETWORK SCALE – 6 (Lubben & Girdondo, 2000).

1. How many relatives do you see or hear from at least once a month?
0 = none   1 = one   2 = two   3 = three or four   4 = five thru eight   5 = nine or more

2. How many relatives do you feel at ease with that you can talk about private matters?
0 = none   1 = one   2 = two   3 = three or four   4 = five thru eight   5 = nine or more

3. How many relatives do you feel close to such that you could call on them for help?
0 = none   1 = one   2 = two   3 = three or four   4 = five thru eight   5 = nine or more

3. For these next six questions*, please indicate the extent to which you agree with each of the following statements.

*Note: The Brief Resilience Scale (Smith et al., 2008).

1. I tend to bounce back quickly after hard times.
1 = strongly disagree   2 = disagree   3 = neutral   4 = agree   5 = strongly agree

2. I have a hard time making it through stressful events (R).
1 = strongly disagree   2 = disagree   3 = neutral   4 = agree   5 = strongly agree

3. It does not take me long to recover from a stressful event.
1 = strongly disagree   2 = disagree   3 = neutral   4 = agree   5 = strongly agree

4. It is hard for me to snap back when something bad happens (R).
1 = strongly disagree   2 = disagree   3 = neutral   4 = agree   5 = strongly agree

5. I usually come through difficult times with little trouble.
1 = strongly disagree   2 = disagree   3 = neutral   4 = agree   5 = strongly agree

6. I tend to take a long time to get over setbacks in my life (R).
1 = strongly disagree   2 = disagree   3 = neutral   4 = agree   5 = strongly agree

4. Please answer the following questions to the best of your ability:

Your loved one's diagnosis: _____

How did you (and your family) learn about _____'s illness?

How long have you been a caregiver for your loved one?

Would you please share your story with me?

How does your family support your caregiving efforts?

Do you have family or friends who are helping you with this role?

How would you describe your family involvement?

5. We are going to review a list of support services provided by your hospice for a moment.

Let's begin with respite care.
Have you taken advantage of this service?
     If yes, then ask what was that experience like for you?
     How was it helpful?
     When did you use these services?

If the answer is no, then ask why not? What kinds of barriers were there to you using this service?

Did you take advantage of any formal grief counseling offered by your hospice?
Social worker
Chaplain
Bereavement Counselor
Private Counseling
Group Counseling
Grief Workshop
Children's Bereavement Camp

6. Caregiver Demographics

Sex: M   F

Age: _____

Primary Race Identification:
Caucasian   African-American   Native Hawaiian/Pacific Islander
Other_____

Marital Status:
Married/Partner   Widowed   Divorced   Never Married   Unknown

Education:
Less than High School   Some College/trade school   4 yr. College
          Graduate/Professional

Work Status:
Unemployed   Part time   Full time   Retired

Relationship to patient:
Spouse/Partner   Adult Child   Sibling   Other   Unknown

Resides with patient:
Yes   No   Unknown

APPENDIX A (REVISED)

1. Please listen to the descriptions for each category and choose the one that most closely describes your family's style of communication.

Family A (Manager)	Family B (Carrier)
One family member, the patient or the caregiver, is in charge of making decisions, and controls the decision-making process.	Family members do not really talk about the patient's illness, rarely discuss options and care with each other, and find support from others outside of the family.
Family C (Partner)	Family D (Loner)
Family members talk openly about the patient's treatment, advance directives, death and dying, and family support each other.	Family members do not talk regularly and do not talk much about the patient's illness, leaving the primary caregiver with little support or help.

2. For these next three questions*, think about your family: the people to whom are you are related by birth, marriage, adoption, etc.

*Note: Adapted from the LUBBEN SOCIAL NETWORK SCALE – 6 (Lubben & Girdondo, 2000).

1. How many relatives do you see or hear from at least once a month?
0 = none   1 = one   2 = two   3 = three or four   4 = five thru eight   5 = nine or more

2. How many relatives do you feel at ease with that you can talk about private matters?
0 = none   1 = one   2 = two   3 = three or four   4 = five thru eight   5 = nine or more

3. How many relatives do you feel close to such that you could call on them for help?
0 = none   1 = one   2 = two   3 = three or four   4 = five thru eight   5 = nine or more

3. For these next six questions*, please indicate the extent to which you agree with each of the following statements.

*Note: The Brief Resilience Scale (Smith et al., 2008).

1. I tend to bounce back quickly after hard times.
1 = strongly disagree   2 = disagree   3 = neutral   4 = agree   5 = strongly agree

2. It does not take me long to recover from a stressful event.
1 = strongly disagree   2 = disagree   3 = neutral   4 = agree   5 = strongly agree

3. I usually come through difficult times with little trouble.
1 = strongly disagree   2 = disagree   3 = neutral   4 = agree   5 = strongly agree

4. Please answer the following questions to the best of your ability:

How did you (and your family) learn about _____'s illness?

How long have you been a caregiver for your loved one?

Would you please share your story with me?

How does your family support your caregiving efforts?

Do you have family or friends who are helping you with this role?

How would you describe your family involvement?

What was your biggest challenge as a caregiver?

Would you do it again?

5. We are going to review a list of support services provided by your hospice for a moment.

Let's begin with <u>respite care</u>.
Have you taken advantage of this service?
      If yes, then ask what was that experience like for you?
      How was it helpful?
      When did you use these services?

      If the answer is no, then ask why not? What kind of barriers were there to you using this service?

Did you take advantage of any formal grief counseling offered by your hospice?
      Social worker

Chaplain
Bereavement Counselor
Private Counseling
Group Counseling
Volunteer Services

APPENDIX B

The coding technique used in the study is shown herein to delineate the process

coding cycle which examined the family communication patterns typology suggested by

Wittenberg-Lyles et al., (2012, in press). This family communication patterns typology is

a further adaptation, refinement and application of the revised family communication

patterns scale (RFCPS) by Ritchie and Fitzpatrick (1990) and Fitzpatrick & Ritchie

(1994). Both the scale and the derivative typology represent an adaptation of the family

communication pattern theory (Koerner & Fitzpatrick, 2002). This coding design

included identification of the following:

1. Unit of analysis from transcript data.

2. Relevant rules, or techniques or generalizable procedures applied in the family

   communication patterns as found in the narratives of the hospice family

   caregivers and therefore, contextualized in the end of life area.

3. Identify impact of interaction on the process and/or outcomes for hospice family

   caregiver communication types.

Coding Procedure/Explanation of Codes

1. Unit of analysis: A unit of text constituted a complete thought indicating one or more

   of the components of the Family Communication Pattern typology described above.

Review each unit for its impact on the process or outcomes of the hospice family

caregiver. Code only those units of analysis representing the hospice family

caregivers, their communication styles and any emergent themes related to their

experiences.

Note: Each of the following categories with the options listed has been uploaded into

QSR NVivo 9.0 for coding.

2. Rules.

The rules described below were identified during the initial coding process. The

coding system allowed for additions, deletions, and modifications.

Description of Rule	Rule Elaboration
A. Hospice Family Caregivers were sorted into one of four communication types: Manager, Partner, Carrier or Loner.	a. These categories were self-selected by the participants and exclusive in nature. b. All categories were grouped together to examine for possible similarities within and between the groups.
B. Hospice Family Caregivers were asked three questions about their informal social support network based on the LSNS family subscale.	a. Potential answers ranged from 0 to 9+ for each question. b. These numbers represented the number of family members offering social support during the time the family caregiver's patient was under the care of hospice. c. The higher the number, the greater the informal social support available to the family caregiver. d. Caregiver types continue to be

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Description of Rule	Rule Elaboration
	group by category to continue examination for possible similarities within and between the groups.
C. Hospice Family Caregivers were asked three questions about their perceived resilience as adapted from the BRS.	a. The resilience questions were totaled to calculate the perceived resiliency.
	b. Potential answers ranged from 3 to 15, with 3 being the lowest level of resiliency, 9 being the average level of resiliency, and 15 being the highest possible level of resiliency.
	c. Caregiver types continue to be group by category to continue examination for possible similarities within and between the groups.

D. Hospice Family Caregivers were asked about use of hospice formal social support services.	a. The use or non-use of the hospice agency's formal support services was noted by type:
	   i. chaplain,
	   ii. social worker,
	   iii. volunteers

E. Examine family communication patterns within the caregiver types for four different family communication practices.	a. Supportive messages b. Blocked communication c. Self-censored speech d. Use of third parties as family relationship mediators
F. Examine the overall satisfaction with and impact of the use of hospice by each family caregiver type.	a. These pronouncements on the utilization of the hospice will be expressed through the participants' narratives and will be noted as either positive or negative.

3. Identify impact of interaction on the process and/or outcomes

    a. Positive impact on the communication for each family caregiver type

    b. Negative Impact on the communication for each family caregiver type

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CURRICULUM VITAE

Paula K. Baldwin returned to school in January 2004 to complete her undergraduate degree. She went on to complete her Bachelor of Arts degree in Communication at the University of Texas at San Antonio in 2007. Paula received her Masters of Arts in Communication from Texas State University – San Marcos in 2009. Prior to finishing her Doctor of Philosophy in Communication at George Mason University, Paula was offered and accepted a Post Doctoral Fellowship at the University of Missouri (Columbia) in the Department of Family and Community Medicine in the School of Medicine.